

# Introduction

This *Patient and Family Guide to Hospice Care* is designed to be a practical source of information about hospice care. It introduces you to the history and philosophy of the hospice movement. It describes the services most hospice programs offer. It gives you a profile of the various members of the interdisciplinary hospice team. It provides answers to many of the questions patients and their families have about caregiving, symptom management and pain control, and the grieving process.

Some caregivers find it helpful to write down messages and notes during the course of hospice care. Forms to help you do this are included. If you like, you may copy these pages so you won't run out of space.

Whether you are a patient, a primary caregiver, or a friend or family member (and by the way, we use "family" in the broadest, most inclusive sense of the word), we hope you will find this guide a valuable source of information, practical advice, and support. Keep it close by. Use it as your companion and organizing tool throughout your hospice care experience.

## Understanding Hospice Care

During the Middle Ages, the term "hospice" was used to signify a place where weary pilgrims could stop, rest, and refresh themselves before continuing on with their journey. In 1967, a British physician, Dr. Cicely Saunders, began using the term to symbolize a new kind of care for the dying. In a London suburb, she founded St. Christopher's Hospice which cared for their patients by offering supportive care and pain control. The patients at St. Christopher's came there because they had reached a point in their various illnesses where they were no longer looking for a cure. They wanted to make the most of the time left to them, to live out their lives at the highest level of quality possible, even if that compromised how long they would live.

Since its beginnings in 1967, the hospice movement has spread quickly throughout the world. In the United States alone, there are now over 1,500 hospice programs affiliated with the National Hospice Organization. These programs serve over 100,000 patients a year, and are recognized by patients, physicians, and insurance carriers as providing a high quality, cost-effective medical alternative for persons with limited life expectancies.

Today, hospice care still focuses on helping patients live out their lives at the highest level of quality possible. Hospice care does *not* support euthanasia or assist patients in expediting death in any way. While emergency nursing services are available 24/7, if needed, it does *not* provide 24/7 *live-in* service.

## What Services Does Hospice Care Include?

Hospice organizations vary greatly in size, but their philosophy and the services they offer remain largely the same. All hospices generally agree that basic hospice care should include the following elements:

- Care which focuses on the emotional, social, and spiritual needs of a dying person and that person's family, as well as on physical and medical needs;
- Care which is directed as much as possible by the patient, working together with the family and the hospice staff;
- Support and services provided by an interdisciplinary team composed of physician, nurses, social worker, counselors, therapists, chaplain, trained volunteers, and home health aides;
- Nursing care and support available for patients and primary caregivers on an on-call basis, 24 hours a day, 7 days a week

- Home-based care if possible; but if a patient's symptoms cannot be managed at home, then inpatient care provided in as pleasant and homelike atmosphere as possible, where family and friends are encouraged to be present. Hospice care often can be provided in area nursing homes;
- Bereavement support.

### ***Getting Started and Timing***

It is important for someone entering hospice care to have three things:

1. An understanding of their disease prognosis—that they have been diagnosed with a terminal illness, a prognosis of 6 months or less if it follows a normal course, and also an understanding of the kinds of services hospice does and does not provide;
2. The cooperation of their personal physician who is willing to work with the hospice team to provide care;
3. A family member or close friend who is willing to be the primary caregiver, if hospice care is to be provided at home.

All three of these elements are the key. The patient must understand and consent to the kind of care he or she will be receiving. The physician must be willing to support this kind of care. Hospice will require that there be a primary caregiver when patient is unsafe to be left alone.

*To get the most out of hospice care it is important that it begin neither too early, nor too late. Too early is when a patient is still seeking a cure. Too late is when death is very near and there is little or no time left for hospice care to make a contribution to quality of life for patient and family.*

### **The Family's Role in Hospice Care**

Even fifty years ago, it was common for people to die at home, surrounded by loved and familiar faces and possessions. Now, most people die in hospitals or other institutions, surrounded by tubes and monitors and other technological equipment. Hospice care seeks to take death out of this institutional setting and relocate it to an environment where the patient is most comfortable.

The families who have been supported by a hospice program in caring for their dying loved ones almost universally consider it a positive, empowering experience. Hospice team members are trained to be sensitive to the needs of patient *and* family. If your mother wants to die at home, and you wish to support her in this, but are worried whether you can provide the care she needs, hospice will give both training and emotional support. Hospice programs also offer the option of respite care. Respite care is having a volunteer care for your loved one for a few hours so that you can have a break. It provides much needed time for rest and renewal. Sometimes, caring for a dying friend or relative seems an overwhelming task; hospice care works to make it manageable.

Some people worry about having someone who is dying in the home if children are present. They are afraid it will be a negative or frightening experience for the children. You need to assess your own child's or children's needs and strengths, and their relationship with the person who needs care. However, it is helpful to know that for many families with children, taking care of a dying family member at home turns out to be a source of great family strength and positive energy. Your children, like you, will need education and support for this to be a good experience, but with the needed support, it can be a rare time of closeness and caring for them and can teach them much about life and family values.

Clearly, if your friend or relative makes a choice for hospice care, and you are involved as a primary caregiver, the experience will have a significant impact on your life. It will be both physically and emotionally draining. However, it can also be deeply satisfying for you both. If you might be involved in a caregiving role in a hospice setting, you should feel free to talk with hospice personnel yourself. Find out what the expectations are of you and exactly what kind of help is available. Talk with persons who have cared for a parent or other relative or friend with hospice support and see how they experienced that relationship. It is a major commitment. Take time to make a good decision for yourself.

Hospice care is not for everyone. However, for those who choose it, it can provide compassionate, sustaining care for the dying and their families. It is an option well worth considering.

## Paying For Hospice Care

*If you have Medicare Part A or Medicaid coverage, you may be eligible for the Medicare or Medicaid Hospice Benefit. A Hospice staff person will help you determine your eligibility. If you elect the Medicare (or Medicaid, if available) Hospice Benefit the following will be covered:*

- Intermittent home visits by the Hospice staff
- Medications
- Supplies
- Medical Equipment
- Short-term inpatient respite
- Lab tests
- Outpatient procedures to alleviate symptoms
- Hospitalizations for symptom management

*As long as these items or services are:*

- Related to your terminal illness;
- Authorized by your Hospice provider as palliative and part of your Hospice plan of care; and
- Obtained through a contracting provider approved under the program.

Office visits to see your primary physician will be covered in the same way as before you elected the Medicare or Medicaid Hospice Benefit.

*If you access care without consulting your Hospice team, neither Hospice nor Medicare/Medicaid will be responsible for the charges associated with the care you obtain.*

*If you decide to change your approach to treatment from a comfort-oriented one to a more aggressive or curative approach, you may revoke the Medicare or Medicaid Hospice Benefit and your regular Medicare/Medicaid benefits will be resumed.*

*If you have private insurance, Hospice will clarify whether you have hospice coverage and its scope.*

*If you have two insurance policies, please inform your hospice team, so they can work to coordinate and maximize your coverage.*

*If you have limited or no coverage for hospice services, Hospice staff will work with you to determine your potential eligibility for Financial Aid.*

# The Hospice Team

## Nurses

Often, the first person you will meet from the hospice team is a nurse. During this visit the nurse will explain the hospice philosophy and services. The nurse will work with you to determine which hospice team members will visit you and your family. The nurse's primary goal is to provide symptom management and comfort.

### **The hospice nurse will:**

- Assess your comfort and any symptoms which may need attention, such as pain, nausea, etc.;
- Work in coordination with your physician to manage symptoms;
- Perform procedures such as placing and maintaining catheters, wound care, blood draws, etc.;
- Teach the caregiver the proper use of catheters, routine dressing changes, medication;
- Suggest and help in obtaining needed equipment and services;
- Discuss the effects of illness and treatment;
- Listen to your concerns and offer support.



## Social Workers

Hospice social workers work closely with patients and their families to create and maintain a supportive in-home care system to ensure the patient's safety and comfort, and to address the special needs of caregivers.

Hospice social workers are available to help patients and their families address the many personal, financial, emotional and care planning issues that arise.

### **The hospice social worker is able to:**

- Identify community resources and help with referrals to them;
- Determine eligibility for state and local assistance programs;
- Clarify insurance coverage and answer questions regarding financial concerns;
- Help patients and families arrange for added care giving support at home or in an alternative care setting;
- Provide information concerning advance directives, such as a health care directive (living will) and appointment of a health care representative or proxy;
- Assist in funeral and memorial planning;
- Listen to your concerns and provide emotional support.

Social work visits vary in frequency and length depending on the needs of patients and their families. A social worker will usually contact you by telephone within one week of admission to schedule an initial appointment.

## Chaplain

The Hospice Chaplain is available to help with spiritual concerns which may arise. Sometimes a listening ear or a thoughtful reading can help you find meaning in the midst of a difficult time. The chaplain uses a nondenominational approach and can also help connect you with various religious organizations. The chaplain does not replace your minister, rabbi, or priest.

We believe that your mental and spiritual well-being is as important as your medical condition. The chaplain is specially trained to help you and your family with spiritual issues or concerns arising from terminal illness. The chaplain is available as needed.

### **The hospice chaplain:**

- Is available to meet with you and/or your family to share hopes, fears, dreams and concerns, whether spiritual or otherwise;
- Will support you in your exploration or struggles with spiritual and/or emotional issues;
- Can provide spiritual counseling, respecting your personal beliefs;
- Will not impose any particular religious orientation;
- Will pray with you if requested;
- May be available to assist you in planning a funeral, memorial service, or other observance you wish to have conducted;
- Can help obtain clergy services from the denomination of your choice;
- Can teach relaxation techniques to help achieve greater peace.

### **Therapy Services**

Physical, Occupational, and Speech Therapists are available to assist in promoting the independence, quality of life, and safety of the patient and family. Your hospice nurse can help determine if a referral to one of these therapists might be helpful.

#### **The Therapist may:**

- Evaluate the medical equipment needs;
- Provide or assist in arranging for equipment as needed, such as hand held showers, bath seats, walkers and canes;
- Train family and caregivers in proper use of equipment;
- Identify safety hazards;
- Help the patient maximize their strength and mobility through the use of equipment and exercise programs;
- Evaluate leisure interests and teach skills and activities that improve quality of life;
- Teach transfer skills and energy-saving techniques to maintain safety for the patient and caregivers;
- Teach family and caregivers exercises for the bed bound patient that may relieve pain and discomfort caused by lack of mobility;
- Evaluate communication or swallowing difficulties and recommend ways of handling these.

### **Home Health Aides**

Home Health Aides are certified nursing assistants. They provide personal care needs. They may visit two or three times per week, depending on the situation. The home health aides work closely with the nurses and other hospice team members providing some assistance with personal care needs. Some of the services they provide include:

- Bathing the patient and changing bed linens
- Shampooing, grooming and shaving
- Wound care
- Skin care
- Assistance with toileting
- Light homemaker services

### **Hospice Volunteer Program**

The Volunteer Coordinator works closely with all team members, especially nurses and social workers to determine how a volunteer and the various services they offer may benefit both the patients and caregivers. The coordinator will contact you, verify your requests, and introduce the volunteer to you.