

## Hospice Tips

### **What is Hospice?**

Hospice care is provided by a team of professionals and volunteers trained to address the medical, social, emotional and spiritual needs of a patient, who is in the terminal phase of an illness and is no longer seeking life-prolonging treatment. A physician makes a referral, when the prognosis is determined to be six months or less. The hospice team provides what is known as “palliative” care, which focuses on eliminating suffering and providing comfort and support. The team is also dedicated to insuring a dignified death. Hospice will be provided in your own home *if you have a caregiver*. If you do not, hospice services will be delivered within an inpatient setting.

### **Obtaining a Hospice Referral**

If you have not already discussed hospice with your physician, we suggest that you do so. You may not need them right now, but we strongly believe that hospice can be a great help in assisting people to manage pain and other symptoms. In addition, should you choose to hasten your death, there are advantages to being on hospice at the time. (Your Client Support counselor may have already discussed these with you. If not, ask.)

To help you have this discussion with your physician, the following sample conversation may serve as a guide:

“I want to have a conversation with you about how I can maintain control of my life as my illness progresses. I appreciate all you have done to help me fight this disease, but I have come to a place where I want to redirect my remaining energy. The quality of my life is much more important to me than the number of days I have left. I believe it is time to talk about a referral to hospice and “comfort care” *only*. I want my pain to be kept under control, and I want to be kept comfortable until my death – even if this means I might sleep all of the time. If I am unable to find a caregiver, I would like a referral to an in-patient facility with hospice support.

I am no longer interested in traditional or experimental procedures designed to prolong my life. At this time, I am seeking only one thing: the peace of mind that comes with knowing hospice will be available to me at the time of my choosing. With a referral in place, I can enjoy whatever time I have left; free from the fear of intolerable suffering.”

In addition, you might want to add the following:

- If my pain or suffering becomes intractable, even with traditional pain management, I want the option of total sedation.\* Are you willing to honor this request?
- If you cannot support this request, please refer me to a physician who will.

\* “Total” or “palliative” sedation is a medically-induced coma. The patient becomes completely unaware of any suffering. Sometimes the coma is for a brief period of time until symptoms can be brought under control. At other times it continues until death.

## **Finding a Hospice**

The following serves as a guideline in your search for hospice. You may begin, even if you have not yet received a referral:

- Ask friends/family who have had experience with hospice in your community. A personal recommendation is a good place to begin.
- Ask the physician who refers you if he or she prefers a particular one. (This does not mean you have to choose that one.)
- Both not-for-profit and for-profit hospices provide good care.
- Some insurance companies pay for only a particular hospice. When you contact a hospice, ask if they take your insurance.
- When researching hospices, you may notice a reference to “NHPCO.” This stands for The National Hospice and Palliative Care Organization. This is a membership organization and does not mean that their care will be better than non-member hospices.

Once you’ve found a hospice, call (or have a family member call) and ask to speak to an intake person. Make sure you have paper/pen to take notes. Explain the situation, tell them where you live, and ask the following questions. *Listen for concern, kindness and thoughtful responses.*

- Do you see patients in my area? If not, which hospice(s) do?
- If you do not have a caregiver in your home (or if you might need more care than can be delivered at home) ask: Where do you admit your inpatients?
- How long have you been in business? What services do you provide?
- As a hospice patient, may I continue to see my own doctor?
- What is your week-end and night coverage?
- Are you affiliated with any particular religious institution? If so, ask how that influences the care they deliver and the end-of-life options available. (Do **NOT** mention any plans you may have to hasten your death. That conversation may/or may not take place with the appropriate hospice professional at a future time.)
- What is your philosophy on pain management? (Listen for words that make sense to you, like: “Our goal is to keep the person as pain-free as possible. This is almost always possible.” *Be concerned* if they say something like, “Not all pain can be controlled, but we do our best.”) A good hospice has good pain management.
- Would you provide “palliative sedation” if my pain or suffering became impossible to manage?

### **Making the Decision**

Think of yourself as a consumer. The “product” is peace of mind at a very vulnerable time. If you feel very positive about the first hospice you speak with, then you simply ask, “What is the next step?” If, however, you would rather look into other options, simply thank them. Then, after you have completed your search, compare the notes you have taken. If you are able, talk with a friend or family member and seek their input. If you need clarification on a point, do not hesitate to call that particular hospice back. These are the people who will play a vital role in the last months and days of your life. You want to feel confident that you will be in good hands; that you will be treated competently, respectfully and compassionately.

### **Once you have chosen a hospice ...**

- A nurse and/or social worker will come to your home and complete an intake interview. This visit may last more than an hour. Make sure any friends or family, who will be involved in your care, are present.

- *Take care of yourself.* The interview consists of many questions and forms to sign. Depending on your status that day, it may be exhausting. If you become too weak or tired to pay attention, ask to have them return the next day.
- If you have a preference for a male or female nurse, let them know.
- When you meet your nurse for the first time, describe any special needs or concerns you have. Be clear about what you want. Do you like to be kept informed? Are you uncomfortable discussing feelings? Do you have specific fears about pain, etc? Are there family “issues” that are contributing to your stress?
- Read through the materials you are given. Make sure everyone involved in your care reads them. Feel free to ask questions when your nurse visits, or by calling the hospice in-between visits.
- *You are in charge.* If you want the nurse to come more or less frequently, tell him/her. If you are *uncomfortable* with the nurse who has been assigned to you, call the hospice and ask to speak with the nursing supervisor. Explain your concerns.
- If you find that the hospice you have chosen is not being responsive to your needs, even though you have brought this to their attention, you may always “fire” them and find a new one. (This rarely happens. But it is your right.)

### **If a Crisis Develops**

Because you are now a hospice patient, the response to “life-threatening” situations may differ from what would happen in an earlier stage of your illness. For instance:

- Hospice should be called BEFORE calling 911. Make sure anyone staying in the home knows this. Post the hospice number near every phone.
- Hospice will provide you with an out-of-hospital do-not-resuscitate order form. If emergency services *are* called to your home, this document will inform them that they are not legally bound to perform CPR or resuscitation efforts.