



## *Hospice Care: Comfort and Compassion When It's Needed Most*

*W*hen it comes to creating memories and sharing in significant life events, the family is the focal point for commemoration and celebration. We plan for weddings, the birth of a child, going off to college, and retirement. Despite the conversations we have for these life events, rarely, if ever, do we have conversations about how we want to live in the final phase of our lives ... until a crisis hits.

Death and dying — once-taboo subjects — are becoming increasingly relevant for Baby Boomers and their aging parents. We know from research that Americans are more likely to talk to their children about safe sex and drugs than to talk to their terminally ill parents about end-of-life care options and preferences. With approximately 2.4 million Americans dying each year — and the number growing — it is vital that thoughtful, serious, personal conversations take place about the kinds of experiences Americans would want for themselves or their loved ones as the inevitable end-of-life draws near. Often such conversations are avoided out of an understandable desire to spare each other's feelings. They need not be.

Experts agree that the time to discuss your views about end-of-life care, and to learn about the end-of-life options available, is *before* a life-threatening illness occurs or a crisis hits. This greatly reduces the stress of making decisions about end-of-life care under duress. By preparing in advance, you can avoid some of the uncertainty and anxiety associated with not knowing what your loved ones want. Instead, you can make an educated decision that includes the advice and input of loved ones.



### *Plan Ahead*

Let your loved ones know *now* — when you are still able to effectively communicate — what your preferences for treatment would be if you were confronting a terminal illness. For example, you may want to indicate that if you ever become terminally ill, your preference is to receive hospice care.

## *Decide what you want for your own end-of-life care.*

A few simple steps you can take to ensure that your end-of-life wishes are followed, when the need arises:

- Draw up a living will of written instructions to make known what you want done if, for example, you are seriously ill and the only way you can be kept alive is by artificial means.
- Have a durable power of attorney in place that authorizes a person of your choosing (usually a spouse or close relative) to make decisions if you become unable to do so for yourself. Make sure to communicate your wishes to this person and make sure this person agrees to assume the responsibility.

*Because every state has different laws, it is in your best interest to consult a lawyer about these documents.*

These and other advance directives can be useful tools for making known your end-of-life care wishes. However, they are not intended to be used as stand-alone documents. It is also important to have detailed personal conversations with your family and loved ones about these issues.

### *Discuss Your Wishes Early*

Discuss your end-of-life wishes with your family and loved ones now — before a crisis hits. This is essential to ensuring that your end-of-life care wishes are met. You may want to use the following occasions as opportunities for having this conversation:

- Around significant life events, such as marriage, birth of a child, death of a loved one, retirement, birthdays, anniversaries, and college graduation;
- While you are drawing up your will or doing other estate planning;
- When major illness requires that you or a family member move out of your home and into a retirement community, nursing home, or other long-term care facility; or

## *Discuss your wishes with your family and close friends.*

- During holiday gatherings, such as Thanksgiving, when family members are present.

When appropriate, include your children in these conversations, not just your parents. It is never too early to start thinking about these issues. Have regular discussions about your views on end-of-life, since they may change over time. And don't forget to discuss your end-of-life wishes with your doctor.

### *Take The Initiative*

Even if you have done everything to communicate your wishes, you may find yourself in a situation where you need to take the initiative and have the discussion with family members or loved ones who have not shared their thoughts with you. Here are a few helpful pointers to keep in mind as you plan for having this conversation:

#### **1. Do Your Homework**

Before initiating the discussion, learn about end-of-life care services available in your community.

Become familiar with what each option offers so you can determine which ones meet your own, or your loved one's, end-of-life needs and desires.

#### **2. Select an Appropriate Setting**

*Plan* for the conversation, since this is not a discussion to have on the spur of the moment. Find a quiet, comfortable place that is free from distraction to hold a one-on-one discussion. Usually, a private setting is best.

#### **3. Ask Permission**

People cope with end-of-life issues in many ways.

Asking permission to discuss this topic assures your loved one that you will respect his or her wishes and honor them.

Some ways of asking permission are:

*“I’d like to talk about how you would like to be cared for if you got really sick. Is that okay?”*

*“If you ever got sick, I would be afraid of not knowing the kind of care you would like. Could we talk about this now? I’d feel better if we did.”*



Another method of initiating the conversation is to share with your loved one an article, magazine, or story about the topic. Even watching a TV show or movie on the topic together can encourage the conversation. If you think your loved one would be more comfortable with someone else present, you may want to invite a social worker or spiritual advisor to help in this regard.

#### **4. Know What To Expect**

Keep in mind that you have initiated this conversation because you care about your loved one’s well-being — especially during difficult times. Try to focus on maintaining a warm and caring manner throughout the conversation by using nonverbal communication to offer support. Allow your loved one to set the pace. Nodding your head in agree-

ment, holding your loved one's hand, and reaching out to offer a hug or comforting touch are ways that you can show your love and concern.

Understand that it is normal to encounter resistance the first time you bring up this topic. Don't be surprised or discouraged; instead, plan to try again at another time.



Questions to ask your loved one about his or her end-of-life care:

*“How would you like your choices honored at the end-of-life?”*

*“Would you like to spend your final days at home or in a home-like setting?”*

*“Do you think it’s important to have medical attention and pain control tailored to fit your needs?”*

*“Is it important for you – and your family – to have emotional and spiritual support?”*

*Pick a substitute decision-maker to speak for you in case you can't speak for yourself.*

If your loved one responds “yes” in answer to these questions, he or she may want the kind of end-of-life care that hospice provides.

## **5. Be a Good Listener**

Keep in mind that this is a conversation, not a debate. Sometimes just having someone to talk to is a big help. Be sure to make an effort to hear and understand what the person is saying. These moments, although difficult, are important and special to both of you.

Some important things to do:

- Listen for the wants and needs that your loved one expresses.
- Make clear that what your loved one is sharing with you is important.
- Show empathy and respect by addressing these wants and needs in a truthful and open way.
- Verbally acknowledge your loved one's rights to make life choices — even if you do not agree with them.

## *Explore Hospice Care*

If you — or those you love — are struggling to cope with a life-threatening illness, help is available through hospice care. Hospice programs are well-equipped to provide quality care focusing on comfort and dignity for patients and loved ones.

Considered to be the model for quality, compassionate care at the end-of-life, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is extended to the patient's loved ones, as well. At the center of hospice is the belief that each of us has the

*Put your end-of-life wishes  
in writing.*

right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so. The focus is on caring, not curing and, in most cases, care is provided in the patient's home. Hospice care also is provided in freestanding hospice facilities, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness.

Typically, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the terminally ill individual. Members of the hospice staff make regular visits to assess the patient and provide additional care or other services. Hospice staff are on-call 24 hours a day, seven days a week.

The hospice team — which includes the patient, family/caregiver, physicians, nurses and other health care professionals, home health aides, and trained volunteers — develops a care plan that meets each patient's individual needs for pain management and symptom control. The plan outlines the medical and support services required such as nursing care, personal care (dressing, bathing, etc.), social services, physician visits, counseling, and homemaker services. It also identifies the medical equipment, tests, procedures, medication and treatments necessary to provide high-quality comfort care.

To learn more about hospice care, see the National Hospice Foundation's brochure, "*Hospice Care: A Consumer's Guide to Selecting a Hospice Program.*" This brochure contains information on the services provided through hospice care and the key questions to ask when selecting a hospice program.

Additionally, it will help you choose a hospice program that best suits your needs and wishes, as well as those of your family and loved ones.





### *Acknowledgment*

This brochure was produced with the help of the National Hospice and Palliative Care Organization (NHPCO) and NHPCO-member hospice professionals. NHPCO is committed to improving end-of-life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones. This organization, which represents most hospice programs in the United States, has a hospice locator program of its members.

To find an NHPCO member hospice, call NHPCO's HelpLine at 1-800-658-8898 or log on to their web site at [www.nhpc.org/database.htm](http://www.nhpc.org/database.htm).



### *National Hospice Foundation*

The National Hospice Foundation, a 501 (C) (3) charitable organization, was created in 1992 to broaden America's understanding of hospice through education and research. Its mission is to expand America's vision for end-of-life care. In doing so, it engages and informs the public about the quality end-of-life care that hospice provides.

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