

COMMUNICATING

End-of-Life Wishes



Caring  *Connections*
a program of the
National Hospice and Palliative Care Organization

Hospice

It's About How You LIVE

*When it comes to creating memories,
the family is often at the heart
of sharing in life events.*

*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 do we
have conversations about how we want to
be cared for at the end of our lives.*

*With roughly 2.4 million Americans dying
each year, it is important that personal
conversations take place about the kinds of
experiences you want for yourself and the
wishes of your loved ones before facing an
end-of-life situation. We know from
research that Americans are more likely to
talk to their children about safe sex and
drugs than to talk to their parents about
end-of-life care choices.*



COMMUNICATING

End-of-Life Wishes



Communicating End-of-Life Wishes

Experts agree the time to discuss your views about end-of-life care, and to learn about the end-of-life care choices available, is before a life-limiting illness occurs or a crisis happens. By preparing in advance, you can help reduce the doubt or anxiety related to making decisions for your family member when they cannot speak for themselves.



Plan Ahead

The time to communicate end-of-life care wishes is now when you and your loved ones are still able to discuss your choices. Review the steps below and share them with your friends and family to communicate end-of-life wishes.

Caring Connections
A Division of the
NATIONAL ORGANIZATION FOR ASSISTED LIVING



COMMUNICATING

End-of-Life Wishes

The following are simple steps to ensure that end-of-life care wishes are followed:

- ◆ Draw up a living will of written instructions to communicate care and treatment wishes and preferences in the event you cannot speak for yourself.
- ◆ Have a durable power of attorney in place that allows a person of your choosing to make medical decisions for you if you become unable to do so.

Provide your family doctor with a copy of this document. Make sure to communicate your wishes to this person and make sure that this person agrees to assume the responsibility.

Since every state has different laws it is important to use state-specific advance directives. Contact NHPCO to receive a state-specific advance directive:

www.caringinfo.org ◆ caringinfo@nhpco.org

HelpLine 800.658.8898 ◆ Multilingual Line 877.658.8896

Advance directives can be useful tools for making end-of-life care wishes known, however it is just as important to have personal conversations with family and loved ones about these issues.



Discuss Your Wishes Early

Discuss your end-of-life care wishes with family and loved ones now — before a crisis happens. The following can be used 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, or college graduation
- ◆ While drawing up a 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 longterm care setting
- ◆ During holiday gatherings, such as Thanksgiving, when family members are present
- ◆ When a friend or another family member is facing illness or an end-of-life situation

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

Whenever possible, include your children in these conversations, not just your parents, spouse or partner. It is never too early to start thinking about these issues. Have regular discussions about your views on end-of-life care, since they may change over time. And don't forget to discuss your end-of-life care wishes with your doctor. Here are a few helpful pointers to keep in mind as you plan for having this conversation:

1. Do Your Homework

Before beginning the discussion, learn about end-of-life care services available in your community. Become familiar with what each option offers so you can decide which ones meet your loved one or your own, end-of-life care needs and wants.

2. Select an Appropriate Setting

Plan for the conversation. Find a quiet, comfortable place that is free from distractions to hold a one-on-one discussion or family meeting. Usually, a private setting is best.

3. Ask Permission

People cope with end-of-life care issues in many ways. Asking permission to discuss this topic assures your loved one that you will respect and honor his or her wishes.

Some ways of asking permission are:

"I'd like to talk about the best way someone might care for you 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."

"I want to share my wishes about how I'd like to be cared for in the event I was sick or injured; can we do that now?"

Another method of beginning the conversation is to share an article, magazine, or story about the topic with your loved one. 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, you can suggest they talk to another family member, a friend or faith leader.

4. Begin the Conversation

Keep in mind that you started this conversation because you care about your loved one wellbeing — especially during difficult times. Allow your loved one to set the pace. Nodding your head in agreement, holding your loved one 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 for your loved ones to avoid this discussion. Don't be surprised or upset; 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 homelike setting?”

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

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

If your loved one responds “yes” in answer to these questions, he or she may want the 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 considerations:

- ◆ Listen for the wants and needs 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.
- ◆ Acknowledge your loved one right to make life choices — even if you do not agree with them.

6. Call Hospice

If you — or those you love — are struggling to cope with a life-limiting illness, help is available through hospice. Hospice programs provide quality care focusing on comfort and dignity for persons who are ill, and their loved ones. Here are some important things to know about hospice:

- ◆ Hospice provides a team of professionals that offer expert medical care, pain management, and emotional and spiritual support to meet the needs and wishes of the person who is ill.
- ◆ Emotional support is also provided to the patient's loved ones.
- ◆ Hospice focuses on aggressively treating pain or symptoms to make the person as comfortable as possible. Care is usually provided in the person's home.
- ◆ Hospice also is provided in hospice facilities, hospitals, and nursing homes and other longterm care facilities.
- ◆ Hospice services are available to patients of any age, religion, race, or illness, regardless of their method of payment.
- ◆ Members of the hospice staff make regular visits to assess the person who is ill and provide extra care or other services. Hospice staff is on-call 24 hours a day, seven days a week.
- ◆ The hospice team — which includes the person who is ill, family/ caregivers, doctors, nurses, social workers, spiritual caregivers, counselors, home health aides, and trained volunteers — develops a care plan that meets each person's individual needs for care and support.
- ◆ The care plan describes the services needed such as nursing care, personal care (dressing, bathing, etc.), emotional support, and doctor visits. It also identifies the medical equipment, tests, procedures, medication and treatments necessary to provide high-quality comfort care.
- ◆ After death, hospice provides grief services and support for family members for at least 12 months.
- ◆ Hospice is a benefit under Medicare and is often covered by private insurance.



Caring Connections
a program of the
National Hospice and Palliative Care Organization

For more information, or to locate a hospice
in your area, contact Caring Connections:

www.caringinfo.org ♦ caringinfo@nhpco.org

HelpLine 800.658.8898

Multilingual Line 877.658.8896



Compliments of

EmblemHealth[®]

GHI and HIP are EmblemHealth companies

If you are an EmblemHealth, GHI or HIP member and would like more information about Dignified Decisions, our end-of-life care program, please call 1-800-447-8557 or send an e-mail to DD@emblemhealth.com.

Item #: 810001 – Communicating End-of-Life Issues

For additional copies of this and other NHPCO products,
order online at www.nhpco.org/marketplace or toll-free at
800/646-6460 • 877/779-6472 (fax)

©2000-2009 National Hospice and Palliative Care Organization.