

# *Talking to Your Family About End-of-Life Care*



Advocate at Home

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Sharing in significant life events—during both happy and sad occasions—often strengthens our bond with family and close friends. We plan for weddings, the birth of a child, going off to college and retirement.

It's easy and enjoyable to plan for the happy occasions and often we invite those who are significant in our lives to share in the major decision-making surrounding a celebration.

Yet we often avoid discussing solemn events in our lives, including serious illness and death. While we will all experience death in our own lives, many people do not want to confront the emotion-laden issues surrounding this final phase of life until a crisis occurs.

Most experts in issues of death and dying agree that the time to discuss your views about end-of-life care—and to learn about end-of-life issues and preferences—is before a life-threatening illness or crisis occurs. Ironically, discussing these issues before the fact actually reduces stress on family members or close friends because it prevents them from being forced to make difficult decisions and to guess what your preferences may be during times of crisis and extreme stress. By preparing in advance, you can make educated decisions that include the advice and input of loved ones.

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## What to Say and When to Say It

Few of us understand how to begin the dialogue on such a sensitive topic. Popular research tells us that Americans are more likely to talk to their children about safe sex, drugs and crime than they are to talk with their terminally ill parents about end-of-life care options and preferences. And while many family members have not discussed their end-of-life preferences, most people do have specific opinions on how they would or would not like to spend their final days.

No matter how you choose to begin, it's important to approach the conversation with sensitivity. People cope with end-of-life issues in many ways. You may want to begin by sharing a newspaper or magazine article about the topic. Even watching a TV show or movie where end-of-life issues are portrayed can encourage the conversation. Here are a few suggestions to open the topic:

- "That program has me thinking about what it would be like to be faced with a terminal illness and what type of care I would want. What do you think you would want if you were in that situation?"
- "How sad that there was so much conflict because the children didn't know what their father wanted. It's too bad he never told them what he wanted before so they wouldn't have to try and decide on their own. You know, Mom, I'm not sure we know what you'd want us to do if you were in a similar situation. Let's talk about it."

Don't feel you need to cover every topic at once. Views about end-of-life care can change depending on age, health and other circumstances. Whether you are the parent or the adult child, let your loved ones know now what your preferences for treatment would be if you were confronting a terminal illness—and ask what they would want, too.

Drawing up a living will and power of attorney for health care can legally assure that you have selected a friend or family member who will honor your wishes if you are unable to make decisions regarding end-of-life care for yourself. Because every state has different laws, you will want to consult an attorney regarding these documents. The living will and power of attorney for health care will go a long way toward assuring you that your wishes will be honored if the time comes when you cannot speak for yourself. Drawing up these important legal documents is also a natural occasion to begin conversations about end-of-life care:

- “Your mother and I have just talked with our lawyer about this document they call a living will. Would you help us fill it out?”
- “I had a physical today and my doctor asked if I'd ever filled out a living will. I guess we need to take care of it—it would sure make life easier for the family. What do you think?”

Life is uncertain and it is never too early to start thinking about these issues. Have regular discussions about your views on end-of-life issues since they may change over time. And remember to discuss your end-of-life preferences with your doctor.

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## **Ask the right questions, then listen carefully**

Keep in mind that this is a conversation, not a debate. Whatever your role may be in the discussion, be sure to make an effort to hear and understand what your loved one is saying. These moments, although difficult, are important to both of you. Listen for the wants and needs that your loved one expresses. Make clear that what your loved one is sharing with you is important. Whether you see yourself as the potential patient or caregiver, show empathy and respect by addressing these wants and needs in a truthful and open way. And verbally acknowledge your loved one's right to make life choices—even if you do not agree with them.

Decisions about end-of-life medical treatments are personal and should be based on your values and beliefs. It is impossible to foresee every type of circumstance or illness that might occur. For that reason, it can be helpful to think in more general terms about the quality of life that is important to you. Consider your overall attitude toward life,

including the activities you enjoy and situations you fear. Then try to answer these questions for yourself:

- What makes your life worth living? What would be important to you if you were dying?
  - What kinds of medical treatment would you want at the end of your life? Are there treatments you especially want or do not want? Should medical technology be used to keep you alive as long as possible? Do you want only treatments that focus on controlling pain and symptoms and keeping you comfortable?
  - How do you feel about pain management? Would you want as much as necessary, even if it meant making you unconscious? Or is maintaining alertness—even if it means being in some pain—more important to you?
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## **Consider Hospice Care**

If you or a loved one is struggling to cope with a life-threatening illness, help is available through hospice care. Advocate Hospice provides quality care focused on comfort and dignity for patients and loved ones. At the center of our hospice is the belief that each of us has the right to die pain-free with dignity, and our families have the right to receive the necessary support to allow the patient to spend their final days in dignity. The focus is on caring, not curing, and in most cases, care is provided in the patient's home. Hospice care may also be provided in freestanding hospice facilities, hospitals, nursing homes and other long-term care facilities.

As the model for quality, compassionate care at the end of life, hospice 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. Specific hospice services extend support to the patient's loved ones as well. At Advocate Hospice, we partner with our patients and families and support their efforts to make every day count.

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## **Advocate Hospice Philosophy**

At Advocate Hospice, we believe our patients—and their families—have the right to choose how to live every day of the rest of their life, even while facing a life-limiting illness. Through this belief:

- We acknowledge that each patient's unique beliefs and values should guide how we deliver comfort and care
- We teach patients and their families that choices available through hospice care can improve the quality of their time together
- We strive to minimize anxiety, pain, fear and stress
- We will always preserve patient dignity

At Advocate Hospice, we partner with our patients and families and support their efforts to make every day count. For more information on how Advocate Hospice and our bereavement programs can help you and your loved ones, call **630.963.6800** in Chicagoland, or **309.268.5930** in Central Illinois.

Advocate at Home provides a full spectrum of outstanding services, including nursing care, hospice care, medical equipment, home infusion, and respiratory and rehabilitation therapies, along with innovative programs that help patients make successful transitions from the hospital. By providing innovative home care solutions and the best possible health experiences, Advocate at Home helps patients remain in their homes.

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If you have questions or would like to learn more about hospice care, please call Advocate Hospice in Chicagoland at **630.963.6800** or in Central Illinois at **309.268.5930**.

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