

Talking to Your Family about End-of Life Issues

Recent national events have caused many of us to think about the care we would want to receive at the end of our life and to talk about it with family and friends. Many people have also created medical directives that communicate the type of care we would or would not want to receive. (For a discussion of medical directives in Texas, see http://fcs.tamu.edu/money/your_money/money_pdfs/you_have_the_right_to_decide.pdf).

But once we have created these documents, what do we do with them? The most important step is to talk about them with family and friends. If no one knows they exist, they can't be utilized if they ever need to be.

Studies have shown that health care agents who are family members are correct about patient's preferences only about 70 percent of the time, and doctors are even less aware of the patient's wishes.

It's not surprising that families are often not aware of your wishes since most families rarely talk about these issues. It's not easy or comfortable to talk about illness, death, or losing somebody you love. Your family needs your help to make appropriate decisions on your behalf. Nobody knows better than you how you want to be cared for if you are not able to recover from a serious illness or injury.

Before you can talk to your family about what you would want in certain situations, you need to think about it yourself. Ask yourself the following questions. You may even want to write down your thoughts about each.

- Are there some basic functions you believe you must have in order to feel that you would want to continue to live (for example, to be able to recognize loved ones or to respond to others)?
- Do you have spiritual or religious beliefs that affect your attitudes about a terminal illness, treatment decisions, or death and dying? (For example, some people believe that life-sustaining treatments should never be withdrawn. Others believe that when there is no hope of recovery, death should be allowed to occur.)
- Are there specific kinds of life-sustaining treatment you would want to have if you were diagnosed with a terminal condition? (For example, some people feel that if they could not eat or drink, they would want a feeding tube under all circumstances. Others say they would want it tried for a short time.)
- Are there specific kinds of life-sustaining treatment you would not want to have if you were diagnosed with a terminal condition? (Unlike the example above, other people would choose to forgo a feeding tube if they could not eat or drink.)
- Is there a particular doctor you want to help your family make decisions about your care?
- Do your family and doctor know who you have designated as your health care agent to make health care decisions on your behalf?
- Is there anyone you do not want involved in your health care decisions (for example, specific family members, friends, or professionals)?

- If given a choice, where would you prefer to die (for example, at home, the hospital, a nursing home)?

Source: *Talking to Your Doctor and Family about Difficult Health Care Decisions*. Oregon State University, Extension Service Publication EC 1386.

Once you have thought through these questions, it's time to talk to others. Sometimes when a person tries to initiate a serious conversation about health care decisions, other people become afraid. For example, if an older parent starts such a conversation, the adult son or daughter might say, "Oh Mom, we don't need to talk about this. You're going to outlive us all."

It's important to begin your conversation in a way that lets others know you want to be taken seriously. Perhaps you could start by saying something like, "I want to talk to you about something that is important to me. I hope you will be willing to listen."

If you know of a specific situation that you can discuss, such as a friend who was terminally ill, or a story in the news (like Terri Schiavo), you might talk about what you would have wanted if you were that person. For example, "Remember what happened to Mary after her third stroke. If that ever happens to me, I would want"

Talk to your family about your wishes, and tell them who you have chosen to be your health care agent. Explain that this is the person you want to be responsible for helping the medical team understand your wishes regarding terminal illness and other health care issues. If you express your feelings to all

of your family, conflict will be less likely to arise later.

Try to discuss these issues with your family when you are all together. This way, everyone hears the same thing at the same time. Pick a time when you are not celebrating some special occasion or holiday. Make sure everyone is well rested and alert. This is likely to be an emotionally draining experience for some of them. If it is not possible to get your entire family together at the same time, discuss it with them individually or in small groups.

Consider making a video or audio tape in which you talk about your feelings and wishes concerning your health care decisions. If you are not comfortable making a tape, write a personal letter addressed to your family and friends.

Tangible expressions of your wishes are comforting to families during times of crisis. It helps everyone know that the decisions that are being made are the ones you would want. No matter what your age or situation—whether you are married, single, widowed, or divorced—planning is an important way to make your life more secure, to ensure that you have maximum control over your life and future, and to give you and those you love peace of mind.

Additional Resource

American Bar Association *Advance Planning Tool Kit*
http://www.americanbar.org/groups/law_agin/resources/consumer_s_toolkit_for_health_care_advance_planning.html.

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