

How to Talk with Your Loved Ones

Remember, it's up to you to take the initiative and express your wishes. Your family or loved ones are not likely to raise the issue for you. Talking about end-of-life issues can be difficult for anyone. One way to approach the subject is to talk about why you have decided to talk about these issues. For example:

- Did a particular event cause you to make the decision?
- Did an article in the newspaper or something that happened to a family member make you think about it?
- What is motivating you to take these actions now?

Sometimes sharing your personal concerns and values, spiritual beliefs, or views about what makes life worth living can be as helpful as talking about specific treatments and circumstances. For example:

- What aspects of your life give it the most meaning?
- How do your religious or spiritual beliefs affect your attitudes toward dying and death?
- What is your attitude towards death?

Sharing your end-of-life care decisions with your loved ones will also help them ensure your wishes are followed. Decisions may include answers to the following questions:

- How important is it to you to be physically independent and stay in your own home?
- Would you want your healthcare agent to take into account the effect your illness has on any other people?
- Would you prefer to die at home if possible?

Reassess your decisions over time. These are not simple questions and your views may change. It is important that you review these issues and discuss your choices as your personal health or circumstances change your life.

What To Do If Family Members Disagree

To ensure your wishes are followed, be certain that the person you appoint to be your healthcare agent understands your wishes and will abide by them. Your agent has the legal right to make decisions for you even if close family members disagree. However, should close family members express strong disagreement, your healthcare agent and healthcare provider may find it extremely difficult to carry out the decisions you would want.

If you foresee that your healthcare agent may encounter resistance from your family members, the following steps can help:

- Communicate with family members you anticipate may object to your decisions.
- Tell them in writing whom you have appointed to be your healthcare agent and explain why you have done so.
- Let them know that you do not wish them to be involved with decisions about your medical care and give a copy of these communications to your healthcare agent as well.

Give your primary physician copies of written communications you have made. Prepare a more specific, written living will. Make it clear in your documents that you want your agent to resolve any uncertainties that could arise when interpreting your living will. A way to say this is: "My agent should make any decisions about how to interpret or when to apply my living will".

An important part of communicating your end-of-life wishes is discussing with your loved ones what you may need from them if you are faced with a life-limiting illness. Some questions that you may want to ask are:

- Will you seek out information about my illness, advance directives, your roles as caregivers, and what to expect as I near the end of life?
- Will you respect my wants and needs, even if they are different from what they used to be and if you don't agree with my choices?
- If I cannot communicate for myself, will you advocate for me to make sure that what I want is done, even if you would not make the same choices yourself?

How to Talk with Your Healthcare Providers

Talking with your doctor or healthcare providers about your end-of-life wishes is a discussion to have before a crisis occurs. Chances are that he or she is waiting for you to start the conversation.

When you discuss your concerns and choices:

- Ask your doctor to explain treatments and procedures that may seem confusing before you complete your directives.
- Talk about pain management options.
- Let your doctor know that you are completing your advance directives.
- Make sure your doctor is willing to follow your directives. The law does not force physicians to follow directives if they disagree with your wishes for moral or ethical reasons.
- Give your doctor a copy of your completed directives. Make sure your doctor knows the name and telephone number of your appointed healthcare agent.
- Assure your doctor that your family and your appointed healthcare agent know your wishes.

You may ask your doctor specifically:

- Will you talk openly and candidly with me and my family about my illness?
- What decisions will my family and I have to make, and what kinds of recommendations will you give to help us make these decisions?
- What will you do if I have a lot of pain or other uncomfortable symptoms?
- How will you help us find excellent professionals with special training when we need them (e.g., medical, surgical and palliative care specialists, faith leader, social workers, etc.)?
- Will you let me know if treatment stops working so that my family and I can make appropriate decisions?
- Will you still be available to me even when I am close to the end of my life?

Talking with Others about Their End-of-Life Wishes

Even if you have done everything to communicate your own end-of-life 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 end-of-life wishes with you. Here are a few helpful pointers to keep in mind as you plan for having this conversation:

Select an Appropriate Setting

Plan for the conversation; find a quiet, comfortable place that is free from distraction to hold a one-on-one discussion. Usually, a private setting is best.

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 would 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 would feel better if we did.”

Know What To Expect

Keep in mind that you have initiated this conversation because you care about your loved one’s wellbeing – especially during difficult times. Allow your loved one to set the pace. Try to focus on maintaining a warm and caring manner throughout the conversation by showing your love and concern:

- Nod your head in agreement
- Hold your loved one’s hand
- Reach out to offer a hug or comforting touch

Questions you may want to ask your loved one about his or her end-of-life care wishes include:

- If you were diagnosed with a life-limiting illness, what types of treatment would you prefer?
- Have you named someone to make decisions on your behalf if you become unable to do so?
- How would you like your choices honored at the end of life?
- What can I do to best support you and your choices?

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.

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 you can do are:

- Listen for the wants and needs that your loved one expresses.
- Make clear that what your loved one is sharing with you is important to you.
- 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 those choices.

Having conversations with your loved ones about their end-of-life wishes can be a sensitive discussion. These conversations matter and are needed to learn about your loved one's wishes so that those wishes can be honored at the end of life.