

Communicating Your End-Of-Life Wishes

Decisions about end-of-life care are deeply personal, and are based on your values and beliefs. Because it is impossible to foresee every type of circumstance or illness, it is essential to think in general about what is important to you. Conversations that focus on your wishes and beliefs and why you are making them will relieve loved ones and health care providers of the need to guess what you would want.

It's all about talking...talking with your loved ones about your health care preferences; talking with your doctor about your options so that you can make informed decisions; and talking with your health care agent so your wishes are honored if you can not make decisions yourself. Talking before a crisis can help you and your loved ones prepare for difficult decisions related to health care at the end of life. This section will help you voice your decisions and plans for your care at the end of life to others.

- How to talk with your loved ones about end-of-life care issues
- How to talk with your health care agent about your end-of-life care wishes
- How to talk with your doctor about your end-of-life care wishes
- How to talk with your faith leader about your end-of-life care wishes
- How to talk with your loved ones about end-of-life care issues

When discussing your end-of-life wishes with loved ones, you should consider your:

- Overall attitude toward life, including the activities you enjoy and situations you fear;
- Attitude about independence and control, and how you feel about losing them;
- Religious or spiritual beliefs and moral convictions, and how they affect your attitude towards serious illness;
- Attitude toward health, illness, dying and death; and
- Feelings toward doctors and other caregivers.

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. To ensure that your end-of-life wishes are honored, it is essential to discuss your wishes with your loved ones now – before a crisis hits. 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 and financial planning;
- Before and after annual medical checkups;
- During holiday gatherings, such as Thanksgiving, when family members and loved ones are present.

Discussions might also be prompted by:

- Newspaper articles about illness and funerals
- Movies
- Television talk shows, dramas and comedies
- Magazines and books

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?
- How important is it to be physically independent and to stay in your own home?
- Would you want your health care agent to take into account the effect of your illness on any other people?

One final point: 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 in your life.

Ask Your Loved Ones...

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 disease, advance directives, your roles as caregivers, and what to expect as I get sicker and near the end of life?
- Will you respect my wants and needs, even if they're 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?

- Will you stay with me even if the going gets rough?

How to talk with your health care agent about your end-of-life care wishes

Your health care agent needs to know about the quality of life that is important to you and when and how aggressively you would want medical treatments provided. Talking to your agent means discussing values and quality-of-life issues as well as treatments and medical situations. Because situations could occur that you might not anticipate, your agent may need to base a decision on what he or she knows about your values and your views of what makes life worth living. These are not simple questions, and your views may change. For this reason, you need to talk to your agent in depth and over time.

The following questions may help you discuss these issues with your health care agent:

- How do you want to be treated at the end of your life?
- Are there treatments you particularly want to receive or refuse?
- What are you afraid might happen if you can't make decisions for yourself?
- Do you have any particular fears or concerns about the medical treatments that you might receive? Under what circumstances?

The following questions may also help you to clarify your wishes to your health care agent:

- Would you want to receive aggressive treatments (such as mechanical ventilation, antibiotics, or tube feeding) for a time, but have them stopped if there were no improvement in your condition?
- What kind of treatment would you want if you were in a state of prolonged unconsciousness and were not expected to recover?
- Would you want life support or would you rather receive palliative (comfort) care only? What are your views about artificial nutrition and hydration (tube feeding)?
- Do you want to receive these types of treatment no matter what your medical condition? On a trial basis? Never?
- If your heart stopped, under what circumstances would you want doctors to use CPR to try to resuscitate you?

How to talk with your doctor about your end-of-life care wishes

Do not wait until a crisis occurs before discussing concerns about end-of-life treatments with your doctor. Chances are that he or she is waiting for you to start the conversation.

When you discuss your concerns and choices:

1. Let your doctor know that you are completing advance directives.
2. Ask your doctor to explain treatments and procedures that may seem confusing before you complete your directives.
3. Talk about pain management options.
4. Make sure your doctor knows the quality of life that is important to you.
5. 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.
6. Give your doctor a copy of your completed directives. Make sure your doctor knows the name and telephone number of your appointed health care agent.
7. Assure your doctor that your family and your appointed health care 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 support me in getting hospice care?
- Will you still be available to me even when I'm sick and close to the end of my life?

How to talk with your faith leader about your end-of-life care wishes

It may also be helpful to talk with your faith leader about your wishes and care at the end-of-life from a spiritual perspective. The following are questions to help guide your discussion:

- In what ways is your spirituality/religion meaningful for you?
- How is your spirituality/religion important to you in daily life?
- What specific practices do you carry out as part of your religious and spiritual life (e.g. prayer, meditation, service, etc.)
- How do your religious or spiritual beliefs affect your attitudes toward dying and death?
- Are there religious or spiritual practices or rituals that you would like to have available in the hospital or at home?
- Are there religious or spiritual practices that you wish to plan for at the time of death, or following death?
- When you are afraid or in pain, how do you find comfort?
- You may want to ask your faith leader specifically:
- Will you understand and support my need for my spiritual self to be nourished and to grow, even as my physical being deteriorates?
- If I have negative feelings like frustration, sadness, despair, anger at God or life, will you listen empathetically?
- Will you help me if I have problems communicating with my family or friends?
- Will you continue to visit me even if I get very sick or it is difficult to talk with me?
- Will you visit with my family and help them with their spiritual concerns about my illness?
- Will you just sit and be with me, even if I don't want to talk?

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