

End-of-Life Wishes... **Starting the Conversation**

From seriousillness.org, a community resource for southwest Michigan

You can help the person you care for, and yourself, by initiating a conversation about his or her wishes regarding end-of-life care. Although it is often difficult to speak honestly and openly about death and dying, it can be even more uncomfortable to have to make end-of-life decisions concerning a loved one without having had such a discussion. The majority of people who die from an illness, as opposed to a car accident or some other sudden means of death, will go through a period of days or weeks when they move in and out of consciousness and are unable to talk. This is why it is important to talk, while you still can, about the person's wishes for life sustaining treatment.

Barriers to talking

Most families find that bringing up the topic is the hardest part. Once everyone gets past the initial discomfort, many find themselves relieved to have the issues out into the open. If the time does come when the person who is being cared for can no longer speak for him/herself, family members who know their loved one's wishes are spared the guilt and anxiety of trying to make difficult life-support decisions without previous guidance. As a potential decision maker, you may find it is in your best interest to start the quality of life conversation and encourage the person you care for to write down his or her wishes in an advance directive.

Although 75% of Americans say they are in favor of advance directives, only 30-35% of them actually write one. The biggest barrier is procrastination-not getting around to it. In an ideal world, every adult would have an advance directive, no matter his or her age. Sudden accidents or illnesses occur all too frequently and often take us off guard. Within the context of a serious illness, there may be no time to put this decision off.

Conversation starters

The American Bar Association tool kit is an excellent and very accessible resource to help patients and their families discuss matters concerning end of life care. The kit's articles address topics such as weighing the odds of survival, your personal priorities and spiritual values, how to select a health care representative, and how to be a health care representative.

There probably is no right time or right way to start a discussion about dying. Unless there is a story in the news that provides a good opening, you may want to begin with an indirect reference. For instance, you can talk about a friend who had problems when her parent died because the parent had not spoken with family members or written an advance directive. By expressing the personal distress you would feel if you were in that situation, you then can shift to asking the person you care for what he or she would like to have done "just in case." Many people who are sick care very deeply about not causing their family members pain or anguish. Once they realize that not talking about the situation will make it harder on the ones they love, they often can get past their resistance. Some are even relieved because they had wanted to talk about it but didn't know how to bring up the subject!

Sometimes it helps to open the conversation by acknowledging how awkward you feel: "I have something on my mind that is really uncomfortable to talk about, but I feel we need to. I wouldn't be a good [son/daughter/wife] if I didn't find out about your wishes for care if you get to the point at which you can't express them yourself."

Alternatively, if you know that the person you care for is very particular about how things are done, you might want to start the conversation by emphasizing his or her ability to remain in control, even at the end, through an advance directive. People with a serious illness often feel powerless about their disease and their situation. By planning ahead for their care, they will at least be able to direct those things that are still within their power to control.

Some people say their attorney advised them to have the conversation: "My attorney was talking to me about my need for an advance directive, and I realized I don't know much about you and your wishes." Others might start it by noting something about famous people. For instance, "Neither Richard Nixon nor Jackie Kennedy was on life support when they died. I wonder if they had an advance directive."

Responding to resistance

Here are a few of the ways people often respond when someone brings up the subject of end-of-life decisions:

"It'll be okay. I'll beat this thing. We don't need to discuss life support."

Denial is one of many ways we cope with problems that seem overwhelming. Although it is frustrating for family members, it can be a very important strategy for the person who is confronting mortality. However, it doesn't relieve you of the need to have the conversation. Rather than force the person you care about to accept the terminal nature of the disease, you can frame your need for a conversation in the context of "just in case." In a gesture of unity, you could also decide to make an advance directive yourself and suggest that the two of you do it together. This helps prevent the person who is ill from feeling marginalized and set apart. As a side benefit, it can provide you with an advance directive. People with terminal illnesses are not the only ones who need such a document. Accidents happen all the time, and those who may have to care for you would likely appreciate having a directive to help them make decisions on your behalf.

"It's all in God's hands."

Those who are religious or have strong life philosophies may believe the moment of death is out of our control. Whether or not you agree with these beliefs, you can affirm your loved one's conviction and still point out that "a Higher Power has given us the responsibility to determine how we live up until death." You can communicate your need to know more about the person's wishes in case he or she is unable to describe those wishes when they are needed.

"It's too painful to talk about. Besides, talking about it is bad luck. It will only make it happen."

Rather than challenge your care receiver's beliefs about a premature demise, focus instead on the pain it will cause you if you don't have the discussion. You can first acknowledge his or her pain and discomfort with the subject. You can then share that you too are in anguish at the prospect of making tough decisions and living with the guilt of making a decision that is different than what he or she would have wanted. You can also acknowledge discomfort by not insisting on an immediate conversation. Instead you can ask to set up a specific time in the next few days when the two of you can get together and talk. Sometimes spending a little time with the idea can make it easier to address later.

“There’s no need to talk. You know me. I don’t want any heroics.”

Although this is a simple, straightforward response, unfortunately end-of-life decisions are not always about heroic measures. For instance, from what this person has said, one could reasonably assume that he or she would not want cardiopulmonary resuscitation (CPR), but what about antibiotics in the case of an infection with pneumonia? Or what about tube feeding if he was no longer taking in food or water?

When family members disagree

The person who is ill may have very clear thoughts about what he or she wants in terms of care at the end of life, but family members may not agree. This situation can make things very difficult for the professionals involved. They are legally and ethically bound to follow the patient’s wishes. If all the paperwork is complete and available, then there is no question about what will be done.

Professionals recommend that you keep several copies and distribute them liberally so they are not difficult to find when they are needed. For instance, a safe deposit box is OK, but your doctor and lawyer should have copies, as should your health representative and your local hospital. Some even suggest keeping a copy in the glove compartment of your car and at home in your desk. If the person you care for is homebound, you may want to keep a copy in a drawer by the bedside so it is readily available for emergency medical personnel in case there is a call to 911.

To facilitate access to the advance directive, for a fee you may have it registered with the U.S. Living Will Registry. This organization stores advance directives electronically, enabling hospitals and health providers from around the country to have the paperwork faxed to them 24 hours a day, 7 days a week. Check with your state attorney general as some states are now offering this service for free. You can also register with Google Health and upload an advance directive at no charge.

With all the paperwork in place, your care receiver will have his or her wishes honored. However, that does not mean the situation will be a comfortable one if there is disagreement within the family. If a relative has strong feelings that are contrary to the wishes of the patient (whichever direction they lean), you would do well to resolve the conflict as soon as possible. Bringing in a professional such as a counselor, social worker, chaplain, or other spiritual advisor can help immeasurably. These professionals can help the patient express his or her feelings about quality of life in a safe environment. They can also provide opportunities for the dissenting family members to not only be heard, but also be guided to an understanding and acceptance of the patient’s decision. Time and resources spent gaining family consensus before the death will be a good investment for helping everyone constructively process events after their loved one has died.

For more information on Advance Directives and end-of-life resources, please visit:

www.hospiceathomecares.org

www.lakelandhealth.org/advancedirective

(269) 429-7100
(800) 717-3811
www.hospiceathomecares.org



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