Planning for End-of-Life Care Decisions

Because of advances in medicine, each of us, as well as our families and friends, may face many decisions about the dying process. As hard as it might be to face the idea of your own death, you might take time to consider how your individual values relate to your idea of a good death. By deciding what end-of-life care best suits your needs when you are healthy, you can help those close to you make the right choices when the time comes. This not only respects your values, but also allows those closest to you the comfort of feeling as though they can be helpful.

There are several ways to make sure others know the kind of care you want when dying.

Talking About End of Life Wishes

The simplest, but not always the easiest, way is to talk about end-of-life care before an illness. Discussing your thoughts, values, and desires will help people who are close to you to know what end-of-life care you want. For example, you could discuss how you feel about using life-prolonging measures or where you would like to be cared for. For some people, it makes sense to bring this up at a small family gathering. Others may find that telling their family they have made a will (or updated an existing one) provides an opportunity to bring up this subject with other family members. Doctors should be told about these wishes as well. As hard as it might be to talk about your end-of-life wishes, knowing your preferences ahead of time can make decision making easier for your family. You may also have some comfort knowing that your family can choose what you want.

On the other hand, if your parents are aging and you are concerned about what they want, you might introduce the subject. You can try to explain that having this conversation will help you care for them and do what they want. You might start by talking about what you think their values are, instead of talking about specific treatments. Try saying something like, “when Uncle Walt had a stroke and died, I thought you seemed upset that his kids wanted to put him on a respirator.” Or, “I’ve always wondered why Grandpa didn’t die at home. Do you know?” Encourage your parents to share the type of care they would choose to have at the end of life, rather than what they don’t want. There is no right or wrong plan, only what they would like. If they are reluctant to have this conversation, don’t force it, but try to bring it up again at a later time.
Advance Directives and Other Documents

Written instructions letting others know the type of care you want if you are seriously ill or dying are called *advance directives*. These include a living will and health care power of attorney. A *living will* records your end-of-life care wishes in case you are no longer able to speak for yourself. You might want to talk with your doctor or other health care provider before preparing a living will. That way you will have a better understanding of what types of decisions might need to be made. Make sure your doctor and family have seen your living will and understand your instructions.

Because a living will cannot give guidance for every possible situation, you probably want to name someone to make care decisions for you if you are unable to do so for yourself. You might choose a family member, friend, lawyer, or someone in your religious community. You can do this either in the advance directives or through a *durable power of attorney for health care* that names a *health care proxy*, who is also called a *representative, surrogate, agent, or attorney-in-fact*. “Durable” means it remains in effect even if you are unable to make decisions. A durable power of attorney for health care is useful if you don’t want to be specific—if you would rather let the health care proxy evaluate each situation or treatment option independently. A durable power of attorney for health care is also important if your health care proxy, the person you want to make choices for you, is not a legal member of your family. Of course, you should make sure the person and alternate(s) you have named understand your views about end-of-life care. If you don’t name someone, the state you live in probably has an order of priority based on family relationships to determine who decides for you. A few states let people name a health care proxy by telling their doctor, without paperwork.

Don’t confuse a durable power of attorney for health care with a *durable power of attorney*. The first is limited to decisions related to health care, while the latter covers decisions regarding property or financial matters.

A lawyer can prepare these papers, or you can do them yourself. Forms are available from your local or State government, from private groups, or on the Internet. (See *To Learn More* below.) Often these forms need to be *witnessed*. That means that people who are not related to you watch as you sign and date the paperwork and then sign and date it themselves as proof that the signature is indeed yours. Make sure you give copies to your primary doctor and your health care proxy. Have copies in your files as well. Hospitals might ask for a copy when you are admitted, even if you are not seriously ill.

Sometimes people change their mind as they get older or after they become ill. Review the decisions in your advance directives from time to time and make changes if your views or your health needs have changed. Be sure to discuss these changes with your health care proxy and your doctor. Replace all copies of the older version with the updated ones, witnessed and signed if appropriate.
You should also give permission to your doctors and insurance companies to share your personal information with your health care proxy. This lets that person discuss your case with your doctor and handle insurance issues that may come up.

Do you live in one state, but spend a lot of time in another? Maybe you live in the north and spend winter months in a southern state. Or possibly your children and grandchildren live in a different state and you visit them often. Because states' rules and regulations may differ, make sure your forms are legal in both your home state and the state you travel to often. If not, make an advance directive with copies for that state also. And make sure your family there has a copy.

To view the original article and find additional resources go to https://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care/planning-end-life-care-decisions