Starting the Conversation

If having a conversation about advance care planning is so important, why is it so hard? Often loved ones are uncomfortable discussing this subject, particularly if they are relatively healthy. However, having a conversation now, before a crisis, is much easier and more valuable than waiting until you are ill. Having time for discussion and reflection also helps families and loved ones understand each other’s views, which will lead to dignity and peace of mind for everyone.

Here are a few tips to help you start the conversation:

• Make a list of your thoughts and wishes.

• Include everyone who will be involved in your care, such as family, friends, a doctor, or clergy.

• Take advantage of specific conversation triggers which can be events such as:
  > The death of a colleague or friend
  > Newspaper articles about illness and funerals
  > Movies
  > Sermons
  > Financial planning
  > Annual medical checkups
  > Family occasions, such as baptisms, marriages, and funerals
  > Magazines and books

• Take the lead by being open and direct during the conversation.

• Prepare to have more than one discussion, understanding that it may take time for your loved ones to understand your wishes.

• If you have trouble talking to your loved ones in person, try an audio recording, or keep a journal or video of what you would like them to know.

We encourage you to begin talking with your loved ones — it could be one of the most important conversations you will ever have.

Tools

Because this is a difficult subject, there are a number of online resources to assist you in making your conversation a little easier.

engagewithgrace.org
Engage with Grace is based on the story of a 32-year-old woman who almost died in the hospital without being able to touch or hold her 2-year-old daughter. The website includes a 10-minute video telling the woman’s story.

americanbar.org
This consumer tool kit for health care advance planning is put together by the American Bar Association. It includes several tools to help you in planning.

gowish.org
This is a card game that assists you in thinking about end-of-life considerations and categorizing them as “very important, somewhat important, or not at all important.”

polst.org
In addition to an explanation of the POLST (Physician Orders for Life-Sustaining Treatment), this resource describes how the POLST works with an advance directive.

prepareforyourcare.org
PREPARE can help you make medical decisions for yourself and others, talk with your doctors, and get the medical care that is right for you.
What is advance care planning?

When you become ill, you have the right to choose your treatment options. But what if you became seriously ill and were unable to decide for yourself? Who would speak for you? Would they know what you want and don’t want?

Advance care planning is the process of planning for future medical care should you become unable to make your own decisions due to a life-limiting illness or injury.

Why do I need an advance directive?
An advance directive gives you control over your health care decisions, and provides the information to your health care team for you if you are unable to communicate. It guides the decisions of the health care team and provides comfort to your family, preventing them from guessing what it is that you would want. Studies show that families that engage in the advance care planning process have less stress, confusion, and guilt about their decisions.

When do I need to create an advance directive?
The best time to create an advance directive is before you are sick — when you have a clear understanding about your options and can communicate them to your loved ones and your doctor.

Advance planning glossary

Health care power of attorney: A kind of power of attorney in which someone appoints another person, such as a spouse, adult child, friend, or faith leader, to make health care decisions should the person become unable to do so.

Advance directive/living will: A legal document that communicates wishes about lifesaving medical treatments in the event a person has a terminal condition and is unable to communicate health care directives.

Life-support treatments: Refers to medical or surgical treatments that use artificial means to restore life and without which the patient will die. Life-support treatment can include:
- Antibiotics
- Breathing machine/ventilator/respirator
- Cardiopulmonary resuscitation (CPR)
- Tube-feeding
- Kidney dialysis
- Intravenous (IV) fluids

Comfort measures/comfort care: Medical care provided with the primary goal of keeping a person comfortable rather than prolonging life. Comfort measures are used to relieve pain and other symptoms.

Do-not-resuscitate order (DNR): Indicates that for medical reasons or a terminal condition, CPR is inappropriate in the event of cessation of the heartbeat or breathing.

Documenting your wishes
You have several options to make your loved ones and your doctors aware of your wishes:

- You can prepare an advance directive or living will that states your wishes in written form.
- You can appoint a health care agent and prepare a living will.

The Pennsylvania Advance Health Care Directive (upmc.com/advancedirective) is an example of an easy-to-use living will that talks about your medical wishes but also your personal, emotional, and spiritual needs. It helps you appoint a health care agent. The Pennsylvania Advance Health Care Directive is the advance directive tool UPMC has chosen to provide to patients and employees.

There are several other advance directives available so that you can choose the one that best meets your needs:

- Caring Conversations practicalbioethics.org
- Allegheny County Bar Association acba.org
- Project Grace projectgrace.org
- National Hospice and Palliative Care Organization caringinfo.org
- Five Wishes www.agingwithdignity.org