

Some Things That Have Helped Other People Talk with their Doctors

- Make a list of your concerns and bring it with you. Ask your most important questions first, and make a plan with your doctor to talk about anything you don't have time to cover.
- Bring a list of your medicines. Include any over-the-counter medicines or herbs you take.
- If your doctor changes your medicine, ask for a written list of all the medicines you're supposed to take. Ask what you should do with medicines you don't need anymore.
- Have a family member or friend go with you to doctor visits.
- Ask your doctor to repeat anything you don't understand. Try saying it back in your own words.
- Take notes or have your family member take notes. Use a tape recorder if you like. If something is especially important to remember, ask your doctor to write it down.

Patient Education And Caring: End-of-Life (PEACE) Series

This is general educational information, see your doctor about your own care.

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Living Well with a Serious Illness

Talking with Your Doctor When the Future Is Uncertain

People who are sick enough to be coming to the end of life often have concerns about how to get the best care. So do their families.

Your doctor wants to help you choose the options that are best for you.

For More Information

Agency for Healthcare Research and Quality
Your Guide to Choosing Quality Health Care
2101 E. Jefferson St., Suite 501
Rockville, MD 20852, 1-800-358-9295
<http://www.ahrq.gov/consumer/qntascii/qntcover.htm>

Americans for Better Care of the Dying
4125 Albemarle Street NW, Suite 210
Washington, DC 20016, 202-895-9485
www.abcd-caring.org

Hospice Net
www.hospicenet.org

Growth House, Inc.
www.growthhouse.org

Talking with Your Doctor About End-of-Life Care

Serious illness, death, and dying are hard things to talk about. It is important to find a doctor who you trust and who will take the time to listen to you and your family. Tell your doctor what you understand about your illness. It may help if you think about what is important to you as you face the future—and ask your doctor what to expect.

- As you think about your illness, what is the best or worst thing that might happen?
- What are your hopes for the future? What matters most?
- What are your fears? Are you concerned about suffering? Maintaining your dignity? Being a burden to your family?
- What is most difficult for you about this illness?

It may help to make an appointment just to talk about your concerns with your doctor.

Questions for You and Your Doctor

Questions About Your Care

- What are the options for my care? What usually happens in conditions like mine?
- Will you keep caring for me as long as I live?
- Will I need to go into the hospital or a nursing home? Will you still be my doctor?
- What can hospice provide for me and my family? When is hospice care an option?
- Who should I call when I have questions? Who should I call at night or on weekends?
- How will I get help with insurance questions and medical costs?
- When I'm ready, will you talk with me about how I may die?

Questions About the Quality of Your Life

Tell your physician about how you and your family are managing.

- Is there anything more that can be done to help me live comfortably?
- Is there help for my family?
- Who can I talk to about emotional, social, spiritual, or other concerns?

Some Helpful Words

Comfort Care

Sometimes called palliative care—helps relieve pain and other symptoms and helps improve the quality of one's life.

Hospice Care

A kind of comfort care—offers a broad set of services to help people live their remaining life fully, in dignity, and with little or no pain and other symptoms. Hospice includes help for the family and can be provided around-the-clock in the home, hospital, nursing home, or hospice facility. Services include pain relief, nursing care, spiritual counseling, home helpers, and family support during caregiving and bereavement. Most insurance covers hospice for people expected to live 6 months or less. People who do well may leave and return later.

Planning for the End of Life

- Will I know when my condition gets worse?
- When treatment stops working, will you tell me (or my family)?
- Will I get all the care I want?
- What is a do-not-resuscitate order? A feeding tube?
- How will decisions be made if I am too sick to speak for myself? Do I need a living will or durable power of attorney?
- I want your best advice—but my family and I want to make the final decisions. Will you support us when that time comes?