

How to Talk to Your Doctor About Your End-of-Life Options

Talk With Your Doctor

If you have a serious or terminal illness, it is important to ask and be informed about all available end-of-life options. It is also important that your medical providers know about your priorities and values, and that they are willing to provide you with the care you want.

At your next appointment, discuss end-of-life priorities and concerns with your doctor. Ask about your options, including the benefits and burdens of each so you can make informed decisions. Remember that you and your doctor are partners in your healthcare, and your doctor needs to know what is important to you.

If you are a Medicare beneficiary, you can ask your doctor about adding advance care planning to your annual wellness visit or routine office visit. As of January 2016, Medicare reimburses doctors for 30 minutes of advance care planning with patients. This service includes early conversations between patients and doctors, both before an illness progresses and during the course of treatment, to decide on the type of care that is right for them. It also encourages doctors to make time for lengthy end-of-life discussions and facilitate patient choices.

Before You Have the Conversation

- > Be sure to make it clear you want to talk about end-of-life care. It helps your doctor and the healthcare team to know in advance.
- > Decide whether you want a family member to join you when you talk with your doctor. If you prefer a private conversation, let the staff know when you make the appointment.

Studies show the single most powerful thing a person can do to improve the chance for gentle dying is, simply and courageously, to talk about it with your doctor and family.

- > Bring your advance directive and any other information about your end-of-life care priorities with you.
- > You may also bring a copy of our Good to Go Toolkit to review your priorities and particular wishes with your doctor. The Good to Go Toolkit and other helpful tools are available through our End-of-Life Information Center at <https://www.compassionandchoices.org/eolc-tools/>.

Starting the Conversation

- > Talk with your doctor — not office staff, a nurse or a physician's assistant — about your values and priorities for your end-of-life care.
- > Only you can decide what you want.
- > You may want to use our Questions to Ask Your Doctor Checklist below as a guide. The questions are designed to begin the conversation with your doctor.

Questions to Ask Your Doctor About End-of-Life Care if You Are Terminally Ill

Bring this list of questions with you to your doctor's appointment when you're ready to talk about your end-of-life choices. Not all questions may suit your preferences — just choose the ones that matter to you.

Please provide me with the facts; are you saying that there is no cure and this is a terminal illness?

What can I expect from this illness? What is my life expectancy?

What can I expect about my ability to function on my own?

What big changes in my health should I be prepared for?

Can you tell me the full range of my end-of-life options, including the benefits and burdens of each so I can make a fully informed decision? Please include options such as continuing or stopping curative treatment, voluntarily stopping eating and drinking, hospice, palliative sedation, and medical aid in dying.

Will you consider my priorities around quality of life, especially when making recommendations for my care?

Will you make sure my healthcare priorities around quality of life are added to my medical record?

What end-of-life care do you recommend?

Will you refer me to hospice as soon as I am eligible?

When I near the end of life will I be able to spend my last days at home?

Am I eligible for medical aid in dying? If not, what will my condition look like when I am eligible? Would you give me a prescription for aid-in-dying medication if I qualified and it was authorized in our state?

If I decline and can't make decisions for myself, I've designated [name of healthcare proxy] to make decisions for me in [name of document]. Can you assure me you would help them honor my wishes and allow a natural death for me if the quality of my life has deteriorated?

Will you or one of your staff help me create an advance directive and/or will you write a physician order for life-sustaining treatment (POLST) for me?

For Those Who Are NOT Terminally Ill But Want to Discuss End-of-Life Care With Their Doctor Now.

As mentioned above, the time to plan for end-of-life care is before you need it. You can begin this conversation with your doctor now so that in the event you are diagnosed with a terminal illness, you and your doctor will have a foundation for moving forward with honoring your choices.

I value quality of life. Should I become terminally ill, I would like to have the full range of end-of-life options explained to me including the benefits and burdens of each care option. I hope you will honor my decisions and respect my values, as I respect yours. Would you provide me with the options that I might be interested in? If you will never be willing to honor my requests, please tell me now.

More Tips

- > When you don't understand what your doctor is saying, ask them to say it another way.
- > This can be just the first of many talks with your doctor. You don't have to cover everything in one visit.
- > Make sure your priorities and choices are documented in your medical record.

- Your preferences may change as time passes. Make sure you talk with your doctor about any changes to your end-of-life care priorities.

Be Ready for Your Doctor's Response

Make sure you and your doctor fully understand each other. What may seem clear to you isn't necessarily what your doctor means. Ask more questions.

Your doctor's response:

"I will help you," or "I will be there for you when the time comes."

What it means:

This could mean many things, such as "I will refer you to hospice and palliative care," or "I will be sure you are kept comfortable, but I may not provide medical support for your decision to choose palliative sedation, voluntarily stopping eating and drinking or write request aid-in-dying medication."

Your response:

Ask follow-up questions so you can get clarity. "Will you provide medical support for my decisions when the time comes? Will you write a medical aid-in-dying prescription for me when the time comes?"

Your doctor's response:

"Let's talk about that when the time comes," "We can talk later," or "For now, let's focus on treatment."

What it means:

It may simply be that there is not enough time. Or it may be that your doctor is not listening closely to your needs. Gently or firmly let your doctor know that you want to talk about these issues now.

Your response:

It's your right to talk about it, so you can insist on it. "I really want to talk about it now," or "Can we make another appointment when we have time to talk about it?"

Your doctor's response:

"I don't know anything about medical aid in dying."

What it means:

Your doctor may have no experience with medical aid in dying, even if your state has a law authorizing it.

Your response:

"I can put you in touch with Compassion & Choices' Doc2Doc program. They have physicians who can talk with you physician-to-physician, provide you with a packet of information and answer your questions. The toll-free number is 1-800-247-7421."

If your doctor has questions

Let your doctor know about Compassion & Choices' Doc2Doc Consultation program and that they can contact one of our medical directors, each with years of experience in end-of-life medical care, by calling 1-800-247-7421.

When You and Your Doctor Disagree

If your doctor declines your request for palliative sedation, voluntary stopping eating and drinking or medical aid in dying, first explore why. Some healthcare systems, particularly Catholic healthcare facilities, do not support the full range of patient options.

Consider seeking a referral to another doctor or re-establish care with a new healthcare system that supports patient choice.

A doctor who says, "I would never do that," or, "I'm against that," may be less willing to provide palliative (comfort) care or give you an early referral for hospice.