






Your Guide for Talking with a Health Care Team

How to talk about the care that is right for you or someone you care for.

Institute *for* Healthcare Improvement

the **conversation** project

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We can't plan for everything. But we can talk about what is most important — in our life, and in our health care — with those who care for us.

The Conversation Project wants to help everyone talk about their wishes for care through the end of life, so those wishes can be understood and respected. We created this guide to help you start a conversation with a health care team (and keep talking) so you can have a say in your health care — or help someone you care for have a say — today and tomorrow.

Since anyone's health status can change suddenly, it's a good idea to start the conversation right away, before a medical problem happens. That way, your care plan can be built on what's important to you — and available when you need it.

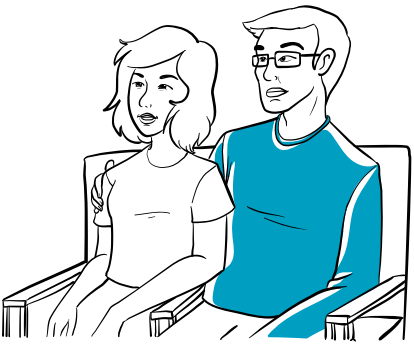
It's also important to talk with those close to you about what matters in your care, and to choose a proxy — someone who can speak on your behalf if you can't make your own health care decisions. If you haven't had those conversations yet, visit our Conversation Starter Guide and Guide to Choosing a Health Care Proxy for help.

In this guide, we refer to the members of a health care team — doctors, nurses, physician assistants, nurse practitioners, and others — as "clinicians."

Since you can use this guide to advocate for yourself or someone else, when we refer to "you," we mean you or the person you're advocating for.

This document does not seek to provide legal advice.





It always seems too soon, until it's too late. We'll help you take it step by step.

How to use this guide

You can use this guide as a workbook to make notes on WHO to talk to, HOW to set up an appointment, and WHAT to say when you get there.

STEP 1
Think About What Matters to You 4

STEP 2
Plan Your Talk 5

STEP 3
Start Talking. 7

STEP 4
Keep Talking 10

Definition of Medical Terms. 11

If you are completing this document on a computer, first save it to your desktop with a name you can easily find again. Then open your saved document and type in your answers. (Otherwise, what you type will not be saved.)

Completing it on your computer will create a digital document that you can easily share with others.

STEP 1

Think About What Matters to You

Why is it important to talk to your health care team?

Talking with a health care team helps create a care plan that's right for you — a plan that will be available when you need it. When you share your values, preferences, and wishes with your clinicians, you become part of the team that helps you get the right care.

The best care is possible when you and your clinicians share in decision-making about tests, treatments, and care plans based on good medicine and your preferences and values. Together, as one team, you can decide which treatments are right for you — especially if your health changes.

Think about what matters to you — and what you will say.

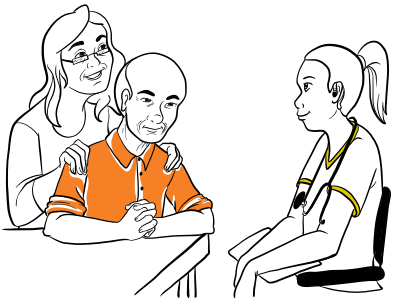
As you get ready to start a conversation with your clinicians, there are some helpful ways you can prepare. First, if you haven't already thought about what matters most, read our Conversation Starter Guide for help taking that first step. Here's a good place to start.

Try finishing this sentence:

- What matters to me through the end of my life is _____.

  Answering this question can help you start thinking about what you need to have a good life. Some ideas: being able to recognize my children; being independent; being able to spend time with the ones I love.

If you've already completed our Conversation Starter Guide, what else do you need to think about or do before you feel ready to have a conversation with your clinicians?



STEP 2

Plan Your Talk

As you plan your talk, keep in mind:

- You can have a say in your care now. You don't need to wait for your clinicians to start a conversation. You can talk with your clinician in person or by phone or computer.
- The goal of this conversation is not to make specific medical decisions. Instead, it's an opportunity for your health care team to listen and learn about what is important to you. For example, you may have concerns about how your care could affect your financial situation. In this conversation, you can talk with your clinicians about the costs of certain care decisions.
- If you are diagnosed with a serious illness, you could talk to your health care proxy or another support person. That person can join you at an upcoming appointment in person or by phone, so they understand your diagnosis, treatment, and decisions. You can even ask them to take notes. For example, you can tell your clinicians, "I brought my partner with me today. I want to talk to you about my health care wishes, and she's my proxy. I want her to be part of this."
- It can be helpful to have a support person or proxy with you. However, it's also OK if you're not ready yet to share your health information. If you want to have a private conversation with your clinicians, you can ask for one when you arrive. You can even call before your appointment to set it up. That way, the team can arrange a private conversation in a way that won't make your support person feel uncomfortable. You might say, "Could you please tell Dr. Jones that, at my visit on Friday, I'd like to talk to her alone about my future health care decisions? My sister is coming with me and it would help if Dr. Jones could ask her to step out for the last part of the visit."

› Next, you can think about who to talk to, when, and what you want to talk about.

You can talk to your primary care doctor or anyone else involved with your health care. It's important to choose someone you're comfortable talking to. If possible, choose someone who already knows you and your health status.

WHO do you want to talk to?

Check all that apply:

- ◯ My primary care doctor
- ◯ My nurse practitioner or physician assistant
- ◯ My nurse
- ◯ My specialist, if you have a chronic condition (heart doctor, lung doctor, psychiatrist, etc.)
- ◯ My therapist, social worker, or psychologist
- ◯ My case manager
- ◯ My admitting team, if you are hospitalized
- ◯ My staff physician or nurse at your nursing home or assisted living facility
- ◯ My palliative care specialist
- ◯ Other: _____

› Then, plan for a good time to start the conversation (ideally as soon as possible).

WHEN would be a good time to talk?

Check all that apply:

- ◯ At my next annual physical, in-person or virtually
- ◯ At my next routine follow-up appointment, in-person or virtually
- ◯ After a visit to the emergency room
- ◯ Before surgery
- ◯ When I'm admitted to the hospital
- ◯ If I have a new diagnosis (for example, heart or lung disease, cancer)
- ◯ Other: _____

Would you like an interpreter to be there when you talk to translate?

- ◉ Yes
- ◯ No



STEP 3

Start Talking

When you're ready to talk to your health care team, here are some ways to start a conversation.

- Call or email your clinicians' office before your appointment, if possible.

  You can plan to have this talk at an in-person or virtual visit. It helps your clinicians if they know in advance that you want to take time during your visit to discuss your care preferences, now and through end of life. That way, they can make sure to set aside time for this important conversation.

  You might say:

  - "Could you please tell Dr. Jones that, at my visit on Friday, I'd like to talk to her alone about my future health care decisions?"

- Prepare your opening line.

  When you meet with your clinician, start simply. You might say:

  - "I want to talk about my goals for care and living with my serious illness."
  - "I want to have a conversation about my wishes for end-of-life care."

Share what matters.

Here are some things you can talk about:

- You might say, "Have you heard about The Conversation Project? It's a campaign to help people talk about their preferences for care through the end of life. Here's what I've thought about so far."
- You can share the information in this guide, especially Step 1 ("Think about what matters to you") and Step 2 ("Plan your talk").
- You can complete our Conversation Starter Guide and bring it with you to your appointment.
- Our What Matters to Me Workbook is another resource to help prepare you for the conversation.

You may want to share your thoughts about illnesses, treatments, and health care experiences of people close to you. Below are some examples just to get you started. There are no "right" or "wrong" preferences when it comes to care through end-of-life. The important thing is to share what matters to you.

- "My cousin was diagnosed with a serious illness, and didn't want to know how quickly it would progress — but I would want you to tell me your best estimate for how quickly it would progress."
- "My nephew recently died in the hospital after weeks of aggressive care. That's what he wanted, but I don't want that. I think I might prefer to die at home. How can we make a plan for that when the time comes?"
- "I am concerned about health care costs and how they may affect my finances. Who can I talk to to understand the costs of different treatments?"

You can also tell your clinicians about important personal events you want to be a part of. You might say:

- "My best friend is getting married later this year and I'd really like to be there. Can you help me understand what I might need to do to make it to the wedding?"

What to do in case of a health emergency.

Sometimes, it's not possible to plan ahead for a conversation. When a health crisis occurs, it's just as important to advocate for what matters to you in your care. It's helpful if you or your advocate speaks to your clinicians about your care right away, and share the above points about your preferences. That way, your clinicians can have them in mind when planning your care.

Ask questions.

To make sure you have all the information you need, ask a lot of questions. It is OK to ask questions of your clinicians, even if it feels uncomfortable or scary. Having a say in your care is only possible when you have all the information you need. Having a say will also help your clinicians make the best possible decisions in your care.

If you want to know about numbers and statistics, ask if they are available. If you don't understand something, ask your clinicians to explain it in a different way. You can even ask your clinicians to write things down for you.

If you have a medical condition, here are some questions you can ask to help you understand it and make plans for your care.

- "Can you tell me what I can expect from this illness? What is my life likely to look like 6 months from now, 1 year from now, and 5 years from now?"
- "What can I expect about my ability to function independently?"
- "What are some possible big changes in my health that I should be prepared for?"
- "What costs should I expect with this plan?"
- "What can I expect to get better if I choose this treatment? What are my other choices?"
- "What can I expect if I decide to do nothing? What will my quality of life be like?"

Ask your clinicians to write down your discussion, and your wishes, in your medical record. When you choose a proxy, let your clinicians know who that person is right away.

If you have started to create an advance directive, bring that with you to the appointment. If not, you can ask your care team for the form. An advance directive is an important legal document that helps make sure your choices are known.

Plan to talk again in the future.

If you need to make a decision, take the time you need. You might say:

- "I'd like to talk this over with my siblings. Can we have another conversation in a couple of weeks?"

STEP 4

Keep Talking

It's important to have many conversations with your clinicians over time. The conversation can continue and change as your health changes. To get the best care possible, keep your clinicians updated so they understand what's most important to you.

Here are some of the reasons you may need to start conversations more often.

My clinician doesn't want to talk or doesn't agree with my choices.

It's your right as a patient to talk about the kind of care that is right for you. You can and should advocate for yourself. Here are some things you can say or do.

- Mention that your condition can change over time. "Yes, I am doing well now, but things can change at any moment and I want us both to be prepared."
- If there isn't enough time, suggest scheduling another appointment specifically to focus on the conversation.
- If you continue to feel resistance, or your clinician asks you to make choices you don't agree with, you may need to consider seeking a new clinician.

You know yourself — and what you want from your health care — best. It's important for you to have a say in your care.

I got two different opinions from two of my clinicians.

If this happens, it's a good idea to arrange a meeting or call with both clinicians to talk at the same time. We do this in other areas of life when people have different opinions. It's extra important when it comes to your health care.

If you're not comfortable bringing together two clinicians at the same time, you can ask them each separately about the disagreement. Tell them you've received a different opinion and you'd like help understanding the difference.

Definitions of Medical Terms

Here are some common medical terms that might come up during your conversations with your health care team.

Advance Care Planning

This is the process of making plans now for the care you want in case of a serious illness. It includes stating your preferences around your health care through end of life, and choosing a representative — your "proxy" or "agent" — to make decisions for you if you become unable to express them yourself.

Advance Directive

An important legal document that helps make sure your choices are followed, the advance directive has two parts: the health care proxy and your living will.

1. Health Care Proxy: This is the part of the advance directive where you name the person you have chosen to make health care decisions on your behalf, if needed, as well as an alternate if your first choice is unavailable. The title can vary by state, but this person may be known as a health care proxy, agent, power of attorney for health care, or surrogate decision-maker.
2. Living Will: This is the part of the advance directive where you describe your preferences and wishes for your health care if you cannot speak for yourself. These are many of the same things you may have thought about and discussed throughout this guide.

Hospice Care

This approach to care focuses on providing a person with a terminal illness (expected to live six months or less) and their family with comfort, pain relief, support services, and spiritual care.

Palliative Care

The goal of palliative care is to help people get relief from pain, emotional distress, spiritual distress, and other symptoms that can occur during an illness. A person can receive palliative care at any stage of a serious illness, including when pursuing potentially life-extending treatments.

POLST

POLST has different names in different states. At the national level, it is simply called POLST: Portable Medical Orders, or POLST for short. POLST is an approach to end-of-life planning based on goals of care conversations between patients, people they care about, and their health care team. It's designed to help patients who are seriously ill or have advanced frailty choose the treatments they want or do not want, and make sure that their wishes are documented and honored. These treatment wishes are documented on a portable medical order called a POLST form. You can learn more about POLST at www.polst.org

Here are brief explanations of some of the treatments your care team might mention in a conversation about a serious illness.

Intubation/Mechanical Ventilation

If a person can't breathe on their own, a breathing tube might be placed in their throat and into their lungs. The tube connects them to a machine that can breathe for them. Mechanical ventilation can be used short-term or long-term, depending on the person's needs and preferences.

Artificial Nutrition and Hydration

If a person can't eat or drink on their own, fluid and nutrients can be delivered into a vein or through a tube in their nose or stomach. This tube is sometimes called a "PEG tube," which stands for percutaneous endoscopic gastrostomy. This approach can be used short-term or long-term, depending on the person's needs and preferences.

CPR (Cardiopulmonary Resuscitation)

If a person's heart stops, attempts are made to restart their heart with chest compressions or electricity. It can be helpful to know that CPR sometimes results in broken ribs.

DNR (Do Not Resuscitate)

An order in a patient's medical chart that instructs the health care team not to try to revive the patient if their breathing or heart has stopped. If this is your preference, it is helpful to have a DNR in your living will as well as in your medical file if you go to a hospital. Otherwise, without a DNR, the health care team would make efforts to restart your heart or breathing.

Comfort Care

When care designed to cure a condition is no longer likely to help, medication or other non-invasive care is used solely to keep a person comfortable through the end of life.

A Time-Limited Trial of Life-prolonging Therapies

This is a short-term trial (usually days) of all possible life-saving medical care intended to extend the length of life. It's based on the understanding that if treatment is not successful and it appears that a person's chances of survival are low, or that their quality of life will conflict with their preferences, they would discontinue the treatments focus on extending the life, and focus on the person's comfort.

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