Someone I care about received a tough diagnosis. How can I help?

We're sorry to hear the news and are glad you're available to be supportive. 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 matter most.

To make that easier, we'll share some ideas here that can be helpful when someone you know has a serious illness, and some suggestions for how to talk with the person who is on your mind. First, we want to make two important things clear:

- This is a list of ideas, not a to-do list. You can use it as a reference. It includes three main ideas: 1) how to talk about what's important, 2) choosing a health care proxy, and 3) talking with the health care team. It also has some general tips for having the conversation, including how to begin. You do NOT need to do everything on the list. Please pick the parts you find most helpful.
- Follow the lead of the person you want to support. You may feel unsettled, stressed, angry, sad, or frustrated. You may have a picture in your mind of what you would like to do. Please work to keep your person at the center of each conversation and decision. This can be hard, especially if their decision is different than what you would choose for yourself or them.

Three ideas to consider

1. If the person wants support to think and talk about the care that's right for them...

Take a look at the <u>What Matters to Me Workbook</u>. This workbook can help your person think about what is most important to them and come up with a plan to talk with their health care team. It can also help them plan for how they want to talk about their illness with others. For example, they'll see questions like these:



2. If the person could use guidance on picking someone to make health care decisions for them if needed...

Try the <u>Choosing a Health Care Proxy</u> guide. A health care proxy is the one person who speaks on someone's behalf if they can't make their own health care decisions. (Sometimes a proxy is also known as a health care agent, power of attorney for health care, or surrogate decision-maker.) If the person on your mind is unable to speak due to an accident or illness, their proxy would advocate for them. This guide talks about what a proxy does, who to pick, and tips for having a conversation with that person. Here are some examples:

- Will the person make decisions that follow your wishes?
 - Your proxy may need to make certain decisions on your behalf even if their own wishes are different from yours. This may be emotionally difficult for some people.
- Talk about what it means to be a proxy.
 - They would have the legal power and responsibility to make medical decisions for you if you're unable to make them for yourself.
 - They can talk with your doctors, read your medical records, and make decisions about tests, procedures, and other treatment.

(If you already are someone's proxy, check out <u>this guide for being a health care proxy</u>. There are also specialized guides if you are caring for a person living with <u>Alzheimer's</u> <u>or another form of dementia</u>, or for a <u>child with a serious illness</u>.)

3. If the person would like help with conversations they will have with the health care team:

Look at the <u>Talking with a Health Care Team</u> guide. For either the person with the serious illness or their proxy, this guide has tips on how to talk with a health care team about goals for care and next steps. It also has guidance for what to do if two different members of the team have different opinions about the best plan. Here's a look inside:

the conversation project

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."

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?"

Here are a few ways you might "break the ice" to bring up these ideas with the person you care about.

Parts of the conversation will depend on your relationship with this person and the role you might play in their care. Please make your own changes and say what feels best for your situation. Here are some ideas:

- "I recently heard about The Conversation Project, and they have some free resources to help people with similar diagnoses think and talk about the kind of care they want to receive. Would it be helpful if I look into it and share the most helpful resources with you?"
- "I love you and I want you to live your best life until the very end. What should I know and what can I do to ensure that?"
- "As you think about your future with your illness, what gives you strength right now? Do you have any fears and worries? How can I best support you?"
- "I was thinking about what happened to _____, and it made me realize _____."

For example: You might talk about someone else you know with a serious illness, or someone in a movie or book, and how their experience made you want to talk about what's important to your person.

"When it comes to talking about illness, we usually _____, and now I'm thinking _____."

For example: "I know we don't really talk about this stuff in our family, but I'm concerned we'll be caught off guard if Mom ever needs us to step in on her behalf."

• "I think ______ is most important to you in the coming weeks, is that right?"

For example: Keeping your pain under control even if you can't walk around as much, getting enough medical care, not getting too much medical care

• "I want to make sure we know what's most important to you, so we can have a more useful conversation with your health care team."

If your person doesn't have the energy or interest to have long conversations, that's okay. You might try asking a few questions about what matters most to them, whether they have a health care proxy or not, and whether they have any concerns about the type of care they might receive. Start there and follow their lead.

As you begin these conversations, we offer these tips.

- Be sure to listen. Remember, you don't need to solve everything with one conversation.
- Avoid talking a lot about your own wishes for them, or what you would want if you were in their shoes.
- Don't force the person to have these conversations if they aren't ready yet or aren't interested at all. Many people are open to these conversations, but if your person isn't, be sensitive. You can try to revisit in the future or accept that it might not be a high priority for them at this time. Your person also might be interested in the materials but not in talking about it with you. That's okay.
- Emphasize the benefits of conversations and the clarity they can provide. Don't focus on negative or scary stories or worries about what could happen.
- Be sure you understand what your person is okay with you sharing (or not) with others about their health and what's important to them.
- Find a good support for yourself. If you're reading this, you likely care a lot about your person. Be sure to find other people to lean on and ways to be kind to yourself. (Avoid leaning on your person or others who are very close to them. For more about this idea, read "<u>How not to say the wrong thing</u>".) This is important both for you and for your person.

As you go forward, please take care and know that The Conversation Project will be here as a resource for you and your person.