

# Talking about your illness with loved ones and caregivers

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This booklet can help you talk with your loved ones about your illness and the future. It is based on what you have already talked about with your clinician.

Talking about your illness with friends and family may not be easy, but it will help them understand what is important to you. It will also help them support you and your decisions and help them prepare for what is ahead.

Before you talk to your loved ones, think about when and where you want to talk. Choose a time and place when you feel relaxed. Be sure you have time to talk for a while. You can use the words in this guide, or use your own words — whatever is easier for you.

## **Start the conversation**

“I am doing OK right now, and even though there is no rush, my doctors think we need to begin talking about my future care.”

“They believe in being prepared and want to know my goals and wishes for medical care.”

“Since you are important to me, I’d also like you to be part of the conversation.”

“If at some point I can’t speak for myself, I want you to be able to make decisions for me. If we can talk about that in advance, I think it will be easier on you.”

## **Check in with your loved one**

### **Understanding**

“What is your understanding now of where I am with my illness?”

### **Information**

“I know that it may not be easy, but I would like to share information about my illness with you. Is that okay?”

“How much information about what is likely to be ahead would you like from me?”

“My doctor and I talked about the outlook for my illness— can I share that with you?”

## **Share what is important to you**

### **Goals & wishes**

“I’d like to share some of my goals that might affect my healthcare decisions. Some things I’m looking forward to are...”

EXAMPLES: Meeting my new grandchild, celebrating my next birthday, etc.

### **Fears & worries**

“My biggest fears and worries about my future with this illness are...”

EXAMPLES: Not being able to make decisions for myself, or having to ask others for help with basic needs.

### **Strengths**

“Several parts of my life give me strength. I want you to know about them so you can help me stay in touch with them if I am having a tough time.”

EXAMPLES: I feel best when I have the people I love around me, which is why the hospital is so tough for me.

### **Abilities**

“I can’t imagine not being able to do certain things...”

EXAMPLES: Not being able to recognize or interact with people, not being able to care for myself, etc.

### **Tough choices**

“I know that we may have to choose between treatments that are hard to go through and more time.”

EXAMPLES: Being in the hospital, having a feeding tube, living in a nursing home, being on a breathing machine, more chemotherapy, etc.

“Here’s how I think about those choices...”

### **Plan to talk again**

“Do you have any questions about what we have discussed?”

“I would like to talk with you about my illness and medical care as my treatment continues. Is that okay?”

“I know this was probably not an easy conversation. How do you feel now that we have talked?”

“Are there other people we should talk with?”

### **TIPS:**

- Pick a time when you feel relaxed and have time to talk.
- Choose a place where you are comfortable.
- You can read the words above out loud or use your own words — whatever feels best to you.
- Remember to talk again with your loved ones / caregivers as your situation or wishes change.

## Notes

You can use this page to write down ideas from your talk, questions for your clinician, or any other thoughts.

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