

# Conversation Guide

## An ongoing conversation...

Advance care planning is a work in progress. That's because as circumstances change, your mind may change, too. Keep the conversation open—revisit your decisions (and update any forms) as often as you need to.

Experts say that a thoughtful conversation with those you trust is the most valuable part of advance care planning. This section offers questions and scenarios to help you discover and share what is most important to you in the face of serious illness.

## How do I start the conversation?

Whether you're talking about your own wishes or trying to find out the wishes of someone close to you, getting started on a care-planning conversation can be difficult. But if your family knows you want to talk, they may be more willing than you think. To bring up the topic of advance care planning, consider the ways shown below.

### Reflect on the experience of someone in your family.

*"When Uncle Martin died, he made it so easy on his children. They all knew what kind of care he wanted and didn't want. Everyone seemed so peaceful in his last days."*

*"I wonder if Grandma would have wanted her life to end like it did. I don't think she would want us to remember her the way she was those last few years."*

### Take your cues from popular culture.

*"Did you see that episode of ER where the guy was on life support forever? I want to talk about how it's going to be for me."*

*"I heard that my favorite actress didn't want any life support at all in her last days. But what I can't figure out is where you draw the line between normal medicine and unnatural intervention."*

### Bring it up when you're attending a funeral or reading the obituaries.

*"I wonder what the last weeks of life were like for these people. When it's my turn, I want..."*

*"It says she died after a long battle with cancer. I'm not sure I want a long battle, if it comes to that. I'd rather have..."*

### Talk in terms of someone else's needs.

*"My doctor says I have to tell him who's going to make medical decisions for me if I can't make them myself."*

*"My lawyer needs to know what kind of end-of-life care I'm planning."*

*"I know you'll feel better if you really understand what I'd want."*

## What do we talk about?

When you first sit down to discuss your future medical care, you may not have a very clear idea about what will be best for you. That's all right. Having this conversation can help you discover what you want. Try the approach below to help you and those close to you understand good ways to handle a variety of possible situations.

### 1 ] Talk about basic VALUES

The way you feel about some things remains constant across many situations. Talk about your basic beliefs and fears about health, illness, and the end of life. This will help give your healthcare agent a better sense of how to make decisions for you in a variety of situations.

*Consider the following:*

- **Do you have fundamental beliefs about life and medicine?**

Do you believe that life should be preserved at all costs? Do you believe that life should not be prolonged through extensive intervention? Are some medical treatments against your beliefs?

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- **Describe what you consider to be a good death.**

Where is a good place to be? Who is there? How long does it take? What happens in the time (days or weeks) before your death?

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- **Which of these do you fear most?**

- Pain
- Losing the ability to think
- Losing the ability to communicate
- Being a financial burden on your loved ones
- Being removed from life support too soon



## 2] Talk about ISSUES that may influence your care decisions

The medical treatment you want depends on your changing health and situation. As you think about what you want, remember that these issues may be a factor:

- **Prognosis.** Given different treatment options, what are the chances that you can regain your health or extend your life? Would your prognosis affect your care decisions? In what way?

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- **Length and invasiveness of treatment.** How long will the treatment(s) last? How much will it hurt? How much will it cost? In what ways—if any—might the answers to these questions affect your decisions about your care?

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- **Setting.** For this treatment or level of care, will you need to be moved to a nursing home or other care facility? What are the chances that you'll be able to return home after this treatment? How do you feel about being hospitalized? What about hospice?

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- **Day-to-day caregiving.** Would you be cared for by a member of your family? By a professional? By a volunteer? What are your feelings about being bathed or fed by a caregiver, if you can't do it yourself?

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### 3] Talk about different SCENARIOS

Even if you've thought about your basic beliefs and the factors that may influence care decisions, it can be difficult to predict the right plan for you. It may be easier to think about what you might want in a specific situation. So talk through these scenarios. What kind of treatment would you want?



- **You've suffered a stroke.** You're alert, but can't communicate or care for yourself. You live in a full-time care center. Your family comes to visit regularly. When spoon-feeding is no longer possible, do you want to be fed through a tube?

Notes: \_\_\_\_\_

- **You've been diagnosed with cancer.** Your doctor recommends chemotherapy. The chemotherapy will likely have severe side effects, including nausea and weakness. Would you be willing to endure the treatment's side effects if your chances of regaining your current health were small—less than 5 percent? Or if your cancer was probably going to end your life, but the chemotherapy might give you 6 more months to live?

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- **You have Alzheimer's disease.** You live with your daughter—but you don't recognize her anymore. She has hired someone to stay with you while she's at work, and the expense is hard on her family. You've had pneumonia three times this year. The next time you get pneumonia, do you want antibiotics, or just comfort care until death comes?

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- **You've been in a chronic vegetative state for 16 months.** Your doctors don't expect you to recover. In your Living Will, you indicate that you don't want to be kept alive on life support. But your children don't agree with each other about withdrawing life support. Would you rather your children follow the wishes outlined in your Living Will, or would you rather they agree with each other on whatever decision is made?

Notes: \_\_\_\_\_