

Advance Care Planning – Conversation Guide

We'd like to think our loved ones will always be healthy, independent, and able to make decisions for themselves, but things can change suddenly. They might have an accident or a serious illness and no longer be able to make decisions or speak for themselves. When that happens, doctors often turn to their loved ones to speak for the person who is hurt or ill. If that happens, will you know what care they would want?

Talking with loved ones now and helping them plan for future medical needs is the best way to make sure that their wishes will be respected. But, talking about this is not always easy.

The Coalition for Compassionate Care of California has developed this guide to help you start the conversation.

In it you will find:

- Suggestions on how to raise the issue
- Responses to concerns they might express
- Questions you might want to ask

As your loved one reflects on and expresses their wishes, we recommend you encourage them to:

- Write their wishes down in an Advance Health Care Directive document. An Advance Health Care Directive is a statement, shared with both family and the doctor, about how someone wants to be treated if they become seriously ill and cannot speak for themselves.
- Appoint a spokesperson – a Healthcare Power of Attorney or “Agent” – you or someone else who understands their wishes and will be able to speak for them if they are unable to do so.

Once you start talking, don't feel that you need to get everything done at once. Rather, view it as a process. Even after your loved one has made their wishes known, these wishes may change over time. Once you've started, however, it will be easier to talk about changes or related issues in the future.

Keep in mind that other family members and loved ones also need to understand your loved one's wishes. Depending on how close they may be, geographically or emotionally, this can be challenging. Encourage your loved one to talk to family members – one at a time or at a family gathering. Offer to support them as they reach out to any who may be resistant. The more those close to your loved one are aware of their wishes, the more likely those wishes will be carried out.

Ways to Raise the Issue

Talk about the recent illness or death of a relative or someone you know, or someone in the news, like a celebrity. What did you think about what happened with so-and-so? Is that the kind of care you would have wanted? Why or why not?

Share an article or story about the topic. Maybe there was a movie, a segment on the evening news, or a TV show that got you thinking.

Use the opportunity of a medical appointment or build on a financial planning session to discuss their wishes.

April 16 is officially “National Healthcare Decisions Day,” with many healthcare organizations, nonprofits, and media outlets participating to encourage these important conversations. This can be a great opportunity to raise the issue. (See <https://theconversationproject.org/nhdd/> for more information and resources.)

Responding to Concerns

“I am feeling fine, so we don’t need to talk about this now. We can wait and handle things as they come up.”

We’d both like to think that you will always be healthy and able to make decisions for yourself. But things can happen suddenly. Things can change. You might have an accident or develop a serious condition and not be able to speak for yourself. So, making your wishes known now will help everyone, including the doctors, be able to care for you the way you want.

Or...

You make decisions every day about your life and your healthcare. I’ve seen how independent you’ve always been, how you have operated on your own for so long. That’s why I want to understand your wishes to make sure that you maintain your independence as long as possible. Why leave really important decisions to chance?

There is no need to talk about this because “The doctor will make the decisions anyway,” or “I trust you (or another loved one) to know what to do,” or “It’s all in God’s hands anyway...”

Though your doctor will help, she or he will still turn to us (your family) to make the choices for you. It will be very difficult for us to know what to do if you haven’t talked about your wishes.

And, it puts a real burden on all of us to have to make decisions on your behalf when we aren’t sure what you would want.

“My attorney has taken care of it all,” or “I’ve already filled out the form.”

It’s great that you have already started the planning process. If the time comes that you can’t make decisions for yourself, it would help me and others who love you if we could understand what care you would want. Perhaps we could start by sitting down together and reviewing your form.

“This is too hard (or morbid or depressing) to talk about.”

While it can be hard to talk about, it’s very important for our family. If we have to guess what you would like, we will feel anxious about making the right decision. And, we may disagree and not know what to do. Talking about this now will be a wonderful gift you can give to me and all of us who love you. Let’s see how it goes.

Questions You Might Ask

- Who do you want to make medical decisions for you if you are unable to speak for yourself?
- If you could plan them today, what would the last months or weeks of your life look like?

- Who would be there?
- Where would you like to be?
- What are your ideas and hopes about the end of your life?
- What are your fears or concerns about serious illness or the process of dying?
- Have you thought about what kinds of care or treatment you might want or not want during a severe illness or when you are dying?
- Where would you prefer to spend your last days if you are ill? At home, with one of us, in a nursing home, or in the hospital?
- Do you believe that life should always be preserved as long as possible? If not, what kinds of mental or physical conditions would make you think that life-prolonging treatment should no longer be used? For example, if you were:
 - Unaware of your surroundings
 - Unable to appreciate or continue important relationships
 - Unable to think well enough to make everyday decisions
 - In severe pain or discomfort
- Is there any particular music, flowers, photographs or art you would like or not like to have around you near the end of life?
- If possible, would you want to donate organs or tissue?
- What are your wishes regarding a funeral? Burial vs. cremation?