

Discussing Health Care Choices



As someone living with cystic fibrosis (CF), you may feel uncertain, overwhelmed, or frightened about some of the decisions that you and your family will need to make about your medical treatments, now or in the future.

Your doctors may suggest changing your treatments over time. Adults have the right to decide whether to accept or refuse any treatment that is offered by a doctor or another health care professional. While parents or guardians make this choice for their children, adolescents most often participate in planning their care.

To make decisions about a treatment, you need to have information. Good decisions can be made only when you understand the recommended treatment, how it may help, the possible risks, and what other treatments might be available. This applies to everything from daily CF care that keeps you healthy, to treatments offered in the hope of prolonging your life when you are very ill, like breathing machines in the event of severe respiratory failure. You may be offered some treatments to help you stay well or recover, and other treatments that are meant to reduce symptoms or other CF-related problems so that you can have a better quality of life.

What Do I Need to Do?

First, have a conversation with your CF care team and your family or other loved ones so that you can work together to create a treatment plan that best meets your needs. Make sure to tell them about symptoms or problems you are having that bother you or get in the way of doing things that matter to you. It is important to let them know if you are having difficulty tolerating daily care, and about any obstacles you are facing that may make it hard to complete a new treatment. Make sure they are aware if there are particular treatments or side effects that you are especially concerned about, or hope to

avoid. These discussions should be part of routine care to manage CF, and they become even more important if you develop serious symptoms or advanced disease.

Ask your CF team the questions you have about your illness, test results, and recommended treatments, such as:

- *What do you think is causing this symptom?*
- *How likely is it to get better on its own without a new treatment? Is it likely to get worse?*
- *Are there steps I could take on my own to help manage the problem?*
- *How might a new treatment help, and how often does it work for people in my situation?*
- *What are the possible risks, side effects, or burdens of the treatment?*
- *How much time will the treatment take, and how long will I need to continue it?*
- *Will there be costs not covered by insurance?*
- *Are there other treatment options I could try?*

What Should My Family and Caregivers Do?

Parents, guardians, and CF teams taking care of children with CF should help them learn about CF and increasingly involve them in decisions as they mature. Ask children how they are feeling physically and emotionally, and discuss their CF and treatments in a way that is appropriate to their development. As children move into adolescence, they will start to meet alone with members of their CF team more often, building skills they will need to collaborate in planning their care as adults with CF.

Many adults involve their family members or other significant persons when an important decision is needed. **If this is true for you, be sure to have the most important people available when you see your CF team.** If this is not possible, ask to schedule another appointment or phone call to explain things again with you and your family together.

Some people want specific members of the family to make the decisions for them. You can ask your doctor to speak to the person you want to make decisions about your care. **Your doctor may not want to speak to anyone else until you make it clear that this is what you want.**

Because it is possible for people to lose the ability to directly communicate their wishes, even temporarily, it is important that you plan for this. This is called **advance care planning**. Most people choose a member of the family or other loved ones and caregivers to make decisions in case something happens that makes them unable to speak for themselves. This person is called your **agent**, and you select your agent by completing a form called a **Health Care Proxy**.

- Your agent should be someone who knows your values and preferences for health care. It's best to select your agent while you are still relatively healthy, rather than to wait for a crisis, when people will have a lot of emotions to deal with.
- Have a discussion with your agent about your wishes regarding medical care. What kind of care would you want? Where do you wish to be, and with whom? Think about the goals you have and what is important to you. It's helpful to include other family members in this discussion, or to discuss the key points with them at some other time. This may help to avoid family conflict later. **It is important to update your wishes if things change over time.**

Are There Laws That Affect Making Decisions About Health Care?

There are laws that health care professionals must follow that affect how decisions get made about your health care. These laws are somewhat different in different states. In general, if you select an agent, doctors must do as the agent says. If you don't select an agent, and the time comes that you cannot make decisions for yourself, the law tells doctors to ask specific family members to make decisions for you. **One of the reasons that advance care planning is such a good thing to do is that it makes sure that your wishes can be followed no matter what the law says.**

After you've read this handout, you should see the complementary handout on *Advance Directives*, in this series, which will give you more detailed information about how to make your wishes known.