



Advance Directives

No one likes to think about being so sick that it becomes impossible to make your own decisions. But people with a serious illness may find themselves in this situation, and it is good to be prepared. Advance directives are a way of making your wishes known if you become very ill and are unable to speak for yourself.

They let you choose who you want to make decisions for you, and describe the kinds of treatments that you would or would not want. Although it is hard to talk about and plan for a time when illness becomes very serious, doing so can be a gift to your loved ones. If you become unable to speak for yourself, your family will be asked to make decisions about your care. **By creating advance directives, you help prepare them for this.**

Making Decisions About Your Health Care

Most people with cystic fibrosis (CF) are used to making their own decisions about the treatments they want or don't want. You have the right to accept or decline any medical care that is offered to you, including treatments or procedures that may keep you alive longer. Parents or guardians make these decisions for their children with CF, who can provide increasing input as they develop and mature. Most patients involve their loved ones in these decisions, even when they are adults.

It's important to think ahead about who would make decisions for you if you became too ill to make them yourself, and what decisions you would want made.

Some people want "everything done" in the hope of living longer, even if a medical treatment has only a small chance of working and may cause serious side effects or burdens. Others feel that, when a disease becomes very serious, their quality of life is more important than just trying to stay alive longer. They don't want a treatment that has only a small chance of working and could lead to serious side effects or burdens.

The Cystic Fibrosis Foundation recommends that individuals with CF discuss advance directives and their overall values and preferences for treatment with their health care providers and caregivers. This is important to do even though treatments for CF are improving. It is important that everyone discusses their treatment preferences and directives with their families, loved ones, and treatment team.

Making Your Advance Directives

Although each state has different laws about advance directives, general information includes the following:

- A **Health Care Proxy** is a legal document that lets you name one or more people who will speak for you in the event that you cannot make your own decisions. These are people who you trust, and they become your "health care agents." It is important that the person you want to name as your agent knows that you are doing this and understands your wishes concerning medical treatments. **Have a talk now to discuss the kind of decisions that you would make if you were very ill and faced with difficult treatment choices.**

If you are not yet an adult, your parent or guardian can make decisions about your medical care without needing a Health Care Proxy. However, it is still important to tell them about your wishes for treatment so that they can take these preferences into account as they make decisions. The *Five Wishes* website (fivewishes.org) can provide more information on ways that you and your parent or guardian can discuss your preferences.

When completing your Health Care Proxy, you may include a statement of your treatment wishes, including anything you don't want your agent to do, or you can complete a separate Living Will.

- A **Living Will** is a document that explains your health care wishes, especially about end-of-life care. You *cannot* use a Living Will to name a health care agent; you must use a Health Care Proxy for that. When you create a Living Will, you write a statement describing your personal health care wishes.
- A “**Do Not...Order**” expresses your wish to avoid a specific medical intervention. These can include a **Do Not Resuscitate (DNR) order**, which means if your heart stops beating it will not be restarted and no CPR will be performed. A **Do Not Intubate (DNI) order** means that no breathing tube will be placed in your throat if you cannot breathe on your own to remain alive. Another order includes **Do Not Hospitalize (DNH)**, which means you would not want to go to the hospital and would receive treatment only at home. Other procedures can follow the same process.

If your illness becomes very serious and you become unable to speak for yourself, your values and preferences about care will be respected if you have an advance directive. In the absence of advance directives, each state has laws about who would make health care decisions for you if you were unable to make decisions for yourself. You can cancel or change an advance directive at any time, and discussions with your team should be repeated regularly to update them.

After You Complete Advance Directives

There are a number of important things to do after your advance directives are signed.

- Make several copies and keep one at home in a safe place.
- Let others in the family know where it is.
- Give copies to your health care agent, close family members, your CF care team, and anyone else you choose to involve in your health care.
- Consider carrying a wallet card giving information about the existence and precise location of your Health Care Proxy or Living Will.

Remember: Advance directives are for everyone, and the best time to put one in place is when you are relatively well.