

The NIH advance directive is a legal document that allows you to indicate in writing your wishes regarding future health care and medical research decisions. The NIH advance directive document only takes effect if and when you lose the ability to make decisions.

### What is an advance directive?

An advance directive is a written document you can use to:

- state your health care choices
- state your wishes about research participation
- name someone to make decisions for you

If you become unable to make your own decisions, your doctors will then use your advance directive and discussions with the person you name as your decision maker to guide the medical and research care they provide to you. The goal is to ensure that your wishes guide these medical and research decisions as much as possible within the context of your changing clinical situation.

### The NIH advance directive form has four parts:

**Part 1** is similar to a **durable power of attorney (DPA) for health care**. A durable power of attorney for health care allows you to name someone you trust as a “decision-maker” for all types of health care decisions in the event you are temporarily or permanently unable to make your own decisions. At the NIH, the person you name as your decision-maker (your proxy) will also have the authority to make decisions about your research participation. The best decision-maker is someone who knows you well, and who is available and willing to make the decisions you want them to make. The person you name as decision-maker must be 18 years of age or older, and cannot be your physician.

**Part 2** allows you to indicate your wishes about medical **research participation** in the event you become unable to make your own decisions. Keep in mind that the main goal of research at the NIH is to improve care for others.

**Part 3** is similar to a **living will**. A living will allows you to state in advance the kinds of care you would or would not want should you become unable to make decisions yourself. This includes your preferences about life-support procedures if you become permanently unconscious or terminally ill and unable to communicate.

**Part 4** consists of a **list of issues** for you to consider and discuss. This list is provided to help you think about and make informed decisions about your health care and research choices. The list is located on the back of the NIH advance directive form and includes information about medical conditions relevant to end-of-life decision making, various treatment options, and types of research. There may be other issues you want to include in your advance directive that are not on this list.

### Answers to Frequently Asked Questions about Advance Directives

#### Do health care providers have to follow your advance directive?

Yes. If the directive complies with the law, your doctors will use it to ensure your wishes guide your medical and research decisions within the context of your changing clinical situation.

#### What should you tell the person you name as your decision-maker?

First, you should make sure the person you name is willing to serve as your decision-maker and understands what the role involves. Then, you should discuss with the person you name your wishes for your medical care and research participation if you become unable to make your own decisions. Your decision-maker will be able to make sure your wishes are carried out only if you discuss your wishes with him or her.

### **If you complete an advance directive, how long is it good for?**

Once you complete an advance directive, it remains in effect unless you make changes. It does not expire. However, you should review your advance directive periodically, and any time you experience a significant change in your medical status, to make sure it reflects your current wishes. Be sure to let the NIH medical team, your decision-maker, and anyone else who has a copy of your advance directive know of the changes.

### **Can you change your advance directive at any time?**

Yes. Advance directives can be changed at any time as long as you are still able to make decisions. You can change your wishes by completing a new advance directive or by informing your physician and your decision-maker that you have changed your mind.

### **If you do not have an advance directive, who makes medical decisions for you if you are unable to communicate?**

At the NIH, we use a legal order of decision-makers for people who don't have an advance directive. If you do not fill out an advance directive, the first person on the following list who is available will make decisions for you: 1) your legal guardian, 2) your spouse, 3) your adult children, 4) your parents, 5) your adult siblings, and then 6) other relatives or close friends.

### **Are advance directives completed elsewhere accepted at the NIH?**

Yes. If you have an advance directive from somewhere else, it can be used as evidence of your wishes at the NIH. In order to use your other advance directive at the NIH, you need to provide a copy to the research team. We encourage you to fill out an NIH advance directive form because it specifically addresses research participation, and allows us to document your most up-to-date wishes in your NIH chart.

### **How can you know in advance what types of medical situations you might face in the future?**

You can begin to think about the situations you are likely to face by talking with your research team. Then, you should think about what is most important to you, and what you would want in those situations. There is also a list of issues for consideration and discussion on the back of the NIH advance directive form.

### **When should you talk to your research team about advance directives?**

You should speak with your NIH research team about advance directives as early in your medical treatment or research participation as possible. It is important for you to discuss your wishes while you are capable. Early and open discussion about your preferences enhances communication with the NIH research team, and helps us to honor your wishes in the future.

### **If you would like more information about advance directives and a copy of the NIH advance directive form, please ask your physician, nurse, or social worker.**

Additional services at the NIH that you may find helpful in thinking about your wishes include:

- Pain and Palliative Care Program 301 594-9767
- Spiritual Ministry 301 496-3407
- Department of Social Work 301 496-2381



Clinical Center Communications



Everyone at the National Institutes of Health is committed to respecting your wishes about health care and medical research participation. As long as you are able to make decisions, we will determine what you want by speaking with you. However, due to an illness or injury you could lose the ability to make or communicate your own decisions. If you cannot communicate, it would be helpful to know your wishes about whether you would want to be maintained on life-support, or if you want to participate in research that involves some risk. We encourage you to think carefully about your health care and research participation choices and to discuss them with your family, friends, and healthcare providers.