

Planning for Future Health Care and Research Decisions

Dear NIH Research Participant,

There may be times when an illness or other event takes away your ability to make or communicate decisions about your medical care. During these times, your health care team cannot provide the medical treatment you want unless you make your wishes known. One way to make sure your health care team knows your wishes for your medical treatment and research participation is by completing an advance directive.

Your advance directive will only take effect if you lose the ability to make decisions and will stay in effect until you are able to make decisions again. In the event of your death, your advance directive will no longer be valid. Your next-of-kin will make decisions regarding final arrangements, unless you have made prior plans.

If you already have an advance directive, please share it with your health care team. If you have more than one advance directive form on file, be aware that only one advance directive may be active at a time. Talk to your health care team about which document should be your active advance directive.

If you do not have an advance directive, you may use the advance directive form offered at the NIH. Most advance directive forms only ask what you would or would not want if you cannot make your own decisions. However, since the NIH Clinical Center is a research hospital, we also want to know whether you want to continue to participate in research if you lose the ability to make your own decisions. Accordingly, we encourage everyone to fill out Part 1 (My Research Preferences).

If you have any questions, please read the section "Questions and Answers about my NIH Advance Directive."

The NIH Clinical Center

The Three Parts of the NIH Advance Directive

- Part 1** allows you to choose your preferences about research participation if you lose your ability to make your own decisions.
- Part 2** allows you to appoint someone to make decisions for you about your treatment and research participation. The person you choose is known as your health care decision maker or Legally Authorized Representative. This part of the form is sometimes referred to as a Durable Power of Attorney for health care.
- Part 3** allows you to choose your health care preferences. This part of the form is sometimes referred to as a Living Will. This section allows you to decide about life-sustaining procedures. You should provide a copy and discuss your preferences with your family, Legally Authorized Representative, and health care team. Before filling out this form, please think about the information in the next section.

Considerations and Discussion Points

Talking about end-of-life issues can be hard. We value and respect your decisions, and want to make sure you are well informed and have every opportunity to ask questions, discuss your preferences, and address concerns with your family and Legally Authorized Representative. The medical conditions and treatment options listed in the next section provides examples that can help you to have these conversations.

Life-Sustaining Treatment Options

Intubation/ Invasive Mechanical Ventilation:

If you cannot breathe well enough on your own, a breathing tube will be inserted to provide oxygen directly to your lungs.

Eating and Drinking Support:

If you cannot eat or drink on your own, there are options for artificial nutrition and hydration. Nutrition and hydration can be given directly through a vein, or a tube that goes through your nose or stomach.

Cardiopulmonary Resuscitation (CPR):

If your heart stops working, CPR may be provided. Efforts may include shocking or pushing on the chest to restart your heart. Also, a breathing tube may be inserted into your mouth, nose or throat and connected to a machine which will pump oxygen into your lungs.

Comfort Care

All patients deserve relief from pain and suffering at the end-of-life. Comfort care focuses on the treatment and relief of physical, psychosocial and spiritual symptoms. Talk with your family and health care team about your options and wishes for receiving comfort care.

Types of Research

Research with the potential for direct medical benefit:

Research that might help you.

Research with no potential for direct medical benefit:

Research that will not help you medically, but may allow researchers to learn things that might help other people in the future.

Research is divided into two categories of risk:

Minimal risk and greater than minimal risk of harm.

Examples of minimal risk include getting a physical exam and having your blood drawn.

Examples of greater than minimal risk include taking an experimental medication or having a surgical procedure.

Questions and Answers about my NIH Advance Directive

1. Do healthcare providers have to follow my advance directive?

Your advance directive will be followed to the best of your health care team's ability. In rare cases, an advance directive may not be followed if it conflicts with medical standards.

2. How long does an advance directive last?

Once you complete your advance directive, it will remain valid during your lifetime unless you make a new advance directive or revoke your existing advance directive.

3. Can I use an advance directive form from somewhere else?

Yes. You must provide a copy of that form to your health care team. It is also important to complete Part 1 of the NIH Advance Directive so that your health care team knows your preferences for your research participation. If you have more than one advance directive form on file, tell your health care team which form is active.

4. Do I need an advance directive and must I complete all parts of the form?

Generally, having an advance directive is optional for Clinical Center patients. However, some protocols may require that you have an advance directive in your medical record. You may complete as many or as few parts of the NIH advance directive as you choose, unless otherwise required by your protocol.

5. Who can I designate to be my Legally Authorized Representative?

The person selected must be 18 years or older, willing to follow your wishes and act in your best interest, and accessible to your health care team. *In general, a person who is a member of your direct health care team should not be designated.*

Questions and Answers about my NIH Advance Directive

6. *What happens if I do not have an advance directive and cannot communicate my wishes?*

If you do not have an advance directive, the medical care you receive may not include your wishes or choices. If you have not selected a Legally Authorized Representative, your next-of-kin will make the decisions about your medical care. Your next-of-kin will be identified according to the list below. If the person at the top of the list does not exist or is not available, your health care team will contact the next person on the list until your next-of-kin is identified:

1. *Your spouse or domestic partner*
2. *Your adult child (ren)*
3. *Your parent(s)*
4. *Your adult sibling(s)*
5. *Other relative(s)*

7. *Who can witness an advance directive?*

Two witnesses are needed. A witness must be at least 18 years of age, and can include your family or any employee at the Clinical Center acting in good faith. The witnesses must be present when you sign the document. The individual whom you designate as your Legally Authorized Representative cannot serve as your witness.

8. *Does the advance directive need to be notarized?*

No. The NIH Advance Directive form does not need to be notarized.

9. *Is my advance directive still valid in the event of my death?*

No. In the event of your death, your advance directive will no longer be valid.

10. *Is the Legally Authorized Representative in my advance directive authorized to make decisions after I die?*

The responsibilities of your Legally Authorized Representative end when you die. In the event of your death, your next-of-kin will make decisions regarding final arrangements, unless you have designated an after-death decision maker in writing. If you have not designated an after-death decision maker and would like to, please speak with your social worker or other member of your health care team.

11. *Who should I contact if I have more questions or need more information?*

Remember, you are not alone. Please do not hesitate to speak with your nurses or any member of your health care team. Additional services at the Clinical Center that you may find helpful when thinking about your wishes may include:

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| • Pain and Palliative Care
301-594-9767 | • Department of Bioethics
301-496-2429 |
| • Department of Social Work
301-496-2381 | • Spiritual Care
301-496-3407 |