

# NIH ADVANCE DIRECTIVE FOR HEALTH CARE AND MEDICAL RESEARCH PARTICIPATION

## INSTRUCTIONS

The NIH is committed to respecting your health care and medical research participation wishes. As long as you are able to make decisions for yourself, we will determine what you want by speaking with you. However, it is possible that you may lose the ability to make your own decisions. At that point, it could be difficult for us to determine what kind of care you want. The NIH advance directive addresses this difficulty by allowing you to indicate in advance your health care and medical research wishes. This form goes into effect only if you lose the ability to make your own decisions. If you are completing this form, and have a non-NIH Advance Directive that you would like to remain in effect during your stay at the NIH, a copy of the non-NIH Advance Directive must be attached to this form.

The NIH advance directive is designed for use at the NIH Clinical Center. In addition, it can provide evidence of your wishes outside the Clinical Center. You can change this form at any time. You may fill out as much or as little as you want. This form must be signed and witnessed. You should keep the gold copy and give the pink copy to the person you name in part 1, if any. You should then give the remaining copies to your nurse or doctor. If you have any questions, or would like additional information, please speak with the members of your medical team, or contact the Department of Clinical Bioethics (301-496-2429).

**PART 1 YOUR CHOICE FOR A SUBSTITUTE DECISION MAKER:** This section is similar to a **Durable Power of Attorney** (DPA) for health care. It allows you to name someone to make medical research and health care decisions for you if you ever become unable to make these decisions for yourself. To ensure that the person you name can make the decisions you want, you should discuss your health care and medical research wishes with the person you name.

**PART 2 YOUR WISHES ABOUT MEDICAL RESEARCH PARTICIPATION:** This section allows you to indicate any wishes you have about your medical research participation in the event you become unable to make your own decisions. Some issues you may want to consider are listed on the back of this form. You should discuss your medical research wishes with your research team.

**PART 3 YOUR WISHES FOR HEALTH CARE:** This section is similar to a **Living Will**. It allows you to indicate any wishes you have for your health care in the event you become unable to make your own decisions. Some issues you may want to consider are listed on the back of this form. You should discuss your health care wishes with the doctor taking care of you.

# Issues for Consideration and Discussion

Think about the things that are most important to you (your core values). Use these core values to decide which treatments you would or wouldn't want, and what types of research, if any, that you would be willing to participate in, if you lost the ability to make your own decisions. For instance, some people value certain abilities (such as the ability to communicate) so much that they would not want to be kept alive if they lost these abilities. In contrast, some people value life itself so much that they would want treatments to keep them alive no matter what their circumstances. Below are some additional issues that you may want to consider in thinking about, and discussing, your preferences with your doctor, substitute decision maker and family.

## MEDICAL CONDITIONS RELEVANT TO END OF LIFE DECISION MAKING

**Terminal Condition:** A medical condition from which, in the opinion of the patient's doctors, there is no reasonable chance of recovery and the use of life-sustaining treatments would only prolong the dying process.

**Permanent Coma:** A complete loss of consciousness that the patient's doctors believe is not reversible.

**Loss of the capacity for communication:** The inability to communicate and interact with others.

**Loss of the capacity for self care:** The inability to perform the activities of daily living such as bathing, eating, and dressing without substantial assistance from others.

**Intractable Pain:** Persistent and significant pain that continues despite maximum pain relief efforts.

## TREATMENT OPTIONS

**Emergency resuscitation:** The attempt to restart a person's breathing and/or heartbeat. Resuscitation efforts may include Cardiopulmonary Resuscitation (CPR) which involves pushing on the patient's chest or inserting a breathing tube in the patient's throat. Resuscitation efforts may also include the use of drugs or electric shock.

**Do Not Resuscitate (DNR) order:** When patients do not want emergency resuscitation attempted in the event their breathing or heart stops, instructions are written not to attempt resuscitation. This is called a DNR order.

**Ventilatory Support:** A ventilator is a machine that helps patients' breath when their lungs fail. Ventilator support often involves a breathing tube being placed in the patient's throat.

**Artificial Nutrition and Hydration:** Nourishment and fluids provided by tubes into the stomach or veins or by other artificial means.

**Comfort Measures:** Treatments, such as pain killers, that are intended to keep patients comfortable.

## KINDS OF RESEARCH

**Research with the potential for direct medical benefit:** Research that offers the chance of improving the subject's medical condition.

**Research with no potential for direct medical benefit:** Research that does not offer the chance of improving the subject's medical condition, but will help doctors learn more about the disease under study and thus may help others with that disease.

In general, clinical research is divided into two categories of risk: minimal risk and greater than minimal risk of harm. Minimal risk means that the likelihood and degree of harm that you might experience in the research are no greater than those encountered in everyday life such as routine physical examinations and blood tests.

# MEDICAL RECORD

# NIH Advance Directive for Health Care and Medical Research Participation

## PART 1: Your Choice for a Substitute Decision Maker

I authorize the person(s) named below to make decisions for me concerning my health care and participation in medical research in the event that I become unable to make these decisions for myself:

Primary Substitute Decision Maker	Alternate (Used if Primary Substitute Decision Maker is Unavailable)
Name:	Name:
Address:	Address:
Telephone #	Telephone #

## PART 2: Your Wishes About Medical Research Participation

A. If you lose the ability to make decisions, you may continue in your present study or be enrolled in a new study if your substitute decision maker agrees. You may also initial the following statements that reflect your wishes.

If I lose the ability to make my own decisions:

I do NOT want to participate in any medical research.

I am willing to participate in medical research that might help me.

I am willing to participate in medical research that will not help me medically, but might help others and involves minimal risk of harm to me.

I am willing to participate in medical research that will not help me medically, but might help others and involves greater than minimal risk of harm to me.

B. You can use this space to indicate any values, goals, or limitations you would like to guide your participation in medical research. For more space use the NIH-200-1 Continuation form.

## PART 3: Your Wishes for Health Care

A. You may initial the statements below that reflect your wishes. Your doctors can then make medical decisions for you based on your wishes and specific situation. If you have any questions about the situations you might face in the future, please speak with your medical team.

I want all effective treatments for keeping me alive, no matter what my condition.

**OR**

I do NOT want life-sustaining treatments if:

I have a condition that cannot be cured and will soon lead to my death, and life-sustaining treatment will only prolong the process of dying.

I am in a permanent coma.

I am awake, but have permanently lost the ability to communicate and interact with others.

B. You can use this space to indicate any values, goals, or limitations you would like to guide your healthcare. For more space use the NIH-200-1 Continuation form.

\_\_\_\_\_  
**Patient Signature**

\_\_\_\_\_  
**Print Name**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Witness Signature**

\_\_\_\_\_  
**Print Name**

\_\_\_\_\_  
**Date**

Patient Identification

NIH Advance Directive for Health Care and Medical Research Participation

NIH-200 (10-00)

P.A. 09-25-0099

File in Section 4: Advance Directives

WHITE-Medical Record    GOLD-Patient    PINK-Substitute Decision Maker