

# ADVANCE DIRECTIVES FOR HD INDIVIDUALS AND THEIR FAMILIES

## *INTRODUCTION TO THE ADVANCE DIRECTIVES WORKBOOK*

This is a workbook intended to guide you in making decisions about your future. Although this was designed for Huntington's disease patients and their families, it can be a useful guide for others. Please note that we are calling this a "workbook" because it is not a legal document. Use it as a guide for discussions with your family about your feelings and wishes. Consult <http://www.partnershipforcaring.org> for more information and for your State's legal forms.

## WHAT ARE ADVANCE DIRECTIVES AND WHEN ARE THEY NEEDED?

In most health care situations, you have the right to make decisions about your medical treatment. Based on the information you receive, as well as your values and beliefs, you must weigh the risks and benefits of the proposed treatment, the likelihood of success and any alternative course of treatment. You decide which treatments you want and which ones to refuse. There may be a time when your illness, injury or disability prevents you from being able to make your own decisions. Even if you are unable to make the decision, a decision will still be made with the use of a health care advanced directive. The question is: How much control do you wish to exert over those decisions?

Courts have almost always followed the expressed wishes of competent adults. A competent adult can communicate preferences about future medical treatment through legal documents called advance directives, which are also called medical powers of attorney. You can control your health-care decisions even if you become incapacitated in the future. Prepare your advance directives while you are capable of making your own decisions.

### ADVANCE DIRECTIVES INCLUDE:

- a health care proxy (medical power of attorney) where you appoint someone to make health care decisions for you;
- a living will where you write instructions to your doctor about treatment and life-sustaining procedures;
- a non-hospital DNR – do not resuscitate order
- your decision about brain donation for diagnosis and research purposes

*Some states claim that if you appoint a health care proxy, then a living will is either not necessary or can become unintentionally too restrictive. Most elder law attorneys recommend the use of both documents.*

*If, for any reason, the health care proxy fails, then the living will will be recognized. We have written this workbook to help you write what you wish and to help guide your health care proxy in the future.*

*Deborah Thorne is available to discuss health care proxy.*

Once you have completed this workbook, you should consult an elder lawyer to obtain legal advice and State-approved forms as the law differs slightly from state to state. We invite your comments and suggestions. Please write us at:

The HD Center of Excellence  
Columbia University, P & S Unit 16  
630 West 168 Street  
New York NY 10032

## HEALTH CARE PROXY

The health care proxy form is the law in all states and is a written document. See pages 6 & 7. There are very few restrictions in the law about who can be your health-care representative or health care surrogate, also called health care proxy. It can be anyone who knows you well and whom you trust such as a spouse, partner, relative, friend or spiritual advisor or attorney. The health care proxy should be an adult (18 years of age or older) and be able to make decisions. Your health care proxy should never be forced to make a decision or be asked to act alone without the help of health care professionals. You should appoint an alternate health care proxy in case your first choice is unable or unwilling to make health-care decisions. It is essential that your doctor and other health care providers know who you have appointed. Your physician can not be your health care agent.

The person you choose should be someone who knows your values, religious beliefs and preferences about medical treatment. It is helpful if the person is in frequent contact with you and lives nearby. Only a small percentage of people have chosen a health care proxy, discussed their wishes and given specific instructions to their health care proxy. So you are doing something rare and special. What you are doing is very important and helpful to the people who care about you. The best time to name your health care proxy is now and not later. By executing a health care proxy, you will be maintaining your self-respect, independence, and dignity during your illness.

## A LIVING WILL

A living will is a set of instructions to your doctor about treatment and life-sustaining procedures. See pages 8, 9 & 10. You should discuss these instructions with your doctor and any other health care provider so that both of you understand clearly what you wish to have happen. Your discussion should be a two-way street: for you to offer information to your doctor and for you to gather information from your doctor. You want your doctor to honor your wishes. You cannot do this without the doctor's understanding. These instructions do not become effective until you are unable to make a health-care decision and your health care provider is aware that you have written instructions about treatment and life-sustaining procedures. Your doctor and one other doctor must certify in writing that you are unable to make health care decisions in your best interest before these instructions can be followed.

You can change your mind and revoke (cancel or take back) your instructions to your doctor about treatment and life-sustaining procedures at any time, regardless of your physical condition, provided you have mental capacity to make decisions. You can change your mind at any time about treatment and life sustaining procedures, provided that you have mental capacity. You can revoke these instructions by tearing up this document, by signing and dating a written statement that you revoke these instructions or by telling one adult in the presence of another adult who acts as witness that you revoke these instructions. When you change your mind, be sure to also tell your doctor or other health care provider.

## WHAT ISSUES ARE ADDRESSED IN A LIVING WILL?

- Diagnostic tests and procedures to discuss in detail with your doctor
- Tube feeding, also called artificial nutrition, see discussion on page 3
- Do not hospitalize order; see discussion that follows on page 3
- Do not resuscitate order when your breathing or heart stops, see page 9
- Prolonged maintenance on a respirator, called ventilator support

## WHAT IS TUBE FEEDING OR ARTIFICIAL NUTRITION?

A feeding tube provides food and fluids. It may be the only method available when swallowing ability is completely lost. It may be used to provide supplements when the person can still eat their favorite foods but needs to receive more nutrition through the tube. Tube feeding is a common late-stage treatment because caloric needs remain high while swallowing safety declines. The tube is made of soft, pencilwide plastic and is inserted into the gastro-intestinal tract, usually the stomach, but occasionally the small intestine. A gastrostomy tube [GT] is the term for the stomach insertion. A jejunostomy tube [JT] inserted into the small intestine. The JT is employed when there is an increased risk of aspiration.

Aspiration occurs when food goes into the lungs instead of the stomach. This causes pneumonia, which may be serious.

Feedings may be several times a day or may run continuously. The tube may be disconnected between feedings for sleeping, walking, social activities and to decrease an uncomfortable feeling of fullness. The formulas are nutritionally complete and may be lactose free, kosher, sodium controlled and special formulas for other medical conditions. Additional water is added for hydration. Medications may be given through the tube.

The recommendation to place a feeding tube can be made by any health care professional when weight cannot be maintained or swallowing becomes dangerous. However, the person with HD, their family, doctor and other health professionals make the final decision together. Some people choose not to have a feeding tube, because they feel the quality of their lives is compromised.

**Advantages of tube feedings:** A feeding tube is a practical way to ensure that you receive nutrition and fluids without fear of choking. You will feel comfortably full. You will gradually gain weight, feel better and be healthier. You may still be able to eat small amounts for pleasure. As you know, low weight is a serious health risk in the later years of HD. The other benefits of having a feeding tube must be carefully discussed so you can make an informed decision.

**Disadvantages of tube feedings:** Tube feeding is not always a perfect solution. The tube is inserted during a surgical procedure, during which there is a small risk of infection or bleeding. It is not clear why some people with HD may continue to lose weight and feel hungry even with a feeding tube. Vomiting, aspiration and constipation can still occur with a feeding tube. When your feeding tube accidentally comes out, hospitalization may be necessary to re-insert it.

## WHAT IS A DO NOT HOSPITALIZE ORDER?

When you are admitted to the hospital, you are often surrounded by clinicians who are not HD experts and do not know you well. In the later years of HD, you and your family may prefer the comfort of the place where you live. When your condition changes, the DO NOT HOSPITALIZE order is one way for your family to influence the level of care and type of clinical intervention prescribed. With this order in your medical records, you will not be hospitalized before your family and your physician have discussed the best plan for you. These orders are very helpful when there is a sudden change in your status and the primary care physician cannot be contacted.

**Advantages of hospitalization:**

In the hospital, clinicians may be able to quickly diagnose and treat dangerous or painful conditions. You have the advantage of specialists and highly technical diagnostic tools and interventions, including blood transfusions and the use of the operating room. The most common reasons for hospitalization are:

- Aspiration pneumonia
- Feeding tube placement or complications
- GI bleeding or inflammation
- Falls that cause fractures or subdural hematomas [a blood collection on the brain]
- A general infection, called sepsis
- Blood in the urine
- Psychiatric disturbances that do not respond quickly enough to medication

**Disadvantages of hospitalization:**

*Every time you are transferred to the hospital, you may face the following:*

- Hospital staff members, who misunderstand your speech, underestimate your ability to answer questions or misinterpret your facial expressions and body movements
- Unfamiliar surroundings and accompanying anxiety
- Greater risk of infection
- Increased use of sedating medication
- Repeated diagnostic tests include blood pressure measurements, blood specimens, and X-rays
- Intensive treatment and increased risk of side effects from treatment.

## WHAT IS A DO NOT RESUSCITATE [ "DNR" ] ORDER?

The "do not resuscitate [DNR]" order is written by the doctor in consultation with the health care proxy and other family members. This order states that cardio-pulmonary resuscitation will be withheld when a person's breathing or heart stops. When anyone is admitted to a hospital or nursing home, the staff is required by law to perform cardio-pulmonary resuscitation [CPR] if and when breathing or the heart stops unless there is a DNR order in effect. Resuscitation is a standard procedure intended to save life. An important part of a living will is to decide whether or not to resuscitate. The DNR order instructs the staff to not use chest compressions or electrical stimulation to restart the heart and not use assisted breathing.

Making a DNR decision requires discussion and consultation with your family, your health care professional and your clergy. When a DNR order is written and on the chart, the staff and doctors will remain available and attentive, but their focus will be to give supportive care and comfort (palliative) measures and not invasive life-saving treatments. The DNR order must be made at each admission and with each new event. The decision to not resuscitate can always be changed and a request be made "to do everything possible," provided the patient has mental capacity.

**These are only some of the issues** to discuss with your family and your health care professionals. Other issues not described in this workbook include diagnostic testing, the use of a machine to breathe for you, called a respirator or ventilator and non-hospital DNR. You may choose to not complete this workbook and instead complete the short form called Health Care Proxy with Advance Declaration which is printed on pages 6-7.

## DECISIONS ABOUT BRAIN DONATION

### WHY SHOULD I DONATE MY BRAIN? WHY IS IT IMPORTANT IN HD?

Donating your brain tissue in the hours immediately after your death will add to our current understanding of what causes HD. This is also a gift of knowledge to your family. Direct analysis of the shape of the nerve cells, its contents, how the nerve cells communicate with each other and where else in the brain there are changes is only possible with brain donation.

### WHEN DO I NEED TO MAKE A DECISION?

When you are thinking about it [like right now]. When you can weigh your options and make an informed choice.

### WHAT IS THE PROCEDURE FOR BRAIN DONATION THROUGH THE NEW YORK BRAIN BANK?

- Call the research nurse at Columbia University’s Center for Parkinson’s Disease and Other Movement Disorders at 212-305-5779. Speak slowly and clearly. Leave your complete name, address including zip code and your telephone number. Tell her you want to receive information about the brain donor program for Huntington’s disease. It will be mailed promptly.
- Brain donation [also called post-mortem examination or autopsy] will provide an accurate diagnosis, not disfigure your face or body, not delay the funeral and is free of charge. Pre-planning is the best, because the details of your plan will inform all the people involved.
- We are also on-call 24 hours a day, 7 days a week, for emergencies and brain donation at telephone number 212-305-5277. Or you can page 917-899-2045, enter your telephone number after the beeps and the on-call doctor will call you back. Over the telephone we work together with your next of kin, family or friends to carry out your wishes.

## PRACTICAL TIPS ABOUT YOUR ADVANCE DIRECTIVES

- Talk to your family and tell them “This is important to me and I would really like you to listen.” Tell them why you want them to know about your advance directives. Ask them to help fulfill your wishes when you can no longer make decisions for yourself.
- Talk to your health care proxy about your advance directives on a regular basis. Discuss how to inform anyone who might object to the choices you have made. Talk to your doctor and review your advance directives at least once a year at an appointment closest to your birthday to discuss any new treatments that change your living will.
- See an elder law attorney to prepare your advanced directives.
- Make sure your advance directives are widely available.
  - 2 originals should be filed with your important papers,
  - 1 original to each of your doctors,
  - 1 original to your health care proxy and 1 copy to your alternate health care proxy.
  - 1 original should remain with your elder law attorney
  - 1 original should be readily available at a moment’s notice
  - Give an original to the social worker if you are admitted to a hospital or nursing home.
  - Make sure that they are entered into your medical file!

## ADVANCE DIRECTIVES FOR

PRINT YOUR FULL NAME HERE

I understand that as a competent adult I have the right to make decisions about my health care. There may come a time when I am unable, due to physical or mental incapacity, to make my own health-care decisions. In these circumstances, those caring for me will need direction concerning my care and they will require information about my values and health-care wishes. In order to provide the guidance and authority needed to make decisions on my behalf:

I, \_\_\_\_\_, hereby declare and make known my instructions and wishes for my future health care. This advance directive for health care shall take effect in the event I become unable to make my own health-care decisions, as determined by the physician who has primary responsibility for my care, and any necessary confirming determinations. There are six (6) sections of this workbook, labeled A – F, which will guide my family and may become part of my permanent medical record.

### A. APPOINTMENT OF MY HEALTH CARE PROXY

I hereby designate:

\_\_\_\_\_  
PRINT FULL NAME HERE

\_\_\_\_\_  
PRINT FULL STREET ADDRESS HERE

\_\_\_\_\_  
CITY

\_\_\_\_\_  
STATE

\_\_\_\_\_  
ZIPCODE

\_\_\_\_\_  
TELEPHONE OR CELLPHONE NUMBERS

as my health-care proxy to make any and all health care decisions for me, including decisions to accept or to refuse any treatment, service or procedure used to diagnose or treat my physical or mental condition, and decisions to provide, withhold or withdraw life-sustaining measures. I direct my health care proxy to make decisions on my behalf in accordance with my wishes as stated in this document, or as otherwise known to him or her. In the event my wishes are not clear, or a situation arises I did not anticipate, my health-care proxy is authorized to make decisions in my best interest, based upon what is known of my wishes.

I have discussed the terms of this designation and my health care proxy has willingly agreed to accept the responsibility for acting on my behalf.

## B. ALTERNATE HEALTH CARE PROXY:

If the person I have designated to be my health care proxy is unable, unwilling or unavailable to act as my health care representative, I hereby designate the following person(s) to act as my health care proxy in the order of priority stated:

1) \_\_\_\_\_  
PRINT FULL NAME HERE

\_\_\_\_\_  
PRINT FULL STREET ADDRESS HERE

\_\_\_\_\_  
CITY STATE ZIPCODE

\_\_\_\_\_  
TELEPHONE OR CELLPHONE NUMBERS

2) \_\_\_\_\_  
PRINT FULL NAME HERE

\_\_\_\_\_  
PRINT FULL STREET ADDRESS HERE

\_\_\_\_\_  
CITY STATE ZIPCODE

\_\_\_\_\_  
TELEPHONE OR CELLPHONE NUMBERS

## C. GENERAL INSTRUCTIONS TO MY DOCTOR ABOUT TREATMENT AND LIFESUSTAINING PROCEDURES, ALSO CALLED MY LIVING WILL

I have initialed and dated ONE of the following two general statements:

1) \_\_\_\_\_ I direct that **all medically appropriate measures be provided** to sustain my life, regardless of my physical or mental condition. [Skip to Section D and continue.]

2) \_\_\_\_\_ **There are circumstances in which I would not want my life to be prolonged by further medical treatment.** In these circumstances, life-sustaining measures should not be initiated and if they have been, they should be discontinued. I recognize that this is likely to hasten my death.

In the following three situations, I specify the circumstances in which I would choose to forego life-sustaining measures. I have initialed and dated those with which I agree.

a) \_\_\_\_\_ **I realize that I have been diagnosed as having an incurable and irreversible illness.** My condition may cause me to experience severe and progressive physical or mental deterioration and/or permanent loss of capacities and faculties I value highly. If, in the course of my medical care, the burdens of continued life with treatment become greater than the benefits I experience, I direct that life-sustaining measures be withheld or discontinued. I also direct that I be given all medically appropriate care necessary to provide for my personal hygiene and dignity, make me comfortable and relieve my pain.

b) \_\_\_\_\_ **If there is a time when I become permanently unconscious,** and it is determined by my doctor and at least one additional expert doctor who has personally examined me, that I have totally and irreversibly lost consciousness and my capacity to interact with other people and my surroundings has been lost, I direct that life-sustaining measures be withheld or discontinued. I also direct that I be given all medically appropriate care necessary to provide for my personal hygiene and dignity, make me comfortable and relieve my pain.

c) \_\_\_\_\_ **If there is a time when I become terminally ill,** and it is determined by my doctor and confirmed by at least one additional expert doctor who has personally examined me that I am terminally ill, I direct that life-sustaining measures be withheld or discontinued. I also direct that I be given all medically appropriate care necessary to provide for my personal hygiene and dignity, make me comfortable and relieve my pain. I have initialed and dated ONE statement. To me, "terminally ill" means that 1) \_\_\_\_\_ I will die in a few days.

2) \_\_\_\_\_ I will die in a few weeks

3) \_\_\_\_\_ My life expectancy is 6 months or less.

## D. SPECIFIC INSTRUCTIONS FOR MY LIVING WILL

In the following situations, I specify when I would choose to accept or forego life-sustaining measures. I have initialed and dated those statements with which I agree.

1) In the event I suffer a cardiac arrest (**my heart stops**), I direct that cardio-pulmonary resuscitation (CPR)

a) \_\_\_\_\_ be provided to preserve my life

b) \_\_\_\_\_ not be provided and that I be allowed to die

2) In the event I suffer a respiratory arrest (**my breathing stops**), I direct that cardio-pulmonary resuscitation (CPR)

a) \_\_\_\_\_ be provided to preserve my life

b) \_\_\_\_\_ not be provided and that I be allowed to die

3) In the event I am **unable to swallow enough food and fluids to sustain my life**, I a) \_\_\_\_\_ would allow a change in the texture of my food for easier and safer eating

b) \_\_\_\_\_ would not allow such a change and I would be allowed to die

4) In the event I am **unable to swallow enough food and fluids to sustain my life**, I direct that artificial nutrition by feeding tube into my stomach or small intestine

a) \_\_\_\_\_ be provided to preserve my life

b) \_\_\_\_\_ not be provided and that I be allowed to die

5) In the event I suffer **repeated high fevers** and health interventions are unable to bring my fever down to normal, I direct that intravenous infusion (an IV inserted into my vein to give me fluids) with or without IV antibiotics

a) \_\_\_\_\_ be provided to preserve my life

b) \_\_\_\_\_ not be provided and that I be allowed to die

6) \_\_\_\_\_ In the event I suffer **repeated pneumonias** (more than 2 events requiring either hospitalization or CPR or IV infusions) and health interventions are unable to treat my pneumonia, I direct that I be allowed to return to the care of those who know me best and can provide for my comfort in familiar surroundings. This approach is known as end-of-life or hospice care.

7) \_\_\_\_\_ In the event that I do not want to be hospitalized and instead receive my care in familiar surroundings, I choose the **DO NOT HOSPITALIZE** option at this time. This approach is known as end-of-life or hospice care.

8) \_\_\_\_\_ In the event that I do not want to continue to receive renal dialysis and instead receive my care in familiar surroundings, I choose the **DISCONTINUE DYALYSIS** option at this time. This approach is known as end-of-life or hospice care.

**For additional instructions, attach a sheet of plain white paper behind this page.**

## E. SPECIFIC INSTRUCTIONS REGARDING BRAIN DONATION

- 1) \_\_\_\_\_ I **wish to make a gift** of my brain tissue for diagnostic and research purposes.
- 2) \_\_\_\_\_ I **do not wish to make a gift** of my brain tissue for diagnosis or research purposes. If I have initialed and dated the first statement, I have initialed one of the following:
- a) \_\_\_\_\_ I have contacted the National HD Brain Donor Program at the New York Brain Bank/Columbia University [212-305-5779] to make a pre-plan.
- b) \_\_\_\_\_ I have not contacted the National HD Brain Donor Program and direct my health care proxy to call 212-305-5779 to make a pre-plan.
- c) \_\_\_\_\_ I have not made a pre-plan and rely on others at the time of my death to call the 24-hour emergency telephone number at 212-305-5277.

\*\*\*\*\* **Congratulations!** \*\*\*\*\*

**YOU HAVE JUST COMPLETED THE ADVANCE DIRECTIVES WORKBOOK. The next two pages that follow are the standard format for signature pages. Look them over and decide who will help you. The last page provides the standard format for a non-hospital order not to resuscitate.**

**Remember that this is a workbook. These pages are not the same as legal documents. Now you need to consult an elder care lawyer to review this workbook.**

**If you do not have a lawyer and need our assistance, please contact your HD social worker for a list of elder care lawyers with whom they have worked.**

## F) SIGNATURES AND WITNESSES TO MY ADVANCE DIRECTIVES

I understand the purpose and effect of this document and sign it knowingly, voluntarily and after careful deliberation.

Signed this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_\_

Signature \_\_\_\_\_

Printed name \_\_\_\_\_

Address \_\_\_\_\_

**WITNESSES:** As witnesses, we declare that the person who signed this advance directive did so in my presence, that this person is personally known to me and that he or she appears to be of sound mind and free of duress or undue influence. I am 18 years of age or older and am not designated as the health care proxy or alternate health care proxy.

\_\_\_\_\_  
PRINT FULL NAME OF WITNESS #1

\_\_\_\_\_  
PRINT FULL STREET ADDRESS HERE

\_\_\_\_\_  
CITY STATE ZIPCODE

\_\_\_\_\_  
SIGNATURE DATE

\_\_\_\_\_  
PRINT FULL NAME OF WITNESS #2

\_\_\_\_\_  
PRINT FULL STREET ADDRESS HERE

\_\_\_\_\_  
CITY STATE ZIPCODE

\_\_\_\_\_  
SIGNATURE DATE

COPIES or the original of this document has been given to the following people including my health care proxy, my alternate health care proxy, family member(s), doctors, social workers and others concerned with my care.

1) \_\_\_\_\_  
PRINT FULL NAME HERE

\_\_\_\_\_  
PRINT FULL STREET ADDRESS HERE

\_\_\_\_\_  
CITY STATE ZIPCODE

\_\_\_\_\_  
TELEPHONE OR CELLPHONE NUMBERS

2) \_\_\_\_\_  
PRINT FULL NAME HERE

\_\_\_\_\_  
PRINT FULL STREET ADDRESS HERE

\_\_\_\_\_  
CITY STATE ZIPCODE

\_\_\_\_\_  
TELEPHONE OR CELLPHONE NUMBERS

3) \_\_\_\_\_  
PRINT FULL NAME HERE

\_\_\_\_\_  
PRINT FULL STREET ADDRESS HERE

\_\_\_\_\_  
CITY STATE ZIPCODE

\_\_\_\_\_  
TELEPHONE OR CELLPHONE NUMBERS

4) \_\_\_\_\_  
PRINT FULL NAME HERE

\_\_\_\_\_  
PRINT FULL STREET ADDRESS HERE

\_\_\_\_\_  
CITY STATE ZIPCODE

\_\_\_\_\_  
TELEPHONE OR CELLPHONE NUMBERS

**APPENDIX A. State of New York,  
Department of Health, Non-Hospital  
Order Not to Resuscitate**

**APPENDIX B. Health Care Proxy  
with Advance Declaration**

STATE OF NEW YORK  
DEPARTMENT OF HEALTH  
NON-HOSPITAL ORDER NOT TO RESUSCITATE  
(DNR ORDER)

Person's Name \_\_\_\_\_ PRINCIPAL Date of Birth \_\_\_\_\_

Physician's Signature: \_\_\_\_\_

Print Name: \_\_\_\_\_

License Number: \_\_\_\_\_

Date: \_\_\_\_\_

It is the responsibility of the physician to determine, at least every 90 days, whether this order continues to be appropriate, and to indicate this by a note in the person's medical chart. The issuance of a new form is NOT required, and under the law this order should be considered valid unless it is known that it has been revoked. This order remains valid and must be followed, even if it has not been reviewed within the 90 day period.

\_\_\_\_\_  
CITY STATE ZIPCODE

\_\_\_\_\_  
SIGNATURE DATE