HDSA Family Guide Series

Advance Directives for Huntington's Disease

Huntington's Disease Society of America

Advance Directives for HD

Family Guide Series

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Disclaimer

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Introduction

Having an idea about the kind of medical care you want as you progress through the Huntington's disease (HD) process is important. HD may eventually rob you of your ability to communicate and think clearly, but it does not have to rob you of your right to have the care you want and deserve.

This booklet has been developed to simplify and take the mystery out of this process. It is meant to provide you with a basic understanding of:

- Why Advance Directives are important
- How to start the advance planning process
- What to put into an Advance Directive
- What medical and care issues to consider as you write your Advance Directive
- How to speak with loved ones and healthcare providers
- Advance Directive terminology
- The common myths and misunderstandings about Advance Directives
- Where to find templates, forms, and state-specific information.

Why create an Advance Directive?

Advance Directives are documents that let you put your health care wishes on paper so that medical providers, family members and others will know what you want. In most cases, it avoids the need for guardianship, an expensive and difficult legal process. Most importantly, it is meant to ensure that you choose what you want for your care, who will speak for you, and where you will receive your care.

As you consider whom to choose to represent you and carry out your wishes, you should have conversations with your family, your doctor, and others who may be involved in your final care and treatment decisions. Then you must write your wishes down and sign the document to make it official. Fortunately, this is an easy process to do and many tools are available to help you.

If you choose not to complete these documents, you will lose the ability to guide your loved ones to make difficult health care decisions in the way that you would want, when they really need guidance. Completing an Advance Directive is really a gift to your loved ones so they can feel confident in making the choices you would want to make for yourself.

Where to Start!

This section will give you the information you need, from what to think about putting in your Advance Directive, all the way to where to find the documents.

Reflect on your values

Advance Directives are utilized if a person is no longer able to speak for themselves. In Huntington's disease, this usually occurs towards the end of the disease, as a person becomes less able to communicate or make decisions about complicated medical matters. As you prepare for that time, it is important to help others understand what is important to you: your values and your religious and spiritual beliefs. These questions may help you to begin thinking about your values and prepare you for a discussion with your family:

- What gives your life meaning?
- What do you think are the most important considerations for your end of life care?
- What types of care do you particularly want (and not want) as you reach the end of life?
- What do you fear most about the dying process or death?
- What are your sources of strength?
- How does faith influence your thinking about these issues?
- Can your loved ones respect your wishes even if they disagree?

Choose your Agent

An Advance Directive is the best way to ensure you know who is speaking for you when you are unable to speak for yourself. So how do you choose this person?

Select a person who knows you well, but who will have the clearest mind at the most chaotic time. Your health care Agent must be able to put his or her own emotions and beliefs aside and be able to act in your best interest and carry out the wishes and intentions you have laid out for yourself. Although many people choose their spouse, parent, child, or next of kin as their Agent, others choose an individual that is not as directly related to them. While an Advance Directive gives you a way to explain what you would like to happen in most situations, it is impossible to account for every possible scenario, so your Agent should be someone whom you trust to know your values and wishes and be able to best act with that in mind.

The first thing you will want to think about is who can make difficult decisions for you as you lose the ability to make these decisions for yourself. This will often be a close family member or spouse, but it can be anyone you select. You should talk with that person first, and make certain they are comfortable with making the decisions you will need them to make in order to carry out your wishes (as opposed to their own wishes for you).

While some families have similar values, it is important to have a discussion with your family and the person you plan to appoint as your Agent to ensure that they do know what your values and wishes are in the event you cannot act or speak for yourself.

Having the documents is important but it is really only the first step. Unless your family and your Agent know your wishes, they cannot be expected to carry them out. You should include in this discussion anyone close to you, but especially those named in the document(s) to carry out your wishes.

Things to discuss and think about with family and agent:

- Which aspects of HD most frighten you? What capabilities do you think are most important to your meaningful life? Talking? Being able to interact with others and your surroundings? Being able to eat?
- If you were losing weight or choking frequently, would you want doctors to insert a feeding tube through the skin into the stomach?
- If you were to have a new serious diagnosis unrelated to HD, such as cancer or a heart attack, how aggressively do you want your doctor(s) to treat that new health problem?
- Would there come some point in the disease where you would no longer want hospitalization or treatment with antibiotics? If so, how would your family recognize that point?

Some people find it helpful, also, to speak with their minister or other religious or faith leader, to explore and understand any principles or faith-based guidelines that can help to guide these difficult decisions.

Consider your health care needs and wishes

Before you sit down to write out your wishes for future medical treatments, it is important to consider your options and weigh these options against your own personal values and beliefs. There are a number of medical treatments that a person with HD might chose to have, or might prefer not to have, at some point in the course of the disease.

Cardiopulmonary resuscitation (CPR). The need for CPR would be unrelated to HD, but could arise in the setting of a heart attack or other cardiac emergency. CPR may include manual chest compressions, the insertion of a breathing tube, electrical shocks to change or restart the heart rhythm, and medications. CPR is almost always followed by admission to the Intensive Care Unit of a hospital.

Placement of a gastrostomy feeding tube. The decision of whether or not to place a gastrostomy feeding tube is very common, because HD eventually affects an individual's ability to chew and swallow safely, leading to choking, weight loss, and aspiration pneumonia. If you are experiencing any of these problems, would you want a permanent tube passed through the skin into the stomach to make it easier to take food, fluids, and medications? Why or why not?

Insertion of a breathing tube and use of a ventilator (intubation). This would be considered in a situation of respiratory failure, as with chronic lung disease or acute infection (pneumonia), and would probably not be a direct consequence of HD. In the case of an infection, intubation may be temporary; in individuals with severe chronic lung disease, intubation would likely be permanent.

Pain management. Pain management and comfort care can be important medical goals where medical improvement and recovery from a terminal condition is not possible. Although medical professionals do what they can to control pain and reduce suffering, many people find that the Advance Directives are an appropriate place to emphasize their desire for comfort as a primary treatment goal.

Doctors always do everything they can to treat patients and to prolong life, unless they are instructed otherwise. Other medical treatments that some people with HD have asked doctors NOT to provide or perform at a certain point in the disease include hospitalization, dialysis, antibiotics, and intravenous fluids.

Write & Execute Your Advance Directive Document

Now that you have reflected on your own values and wishes for medical treatment and selected your health care agent, you are ready to put your desires into a document that will speak for you in the future. An Advance Directive usually means both a Durable Power of Attorney for Health Care (where you write down who you chose as your Agent) and a Living Will (where you explain your values and wishes). It is recommended that you execute both types of Advance Directives because nobody has a crystal ball to see into the future. Having both documents will best protect you in the event something unexpected happens.

It is best to find and use documents that meet the laws of the state in which you live. Many states offer some or all of these documents free from the state Bar Association or Attorney General's office. You also can typically obtain free copies of forms from your local hospital or HDSA social worker. The Internet Resources section (Page 25) of this booklet provides several websites where state-specific forms can be downloaded. You do not need to consult an attorney to fill out the forms in your state.

After you complete the document, you should sign and date it. Because you can cancel an Advance Directive at any time, dating the document makes it clear which is the most current version. If you change your mind and execute a

new document later, it will be clear that the one with the later date replaces the earlier form. For medical directives you do not need to have a notary sign the form, but it is advisable to do so. Notarizing the document provides additional evidence of its soundness.

While the involvement of an attorney is not required, you should know that elder law attorneys are an additional resource for you. If you are unsure about the process for writing your Advance Directive, or have a complicated financial or family situation, you may benefit from the involvement of an elder law attorney during your planning process.

Things to include in your Advance Directive

Inventory of values

Even if you execute an Advance Directive, writing down the principles, guidelines, or values that underlie your medical decisions, based on your reflection and discussions with family and others, helps the people around you to understand how you would respond in an unusual or unexpected medical situation.

Agent

The Living Will should specify the individual who will serve as your Agent, and speak for you when you are no longer able to do so. You may want to have a separate agent for health care and financial decisions.

End of life wishes

You may include comments in the Advance Directive about your desires and your fears about what happens as you die. What makes life meaningful to you? At what point would life no longer be worth living? What prayers, rituals, or music would you like at your bedside? Would you like hospice care? What type of ceremony would you like after your death? What are your wishes for the disposition of your body?

Living Will

A Living Will should describe the medical treatments you wish to have, and those you wish to forego. Specific medical procedures to consider commenting on were described on pages 7 and 8, in the section on considering health care needs and wishes.

You can also include in your Living Will instructions about organ donation, autopsy, and comments about your spiritual or religious beliefs.

Organ Donation – All states make it as easy as possible to provide for organ donation, with many states providing the information on the back of your driver's license. Even if you do not have this notation on your driver's license, you can include it in your directive to physicians, usually as a line in your Living Will/Advance Directive. The HD research community has benefitted greatly from the generosity of people with HD who were willing to donate their brain for research after death. It is critical to make arrangements prior to death. Contact the HDSA Helpline, your local HDSA Center of Excellence or the Harvard Brain Tissue Resource Center (1-800-Brain Bank) for more information. Some people wish to donate their body to a medical school for education or research purposes. Others wish to make a living organ donation (heart, kidney, eyes, etc.) or donation of tissue and bone. Check with your local medical school or organ donation organization to see if your diagnosis of HD or other limitations would exclude your donation.

Spiritual or Religious Rituals – If you have specific wishes for your spiritual care during your end of life care, or after your death, you can specify your wishes in your Advance Directive. These wishes may be written in the "Additional Information" section.

Autopsy Instructions – Some states include a way for you to indicate your wishes for an autopsy, or that an autopsy not be performed. If your state does not include this, you can write in your wishes in the "Additional Information" section.

Important points to remember:

1. A Durable Power of Attorney for financial affairs may also be executed. That document would enable your Agent to make financial decisions such as paying your bills and using your assets to pay for your care. This may be a different Agent than the person you appoint for health care decisions. You may need an attorney to assist you with your financial decisions.

2. If you complete more than one Durable Power of Attorney you should specifically state "I hereby revoke and render ineffective any Power of Attorney I have previously issued to any other person on a date prior to (fill in the date you sign the current document)." You may want to specify a particular Power of Attorney, such as "I revoke the prior Power of Attorney given to my ex-spouse."

3. You need to have an Advance Directive for the state in which you reside. If you move to another state, you will need to execute an Advance Directive for that state.

4. Many states require you be in the last six months of expected life before a Living Will becomes effective because they define the last six months as "terminal or irreversible." If you need help with medical decisions for a longer period of time you should also have a Health Care Proxy.

Guardianship – A guardianship order may be sought where the person has not executed a Living Will or Durable Power of Attorney. A guardianship order is almost never preferable to a Power of Attorney and may leave family members in disagreement and confusion for years after your passing. Courts are unlikely to overturn a Power of Attorney unless there is substantial evidence to suggest the individual's interests are not being represented. The possibility of guardianship is itself a reason to execute an Advance Directive.

Special Issue: Juvenile onset HD

Parents of children with Juvenile onset HD may have additional unique situations because they can execute Advance Directives for minors with HD. When the individual reaches the age of majority, the now-adult child should execute their own Advance Directive based on their decision making capacity. If the child lacks the ability to execute these documents upon reaching the age of majority, the decision-maker will be determined by state statute. Guardianship may be necessary.

For more information about this, contact an attorney with specialization in family law.

Your physician's role

Your physician can provide valuable input to help you consider advance planning decisions, including the types of medical treatments that might be offered. Your physician may help you think of situations you hadn't thought about when writing your Advance Directive. They can also answer questions or clarify how one medical situation may lead to another.

It is important that you give your physician a copy of your Advance Directive and that you bring a copy with you to every encounter with a new medical provider or institution.

Keeping, Updating & Revoking Your Advance Directive

Where should you keep your signed documents?

You will want to put these documents in a place where they will be both safe and accessible when you can no longer remember or explain where they are located. You should make several copies of the completed forms and give one to your Agent, one to your physician, and make the others easily available to your family members. Keep the original in a fire-proof, flood-proof safe place where family and loved ones will be able to locate it.

A couple of pointers for you to consider:

1. Lawyers (family and otherwise): If you consulted an attorney when you wrote the documents he or she may be a good choice to keep the document, but only if your family knows this! Otherwise, if you have a close and reliable family member that is a lawyer, they may be a good resource for this important task because they will likely be aware of your care, even if they are not the designated Agent.

2. Technology: In a time of on-line storage, it may be possible to store a scanned copy of the document in the "cloud". This will not be the original document, but it can serve as a convenient way to ensure that the information is available anywhere there is an internet connection. You should give directions on where to find the original, physical document along with your online copy.

When to update your Advance Directive

You should review your end of life plans every ten years (every time you have a birthday that ends in a zero is a good way to remember this). You should also review your end of life documents when a major event in your life occurs, such as a birth, or divorce, or marriage, or death in the family, especially if the affected person is a spouse or appointed health care agent. Additionally, you should also update your Advance Directives after the diagnosis of a new significant health problem (e.g. a diagnosis of cancer or heart attack). It is also useful to review and update your Advance Directives after a hospitalization (e.g. this is my third hospitalization for dehydration and aspiration pneumonia in the last month; I now think that I would like a feeding tube. Or, I would not like to be hospitalized the next time I become sick). Your medical team should help you to understand your prognosis, and your family should know what your new Advance Directives say and why you have made changes.

Revoking your Advance Directive

You retain the right to revoke your Advance Directive as long as you have capacity to execute legal documents. You may choose to replace your Agent with someone else or to change the language in your Living Will concerning what medical treatments you will accept and decline. Until you lack decision making capacity (defined in the Terminology section on page 16), you have control over these documents at all times.

Terminology

There is a lot of terminology that has to do with advance planning. In this section, we will go over the most commonly used terms and concepts.

Advance Directives

Advance Directive – An Advance Directive is a document that gives directions to your doctors and to your loved ones about what medical care you want and do not want when you become unable to express your wishes. It is a legally approved way to make sure your values and health care decisions are carried out, even if you cannot make your wishes known due to cognitive limitations or other medical conditions. It is a simple, private way to ensure that your life is lived until the last on your own terms.

- **Directive to physicians** – The term "directive to physicians" may refer to a number of different documents about the care you desire at the end of life. These include a Living Will, a Durable Power of Attorney (DPOA), a Do-Not-Resuscitate order, and organ donation directions.

- **Do-Not-Resuscitate (DNR) order** – This is a very common type of directive to physicians. This gives directions to medical providers that in the event you suffer a life threatening event (such as a heart attack) you do not wish to be given life saving treatment. DNRs can be issued for care while in the hospital (most common) or out of the hospital. Most states require separate documentation for an out of hospital DNR.

- **Durable Power of Attorney (DPOA)** – This is a document where you choose a person to have the authority to handle matters as designated in the document. It takes effect even if you are no longer able to make decisions for yourself. Those who have complex financial affairs should incorporate a Durable Power of Attorney for financial matters into their end of life planning.

- **Durable Power of Attorney for Health Care** – This document gives authority to someone that you choose who can then make health care decisions for you when you can no longer make them for yourself. Unlike a guardianship, the person authorized is appointed by, and can be revoked by, the individual. A Durable Power of Attorney for Healthcare may also be called:

    - Health Care Proxy
    - Health Care Power of Attorney
    - Medical Power of Attorney
    - Health Care Agent (the Agent is the person who holds the DPOA)

- **Living Will** – Lets you state your wishes for end of life care in advance so that you receive care according to your values when you are in a terminal or irreversible condition.

- **A "Living Will" may also be called an Advance Directive**

Agent – We used the term "Agent" throughout this booklet to refer to the person to whom you have given authority to make certain decisions about your medical and/or financial matters when you are no longer able. In a broad sense, the term "Agent" means someone who has the power to make decisions for you. If you do not choose someone to make decisions for you the

laws of most states provide a list of individuals who will be given that authority without your consent. Additionally, the courts can intervene to appoint someone as a "guardian" if you have not appointed an Agent through a Power of Attorney. Many people sign a Power of Attorney to avoid the use of a guardianship which is more cumbersome and expensive.

Guardian – Guardianship may be granted where decision making capacity is so impaired that the individual is unable to care for their personal safety or provide themselves with food, shelter, clothing and medical care. A guardian is appointed by the courts to make medical and/or financial decisions, or both, when a person is unable to make decisions for him or herself. Guardianship may be granted as voluntary, involuntary, limited or temporary.

Surrogate decision making statutes – These state laws define who will have the legal authority to make decisions for a person when they are unable to make decisions for themselves. Although these statutes are clear on the face of it, disputes at the bedside between family members are not uncommon. The case of Terri Schiavo may be familiar to many as an illustration of these disputes that sometimes reach into the highest levels of the legal system, and leave the individual between fighting relatives and their lawyers. These controversies are almost always avoidable through the use of directives to physicians.

Decision-making ability

In end of life decision-making, the terms "competence" and "capacity" are often used interchangeably to mean the same thing: the ability to make medical decisions for oneself. However, the two terms are slightly different.

Competence – This is a legal term about your ability to make your own decisions. Competence is often described as the "ability to understand and appreciate the nature and effects" of one's decision.

Capacity – This is a medical term about your ability to make medical decisions. If you are unable to make decisions about your own care, your Agent will become your decision maker. This protects you from decisions that do not reflect your own values and wishes. An assessment about your capacity to make decisions would include whether you have the:

- Ability to **understand** the diagnosis and treatment options
- Ability to **appreciate** what these mean to your health and well-being
- Ability to **reason** about these options
- Ability to **express** a choice clearly and consistently

Informed consent – The law requires that a person or their Agent be informed of the risks characteristic in any procedure. This is done so that everyone will be respected for their own unique humanity and individual autonomy.

Beyond Advance Directives

Advance Directives are usually written when a person is healthy and may not address all the possible health situations that can occur over a person's lifetime. Some states have developed additional types of Advance Directives documents that address specific symptoms or situations in more detail.

Out-of-hospital DNR (OHDNR) –
Many states have statutes for OHDNR orders. An out-of-hospital DNR order is signed by a person's physician and directs emergency medical services (EMS) providers to withhold CPR. Many people do not realize that if an ambulance is called, EMS typically must begin CPR and other life-sustaining measures. The OHDNR allows them to have a legal basis to withhold these interventions. Check to see if there are OHDNR laws in your state.

Physician (Provider) Order for Life-Sustaining Treatment (POLST) – There are two major differences between the POLST document and the typical Advance Directives document. The first is that the POLST, unlike the Advance Directive, is signed by a physician (or in some states, a nurse practitioner or physician assistant), so the directives are recognized by health professionals as a "Doctor's Order" to be obeyed. The second is that the POLST document specifically asks for a response about a variety of possible treatments. It is easier for health providers to understand and execute the wishes written in the POLST. A POLST is not appropriate for a person who has no health problems because it is so specific. But as HD progresses, and you and your family may better understand what kinds of medical problems and treatment decisions are likely to arise, the POLST may be helpful. About 13 states use the POLST document, and a number of other states are developing such a document. Check *www.ohsu.edu/polst/index.htm* for more information about the POLST document.

Psychiatric Advance Directives (PAD) – Whereas most Advance Directives give instructions for care at the end of life, PADs are designed to document your wishes for future mental health treatment, in the event that you lose capacity to give or withhold consent to treatment during acute episodes of psychiatric illness. According to the National Resource Center on Psychiatric Advance Directives (2013), 25 states have statutes for PADs.

Common Myths & Misunderstandings

There are many misunderstandings about Advance Directives. Here are a few:

Myth: *Only the person with HD needs an Advance Directive.*

Fact: All adults should have Advance Directives. Caregivers also need to consider who will make decisions for them should their health become compromised.

Myth: *I'm healthy/young; only people with symptoms need these documents.*

Fact: Many of the most high profile cases regarding conflict over end of life decision-making involved previously healthy young adults. The time to complete these documents is not once disease or sickness has begun. In HD especially, unawareness or other psychiatric or cognitive symptoms can make completing these documents later impractical or even impossible.

Myth: *I've already completed these documents, so I never need to worry about this again.*

Fact: These documents should be revisited periodically.
Your wishes may have changed, you may have moved to another state, or you may want to change your mind about who you will name to be your legal representative.

Myth: *I have a will; that's all I need to do.*

Fact: A will won't help with your medical decision making.

Myth: *I want all life-saving measures no matter what. I don't need a Living Will because those are only for people who don't want medical intervention.*

Fact: Advance Directives are to communicate your wishes and allow them to be legally enforced no matter what those wishes are. Choosing a legal representative and documenting your preferences will help ensure that your wishes are followed, no matter what they are.

Myth: *You have to use your own state's form for your Advance Directive to be valid.*

Fact: While it is usually best to use a form that you know is valid in your state, any document is better than no document. States do differ on some requirements such as witnessing or notarization.

Myth: *Doctors have to follow Advance Directives.*

Fact: Doctors can refuse to follow your wishes if they personally object or find your wishes medically inappropriate. In these cases, they have an obligation to transfer your care to another provider.

Myth: *If I name a health care proxy, I don't get to make my own medical decisions anymore.*

Fact: As long as you are still competent, you always have the right to override the decision of your designated agent and you may change or revoke the directive.

Myth: *I should wait until I am sure about everything before signing an Advance Directive.*

Fact: Most people are not sure about what they would want in all situations. It is better to execute the document and then make changes along the way. The most important thing is sharing your wishes with your Agent so they represent you as best as they are able.

Myth: *Just talking to my doctor and family is enough.*

Fact: Talking to your doctor and family is essential. Getting your wishes in writing helps them have something to refer to down the road and also provides the legal tool necessary to enforce your wishes.

Myth: *If I am at home and do not want to be resuscitated my Advance Directive is good enough.*

Fact: Advance Directives usually won't help in this situation. EMS must attempt to resuscitate a person and take them to the hospital. In some states there are special out-of-hospital DNR forms or bracelets that can be used. See the section in this booklet on POLST (page 20) or check with your state about the specific rules in your area.

Myth: *A Living Will is good enough.*

Fact: A Living Will, no matter how well drafted, may not anticipate all possible scenarios. A Health Care Power of Attorney is a much more flexible document because it allows you to choose an agent who can make legally-binding decisions in the grey areas that may be more likely to actually occur.

Myth: *I need a lawyer to create an Advance Directive.*

Fact: Lawyers can be important for comprehensive estate planning, but Advance Directives do not require a lawyer, are not difficult to complete, and are readily available, usually for free.

Myth: *My Agent can take care of my wishes after death.*

Fact: Just as a person cannot make decisions for him/herself after death, the Agent has no authority to make decisions after the person dies. Proper legal planning will include an executor of the estate, who has the legal authority to attend to the affairs of someone who is deceased.

Myth: *I have a financial Power of Attorney already written. I don't need any other documents.*

Fact: Often this is a separate legal document from the Health Care Power of Attorney. You can name the same person for both roles if that is best for you.

Myth: *Having an Advance Directive means all of my personal matters can be dealt with by my Agent.*

Fact: A Health Care Power of Attorney only allows the person to make your medical decisions for you. Financial matters require a different document. Social Security may require different forms such as representative and representative payee.

Internet Resources

Many resources are available on the internet. You can find all of these resources listed on the HDSA website at ***www.hdsa.org/onlineresources***. Here are a few that are especially useful:

General information

American Bar Association Commission on Law and Aging

The American Bar Association has developed several toolkits for you to use as you consider and implement your Advance Directive.

This toolkit includes links to workbooks that assist with advance care planning as well as links to forms: ***www.americanbar.org/content/dam/aba/migrated/aging/toolkit/tool10.authcheck-dam.pdf***

This resource includes information to help you choose a health care agent, questions to help you make an informed decision about medical interventions at different stages of illness, questions of personal and spiritual values, and decisions about care at end of life and beyond, as well as a quiz for your health care agent to test their understanding of your wishes: ***www.apps.americanbar.org/aging/publications/docs/lawyers_tool_kit_bk.pdf***

Caring Conversations®

Caring Conversations®, by the Center for Practical Bioethics is designed to guide individuals through the process of advance care planning. Each copy of Caring Conversations includes a Health Care Directive form and a Durable Power of Attorney for health care form. The site also has links for Courageous Conversations, designed for military veterans, and Caring Conversations for Young Adults, a starting point for young adults and their families to talk about topics like organ donation, do-not-resuscitate orders, and serious illness. ***www.practicalbioethics.org/resources/caring-conversations.html***

State-specific forms

Caring Connections

Caring Connections provides links to forms for every state: ***www.caringinfo.org***

Five Wishes

Available in over 25 different languages, this site provides links to an alternative Advance Directive document: ***www.agingwithdignity.org/five-wishes.php***

Psychiatric Advance Directives

National Resource Center on Psychiatric Advance Directives

The National Resource Center on Psychiatric Advance Directives offers information about preparing Advance Directives for individuals with psychiatric disorders and includes information on which states recognize these documents: ***www.nrc-pad.org/***

National Alliance for Mental Illness (NAMI)

NAMI provides information about states with specific psychiatric Advance Directive laws: ***www.nami.org/Template.cfm?Section=Issue_Spotlights&template=/ContentManagement/ContentDisplay.cfm&ContentID=8386***

Notes

Notes

HELP FOR TODAY. HOPE FOR TOMORROW

HDSA Mission

To improve the lives of people with Huntington's disease and their families.

Huntington's Disease Society of America
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505 Eighth Avenue, Suite 902
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Phone: 212-242-1968
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Helpline: 888-HDSA-506
Fax: 212-239-3430
Email: hdsainfo@hdsa.org
Web: www.hdsa.org

Huntington's Disease Society of America

Check List

Here is a checklist to help you start planning. HDSA is also here to help you find the resources you may need. Call the HDSA Helpline at 888-HDSA-506 for resources in your area.

- ❑ I have thought about my values and how they factor into end of life decisions
- ❑ I have thought about where and how I want to be cared for when I am no longer able to care for myself
- ❑ I have spoken with my family about my end of life wishes
- ❑ I have appointed an Agent to make health care decisions and discussed my end of life wishes with this person
- ❑ I have discussed my end of life wishes with my medical team
- ❑ My Living Will is signed, notarized, and a copy has been given to my physician
- ❑ I have considered whether I also need an Agent for financial matters

Huntington's Disease Society of America

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