



Huntington's Disease Society of America

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HDSA encourages all attendees to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, nutritional supplement or regimen that may have been mentioned as part of any presentation.

Health Care Planning

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Personal planning

- Living positively with HD
- Think about your values
- Start planning ahead
- Talk to your family about end of life wishes
- Find the forms you need to make sure your wishes are followed

Living Positively

- Though chronic disease admittedly imposes many limitations, challenges and adds new problems to daily living, it does not have to stop you from living life with happiness and gaining fulfillment from interactions with family, friends and other loved ones.
- Quality of life includes factors like freedom, happiness, art and innovation. Focus on enjoyment of what can be done rather than what cannot be done.
- Make time for recreation and enjoyment of your family, friends and self. Take time off from stressful situations.

Living Positively

- Nutrition, exercise and weight management can all lead to more quality time
- Adaptation to change is fundamental to focus on the present rather than the past
- Comparison to the past or to others is detrimental to a positive attitude that is so important for healthy living

Explore your values

- What is important to you?
- What are your fears concerning the end of life?
- How do you want to be remembered?
- What gives your life purpose and meaning?
- What is important for others to know about the spiritual or religious part of your life?

What do *you* want?

- **Would you want your doctor to withhold or withdraw medical treatment, if that medical treatment will only prolong dying?**
- **Would you want cardiopulmonary resuscitation (CPR) to restore stopped breathing and/or heartbeat?**
- **Would you want to continue mechanical respiration, i.e. use machines to keep you breathing?**
- **Would you want tube or intravenous feeding and water?**
- **Would you want maximum pain relief even if it hastens your death?**
- **Would you want to donate your organs and/or tissues?**

Planning ahead

- Talk to your family about your wishes for end of life care
 - Start with a story of someone else’s experience:
“Jackie Kennedy did not want to be put on life support, and she died at home. I wonder if she made her wishes clear in advance?”
- Use news items, movies, books as a starting point
- Be firm and straightforward about your wishes
- Point out the consequences of not talking now
- Ask someone to be your spokesperson

Find the forms you will need

- Medico-legal forms:
 - State specific advance directive forms
 - Durable power of attorney for health care
 - Do not resuscitate orders (DNR)
 - Out of hospital DNR
 - Declaration for mental health treatment
- Financial forms
 - Insurance planning
 - Estate planning
 - Funeral planning

Legal Issues to prepare for medical care

- Guardianship vs. health care proxy
- Advance directives / power of attorney / DNR
- How to fill out the forms
- What your health care agent needs to know
- Financial considerations
- How to find additional help

Guardianship v. Medical Power of Attorney

- **Durable Power of Attorney**

- Agent appointed by the patient
- Term: can be revoked
- Powers: medical, financial
- Patient retains all other legal powers

- **Guardianship**

- Appointed by court
- Term: until court terminates
- Powers: Plenary (also limited, temporary)
- Ward cannot contract, select residence, consent to medical treatment

Medical Planning

Advance directives / living will / directive to physician

Durable power of attorney for health care /
Medical power of attorney

ABA / AMA and AARP recommended form

www.abanet.org/lawinfo/abd.pdf

Or get your state promulgated form

www.caringinfo.org/stateaddownload

Mental Health Directives

Declaration for Mental Health Treatment

I _____, being an adult of sound mind, willfully and voluntarily make this declaration for mental health treatment to be followed if it is determined by 2 physicians or the court that my ability to receive and evaluate information effectively or communicate decisions is impaired to such an extent that I lack the capacity to refuse or consent to mental health treatment. "Mental health treatment" means electroconvulsive treatment, treatment of mental illness with psychotropic medication, and admission to and retention in a health care facility for a period up to 17 days.

I understand that I may become incapable of giving or withholding informed consent for mental health treatment due to the symptoms of a diagnosed mental disorder. These symptoms may include:

PSYCHOTROPIC MEDICATIONS

If I become incapable of giving or withholding informed consent for mental health treatment, my wishes regarding psychotropic medications are as follows:

_____ I consent to the administration of the following medications:

_____ I do not consent to the administration of the following medications:

Conditions or limitations: _____

ELECTROCONVULSIVE TREATMENT

If I become incapable of giving or withholding informed consent for mental health treatment, my wishes regarding electroconvulsive treatment are as follows:

_____ I consent to the administration of electroconvulsive treatment.

_____ I do not consent to the administration of electroconvulsive treatment.

Conditions or limitations: _____

(continued)

Tips for preparing your advance directive

- You do not need a lawyer to fill out this form
- Find out what types of life sustaining treatment are available and decide which you do not want before filling out the form
- Let your loved ones and doctor know your wishes
- Ask someone to look over the form to make sure you have put everything down that you want to include
- If your wishes change make a new directive
 - Each decade
 - Death of a loved one
 - Divorce
 - Diagnosis
 - Decline

After your advance directive is prepared

- Make several copies and give them to your doctor, loved ones, health care agent
- Do not keep your advance directive in a safe deposit box – others will need to see it
- Give notes or worksheets and explanations to your health care agent
- Carry an advance directive wallet card with you
- Have a copy placed in your medical record at the hospital or nursing home
- You may need to complete a DNR if you want to avoid cardio-pulmonary resuscitation (CPR)
- See if your state has Advance Directives for Health Treatment

Information for Health Care Agents

- Talk to your loved one to make sure you know what they want
- The health care agent has the power to make any and all health care decisions the patient would make for herself:
 - Receive medical information
 - Consult with the medical team
 - Review the medical chart
 - Ask questions / get explanations
 - Discuss treatment options
 - Request second opinions
 - Consent to procedures or refuse treatment including life-sustaining
 - Authorize transfer to another hospital or facility

Health Care Agent Responsibilities

- Find out the medical facts
- Find out the options
 - Including what would happen if we do nothing?
- Ask what the patient would want if she knew all the facts and options
 - If you know her preferences follow them
 - If you don't know but can figure it out from her values and past choices, follow this *even if it is not what you would choose for yourself*

Financial issues

- Start by talking to family members
- Make a financial inventory list
- Sign a **durable power of attorney** for financial affairs – get the right form for your state
- This form should be properly notarized and witnessed
- It will need to be filed with the state *only* if real estate is involved

Take care of loved ones

- Make a will
 - List of financial inventory
 - Who will be the executor
 - Who will act as guardian for young children
- Set up trusts for special needs
- Update your beneficiaries
 - The person named will get the insurance or other funds
 - “Trust A under the will of John Smith” allows for more control and latitude
- Set up POD accounts

Keep documents accessible

- Keep originals of your durable power of attorney, advance directives, and will in a safe place in your home, and let people know where that is.
- Keep the copies in a safe deposit box

Find sources of financial help

- Health insurance
- Medicare / Medicaid
- Life insurance
- Disability insurance / long term / short term
- Retirement savings
- Home equity
- Social Security Disability Income

Other sources of health care planning advice

- Elder law attorneys / Asset planning attorneys
 - www.findlegalhelp.org or ask your local bar association
- Financial planners
 - <http://www.fpanet.org/plannersearch/search.cfm>
- Questions to ask:
 - Will the lawyer provide a free consultation for an initial interview?
 - How long has the lawyer been in practice?
 - What percentage of the lawyer's practice is elder law / asset planning?
 - What experience does the lawyer have working with people who are at risk for serious disease?
 - What type of fee arrangement does the lawyer require? Are the fees negotiable?
 - What type of information do you need to provide?
 - Ask for referrals.

Resources

- Information about planning for medical decisions: www.seniorservicesassoc.org/living_wills_and_healthcare_powe.htm
- Financial planning from National Hospice and Palliative Care Organization (NHPCO): www.nhpc.org
- Legal information from the American Bar Association: www.abanet.org/lawinfo/abd.pdf
- Legal information from Health Lawyers Association: http://www.healthlawyers.org/Template.cfm?Section=Public_Information_Series&Template=/ContentManagement/ContentDisplay.cfm&ContentID=6861
- New York End of Life guide: <http://www.oag.state.ny.us/health/EOLGUIDE012605.pdf>