# Caregivers' Guide to Communicating with Healthcare Providers

# Huntington's Disease

Family Guide Series

Huntington's Disease Society of America

# Caregivers' Guide to Communicating with Healthcare Providers

## Family Guide Series

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## Disclaimer

Statements and opinions in this book are not necessarily those of the Huntington's Disease Society of America, nor does HDSA promote, endorse, or recommend any treatment mentioned herein. The reader should consult a physician or other appropriate healthcare professional concerning any advice, treatment or therapy set forth in this book.

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# Overview

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As a family caregiver, you are an essential partner in your loved one's treatment. Your input and communication with the medical team can improve quality of care and quality of life for your loved one – and yourself!

HD is a disease that progresses over years. Changes may be very slow and subtle or they may seem to come on quickly. Whatever the pace of change in symptoms, you are the eyes and ears of the medical team between appointments. Your observations are critical to getting the best possible care for your loved one.

This guide contains a number of strategies for presenting what you see and experience during caregiving in an effective way.

# Challenges

## The Difficult Transitions

Caregiving and HD – it's not easy! HD is a disease of difficult transitions and there are features of the disorder that may make these changes more complicated.

Difficult transitions typically include:

- The transition from health to early HD.
- Poorer performance at work and home.
- Reduced abilities creating safety issues (i.e. Is it still safe to drive?).
- Growing need for caregiving and supervision.
- Decisions surrounding later stage care.

Features of the disease which make these transitions more difficult may include:

- Unawareness of symptoms on the part of the person with HD.
- Cognitive and behavioral changes that appear before the movement disorders in early HD.
- Psychiatric and emotional changes that appear unpredictably.
- The struggle between the desire to maintain independence vs. an increasing need for care.

## Challenges at the Doctor's Office

Your loved one's medical team wants to provide the best care possible, but they may be limited by training, experience or time pressures.

In trying to talk to your loved one's doctors about what you have observed as a family caregiver, you may encounter some of the following difficulties:

- If they have not had experience with HD, they may not appreciate the symptoms and signs of early HD, especially the emotional and cognitive symptoms.
- Emotional outbursts caused by HD are unpredictable and the doctor may never see what you are describing.
- Doctors may feel that you are being emotional and that symptoms are being exaggerated.
- You may feel frustrated, alone and ignored.

## No time to Talk

Other challenges may arise from having limited time with the doctor. A typical medical appointment allows only about 7 minutes with the doctor (HDSA Centers of Excellence are an exception to this). This limited communication with the doctor can create situations where the progression of the disease is not being acknowledged.

You may find it difficult to talk about troubling behavior with your loved one present. It may be necessary to schedule a separate consultation with the doctor, so that you have the privacy and time to talk openly about your concerns.

# What You Can Do

## Caregiving and HD

You know that you have an important role to play in your loved one's treatment.

The question is how to bring important symptoms to the attention of the medical team? How do you build credibility so that you will be believed?

Be prepared!

- Understand the symptoms of HD,
- Keep track of possible symptoms,
- Come to the appointment with observations/questions,
- Ask for action and follow up.

## Understand the Symptoms of HD

HD is not a common disease. Some people still think of it only as a movement disorder! The more you understand about HD, the easier it will be to identify symptoms and present them to the medical team. There are many resources and publications available on the HDSA website, www.hdsa.org, that can educate you about HD.

## Keep Track

When you see something that may be symptomatic of HD or that may indicate the progression of the disease, write it down in a notebook and include the date. Occurrences may include outbursts, impulsivity, aggression, obsessions, etc.  These notes will reveal patterns of behavior that can alert the medical team to symptoms they may not be able to observe during the appointment.

Other things you may want to keep in your notebook include:

- Notes from conversations you have had with the medical team, for example, the date when you first brought a symptom to their attention.
- A current list of your loved one's medications and any side effects you have observed.
- Any questions/concerns your want to discuss with the doctor. Write them down – you cannot assume you will remember them all during the appointment.

## Summarize

When you go to talk to your loved one's doctor, bring a one-page summary of symptoms you have observed since the last appointment. The log will alert the doctor to the behavior patterns that you see. As stated above, specific dates and examples of changes in abilities and daily function are most useful.

**Important** - *Ask the physician to include the changes you've noted in the visit record and office notes. This will ultimately be helpful in requesting evaluations and assessments to build the case for cognitive and behavioral impairments for determination of disability.*

## Ask for Action and Follow up

At the end of an appointment, repeat what you and the doctor have decided upon, for example:

- Starting or changing medication
- Changes in nutrition
- Recommendations for psychiatric evaluation or counseling
- Recommendations for allied health assessments such as physical therapy
- At the next appointment, follow up or report results.

The process may be frustrating, but try to avoid getting angry. Keep calm and use facts.

Do not hesitate to call the nearest HDSA Center of Excellence for advice if you live too far away to be seen there.

Ask for referrals to Neurology and/or Psychiatry if needed.

In some cases, you may need to seek a second opinion from a different doctor.

# Referrals, Evaluations and Assessments

HD is a disease with many facets that affect the entire person. While there is currently no cure for HD, there are many aspects of the disease that can benefit from treatment. You may wish to talk to your loved one's medical team about some of the following options, which may improve functioning and quality of life.

*Neurologist*

- Provides diagnosis of HD, management of chorea or motor symptoms.

*Psychiatrist*

- Helps with conditions that may or may not be caused by HD: depression, anxiety, behavioral difficulties, OCD or psychosis.

*Therapist*

- Provides supportive counseling at initial diagnosis or during difficult transitions.
- Provides assessment and treatment for frequent or severe irritability/anger.

*Occupational therapist*

- Suggests strategies or adaptive equipment to increase functional independence in daily life.

*Physical therapist*

- Teaches functional/balance exercises.
- Evaluates gait difficulties and need for home mobility equipment.
- Provides exercises to reduce pain, increase flexibility, and build strength, function and range of motion.

*Speech-Language pathologist*

- Offers exercises and strategies to address swallowing and/or speech difficulties.
- Trains in the use of communication devices.

*Dietician or nutritionist*

- Addresses weight loss (or gain).
- Adapts diet to address to swallowing difficulties.

# Working Together

By building lines of communication with the medical team, you can help improve your loved one's level of care. Medical professionals may also be able to help the person with HD to be more responsive and cooperative at home – sometimes they just need to hear it from someone other than the caregiver. In addition, your careful note taking and conversations with the medical team, helping them to see what you see, may be beneficial in supporting an application for disability benefits.

# Caring for the Caregiver

Caregiving challenges will arise throughout the course of HD. Your health and well being are essential if you are to continue looking after your loved one. Your loved one is not the only one who may need a doctor's care. You may find that a therapist is an important part of **your** medical team. Ask your doctor for a referral.

Make time to take care of yourself. Ask your family and friends for help when you need time off from caregiving. Your social worker or local HDSA Chapter may be able to give you information about respite services. Share the care – it's never too early to seek help.

# HDSA Centers of Excellence

HDSA Centers of Excellence are designated centers for accessible and expert diagnosis and care for HD. Core personnel include a neurologist, social worker, nurse and other medical professionals. Personnel are available by phone to speak to patients, families and other health care providers. Center of Excellence social workers are excellent resources for referrals to specialists, information about disability, caregiver support and care facilities. HDSA has 21 Centers of Excellence located across the US. To find the one closest to you, go to www.hdsa.org and click on "Living with HD."

# Local HDSA Chapters and Support Groups

There are 39 HDSA Chapters and Affiliates nationwide in addition to 139 support groups. Chapters can put you in touch with other families affected by HD, who can be excellent resources for finding medical professionals and for providing caregiver support.

Many chapters have social workers who can help you and your loved one in many ways. They are very knowledgeable about resources for people with HD in your state and region. Support groups can offer emotional encouragement as well as information about community based resources. Locations for your closest HDSA chapter, affiliate or support group can be found on the HDSA website, www.hdsa.org.

# The HD CARE Kit

As HD progresses, there may come a time of crisis when your loved one comes in contact with law enforcement or emergency medical personnel. Having an HD CARE Kit of important numbers and documents organized and close at hand may help to prevent dangerous misunderstandings during this encounter.

Your HD CARE KIT should contain these important documents:

**List of emergency numbers**

**One-page psychiatric history summary**

**Recent picture and description**

**Copy of criteria for emergency evaluation**

**Copy of criteria for civil commitment**

**Petition form for emergency evaluation**

**Petition form for civil commitment**

**Signed Medical Release**

**Medical Power of Attorney**

**Patient's Advance Directive**

# The HD CARE Kit

More information on the HD CARE Kit is available on the HDSA website, at www.hdsa.org. Click on "Living with HD" and then go to "Publications for Download." You will find the link to the HD CARE Kit under "Caregiving."

Information changes constantly. For the most up to date list of HDSA Chapter, Affiliates, Centers of Excellence and Support Groups, please go to www.hdsa.org or call 800-345-HDSA (4372).

# Notes

# Notes

# HELP FOR TODAY. HOPE FOR TOMORROW

## HDSA Mission

The Society is a National, voluntary health organization dedicated to improving the lives of people with Huntington's Disease and their families.

To promote and support research and medical efforts to eradicate Huntington's Disease.

To assist people and families affected by Huntington's Disease to cope with the problems presented by the disease.

To educate the public and health professionals about Huntington's Disease.

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