

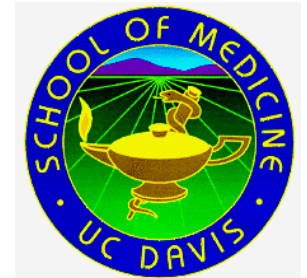


# Talking to Your Loved One's Doctors

## Strategies for Successful Communication



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# Talking to Your Loved One's Doctors

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- The difficult transitions
- What the caregiver can offer to the medical team
- Overcoming obstacles
- Learning to work together
- Resources and HD Care Kit

# Huntington's Disease Stages

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- Stage 0: Presymptomatic
- Stage 1: Slightly lower performance at work and home; independent at home
- Stage 2: Can still work (lower level), still mostly independent at home
- Stage 3: Difficult to work, starts to need help with financial, home activities
- Stage 4: Unable to work. Needs major assistance with care
- Stage 5: Full-time nursing care required

*Adapted from Shoulson et al, Quantification of Neurological Deficit,  
Boston:Butterworth, 1989*

# Difficult Transitions

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- The transition from health to early HD
- Poorer performance at work and home
- Qualifying for disability
- Is it still safe to drive?
- Increasing needs for caregiving and supervision
- Later stage care needs

# The Features of HD May Make the Transitions More Difficult

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- Unawareness of symptoms on the part of the person with HD
- Cognitive and behavioral changes may appear before movement disorders in early HD
- Although movement-related and thinking changes progress predictably, psychiatric and emotional changes are often quite unpredictable
- The desire to maintain independence vs. the increasing need for care may become a source of conflict

## Caregiving – *It's Not Easy!*

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- As a family caregiver, you are an essential partner in your loved one's treatment.
- Caregiving challenges change throughout the course of HD.
- Your input and communication with the medical team can improve quality of care and quality of life for your loved one - *and yourself!*
- *Share the care – it's never too early to seek help.*

## Challenges – *"Is it HD?"*

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- Symptoms of depression or anxiety can mimic early-stage HD.
  - Whether it's HD or not, those symptoms are treatable!
- "Honey, I think we need to see the doctor."
  - Very difficult conversation to initiate; remember that the person with HD may not be aware of their symptoms.

## Challenges – “*Show me*”

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Doctors may not appreciate the symptoms and signs of early HD

- While movement disorders are visible, it can be difficult to see changes in behavior and cognition
- Emotional outbursts are unpredictable and the doctor may never see the behaviors you see
- Doctors may feel that the caregiver is being emotional and that symptoms are being exaggerated



## Challenges – “*Do you hear me?*”

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- Time limits at medical appointments
  - In a typical medical appointment, you have about 7 minutes with the doctor
- Limited communication with the doctor can create situations where the progression of the disease is not being acknowledged
- Treatable symptoms like depression and anxiety may be overlooked or not addressed fully
- You may feel ignored and alone

# Building Credibility – Being Believed

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As a family caregiver, you are an essential partner in your loved one's treatment.

- How can you bring important symptoms to the attention of the medical team?
- How do you get them to listen to you?

# Building Credibility – Being Believed

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*Be prepared!*

- Understand the symptoms of HD
- Keep track of symptoms
- Come to the appointment with questions
- Ask for action and follow up

# Keeping Track of Symptoms

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- Keep an incident log of symptoms – include the dates of outbursts, impulsivity, aggression, etc.
- Make a note of conversations you have had with the doctor – for example, when you first brought a symptom to their attention
- Keep a current list of your loved one's medications and any side effects you have observed.
- Write down your questions as they come to you – you cannot assume you will remember them

# Building Credibility – Being Believed

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- Bring a one-page summary of symptoms with you to the appointment – specific dates and examples of changes in abilities and daily function are most helpful
- The log will help the doctor see the behavior patterns that you see and help establish cognitive and behavioral impairments for determination of disability
- Ask the physician to include the changes you've noted in the visit record and office notes

# Building Credibility – Being Believed

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- The process may be frustrating, but try to avoid getting angry. Use facts.
- Call your nearest HDSA Center of Excellence for advice if you live too far away to be seen there.
- Ask for referrals to Neurology, Psychiatry if needed.
- In some cases, you may need to seek a second opinion from a different doctor.

# Asking for Action

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- At the end of an appointment, repeat what you and the doctor have decided on, 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.

# Asking for Evaluations/Assessments

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- Referral to a neurologist
  - Initial diagnosis
  - Management of chorea or motor symptoms
- Referral (or self-referral) to a therapist
  - Supportive counseling at initial diagnosis or advancing stages
  - To help treat mild-moderate depression, anxiety or behavioral difficulties
- Referral to a psychiatrist
  - Frequent or severe irritability/anger
  - Symptoms of depression, anxiety, OCD or psychosis



# Additional Assessments

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- Occupational therapy
  - Exercises or adaptive equipment for activities of daily living related to hand function
- Physical therapy
  - Teach functional/balance exercises
  - Evaluate gait difficulties and need for home mobility equipment
- Speech and language therapist
  - Swallow and/or speech difficulties
- Dietician or nutritionist
  - For weight loss (or gain), dietary changes for swallowing difficulties

# 39 HDSA Centers of Excellence



The HDSA Centers of Excellence provide an elite multidisciplinary approach to Huntington's disease care and research. HDSA currently has 39 Centers of Excellence across the United States. At these world-class facilities, patients benefit from expert neurologists, psychiatrists, therapists, counselors and other professionals who have deep experience working with families affected by HD and who work collaboratively to help families plan the best HD care program throughout the course of the disease.

<http://hdsa.org/about-hdsa/centers-of-excellence/>

# HDSA Centers of Excellence

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- These are designated centers for accessible and expert diagnosis and care for HD.
- Core personnel include 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.

# Local HDSA Chapters and Support Groups

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- Many Chapters have social workers who can help in many ways.
- 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.
- Listings are available on the HDSA website, [www.hdsa.org](http://www.hdsa.org)

## Creating an HD Care Kit

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- 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 may help you to prevent dangerous misunderstandings during this encounter.
- HD Care Kit forms - can be downloaded by clicking on the link that will appear with this webinar when it appears on the HDSA national web site.

# Creating an HD Care Kit

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The CARE kit should contains 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

# Working Together

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- By learning how to communicate with medical professionals, you can help improve the care of your loved one with HD
- 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 their caregiver*

# Finally, Don't Forget ... *Yourself!*

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- Your loved one is not the only one who may need a doctor's care
- Your health and well-being are essential if you are to look after your loved one
- A therapist may become an important part of your medical team
- Make time to take care of yourself. Look into respite services.



# The HDSA Website: [www.hdsa.org](http://www.hdsa.org)

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The HDSA website can put you in touch with people who are there to help –

- HDSA Centers of Excellence
- Support groups in your local area
- Your local HDSA chapter
- HDSA Social Workers