Huntington's Disease Society of America

# Managing Challenging Behaviors

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# Our Goal Together

To Review:

- **Challenging Behaviors in HD**
- **Psychiatric problems common in HD**
- **Provide helpful strategies for both patients and families**
  - Behavioral techniques
  - Medication overview

# In HD, **Brain Changes** *Cause* **Behavioral Changes**

- **Psychiatric symptoms -- earliest and most disabling symptoms in the disease.**

- When caregivers face these challenges, remember:
  - **It's the disease, not the person**
  - **The person with HD faces a series of losses**. Frustration, anger, withdrawal can be the result of these losses.

- **Understanding these concepts helps direct strategies**

# Symptoms in Huntington's disease

Impulsivity

Balance problems

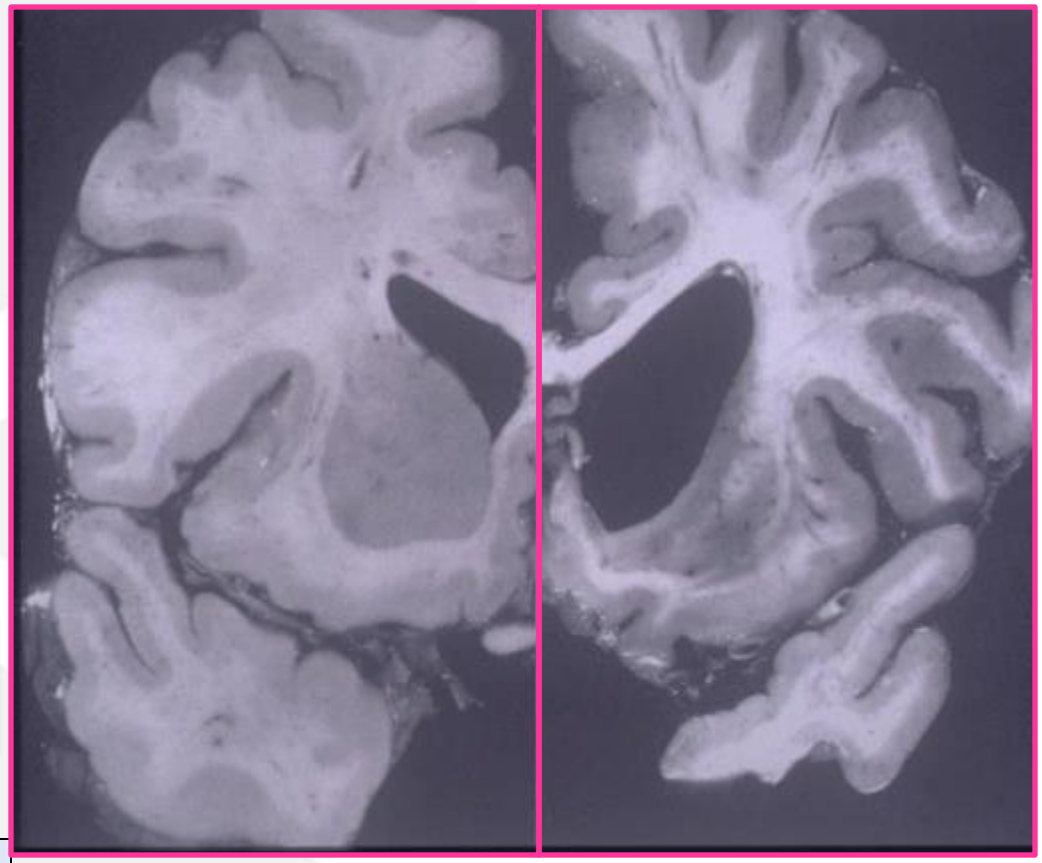
↓Creativity

Slow eye movements

Episodic anger Irritability

Slowness of movement

Depression, anxiety



Normal

Advanced HD

Chorea: involuntary movements

↓Multi-tasking

Restless, fidgets

↓Organizing Concentrating Prioritizing

Fine motor tasks

Trouble swallowing

OCD Psychosis

# Challenging behaviors

- **Unawareness**
- **Impaired executive function**
- **Apathy**
- **Irritability and disproportionate anger**
- **Anxiety**
- **Obsessive thoughts and compulsive behaviors**
- **Depression and suicide**

# Unawareness

# Unawareness

- **This is hard-wired; not simply “denial.”**

- **Examples:**
  - Failure to recognize the early symptoms of HD
  - Unawareness of decline in performance at home or work
  - Lack of recognition of need to stop driving

- **Consequences**:
  - Delays in diagnosis, failure to get help when needed
  - Job and personal losses
  - Externalization and blame of others

# Unawareness Strategies

- **Confrontation often fails**. Don't try to "inject" insight.
- **Seek help from medical team**: primary care physician, neurologist, SW, psychologist or psychiatrist
- **Seek help from outside agencies**: driver evaluation, job performance evaluation, case manager

# Unawareness Strategies

**Examples that may not work:**

- "You have Huntington's – you can't drive."
- "Your attention and motor skills aren't sufficient for driving. We don't want you or others to be hurt."

– **Try**: "I'll drive you – I was planning to go there today."
– **Be selective**. Choose only important issues for intervention.
  - Identify the key issues that need intervention
  - Acceptance of other issues

# Reduced Executive Function

# What is Executive Functioning?

**Speed of thinking, planning, prioritizing, organizing, concentration, decision making, flexibility, creativity**

- Leads to changes in function, including reduced ability to carry out activities at work and at home
  - Poor performance at work, or work may appear sloppy, incomplete, or disorganized
  - Loss of initiation: can't get started
  - Perseveration: getting stuck on certain ideas or activities
  - Lack of inhibition, inappropriate behavior, impulsiveness
  - Inability to recognize others' emotions
  - Lack of recognition of hunger, thirst, even pain

# Reduced executive function: Strategies

- **Behavioral techniques**
  - Rely on routines. Use calendars, schedules and lists
  - Break tasks down into small steps: one thing at a time
  - Simplify
  - Use prompts and cues
  - Offer choices rather than open-ended questions
    - **Example** "Would you rather have oatmeal or eggs?" instead of "What would you like for breakfast?"
  - Use short sentences with 1-2 pieces of information

# Apathy

# Apathy

- Loss of ability to start activities, often with loss of inner drive
- **Important brain circuits** involved in motivation, timing, switching from one activity or task to another **are damaged**
- **Apathy may be a feature of depression**, but many people with HD who suffer from apathy are *not* depressed
- Examples:
  - Getting out of bed
  - Completing household chores
  - Personal hygiene
  - Managing finances
  - No longer cares about things that used to be important

# Apathy: Strategies

- Medical evaluation (rule out depression/metabolic problems)
- **Behavioral strategies are the most successful**
  - Simplify routines
  - Set up a daily schedule for wake-up and bedtimes, meals
  - Use a calendar for activities such as chores
    - Involve the person with HD in creating of the schedule!
  - Offer cues and prompts (phone alarms, verbal reminders)
  - Environmental stimulation:  Adult Day Health Programs
- **If apathy is severe, seek psychiatric care for possible use of stimulant medications**

# Irritability / Anger

# Irritability and disproportionate anger

- **Frustration / anger about loss of abilities is COMMON**
- **Loss of the ability to regulate emotions**
  - The person with HD may lose their patience or tolerance for things that never used to bother them
  - They may find it difficult to shrug off minor irritations
  - There may be sudden, explosive anger episodes
- **May also be a feature of depression**

- **Behaviors**: screaming, swearing, threatening, slamming doors, hitting walls, pushing, striking or hurting others

# Irritability and disproportionate anger

- **Behavioral strategies are most helpful**
  - Create a calm environment if possible
  - Set up daily schedule and weekly calendar
  - Identify anger triggers and avoid them
  - Use distraction, re-direction
  - **Practice de-escalation**: soft voice, respectful words, give space (including exit), don't use touch, leave the scene
    - Safety is critical
    - Call authorities if necessary

# Irritability / anger (continued)

- **Reduce alcohol intake and eliminate recreational drugs**
- **Remove weapons from the home**
- **Identify and treat depression or anxiety**
- **If anger episodes are <u>frequent, severe or don't respond to the above</u>, meet with neurologist or psychiatrist for medications**

# Anxiety: Strategies

- Create a calm environment
- Use schedules, calendars
- Simplify routines
- Allow plenty of time to complete daily tasks
- Counseling: cognitive-behavioral therapy
- Seek medical or psychiatric care for medications: SSRIs

# Obsessive thoughts and compulsive behaviors

- **Obsessive thoughts**: recurrent, intrusive thoughts or impulses.
  - Concern with germs/contamination
  - Fixation on perceived past insults/injustices
- **Compulsive behaviors:** behaviors or routines which must be performed to reduce inner discomfort. Examples:
  - Compulsive exercise: walking 7 miles a day
  - Compulsive eating or drinking
  - Compulsive video-gaming
- **Strategies**:
  - Behavioral: structure the environment
  - Seek care from a neurologist or psychiatrist for medications

# Depression in HD

- **Very, very common!**
- **Thoughts of suicide may occur**
  - Most commonly occurs around the time of diagnosis and early in the illness
  - over 25% of patients with HD attempt suicide at some point in the illness.
  - Reported rates of completed suicide among individuals with Huntington's disease range from 3-13%
  - **Treatment of depression** with counseling, medications, and family and community support **prevents** suicide

# Managing depression

- Recognition is important
- Counseling: cognitive behavioral therapy may help
- Seek medical care for anti-depressant medications such as SSRIs
- **For suicidal ideation, seek immediate help with crisis line, emergency department visit, or police if indicated**

# How common are these symptoms?

- Depression 20-60%
- Anxiety 35-60%
- Irritability 40-70%
- Apathy 35-75%
- Obsessions/compulsions 25-50%
- Psychosis 10%

# Medications in HD

Goal:

**Treat psychiatric / behavioral problems aggressively**

**We are very mindful of SIDE EFFECTS**

--good side effects (sedation at night, appetite)

--bad side effects (worsening chorea, rigidity, confusion)

--drug—drug interactions

# Medications in HD

- **Antidepressants** (Zoloft, Celexa, Effexor)
- **Antipsychotics** (Haldol, Zyprexa, Seroquel)
- **Mood stabilizers** (Depakote, Lithium)
- **Stimulant agents** (Ritalin)
- **Dementia medications** (Aricept, Namenda)
- **Dopamine depleters** (e.g. tetrabenazine)
- **Anti-glutamate agents** (e.g., amantadine)

# Additional issues

- **Distress at awaiting results of genetic testing**
- **Guilt at passing on autosomal dominant condition**
- **Coping with a progressive illness with midlife onset**

# Toolbox for managing challenging behaviors

- **Understand the basis of the change in behavior**
- **Routines, routines, routines  (simplify)**
- **Provide structure, prompts and cues**
- **Calm environment**
- **Regular medical care: physical and psychiatric**
- **Recognize danger signs**
- **Ask for help early.  Share the care!**
- **HDSA website**

# Additional Important Points

- **Help for family members, “caregiver distress”**
- **Reported higher rate of suicide in HD patients** (combined risks of dementia and depression, family history of suicide in other HD patients)
- **Availability of treatment / medications**

# Acknowledgements and Thank You

**Patients and families affected by HD**

**Our Team:**


UC DAVIS HEALTH SYSTEM

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