



# Psychiatric and Behavioral Challenges in HD

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# Disclosure

- Advisory Board for Lundbeck Inc.

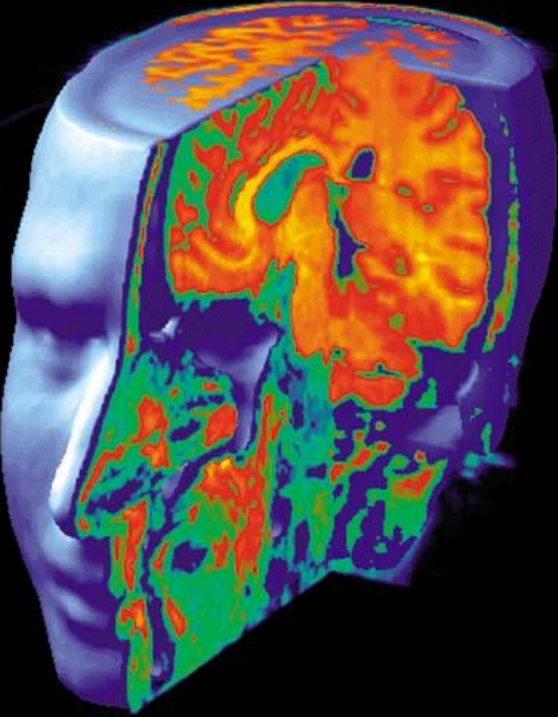
# Our Goal Together

To Review:

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

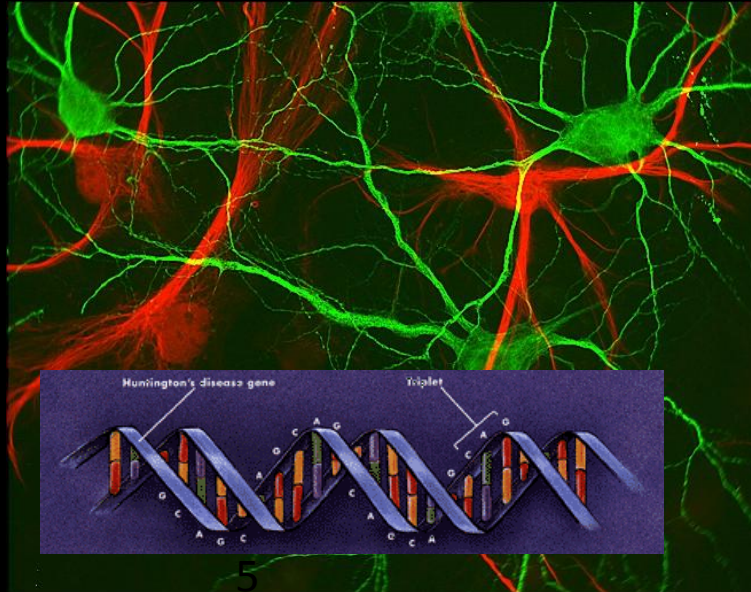
# In HD, Brain Changes Cause Behavioral Changes

- **Psychiatric symptoms -- earliest and most disabling symptoms in the disease.**
- When caregivers are faced with 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 strategy**



Connections between the frontal lobes and the striatum maintain thinking and movement abilities and help regulate emotions.

Loss of these connections in HD leads to loss of abilities, changes in thinking and behavior.



# Challenging behaviors

- **Unawareness**
- **Impaired executive function**
- **Apathy**
- **Irritability and disproportionate anger**
- **Obsessive thoughts and compulsive behaviors**
- **Mood disorders 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

“Hey doc... speak English”

# 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
  - Work may appear sloppy, incomplete, disorganized, poor performance, etc...
  - 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 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 d/o)
- **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, kind 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 frequent, severe and don't respond to the above, meet with neurologist or psychiatrist for medications**

# 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

# 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)



# Depression in HD

- **Very very common!**
- **Thoughts of suicide may occur**
  - Most commonly occurs around the time of diagnosis
  - 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**

# Managing anxiety

- 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

# Additional issues

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

# Review

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

## 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**
- **A Physician's Guide to the Management of HD, 3<sup>rd</sup> edition**
- **Ask for help early. Share the care!**

# Acknowledgements and Thank You

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