



Managing Challenging Behaviors

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Presenter Disclosures

Dr. Vicki Wheelock

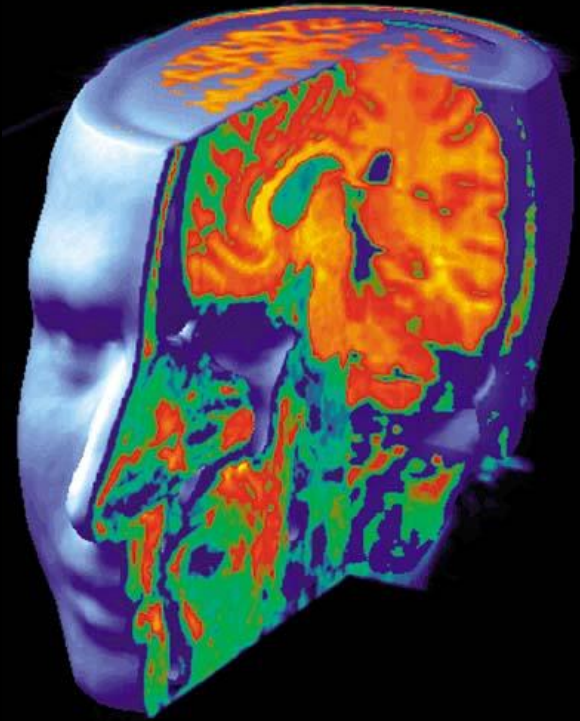
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Understanding the basis of challenging behaviors in people with HD is the key to learning to manage them. This workshop will describe common behavior challenges, including apathy, irritability and unawareness, and will provide patients and caregivers with strategies that will help. We will review behavioral techniques, caregiver support and medication management.

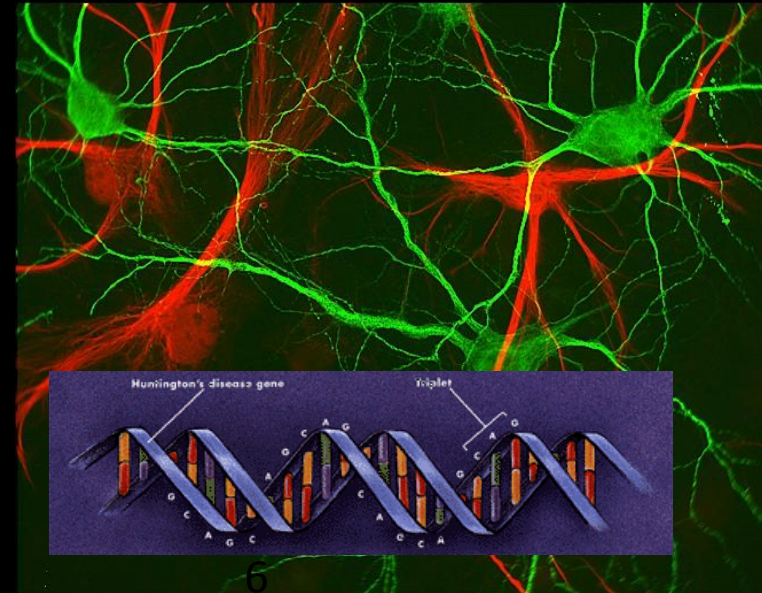
In Huntington's disease, brain changes lead to behavior changes

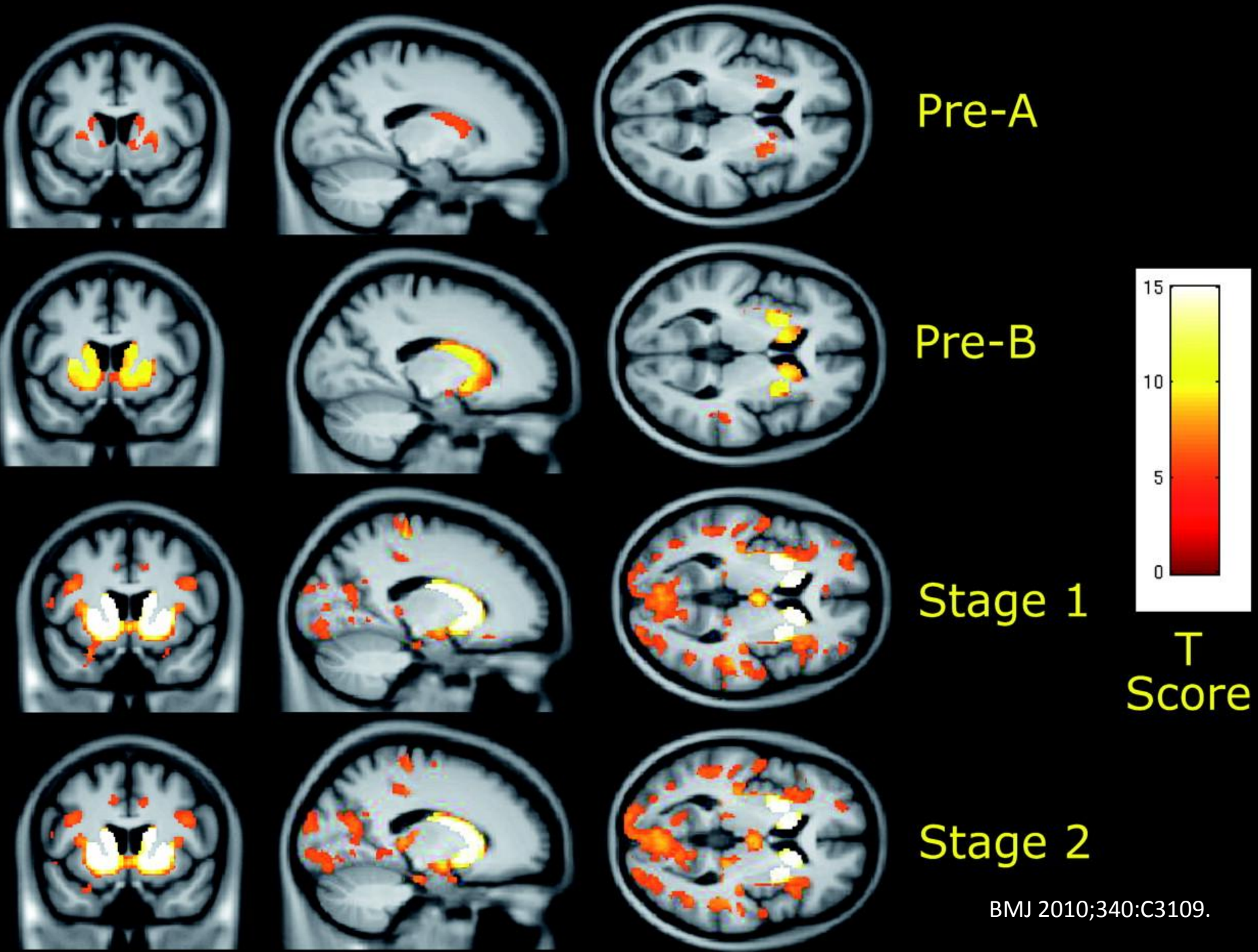
- Reports from families and people affected by HD suggest that changes in thinking and behavior are among the earliest and most disabling symptoms in the disease.
- When caregivers are faced with these challenges, remember:
 - It's the disease, not the person
 - The person with HD faces a series of losses. Frustration, anger, withdrawal can be the result of these losses.
- Understanding the basis of these changes leads to strategies to help the person with HD, their families and their caregivers



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 suicidality

Unawareness

- This is hard-wired; not simply “denial.”
- Can include lack of recognition of symptoms, change in abilities, appearance and behavior
 - May be selective for specific issues, such as driving
- 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
 - Endangerment

Unawareness

- Strategies
 - Confrontation will fail. Don't try to enforce insight.
 - Seek help from medical team: primary care physician, neurologist, psychologist or psychiatrist
 - Seek help from outside agencies: driver evaluation, job performance evaluation, case manager
 - Examples that won't 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

- Executive function:
 - Speed of thinking, planning, prioritizing, organizing, concentration, decision making, flexibility, creativity
- Leads to notable 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
 - Minimize distraction
 - Break tasks down into small steps: one thing at a time
 - Simplify
 - Use prompts and cues
 - Offer choices rather than open-ended questions
 - Try, “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

- 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 to identify and treat metabolic disorders or depression
- Recognize the limitations caused by the disease: be realistic
- 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
 - Use reminders: smart phone alarms, verbal reminders
 - Environmental stimulation: Adult Day Health Programs
- If apathy is severe, seek psychiatric care for possible use of stimulant medications

Irritability and disproportionate anger

- Frustration and anger about the 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
- Examples:
 - Anger outbursts at work
 - Road rage
 - Anger at home

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
- 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 medication

Obsessive thoughts and compulsive behaviors

- Obsessive thoughts: recurrent, intrusive thoughts or impulses. Examples:
 - 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

Mood disorders

- Mood disorders may be challenging to recognize in a person with HD because of the loss of executive function and movement-related problems
- Anxiety disorder: excessive worry and anxiety which is difficult to control and interferes with daily function.
 - Symptoms: feeling wound-up, tense, restless, can't concentrate, poor sleep
- Depression: depressed or sad mood, loss of interest or pleasure in daily activities.
 - May have difficulty with concentration, sleep, change in appetite, feelings of guilt, thoughts of suicide
 - May appear tearful or grieving, but not always

Depression in HD

- Very common. May occur:
 - before diagnosis
 - at the time of diagnosis
 - later in the disease
- 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 anxiety

- Create a calm environment
- Use schedules, calendars
- Simplify routines
- Allow plenty of time to complete daily tasks
- Counseling: cognitive-behavioral therapy
 - May be less effective in HD due to brain changes
- Seek medical or psychiatric care for medications: SSRIs

Managing depression

- Recognition is important
- Counseling: cognitive behavioral therapy may help
 - May be less effective in HD due to brain changes
- 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

Toolbox for managing challenging behaviors

- Understand the basis of the change in behavior
- Routines, routines, routines
- Simplify. Reduce distractions
- Provide structure, prompts and cues
- Calm environment
- Regular medical care: physical and psychiatric
- Consider mood disorders: anxiety, depression
- Recognize danger signs
 - Seek medical and professional help
- A Physician's Guide to the Management of HD, 3rd edition
- Ask for help early. Share the care!



Thank you!

- Patients and families affected by HD
- Dr. Martha Nance, Dr. Jane Paulsen, Dr. Adam Rosenblatt
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- Les and Margaret Pue Foundation

