Managing Challenging Behaviors in HD

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

- HD is a neuropsychiatric disease with prominent features of behavior and psychiatric 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 loses.
- 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 thoughts of suicide
- Psychosis
- Substance abuse
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 the need to stop driving
- Consequences:
  - Delays in diagnosis, failure to get help when needed
  - Job and personal losses
  - Externalization and blame of others
  - Endangerment
Strategies to Manage Unawareness

- Confrontation will fail. Don’t try to force 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 most important issues for intervention.
  - Identify the key issues that need intervention
  - Learn to accept smaller or minor issues when possible.
Reduced Executive Function

- Executive function refers to control of behavior and thinking that involves the frontal lobes of the brain or their connections.

- Executive function includes:
  - Speed of thinking,
  - Planning, prioritizing, and organizing,
  - Concentration,
  - Decision making,
  - Flexibility, and
  - Creativity

- Leads to notable changes in function, including reduced ability to carry out activities at work and home.

- Affects relationships with spouses, partners family members and friends.
Examples of Loss of Executive and Frontal Lobe Function

- Work may appear sloppy, incomplete, disorganized; missed deadlines, poor performance
- Loss of initiation: can’t get started
- Perseveration: getting stuck on certain ideas or activities
- Lack of inhibition, inappropriate behavior, impulsivity
  - May affect social and sexual behavior
  - May sometimes lead to unlawful behavior
- Inability to recognize others’ emotions
- Lack of recognition of hunger, thirst, even pain
Strategies for Reduced Executive Function

- 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
Strategies for Impaired Judgment, Impulsivity, Potentially Harmful Behaviors

- The person with HD may have behaviors or perform actions that are completely out of character for them.
- Sometimes they may realize that their behaviors are out of bounds, but often they do not.
- Treating the patient with compassion does not include blind acceptance of all behaviors because they are ill.
- Set limits and boundaries. Talk to their physician and seek help. Don’t wait to call the authorities if you suspect that the person with HD or others might be harmed.
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 or tasks at work
  - Personal hygiene
  - Managing finances
  - No longer cares about things that used to be important
Strategies to Manage Apathy

- 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 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
  - Anger at home directed at loved ones
  - Road rage
Strategies to Manage 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 or restraint, leave the scene
Strategies to Manage Irritability and Disproportionate Anger (cont.)

- Remember that depression or anxiety can be a cause. Seek medical evaluation.
- Safety is critical; call authorities if necessary
- Reduce alcohol intake and eliminate recreational drugs
- Remove weapons and other means of harm from the home
- 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 cleanliness that disrupts normal function
  - 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, sometimes agitation.
  - 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 and diagnosis 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 those with thoughts of suicide, seek immediate help
- Remove weapons or other means of self injury
- Use crisis line, emergency department visit, or call authorities if indicated
Challenging Behaviors

Delusions and Hallucinations: Psychosis in HD

- Delusions are false beliefs, often held with strong conviction
  - May be paranoid, i.e. that someone or something intends to harm the individual

- Hallucinations may be auditory (sounds or voices), visual (forms, animals, people), tactile (sensations of touch), or even smells or tastes
  - Insight may be preserved (the person recognizes that the perception is not real) or absent

- Either may appear at any stage of HD
Delusions and Hallucinations

- The cause may be medical (certain medications, illnesses, infections, trauma) or caused by recreational drugs.
- A person with psychosis may endanger themselves or others.
- New onset of delusions and/or hallucinations is a cause for prompt medical evaluation and treatment.
Strategies for Delusions and Hallucinations

- **Always** seek prompt medical evaluation. Don’t wait!
- Remove weapons and other means of harm from the environment
- Avoid alcohol, marijuana and recreational drugs
- If there is any concern for the safety of the person with HD or of family members, call the authorities and ask them to transport the patient to a facility for medical evaluation.
Substance Abuse and HD

- Substance abuse (alcohol or recreational drugs) is very common in our population.
  - If a person with a history of substance abuse develops HD, they are far more likely to have significant and serious behavior disorders.

- Alcohol is a brain toxin, and people with HD have less tolerance for the effects of alcohol.
  - They will become intoxicated with smaller amounts.

- Cannabis (marijuana) can cause paranoia and hallucinations.

- Brain changes in HD can cause lack of judgment, lack of inhibition, impulsivity, anger outbursts and psychiatric disturbances which can be worsened by substance abuse.

- Sometimes, HD itself will lead to substance abuse.
Strategies for Substance Abuse and HD

- All HD patients should reduce alcohol intake, and for some abstinence may be necessary.
- Cannabis and other recreational drugs are not recommended because they may promote difficult psychiatric symptoms.
- Recognize the signs of alcohol or recreational drug dependence
- Seek treatment for alcohol and drug dependence when necessary.
Red Flags in Managing Challenging Behaviors

Seek help immediately for the following:

- Alcohol and recreational drug dependence
- Anger and aggressive behavior
- Depression with thoughts of self-harm or injury
- Paranoid thoughts
- “Command” hallucinations directing to the person to harm themselves or others
Crisis Interventions

- Emergency department visit
  - Rapid medical and psychiatric evaluation (if available)
  - Be prepared to describe the symptoms or behavior of concern
  - Bring list of all medications and mention substance abuse if applicable

- Hospitalization
  - May be admitted to medical or sometimes neurological floor for medication adjustment, observation
Crisis Interventions (cont.)

- Psychiatric hospitalization
  - May be indicated for significant psychiatric symptoms in order to start or adjust medications and observe.
  - All states have statutes about voluntary or involuntary hospitalization.
  - In California, a patient may be placed on a 72 hour hold (called a “5150”) for psychiatric assessment if they are found to be gravely disabled or a danger to self or others. A subsequent additional 14 day hold (“5250”) requires a hearing before a judge or court officer.

- Arrest and incarceration: May rarely be necessary.
One Last Word for Family Members and Caregivers

- Remember that the stresses and losses faced along your journey with HD may lead to your own physical, emotional and psychiatric challenges.

- Learn to recognize the signs of depression, anxiety, anger, hopelessness, exhaustion, sleep deprivation and possible substance abuse in yourself.

- Seek support from your physician. Find a local HD support group, and call the Center of Excellence social worker. See a therapist for supportive counseling. Ask for caregiving help so that you can maintain adequate sleep, good nutrition, regular exercise and periodic breaks.
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: medical and psychiatric
- Consider mood disorders: anxiety, depression
- Recognize danger signs
  - Seek medical and professional help
  - Call authorities if necessary
- Ask for help early. Share the care!