



Driving Cessation and HD

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- The recommendations made are general guidelines
- All attendees are encouraged to consult with their primary care provider, neurologist or other healthcare provider about any advice, exercise, medication, treatment, intervention, nutritional supplement or regimen that may have been mentioned as part of this presentation.

Presenter Disclosures

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose

Arik Johnson, PsyD

Objectives

- Discuss common concerns regarding driving and Huntington's disease (HD)
- Discuss signs that it is time for a person with HD to consider stopping driving
- Provide practical ideas about how to talk about driving cessation

Huntington's Disease: General Overview

- Huntington's Disease (HD) is a hereditary neurodegenerative disease caused by an expansion in the huntington gene
- People who have HD generally begin to show symptoms in their mid-thirties to mid-forties
- Symptoms will progress and worsen over time
- There is no way to tell at what pace a person will develop symptoms, how the symptoms will present, or when that individual will die from the disease

Huntington's Disease: General Overview

- Symptoms of HD fall into three categories:
 - Motor
 - Cognitive
 - Psychiatric
- Currently, a diagnosis of HD is made based on the presence of motor symptoms

How Huntington's Disease Impacts Driving

“Signs it’s time to talk”

How HD Impacts Driving

- Safety is the main concern
 - The person with HD who is behind the wheel
 - Family members or friends who are in the car
 - Other people on the road (or on the sidewalk, or in their homes, etc.)
- The three clusters of symptoms of HD can directly impair an individual's ability to drive

Motor Symptoms of HD and Driving

- Uncontrolled movements
- Loss of control of voluntary movements
 - Pumping the gas or breaks
 - Difficulty maneuvering the vehicle
 - Poor steering control
 - Keeping the car straight
 - Drifting into other lanes
 - Problems checking mirrors due to head movements

Cognitive Symptoms of HD and Driving

- Memory and learning
 - “Where are my keys?”
 - Difficulty figuring out how to work the features of a new car
 - Getting lost
- Perceptual skills - Sense of timing
 - “Cutting it too close” when making a turn
 - Problems merging into traffic
 - Not slowing down as the light is changing

Cognitive Symptoms of HD and Driving

- Perceptual skills - Spatial perception
 - “Bumping into” parked cars or or other objects
 - Running into curbs
 - Hitting the garage when pulling in to park
 - Tailgating
 - “Near misses”
 - Fender-benders

Cognitive Symptoms of HD and Driving

- Executive functioning - Attention
 - Distractibility
 - Not seeing street signs or traffic lights
 - Paying too much attention to activity on the side of the road
 - Difficulties multitasking
 - Getting overwhelmed driving the kids to school
 - Difficulty changing lanes while approaching a stop light
 - Cell phone use while driving is NEVER a good idea!!!

Cognitive Symptoms of HD and Driving

- Executive functioning - Judgment and decision making
 - Speeding across an intersection
 - Changing lanes erratically on the freeway
 - Not anticipating potentially dangerous situations
 - Cell phone use while driving is NEVER a good idea!!!

Psychiatric Symptoms of HD and Driving

- Anger and irritability
 - Road rage
 - “G*\$ d*#@ it! Quit screwing me up!”
- Frustration
 - “It’s too hard to drive with all this racket in the car!”
 - “I just can’t figure out where this place is!”

Psychiatric Symptoms of HD and Driving

- Anxiety
 - Decreased confidence behind the wheel
 - Increased worries about driving
 - Hypervigilance: Over-focus on the road, what's happening around the car, etc.
- Depression
 - Less concern for one's own well being
 - Impacts cognitive processes

We all hope it doesn't come to this...



How to Talk to the Person with HD about Stopping Driving

Talking about HD and Driving Cessation

- Some basic thoughts on talking about stopping driving
 - Nobody wants to have this conversation
 - It's difficult for the person with HD, the family, and even healthcare providers
 - Driving is associated with independence and freedom
 - Giving up driving is “an obvious sign” the disease is getting worse
- That said, it is NOT an impossible conversation

Talking about HD and Driving Cessation

- Ideally, the conversation starts early and the person with HD eventually stops driving voluntarily
 - Awareness of changes over time
 - Awareness of consequences
 - Safety first – for both self and others
 - Address concerns about loss of independence
 - Explore alternatives (ie: ride programs, public transportation, taxis, volunteer drivers, etc.)
 - Reinforce self-limiting behaviors (gradual decreases in driving)

Talking about HD and Driving Cessation

- Family members often have mixed feelings about talking about driving cessation
 - Need for the person with HD to drive (ie: to work, to chauffeur kids, to run errands, etc.)
 - Worry about the impact on the person with HD's self-esteem
 - Fear of how the person with HD will react
- Family input is important, but is often difficult for the person with HD to hear
- Family input is important for the person with HD's medical doctor to hear

Talking about HD and Driving Cessation

- Doctors should talk about driving concerns from an early stage on
 - Educating people with HD and families about the progressive symptoms and the impact on driving
- It is difficult to assess driving ability in the clinical setting, so referrals to outside testing agencies are often made
 - Private agencies and state motor vehicle agencies
- Sometimes the doctor's words carry more weight
- Doctors and mandatory reporting
 - Six states require MDs to report: CA, DE, NJ, NV, OR, PA

Talking about HD and Driving Cessation

- Tips for a successful transition to stopping driving
 - Start the discussion early
 - Have frequent and short conversations
 - Talk from a place of concern
 - Emphasize safety and well being
 - Recognize the impact on the person with HD
 - Establish social support (emotional support, help with rides, etc.)
 - Involve outside help when needed (other family members, doctors, etc.)

Talking about HD and Driving Cessation

- What if the person with HD refuses to stop driving?
 - File a report with the state motor vehicle agency
 - Some states allow for confidential reporting
 - Results in the person with HD being called in for an assessment
 - Take away the keys
 - Disable the vehicle
 - Sell the vehicle
 - Contact local law enforcement

The reason that we have to talk about driving and Huntington's disease at all is because of the impact of this disease on a person's ability to drive safely.

Safety, first and foremost.

Helpful Resources for Talking about Driving

- [At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia & Driving](#)
- [We Need to Talk...: Family Conversations with Older Drivers](#)
- [Huntington's Victoria Information Sheet: Driving and Huntington's Disease](#)

Recap

- Discussed common concerns about the impact of Huntington's disease and driving
- Identified signs indicating it is time for a person with HD to consider stopping driving
- Explored practical ideas about how to talk about driving cessation

Questions?

Thank you very much!

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