

Driving Cessation in HD

Driving Cessation in HD - Safety First & Foremost

Due to the complexities of Huntington disease (HD), a driving assessment is crucial for the individual with HD, family and friends as well as the general public. Driving is a complicated process that involves concentration, judgment and processing multiple stimuli.

Driving ability should be monitored from the time of diagnosis by the person themselves, family, caregivers, family doctor and neurologist. The earlier the discussion is started and revisited as needed, the more likely the HD client will accept driving restriction or cessation when necessary. Family members often have the greatest insight into their loved one's ability to drive, but are often reluctant to speak up. Individuals and families should be encouraged to think ahead and develop a plan for driving cessation, however this can be a difficult topic, so it is important to have opportunities to speak alone with the doctor/neurologist in order to share concerns and be able to access advice and support as needed. At ANY time that a family has concerns, it is important to follow up with professionals as safety of the family member and the community needs to be the first and foremost consideration.

Driving cessation is complicated by four factors:

1. Difficulties in predicting driving abilities in an office setting
2. The importance of driving for maintaining independence and self-esteem
3. The lack of insight about driving impairment found in many persons with HD
4. The reluctance of family members to enforce driving restriction due to fear of damaging the relationship with their loved one

How Does HD Impact Driving?

Motor Symptoms

Involuntary movements and less control of voluntary movements affect driving ability.

Warning Signs

- Erratic driving - pumping the brake or gas
- Difficulty controlling the vehicle - challenges with steering hand over hand or using turn signals
- Manouvering - drifting from lane to lane, slow to make corrections
- Checking mirrors - difficulty or forgetting to check blind spot, rearview and side mirrors

Cognitive Symptoms

Warning Signs:

- Memory/Learning - forgets where the keys are, where the grocery list is
- Learning how to operate new vehicle is often challenging
- Getting lost while driving
- Perceptual Skills and Sense of Timing - challenge assessing speed and location of one's own car as well as others on the road
- Making decisions that increase the chance of an accident - having too many 'close calls,' 'near misses' and 'fender benders'
- Ineffective merging into traffic
- Difficulty with decision making with multiple factors - unable to change lanes while slowing at stop lights
- Spatial perception - bumping into cars while parking or in traffic, running into curbs
- Tailgating - too close OR too far away - not able to judge distance

SUGGESTION - Check the car for any minor body damage. **1/3**

Cognitive - Executive Functioning: Attention

Warning Signs:

- Distractibility - difficulty "reading" road signs - missing speed limits, construction zones, stop signs
- Multi-tasking - too much distraction inside or outside the car makes concentrating on driving difficult
- Changing lanes - not slowing down, checking the blind spot and looking for other cars

Judgment and Decision Making

Most of us weigh our options and choose the best one for each new situation as it arises. Individuals with HD may have a difficult time with this, particularly while driving.

Examples include:

- Speeding through an intersection when the light has turned red
- Changing lanes erratically
- Not anticipating potentially dangerous situations - cannot see three steps ahead in traffic, lacks the ability to forecast

Perseveration could mean the individual is hyper-focused on other matters, limiting basic driving attention.

Psychiatric Symptoms

Warning Signs:

- Anger/Irritability - resulting in yelling, cursing or road rage
- Blaming others rather than focusing on own driving behaviour
- Frustration - finding it hard to focus while driving, getting lost, difficulty navigating and following directions
- Anxieties - increased worry and fear about driving, decreased confidence
- Hyper-Vigilance - too focused on outside distractions
- Depression - not as concerned for own well-being or safety, impacts on cognitive processes such as slowed response and memory

HD symptoms can be compounded by related factors such as depression.

Conversation Tips

- Start discussion as soon as possible
- Do it simply and gently one step at a time, having frequent and short discussions
- Come from a place of concern, that you want the individual to be aware of the progression and changes over time, and the consequences that come regarding safety for the individual, themselves and others
- Acknowledge and validate the loss of independence and discuss putting a plan in place
- Reinforce graduated self-limiting behaviour i.e. individual choosing to stop driving at night, avoiding highway driving or at heavy traffic times
- Involve appropriate professionals in the assessment process

Referrals for Driving Assessment

When the time comes, a neurologist may refer individuals with HD for a formal driving assessment, usually administered by specialized occupational therapists. These assessments are available at some hospitals and rehabilitation centres or provincial transportation ministries (varies by province or territory). Organizations such as Drive Able are capable of assessing driving ability. Although a fee may be incurred, this assessment is helpful for family members, the individual and the physician involved by providing objective information about the individual's performance. In many cases, patients, with the help of their families, will realize the time has come and will voluntarily stop driving. If, after an assessment, family members still have concerns, these should be discussed further with the individual and with professionals.

The Refusal to Stop Driving – What to Do?

File a provincial motor vehicles report

- Take away car keys
- Disable vehicle
- Sell vehicle
- Contact local law enforcement - speak to them first about HD and inform them of client characteristics
- Ask yourself if you would want your child to ride with this person, then take preventive action

Being Proactive and Planning Ahead

At some point, every individual with HD will lose the ability to drive, therefore, it is important to be proactive about planning for the future by having ongoing discussions about safe driving, having the neurologist monitor the ability to drive and make referrals for assessment as needed, as well as determining how family and friends can marshal their forces to develop a plan that includes a driving support system, company (to avoid isolation), assistance with errands and knowing in advance about existing community transportation options and available financial help.

- An ID card will be needed when a driver's licence is no longer available
- Find creative ways to help maintain independence

Always remember – safety first!