

DRIVING AND HUNTINGTON DISEASE (HD)

About Driving and HD

Driving is an important part of independence for many people. It allows freedom, connection, and choice. Because driving requires quick thinking, good judgment, focus, and coordination, changes caused by Huntington disease (HD) can make driving unsafe earlier than for most people. Talking about driving early and planning ahead can help families stay safe and reduce stress when it's time to make changes.

Why Safety Comes First

Losing a driver's licence can be upsetting for both the person with HD and their family, but safety must always be the priority. Planning early helps:

- Keep the person's dignity and independence for as long as possible
- Prepare for safe transportation options before a crisis
- Support the whole family through the transition

Planning Ahead

- Start early. Talk about driving before it becomes unsafe. These are easier, calmer talks when started early
- Have more than one conversation. A series of short, gentle talks is better than one big discussion
- Pay attention to changes. Watch for dents, scrapes, or other signs of driving problems
- Explore options. Look at bus routes, taxis, community transportation, or rides from friends and family
- Keep independence in mind. The goal is to help the person stay connected, active, and safe

Talking About Driving

- Speak gently and with respect, taking it one step at a time
- Ask if the person has any worries about their driving
- Share specific examples of unsafe situations you've noticed
- Emphasize safety for everyone, not blame
- Involve professionals such as doctors, nurse practitioners, optometrists, or occupational therapists for assessments (some may charge a fee)

Signs That Driving May No Longer Be Safe

Possible warning signs include:

- Trouble entering or exiting traffic or changing lanes
- Stopping in traffic for no reason
- Difficulty using the gas and brake pedals smoothly
- Weaving or drifting between lanes
- Speeding or going too slow
- More near-misses, accidents, or traffic tickets
- Delayed reactions or easily getting distracted
- Getting lost while driving
- Anger or frustration toward other drivers

Feedback from others can also help:

- Do friends or family avoid riding with the driver?
- Do other drivers honk or show irritation? If so, it's time to discuss stopping driving

Supporting a Person Who Can No Longer Drive

- Listen with empathy. Losing a licence can feel like losing freedom or identity.
- Acknowledge their efforts. Some may already limit driving (for example, avoiding highways or night driving)
- Find alternatives. Help arrange other transportation, such as:
 - Public transit
 - Taxi or rideshare services
 - Community transport or volunteer driver programs
 - Friends and family
 - Home delivery services for groceries and medication
- Encourage connection. Support social activities to prevent isolation
- Replace the licence. Help the person get another photo ID card

If the Person Refuses to Stop Driving

- Talk with a doctor or healthcare provider. They can arrange a medical driver's assessment
- Doctors are required by law to report unsafe driving to provincial authorities
- A formal driving assessment by a specialized occupational therapist may be available through hospitals, rehabilitation centres, or provincial transportation offices (fees may apply)
 - These assessments often help people understand the situation more clearly and agree to stop driving

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If the person still refuses, ask yourself, “Would I feel safe letting a child ride in this car?”

If the answer is no:

- Contact your Huntington Society of Canada Family Services team for support
- File a report with the provincial motor vehicle office
- Remove or disable the car keys or vehicle if needed
- If there is immediate danger, contact local law enforcement

Factsheet developed by the HSC Family Services team. Reviewed by Tanya Greaser, BA, BSW, RSW, Registered Social Worker and Family Services Educator, and Dr. Justyna R. Sarna, MD, PhD, FRCPC (Neurology), Calgary AB

RESOURCES

Reach out to your local Resource Centre Director (RCD) of the Family Services Program at HSC for ongoing support and education at hdsupport.ca

If you are ready to receive individual or group support from the Huntington Society of Canada, you can self-refer here: <http://contactme.cloud/form/huntingtonsociety>

Informational fact sheets for family and friends impacted by HD are available to view, print and download at hdfactsheets.ca

Healthcare professionals and caregivers needing a more in depth understanding on caring for someone with HD can find guides at hdresources.ca