



Huntington's
Disease
Association



Tips for driving with Huntington's

Helping to keep you safe



How might Huntington's disease affect driving?

Huntington's disease can impact driving in different ways. Thinking can be slowed down, meaning it is more difficult to make the quick decisions needed to maintain safety while driving. It can get harder to concentrate and stay focused to avoid hazards. The multi-tasking necessary to drive a car and react to situations as they arise can also be affected. Involuntary movement can make it more challenging to operate the steering wheel and other controls.

If you have had a positive predictive gene test for Huntington's, you do not need to inform the DVLA. **You must tell the DVLA if you have Huntington's disease and it causes symptoms.** Because you tell the DVLA you have symptoms, this does not mean that you will automatically have your licence revoked. The DVLA may contact your doctor for further information and/or ask you to undertake an assessment. The DVLA will decide if you need to get a new shorter licence, which may last for 1,2,3 or 5 years; or if you are required to adapt your car by fitting special controls; or if you are required to stop driving.

If you are permitted to continue driving, it is important that symptoms that might impact driving safely are reviewed. To inform the DVLA that you have symptoms visit www.gov.uk/huntingtons-disease-and-driving and follow the link to the form. Medical conditions that could affect driving should also be disclosed to your car insurer as failure to do so could invalidate your policy and lead to any claims being refused.

Although the independence and freedom that driving offers are very important, your safety, and the safety of passengers, pedestrians and other road users must be the priority.





Continuing driving – what might help?

If you have early symptoms of Huntington's disease, and you have informed the DVLA, and been told that you are permitted to continue driving for the moment, then here are some ideas to make things easier:

- Avoid distractions as much as possible. This might mean passengers knowing not to speak to you more than necessary when driving or avoiding having the radio on.
- Hunger can impact on concentration so make sure that you have eaten before setting off. Pack snacks and drinks to take with you on your journey so you can take a break and have something to eat.
- Tiredness can greatly impact on Huntington's symptoms. If you haven't slept well then you should consider whether it is safe to drive that day. Take regular breaks if travelling any distance.
- Plan the route before you go to reduce the amount of decision-making you do en route.
- If you need to use a Sat Nav but find it distracting, ask a passenger to follow it on their phone with the volume off or ask them to follow a map and guide you.
- Make sure that someone knows where you are going. Have their contact details handy so you can get in touch if something unexpected happens or you get lost. There are apps available that will allow people you trust to track your route via their smart phone.





- If you have slurred speech, take an 'I have HD card' with you that explains that you have Huntington's disease and you are not drunk. These are available via the [Huntington's Disease Association website](https://www.huntingtons.org.uk/).
- Consider getting a Radar key so that you can access disabled toilets along your journey.
- Apply for a Blue Badge via your local authority. This will enable you to park closer to amenities. www.gov.uk/apply-blue-badge
- Consider an automatic car to simplify driving. This decision should be weighed up against potential challenges with learning how to operate a car that is new to you.
- If there is a question over your driving safety then 'Driving Mobility' centres are located across the country and can offer an independent assessment of your driving. The centre will discuss with you the implications of the results of your assessment. To find your nearest Driving Mobility centre please visit: www.drivingmobility.org.uk/assessments/
- Consider using a Motability scheme to access an adapted vehicle. There are adaptations that can help with steering and getting in and out of a car. To be eligible you must be in receipt of a qualifying benefit – such as higher rate mobility component of Personal Independence Payment, visit: www.motability.co.uk/





Thinking about giving up driving?

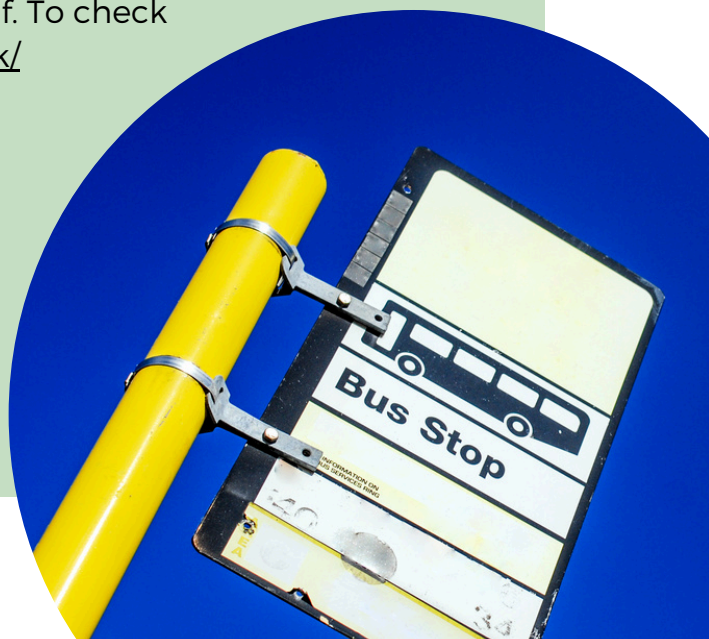
As time goes by, if you have Huntington's disease you may feel that you are getting to a point where you need to give up driving. There may be some signs that you are struggling with this – for example you may have had some bumps or scrapes in the car or got lost or perhaps you just feel less confident when on the road. It might be that other people are expressing concerns about your driving.

If you have Huntington's disease it may be difficult for you to identify when is the right time to give up driving. If you have appointments with a Huntington's disease specialist ask their advice. If you have people around you who you trust then it may be a good idea to ask their advice. Driving Mobility can also offer impartial advice www.drivingmobility.org.uk/

It is important to explore other options for getting out and about. You may be entitled to a bus pass that lets you travel at a reduced rate. To find out how to apply for a bus pass in your area please visit: www.gov.uk/apply-for-disabled-bus-pass. Reduced cost train travel is available with a disabled person's railcard: www.disabledpersons-railcard.co.uk/. In some areas charities such as Age UK and Royal Voluntary Service run door to door transport services.

If you have family and friends supporting you it might be a good idea to plan with them how you are going to get around. It may be that they can support with lifts. Look into whether you are entitled to Personal Independence Payment which you could use to help cover taxi costs.

It may be that you are entitled to apply for a Motability vehicle that someone else can drive on your behalf. To check eligibility please visit: www.motability.co.uk/





What if you are worried about someone's driving?

Sometimes a person with Huntington's disease may not fully see all the problems they are having with driving. It can help to have several conversations where the idea of giving up driving is gradually discussed. As ending driving can feel like a loss of independence it can be difficult to accept, so it is important to be sensitive.

It might be that you suggest they have an assessment of their driving at a Driving Mobility centre to help put your mind at rest as you are worried about them and other people. A Driving Mobility assessment provides an objective opinion of someone's driving. It may either offer you some reassurance that their driving is okay for the moment or provide evidence to the person with Huntington's that there is a problem.

It might be helpful to point out that when you stop driving you also stop paying for things such as motor insurance, car tax and petrol. The money saved can now be used for other things.

Discuss that if they have symptoms and were to have an accident then this could have serious implications for their insurance if they had not informed the DVLA that they were symptomatic.

If you are concerned about the effect on your relationship of having conversations about giving up driving then it may be that it may be that there is a doctor who is willing to have this discussion with them.

It may help when having conversations to put the emphasis on safety and well-being rather than pointing out driving errors.





If someone's driving is dangerous but they will not stop despite encouragement to do so, consider writing to the DVLA or filling out the form on their website. The most important thing is the safety not only of the person but also of other road users and pedestrians. The DVLA website states 'All Third Party Notifications are treated with the strictest confidence and we will never reveal to the licence holder or any other enquiring party where the information came from originally.' www.gov.uk/contact-the-dvla.

For further advice you can call the DVLA on 0300 790 6806.

If you feel that there is an immediate danger to life then you should phone the police on 999.



Get in touch

For advice and support or
to speak to a Specialist
Huntington's Disease
Adviser

Email: **info@hda.org.uk**

Phone: **0151 331 5444**

www.hda.org.uk

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