Huntington’s Disease

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Our society values independence highly and the ability to drive is held in high esteem; however, holding a licence to drive is a privilege, not a right, and as such we have a responsibility to ourselves, and to others, to ensure that we drive safely and lawfully.

It is important that all drivers are aware of the legal position regarding disability and driving and that we realise the consequences of failure to disclose relevant information. Complying with the law does not automatically mean that your licence will be revoked.

The law

In the UK there is a legal duty for driving licence holders to inform the Driver and Vehicle Licensing Agency in Swansea when they are aware of a “relevant” or “prospective” disability that could affect their ability to drive.

GPs and other doctors are responsible for informing patients of their medical condition and may advise their patients to stop driving. However, the onus is on the individual to inform the DVLA.
Relevant disability includes:

- Conditions likely to be applicable to Huntington’s disease
- Epilepsy
- Severe mental disorders
- Persistent difficulty with the use of arms or legs
- Any other disability likely to cause the driving of a vehicle to be a source of danger to the public
- Any other condition likely to last for more than three months

Prospective disability means any other condition which by reason of its intermittent or progressive nature may become a relevant disability in the course of time. This includes degenerative conditions.

**Huntington’s disease**

- People who are at risk of Huntington’s disease are not obliged to inform the DVLA of their risk status as long as they remain free of symptoms.

- Similarly, people who have been given a positive test result but are pre-symptomatic are not obliged to inform the DVLA of their risk status. However, when
symptoms of Huntington’s disease begin to develop they must inform the DVLA of them.

- People who have had a positive diagnosis of Huntington’s disease and are symptomatic should inform the DVLA of this, in order to comply with the law; as stated above.

- People with Huntington’s disease may refuse to accept advice to declare their disability, or to stop driving, and this can cause disagreements and anxiety for carers and family members.

In exceptional circumstances it is possible for a doctor to inform the DVLA without their patient’s consent.

The DVLA ignores anonymous letters; however, signed communications will be treated confidentially and concerns acted upon.

You ought to inform your insurance company at the same time. If they are not told they could refuse to indemnify in the event of a claim.

**Consequences**

Failure to disclose information that relates to an individual’s medical fitness and which affects his/her ability to drive can lead to penalty points, disqualification, and a fine.
• LC30 driving after making a false declaration about fitness when applying for a licence.

• LC40 driving a vehicle having failed to notify a disability.

• LC50 driving after a licence has been revoked on medical grounds.

The above licensing offences each incur 3-6 penalty points and/or disqualification and stand as offences in their own right. If further offences are incurred whilst driving i.e. careless driving, reckless driving, speeding, etc., penalties and fines incurred will be steeper.

**Insurance**

It is an offence to drive whilst uninsured against third party risks in the UK and any accident that occurs whilst uninsured is likely to incur considerable expense. Failure to disclose relevant information to your insurance company may result in their refusal to cover you in the event of an accident; thus invalidating insurance cover.

**What happens next?**

The power to grant, refuse or revoke a driving licence lies with the Secretary of State via the DVLA; which has a Medical Advisory Unit staffed by medical personnel.
Medical assessment of disability is undertaken by the Medical Advisory Unit and your general practitioner.

The DVLA has a number of options available to them which may include:

- Restricting your driving licence to 1, 2 or 3 years, which enables a regular medical review to take place.

- Requesting a re-test or an assessment at one of their centres.

- Revocation of your licence.

**If you are in doubt about whether you need to inform the DVLA:**

1. Ask your doctor for advice

2. Write to the Drivers Medical Group:
   DVLA, Swansea, SA99 1TU.

3. Telephone DVLA Customer Enquiries Unit:
   Phone: 0300 790 6801.

4. Contact the Huntington’s Disease Association

For up to date information and forms please see website:
https://www.gov.uk/huntingtons-disease-and-driving
Fact sheets available from the Huntington’s Disease Association:

- General information about Huntington’s disease and the Huntington’s Disease Association
- Predictive testing for Huntington’s disease
- Talking to children about Huntington’s disease
- Information for teenagers
- A young adult’s guide
- Eating and swallowing difficulties
- Huntington’s disease and diet
- The importance of dental care
- Communication skills
- Behavioural problems
- Sexual problems
- Huntington’s disease and the law
- Huntington's disease and driving
- Advice on life assurance, pensions, mortgages etc.
- Seating equipment and adaptations
- Checklist for choosing a care home
- Advance Decision to Refuse Treatment (ADRT)
- A carer’s guide
- Challenging behaviour in Juvenile Huntington’s disease
- A brief guide to Juvenile Huntington’s disease for children’s hospices and palliative care services
- A teacher’s guide
- A young person with Juvenile Huntington’s disease at school

All fact sheets can be downloaded free of charge from our website www.hda.org.uk or ordered by phone 0151 331 5444 or email info@hda.org.uk

For a publication price list/order form, membership form, details of our Specialist Huntington’s disease Advisers and local Branches and Support Groups, please phone 0151 331 5444 or email info@hda.org.uk