

Mobility

Staying independent and being able to get out and about is an important part of all our lives so we can continue doing the things we enjoy. For people with Huntington's disease this can become problematic as mobility becomes more affected.

Balance and co-ordination can be compromised which, in turn, poses a higher risk for falls and/or stumbles. Consideration may have to be given for aids and equipment in order to maintain safety and independence.

1. Why is my mobility affected?

Huntington's disease causes changes in different parts of the brain. One of these leads to a motor disorder which manifests as the presence of involuntary (or unintentional) movements, called chorea, and the impairment of voluntary (or intentional) movements. This can ultimately impact on walking and the ability to maintain a stable gait. Muscles that support an upright neck and trunk grow weak and changes in muscle tone cause asymmetrical posturing which looks like a person is leaning backwards, forwards or to one side. Falling becomes more likely as there is reduced co-ordination, prolonged muscle contractions and dystonia (contracting of specific muscle groups). Similarly, muscles in the feet weaken and sensory changes may be taking place, leading to abnormal foot placement and stumbling. Visual spatial awareness can be impaired and this can also lead to falls as distances are misjudged.

What can I do to help myself?

Mobility impairment can be managed for quite some time by taking your time, wearing suitable footwear and always ensuring that you are safe. Some people find that medication helps. Over time, you may need to think about a walking aid or equipment to help you at home and/or outdoors. This could be a walking frame, however, because of the loss of co-ordination, some people find that these to be a hindrance that can increase the risk of falling.

Research shows that exercise is beneficial for someone with Huntington's disease. It can also maximise functional ability. So take daily exercise e.g. walking, cycling or become involved in an aerobic class. You can follow an exercise programme within your own home and can view one [here](#). A physiotherapist can guide you through an exercise programme and give advice on walking aids and seating alternatives. Ask your HD Specialist to make a referral for you if you have any mobility issues and are no longer safe in your home or when going outdoors.

What medications can help with movements?

Some medications, for example, anti-psychotics or anti-depressants, may limit some movement for a while. However, they are not successful for everyone and will require regular review as some medications can exacerbate underlying issues (e.g. Tetrabenazine which can be very successful in treating the movement disorder but may cause severe depression). Many people with Huntington's disease do not notice their movements at all, or find that they are not bothersome. If this is the case, it would be appropriate to avoid treatment while you are coping.

2. Optimising mobility and preventing falls

If you feel that you are no longer safe in your home, you can be referred to an Occupational Therapist (OT) for assessment. They will visit you and consider where they can reduce the risk of falls, identify hazards and take necessary action. This may be requesting handrails for your bathroom or internal/external stairs. They can also think about your safety in relation to getting in and out of your bath, and may decide a wet room shower is better. Simple pieces of equipment, such as a bed raiser, can help you to get in and out your bed safely. Consideration of installing a Community Alarm, if you live alone, should be made. Ask your HD Specialist for more information.

When outdoors think about how safe you are, and consider the following:

- Try to go out when it is less busy
- Go out accompanied if you feel safer
- Wear suitable footwear
- Use pedestrian crossings
- Always let someone know where you are and when you are likely to return. Carry your mobile phone/Scottish Huntington's Association wristband/information wallet.

- Consider using the community transport scheme and, if appropriate, mobility services
- Consider a Blue Badge for use with your car

Useful links

[Blue Badge Information](#) - local authorities also have contact numbers and paper application forms

[Contact a Scottish Huntington's Association HD Specialist](#)

[Scottish Huntington's Association Financial Wellbeing Service](#)

[National and Regional Care Frameworks for Huntington's disease](#)

[Scottish Huntington's Association Youth Service](#)

[Sign up for regular updates from Scottish Huntington's Association](#)

[European Huntington's Disease Network: Occupational Therapy for People with Huntington's Disease - Best Practice Guidelines](#)

[European Huntington's Disease Network: Physiotherapy guidelines for HD](#)

Updated January 2022