

OCCUPATIONAL THERAPY CLINICAL TIPS FOR HUNTINGTON'S DISEASE

Community living skills and outdoor mobility

Enabling people with Huntington's disease to participate in activities outside the home may have a positive effect on physical and mental well-being. However, McCabe et al (2008) found that 19% of patients and 88% of carers reported that their illness had adversely affected their recreational activities. The reasons reported were that people found it difficult to access community and recreational activities due to the lack of suitable and affordable transport and lack of adequate support to participate in an activity due to severity of symptoms. People should be reviewed regularly as their functional abilities will change over time.

1. Safety

- 1.1 Assess the individual's road safety skills in their local community. People with Huntington's disease can be impulsive and often have difficulty judging the speed of traffic, as well as processing information and initiating movement. All of which can increase the risks of injury with serious consequences
- 1.2 Where possible, develop management strategies such as the use of pedestrian crossings or going out accompanied. Sometimes walking aids prompt traffic to be more cautious around someone and hi-vis clothing means that people are more visible
- 1.3 Encourage use of suitable footwear to maintain gait stability
- 1.4 Assess people's ability to transfer safely in/out of transport. Consider whether the individual can maintain a safe posture in the car seat and whether the driver is at risk from their involuntary movements if they are travelling in the front seat. Local regional driving assessment centre can offer advice
- 1.5 You may notice changes in a person's behaviour, cognition and function which can affect driving. In the UK licence holders have a legal duty to notify the DVLA of their condition as Huntington's disease will have an impact on safe driving. Medical enquires and an assessment will be carried out by the DVLA. Discussion around driving may need to be handled sensitively as driving can be core to independence and sense of self and the person may be reluctant to give up driving. Alternatively they may be unable to assess the risks they pose to themselves and others. The Driver and Vehicle Licensing Agency have published a useful guidance 'Assessing fitness to drive - a guide for medical professionals'
- 1.6 Assess whether the person can use their mobile phone independently or do they need assistance. Consider a phone with an SOS button. GPS on mobile phones can be useful to locate people if they get lost and apps are available that can alert people if someone gets lost or has a fall. Other stand-alone GPS trackers are also available

2. Schemes

- 2.1 Find out what local public schemes are available to assist the person, such as shop mobility
- 2.2 Assess and assist the individual in using these services
- 2.3 In the UK, provide information about the National Key Scheme (NKS) for accessing toilets in public. This was formerly known as the RADAR (Royal Association for Disability Rights) key scheme. For details please see the clinical tips for social and leisure activities
- 2.4 Again in the UK, provide information on dial a ride schemes, community transport, bus pass schemes and blue badge where needed
- 2.5 Provide information on local taxi firms who have wheelchair accessible transport
- 2.6 Consider accessing a support worker, befriending service or volunteers to assist people with community access and provide an outing protocol to cover most eventualities

3. Planning

- 3.1 If people have memory problems, provide them with a written or verbal reminder of items to take when going out such as wallet or purse, keys, phone, travel pass. The written reminder can go on the front door or somewhere where the person will see it. Motion activated sensors with taped voice messages are also available. Use the list function on mobile phones as prompts for shopping lists, things to do
- 3.2 Help to plan out the route and perhaps have a trial run to familiarise the route to ensure a person is fully aware of where they need to go
- 3.3 If someone is likely to have to give up driving, they may need a period of planning and adjustment to get used to using public transport and support to do this in order to feel confident. This may need to be approached relatively early in the disease process to ensure that people maintain this skill and so can use it to prevent social isolation

- 3.4 Suggest that people avoid the shops at busy, crowded times when they are more likely to bump into others and become overwhelmed
- 3.5 Assess whether the person is able to budget and manage their money appropriately. People with Huntington's disease can be impulsive and struggle with forward planning so their money runs out. Strategies to help with this may be paying bills by direct debit and having a daily allowance rather than access to all their monthly money in one go
- 3.6 Signatures can change over the course of the disease progression which may cause problems such as signing cheques. Therefore, it is advisable to contact the bank regarding strategies to put in place like a signature stamp. People may need to have an appointee or someone with lasting power of attorney for finance and property to manage their money for them and so will need legal advice regarding this
- 3.7 Handling money can be physically difficult and an individual may be prone to dropping and losing coins or notes, therefore supervision may be needed when paying for items. Consider easy to access wallets, money belts and purses. Occupational therapists should be aware that people with money handling difficulties often will hand over large denomination paper money to cashiers and are open to exploitation as a result of this
- 3.8 Memory and cognitive problems may make remembering pin numbers and passwords challenging. It is not advisable for people to write these down as they may lose them. Some banks offer payment/withdrawal books instead of cards. Contactless payment is another option, but whilst making payment easier, an individual may lose track of their spending

4. Equipment

- 4.1 People with Huntington's disease may find it difficult to accept that they need to use a wheelchair, so this subject needs sensitive handling. Consider the timing of referral to local wheelchair services
- 4.2 Ensure that external grab rails and path rails are in place as required, between the home and public highway

5. Awareness

- 5.1 With the person's consent, it may be useful to liaise with staff at the recreational facility (leisure centre, pub, club, café, etc.) to explain the support the individual needs or who to contact should help need to be provided
- 5.2 Provide Huntington's disease ID badge, these can be obtained from the Huntington's Disease Association in the UK if required

References

McCabe M P, Roberts C, and Firth L (2008) Work and recreational changes among people with neurological illness and their caregivers. *Disability and Rehabilitation*. 30(8) 600-610.

www.gov.uk/government/publications/assessing-fitness-to-drive-a-guide-for-medical-professionals

Completed September 2016

Produced by the UK HD special interest group for occupational therapists:

Authors: Kirsty Page, Louise Oakley, Alex Fisher, Zhanna Flower, Poppy Hill.

Contributors: Nicola Pendry, Sarah Sharland, Eleanor Winning, Clare Cook, Freya White, Suzi Kerrell-Vaughan, Emma-Louise Simpson, Jake Reed, Vicki VanEsch, Kirsty Berry, Sarah Hayes.

This document was based on Occupational Therapy for People with Huntington's Disease: Best Practice Guidelines. Written by Clare Cook, Kirsty Page, Anne Wagstaff with support from the members of the European Huntington's Disease Network, Occupational Therapy Working Group.

Huntington's Disease Association www.hda.org.uk European Huntington's Disease Network www.ehdn.org
Please send any comments or questions to info@ohtd.co.uk