

OCCUPATIONAL THERAPY CLINICAL TIPS FOR HUNTINGTON'S DISEASE

Social and Leisure

Huntington's disease can have a detrimental effect on an individual's ability to engage in social and leisure activities. This can be due to motor, cognitive and neuropsychiatric changes as well as practical aspects like loss of earnings, inability to access environments or to be understood.

Reduced concentration and executive impairment can make previously enjoyed pastimes difficult, particularly the ability to plan and initiate activity (Quarrell 2008). The distinction between this and the issue of apathy is difficult to define but is just as relevant as the person with Huntington's disease will appear to lack the drive to undertake any meaningful activity. Apathy can be confused with depression which can also have a significant effect on quality of life (Epping and Paulsen 2011). As yet, there is no evidenced based intervention that appears to improve apathy (Krishnamoorthy, Craufurd 2011, Andrews 2015); therefore, it is important that the occupational therapist educate others that this is not laziness but a very real problem due to the disease process. Goal orientated behaviour should be encouraged by offering a consistent opportunity for purposeful activity preferably set up in an enriched and stimulating environment so as to offer the person with Huntington's disease the best chance at enjoyment and success. Despite the lack of any known intervention at present which rehabilitates the person's cognition (Andrews 2015), it may be that certain approaches such as cognitive stimulation, remediation or rehabilitation, when started early enough, creates cognitive reserve to delay deterioration in these skills. Even if not, engagement in social activity should be supported as it is thought to reduce depression and anxiety and improve wellbeing (Sarris, O'Neil et al. 2014). Additionally, people with Huntington's disease value social activity as it can fill the void once paid occupation is no longer a viable option for them (McCabe, Roberts et al. 2008).

Lastly, as interacting with others lies at the heart of engaging with them successfully, occupational therapists should be aware that people with Huntington's disease are impaired in recognising other people's emotions as well as understanding their thoughts and feelings (Bodden, Dodel et al. 2010). Whilst there is little in the literature in the way of linking these issues to problems in function and how to manage them, there are conditions with similarities (i.e. Autism) and occupational therapists should endeavour to mine strategies from these and use them in advising companions of how their friends and loved ones may be seeing the world about them.

1. Identifying leisure and social activities

- 1.1 Involvement of a carer/relative may be useful, where a person lacks insight, is apathetic or where communication difficulties exist
- 1.2 Occupational therapists should also consider the impact of caring for someone with Huntington's disease on a carer's social and recreational activities and whether this can be mediated
- 1.3 An interest checklist tool can be very useful for providing a wide selection of suggestions. This eliminates using the recall aspect of cognition and uses the recognition part of our brain thus easing processing of information given. Be mindful of not overloading the person
- 1.4 If speech or swallowing issues have not been addressed occupational therapists should make a referral as soon as possible to their local speech and language therapist. Given the sometimes rapid onset of speech impairment alongside understanding problems, this may give the person with Huntington's disease time to adjust to new strategies for communication
- 1.5 If communication is significantly reduced, try using communication aids specific to that individual or provide pictures of that activity if appropriate to generate engagement and interest

2. Cognition

- 2.1 Individuals may not be able to picture an alternative reality to the one they are in. They then struggle to picture the enjoyment of an activity and decline the opportunity. Consider using lots of encouragement and positive reinforcement. Another tip is to try skipping the initial decision part of the process and begin initiating the task with them. Observe whether negative or positive feedback is generated before continuing

- 2.2 Individuals may struggle to identify what they want to do if open questions, such as ‘what would you like to do today...’ as this is relying on the person’s recall ability. It may be more effective to use recognition to aid the decision making process i.e. ‘would you like to go into town today shopping or go for a drive in the car’? Too many options could create overload and confusion
- 2.3 When helping someone to make decisions keep information simple and succinct and allow time to process and respond
- 2.4 Some people may no longer wish to take part in an activity or a particular leisure pursuit that they previously loved. This may be hard for relatives to understand, but that activity may no longer offer that individual any positive feedback and could well be a reminder of their functional deterioration
- 2.5 Due to physical symptoms of Huntington’s disease people can sometimes be exposed to negative feedback from members of the public misinterpreting their presentation for intoxication. This may significantly affect someone’s motivation to leave the “safety of home” thus leading to social isolation and occupational deprivation. There is no easy solution but some people try using this opportunity to educate local shops and venues with literature on Huntington’s disease. This has generated a positive outcome for many. In addition, ID badges such as the ones produced by the Huntington’s Disease Association can help in any negative social situations. Detailing the Next Of Kin on the card should help if the individual is in too heightened an anxious state to think or act clearly

3. Fatigue management

- 3.1 Bear in mind that fatigue management is a common challenge for someone with Huntington’s disease and does impact on overall functional performance.
- 3.2 Fatigue levels may also be variable from day to day.
- 3.3 Consider the best part of the day to undertake activity, and consider recovery time needed
- 3.4 Be mindful of physical and cognitive demands of leisure activities on individuals and be flexible in approach when dealing with this
- 3.5 Postural management is an important factor in managing energy demands. Plan rest breaks and ensure that facilities have places to take a break
- 3.6 Consider, where possible, environments that are not over stimulating

4. Psychological issues

- 4.1 Anxiety is a common issue in Huntington’s disease and can increasingly impact on someone’s occupational engagement
- 4.2 Consider using a graded approach with activities, particularly if going out of the home environment and offer lots of positive reinforcement
- 4.3 Some people may feel less anxious if they have their leisure activities for the week clearly prompted by a visual calendar or diary sheet or on their mobile phone
- 4.4 If planning ahead for an outing or activity generates too much pre anticipation and anxiety, try leaving knowledge of activity until the last minute
- 4.5 Try educating relatives to be realistic with their expectations. This will help reduce frustration about why certain situations, which may have previously been enjoyable may now generate anxiety and agitation

5. Activities for progressed and late stages of HD

- 5.1 Try to provide activities that again fit with what you know of that person and from feedback of those who know the individual best
- 5.2 Therapeutic sensory activity is worth exploring in late stage Huntington’s disease, such as gentle hand and foot massage, aromatherapy, relaxing music, visual stimuli. If a person is unable to communicate their needs, wishes and choices observe for changes in body language to help assess the benefit to that individual

6. Finances

- 6.1 If an individual’s function is affected and they have not applied for disability benefits, the occupational therapist should be proactive in signposting to the appropriate support. In the UK these include Citizen’s

Advice Bureau, Age UK and local care centres. The occupational therapist may be required to write a supporting letter

- 6.2 The costs of leisure activities can be challenging but try exploring activities via the internet or community centres and libraries that offer classes or activities for free in the area or at reduced rates if on certain benefits. Leisure cards are offered by some areas and this enables discounted entry to certain leisure activities
- 6.3 In some areas GPs prescribe and fund certain healthy lifestyle activities i.e. gym membership and some exercise classes
- 6.4 In the UK cinemas offer free entry for carers if accompanying someone with a disability however certain criteria needs to be met <https://www.ceacard.co.uk/cares>

7. Support groups for HD

- 7.1 The HDA will have knowledge of local Huntington's disease support groups in England and Wales, SHDA for Scotland. Many of these groups provide additional outings throughout the year

8. Physical considerations of leisure activities

- 8.1 Environmental considerations are covered elsewhere in these guidelines; for mobility concerns occupational therapists may wish to consult the EHDN Physiotherapy clinical guidelines (Quinn and Busse 2013)
- 8.2 Consider whether an activity could be adapted to continue successful and safe participation. Explore whether equipment, assistive technology or conducting a task differently facilitates engagement
- 8.3 Planning in advance can mitigate issues. Try looking at Euan's Guide (<http://www.euansguide.com>) for ideas about access to places/events. Set up by a gentleman who had Motor Neurone Disease, it is updated regularly by followers
- 8.4 Plan for toilet access before an outing. You can purchase National Key Scheme (NKS) keys for disabled toilets from <http://www.disabilityrightsuk.org>. They cost £4.50 each or £8 for a key and location finder. Locations can also be found by searching for 'toilets' on your council website. Discourage patients from buying keys elsewhere as there are plenty of fakes on the internet

9. Smoking

- 9.1 Occupational therapists are health professionals and as such, they have a duty to give clear messages to those they work with about healthy lifestyle choices, such as smoking cessation. If the person with Huntington's disease has consented to a referral, the occupational therapist can refer them onto NHS choices or their Trust's smoking cessation advisory service. Alternatively the person can be signposted to the <http://www.nhs.uk/smokefree>. If the person is admitted into hospital or another facility, occupational therapists should refer to the local policy
- 9.2 It is not always possible to alter someone's ingrained habits as well as beliefs. Therefore, the occupational therapist can offer advice to the individual and their companions of the potential and increasing risk of fire, such as of the result of excessive movement but also the impact of lack of judgement
- 9.3 If the risk is due to the latter, occupational therapists should determine if the individual has the capacity to understand the risks of their actions and determine a pro-active plan accordingly
- 9.4 Refer to the Mental Capacity Act 'Code of practice' <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>.
- 9.5 In the community, a joint visit with the local fire brigade is recommended. If not possible, at the very minimum, occupational therapists should advise the individual and/or companions to contact the fire service for a fire assessment visit which may include the fitting of free smoke alarms. A strategy should be addressed for maintenance of these (i.e. testing/changing batteries). Furthermore contacting the fire service is important for individuals who have mobility issues as these can impact on evacuation in the event of future incidents. If the individual is felt to have difficulty in responding to the consequences of a smoke or fire alert independently, a referral to telecare should also be made
- 9.6 Often the smoking behaviour of a person with Huntington's disease can become impulsive due to cognitive or mood change. If possible, consider the adoption of a smoking schedule which should be encouraged and monitored by companions or care staff

- 9.7 Be mindful of the environment in which the person smokes and guide them towards a more fire retardant and clutter free area
- 9.8 The risk of fire can also be reduced by the use of smoking robot / smoking aprons / smoking clothing covers / fire retardant clothing and furniture. Further steps can include buying branded cigarettes only as black market products do not have the extinguishing band near the filter which stops them burning
- 9.9 Other measures include getting an individual in the habit of using a smoke snuffer either on its own or in an ash tray, as well as using self-extinguishing ash trays. A maintenance strategy for emptying and cleaning the latter should be addressed. Lastly – lighters should be used in preference to matches, whilst these may be difficult to coordinate and use, they are self-extinguishing

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Completed September 2016

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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
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