

OCCUPATIONAL THERAPY CLINICAL TIPS FOR HUNTINGTON'S DISEASE

Self-Care

People with Huntington's disease often report that their self-care routines become slower because of movement difficulties and difficulty in concentrating and planning the tasks. Some people gradually stop initiating self-care routines and need prompting and support and this can result in self-neglect. It can become difficult to engage the person in self-care tasks due to a combination of behaviour, physical and cognitive deterioration. Persons with Huntington's disease in the later stages will require carers to complete self-care tasks for them. Discussions around the availability of care packages to assist with self-care should be undertaken with the individual and/or family and carers.

1. Establish routines

- 1.1 Consider the best time of day to carry out self-care tasks and keep this time as consistent as possible
- 1.2 Identify the tasks the person can or wants to do for themselves
- 1.3 Consider who/how/when and where you present the activity to the person.
- 1.4 Eliminate external stimuli wherever possible to enable focus of attention, for example turn off radio/TV keep 'chit chat' to a minimum
- 1.5 Carers may need to organise the environment, such as, setting up the shower, laying out clothes
- 1.6 Carers may need to initiate the activity or task parts, for example simple commands can encourage the person with Huntington's disease to assist, such as lifting limbs for dressing
- 1.7 Use short sentences conveying one piece of information at a time and allow the person time to respond as a reply or action can be delayed. Questions with limited choices which require less effort to process may help
- 1.8 Break down the activity using activity analysis and consider forward and backward chaining
- 1.9 Carers may need to be flexible in responding to people's needs quickly as the person with Huntington's disease 'can't wait'
- 1.10 Keep routines short. Not everything needs to be done on the same day
- 1.11 Carers may need to be discreet and flexible in helping the individual with managing their appearance and hygiene such as removing dirty clothes

2. Toileting

- 2.1 Assess for and provide handrails to assist transfers onto/off the toilet where appropriate
- 2.2 Alternatively assess for a toilet frame fixed to the floor.
- 2.3 Use a sturdy toilet seat, involuntary movements caused by Huntington's disease and heavy transfers may result in the toilet seat becoming loose or breaking
- 2.4 When purchasing a toilet seat, consider one with the sturdiest bolts or preferably one where the bolts insert at a right angle into the toilet seat. Be prepared to replace the toilet seat frequently
- 2.5 Consider a padded toilet seat if person is spending a lot of time on the toilet or skin integrity is a concern
- 2.6 Where appropriate, assess for and provide a padded backrest around the cistern if the person has strong extensor movements
- 2.7 Commodes which wheel over the toilet can be useful
- 2.8 Wash and dry toilets may be useful for maintaining independence in self-hygiene, consider the impact of chorea movements, positioning, other equipment in use and cost
- 2.9 Consider the use of different hygiene products, such as cleansing toilet wipes
- 2.10 If someone is requesting the toilet respond immediately as they may not be able to 'wait'
- 2.11 Some people may benefit from regular toileting routines
- 2.12 Plan ahead where toilets are available when going out
- 2.13 Where continence is a particular difficulty to the person with Huntington's disease and the caregiver a referral to the continence advisor/local nurse should be made without delay

3. Bathing and showering

- 3.1 Assess for and provide appropriate bathing equipment. The choice of equipment will depend on the person's presentation, space in the bathroom and carer support
- 3.2 If at all possible consider the progression of Huntington's disease when choosing equipment
- 3.3 Reassessment is vital as the patient's physical, cognitive and behaviour changes
- 3.4 Waterless shampoo and body wash can be useful if individuals are bed bound or are anxious around water

Bathing

- 3.5 Assessment for a bath board/swivel bather in early stages of Huntington's disease can be useful
- 3.6 Consider falls getting into and out of the bath

- 3.7 Consider involuntary movements and postural control when using bath lifts; these can be limited in their suitability for people with Huntington's disease
- 3.8 Assess whether posture can be maintained once in the bath; in later stages of the condition the person may need postural support in the bath
- 3.9 Detachable shower cradles can be used to hoist someone in and out of the bath

Showering

- 3.10 Wet rooms should have non slip floor tiles, avoid glass shower screens
- 3.11 Avoid wall mounted shower seats as people can hit their head on the wall
- 3.12 Use sturdy shower chairs; consider 4 lockable brakes if the chair needs to be moved and whether postural support is required
- 3.13 Tilt in space shower chairs, shower cradles and molded shower chairs may be useful as Huntington's disease progresses
- 3.14 Training for carers in use of equipment should be regularly reviewed and documented

4. Grooming

Assess and where appropriate suggest strategies to assist with grooming, such as:

- 4.1 Using an electric shaver or beard trimmer can be safer than a wet shave
- 4.2 Good foot care is essential, signpost to GP/podiatrist.
- 4.3 Shorter hairstyles are easier to manage but for those people who wish to keep longer hair a 'tangle teaser' brush or spray in conditioner helps to keep hair manageable
- 4.4 Other aspects of grooming such as waxing, manicures and pedicures can often be arranged with local beauticians. It is important for carers to maintain these activities when the person can no longer do them themselves. Grooming tasks can promote social interaction and inclusion, emotional well-being and offer a sensory stimulating activity

5. Teeth

- 5.1 Oral care is often forgotten and can be a source of neglect which leads to complications and infections (Manley, Lane et al. 2012)
- 5.2 Independent dental/oral hygiene may become difficult for the person due to their movement difficulties and can be addressed by using an electric toothbrush or assistance from carers
- 5.3 If you don't have access to specialist dentistry and oral care advice then consider the type of toothbrush and paste; soft bristle, angled, multi headed and low foam toothpaste
- 5.4 If there are swallowing problems or aspiration is high risk refer to speech and language therapist

6. Menstruation

- 6.1 A discussion around managing menstruation should take place and a medical opinion should be sought to discuss medical management of menstruation
- 6.2 For those people who do not chose to manage menstruation in this way, the occupational therapist can encourage the use of pads rather than tampons as these can be difficult to insert with co-ordination difficulties. This also minimises the risks of tampons being 'forgotten' and left in
- 6.3 Where possible a routine for changing sanitary wear should be established such as ensuring there is always a replenished supply of sanitary towels in the bathroom or handbag if going out
- 6.4 Feminine hygiene wipes can be helpful to maintain hygiene

References

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Manley G et al (2012) Guideline for oral healthcare of adults with Huntington's disease. *Neurodegenerative Disease Management*, 2(1), pp.55-65

Pollard J (2008) *Hurry up and wait! A Cognitive Care Companion, Huntington's disease in the middle and more advanced years.*

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Huntington's Disease Association www.hda.org.uk European Huntington's Disease Network www.ehdn.org
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