

OCCUPATIONAL THERAPY CLINICAL TIPS FOR HUNTINGTON'S DISEASE

Eating and Drinking

People with Huntington's disease experience difficulties with eating and drinking due to cognitive, physical and psychological changes. Each stage of the disease will impact on an individual's functional independence, such as involuntary movements resulting in dropped food and reduced nutritional intake, decreased ability to self monitor resulting in cramming food. Any of these changes can lead to frustration, embarrassment and/or anxiety of choking.

Signs such as choking, coughing, a gurgling voice and recurrent chest infections can all indicate a problem with swallowing (dysphagia) and referral should be made to a speech and language therapist for specialist assessment and management. Some people with the disease choose to have a PEG (percutaneous endoscopic gastrostomy) as the effort and risks associated with swallowing become too great. Discussions regarding a PEG as an option should be started early by to obtain a person's wishes in advance to avoid the decision being rushed or made in an emergency situation by a team not knowing the person well.

Many individuals with the disease have increased energy requirements due to involuntary movements and changes in metabolic balance due to the disease. It is essential to provide adequate nutrition and a referral to a dietician should be considered.

1. General Tips

- 1.1 Eating and drinking are complex skills often requiring a multi-disciplinary approach. Check for any existing speech and language and physiotherapy treatment plans
- 1.2 When issuing equipment, in particular to support drinking, ideally liaise with the speech and language therapist as some equipment may adversely affect swallow function
- 1.3 Carers may need to closely supervise, prompt or offer assistance during meals due to the high risk of choking or an individual's ability to carry out the functional task
- 1.4 Anxiety, depression or behaviour changes need to be observed. Reduce anxieties such as fear of choking, consider meal time routines, offer support and supervision and consider a quiet distraction free environment
- 1.5 Offer meals when a person is most alert and when they have the most energy, larger meals may be offered in the morning. Conserve energy between meals
- 1.6 If fatigue is an issue, give smaller meals more frequently or alternatively carers may assist feeding towards the end of a meal to help to reduce fatigue
- 1.7 Encourage self feeding for as long as possible as this promotes a safer swallow than assisted feeding
- 1.8 If people are anxious about eating out, ask to be seated at a table in a quieter area of the restaurant. Choose a meal which will be easy to manage and that is appropriate for their swallowing capability. Take any adapted equipment with you
- 1.9 Food spillage is an inevitable result of eating if involuntary movements are present. Carers need to be aware of dignity issues and the risk of the person slipping on dropped food
- 1.10 An occupational therapist as part of the multidisciplinary team may be involved in capacity assessments, best interest decisions about eating and drinking including PEG insertion when a person has dysphagia or is losing weight. Health Authorities may have different approaches to PEG feeding, in some areas is very rare for a person with Huntington's disease to be given a PEG

2. Cutlery and Crockery

- 2.1 Simplifying the activity such as using a fork or spoon may improve function
- 2.2 Where involuntary and uncoordinated movements and muscle weakness are observed consider adapted cutlery such as built up handles, angled cutlery and straps on cutlery
- 2.3 Weighted cutlery and cups may reduce involuntary movement
- 2.4 Contoured dishes, plate guards and non-slip mats beneath may improve function and decrease spills
- 2.5 If liquid is being split from a cup consider cups with lids such as camping mugs, as well as non-spill beakers which in theory can't be knocked over. Spouted beakers and/or straws can also help reduce fluid spilt. However, if drinks are thickened the aperture size of the spout or straw, needs to be considered
- 2.6 Consider the size and type of cutlery, such as smaller spoons to reduce cramming and shatterproof plastic to minimize damage to teeth and gums

- 2.7 If an individual is taking a significant amount of time to consume food a warming bowl which has a hot water reservoir built in may help
- 2.8 Clothes protectors can help with food spillages; more discreet options are now available such as pashmina and neckerchief style

3. Positioning

- 3.1 Advise on posture and positional changes as the disease progresses
- 3.2 Where possible individuals should be seated upright to aid functional skills and reduce risk of aspiration and choking
- 3.3 Ensure an individual has a stable base in seating: pelvis fixed (consider a pelvic belt), trunk and feet well supported
- 3.4 Consider type of table so that elbows and arms can be stabilized, sometimes people find their own ways of stabilizing themselves
- 3.5 People with excessive movements may benefit from a chest harness when eating to maintain their position
- 3.6 Head supports or hands on support may be considered for individuals who have difficulty keeping their head up or have excessive head movements whilst eating/drinking
- 3.7 An individual may reach the point when self feeding is no longer possible and they are fully dependent on carers
- 3.8 If an individual is being fed in bed or PEG fed, the bed head must be profiled at a 45° angle to reduce the risk of aspiration
- 3.9 Individuals should be encouraged to remain sitting upright after being fed to reduce the risk of aspiration, reflux and aid digestion

4. Cognitive Aids

- 4.1 An individual may need support and gentle direction to ensure that they remember to eat and drink; they may be able carry out the task but are unable to initiate it due to cognitive and/or mood difficulties. Without this support this may lead to severe self-neglect
- 4.2 Carers may need to gently prompt an individual to adequately pace themselves if self monitoring is a problem
- 4.3 Reduce distractions, such as turning off the TV or limit conversation; promote a relaxed environment
- 4.4 Offer specific, limited choices e.g. rather than asking “what would you like to drink”, ask “would you like a hot drink or cold drink”, “tea or coffee”. Too many choices can be confusing
- 4.5 A routine tailored to the individual’s own needs can ensure that individuals eat regularly. Not everyone eats at traditional meal times, for example an individual may be awake during the night, so a flexible approach is advised
- 4.6 Appropriate, visible snack foods in the kitchen or living room may prompt the person with Huntington’s disease to eat if they have difficulty initiating the task

References

Nambron R, Silajdzic E, Kalliolia E et al. A Metabolic Study of Huntington’s Disease. *Plos one* January 2016.

Hamilton A, Heemskerk AW, Loucas M et al. Oral feeding in Huntington’s disease: a guideline document for speech and language therapists. *Neurodegen.Dis.Manage.* 2(1) 45-53 (2012).

Huntington’s Disease Association. Huntington’s Disease Eating and Swallowing Fact sheet (2015).

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