

Huntington's Disease

What is Huntington's Disease?

Huntington's Disease (HD) is an inherited condition which can affect movement, behaviour and cognition. A combination of the symptoms caused by Huntington's Disease can lead to difficulties in communication and swallowing.

If you wish to know more information about your HD diagnosis and support available in your area, please visit the charity website on www.hda.org.uk

How can HD affect communication?

Many people with HD experience difficulties with their communication/speech. This could include:

- Slurred imprecise or slower speech
- Difficulties controlling the rate of speech (e.g. talking too fast or too slow)
- Difficulties with changing the volume or pitch of your voice
- Hoarse or breathy voice
- Difficulties coordinating the movements needed for speech
- Word-finding difficulties
- Difficulties initiating conversation
- Getting stuck on certain words or phrases (perseveration) – repeating themselves or others
- Difficulties maintaining a topic
- Switching topics inappropriately
- Difficulties understanding information
- Difficulties with reading and writing

People with HD can experience decreased cognitive functioning, which may also impact on communication. People may experience:-

- Slow thinking/slow learning/reduced attention and inability to follow fast conversations
- Losing one's train of thought while speaking
- Difficulties problem-solving and forward planning

- Problems storing and retrieving memories
- Difficulty making sense of perceptions/concepts
- Problems with language e.g. word-finding difficulties
- Difficulty sequencing actions, making it harder to carry out everyday tasks.

How can speech and language therapy help?

Your speech and language therapist can:

- Assess your communication needs
- Offer advice and support
- Provide strategies to support you and your communication partner
- Discuss alternative methods of communication if speech becomes difficult

How can HD affect swallowing?

Swallowing difficulties may include:

- Impulsivity whilst eating and drinking, further affected by possible jerky chronic movements when trying to feed
- Drooling and spillage of food/liquid from the mouth
- Difficulties chewing food and clearing from the mouth
- Difficulty initiating a swallow
- Delayed swallow reflex
- Coughing or choking on food, drink or saliva
- Food sticking in throat and a need to swallow repeatedly for each bite/sip
- Reduced coordination of swallowing alongside breathing
- Gurgly voice
- Repeated chest infections
- Reflux or heartburn

Reduced nutritional and/or fluid intake can also, in turn, cause:

- Weight loss
- Fatigue

People with HD tend to need a high-calorie diet. A dietitian can help work out an appropriate diet plan specific to your needs.

How can speech and language therapy help?

The Speech and Language Therapist will assess the safety of your swallow and offer advice on ways to help reduce risk by:

- Recommending the safest food and drinks for you to have. This may include avoiding hard, dry or crumbly textures.
- Advising on safest swallowing strategies. This may include advice on safe posture, appropriate sized mouthfuls/sips, safe speed of feeding and advice on environmental changes.
- Liaising with other professionals, such as your GP, Dietitian, Occupational Therapist and Specialist Nurse where appropriate.

Alternative methods of eating and drinking (e.g. feeding tubes) may need to be explored in the long-term.

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How to contact us

Speech and Language Therapy Departments
Office hours: Monday-Friday 9am - 4.30pm

University Hospital of North Durham
Telephone: 0191 3332591

Darlington Memorial Hospital
Telephone: 01325 743152

Useful contacts

North Specialist Team at Walkergate Park –
0191 2875206

Huntington's Disease Association's
Specialist Advisor – 0191 2622358

Charity Website:

www.hda.org.uk
www.ninds.nih.gov/disorders/huntington
www.nhs.uk/Conditions/Huntingtons-disease

Contact details



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We need your comments, concerns complaints and compliments to deliver the best service possible. Please let us know by speaking to a member of our staff. We learn from your feedback and use the information to improve and develop our services.

If you would like to talk to someone outside the service contact the **Patient Experience Team** on **0800 783 5774**, or email cdda-tr.PatientExperienceCDDFT@nhs.net.

We can make this information available in Braille, large print, audio or other languages on request.