Huntington's Disease Association

Huntington's disease

Eating & Swallowing

Fact Sheet

Revised January 2015

Eating and Swallowing

People with Huntington's disease can experience difficulties with eating, drinking and swallowing. These can be among the most challenging aspects of this condition and can affect not only the person with Huntington's disease but also their family and/or carers. This fact sheet explains the signs of eating, drinking and swallowing difficulties, the reasons for these in Huntington's disease, key ways to manage them, and some handy hints for safer eating, drinking and swallowing.

What are the signs of eating, drinking and swallowing problems?

Common signs include:

- Physical difficulty self-feeding, i.e. using utensils to place food or drink in the mouth
- Difficulty controlling food or drink in the mouth
- Food or drink spilling forward out of the mouth
- Difficulty chewing food
- Difficulty actually swallowing
- Coughing or 'choking' during or after swallowing the food or drink
- Bringing food or drink back up
- A wet, 'gurgle' sounding voice
- The sensation of food or drink 'catching' in the throat; food 'sticking' in the throat or a feeling that food or drink has 'gone down the wrong way'
- Disinterest in eating and drinking
- Changes in appetite
- Heightened anxiety or fear of eating or drinking

Enduring symptoms may include social isolation especially at meal-times, unexplained weight loss and/or frequent chest infections.

It is important that where these symptoms are identified in the person with Huntington's disease, contact is made with their GP and/or medical team to request a referral to the local Speech &

Language Therapy Service for specialist assessment and intervention.

What are the effects of eating, drinking and swallowing problems?

There are several reasons why eating, drinking and swallowing problems need to be managed properly:

- **Aspiration** – is the technical term given when a 'foreign substance' such as food, drink, saliva, refluxed acid and/or medication enters the airway to the lungs. Usually if this happens we describe it as something 'going down the wrong way' and people will typically cough. If a person has eating, drinking and swallowing problems because of Huntington's disease they may be at risk of aspiration. It is important to try and manage this risk of aspiration occurring because it can lead to chest infections and sometimes, aspiration pneumonia.

- **Aspiration Pneumonia** – is an infection of the lungs caused by accidental inhalation of a 'foreign substance' into the lungs. It is a potentially serious, may be a fatal condition that requires attention from the medical team.

- **Choking** – if a person has eating, drinking and swallowing problems because of Huntington's disease they may be at risk of choking and difficulty breathing because the airway to the lungs has been obstructed by for example food blocking the windpipe.
- **Malnutrition** – is the condition that develops when the body does not get the right amount of nutrients (energy, protein, vitamins and minerals) that are necessary to maintain a healthy body. If a person has eating, drinking and swallowing problems because of Huntington's disease they may not be able to eat a balanced, high calorie diet that meets their individual needs for a healthy body and mind.

- **Dehydration** – is the condition that develops when your body does not get enough fluids and salts, which may occur if the person with Huntington's disease because they have difficulty swallowing and drinking adequately.

- **Managing symptoms of Huntington's disease** – if the person with Huntington's disease has difficulty eating, drinking and swallowing other symptoms of their condition such as behaviour, concentration, memory, mood, choreiform movements and physical skills may be harder to control and manage.

- **'Quality of life'** – eating and drinking is considered an essential part of daily living, which for most people is used to promote enjoyment, pleasure and socialisation. Where a person with Huntington's disease has eating, drinking and swallowing problems, they may feel that their own and their family/or carers quality of life is negatively affected.

What are the reasons for eating, drinking and swallowing problems in people with Huntington's disease?

- **Changes in the muscles used to eat, drink and swallow** – there are different muscle groups involved in the process of eating, drinking and swallowing. Upper limb muscles of the arm and hand are used to for example prepare meals and to place the food or drink in the mouth when eating and drinking. Muscles of the face and throat are used to for example chew food, control the food or drink in the mouth, pass it to the back of the mouth and down the throat, and to swallow.

  Both these muscle groups can be affected by Huntington's disease, in particular muscle strength and range of muscle movement can change, which makes the action of eating, drinking and swallowing difficult. To add because of choreiform movements, the control and co-ordination of these muscles groups can impact on the efficiency, effectiveness and time taking eating, drinking and swallowing.

As a result of the physical changes in these muscles there can be specific problems across all phases of the actual swallow mechanism itself such as:

a) Difficulty placing the food or fluid in the mouth; closing the lips together to keep the food or drink in the mouth; chewing the food or holding the drink in the mouth in preparation to transfer the food or drink to the back of the throat

b) Co-ordination, timing and speed of transfer of the food or drink to the back of the throat; sometimes food or drink may transfer too quickly, too slowly and/or be uncoordinated and

c) Difficulty with food or drink being efficiently and effectively swallowed so as to enter the oesophagus (tube to the stomach) and not 'go down the wrong way' into the airway to the lungs.

- **Changes in appetite** – At different points during the condition, the person with Huntington's disease can have changes in appetite. This can be for a variety of reasons such as changes in diet, actual difficulties eating, drinking and swallowing, fatigue and fear of spilling foods or choking, anxiety, frustration or an over-all change in their mood such as depression. Any one or a combination of these factors can result in the person with Huntington's disease having a loss of appetite and although hungry, they may actually refuse to eat.

  Alternatively, people with Huntington's disease can have a voracious appetite. Even though they are eating frequently and often big meal portions, they always seem to be hungry. As a result of this they can have a tendency to take too big a mouthful of food and/or to cram as much food into their mouth. This can lead to spillage of food out of the mouth, storing of food in their cheeks and/or reduced control and co-ordination of the swallow mechanism and risk of aspiration or choking.

- **Changes in cognition** - as mentioned above, the person with Huntington's disease may experience anxiety and/or depression, which may manifest because of their difficulties with eating, drinking and swallowing. This may also arise because of changes in their cognition and mental health.

  Anxiety and stress often trigger visible chorea, which can then affect eating, drinking and swallowing. The actual fear of choking, drooling or the embarrassment of making a mess while eating or drinking can actually increase the chance that it will happen.

  Where the person with Huntington's disease has a change in cognition, they may also have reduced insight, self-awareness and self-monitoring. As a result, some eating and drinking habits for example storing food in her their cheeks, taking too big a mouthful of food or drink, 'cramming' food into their mouth may be difficult to self-manage. This is where the role of family and/or carer can aid the situation as they can act as a monitor and give advice when necessary. However, it is acknowledged that this may not be easy. Many people with Huntington's disease show great resistance to change in their life-style, which can make it difficult to introduce new habits and ideal food or drink textures to the daily routine.

- **Weight loss** in this condition has long been observed and is frequently attributed to involuntary choraic movements. Although many theories have been suggested, the cause of weight loss is still unclear. Most recent evidence proposes that the weight loss may be a manifestation of an underlying biochemical defect. Whatever the cause, the fact remains clear that a greater calorie intake is needed.

  Where weight loss is observed the person with Huntington's disease may not have sufficient energy; making eating, drinking and swallowing an effortful, difficult and tiring activity.

It is important where there are problems identified managing the weight of the person with Huntington's disease that contact is made with their GP and/or medical team to request a referral to

the local Dietetic Service for specialist assessment and intervention.

How are eating, drinking and swallowing problems assessed?

Recognising the signs and symptoms of eating, drinking and swallowing difficulties is the first point from which assessment begins. The person with Huntington's disease, their family and/or carers are pivotal in identifying these difficulties and reporting any observations to their GP and/or specialist medical team involved.

Once alerted that there are concerns about eating, drinking and swallowing, a referral should be made to the local Speech & Language Therapy Service. It is the role of a Speech & Language Therapist to assess eating, drinking and swallowing problems. Assessment may involve:

- Discussion with the person who has Huntington's disease, their family and/or carers.
- Discussion with the medical team and other health and social care staff involved.
- Meal-time observation.
- Bedside swallow assessment, which is a non-invasive, non-instrumental clinical assessment of the person with Huntington's disease swallow function.

In some cases further tests such as a videofluoroscopy, which is a recorded dynamic continuous x-ray may be carried out to investigate in more detail the swallow function. This is typically carried out in a specialist x-ray clinic by a Radiologist and Speech & Language Therapist.

How are eating, drinking and swallowing problems managed?

From information obtained during assessment of eating, drinking and swallowing problems, the Speech & Language Therapist in

collaboration with the person with Huntington's disease, their family, carers, medical team and other health and social care staff will develop a personalised care plan. This may involve:

- Food and fluid texture modification – changes to the consistencies of food or fluid textures and advice on textures to avoid can be recommended by your local speech & language therapist so that that the person with Huntington's disease can easily and safely eat, drink and swallow.

- Changes to meal times – what time the person with Huntington's disease eat or drink throughout the day and evening, how often they eat and drink, and the portion size of their meal or drink may be reviewed to ensure it is the most suitable considering their daily presentation, mood, levels of fatigue, concentration and their medication regime to name a few factors.

- Changes to the meal-time environment – it is important to 'set the scene' ensuring the environment suits the person with Huntington's disease individual needs that can promote a pleasurable and safe place to eat and drink . For example the dining area should have good lighting; it should be a calm and quiet area that is free from distractions such as lots of people present and/or television or music system being switched on.

- Advice on specialist eating and drinking equipment – there are a variety of small aids from specialist crockery, cups, cutlery, place mats, tablecloths and straws that are available to help the person with Huntington's disease self-feed. Some of these items are readily obtained from shops, supermarkets or disability living centres and associated web-sites. However, it is important to seek specialist assessment and advice from a local Occupational Therapist before

making any purchase. To access a local Occupational Therapist, contact your GP or medical team to request a referral to this service.

- Advice on seating, posture and positioning at meal-times – good body posture and head position are important for safe eating, drinking and swallowing. Ideally the person with Huntington's disease should be sitting upright in a chair, looking forward with their head held upright when eating and drinking. If they cannot sit in a chair then they should be sat comfortably as upright as possible in the bed or a wheelchair. In some cases, specifically designed seating aids, chairs and wheelchairs may be used to help promote optimal seating position especially where the person with Huntington's disease has body and/or head choreic movements. Where specialist seating and associated equipment is necessary it is important to access specific assessment and advice from your local Physiotherapist and/or Occupational Therapist. They can be accessed by your GP or medical team making a referral to their Service.

  When considering optimal seating, posture and positioning it is vital to also consider access to and from the person with Huntington's disease especially in the case of emergency.

- Advice on assisted feeding – dependent upon the individual skills of person with Huntington's disease, 'assisted feeding' may take one or a combination of three forms.

  Firstly, it may entail closely supervising the person with Huntington's disease self-feeding at meal-times. Secondly, it may be that someone supports the person with Huntington's disease self-feed by for example giving lots of physical and verbal prompts to

help them self-feed and/or taking over feeding when they show signs of tiredness. Thirdly, as the condition progresses, the person with Huntington's disease may need to be fed their meal or given their drinks by family and/or carers.

Dependent on the form of assisted feeding and support, advice can be given that is unique to the person with Huntington's disease, their family and/or carers' individual needs.

Alternative feeding method

For some people with Huntington's disease eating, drinking and swallowing may become such a significant problem that a different method of feeding needs to be considered. Primarily this will include a gastrostomy, where a tube is inserted into the stomach via the abdomen. There are different forms in which a gastrostomy is offered, the difference being how the tube is inserted. The most common of these and that which most often is suggested for people with Huntington's disease is Percutaneous Endoscopic Gastrostomy (PEG).

There are advantages and disadvantages linked to this form of feeding and any decision made is unique to the individual with Huntington's disease, their circumstances and their specific needs. It is therefore crucial that in making a decision for alternative feeding, the person with Huntington's disease, their family, carers, medical team and health and social care staff carefully and thoroughly discuss the options available.

Oral Care

Looking after your mouth, teeth and gums is a vital part of everyday living. It is particularly important when the person with Huntington's disease has eating, drinking or swallowing difficulties and maintaining a routine of oral care can be challenging. Regular visits to your local dentist are advisable. They can recommend the most appropriate oral care regime, most suitable toothbrush and toothpaste or mouthwash to

use according to the person with Huntington's disease individual needs.

Saliva Management

When the person with Huntington's disease has difficulty eating, drinking and swallowing, this may extend to difficulty managing their own saliva. This may present as problems with one or a combination of difficulties including:

- Dry mouth
- Copious amounts of thin, watery saliva that the person with Huntington's disease may have difficulty controlling in their mouth and swallowing leading to for example drooling and/or a wet sounding voice
- A build-up of phlegm or thick, sticky tenacious mucous that may feel is 'sticking at the back of the throat' and that looks stringy when the person with Huntington's disease cough to clear the product

It is important to be aware of these difficulties and report this information to your local Speech & Language Therapist for their assessment, practical advice and, liaison with the medical team and other health and social care team members to try and best manage the problem.

Handy hints for safe eating, drinking and swallowing

Every person with Huntington's disease problems eating, drinking and swallowing are unique to them and their situation. It is important for an individual care plan to be developed that considers their specific needs. However, here are some general helpful tips for safer eating, drinking and swallowing:

- Establish a routine at meal times; have meals and snacks at regular times across the day and evening.
- Ensure the environment is calm, quiet and free from distractions e.g. turn off the TV or radio, and sit in a part of the room where there are fewer people.
- Try not to eat and drink alone.
- Allow yourself time to eat and drink.
- Take small mouthfuls of food or drink – DO NOT EAT AND DRINK AT THE SAME TIME.
- Make sure you have swallowed the first mouthful of food or drink before taking the next – DO NOT FILL UP YOUR MOUTH WITH TOO MUCH FOOD OR DRINK.
- Thoroughly chew your food; rest if you need to in between mouthfuls of food or drink.
- Ensure the food or drink is at the right temperature for you to eat, drink and swallow.
- Make food look attractive so you want to eat it.
- Ensure that you are alert, calm and sitting upright in a comfortable position when eating and drinking. Your head should be held upright in a mid-line position when swallowing food or drink.
- Concentrate on the task of eating and drinking – talking in between courses of your meal or drink not during the activity itself.
- Rest before and after meals and drinks – sit upright for at least 30 minutes after you have finished your meal or drink.

- Make sure family and carers are aware of your eating, drinking and swallowing problems and where in place, are familiar with your individual care plan so they can support and encourage you.

- Speak with your Speech & Language Therapist or medical team (GP, hospital doctor, nurse, dietician, occupational therapist or physiotherapist) if you need more help and information.

A final point

Throughout this fact sheet reference has been made to the role of health and social care staff to assess and offer intervention to meet the person with Huntington's disease individual needs. Where signs and symptoms of eating, drinking, swallowing and weight management are identified in the person with Huntington's disease do not hesitate to consult your GP and/or medical team to request referral to the specialist clinical team:

- Speech & Language Therapy – to assess and treat eating, drinking and swallowing difficulties
- Dietetics – to assess and advise on nutrition, hydration needs, and weight management
- Physiotherapist – to assess and advise on suitable body posture, head position and seating
- Occupational Therapy – to assess and advise on suitable seating and specialist feeding utensils

Remember effective management of eating, drinking and swallowing problems should be a team approach that includes the person with Huntington's disease, their family, carers, the medical team and health & social care professionals.

Further information

Huntington's Disease Association (HDA)
Suite 24, Liverpool Science Park IC1, 131 Mount Pleasant, Liverpool, L3 5TF
Tel: (0151) 331 5444
Website: http://hda.org.uk/

British Dietetic Association (BDA)
5th Floor, Charles House, 148/9 Great Charles Street Queensway, Birmingham, B3 3HT
Tel: (0121) 200 8080
Website: http://www.bda.uk.com/

British Association of Occupational Therapists and College of Occupational Therapists (BAOT/COT)
College of Occupational Therapists
106 - 114 Borough High Street, Southwark, London, SE1 1LB
Tel: (020) 7357 6480
Website: http://www.cot.co.uk/

Disability Living Foundation (DLF)
380-384 Harrow Road, London, W9 2HU
Tel: (020) 7289 6111
Website: http://www.dlf.org.uk/

Dysphagia Online
http://www.dysphagiaonline.com/

Chartered Society of Physiotherapy (CSP)
14 Bedford Row, London, WC1R 4ED
Tel: (020) 7306 6666
Website: http://www.csp.org.uk/

Royal College of Speech & Language Therapists (RCSLT)
2 White Hart Yard, London, SE1 1NX
Tel: (020) 7378 8120
Website: http://www.rcslt.org/

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Fact sheets available from the Huntington's Disease Association:

- General information about Huntington's Disease and the Huntington's Disease Association
- Predictive Testing for Huntington's Disease
- Talking to Children about Huntington's Disease
- Information for Teenagers
- A Young Adults Guide
- Eating and Swallowing Difficulties
- Huntington's Disease and Diet
- The Importance of Dental Care
- Communication Skills
- Behavioural Problems
- Sexual Problems
- Huntington's Disease and the Law
- Huntington's Disease and Driving
- Advice on Life Assurance, Pensions, Mortgages etc.
- Seating Equipment and Adaptations
- Checklist for Choosing a Care Home
- Advance Decision to Refuse Treatment (ADRT)
- A Carers Guide
- Challenging Behaviour in Juvenile Huntington's Disease
- A Brief Guide to Juvenile Huntington's Disease for Children's Hospices and Palliative Care Service
- A Young Person with Juvenile Huntington's Disease at School

All fact sheets can be downloaded free of charge from our website www.hda.org.uk or ordered from Head Office.

For a publication price list/order form, membership form, details of our Specialist HD Advisers and local Branches and Groups, please call Head Office on:
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