

# Huntington's Disease Association



## Eating and Swallowing in HD

May 2012

Difficulties with eating and swallowing (dysphagia) and maintaining a constant body weight are among the most troublesome complications of Huntington's disease. There are many factors involved and many reasons why these problems occur. These include:–

### **Changes in appetite**

Most people with Huntington's disease have voracious appetites. They always seem to be hungry and have a tendency to cram food into their mouths to try to satisfy their hunger, causing problems with choking and loss of food by spillage. Behavioural problems can often be attributed to the severe hunger of the sufferer which has not been duly met by the diet. This problem is a common occurrence when speech and communication problems are present and the carer finds it difficult to understand what the person is trying to say and therefore may not be aware of his/her need to eat. Appetite can be affected by a number of other factors such as the fear of spilling things, fatigue, changes in the diet, and irritation over the difficulties experienced when eating and drinking, all of which can make eating a frustrating, upsetting and even confrontational time. Although hungry, the sufferer may therefore actually refuse to eat very much food at all.

### **Choreiform movements – problems of chewing and facial control while food is in the mouth**

Feeding and eating difficulties arise from the choreiform movements of the face and neck, incomplete lip closure and irregular movements of the diaphragm. The loss of fine muscle control and co-ordination can make eating a tiring and frustrating experience.

### **Deterioration of the muscles involved in swallowing**

Choking frequently occurs during eating and drinking, and is attributed to the abnormalities present in several phases of ingestion.

a) The anticipatory phase: this includes the decision before the food enters the mouth. The person with HD can make an inappropriate food selection and is incapable of monitoring rapidity and quantity of food intake. Cognitive impairment rather than chorea is responsible here.

b) Mastication or chewing: choking occurs here because the person with HD often “squirrels” food whilst in the mouth until there is too much food to swallow safely.

c) The actual swallowing: sometimes there is a too rapid or immediate attempt to swallow which triggers coughing and choking.

### **Weight loss**

More calories are needed. Weight loss in Huntington's disease has been long observed and frequently attributed to the involuntary movements. The cause of the weight loss is still unclear and many theories have been put forward. One theory is 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 required.

Because this is a problem relating to each individual we recommend that a dietician be contacted who will work out an appropriate diet plan. Ask your own GP to refer you to the dietician in your area. Even with an increase in calorie intake, the problem of weight loss may not be solved. Many people with HD do not maintain their body weight and become emaciated, suffering the consequences of tissue breakdown and susceptibility to other illnesses.

### **Changes in mood**

As previously mentioned, the presence of anxiety or depression can affect the person's appetite. Anxiety and stress often trigger visible chorea and can therefore affect the swallowing process. The actual fear of choking, drooling or the embarrassment of making a mess while eating can actually increase the chance that it will happen. Many people with HD show great resistance to alterations to their life-style, which can make it very difficult to introduce the correct food into the diet.

The selection, preparation and arrangement of food are important in most cultures. Many of our memories of family life and friends are tied to eating food and drink. A pleasant family meal is an important part of that family's life, a chance to talk, show love and concern, play roles in the family, catch up on the news. Yet this important part of family life can become a frustrating, tearful, angry time when someone is unable or unwilling to select, prepare and eat food in the usual way. Someone who for years has shopped, cooked and enjoyed food may now feel lost and worthless because all or some of these things are difficult, tiring or even impossible.

Anything that can be done to make food selection, preparation and eating retain its place is worth consideration. The benefits are too important to lose.

The following information includes general principles and practical skills that should be carried out to make the whole feeding process less frustrating for the individual, family and other carers.

It should be remembered that nutrition is an important consideration in the health care of any person in subsequently preventing the development of a secondary illness.

## **1. Preparation for eating**

Before mealtimes be prepared to prevent distractions happening during the meal.

Assemble the appropriate feeding aids within easy reach of the dining area. Prepare food that is easily swallowed and of the correct consistency and texture. The consistency of a stiff mousse or porridge is often easiest to swallow.

Position the chair, that the person with HD will sit on whilst eating, away from the wall, out of the corner and near the outside of the table so that the person is readily accessible should choking occur.

To help prevent fatigue occurring during mealtimes it is advisable that the person with HD rests for half an hour to two hours before eating.

Passive limb exercises performed prior to meals can reduce tension caused by anxiety, which can often help to minimise the choreic movements.

## **2. Mealtime Aids**

There are many aids available that although fairly simple in context can make a mealtime the pleasant time it was always meant to be.

The Disabled Living Foundation has a substantial collection of aids to assist people with disabilities with all the activities of daily living. As there are many aids available to meet some of the needs of people with Huntington's disease, it would be impossible to mention them all in this fact sheet. The following information gives a summary of useful aids and some hints on how to use equipment that is already available in the average household.

Plastic cups, plates and bowls are light in weight, durable and easy to manage when there is poor control of movement.

Scoop bowls and plate guards can be used to stop food being pushed off the plate.

A preheated hot plate maintains the warmth of the main course throughout the meal, an important necessity as the person with HD requires more time to eat and this ensures that the meal remains warm and appetising.

Cutlery is easier to hold if the handles are large and “fat”. You can build up handles yourself, using rubber and taping in place. Some brands of bicycle handlebar grips fit ordinary household cutlery, the “fatter grip” can lessen choreic movements. Some people have improvised their cutlery quite satisfactorily using rubber hair rollers or the foam type.

A hand strap or grip can be added to cutlery. The strap, often of velcro, fits around the fingers and makes the utensil easier to grip and hold during eating.

A double-handed cup, preferably with a spout, is an important piece of equipment to aid drinking.

Ordinary cups and mugs can be made into a double-handed cup by using Gripkit. A two-part epoxy compound which, when mixed together, rather like plasticine can be moulded to any shape and stuck to any surface. When fully hardened it is very strong.

Fill any cup or mug only halfway to cut down on the chance of spills.

Flexible straws or straws with one-way valves assist drinking. Larger straws are available for thicker substances.

A bulldog clip can be put on the side of a glass or beaker and a flexible drinking straw passed through it to promote stability of the straw whilst drinking.

A non-slip mat will stop the plate, bowl or cup moving during eating. A damp flannel placed under the plate has proved equally useful.

Plastic tablecloths can be attractive, useful, and easy to keep clean. Also, warm plates will not slip on a plastic cloth.

Plastic aprons can also be useful. There are many available that are not expensive. Look out for those with pockets so that small items can be carried safely.

### **3. Positions for eating and drinking**

Never administer fluids, solids or medications while the person with HD is lying down or in a reclining position.

Maintain a secure, comfortable and upright position throughout the meal. The person should be

seated upright in a chair at a 90 degree angle, and then asked to lean slightly forward. The feet should be flat on the floor and the elbows can be put firmly onto a waist-high table using the arms and palms of the hand to steady the body. This position helps to reduce and stabilise the choreic movements.

Throughout the meal the head should be kept slightly down and forward. Throwing the head back whilst eating and drinking increases the risk of gagging or choking. If the head is unsteady, steady it by placing the palm of one hand to the person's forehead or behind the neck or back of the head.

If the person with HD has to remain in bed for mealtimes use a sitting position with the head of the bed elevated to a 45-90 degree angle, using pillows or a foam wedge placed under the mattress, and place at least three pillows horizontally behind the shoulder and neck.

The carer should be seated in front of the person they are feeding in his/her clear field of vision.

#### **4. Environment during meals**

Even the smoothest run household can be chaotic at mealtimes. Sometimes such a situation will make the person with Huntington's disease irritable, anxious and unwilling to eat. Perhaps a quiet meal before or after the rest of the family, with companionship available, will be the only answer. However, the following information about the environment during meals is worth keeping in mind when assisting with someone's diet.

Ensure the surroundings are as attractive and pleasant as possible. A little soft music from a radio or a favourite record can help the mood of the occasion, dining therefore being made as much a social as a nutritional event.

Avoid emotional situations which interrupt the swallowing process and cause difficulties controlling secretions. Coughing and choking are exacerbated by tension.

Maintain an unhurried environment free from too many comings and goings.

#### **5. Schedule for meals and breaks**

This feeding process should be at least half an hour to an hour in duration. Eating can be a tiring experience so allow as much time as necessary for mealtimes. Even if you have a thousand other things on your mind or things to do, make sure you look as if you "had all the time it takes" and that you do not regard the assistance as a chore to be done as quickly as possible.

It is always a good idea to plan for smaller and more frequent meals, particularly when meals seem to be lasting too long; for example, instead of having three large meals a day try four to six smaller ones supplemented by high calorie drinks. Schedule high calorie snacks and nutritional breaks between main meals. Serve smaller portions with refills so that the task of eating seems less daunting. Postpone eating if the person with HD is tired or upset. Restart at a more convenient moment.

## **6. The diet of the person with Huntington's disease**

Generally speaking, the diet of the person with Huntington's disease should contain foods that are easy to chew and digest, are nourishing, varied, easy to swallow without difficulty and provide for adequate vitamin, mineral and calorie intake. When the person is newly diagnosed he/she does not usually have too much of a problem eating and a normal everyday balanced diet with a slightly increased quantity is adequate. This is a good time to ask your GP to arrange a consultation with a dietician. Normal weight can be recorded and arrangements made for further periodical advice. As feeding difficulties present themselves, pay particular attention to the type of foods eaten. Foods particularly easy to swallow are soups, sauces and soft scrambled eggs. It is a good idea to add cream, butter or 'gold top' milk. For variety use ice cream and yoghurt. The thick and creamy yoghurt is the right consistency.

Food that is transformed into a poor consistency by incomplete oral movement such as white bread, or bacon which becomes stringy. Tomato and other skins are often difficult to remove from the hard palate with the tongue which lacks co-ordination.

Small, coarse and hard foods that may be inhaled accidentally such as peanuts, potato crisps, hard toast. Bread and butter put in the oven for a few minutes makes a good substitute for toast.

Avoid over-spiced and sharp food.

Take poultry and meat off the bone.

Avoid fish with bones (such as kippers, plaice) unless filleted completely.

Avoid shredded vegetables like coleslaw, carrots and lettuce.

Avoid mixing food textures, never give the person a mouthful of fluid to wash down the food. The two differing textures are confusing in the mouth and invariably the person gags and chokes.

Drinks often create the greatest problems. If drinking water causes choking, try using chilled water, or if this does help, avoid giving water. Drinks that are too thin in texture do present problems. Try adding an enriched cereal or rice cereal to thicken soups, drinks and sauces. Juice that is already thick, like tomato and pineapple juice are easier to swallow.

Liquids with bits in it like minestrone soup are particularly difficult to manage.

### **Foods to avoid –**

Coffee, tea and soft drinks given on their own without some modification should really be avoided. They are just too thin and non-nourishing to be worth it.

If, in particular, coffee or tea are avoided and there is a lot of objection, try making an ingredient in a shake or thicker drink or accompany them with a crumpet or roll for dunking. Many person with HD become obsessive towards tea-making and drinking, to take this activity away from them could be more detrimental than beneficial.

Carob added to drinks and soups act as a thickener and does not alter the flavour of the dish.

It has been found that tea made with tea leaves causes more problems than if made with tea bags. The small tea leaves that escape the strainer stick to the hard palate and can cause choking.

## **7. Eating the meal and tips on feeding someone**

As the disease progresses, it is probable that the person with HD will become unable to self-feed. This loss of a basic self-care skill can be very hurtful to the person and can result in all sorts of reactions to the need to be fed or to the need to eat at all. If you are sensitive to these feelings, much can be done to make the task easier and more pleasant for both the carer and the person eating.

Before starting the meal and in between courses, offer the person with HD a few sips of iced water which can often assist swallowing.

Both the carer and the person with HD should be comfortable and relaxed. Face the person you are feeding.

Throughout the meal, the person should be encouraged to eat slowly and chew the food well.



### **To make swallowing easier:**

encourage the person to breathe out before placing food into the mouth;

using a small spoon or fork, take a small amount of food and place it into the person's mouth;

ask the person to close his/her lips tightly together as soon as the cup or spoon has been taken away;

ask the person to breathe in and out through his/her nose; ask the person to chew the food, then pause;

ask the sufferer to stop breathing and swallow. You cannot breathe and swallow at the same time.

Stroking the larynx whilst the sufferer is swallowing encourages laryngeal elevation and therefore actually helps swallowing. Gently massaging the face and neck muscles at the upper jaw angle just below the ear before and during a meal can be helpful towards relaxing the person and assisting the swallowing process.

If the person feels that the food is sticking in his/her throat, ensure that the food is of the correct consistency and the texture is not too dry.

Encourage the person to cough and try to clear his/her throat between courses and at the end of a meal.

Do not introduce more food into the person's mouth until the previous mouthful has been swallowed.

Allow for frequent rests and pauses throughout the meal. Always watch for signs of fatigue or anxiety and re-commence feeding at a more appropriate time.

Encourage assistance from the person who is eating. Perhaps they could manage drinking from a straw by themselves or holding small pieces of finger food.

### **8. Activities after meals**

After meals the person with HD should sit up for fifteen to thirty minutes to aid digestion and avoid

aspiration.

Perform or encourage oral hygiene (cleaning of teeth etc.) after all meals and snacks to prevent aspiration of food particles that might be inside the person's mouth.

Be able at the end of each session to evaluate the amount of food consumed ensuring adequate nutritional intake.

## **9. Taking medications**

Tablets when in the form of capsules or enteric coated (sugar coated) are the easiest to swallow.

If pills are difficult to swallow crush them and place in custard or some other dessert which can be easily swallowed.

Most medications are more easily administered in a thick liquid form. Liaise with the pharmacist and seek his/her advice about such preparations.

## **10. Coping with constipation**

There are many causes of constipation so always check with your GP first. Some of the main causes are:-

Lack of exercise. The normal function of the gastrointestinal tract is impaired by immobility and hence constipation is often a problem.

Lack of fluid. A normal diet should have at least two to three litres or 6 to 8 glasses of fluid a day.

Lack of fibre in the diet. Increasing the daily intake of fruit, vegetables, wholemeal cereals, prunes and prune juice will help. If this is not satisfactory add natural bran to foods such as puddings, stews and soups. It is possible however to add too much fibre to the diet so check with your GP first. – Hot lemon water stimulates the bowel and can often relieve constipation.

Constipation has been found to be the source of some faecal incontinence and diarrhoea particularly when the person with HD has had a long history of constipation. Have a word with your GP if such a situation should arise.

## **11. Emergency measures for choking** Choking is a serious problem which can occur with

Huntington's disease. Many people with HD fear a choking attack and this can be an alarming experience. Should choking occur, a calm, reassuring person who acts appropriately in this situation is the best antidote.

**Choking can be caused by a number of factors:-**

A poor technique of feeding by the carer; the wrong type of food given such as the consistency and texture; the wrong environment, too much background noise leading to poor concentration; eating too quickly.

When feeding someone with Huntington's disease, one must have a knowledge of how to cope with someone who is choking. Never try to wash food down with fluids. This will only increase the person's distress.

The universal choking signs are that the sufferer is unable to speak or cough, and will clutch at his/her throat. Try the "*Heimlich Manoeuvre*".

The aim of the Heimlich Manoeuvre is to remove food or other objects from the airway of a person.

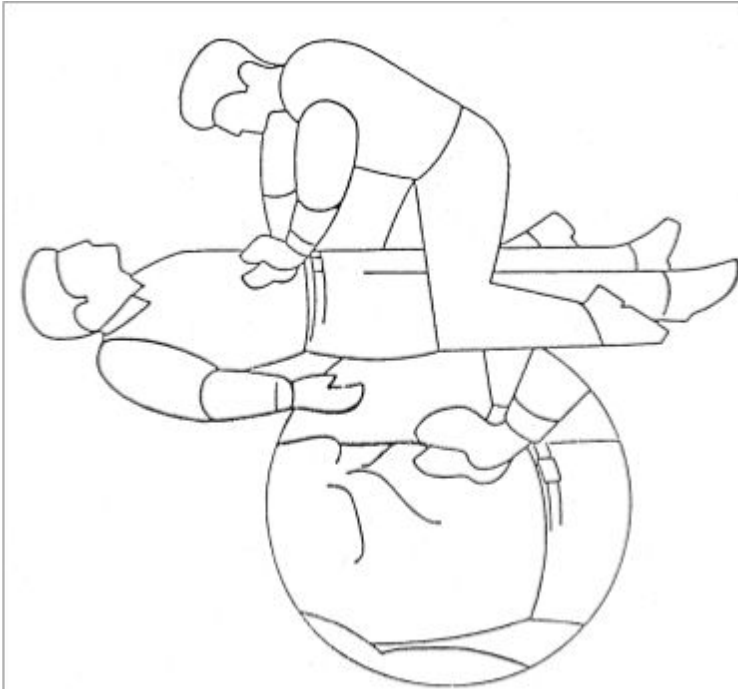
**(a) If the person is sitting or standing: Diagram 1**

- Stand behind the choking person and wrap your arms around his/her waist.
- Place the thumb side of your fist against the abdomen, and grasp your fist with the other hand.
- Press into the abdomen with an upward thrust by pulling quickly upward with your hands clasped.
- Repeat several times if necessary.



**(b) If the person is lying down: Diagram 2**

- Position the person face up.
- Position your hands with the heel of one hand between the navel and the ribs.
- Put your other hand on top.
- Press quickly inwards and upwards.
- Repeat as necessary
- If there is no response or you are very concerned, dial 999 for professional medical help



**(c) If the choking person is alone:**

He/she can achieve something of the same effect by contracting the abdomen sharply inwards against the back of the chair or against the wall.

After an attack of choking, the person should be sat up and tilted slightly forward and encouraged to breathe rhythmically and deeply until the attack passes.



## **Useful Addresses**

### **Disabled Living Foundation**

380/384 Harrow Road

London W9 2HU

Tel: 020 7289 6111

Helpline: 0845 130 9177 from 10am – 4pm, Monday to Friday Web: [www.dlf.org.uk](http://www.dlf.org.uk)

Other organisations who have substantial supplies of eating and drinking aids:

### **HNE Genetics**

1 Regent Road, City Liverpool L3 7BX Tel: 0151-236 5311

For specialised cutlery, plate guards etc. Mail order catalogue available.

### **Mothercare Ltd**

Cherry Tree Road

Watford

Herts WD24 6SH

Tel: 01923 241000

Web: [www.mothercare.com](http://www.mothercare.com)

For stay warm plates.

### **Nottingham Rehab Supplies**

Clinitron Health House Excelsior Road

Ashby Park Ashby-de-la-Zouch Leicestershire

LE65 1JG

Tel: 0845 121 8111 Web: [www.nrs-uk.co.uk](http://www.nrs-uk.co.uk)

For mug with two handles, Pat Saunders drinking straws (with non-return valve preventing liquid from returning down straw). Catalogue available containing a range of items for people with disabilities.

### **Boots The Chemist**

For a wide range of aids, including flexible straws.

*With grateful thanks to Estelle Klasner for writing this fact sheet.*

# Fact sheets available from the HDA

The HDA provide fact sheets about all aspects of Huntington's disease. All fact sheets can be downloaded free of charge from our website [www.hda.org.uk](http://www.hda.org.uk) or ordered from Head Office.

For a publication price list/order form, membership form, details of our Regional Care Advisers and local Branches and Groups, please call Head Office on 0151 331 5444 or email [info@hda.org.uk](mailto:info@hda.org.uk)

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