

Nutrition in Huntington's disease

As Huntington's disease progresses, it can be a constant challenge to ensure that you continue to eat well and take in enough calories to maintain your weight at an acceptable level.

Research has shown that people with Huntington's disease need a higher than average calorific intake and may have a lower than average weight. More movements and metabolic changes can cause significant weight loss and you might need to see a dietician. There may also be a time when you begin to consider alternative methods of feeding if you can no longer physically take in the required amount of calories or have difficulties with swallowing.

1. Nutritional intake

Due to cognitive and physical changes associated with Huntington's disease, it is important that you eat a healthy diet that reduces significant weight loss. A person with marked movements (chorea) will use up more energy so will require more calories. Appetite may change due to swallowing difficulties, apathy or low mood/depression. Some people can be fearful of spilling foods which can cause embarrassment.

What should I do?

If you have problems with your eating and drinking, discuss this with your HD Specialist. They can refer you to a Speech and Language Therapist for a swallow assessment and, in turn, can give you or your carer advice about any areas which may need to be changed. It could be that your diet requires to be modified e.g. food texture needs to change in order to suit your swallowing ability, which can become compromised as muscles weaken and do not work as well as they used to.

Coughing, choking, a 'gurgly' or wet sounding voice, food left in the mouth or recurrent chest infections are signs that there may be swallowing problems. Please discuss with your HD Specialist or GP.

In order to have more control of food in your mouth, you may consider having your food and drinks thickened so they are safer to swallow. This is done by adding a thickener prescribed by your Speech and Language Therapist or GP. If you do not want to see a Speech and Language Therapist, you may want to think about making small changes yourself such as eating foods which are softer, cutting it into smaller pieces, taking your time or always ensuring that you use gravies, sauces and other liquids to moisten/soften your food. Sitting in an upright position can help and reduce the risk of choking.

2. What foods are hard to swallow or should I avoid?

- Foods which have several elements e.g. grapes and apples which have skin, flesh and juice
- Very dry, crumbly foods e.g. dry biscuits/crackers which can break up and lodge in your throat
- Stringy foods e.g. lettuce and pineapple
- Very hard foods e.g. peanuts and sweets
- Grains e.g. rice and sweetcorn

It is often said that people with Huntington's disease should have around 5000 calories per day. This can be very difficult to achieve, especially if there is a fear of choking and/or if eating has become a burden. You should still try to eat as much as you can and make it as enjoyable as possible. Simple steps such as meal fortification can help. This means adding extra calories to your food e.g. honey, full fat milk, cream, butter and sugar. Eating smaller meals every couple of hours can be beneficial. Some people experience an insatiable hunger and are always looking for something to eat, while others have cravings. There is no harm in indulging in these cravings as long as a well-balanced diet is optimised, if possible. Changes in weight should always be discussed and monitored. A review of your

medications can sometimes identify the cause of a change in appetite and weight. You might not realise that you are hungry until food is placed in front of you.

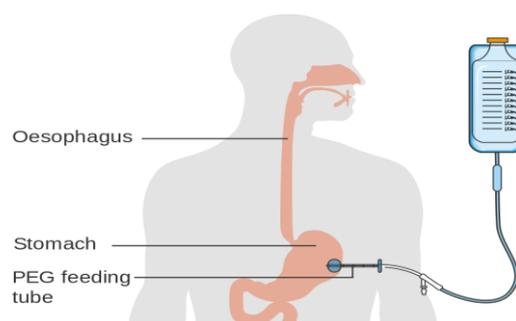
When eating your meal, always ensure that distractions are kept to a minimum as noise and ongoing activity can be overwhelming and cause you to lose concentration. For example, create a quiet atmosphere by switching off TV/radio, keep conversations simple, allow enough time to eat your meal and focus only on this task.

3. Will I have to have a feeding tube?

The simple answer is no. Only a small amount of people with Huntington's disease will have a feeding tube inserted as most can tolerate a modified (usually pureed) diet even in more advanced stages. Many people have an Advance Directive drawn up which outlines their wishes regarding tube feeding when they no longer have the capacity (ability) to make this decision.

If problems do arise and you begin to struggle with your swallow (dysphagia) or you can no longer achieve adequate nutrition, it may be time to consider tube feeding. This can be in the form of a Percutaneous Endoscopic Gastrostomy (PEG) and can be used as a sole means of nutritional support. Or it can be used as a half and half regimen, whereby, you can still eat, or have 'tasters', while having your nutritional intake topped up via liquid feeds passed directly into your stomach through the flexible tube. This is, however, a very personal choice.

Where is the PEG sited?



PEG insertion is a surgical procedure to place the gastrostomy tube directly into the stomach through a small incision in your abdomen. The process usually takes 20-30 minutes and involves a local anaesthetic.

Useful links

More about PEG feeding at www.tube-feeding.com

[Contact a Scottish Huntington's Association HD Specialist](#)

[National and Regional Care Frameworks for Huntington's disease](#)

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