

Huntington's disease - diet issues

Huntington's disease (HD) is a severely debilitating inherited condition in which selective brain cell death results in a progressive loss of cognitive (thought-related), physical and emotional function. Common complications include problems with eating and swallowing (dysphagia), particularly as the disease progresses. The loss of muscle control and coordination means that spilling food from the mouth and choking are possible. Other associated symptoms, such as dementia, may prevent the person from choosing appropriate foods or eating at a manageable speed.

Weight loss is often associated with HD, but it doesn't appear to be a direct result of diet. Some researchers think that weight loss may be linked to other biochemical changes in the body, caused by the disease. It is strongly recommended that a person with HD and their carers seek professional advice to make sure the diet is nutritious, calorie dense and easy to eat.

A range of eating and swallowing problems

A person with HD is more likely to choke. Some of the eating and swallowing problems they may experience include:

- Enormous increase in appetite
- The tendency to try and eat quickly to satisfy urgent hunger
- Loss of fine motor control in the face and neck that prevents efficient chewing and swallowing
- Inability to close the lips together properly, allowing food to spill out of the mouth
- Irregular diaphragm spasm, increasing the risk of inhaling rather than swallowing food
- Swallowing too soon, which is a choking hazard
- Fear of embarrassment, choking or making a mess – this can exacerbate muscular jerking (chorea), which in turn makes eating more difficult
- Other complications of the disease, such as changes to thinking ability – these may prompt the person to choose inappropriate foods or try to cram too much food in the mouth at one time.

Food serves many purposes

Food is more than just fuel for our bodies – it is a meaningful social and cultural event. It is important that the person with HD is able to select, prepare and eat their choice of food whenever possible. For example, if the person with HD can no longer peel vegetables, perhaps they can wash them.

Food suggestions

Always seek the advice of a dietitian who understands the challenges faced by those with HD. General suggestions on food choices include:

- Choose frequent small meals instead of three main meals spaced widely apart.
- Always have second serves.
- Choose soft, easy-to-chew and easy-to-swallow foods (aim for the consistency of porridge).
- Use plenty of sauces and gravies to help make main meals easier to manage.
- Add plenty of custards, icecream and cream to desserts.
- Avoid hard foods like nuts and lollies.
- Avoid foods that separate into 'strings' or sections while being chewed, such as bacon or tomatoes.

- Try to choose foods high in nutritional and calorific value. For example, have a protein-supplemented milkshake rather than a cup of black tea, and eat iced cake instead of water crackers.
- Avoid non-fat or low fat products – always choose full fat varieties.
- Drink fortified beverages, such as protein milkshakes or nutritional supplement drinks.

Before the meal

Distractions can seriously impair eating for the person with HD. Suggestions include:

- It may be helpful if the person with HD rests for one or two hours before mealtime.
- Create a calm and relaxed eating environment. Turn off the television and radio.
- Remember that anxiety makes chorea worse, so try to keep the mood light and cheerful.
- The person with HD should sit in an accessible spot at the table, just in case choking occurs and a carer has to quickly come to their aid.
- Put all eating aids within easy reach.

During the meal

Suggestions include:

- The person with HD should be sitting upright while eating, never in a reclining position.
- To reduce the risk of choking, the person with HD should angle their head down towards the plate.
- Use non-slip table mats.
- Use lightweight utensils, such as plastic knives and forks.
- Utensils with thick handles are easier to hold. Regular cutlery can be converted by slipping the handles into appropriate lengths of foam rubber tubing.
- You may like to consider strapping the utensils to the hands.
- Use eating aids, such as plate guards, to prevent food being spilled onto the table.
- A double-handled drinking cup with spout can make drinking more manageable. Alternatively, use a drinking straw secured into a plastic cup.
- A person with HD typically takes a long time to eat. It may help to reheat their meal at regular intervals.
- A plastic apron can protect clothes from food spillage.
- The person with HD should never try to drink while they have a mouthful of food – the contrasting texture can be confusing and prompt choking.
- The person with HD should never be rushed. Allow up to one hour per mealtime.
- The person with HD should remain sitting upright for about half an hour following a meal. Lying down too soon after eating increases the risk of reflux and possible choking.

Being fed by others

As the disease progresses, the person may be increasingly unable to manage at mealtime and may have to be fed by their carer. Suggestions for the carer include:

- Be sensitive to their feelings. The fact they can no longer feed themselves can cause a wide range of emotions including despair, embarrassment and stress.
- Sit opposite the person you are feeding.
- Make sure you appear to have all the time in the world – the person with HD may feel anxious and tense if you seem in a hurry.
- Suggest they breathe out before taking a forkful. Remind them to stop breathing when it comes time to swallow.
- A gentle massage of the face and throat may help the person to swallow.
- Help them to be as autonomous as possible during mealtimes. For example, they may be able to hold their own drinking cup if you guide it to their mouth.

Tube feeding

A person in the later stages of HD may be unable to chew and swallow safely or effectively, and tube feeding may be suggested as an option. Generally, the type of tube used for people with HD is a percutaneous endoscopic gastroscopy tube (PEG tube), hence the common reference to PEG feeding. Insertion of a PEG tube usually involves a day procedure in a hospital. PEG feeding may not solve all the problems faced at this stage and the decision to tube feed is an emotional one; therefore, it should be sensitively discussed beforehand with health care professionals.

Where to get help

- Your doctor
- An accredited practising dietitian, contact the Dietitians Association of Australia
- The Australian Huntington's Disease Association (Vic) Tel. (03) 9563 3922

Things to remember

- Common complications of Huntington's disease (HD) include problems with eating and swallowing (dysphagia), particularly as the disease progresses.
- Weight loss is often associated with HD.
- It is strongly recommended that a person with HD and their carers seek professional advice to make sure the diet is nutritious, calorie-dense and easy to eat.

This page has been produced in consultation with, and approved by:

Huntington's Victoria

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