

Swallowing problems

The brain damage caused by prion disease sometimes causes swallowing problems which are distressing for patient and carers alike. These problems may also lead to malnutrition. If eating and/or swallowing become difficult, it is important to ask your GP for a referral to a speech and language therapist for advice.

The process of swallowing

Swallowing gets food from the mouth through the throat (pharynx) and down the oesophagus into the stomach. The throat divides into two tubes at its base – the one at the front is the windpipe, leading to the lungs, and the one at the back is the oesophagus. It is vital that food doesn't get diverted into the windpipe, otherwise breathing may be obstructed. To stop this happening, there is a reflex which causes the windpipe to close while food passes down the oesophagus. Should any food accidentally enter the windpipe, coughing – another reflex – should remove it.

Swallowing is a three-stage process:

- In the oral preparation stage, the lips, tongue, cheeks and teeth work together, breaking food into a soft ball that can readily be swallowed. The tongue forms a cupped shape around liquids and holds them ready to swallow.
- During the pharyngeal stage, the tongue squeezes food or liquid to the back of the mouth, which triggers the swallow reflex, temporarily closing the windpipe. Muscles in the wall of the throat help food and liquid pass into the oesophagus by a set of wave-like movements called peristalsis. Once the food is safely past the opening of the windpipe, it re-opens.
- During the final – or oesophageal – phase, food and drink complete their journey down the oesophagus to the stomach, aided by further peristaltic waves.

Brain damage may affect any of these stages. For instance, muscle movement in the throat could become slow or lacking in co-ordination. The swallow or cough reflex may be affected or the

co-ordination of the three stages of swallowing may be lost. If someone can cough on request, it doesn't necessarily mean their cough reflex is in working order. Similarly, even if someone can't cough on request, it can't be assumed they don't have a protective cough reflex.

Symptoms Symptoms indicating a swallowing problem – known clinically as dysphagia – include:

- Being unaware of food when it arrives in the mouth and not doing anything with it (eg, failing to chew)
- Difficulty in chewing and/or moving food to the back of the mouth
- Spitting out lumps of food
- Eating too fast or putting too much in the mouth
- Refusal of food and/or liquids
- Talking with food or liquid in the mouth and forgetting to swallow
- Coughing/choking on food and/or liquids
- Food not going down or getting stuck in the throat
- A 'wet' or 'gurgly' voice after swallowing
- Difficulty in swallowing tablets
- Dribbling
- Chestiness or recurrent chest infection. If food enters the windpipe, it may cause infection.

Referral to a speech and language therapist is vital if a person with dementia caused by a prion disease develops any of these symptoms. A dietician, occupational therapist, physiotherapist or district nurse may also need to be involved. Here are some of the 'self-help' measures they may suggest to deal with swallowing difficulties.

Eating strategies

- Sitting upright with the chin down is a safer way to eat. If the head is back, the windpipe is more open which slows the swallow reflex.
- Small sips of liquid, perhaps from a teaspoon, are preferable to the use of feeder beakers which encourage the head to tip back.
- Small mouthfuls of food are best.
- Alternating food and drink will help clear the mouth of food.
- Encouraging the swallowing of food twice is helpful to clear the mouth.
- If the person has not swallowed what is in the mouth, presenting an empty teaspoon may encourage the important 'second swallow'.
- Frequent swallows will help prevent dribbling.
- You need to check the person's mouth after eating to make sure no food or liquid remains.
- You may need to sit with the person while they eat to help them with these strategies. This means that mealtimes may take much longer than before.

Dietary changes

Sometimes small and simple changes in diet can make a big difference.

- Avoid 'difficult' foods: mixed textures such as cornflakes in milk or minestrone soup; stringy textures like bacon, cabbage, and runner beans; floppy textures like lettuce; small, hard textures such as peanuts, peas, sweetcorn or broad beans.
- Cooking food for longer so it can be mashed is useful, or liquidising in a blender.
- Thickening agents can be used to give foods an easy-to-control yoghurt- or porridge-like consistency. However, take advice from the speech and language therapist over the use of these agents.
- Nutritional supplements may be necessary.
- Crushing tablets or using liquid medications may be useful. Seek your GP's advice.

Equipment such as specially-designed cups, cutlery, plates and mats may be useful. An occupational therapist can advise on these.

Where swallowing difficulties interfere with someone's ability to take in sufficient nourishment, you may need to consider parenteral (tube) feeding. This decision can only be made by consultation with the patient/family/carers, dietician, speech and language therapist, and doctor.

Contacts

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