Fact Sheet: Swallowing Problems

About the CJD Support Network

The CJD Support Network is the leading care and support charity for all forms of CJD. The CJD Support Network:

- Provides practical and emotional support to individuals, families and professionals concerned with all forms of CJD
- Provides emotional support to people who have been told that they are at a 'higher risk' of CJD through blood or surgical instruments
- Links families with similar experiences of all forms of CJD
- Offers financial support for families in need
- Provides accurate, unbiased and up-to-date information and advice about all forms of CJD
- Provides a national helpline on all forms of CJD
- Promotes research and the dissemination of research findings
- Promotes good quality care for people with all forms of CJD
- Encourages the development of a public policy response for all forms of CJD
- Provides support, education and training to professionals concerned with CJD

For more information about the activities of the CJD Support Network, contact:

Admin and general enquiries - admin@cjdsupport.co.uk or +44 (0)7494 211476
Support - support@cjdsupport.co.uk or 0800 774 7317
Website - www.cjdsupport.co.uk
Post - PO Box 3936, Chester, CH1 9NG

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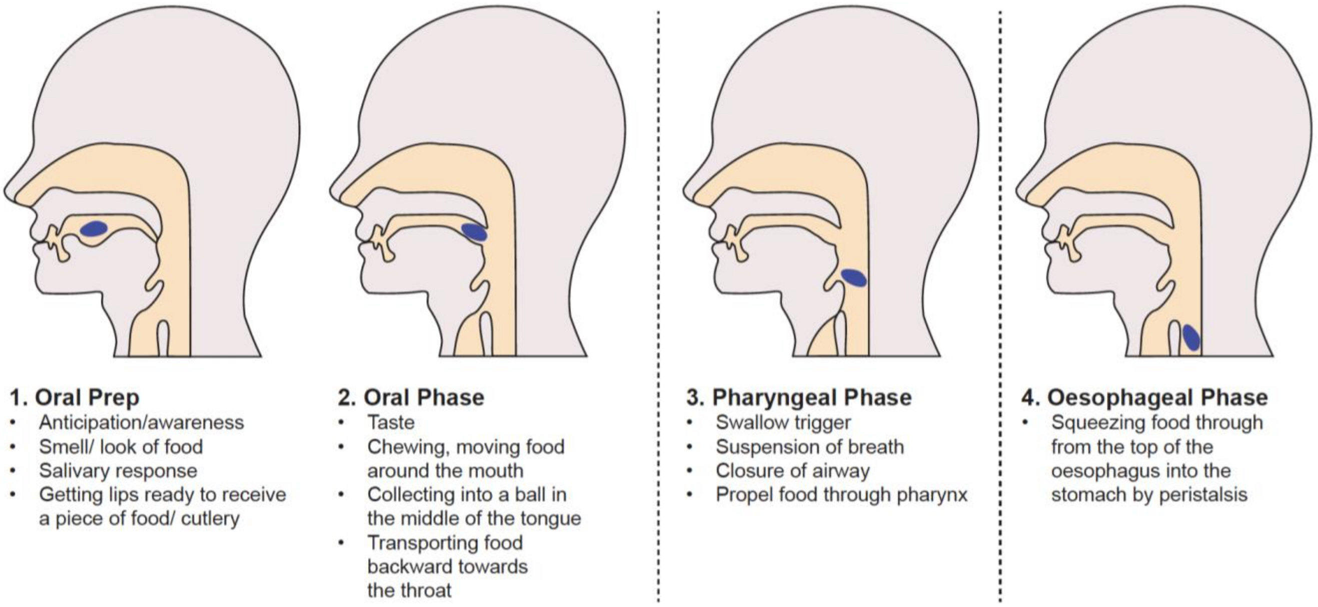
Swallowing problems

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 four-stage process (figure 1, below):



1. Oral Prep
- Anticipation/awareness
- Smell/ look of food
- Salivary response
- Getting lips ready to receive a piece of food/ cutlery

2. Oral Phase
- Taste
- Chewing, moving food around the mouth
- Collecting into a ball in the middle of the tongue
- Transporting food backward towards the throat

3. Pharyngeal Phase
- Swallow trigger
- Suspension of breath
- Closure of airway
- Propel food through pharynx

4. Oesophageal Phase
- Squeezing food through from the top of the oesophagus into the stomach by peristalsis

Figure 1 Stages of the normal swallow

- In the oral preparation and oral phase, 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 phase, 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.

The process of swallowing (continued)

Brain damage may affect any of these stages. For instance, muscle movement in the throat could become slow or lacking in coordination. 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.

Further information and contacts

Further information about CJD may be found on the CJD Support Network website at www.cjdsupport.co.uk our fact sheets are also available by post on request to the Network. Support and information may be obtained from the organisations below:

CJD Support Network	Address – PO Box 3936, Chester, CH1 9NG Website – www.cjdsupport.co.uk Phone – 0800 774 7317 Email – admin@cjdsupport.co.uk or support@cjdsupport.co.uk
National CJD Diagnostic Advisory Service	Based in Royal Infirmary of Edinburgh Website page with contact information - www.cjd.ed.ac.uk Email - loth.securecjd@nhs.scot
UK National CJD Nursing Service/National Care Fund	Address - Department of Clinical Neurosciences, Clinical Offices, 2nd Floor 50 Little France Crescent, Edinburgh Bio-Quarter, Edinburgh, EH16 4TJ Website – www.cjd.ed.ac.uk Phone - 0131 312 0193 / 0131 312 0192 Email - Terri Awe (primary contact) -terri.awe@nhs.scot, Juli Jose (additional contact) juli.jose@nhs.scot
National Prion Clinic	Address - National Prion Clinic, Institute of Prion Diseases, Courtauld Building, 33 Cleveland Street, London, W1W 7FF Website - www.ucl.ac.uk/national-prion-clinic Phone - 020 7679 5142 / 020 7679 5036 Email - uclh.prion.help@nhs.net