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Multiple Sclerosis Society

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MS Essentials

For people living with MS

Swallowing difficulties

Multiple sclerosis (MS) can cause swallowing difficulties – also known as 'dysphagia'. Between 30 and 40 per cent of people with MS experience difficulties with swallowing at some time[1], though for some people changes are so small that they are hardly aware of them.

Picking up these small changes to swallowing can help avoid possible complications. This booklet points out some of the signs to look out for and ways to manage them. Health care professionals including speech and language therapists can help diagnose problems and find the best treatments with you, but there are also techniques that you, your family or carers can learn to help with swallowing.

Just like any other symptom of MS, swallowing difficulties may come and go. For example, temporary changes in swallowing can happen during a relapse and improve, or disappear completely, over time.

For others, swallowing can become more difficult in the long term. But however long symptoms last, there are practical things that can help you manage the changes effectively and make swallowing as comfortable and easy as possible.

Contents

How do we swallow

When swallowing works perfectly, it is hard to imagine the many different processes involved with each swallow – many happen without any conscious thought. From the moment food or drink goes into the mouth to the time it reaches the stomach, the swallowing process involves dozens of muscles and many sensory messages to and from the brain.

After food enters the mouth, the tongue and teeth move it backwards, crushing, grinding and mixing the food with saliva. This creates a ball of food ready to be swallowed, called a **'bolus'**.

1 The first action of swallowing is one that we consciously control. The **tongue** pushes the bolus up and backwards, pushing it hard against the roof of the mouth, so that it squeezes backwards towards the **throat**.

From this point onwards, swallowing becomes an automatic action. Rather than being consciously controlled, swallowing is now a series of reflex actions, responding automatically to messages from the part of the brain connected to the spinal cord, known as the 'brainstem'.

There are two parts to this automatic swallowing process. The first is known as the 'pharyngeal' stage, named after the medical term for the throat, the 'pharynx':

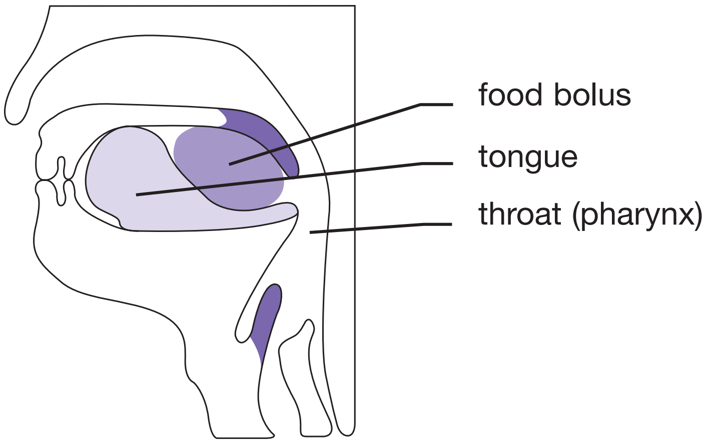
2a The **soft palate** is raised to block off the nasal passages that lead upwards to the nose. At the same time, the tongue pushes the bolus backwards, out of the mouth and into the throat.

2b As soon as the bolus enters the throat, the **epiglottis** and **voicebox** move to close the airway that leads down to the lungs. This is what stops food going down 'the wrong way'.

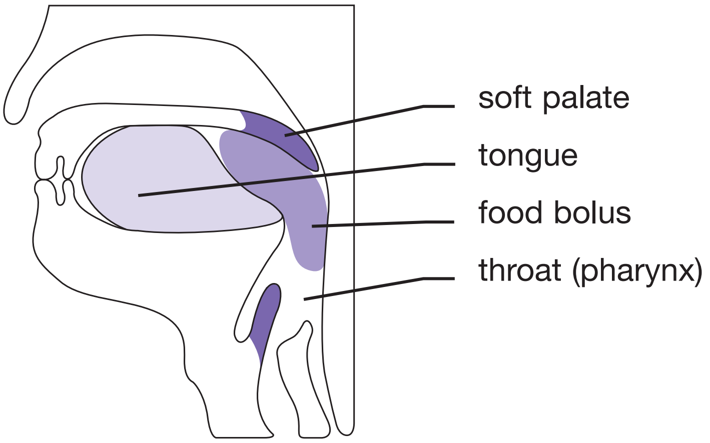
3 The second stage of this automatic swallowing action begins as the throat muscles squeeze together to push the bolus further down towards the stomach. The tube that connects the throat and the stomach is known as the **'oesophagus'**. A complex arrangement of muscles run all the way down the oesophagus. These contract and relax in turn to create a wave effect, known as 'peristalsis'. This wave transports the bolus to the stomach.

Once the bolus reaches the stomach, the entrance to the stomach opens to let the food pass through. It closes again once food has gone down, to prevent the contents of the stomach from escaping back up into the oesophagus. If this happens, it can cause the sharp pains often known as 'heartburn'.

1


food bolus
tongue
throat (pharynx)

2a


soft palate
tongue
food bolus
throat (pharynx)

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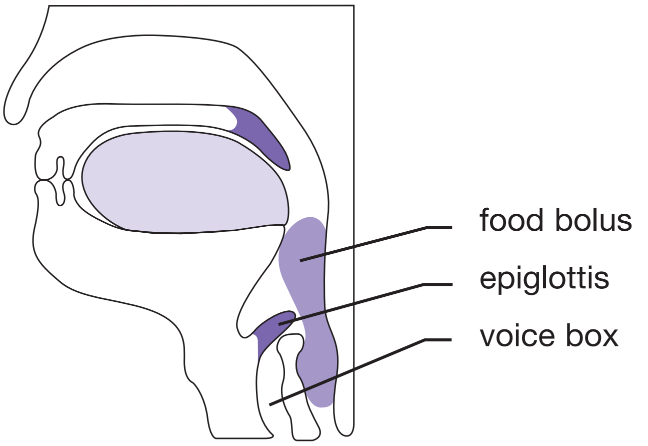
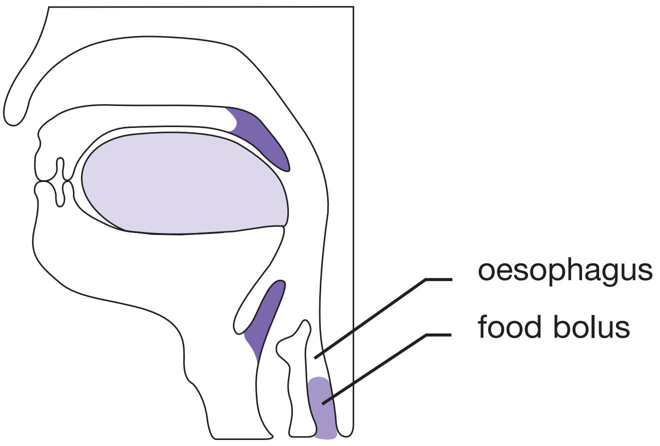

food bolus
epiglottis
voice box

3


oesophagus
food bolus

Swallowing difficulties

It is not uncommon to feel worried or anxious about swallowing difficulties. Swallowing is such an everyday part of living that any changes can be a shock. But if you do notice changes, that does not mean they will inevitably get worse, and with proper care, problems can be managed effectively and safely.

What problems can occur?

Ways to manage swallowing difficulties may be more effective if the problem is picked up early.[2] So, even if problems are not serious, let your doctor or MS nurse know if you are aware of one or more of these signs:

- Problems chewing
- Food sticking in the throat
- Food or drink coming back up
- Sluggish movement of food going down, or difficulty moving food back through the mouth
- Coughing and spluttering during and after eating
- Excessive saliva, which may cause dribbling

Monitoring and managing these signs could help you avoid more serious problems that might develop if left unchecked:

- 'Aspiration': when food or drink trickles down the windpipe into the lungs – when it 'goes down the wrong way'. This can be very subtle and you may not even be aware it is happening (this is known as 'silent aspiration'). However, aspiration can lead to chest infections.[1] If you get several chest infections, it is important that the causes are investigated fully, so that aspiration and swallowing difficulties are not overlooked.
- Malnutrition or dehydration: over time, the body might not get all the energy and nutrients it needs if difficulties are left unrecognised and unmanaged.[1]

What can cause swallowing difficulties?

The medical name for swallowing difficulties is 'dysphagia'. MS can cause dysphagia if there is damage to any part of the brain that controls swallowing, or damage to the connections between the brain and the spinal cord (the 'brainstem').[3] Messages in the brainstem control the movements of the body, so damage to this area can lead to a combination of symptoms affecting muscles, including the muscles used in swallowing.[1]

Because of the role the brainstem plays in swallowing and mobility, people with MS who are more physically impaired are more likely to experience swallowing difficulties, but they can happen at any time in MS.[1] For example, some people have swallowing difficulties during a relapse, which disappear as they recover.

Symptoms may vary through the day. Heat, fatigue and stress might all have an effect in making swallowing more difficult and could be influenced by other MS symptoms, such as fatigue or pain. But swallowing might also become more difficult because of other aspects of daily life, such as stress and anxiety, or rushed mealtimes. Finding the causes of difficulties and factors which make problems worse can help find the best ways to manage your difficulties.

Recognising swallowing difficulties

Recognising the problem early on can help with finding effective ways to manage swallowing difficulties and help avoid possible complications.[4] You might be aware of problems yourself, or it may be friends and family who notice the first changes. It could be your doctor or MS nurse. Some of the signs will be obvious, others may be more subtle – and you may have developed ways of coping with minor changes almost without realising.

Diagnosing the problem

Your doctor or MS nurse may refer you to a speech and language therapist to help diagnose the problem. As well as asking questions, a speech and language therapist may watch you eating and drinking, to discover the exact difficulties you are having. Through this, they might notice issues in the early stage of swallowing – in the mouth – or later, as food or drink goes down the throat.

If it is difficult to tell what is happening with your swallowing, they might also suggest a referral to a radiologist for a ‘video-fluroscopy’. This is a moving x-ray of the swallowing process. By watching how food passes through the mouth and down to the stomach, problems happening inside the body can be seen.

Managing swallowing problems needs to be tailored to your own needs and situation, which might change over time. MS is an unpredictable condition, so a speech and language therapist may need to reassess your needs several times, to see if your situation has changed, and if techniques are still effective. If you feel your needs have changed, ask for a new assessment. If you do not have the details of your speech and language therapist, your GP or MS nurse can refer you.

Managing swallowing difficulties

Once the type of difficulty has been identified, the speech and language therapist or dietitian can work with you to find the best ways to manage it. This will be an individual thing and it is important that you can find techniques that work for you. For example, there may be certain causes, such as fatigue or stress, that act as ‘triggers’ to make swallowing more difficult. Controlling these triggers could help to reduce the difficulties you experience.

Different techniques help with different problems, which is why it is important to have the advice of a health professional to help find what suits you. They may suggest some of the following techniques for you, your family or carers:

- Keeping a good, upright posture when eating and remaining upright for at least 30 minutes after the meal. A physiotherapist can help with posture. There may be other changes to posture or movement techniques suggested by a speech and language therapist, tailored to your own needs.
- Eating in a relaxed atmosphere. Swallowing can sometimes be easier if you are relaxed. Being relaxed might help you concentrate on your swallowing, or help the muscles involved to work to the best of their ability. Some find it best to eat in a quiet atmosphere, without radio, TV or conversation for distraction.
- Not rushing a meal. If the swallowing process is not in perfect working order, allowing it the time to deal with each swallow in turn can be helpful.
- Chewing well. This helps make the bolus of food a good consistency for swallowing, mixing it well with the saliva.
- Alternate liquid with solid. For some people, swallowing problems mean that food gets stuck, or travels only very slowly towards the stomach. Drinking between mouthfuls can help to keep the food moist and wash it down.
- Avoid speaking whilst eating. The two different processes can interfere with each other and could increase the chance of choking.

- Adapt the food you choose so it suits you better – but remember to keep it appetising. Some people find that very thin liquids are more likely to go down the wrong way, so use thickeners to make them easier to swallow. You might benefit from eating softened foods, or from moistening dry foods with gravy or custard. Speech and language therapists can suggest appropriate changes to your food and drink, to get the right consistency for you. If you do need to adapt the foods you eat, it is important to still have things you like. See page 10 for easy-to-swallow recipe books.
- To ensure you are getting the nutrition you need, a dietitian can help you plan what you eat. For example, small, more frequent meals and milky drinks might help you get enough calories if you find it uncomfortable to eat larger meals. Nutritional supplements are helpful for some people. For more information on nutrition and getting a balanced diet, see the MS Society publication Diet and nutrition.

Managing anxiety

Any new symptom can cause worry and take some adjusting to, and this may be particularly true when an everyday activity like swallowing is affected.

Left untreated, anxiety about swallowing can become a vicious circle – swallowing problems and anxiety can each make the other worse. But there are ways to manage and treat both issues and break the cycle. The next chapter of this booklet looks at ways to manage swallowing difficulties. If you experience ongoing anxiety, support is available from a number of health care professionals and your GP or MS nurse can make suitable referrals. The MS Society free publication Mood, depression and emotions has further information on managing anxiety – see page 9 of this booklet for details of how to order a free copy.

A particular cause of anxiety for some people is the thought of choking whilst eating or drinking. With proper care and a good awareness of the issue, choking can be avoided. Simple techniques such as those mentioned above can help prevent it. As a precaution, people involved in the care of someone with swallowing difficulties can be trained in first aid techniques to prevent choking. St John Ambulance can arrange this training. Your nearest contact will be listed in the local phone book.

Dental hygiene

Dental problems can make it harder to chew or swallow, so it is important to have regular check ups with your dentist. If you have an ongoing problem with a dry mouth, this can affect the health of your teeth and gums. Some drug treatments can cause a dry mouth, so making adjustments to medication may improve things. Your dentist may recommend a mouthwash or fluoride gel to help avoid problems and can give advice on the easiest ways to brush effectively.

Managing more severe swallowing difficulties

Sometimes, swallowing or chewing is so difficult that a person experiences weight loss or dehydration. If softening food, thickening drinks and eating smaller meals fail to stop these problems, the use of a direct liquid feed may be appropriate. In the short term (usually no longer than three or four weeks), some people can benefit from 'nasogastric tube feeding'. Liquid food passes through a very thin tube through the nose and into the stomach, avoiding the need for chewing or swallowing.

If severe swallowing difficulties persist, a PEG ('percutaneous endoscopic gastrostomy') system is more common. This allows nourishing liquid food to go directly through a tube into the stomach and can be a relief to those who have severe chewing or swallowing difficulties. People can sometimes continue to eat a little by mouth, so they don't lose the chance to enjoy their favourite foods. The PEG tube is usually fitted under local anaesthetic and the process is fully reversible if no longer needed. Even so, it can still be a major change for a person with MS and their carers. Some adjustments to a person's lifestyle are inevitable and carers will need to learn to care for the PEG tube. District nurses and community dietitians can help when considering PEG feeding, or if issues arise once a PEG system is fitted. Most manufacturers of PEG systems also have 24-hour helplines and employ specialist nurses to help PEG users and their carers.

Further information

MS Society publications

The MS Society has publications on a wide variety of topics, including information for people just diagnosed, types of MS, managing relapses, and social services. For a publications list and order form visit the website www.mssociety.org.uk or call 020 8438 0799 (Monday to Friday, 10am-3pm).

MS Society website and magazine

Keep up to date with news relating to MS with the MS Society website www.mssociety.org.uk and members' magazine, *MS Matters*. Details about *MS Matters* are on the web and in the Society's publications list.

MS Helpline

The award winning MS Helpline offers confidential emotional support and information to anyone affected by MS, including family, friends, carers, newly diagnosed or those who have lived with the condition for many years. Information about MS is available in over 150 different languages by speaking to a Helpline worker via an interpreter. Call freephone **0808 800 8000** Monday to Friday, 9am-9pm, except bank holidays, or email **helpline@mssociety.org.uk**.

MS Society National Centre, Information Centre

Based at the MS National Centre in London, the Information Centre is equipped for visitors to read or locate books and journals or view videos and DVDs. The Information Centre also runs an information line: 020 8438 0799, Monday to Friday, 10am-3pm, which you can call to request publications, research articles or other information about MS.

Local information centres

There are MS Society local information and support centres in many locations around the country. These centres are staffed by volunteers who can help you with information about MS and services in your area. Call 020 8438 0799 for the details of your nearest centre.

Local branches

The MS Society has a network of some 340 local branches across the UK. The branches – run by trained volunteers – provide information about MS and local services, a chance to meet others affected by MS and take part in a range of activities. For more information check the MS Society website or call 020 8438 0759.

Further reading and useful websites

www.easytoswallow.co.uk

This website contains recipes for soups, main courses and desserts that people find easier to swallow.

I-Can't-Chew-Cookbook. Delicious soft-food recipes for people with chewing, swallowing and dry-mouth disorders, by J Randy Wilson. Published by Hunter House Publishers (2003), ISBN: 0897934008. This American book contains recipes for a wide variety of meals and includes nutritional information for each one. As this is an American book, the measurements for recipes may differ from UK scales.

Recipe Collection: Easy-to-Swallow Meals. Produced and published by the Motor Neurone Disease Association (Revised 1996). Contains a range of meals to suit people with swallowing difficulties. This book is available free of charge by calling 08457 62 62 62 or writing to: MND Association, PO Box 246, Northampton NN1 2PR.

Useful organisations

Disabled Living Foundation (DLF)

Provides information and advice on equipment to enhance independence.

380-384 Harrow Road
London W9 2HU
Helpline 0845 130 9177 (Monday to Friday, 10am-4pm)
Textphone 020 7432 8009
www.dlf.org.uk

PINNT – Patients on Intravenous and Nasogastric Nutrition Therapy

A charity providing information and support for anyone using PEG or other feeding sytems.

PO Box 3126
Christchurch
Dorset BH23 2XS
www.pinnt.co.uk

References

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3 Logemann, J. A. (2000) Dysphagia. *In:* J. S. Burks and K. P. Johnson (eds.) *Multiple sclerosis: diagnosis, medical management and rehabilitation*. New York, Demos Medical Publishing. p.485-90.

4 National Institute for Health and Clinical Excellence (2003) *NICE clinical guideline 8. Multiple sclerosis: management of multiple sclerosis in primary and secondary care*. London, NICE.

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Disclaimer: We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. The law and government regulations may change. Be sure to seek local advice from the sources listed.

Suggestions for improvement in future editions are welcomed. Please send them to infoteam@mssociety.org.uk.

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Multiple Sclerosis Society

Multiple sclerosis (MS) is the most common disabling neurological condition affecting young adults and we estimate that around 85,000 people in the UK have MS. MS is the result of damage to myelin – the protective sheath surrounding nerve fibres of the central nervous system. This damage interferes with messages between the brain and other parts of the body.

For some people MS is characterised by periods of relapse and remission while, for others, it has a progressive pattern. For everyone, it makes life unpredictable.

The MS Society is the UK's largest charity dedicated to supporting everyone whose life is touched by MS. It provides respite care, a freephone MS helpline, grants for home adaptations and mobility aids, education and training, MS specialist nurses and a wide range of information. Local branches cater for people of all ages and interests and are run by people with direct experience of MS.

The MS Society also funds over 50 vital MS research projects in the UK.

Membership is open to people with MS, their families, carers, friends and supporters. You can help the work of the MS Society by:

- becoming a member
- making a donation
- offering your time as a volunteer

Contact information

MS National Centre
372 Edgware Road
London NW2 6ND
Telephone 020 8438 0700

MS Society Scotland
National Office
Ratho Park
88 Glasgow Road
Ratho Station
Newbridge EH28 8PP
Telephone 0131 335 4050

MS Society Northern Ireland
The Resource Centre
34 Annadale Avenue
Belfast BT7 3JJ
Telephone 028 9080 2802

MS Society Cymru Wales
Temple Court
Cathedral Road
Cardiff CF11 9HA
Telephone 029 2078 6676

National MS Helpline
Freephone 0808 800 8000
(Monday to Friday, 9am-9pm)

www.mssociety.org.uk

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