



Swallowing difficulties

We're the MS Society. Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to stop MS.

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About this booklet

At least a third of people with multiple sclerosis (MS) probably experience some changes in their swallowing at some time. Health care professionals might call swallowing difficulties 'dysphagia'.

Changes might be so small that they're hard to notice. But even picking these up can help avoid possible complications.

For some people, these changes come and go, or happen during a relapse and never reappear. But for others, they can be an ongoing issue. Any changes to swallowing can feel strange and worrying, even if they're small changes. But however your swallowing is affected, there are things you can do to make swallowing as easy, comfortable and safe as possible.

This booklet points out some of the signs to look out for and ways to manage them. Health care professionals can help, but there are also techniques that you, your family or your carers can learn to help with swallowing.

We sometimes refer to other organisations that can offer help with different issues. You can find their details in 'Useful organisations'.

How do we swallow?

When swallowing works perfectly, it's hard to imagine how complicated it really is. Most of it happens without us having to think about it. But it's actually quite a complicated sequence of events. There are several stages to swallowing. They all have to happen in the right order, at the right time.

Swallowing involves dozens of muscles and many sensory messages that go to and from the brain.

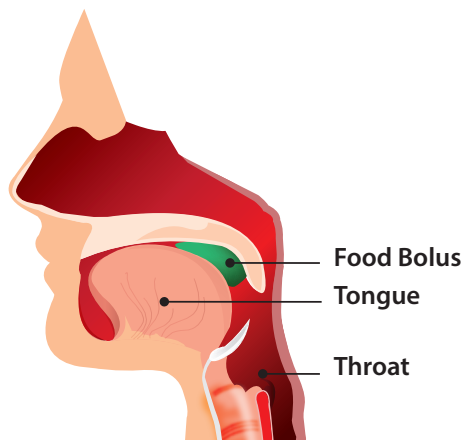
Strictly speaking, putting food into our mouths and chewing it is not part of swallowing. But even this is a complicated process of holding the food in our mouths, pushing it backwards and preparing the food to swallow.

This all needs the coordination of the tongue, lips and teeth.

When the food is chewed and ready to be swallowed, it's known as a 'bolus' (a ball).

Stage 1

We decide to start swallowing by pushing the bolus up and backwards with our tongue – towards the throat.

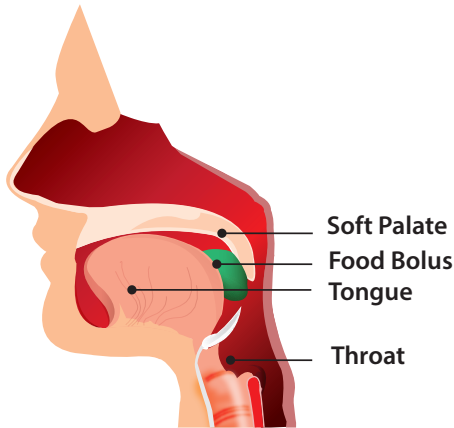


From this point on, we don't consciously control our swallowing. It's now a series of reflex actions which respond automatically to messages from the 'brainstem'. The brainstem is the part of the brain connected to the spinal cord.

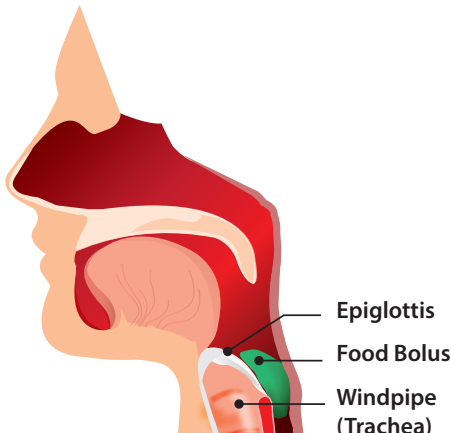
Stage 2

First, the soft palate at the back of the mouth lifts up. This blocks off the passages going upwards to the nose. Now the bolus has only one way to go – down the throat. At the same time, the tongue pushes the bolus backwards and out of the mouth.

How do we swallow?

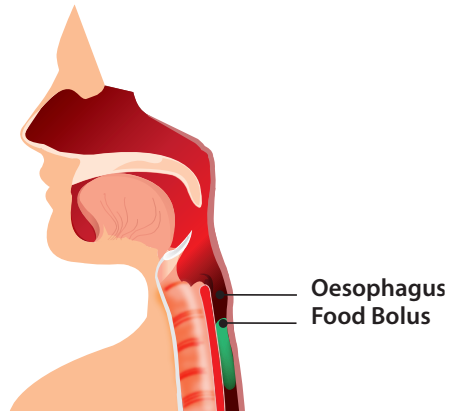


As soon as the bolus goes into the throat, the **epiglottis** and the **voice box** move to close the airway (your ‘windpipe’) that leads down to the lungs. This is what stops food going down ‘the wrong way’. Now the throat muscles squeeze together, pushing the bolus further down, into the **oesophagus** – the pipe that leads to the stomach.



Stage 3

Now the bolus is in the oesophagus, it’s carried along on a wave of muscles, contracting and relaxing in turn – a process known as ‘peristalsis’. The bolus rides this wave all the way to the stomach, where the entrance opens to let the food in and closes behind to stop things escaping back into the oesophagus.



‘Heartburn’

The sharp pains known as ‘heartburn’ are caused by the entrance to the stomach not closing properly and letting the contents of the stomach escape back up into the oesophagus.

Swallowing difficulties

It's 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 doesn't mean they will inevitably get worse. And with proper care, problems can be managed effectively and safely.

I noticed I had a dry mouth and needed to over-chew each mouthful. **Yasmin**

Every so often – not when I'm eating – I notice that saliva's starting to go to the back of my mouth and I need to swallow quite quickly before it goes down the wrong way. It's as though I'd forgotten to swallow. **Sally**

Recognising swallowing difficulties

Recognising swallowing difficulties early on can help you find effective ways to manage them and help you avoid possible complications.

You might be aware of problems yourself, or it might be friends and family who notice the changes. It could be your doctor or MS nurse. Some of the signs will be obvious, others could be more subtle – and you might have developed ways of coping with minor changes almost without realising.

Even if problems are not serious, let your doctor or MS nurse know if you notice:

- changes in your speech (can go hand in hand with small changes in swallowing)
- problems chewing
- food sticking in your throat
- food or drink coming back up
- sluggish movement of food going down, or difficulty moving food back through your mouth

Swallowing difficulties

- you take longer to finish meals than usual
- coughing and spluttering during and after eating
- excessive saliva, which might cause dribbling

Keeping an eye on these signs could help you avoid more serious problems that might develop if left unchecked, such as:

‘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 might not

even be aware it’s happening as it doesn’t trigger a cough (‘silent aspiration’). A cough is the body’s way of protecting the lungs by stopping ‘things going down the wrong way’. But aspiration can lead to chest infections. If you get several chest infections, it’s 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.

Notes:

What's causing swallowing difficulties?

MS can cause swallowing difficulties if there's damage to any part of the brain that controls swallowing – or if there's damage to the connections between the brain and the spinal cord (in the 'brainstem').

Messages in the brainstem control the way the body moves, so damage to this area can affect many different muscles. This can include the muscles used for swallowing. People who are more physically affected by their MS are more likely to experience swallowing difficulties. But changes can also happen during a relapse, with the symptoms disappearing as the relapse passes.

Living with MS

You might find that how you swallow changes through the day. Heat, fatigue and stress might all make swallowing more difficult. This might be influenced by MS symptoms, but it could also be because of other aspects of daily life – worries and anxiety, or rushed mealtimes. Managing

these stresses and symptoms could help you find the best ways to manage swallowing difficulties.

Diagnosing the problem

Because swallowing is a complicated process, with different stages, it can help to find out exactly which part is not working properly.

To find out more, your doctor or MS nurse might refer you to a speech and language therapist. After investigating, a speech and language therapist can recommend ways to manage the problem.

A therapist will ask questions about your swallowing and speech. They may also watch you eating and drinking, to discover the exact difficulties you're having. This helps them to notice any issues in the mouth or throat.

If it's still hard to tell what is happening with your swallowing, they might suggest you have a 'video-fluoroscopy'. This is a moving x-ray of the swallowing process. Therapists watch how food goes backwards through the

What's causing swallowing difficulties?

the mouth and see if anything goes the wrong way (towards the lungs).

Another approach could be to use a tiny, flexible video camera to look at the back of the mouth, the throat and oesophagus while you swallow. This is called a 'fibre-optic endoscopy'.

If things change

Because your swallowing could change, you might need to go back to a speech and language therapist at different times.

They can check if things have changed, and if techniques to manage the problem are still effective. If you think your needs have changed, ask for a new assessment. If you don't have the details of your speech and language therapist, your GP or MS nurse can refer you.

Dental hygiene

Dental problems can make it harder to chew or swallow. It's important to keep your mouth as clean and healthy as possible, and 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 could improve things. Your dentist might recommend mouthwash or fluoride gel, for example, to help avoid problems. They can also give advice on the easiest ways to brush effectively. Alternatively, if you tend to drool or dribble saliva excessively, find out from your speech and language therapist, MS nurse or GP about medication which can help reduce this.

For more about dental health, and finding a dentist, see the MS Society factsheet '**Oral health**'.

Managing swallowing difficulties

Once the problem has been diagnosed, you and the speech and language therapist can work together to find the best ways to manage it. A dietitian might also be involved.

It's important that the techniques work for you. They need to suit who you are and what you do.

It's important to have the advice of a health professional, because different techniques can help with different problems. They might suggest some of the following techniques for you, your family or carers:

Posture

Keep a good, upright posture when eating and drinking, and stay upright for at least 30 minutes after the meal. A physiotherapist can help with posture. A speech and language therapist might suggest other changes to posture or movement.

Relaxed atmosphere

Eat in a relaxed atmosphere. Swallowing can sometimes be easier if you're relaxed.

Being relaxed might help you concentrate on your swallowing, or help the muscles involved to work to the best of their ability. Some people find it best to eat in a quiet atmosphere, without radio, TV or conversation for distraction.

If I've put too much into my mouth, best thing is to relax and take some out! I need to concentrate on what I'm doing, not rely on it all working automatically. **Sam**

Eat slowly

Don't rush a meal. If the swallowing process isn't in perfect working order, allowing it the time to deal with each swallow in turn can be helpful.

Chew well

Chewing well helps get the food ready 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

Managing swallowing difficulties

towards the stomach. Drinking between mouthfuls can help to keep the food moist and wash it down.

I have to chew only small amounts at a time, and have a drink near me just in case

Shirlee

Avoid speaking while eating

The two different processes can interfere with each other and could increase the chance of coughing or choking.

Other symptoms

Swallowing difficulties might be affected by other symptoms, such as fatigue or muscle stiffness. Finding ways to manage these might help with swallowing too. For example, if you often get fatigued in the evening, would it be practical to have your main meal at midday instead?

Choose the food carefully

There are ways of adapting the food you like to suit you better. If very thin liquids are likely to go down the wrong way, thickeners could make them easier to

swallow. A speech and language therapist will explain and advise on thickeners you can get on prescription. You might try eating softened foods, or moistening dry foods, perhaps with a sauce. Speech and language therapists can suggest ways to get the right consistency for you. Easy-to-swallow food can still be appetising – see ‘**Further information**’

Get nutritional advice

To make sure you’re getting the nutrition you need, a dietitian can help you plan what you eat. For example, if you find it uncomfortable to eat larger meals, then smaller, more frequent meals and milky drinks might help you get enough calories. Nutritional supplements are helpful for some people. For more about diet and MS, see the MS Society booklet ‘**Diet and nutrition**’.

Don’t forget dental hygiene

Whether or not you eat food by mouth, it’s important not to forget dental hygiene – for comfort as well as to avoid infection.

If you feel anxious

Any new symptom can cause worry and take some adjusting to, and this can 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 circle.

If you keep feeling worried, you can get support from various health care professionals. Your GP or MS nurse can make a referral to them for you. If you have concerns about your swallowing, contact your local Speech and Language Therapy department (through your GP or MS Nurse) and ask for a swallowing assessment.

The MS Society booklet '**MS and your emotions**' has more information about managing anxiety.

Worried about choking

A particular cause of anxiety for some people is the thought of choking while eating or drinking.

With proper care and a good awareness of the issue, choking can be avoided. Simple techniques such as those mentioned earlier in this booklet 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 and the Red Cross, for example, can arrange this training.

When I was having a bad relapse, any changes in chewing and swallowing felt strange and alarming. **Yasmin**

It was very scary and I would continue to cough for some time afterwards. But we would make a joke out of it. I'm thankful that any time it happened it was not too embarrassing. **Shirlee**

Managing more severe swallowing difficulties

If swallowing or chewing becomes very difficult, weight loss or dehydration could become an issue. Softening food, thickening drinks and eating smaller meals might be practical ways to stop these problems. But if that doesn't work, using a direct liquid feed might help.

In the short term (usually no longer than three or four weeks), some people benefit from 'nasogastric tube feeding'. Liquid food passes through a very thin tube through the nose and into the stomach. This avoids the need for chewing or swallowing.

If severe swallowing difficulties persist, a PEG ('percutaneous endoscopic gastrostomy') might be more appropriate. 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.

If you have a PEG fitted, you can still sometimes continue to eat a little by mouth, so you don't lose the chance to enjoy your favourite

foods. The tube itself can be tucked under clothes when it's not being used.

The PEG tube is usually fitted under local anaesthetic in hospital and the process is fully reversible if it's no longer needed. Even so, it can still be a major change for you and your carers. Some adjustments to your lifestyle are inevitable and carers will need to learn to care for the PEG tube.

District nurses and community dietitians can help when you are considering PEG feeding, or if issues arise once a PEG system is fitted. They will tell you about possible complications as well as how it can help you. Most manufacturers of PEG systems also have 24-hour helplines and employ specialist nurses to help PEG users and their carers.

The charity **PINNT** has more information in their factsheet on PEG feeding.

Useful organisations

British Red Cross

Find a local first aid training course.

☎ 0344 871 11 11

💻 www.redcross.org.uk

Disabled Living Foundation (DLF)

Provides information and advice on equipment to enhance independence.

34 Chatfield Road, Wandsworth, London, SW11 3SE

☎ Helpline 0300 999 0004
(Monday to Friday, 10am-4pm)

✉ helpline@dlf.org.uk

💻 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 systems.

PO Box 3126

Christchurch

Dorset BH23 2XS

💻 www.pinnt.com

Royal College of Speech and Language Therapists

Their website includes an online directory of speech and language therapists.

☎ 020 7378 3012

💻 www.rcslt.org

St John Ambulance

Find a local first aid training course.

☎ 08700 10 49 50

💻 www.sja.org.uk

Further information

These books are available to borrow from the MS Society library.
Call 020 8438 0900 or email librarian@mssociety.org.uk

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 (2004), 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 0808 802 6262 or writing to:

MND Association

PO Box 246

Northampton NN1 2PR

Notes:

Further information from the MS Society

Library

For more information, research articles and DVDs about MS, contact our librarian.

☎ 020 8438 0900

✉ librarian@mssociety.org.uk

💻 www.mssociety.org.uk/library

Resources

Our award winning information resources cover every aspect of living with MS.

☎ 020 8438 0999

✉ shop@mssociety.org.uk

💻 www.mssociety.org.uk/publications

Helpline

The Freephone MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers.

Information is available in over 150 languages through an interpreter service.

☎ 0808 800 8000
(weekdays 9am-9pm)

✉ helpline@mssociety.org.uk

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If you have any comments on this information, please send them to resources@mssociety.org.uk or you can complete our short online survey at www.surveymonkey.com/s/MSresources

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.

References

A list of references is available on request, and all cited articles are available to borrow from the MS Society library (there may be a small charge). Contact the librarian on 020 8438 0900, or visit www.mssociety.org.uk/library

This resource is also available in large print. Call 020 8438 0999 or email shop@mssociety.org.uk

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