Welcome to this Choices leaflet about speech and swallowing…

MS-UK believes we must listen to the voices of people affected by multiple sclerosis (MS) to shape the information and support we provide. It is these people that bring us perspectives that no one else can give.

For every Choices leaflet we produce, MS-UK consults the wider MS community to gather feedback and uses this to inform our content. All of our Choices leaflets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

This Choices leaflet has been designed with you in mind. We hope it will answer some of your questions and also provide some first-hand experience from those who have been in your position - people who can truly understand and empathise with your current thoughts and feelings.

Every time you find bold text with quotation marks like this, it is a quote directly from someone affected by multiple sclerosis.
### Contents

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Why does MS cause speech problems?</td>
<td>4</td>
</tr>
<tr>
<td>Why does MS cause swallowing difficulties?</td>
<td>8</td>
</tr>
<tr>
<td>Sources</td>
<td>13</td>
</tr>
<tr>
<td>About MS-UK</td>
<td>14</td>
</tr>
</tbody>
</table>
Why does MS cause speech problems?

Problems with speech are a common symptom of multiple sclerosis (MS). Difficulties can result when lesions occur in the area of the brain that facilitates speech. In addition, fatigue can affect the voice, making it very weak, especially towards the end of the day when you are tired or during periods of relapse (1).

My speech is a lot slower and I find it difficult to ‘find’ the vocabulary that I want at the time I want it.

The most common changes in speech and communication in MS are listed below.

**Dysarthria**

This is the medical term for difficulty in finding the right words or forming sentences. It is considered the most common communication disorder in those with MS. It is caused by neuromuscular impairment, which results in disturbances in motor control of the speech mechanism. For example, damage in one part of the brain might affect the muscles of the tongue and lips, making it difficult to pronounce precise sounds. Damage in another area might weaken the diaphragm, affecting breath control and volume (1).

**Dysphonia**

This voice disorder often accompanies dysarthria because the same muscles, structures and neural pathways are used for both speech and voice production. Therefore, voice quality, nasal resonance, pitch control, loudness and emphasis may also be affected in those with MS (1).
Dysphasia (aphasia)

This is a language disorder; difficulty in finding the right words or forming sentences. The symptom in MS is usually about recalling the correct words when they are needed at a particular moment rather than the permanent loss of knowledge. This can cause language difficulties, such as difficulty understanding language (receptive dysphasia) or difficulty with language output (expressive dysphasia) (2).

"Sometimes when I speak words just do not come out properly."

Medications

These may worsen or trigger speech, language and cognitive problems. Some medications cause dry mouth, which can make it hard to speak and swallow. Medications also might aggravate weakness, reduce alertness or cause fatigue, all of which can hamper a person’s ability to communicate (3).

"My speech is mainly affected when fatigue is high. Starts with slurring and then moves on to full aphasia with inability to form words or sentences."
In summary, the changes MS can cause to your speech include (4):

- Slurred, imprecise or slower speech
- Low-volume weak or altered voice
- Difficulty with resonance and pitch control
- Sounding like you’re speaking through the nose
- Long pauses between words or between syllables (scanned speech)

My voice is quieter, hoarse and often has no power. It is a great effort to produce sound when this happens.

If you are having problems with your speech, you may find it helpful to:

- Take a good breath before you start speaking
- Put extra effort into stressing key words
- Speak slowly, saying one word at a time if necessary
- Leave a clear space between each word
- Make sure you’re in the same room as the person you’re talking to and face them
- Attract the listener’s attention – for example, by touch or calling their name before you begin talking to them
- Keep sentences short and avoid long conversations if you’re feeling tired
- Reduce background noise – for example, switch off the TV or radio
- Repeat yourself if needed
Treatments

Communication problems may affect your relationships with family and friends, and can make social situations challenging. Failing to speak clearly or make yourself understood can have a huge impact on your self-confidence and quality of life. However, a speech and language therapist (SLT) is almost certain to be able to offer you help. They will devise strategies and exercises to help you cope with your speech problems by achieving more control over the way in which you form words and sentences. This may include:

• How to strengthen the muscles you use when you talk
• The importance of good posture
• Clear articulation
• Managing the speed at which you talk
• Making the most of intonation and emphasis
• Avoiding over exertion
• Avoiding speech when there is a lot of background noise

Self-management tips

• If you are relaxed and happy your speech will be easier and both you and the person you are communicating with will find it a less stressful experience
• Take your time and repeat yourself if needed
• Think about background noise when communicating. Don’t try and compete with the TV or radio and cut out environmental noise if you can
• Your nonverbal communication will help people understand you. Your body language, physical gestures and even raised eye brows can help get your message across and aid communication
Why does MS cause swallowing difficulties?

Swallowing is such an automatic response that we give it little thought, unless it starts to give us a problem. The medical term for swallowing difficulties is dysphagia. Over 30% of people with MS have some degree of difficulty in swallowing. This is due to myelin damage in the part of the brain that controls the swallowing mechanism or in the nerves connected to it (5).

Learn what your problem foods are and plan for them by eating extra-slowly and having very small portions.

What happens when we swallow?

We use around 50 pairs of muscles and a number of nerves in order to swallow safely (6). In order to swallow safely the following functions of the body are used - motor activity, sensory, coordination and autonomic functions. All of which are functions of the body that can be affected by MS.

It is a complex process that happens in three stages, the oral phase, the pharyngeal phase and the esophageal phase (6).

The oral phase is when food is placed into the mouth. When chewing starts, saliva mixes with the food and it is moved around the mouth by the tongue and jaw. This process makes the food the right size and texture to swallow. The tongue and other muscles propel the food towards the back of the mouth in a front-to-back squeezing action. At this point, sensory receptors are activated to start the involuntary phase of the swallow.
In the pharyngeal phase, a number of things are all happening at once. As food enters the upper portion of the throat (pharynx), the soft palate rises to make sure food does not enter the nose. The larynx (voice box) elevates and also moves forward allowing the epiglottis to drop down covering the trachea (windpipe). This prevents food from entering the airway and the lungs. Food is propelled down the throat, the esophageal sphincter opens and food is entered into the esophagus. During this phase breathing stops temporarily.

The final phase, the esophageal phase, a number of motor contractions occur to move the food down the esophagus – the tube that carries food and liquid to the stomach. As it moves through the lower esophageal sphincter opens allowing the food/liquid to pass in to the stomach.

This whole process takes just seconds but can easily be impacted if just one of those functions is affected.

Swallowing and choking can be avoided by very careful food preparation, as well as eating slowly with concentration.

What problems could you experience with swallowing?

Some of the affects that are caused by swallowing difficulties can be:

- Coughing and choking when eating or drinking
- Slowed or delayed swallow
- Difficulty chewing food or controlling liquids in your mouth
- A build-up of excess saliva and this may cause you to dribble
• A sensation that food or tablets are ‘stuck’ in the throat
• Bringing food back up, sometimes through the nose
• Aspiration (food going down the windpipe and into the lungs)
• Chest/lung infections that reoccur
• Weight loss
• A weakening or softening of the voice

Dysphagia can lead to complications such as dehydration, malnutrition, upper respiratory infections and aspiration pneumonia (6).

**Treatments**

Early detection and appropriate treatment can successfully reduce the problems associated with swallowing difficulties. It is important that carers, family members and friends also recognise this as a potential problem and understand that it is not limited to people with more advanced MS and can in fact happen to anyone with MS.

I relapsed a long time ago and my swallowing became a problem. I was seen by a speech therapist who gave me mouth exercises. This solved the problem. I still get the odd problem. I just ensure I eat my food slowly and don’t rush it.

**Self-management tips**

To help prevent issues with swallowing you can try the following:

• Correct positioning of the neck, trunk, legs and arms
• Tuck your chin when you swallow (even a centimetre or so will help close the airways)
• Avoid rushing your meals and take time to chew well
• Take sips of liquid with solid food to moisten it and avoid speaking whilst you are eating
• Be aware of your environment, don’t have too many distractions
• Introducing softer foods into your diet or liquidise some of your food
• Remain upright for at least 30 minutes after your meal
• Posture is very important and you can sometimes get support and advice around these issues from a physiotherapist either via NHS health services, privately or at your local MS therapy centre

If you are seeking the support of health professionals, depending on your needs, there may be a multidisciplinary approach taken to supporting speech and swallowing difficulties. This means that there will likely be many professionals involved in assessing and addressing your speech and swallowing issues.

Here’s a list of some of the health professionals who may be involved and their roles:

• A speech and language therapist’s job is to help deal with problems related to communicating, eating, drinking and swallowing
• A dietician’s role may be to advise on the types of food that are likely to be easy to swallow and to ensure that you are getting good levels of nutrition. A dietician may also give you advice on thickening drinks or blended foods
• A radiologist may be involved to complete a video-fluoroscopy, which takes a moving X-ray and can verify the exact nature and location of your swallowing problem
If swallowing problems become prolonged and an ongoing issue that could potentially put you at risk, nutrition can be provided through a procedure called a ‘percutaneous endoscopic gastrostomy’ (PEG). This involves a tube being inserted through the abdomen directly into your stomach bypassing the part of the swallowing mechanism that is not working effectively.

Family carers or paid carers can easily be trained to use a PEG feeding system and should be taught to do so by the health professionals involved.

It is recommended that first aid treatment should be learned by you and your family carers if you are concerned about the risk of choking. The Red Cross or the St John Ambulance service may offer free or discounted first aid training courses in your area.

- Red Cross www.redcross.org.uk
- St John Ambulance www.sja.org.uk/sja/first-aid-training-courses.aspx

A referral to a speech and language therapist (SLT) can be made by your MS nurse, GP, member of your neurology support team, or a social care professional such as a social worker. Often the perception of speech and language therapists is that they are only in place to help with talking, this is not the case.

Speech and language therapists are trained professionals in all aspects of communication and swallowing. Speech and language therapists are often the key health professional to work with if there is an issue with speech or swallowing. You may be seen in your own home or a clinic depending on services in your area (7).
Sources


Last reviewed: March 2019
About MS-UK

MS-UK is a national charity formed in 1993 supporting anyone affected by multiple sclerosis. Our hope for the future is a world where people affected by MS live healthier and happier lives.

MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis; whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

We will always respect people’s rights to make informed decisions for themselves.

The MS-UK Helpline

We believe that nobody should face multiple sclerosis alone and our helpline staff are here to support you every step of the way.

Our service is informed by the lived experience of real people living with MS, so we can discuss any treatments and lifestyle choices that are of benefit, whether they are clinically evidenced or not.
New Pathways

Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

Available in print, audio version, large print and digitally.

MS-UK Counselling

MS-UK Counselling is open to anyone living with MS and is the only service of its kind available in the UK. Whether you want support coming to terms with a diagnosis or to improve your mental wellbeing, our counselling service is focused on helping you.

All of our MS-UK counsellors are BACP registered or accredited with an in depth knowledge of MS.
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