

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.

We rely on the generosity of people like you to fundour vital work. If you would like to make a donation, you can do so by:

- Calling us on: 0300 500 8084.
 Lines are open Monday to Friday, 9am 5pm
- Visiting us at: mssociety.org.uk/donate
- Posting your donation to: MS Society, National Centre, 372 Edgware Road, London NW2 6ND. Please make cheques payable to the 'MS Society.'

Contents

About this booklet	1
How do we speak?	5
How can MS affect speech?	6
Coping with speech and communication difficulties	8
Identifying speech difficulties	10
Managing speech difficulties	11
Useful organisations	16
Further information	19

About this booklet

Speech difficulties of some kind are quite common for people with MS. They can often come and go through the day, perhaps lasting only a few minutes at a time. Symptoms might appear during a relapse and fade away afterwards.

For many people, any changes are mild and don't stop them from being understood and communicating with others.

For other people, speech difficulties might be longer lasting and result in difficulty communicating. However your speech difficulties affect you, there are practical ways that may help to manage these changes. Sometimes, working with a speech and language therapist to find techniques can also help.

This booklet includes some suggestions of things you can do to improve communication – both by yourself, and with the help of a speech and language therapist. It also includes information about communication aids that may help if your problems last longer and affect communication more strongly.

How do we speak?

Speaking is a complicated process. It involves physical actions to produce sound, thoughts and responses from the brain (which control these actions and decide what we say.)

The first event happens in the brain, where a message is created that we want to communicate. Maybe we're responding to what someone else has said, or to the situation we are in. Along with this desire to communicate come ideas and feelings about what we want to say.

The brain has to translate all of this into language, and then into messages that tell muscles how to form those words and sentences.

All of this thinking happens in a tiny fraction of a second, so we 're not usually aware it's taking place.

Messages from the brain then go to muscles in several places, controlling different parts of the speech process, often at the same time. When we talk, there are constant messages passing to and fro, adjusting and coordinating these actions to create the accent, volume, tone and precision of our words.

The lungs

These push air upwards through the windpipe and the voice box and out through the nose and mouth. A large sheet of muscle that stretches right across the bottom of the rib cage, known as the diaphragm, helps to control how much breath is used, and how forcefully it's pushed out.

The voice box ('larynx')

Air passes through the vocal cords, inside the voice box. The vocal cords are two thin membranes that can be pulled tight to let air pass through a small gap between them. The force of the air pushing through this gap makes the cords vibrate and it is this vibration that creates sound. The tighter the vocal cords are pulled, the higher the pitch of the sound produced.

Tiny changes in the tension of

How do we speak?

these cords create the natural ups and downs of speech, such as the way a sentence rises at the end of a question.

The throat, mouth and nasal cavity

By changing their shape, and the way the air passes through them, they adjust the tone of the sound coming from the vocal cords.

The lips, tongue, jaw and palate

Together, their movements create the particular vowel and consonant sounds we speak – the 'articulation' of speech. They also affect the tone of sounds produced.

I want to Brain - messages go between communicate... Now, here and the parts of the body what do I want to say? involved in the speech process And how do I say it? Right, got it. Nasal cavity and mouth cavity - together with the throat these adjust tone Tongue - together with lips, jaw and palate create vowel and consonant sounds Air passes through the voice box (or larynx) between the vocal cords inside Windpipe Lungs push air upwards **Diaphragm controls** the breath

How can MS affect speech?

Like other symptoms of MS, speech difficulties can be the temporary result of a relapse or they can last for longer. They can improve over days, weeks or months. They might also appear several times a day, but last for only a few minutes at a time. Some people find their speech problems get worse when they're tired.

Dysarthria

The most common form of speech problem for people with MS is 'dysarthria'. The changes it can cause to your speech include:

 slurred, imprecise or slower speech, sometimes sounding as if you're drunk

- 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

Dysarthria is caused by MS damage in different parts of the brain, which affects the way speech is produced. 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.

I've started to avoid using names because they slip my mind just at the very point of saying it. I go high pitched and very gruff sounding all in one fell swoop sometimes. I'm glad to say that it doesn't embarrass me so much but I think it may be because I've always been a bit of a scatter head and have laughed at myself before anyone else has had the chance to.

I sometimes find it hard to understand what's being said and often now have problems with finding what I want to say, forgetting the words, etc. I also have cognitive difficulties, finding it difficult to know what to say or getting confused.

Carole

The connections between the brain and the spinal cord – the area known as the 'brainstem' – are particularly important for controlling speech. Damage to this area is often accompanied by mobility problems as well. However, speech difficulties can happen at any stage in MS, to a greater or lesser degree, and people with speech difficulties don't always have mobility problems as well.

Dysphasia

Another type of communication impairment that can happen with MS is 'dysphasia', though this is rare. Dysphasia is a language disorder that can make it hard to understand what's being said ('receptive dysphasia'), or difficult to recall vocabulary or find the right way to say something ('expressive dysphasia').

Cognitive difficulties

MS can also cause other changes in memory and thinking that might affect how someone speaks, known as 'cognitive difficulties'. These do not affect everyone with MS, and when they do they are often mild.

If you're having difficulties communicating, then it's worth considering whether they might be caused by cognitive problems. There are techniques that you can learn that can help with memory or word-finding. There's more information in the MS Society booklet **Memory and thinking**.

Side effects of drugs

Some drug treatments, including those used to treat bladder problems, can cause a dry mouth as a side effect. This can make speaking more difficult. If this is an issue for you, speak to your doctor. You may be able to adjust your medication to reduce this side effect. For more information on dry mouth and ways to manage it, see the MS Society factsheet **Oral health**.

Recognising speech difficulties

Sometimes changes in speech are so small that you might not notice them yourself. It could be friends or family who are first aware of a change, or it could be your doctor or MS nurse. Some of the signs will be obvious, but others might be more subtle.

Coping with speech and communication difficulties

Speaking is a major way of communicating with other people. If your ability to talk is changed, this can also affect how you feel about yourself and how you relate to others. Some people feel less confident, distressed, frustrated or tired.

Speech difficulties can also make social situations awkward or uncomfortable. If people don't understand your MS, they might make assumptions about why you're slurring your words or speaking louder than usual. But it's not always easy or appropriate to explain and some people start to avoid potentially embarrassing social situations.

The rest of this booklet outlines things that you can do to help manage speech difficulties – alone, with family and friends, and with the help of a speech and language therapist.

However, even with all these techniques, it's not always possible to overcome all changes to your speech. And if changes to your speech or communication skills are having an impact on you emotionally, or preventing you from communicating your message effectively, it's important not to ignore this.

Stress and anxiety, for example, can actually make speech difficulties worse.

I've experienced speech difficulties during relapses and it made me feel very awkward, embarrassed and sensitive about who I would speak to and their view of me. I've had comments made about being drunk due to slurring and mobility problems. This can be embarrassing, especially in my line of work. But support from my family gives me the confidence to deal with this.

Ashlee

Coping with speech and communication difficulties

If you do feel anxious or embarrassed about your speech difficulties, speak to your doctor, MS nurse or other health care professional, as there may be treatments that can help. You may also find it helpful to connect with other people with MS who have speech difficulties. The MS Society's online message boards are one way of doing this:

www.mssociety.org.uk/forum

The charity **Speakability** also offers support to people affected by dysphasia.

ASSISTANCE CARD

It can help if people around you understand why you have problems with your speech. The MS Society produces a creditcard-sized assistance card you can use to let people know you have MS and may have difficulties with your speech.

To request one contact:



shop@mssociety.org 020 8438 0999

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Helpline: 0808 800 8000

Identifying speech difficulties

If your speech difficulties are mild, or they only last for a short time, you may not want help with managing them. But if you do, the first step in managing speech difficulties is to identify the specific problem, or problems, you're having. In order to do this, your doctor or MS nurse may refer you to a speech and language therapist.

A speech and language therapist will carry out different tests with you, to see exactly which parts of the speech process are affected. For example, these could include

checking how quickly and accurately your lips and tongue can form different shapes and movements, or looking at your breath control.

Problems might be caused by a number of different things. These could be combined and they might change over time. MS is an unpredictable condition, so a speech and language therapist might assess your needs regularly, to see if your situation has changed, and if your treatments are still effective.

I do get affected by slurring and a slowing of speech in a weak voice - usually when tired or maybe just having an 'episode'. Fortunately they haven't been long lasting but occur sporadically. It's a little upsetting when it happens and I always worry that I won't recover fully but as with my MS I've learnt to manage my condition as best I can. This is helped in a big way by my husband looking out for me and recognising various symptoms, often before me.

Denise

Managing speech difficulties

Once your specific speech difficulties have been identified, a speech and language therapist can work with you to find ways to manage them. Its important to get advice from a health professional, so that you can find the best methods for you.

If your speech difficulties are caused by muscle stiffness or spasms, there might be drug treatments to help relieve them. But, in most cases, you'll need to learn how to compensate for problems, so that you can find ways to make communication and speaking as easy as possible – both for you and for other people.

There are lots of simple adjustments which might help make communication easier.

Things you can try yourself

These are some of the things you can try yourself:

- when you need to communicate, don't try to compete with other noises, such as TVs and radios.
 Remove noise distractions where possible
- make sure you have someone's full attention before starting to tell them important information, and be prepared to repeat things if necessary
- whenever you can, try to communicate face-to-face. Your facial expression and other forms of non-verbal communication – such as gestures, body language and eye contact – can help the listener to understand what you are trying to say

I've now developed ways of dealing with my difficulties, which enable me to feel confident when speaking, like speaking slower, giving me time to think. This can take some time to get used to but the difference isn't as noticeable to others as you may at first think.

Ashlee

These things happen, especially when I'm in a noisy or busy place or with more than one person there, for example going for a meal with several people. I often don't go because I find things hard and also it adds to my fatigue if I'm having difficulties. Thankfully my friends are very understanding and know that I have problems at times.

Carole

- if a conversation goes on for a long time, you may find that your speech can sometimes become less clear. If this happens you might want to explain that you need a break before starting the conversation again
- if you have problems finding the right word, or remembering what you are trying to say, take your time and use notes if necessary
- try to remain relaxed and take regular pauses for breath when you're speaking. Avoid rushing
- if you can laugh or smile about things, both you and the person you're talking to may feel less anxious about not understanding or being understood

- if you're feeling self-conscious, remember that other people might not be as aware of your speech difficulties as you are
- good posture can help you to speak more easily. Pillows and foam supports can help to support your posture when you're sitting or lying down. A physiotherapist can help with posture. For more information, see the MS Society factsheets on posture and movement
- if you have difficulty making yourself heard on the phone, something as simple as raising the volume control might help.
 You could also try alternatives to phone calls – for example, sending texts, either by using a mobile phone or a textphone

Managing speech difficulties

Or you may prefer to send an email rather than make a phone call.

 if you need to speak in public, using a microphone could be useful. You might find useful products online.

The **Disabled Living Foundation** has more information about microphones and other useful aids and equipment

Things you can try with the help of a speech and language therapist

Here are some things a speech and language therapist may be able to help with:

 breath control. A speech and language therapist may encourage you to practise breathing in and out in a controlled way – so that you can make longer sentences in one breath. Other exercises can help to emphasise certain words in a sentence, and to catch quick breaths between thoughts. They can also show you how to monitor your own breathing and be sure you are doing it in the most effective way

- speech difficulties affecting volume and pitch, or making speech breathy and hoarse, may be caused by problems with the palate or the vocal cords. A speech and language therapist may recommend exercises that strengthen or relax the muscles controlling the vocal cords
- other exercises, to help with the movement of the jaw, the tongue and the lips, can help with clear articulation and pronunciation

A group situation I try sucking an ice cube and just quietly remain calm without attracting attention and remain in the background! If it's a smaller gathering I just say I'm a bit tired and it's generally understood that I will join in when I'm ready again.

Denise

Tips for your family, friends and carers

Here are some tips for families and carers:

- try to understand the difficulties the person has with their speech. This can make it easier to work around the problem and keep communication clear for everyone
- most people who have MS speech difficulties have problems with the physical process of creating speech. Don't assume that someone has trouble finding words or understanding what you're saying
- when speaking with someone who has speech difficulties, remember that it can be frustrating and tiring for them to talk
- be honest when you really haven't understood something
- try to be patient, and don't always finish their sentences for them
- If someone becomes upset or frustrated about not finding the right words or being understood

properly, it will often make them more anxious and their speech may become more difficult. Try to keep calm and understanding, and reassure them if necessary

Communication aids

If your speech is affected more severely, and it becomes very difficult for you to communicate in this way, a communication aid might be helpful. There is a range of gadgets available - sometimes known as 'augmentative and alternative communication' devices. They can help by, for example, translating written words into speech.

Finding the right one for you depends on your overall situation, not just how your speech is affected. Certain symptoms, such as tremor or weakness in your hands, vision problems or cognitive difficulties may mean that you're unable to use some aids.

A speech and language therapist can suggest options and work with you to learn how to use them.

Managing speech difficulties

The MS Society provides grants to people with MS for an item needed as a direct result of their MS. This is when there's no health or social care services funding available for it. This could include communication aids.

Call **0300 500 8084** and ask to speak to the Grants Team for more information.

Useful organisations

Disabled Living Foundation (DLF)

Provides information and advice on equipment to enhance independence.

34 Chatfield Road, Wandsworth, London, SW11 3SE

Company to Friday, 10am-4pm)
 Company to Friday, 10am-4pm)
 Company to Friday, 10am-4pm
 Company to Friday, 10am-4pm
 Company to Friday
 Compan

www.dlf.org.uk

Speakability

The national aphasia organisation Speakability is now part of the Stroke Association.

Contact them on:

www.stroke.org.uk/ finding-support/aphasia-andcommunicating

Text Relay

Text Relay, formerly known as RNID Typetalk and BT TextDirect, connects speech or hearing impaired people using a textphone with people using a telephone or another textphone.

Textphone 0800 500 800

**** 0800 500 888

www.textrelay.org

Notes



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

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.

- → helpline@mssociety.org.uk

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

About this resource

With thanks to Professor Mike Barnes, Kathryn Bellshaw, Holly Froud, Kirsty Harrison, Kate Richardson, Nancy Sigakalele and all the people affected by MS who contributed to this publication.

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

Illustration by Damion Mulrain

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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

Contact us

MS Helpline

Freephone 0808 800 8000 (weekdays 9am-9pm) helpline@mssociety.org.uk



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