



7C

Speech and communication support

Information for people with or affected by motor neurone disease

Motor neurone disease (MND) can cause weakness in the tongue, lips, vocal cords and chest, causing your speech to become faint, slurred or unclear.

If your speech is affected by MND, or you are concerned about how this may affect you in the future, you may be looking for information about alternative ways to communicate and how to access further support.

This information is split into the following sections:

- 1: How will MND affect my ability to speak and communicate?**
 - 2: How can I use my own speech for as long as possible?**
 - 3: Is there anything else that can help me?**
 - 4: How do I get a communication aid?**
 - 5: What is voice banking?**
 - 6: How do I find out more?**
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 This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.

 This symbol is used to highlight **quotes** from other people with or affected by MND.



The MND Association has been certified as a producer of reliable health and social care information.

www.england.nhs.uk/tis

1: How will MND affect my ability to speak and communicate?

About nine in ten people with MND will be affected by weakness of the muscles involved in speaking. This can cause:

- speech to become slow, slurred and unclear
- air to escape out of the nose giving your speech a nasal quality
- your speech to sound hoarse, low pitched and monotonous
- weakened breathing which causes your speech to become soft and faint
- difficulty with making certain sounds.

Your gestures and facial expressions can also be affected, which means communication can become very difficult. Techniques and equipment can all help to provide solutions.

If you start to experience any problems with speech or communication, it is important to discuss your wishes regarding your future care with your main carer, family and health and social care team.

As your speech deteriorates, conversations are likely to become more difficult, particularly if some of the health and social care professionals you meet have little or no experience of MND. It is best to make complex or difficult decisions as early as you feel able to.

 For more information about how speech is formed and affected by MND, see: *Living with MND* – our main guide for people with MND

The effects of MND on speech can cause a range of emotions, including:

- isolation
- frustration
- fear and anxiety
- low self-esteem and lack of confidence
- loss of control due to being misunderstood.

 For more information about managing the emotional impact of MND, see: Information sheet 9C – *Managing emotions*

Ensuring your communication needs are well met can help you cope with the changes to your voice and speech. A speech and language therapist (SLT) can offer guidance and equipment to support you to communicate. Ask for a referral to one as soon as possible, even if you feel your speech is still adequate.

2: How can I use my own speech for as long as possible?

At first, you may not need to use a communication aid. Adapting how you speak may help you prolong the use of your own speech and make it easier for you and those around you. You may find it helpful to:

- speak more slowly
- pause more frequently to take a breath
- try to clear your mouth of saliva before you speak
- emphasise words and break them into distinct syllables
- use short sentences
- start sentences with a key word to get your point across early
- avoid background noise
- use gestures to emphasise or replace speech.



"If I cannot say as much as I used to say, I have to say it better. So the choice of words becomes crucial."

It is important to be aware that as MND progresses, speech and communication can become increasingly tiring and difficult. It can also become harder for others to understand you, so it is worth being aware of the types of aids available that you may wish to use in the future.

Consider recording your own voice while it is still clear. You may be able to use your recording for future use as a synthesised voice in computer based communication aids. This is known as 'voice banking'. See section 5: *What is voice banking?* to find out more.

In the meantime, some of the following suggestions may be helpful:

- work out some hand signals for frequently used phrases with your immediate family and carers
- if you find it difficult to use your hands, work out a 'yes' or 'no' signal which could be a particular sound, slight head movement, limb movement, blinking or eyebrow raising
- compile a list of regular questions, needs and personal words so someone can go through the list until you indicate yes or no by an agreed signal
- carry a message to help you avoid repeating explanations when you meet other people (we can supply pocket sized notepads and a card with an explanation from the MND Association)
- if you are able to write, keep a pen and pad nearby
- use a text phone or tablet computer to type and show what you want to say.

Different situations and environments will need different methods. What works in a quiet sitting room with friends may not work in a noisy shop. It is worth practising different techniques to help you cope in a range of situations.

How can my family and carers help me?

Share your frustration and challenges with your main carer, family and friends. Involve them in finding ways to help. It may be useful to show them the following tips to help them feel more prepared:

- face one another and watch the person's face and lips
- for longer conversations, sit in a quiet room, turn the television off and avoid distractions
- keep a pencil and paper or a communication board handy
- be aware of fatigue through keeping visits short and allowing the person with MND to have rest beforehand
- encourage the speaker with MND to pause between phrases and rest often.



"Family and friends tell me they need time to tune into my speech, so it is important not to give up too easily".

They may also find the following tips about the process of communication helpful:

- impaired speech does not mean impaired understanding, so don't feel you have to simplify statements for someone with MND
- don't change the speed or volume of your speech, unless the person with MND has hearing loss
- be patient if the person with MND speaks slowly, as it may be taking a lot of effort
- encourage over-articulation of speech to make up for slower and weaker movements as this will help make speech clearer
- if speech is becoming tiring for the person with MND, encourage them to gesture or point using their eyes
- use questions that only need a yes or no answer. For example 'Would you like a cup of tea?' rather than 'Would you like tea or coffee?'
- ask one question at a time
- do not finish someone's sentences for them unless they have agreed that they are happy for you to do this.

3: Is there anything else that can help me?

If your ability to speak and communicate is affected by MND, a range of techniques and aids can help. These techniques and aids are known as augmentative and alternative communication (AAC).

AAC falls into three groups:

Unaided communication: this involves techniques such as body language, gesture, pointing, signing and facial expression. See section 2: *How can I use my own speech for as long as possible?* Communicating in this way can help at first, but may become difficult over time, depending on your symptoms.

No-tech and low-tech communication aids: simple, non-electronic tools such as word or image pointer boards, notepads and whiteboards. See section 3: *Is there anything else that can help me?* for more information.

High-tech communication aids: electronic aids, including speech-to-text and text-to-speech communication devices and software for smartphones, tablet computers, laptops and personal computers. For more information see section 3: *Is there anything else that can help me?* for more information.

There is no 'best' type of communication aid as individual preferences, abilities and needs can vary. Assessment by a qualified SLT can help you find appropriate solutions by considering your current and future needs. This is important as some aids can be very expensive and will not suit everyone.

It is worth learning about communication aids before you need them as it may take time and practice to become confident and skilled at using them, whether low-tech or high-tech. This way any questions you may have about the aids can be solved more easily through spoken conversation.

Ask your GP or a member of your health and social care team to refer you to an SLT with relevant experience of MND if you do not already have one.

What simple (no-tech and low-tech) solutions are there?

Low-tech solutions include those that don't need batteries or a power supply to work. They can be used either on their own, alongside electronic aids or as a back-up.



"Electronic aids are not for me – at this stage a notepad and pen are much easier."

Writing: Depending on how MND affects you, using a pen and notepad to write can be a quick, simple way to communicate. Some people prefer to use a whiteboard that wipes clean to save paper. Writing may become more difficult if your arms and hands become affected by MND, so try to practise other solutions.

Communication boards or books: Letter, word or image boards and books, such as an alphabet board, enable you to point to letters or words to create your message. There are different designs available or you can create your own. If need be, someone else can scan their finger across the board until you signal the correct choice through blinking, nodding or another method. A laser pointer can also be attached to a pair of glasses, a hat or a headband, so you can signal by moving your head.

Eye-pointing frames (sometimes known as E-Tran frames): These stiff, transparent frames allow you to indicate a letter, word or symbol by directing your gaze at the appropriate section. They are available in a range of formats, to include the alphabet, phrases and symbols, depending on your needs. These can be personalised to include your choice of messages.

What electronic (high-tech) solutions are there?

High-tech communication aids are those that use electricity or batteries. They vary significantly in how they work and what they can achieve.

Some of the more sophisticated systems are very expensive, so it is essential to get advice from your SLT, equipment to trial, and arrange funding. They can also refer you to a specialist service if appropriate. For more information about funding for AAC, see section 4: *How do I get a communication aid?*

Some commonly used high-tech communication aids include:

Voice amplifiers: If your speech is clear but faint, these portable devices can give you control over the volume of your voice. A range of different microphones are available, such as headsets, handheld and clothing clips.

Voice output communication aids (VOCAs): These are known as text-to-speech devices. You can select a word, symbol, letters or sentences with your finger or, if needed, using a keyboard, pointer, adapted mouse, joystick, a switch, or eye tracking. Once selected the VOCA will speak for you using either recordings of a human voice or a synthetic voice.

Computer based systems: These programmes come in a range of styles and vary in their complexity. Programmes are available for mainstream equipment, including personal computers, laptops, tablets and smartphones. In addition to voice output, these systems can be customised. For example, you may be able to make your own on-screen word grid. They can be operated by different parts of your body using adapted mice, joysticks, switches or other equipment.



"I have a smartphone and haven't looked back. I intend to get a tablet later and ensure this support is up-to-date."

Speech-to-text programs: If you have difficulty typing due to weakness in your arms or hands, but still have use of your voice, these programs can help turn your speech into text for communications such as emails and letters. Many computers, smartphones and tablets have this function built in.

What if I have difficulty lifting my head?

MND may cause problems with the muscles that support your neck, which can make it difficult to use some communication aids as your eye level drops. A collar or head support can raise your eye level to help you, whether using simple or electronic aids. Good neck support will also be important if you use a wheelchair.

An assessment by an occupational therapist or physiotherapist is essential to ensure the collar or head support suits your needs. Ask your GP or a member of your health and social care team for a referral.

In some cases a device can be mounted in a more appropriate position, either attached to a wheelchair, a desk or bed, or on a floor stand.

What if I have limited hand and arm function?

If you find it difficult to use your arms and hands to operate communication aids, your SLT can refer you to an occupational therapist who can advise about adapted controls and switches. These can enable you to control your communication aid using your:

- foot
- knee
- chin
- head
- breath
- mouth
- eyes.

What if I have trouble with spelling or word recognition?

Symbols and images may be quicker to identify if you experience problems with spelling and word recognition. Discuss your spelling difficulties with your SLT to ensure these needs are taken into account. They may be able to provide strategies and suggestions to help.

With MND, some people experience changes to the way they think and behave, which can impact on communication. If you or someone else has noticed any changes to your thinking or behaviour, including a change in the way you spell or recognise words, ask your neurologist for advice.

 For more information about changes to thinking with MND, see: Information sheet 9A – *Will the way I think be affected?*

 For information for carers about changes to thinking with MND, see: Information sheet 9B – *How do I support someone if the way they think has been affected?*

Will I need to change to a different aid in the future?

As MND progresses, your needs for communication equipment are likely to change. This is an important consideration if you are thinking of buying equipment yourself. It is important for your SLT to regularly review your needs with you.

Ensure you discuss any changes to your needs with your SLT as quickly as possible rather than waiting for your review.

Always be prepared to try something again, as an aid that is unsuitable now may become relevant in the future. Technology is also advancing rapidly and improved solutions may become available.



“It is very hard to anticipate the progression of the disease before the effects are actually happening to you.”

What if I have never used a computer?

Most communication devices can be programmed to suit your ability to operate a computer, as well as your communication needs. If it still doesn't suit you, your SLT can help you find other ways to communicate. Your SLT can teach you and those who support you how to use the device.

Another option would be to choose a dedicated communication aid, rather than using a program on a computer. Powered with rechargeable batteries, with a keyboard and display screen, these can be operated by an alternative method if you have limited hand movement. You type a sentence and press a button for the machine to speak it, and you can select from a range of voices. Frequently used words and phrases can be pre-set and text prediction can be used to speed up communication.

What happens if I cannot use my electronic aid for any reason?

Try to use a combination of high-tech and no-tech or low-tech options. This ensures you have a simple means of communication if:

- you are unable to use a high-tech option in a particular location
- there is a power failure
- the high tech communication aid breaks down.

4: How do I get a communication aid?

In the first instance, your SLT will assess your ability to speak. Ask your GP or a member of your health and social care team for a referral if you have not had one. You may be given an opportunity to try out various communication aids before a final decision is made. If your SLT is able to provide you with a suitable communication aid, this can then be loaned or in some cases gifted to you.

Depending on your needs, you may be referred to a specialist centre for a more detailed assessment. It is important for your future needs to be considered during the assessment so any possible solutions take account of how MND is likely to progress.

In many cases equipment is provided on long term loan following assessment. If you qualify for specialised services, equipment can be funded and provided following assessment.

What funding is available?

Try not to rush into private purchases before being assessed, as many communication aids are very expensive and your needs are likely to change as MND progresses.

You may be able to access support and funding for communication aids from:

The NHS: you are strongly recommended to consult your SLT for an assessment. They will support requests for equipment trials and funding requests from local authorities or health and social care trusts in Northern Ireland. They can refer you to a specialised AAC service known as a 'hub' if complex high-tech equipment is needed.

Equipment provided under the NHS is normally loaned for as long as you need it and replaced as your needs change. If there is a problem with the equipment contact your SLT. They may be able to solve any issues, or will refer back to the relevant specialised AAC service if necessary.

The MND Association: we may be able to offer a limited amount of financial support where statutory services cannot supply. This can only be given following an assessment by your SLT.

Other charities: some organisations will fund communication systems. See *Useful organisations* in section 6: *How do I find out more?*

Access to Work scheme: If you are employed, this scheme offers advice, support and information for you and your employer. Access to Work may help with costs for communication aids to enable you to continue working. For England and Wales, contact Access to Work to apply. For Northern Ireland, contact your local job centre or social security office. See *Useful organisations* in section 6: *How do I find out more?* for contact details.

 For more information about support at work, including Access to Work see: Information sheet 10E – *Work and motor neurone disease*

What if I choose to buy my own communication aids?

If you decide to purchase your own communication aid, always get advice from your SLT first to ensure it will meet your needs as mistakes can be costly. You would need to consider not only the equipment itself, but also any software, switches and mounting that are needed.

It is worth checking the following with private suppliers before making a purchase:

- if they offer free trials of the equipment
- if they offer ongoing advice, training and support
- what to do if the equipment stops working and how long a repair or replacement would take
- whether the equipment needs to be serviced regularly
- whether they offer extended warranties.

Try to check with others if they have had any experience with the supplier and product.

5: What is voice banking?

Depending on how advanced your speech problems are, it may be possible to record your own voice, which can then be used to create synthetic speech on a computer or tablet. This is known as voice banking.

Your own voice can only be banked successfully if the way you speak is still clear, so it needs to be recorded before speech problems have significantly advanced. It usually involves speaking between 600 and 3500 phrases, using a computer program.

 For more information on voice banking, see: Information sheet 7D – *Voice banking*

If you can't bank your voice, or wish to try a simpler option, you can try message banking, where you record yourself saying set phrases, which can then be played on a communication aid. When these phrases are played, it will sound exactly like you, but you will be limited to the amount of phrases you have recorded.

6: How do I find out more?

Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information.

The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation or have any questions, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

Adult social care services (sometimes called social services)

For adult social care contact your local authority through your area telephone directory, or search for local authorities at GOV.UK

Website: www.gov.uk
www.nidirect.gov.uk (for Northern Ireland)

The Aidis Trust

Charity that provides electronic communications aids and specialised computer equipment to people with disabilities to aid their communication.

Address: Floor 8, Beckwith House, 1 Wellington Road North, Stockport, SK4 1 AF
Telephone: 0845 235 0641
Email: via the website
Website: www.aidis.org

Communication Matters

Communication Matters is a UK-wide organisation supporting people of all ages who find communication difficult because they have little or no clear speech.

Address: Leeds Innovation Centre, 103 Clarendon Road, Leeds, LS2 9DF
Telephone: 0845 456 8211
Email: admin@communicationmatters.org.uk
Website: www.communicationmatters.org.uk

GOV.UK

Online government advice on a variety of welfare topics, including support for people with disabilities.

Email: email addresses are provided on the website, related to each enquiry
Website: www.gov.uk
www.nidirect.gov.uk (Northern Ireland)

Health in Wales

Information on NHS services in Wales, including a directory of the Welsh health boards.

Email: through the website contact page

Website: www.wales.nhs.uk

Information Technology Can Help (ITCH)

The ITCH Network provides disabled people with effective Information Technology solutions including free IT support for people with disabilities.

Telephone: 0800 269 545

Email: enquiries@abilitynet.org.uk

Website: www.itcanhelp.org.uk

MND Scotland

MND Scotland provides care, information and research funding for people affected by motor neurone disease in Scotland.

Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website: www.mndscotland.org.uk

Next Generation Text Service

Enables you to call other people by typing messages that a relay assistant will read out to the other person on the phone.

Address: NGT Team, c/o Internal Box 14, Telephone House,
170 – 175 Moor Lane, Preston, Lancashire PR1 1BA

Telephone: 0800 7311 888

Textphone: 0800 500 888

Email: through the website contact page

Website: <http://ngts.org.uk/>

NHS Choices

The main online reference for the NHS.

Address: Customer Service, Richmond House, 79 Whitehall, London SW1A 2NL

Telephone: 0207 210 4850

Email: through the website contact page

Website: www.nhs.uk

NHS 111

The NHS online/telephone service if you need urgent, but not life-threatening medical help or advice. Available 24-hours a day, 365 days a year.

Telephone: 111

NHS Direct Wales

Health advice and information service for Wales.

Telephone: 0845 4647

Website: www.nhsdirect.wales.nhs.uk

NHS Northern Ireland

Information on NHS services in Northern Ireland. This is an online service only.

Email: through the website contact page

Website: www.hscni.net

NI Direct

Providing government information for Northern Ireland on a variety of welfare subjects, including health services and support for disability.

Email: through the website contact page

Website: www.nidirect.gov.uk

Speakbook

An inexpensive, low-tech communication tool that allows you to talk with a speaking partner using only your eyes. Available as a free download, you will need to print it off.

Website: www.speakbook.org

SpeechBubble

A website that helps you find out about the types of communication aids currently available.

Email: through the website contact page

Website: <http://speechbubble.org.uk>

Tobii Dynavox message banking

A pilot project allowing people to record and store an unlimited amount of recorded messages.

Website: www.mytobiidynavox.com/messagebank

References

References used to support this information are available on request from

Email: infofeedback@mndassociation.org

or write to:

Care Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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Further information

You may find these information sheets from the MND Association helpful:

7A – Swallowing difficulties

7B – Tube feeding

7D – Voice banking

9A – Will the way I think be affected?

9B – How do I support someone if the way they think is affected?

10E – Work and motor neurone disease

We also provide the following guides:

Living with motor neurone disease – our main guide to help you manage the impact of the disease

Caring and MND: support for you – comprehensive information for unpaid or family carers, who support someone living with MND

Caring and MND: quick guide – the summary version of our information for carers

You can download most of our publications from our website at www.mndassociation.org/publications or order in print from the MND Connect helpline, who can provide further information and support.

MND Connect can also help locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional care development adviser.



MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association, PO Box 246, Northampton NN1 2PR

MND Association website and online forum

Website: www.mndassociation.org

Online forum: <http://forum.mndassociation.org> or through the website

We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them.

If you would like to provide feedback on any of our information sheets, you can access an online form at: www.surveymonkey.com/s/infosheets_1-25

You can request a paper version of the form or provide direct feedback by email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, PO Box 246 Northampton NN1 2PR

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