

8: Speech and communication

This section explores how MND can affect your ability to communicate and what can help.

The following information is an extracted section from our full guide *Living with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: www.mndassociation.org/publications

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



Living with
motor neurone disease

8: Speech and communication

This section explores how MND can affect your ability to communicate and what can help.

We communicate for many reasons – to get things done, access what we need and take part in social activities. Also, to share our thoughts and feelings. Speech and writing are the main ways we do this, but we also use gesture, facial expression, laughter and tears. MND can affect your ability to do all these things. One of the challenges with MND is to find ways to overcome these problems and be able to communicate your needs.

As problems with speech and communication get worse over time, try to have open conversations about your wishes for future care as soon as you feel ready.

See Further information at the end of this section for more resources.

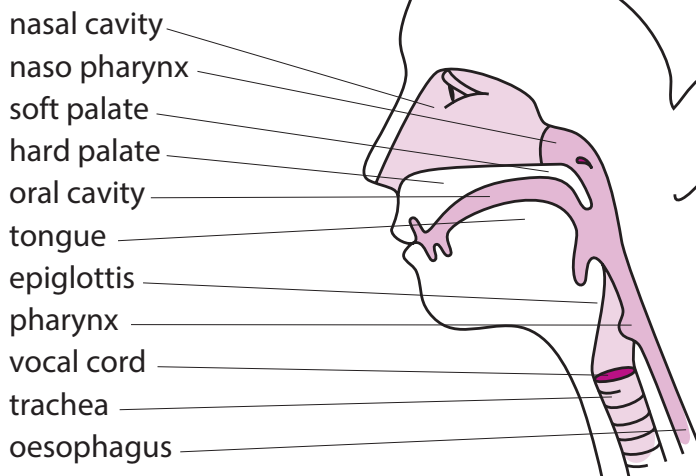


“ I can still talk but find it hard to concentrate or hold complex discussions. The advice on having these difficult discussions as early as possible is crucial.”

What happens when we talk?

When we speak, air from the lungs passes up the windpipe and through the vocal cords, which vibrate to produce sound. We shape this sound by using muscles to control movement of the tongue, lips, teeth and roof of mouth (palate).

How we speak



How does MND affect speech?

Most people with MND will experience some difficulties with speech, although not everyone. When muscles in the mouth, throat and chest are affected, it can cause:

- weakness in the muscles of the tongue and lips, causing slow, slurred and unclear speech that may be difficult for others to understand
- weakness in your soft palate (at the back of the roof of your mouth), allowing air to leak out of the nose and giving your voice a nasal quality
- weak vocal cords, which can make your voice sound hoarse
- weakened breathing or breath support, making your voice soft and faint.

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

Who can help?

Your GP can refer you to a speech and language therapist (SLT), who can advise on how best to use your voice, ways to help your speech or any communication aids that may help you communicate.

How can I improve my speech, unaided?

You may find it helpful to:

- speak more slowly
- pause frequently to take a breath or clear your mouth of saliva
- over emphasise words and break them into distinct syllables
- save energy by using short sentences
- get your meaning across quickly by starting with a key word

- avoid background noise
- make sure your listener is actively listening and watching for non verbal clues
- use gestures to emphasise or replace speech.

What can I do if my speech gets worse?

- work out hand signals for frequently used phrases with those involved in your care
- establish a ‘yes’ or ‘no’ signal, which could be a sound, a movement, blinking or eyebrow raising
- list things you often need, so your partner can go through the items until you indicate yes or no.

A speech and language therapist (SLT) would be able to work with you to develop these skills, as needed.

“ Try new ways to communicate as physical ability changes. For example, turning your head right can mean ‘yes’, to the left ‘no’ and looking straight ahead ‘don’t mind’ or ‘don’t know’.”

People close to you are more likely to understand your speech if it becomes affected, but often strangers can’t. People can get the wrong impression or misunderstand. For example, strangers may think you’re drunk, which can be hurtful and embarrassing. Other common mistakes are people thinking you have a hearing impairment or that you’re emotional.

“ When trying to say thank you, I sound as if I’m cursing... if people say things like ‘Don’t get upset’ or ‘I’m being as quick as I can’, I know my attempts to speak have been misunderstood.”

It can help to:

- carry a message to help you avoid having to explain what's happening all the time (we supply pocket sized notepads and cards that do this)
- keep a pen and pad handy or a wipe clean 'magic slate' for quick messages – some people type text on phones or computer tablets to show what they want to say.

It is important to remember that you will need to deal with different situations and environments. What works in a quiet sitting room with friends may not work in a noisy shop. It's worth practising different tactics to use in a range of situations.

Communication can become more difficult if your arms and hands are also affected. However, there are aids to support you with this.

See later heading *Are there other ways to communicate?*

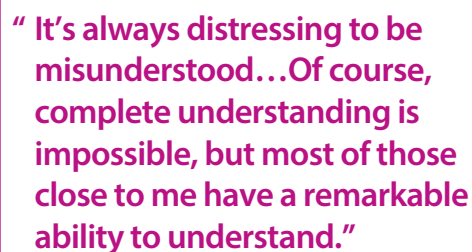
Is there any advice for families and carers about communication problems?

Share your frustration and challenges with your main carer, family and friends. Involve them in finding ways to help you communicate.

You can also show them the following tips.

- Don't change the speed or volume of your speech, unless the person with MND has hearing loss.
- Impaired speech does not necessarily mean impaired understanding, so don't feel you have to simplify the way you speak.
- Be patient if the person with MND speaks slowly, as it takes them a lot of effort and allow for pauses or moments to rest.
- Encourage over-articulation of speech to make speech clearer and watch the person's face and lips.

- For longer conversations, sit in a quiet room facing each other and avoid distractions.
- Keep a pencil and paper or communication board handy and, if speech is tiring, encourage the person with MND to gesture or use eye pointing.
- Try not to finish sentences for them, as this can cause confusion if wrong – unless you have asked and they agreed for you to support in this way.
- Ask questions that can be answered with yes or no. For example 'Would you like a cup of tea?' rather than 'would you like tea, coffee or a cold drink?'
- Try not to mix yes and no questions together, which can confuse. For example, 'Are you warm enough or shall I put the heating on?'



“ It's always distressing to be misunderstood...Of course, complete understanding is impossible, but most of those close to me have a remarkable ability to understand.”

Are there other ways to communicate?

Communication is usually described in two main groups:

- **Unaided communication (also known as total communication):** such as body language, gesture, pointing, signing, and facial expression. These may become difficult with MND, depending on your symptoms.
- **Aided communication:** from simple non-electronic systems to electronic systems using software technology.

Where techniques or communication aids replace speech, they are known as Augmentative and Alternative Communication (AAC). Each solution has pros and cons, depending on your preferences and abilities.

Ask your speech and language therapist for advice, as not all technologies suit everyone and can be expensive.

Non-electronic communication aids

Communication aids without a power source are usually known as low tech, and include:

- pen and paper
- writing boards, wipe boards, magnetic sketch boards or digital writing slates
- communication charts and image boards
- alphabet or word boards and booklets, including eye-pointing frames (E-Tran frames) on transparent plastic where you indicate a letter, word or symbol with eye movement.

With alphabet boards, you point to letters or words to create a message. The person you're communicating with can also scan their finger across the board, until you signal they have made the correct choice. The alphabet can be handled in sections such as A-K or L-Z, to speed up this process. There are different designs or you can create your own.

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

Electronic communication aids

Communication aids that use a powered device are usually known as high tech, and include:

- voice amplifiers if you need help with the volume of your speech
- voice activated computer applications if you have difficulty typing
- voice output communication aids if you have difficulty speaking
- other computer based systems, from general email to systems that rely on movement from eye tracking.

These can be used on personal computers, laptops, tablets and smartphones, including apps (software applications you download for a specific purpose).

“ I have a smartphone and haven't looked back. I intend to get a tablet later, to ensure it is the most up to date.”

See Further information at the end of this section about our resources on speech and communication.

How do I find out about voice and message banking?

A wide range of realistic voices are now available with speech software, including voices with regional accents. You may be happy to use these, but they won't sound like you. If you want to preserve a sense of identity, there are ways to record or 'bank' your own voice for use with speech software.

See Further information at the end of this section for resources, and watch our voice and message banking animation at: www.mndassociation.org/speech

Voice banking

When you bank your own voice, you record a set number of phrases. These are used to create a version of your voice that enables speech software to 'speak' any message you want.

You need to do this as early as possible for the process to work, before speech problems progress. If your voice has already changed, a friend or relative may be willing to bank their voice for you, so that you can use a voice or accent that feels familiar.

“ Voice banking was mentioned, but we didn’t comprehend how useful it could have been...I think the more voice banking is talked about, the more it will become a vital tool for people with MND and their carers.”

The final result may feel a little robotic, but it will sound more like you than a supplied voice. Prolonging the use of your voice in this way can help you and those close to you, but ask a speech and language therapist for guidance. Voice banking can be expensive, depending on the software used. It takes time to record the words and phrases needed, but the process is getting quicker as software continues to develop.

“ With new voice banking software, I only had to record a few hundred phrases.”

Message banking

As well as creating a version of your voice to form new messages, you can record common questions, responses or messages to simply replay. In this way, the messages will sound exactly as you recorded them. They can be programmed into speech software, so they are easily available in the communication aid of your choice.

You may find message banking particularly useful for expression. For example, to record the sound of your laugh or affectionate responses for use with your family and friends.

“ I didn’t want MND to define me. I wasn’t in denial, but wanted to still be me for as long as possible.”

What else do I need to think about with communication aids?

A speech and language therapist, with relevant experience of MND, can assess your current and future needs. The following may be useful:

I want to use computerised speech, but have never used a computer:

If you have never used a computer before, you may feel wary. However, it is worth asking someone to show you how to use the controls and try to explore. A portable electronic communication aid may be an easier option than a computer or laptop. Powered by rechargeable batteries, you can operate the keyboard and display screen with an adapted switch if you have limited hand movement. You type a sentence, then press a button for the machine to speak it, from a selection of voices. Frequent words and phrases can be pre-set and text prediction can speed up communication.

Is using a computer to communicate worth the effort?

Computers, laptops, tablets and smartphones can all help you to communicate, join social groups, find information and services, and be entertained. This can include synthesised speech, the internet, music and video online, email, online forums, social networks, office software, creative software and games.

Using my computer or electronic aid is difficult with restricted hand and arm function:

If your speech is unaffected, you can operate a computer by speaking commands into a voice recognition system. If not, try using adapted switches or more complex eye tracking systems, where you select items on screen through eye or head movement.

Assessment by a speech and language therapist is needed, as this type of system may not suit everyone and they can be expensive.

“ I use a computer controlled by my eye movements to surf the web, read and write emails, and even use spreadsheets... I lead an active life thanks to this new technology which is improving all the time.”

If you have problems with arm or hand movement, ask to be assessed by an occupational therapist. They can help advise on other equipment, such as arm supports, clamps to hold hardware in place or an adjustable table.

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

Try to use a combination of high and low-tech options. This ensures you have a simple means of communication should your system break down, run out of power or for situations when you cannot use this type of aid.

I'd like a smartphone or tablet to make use of the latest apps:

Wireless technology enables internet access and apps, through the use of a computer, laptop, tablet, smartphone or other portable device. You may find a touch screen helpful, but if you have restricted hand function, a keyboard or adapted controls may be easier to use.

“ Apps give ease of use for today's way of life!”

I find it hard to lift my head, which makes using aids difficult:

You may need to be assessed for a head support, to raise your eye level. This will make it easier for you to use a range of communication aids.

I have started to have trouble with spelling and word recognition:

With MND, some people experience changes to thinking and the way they process information. For example, spelling may become an issue. If this makes word grids or text based software difficult to use, you may find symbols and images quicker to identify. If you are being assessed for communication aids, explore this type of difficulty with your speech and language therapist to ensure your needs are met.

“ New formats generally need to be got used to.”

Where can I try out different communication aids?

A speech and language therapist, with relevant experience of MND, can advise on solutions suited to your needs. They may demonstrate some of them or refer you to a specialist centre to try out a variety of equipment, with advice about how it can be funded.

Speech and language therapists who are unfamiliar with MND, may find our *AAC Pathway* useful. This helps them identify likely communication needs and appropriate solutions to suit each individual. This is available to professionals through our Communication Aids Service.

See Section 12: How we can help you for contact details.

Is there funding for communication equipment?

Try not to rush into private purchases before being assessed, as communication aids can be 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: your speech and language therapist is your main contact to find out what is available.

The MND Association: we may be able to offer a limited amount of financial support or equipment loan for communication needs, where health or social care services cannot supply. This can only be given following an assessment by a speech and language therapist.

See Further information at the end of this section for details about our Communication Aids Service.

Other charities: some organisations will fund communication systems. If employed, your employer may also be able to apply to these organisations for support at your place of work.

Access to Work scheme: this scheme offers advice, support and information for you and your employer. The scheme may help with costs for assistance to enable you to continue working, including communication aids. Contact your local Jobcentre Plus or see: www.gov.uk/access-to-work

See Section 10: Finance, work and social care.

Home communication systems

Seek guidance from your occupational therapist on communication aids around the home.

These include:

Telephones:

If you still have the ability to speak, but have weak arms and hands, try a hands-free system. This will have a built in microphone and loudspeaker so that you can talk without lifting the handset.

Smartphones enable texting, storage of contact numbers, internet access and wider functionality. This includes the ability to download apps or speech software (you can also do all of these with tablet computers and laptops if you need a bigger screen).

Alarms and telecare:

You can wear a small alarm button, usually around the neck or on a wristband. If you are in difficulty and need urgent help, you press the button. A signal passes down a telephone line to alert an emergency service and personal contact of your choice. These are known as telecare assistive technologies. Ask your local adult social care service about systems and costs.

If you just need assistance from someone else in the house, beepers or intercoms are available. You can also use a simple solution, such as a doorbell connected to a switch or pressure pad.

Environmental controls:

You can control electrical devices around the home using remote control to prolong independence. This can include items such as doors and curtains if they have a connecting device fitted. Adapted switches can help you do this, using different parts of your body.

Even if you don't need this immediately, it helps to find out how to access these systems in case your situation changes. Ask about environmental controls if you have a needs assessment with adult social care services. Your occupational therapist can also advise.

Simple plug-in timers can also be used to control heaters, appliances or lighting.

If your speech is unaffected, voice activated support from virtual household assistants can help, using systems such as Siri, Google Assistant, Amazon Alexa or Cortana. These can be operated from a smartphone, computer device or a separate 'pod' and other brands are likely to be developed.

Key points

- If you would like to explore voice banking, look at the options as soon as possible. Your voice has to be recorded before speech problems develop, for the technology to work well.
- If you have speech problems, take your time and say the important things first to make your needs known.
- To avoid wasting time and money on unsuitable aids, get advice from your speech and language therapist first and try out devices before purchase.
- Have regular reviews with your speech and language therapist as your needs change.
- Keep a low tech aid to hand, in case communication devices break down.
- If your speech is becoming affected, try to have important discussions about future planning before it becomes more difficult to question and communicate.

See also [Section 5: Family, children and friends](#) and [Section 11: Planning ahead](#).

Further information:

From our range of information sheets:

- 1A:** *Nice guideline on MND*
- 1B:** *How do I get information in other languages or formats?*
- 7A:** *Swallowing difficulties*
- 7C:** *Speech and communication support*
- 7D:** *Voice banking*
- 13A:** *Sex and relationships for people living with MND*
- 13B:** *Sex and relationships for partners of people living with MND*

From our guides and other publications:

Understanding my needs: a booklet in which you record your needs and preferences to guide all those involved in your care.

MND Alert Card: a card to carry in a purse or wallet that alerts medical staff that you have MND if you are unable to communicate. You can add key contacts onto the card.

MND Alert Wristband: a wristband that alerts medical staff that you have MND if you are unable to communicate. It includes a warning that you may be at risk with oxygen and a web link for professionals if they need more detail.

Information to pass to your health or social care professionals:

P10 Voice banking

MND Association AAC pathway: our full and summary guidance for professionals providing support on communication aids.

Download our publications at:

www.mndassociation.org/publications

Or order them from **MND Connect**, our support and information helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**.

MND Connect can also help you find external services and providers, and introduce you to our services, where available in your area, including your local branch, group, Association visitor or regional care development adviser (RCDA).

See [Section 12: How we can help you](#).

Communication Aids Service:

For guidance about speech and communication support contact

0808 802 6262 or email:

communicationaids@mndassociation.org

Online forum:

A safe place to share information and support with others affected by MND at:

<http://forum.mndassociation.org>

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For references and acknowledgements please refer to the full guide, *Living with motor neurone disease*.

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**This resource has been evidenced,
user tested and reviewed by experts.**



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