



8: Speech and communication

This section will help you understand how MND can affect your ability to communicate and what can help.

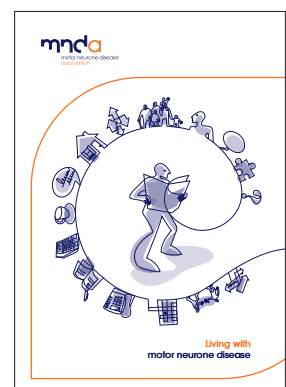
The following information is an extracted section from our full guide *Living with motor neurone disease*.

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 will help you understand how MND can affect your ability to communicate and what can help.

We all need to get things done and to share our thoughts and feelings with others. Communication is not just about speech and writing. We also express ourselves by gestures, facial expressions, laughter and tears.

MND may affect your ability to do all these things. One of the main challenges of living with MND is to overcome these problems, if they happen.

This is important, not only to reduce any sense of isolation, but to remain able to communicate your needs and wishes. It can also help to plan ahead as much as possible, as difficult, sensitive or lengthy discussions may become harder to manage if you do have speech and communication problems.

See Further information at the end of this section for details about our information sheets on speech and communication, and swallowing.

What is happening when we talk?

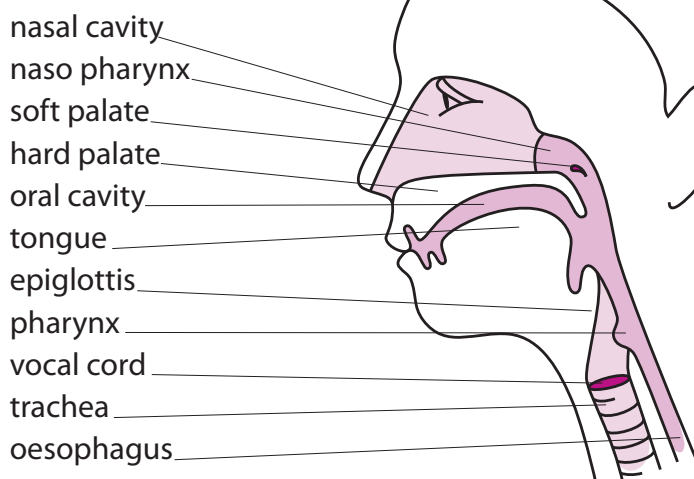
When we speak, air from the lungs passes up the windpipe and through the vocal cords, which vibrate and produce sound. Shaping this sound with the muscles of the tongue, lips, teeth and palate produces speech.

How MND can affect speech

Not everyone with MND experiences problems with speech, but for some people muscles in the mouth, throat and chest are affected. This can cause:

- weakness in the muscles of the tongue and lips, making it difficult to speak clearly

How we speak



- difficulty with sounds such as consonants 'p', 'b', 't', 'd', 'k', 'g'
- weakness of the soft palate, allowing air to leak out of the nose giving your voice a nasal quality
- weak vocal cords, which can make your voice sound hoarse, low pitched and monotonous
- speech to become slow, slurred and indistinct, making it difficult to produce intelligible speech
- problems with muscles in your chest, which can affect your breathing so that your voice becomes soft and faint.

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 if it changes, recommend appropriate therapies or assess your needs for equipment to help you communicate.

Extending your ability to speak, unaided

You may find it helpful to:

- speak more slowly
- pause more frequently to take a breath and clear your mouth of saliva
- over emphasise words and break them into distinct syllables
- save energy by using short sentences
- get your meaning over early in a sentence 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.

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

If speech problems are increasing

- work out some hand signals for frequently used phrases with your immediate family and other carers
- establish a 'yes' or 'no' signal, which could be a particular sound, slight head movement, limb movement, blinks or eyebrow raising
- compile a list of regular questions and requests so your partner can go through the list until you indicate yes or no by an agreed signal.

You may not realise how your voice sounds to others. People close to you are more likely to understand what you're saying, but often strangers can't. Strangers may think that you are drunk, which can be hurtful and embarrassing, or that you have a hearing impairment. It can help to:

- carry a message to explain to strangers and to help you avoid repeating explanations (we can supply pocket sized notepads and a card with an explanation from the MND Association)
- keep a pen and pad handy or a wipe clean 'magic slate' – some people use text phones or computer tablets to type and show what they want to say, but this can become difficult if your arms and hands are affected.

When you know that you are going to be seeing your doctor or other professional, you may find it helpful to prepare a written list of the main things that you want to say or ask.

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 so that you can cope in a wider range of situations.

Advice for families and carers

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

It may help to show them the following tips:

- 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 a hearing loss
- be patient if the person with MND speaks slowly, as it may be taking a lot of effort
- encourage the speaker with MND to pause between phrases and rest often
- encourage over-articulation of speech to make up for slower and weaker movements as this will help make speech clearer
- 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
- if speech is becoming tiring for the person with MND, encourage them to use eye pointing or gesture
- 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?'

Alternative ways of communicating

There are a huge range of techniques and aids to support or replace spoken communication. The term used to describe these is Augmentative and Alternative Communication (AAC).

There is no 'best' type of AAC system for someone with MND. Each solution has pros and cons and the most suitable one for an individual will depend on their personal preferences, abilities and needs.

Specialist assessment, with a speech and language therapist, is necessary to help you identify the most appropriate solutions by considering both current and future needs. This is important as some technologies can be very expensive and will not suit everyone.

There are two main types of AAC system:

Unaided 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 tools (non-electronic) to electronic systems and software technology.

Simple tools include:

- pen and paper
- writing boards, wipe boards, magnetic sketch boards or slates
- communication charts
- letter, word or image boards and books, such as an alphabet board where you point to correct letters or words to create your message. If need be, someone else can scan their finger across the board until you signal 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 available or you can create your own.
- Eye-pointing frames (E-Tran frames) on stiff, transparent plastic allow you to indicate a letter, word or symbol with eye movement.

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

Electronic and software communication aids include:

- voice amplifiers if your speech is clear, but faint
- voice activated computer applications where you have difficulty typing
- voice output communication aids where you have difficulty speaking

- computer based systems, which can range from general email to sophisticated eye gaze systems.

Depending on the system requirements, electronic and software communication aids can be operated on a variety of equipment, including personal computers, laptops, tablets and smartphones. Some solutions are now available as an app (an app is a special software 'application' that can be quickly downloaded and used on portable devices like smartphones and tablets).

" 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 - our information sheet on *Speech and communication support provides more details about communication aids.*

What do I need to consider?

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

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

A portable electronic communication aid may be an easier option. Powered by rechargeable batteries, with a keyboard and display screen, these can be operated by a single switch 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.

" My progress in learning voice recognition gives me hope that I can still negotiate the internet and suchlike without the use of my limbs."

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

If your speech is unaffected, voice recognition systems allow you to operate a computer by speaking commands. If not, you may be able to use adapted switches or more complex eye-gaze systems to continue operating a computer independently. Eye gaze and similar tracking systems allow you to select items on the screen through eye or head movement. For communication aids, you need to be assessed by a speech and language therapist, as not all solutions suit everyone and some can be very expensive.

If you have restricted arm or hand movement, you also need to be assessed by an occupational therapist. Other equipment may be needed, such as arm supports, clamps to hold hardware in place or an adjustable table.

I don't like the synthetic voices on speech systems and would like to know more about voice banking:

Advances in software have made it possible to select a wider range of realistic synthetic voices, which can be used through speech software.

A synthetic version of your own voice may be able to be used if 'banked' before speech problems have advanced. If your own voice has already changed, a friend or relative may be willing for you to bank their voice for use in the future. This may help you to find a voice or accent that feels more suitable.

Voice banking can be expensive, depending on the software used. It may take time and patience, as a lot of words and phrases need

to be recorded for it to work. A speech and language therapist may be able to advise, as these systems are relatively new.

See Further information at the end of this section - our information sheet on *Speech and communication support* provides more details about voice banking.

I don't currently use a computer – is it worth the effort?

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

What happens 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:

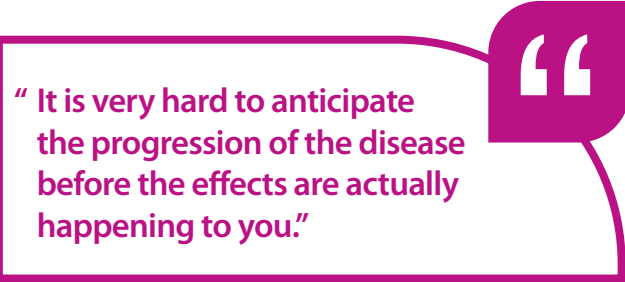
Wireless technology can offer a range of solutions through internet access and apps. Try various options before purchase to find what suits you. For example, some people find touch screens helpful, but if you have restricted hand function a keyboard or alternative method of access may be easier to operate.

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

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

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.



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

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

What you use is likely to change as your MND progresses. Also technology is advancing rapidly in this arena, so improved solutions may become available as your needs change. What may not have been suitable at one point may become relevant in the future, so always be prepared to try something again.

Where can I try out different communication aids?

A speech and language therapist with relevant experience of MND, can advise on the solutions most suited to your needs and will be able to demonstrate some of them. You may also be referred to a specialist centre where you can try out a wide 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 14: *How we can help you for contact details.*

Is there any funding available to help with the cost of 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: you are strongly recommended to consult your speech and language therapist to find out what is available.

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

Other charities: some organisations will fund communication systems. If you work, these sources of help can sometimes be sought through your employer.

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 look for further detail at:

www.gov.uk/access-to-work

For more on work related matters and other financial support, see Section 10: *Your finances.*

Other communication systems

Most of the following solutions are generally available, or seek guidance from your occupational therapist.

Telephones:

It may be helpful to use:

- a hands-free system with a built in microphone and loudspeaker to enable you to talk without lifting the handset
- a mobile or smartphone to enable texting, stored contact numbers and wider functionality

Alarms:

Telephone systems can be activated by a small alarm button, usually worn around the neck or on a wristband. These are known as telecare assistive technologies. Ask your local adult social care service about available systems and costs. This type of system would automatically contact emergency services and a contact of your choice, should you need urgent help.

You may also need to alert others in the house if you need assistance. Special beepers are available or intercoms which can be plugged into 13 amp sockets. You can also use a simple solution, such as a doorbell connected to a switch or pressure pad.

Environmental controls:

These allow you to control electrical facilities around the home, such as the TV, using a remote device. This means you don't have to keep asking for help and can maintain independence for longer.

Ask about environmental controls if you have a needs assessment - even if you don't need this support immediately, it may help to know how to access these systems in case your situation changes.

Key points

- If you have speech problems, take your time, say the important things and ensure you make your thoughts and wishes known.
- If you sense that your speech is becoming affected, you may wish to have difficult discussions while it is still relatively easy to question and communicate.

See also Section 5: Family, children and friends and if you are ready to think about the later stages of MND, Section 11: Planning ahead.

- To avoid wasting time and money on unsuitable aids, get specialist advice from your speech and language therapist even if buying your own communication aids. Always try out devices before purchase.
- Always have a simple method of communication available, especially if you tend to use electronic aids that may break down.
- Try to have regular reviews with your speech and language therapist as your needs are likely to change.
- 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.

Further information:

We have a range of numbered information sheets, including:

- 1A: Nice guideline on MND**
- 6A: Physiotherapy**
- 6B: Complementary therapies**
- 7A: Swallowing difficulties**
- 7C: Speech and communication support**
- 13A: Sex and relationships for people living with MND**
- 13B: Sex and relationships for partners of people living with MND**

We also provide the following publications:

Caring and MND: support for you
a comprehensive guide focused on the wellbeing of family and unpaid carers.

Caring and MND: quick guide
a small A5 booklet to help someone new to the caring role become aware of available support.

Most of our publications can be downloaded from our website: **www.mndassociation.org** or you can order them from **MND Connect**, our support and information helpline:
Telephone: **0808 802 6262**
Email: **mndconnect@mndassociation.org**
MND Connect can also help you 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 (RCDA).

See Section 14: How we can help you.

Communication Aids Service:

For guidance about speech and communication support.

Telephone: **01604 611767**

Email:

communicationaids@mndassociation.org

Online forum:

<http://forum.mndassociation.org> hosted by the MND Association for you to share information and experiences with other people affected by MND.

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

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www.theinformationstandard.org