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Speech and communication support

Information for people with or affected by motor neurone disease, or Kennedy's disease


Motor neurone disease (MND) can cause weakness in the muscles used for speaking, such as the tongue, lips, vocal cords and chest. This can cause speech to become faint, slurred or unclear. If you are living with Kennedy's disease, you may be affected in a similar way and also find this information sheet useful.

This information sheet includes ways to help you to communicate with speech for as long as possible, other 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 are voice banking and message banking?**
- 6: **How do I find out more?**



 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.

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

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

About 9 in 10 people with MND will be affected by weakness of the muscles that help you speak. This can cause:

- speech to become slow, slurred and unclear
- air to escape out of the nose giving speech a nasal sound
- speech to sound hoarse, low pitched and flat
- weakened breathing which causes speech to become soft and quiet
- difficulty with making certain speech 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, often using a mix of approaches.

Discuss your wishes for future care as early as possible, with your main carer, family and health and social care team. You may experience changes to speech and communication that could make these conversations challenging. If you need ventilation support with your breathing, this can also affect your speech.

When MND affects speech, conversations are likely to take longer and feel tiring. Some professionals may not have a great deal of experience with MND, so this could be challenging for them too. It is best to make complex or difficult decisions as early as you feel able to.

For more on how MND affects speech, and the sort of difficult decisions you may need to make, see: Sections 8 and 11 of our *Living with MND* guide

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 our booklet: *Emotional and psychological support*

Ensuring your communication needs are well met can help you cope with changes to your voice and speech. A speech and language therapist (SLT) can offer guidance and equipment to support communication, including having early conversations about voice and message banking. Ask for a referral to an SLT as soon as possible, even if you feel your speech is not yet affected. Your GP, neurologist, MND care centre or network co-ordinator or wider health and social care team may be able to refer you to an SLT. In some areas, you may be able to refer yourself for this type of support.

What is the Communication Access Symbol?



The Communication Access Symbol aims to help you find organisations and venues with staff members trained in communicating with people with communication difficulties. Look out for the symbol as more places adopt it. For more information, see: www.communication-access.co.uk

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

At first, you may be able to adapt the way you speak to make it easier to communicate with those around you.

You may find it helpful to:

- avoid background noise, for example turning off the television when talking
- speak slower
- pause more often 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
- 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 communication aids available that you may wish to use in the future.

Consider making a recording of your own voice while it is still clear. You may be able to use this to create a synthesised voice for use in computer-based communication aids in the future (for example communication aid apps). This is known as 'voice banking'. See section 5: *What are voice and message banking?* to find out more.

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

- If your speech is clear but quiet, a voice amplifier can help others hear you, with less effort, (see also section 3: *Is there anything else that can help me?*)
- if you can write things down, keep a pen and pad nearby
- use a text phone or tablet computer to type and show what you want to say
- use an LCD writing tablet to write on with the pen provided or your finger
- work out some hand signals for frequently used phrases with your immediate family and carers
- try different ways to signal or gesture your needs, in case it gets harder to use your hands, for example, head or eye movements
- create 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
- plan important conversations before you have them, what you want to say and how you could say it with least effort
- 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).



"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'."

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 trying different ways to help you cope in a range of situations.

How can my family and carers help me?



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

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.

General guidance:

- look at each other when speaking and watch the person's face and lips
- for longer conversations, sit in a quiet room and avoid distractions
- Keep a pad and pencil, LCD e-writer or communication board close by (see section 3: *Is there anything else that can help me?*)
- encourage the speaker with MND to pause between phrases and rest often
- encourage the person with MND to emphasise each word 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.

Asking questions:

- 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 and allow the time it takes for the person with MND to answer
- if you are struggling to understand what the person is saying, asking yes or no questions to find out what they were saying can be more helpful than asking the person with MND to repeat themselves.

Agree some 'house rules' for conversations that will help the person with MND communicate in the way they want to, for example:

- while the person with MND is writing their message using pen and paper, make sure no one changes the subject or talks between themselves
- be open with all family, friends and visitors about how they can best support a conversation. Provide support to help them get used to communicating in this new way
- be aware of fatigue and keep visits short, which may allow the person with MND to have rest beforehand
- 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
- instead of finishing someone's sentences (which could be wrong), give them time, then ask if it's okay to suggest what they might need
- don't simplify statements for someone with MND, difficulty speaking does not mean difficulty understanding.

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 are known as augmentative and alternative communication (AAC).

AAC falls into three groups:

Unaided communication (also known as no-tech AAC): this involves techniques using your body, such as body language, gesture, pointing, signing and facial expression. Communicating in this way can help at first, but may become difficult over time, depending on your symptoms. See section 2: *How can I use my own speech for as long as possible?*

Low-tech communication aids: simple, usually non-electronic tools such as word or image pointer boards, notepads and whiteboards. See heading *What simple (low-tech) solutions are there?* for more information.

High-tech communication aids: usually powered by battery or electricity and produce speech or text. This includes speech-to-text and text-to-speech communication devices and software for smartphones, tablet computers, laptops and personal computers. See heading *What high-tech solutions are there?* for more information.

There is no 'best' type of communication aid, as individual preferences, abilities and needs 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 may help to get used to a combination of low-tech and high-tech communication aids, as different types may be more helpful in different situations. If you start to use a communication aid ask for reviews with your SLT as your needs change over time.

It is worth finding out 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. In some areas you may be able to self-refer, check with your health and social care team whether you can do this where you live.

What simple (low-tech) solutions are there?

Low-tech solutions generally 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 or an LCD writing tablet, to save paper. Writing may become more difficult if your arms and hands become affected by MND, so try to practise other solutions as well.

We can provide a pocket sized notepad which contains the words 'I can understand you but have difficulty speaking, please read on...'. If you feel this may be helpful, contact our helpline team, MND Connect, to order (see *Further information* at the end of this sheet for contact details).

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. Your SLT may be able to provide you with a communication board or book, create one for you, or you can create your own.

If needed, 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 high-tech solutions are there?

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

Some of the more advanced systems are very expensive, so it is essential to:

- get advice from your SLT
- trial equipment if possible, before loaning or buying
- arrange funding.

An SLT 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: Some people with MND prefer to use their speech for as long as possible before using other methods of communication. A voice amplifier can maximise the volume of speech. This can be helpful if your speech is clear but faint. A range of different microphones are available, such as handheld, headsets and ones that clip onto your clothes.

Voice output communication aids (VOCAs): These are also 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 tracker. Once selected, the VOCA will speak for you using either recordings of a human voice or a computerised (synthetic) voice. Similar technology exists for making telephone calls, if speaking becomes difficult, (see *Relay UK* in *Useful organisations* at the end of this sheet).

Computer based systems and communication apps: 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 can save words and phrases you use regularly so you don't have to type them every time. You may also 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 now have this function built in, or you can download speech-to-text software or apps. This technology exists for making telephone calls (see *Next Generation Text Service* in *Useful organisations* at the end of this sheet).

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, head support or trying different positioning 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, such as 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 work with your occupational therapist to look at different ways of using a control or a switch. These often use a part of your body that can still move well, such as 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 sometimes find spelling or reading difficult. Discuss your spelling difficulties with your SLT to ensure these needs are taken into account. They may be able to provide strategies and ideas 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 our booklet *Changes to thinking and behaviour with MND*

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

As MND progresses, your needs for communication equipment are likely to change. It is important to think about this, especially if you are thinking of buying equipment yourself, as it may only be helpful for a short time. 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.

Be prepared to try something again, as an aid that is unsuitable now may become helpful in the future. Technology is rapidly advancing 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 is to choose a tablet or other type of communication aid, rather than using a program on a computer. These are usually powered with rechargeable batteries, with a keyboard and display screen.

If you have limited hand movement, you can operate these another way. 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. Ask your SLT for more information.

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 means of communication if:

- you are unable to use a high-tech option in a particular place, such as the bathroom
- 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 yet had one. You may be able to try out various communication aids before a final decision is made. If your SLT can provide you with a suitable communication aid, this may be available for long term loan.

Depending on your needs, you may be referred to a specialist centre for a more detailed assessment. It is important for the assessment to consider your future needs, so that possible solutions take into account how MND is likely to progress. 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: ask 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 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. Contact your SLT if there is a problem with the equipment. 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 or communication aids on loan where the NHS, or your local health and social care trust in Northern Ireland, 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 aid?

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


Depending on how advanced your speech difficulties are, it may be possible to record your own voice, which can be used to create a computerised (synthetic) voice, for future use on a computer or tablet. This is known as voice banking.

Voice banking works best before your speech shows any changes at all. You record yourself speaking as few as 50 phrases, (but most providers need more) and they can create your banked voice. If your voice has begun to change there are still options for recording your voice such as voice repair.

You can also 'bank' messages, where you record yourself saying set phrases, as well as phrases that may be personal to you, which can then be played on a communication aid. Ask those close to you if you have any sayings or speech habits you say a lot, that they like hearing. Message banking can be helpful for when you want phrases or sounds to be played exactly how you would say them yourself, for example:

- saying 'I love you'
- calling a pet over to you
- your laugh
- reading a bedtime story if there are children or young people in your family.

It is a good idea to look at completing both voice and message banking together.

 For more detail on voice and message banking, see:
Information sheet 7D – *Voice banking*

 See our short animation *What is voice and message banking?* at:
www.mndassociation.org/speech

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 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).

AbilityNet

Provide free IT support for older people and disabled people.

Telephone: 0800 048 7642

Email: enquiries@abilitynet.org.uk

Website: www.abilitynet.org.uk

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, search for
health and social care trusts)

Association for Rehabilitation of Communication and Oral Skills (ARCOS)

Charity that can provide communication equipment on loan and training for carers.

Address: Hatherton Lodge, Avenue Road, Malvern, Worcestershire WR14 3AG

Telephone: 01684 576795

Email: admin@arcos.org.uk

Website: www.arcos.org.uk

Communication Matters

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

Address: 3rd Floor, university House, University of Leeds, Leeds LS2 9JT

Telephone: 0113 343 1533

Email: admin@communicationmatters.org.uk

Website: www.communicationmatters.org.uk

GOV.UK

Online government advice on a variety of welfare topics for people living in England and Wales, including support for disabled people.

Website: **www.gov.uk**

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**

MND Scotland

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

Address: 6th Floor, Merchant Exchange, 20 Bell Street Glasgow G1 1LG

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website: **www.mndscotland.org.uk**

NHS UK

The main online reference for the NHS.

Website: **www.nhs.uk**

NHS 111

The NHS 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 (England and some areas of Wales)

NHS Direct Wales

Health advice and information service for Wales.

Telephone: 0845 4647 (or 111 if available in your area)

Website: **www.nhsdirect.wales.nhs.uk**

Health and Social Care Northern Ireland (NHS Northern Ireland)

Online information on health and social care services in Northern Ireland.

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**

Relay UK Team

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, Internal Box 14, Telephone House,
170–175 Moor Lane, Preston, Lancashire PR1 1BA
Telephone: 0800 7311 888
Textphone: 0800 500 888
Email: text.relay.helpline@bt.com
Website: www.relayuk.bt.com

The Sequal Trust

A charity which can provide communication aids to disabled people.

Address: The Sequal Trust, 2C Wharf Road, Ellesmere SY12 0EL
Telephone: 01691 624 222
Email: info@thesequaltrust.org.uk
Website: www.thesequaltrust.org.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: <https://acecentre.org.uk/project/speakbook/>

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 project allowing people at risk of losing their voice to store an unlimited amount of recorded messages to play back later.

Website: www.mymessagebanking.com

References

References used to support this document are available on request from:

Email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park, Northampton NN3 6BJ

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Further information

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

1A – *About the NICE guideline on motor neurone disease*

7A – *Swallowing difficulties*

7B – *Tube feeding*

7D – *Voice banking*

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

Emotional and psychological support - Identifying difficult emotions that may happen for people with a diagnosis of MND and their carers.

Changes to thinking and behaviour - Some people with MND experience changes to the way they think and behave. This guide includes information for people with MND, their carers and families.

Our animation – *What is voice and message banking?* along with other animated overviews: **www.mndassociation.org/animations**

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 MND Association staff.

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park,
Northampton NN3 6BJ

MND Association website and online forum

Website: **www.mndassociation.org**

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

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with or affected by MND, or Kennedy's disease. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

To feedback on any of our information sheets, access our online form at:
www.smartsurvey.co.uk/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, Francis Crick House, 6 Summerhouse Rd,
Moulton Park, Northampton NN3 6BJ



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