MND Association

7C

Speech and communication support

Information for people with or affected by Motor Neurone Disease (MND) or Kennedy's disease

With motor neurone disease (MND) or Kennedy's disease, you may find the muscles you use to speak get weaker, including the tongue, lips, vocal cords and chest muscles. Your speech may become faint, slurred or unclear. This information sheet looks at ways to help you use speech for as long as possible and explore other ways to communicate when needed. The content includes:

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?**

Trusted Information Creator
Patient Information Forum

This content has been evidenced, user tested and reviewed by experts. See: piftick.org.uk

This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.

This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in section 5: **How do I find out more?**

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

About 9 in 10 people with MND are affected by weakness of the muscles that help control speech. This can affect people with Kennedy's disease too.

These changes 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 over time. This can make it increasingly difficult to communicate. Techniques and equipment can all help and a mix of approaches often works best.

Discuss your wishes for future care as early as possible, with your main carer, family and health and social care team. This can feel emotional, but changes to speech and communication can make these conversations even more challenging.

If you need ventilation support with your breathing, this can also affect how you speak.

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.

See our booklet: **Telling people about MND**.

If you find it harder to communicate, you may feel mixed emotions, including:

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

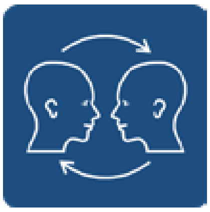
See our booklet: **Emotional and psychological support**.

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 early conversations about voice and message banking.

Ask for referral to an SLT as soon as you can, even before your speech is affected. Your GP, neurologist, MND care co-ordinator or wider health and social care team can refer you. In some areas, you may be able to refer yourself for this 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 and see: **communication-access.co.uk**

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

At first, you may be able to change how you speak to communicate, including:

- avoiding background noise, for example turning off the television when talking
- speaking more slowly and pausing often to take a breath
- clearing your mouth of saliva before you speak
- emphasising words and breaking them into distinct syllables
- using short sentences or starting them with a key word to make your point
- using gestures to emphasise or replace speech.

As symptoms progress, speech and communication can become more tiring. It can also become harder for others to understand you, so it is worth being aware of the types of communication aids available. You may wish to use these in the future.

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

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 future use in communication aids or apps on mobile devices. This is known as voice banking, covered later in this sheet.

See also information sheet: **7D Voice banking and message banking** and our animation **What is voice banking and message banking?** at: **mndassociation.org/animations**.

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
- if your ability to write is unaffected, keep a pen and pad nearby
- use a text phone or tablet computer to type and show what you want to say
- work out hand signals for common phrases, to use with your family and carers
- if it gets harder to use your hands, try head or eye movements
- keep a list of regular questions or needs so that others can go through this until you signal yes or no
- plan discussions in advance, so you can say what you need with least effort
- carry a message to avoid repeating yourself with others (we supply notepads and a speech card to help).

“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’”.

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?

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.

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

For 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, communication board or screen device close by
- encourage the person with speech difficulties to pause and rest often
- ask the person to emphasise each word to make their speech clearer
- if they find speaking gets too tiring, suggest they gesture or point with their eyes.

When asking questions:

- use questions that only need a yes or no answer, such as, ‘Would you like a cup of tea?’ rather than ‘Would you like tea or coffee?’
- ask one question at a time and give time for the person to answer
- if you don’t understand what they’re saying, ask yes or no questions to find out. This is more helpful than asking them to repeat something.

Agree how to approach conversations:

- if the person is writing a message on a notepad or device, make sure no one changes the subject or talks between themselves
- be open with all family, friends and visitors about how they can support during conversations and help them as they get used to this
- be aware of fatigue and keep visits short, so the person can rest before and after
- don’t change your speed or volume of speech, unless the person has hearing loss
- be patient if the person speaks slowly, as it may be taking a lot of effort
- instead of finishing their sentences (where you could be wrong), give them time and ask if it’s okay to suggest what they might need
- don’t simplify your words, difficulty speaking does not necessarily mean they have difficulty understanding.

3. Is there anything else that can help me?

If your ability to speak and communicate is affected by MND or Kennedy's disease, a range of techniques and aids can help. These are known as augmentative and alternative communication (AAC) and fall into three groups:

Unaided communication (also known as no-tech AAC)

This uses physical techniques, such as body language, gesture, pointing, signing and facial expression. This may become harder over time, depending on your symptoms.

Low-tech communication aids

These involve simple tools, usually non-electronic, such as word or image pointer boards, notepads and whiteboards.

High-tech communication aids

These include powered speech-to-text and text-to-speech communication devices, usually through software for smartphones, tablet computers, laptops and computers.

There is no best communication aid, as individual preferences, abilities and needs vary. As some aids can be very expensive and will not suit everyone, seek assessment by a qualified SLT to explore your current and future needs. This can help you find appropriate solutions.

Find out about communication aids before you need them, as you may need to practise. It may help to get used to a combination of low-tech and high-tech aids, to use in different situations. If already using a communication aid, ask your SLT to review your needs if they change.

What simple (low-tech) solutions are there?

Low-tech solutions generally 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.

Writing

If your grip and writing ability are unaffected, using a pen and notepad can be a quick, simple way to communicate. You may 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 are affected, so practise other solutions as well.

See our notepad, with the words: 'I can understand you but have difficulty speaking, please read on…' Order through our MND Connect helpline. Find contact details in section 6: **How do I find out more ?**

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 form a message. Your SLT may be able to provide you with a communication board or book, create one for you, or create your own. If needed, someone else can scan their finger across the board until you signal your choice by blinking, nodding or another method. A laser pointer attached to a pair of glasses, hat or headband can help you signal by moving your head.

Eye-pointing frames (or 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.

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

What high-tech solutions are there?

High-tech communication aids are usually powered by electricity or batteries. They vary in how they work and what they can do. An SLT can refer you to a specialist service if appropriate. As some advanced systems are very expensive, you need to:

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

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 or that clip onto your clothes.

Voice output communication aids (VOCAs)

These are also known as text-to-speech devices, where you select a word, symbol, letters or sentences. This can be done with your finger or by using a keyboard, pointer, adapted mouse, joystick, a switch, or eye tracker. Once selected, the VOCA will speak the words for you using a recorded voice or a computerised (synthetic) voice. Similar technology exists for making telephone calls, if speaking becomes difficult.

Computer based systems and communication apps

These programs vary in style and complexity. They can be used on smartphones, tablets, laptops and computers. In addition to voice output, these systems can be customised by saving common words, phrases and word grids, so you don't have to type them every time. 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 turn your speech into text for communicating by email or other needs. 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 section 6: **How do I find out more?** for Relay UK's contact details, for support with text messages.

What if I have difficulty lifting my head?

If you have problems with the muscles that support your neck, your eye level drops. This can make it more difficult to speak or use communication aids. Some devices can be mounted in a better position, such as on a wheelchair, desk, bed or floor stand.

A collar, head support or different positioning can raise your eye level to help you. An assessment by an occupational therapist (OT) 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.

What if I have limited hand and arm function?

If you find it difficult to use your arms and hands, your SLT can work with your OT 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 or knee
- chin, head or eyes
- breath or mouth.

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 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.

See booklet **Changes to thinking and behaviour**.

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

Your communication needs are likely to change as symptoms progress. Equipment may only be helpful for a short time, so ask your SLT to assess your needs before making expensive purchases. Let your SLT know about any symptom changes, rather than waiting for a review and be prepared to try something again. An aid that is unsuitable now may become helpful in the future as technology improves.

What if I have never used a computer?

Most communication devices can be programmed to suit your computer ability, as well as your communication needs. If needed, your SLT can help you find other ways to communicate, and teach you and those who support you how to use the device.

Another option is to choose a simple tablet or other communication aid, rather than using a computer app.

These are usually powered with rechargeable batteries, with a keyboard and display screen. You type a sentence so the machine can speak it, from a range of voices. If you have limited hand movement, you can operate these another way. 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 no-tech, low-tech and high-tech options. This ensures you have a means of communication if:

- you are unable to use a high-tech option in a particular place, like 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.

Your SLT may be able to provide a suitable communication aid on long term loan. You may be able to try out various communication aids before a decision is made.

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 your symptoms are likely to progress. If you qualify, 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.

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

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 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 fund communication systems.

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 information sheet: **10E Work and motor neurone disease**.

What if I choose to buy my own communication aid?

If you decide to buy a communication aid, 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.

Before making a purchase, it's worth checking the following with private suppliers:

- Do they offer free trials of the equipment?
- Do they offer ongoing advice, training and support?
- Who do you contact if the equipment stops working?
- How long does a repair or replacement usually take?
- Does the equipment needs to be serviced regularly?
- Do they offer extended warranties?

Try to check if anyone else has any experience with the supplier and product.

5. What are voice banking 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 and personal phrases. These can then be played on a communication aid.

Ask those close to you if you have sayings or speech habits they like hearing. Try to complete voice and message banking together, so the tone of voice is the same.

Message banking can also be helpful for phrases or sounds you want played exactly how you would say them, such as:

- saying ‘I love you’
- calling a pet over to you
- laughing
- reading a bedtime story (for any children or young people in your family).

See also information sheet: **7D Voice banking and message banking** and our animation **What is voice banking and message banking?** at: **mndassociation.org/animations**.

6. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

Adult social care services
Use the following search terms to find your local adult social care services.
Website: find your local council at **gov.uk** (England and Wales)
health and social care trusts at **nidirect.gov.uk** (Northern Ireland)
find my council at **careinfoscotland.scot** (Scotland)

AbilityNet
Provide free IT support for older people and disabled people.
Tel: 0800 048 7642
Email: enquiries@abilitynet.org.uk
Website: **abilitynet.org.uk**

Association for Rehabilitation of Communication and Oral Skills (ARCOS)
Charity that can provide communication equipment on loan and training for carers.
Tel: 01684 576795
Email: admin@arcos.org.uk
Website: **arcos.org.uk**

Communication Matters
Supports people of all ages with little or no clear speech.
Tel: 0113 343 1533
Email: admin@communicationmatters.org.uk
Website: **communicationmatters.org.uk**

Government information
Online government information about benefits and support.
Website: **gov.uk (**England and Wales)
nidirect.gov.uk (Northern Ireland)
gov.scot (Scotland)

MND Scotland
Care, information and research funding for people affected by MND in Scotland.
Tel: 0141 332 3903
Email: info@mndscotland.org.uk
Website: **mndscotland.org.uk**

NHS and UK healthcare
Information about NHS Services and healthcare across the UK.
Tel: 111 (England, Wales and Scotland)
Available via individual trusts website contact page (Northern Ireland)
Website: **nhs.uk** (England)
nhs.wales (Wales)
hscni.net (Northern Ireland)
nhs24.scot (Scotland)

Relay UK Team
Call others by typing messages that a relay assistant will read out to the other person.
Tel: 0800 7311 888
Textphone: 0800 500 888
Email: text.relay.helpline@bt.com
Website: **relayuk.bt.com**

The Sequal Trust
A charity which can provide communication aids to disabled people.
Tel: 01691 624 222
Email: info@thesequaltrust.org.uk
Website: **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: **acecentre.org.uk/resources/speakbook**

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: **mymessagebanking.com**

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Nicky Withford-Eaton	Lecturer and Speech and Language Therapist, Birmingham City University.

References

References used to support this resource are available on request:
Email: infofeedback@mndassociation.org

Or write to:

Information feedback,
Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road
Moulton Park
Northampton NN3 6BJ

Further information

We offer a wide range of information about MND and Kennedy's disease. You may find the following resources helpful, relating to this sheet.

Information sheets

1A NICE guideline on Motor Neurone Disease
7A Swallowing difficulties
7B Tube feeding
7D Voice banking
10E Work and motor neurone disease

Booklets

Caring and MND - quick guide
Emotional and psychological support
Changes to thinking and behaviour

Large guides

Living with MND
Caring and MND - support for you

Other resources

Our animation **What is voice and message banking?** and other animated overviews at: **mndassociation.org/animations**

Search for information by need at: **mndassociation.org/careinfofinder**

Find information for professionals at: **mndassociation.org/professionals**

Download our information at: **mndassociation.org/publications**

Find information in other languages at: **mndassociation.org/languages**

Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect
Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: **mndassociation.org/mndconnect**
Tel: 0808 802 6262
Email: mndconnect@mndassociation.org

Support services
Find out about our support services at: **mndassociation.org/our-services**

Local and regional support
Find out about our branches and groups at: **mndassociation.org/local-support**

MND Association Benefits Advice Service
For help to identify claims and how to apply, visit: **mndassociation.org/benefitsadvice** or call our MND Connect helpline.
Tel: 0808 802 6262

MND Association website and online forum
Website: **mndassociation.org**
Online forum: **forum.mndassociation.org**

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 MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on this or any of our information sheets, access our online form at:
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
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or you are a carer, contact us at:
infofeedback@mndassociation.org

Motor Neurone Disease Association
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Tel: 01604 250505
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