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

If you are living with motor neurone disease (MND), it is likely that the muscles in your mouth, throat and chest will be affected. If you are living with Kennedy’s disease, the muscles in your tongue and lips may be affected. This can cause speech and communication difficulties, and you may need to consider other ways to communicate.

This might mean using communication aids. If computer-based, these often have a voice output, so that what you type in can be ‘said’ out loud. If you wish to use a computerised version of your own voice with a communication aid in the future, you can ‘bank’ your voice.

You can also ‘bank’ recorded messages, where you may want your communication aid to say things exactly how you would with your natural speech.

This information sheet explains how voice banking and message banking work. The content is split into the following sections:

1: What is voice banking?
2: How do I bank my voice?
3: What is message banking?
4: 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: What is voice banking?

MND can cause weakness in the tongue, lips, soft palate (back of the roof of the mouth), vocal cords and chest, causing speech to become faint, slurred or unclear. If you are affected in this way, you may need to communicate in other ways. This is often called alternative and augmentative communication (AAC).

AAC includes the use of communication aids, which range from low-tech aids, such as a pen and paper, to high-tech aids that are powered by electricity or batteries.

For more information about a range of speech and communication aids, see: Information sheet 7C – Speech and communication support

Powered communication aids are often provided with standard voices that speak the messages you enter into them. This can be very useful, but you may feel a loss of identity when communicating with a different voice to your own.

“Knowing that my voice was probably going to be lost spurred me on to look at voice banking.”

Voice banking is where you can record yourself reading a set list of sentences. A voice banking provider then uses your recording to create a version of your own voice. If needed this can be used on a communication aid so the voice sounds more like you.

If you prefer, instead of reading a set list of sentences you may find it easier or more motivating to read the short, illustrated storybook I Will Always Be Me. See section 2: How do I bank my voice? under heading What does voice banking involve? for more information.

What will my banked voice sound like?

Your banked voice will resemble parts of your natural voice. It won’t be identical, but it will sound similar to you. People will recognise it as you, rather than a standard voice provided on a powered communication aid.

The clearer your voice is when recording, the higher quality the banked voice will be. This means that the earlier you record your voice, the better. Voice banking is more effective if the phrases are recorded before your voice has been seriously affected by MND. Voice banking will not repair your speech in any way.

“Speech can deteriorate rapidly, as in my husband’s case, so there is a timescale to work towards.”

You can still bank your voice if MND has started to affect it, but you will hear the changes in your own voice reflected in the version created by the voice banking provider.
Does voice banking work for everyone?

Everybody is different and voice banking may not be suitable for everyone. You may decide low-tech communication aids work better for you. You may also prefer to use the standard voices that already exist on some devices, as these may be clearer. See also What if I can’t bank my voice? in section 2: How do I bank my voice?

“This technology became available too late for me… more emphasis is needed on getting started immediately after diagnosis.”

Even when using high-tech or powered communication aids, it is a good idea to get familiar with some low-tech aids as a backup. This way, if your communication aid fails for any reason, you can still communicate another way.

Depending on the provider you choose to bank your voice with, the process can be demanding and you may find it tiring. However, you can complete the voice banking process in ‘chunks’ over a number of sessions if needed.

“I did about 150 sentences in a session, no more. Don’t rush, and try to ensure the room remains quiet without a change in background noise.”

For more on fatigue with MND, see our booklet, Personal care

2: How do I bank my voice?

Who can help me to bank my voice?

You might not need any help, but voice banking services should provide guidance on how to bank your voice on their website. If you need support with this, your health and social care team may be able to assist.

Ask for information about voice banking from health and social care professionals as early as possible. Being fully informed about your options can enable you to make decisions based on your needs and preferences.

Your speech and language therapist (SLT) may be able to arrange for support and training for you, and for anyone helping you to record your voice. If you would like to discuss voice banking, ask your GP or wider health and social care team for a referral to an SLT as soon as possible. Your SLT can assess your needs to work out which communication aids will best suit you and whether your voice can be successfully banked.

You may also need the help of a friend or family member to:
• operate the computer controls required for voice banking programs
• help with anything physical, for example putting on headphones
• resolve any technical issues
• help with downloading the software, logging in and entering passwords.

MND Connect and our MND Association Communication Aids Service can also provide guidance on the voice banking process. See Further information in section 4: How do I find out more? for details.

What equipment will I need to bank my voice?

Check with your speech and language therapist (SLT) or voice banking supplier before buying equipment to bank your voice, as unsuitable purchases can be costly. Your SLT may be able to loan some of the equipment needed for the voice banking process.

Our MND Association Communication Aids service may be able to loan the necessary equipment if you do not own it or if it cannot be loaned from your SLT. See Further information in section 4: How do I find out more? for details.

You will need the following:

**Voice banking service:** A number of voice banking services are available. We are not able to make recommendations, but to help your search, we have listed some of the available options under Voice banking services in section 4: How do I find out more? New services continue to emerge as the technology improves. Discuss with your SLT, wider health and social care team or MND Connect, before making a choice on which voice banking provider will work best for you.

You can also ask other people with or affected by MND about voice banking through our online forum, at: https://forum.mndassociation.org which provides a safe space to share experiences and support.

**Computer:** Voice banking services are accessed online, so for most services you will need a PC or laptop with access to the internet for at least some parts of the process. Certain services may need you to use a particular internet browser. Your voice banking provider will be able to advise you on this. The computer you use will also need to have a USB port, so you can plug a suitable microphone into it.

Usually tablet computers and smart phones are not powerful enough to bank your voice. However, some services are beginning to offer apps that allow you to voice bank on tablets or smartphones. But it is likely that the voice created will be of a poorer quality compared to one created using a PC or laptop with a headset microphone.
Once created, you can use your banked voice in communication aid apps on your tablet or smart phone. Look at which communication programme you might want to use before recording, as not all tablets and apps will be compatible with all banked voices.

**Microphone:** If using a PC or laptop it is important to use a high quality headset microphone, as the better the recording is, the better your banked voice will sound. These microphones plug into the USB port of a computer or laptop. Desktop or built-in microphones on PCs or laptops are **not** suitable.

Your voice banking provider will be able to advise you on the type of microphone they recommend. Position the microphone to the side of the mouth, level with the jaw, to avoid feedback or breathing noises.

**Somewhere to do the recordings:** Record your voice somewhere quiet with no background noise. It does not need to be as quiet as a recording studio, so voice banking can be done at home. Remove anything that may make a noise and affect the recordings, for example a telephone or ticking clock.

Some voice banking services will ask for test recordings first to check the recording is suitable. It is important to record in the same place every time. Try to record at the same time of day - many people with MND find that their voice is strongest in the morning. It can be useful to have a drink to hand to keep your mouth and lips moist.

**What does voice banking involve?**

Voice banking usually involves recording yourself saying a number of phrases, using a computer program. Depending on which voice banking service you choose, the number of phrases you need to record can range from 50-3000.

You may find it takes less time to read the online storybook *I Will Always Be Me*, which banks your voice as you read. Recording can take as little as half an hour depending on your symptoms. The process of reading the short storybook, which is written from the viewpoint of someone living with MND, may appeal more to you than a list of phrases. You could share the experience with your family or friends, or simply find it a motivating way to finish the task of recording all the phrases you need. See section 4: *How do I find out more?* for further details.

Depending on the strength of your voice and how tired you become, voice banking can take different lengths of time for different people. However you choose to start banking your voice you can always pause and go back to reading and recording at a pace to suit you.

“I found it very therapeutic actually recording my voice. Every day, 10am, coffee and biscuits, shutting myself in my study for an hour a day for 10 days.”
You may need to pay a fee at the start of the voice banking process, or to download your banked voice on to your own device. These prices can vary, so:

- contact voice banking providers in advance to find out the cost before you begin the voice banking process
- check that the voice banking service you choose is compatible with the computer or tablet and the software or app you wish to use your banked voice on.

The Communication Aids Service at the MND Association can provide guidance on up-to-date costs for each service. The service may also be able to provide a limited amount of funding to support with the voice banking process. See Further information in section 4: How do I find out more? for contact details.

You need to have a compatible device, with the correct software or app that your banked voice can be programmed into.

The steps are as follows:

1. Register with your preferred voice banking service. Check whether you need to pay before or after you complete the recordings. If seeking funding from our MND Association Communication Aids Service, submit a support grant form before you make any purchases.

2. Your voice banking provider may ask you to complete a test recording to check the noise levels and microphone are suitable. This is usually straightforward.

3. You can change settings, such as the language, if this is available.

4. Record a short set of phrases and send these to the service to be checked.

5. If the recordings are successful, the voice banking service will tell you to continue recording the remaining phrases. It may take more than one try to get the recording quality right, so don’t be discouraged if the first attempt is unsuccessful.

Once recording is complete, your voice banking service will create a voice from the recordings. The created voice will vary depending on the service used. For more information, contact our Communication Aids Service. For details, see Further information in section 4: How do I find out more?

What if I can’t bank my voice?

If your voice is weak or unclear, some voice banking services offer ‘repaired’ synthetic voices that blend in other voices or can even design your own bespoke synthetic voice from scratch.
Alternatively, someone else can record their voice for you to use. This needs to feel right for you both. You may want to ask a friend or relative with a similar voice or accent to help with this. Although their banked voice will not be based on your own voice, it may be closer than standard voices on communication aids. Discuss this first with those close to you, such as a partner or family members, as they may feel differently about you using somebody else’s voice to communicate.

If using a ‘repaired’ voice or asking someone else to bank their voice for you does not feel right, you can still use different types of AAC to communicate with people. This includes using the standard voices available on powered communication aids. These voices may not sound like you, but should be clear in quality. In most cases, there will be a range of male and female voices on offer, so you have a choice.

“Regardless of which system I used, the problem I had was with the dexterity of my hands. I managed it but I am guessing that if someone has less mobility in their hands that it would be an issue.”

For suggestions on how to open conversations about the disease, see our booklet: *Telling other people about MND*

### 3: What is message banking?

Message banking is where you record key phrases and store them to play back exactly as you recorded them. This can be helpful when tone and emotion are particularly important, for example:

- calling your pet over
- your laugh
- reading a bed time story if you have children
- saying ‘I love you’

You can use a combination of banked messages and your banked voice with a communication aid. With message banking, you can only play the exact recordings you have made, so it is a good idea to think ahead with those close to you about the sort of things you may wish to record.

**What equipment do I need to bank messages?**

You can use specialist software and apps to bank messages. However, you can also use devices you may already own to make recordings, such as:
• a mobile phone or tablet device
• a computer

Communication devices and apps that are compatible with a banked voice are also likely to be able to play banked messages. Always check this with your health and social care team, MND Connect or the MND Association Communication Aids Service (see Further information at the end of this sheet for contact details).

4: How do I find out more?

Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information. The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation or have any questions, contact our MND Connect helpline (see Further information at the end of this sheet for details).

We have split these organisations into two groups in alphabetical order for ease of reference. The first group contains a list of currently available voice banking providers, and the second a list of other organisations that you may find useful.

Voice banking services

CereVoice Me
Online voice cloning tool that allows you to create a computer version of your own voice. Cerevoice Me voices are compatible with various text to speech software programs on Windows, Apple OS (Mac) and Android devices.
Email: through the website contact page
Website: www.cereproc.com/en/products/cerevoiceme

I Will Always Be Me
Bank your voice as you read a short online storybook called I Will Always Be Me. Developed by leading technology companies, including Dell and Intel, this project is supported by the MND Association. Using the latest technology, the facility helps you record the story for free. SpeakUnique then creates your digital voice from the recording as a paid service. The MND Association has funding with help from Dell and Intel to support people with MND to take part. You can then use your digital voice with the SpeakUnique app on a communication aid.
Email: support@iwillalwaysbeme.com
Website: www.iwillalwaysbeme.com
**ModelTalker**
Speech synthesis software package designed to benefit people who may lose or are losing their ability to speak. ModelTalker voices are compatible with various text to speech software programs on Windows, Android, Apple OS (Mac) and iOS devices (iPads and iPhones).

Email:  staff@modeltalker.org  
Website:  [www.modeltalker.org](http://www.modeltalker.org)

**My-own-voice**
This web service allows you to create a synthetic voice using your own voice. My-own-voice voices are compatible with various text to speech software programs on Windows, Android, Apple OS (Mac) and iOS devices (iPads and iPhones).

Email:  through the website contact page  
Website:  [www.acapela-group.com/solutions/my-own-voice](http://www.acapela-group.com/solutions/my-own-voice)

**SpeakUnique**
SpeakUnique creates personalised synthetic voices for use in communication aids, and can create ‘repaired’ synthetic voices by blending in other voices. SpeakUnique voices are compatible on Windows, Android and IOS devices (iPads and iPhones).

Email:  info@speakunique.co.uk  
Website:  [www.speakunique.co.uk](http://www.speakunique.co.uk)

**The VoiceKeeper**
Voice banking technology used to create and preserve an authentic version of your voice. Also available as an iOS (iPad or iPhone) app requiring no need for a laptop, PC, headset or microphone. TheVoiceKeeper voices are compatible on Windows devices.

Email:  through the website contact page  
Website:  [www.thevoicekeeper.com](http://www.thevoicekeeper.com)

**VocaliD**
Online synthetic voice creation. Vocalid voices are compatible with various text to speech software programs on Windows devices.

Email:  hello@vocalid.ai  
Website:  [https://vocalid.ai](http://https://vocalid.ai)

**Other useful organisations**

**AbilityNet**
Offer free IT support to older people and disabled people.

Telephone:  0800 269 545  
Email:  enquiries@abilitynet.org.uk  
Website:  [www.abilitynet.org.uk](http://www.abilitynet.org.uk)
Adult social care services (sometimes called social services)
For adult social care contact your local authority in England and Wales, or your local health and social care trust in Northern Ireland.
Website:  www.gov.uk
(for England and Wales, search for local authorities)
www.nidirect.gov.uk
(for Northern Ireland, search for health and social care trusts)

Audacity
Free to download software that enables you to make audio recordings. Compatible with Windows and Apple OS (Mac) computers.
Website:  www.audacityteam.org

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 for people in England and Wales on a variety of welfare topics, including support for disabled people.
Email:  email addresses are provided on the website, related to each enquiry
Website:  www.gov.uk

MND Scotland
MND Scotland provides care, information and research funding for people affected by motor neurone disease in Scotland.
Address:  Unit 8, 76 Firhill Rd, Glasgow G20 7BA
Telephone:  0141 332 3903
Email:  info@mndscotland.org.uk
Website:  www.mndscotland.org.uk

NI Direct
Providing government information for Northern Ireland on a variety of welfare subjects, including health services and support for disabled people.
Email:  through the website contact page
Website:  www.nidirect.gov.uk
**Tobii Dynavox message banking**
A pilot project allowing people to record and store an unlimited amount of recorded messages.

Address: Sheffield Science Parks, Cooper Building, Arundel Street, Sheffield S1 2NS
Telephone: 0114 481 0011
Email: through the website contact page

**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](http://speechbubble.org.uk)

**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 Industrial Estate, Moulton Park, Northampton NN3 6BJ

**Acknowledgements**
Special thanks to Lee Millard, living with MND, for his kind permission to use quotes from his work on voice banking, see his blog at: [www.onein400.com](http://www.onein400.com)

We would like to thank the following for their kind assistance and guidance in the original development or later review of this sheet:

Jennifer Benson, Speech and Language Therapist and Cross-Site Clinical Specialist in Dysphagia and Nutrition, Diana, Princess of Wales Hospital, Grimsby

Richard Cave, Advanced Specialist Speech and Language Therapist, Royal Hospital for Neuro-disability, London
Further information

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

7C – *Speech and communication support*
11C – *Equipment and wheelchairs*

We also provide the following guides:

*Living with motor neurone disease* – our main guide to help manage 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
*Making the most of life with MND* – ways to continue activities or hobbies you enjoy.
*Telling other people about MND* - ways to communicate about the disease to family, children, friends and health and social care professionals, including using advocates.

You can download most of our publications from our website at:  
[www.mndassociation.org/publications](http://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](http://www.mndassociation.org)  
Online forum: [https://forum.mndassociation.org](https://forum.mndassociation.org) or through the website.

**Communication Aids Service**  
The Communication Aids Service at the MND Association can provide guidance and support on voice banking, including loans of laptops and microphones to use for the voice banking process. The service may also be able to provide limited financial assistance and communications aids loans if they are unavailable or delayed through health and social care services.

Email: communicationaids@mndassociation.org
What is the Communication Access Symbol?

The Communication Access Symbol aims to help you find organisations and venues with staff members trained to communicate with people with communication difficulties. The symbol is still in its early days, with a small number of organisations currently trained and displaying the symbol. Look out for the symbol as more places adopt the symbol.

For more information, see:
www.communication-access.co.uk

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@mnlassociation.org

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

Last revised: July 2020
Next review: July 2023
Version: 4

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Company Limited by Guarantee No. 2007023
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