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 voice 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 record yourself speaking a set list of sentences, for a voice banking provider to create a version of your own voice to use with a communication aid. This means the voice coming out of the communication aid will sound more like you.

What will my banked voice sound like?

Your banked voice will resemble parts of your natural voice, but it will not be identical. However, your banked voice is still likely to sound similar to you and 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 this will be reflected in the version of your voice that the voice banking provider creates for you.
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, or that you would 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 information on feeling tired, see: Information sheet 11D – Managing fatigue

2: How do I bank my voice?

This section provides guidance if you are considering banking your voice.

Who can help me to bank my voice?

You might not need any help with banking your voice. Voice banking services should provide guidance on how to bank your voice on their website.

However, if you do need support with banking your voice, 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 anyone that can help you 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 the 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.

The MND Association Communication Aids service may be able to loan laptops and USB headset microphones if you do not own the equipment and it cannot be loaned by 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 we detail some of the available options in Voice banking services in section 4: How do I find out more?

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 discuss voice banking with other people with or affected by MND on our online forum. See Further information in section 4: How do I find out more? for details.

**Computer:** Voice banking services are accessed online, so 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.

Tablet computers and smart phones are not powerful enough to bank your voice. However, they can often be used with an app as a communication aid with your banked voice, once it has been created. 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:** 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 what 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 provider you choose to use, the number of phrases you need to record can range from 220-3000. Depending on the strength of your voice and how tired you become, voice banking can take a different length of time for different people. For some it may take a few hours, but other people find it takes weeks.

You do not have to complete voice banking in one sitting, you can spread this out into more manageable chunks over days or weeks, if needed. You can save and return to your recordings whenever you wish to.

“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 what charges may be made 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.
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 you will be seeking funding from the 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 that you can continue to record 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.

You need to have a compatible device, with the correct software or app that your banked voice can be programmed into. 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, someone else can record their voice for you to use, if this feels right for you both. You may want to ask a friend or relative with a similar voice or accent to help with this. Although the banked voice will not be based on your voice, it may be closer than the standard voices available on a communication aid.

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 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.

“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.”
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

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

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, Apple OS (Mac) and iOS (iPads and iPhones) and Android devices.

Email: through the website contact page
Website: www.acapela-group.com/solutions/my-own-voice

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/
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

**Adult social care services (sometimes called social services)**
For adult social care contact your local authority or in Northern Ireland, your local health and social care trust.
Website: [www.gov.uk](http://www.gov.uk) (search for local authorities)  
[www.nidirect.gov.uk](http://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](http://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](http://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](http://www.gov.uk)

**MND Scotland**
MND Scotland provides care, information and research funding for people affected by motor neurone disease in Scotland.
Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA  
Telephone: 0141 332 3903  
Email: info@mndscotland.org.uk  
Website: [www.mndscotland.org.uk](http://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](http://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, PO Box 246, Northampton NN1 2PR

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Further information

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

7C – *Speech and communication support*
11C – *Equipment and wheelchairs*
11D – *Managing fatigue*

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
*Making the most of life with MND* – our booklet on finding ways to continue taking part in activities or hobbies you enjoy.

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, PO Box 246, Northampton NN1 2PR

**MND Association website and online forum**
Website: [www.mndassociation.org](http://www.mndassociation.org)
Online forum: [http://forum.mndassociation.org](http://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
We welcome your views

Your feedback is really important, as it helps us to develop new materials and improve our existing information, for the benefit of people living with MND and those who care for them. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

If you would like to provide feedback on any of our information sheets, you can access an 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, PO Box 246, Northampton NN1 2PR