

P10

Voice banking for people with MND

Information for health and social care professionals

Many people with motor neurone disease (MND) will experience weakness in the bulbar region, affecting muscles of the mouth, throat and tongue. This weakness can lead to problems with speech and voice, which will affect ability to communicate (dysarthria).

Augmentative and alternative communication (AAC) is an important clinical intervention for many people with MND. Some people with MND may want to bank their voice for future use within high-tech AAC systems.

This information is for health and social care professionals. It gives an overview of what voice banking is, what the process involves and where to find more information.

What is voice banking?

Voice banking is a process that allows a person to record a set list of phrases with their own voice, while they still have the ability to do so. This recording is then converted to create a personal synthetic voice. When the person is no longer able to use their own voice, they can use the synthetic voice in speech-generating communication devices to generate an infinite number of words and sentences. The voice created will be synthetic and not be a perfect replica of the person's natural speech, but it will bear some resemblance.

Voice banking is not the same as a digital legacy

If the end goal of the person with MND is not to use a high-tech AAC system with voice output, voice banking should not be considered. Some people confuse it with leaving a digital legacy, such as www.recordmenow.org

How does voice banking work?

The person with MND will record a number of phrases that are then combined to create a synthetic voice. This voice will be used to vocalise any sentence entered into a speech-generating communication device.

The number of phrases to be recorded varies between service providers but, generally, it will be between 600 and 3500 sentences. This will take a minimum of six to eight hours to record over a period of time, usually weeks or months. It may take longer if someone needs to take a lot of breaks.

Does voice banking work for everyone?

Not everyone will be able to bank their voice for future use. People with MND who already have dysarthria may not be able to bank their voice, as sentences need to be pronounced well as they are recorded. Therefore, it is imperative that a person with MND who wishes to bank their voice does so as early as possible, ideally before bulbar symptoms develop.



A discussion about voice banking can be difficult, but any decisions around voice recording are time-limited.”

Richard Cave, Advanced Specialist Speech and Language Therapist

It is possible to bank a voice with mild dysarthria while speech is still fully intelligible. However, it is important to make sure the person with MND knows that the voice they put in will be the voice they get out, not an improved version.

It may be that a conversation about voice banking needs to happen before a person has come to terms with the possibility that they may lose their voice. However, the subject needs to be raised early to give people time to consider whether they want to bank their voice, to give time to complete the process, and for it to have the best chance of being successful.

What equipment is needed for voice banking?

Voice banking service

There is a range of voice banking services available. We are not able to make recommendations, but some of the available options are listed on page 4.

Computer

Voice banking services are accessed online, so a PC or laptop is required, with access to the internet for some or all of the time. Certain services may need to use a particular browser, such as Google Chrome or Internet Explorer. These are free to download on to any computer.

Tablets do not usually have the processing power needed for voice banking, so are not recommended for the recording process. They may, however, be used with the synthetic voice as a communication aid.

Microphone

A suitable microphone is important. This should be a headset model with a USB connection, that allows the person to keep a consistent distance from the mouth to the microphone.

Desktop or built-in microphones on PCs or laptops are not suitable. Individual companies will advise on which headset they feel works best with their software – see individual websites for details.

Recording environment

The recording environment should be quiet and have no background noise. Some of the services need a microphone test to be carried out first to make sure the recording environment is suitable. It is important that the same recording environment is used every time.

Voice banking can work well when the recording is made at home, and it does not need to be as quiet as a recording studio to be successful.

Specialist support

The speech and language therapist may need to support the person with MND for voice recording to have a chance of success:



I have set up and trained the person with MND and their family/carers over more than one visit, kept in phone contact as progress was made, and then helped to download the final voice to the person's device or app.” Richard Cave, Advanced Specialist Speech and Language Therapist

The voice banking process

Depending on the service provider, the process will vary slightly, but follows a similar pattern:

- 1 The person with MND registers with their preferred service provider and pays any required fees.
- 2 An initial calibration test will take place to establish whether the recording environment and microphone are suitable. This is straightforward to do and no technical knowledge or skill is required.
- 3 The person with MND can change settings such as the language, if this is available.
- 4 An initial set of screening phrases are recorded and then automatically sent to the service provider for analysis.
- 5 If the recordings are deemed to be suitable, the person with MND will be notified that they can continue to record the remaining phrases. It may take more than one attempt to get the optimum sound when recording the screening sentences, so the person should not be discouraged if the first attempt is unsuccessful.

Professional support

Family members and carers may need to be trained how to support people with the process of voice banking, if help is needed to operate computer controls or set up the microphone. Professionals may also need to provide support with technical issues, such as:

- how to download the app or operate the software online
- choosing which version of the software is most suitable for which computer
- login and password details
- how to operate the computer control of the software
- how to set up the microphone and volume levels

After recording

Once recording is complete, the voice banking service provider will create a synthetic voice. This can then be downloaded on to a suitable speech-generating communication device, with software or a programme that allows selection and use of the personal synthetic voice.

The synthetic voice created will vary depending on the voice banking service used. Any synthetic voice created should be suitable for use on Microsoft Windows-based software and may also be compatible with Android devices. Apple iOS devices, such as iPads, are less likely to support the synthetic voice, although some apps do allow for this (see page 4).

Tips for successful voice banking

- Use a headset microphone with a USB connection. A suitable device should be available to purchase for under £50. It is best to check with the voice banking service provider before making a purchase. See individual voice banking service provider websites for advice on which headset to purchase for each product.
- Position the microphone to the side of the mouth, level with the jaw, to avoid feedback or audible breath noises. All voice banking service providers offer the chance to re-record any sentence if the recording is not good, and some will rate the recording as you go along.
- Have a drink of water to hand and take regular drinks to keep the mouth and lips moist. This helps to reduce noises made when the lips part to begin speaking.
- Record in the same environment each time. There is no time limit on how long to take to complete the recordings, so it is possible to do this over several days/weeks/months. However, it is recommended that the voice quality remains consistent throughout recording, so it is advisable to complete the process as soon as possible.
- Try to record at the same time of day, if recording on multiple days. For people with MND it is often recommended that recordings are made in the morning, when the voice tends to be strongest.
- If the person's voice is not strong enough to bank, consider using a friend or relative who has a similar sounding voice to make the recordings.



I worked with a family member to record their voice on behalf of the person with MND. This can work well, but it needs a lot of discussion with the person and their family, particularly around issues of identity.”

Richard Cave, Advanced Specialist Speech and Language Therapist

Options for voice banking

We have included details below of voice banking services currently available online. These are not provided as recommendations for any particular service, but as links for professionals to find out more about the options available online. To see our most up-to-date information on service providers, visit www.mndassociation.org/voicebanking

The MND Association is not responsible for the content or products on any of the following websites.

CereVoice Me (www.cereproc.com/en/products/cerevoiceme)

This service currently costs £499, which includes a microphone that is sent to be used for the recordings. Payment is made upfront, but will be refunded if the person is unable to proceed beyond the initial trial phrases. Once the full recording process is started, the costs will not usually be refunded. This product is currently only available in English but will soon include a French option, with other languages to follow. One aspect of this service is that it is possible to tweak the final voice.

ModelTalker (www.modeltalker.org)

As of 1 July 2017, this service costs \$100 US Dollars (about £80), payable when the person downloads the completed voice to their device.

The person will need to purchase a USB headset microphone – see the ModelTalker website for the model they recommend. ModelTalker voices can be used on Windows and Mac-based devices, and iOS and Android mobile devices. They can be built in to the Predictable and ChatAble apps.

ModelTalker is currently only available in American (English) language, but this does not affect the accent of the synthetic voice. During recording, all sentences will be rated with a colour for quality: green being acceptable quality, followed by yellow for adequate and red for unacceptable. Although ModelTalker is set up for American (English) pronunciation, this doesn't make it more difficult to complete recording of the sentences. However, the person recording should aim to accept all sentences rated yellow, rather than making endless attempts for a green rating. This should not affect the quality of the final voice.

My-own-voice (www.acapela-group.com/voices/voice-replacement)

There is currently no charge for completing the recording process, but a charge of around €2400 (approximately £2000) is applied if the person wishes to download their synthetic voice on to a device. They will also need to purchase a microphone to record phrases. The user interface is available in English or French, but recordings can be made in a range of different languages. My-own-voice synthetic voices can be used on the Proloquo4Text app for iPad.

VocaliD (www.vocalid.co)

This service offers 'vocal legacy' and 'bespoke voice' options. Vocal legacy is a voice banking service that someone should use if they are able to record the 3500 sentences required. For information about the 'bespoke voice' service please see the section on Voice Repair on page 5). The cost for both of these services is currently \$1499 (approximately £1200). A microphone would need to be purchased.



I haven't yet come across a person who is not happy with the banked voice compared with the standard offerings on their software. The voice is an approximation, but a recognisable one."

Richard Cave, Advanced Specialist Speech and Language Therapist

Please note, this is not an exhaustive list and other options may be available. Costs or services offered may change at any time.

Message banking

Message banking is a recording process that allows a person to record particular phrases that they may say on a regular basis, such as 'Hello' or 'My name is...'

It can be used to record particular phrases a person may say that are particularly meaningful to them, their family or friends. Messages could be used for humour or include terms of endearment, and may reflect a person's personality or culture. They may also be recorded in different languages. It may be useful to involve family members or friends to suggest ideas for specific messages.

The recorded messages can be played back directly on devices, such as smartphones or tablets. There is no limit to the number of phrases a person can record, but as a synthetic voice is not being produced, it is important to bear in mind that bespoke sentences cannot be created from the recordings at a later date.

If a large number of messages are recorded, thought needs to be given to how these messages are organised.

You can access a message banking service at www.mytobiidynavox.com/messagebank

Alternatively, any Microsoft Windows PC (from Windows 7 onwards) will have a feature, either called Sound Recorder or Voice Recorder, that allows a person to record and save individual phrases. If these messages are saved in mp3 format, they can be used in certain AAC software.

Voice repair

This is a developing technique that uses a database of healthy human voices to supplement a voice that has already deteriorated in quality by the time it is recorded.

The MND Association is involved in a research project in Edinburgh that is capturing regional accents. This project, in time, may be able to offer a UK-wide voice repair service. For more information, please visit www.speakunique.org

VocaliD have launched a voice repair service, called 'Bespoke Voice'. There is currently a charge of \$1499 (approximately £1200). For more information please visit www.vocalid.co

Find out more

If you would like to find out more about voice banking, please contact our Communication Aids Service. This service helps people affected by MND and health and social care professionals with queries about communication aids. The service provides limited financial support for communication aids or some items on loan, if unavailable or delayed through health and social care services.

Our aim is to improve provision and information on a local and national level, through collaboration with professionals. Call **01604 611767** or email communicationaids@mndassociation.org

Other support from the MND Association

We support health and social care professionals to provide the best possible care for people living with MND, their carers and families. We do this in a number of ways:

MND Connect

Our helpline offers help, information and support, and signposting to other services and agencies. The service is for people living with MND, carers, family members, health and social care professionals and Association staff and volunteers who directly support people with MND.

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Information resources

We produce high quality information resources for health and social care professionals who work with people with MND. We also have a wide range of resources for people living with and affected by MND.

Downloads of all our information sheets and most of our publications are available from our website at **www.mndassociation.org/publications**. You can also order our publications directly from the MND Connect team.

MND Association website

Access information for health and social care professionals on our website at **www.mndassociation.org/professionals**

Education

Our education programme is designed to improve standards of care and quality of life for people living with and affected by MND. Opportunities include online modules and face-to-face training, such as conferences and masterclasses. Find out more at **www.mndassociation.org/education**

MND support grants and equipment loan

Where statutory funding or provision has been explored and is not available, we may be able to provide a support grant or equipment loan.

Our support grant service consists of providing care and quality of life grants for people with MND. This service is supported by MND Association branch and group funds, and by the Association's central fund.

Our equipment loan service is focused on three core items of equipment to help people with day-to-day tasks and communication:

- riser-recliner chairs
- specialist communication aids
- portable suction units.

For suction units, a small charge is made to statutory services for carriage, maintenance and cleaning.

Referrals for support grants or equipment loan need to be made by an occupational therapist, speech and language therapist or other relevant health or social care professional. For enquiries about MND support grants or equipment loan, call the MND Support Services team on **01604 611802**, email **support.services@mndassociation.org** or visit **www.mndassociation.org/getting-support**

Wheelchair service

If you are seeking information on wheelchairs, or if there are delays in assessment or provision of an appropriate wheelchair for someone with MND, our wheelchair service may be able to help, through training, joint assessments, advice or support. For our wheelchair service, call MND Connect on **0808 802 6262** or email **wheelchairs@mndassociation.org**

Research into MND

We fund and promote research that leads to new understanding and treatment and brings us closer to a cure. Contact the Research Development team on **01604 611880** or **research@mndassociation.org**. Alternatively, visit **www.mndassociation.org/research** for more information. For the latest research news, visit our research blog at **www.mndresearch.wordpress.com**

Our peer-to-peer research and care community blog (RECCOB) has a number of reporters who write updates on MND-related workshops and events around the world. Subscribe for email alerts at **www.reccob.wordpress.com**

International Symposium on ALS/MND

Each year we organise the world's largest clinical and biomedical research conference on MND. It is the premier event in the MND research calendar for discussion on the latest advances in research and clinical management, attracting more than 800 delegates from at least 30 countries. Find out more at **www.mndassociation.org/symposium**

MND Association membership

Join us now and help fight MND. Membership costs £12 for individuals. It is free for people with MND and for carers, spouses or partners of people living with MND. Call **01604 611855** or email **membership@mndassociation.org**

Local support

Regional care development advisers

We have a network of regional care development advisers (RCDAs) covering England, Wales and Northern Ireland. RCDAs have specialist knowledge of the care and management of MND. They work closely with local statutory services and community care providers to ensure effective support for people affected by MND. RCDAs provide education for health and social care professionals in MND, and are champions at influencing care services in their respective areas.

MND care centres and networks

Care centres and networks are teams of professionals who are specialists in MND. We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist clinical expertise from diagnosis onwards.

Branches and groups

We have volunteer-led branches and groups nationwide providing local support and practical help to people with MND and their carers.

Association visitors (AVs)

Association visitors provide one-to-one local support to people affected by MND. Managed by regional care development advisers, they are volunteers with experience of MND who can visit people affected by MND within their homes or contact them by telephone, email or through local support groups. They can also provide a link with health and social care professionals. You may be in contact with Association visitors following up on queries from the families they support.

Feedback

If you have any feedback on this information sheet, please email **infofeedback@mndassociation.org**

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MND Association

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About us

The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND.

Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them, both now and in the future.

We are the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

Our mission

We improve care and support for people with MND, their families and carers.

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND.

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

About MND

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, sound and feeling.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- It affects people from all communities.
- Some people may experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia.
- MND kills a third of people within a year and more than half within two years of diagnosis.
- A person's lifetime risk of developing MND is up to 1 in 300.
- Six people per day are diagnosed with MND in the UK.
- MND kills six people per day in the UK.
- It has no cure.



mndconnect
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