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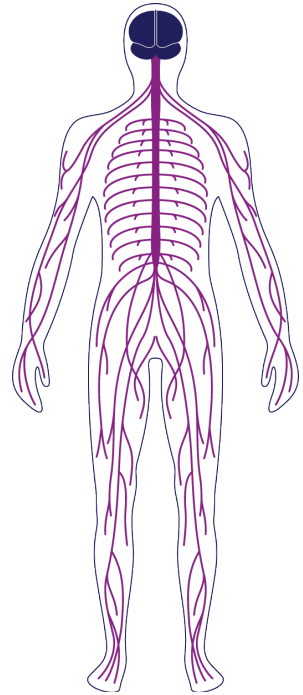
motor neurone disease
association



**Motor neurone disease:
Communication, speech and
language support**

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.
- It can leave people locked in a failing body, unable to move, talk and breathe.
- It affects people from all communities.
- Some people may experience changes in thinking and behaviour, with some experiencing a rare form of dementia.
- MND kills a third of people within a year and more than half within two years.
- 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.



Would you like to find out more?

You can contact our helpline MND Connect if you have any questions about MND or want more information about anything in this booklet.

mndconnect
0808 802 6262
mndconnect@mndassociation.org

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Introduction

Motor neurone disease (MND) is a progressive and ultimately fatal disease caused by degeneration of the motor neurones, or nerves, in the brain and spinal cord.¹

It typically results in loss of ability to walk, use the arms and hands, speak, swallow and ultimately breathe. A third of people with MND die within a year of diagnosis and more than half die within two years.²

More than 80% of people with MND experience slurred, quiet or complete loss of speech (dysarthria).³ 25-30% of people with MND have dysarthria as a first or predominant sign in the early stage of the disease.⁴ Deteriorating speech has a major impact on the quality of life of people with MND and their families, friends and carers.⁵

Once speech problems begin, communication often deteriorates so rapidly that there is little time to implement appropriate support, so timing of referral for assessment and intervention is crucial.

Appropriate support from health and social care professionals, and access to augmentative and alternative communication (AAC) can help people with MND to continue to communicate effectively and improve quality of life.^{6,7}

This booklet contains information on speech and language problems in MND, and the support available. It has been designed to help health and social care professionals to provide appropriate support to people with MND, their families and carers.

Our resources for people with MND include:

Notepad for people with speech difficulties – explains the person has difficulties speaking, with space to write messages

Speech card – can be shown to let others know they have problems speaking but can understand what is being said

Information sheet 7C – *Speech and communication support*

Information sheet 7D – *Voice banking and message banking*

Information sheet 11E – *Environmental controls*

An easy read guide to MND – a guide for people with reading difficulties or learning disabilities

Telling people about MND – a guide about explaining about MND to others

Voice and message banking animation

www.mndassociation.org/speech

Download from **www.mndassociation.org/publications** or contact MND Connect to order hard copies. Call 0808 802 6262 or email **mndconnect@mndassociation.org**

Information in other languages and formats

We provide some of our publications in a range of languages. To help someone make an important decision about treatment and care, we may also be able to translate additional information from our range.

Visit **www.mndassociation.org/languages** for further details.

Causes of communication difficulties in MND

Physical and cognitive changes caused by MND can impact on the person's use of speech and language for communication. Changes to physical function may mask those related to cognitive change.⁸

Physical causes:

MND causes muscle weakness and/or spasticity, reducing range of movement in the tongue, lips, facial muscles, pharynx and larynx.

People may experience:

- speech becoming slow, slurred and unclear
- a nasal quality to their speech due to incomplete closure of the soft palate
- voice that sounds strained, hoarse, low pitched and monotone
- weakened breathing which causes speech to become soft and faint, or cause the person to pause for breath, disrupting the flow of speech
- difficulty making certain speech sounds, particularly consonants such as 'p', 'b', 't', 'd', 'k', 'g'
- difficulty managing saliva at the same time as speaking.

This may rapidly lead to complete loss of speech, even though limb function may be maintained for many months. This is often the case in people with bulbar onset MND, where the muscles in the throat and mouth are affected first.

A small proportion of people with MND are ventilated via a tube in their trachea (windpipe), known as a tracheostomy. A cuff is attached around the outside of the tube, which can be inflated and deflated. Some cuffs can prevent voice production, but some adaptations may allow speech to continue. The options should be explored with the person's respiratory team. If the person lost use of their voice prior to insertion of the tracheostomy, these adaptations will not help to improve speech.

Cognitive causes:

Up to 50% of people with MND experience some degree of cognitive change. This increases to 80% in the final stage of the disease. Up to 15% develop frontotemporal dementia (FTD). People may experience difficulties with social cognition, behaviour, use of language and executive function (the mental processes that enable us to plan, focus attention, remember instructions, and multitask).

Difficulties with language may include:

- reduced verbal expression and initiation (not due to physical disability)
- problems with spelling, which will affect whether people with severe dysarthria can use word-based communication aids
- impaired naming of objects, including difficulty with finding the name of objects presented to them
- perseveration – repetition of a word, phrase, gesture or activity that is no longer appropriate to the situation
- echolalia – repeating parts of another person’s speech that have just been heard
- word-finding difficulty in conversational speech – when people pause to search for an appropriate word or name. This may lead to circumlocution, where people talk around a word as they search for it
- semantic paraphasia – mixing up names for closely associated objects, eg ‘spoon’ instead of ‘fork’
- phonological paraphasia – where people say part of an intended word, eg pun instead of spun
- difficulties understanding complicated sentences
- impaired comprehension of words – sometimes worse for verbs than nouns.

Problems with cognition can affect the ability to use augmentative and alternative communication (AAC). It is important for communication difficulties to be assessed as soon as possible if cognition is affected as there may be a need for early discussions on future planning.

A speech and language therapist (SLT) or occupational therapist (OT) may do an initial assessment of cognition, followed by a referral to a neuropsychologist.

It may be difficult for friends and family to understand the impact of cognitive change on communication, and time should be taken for explanation and support.

Further information

Cognitive change, frontotemporal dementia and MND booklet

Information to share

Changes to thinking and behaviour for people with MND

Download from **www.mndassociation.org/publications** or contact MND Connect to order hard copies. Call 0808 802 6262 or email **mndconnect@mndassociation.org**



The impact of communication difficulties

The psychological impact of losing speech is often overlooked.⁹ Research suggests speech loss, particularly the initial onset, has a strong impact on quality of life.^{6,7}

A speech and language therapist (SLT) can help the person prepare for impending changes to speech and can play a key role in setting realistic expectations, educating carers and family about anticipated change and initiating discussions about AAC.⁶ They can also support the person to bank their voice - see *Voice and message banking* on page 20.

It is essential for health and social care professionals to be aware and sensitive to the emotional and social impact of speech difficulties. People may feel embarrassed and develop a lack of confidence and self-esteem. Some people may withdraw from social situations and become increasingly isolated.

Without appropriate support to make their thoughts and wishes known, the person may lose self-determination and control over their life and their environment. The inability to communicate with others can often lead to frustration, isolation, fear and sadness.⁵

Using appropriate AAC can have a positive impact on quality of life^{10,11}, help people with MND maintain relationships and reduce frustration.

Some people may be reluctant to acknowledge potential speech loss or discuss AAC while their speech can still be understood. However, speech decline may happen rapidly, making the introduction and use of AAC more challenging.

Sensitive discussion and introduction to AAC at an early stage can help the person to come to terms with potential speech loss and plan ahead. See pages 14-19 for further information about AAC for MND.

Information to share

Emotional and psychological support for people with or affected by MND

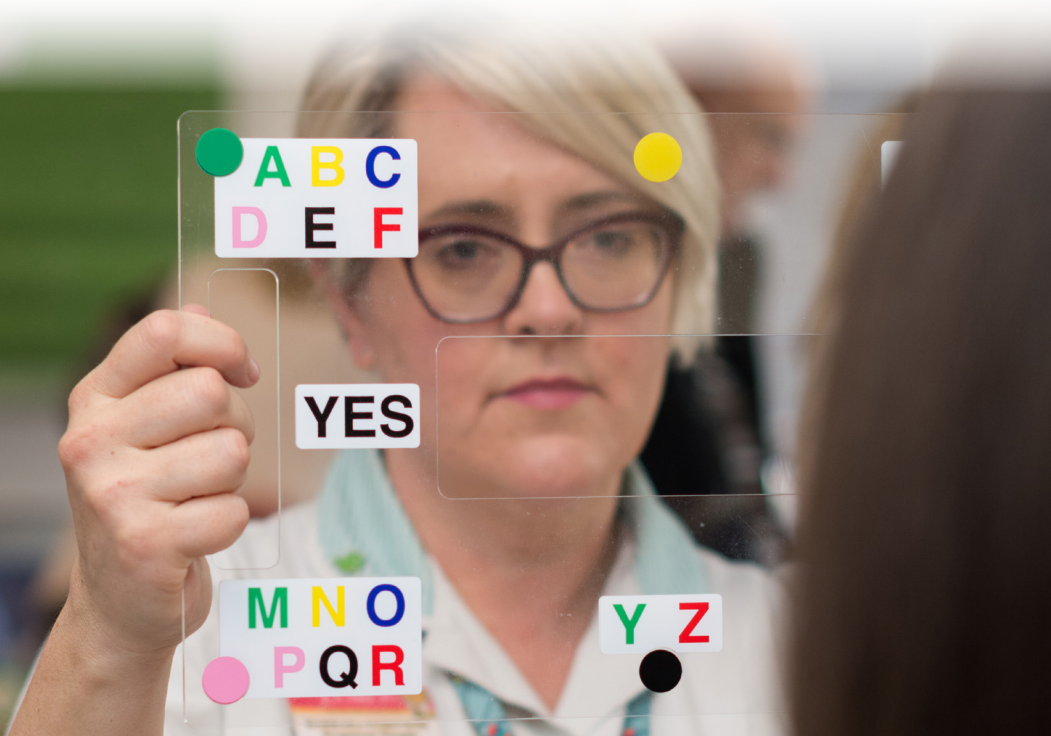
Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Communication Access Symbol



The Communication Access Symbol aims to help people find organisations and venues with staff members trained in communicating with people with communication difficulties. A number of organisations are now trained and are displaying the symbol.

If your organisation would like to sign up, or you would like more information, visit www.communication-access.co.uk



The role of professionals

The NICE Guideline on MND stresses the value of multidisciplinary team working to achieve the best outcomes for people with MND. This type of support is associated with increased survival time and improved quality of life.^{13,14} Good co-ordination and communication between professionals is essential.

The MND Association's AAC Pathway has been developed to provide a framework for service delivery to help professionals better meet the needs of people with MND. See pages 23-31.

Speech and language therapist (SLT)

SLTs provide treatment, support and care for people who have difficulties with communication, eating, drinking or swallowing. They aim to ensure that people with MND always have a way of communicating, regardless of their level of disability.

The local SLT can carry out the initial assessment of the person with MND's communication and swallowing needs. This may include an introduction to AAC and voice banking (see page 20), as well as strategies for communication. Such strategies are important and should form a central part of the clinical intervention alongside any AAC implementation.

The SLT should consider all aspects of spoken and written communication, including use of everyday technology such as the ability to access a phone, tablet or PC for emailing, remote face-to-face communication (eg via Zoom or Skype), access to voice assisted technologies (eg via Alexa or Siri), and wider use of social media.

Some of these aspects will also involve working together with an occupational therapist and assistive technology specialist to find the best solution – see next heading.

Wherever possible, people with MND should be assessed by a therapist with specialist knowledge of MND and AAC. If this is not possible, it is essential for the assessor to have direct access to a therapist with this knowledge.

The local SLT will refer the person with MND to the specialist AAC service for support if their needs cannot be met by the local SLT service and they meet the criteria. For further information, see the AAC Pathway on page 23.

SLTs also play a key role in supporting people affected by cognitive change or dementia to make decisions, demonstrate their mental capacity or express their wishes, preferences and decisions.

Occupational therapist (OT)

Occupational therapists (OTs) can help support communication by providing appropriate seating and positioning to improve posture and mobility.

They can also help identify appropriate access methods to assist a person to use AAC equipment such as switches and pointers controlled by different parts of the body. See page 19 for further information about access methods.

OTs can also provide support in finding solutions to challenges faced by people affected by cognitive change or frontotemporal dementia.

The OT and SLT should work together to provide suitable environmental controls, which may be integrated into the person's AAC device. See page 22 for further information about environmental controls.

Orthotist

Orthotists assess for and provide supportive devices which are worn to help improve function, relieve pain and support the body. In MND, orthotists may be involved in supporting someone with their walking, hand movement or neck support.

In order to effectively use certain communication aids, the person with MND may require an appropriate head support if they have neck weakness. Hand/wrist orthosis can help to keep the hand in a functional position if the person with MND retains the ability to move their hand and experiences spasticity.

Communication strategies

The following are also important in supporting all levels of communication irrespective of speech ability.¹⁶ For practical problem solving, the communication strategies below can be helpful. They are not appropriate for everyone but should be incorporated into any intervention as required.

- Establish how the person with MND prefers to communicate – making communication style preferences explicit can help everyone. There are no hard rules here.
- Encourage the person with MND to make a written list, or store a message on their AAC system before any appointments, of the specific areas they wish to discuss. This is particularly valued by medics with limited time.
- Have a pen and paper or an e-writer such as a Boogie Board handy so that the person, if they are able, can write down any appropriate words: this helps to reduce frustration and misunderstanding.
- It may be helpful for the person to create a list of helpful strategies to share with communication partners.
- Ensure all communication partners are looking at each other when they speak. Lip reading and other facial and gestural cues can help listeners to understand.
- Be aware of fatigue level which directly impacts speech. Phone conversations or gatherings should be planned for times when energy levels are higher and allow for breaks.
- Reduce background noise or talk in a quiet room.
- Ensure the room is well lit so you can see the person's facial expressions and lip movements.
- Encourage the person to alert communication partners if they are shifting topics and name the new topic. Unclear speech is much easier to understand once the context is established.
- If speech is slow, conversations may move too quickly for the person to fully participate. Develop a clear, turn-taking signal or gesture that lets listeners know when they have something to add.

- If combining eating and speaking becomes challenging, the person may consider eating and drinking prior to social gatherings so they can focus on enjoying the company.
- Teach others who occasionally don't understand some words to repeat back any part of a sentence that they did understand rather than saying, "What?". They can substitute the word "blank" for the word they missed. Then the person only has to repeat back the word or words in question rather than saying the whole sentence, saving energy and frustration.
- If they have repeated a few times and it is still not understood, they could consider spelling it aloud or using a finger to spell on the listener's palm or on a table. Often just providing the first letter of the word in question is enough to help others understand.
- Make sure any necessary AAC system is available and the person with MND is in the best position to access it.
- Find out whether the person uses a simple code for 'yes' and 'no' - this can be a movement of any part of the body that can be carried out reliably and does not cause fatigue, for example thumbs up or down, or blinking depending on how MND affects the person.
- Make it easier for the person to contact you - if they struggle to speak on the phone, they may prefer to use email or text messaging.
- Offer to make an audio recording of discussions or appointments so the person can listen back later when they are less fatigued, or if they missed any detail.

Augmentative and Alternative Communication (AAC)

Augmentative and Alternative Communication (AAC) is the term used to describe methods of communication that supplement speech and writing when these are impaired. Although AAC cannot replace natural speech, it can make an important contribution to a person's communication if introduced and supported appropriately. AAC can play a central role in the management of someone with MND. It is difficult to predict when speech problems in MND will develop, and some people experience very rapid speech deterioration once it starts.¹²

Discussions about AAC and voice banking (see page 20) should ideally start as early as possible to help the person become familiar with it before it plays a major role in how they communicate. Such discussions must be managed with sensitivity and should be tailored to the individual's needs.

Information to share

Information sheet 7C – *Speech and communication support*

Download from **www.mndassociation.org/publications** or contact MND Connect to order hard copies. Call 0808 802 6262 or email **mndconnect@mndassociation.org**

Using AAC can help people with MND to:

- maintain relationships
- feel less frustrated
- participate in family and community life
- be more independent
- communicate important decisions about their treatment or care.

AAC ranges from unaided systems, such as signing and gesture, to aided systems, such as low-tech picture or letter charts, through to complex computer technology.¹⁵

The options can be broadly categorised as:

- **low-tech:** simple, non-electronic aids such as pen and paper, communication boards/books
- **high-tech:** computerised devices including voice output communication aids (VOCAs), speech-to-text devices and software for smartphones, tablets and computers.

There is no single best approach to AAC for MND. Most people will benefit from using a range of aids and techniques to support their communication throughout the disease course. A combination of all of the above is often needed, as the most appropriate way of communicating will be very dependent on the communication situation.

Those who choose to use high-tech communication aids benefit from having a low-tech option as a back-up in case of power failure, or a change in their needs that make it difficult to use their high-tech aid. There is also the recognition that one device or system may not work in all situations or environments, so more than one solution may be appropriate.

A comprehensive and cohesive assessment process is necessary to address the total communication needs of the person with MND. See page 23 for information about the AAC Pathway.

Any AAC solutions introduced should consider the progressive nature of MND. Ideally there should be a range of access options that can be adapted as the person's needs change over time, for example an item that initially uses a hand control that can be changed to eye-tracking, or touch screens with adjustable sensitivity.

When a person with MND is no longer able to use their hands to type on a device (known as direct access), alternative access methods will need to be considered, such as eye tracking or switching and scanning. These methods are critical for ongoing communication, but will also slow down the rate at which communication happens.

This is another time of big adjustment for the person with MND as they adapt to a new, slower way of communicating.

If the person has cognitive change: Consider use of picture based systems. Some people will communicate through their behaviour and expressions of emotions. This requires a flexible approach and use of verbal and non-verbal communication techniques to establish what works best for the person. Approaches may need to adapt as the person's cognitive needs change.

Low-tech

A low-tech, non-electronic option should be introduced even if a person uses a high-tech system. There will always be situations when it may be easier and more appropriate for the person with MND to use a low-tech communication system and it is important to have a back-up system in case technology fails. Options include:

- **Alphabet chart:** This can be used for improving intelligibility of speech with a technique called initial letter pointing. The person points to the first letter of each word as they say it. This paces the speech and also gives the conversation partner a clue to the initial letter of the target word. An alphabet chart can also be used for spelling out complete words. They can be provided in a QWERTY or ABC layout according to preference.
- **Alphabet chart or phrase chart used with partner scanning:** The communication partner scans through the alphabet or phrase chart by pointing to each letter or phrase. The person with MND uses an agreed way to indicate when the target letter or phrase is reached.
- **Eye transfer board or frame (E-Tran):** This is a transparent plastic board printed with colour-coded letters. The person with MND can spell out words to a communication partner by looking first at the letter group and then at the colour block of the target letter.
- **Speakbook:** This is a template communication book which contains messages the person can select using their eyes using a similar system to the eye transfer frame. It is customisable and can be used in any language. It can be downloaded for free, and once printed it can be laminated to be used with dry-wipe pens. Visit <https://acecentre.org.uk/project/speakbook>

- **Writing:** Where possible, this will be the preferred method of communication for some people. As well as using paper sheets or a notebook, a wipe-clean whiteboard or LCD writing tablet such as a Boogie Board may also be used.

High-tech

Over recent years there has been a high demand for flexible systems that can be used for both face-to-face communication and computer access.¹⁴

Some commonly used high-tech communication aids include:

- **Voice output communication aids (VOCAs):** The person can select a word, symbol, letters or sentences with their finger or, if needed, using a keyboard, pointer, adapted mouse, joystick, a switch, or eye tracker.

Once selected, the VOCA will 'speak' the words or sentences the person has typed, using either recordings of a human voice or a digitised (synthetic) voice. If the person with MND has carried out voice and/or message banking (see page 20), their synthetic voice and recorded phrases will be added to these devices.

Some VOCAs are 'dedicated' devices – designed just for typing and speech output but many are now computer-based systems using communication apps. These programmes come in a range of styles and vary in their complexity.

Programmes are available for mainstream equipment, including personal computers, laptops, tablets and smartphones. In addition to voice output, these systems can be customised. For example, the person may be able to make their own on-screen word grid.

They can be operated by different parts of the body using adapted mice, joysticks, switches or other equipment. They can also be integrated with social media programmes and environmental control systems (see page 22).

- **Speech-to-text programs:** If a person has difficulty typing due to weakness in their arms or hands, but still has use of their voice, these programs can help turn speech into text for communications such as emails and letters. Many computers, smartphones and tablets now have this function built in, or you can download speech-to-text software or apps.
- **Voice amplifiers:** Some people with MND prefer to use their speech for as long as possible before using other methods of communication. An amplifier can maximise the volume of speech where volume has reduced due to breathlessness, which is helpful if articulation is normal. A range of different microphones are available, such as handheld, headsets and ones that clip onto clothing. A voice amplifier will not be of value for people with dysarthria.

Access methods

There is now a greater choice of access methods including a wide range of joysticks, adapted mice and eye tracking technology (often referred to as eye gaze). With alternative access methods there is the potential to use the internet, which can increase independence and reduce social isolation.

There are a wide range of options including switches that can be operated using virtually any movement of almost any part of the body, muscle movement or breath. New switches known as EMG switches are being developed which can be controlled using the tiny signals which activate muscles. An occupational therapist can help find appropriate solutions.

Communication Aids Service

The MND Association can offer people with MND equipment loan and financial support for communication aids. We can also provide guidance on how to obtain equipment and support from health and social care services. Visit www.mndassociation.org/communicationaids for further information.

Voice and message banking

Voice banking

Voice banking is a process which allows a person to use a synthetic version of their own voice with a VOCA AAC device. In order to bank their voice, the person with MND records a list of phrases with their own voice, while it is strong enough to do so.

This recording is converted to create a personal synthetic voice for use with voice output communication devices. An infinite number of words and sentences can be generated in the synthetic voice using the communication device for when the person is no longer able to use their voice.

People with MND with severe dysarthria may not be able to bank their voice, as sentences need to be pronounced intelligibly as they are recorded. However, some services are able to produce 'repaired' synthetic voices by mixing in other recordings or create synthetic voices from scratch. See Information sheet P10 – *Voice banking for MND* (details on next page) to find out more.

Information about voice banking should be provided as early as possible after diagnosis by the SLT or member of the multidisciplinary team. This needs to be managed sensitively.

If the person with MND decides to bank their voice, the SLT should try to arrange to start the process as soon as possible. If there is no experience of voice banking within the team, advice can be sought from the MND Association. Call MND Connect on 0808 802 6262 or email **communicationaids@mndassociation.org**

The MND Association will fund the cost of voice banking for any individual living with MND up to a maximum of £500 if self-funding is not possible or desired. Unlike communication aid provision, voice banking is not strictly considered to be funded by NHS services, although there is an expectation that NHS services will assist and support with the process of voice banking or to offer advice.

Message banking

Message banking is a process that allows a person to record particular phrases in their own natural voice that they may say on a regular basis, such as 'Hello', 'My name is....' or 'I love you'. It can also be used to record sounds unique to the person, such as their own laugh.

The recorded messages can be organised, stored and played back directly on devices such as smartphones, tablets, or on the communication aid. There is no limit to the number of phrases a person can record with their natural voice, but this may take time and effort, depending on how the person's MND affects them.

Further information

Information sheet P10 – *Voice banking for MND*

Information to share

Information sheet 7D – *Voice banking and message banking*

Download from www.mndassociation.org/publications or contact MND Connect to order hard

Voice and message banking animation

www.mndassociation.org/speech

Voice Banking information from the Royal College of Speech and Language Therapists (RCSLT)

www.rcslt.org/speech-and-language-therapy/clinical-information/voice-banking

www.rcslt.org/-/media/docs/RCSLT_Voice_Banking_A4_4pp_BOOK.PDF

Download from www.mndassociation.org/publications or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org

Environmental controls

Environmental controls can assist someone with MND to operate a wide range of appliances and equipment using a remote control or switch. Environmental controls can be programmed to operate doors, alarms, curtains, lights, fans and almost any other electrical appliance with the appropriate receiver.

The person can select their options using a wide range of switches and buttons – see *Access methods* on page 19. Some have a scan and switch system, where options appear on the screen and the person uses a switch to select when the correct option appears.

Some environmental control systems can be integrated with communication aids, wheelchairs and riser recliner chairs, so a multidisciplinary approach is recommended.

A person with MND can be assessed for suitable environmental controls by the local OT. If the person is eligible, they will be referred to a specialist environmental control service. The referral or assessment may also involve a specialist SLT. In some areas, referrals can be made by any health and social care professional.

Further information

Occupational therapy for motor neurone disease

Information to share

Information sheet 11E – *Environmental controls*

Download from **www.mndassociation.org/publications** or contact MND Connect to order hard copies. Call 0808 802 6262 or email **mndconnect@mndassociation.org**

AAC Pathway for MND

The aim of the AAC Pathway for MND (see next page) is to provide a framework for service delivery to better meet the needs of people with MND.

It aims to help the reader identify the steps involved in the provision of AAC, and to inform commissioners of the infrastructure needed to provide an effective and efficient service to meet the needs of people with MND.

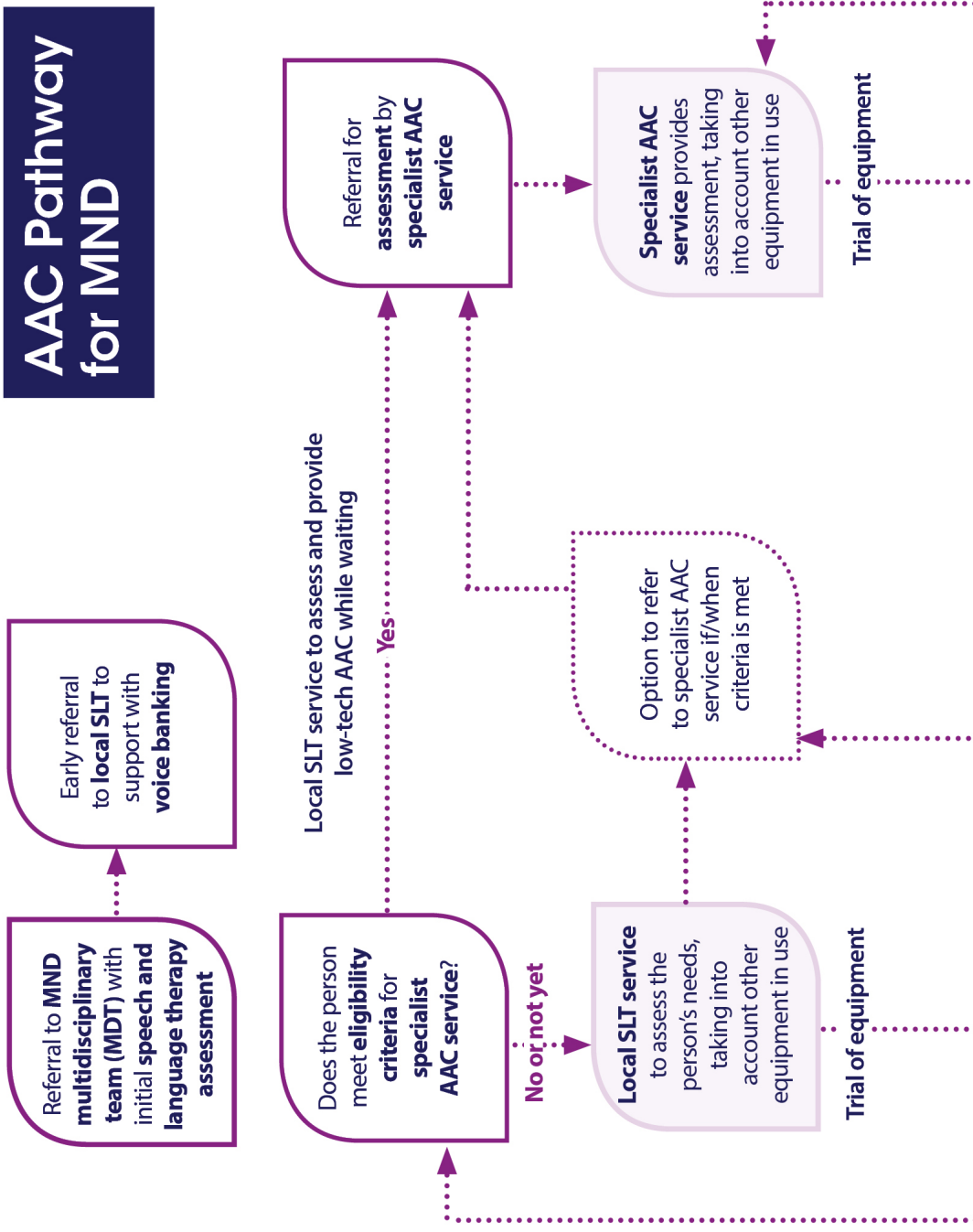
The AAC Pathway for MND is aimed at everyone involved in the care of people with MND, from service providers to individual health and social care professionals. They may also be of interest to people with MND and their carer or family.

The pathway includes information for England, Wales and Northern Ireland. As there is no formal guidance for Northern Ireland, services may not strictly conform to the pathway.

This guide provides a brief summary of the AAC Pathway. The full version is available from <https://bit.ly/AAC-Pathway> or from our MND Connect Helpline. Email mndconnect@mndassociation.org or call 0808 802 6262.



AAC Pathway for MND



Provision

Local SLT service provides equipment

Training and support for person with MND, family and carers

AAC needs and equipment monitored by **local SLT service**

Equipment provided locally returned to **local SLT service**

If there are delays in funding or provision, **MND Association** may be able to provide funding or short-term loan

MND Association provides information about accessing training and support

Equipment provided by MND Association returned when no longer required (unless gifted)

Specialist AAC service provides equipment as appropriate

Training and support for person with MND, family and carers

Equipment needs monitored by **local SLT service** and reviewed by **specialist AAC service**

Equipment provided by **specialist AAC service** returned for recycling

Review

Return

The headings in this section relate to the left-hand column of the AAC Pathway on the previous page.

Diagnosis

A diagnosis of MND triggers eligibility for an assessment by an SLT. This referral will normally come from a neurologist and may be part of a referral to a multidisciplinary team. However, someone with MND may also self-refer to speech and language therapy services.

A person diagnosed with MND should have a referral to the SLT service even if they are not, at that point, presenting with bulbar signs, so that voice banking can be discussed and arranged at the earliest possible opportunity, and information can be shared about AAC.

Referral

All initial referrals for people with MND should be assessed by a therapist with specialist knowledge of MND, AAC and voice banking. If this is not possible, it is essential for the therapist to have direct access to another therapist with this knowledge. The initial assessment may be either at a local clinic, MND care centre or in the person's home.

During the initial referral assessment, a decision should be made about whether the AAC needs of the person with MND can be managed by the local SLT service, or whether a referral to a specialist AAC service is needed.

Assessment

The aims of the initial assessment are to:

- get a baseline measure of communication needs
- share information about AAC, demystify the terminology, the assessment process and funding
- discuss voice banking.

Assessment should include:

- type of MND (bulbar or limb onset) and date of diagnosis
- rate of progression

- spoken, written and digital communication
- physical skills, including mobility and dexterity
- vision and hearing
- speech and language presentation
- cognition - memory, processing and potential for new learning
- past skills and present requirements, especially in relation to technology
- communication environment
- support network
- the current and future needs and concerns of the person with MND and their significant communication partners.

Information about voice banking should be provided as early as possible after diagnosis by the SLT or member of the multidisciplinary team. This will allow the person with MND the best opportunity of completing the process with optimal voice quality.

A low-tech AAC option should be introduced even if a person is using or is likely to use a high-tech system.

Education for family, friends and carers should be considered. It is important to have a way of indicating yes and no consistently that everyone understands.

Assessment at a specialist AAC service

The timing of referral to a specialist AAC service needs to be carefully planned and discussed depending on the nature of the person's MND and the rate of progression.

Referral for specialist assessment can be made on an anticipatory basis, to enable people living with MND and their carers to discuss the various options, feel comfortable using the AAC, and support AAC acceptance and use ideally before it is needed. A late referral may mean that it is difficult to provide equipment, relevant training and support within a reduced time frame.

Specialist AAC assessment should ensure that AAC and environmental control considerations are coordinated. It is recommended to work with wheelchair services to ensure mounting solutions are considered.

Where possible, the local SLT should attend the assessment, as they will also be involved in the ongoing care and support of the person with MND.

Where possible, the system(s) or programme(s) recommended should have alternative access solutions that can be introduced as MND progresses, for example, an item that initially uses direct hand/finger control can be changed to touch screens with adjustable sensitivity, or eye-tracking. This will minimise the need for new learning.

England

In England, people with rapidly progressing diseases, such as MND, can be referred up to 18 weeks prior to meeting the criteria, in the opinion of the treating SLT. This is good practice as an assessment can be a number of weeks after referral to the specialist AAC service.

The referral for specialist assessment should be actioned as soon as possible if the criteria (below) is met, or expected to be met within 18 weeks.

According to the NHS England Communication Aid Service Specification, an individual who would access a specialist AAC service would have both of the following:

- a severe/complex communication difficulty associated with a range of physical, cognitive, learning, or sensory deficits
- a clear discrepancy between their level of understanding and ability to speak.

In addition, an individual must:

- be able to understand the purpose of a communication aid
- have developed beyond 'cause and effect' understanding
- have experience of using low tech AAC which is insufficient to enable them to realise their communicative potential.

If there are no presenting speech or access issues at the point of referral, and the SLT has indicated the situation is unlikely to change within 18 weeks, general information and signposting should be given by the local AAC service. Initial advice on low-tech solutions should be given as appropriate.

Northern Ireland

People with MND who have queries round AAC are encouraged to make early contact with their local Health and Social Care Trust. The local Trust-based SLT works with the person to make decisions around communication needs and will guide them through the AAC assessment and provision processes.

In general, people with progressive neurological conditions such as MND are referred to the Communication Advice Centre (CAC) service for specialised assessment. The referral must be made by the local Trust-based SLT.

The CAC encourages early referral for people with rapidly progressing conditions such as MND so the full range of AAC possibilities for both current and future needs can be explored. The CAC team completes the assessment with the support of the local SLT team. The local SLT and Trust remain responsible for the long-term care and support of the person with MND.

Wales

In Wales, referral to specialist services is largely based on the type of equipment a person requires. Where the need is for low tech or less complex equipment, this must be provided as close to a person's home as possible by the local SLT service.

Where more complex, programmable equipment, which requires the expertise of specialist staff is required, this will be provided via the National Specialist AAC service which is part of the Electronic Assistive Technology (EAT) Service. The staff from the EAT service will work alongside the local team to meet the person's needs.

Trial

Following assessment, (either locally or at a specialist AAC service) there should be an opportunity to trial equipment, software or applications for a minimum of two weeks. The length of time may vary according to the type and availability of equipment. Equipment may be provided from the local SLT clinic or specialist AAC service. A trial can also be arranged direct from a supplier although there may be a cost for this service.

Free trials of software or applications are also available from some suppliers. A review appointment should then be arranged to evaluate the trial before equipment is ordered or purchased by or for the person with MND.

Provision

All costs of AAC should be included in funding applications, even if a negative decision is anticipated. This ensures the true cost of supporting a person with MND in their communication needs is made clear. This may be masked if funding for equipment is not requested from statutory services.

Once a decision is made on the appropriate equipment for the person, a report including the rationale for the decision and a detailed quote should be produced. A copy of the funding report should be available for the person with MND in the event of them deciding to self-fund.

Self-funding, especially of mainstream hardware such as laptops, tablets or iPads should be discussed as an option. This can reduce delays in the supply of an effective system of communication and environmental control.

While funding for AAC equipment is being secured, it may be possible to request a short-term loan of equipment from the MND Association, if the equipment is in stock. There is usually a significant waiting list.

Any equipment remains the property of the organisation that provided it, unless it is gifted to the person.

MND Association support services

Funding for AAC for those with complex needs should be met through specialised commissioning. For those with needs that do not qualify for referral to specialist AAC services, funding for AAC should initially be sought from local statutory services.

If NHS funding has been explored without success, and the welfare of the person with MND is compromised, the MND Association may be able to provide an equipment loan or financial assistance where a need has been assessed by a health or social care professional and/or where support would improve quality of life.

For further information about support grants or equipment loans, call 0808 802 6262 or email communicationaids@mndassociation.org

Training and support

Whether equipment is provided by the NHS or MND Association, the person and any carers should receive training to enable them to feel confident using it. This may include support from the local SLT, specialist AAC centre and/or the supplier. Voice banking support and training can also be provided by the MND Association directly.

All equipment provided must have clear, written instructions to which the person living with MND, their significant others and carers can refer to, as required.

Contact details of the SLT, the specialist AAC provider or the company supplying the equipment should be provided in case there are any problems, and regular proactive follow up should be scheduled.

Review

Ongoing and regular review by the local SLT and the provider of the AAC will be arranged to address changing needs regarding access to technology and/or speech output. As their needs change, the person with MND will need re-referral for assessment or review/reassessment by the specialist AAC centre.

Towards the end of life in particular, it will be important to ensure that low-tech aids are available to support communication requirements, with appropriate training given to the person's significant communication partners and carers.

Return

When equipment is no longer required:

- if provided by the AAC specialist centre, it should be returned to the specialist AAC centre
- if provided by the local SLT service, it should be returned to the local SLT service
- if loaned by the MND Association it should be returned to us for checking, resetting or recycling as appropriate.

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How we can support you

MND Connect

Our helpline offers help, information and support to people living with MND, carers, family and health and social care professionals.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

Information resources

We produce high quality information resources people living with MND, carers, family members and health and social care professionals.

www.mndassociation.org/publications

MND Association website

We have a wide range of information to support health and social care professionals working with people affected by MND.

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.

www.mndassociation.org/education

Support grants and equipment loan

Where statutory provision is not available, we may be able to offer a support grant or loan equipment.

www.mndassociation.org/getting-support

Research into MND

We fund and promote research that leads to new understanding and treatment and brings us closer to a cure.

www.mndassociation.org/research

MND Register

The MND Register aims to collect information about every person with MND to help plan care and discover more about the disease.

www.mndregister.ac.uk

Regional staff

We have a network of regional staff with specialist knowledge of MND. They work closely with local statutory services and community care providers. Contact MND Connect for further information.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

MND care centres and networks

We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist MND care.

www.mndassociation.org/care-centres

Branches and groups

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

www.mndassociation.org/branchesandgroups

Association visitors (AVs)

AVs are trained volunteers who provide one-to-one local support to people affected by MND.

www.mndassociation.org/associationvisitors

We value your feedback

We would greatly appreciate your feedback on this guide. Please visit **www.smartsurvey.co.uk/s/mndprofessionals** or email your comments to **infofeedback@mndassociation.org**

Visit our webpages for health and social care professionals:
www.mndassociation.org/professionals

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