MND Association | For professionals

PG15

AAC pathway for Motor Neurone Disease

Motor Neurone Disease (MND) results from the progressive loss of motor neurones in the brain and spinal cord.[1] These are the nerve cells that control movement. It leads to muscle weakness and can cause difficulties with movement, breathing, swallowing and speaking.[2]

More than 80% of people with MND experience slurred, quiet or lost speech (dysarthria).[3] For some, this is an early or predominant sign of the disease.[4] Speech deterioration can significantly affect the quality of life of people with MND and those around them.[5]

Timely access to appropriate assistive and augmentative communication (AAC), supported by health and social care professionals, can help people with MND communicate for as long as possible and maintain quality of life. The AAC Pathway for MND supports everyone involved in MND care to identify the steps needed to provide effective AAC, and can be used for education and training, assessing clinical practice, and supporting discussions with managers or commissioners about AAC provision.

Information to share with people with or affected by MND:

Information sheet 7C — Speech and communication support

Information for professionals:

Booklet — Communication, speech And language support

See page 16 for details of how to order publications.

1. Introduction

Speech is a powerful medium for expressing identity, communicating mood, emotion, geographical, social and educational background, health status, gender, as well as the content of the message.[8] Once speech problems begin, communication can often deteriorate so rapidly that there is little time to implement effective support, so timing of referral for assessment and intervention is crucial.

Augmentative and alternative communication (AAC) is the term used to describe methods of communication that can supplement speech and writing when these are impaired. AAC ranges from unaided systems, such as signing and gesture, to aided systems, such as picture or letter charts, through to complex computer technology accessed by eye tracking or switches that can be activated with a small movement by a part of the body.[3]

This information sheet focuses on service provision for people with dysarthria. Other communication issues, such as general computer access issues for those with upper limb difficulties in the absence of any speech or language impairment may access a wide range of different, non-AAC services.

AAC support is outlined in England by the NHS Service Specification – “Complex Disability Equipment: Communication Aids (Specialised AAC services)”, and in Wales by the Welsh Health Circular 2019/018 – “Augmentative and Alternative Communication (AAC) Pathway”. Scotland follows the “Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016”. Northern Ireland lacks formal guidance, and services may not align strictly with the pathway and criteria detailed here. This information sheet, developed with local services, will be updated as guidance evolves.

NICE Guideline on MND

In 2016, the National Institute for Health and Care Excellence (NICE) published Guideline NG42 – “Motor neurone disease: assessment and management”. It aims to improve care from the time of diagnosis through to end of life. The guideline includes specific recommendations regarding communication support. These are included in the relevant sections of this information sheet. The NICE recommendations compliment this pathway, and should be taken into account alongside it when supporting someone with MND.

2. Developments in AAC

Over recent years there has, not surprisingly, been a high demand for flexible systems that can be used for both face-to-face communication and computer access.[14] If a person is still able to use speech to verbally communicate, they may still need computer access adaptations to allow them to use forms of communication such as social media and email if they have muscle weakness in their arms.

There is now a greater choice of access methods including a wide range of switches, joysticks, adapted mice and eye tracking technology (eye gaze). Alternative access methods can help a person with MND to keep using their own devices, such as a smartphone or tablet, and access to specialist AAC equipment. If a person with MND can access the internet and apps, their independence can be supported and the risk of social isolation reduced. Development in technology has also given the potential to integrate voice output communication aids (VOCAs) and environmental control programmes.

A single device or system may not work in all situations and more than one solution may be appropriate. A comprehensive assessment process is necessary to address the person's total communication, access, and environmental control needs.

Voice and message banking

Voice banking is a process which allows a person to create a synthetic version of their natural voice. This is done by recording a list of phrases in their own voice, while it is strong enough to do so, or by using existing recordings of their voice. These recordings are converted to create a personal synthetic voice for use as part of a speech-generating communication device. An infinite number of words and sentences can be generated when the person is no longer able to use their voice. Voice banking should be offered as early as possible, ideally before speech quality deteriorates. Alternatively, recordings can be used.

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, calling a pet, or singing songs. Message Banking enables a person to record important and personal messages in their own voice and should be discussed at the same time as voice banking. Some voice banking tools amalgamate voice banking and message banking together into the same system.

Information to share with people with or affected by MND:

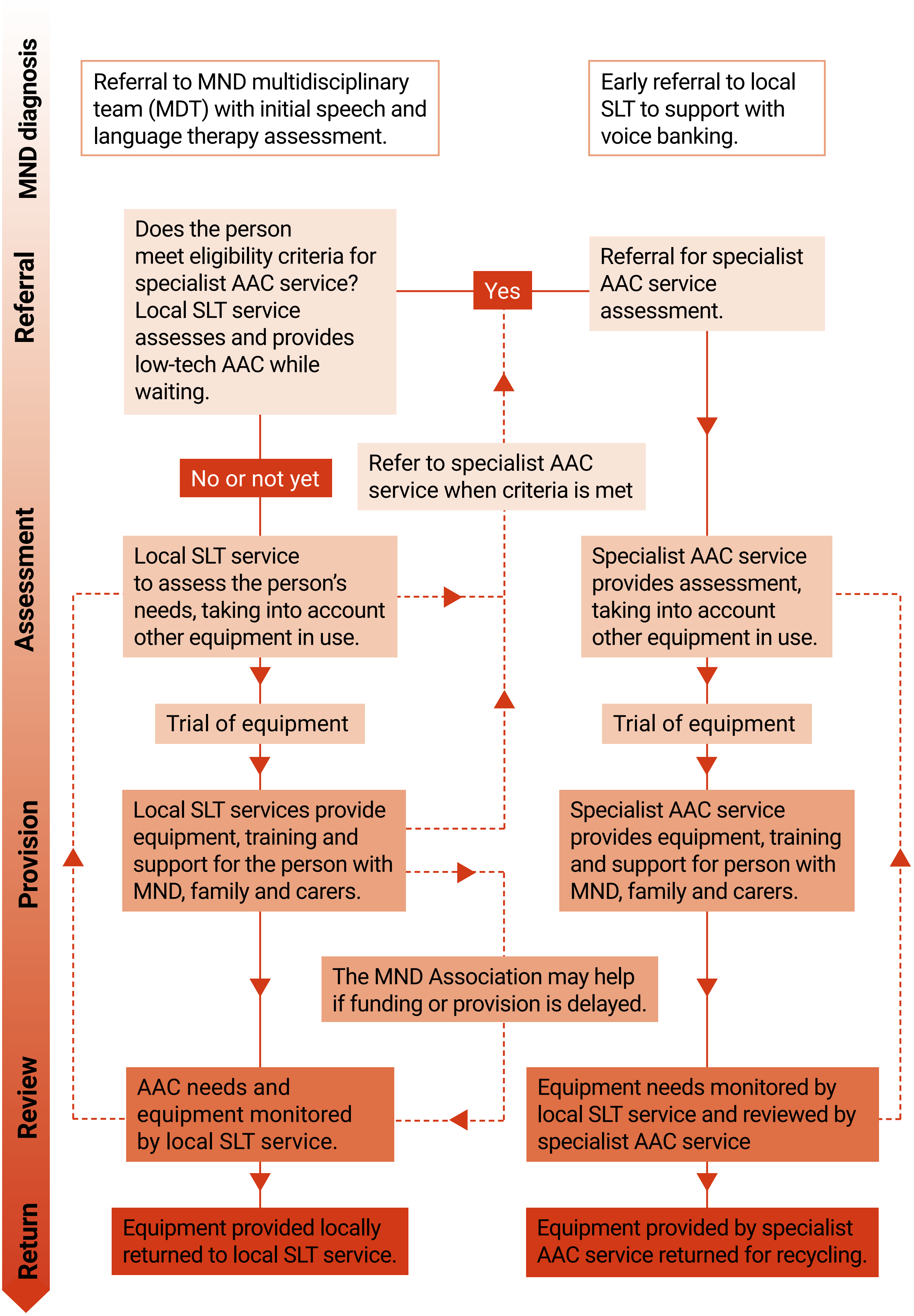
Information sheet 7D — Voice banking

Information for professionals:

Information sheet P10 — Voice banking

See page 16 for details of how to order publications.

3. The pathway



Referral to MND multidisciplinary team (MDT) with initial speech and language therapy assessment.

Early referral to local SLT to support with voice banking.

Does the person meet eligibility criteria for specialist AAC service? Local SLT service assesses and provides low-tech AAC while waiting.

Referral for specialist AAC service assessment.

Refer to specialist AAC service when criteria is met

Local SLT service to assess the person's needs, taking into account other equipment in use.

Specialist AAC service provides assessment, taking into account other equipment in use.

Trial of equipment

Trial of equipment

Local SLT services provide equipment, training and support for the person with MND, family and carers.

Specialist AAC service provides equipment, training and support for person with MND, family and carers.

The MND Association may help if funding or provision is delayed.

AAC needs and equipment monitored by local SLT service.

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

Equipment provided locally returned to local SLT service.

Equipment provided by specialist AAC service returned for recycling.

The aim of the AAC Pathway for MND (see page 4) is to provide a framework for service delivery to better meet the needs of people with MND. The pathway goals are to provide a positive impact on the quality of life of the person and control over their environment. Ultimately, to help maintain independence for longer.

It is important to ensure a comprehensive assessment process that takes account of current and likely future needs, including education, training and support for people with MND and carers. Provision of the right equipment and training provided at the right time can be cost effective.

The desired outcomes are that:

- the current and future communication and access needs of the person with MND and their family or carer are effectively met
- quality of life for the person with MND is maintained or increased
- independence for the person with MND is maintained or increased
- a plan is in place for regular review as the access and communication needs change due to MND progression
- the implemented solution is reliable
- there is availability of technical support if needed
- the person living with MND, significant others and carers have knowledge and skills to know how effectively use and support the use of AAC in daily life.

In addition, an ongoing assessment and review process should lead to a more cost-effective and efficient service with timely provision of appropriate AAC solutions for people with MND.

Please note: The headings below relate to the headings on the left-hand side of the pathway on page 4.

Diagnosis

NICE Guideline recommendation 1.11.1

When assessing speech and communication needs during multidisciplinary team assessments and other appointments, discuss face-to-face and remote communication, for example, using the telephone, email, the Internet and social media. Ensure that the assessment and review is carried out by a speech and language therapist without delay.

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
- information can be shared about AAC, the terminology can be demystified, the various options that may be of use in the future can be discussed
- the assessment process and funding can be explained.

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. This decision may change quickly, so it is important that it is reviewed regularly.

Some people might choose to access support from an independent SLT. People should check that the SLT has sufficient knowledge and experience of MND, AAC and voice banking to be right for them, with access to appropriate equipment. The independent SLT should regularly liaise with the supporting NHS team to ensure good communication and a linked up service. The independent SLT can work alongside or instead of the NHS SLT. Visit **ASLTIP.com** for a register of independent SLTs.

Assessment

The aims of the initial assessment are to:

- get a baseline measure of communication needs, knowledge and expectations that can inform future intervention around AAC
- sensitively share information about AAC, demystify the terminology, the assessment process and funding. It can be useful to demonstrate various options that may be of use in the future, but this depends on whether the person with MND is ready for that conversation. Sometimes it is enough to offer reassurance that they will not be left unable to communicate and there are a variety of options that can be considered when necessary
- support people with MND to make informed choices about what AAC may work for them in their lived experience
- discuss voice and message banking (ideally demonstrate using the therapist's own voice bank). Put in place plans to complete the process if the person with MND decides to proceed.

The World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF) highlights the factors to be considered when assessing an individual for AAC. These should include:

- the individual, their impairment(s), predicted progression, abilities, learning
- their communication requirements, preferences, life experiences and attitudes
- the tasks the individual wishes and needs to undertake
- the individual's care networks and the social, cultural and physical environments in which the individual and their AAC system will operate.[15]

Assessment should therefore include:

- type of MND (bulbar or limb onset) and date of diagnosis
- rate of progression
- spoken and written communication, including email, text messages and social media use
- 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 needs and concerns of the person with MND and their significant communication partners about their current and future speech, communication, and access needs, in all situational contexts that apply (for example work, home, leisure activities), and using different mediums (such as video call, mobile phone, tablet, computer)
- acknowledgement that AAC needs are likely to encompass both high and low tech methods to suit different situations and locations, and consideration of this during assessment.

Information about voice and message 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, or identify alternative methods, such as using existing recordings.

If the person with MND decides to bank their voice, the SLT should arrange to start the process as soon as possible. If there is no experience of voice banking within the team, advice and training can be sought from the MND Association.

A low-tech AAC option should be introduced even if a person is using or is likely to use a high-tech system. There will always be situations when it may be easier and more appropriate for the person to use a low-tech communication system (such as in the bathroom), and it is important to have a back-up system in case technology fails. Options could include alphabet charts, Eye Transfer Board or frame (E-Tran). For some, writing may be the most effective and quick option, using a pen and paper, or an electronic LCD writing tablet (for example Boogie Board).

Education for family, friends and carers is an important area that needs to be planned for. It is important to have a way of indicating yes and no consistently that everyone understands. A method for attracting attention should be agreed, for example using a portable doorbell that they can hold in their hand, a baby monitor, or a switch linked into a built-in buzzer on a communication aid. Some people use a simple bell they can knock with their head, foot etc.

If the person presents with bulbar signs:

- voice amplification could be considered, to help the person to continue communicating verbally for longer
- voice output communication aids (VOCAs) should be introduced when appropriate.

If the person presents with limb weakness (but no bulbar signs):

- alternative methods of access to technology should be introduced
- a referral should be made to the environmental control service, in partnership with the occupational therapist, to explore computer access and environmental control options to enable continued interaction with their environment and technology (for example operating lights/television/radio, accessing the internet/computer programmes). This will also support communication with functions such as email and social media where computer access is needed.

Assessment at a specialist AAC service

NICE Guideline recommendation 1.11.3

Liaise with, or refer the person with MND to, a specialised NHS AAC hub if complex high technology AAC equipment (for example, eye gaze access) is needed or is likely to be needed.

NICE Guideline recommendation 1.11.4

Involve other healthcare professionals, such as occupational therapists, to ensure that AAC equipment is integrated with other assistive technologies, such as environmental control systems and personal computers or tablets.

Referral to a specialist AAC service should align with the individual's MND progression. Early referral allows time for exploration, training, and adjustment before urgent need arises. Delayed referrals risk insufficient time for equipment, training, and support, and may be affected by fatigue.

AAC assessments should coordinate with Environmental Control and, if necessary, wheelchair services for mounting solutions. The local SLT should ideally attend, as they will support ongoing care. The assessment can take place at the specialist service, or wherever best suits the person (for example at home, work, or the hospital).

Training and support should be provided to both the individual and their carers. Systems should allow for alternative access solutions as MND progresses, such as switching from hand/finger control to touch screens or eye-tracking, minimizing the need for relearning.

England[5]

In England, people with rapidly progressing diseases, such as MND, can be referred for specialist assessment 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 should be actioned as soon as possible if the criteria (below) are 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:[5]

- 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 achieve their communicative potential.

Exclusion criteria would be:

- only pre-verbal communication skills
- not having achieved "cause and effect" understanding
- impaired cognitive abilities that would prevent the user from retaining information on how to use equipment.

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[9]

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

Scotland

In Scotland, the Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016 requires health boards to provide communication equipment and support to individuals who have lost their voice or struggle to speak. The Scottish Government's "National Augmentative and Alternative Communication (AAC) Core Pathway" outlines the key elements of care for those needing AAC.

Visit **gov.scot/policies/social-care/assisted-communications** for further details on AAC in Scotland, or contact MND Scotland. Call 0141 3323903 or email info@mndscotland.orguk.

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 an AAC equipment 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

NICE Guideline recommendation 1.11.2

Provide AAC equipment that meets the needs of the person without delay to maximise participation in activities of daily living and maintain quality of life. The use of both low-level technologies, for example, alphabet, word or picture boards and high-level technologies, for example, PC or tablet-based voice output communication aids may be helpful. Review the person's communication needs during multidisciplinary team assessments.

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 for 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 funding quote should be produced. Ideally, equipment should be ordered through companies and suppliers who are able and willing to provide ongoing support as MND progresses.

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 or tablets, and potential mainstream environmental control systems such as Alexa, Google Home or others, should be discussed. This can reduce delays in the supply of an effective system of communication and environmental control.

If a person does not yet meet the criteria for specialist assessment and requires a relatively straightforward, text-to-speech communication aid with direct hand/finger access, then this should be managed by the local SLT service. In Wales, specialist AAC services will provide any device that is programmable, including iPads and other tablets, even if direct access is possible.

While funding for AAC equipment is being secured, it may be possible to request support from the MND Association. Call 0808 8026262 or email connect@mndassociation.org.

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 (for example a person that cannot communicate easily using speech but can control a tablet or a smartphone with their hands), 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, an application can be made to the MND Association for support.[17]

Support grants may be provided by the MND Association where a need has been assessed by a health or social care professional and/or where support would improve quality of life, and where one or more of the following applies:

- equipment or service provision is not the responsibility of a statutory service
- delay in provision by statutory services is unacceptable based on assessed need
- it is provided as a short-term, interim measure while awaiting provision from statutory services.

It is important to engage with local statutory services where they have responsibility to provide equipment. Even where the MND Association provides support, the local SLT teams should continue to work with local statutory services and hold them to account to provide equipment where it is their responsibility.

For further information about support from the MND Association, call 0808 8026262 or email mndconnect@mndassociation.org.

Training and support

NICE Guideline recommendation 1.11.6

Provide ongoing support and training for the person with MND, and their family members and/or carers (as appropriate), in using AAC equipment and other communication strategies.

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.

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. This information may be included as a physical document or an electronic document/webpages.

The SLT, specialist AAC service or the AAC provider must provide training and support for the provided equipment, to the level that the person with MND, their family and carers are comfortable and confident with the daily operation and use of the provided AAC.

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. If a fault occurs, the provider of the equipment should be contacted in the first instance. Wherever possible, a loan device should be provided while the AAC is repaired or replaced.

If faulty equipment is the property of the MND Association, please contact us for advice. Call 0808 8026262 or email connect@mndassociation.org.

All equipment should be maintained in a safe condition.

Review

NICE Guideline recommendation 1.11.5

Ensure regular, ongoing monitoring of the person's communication needs and abilities as MND progresses, and review their ability to use AAC equipment. Reassess and liaise with a specialised NHS AAC hub if needed.

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 or speech output. The local SLT should contact the specialist AAC centre to request a review or reassessment if this is needed sooner than anticipated.

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.

References

1. Bäumer D, et al. ‘Advances in motor neurone disease.’ Journal of the Royal Society of Medicine. 2014; 107(1):14–21.
2. SEALS Registry. For background information on SEALS see ‘Neuroepidemiology’ (2007) 29:44–8.
3. Communication Matters. ‘What is AAC?’ (Accessed: **communicationmatters.org.uk/page/what-is-aac** May 2021).
4. Communication Matters. ‘How Assessment Services are organised in the UK’ (Accessed: **communicationmatters.org.uk/page/assessment-services** May 2021).
5. NHS England. ‘Service Specification for Complex Disability Equipment: Alternative and Augmentative Communication Aids (All Ages).’ (Accessed: **england.nhs.uk/wp-content/uploads/2018/08/Complex-disability-equipment-alternative-and-augmentative-communication-aids-all-ages.pdf** December 2024).
6. Communication Matters. ‘AAC Quality Standard for Commissioners.’ (Accessed: **communicationmatters.org.uk/page/national-standards-aac-services** December 2024).
7. MND Association. ‘Equipment loan for MND.’ Accessed: **mndassociation.org/equipmentloan** December 2024).
8. Nathanson, E. 2016. ‘Native voice, self-concept and the moral case for personalized voice technology.’ Disability and Rehabilitation, 8288(May), 73–81. **doi.org/10.3109/09638288.2016.1139193**
9. Welsh Government (2019). ‘Welsh Health Circular 2019/018 – Augmentative and Alternative Communication (AAC) Pathway.’
10. Scottish Government. Policy: ‘Social care – Assisted Communication support.’. (Accessed: **gov.scot/policies/social-care/assisted-communications** December 2024).

How we can support you and your team

Our MND Connect helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. They can also provide further information about our services mentioned below.
Email: **mndconnect@mndassociation.org**
Phone: **0808 8026262**

MND Association website

Our website offers supporting information on MND, our work, services, and how to get involved.
mndassociation.org/professionals

Stay updated on events, publications and opportunities for professionals.
mndassociation.org/educationupdate
X: **mndeducation**
Bluesky: **mndeducation.bsky.social**

Information resources

We produce high quality information for people with MND, carers, families and professionals, available in multiple formats and languages.
mndassociation.org/pro-info-finder
mndassociation.org/careinfofinder

Education

Our education programme aims to improve standards of care and quality of life. Opportunities include webinars and face to face equipment training.
mndassociation.org/education

MND Professionals’ Community of Practice

A peer led group supporting cross disciplinary learning in MND care. Membership can contribute to CPD and offers access to networking and learning events.
mndassociation.org/cop

Local support

We offer online and local peer support, plus trained volunteers who provide practical help by phone, email or visits.
mndassociation.org/local-support

We fund and develop specialist care centres and networks across England, Wales and Northern Ireland, offering multidisciplinary care.
mndassociation.org/care-centres

Financial support

We offer a range of grants to support people living with MND, their families and unpaid carers. These are not in place of any statutory funding that should be available.
mndassociation.org/getting-support

MND register

The Register aims to collect information about everyone with MND in England, Wales and Northern Ireland to support care planning and research.
mndregister.ac.uk

Research into MND

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND. We also produce information sheets on MND research for people with or affected by MND.
mndassociation.org/research

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We value your feedback

Your feedback helps improve our information for the benefit of people living with MND and those who care for them. Visit **smartsurvey.co.uk/s/mndprofessionals** or email your comments to education@mndassociation.org.

If you would like to help us by reviewing future versions of our information resources, please email us at education@mndassociation.org.

How to order our publications

Our publications are free for anyone with or affected by MND or Kennedy's disease, including professionals. Health and social care professionals can also order items on behalf of someone with or affected by MND or Kennedy's disease.

Download from **mndassociation.org/publications** or contact MND Connect to order hard copies. Call 0808 8026262 or email mndconnect@mndassociation.org.

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

Tel: 01604 250505
Email: enquiries@mndassociation.org
Website: mndassociation.org

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Every day we support people affected by Motor Neurone Disease. Because with MND, every day matters.