

AAC Pathway for motor neurone disease

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 can result in loss of the 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, known as dysarthria.³ For some, dysarthria is 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

Speech is a powerful medium of identity, communicating mood, humour, geographical, social and educational background, health status, gender - as well as the content of the message.⁸ Once speech problems begin, communication often deteriorates 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 low-tech 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

Effective support from health and social care professionals, and access to appropriate AAC can help people with MND to communicate effectively for as long as possible and improve quality of life.

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. It aims to ensure that people with MND get the best possible support in relation to their communication needs by helping professionals to identify the steps involved in providing effective AAC.

The AAC Pathway can also be used to:

- develop standards to assess the clinical practice of health professionals
- educate and train health and social care professionals
- support communication with managers or commissioners on how or why certain clinical practice should be adopted
- improve communication with the person who has MND, their communication partners and carers.

This information sheet focuses on service provision for people with speech impairment. 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.

This document includes information for England, Wales and Northern Ireland. AAC support from England is outlined in *NHS Service Specification - Complex Disability Equipment: Communication Aids (Specialised AAC services)*. In Wales, it is laid out in the *Welsh Health Circular 2019/018 - Augmentative and Alternative Communication (AAC) Pathway*.

Currently, there is no formal guidance for Northern Ireland, and services may not strictly conform to the pathway and criteria in this information sheet. The information in this document has been developed with the support of services to ensure accuracy, and will be updated as the guidance for Northern Ireland develops.

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.

Information to share with people with or affected by MND:

Information sheet 1A – *About the NICE Guideline on MND*

Information sheet 7C – *Speech and communication support*

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

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 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 could 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 total communication, access, and environmental control needs of the person with MND.

Voice banking

Voice banking is a process which allows a person to record 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 speech-generating communication devices.

An infinite number of words and sentences can be generated when the person is no longer able to use their voice. Although some services can repair impaired speech, voice banking should be offered as early as possible, ideally before the quality of speech deteriorates.

Further information

Information sheet P10 - Voice banking

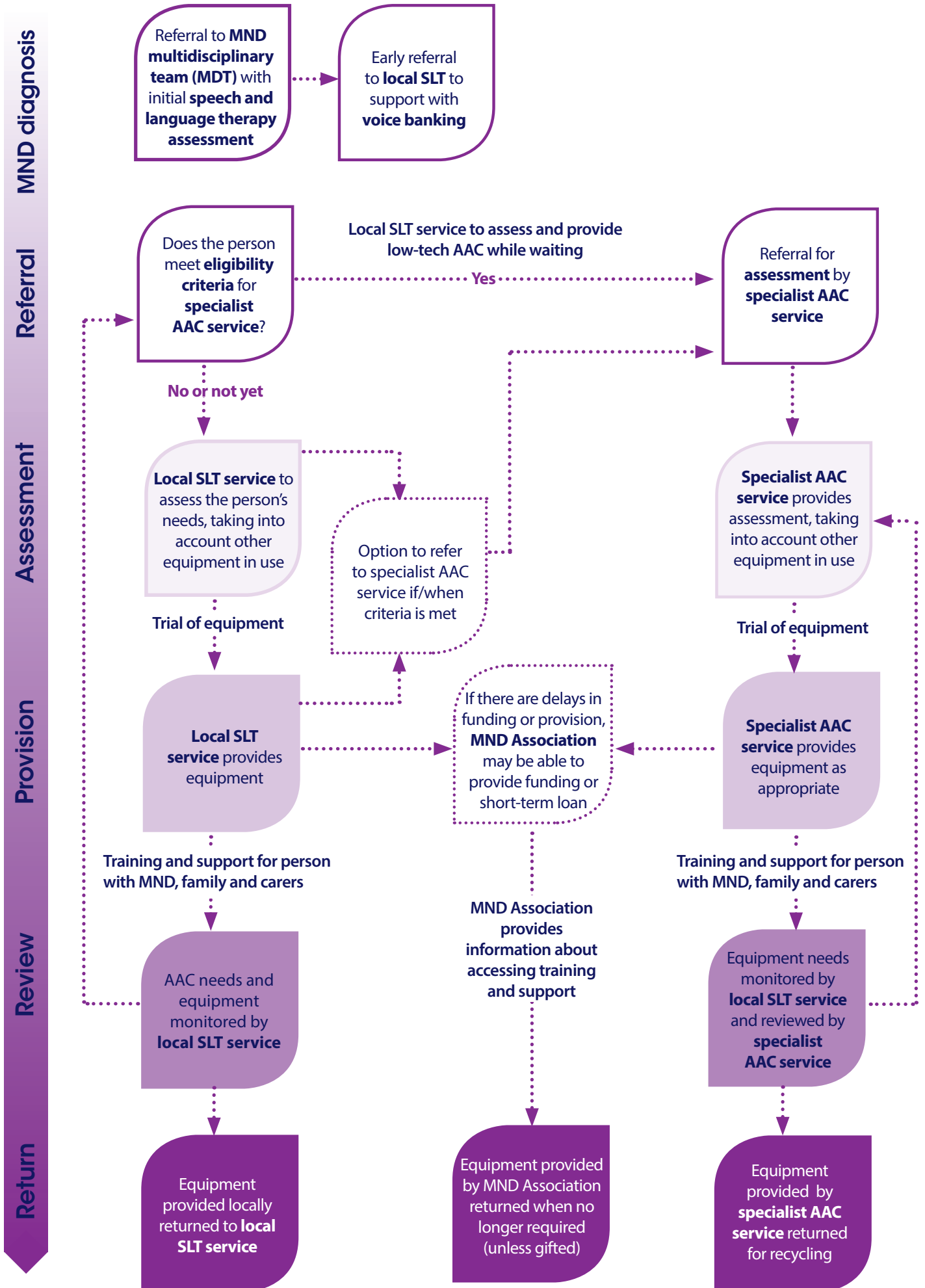
Information to share with people with or affected by MND:

Information sheet 7D – Voice banking

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 pathway

The aim of the AAC Pathway for MND (see page 3) 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 that there is a robust assessment process that takes account of current and likely future needs, including education 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 use of the AAC Pathway for MND should be evaluated in partnership with people with MND and carers through ongoing and regular review, satisfaction surveys, as well as audit of the provider partners within the service. This will include speech and language therapists (SLTs) in the local and specialist AAC services, and equipment suppliers.

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 3.

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.

Assessment

The aims of the initial assessment are:

- to get a baseline measure of communication needs that can inform future intervention around AAC
- to 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
- to discuss voice 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 (eg work, home, leisure activities), and using different mediums (eg video call, mobile phone, tablet, computer).

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.

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.

Further information

Information sheet P10 - *Voice banking*

www.mndassociation.org/voicebanking - our webpage for voice banking

www.mndassociation.org/communicationaids - webpage about our communication aids service

Information to share

Information sheet 7D – *Voice banking*

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

Call 0808 802 6262 or email mndconnect@mndassociation.org

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 (eg 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 (eg Boogie Board).

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. 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
- voice output communication aids (VOCAs) should be introduced at an appropriate stage.

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 (eg operating lights/television/radio, accessing the internet/computer programmes).

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.

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. If required it is also recommended to coordinate with wheelchair services to ensure mounting solutions are taken into account.

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. The appointment may be at the specialist AAC service or wherever is most appropriate for the person with MND, for example at home, work or hospital.

Appropriate training and support should be provided for the person with MND and those who will be supporting them. 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.

England⁵

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 Specification⁵, 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.

Exclusion criteria would be:

- preverbal communication skills
- not having achieved 'cause and effect' understanding
- have 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. This will include advice on how to engage local funders for funding appropriate AAC (for example, the Local AAC Service Toolkit available at <https://localaactools.co.uk>). 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.

Wales⁹

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

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 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. Ideally, equipment should be ordered through companies and suppliers who are able and willing to provide 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, tablets or iPads, and potential environmental control systems such as Alexa, Google Home or others, should be discussed as an option with the person and their family. 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 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 (eg 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 to request an equipment loan or financial assistance.¹⁷

An equipment loan or support grant 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 by statutory services.

It is important to engage with local statutory services where they have responsibility to provide equipment. Even where the MND Association provides loan equipment, 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 grants or equipment loans, call 0808 802 6262 or email communicationaids@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. 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. 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 802 6262 or email communicationaids@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 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 provided by the MND Association, if loaned, it should be returned to the MND Association for checking, resetting and recycling as appropriate.

References

- 1 Bäumer D, Talbot K and Turner MR. *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: <http://www.communicationmatters.org.uk/page/what-is-aac> May 2021).
- 4 Communication Matters. *How Assessment Services are organised in the UK* (Accessed: <http://www.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: <http://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-d/d01/> May 2021)
- 6 Communication Matters. *AAC Quality Standard for Commissioners*. (Accessed: <http://www.communicationmatters.org.uk/page/national-standards-aac-services> May 2021).
- 7 MND Association. *Equipment loan for MND*. Accessed: <http://www.mndassociation.org/equipmentloan> May 2021).
- 8 Nathanson, E. (2016). *Native voice, self-concept and the moral case for personalized voice technology technology*. *Disability and Rehabilitation*, 8288(May), 73–81. <https://doi.org/10.3109/09638288.2016.1139193>
- 9 Welsh Government (2019). *Welsh Health Circular 2019/018 - Augmentative and Alternative Communication (AAC) Pathway*.

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How we can support you and your team

MND Connect

Our helpline offers help, information, support and signposting 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 for 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. Opportunities include online modules and face-to-face training.

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 of MND, and brings us closer to a cure.

www.mndassociation.org/research

MND register

The MND Register of England, Wales and Northern Ireland aims to collect information about every person living with MND to help plan care and discover more about the cause of 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 multidisciplinary care for people with MND.

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. They can support people affected by MND in person, by telephone or by email or through support groups.

www.mndassociation.org/associationvisitors

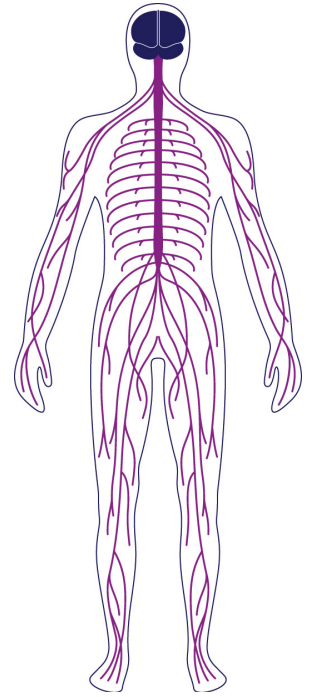
We value your feedback

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

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

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 sight, hearing or sensation.
- 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 some 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.



Would you like to find out more?

Contact our helpline if you have any questions about MND or want more information about anything in this publication.

mndconnect
0808 8026262
mndconnect@mndassociation.org

www.mndassociation.org/professionals