# Augmentative and Alternative Communication (AAC) Pathway for MND: full guidance notes

## Information for health and social care professionals

**The AAC Pathway for MND (page 6) and guidance notes are relevant to the structure of AAC services in England. However, they can provide a pathway for good practice for those working with people with MND across the UK.**

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 results 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]

The aim of the AAC Pathway for MND and accompanying guidance notes is to ensure that people with MND get the best possible support in relation to their communication needs.

The pathway is intended to be clear, practical and easy to use by professionals assessing the communication 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.

A glossary of useful terms can be found on page 12.

Our AAC information can be found online at **www.mndassociation.org/aac**

For further information about MND, visit **www.mndassociation.org/forprofessionals**

## What is Augmentative and Alternative Communication (AAC)?

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.[3]

**Information to share with people with or affected by MND:**
Information sheet 7C – *Speech and communication support*
Information sheet 7D – *Voicebanking*

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

## Who is the AAC Pathway for MND aimed at?

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.

## Aims of the AAC Pathway and guidance notes

The AAC Pathway and guidance notes can 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 on how or why certain clinical practice should be adopted

- improve communication with the person who has MND.

## The challenge of MND

The often rapid and relentless progression of MND poses significant problems of adjustment for people with MND, with an escalating burden on carers and families.[4]

The problems with face-to-face communication and access to technology present specific difficulties for the person with MND that may result in feelings of isolation, low self-esteem, frustration and a loss of control and self-determination.

Surveys carried out by the MND Association from 1995 to 2017 illustrate the common problems people face. Three recurring themes are:

- the time it takes to access the appropriate services

- the lack of awareness among people with MND and their carers about available support

- the need for more regular contact and review.

The rapid progression of MND presents particular challenges to statutory services because of:

- the complexity of the condition

- the speed of response required

- the need for ongoing input and review throughout the course of the condition.

There is a need to commission and provide effective and responsive care management.

## Clinical context

- Incidence of MND is thought to be around 1-2 per 100,000 per year.[5]

- Prevalence is thought to be around 7 per 100,000 of the UK population (from prospective figures calculated by Chio et al 2013).[6]

- MND can occur in any adult, but the risk of MND increases after the age of 40 and peaks in the early 70s, before a decline in incidence. MND is extremely rare below the age of 30.[1]

- The male/female ratio is 3:2, although this varies with age and evens out in later years of life.[7]

Clinical presentation is sub-divided in two ways: by the presence of upper motor neurone (UMN) and/or lower motor neurone (LMN) signs, and the anatomical area first affected.[8]

### Site of onset

- Limb-onset MND affects around two-thirds of people with MND.

- Bulbar-onset MND affects around a third of people with MND.

- Respiratory-onset is rarer, affecting around 3%.[8]

MND is the overarching term used in the UK and Australasia to denote various diseases of the motor nerves, classified by whether they affect UMN, LMN or both.

There is considerable overlap between the different forms of MND. In many other countries, ALS is used as the overarching term instead of MND to describe more than just the specific variant known as ALS.

The variants, or subtypes, are:

### Amyotrophic lateral sclerosis (ALS)[9]

- Most common form of MND, affecting at least 80% of people with the disease.
- Involves upper motor neurones (UMN) and lower motor neurones (LMN).
- Characterised by a combination of muscle wasting with spasticity.
- Arm, leg or bulbar (speech and swallowing) onset.
- The bulbar region is usually affected, but may not be prominent in everyone with ALS.
- Wide variation in age of onset. Mean age at onset is mid-60s.
- Survival is usually less than five years from symptom onset. Where initial onset is in the bulbar region, survival may be shorter (1-2 years).

### Progressive bulbar palsy[10, 11]

- A small group of people with bulbar-onset MND have symptoms relatively confined to the bulbar region for several months (occasionally years), before it moves to involve the limbs.
- Characterised by rapidly progressive speech and swallowing problems, often also with emotional lability. Muscles in the upper limbs, neck and shoulder girdle may become progressively weaker.
- Both UMN and LMN may be involved.
- Overall survival 6 months – 4 years.
- Tends to affect people over 55 years old.

### Progressive muscular atrophy (PMA)[8, 12]

- Accounts for 5-10% of people with MND.
- Characterised by LMN degeneration, with muscle wasting/weakness.
- Limb onset, often with visible fasciculations.
- 'Flail arm syndrome' falls within this group, characterised by slowly progressive, symmetrical, and usually proximal upper limb weakness.
- Survival is often longer than seen in ALS, typically more than four years. If someone presents with a single flail arm or leg, survival is often five to 10 years or more from onset.

### Primary lateral sclerosis (PLS)[8, 10, 13]

- Accounts for approximately 2% of all people with MND.
- Affects UMN only.
- Characterised by spasticity/brisk reflexes. Balance is often impaired.
- Survival is notably longer (more than 10 years from symptom onset).

In some cases, people present with features of PMA or PLS, but go on to develop more typical ALS.[8] It is well recognised that some individuals live considerably longer than the average survival times given.[1]

# NICE Guideline on MND

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 topics such as information and support, organisation of care, managing symptoms and preparing for end of life, including specific recommendations regarding communication support. The NICE recommendations compliment this pathway and should be taken into account alongside it when supporting someone with MND.

**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 (SLT) without delay.

**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.

**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.

**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.

**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.

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

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**Information for you:**
The NICE Guideline on MND is available from:
**www.nice.org.uk/guidance/ng42**

**Information to share with people with or affected by MND:**
Information sheet 1A – *NICE Guideline on MND*
*What you should expect from your care* pocket book

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

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# 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 joysticks, adapted mice and eye tracking technology (eye gaze). With alternative access methods there is the potential to use the internet, which can increase independence and reduce social isolation.

Development in technology has also given the potential to integrate voice output communication aids (VOCAs) and environmental control programmes.

However, there is also the recognition that one device or system may not work in all situations, 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.

## The pathway

The aim of the AAC Pathway for MND (see page 6) is to provide a framework for service delivery to better meet the needs of people with MND. Implementation will have a positive impact on the environment and quality of life of the person, with the potential of maintaining independence for longer.

Ensuring there is a robust assessment process, with the right equipment provided at the right time, can also be more cost effective.

## Outcomes

The use of the AAC Pathway for MND should be evaluated through satisfaction surveys, as well as audit of the provider partners within the service. This will include SLTs in the local and specialist AAC services, and equipment suppliers.

The desired outcomes are that:

• the communication needs of the person with MND and their family or carer are met effectively

• quality of life for the person with MND and their family/carer is increased

• independence for the person with MND is maintained.

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

The MND Association's Outcome Standards set out key outcomes of good care for people living with MND. They are mapped to NHS Outcomes Framework Domains and refer to the Adult Social Care Outcomes Framework where there are shared or complementary indicators.

Within Domain 2 of the Outcome Standards, Enhancing quality of life for people with long-term conditions, one of the indicators is:
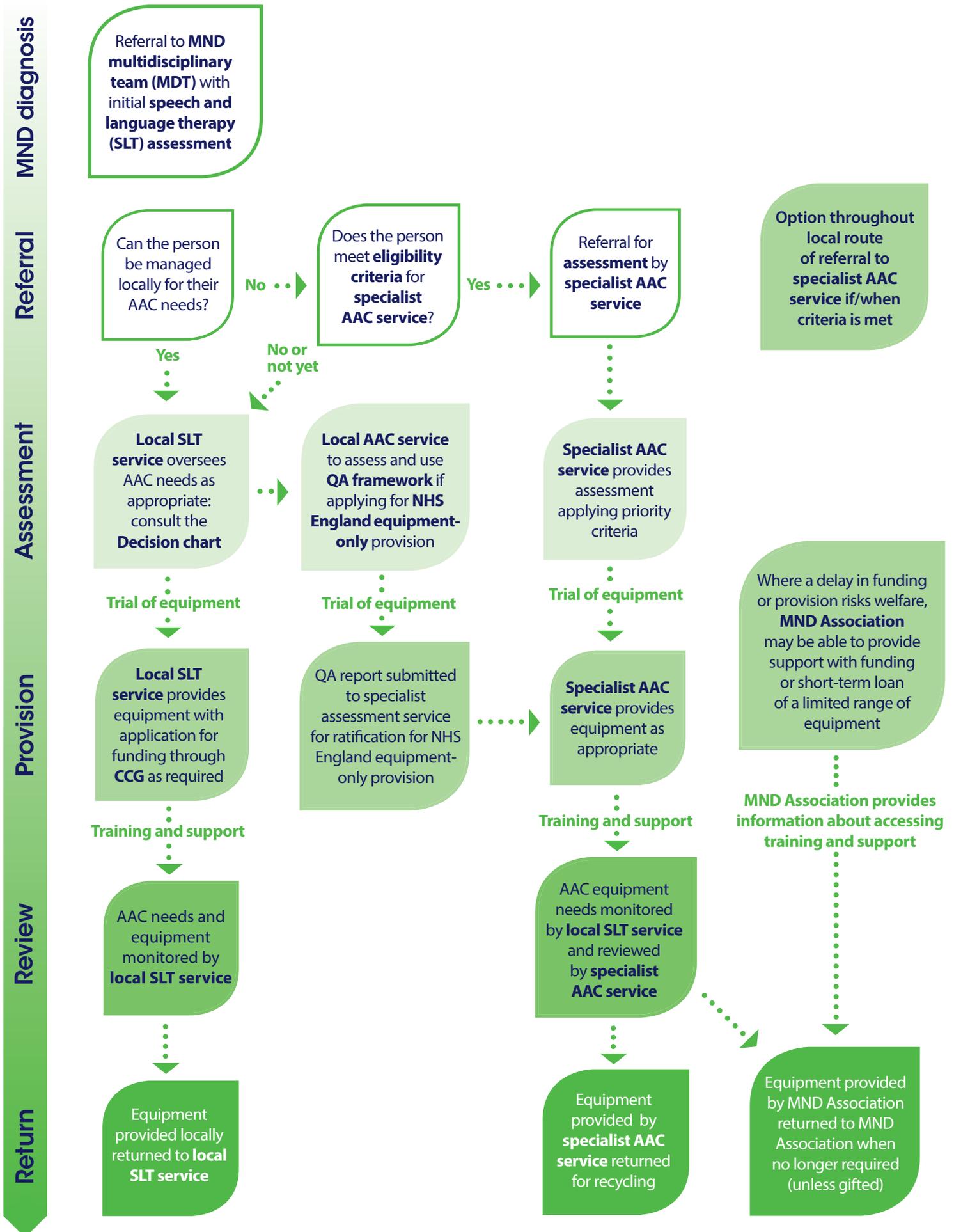
• people with MND supported to maintain effective communication.

Additionally, within Domain 5:

• AAC, environmental controls and wheelchairs provided and maintained in accordance with national standards and guidelines.

The need for various roles within the multidisciplinary team, including speech and language therapists, is highlighted elsewhere in the document.

Ongoing consideration should be given to the training needs of staff providing services. Implementing processes for continuous improvement and succession planning will ensure continuity of care and service delivery.

# AAC Pathway for MND

**MND diagnosis**

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

**Referral**

Can the person be managed locally for their AAC needs?

**No** → Does the person meet **eligibility criteria** for **specialist AAC service**?

**Yes** → Referral for **assessment** by **specialist AAC service**

**Option throughout local route of referral to specialist AAC service if/when criteria is met**

**Yes** ↓

**No or not yet** ↓

**Assessment**

**Local SLT service** oversees AAC needs as appropriate: consult the **Decision chart**

**Local AAC service** to assess and use **QA framework** if applying for **NHS England equipment-only** provision

**Specialist AAC service** provides assessment applying priority criteria

**Trial of equipment** ↓

**Trial of equipment** ↓

**Trial of equipment** ↓

**Provision**

**Local SLT service** provides equipment with application for funding through **CCG** as required

QA report submitted to specialist assessment service for ratification for NHS England equipment-only provision

**Specialist AAC service** provides equipment as appropriate

Where a delay in funding or provision risks welfare, **MND Association** may be able to provide support with funding or short-term loan of a limited range of equipment

**Training and support** ↓

**Training and support** ↓

**MND Association provides information about accessing training and support**

**Review**

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

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

**Return**

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

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

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

**Steps involved in AAC provision:**

# Diagnosis

### 1. Diagnosis of MND

A diagnosis of MND triggers eligibility for an assessment by a speech and language therapist (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 access to AAC and information about voice banking can be discussed at the earliest possible opportunity.

# Referral

### 2. Initial speech and language therapy assessment

All referrals for people with a diagnosis of MND should be assessed by a therapist with specialist knowledge of MND and AAC. If this is not possible, it is essential for the therapist to have direct access to a therapist with this knowledge. It is recognised that there is significant variation among SLTs in their knowledge and experience of AAC. The initial assessment may be either at a local clinic, MND care centre or within the person's home environment.

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

This decision will be based on:

- the experience and competency of the local SLT

- the type of MND and rate of progression

- the wishes of the person with MND and their family or carer.

# Assessment

The aim of the initial assessment is to get a baseline measure of communication needs that can inform future intervention around AAC.

### 3. Local assessment

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 cover:

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

- rate of progression

- 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.

### Voice Banking

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 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.

> **Information for you:**
> 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**

### The importance of low-tech solutions

A low-tech 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 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 person communicating with the person with MND is responsible for scanning through the alphabet or phrase chart. 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**
Based on an eye transfer board or frame, this uses eye pointing to select vocabulary from particular topic areas.

**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 may also be used.

### If the person presents with bulbar signs:
- voice output communication aids (VOCAs) should be introduced at an appropriate stage.

**If the person presents with limb weakness:**

- 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 options.

### 4. Assessment at a specialist AAC service[16]

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.

Although referral for specialist assessment may be made on an anticipatory basis, referral too early may mean that it will be difficult to provide an appropriate long-term solution. However, referral too late may mean that it is difficult to provide equipment with the relevant training and support within a reduced time frame.

People with rapidly progressing diseases, such as MND, are permitted to be referred up to 18 weeks prior to meeting the criteria.

If there are no presenting speech or access issues at the point of referral, general information and signposting should be given by the local AAC service. Initial advice on low-tech solutions should be given as appropriate.

According to the NHS England Communication Aid Service Specification[16], 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.

The referral for specialist assessment should be actioned as soon as possible if the criteria is met, or expected to be met within 18 weeks. This is usually made via a referral form, available on the specialist centre's website or obtained from the specialist centre. Once the referral is received, specialist AAC services will apply the priority criteria for people 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.

Specialist AAC assessment should ensure that AAC interventions are cohesive and coordinated and that access is available to environmental control services as required. Where possible, the local SLT should attend the assessment, as they will be involved in the ongoing care and support of the person with MND.

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. This will minimise the need for new learning.

# Trial

### 5. Equipment trial

Following assessment (either locally or at a specialist AAC service) there should be an opportunity to trial equipment, software programmes 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 programmes 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

### 6. Funding report

Even if a negative decision is anticipated, the true cost of supporting a person with MND in their communication needs 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 will 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 always be discussed as an option with the person and their family. This can reduce delays in the supply of an effective system of communication.

People with MND who are assessed through a specialist AAC centre will receive funding for their equipment directly from NHS England.

A Quality Assurance (QA) framework is in place for those people with MND who are managed by local AAC services with the competencies to support them. A QA framework, completed for the individual, will be submitted to the appropriate specialist AAC service for ratification.

If accepted, funding for that equipment will come directly from NHS England.

If a person does not yet meet the criteria for specialist assessment and is requiring a relatively straightforward, text-to-speech communication aid with direct hand/finger access, then this should be managed by the local SLT service.

Application for funding for AAC equipment can be made to the local Clinical Commissioning Group (CCG) or local SLT service. During this process, it may be possible to request a short-term loan of equipment from the MND Association, if the equipment is in stock.

### 7. MND Association support services

Funding for AAC for those with complex needs should be met through specialised commissioning and NHS England.  The obligation on specialist AAC services to provide equipment, training and support is set out within the service specification.

If SLTs and individuals have thoroughly explored NHS funding without success and the welfare of the person with MND is compromised, an application can be made to the MND Association to request financial assistance or an equipment loan.[17]

A support grant may be awarded by the 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.

Cost of licenses for specialist speech output software or applications can be applied for through the support grant scheme and will become the property of the person with MND.

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

# Training and support

### 8. Equipment provision and training

Equipment provided by the NHS or MND Association should be supported by appropriate training from the specialist AAC service and/or the local SLT with input from the supplier as required.

Equipment funded by NHS England remains the property of the specialist AAC centre involved in the application for its provision. Equipment funded by the CCG remains the property of the local SLT service. Equipment provided by the MND Association remains the property of the MND Association unless it is gifted to the person.

### 9. Servicing and repair

All equipment should be maintained in a safe condition. The person with MND will have the contact details of the SLT and the company supplying the equipment to enable them or their carer to make contact if a problem should arise.

The person with MND and any carers should receive adequate training to enable them to feel confident using the equipment. This may include support from the specialist AAC centre and/or the supplier. They should have clear written instructions to which they can refer if required. The person with MND should also have the contact details of the SLT and the company supplying the equipment to enable them or their carer to call or email if there are any problems.

If equipment is the property of the MND Association, the Association will advise on next steps. If the equipment is a dedicated communication aid, and still under warranty, it can be returned to the supplier for repair.

# Review

### 10. Review

Ongoing review by the local SLT will be arranged to address changing needs regarding access to technology and/or speech output. As their needs change, the person with MND may need referral for assessment or review/reassessment at 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 main carers.

# Return

### 11. Return of equipment

When equipment is no longer required:

- if funded by NHS England, it should be returned to the specialist AAC centre

- if funded by the CCG, it should be returned to the local SLT service

- if funded by the MND Association, where agreed, it should be returned to the MND Association for checking, resetting and recycling as appropriate.

# Glossary of terms and services

### AAC

Augmentative and Alternative Communication (AAC) is any form of communication that supports or replaces speech.[3]

### Local speech and language therapy services

The local speech and language therapy (SLT) service will be the first point of contact for someone who needs assessment for AAC.

### Local AAC services

A local speech and language therapy service with expertise to support people with more complex AAC needs. They are the 'spokes' in the 'hub and spoke' model described below.

### Specialist AAC services

These are Centres of Excellence where a person can be assessed for their AAC needs. Located across the UK, these centres are working towards a 'hub and spoke' model of service delivery, where specialist AAC services are the hubs of specialist knowledge, and local AAC services are the spokes around them. Following assessment, funding for any equipment provided is through specialised commissioning.[18, 19, 20]

### Criteria for specialist assessment (England only)

These are the criteria that need to be met to enable a person to qualify for assessment by specialist AAC services.[16]

### Quality Assurance (QA) Framework

This framework can be used by a local AAC service to support an application for funding through specialised commissioning. The framework will need to be scrutinised by a specialist AAC service before funding can be approved and equipment ordered through the specialist AAC service.[21]

### Quality Assurance (QA) Framework checklist

This is used to check that a robust assessment has been completed with evidence to support the recommended selection of equipment. This is then submitted to the specialist AAC service who will approve (or reject) equipment-only funding through NHS England.

### Equipment-only requests (England only)

In cases where a person meets the criteria for specialist assessment but has been assessed by a local AAC team, equipment can be funded through NHS England specialised commissioning, provided the request has been approved through the NHS England Quality Assurance framework.[22]

### NHS specialist AAC service equipment request report template

This template enables the report author/referrer to ensure that sufficient evidence is reflected in the documentation to enable specialist services to make an informed judgement on the robustness of the assessment process.

### NHS specialist AAC service equipment-only requests QA progression template

This is intended to be used by specialist AAC services to record outcomes following scrutiny of the assessment report. It can be used to document telephone/email discussions with the report author when further information is required.

# 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 December 2017).

**4** Lillo P, Mioshi E and Hodges JR. *Caregiver burden in amyotrophic lateral sclerosis is more dependent on patients' behavioral changes than physical disability: a comparative study.* BMC Neurology. 2012; 12:156.

**5** Thomas Hoppitt et al. A Systematic Review of the Incidence and Prevalence of Long-Term Neurological Conditions in the UK. Neuroepidemiology. 2011; 36(1):19–28.

**6** Chio et al. *Global Epidemiology of Amyotrophic Lateral Sclerosis: A Systematic Review of the Published Literature.* Neuroepidemiology. 2013; 41:118–130.

**7** Blasco H et al. *Amyotrophic lateral sclerosis: a hormonal condition?* Amyotrophic Lateral Sclerosis. 2012; 13(6):585-8.

**8** Cooper-Knock J, Jenkins T and Shaw, PJ. *Clinical and molecular aspects of motor neurone disease.* 2013. Morgan & Claypool Life Sciences. 6.

**9** Talbot, K et al. *Motor Neuron Disease: a practical manual.* Oxford Care Manuals: 2010. P41.

**10** Turner MR and Talbot K. *Mimics and chameleons in motor neurone disease.* Practical Neurology. 2013; 13(3).

**11** Talbot, K et al. *Motor Neuron Disease: a practical manual.* Oxford Care Manuals: 2010. P45.

**12** Wijesekera LC and Leigh PN. *Amyotrophic lateral sclerosis.* Orphanet Journal of Rare Diseases. 2009; 4:3.

**13** Pringle CE et al *Primary lateral sclerosis. Clinical features, neuropathology and diagnostic criteria.* Brain. 1992; 115(Pt 2):495-520.

**14** MND Association. *What are the common AAC options for people with MND?* (Accessed: http://www.mndassociation.org/forprofessionals/AAC+for+MND/What+are+the+common+AAC+options December 2017).

**15** World Health Organisation (WHO). *International Classification of Functioning, Disability and Health.* 2001. www.who.int/classifications/icf/en

**16** NHS England. *Service Specification for Complex Disability Equipment Alternative and Augmentative Communication Communication Aids (All Ages)* (Accessed: http://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-d/d01 December 2017).

**17** MND Association. *Equipment loan for MND.* (Accessed: http://www.mndassociation.org/equipmentloan December 2017).

**18** Communication Matters. *Updated Specialised AAC Services Specifications (England).* 2014. (Accessed: http://www.communicationmatters.org.uk/news-item/2014-updated-aac-services-specs-june December 2017).

**19** Communication Matters. *How Assessment Services are organised in the UK* (Accessed: http://www.communicationmatters.org.uk/page/assessment-services December 2017).

**20** Office of the Communication Champion and Council. *Specialised AAC provision: Commissioning national services.* 2011 (Accessed: http://www.communicationmatters.org.uk/sites/default/files/downloads/standards/AAC_Report_Final_comm_champion_nov_2011.pdf December 2017).

**21** Communication Matters. *AAC Quality Standard for Commissioners.* (Accessed: http://www.communicationmatters.org.uk/page/national-standards-aac-services December 2017).

**22** Communication Matters. *Equipment only requests.* (Accessed: http://www.communicationmatters.org.uk/page/equipment-only-requests December 2017).

### Other background sources

Department of Health. *National Service Framework for Long Term Conditions.* 2005.

NICE Guideline NG42 - *Motor neurone disease: assessment and management.* 2016.

# How the MND Association can support you and your team

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

### MND Connect

Our helpline offers help, information and support, and signposting to other services and agencies. The service is for people living with MND, carers, family members, health and social care professionals and Association staff and volunteers who directly support people with MND.
Telephone: **0808 802 6262**
Email: **mndconnect@mndassociation.org**
Please contact MND Connect if you have any questions about the information in this publication.

### Information resources

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

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

### MND Association website

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

### Education

Our education programme is designed to improve standards of care and quality of life for people living with and affected by MND. Opportunities include online modules and face-to-face training, such as conferences and masterclasses. We offer a bursary up to £250 per year to help professionals access training. Visit **www.mndassociation.org/education**

### MND support grants and equipment loan

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

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

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

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

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

Referrals for support grants or equipment loan need to be made by an occupational therapist, speech and language therapist or other relevant health or social care professional. For enquiries about MND support grants or equipment loan, call the MND Connect on **0808 802 6262**, email **mndconnect@mndassociation.org** or visit **www.mndassociation.org/getting-support**

### Wheelchair service

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

### Communication aids service

This service helps people affected by MND and health and social care professionals with queries about communication aids.

The service provides limited financial support for communication aids or some items on loan, if unavailable or delayed through health and social care services. Our aim is to improve provision and information on a local and national level, through collaboration with professionals. Call MND Connect on **0808 802 6262** or email **communicationaids@mndassociation.org**

### Research into MND

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

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

### International Symposium on ALS/MND

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

### MND Association membership

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

## Local support

### Regional care development advisers

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

### MND care centres and networks

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

### Branches and groups

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

### Association visitors (AVs)

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

# **Feedback** form

Please send us your feedback on
**Augmentative and Alternative Communication (AAC)
Pathway for MND: full guidance notes.**

Thank you for taking the time to provide your feedback on one of our information resources.

This questionnaire can be accessed online if preferred, using the following link:
**www.surveymonkey.com/s/professionalinformation**

What is your profession or specialism?

_____

Did you find this resource useful?

☐ Yes     ☐ Somewhat     ☐ Not really     ☐ No     Please explain your answer

_____

_____

Will this information resource help you to provide people affected by MND with any of the following?
(tick all that apply)

☐ an increased understanding of their symptoms

☐ an increased understanding of their condition            ☐ more confidence

☐ more independence                                         ☐ improved quality of life

☐ an increased ability to raise awareness of their needs    ☐ a greater ability to maintain dignity

Were there any particular topics that were useful to you?

_____

_____

Was there any information that you didn't find useful or relevant?

_____

Are there any other MND-related topics that you'd like more information about?

_____

Do you have any other feedback about this resource or our other information for professionals?

_____

Would you be happy to help us improve our information by becoming an expert reviewer?

☐ Yes (please include your email address below)     ☐ No

Do you have any experiences of working with people with MND you could share as an anonymous
quote or case study for future resources?

☐ Yes (please include your email address below)     ☐ No

Please return your completed form to:
Education and information team
MND Association
PO Box 246
Northampton NN1 2PR

Name:

_____

Email:

_____

## Acknowledgements

Thank you to the following people for their valuable contributions to this information sheet:

**Catherine Harris, Independent Speech and Language Therapist and Chair of Communication Matters**

**Richard Cave, Advanced Specialist Speech and Language Therapist, Compass Electronic Assistive Technology Service**

**Members of the AAC sub-group of NHS Commissioning's Clinical Reference Group for Complex Disability Equipment**

## About us

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

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

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

## Our mission

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

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

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

## About MND

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.

- It attacks the nerves that control movement so muscles no longer work. MND does not usually affect the senses such as sight, sound and feeling.

- It can leave people locked in a failing body, unable to move, talk and eventually breathe.

- It affects people from all communities.

- Some people may experience changes in thinking and behaviour, with a proportion experiencing a rare form of dementia.

- MND kills a third of people within a year and more than half within two years of diagnosis.

- A person's lifetime risk of developing MND is up to 1 in 300.

- Six people per day are diagnosed with MND in the UK.

- MND kills six people per day in the UK.

- It has no cure.

## MND Association

PO Box 246, Northampton NN1 2PR
Tel: 01604 250505
Email: enquiries@mndassociation.org
www.mndassociation.org

 @ deducation

 /mndassociation

**Helplines STANDARD**

**mndconnect**
**0808 802 6262**
mndconnect@mndassociation.org