The AAC Pathway for MND (page 4) 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, to speak, to swallow and ultimately to 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 care in relation to their communication needs. They are intended to be clear, practical and easy to use by professionals assessing the communication needs of people with MND.

They aim to inform commissioners of the infrastructure needed to provide an effective and efficient service to meet the needs of people with MND, and to help the reader identify the steps involved in AAC provision, which are:

- **Diagnosis**
- **Referral**
- **Assessment**
- **Trial**
- **Provision**
- **Training and support**
- **Review**
- **Return**

This summary guidance is an abbreviated version of the full guidance notes and should be used in conjunction with the AAC Pathway for MND (see page 4).

Our AAC information can be accessed online at [www.mndassociation.org/aac](http://www.mndassociation.org/aac)

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

Augmentative and Alternative Communication (AAC) is the term used to describe methods of communication that can be used to 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.\(^3\)
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.

Referral

2. Initial speech and language therapy assessment
During this assessment, a decision will be made as to 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 and/or carer.

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

Assessment

3. Local assessment
If local ongoing management is agreed:

- initial advice on low-tech solutions to support communication should be given as appropriate.

The assessment process will include:

- current communication ability
- physical, sensory, speech, language and cognitive abilities
- communication environment
- support network.

<table>
<thead>
<tr>
<th>Presentation</th>
<th>Action for local SLT</th>
</tr>
</thead>
<tbody>
<tr>
<td>If the person is presenting with bulbar (speech) signs</td>
<td>voice output communication aids (VOCAs) should be introduced at an appropriate stage.</td>
</tr>
<tr>
<td>If the person is presenting with limb weakness</td>
<td>alternative methods of access to technology should be discussed.</td>
</tr>
<tr>
<td>If the person meets the criteria in the service specification</td>
<td>they can be referred for assessment at a specialist AAC service.</td>
</tr>
<tr>
<td>If the presenting problem is with computer access</td>
<td>a referral to the environmental control service should be made in partnership with the occupational therapist.</td>
</tr>
</tbody>
</table>

Voice Banking

Information about voice banking should be provided as early as possible after diagnosis by the SLT or member of the multidisciplinary team (please see information sheet P10– Voicebanking for people with MND). 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.
4. Specialist assessment
If referral to a specialist AAC service is agreed:

• initial advice on low-tech solutions should be given as appropriate
• the referral to the specialist AAC service should be actioned within three working days of the appropriate referral form being completed.

Trial

5. Equipment trial
Following assessment, there will be an opportunity to trial equipment or software programmes or applications for a minimum of two weeks. This trial can be arranged through a local loan bank, from a specialist AAC service or arranged through a supplier. Free software trials are available from some suppliers.

 Provision

6. Funding report
Once a decision is made on the appropriate equipment, a funding report, including a rationale for the decision and a detailed quote, will be produced.

A copy of the funding report can be used to support a funding application to either NHS England from the specialist AAC service, or an application from a local AAC service using the Quality Assurance (QA) framework. Where a person with MND is managed by the local AAC service, an application for funding should be made to the local Clinical Commissioning Group (CCG).

A copy of the funding report will also be available for the person with MND in the event of them deciding to self-fund.

7. MND Association support services
Funding for AAC for those with an established need is a requirement on the NHS. The obligation on specialist AAC services to provide equipment is set out within the service specification. However, 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 the loan of equipment or a support grant towards its purchase or hire.

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.

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.

Review

10. Review
Ongoing review by the local SLT will be arranged as appropriate to address changing needs regarding access to technology and/or speech output systems. This will be particularly important in the later stages of disease progression.
**AAC Pathway for MND**

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

**Can the person be managed locally for their AAC needs?**

- **Yes**
  - Local SLT service oversees AAC needs as appropriate; consult the Decision chart
  - Trial of equipment
  - Local SLT service provides equipment with application for funding through CCG as required
  - Training and support
  - AAC needs and equipment monitored by local SLT service
  - Equipment provided locally returned to local SLT service

- **No or not yet**
  - Local AAC service to assess and use QA framework if applying for NHS England equipment-only provision
  - Trial of equipment
  - QA report submitted to specialist assessment service for ratification for NHS England equipment-only provision
  - Specialist AAC service provides equipment as appropriate
  - Training and support

**Does the person meet eligibility criteria for specialist AAC service?**

- **Yes**
  - Referral for assessment by specialist AAC service
  - Specialist AAC service provides assessment applying priority criteria
  - Trial of equipment
  - Specialist AAC service provides equipment as appropriate
  - Training and support
  - AAC equipment needs monitored by local SLT service and reviewed by specialist AAC service
  - Equipment provided by specialist AAC service returned for recycling

- **No**
  - Return Equipment provided locally returned to local SLT service
  - Equipment provided by MND Association returned to MND Association when no longer required (unless gifted)

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

- 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

- MND Association provides information about accessing training and support
11. Return of equipment
When it is no longer required, equipment funded by NHS England will be returned to the specialist AAC service, and CCG-funded equipment will be returned to the local SLT service. MND Association funded equipment, where agreed, will be returned to the MND Association for checking, cleaning, resetting and recycling as appropriate.

References
2 SEALS Registry (for background information on SEALS see *Neuroepidemiology* (2007) 29:44-8.

Other background sources


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
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Members of the AAC sub-group of NHS Commissioning’s Clinical Reference Group for Complex Disability Equipment
How we can support you and your team

MND Connect
Our helpline offers help, information and 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 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 the 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.

www.mndassociation.org/professionals