

# Improving MND Care Audit

## Designing your development plan - actions to consider

The information in this document is designed to help you consider actions you may wish to take to improve your services for people with MND. The lists are not intended to be exhaustive, but to stimulate ideas and highlight resources that may be useful for yourself or your patients.

Support is available from your local Service Development Manager. For details, email [audittool@mndassociation.org](mailto:audittool@mndassociation.org)

### NICE have developed a range of MND specific resources you may find helpful:

- [Shared learning examples](#) - examples showing how NICE guidance and standards can improve local health and social care services.
- [MND overview pathway](#) - an interactive flow chart to explore everything NICE says about MND.
- [Quality standard QS126](#) - sets out the priority areas for quality improvement in health and social care.
- [Recommendations](#) - summary of NICE recommendations on providing the best possible care to someone with MND.
- [NG42 Full guideline](#) – The complete version of the guideline, including methods, evidence and recommendations.

## Recognition and referral

### Actions to consider:

- Ensure robust protocols are in place to inform professionals about MND and how it may present, and local referral arrangements.
- Flag referrals as urgent, where appropriate.
- One neurologist in the team named as the lead for MND care.
- Triage referrals directly to the named neurologist for the initial outpatient consultation.
- Neurologist to upskill in MND/shadow more-experienced MND specialist neurologists.
- Promote the *Red Flags* tool with GPs in the area so that people are referred to a neurologist with expertise in MND.
- Consider whether the GP referrals for people with suspected MND could be fast-tracked for the initial consultant appointment.

### Recommended resources:

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

## Resources from NICE:

[Recognition and referral recommendations](#)

[Recognition and referral pathway overview](#)

## Information and support at diagnosis

### Actions to consider:

- Ask the patient and their carer how much information they wish to receive about MND.
- Ensure there is a single point of contact for the specialist MND team.
- Provide information about what to do if there are any concerns between assessments or appointments, during 'out-of-hours' or in an emergency, or if there is a problem with equipment.
- Set aside enough time to discuss the person's concerns and questions.
- Written material available in clinic to give to patient/carer.
- Private room to give diagnosis.
- Patient to be invited to bring a relative/friend when the diagnosis is to be given.
- Ensure that a specialist nurse/coordinator is present during diagnosis to ensure outstanding issues are addressed before the patient leaves the clinic.
- Give the person with MND written details of the MND co-ordinator/specialist nurse in the area.
- Keep enough appointment slots free to enable people diagnosed within the last four weeks to have a follow-up appointment.
- Either give follow-up appointment date at initial clinic visit, or arrange for co-ordinator/specialist nurse to phone within a week to arrange follow-up appointment.
- Develop an ongoing checklist on patient records which includes Riluzole being routinely offered.
- Develop a systematic approach to the assessment of the person's needs related to family support, housing, employment status, leisure needs/hobbies, finance.
- Keep referral details of the local social care services in clinic and record if a referral is made.
- Monitor the place, time and way that the diagnosis was given.
- Ensure adequate time is allowed for the appointment.
- Keep a range of information within clinic to give to the person and their carers and record what information has been given.
- Give details of the MND Association website and MND Connect helpline as a source of further information.

### Recommended resources:

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

## Resources from NICE:

[Information and support at diagnosis recommendations](#)

[Information and support at diagnosis pathway overview](#)

## Cognitive assessments

### Actions to consider:

- Routinely check whether the patient or their carer have any concerns about cognition or changes in behaviour at diagnosis and regularly thereafter.
- Introduce a validated cognitive screening tool as part of the assessment of patients where there is reason to suspect there are cognitive changes.
- Identify a person within the team who will be responsible for undertaking cognitive assessment.
- Give training and supervision to key people within the team so that assessment outcomes can be interpreted.
- Provide written information to the patient/carer about how MND may affect cognition.
- Train all team members in the strategies that may help if there is cognitive impairment, so that any care plan takes the cognitive change into account.
- Tailor all discussions to the person's needs, considering their communication ability, cognitive status and mental capacity.

### Recommended resources:

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

## Resources from NICE:

[Cognitive assessment recommendations](#)

[Cognitive assessment pathway overview](#)

## Organisation of care

### Actions to consider:

- Have protocols in place to inform all healthcare professionals and social care practitioners involved in the person's care about key decisions reached with the person and their family members and/or carers.
- Set up regular meetings of the key health and social care professionals in the area who are providing MND care.

- Ensure that key professionals who cannot attend meetings can contribute before MDT meetings and are given updates following the meetings.
- If there is no palliative care expertise within the MDT, then invite a specialist palliative care team representative to attend MDT meetings.
- Develop a referral pathway to ensure timely and appropriate referral to specialist palliative care services.
- Review membership of the MDT based on NICE guidance at least twice yearly.
- Contact managers of the services not represented to request that a professional attends MDT meeting, or links in with the rest of the MDT.
- Map local provision to improve understanding of the local structures and services.
- Clarify with the commissioners/providers who should be providing each service.
- Offer training/awareness raising sessions to develop and increase membership, and ensure that all members of the MDT understand the importance of co-ordinated multi-disciplinary care.
- If it is not feasible for a key member of the MDT to attend meetings (eg due to geographical challenges) consider how that professional can share information with other members of the MDT.
- Ensure your processes ensure continuity of care and avoid untimely case closure.

### Recommended resources:

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

### Resources from NICE:

[Organisation of care recommendations](#)

[Organisation of care pathway overview](#)

### Further support:

Your local Service Development Manager can support you to establish an MDT in your area. For details, email [audittool@mndassociation.org](mailto:audittool@mndassociation.org)

## Psychological and social care support

### Actions to consider:

- During multidisciplinary team assessments and other appointments, discuss the psychological and emotional impact of MND with the patient and family members and/or carers, and ask whether they have any psychological or social care support needs.
- Offer the person with MND and their family and/or carers information about respite care and sources of emotional and psychological support, including support groups, online forums and counselling or psychology services.
- Identify the current provision for psychological support in your Trust/area. This may be within your Trust, or provided elsewhere (eg through mental health services or primary care).

- Identify the current referral routes into this service.
- If there is no current provision, collect data to map the need for the service, and agree the way forward with commissioners of your service.
- Ensure a social care practitioner with knowledge of MND or rapidly progressive complex disabilities discusses the person's needs and preferences for social care, and provides information and support for them to access these services.

### Recommended resources:

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

### Resources from NICE:

[Psychological and social care support recommendations](#)

[Psychological and social care support pathway overview](#)

## Planning for end of life

### Actions to consider:

- Have basic information about Advance Care Planning handy that can reinforce any discussions you may have about planning ahead.
- Have copies of local Advance Care Planning tools readily available.
- Use a prompt within clinical records to remind you to pick up on any indication given to you by the person with MND that they would like to plan ahead, and act on this immediately.
- Communicate with GP if the patient has developed, or is considering developing, an Advance Care Plan.
- Gain the patient's consent to include their details on the end-of-life/Gold Standards Framework register.
- Develop a consistent approach to identifying people with MND who may benefit from having anticipatory medication at home, such as the Just in Case kit.
- Hold copies of the 'Just in case kit' information sheet readily available.
- Routinely record if this has been discussed in the clinical notes.
- Consider anticipatory prescribing, such as the Just in Case kit.
- Offer bereavement support to family and/or carers.

### Recommended resources:

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

### Resources from NICE:

[Planning for end of life recommendations](#)

[Planning for end of life pathway overview](#)

## Management of muscle problems

### Actions to consider:

- Routinely record limb function in the clinical records.
- Refer to physiotherapist for initial assessment at diagnosis or shortly after.
- Hold written information about exercises that will help to maintain function and posture. Record in the clinical notes when this information is discussed and handed to people with MND.
- Routinely ask about muscle problems eg cramps for all people with MND.
- Record in the clinical records any discussion that has taken place about muscle problems and the option for treatment along with any particular preferences of the person with MND.
- Develop a local pathway for the pharmacological treatment for muscle problems.
- Review the treatments for muscle problems during multidisciplinary team assessments, ask about how the person is finding the treatment, whether it is working and whether they have any adverse side effects.
- Check that family members and/or carers (as appropriate) are willing and able to help with any exercise programmes.
- Give advice to the person and their family members and/or carers (as appropriate) about safe manual handling.

### Recommended resources:

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

### Resources from NICE:

[Symptom management recommendations](#)

[Management of muscle problems pathway overview](#)

## Saliva management

### Actions to consider:

- At clinic appointments, routinely ask the person with MND if they have noticed any problems with managing their saliva.
- Develop a treatment protocol for saliva management.
- If the person with MND has problems with drooling of saliva (sialorrhoea), provide advice on swallowing, diet, posture, positioning, oral care and suctioning.

### Recommended resources:

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

## Resources from NICE:

[Symptom management recommendations](#)

[Saliva management pathway overview](#)

## Equipment and adaptations to aid daily living and mobility

### Actions to consider:

- Record the previous and current level of mobility in the person's clinical record, and any impact this may be having on the person's ability to function independently.
- Record the date of any referral in the clinical records.
- Adopt an assessment tool to ensure the person has had a full assessment of their mobility.
- Keep a record of any equipment that has been ordered or issued, and the suitability of that equipment.
- Make timely referrals to the wheelchair service.
- Ensure there is a 'flag' on your clinical system to ensure that the person is reviewed every 3 months as a minimum.
- Keep information to hand about referring to OT.
- Adopt an assessment tool to ensure the person has had a full assessment of their ability to maintain activities of daily living.
- Keep a record of any changes in the person's ability to maintain daily activities, and any equipment that has been ordered or issued, and the suitability of that equipment.
- Ensure that you have written information that can be given to the individual which outlines the funding options available such as local authority, charities, local disability centres etc.

### Recommended resources:

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

## Resources from NICE:

[Equipment and adaptations recommendations](#)

[Support for activities of daily living pathway overview](#)

## Nutrition and hydration

### Actions to consider:

- Ensure you have suitable weighing equipment in the clinic setting, eg standing scales, wheelchair scales.
- Develop a checklist to ensure that the person is weighed and asked about their ability to swallow at every clinic visit, or every three months as a minimum.
- Have written materials in clinic to give to the person with MND promoting the importance of maintaining an appropriate and well-balanced diet and good hydration.

### Recommended resources:

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

See also [MyTube](#).

### Resources from NICE:

[Nutrition and gastrostomy recommendations](#)

[Nutrition and gastrostomy pathway overview](#)

## Gastrostomy

### Actions to consider:

- Hold written information about gastrostomy feeding in clinic.
- Refer to nutrition nurse/dietitian/enteral feeding team.
- Ensure that the referral pathway is clear and the means for making the referral are available in clinic.
- Monitor referral-to-intervention times for gastrostomy placement.
- Record the main carer's views about management of the gastrostomy and their ability/willingness to assist if necessary.
- Record any assessment about mental capacity before making decisions about the appropriateness of gastrostomy placement.

### Recommended resources:

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

See also [MyTube](#).

### Resources from NICE:

[Nutrition and gastrostomy recommendations](#)

[Nutrition and gastrostomy pathway overview](#)



## Communication

### Actions to consider:

- 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.
- Keep a record of any changes to the person's speech or general communication.
- Pathway for assessment and review by SLT established – referrals recorded accurately
- Establish robust links to nearest specialised AAC hub
- 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.

### Recommended resources:

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

### Resources from NICE:

[Communication recommendations](#)

[Communication pathway overview](#)

### Other useful resources:

<https://assistivetechology.org.uk> - NHS England database including resources and service finder with contact details for all the services.

<https://localaactools.co.uk> - Local AAC services commissioning toolkit for the development of local AAC services.

<https://speechbubble.org.uk> - Database of AAC solutions, browsable by presenting conditions.

## Cough effectiveness

### Actions to consider:

- Keep a record in the person's notes that they have been asked about their ability to cough and clear secretions, and any changes in their ability to cough.
- Record any interventions offered and the efficacy of the intervention.

### Recommended resources:

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

## Resources from NICE:

[Cough effectiveness recommendations](#)

[Cough effectiveness pathway overview](#)

## Respiratory function and symptoms

### Actions to consider:

- Ensure that there is a good process to ensure that the person with MND receives a respiratory assessment at, or shortly after, diagnosis.
- Develop a treatment pathway for breathlessness, including pharmacological and non-pharmacological management.

### Recommended resources:

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

## Resources from NICE:

[Respiratory function and symptoms recommendations](#)

[Respiratory function and symptoms pathway overview](#)

## Non-invasive ventilation

### Actions to consider:

- Keep written material available to outline the different ways that breathlessness can be managed, including a trial of NIV.
- Offer a trial of NIV if the person's symptoms and signs and the results of the respiratory function tests indicate that the person is likely to benefit from the treatment.
- Ensure that families and carers have an initial assessment if the person they care for decides to use NIV, which should include their ability and willingness to assist and their training needs. Ensure the carer has been given adequate time to ask any questions about the impact of them of NIV and have had an opportunity to voice any concerns.
- Before starting non-invasive ventilation, the multidisciplinary team together with the respiratory ventilation service should carry out and coordinate a patient-centred risk assessment, after discussion with the person and their family and carers.
- Keep a record of the person's responses to questions about symptoms, and the results of any respiratory tests conducted.
- Record the date of referral to specialist respiratory services.
- Develop a simple respiratory care plan.
- Inform services that may see the person in crisis situations, such as their GP and services that provide emergency or urgent care, that the person is using NIV.

### **Recommended resources:**

All of the MND Association's information resources on this subject are listed in [this leaflet](#). Please note you can click on the resources' names to be taken directly to them.

### **Resources from NICE:**

[NIV recommendations](#)

[NIV pathway overview](#)