

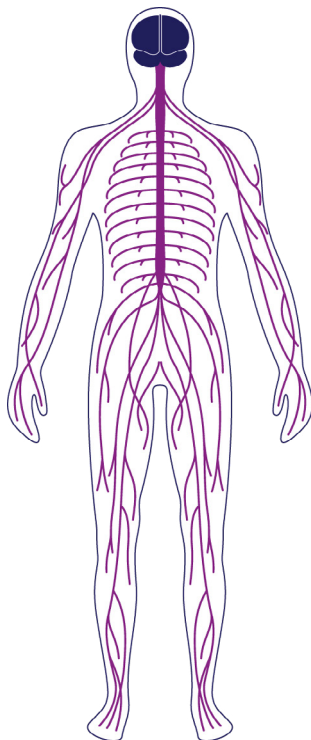
Multidisciplinary team working for MND



For health and social
care professionals

About MND

- MND is a fatal, rapidly progressing disease that affects the brain and the spinal cord.
- It attacks the nerves that control movement so muscles no longer work.
- It can leave people locked in a failing body, unable to move, talk or 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.
- 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 MND Connect if you have any questions about MND or want more information about anything in this booklet.

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0808 802 6262
mndconnect@mndassociation.org

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Introduction

Motor neurone disease (MND) is a progressive, fatal disease that attacks the motor neurones, or nerves, in the brain and spinal cord. About two people in every 100,000 of the general population will develop MND each year¹.

MND can affect how people walk, talk, eat, drink, breathe and think. Not all symptoms affect everyone, and it is unlikely they will all develop at the same time or in any specific order. There is no cure for MND, but symptoms can be managed to help improve quality of life.

The needs of a person with MND will increase as the disease progresses. A large number of health and social care professionals are likely to be involved in their care and support at any one time. Using a multidisciplinary approach can help ensure different services are well co-ordinated so people with MND receive the best possible care.

What is a multidisciplinary approach²?

A multidisciplinary approach involves integrating knowledge, skills and best practices from various disciplines to address problems beyond any individual professional's expertise. By collaborating across different service providers, professionals can develop effective solutions based on a shared and enhanced understanding of complex patient needs.

About this guide

This booklet refers to a multidisciplinary team (MDT) as a group of professionals from a range of disciplines who meet regularly to discuss co-ordination of services for individual patients with MND.

The guide's aim is to help professionals establish and maintain best practice, to improve outcomes for people with MND. It provides suggestions on how MDT working might be implemented, however it is not prescriptive and any development should be tailored to suit local need.

This guide is split into three sections:

- **Section 1: A multidisciplinary approach for MND** introduces the concept of MDT working and how it benefits people living with MND, as well as professionals and services.
- **Section 2: A multidisciplinary toolkit** is designed to help professionals set up, run and manage an integrated MDT, covering assessment, care planning and review.
- **Section 3: Supporting resources** includes an appendix of sample documents used by MDTs, as well as a list of the ways the MND Association can help health and social care professionals in providing optimal MND care.





Section one:
**A multidisciplinary
approach for MND**

NICE Guideline on MND³

The National Institute for Health and Care Excellence (NICE) Guideline NG42 - *Motor neurone disease: assessment and management* aims to improve care from point of diagnosis through to end of life.

It includes topics such as information and support, organisation of care, managing symptoms and preparing for end of life. The guideline stresses the value of multidisciplinary team (MDT) working to achieve the best outcomes for people with MND, and this approach is referred to throughout this leaflet.

It recommends that services “*provide co-ordinated care for people with MND, using a specialist MND multidisciplinary team approach*” and it states that MDTs should:

- include healthcare professionals and social care practitioners with expertise in MND, and staff who see people in their homes
- ensure effective communication and co-ordination between all healthcare professionals and social care practitioners involved in the person’s care, as well as their family members and carers when appropriate
- carry out regular assessments at the multidisciplinary team clinic to assess symptoms and needs. The clinic may be community or hospital based
- provide co-ordinated care for those who cannot attend the clinic, according to the person’s needs.

Although we refer here to recommendations in the NICE guideline, which outline the ideal MDT structure for people with MND, in practice MDTs are often started informally by one or two interested professionals. They may later develop into a more formal structure.

More information about the NICE guideline on MND is available from **www.nice.org.uk/guidance/ng42**

The functions of the MDT



“MDT working is vital as MND issues are complex and multiple. Working together as a team, we can ensure a person is seeing the right professional and receiving the best care.”

-Neurology specialist nurse

Include HSCPs with expertise in MND

MDT core members: The NICE guideline³ recommends the MDT should include the following professionals:

- neurologist
- specialist nurse
- dietitian
- physiotherapist
- occupational therapist
- respiratory physiologist or a healthcare professional who can assess respiratory function
- speech and language therapist
- a healthcare professional with expertise in palliative care.

Even though not all MDTs will be able to involve all the specialists listed above, teams should aspire to fulfil this requirement wherever possible.

Additional disciplines: Research with clinicians⁴ and people with MND⁵ emphasised the need for collaboration among multidisciplinary teams and specialist services, including psychological and emotional support for both patients and their carers.

This is important because people with MND and their families face many challenges, including dealing with the uncertainty of the disease's progression and difficult decisions about their care, the loss of physical abilities and independence, and feelings of isolation.

This often results in high levels of depression and anxiety, leading to a reduced quality of life, increased suicide risk, hopelessness, and difficulty accepting the diagnosis, seeking help or taking up life-prolonging interventions^{5,6}.

Current national guidelines³ state that alongside the core team, the MDT should have established relationships with, and prompt access to, the following disciplines:

- clinical psychology and neuropsychology
- social care
- counselling
- respiratory ventilation services
- specialist palliative care
- gastroenterology
- orthotics
- wheelchair services
- assistive technology services
- alternative and augmentative communication (AAC) services
- community neurological care teams.

Ensure effective communication

For MDTs to work effectively, co-ordination among all individuals involved in a person's care is crucial². This requires clear communication between healthcare professionals, social care practitioners, and the person with MND, as well as their family and carers. Local and voluntary support services also play a key role in MND care⁷.



"It is essential to maintain regular discussion and open lines of communication with the MND co-ordinator and local hospice."

-MDT professional

- Provide contact details and information about the team to everyone involved.
- Agree on a system for recording notes and action points and inform the person with MND about how their personal information is stored.
- Securely share information (eg through NHS mail or encryption) between teams and individuals, and with the person with MND and their family.
- Only share relevant information for the person's care, including key updates and decisions, and explain why it is shared⁸.
- Appoint a key worker, or MND co-ordinator, within the MDT⁹ who advocates for the person with MND, ensuring they stay involved in decision-making and informed about MDT decisions, care and support services.



“People with MND and their families get the care of a team working towards the same goal, who knows what they may need and want.”

-MDT professional

Conduct regular assessments

The multidisciplinary team should regularly carry out co-ordinated assessments, usually every 2–3 months, to review and manage the person's needs and symptoms.

MDT action points: According to the NICE guideline³, MDTs should review the person's response to any treatment, as well as the following areas:

- weight, diet, nutritional and fluid intake, feeding and swallowing
- muscle problems, such as weakness, stiffness and cramps
- physical function, including mobility and activities of daily living
- speech and communication
- cough effectiveness

- saliva problems, such as drooling of saliva (sialorrhoea) and thick, tenacious saliva
- respiratory function, respiratory symptoms and non-invasive ventilation (NIV)
- pain and other symptoms, such as constipation
- cognition and behaviour
- psychological support needs
- social care needs
- end of life care needs
- information and support needs for the person and their family members and/or carers.



“We base our meetings on the NICE guidelines. For example, we discuss whether the person with MND uses non-invasive ventilation or has an advanced decision to refuse treatment form. We keep a record of all these, which members can access.”

-MDT professional

Provide care according to the person's needs

Assessments and information should be adjusted to meet the needs of the person with MND, considering factors like difficulty attending clinics, communication challenges, language barriers, neurodiversity, or other health conditions.

Since MND symptoms can worsen very quickly, a fixed assessment schedule may not always suit every person at all stages of their disease.

It's important to provide proactive and tailored care and ensure continuity¹⁰:

- maintain communication and monitor the person's well-being between visits

- keep a shared record of the person's needs and requests. Consider using our resources to help people with MND communicate their needs to the professionals involved in their care. Forms that may help you include 'Understanding my needs' and the 'MND checklist' – visit **www.mndassociation.org/careinfo**
- following assessments, ensure a case is not closed once care is in place, as this could cause delays as the person's needs change
- ensure there are arrangements in place to trigger earlier assessments if a significant change is identified
- provide tailored information and support. The MND Association offers care information resources for people with MND and their carers in different formats and languages (see page 42).



"We are developing a shared document, a sort of diary, that people with MND can bring to appointments and share with professionals to show what they may want to know, what's important to them, what they are doing and what they don't want."

-MDT physiotherapist



The benefits of MDT working¹¹

The MDT can be an influential body, championing individual patient needs and raising broader issues with commissioners and providers. These may include carers' needs, care pathways, palliative care services, process mapping, quality improvement and audit.

As a result, effective MDT working can be greatly beneficial not only for people with MND, but also for all the health and social care professionals involved in their care and for service provision.

The benefits for people with MND

Research has shown that people with MND value the convenience and quality of unified multidisciplinary care, the expertise in MND care of its professionals, as well as its advocacy potential⁵.



"People appreciate seeing everyone in one sitting, having a point of contact and actually leave the appointment much more informed."

-MDT professional

The benefits of multidisciplinary team working for people with MND include:

- improved survival and quality of life⁹
- fewer unplanned hospital admissions, shorter stays in hospital when they do occur and lower rates of readmission^{7,9}
- knowing who to turn to for advice on specific symptoms and accessing information from different professionals^{7,9,12}
- opportunities to discuss significant issues in a supportive way^{7,9,12}
- easier access from diagnosis onwards to timely support, aids and equipment^{7,9,12}
- improved decision-making processes and continuity of service provision⁷

- having professionals updated with aspects of their care, resulting in faster interventions and fewer delayed referrals⁷
- facilitated access to a wider range of therapies, services, research and clinical trials¹³.



“It allows for patient focused, cohesive care and enables for all members to be consistent in their approach to an individual’s needs. It means we aren’t giving conflicting advice but are all very clear about the person’s wishes and appropriate management approaches.”

-MDT professional

The benefits for professionals

For you as a health or social care professional, this style of working will provide opportunities for:

- gaining experience and expertise in MND care, learning from patients, carers and a wide range of professionals⁷
- developing additional and cross-disciplinary skills and education¹³
- having a collaborative approach to goal setting and problem solving
- increased professional support and cross boundary working²
- improved communication and joined up approach to sharing updated information and decisions, and raising concerns and queries
- increased ability to anticipate and support the changing needs of people with MND in a timely manner
- better understanding of someone’s specific needs and ability to tailor care to them
- networking and building relationships for future collaborations¹²
- improved job satisfaction as a result of greater autonomy and skills enhancement²
- improving understanding of other professions and wider health and social care systems.



“We complement each other’s roles and clinical remits to ensure all areas of care are met by specialists.”

-MDT professional

Additionally, working with people with MND can be challenging and sometimes emotionally exhausting^{6,7}. It is important that everyone involved in their care is well supported. An MDT can provide opportunities for:

- peer support to help deal with challenging cases and deaths
- reflective practice, including celebrating together²
- improving morale
- reducing levels of stress and helping avoid burnout.



“It allows for supportive and open discussion about patient care and experience, which enables ongoing professional learning and emotional support.”

-Speech language therapist

The benefits for services

An effective MDT will result in:

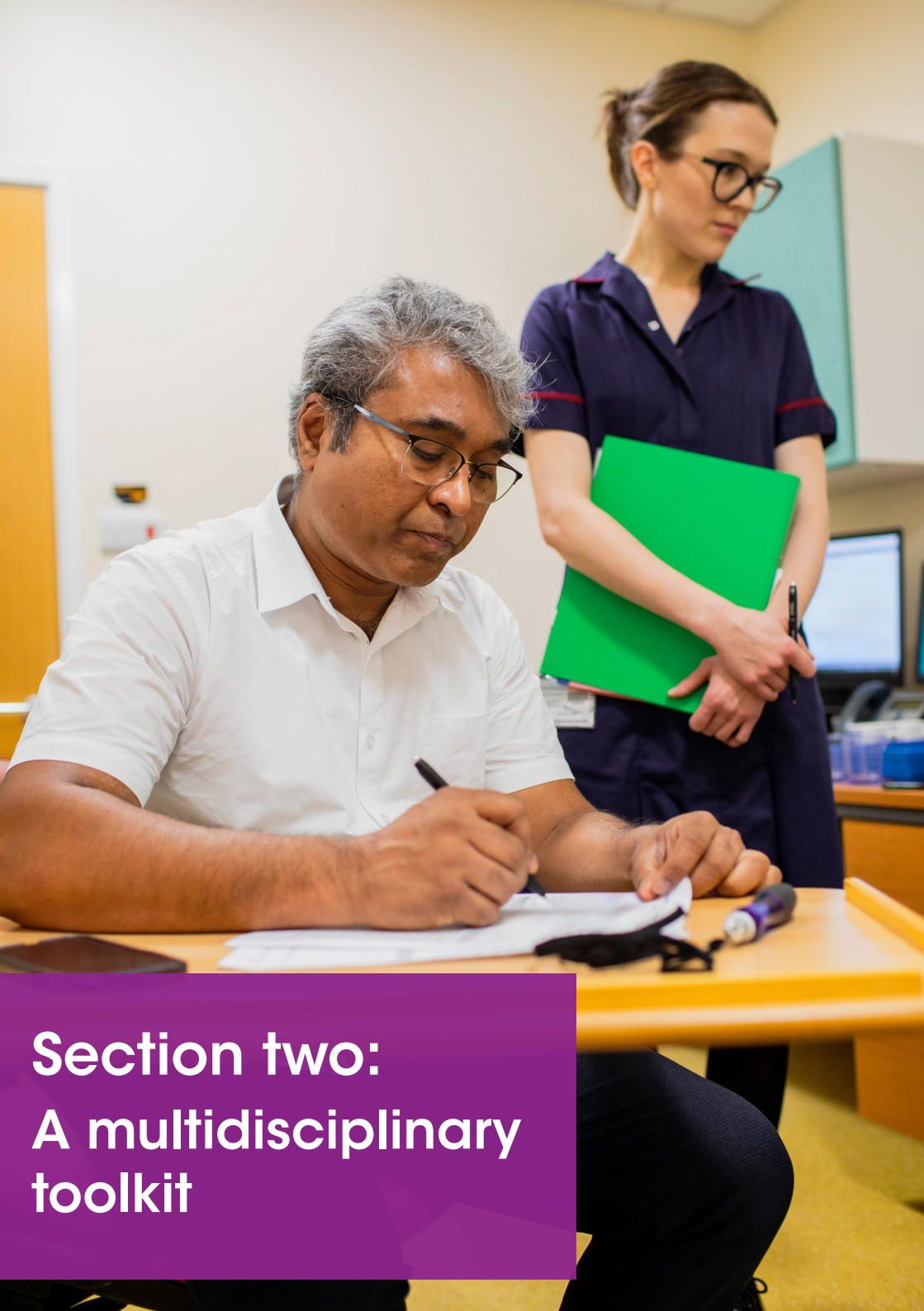
- promotion of best practice and patient-centred and holistic care
- cost effective ways of working⁷
- effective use of resources²
- reduced duplication and gaps in service
- development of support networks
- staff development and retention²
- greater levels of innovation in patient care, associated with higher quality of care.

“

“Developing a shared knowledge of MND care directly impacts and improves patient care. I don’t claim to be a specialist in other disciplines, but now, because of MDT working, I am able to give better advice to the people I see, which also helps reducing delays.”

-MDT member





Section two: A multidisciplinary toolkit

Setting up an effective MDT

Implementing multidisciplinary care can be at times challenging. Common barriers include difficulties in integrating services, communicating across teams, location and time constraints, poor working relationships and lack of funding¹¹.



“One difficulty is the limited availability of MDT members due to reduced funding and, at times, a lack of speed in referrals to others.”

-MDT member

A combination of factors shapes how well MDTs work, including careful planning, staff resources, clarity of roles and responsibilities, shared information and ongoing evaluation¹⁴.



“Communication can be difficult and sometimes a lack of awareness of roles can be an issue. We have addressed this with training, regular ‘keep in touch’ sessions and implementation of reflection and lessons learned during MDT meetings to aid with wellbeing and service improvement.”

-MDT professional

Making the case to establish an MDT

Identifying what services already exist, and what can be adapted to incorporate MND specific care, is an essential first step in creating an MDT. For example, an already established team, such as a community rehabilitation team, might have the right mixture of expertise, and MND care could be integrated into this structure.

Conducting an evaluation will help determine if an MDT is needed, highlight any gaps and provide evidence to support its establishment.

MDT working supports compliance with NICE MND guidelines and quality standards³, against which you can measure care and service provisions.

The MND Association has developed free, easy-to-use resources, based on NICE guidelines, to help health and social care professionals¹⁵:

- benchmark current performance and services
- improve outcomes for MND patients
- plan cost-effective service improvements
- enhance professional practice
- make a business case for a dedicated MND co-ordinator or a formal MDT.

Visit **www.mndassociation.org/audittool** for more information.



“An initial stakeholder meeting was required to start the MDT, with buy in from local organisations.”

-MDT professional

Consider also:

- finding an ally who feels strongly about improving the care pathway may help develop a plan together
- the MND Association’s Service Development Managers (SDMs) can support you in building a business case for an MDT, identifying team members, and setting shared aims and objectives. Contact MND Connect for details of your local SDM (see page 41)
- collecting evidence to show the impact of an MDT approach. For example, inviting people to shadow or attend MDT clinic may help you promote best practice while finding new allies to build your case.

Initial meeting

Facilitate an initial meeting with relevant health and social care professionals to discuss current communication and co-ordination between service areas. It can be helpful to bring data on the number of people with MND in the area, as some professionals may not be aware of this.

It can be useful to conduct a SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis, or similar, to identify what works well and what needs improvement in care, communication, or co-ordination. A SWOT analysis is a simple way to assess the current situation and helps in making the best use of resources, setting clear goals, and organizing management. These are key to planning an effective and sustainable MDT². Consider this as a team and agree how to identify and address weaknesses.

Terms of reference

Developing clear terms of reference can help the MDT remain clear about its purpose and operate smoothly. Teams may hold a workshop session to identify these and agree on how different agencies and individuals will work together.

It may help to include the following topics:

Aims: clearly define the purpose of the group. Some teams may focus specifically on the needs of people with MND, while others may cover broader neurological diseases (see page 35 Appendix 2). MDT's aims could include:

- improve standards of care for people with MND
- enhance communication about MND in a particular area
- identify gaps in service
- reduce duplication.

Meetings: decide when and how often meetings will occur and how long they will last. The frequency and duration will depend on factors like the number of people with MND and team members' availability.



“We found that attendance had dropped, so we sent to everyone a poll to choose a date and time that could work for as many professionals as possible.”

-MDT co-ordinator

Meetings should be short and focused, otherwise professionals may not find the time to attend. In rural areas, longer meetings may however be more effective to account for travelling time. In any case, meetings' duration should ensure that all people with MND are discussed, and every MDT member can contribute.

Regular meetings can help keeping MDT members engaged and communication channels open. Frequency of meetings can vary. However, it should always meet the needs of people with MND and be flexible for unplanned reviews when a person's condition or circumstances suddenly change (see page 36 Appendix 3).

Location: when planning where to hold MDT meetings, consider:

- the physical environment, including noise levels, capacity, comfort and confidentiality
- availability and reliability of technology, including equipment, phones and/or internet connectivity
- accessibility requirements, including parking, public transport and disabled access
- whether meetings should be held in the same place or in different venues each time
- whether virtual meetings could be more accessible, cost and time-effective



“Use of Teams to host MDT has enabled a greater participation over a wider geographical area.”

-MDT professional

Format: agree how meetings will be run. It may help to decide:

- a standard agenda format
- paperwork templates for each person with MND (see page 38 Appendix 5), and how they will be logged
- a method to prioritise patients and points of discussions. Establish, for example, a red/amber/green system
- a system for storing and sharing meeting notes
- a protocol for unplanned reviews.

Chairing arrangements: appoint a dedicated chair and vice-chair and agree on the course of action if neither can attend. These positions may rotate to ease the distribution of workload.

Shared information and IT systems



“One difficulty is accessing systems to read each other’s notes, so we are working on developing a shared care document to address this.”

-MDT member

Sharing clinical notes and records is essential for effective multidisciplinary care. However, while some members may have access to a shared system to store these records, others may not, such as external consultants.

It is important to ensure that external members of the care team also receive appropriate and relevant information to effectively co-ordinate the care of the person with MND. It may be useful to also share with them any summary of records, shortly before they visit a person with MND. This will help reduce the risk of duplication or delays.



“When I know one of the person I am supporting is going to a consultant, I send an email update of a summary of what we did as an MDT. So by the time of the appointment, they already know whether for example, that person has seen a physiotherapist or is having swallowing difficulties.”

-MDT co-ordinator

Whether clinical information is shared with core or external members of the MDT, it is fundamental to follow information governance and data protection laws. The NHS England Information Sharing Policy¹⁶ highlights the need to share information to ensure effective co-ordination of services and outlines the requirements for all NHS England staff when sharing personal information.

When choosing a meeting location, whether that is physical or virtual, and deciding how to record or share data, assess the risk of sharing clinical information between MDT members or with third parties. This can include conducting a data privacy impact assessment to identify and mitigate risks. Consider having an information-sharing agreement, using patient identification numbers, and setting up password protections.

We recommend ensuring you follow your local information governance procedures and consult with the local Caldicott Guardian or information governance expert if you have any concerns. Information about the Caldicott Principles is available at:

www.gov.uk/government/publications/the-caldicott-principles

Finally, make sure that all relevant information is also shared with the person with MND (see pages 33-34 Appendix 1). This includes:

- informing them of the MDT functions and of all the members involved in their care
- disclosing how their care and information are discussed and shared
- updating them about MDT actions and decisions
- discuss any concerns and ensure they can provide or withdraw informed consent to discuss their case in the MDT.

It may be helpful to provide them with information leaflets (Appendix 1) and with a list of all the members and contact details. You could also copy them into emails and letters between professionals, so they are aware of who to contact and who may assist them¹¹.

Roles and memberships

Clearly defining roles and responsibilities is key to effective multidisciplinary and cross-boundaries working within and across teams.

Membership list: identify the core MDT members, ideally ensuring representation of professions recommended in the NICE guideline (see section 1). Include in the list also any additional members who collaborate with the MDT (see page 37 Appendix 4).



“It’s difficult when a member is sick or one of the speciality roles is vacant, because people don’t get the full advantage of specialist advice are referred to a generalist in that field, who may not have experience in MND.”

-MDT professional

If a member cannot attend regular meetings, they should still stay involved by attending virtual meetings, sharing notes beforehand, reviewing minutes afterwards, and sending a deputy. Preferably, the deputy should have the authority to make decisions and liaise and feedback as appropriate. It may be helpful to designate a colleague from each discipline who can attend in place of a member when needed. Ensure they are provided beforehand with all the necessary information to discuss the case.

Key worker: People with MND benefit from having a designated person responsible for co-ordinating their care^{7,11}.

A key worker:

- is knowledgeable about MND and the challenges people with the disease and their family may experience

- acts as a single point of contact for the person with MND
- ensures timely referrals, provisions and appropriate support from diagnosis onwards
- ensures the person with MND has access to information and advice
- informs the person with MND about available support services, including the MND Association and local groups.

The key worker, or a professional with the title of MND Care Co-ordinator, should be an integral part of the MDT. They may change over time, for example if the person with MND can no longer attend clinic. It is important that the MDT acts swiftly to replace them to ensure continuity of care.



“Without an MDT approach and a single point of contact, there can’t be adequate support for people with and affected by MND.”

-MDT member

MDT co-ordinator: Co-ordination of care must be proactive, preferably involving a named individual to act as a liaison between teams and services.

This role may be held by the named key worker or a different team member who maintains contact with the person with MND and their key worker.

The MDT co-ordinator should ensure that:

- distribution lists are up to date
- meeting agendas are prepared and distributed
- a register of attendance is maintained, and issues of attendance are addressed
- cases of MND are prioritised and discussed
- relevant MDT members are included in discussions
- discussions are focused and relevant

- recommendations are clearly summarised and recorded
- responsibility for any resulting actions is clear
- the team has agreed standards of behaviour and etiquette
- teamwork is effective and members collaborate to have a joint and solution-focused approach
- any difficulties or conflicts are addressed promptly.



“As co-ordinators, we occupy that unique role of being able to pull together what happens in the acute hospital and in the community services.”

-MDT co-ordinator

Administrator: It is important to establish administrative support for the MDT to ensure consistency and effective communication.



“A lack of admin support is a huge barrier to sharing information, especially with external services.”

-MDT professional

How this is organised will depend on the nature of the MDT. Whatever arrangements are agreed, the importance of this work should be recognised. The MDT co-ordinator may undertake administrative tasks. These include:

- maintaining up to date membership and distribution lists
- circulating the agenda and other relevant papers
- scheduling the meetings and booking venues
- ensuring any technology or equipment is available and working
- recording actions and discussions
- ensuring actions agreed during the meeting are followed up
- acting as a point of contact for MDT members
- updating electronic records, if not completed during meetings
- ensuring regular reviews are undertaken.

Maintaining an effective MDT

Team Culture^{13,17}



“There must be trust. Nobody is in charge of each other, but it is important for the environment to be supportive and collaborative. Everyone comes from different backgrounds and disciplines, but they all must be respectful and come to a solution as a team.”

-MDT member

Building strong relationships and collaborations between professionals and services is essential for effective MDT working. This requires:

- fostering a culture of openness, support, mutual respect and empowerment
- creating a safe environment where everyone feels comfortable speaking up, regardless of their role or position in the management hierarchy
- taking time to reflect on how the members are working together and how they might improve
- identifying and addressing barriers to communication, such as interprofessional differences, fear of failure and hierarchy
- encouraging people to seek help if necessary, acknowledging contribution and challenging unprofessional behaviour
- supporting participation and shared ownership
- promoting ongoing professional and personal development and learning from and with each other.



“At times it is difficult, but communication is important. Knowledge on MND is varied within some services and I strongly feel everyone should have training on MND.”

-Community nurse

The MND Association regularly hosts events that can support your development and that of MND care services. Among these, the MND Professionals' Community of Practice offers opportunities for MDT members to network and share resources, knowledge and good practice (see page 42).

Monitoring and reviewing the MDT^{13,17}

Creating a safe, honest environment is essential for effective evaluation of the MDT. Regular reflection helps ensure that the team continues to meet its goals and addresses issues that may arise.



"I recently started a meeting to discuss best practice and patient experiences for our development as a team. As a result, we changed our MDT meetings proforma to have a more detailed section on advance care planning. We all found it very useful to reflect on what the people with MND have told us, what we've found hard, but also what have gone well and we have done well."

-MDT professional

Formal review of the MDT can:

- provide an objective analysis of the effectiveness of MND care
- facilitate the development of an improvement plan
- help team members understand how their work impacts other services and people with MND
- identify gaps and promote quicker and more flexible service provision
- provide evidence for service development.

Agree how often reviews will take place (at least annually), who will lead them, and whether to conduct them as a group or separately, comparing the results afterwards. Ensure you flag and address any issues brought up by the person with MND or their families.

Where appropriate, use locally developed audit tools or audit department. You could also consult Appendix 6 (pages 39-40) for an example of a review form.

Building flexibility^{2,17}

An effective MDT will not rely solely on individual expertise and interest to sustain the group. It will be able to absorb changes and adapt by developing a flexible culture that ensures a balance of disciplines, agencies and skills.

Team members may, by choice or through managerial pressure, stop attending the team meetings if they are not working with a person with MND. It can then be difficult to re-engage these professionals, which can lead to a loss of expertise. It may be necessary to recruit new members to replace any lost skills.

The team needs to build flexibility into its structure to handle fluctuations in patient numbers and potential loss of team members.

To ensure continuity of care for people with MND:

- inform relevant MDT members and provide any relevant information if you predict any change in needs or in team membership
- provide contact details of nominated cover members for each discipline, to contact for specialist information
- have protocols in place to transfer care to new team members
- keep records of all necessary MDT arrangements to smooth handover.

Navigating clinical pressures



“All teams are busy so finding a time that suits all is tricky. as MDT colleagues are under increasing clinical pressure we have noticed a reduction in attendance, but they are committed so do try their best to attend and contribute.”

-MDT member

With increasing clinical pressures, it might be more difficult to attend MDT visits and meetings and this can affect the care of people with MND.

- Adapt meeting formats as necessary, for example choosing a time that works better for everyone or moving them online.
- Consider conducting virtual visit or telephone appointments to ensure continuity of care.
- Effectively prioritise MDT visits and action points. This may help to increase the availability to respond to sudden or more frequent changes in needs.
- Ideally all members involved in someone's care will attend MDT meetings. However, if not possible, alternate between members of the same discipline. Ensure that whoever attends is provided with all relevant information to discuss a case, and that they will feedback to you any action points.
- Ensure all people with MND are discussed, even if not all MDT members are present. Professionals from other disciplines or other teams may still be able to give valuable advice. Make sure to follow up with the specialist afterwards.



"Sometimes other members might be able to give advice. For example, there might be multiple palliative care teams covering an area. The professional looking after the person you wish to discuss may not be present, but a colleague from another team may give you some really helpful advice."

-MDT physiotherapist

- To ensure prompt action, maintain in person and online communication with other team members in between meetings and visits. This will also help you access professional and peer support when needed.
- One stop clinics may be challenging due to limited service capacity, or they may become lengthy and inconvenient for people with MND, especially as the disease progresses. Maintain effective communication with other professionals at all times to ensure co-ordinated care even in the absence of joint assessments.



"A lot of the people we see have joint needs for multiple professionals, but might be seen one by one at a time due to limited capacity. But we always look at each other's notes and keep each other updated, so we can tailor our care and keep giving the information they need."

-MDT professional

- Have appropriate administrative support. If possible, nominate someone who is not a clinician. Consider requesting time from the hospice admin team to help reduce the workload of MDT members.



"Given that everyone is under huge pressure, I am always amazed that we have such as good participation as we do. But I think that shows that people find the MDTs worthwhile and supportive."

-MDT co-ordinator



Section three: Supporting resources

Appendices

Appendix 1 - MDT information for people with MND

What are MND MDT meetings?

They are meetings held regularly to discuss the care and services you are receiving.

Why are they necessary?

We know that motor neurone disease can be complex, and you may need services from a large number of people. It is really important that everyone involved in your care communicates well together to make sure that you get the right services at the right time. These meetings help us to communicate better with each other about the care you are getting or need, so we can prevent you waiting unnecessarily for services.

Who takes part?

Health and social care professionals involved in your care, or who may need to be involved in the future.

What do you talk about?

We share information about who is currently providing your services, and what each of these people is doing for you. This helps make sure we are not duplicating services. It also helps ensure you are seeing the best person for your needs. We consider the things which may be causing you difficulties and suggest how these may be sorted out.

Appendix 1 - MDT information for people with MND, continued

What happens with the information?

Each person present will keep their own record of the discussion. If we feel it would be helpful for other people to be aware of the points discussed (eg your GP) we may contact them after the meeting. All health and social care staff are bound by strict confidentiality policies, and only share information (with your permission) on a 'need to know' basis.

What if I don't want you to talk about me?

If you tell us you don't want us to talk about you, then your care will not be discussed at the meeting. You will still continue to receive the services you are entitled to.

How can I get more information?

Speak to any health or social care professional with whom you are in contact or contact us on

<insert phone number> or <insert email address>.

Appendix 2 - Terms of reference

- To improve the care of people with MND.
- To improve communication about people living with MND in the area.
- To ensure patients' needs are reviewed regularly and met by the most appropriate professional.
- To advise on matters relevant to MND practice and policy.
- To provide a regular forum for health and social care professionals to discuss MND patients and develop an action plan.
- To develop strategies which support the continual improvement of services for people with MND.
- To review and respond to reports and action recommendations regarding intervention with MND clients from the Department of Health, NICE and other approved bodies.
- To support and review relevant audits involving the MND Association to ensure compliance to all standards relating to new policies and guidelines on MND.
- To submit updates and reports to relevant groups, boards and management teams regarding strategic issues around MND as required.
- To disseminate key learning from training events and promote evidence based practice.
- To offer mutual support by reflecting on practice and acknowledging difficulties.

Appendix 3 - Meeting arrangements

Frequency and timings

Meetings will be held on the first Thursday of each month from 9.30am to 11.30am.

Location

Meetings will alternate between Zoom and Anytown Hospice.

Format

- A template will be completed for each person with MND known to team members. This will contain core details.
- At the start of the meeting, it will be agreed which patients will be discussed. These will be prioritised using a red/amber/green system. All new patients will be discussed.
- A member of the team will complete the 'issues arising' and 'actions to be taken' part of the template during the meeting.
- The team will agree which other professionals need to be sent a copy of the completed template after the meeting. The admin team at Anytown Hospice will ensure that they are sent.
- The master copies of all the templates will be kept securely in the hospice manager's office at Anytown Hospice.

Accountability

The group will report and be accountable to the Anytown Hospice board.

Chairing arrangements

The meeting will be chaired by Hospice Manager or MND Specialist Nurse. If neither are present, the chair will be agreed at the start of the meeting.

Review

These terms of reference will be reviewed at the beginning of each year as a minimum.

Appendix 4 - Membership list

Core members

- Neurologist, Anytown University Hospital
- MND specialist nurse, Anytown General Hospital
- Occupational therapist, Anytown Community Team
- Dietitian, Anytown Community Team
- Physiotherapist, Anytown Healthcare Trust
- Speech and language therapist, Anytown Healthcare Trust
- Palliative care consultant, Anytown University Hospital
- Respiratory specialist , Anytown University Hospital.

Additional members

- Wheelchair adviser, Anytown Wheelchair Services
- Social worker, Anytown Council
- Service development manager, MND Association
- Hospice manager, Anytown Hospice
- Counsellor, Anytown Hospice.

Appendix 5 – Discussion template

Patient’s name:

Address:

Date of birth:

NHS number:

Date of diagnosis:

Key worker:

Issues arising:

Actions to be taken:

Actions to be taken	By who	By when

Appendix 6 - Review form

	Yes	No	Unsure
All MDT members are committed to service improvement			
MDT members demonstrate mutual trust, respect and support			
The core MDT includes the professions stated in the NICE Guideline on MND			
Membership of the MDT is regularly reviewed to ensure adequate representation from all key professionals/services recommended by the NICE Guideline on MND			
There is clear leadership			
All members are clear about the purpose of the MDT meetings			
Attendance at MDT meetings is supported by management			
MDT members share their learning with others			
There is a single point of contact for the team			
There is an identified key worker or co-ordinator			
Regular meetings are held at which the care of people with MND in the area is discussed			
There is a systematic way of recording notes during the MDT meetings			
Team meetings are used to reflect on practice			
People with MND and carers can easily contact the MDT			
People with MND's requests and feedback are discussed with the MDT			
There is a clear care pathway			

Appendix 6 - Review form, continued

	Yes	No	Unsure
There are clear channels of communication between MDT members			
MDT members can access the information which may be needed by the person with MND at any stage			
There is access to up to date case notes			
Team members can cross refer			
There is an integrated system of assessment and care planning			
The MDT ensures that people who are bereaved can access support			
There is a recognised system of referral to the MDT following diagnosis			
All members of the MDT know what services are available for people with MND in the area			
People with MND can self-refer to the team if necessary			
There is liaison with the MND Association through the team			
The team is used to affect change where there are identified gaps or weaknesses in local services/ equipment provision			
Information, including updates and relevant contacts, is adequately and regularly shared with people with MND and carers			
Gaps in skills are identified and addressed through training and events			

How we can support you

Motor neurone disease affects people from all backgrounds, and the needs of those living with MND are varied and complex. As a health and social care professional, it's crucial to provide the best care possible.

This involves tailoring support to the specific needs of people with MND, signposting relevant information, and working closely with specialist services.

The MND Association offers several resources to help you do that, as well as various services to which you can refer the people with MND you support. Find out more through:

MND Connect

Our helpline offers help to people living with MND, carers, family and health and social care professionals. Our advisers can provide emotional and practical support, including social and financial information, and refer to local support and MND Association's services.

Email: **mndconnect@mndassociation.org**

Phone: **0808 802 6262**

MND Association website

Our website offers supporting information on MND and our work, including the research we fund, the services we provide and how to get involved.

www.mndassociation.org/professionals - discover all resources for health and social care professionals

www.mndassociation.org/support-and-information - discover all help available for people with or affected by MND

Support for health and social care professionals

Professional information resources

We have a wide range of information resources available to support professionals from different disciplines, including booklets, infographic and online courses. Our professional information finder can help navigate them according to profession and topic.

www.mndassociation.org/pro-info-finder

MND Professionals' Community of Practice

A peer led group of health and social care professionals supporting cross disciplinary learning, knowledge exchange and the development of good care for people with MND. You can join to participate to unique networking and learning events. Being an active member could count towards your professional CPD requirements.

www.mndassociation.org/cop

Education

Our education programme is designed to improve standards of care and quality of life for people living with and affected by MND. We regularly organise webinars, workshops, lectures and networking events.

www.mndassociation.org/education

Socials

You can remain updated on all MND information for professionals through our newsletter or social media channels.

www.mndassociation.org/educationupdate

X: **[mndeducation](#)**

Bluesky: **[mndeducation.bsky.social](#)**

Support for people with or affected by MND

Care information resources

We produce high quality information resources for people living with MND, carers and family members. Our publications, available in different formats and languages, can help people understand MND, plan ahead, and talk about MND to other people, including children.

Professionals can share this information with the people they support, or use it to open conversations.

www.mndassociation.org/careinfofinder

Benefits Advice Service

Qualified advisers can help identify benefits the person with MND and carers may be entitled to and advise on how to claim. This service is confidential, impartial and free.

www.mndassociation.org/benefits

Financial support

Where statutory provision is not available, we may be able to offer financial support to help with:

- funding for children and carers
- cost of living expenses
- equipment loans and services, including communication aids and wheelchair support, upon referral from a professional.

www.mndassociation.org/our-services

Online forum

Our online forum is accessible to anyone and can offer first-hand experience of MND, and practical and emotional support.

forum.mndassociation.org/

Local support

The MND Association offers a range of options for support in your local area:

- We fund and develop MND care centres and networks across England, Wales, and Northern Ireland, which offer specialist MND care.
- We run almost 150 online and face-to-face support groups.
- We have trained volunteers and volunteers-led groups that offer practical help and support for people with MND, via phone, email or visiting their own home.

www.mndassociation.org/local-support

Research

Research into MND

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

www.mndassociation.org/research

MND Register

The MND Register aims to collect information about every person with MND to help researchers focus their knowledge and expertise in the right areas.

mndregister.ac.uk



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Acknowledgements

Thank you to all the health and social care professionals who contributed anonymously to this guide.

Many thanks also to the following for their assistance in developing and reviewing this booklet, and previous versions:

Lyn Bevan, MND Clinical Specialist, Phyllis Tuckwell Hospice

Erin Forker, Specialist Dietitian, MND Team at University Hospitals Birmingham NHS Foundation Trust

Ruth Glew, Network Lead Co-ordinator, South Wales MND Care Network

Emma Moore, Specialist Physiotherapist, Sirona Care and Health

Dr Cate Seton-Jones, Medical Director, Phyllis Tuckwell Hospice Care

Rachel Thomson, MRCSLT, Sussex MND Care and Research Network Co-ordinator

Omina Yasmin, MND Clinical Nurse Specialist, LOROS Hospice

We value your feedback

We would greatly appreciate your feedback on this guide. Please visit **www.smartsurvey.co.uk/s/mndprofessionals** or email your comments to **infofeedback@mndassociation.org**

Visit our webpages for health and social care professionals:
www.mndassociation.org/professionals

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Registered Charity No. 294354

PX010

Created 03/25

Next review 03/28

Version 1

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