

mnda

motor neurone disease
association



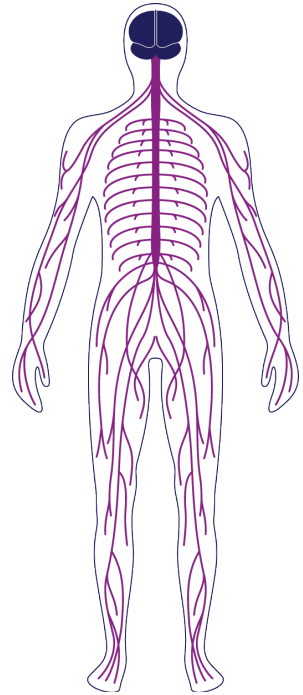
MND Professionals'
Community
of Practice



**Multidisciplinary team
working for MND**

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

mndconnect
0808 802 6262
mndconnect@mndassociation.org

Contents

4 Introduction

Section 1: A multidisciplinary approach for MND

7 NICE Guideline on MND

10 The benefits of multidisciplinary working

12 The function of the MDT

Section 2: A multidisciplinary toolkit

16 Setting up an effective MDT

20 Maintaining an effective MDT

22 Appendices



This guide has been endorsed by the MND Professionals' Community of Practice.

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 year.¹

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.

About this guide

This booklet introduces the core principles for multidisciplinary teams (MDTs) working to support people with MND. It aims to help professionals establish and maintain best practice, to improve outcomes for people with MND.

It is split into two 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 which is designed to help professionals build, develop and sustain an integrated MDT, covering assessment, care planning and review. This section includes an appendix of sample documents used by MDTs.

The MND Association's Service Development Managers (SDMs) can play a key role in supporting the development of local MDTs. This may include identifying team members, establishing shared aims and objectives, and making a business case to establish an MDT. Contact MND Connect for details of your local SDM. Call MND Connect on 0808 802 6262 or email mndconnect@mndassociation.org

What is a multidisciplinary approach?²

A multidisciplinary approach involves drawing appropriately from multiple disciplines to explore problems outside of the professionals' normal scope of practice and expertise to reach joint solutions based on a new understanding of complex situations.

Multidisciplinary and multi-agency working involves appropriately utilising knowledge, skills and best practice from a wide range of professional groups, across service providers. Working together, professionals can reach solutions based on an improved collective understanding of complex patient needs.





Section one:

A multidisciplinary approach for MND

This guide refers to an MDT as a group of professionals from a range of disciplines who meet regularly (either in person or virtually) to discuss and agree treatment, ongoing management and co-ordination of services for individual patients with MND.

Models of care vary greatly, as do individual multidisciplinary teams. This guide provides suggestions on how an MDT might be set up, run and managed, but it is not prescriptive and any development should be tailored to suit local need.

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 working to achieve the best outcomes for people with MND, and this approach is referred to throughout this leaflet.

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

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.

The NICE guideline on MND recommends that services “*provide co-ordinated care for people with MND, using a multidisciplinary approach. The clinic may be community or hospital based.*”

The guideline states multidisciplinary teams 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, and their family members and carers as appropriate

- carry out regular assessments at the multidisciplinary team clinic (usually every 2-3 months) to assess symptoms and needs
- provide co-ordinated care for those who cannot attend the clinic, according to the person's needs.

MDT members and disciplines

The guideline recommends the core multidisciplinary team should include the following disciplines:

- 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.

The guideline acknowledges not all MDTs will be able to involve all the professionals listed above, but teams should aspire to fulfil this requirement wherever possible.

Where a member of the core team is unable to commit to ongoing meetings, it is important they are still involved. This could be by sharing notes prior to the meeting and receiving the minutes afterwards or sending a deputy who can make decisions in their place. Alternatively, they may be able to participate using teleconferencing or video conferencing.

In addition to the core team, the MDT should have established relationships with, and prompt access to, the following:

- 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.

MDT action points

The guideline recommends multidisciplinary teams assess, manage and regularly review the following areas, as well as the person's response to any treatment:

- 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.

The way assessments are carried out should be adapted to suit the person's needs, for example if they have cognitive or behavioural changes, or difficulties with communication.

The benefits of MDT working

The benefits for people with MND

For people with MND, multidisciplinary team working results in:

- increased survival time^{1,4}
- improved quality of life⁵
- fewer unplanned hospital admissions, shorter stays in hospital when they do occur and lower rates of readmission⁴
- access to support from diagnosis onwards
- easier access to support and information
- opportunities to discuss significant issues in a supportive and timely way
- continuity of service provision
- fewer delayed referrals⁶
- access to a wider range of services.

Good care planning across all agencies will allow services to be provided promptly and ensure a rapid and flexible response to the person's changing needs.

The benefits for professionals^{2,7}

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

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

- openness, with understanding and mutual respect of roles
- increased cross boundary working and improved communication
- development of support networks
- development of multidisciplinary teaching and education
- individual professional development and learning
- access to a wide range of professional expertise.

The benefits for services

An effective MDT will result in:

- cost effective ways of working^{1,4}
- reduced duplication
- development of support networks
- minimised gaps in service
- staff development
- enhanced relationships with other disciplines.



The function of the MDT

Identify a key worker for each person with MND

People with MND benefit from having a designated person responsible for co-ordinating their care.⁴ This role is vital in ensuring timely provision of appropriate support. It also ensures the person with MND can access information and advice quickly and easily, and that they are kept informed and involved in decision-making.

This key worker is a named professional within the MDT⁴ who acts as an advocate for the patient. It is essential that they are knowledgeable about MND and the challenges people with the disease and their families may experience. The key worker 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.

Information governance requirements

The person with MND should be given information about the MDT. See appendix 1 on page 22. MDTs should be aware of the need to comply with data protection legislation, in particular when third parties are involved.

The NHS England Information Sharing Policy⁸ highlights the need for professionals and organisations to share information to ensure effective co-ordination of services. This policy sets out the requirements placed on all NHS England staff when sharing personal information. It is good practice to assess the risk associated with sharing clinical information across statutory and charitable organisations.

A data privacy impact assessment will help identify and mitigate any risk. It may be necessary to have an information sharing agreement in place.

We recommend ensuring you work within your locally agreed information governance procedures and liaise with the local Caldicott Guardian or information governance specialist if you have any concerns. Information about the Caldicott Principles can be found at: **www.gov.uk/government/publications/the-caldicott-principles**

Conduct regular multidisciplinary assessments

The MDT should carry out regular, co-ordinated assessments of the person's symptoms and needs, usually every 2–3 months. However, MND symptoms may get worse very quickly. Arrangements should be in place to trigger an earlier assessment if a significant change is identified by the person, family members, carers or healthcare professionals.

Priority should be given to maintaining continuity of care, for example, ensuring a case is not closed once a package of care is in place, because this will cause delays as the person's needs change.

Develop robust systems for communication

For MDTs to be effective, communication and co-ordination between all healthcare professionals and social care practitioners involved in the person's care, and their family members and carers, is essential.

- Securely share (eg via NHS mail or using encryption) information and ideas between different teams and individuals involved, as well as with the person with MND and their family.
- Provide information about who is on the team to everyone concerned, including contact details.
- Agree a process of recording notes and action points within and between teams.

Review activity

Review the MDT regularly (at least annually) to ensure that it continues to meet its objectives.

This process will provide an objective analysis of the effectiveness of the MDT. It will help team members better understand how their work impacts other services, as well as people with MND.

Reviews can help identify gaps and promote quicker and more flexible provision of services and equipment. They also provide evidence for service development.

- Where appropriate, make use of any locally developed audit tools or audit departments.
- Consider using the Transforming MND Care audit⁹ (see page 16-17).

Ongoing professional development

- Organise training to fill gaps in knowledge.
- Offer support to team members to help deal with challenging cases and deaths.
- Provide opportunities for reflective practice.
- Improve understanding of other professions and wider health and social care systems.

Sustaining the MDT

Strong leadership, adequate resources and clarity of roles and responsibilities are essential to ensure the continued effectiveness of an MDT.¹⁰

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 and expertise is lost from the MDT.

The team needs to build flexibility into its structure to allow for fluctuations in patient numbers and the possible loss of team members. It may be necessary to recruit new members to replace any skills or core professions lost.

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



Section two: A multidisciplinary toolkit

If you are a professional looking to set up an MDT for people with MND in your area, this section includes information to help you get started.

Setting up an effective MDT

Making the case to establish an MDT

Establishing what services already exist, and what can be adapted to incorporate MND-specific services, is an essential first step towards establishing an MDT. This evaluation will highlight any gaps, help to identify if an MDT approach is needed, and can be used as evidence to support the development of an MDT.

The right mixture of expertise may already exist in an established team, such as a community rehabilitation team. MND could be assimilated into this structure.

It may help to find an ally who feels strongly that the pathway needs to be improved so that you can work together to develop a way forward.

MDT working supports compliance with the NICE guideline on MND. Research also shows that:

- healthcare teams are more likely to provide high quality patient care if they have clear objectives, high levels of participation, support for innovation and an emphasis on quality
- members of teams that work well together have relatively low levels of stress
- a diverse range of professional groups working together is associated with higher levels of innovation in patient care.¹⁰

Benchmarking current services

Transforming MND Care⁹ is a free, simple to use audit tool developed by the MND Association, based on standards in the NICE guideline on MND (NG42).

The tool has been specifically designed for health and social care professionals working with people with MND.

Transforming MND Care can help you to:

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

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

Initial meeting

Facilitate an initial meeting of relevant health and social care professionals to discuss current levels of communication and co-ordination between service areas. It is a good idea to take along information about the number of people with MND in the area, as some professionals may not know this.

It can be useful to undertake a SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis, or similar, to identify what works well and what does not in relation to current care, communication or co-ordination. SWOT is a simple way to assess the current position and assist in planning an MDT that will be effective and sustainable. Consider this as a team and agree how weaknesses can be addressed.

Terms of reference

Developing clear terms of reference can help the MDT remain clear about its purpose and operate smoothly.

Teams may choose to have a workshop session to identify these and agree how the different agencies and individuals will work together. See page 23 for a terms of reference template.

It may help to include the following topics:

Aims: identify precisely what the purpose of the group is. Some teams choose to meet specifically to discuss the needs of people with MND. Others may choose to focus on a broader area of chronic neurological disease.

The MDT could have a number of aims, including to:

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

Members: name the organisations that will form the core MDT, ideally ensuring representation of professions recommended in the NICE guideline (see page 8-9).

If possible, name the person who will attend from each discipline, as well as a colleague who can attend in their place, liaising and feeding back as appropriate. Ideally, this would be someone with authority to make decisions in their absence.

Meetings: identify when the meetings will be held and how long they will last. Meetings can be virtual or in person. The frequency and duration will depend on factors such as how many people with MND are known to the team, and how much time the members can commit.

Meetings should be short and focused, otherwise professionals may not find the time to attend. In rural areas, where travelling time is a factor, longer or virtual meetings may be more effective.

Regular meetings can help members of the MDT to remain engaged and ensure communication channels stay open. Frequency of meetings can vary but must meet the needs of people with MND.

Location: when planning where MDT meetings will be held, consider:

- the physical environment, including noise levels, capacity, comfort and confidentiality
- the availability and reliability of technology or equipment needed
- the accessibility requirements of any team members, including parking, public transport and disabled access¹⁴
- whether all meetings will be held in the same place in person, whether the venue will vary or whether virtual meetings will promote better attendance.

Video conferencing may provide a solution where access is difficult. It can be more time-efficient for professionals, as there is no traveling time. It can also be more cost effective. However, it is vital to bear in mind data protection legislation when considering this option (see page 12). It is also important to ensure reliable phone and/or internet connectivity.

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

- agree a standard format to the agenda
- decide what paperwork will be used, for example proformas for each person with MND, logging issues and any agreed actions
- agree where documentation will be kept
- decide how notes will be shared after the meeting.

Flexibility is needed to allow for unplanned reviews when an individual's condition suddenly deteriorates or their circumstances change.

Chairing arrangements: appoint a named, dedicated chair and vice-chair. Agree the course of action if neither can attend. The chair may or may not be the same person who acts as the MDT co-ordinator.

MDT co-ordinator: It is crucial that care for people with MND is properly co-ordinated.

To be effective, co-ordination must be proactive, preferably involving a named individual to act as a point of contact for liaison between services, as well as a central point of contact for the person with MND.

The MDT co-ordinator could be a worker from any of the agencies involved, or in some cases, they may be a professional with the title of MND Care Co-ordinator.

The MDT co-ordinator should ensure:

- 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
- any difficulties or conflicts are addressed promptly.

Maintaining an effective MDT

Administration

It is important to establish administrative support for the MDT to ensure consistency and effective communication. How this is organised will depend on the nature of the MDT. The MDT co-ordinator may undertake this role.

Whatever arrangements are agreed, the importance of this work should be recognised.

Tasks may 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.

Peer support

Working with people with MND can be challenging and sometimes emotionally exhausting. It is important that everyone involved in their care is well supported.

An MDT can provide opportunities for peer support and help avoid burnout.

Monitoring and reviewing the MDT

Regular reflection and review of the MDT is important to ensure its sustainability and address issues that may arise.

Formally reviewing the MDT can highlight issues and help produce an improvement plan to increase its effectiveness.

Agree how often reviews will be undertaken and who will take the lead.

See page 25-26 for an example of a review document which can help identify areas that require further action to ensure the MDT is working effectively.

The questions can be answered as a group to reach a consensus, or members can complete it separately and compare results.



Appendices

Appendix 1 - MDT information for people with MND

What are MND MDT meetings? These 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.

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 Amira Ahmed, Hospice Manager or Bill Barker, 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 - 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			
There is a clear care pathway			

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			
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			
Gaps in skills are identified and addressed through training and events			
The MDT ensures that people who are bereaved can access support			

Appendix 5 - 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.

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Rachel Thomson, Sussex MND Network Coordinator

Omina Yasmin, MND Clinical Nurse Specialist, LOROS Hospice

How we can support you

MND Connect

Our helpline offers help, information and support to people living with MND, carers, family and health and social care professionals.

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

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-advice

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.

www.mndassociation.org/education

MND Professionals' Community of Practice

A peer led group of health and social care professionals encouraging and supporting the development of good care for people living with, or affected by, MND.

www.mndassociation.org/cop

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 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.

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 MND care.

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.

www.mndassociation.org/associationvisitors

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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