

Optimal clinical pathway for adults: Motor neurone disease (MND)

National Neurosciences Advisory Group (NNAG)

Published: June 2023



	Page Number
<a>Overview	3
Executive summary	4
Motor Neurone Disease Optimal Pathway	5
<u>←</u> Context	6
Pathway	7
First presentation to diagnosis	7-8
Treatment and ongoing management	9-10
Symptom management	11
Managing advanced MND	12
Defining a specialised MND service	13
Efficiency savings	14

	Page Number
→ Barriers & enablers	15
Patient flow	15
Information sharing and access to research	
and clinical trials	16
Recommendations	17
MND quality standards & key metrics	17-18
Appendix	19
References	19
Clinical working group membership	20



Overview: About the optimal pathway

This pathway is part of a suite of optimal neuroscience clinical pathways that have been developed by the neurological community, with the support of NHS England and the National Neurosciences Advisory Group (NNAG).

The development of this pathway was overseen by NNAG, with input from professional bodies and patient organisations. A 6 week public consultation was held to gather input, views and experience from people affected by neurological conditions and wider stakeholders.

The pathways set out what good treatment, care and support looks like. This includes treatment and support for people who may be experiencing the first symptoms of a neurological condition, right through to people who have lived with a condition for a long time. They set out the aspirations for good care, support improvement of services and enable commissioning of quality services, locally and nationally.



Optimal Clinical Neuroscience Pathways



NEUROSCIENCE

SUBARACHNOID/INTRACRANIAL HAEMMORHAGE

MULTIPLE SCLEROSIS (MS) EPILEPSY

AUTO-IMMUNE

HEADACHE & FACIAL PAIN

NEUROMUSCULAR CONDITIONS

MOVEMENT DISORDERS MOTOR NEURONE DISEASE (MND)

FUNCTIONAL NEUROLOGICAL DISORDER (FND)

TRAUMATIC BRAIN INJURY (TBI)



TRANSITION FROM CHILDREN TO ADULT SERVICES

NEUROGENETICS

PITUITARY TUMOUR

MENTAL HEALTH

REHABILITATION

> FIND OUT MORE

Optimal clinical pathways and resources (NHS England and NHS Improvement. NHS log in required): www.future.nhs.uk/about

Optimal clinical pathways and resources (NNAG): www.nnag.org.uk/optimum-clinical-pathways



VISIT WEBSITE

Neurological patient organisation websites & resources (Neurological Alliance): www.neural.org.uk/membership/our-members

BRAIN TUMOURS



VISIT WEBSITE



VISIT WEBSITE



Motor neurone disease (MND) is a progressive, often rapidly progressive, life-limiting neurodegenerative disorder for which there is no curative treatment. Current treatment strategies are largely supportive. Disease severity at presentation and rates of progression can vary widely. Median survival is 30 months from first symptom onset and 22 months from diagnosis. 10% of patients die within one year of first symptom onset. Patients with early bulbar or respiratory involvement may have worse outcomes.

The prevalence of MND is 3-4 per 100,000 in the UK currently. This figure is rising, in part due to an aging population. 10-15% of cases have an identified genetic aetiology.

In collaboration with the MND Association (the largest UK charity representing people living with MND, their families and carers) 22 MND care centres/networks have been established in the UK. These centres operate within guidance set out in the NICE standards of care for MND and prospectively audit against these standards with formalised lines of reporting to the MND Association. The cornerstone of this approach is multidisciplinary, holistic, patient-centred care.

Access to specialist neuromuscular services continues to show variation across the UK; with access remaining difficult in more remote and rural areas. This remains an under-resourced area of medicine. Greater investment is

needed in MND consultants, multi-disciplinary allied healthcare professionals and the services on which they depend (particularly respiratory services) to ensure equity of access and utilisation of MND services.

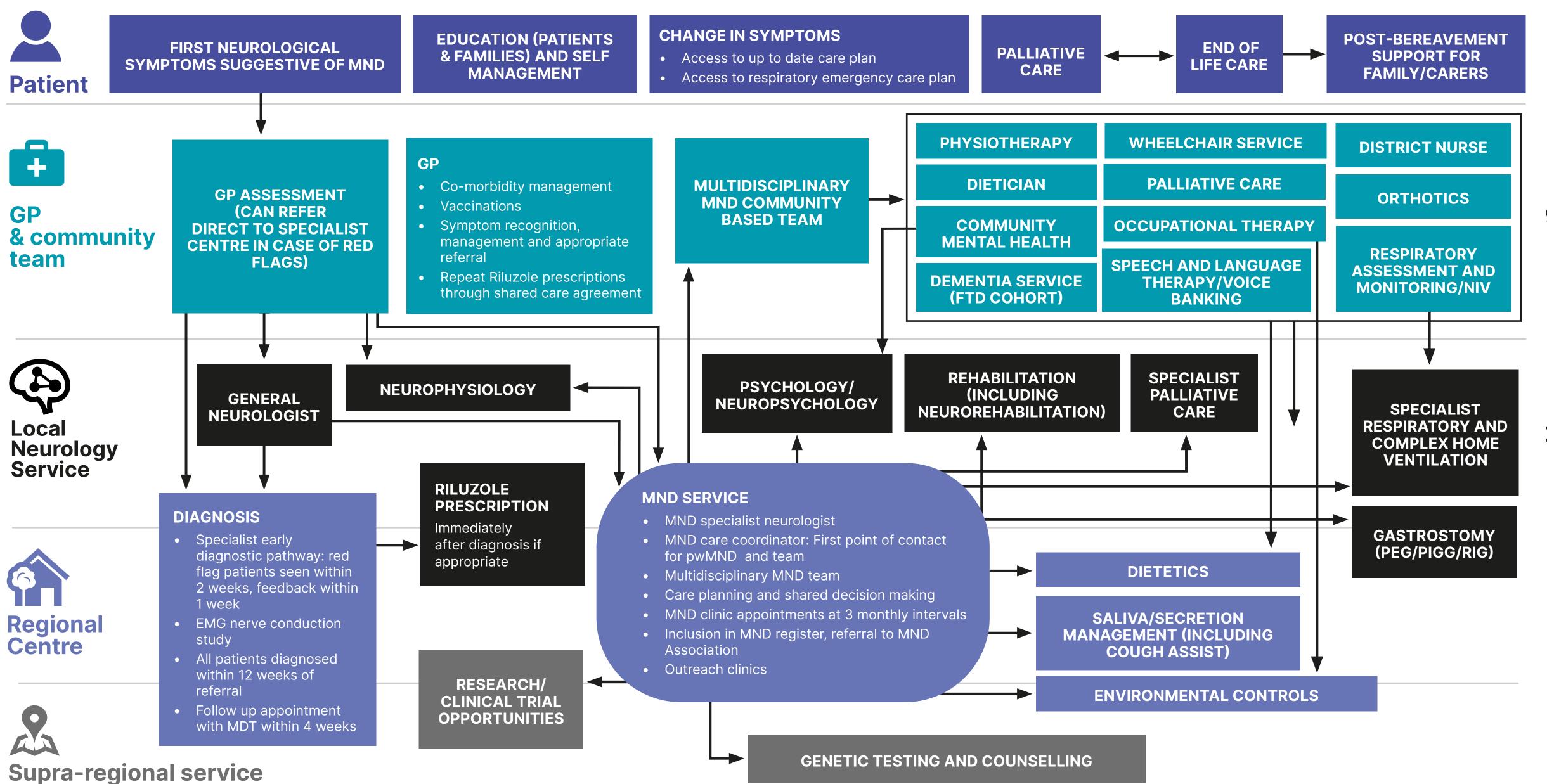
Effective use of specialist and supra-specialist MND services depends on skilled, consistent and comprehensive triage of patients referred from both primary and secondary care settings.

A network model of care/integration of services enables holistic care across traditional boundaries of health and social care and across organisations. This facilitates patients getting the right care, at the right time, in the right place (as close to home as practicable).

This pathway follows the NICE guideline, NG42 Motor neurone disease: assessment and management (updated 2019), working alongside it as a summary of the expectations for care of people living with MND.

The pathway recognises that people living with MND require specialist psychological care. Providing psychological support improves quality of life, enables better utilisation of other therapies and delivers significant cost savings in healthcare (King's Fund 2012).

Executive summary: Motor Neurone Disease Optimal Pathway





MND is a progressive, often rapidly progressive, life-limiting neurodegenerative disorder for which there is no curative treatment. Current treatment strategies are largely supportive. Disease severity at presentation and rates of progression can vary widely but median survival is 22 months from the time of diagnosis. Patients with early bulbar or respiratory involvement may have worse outcomes.

The prevalence of MND is 3-4 per 100,000 in the UK currently. This figure is rising, in part due to an aging population. 10-15% of cases have an identified genetic aetiology.

Respiratory muscle weakness and bulbar dysfunction are common causes of mortality and morbidity in people living with MND. Co-ordinated multi-disciplinary care and good integration with respiratory, dietetics and gastrostomy support services are vital to caring for MND patients.

This document is the output of the Motor Neurone Disease Clinical Working Group's efforts to define the optimum pathway for patients living with Neuromuscular conditions. The guidance outlines:

- The "optimal" pathway for patients living with MND from diagnosis, ongoing management and end-of-life care.
- The definition of "specialised" MND care
- A workforce model to support implementation
- Possible efficiency savings to come out of the optimal pathway
- Potential barriers and provides recommendations regarding patient flow, information sharing, research and clinical trials



Good practice

People living with MND should be referred to a specialist MND service with consultant-led triage to a specialist MND clinic. MND may present with isolated or unexplained symptoms (progressive weakness, speech/swallowing difficulties, cognitive/behavioural change or respiratory symptoms). Diagnosis may be challenging and take some time. The MND Association red flags tool and Royal College of General Practitioners' masterclass are available to support diagnosis.

There are currently 22 MND care centres and networks in the UK, established and supported by the MND Association, the largest charity representing people living with MND and their families. Additional centres and networks may be established alongside ongoing and future specialist service development.

Specialist Motor Neurone Disease services

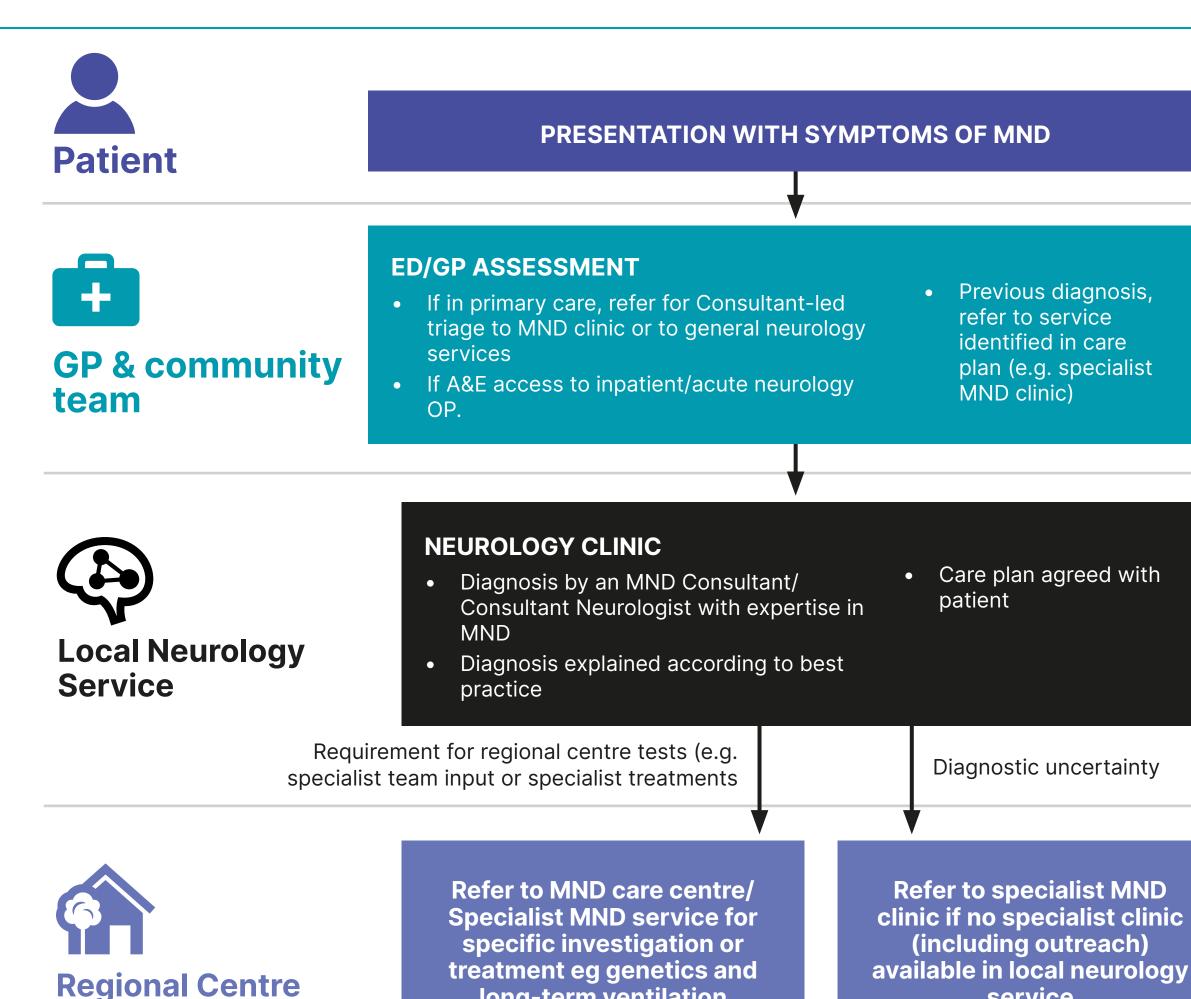
A specialist MND service/clinic should be led and delivered by a physician with expertise in MND. Expertise in MND may be demonstrated by:

- Training and continuing professional development/ education in MND
- Contribution to training/education, conducting research/ enabling patient access to research and information sharing (e.g the UK MND patient registry)
- Caring for people living with MND should form a significant part of their clinical workload (at least 1 session/week)
- Access to specialist supportive services (including genetics and ventilatory support)

service

At diagnosis: the diagnosing physician should agree a care plan with the patient which includes:

- A diagnosis and identification of comorbidities. This may include discussion about progressive disability, quality of life and end-of-life choices. Diagnostic uncertainty (where present) should be discussed, and the patient provided with support
- Discussion of treatment options, including medication, multi-disciplinary rehabilitative therapy, respiratory support, genetics, dietetics and specialist psychological support, signposting to social care needs (e.g. benefits, housing)
- First point of contact (including emergency contact) & specialist MND team contact details, including the MND care co-ordinator
- Recommendations and signposting for independent support services and patient groups, including the MND Association
- Practical self-management actions agreed with patient, with treatment plan developed depending on need



long-term ventilation

MND: Motor neurone disease; OP: outpatient



Pathway: Treatment and ongoing management

Good practice

- 1. MND presents in a variety of ways in terms of symptoms, severity and co-morbidity. Consultant-led triage is essential in order to use highly specialist services efficiently. Presentation of MND shows wide variation and overlap with other neurological conditions. It is a progressive, often rapidly progressive condition, requiring anticipatory and timely support. Whilst it may be possible for some patients to be referred directly to MND services from primary care (where there is a known diagnosis, indicative family history or clearly identifying symptoms), others may first present to general neurology or other secondary care services before referral to a specialist MND team.
- 2. Comprehensive holistic care requires a multi-disciplinary neuromuscular team that collaborates and integrates effectively with other supporting services (e.g respiratory, dietetics, gastrostomy). The MND team would be expected to include consultant neurologist(s) with expertise in MND, MND care co-ordinator, physiotherapist, psychologist, dietician, specialist nurse and access to rehabilitation (including neurorehabilitation), occupational therapy and speech and language therapy. Close collaboration is needed with respiratory (joint clinics), gastroenterology/interventional radiology and palliative medicine.
- 3. A care plan (including an emergency care plan e.g. ReSPECT Plan) A multi-disciplinary care plan, which includes: an emergency plan, a

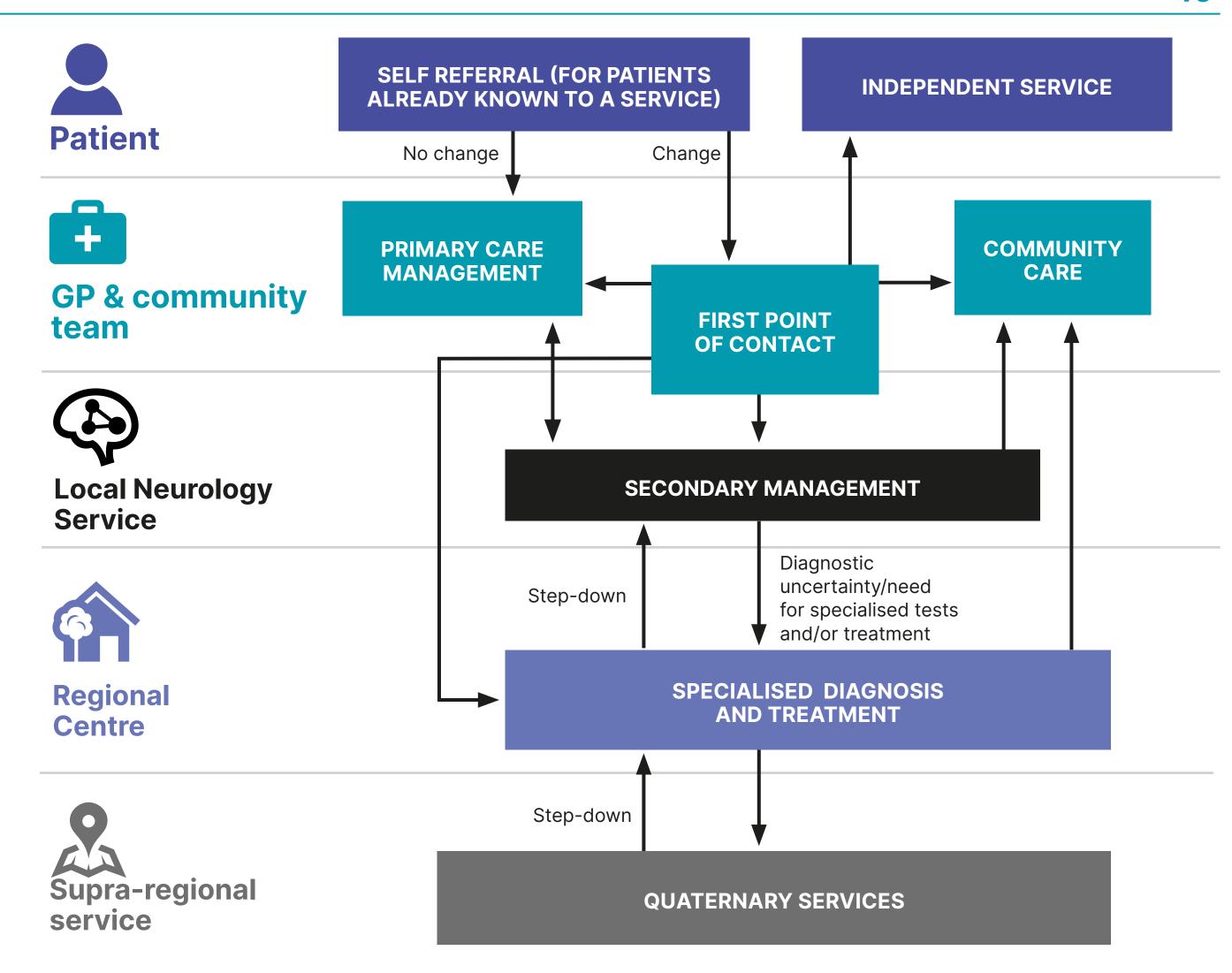
- symptom management strategy, psychological support, advanced care planning, a first point of contact and contact details for the MND team (including the MND care co-ordinator) and the MND Association and other independent support services. Support for families and carers must also be considered.
- 4. Specialised investigations and treatments required for patients with MND Specialist assessment to resolve diagnostic uncertainty (e.g. neurophysiology, MRI, lumbar puncture, genetics) and specialist treatments (e.g. long-term ventilation, cough assist, gene-modifying therapy) are necessary for a proportion of patients and should be accessible with minimal delay to ensure best outcomes.
- 5. Working across traditional boundaries of health and social care and across organisations facilitates patient-centred care e.g. therapy provided by allied healthcare professionals, providing timely adapted housing and equipment (including wheelchairs). Social care requirements are wide ranging and may include assessment for continuing healthcare. Advanced care planning and end-of-life care are important components of care required. The needs of people living with MND are complex and varied. Integration of services improves efficiency and supports better clinical outcomes, facilitates equity of access to care, improved quality of life and more sustainable independent living.



Pathway: Treatment and ongoing management

Secondary care functions include the following:

- Delivering/organising investigations; establishing a diagnosis; delivering treatment (including riluzole); setting up a care plan and collaborating with other supporting services (other medical, psychological support, social care, third sector) and quaternary centres where needed
- Enabling and empowering patient-focussed decisionmaking and self-management; signposting to sources of information and support
- Regular follow-up 2-4 monthly (more frequently if required) with regular surveillance of respiratory function, nutritional state (including weight) and bulbar function. Multi-disciplinary support available in clinics
- Providing a point of contact and source of ongoing support and information
- Triaging the patients directly into appropriate secondary care and primary care treatment
- Collaboration with local services (neurological and supporting services)



MND: Motor neurone disease



Symptom management and specialist MDT care:

At diagnosis people with MND should be offered a comprehensive assessment with the core MDT followed by reviews every three months with professionals who specialise in MND (and work as part of an MDT). These specialists would be based at a neuroscience centre, specialist long term ventilation services, and in community and palliative care settings. Care should be personalised and led by the most appropriate professionals depending on the stage in the condition. There needs to be good quality communication between theses services and joint clinics where appropriate. Care should reflect the most recent research findings e.g. PROGAS study and a requirement for early dietetic involvement.

Core MDT as defined in NICE (2019)

- 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 (MND palliative care expertise may be provided by the neurologist or nurse in the multidisciplinary team, or by a specialist palliative care professional)

The multidisciplinary team should have established relationships with, and prompt access to, the following:

- Clinical psychology and neuropsychology
- Social care
- Counselling
- Respiratory ventilation and cough services
- Specialist palliative care
- Gastroenterology
- Orthotics
- Wheelchair services
- Assistive technology services
- Alternative and augmentative communication (AAC) services
- Community neurological care teams. [2016]
- Rehabilitation (including neurorehabilitation)

Barriers

- Services are frequently provided by teams across different organisations with different patient record systems creating difficulty in communication
- Lack of investment in specialist MND and supportive services
- Organisation of services is such that it can be challenging to provide timely anticipatory support with equipment and adaptations

Enablers

- Technology facilitating virtual meetings between professionals and with patients/families
- Opportunities to develop joint professional clinics eg respiratory, saliva management or palliative care clinics
- Multi-disciplinary care planning across boundaries
- Access to research & national registries



People with advanced MND should:

- Be included on primary care supportive/palliative care register
- Be under regular review with proactive anticipatory management (GP/palliative care services, ventilation services & MND Care Centre/network
- Be given the opportunity to put an Advanced Decision in place and discuss DNAR (recorded with consent)
- Have support in place for family and carers
- Have appropriate care package in place
- Proactive application for Continuing Health Care Funding where needed
- Have specialist equipment in place e.g. wheelchairs, specialist seating, hospital bed, toilet and shower facilities

(North West model for life limiting conditions 2021)

Have an accessible urgent and emergency care plan in place.

Care for people with MND approaching End of Life

- Recognising when people are entering the last few days of life
- Excellent communication and shared decision-making

Symptom Management

- Clinically assisted hydration/nutrition where needed
- Medicines for managing pain, breathlessness, nausea and vomiting, anxiety, delirium, agitation, and noisy respiratory secretions with anticipatory prescribing approaches
- Frequent review

Care for the person, to consider:

- The person's physiological, psychological, social and spiritual needs
- The person's goals and wishes
- The views of those important to the person about future care
- Provide support to be in the preferred place of death NG31 (2015)



Pathway: Defining a specialised MND service

Specialised services are those which require specialist expertise, investigations and/or treatment. Patients with MND should be referred to an MND care centre or network for specialist diagnostic support and multi-disciplinary care. Geographical considerations may mean that shared care with clinicians (Neurology, Respiratory and others) may be the best approach for caring for some people living with MND long-term.

Diagnostic uncertainty may exist for some time, and this also needs specialist management and review.

Referral to a MND Care Centre or MND Care network should also allow access to research, clinical trials and education.

Barriers

- Lack of knowledge about indication, access and benefit of specialist services; including opportunities for shared care (including widespread adoption of shared prescribing protocols e.g. riluzole)
- Commissioning of MND services separately from allied services (e.g. Neuromuscular, respiratory – home ventilation) with associated under-investment
- Lack of access to specialist psychology services (providing psychological support and assessment of cognitive function where needed)
- Lack of investment in complex home ventilation services as greater numbers of patients with MND use them
- Lack of access to neurorehabilitation, environmental controls/other home adaptation, specialised equipment including wheelchairs
- Need for investment in research and clinical trials embedded in the clinical service

Enablers

- A network of clinicians with regular specialist multidisciplinary team meeting and an MND co-ordinator facilitating anticipatory care, with technology to link remotely, allows improved access to specialist services and integration in the face of complex health and social care needs
- Shared decision making between professionals in health and social care, people living with MND, their families and carers
- Improved access to community multi-disciplinary teams
- Better recruitment to a national registry and to research programmes
- Access to genetic testing and genetic counselling can support faster diagnosis, identification of possible risk to family members, and access to appropriate treatments as new gene-targeted therapies come online

MND: Motor neurone disease





Early diagnosis

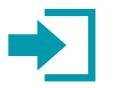
Early diagnosis of MND has the potential to deliver cost savings to the NHS as well as improving clinical outcomes for patients. Early diagnosis reduces unnecessary investigations and allows early appropriate multi-disciplinary input and treatment. Early support will enable independent living, reduce admissions to hospital and support working life for some people living with MND.



Access to appropriate treatment improves outcomes and reduces long-term costs

Multi-disciplinary care contributes significantly to increased quality of life and longevity in people living with MND. Access to appropriate treatment, adaptations and equipment can be associated with significant improvement in disability and may enable ongoing access to work. Non-invasive ventilation in patients with MND who have symptoms of hypoventilation can lead to improvements in quality of life and cognitive function.

Optimising nutrition through dietetics and speech and language therapy input, as well as gastrostomy in some patients, can reduce morbidity and prolong life. MND provides significant challenges to both physical and mental health for those living with MND, their families and carers. Delayed diagnosis and inadequate management of MND can significantly add to the emotional burden of the disease. Mental health problems in people living with long-term conditions (including Neuromuscular Disease) have a significant impact on quality of life, reduce compliance with treatment and increase risk of complications and admission to hospital. There is evidence to suggest that mental health problems increase the cost of care by 45% (The King's Fund 2012). Dedicated psychological support as part of an integrated service can substantially reduce these poor outcomes.



Barriers & enablers: Patient flow

Whilst establishing MND care centres has enormously improved services for people living with MND there are still patients who do not access care centres at all or do so very infrequently. Enhancing the reach of care centres, with both improved understanding of how to access services (including shared care with services local to where they live) and the benefit of them as well as further investment in these services is likely to improve this situation.

Cross-cutting recommendation: support for self-management

Incorporation of self-management in the context of personalised care, shared decision-making and supportive choices across all aspects of care. Care should be timely and in the right place. Social prescribing, personal health budgets and integrated personal budgets may all play a role in enabling this. Improved technology (apps, patient-held interactive records, telemedicine) and ongoing support from online forums (including those provided by the MND Association) enable increased self-management and improved choice for patients

Barrier	Potential solution(s)
It may be difficult for a diagnosis to be reached (or there may be protracted diagnostic uncertainty) outside an MND care centre/network	 Clear guidelines and a pathway of referral of patients to an MND service, disseminated by the MND Association and MND specialist services Education programmes on diagnosis and management of MND Clear pathway for accessing treatments and specialist support
There is a lack of specialist expertise in multi-disciplinary care for people living with MND outside an MND care centre/network	 Education program for multi-disciplinary teams across primary, secondary and community care settings Establishing direct links/integration with specialist MND diagnostic and treatment services across care settings to improve patient flow
Lack of sufficient complex home ventilation services for respiratory surveillance and support	Increased investment in complex home ventilation services and improved integration with specialist MND services
Lack of specialist psychological support services	Increased investment in specialist psychological services (parity with physical treatment)
Insufficient palliative medicine resource in both primary and secondary care	Increased investment in palliative care services as a statutory element of care



Barriers & enablers: Information sharing and access to research and clinical trials

Greater opportunities for information sharing and access to research are required in order to continue to improve services and develop disease-modifying treatments that may substantially improve morbidity, mortality and quality of life in people living with MND.

Increased resource and a commitment to embed the role of national registries and the requirements for research into routine clinical practice for all team members caring for patients with MND.

In 2015 a survey conducted by the Neurological Alliance identified that 20.7% of Neurology patients had taken part in research but that 59.1% reported not having been offered this opportunity but would like to engage in research.

Barrier	Potential solution(s)
Lack of capacity and incentives for Trusts to enable clinicians to participate in research. The main barrier is lack of resource in terms of dedicated time for all health care professionals caring for people living with MND	 Identify and free up capacity through prioritisation and investment Support for the national MND registry and data input Clinician and patient partnerships organisations to improve access to funding and PPI support for projects
Need for increased development of inclusive national networks	 Establish networks to build and deliver research programmes Horizon scanning to identify research opportunities.
Lack of consensus on research priorities	 Develop a formal process for all stakeholders to establish clinical research priorities in MND

MND: Motor neurone disease; PPI: patient and public involvement



Recommendations: MND quality standards & key metrics

Quality Standard	Clinical metric	Patient reported metric
 Appointment in a specialist MND clinic (up to 60 minutes) within 4 weeks of referral 	Percentage of people with MND who have a defined point of contact within the MND service	Were you seen in a specialist MND clinic and how long was the appointment?
2. Provide people living with MND with an emergency care plan, to include a single point of contact (usually the MND care co-ordinator)	Percentage of people living with MND who have an agreed care plan, including a single point of contact	Have you had the opportunity to discuss and receive an emergency care plan, including a single point of contact for you?
3. Provide a follow up discussion (up to 30 minutes) with a member of the specialist MND team within 4 weeks of diagnosis	Percentage of people who have a follow-up discussion with a specialist MND team member within 4 weeks of diagnosis	Did you have a follow-up discussion with a member of the specialist MND team within 4 weeks of receiving your diagnosis and how long was the appointment?
4. Assess respiratory function (lung function, overnight oximetry and carbon dioxide measurements/mouth/ SNIFF pressures where needed) on a regular basis. Availability of respiratory assessments 3 monthly/ when symptoms arise	Frequency of respiratory function assessments & availability when symptoms arise	Have you had breathing assessments? How often have they been & were they available if you have had any breathing problems?
5. Provision of non-invasive ventilation (& cough management/cough assist) for those requiring this	Percentage of patients receiving NIV/cough assist	Have you had a discussion about NIV/cough assist? Have you received treatment with NIV/cough management/cough assist?
6. Assess nutritional state and swallowing, including body weight, routinely in clinic appointments	Percentage of people weighed in clinic and assessed by a dietician and speech and language therapist (SALT)	Are you weighed when you attend the specialist MND clinic? Have you seen a dietician and how frequently? Have you seen SALT and how frequently?
 Assess appropriateness and discuss gastrostomy, including early discussion 	Percentage of people who have a discussion about gastrostomy and who have a gastrostomy	Have you had a discussion about gastrostomy? Have you had a gastrostomy?



Quality Standard	Clinical metric	Patient reported metric
8. Cognitive function should be discussed and assessed in the MND clinic. Where appropriate referral for a formal assessment should be made	Cognitive function should be discussed and assessed in the MND clinic. Where appropriate referral for a formal assessment should be made	Have you discussed cognitive function or had your cognitive function assessed? What form did this take?
 Specialist psychological support should be available for people living with MND, their families and carers 	Percentage of people (patients, families and carers) offered and assessing specialist psychological support	Have you or your family/carers been offered specialist psychological support, and have you chosen to access this support?
10. An opportunity to discuss end-of-life issues should be made available regularly and access to palliative care services enabled when needed	Percentage of people having a discussion about end-of- life, frequency of this discussion and percentage accessing palliative care services	Have you discussed end-of-life issues with the MND team? Have you accessed palliative care services and in what form?
11. Opportunity to discuss drug treatments (including riluzole and medications that may alleviate symptoms e.g. saliva management, pain, spasms) should be available	Percentage of people taking riluzole and other drug treatments for MND symptoms (including saliva management, pain, spasms)	Are you taking any medication for MND (including riluzole) or for symptoms related to MND?
12. Opportunity to receive multi-disciplinary care in the MND clinic and other settings should be available	Percentage of people receiving support from MDT members (who, frequency)	Have you received support from members of the multi-disciplinary team (PT, OT, SALT, dietetics, psychologist, specialist nurse, orthotics, rehabilitation, wheelchair services)?
13. Opportunity to take part in research/clinical trials	Percentage of people who have discussed research/trials and percentage accessing research/trials	Have you discussed research/clinical trials? Have you taken part in research/trials?
14. Assessment of communication needs regularly and access to communication aids	Percentage of people having communication assessment, frequency and access to communication aids	Has your ability to communicate been discussed/ assessed? Have you used any communication aids?



- 1. NICE guideline 2019 NG42 Motor neurone disease: assessment and management (Guideline was published in 2016 and updated in 2019)
- 2. Long-term conditions and Mental Health: the cost of co-morbidities. The King's Fund 2012
- 3. Lyall RA, Donaldson N, Fleming T, Wood C, Newsom-Davis I, Polkey MI, Leigh PN, Moxham J.Lyall RA, et al (2001) A prospective study of quality of life in ALS patients treated with non-invasive ventilation. Neurology 57(1):153-6
- **4.** Newsom-Davis IC, Lyall RA, Leigh PN, Moxham J, Goldstein LH. (2001) The effect of non-invasive positive pressure ventilation (NIPPV) on cognitive function in amyotrophic lateral sclerosis (ALS): a prospective study.
- 5. O'Neill CL, Williams TL, Peel ET, et al. Non-invasive ventilation in motor neuron disease: An update of current UK practice. J Neurol Neurosurg Psychiatry. 2012;83:371e376
- 6. Martin NH et al (2014) Psychological as well as illness factors influence acceptance of non-invasive ventilation in amyotrophic lateral sclerosis: a prospective population study. Amyotrophic lateral sclerosis & Frontotemporal Degeneration 15(5): 376-87

- 7. Martin NH et al (2016) Decision making about gastrostomy and non-invasive ventilation in amyotrophic lateral sclerosis. Quality Health Research 26(10):1366-81.
- 8. Halliday V et al (2021) Delivery of nutritional management services to people with amyotrophic lateral sclerosis. Amyotrophic lateral sclerosis and frontotemporal degeneration. 22: 350-359.
- 9. Van Eijk RPA et al (2021) Challenging the established order: innovating clinical trials for amyotrophic lateral sclerosis. Neurology 10.
- 10. NHS England: North-West model for life limiting conditions 2021
- 11. Community Rehab, Best Practice Standards (2022) Community Rehabilitation Alliance
- 12. National Guidelines, Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care (2008) Royal College of Physicians
- **13.** National Service Framework for Long Term Conditions, (2005) Department of Health

Appendix: Clinical working group membership

Name	Profession	Organisation
Andria Merrison	Consultant Neurologist (Pathway clinical lead)	North Bristol NHS Trust
Alex Massey	Head of Campaigning, Policy and Public Affairs	Motor Neurone Disease Association
Georgina Carr	Chief Executive	Neurological Alliance
Jane Leicester	MND Service Improvement manager	MND Care Centre, Manchester
Sally Hughes	Assistant Director of Care	Motor Neurone Disease Association
Ammar Al-Chalabi	Consultant Neurologist	King's College Hospital NHS Foundation Trust
Kevin Talbot	Consultant Neurologist	 Oxford University Hospitals NHS Foundation Trust
Rhys Roberts	Consultant Neurologist	Cambridge Institute for Medical Research
Chris McDermott	Consultant Neurologist	Sheffield Teaching Hospitals NHS Foundation Trust
Philip Hughes	Consultant Respiratory Medicine	University Hospitals Plymouth NHS Trust
Neil Collin	Interventional Radiologist	North Bristol NHS Trust





National Neurosciences Advisory Group c/o The Neurological Alliance (England) www.nnag.org.uk

The Neurological Alliance is a coalition working together to improve treatment, care and support for people affected by neurological conditions. Together we campaign to ensure people affected by neurological conditions can access high quality, joined up care and support to meet their individual needs, at every stage of their life.

www.neural.org.uk

Email: info@neural.org.uk

Registered by the Charity Commission for England and Wales (registration number 1039034) and a company limited by guarantee registered in England (registration number 2939840).