MND Association | For professionals

PG16

Wheelchair pathway for Motor Neurone Disease

Motor Neurone Disease (MND) results from the progressive loss of motor neurones in the brain and spinal cord. These are the nerve cells that control movement. It leads to muscle weakness and can cause difficulties with movement, breathing, swallowing and speaking.

This pathway supports wheelchair therapists and other professionals to help people with MND access a suitable wheelchair quickly. Use this pathway to record timescales for each step. Suggestions for reflecting on your current practice and service delivery are on the next page.

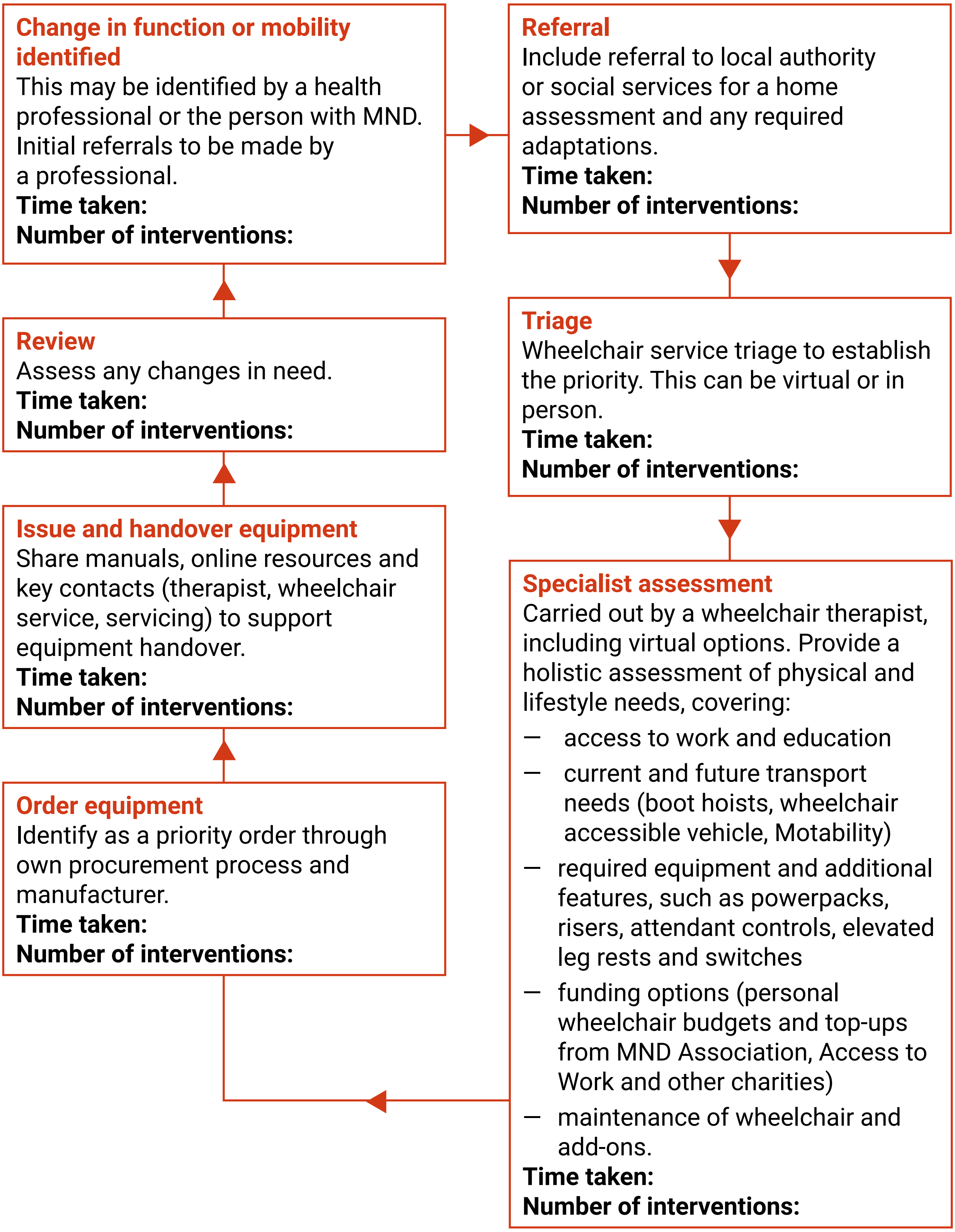
If you have questions or difficulties with wheelchair provision, contact our helpline on 0808 802 6262 or email mndconnect@mndassociation.org

Information to share with people with or affected by MND:

Information sheet 11C — Equipment and wheelchairs

See page 6 for details of how to order publications.

1. Wheelchair pathway



Change in function or mobility identified
This may be identified by a health professional or the person with MND. Initial referrals to be made by a professional.
Time taken:
Number of interventions:

Referral
Include referral to local authority or social services for a home assessment and any required adaptations.
Time taken:
Number of interventions:

Triage
Wheelchair service triage to establish the priority. This can be virtual or in person.
Time taken:
Number of interventions:

Specialist assessment
Carried out by a wheelchair therapist, including virtual options. Provide a holistic assessment of physical and lifestyle needs, covering:

- access to work and education
- current and future transport needs (boot hoists, wheelchair accessible vehicle, Motability)
- required equipment and additional features, such as powerpacks, risers, attendant controls, elevated leg rests and switches
- funding options (personal wheelchair budgets and top-ups from MND Association, Access to Work and other charities)
- maintenance of wheelchair and add-ons.

Time taken:
Number of interventions:

Order equipment
Identify as a priority order through own procurement process and manufacturer.
Time taken:
Number of interventions:

Issue and handover equipment
Share manuals, online resources and key contacts (therapist, wheelchair service, servicing) to support equipment handover.
Time taken:
Number of interventions:

Review
Assess any changes in need.
Time taken:
Number of interventions:

2. Reflecting on your current pathway

This section provides prompts to help you reflect on your current practice and service delivery.

Referral

How are referrals made to your service?

How can referrals and re-referrals for clients with MND be made quickly and marked as a priority?

Do you have a secure email address for referrals or re-referrals?

Triage

How do you prioritise or fast-track MND referrals?

Are there links with the MND care centre, MND community team, and social care occupational therapist to support the pathway?

Can you gain more information about the person, such as:

- When were they diagnosed?
- What type of MND do they have? How fast is it progressing?
- What is their current level of function? The ALS Functional Rating Scale[1] can help predict postural and wheelchair needs.
- Are they known to other healthcare professionals such as a multidisciplinary team or social care occupational therapist?
- What is hand function like? Consider head, leg and foot control.
- What is their current method of transfer?

Specialist assessment

Would having a clinician with a specialist interest in MND streamline your processes?

Is there a training need for the team on MND and its impact?

Can regular assessment slots for specialist controls, complex equipment trial etc be accessed in a timely manner?

Do you consider future-proofing of the chair for the changing postural and functional needs of the client?

Will the client require devices mounted to their chair either now or in the future? For example, communication aids, ventilation or a feeding pump.

Are you able to signpost individuals to transportation and information about how to access an adapted vehicle?

Visit **nice.org.uk/guidance/NG42** (see section 1.9).

Order equipment

Is there an accessible stock of equipment that is suitable for MND clients that could be issued on assessment?

Are you using codes from manufacturers to indicate an order is for MND? They may be able to fast-track orders.

Is there a central procurement process? Is there a fast-track through this?

Can you use funding from a third party for additional features?

Can you utilise personal wheelchair budgets to provide equipment to meet holistic needs? Is there a process in place to make usage of personal wheelchair budgets easy and efficient?

Is there a checking process for urgent or MND orders to ensure they progress in a timely way?

Issue and handover equipment

Do you have regular time slots allocated for urgent or MND cases, so timely appointments can be booked?

Are clients allocated the same wheelchair service therapist to ensure continuity of care?

Is a process in place to ensure all technical changes or alterations can be made before or during issue of equipment?

Regular review

Do you have a regular review service or allocated time slots?

Do you email or call clients for updates?

Do clients have a named person they can contact if they need further support?

Can review requests be taken on without the need for a re-referral process once a person has a product from your service?

References

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

How we can support you and your team

Our MND Connect helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. They can also provide further information about our services mentioned below.
Email: **mndconnect@mndassociation.org**
Phone: **0808 802 6262**

MND Association website

Our website offers supporting information on MND, our work, services, and how to get involved.
mndassociation.org/professionals

Stay updated on events, publications and opportunities for professionals.
mndassociation.org/educationupdate
X: **mndeducation**
Bluesky: **mndeducation.bsky.social**

Information resources

We produce high quality information for people with MND, carers, families and professionals, available in multiple formats and languages.
mndassociation.org/pro-info-finder
mndassociation.org/careinfofinder

Education

Our education programme aims to improve standards of care and quality of life. Opportunities include webinars and face to face equipment training.
mndassociation.org/education

MND Professionals' Community of Practice

A peer led group supporting cross disciplinary learning in MND care. Membership can contribute to CPD and offers access to networking and learning events.
mndassociation.org/cop

Local support

We offer online and local peer support, plus trained volunteers who provide practical help by phone, email or visits.
mndassociation.org/local-support

We fund and develop specialist care centres and networks across England, Wales and Northern Ireland, offering multidisciplinary care.
mndassociation.org/care-centres

Financial support

We offer a range of grants to support people living with MND, their families and unpaid carers. These are not in place of any statutory funding that should be available.
mndassociation.org/getting-support

MND register

The Register aims to collect information about everyone with MND in England, Wales and Northern Ireland to support care planning and research.
mndregister.ac.uk

Research into MND

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND. We also produce information sheets on MND research for people with or affected by MND.
mndassociation.org/research

Acknowledgements

Thank you to the following people for their valuable contributions to this information sheet, and earlier versions:

Maggy Hevicon	Specialist MND Physiotherapist in Wheelchairs and Seating, QEF Mobility Services, Carshalton
Lynne Hills	Specialist MND Occupational Therapist in Wheelchairs and Seating, QEF Mobility Services, Carshalton
Jenny Rolfe	Occupational Therapist, Accora

We value your feedback

Your feedback helps improve our information for the benefit of people living with MND and those who care for them. Visit **smartsurvey.co.uk/s/mndprofessionals** or email your comments to education@mndassociation.org.

If you would like to help us by reviewing future versions of our information resources, please email us at education@mndassociation.org.

How to order our publications

Our publications are free for anyone with or affected by MND or Kennedy's disease, including professionals. Health and social care professionals can also order items on behalf of someone with or affected by MND or Kennedy's disease.

Download from **mndassociation.org/publications** or contact MND Connect to order hard copies. Call 0808 802 6262 or email mndconnect@mndassociation.org.

Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road
Moulton Park
Northampton NN3 6BJ

Tel: 01604 250505
Email: enquiries@mndassociation.org
Website: mndassociation.org

Registered Charity no. 294354

Created: May 2024
Next review: May 2027
Version: 2

Every day we support people affected by Motor Neurone Disease.
Because with MND, every day matters.