



P2

Wheelchairs 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.¹

As the condition progresses, most people with MND will need to use a wheelchair.² It is important that a person with MND has access to a seating assessment and a suitable wheelchair as early as possible.

This information is for health and social care professionals who would like to know how someone with MND can access a suitable wheelchair.

If you have any questions or experience any problems with access to a wheelchair for a person with MND, our helpline may be able to offer advice. Call 0808 8026262 or email mndconnect@mndassociation.org.

- 1. Access to wheelchairs**
- 2. Types of wheelchair for people with MND**
- 3. Wheelchair pathway**
- 4. Suggestions for reflection on your current pathway**



Information to share with people with or affected by MND:

Information sheet 11C – Equipment and wheelchairs
Booklet – Getting around with MND

Information for professionals

Booklet – Occupational therapy for MND
Information sheet P1 – Head supports

See page 12 for details of how to order publications.

1. Access to wheelchairs

In England, Scotland and Wales referral to the local wheelchair service is provided by the NHS, and in Northern Ireland by Health and Social Care Northern Ireland (HSCNI). Referrals should be made by a GP or a healthcare professional, in line with local policy. An assessment will then determine whether or not the person with MND requires a wheelchair and, if they do, the most appropriate wheelchair for their needs.

Timing your referral

The NICE Guideline on the Management of MND³ recommends that professionals should “refer people to wheelchair services without delay if needed. Wheelchair needs should be assessed and a manual and/or powered wheelchair that meets the person’s needs should be provided without delay.”

Provision from statutory services can take several weeks. Because MND is a rapidly progressive condition a timely referral to wheelchair services is critical. Someone with MND should be referred as soon as they are starting to experience mobility problems and are willing to accept the need for a wheelchair. Statutory funded wheelchair services can be accessed by anyone with long term mobility problems (adult or child) and many services will prioritise people with MND.

In England assessments are offered by the NHS through approximately 150 wheelchair services, individually commissioned by their respective Integrated Care Boards (ICBs). Searching on the internet using the client’s address and GP will direct you to the appropriate NHS Wheelchair Service with their respective referral forms and processes.

In Northern Ireland assessments are carried out through the Department of Health, Social Services and Public Safety (DHSSPS) Wheelchair Service. Find more information at: nidirect.gov.uk/articles/equipment-people-disabilities

In Wales assessments are offered by the Artificial Limb and Appliance Service via two Artificial Limb and Appliance Centres. Visit cavuhb.nhs.wales/our-services/artificial-limb-and-appliance-service/wheelchair-service

Assessments for a wheelchair

Once someone has been referred to wheelchair services the request will be triaged to determine the priority for an assessment. The assessment will cover the person's postural and mobility needs, and their level of function. It will consider the person's home and the local environment where the wheelchair is to be used.⁴ It should also consider how the wheelchair is to be transported and how the user's needs may change. It may also include an eye test.

A wheelchair assessment should also take account of whether there is someone available (for example a carer) to push a wheelchair and load it into a car if needed and, if so, whether that person is physically able to do this.

If an unpaid carer has a medical need of their own, or there is no carer in place at all (paid or unpaid), options may include providing the chair with an attendant control at point of issue, or for manual chairs the addition of a power pack. Not all statutory services will fund these items and additional funding from alternative sources may need to be found (see Wheelchair funding, below).

Wheelchair services vary across the country which results in local differences in referral processes and eligibility criteria. Because of these differences, the type of wheelchair a service can provide at a given time can vary. NHS England is working with the National Wheelchair Leadership Alliance to identify and address this.⁵

Wheelchair funding

Some people choose not to wait for a wheelchair to be provided by statutory services. Others do not realise they may be eligible for wheelchair provision. This can lead to an inappropriate wheelchair being purchased privately without an assessment from an appropriate healthcare professional. Timely referral to wheelchair services is therefore critical.

Since 2019, ICBs in England have been expected to introduce personal wheelchair budgets (PWBs) to replace the wheelchair voucher system. PWBs aim to give wheelchair users greater choice and flexibility. People can choose the standard NHS wheelchair, add approved top up options, or select an alternative wheelchair outside the standard range by funding the difference themselves or with support from a third party, such as the MND Association. More information is available on the NHS England website: [england.nhs.uk/personal-wheelchair-budgets](https://www.england.nhs.uk/personal-wheelchair-budgets)

An assessment of clinical need is still carried out and a wheelchair prescription agreed for those who access a personal wheelchair budget. It is important for the wheelchair therapist to discuss all the options with the person with MND, as some arrangements can involve them being responsible for maintenance and insurance costs. It is important to consider who will review the person's mobility and wheelchair provision as MND progresses and the person's needs change.

Some services may not be able to provide certain types of wheelchair, or certain types of wheelchair equipment (controls etc) due to local commissioning criteria. In such cases, alternative funding may need to be sought. MND Connect may be able to help or signpost you to other services. Call 0808 8026262 or email mndconnect@mndassociation.org.

Receiving the wheelchair

A wheelchair may be issued from the stock available at the wheelchair service. Alternatively, it may need to be ordered from a supplier. Procurement processes vary and in some cases specific funding must be secured before an order is placed.

Once received from the supplier, the wheelchair will be adjusted to suit the individual and then the person with MND will be shown how to use it. For powered wheelchairs, they should also be given information about insurance and an outdoor safety test may be completed.

Waiting times for wheelchairs will depend on whether the chair is a standard order or specially configured. In the case of a powered wheelchair, the Wheelchair Service team will aim to provide a powered wheelchair that will meet the current needs of the person for postural support and comfort and have the potential for modification to the seating and drive system as the person's condition changes.

Maintenance and repairs

All wheelchairs provided by statutory wheelchair services will be serviced and maintained as part of the provision. Arrangements may be different for equipment purchased with PWBs. In this case the person with MND should be told who to contact if there is a problem with the wheelchair or an accessory.

Reviewing needs

If a wheelchair no longer meets their needs, the person with MND can self-refer back to the wheelchair service for a reassessment. It is important to maintain this link with the wheelchair service so changes to provision can be made in a timely manner. This may include modifications to the existing chair or a change of chair to one that is more appropriate to the client's needs.

2. Types of wheelchair for people with MND

Each person will be assessed for the type of wheelchair they need. Some people may be assessed as needing more than one type.⁴

A wheelchair for someone with MND should meet their current and future needs as the condition progresses. This will usually mean selecting a high specification wheelchair with a range of functions and postural supports. Initially some of these functions and supports may not be fully used, but over the course of disease progression they often become essential for the continued use of the wheelchair.

Ordering a chair in this way, in advance of actual need, is usually a more cost effective and efficient use of resources as well as being better for the person with MND.

Manual wheelchairs

There are two types of manual wheelchair that are used to meet the needs of people with MND when they are beginning to have mobility problems.

A folding, portable wheelchair

These can be useful and convenient when someone is starting to need help with their mobility. This type of chair is often easy to use and can be folded up to transport in a car boot. It is essential that the wheelchair provides adequate postural support.

A highly supportive wheelchair with tilt-in-space and reclining mechanism

Where a powered wheelchair is neither wanted nor appropriate, these chairs are most often used by those who need more postural support than can be offered by a standard wheelchair. The tilt-in-space mechanism can tilt the whole seat backwards, helping to manage the effect of gravity on posture. It can also relieve pressure on vulnerable areas, helping with positional change and easing the effects of fatigue. These wheelchairs will not fold into a car boot.

Powered wheelchairs

These wheelchairs provide the user with more independent mobility if they are unable to self-propel a manual wheelchair.⁷ They are usually driven using a hand-operated joystick controller but a wheelchair therapist or rehabilitation engineer will assess for the most suitable control system based on the person's level of functional ability. A powered wheelchair may also include a powered tilt-in-space and recline mechanism.

There are many different types of powered wheelchairs, which may be suitable for indoor only, outdoor only, or both indoor and outdoor. There is an increasing selection of lighter folding powered wheelchairs that are designed to be lifted into the boot of a car. These chairs are not provided by the NHS, but may be an option in the early stages of the disease to enable the person with MND continue to use a car for transport.

The NHS will only provide indoor only or indoor/outdoor wheelchairs. As long as the home environment can accommodate larger equipment, the MND Association advocates electrically powered indoor/outdoor chairs (EPIOC) for people with MND, as they have more scope to be effective in the future.

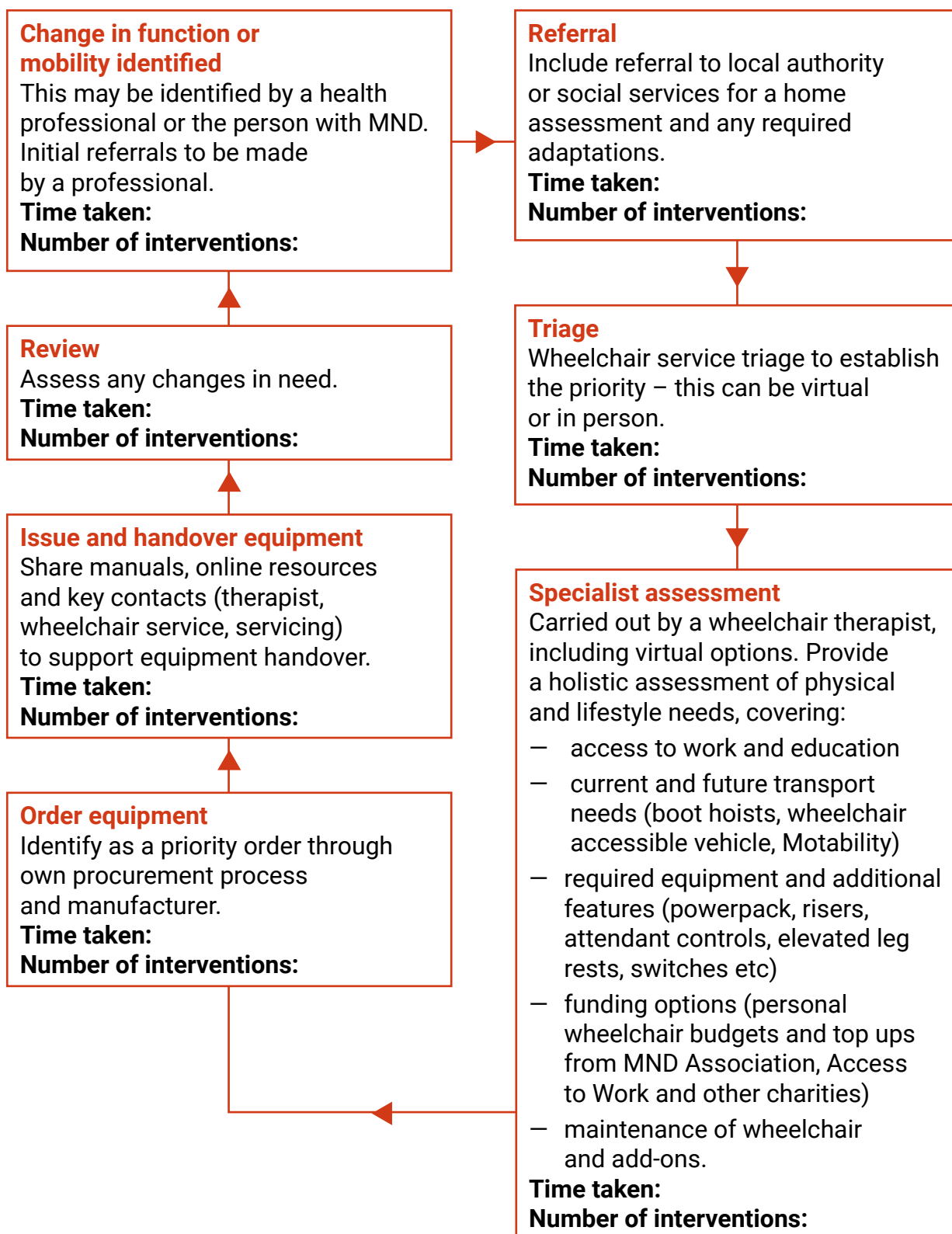
It is not always possible to lift a powered wheelchair into a car due to its weight and size. A boot hoist may be an option if the car is big enough. This will still involve transfer into a car seat. A wheelchair accessible vehicle (WAV) is another option.

Useful features on powered wheelchairs include:

- powered tilt-in-space
- powered recline
- a cushioned, tension-adjustable backrest to accommodate an upper kyphosis (rounded upper back)
- a seatboard that can be supplied with the most appropriate cushion to relieve any areas of pressure
- different headrest options that can be adjusted to suit as the condition progresses
- padded armrests
- independent angle-adjustable foot rests
- controls that can be reprogrammed as needs change, and allow for additional switches or controls to be added
- other additional features which may fall outside of NHS provision, including powered elevating leg rests and seat riser.

3. Wheelchair pathway

This pathway has been designed to help wheelchair therapists and other professionals support people with MND to access suitable wheelchairs without delay. It includes space to record timescales between each stage, helping you identify any bottlenecks or blockages.



4. 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 Scale⁸ can help predict postural/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

See [nice.org.uk/guidance/NG42](https://www.nice.org.uk/guidance/NG42) (section 1.10) for more about 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 adapted vehicle information?

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 need for re-referral process once a person has a product from your service?

References

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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 8026262**

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](https://twitter.com/mndeducation)

Bluesky: [mndeducation.bsky.social](https://bsky.app/profile/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

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Maggy Hevicon	Specialist MND Physiotherapist in Wheelchairs and Seating, QEF Mobility Services, Carshalton

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 8026262 or email mndconnect@mndassociation.org

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