



Wheelchairs for motor neurone disease

Motor neurone disease (MND) is a progressive neurological condition that can cause, among other symptoms, muscle wasting and fatigue. This can lead to mobility problems, including difficulty walking.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. Email wheelchairs@mndassociation.org or call **0808 802 6262**.

Information to share

Information sheet 11C - *Equipment and wheelchairs*

Information for you

Occupational therapy for MND

Information sheet P1 - *Head supports*

MND wheelchair pathway

Download at www.mndassociation.org/publications or contact MND Connect. Call 0808 802 6262 or email mndconnect@mndassociation.org

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 an appropriate health or social care 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

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.

- The NICE Guideline on the Management of MND³

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 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. Search www.england.nhs.uk/wheelchair-services

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

In Wales assessments are offered by the Artificial Limb and Appliance Service via three Artificial Limb and Appliance Centres. Visit www.alas.wales.nhs.uk

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 April 2017 all clinical commissioning groups (CCGs) in England have been expected to develop **personal wheelchair budgets** to replace the wheelchair voucher system.⁶ The aim is to support people's choice of wheelchair, either within the NHS or with third party organisations, or using private funding to purchase a wheelchair that would fall outside of normal statutory provision.

More information can be found at www.england.nhs.uk/personal-wheelchair-budgets

An assessment of clinical need is still carried out for those who access a personal wheelchair budget. It is important to discuss all the options as some arrangements can involve the person with MND 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 (eg certain controls, supports 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 802 6262** 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.

Waiting times for wheelchairs will depend on whether the chair is a standard order or specially configured. Delivery can be sped up if wheelchair services inform the manufacturer that the chair is for someone with MND. Some offer a specific code to use on orders to ensure the quickest time scales possible.

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.

Maintenance and repairs

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

Reviewing needs

If a wheelchair no longer meets the needs of the person with MND, they should be able to self-refer back to the wheelchair service for a reassessment. This may include a change of accessories or chair, for example, from a manual to a powered wheelchair. If the person has opted for a personal wheelchair budget, it is important to clarify how this will affect the process and what they would be entitled to.

Specialist MND wheelchair services

The MND Association funds two specialist wheelchair services based in Carshalton, that cover clinics in London. The specialist therapists employed in these may be able to provide support to local wheelchair services, through training, joint assessments and advice to find the right wheelchair solutions for people with MND.

If the person with MND experiences any problems accessing a specialist assessment or obtaining an appropriate wheelchair, or needs advice, MND Connect may be able to help or signpost to other services. Call **0808 802 6262** or email **mndconnect@mndassociation.org**

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. One is a folding, portable wheelchair, with self-propelling or attendant wheels, and the other offers more support with a tilt-in-space mechanism.

- **A folding, portable wheelchair** 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 mechanism.** Where a powered wheelchair is neither wanted nor appropriate to clinical need, 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 an individual's posture. It can also relieve pressure on vulnerable areas, helping with pressure relief and ease the effects of fatigue. These wheelchairs will be larger than standard manual wheelchairs, and will not fold easily 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, indoor/outdoor and outdoor only. 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, but a boot hoist might be an option if an existing car is big enough. A wheelchair accessible vehicle (WAV) is another option. This will still involve a transfer into a car seat. Our information for people with MND includes Information sheet 8B – *Choosing the right vehicle for you*, which gives more information. Download at www.mndassociation.org/publications or order from MND Connect. Call 0808 802 6262 or email mndconnect@mndassociation.org

Wheelchairs need to be suited to the changing needs of people with MND as the disease progresses.

Useful features to include are:

- 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 pressure-relieving cushion
- different headrest options that can be adjusted to suit as the condition progresses
- padded armrests
- options for adding alternative controls and switches
- independent angle-adjustable foot rests
- controls that can be reprogrammed as needs change.

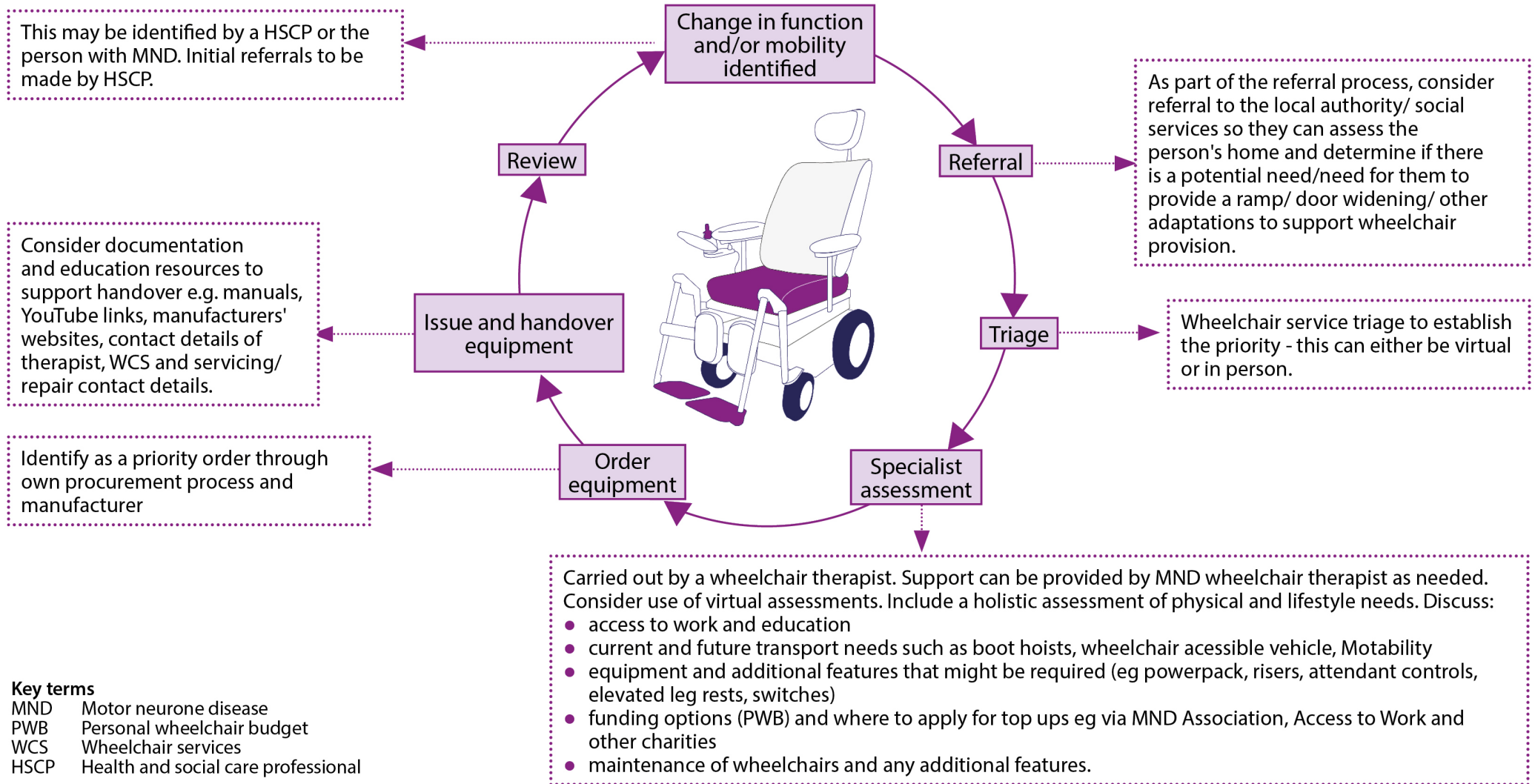
MND Wheelchair Pathway

The *MND Wheelchair Pathway* focuses on the provision of wheelchairs in a timely way and to a specification to meet the users ongoing needs.

It has been developed to support wheelchair services to provide a timely, effective service to people with MND. The first page outlines the ideal pathway for wheelchair provision. The second side includes space to record timescales between each activity for audit purposes, followed by suggestions to aid reflection on your current practice and service delivery.

The pathway is included on the following two pages. Additional copies can be downloaded at www.mndassociation.org/publications or ordered from MND Connect. Call 0808 802 6262 or email mndconnect@mndassociation.org

Wheelchair Pathway for MND

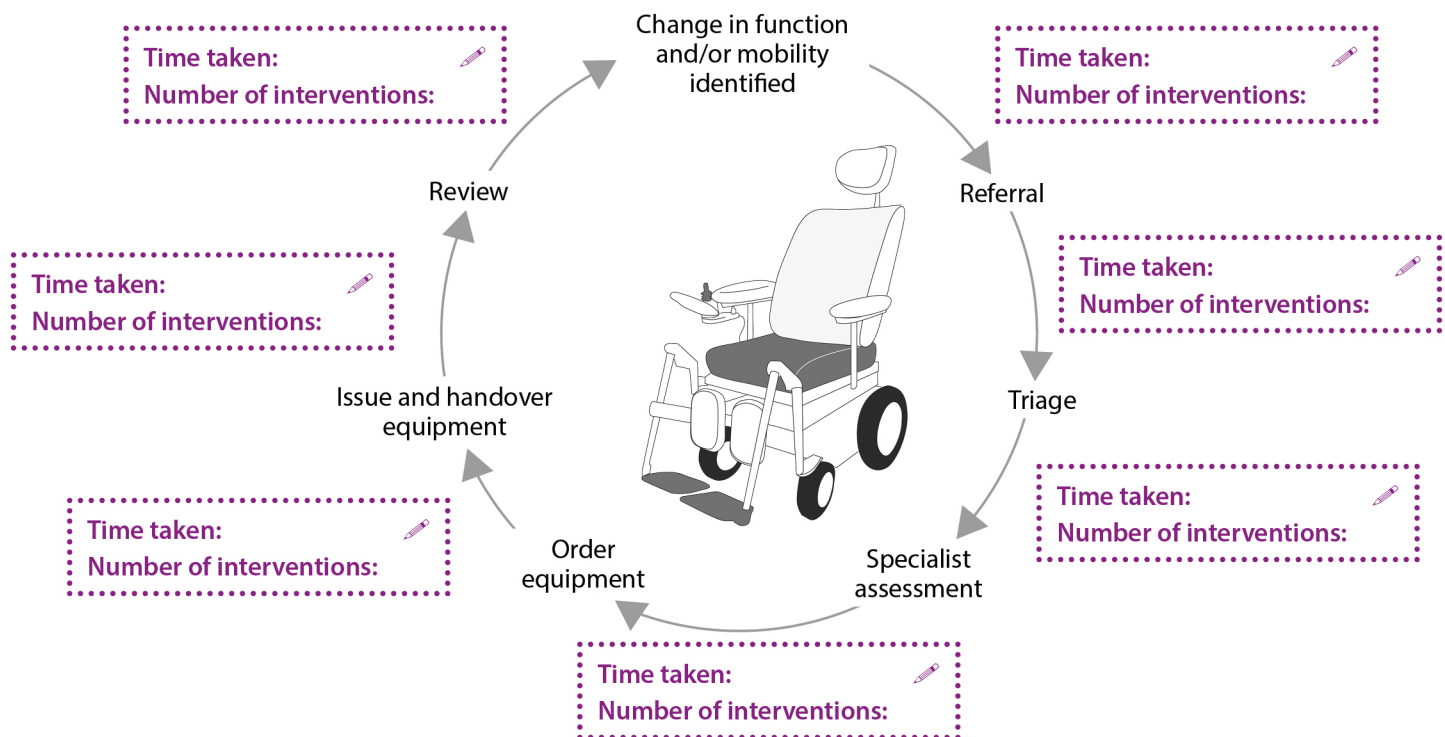


Key terms

MND	Motor neurone disease
PWB	Personal wheelchair budget
WCS	Wheelchair services
HSCP	Health and social care professional

Audit tool

This pathway includes space to record timescales between each activity. This is followed by suggestions to aid reflection 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, eg:
- 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 Scale¹ can help predict postural/wheelchair needs.
- Are they known to other health care 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 for this client group?
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? Eg communication aid, ventilation, feed pump.
Are you able to signpost individuals to transportation and adapted vehicle information?

Visit www.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 PWB to provide equipment to meet holistic needs? Is there a process in place to make usage of PWB easy and efficiently?
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

¹ Cedarbaum JM et al. *The ALSFRS-R: a revised ALS functional rating scale that incorporates assessments of respiratory function.* Journal of the neurological sciences. 1999 Oct 31;169(1-2):13-21.

References

- 1 Bäumer D, Talbot K and Turner MR. *Advances in motor neurone disease*. Journal of the Royal Society of Medicine 2014; 107(1):14-21.
- 2 Trail M et al. *Wheelchair use by patients with amyotrophic lateral sclerosis: a survey of user characteristics and selection preferences*. Arch Phys Med Rehabil. 2001; 82(1):98-102.
- 3 NICE Guideline on MND NG42 (short version) point 1.9.4. www.nice.org.uk/guidance/ng42 Last checked June 2021.
- 4 Rolfe, J. *Planning wheelchair service provision in motor neurone disease: implications for service delivery and commissioning*. The British Journal of Occupational Therapy. 2012; 75(5). 217-222(6).
- 5 National Wheelchair Leadership Alliance: www.nnpcf.org.uk/the-national-wheelchair-alliance-launches-charter-and-national-campaign Accessed April 2021.
- 6 www.england.nhs.uk/personal-health-budgets/personal-wheelchair-budgets Accessed June 2021
- 7 Ward A et al. *Power wheelchair prescription, utilization, satisfaction and cost for patients with amyotrophic lateral sclerosis: preliminary data for evidence-based guidelines*. Archives of Physical Medicine and Rehabilitation. 2010; 91(2):268-72.

Acknowledgements

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Christine Orr, MND Wheelchair Therapist, Leeds Wheelchair Centre

How we can support you and your team

MND Connect

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

Email: mndconnect@mndassociation.org

Phone: 0808 802 6262

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. Opportunities include online modules and face-to-face training.

www.mndassociation.org/education

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 treatment and brings us closer to a cure.

www.mndassociation.org/research

MND register

The MND Register of England, Wales and Northern Ireland aims to collect information about every person living with MND to help plan care and discover more about the cause of the disease.

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 multidisciplinary care for people with MND.

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. They can support people affected by MND in person, by telephone or by email or through support groups.

www.mndassociation.org/associationvisitors

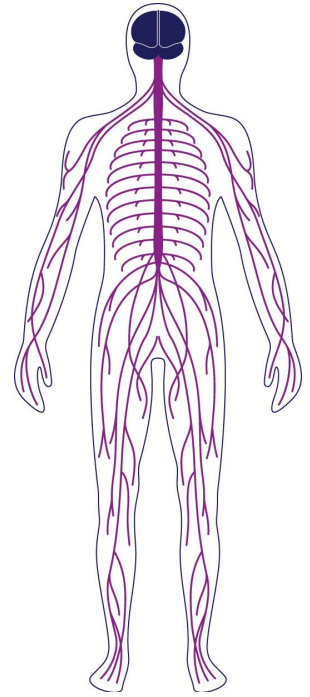
We value your feedback

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

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

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. MND does not usually affect sight, hearing or sensation.
- It can leave people locked in a failing body, unable to move, talk and eventually 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 of diagnosis.
- 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 if you have any questions about MND or want more information about anything in this publication.

mndconnect
0808 8026262
mndconnect@mndassociation.org

www.mndassociation.org/professionals