

P2

# Wheelchairs for people with motor neurone disease

## Information for health and social care professionals

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.<sup>1</sup> As the condition progresses, most people with MND will need to use a wheelchair.<sup>2</sup> 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. It covers:

- **Access to wheelchairs**
- **Types of wheelchair for people with MND**
- **Powered neuro wheelchairs**

If you have any questions or experience any problems with access to a wheelchair for a person with MND, email us at [wheelchairs@mndassociation.org](mailto:wheelchairs@mndassociation.org) or contact MND Connect on **0808 802 6262**.

## 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

The NICE Guideline on the Management of MND<sup>3</sup> states:

*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 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](http://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](http://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](http://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 will consider the person's home and the local environment where the wheelchair is to be used.<sup>4</sup> 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.<sup>5</sup>

### 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.<sup>6</sup> The aim is to support people's choice of wheelchair, either within the NHS or with third party organisations (such as the MND Association), 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](http://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.

Some services may not be able to provide certain types of, or equipment for, a wheelchair due to commissioning criteria. In such cases alternative funding may need to be sought. If statutory funding for an appropriate wheelchair for someone with MND has been explored but problems are encountered, the MND Association's wheelchair service may be able to help.

Search [www.mndassociation.org/wheelchairs](http://www.mndassociation.org/wheelchairs) or phone MND Connect on **0808 802 6262**.

### 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 may need to 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 electric outdoor wheelchairs, they should also be given information about insurance and a road safety test may be completed.

Waiting times for wheelchairs will depend on whether the chair is a standard order or specially configured. However, **powered neuro wheelchairs** (pages 3 and 4) have been designed to suit the needs of those with progressive neurological conditions and, because they come as standard order chairs that are adjusted to the individual on arrival, the wait for a suitable chair is reduced.

### 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.

### Specialist MND wheelchair services

The MND Association funds three specialist wheelchair services based in Carshalton, Leeds and Oxford. The specialist therapists based at these centres 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, email [wheelchairs@mndassociation.org](mailto:wheelchairs@mndassociation.org) or contact MND Connect on 0808 802 6262.

## 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.<sup>4</sup>

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, and the other usually offers more support with a tilt-in-space mechanism.

**Tilt-in-space** is a mechanism that will tilt the whole seat backwards. This helps prevent someone slumping, sliding down or falling to one side, while keeping their head supported in a forward-facing position. It can also relieve pressure on vulnerable areas, helping to prevent pressure sores and ease the effects of fatigue.

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.

Where a powered wheelchair is neither wanted nor appropriate to clinical need, a highly supportive manual wheelchair is most often used by those who need more postural support than can be offered by a standard wheelchair. This type of chair will be larger than a standard manual wheelchair and will not fold easily into a car boot, especially if it includes a tilt-in-space mechanism.

## Powered wheelchairs

These wheelchairs provide the user with more independence for their own mobility if they are unable to self-propel a manual wheelchair.<sup>7</sup> 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. A powered wheelchair may also include a powered tilt-in-space 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. Our information for people with MND includes Information sheet 8 – *Choosing the right vehicle for you*, which gives more information. Download this sheet from [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or see page 5 for details of how to order copies.

## Powered Neuro Wheelchairs

The MND Association has worked with three key wheelchair manufacturers to develop several different models of the powered neuro wheelchair which are suited to the needs of most people with MND and other similar progressive conditions. This specification was developed with key stakeholders, including people with MND, and is designed to enable a high-specification powered wheelchair to be affordable for local wheelchair services.

### Features

Each of the powered neuro wheelchairs is suitable for indoor and outdoor use and all have features that are designed to be adapted as the condition progresses so that further costs can be minimised.

Features include:

- powered tilt-in-space
- 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.

### Find out more

Email us at [wheelchairqueries@mndassociation.org](mailto:wheelchairqueries@mndassociation.org) to find out more about the powered neuro wheelchairs, or visit [www.mndassociation.org/wheelchairs](http://www.mndassociation.org/wheelchairs)

Watch our video on selecting the right wheelchair at [www.youtube.com/watch?v=C82VdIKq4dQ](http://www.youtube.com/watch?v=C82VdIKq4dQ)

Although we are unable to recommend or endorse a particular supplier, the powered neuro wheelchairs are made by:

**Invacare** Pencoed Technology Park, Pencoed, Bridgend CF35 5AQ. Telephone: **01656 776222**  
Email: [ordersuk@invacare.com](mailto:ordersuk@invacare.com) Website: [www.invacare.co.uk](http://www.invacare.co.uk)

**OttoBock** 32 Parsonage Road, Englefield Green, Egham TW20 0LD. Telephone: **01784 744900**  
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**Sunrise Medical** Thorns Road, Brierley Hill, West Midlands, DY5 2LD.

Telephone: **0845 605 6688** Email: [enquiries@sunmed.co.uk](mailto:enquiries@sunmed.co.uk) Website: [www.sunrisemedical.co.uk](http://www.sunrisemedical.co.uk)

## 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](http://www.nice.org.uk/guidance/ng42) Last checked July 2018.
- 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.nnpcof.org.uk/the-national-wheelchair-alliance-launches-charter-and-national-campaign](http://www.nnpcof.org.uk/the-national-wheelchair-alliance-launches-charter-and-national-campaign) Accessed April 2015.
- 6 [www.england.nhs.uk/personal-health-budgets/personal-wheelchair-budgets](http://www.england.nhs.uk/personal-health-budgets/personal-wheelchair-budgets) Accessed June 2018
- 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.

## How the MND Association can support you and your team

We support health and social care professionals to provide the best possible care for people living with MND, their carers and families. We do this in a number of ways:

### Wheelchair service

If you are seeking information on wheelchairs, or if there are delays in assessment or provision of an appropriate wheelchair for someone with MND, our wheelchair service may be able to help, through training, joint assessments, advice or support. For our wheelchair service, call MND Connect on **0808 802 6262** or email [wheelchairs@mndassociation.org](mailto:wheelchairs@mndassociation.org)

### MND Connect

Our helpline offers help, information and support, and signposting to other services and agencies. The service is for people living with MND, carers, family members, health and social care professionals and Association staff and volunteers who directly support people with MND. Telephone: **0808 802 6262**, email: [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

### Information resources

We produce high quality information resources for health and social care professionals who work with people with MND. We also have a wide range of resources for people living with and affected by MND. All our information sheets and most of our publications can be downloaded from our website at [www.mndassociation.org/publications](http://www.mndassociation.org/publications) or you can order them directly from the MND Connect team.

More information for health and social care professionals can be found on our website at [www.mndassociation.org/professionals](http://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, such as conferences and masterclasses. Find out more at [www.mndassociation.org/education](http://www.mndassociation.org/education)

### MND support grants and equipment loan

Where statutory funding or provision has been explored and is not available, we may be able to provide a support grant or some equipment on loan.

Grants may be given to help with aspects of care or quality of life for people with MND, their carers and younger members of the family. Referrals need to be made by a health or social care professional.

Visit [www.mndassociation.org/getting-support](http://www.mndassociation.org/getting-support), call the MND Support Services team on **01604 611802** or email [support.services@mndassociation.org](mailto:support.services@mndassociation.org)

## Communication aids service

This service helps people affected by MND and health and social care professionals with queries about communication aids. The service provides limited financial support for communication aids or some items on loan, if unavailable or delayed through health and social care services. Our aim is to improve provision and information on a local and national level, through collaboration with professionals.

Call **01604 611767** or email **communicationaids@mndassociation.org**

## Research into MND

We fund and promote research that leads to new understanding and treatment and brings us closer to a cure. Contact the Research Development team on **01604 611880** or **research@mndassociation.org**. Alternatively, visit **www.mndassociation.org/research** for more information.

For the latest research news, visit our research blog at **mndresearch.blog**

## MND Association membership

Join us now and help fight MND. Membership costs £12 for individuals. It is free for people with MND and for carers, spouses or partners of people living with MND. Call **01604 611855** or email **membership@mndassociation.org**

## Local support

### Regional care development advisers

We have a network of regional care development advisers (RCDAs) covering England, Wales and Northern Ireland. RCDAs have specialist knowledge of the care and management of MND. They work closely with local statutory services and community care providers to ensure effective support for people affected by MND. RCDAs provide education for health and social care professionals in MND, and are champions at influencing care services in their respective areas.

### MND care centres and networks

Care centres and networks are teams of professionals who are specialists in MND. We fund and develop care centres and networks across England, Wales, and Northern Ireland, which offer specialist clinical expertise from diagnosis onwards.

### Branches and groups

We have volunteer-led branches and groups nationwide providing local support and practical help to people with MND and their carers.

### Association visitors (AVs)

Association visitors provide one-to-one local support to people affected by MND. They are highly trained volunteers with experience of MND who can visit people affected by MND within their homes or contact them by telephone, email or through local support groups. They can also provide a link with health and social care professionals. You may be in contact with Association visitors following up on queries from the families they support.

### We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them.

If you would like to provide feedback on any of our information sheets, you can access an online form at: **www.surveymonkey.com/s/professionalinformation**

You can request a paper version of the form or provide direct feedback by email: **infofeedback@mndassociation.org**

Or write to: Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

## Acknowledgements

Thank you to the following people for their valuable contributions to this information sheet:

**Fiona Eldridge, MND Specialist Occupational Therapist, QEF Mobility Services, Carshalton**

**Krys Jarvis, Chair of National Wheelchair Managers Forum, and Wheelchair and Posture Service Manager, Shropshire Wheelchair and Posture Service**

**Christine Orr, MND Wheelchair Therapist, Leeds Wheelchair Centre**

**Jenny Rolfe, MND Specialist Occupational Therapist, Oxford MND Care and Research Centre**

Last revised 07/18  
Next review 07/21  
Version 1.5

## MND Association

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 @mndassoc

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## About us

The MND Association was founded in 1979 by a group of volunteers with experience of living with or caring for someone with MND.

Since then, we have grown significantly, with an ever-increasing community of volunteers, supporters and staff, all sharing the same goal – to support people with MND and everyone who cares for them, both now and in the future.

We are the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning.

## Our mission

We improve care and support for people with MND, their families and carers.

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND.

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

## 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 the senses such as sight, sound and feeling.
- 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 a proportion 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.



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