

6: Getting around

This section can help you find safe ways to prolong independence and mobility.

The following information is an extracted section from our full guide *Living with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: www.mndassociation.org/publications

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

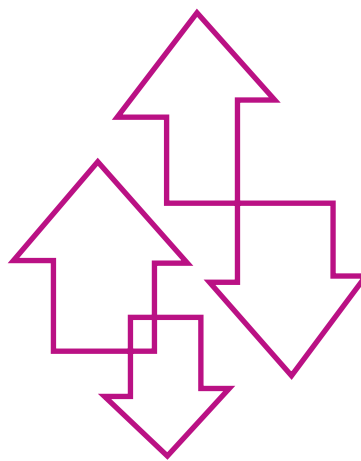
Email: mndconnect@mndassociation.org



Living with
motor neurone disease

6: Getting around

This section can help you find safe ways to prolong independence and mobility.



MND is likely to affect your movement, mobility and posture as the disease progresses. This can be extremely frustrating, as you may need help to do things and get around. You may also be at risk of falls and injury.

Having to change the way you do things can feel difficult. However, accepting support can improve quality of life, and make a real difference for yourself and those close to you.

“ I find inactivity hard – being unable to do daily tasks, drive, travel independently or go mountain walking, which was my passion.”

Who can help me with mobility?

A physiotherapist can:

- assess your needs regarding mobility equipment and walking aids
- recommend a suitable exercise programme
- advise carers on assisted or passive exercise (where they move your limbs)
- provide guidance on positioning for comfort
- advise you and your carer on safe moving and handling
- advise on how to manage falls
- suggest ways to manage fatigue.

Respiratory physiotherapists can also advise on breathing techniques.

An occupational therapist can:

- suggest ways to prolong independence with self care and daily routines
- assess and advise on equipment and technological solutions to promote independence
- assess your home environment for possible adaptation, wheelchair accessibility or assistive equipment, such as grab rails
- advise on prevention of falls
- provide guidance on posture, and how to reduce any pain or discomfort
- advise you and your carer on safe moving and handling
- suggest ways to manage fatigue
- explore ways to maintain social activity, hobbies or interests
- support the psychological and emotional impact of having to adapt to change.

A district or community nurse can:

- help monitor and advise on pain control and medication
- advise on how to manage falls
- advise you and your carer on who can provide guidance on moving and handling
- provide guidance on care for swollen hands or feet.

Will exercise help?

It is the nerves supplying the muscle, rather than the muscles themselves that are damaged with MND. This means excessive exercise is not usually recommended, as it can cause fatigue.

General exercise such as walking and swimming are fine, but try not to push beyond your natural limits. Try to conserve energy for activities you really want to do.

A physiotherapist can advise on exercises and review these as your needs change.

“ I can’t thank my physiotherapists enough for helping to maintain my quality of life. They had full knowledge of MND and tailored my treatment.”

Exercise cannot reverse damage to muscle groups already weakened by MND. However, it can help to:

- maintain muscles not already affected by MND
- extend range of movement in joints
- prevent or ease stiffness and pain
- support your posture.

Assisted exercise (or passive exercise where someone else moves your limbs) can help to relieve stiffness and pain. This type of exercise can also ease any discomfort if lack of mobility causes poor circulation or swollen limbs.

How do I manage fatigue?

You may feel extremely tired (known as fatigue) due to:

- using extra effort because of weakened muscles
- problems with your breathing
- poor sleep
- not eating enough if you have swallowing difficulties.

You may not have all these issues, but think of your energy like a battery – when the power runs low, it needs time to recharge. If you use a lot of energy one day, you may feel extremely tired the next and need rest time.

Try to:

- listen to your body, pace yourself and be flexible with routines
- do the tasks you really want or need to do, and leave or get assistance for others
- use equipment to help you and your carer do things more easily
- manage your time, for example, let people know the best time to visit
- plan a rest day both before and after a busy time, such as a family event
- ask your physiotherapist and occupational therapist how to manage fatigue
- consider relaxation techniques, as advised by your health and social care team
- ask your GP for a referral to a respiratory team if you have any breathing problems (respiratory physiotherapists can also help manage breathing problems).

“ Listen to your body and perhaps do a task in two steps, rather than all at once. You achieve the task in the end, but without the frustration of tiredness.”

What practical support is available?

You need to be assessed for appropriate equipment and aids. This includes looking ahead at your changing needs, as some equipment may no longer be helpful by the time it arrives.

In most cases an occupational therapist is your first contact for advice, assessment and arrangements for equipment. Depending on your needs, other professionals may be involved, such as a physiotherapist or community nurse.

For balance, walking or personal mobility:

- use splints or braces to support joints or problems such as foot drop, where muscles in the foot weaken
- try walking aids like sticks, crutches, a walking frame or a rollator (a frame with wheels), but these may be difficult to use if arms and hands weaken
- ask for a wheelchair assessment if needed (see later heading)



Rollator, or wheeled walking frame

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“ Having someone bend and straighten my fingers and toes eases discomfort if they clench or become rigid.”

If experiencing pain, cramps and/or stiffness:

- ask your GP, physiotherapist or occupational therapist what may be causing the problem, or ask for referral to a neurological specialist
- explore changes to seating and positioning, including use of a riser recliner chair, a riser on a toilet for height and a powered bed
- use pressure relieving cushions and mattresses if you tend to stay in one position for a long time
- use splints, braces or a support collar if helpful
- ask about pain control and medication.

See *Further information* at the end of this section about our resources on managing pain.

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“ When I try too hard to do anything, my muscles become stiff. If I continue to fight, I become stiff all over.”

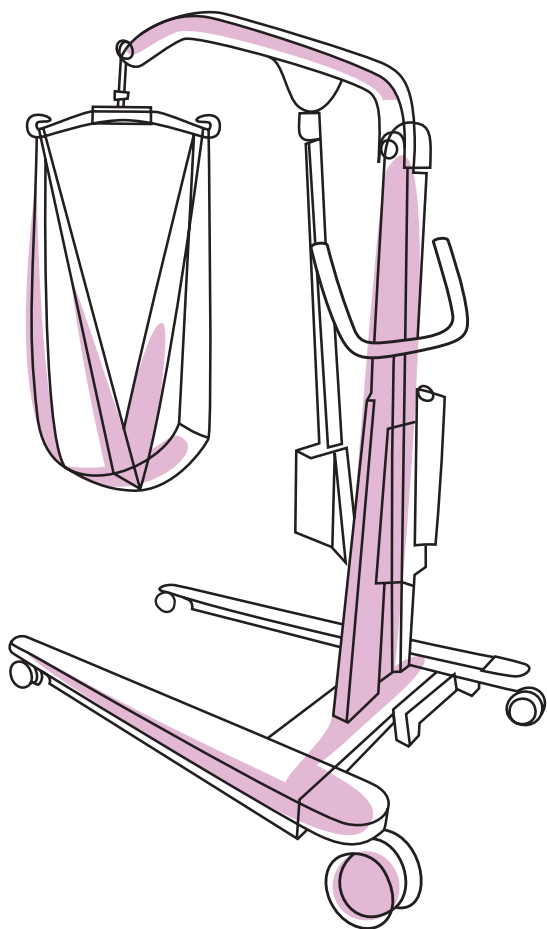
“ When helping someone with MND to move, do it in stages. For example, when getting out of bed, help them sit up, then relax. Help them stand, then relax. Sit them in a nearby chair, then relax.”

To move from chair to bed, bath or toilet:

Ask your occupational therapist, physiotherapist or community nurse about:

- available equipment, such as grab rails, frames around toilets, hoists, riser recliner chairs, adjustable beds, sliding boards and rotating transfer frames
- adapting the bathroom to a level access shower with a wheel-in shower chair
- safe moving and handling techniques for you and your carer to use, including how to manage falls (this guidance may need to be reviewed over time).

A memory foam mattress can make it more difficult to move in bed. Slippery materials may help you slide, but could risk falls.



Mobile hoist

“ When helping someone with MND to move around, don’t leave them unsupported. Even a momentary lapse can make me lose confidence and affects my balance.”

To get in and out of the house:

- use ramps and widen doors
- consider home adaptations, such as door systems that can be opened using environmental controls (these can also control appliances, such as the television).

To move between floors:

- use stair rails and grab rails if safe to do so
- have a rollator on each floor if you find it helpful for balance
- consider if a stairlift will be suitable, as you will need transfer to and from the seat, and possibly a wheelchair on both floors
- install a through-floor lift, which can take a wheelchair up and down
- adapt your home to enable you to live downstairs (and be wheelchair accessible)
- plan any conversions or extensions as early as possible, as these can often take a year or more.

You may be eligible for a Disabled Facilities Grant (DFG) for adaptations or major installations. Ask your occupational therapist to advise, but it can be a lengthy process to get a grant, so explore options as early as you can. You will be financially assessed to work out how much you may need to contribute.

See *Further information* at the end of this section for more on DFGs and adaptations.

If you decide to make adaptations privately, get an assessment through an occupational therapist to work out your needs and what will be safe to use. This also applies to stair lifts and through floor lifts, which are also expensive items with little second-hand value.

Some building adaptations are VAT exempt, so find out as much as you can before any discussions with providers.

“ When deciding to adapt or move to a more accessible home, get information on costs, accessibility and time scales to make a balanced decision. The best technical solution may not be what you want.”

To get in and out of a car:

- ask your occupational therapist for advice, such as using a lever in the door catch for grip or a swivel cushion to help turn into the car
- try a long strap under the feet to help lift them into the car if your carer finds bending difficult
- think about adapting your car or change to a wheelchair adapted vehicle (WAV), which may be accessible through the Motability scheme
- ask a driving assessment centre for guidance.

If you drive and receive a diagnosis of MND, you must notify your car insurer and the DVLA immediately. You may be asked to take a driving assessment if you wish to continue driving. Adapted controls can help you prolong your driving ability.

You may also want to explore the Blue Badge scheme for disabled parking. This can help you park close to your destination and use disabled parking bays. Find information through GOV.UK at

www.gov.uk/apply-blue-badge

See *Further information* at the end of this section for resources on driving, vehicles and general transport.

How do I apply for a wheelchair?

Wheelchairs range from simple manual versions to specialised chairs for posture, and powered chairs for indoor and outdoor use.

A posture and mobility assessment is essential to work out which type of wheelchair will meet your needs. The service providing the wheelchair should review your needs if they change.

Who provides the assessment and funding?

Your GP, physiotherapist or occupational therapist can refer you for assessment, as follows:

- **In England:** through your local NHS wheelchair service
- **In Wales:** through the Artificial Limb and Appliance Service
- **In Northern Ireland:** by the Department of Health, Social Services and Public Safety (DHSSPS) Wheelchair Service.

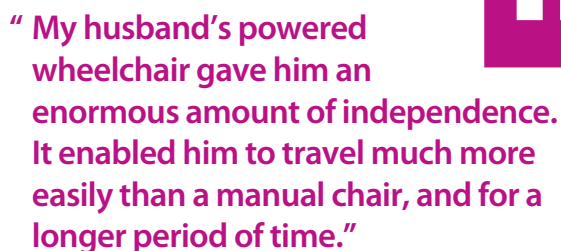
We provide information about equipment and wheelchairs, which covers options on funding, including personal wheelchair budgets in England to choose your own chair after assessment.

See *Further information* at the end of this section for relevant resources.

Powered neuro wheelchairs

Several years ago, the MND Association worked with wheelchair manufacturers to create a range of powered neuro wheelchairs for people living with MND.

Since then, wheelchair design has progressed even further and wheelchair services can assess you for the most suitable option. Your position can be changed in these powered chairs and add ons can be attached, such as communication devices and adapted controls.



“ My husband’s powered wheelchair gave him an enormous amount of independence. It enabled him to travel much more easily than a manual chair, and for a longer period of time.”

See *Further information* at the end of this section about our resources on equipment and wheelchairs.

Private hire or purchase

If you decide to buy privately, seek assessment from a qualified health professional to ensure you purchase the right chair for your needs. This should consider:

- your size, shape and posture
- any pressure relief needs
- how, when and where the chair will be used
- your environment where you live, to check accessibility.

If you are assessed by a local wheelchair service, ask for a copy of your assessment. This can help a local dealer or distributor advise on the most suitable wheelchairs for you to test.

Motorised scooters

Some people may find a scooter useful for a while. Seek an assessment with your occupational therapist, as they can be costly and have limited use. Look online for your nearest Disabled Living Centre, where you can get advice (some offer scooter training). You may need insurance to use a scooter away from the home environment.

See *Further information* for information on choosing the right vehicle and useful organisations.

Wheelchair and scooter safety:

- check brakes and tyre pressure regularly
- carry extra layers of clothing, as temperature control can be more difficult with MND
- ensure clothing and covers are tucked in to avoid getting caught in the wheels
- a wheelchair should never be lifted with someone in it
- a wheelchair should not be pushed forward down a step or kerb
- apply brakes when getting in and out of a wheelchair or a scooter
- move footplates clear when getting in and out of a wheelchair
- use a safety belt, particularly over uneven ground.


Splints and collars may offer extra comfort and security if needed. These can provide hand, foot, neck and chin supports. Talk to your health and social care team to explore suitable options.

Transport and travel

Our information resources include detailed content about:

- driving
- adapted vehicles and the Motability scheme
- Blue Badge
- public transport
- scooters
- disability transport schemes
- holiday and long distance travel
- the ‘fit to fly’ assessment.

See *Further information* at the end of this section for relevant resources.



“ We went on holiday as soon as my husband was diagnosed, but he found he couldn’t walk far. I had to organise help at the airport both ends before going home. All was done with no problem.”

It may be more difficult to get insurance cover for a holiday following diagnosis. It’s worth exploring this as soon as possible when trying to book your travel, as insurance offers and policies change frequently. Our MND Connect helpline cannot recommend one company above another, but may know of existing offers for holiday insurance.

See Section 10: Finance, work and social care for an overview about health and life insurance cover.

Key points

- Always get assessed by an appropriate health or social care professional before deciding on equipment or home adaptations. This will help you make informed choices, based on your likely needs now and in the future.
- If you use a wheelchair and you have a stairlift installed, you will probably need two wheelchairs – one for transfer on each floor.
- If you drive and receive a diagnosis of MND, you must notify your car insurer and the DVLA immediately. You may be able to continue driving, but an assessment is usually needed.

See Further information for resources on driving and choosing a vehicle.

Further information:

From our range of information sheets:

- 1A:** *NICE guideline on motor neurone disease*
- 6A:** *Physiotherapy*
- 6C:** *Managing pain*
- 8D:** *Air travel and ventilation for motor neurone disease*
- 10C:** *Disabled Facilities Grants*
- 11C:** *Equipment and wheelchairs*

From our guides and other publications:

Getting around: our booklet about driving, transport and travelling.

Making the most of life with motor neurone disease: our guide on how to adapt and find ways to continue your hobbies and interests for as long as possible.

MND checklist: our form to help you think about support planning when first diagnosed.

Caring and MND: support for you: a comprehensive guide for carers.

Caring and MND: quick guide: a summary guide for carers.

Information to pass to your health or social care professionals:

- P1:** *Head supports*
 - P2:** *Wheelchairs for people with MND*
 - P11:** *Pain in MND*
- Occupational therapy for motor neurone disease**

Download our publications at:

www.mndassociation.org/publications

Or order them from **MND Connect**, our support and information helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**.

MND Connect can also help you find external services and providers, and introduce you to our services, where available in your area, including your local branch, group, Association visitor or regional care staff contact.

See Section 12: *How we can help you.*

Online forum:

A safe place to share information and support with others affected by MND at:

<https://forum.mndassociation.org>

Motability scheme:

An affordable way for disabled people to lease a car, scooter or powered wheelchair in exchange for their mobility allowance.

Telephone: **0300 456 4566**

Textphone: **0300 037 0100**

Website: **www.motability.co.uk**

The British Red Cross:

The Red Cross can help with short term hire of manual wheelchairs.

Telephone: **0344 871 1111**

Website: **www.redcross.org.uk**

Shopmobility:

Many large centres and retail parks offer schemes where you can book a wheelchair for use while shopping. Search for Shopmobility online to find your local contacts.

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**This resource has been evidenced,
user tested and reviewed by experts.**

For references and acknowledgements please refer to the full guide, *Living with motor neurone disease*.

The full guide can be ordered in hardcopy from our helpline, MND Connect:

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