

6: Getting around

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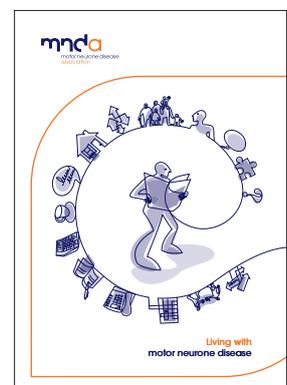
The following information is an extracted section from our full guide *Living with motor neurone disease*.

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 will help you to find safe ways to maintain movement and mobility in your everyday life, to prolong independence and support social contact.

MND affects everyone in different ways, but impact on movement, mobility and posture is to be expected as the disease progresses. This can be extremely frustrating and, for some, may result in falls and injury. It can also restrict living independently at home.

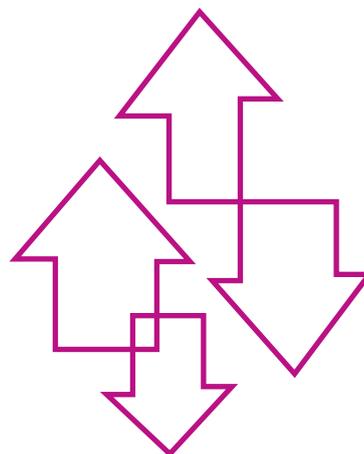
Accepting that you may have to find new ways of doing things can be difficult. However, there are many ways to find support and this can genuinely improve quality of life for yourself and for those close to you.

“ The ability to adapt to change can make such a difference to the experience of living with MND.”

Who can help me maintain mobility?

A physiotherapist can:

- help maximise your movement, mobility, balance and posture
- assess your needs regarding appropriate walking aids
- recommend an exercise programme appropriate for you and advise carers on assisted or passive exercise (where they move your limbs)
- advise you and your carer on moving and handling
- provide guidance on positioning for comfort



- provide advice on how to manage falls
- suggest ways to manage fatigue
- provide advice on respiratory care, which may help relieve fatigue.

An occupational therapist can:

- advise how to maintain independence in all aspects of self care and daily living activities
- provide guidance on falls prevention
- recommend how to retain posture, minimise pain and reduce discomfort
- advise about adapting your home environment for wheelchair accessibility or for equipment to help you with mobility or household tasks
- provide advice to you and your carer on moving and handling
- suggest ways to manage fatigue
- provide guidance on how to maintain social activity and personal hobbies or interests
- support the psychological and emotional impact of having to manage the changes being experienced.

A district or community nurse can:

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

Will exercise help?

It is the nerves supplying the muscle, rather than the muscles themselves that are damaged in MND, so excessive exercise is not usually recommended and can cause fatigue. General exercise such as walking and swimming are fine, but don't push yourself beyond your natural limits.

Try to conserve energy for activities that are important to you. A physiotherapist can advise you and your carer on exercises that will suit you and these exercises need to be tailored to your individual needs. What may suit one person with MND may not be ideal for another.

It is also important to get advice as your condition changes and exercise routines may need to adjust.

“ Physiotherapy has helped me feel proactive rather than a helpless victim.”

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

- maintain muscles not already affected by MND
- maintain range of movement in joints to help prevent stiffness and pain.

Assisted exercise (or passive exercise where someone else moves your limbs) can help to relieve stiffness and pain. This type of exercise can also help ease discomfort if poor circulation occurs and limbs are swollen. Again, a physiotherapist can advise on a programme that will be appropriate.

How do I manage fatigue?

You may find that fatigue is a persistent issue. This may be due to a variety of reasons, such as:

- using extra effort to do things, due to weakened muscles
- feeling tired if you have problems with your breathing

- not eating enough if you experience swallowing difficulties.

Not everyone will necessarily experience all of these issues, but fatigue may still be felt.

It might be helpful to take on the idea that you have a 'bank account' of energy to spend each day. Plan to do essential tasks first or those you really want to do. Leave or get assistance for others. If you overspend on energy one day, you may feel extremely tired the next. Try to:

- listen to your body and pace yourself
- prioritise tasks, manage your time and be flexible with routines
- use equipment to help you do things more easily
- talk to your physiotherapist, occupational therapist and dietitian about ways to manage fatigue
- talk to your health and social care team about any breathing problems
- plan a rest day both before and after a particularly busy time, such as a family event.

What support is available?

You need to be assessed for the most suitable equipment and aids. In most cases an occupational therapist is your first contact for advice and arrangements regarding equipment, but other members of the health and social care team may also be involved. The following indicates the type of support that may be available to help with movement and mobility.

For balance, walking or personal mobility:

- use devices such as splints or braces to support vulnerable joints and assist with problems such as foot drop, where the muscles in the foot become less responsive

- use walking aids like sticks, crutches, a walking frame or a rollator (a frame with wheels). Sometimes this can be difficult if the arms and hands are weak
- consider if a wheelchair may be useful (see later heading).



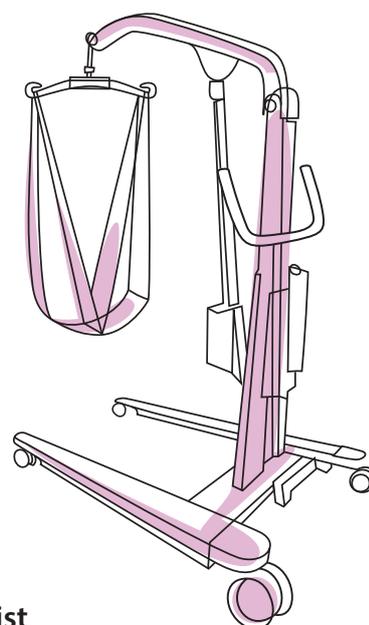
Rollator, or wheeled walking frame

If experiencing pain, cramps and/or stiffness:

- talk to your health and social care team to assess what may be causing the problem
- a physiotherapist or occupational therapist may be able to help
- explore changes to seating and positioning and whether splints, braces or a support collar may be helpful
- use a specialist chair and bed, walking aids and pressure relieving cushions and mattresses
- ask about pain control and medication.

To move from chair to bed, bath or toilet:

- you and your carer need to be shown safe moving and handling techniques and how to use equipment - ask your occupational therapist, physiotherapist, or community or district nurse for advice or guidance to qualified help
- use equipment such as hoists, riser recliner chairs, sliding boards and rotating transfer frames



Mobile hoist

- consider adapting the bathroom to a level access shower and use a wheel-in shower chair
- slippery materials may also assist the ability to move around and slide, eg when in bed, but care must be taken to avoid falls
- a memory foam mattress may make it more difficult to move in bed.

To get in and out of the house:

- use ramps and widen doors
- install environmental controls to open doors and control appliances, such as the television.

To move between floors:

- use stair rails and grab rails if safe to do so
- consider if a stairlift will be suitable, which may depend on how easily and safely a person can transfer to and from the seat - think about how their symptoms may progress
- consider if a through-floor lift will be suitable, which can take a wheelchair - these need space and can be costly, but provide a practical way to access bed and bathroom
- adapt your home to enable you to live downstairs or to be wheelchair accessible
- plan any conversions or extensions as early as possible, as these can often take a year or more.

Local authorities differ greatly in their approaches to assisting people with disabilities with home adaptations such as stairlifts and lifts. This is particularly true with a disease like MND where needs change. However, if you decide to buy or hire a lift privately, please talk to an occupational therapist first. These expensive items have little second-hand value and you need to know if they are safe for you to use.

You may be eligible for a Disabled Facilities Grant (DFG) towards the cost of lifts, conversions and extensions. Ask your occupational therapist to advise, but it can be a lengthy process to get a grant. You will also be financially assessed to work out how much you may need to contribute. Explore options as early as you can.

See Further information t the end of this section for details about DFGs.

To get in and out of a car:

- ask your occupational therapist for advice on equipment and techniques to help, such as a lever in the door catch to help with grip or a cloth swivel cushion to help turn the upper body into the car
- if your carer finds bending and stretching difficult, try a long strap under the feet to help lift them into the car
- think about adapting your car or consider changing to a wheelchair adapted vehicle (WAV), which may be accessible through the Motability scheme.

See Further information at the end of this section for publications 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?

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

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

“ I remain determined to get on with my modified life... my outlook, by necessity, is having to change.”

Powered neuro wheelchairs

A range of powered neuro wheelchairs are now available, suitable for use with MND. The MND Association worked with three wheelchair manufacturers to create these and the resulting wheelchairs can be ordered by all wheelchair services.

Wheelchair support from the MND Association

If all enquiries for wheelchair support have failed through external wheelchair services, we may be able to help. A Department of Health grant, along with other funding, helps us provide specialist MND wheelchair therapists at various MND care centres and networks. These therapists can advise you and assist wheelchair services with training, guidance and support.

See Further information at the end of this section for relevant publications and Section 14: How we can help you for details about the MND Association Wheelchair Service.

Private hire or purchase

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

- your size, shape and posture
- any pressure relief needs
- how, when and where the chair will be used
- your environmental needs, 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.

The British Red Cross

This independent charity lends or hires manual wheelchairs for short periods.

See Further information at the end of this section for contact details.

Shopmobility

Many large shopping centres and retail parks offer schemes where you can phone ahead and book a wheelchair. Look for your local contact in the telephone directory or search for *Shopmobility* online.

Scoters

Some people may find a scooter useful for a while, but an assessment should be undertaken with your occupational therapist, as they can be costly and have limited usefulness. Your nearest Disabled Living Centre can offer advice and some centres 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.

Wheelchair and scooter safety:

- check brakes and tyre pressure regularly
- carry extra layers for warmth if likely to be in cold conditions for long periods, 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 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.

“ The Motability car has given Dad a new lease of life and so much freedom, so the benefits really do outweigh the costs.”

Transport and travel

We provide a range of information sheets to answer your concerns about:

- driving
- adapted vehicles and the Motability scheme
- Blue Badge
- public transport
- scooters
- disability transport schemes
- holiday and long distance travel.

See Further information at the end of this section.

Key points

- If you are a driver who has been diagnosed with MND, you must notify your car insurer and the DVLA immediately. This does not necessarily mean you will have to stop driving, but you may need to be assessed.

See Further information for information on driving

- Always get an independent assessment by an appropriate health and social care professional before making major decisions about aids or home adaptations. The professional will be able to help you consider both present and future needs to help you make an informed choice.
- Bear in mind that if you use a wheelchair and you have a stairlift installed, you will probably need to purchase another wheelchair – one for transfer on each floor.

Further information:

We have a range of numbered information sheets, including:

- 1A:** *NICE guideline on motor neurone disease*
- 6A:** *Physiotherapy*
- 8E:** *Air travel and ventilation for motor neurone disease*
- 10C:** *Disabled Facilities Grants*
- 11C:** *Equipment and wheelchairs*
- 12A:** *Driving*
- 12B:** *Choosing the right vehicle*
- 12C:** *Travel and transport*
- 12D:** *Planning a holiday*

Most of our publications can be downloaded from our website: www.mndassociation.org or you can order them from **MND Connect**, our support and information helpline: Telephone: **0808 802 6262** Email: mndconnect@mndassociation.org MND Connect can also help you locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional care development adviser (RCDA).

See Section 14: *How we can help you.*

MND Association Support Services:

Email:

support.services@mndassociation.org

Telephone: **0808 802 6262** for guidance on our financial support and equipment loan services.

Online forum:

<http://forum.mndassociation.org> hosted by the MND Association for you to share information and experiences with other people affected by MND.

The British Red Cross:

www.redcross.org.uk or telephone **0344 871 1111** to find out about short term hire of manual wheelchairs.

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

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The MND Association has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org