

Movement & Mobility

“I used to enjoy walking holidays with my husband and did everything on the run. Now I need to plan my daily routines to avoid over tiredness and use equipment so that I can stay independent”

People with MND may develop varying problems with mobility. We take for granted everyday activities such as climbing stairs, getting in and out of the bath, driving, digging the garden or playing with the children, until something happens that affects our ability to do them easily. This section uses a problem solving approach to help you find the expert advice and equipment you need to enable you to make the best of living with MND.

The topics covered in this section are:

- Professionals who can help
- Exercise
- Fatigue
- Driving
- Travel
- Mobility around your home
- Wheelchairs
- Comfort and positioning
- Lifting and transferring
- Controlling your environment



Professionals who can help

What can a Physiotherapist do?

- Help you plan an exercise programme to suit you
- Improve your balance, posture and co-ordination
- Help you reduce muscle stiffness and discomfort
- Give advice about walking aids
- Give advice on splints, collars and braces for support



What can an Occupational Therapist do?

- Give advice on alternative ways of doing day-to-day things
- Advise you about equipment that is available to help maintain your independence in certain tasks and arrange a trial of an aid or appliance
- Advise you on ways to adapt your home for independence and safety

Referral is normally through your GP, Local Health Centre or MND Nurse Specialist

→ See ‘Who to Contact When You Are First Diagnosed?’ section for advice on how to be referred.

Exercise - Can exercise help? - Exercise is important to:

- Maintain or improve muscles not affected by MND
- Maintain the flexibility of muscles that are affected
- Conserve the flexibility of joints in the neck, trunk and limbs

General exercise such as walking and swimming are fine, but don't push yourself beyond your natural limits. Because it is the nerves supplying the muscle, rather than the muscles themselves that are damaged in MND, excessive exercise is not usually recommended and can cause fatigue. It will become more important to conserve your energy for activities that are important to you. A physiotherapist can advise you and your carer on exercises that will suit you. Make sure you get advice as your condition changes.

Help with balance

For those with good leg strength but problems with balance, a walking stick may be all that is necessary.

- 'Foot drop' can occur if the muscles in your feet become weak. You may begin to stumble, probably the most common cause of falls in and outside the home. Again a physiotherapist will be able to advise on getting a splint (known as ankle foot orthosis - AFO) that will support the position of your foot to reduce stumbling.

An AFO may also be useful for pedal control when driving.

- Support collars and shoulder braces can greatly reduce neck and shoulder pain as well as improving balance and posture. Many supportive devices come ready made in a range of sizes. Some collars, such as the Headmaster Collar and the Oxford Collar, are designed with MND in mind.



Fatigue

Fatigue can be a major problem for people with MND. Unfortunately there is no advantage in 'pushing yourself'. Rather, the key is to try and conserve energy for what you really want to do.

- Learn to respect your body's limitations and pace yourself
- Try and find short cuts for things you have to do
- Use gadgets and labour-saving devices
- Get some expert advice on ways of doing this

It might be helpful to take on the idea that you have a certain 'package' of energy to spend each day. Plan to do valued and essential tasks first and leave or get assistance for others. Overspend on energy one day may lead to feeling extremely tired the next.



Driving

Can I still drive?

A diagnosis of MND does not automatically stop you from driving, but you should seek approval from a medical practitioner. You are required to inform your insurance company who may seek a medical report on your continued ability to drive. On renewing your drivers licence you will need to submit a Medical Report form D501 with your Driving Licence Application form D401. You may voluntarily choose to have your licence renewed with the medical report prior to your current licence expiring, if the coding of the licence will change.

The Insurance Federation of Ireland and Insurance Information insists that disabled drivers are not charged extra based on their disability. Under the Equality Act, insurers should quote insurance based on statistically proven risk factors and the driver's individual record. If you have difficulty obtaining vehicle insurance you should contact the **Irish Insurance Federation**, Insurance House, 39 Molesworth Street, Dublin 2, (01 6761820) or www.iif.ie.

Disabled persons parking card

The Parking Permit scheme was born out of a basic necessity to maintain independence for people with limited mobility. A person with a physical disability can require access to a disabled parking bay because of its size (accessible parking bays are larger than the standard parking space) and their proximity to daily facilities. The parking card can be used by a disabled person in any vehicle in which he or she is traveling (either as a passenger or driver).

The parking cards are issued by the Irish Wheelchair Association and the Disabled Drivers Association. Application forms are available from either organisation. → See '**How the IMNDA And Other Organisations Can Help**' for contact details. A section of the application form will have to be completed and signed by your GP. There are set criteria to be met before you are issued a parking card. The IWA (Irish Wheelchair Association) are very aware of the needs of people with MND and take this into account when processing applications. Contact the MAATS Administrator (Tel: 045 893094) in the IWA for any queries regarding the parking card.

Tax relief for vehicles purchased for use by people with disabilities

This scheme provides for a range of tax reliefs in connection with the purchase and use of motor vehicles. The scheme is open to persons who meet the specified medical criteria and have obtained a Primary Medical Certificate to that effect. They can apply for relief as either a driver or as a passenger. There is a provision for a family member of a person with a disability who purchases a vehicle for the transport of that person as a passenger to apply. This scheme applies to the purchase of new and previously owned vehicles.

Relief in respect of Vehicle Registration Tax (VRT) and Value Added Tax (VAT) is subject to a maximum amount. A person qualifying for the scheme may also apply for a repayment of excise duty on fuel used in vehicle for the transport of the person with the disability up to a maximum of 600 gallons (2,728 litres) per year. Vehicles admitted to the scheme are exempt from the payment of annual road tax.

For further information or assistance in making an application contact **The Office of the Revenue Commissioners** Central Repayments Office on Tel: 047 62 100.

Primary Medical Certificate

Medical assessment and issue of the Primary Medical Certificate is carried out by the Senior Area Medical Officer attached to the HSE Local Health Office. Your application for the Primary Medical Certificate should be accompanied by letters from your GP and Consultant Neurologist confirming your diagnosis of MND and detailing how it affects you day to day. A medical assessment by the Senior Area Medical Officer will take place at your Local Health Centre or at your home if you are unable to travel to the Health Centre. If you are granted the Primary Medical Certificate your case will be re-assessed after a period of two years.

The criteria for a Primary Medical Certificate are that you must come within at least one of the following criteria:

- Be wholly or almost wholly without the use of both legs
- Be wholly without the use of one leg and almost wholly without the use of the other leg such that they are severely restricted as to the movement of the lower limbs
- Be without both hands or without both arms
- Be without one or both legs
- Be wholly or almost wholly without the use of both hands or arms and wholly or almost wholly without the use of one leg
- Have the medical condition of dwarfism and have serious difficulties of movement of the lower limbs

Where the issue of a Primary Medical Certificate is refused, the decision may be appealed to the Disabled Drivers Medical Board of Appeal, National Rehabilitation Hospital, Rochestown Avenue, Dun Laoghaire, Co. Dublin. This is an independent board whose decision is final. If you have been refused for a Primary Medical Certificate you can re-apply should a change occur in your medical condition to the extent that the criteria could be met.

If you currently receive the higher rate payment of Mobility Allowance and you receive a Primary Medical Certificate your Mobility Allowance payment will be reduced to the lower rate of payment.

For application forms/further information on the Primary Medical Certificate contact your **HSE Local Health Office**.

Exemption from toll charges

Holders of the Primary Medical Certificate who have an adapted vehicle registered in Ireland are exempt from toll charges on national roads throughout Ireland. Once your vehicle is registered on the Tax Relief for Vehicles Purchased for use by People with Disabilities scheme, when you travel through the M50 toll, the system will automatically read your vehicle licence plate and note your exemption. For all other toll roads you will need to apply for a Concessionary Travel Card. This looks similar to the Disabled Persons Parking Card and is displayed in the dashboard. Applications for Concessionary Travel Cards can be made through each Toll Road company. Contact Eurolink Tel: (046) 954 0266 or the **Irish Wheelchair Association** (Tel: 045 893094) or please visit www.eurolink-m4.ie

Adapting a vehicle

Buying or adapting a car can be expensive and your long-term needs should be taken into account. We strongly recommend that you get advice from your Physiotherapist, Occupational Therapist or a specialist disabled driver organisation. Car seats that swivel out for easier access can be fitted to some models of cars. The IMNDA can provide information and will attempt to help finance the adapted car seats by arrangement through your Occupational Therapist.

Travel

“Not to be cheated out of our much needed holiday, we decided to travel abroad to Portugal. The holiday was relaxing and although there was not much to do, the beaches were excellent. We have travelled by plane a number of times since MND and each time it has been an enjoyable experience”

You may find travelling by public transport difficult. Some parts of the country do run special transport schemes for people with disabilities.

A few additional suggestions

- An increasing number of taxis will carry portable ramps to enable wheelchair access
- Check platform access before rail journeys if steps and stairs are difficult
- It may be possible to make special arrangements with the rail company

Air travel

- Under EU Regulations, managing bodies of airports have legal responsibility for the provision of assistance services to persons with reduced mobility when travelling by air
- Make sure the airline knows what help you will need. Contact your airline with details of your assistance requirements at least 48 hours in advance of the departure of your flight or at the time of booking if possible
- Inform the airline if you will need assistance boarding & disembarking the plane



- Check that it is possible to take your wheelchair with you. Some airlines will not carry powered chairs or buggies with wet-cell or spillable batteries
- You will not be able to travel while remaining in your own wheelchair. You will need to transfer into a specially adapted narrow wheelchair to be taken into and around the plane, and transfer into the aeroplane seat for flying
- Check whether you will be able to use the toilet as toilets tend to be small and not very accessible
- Check that you have adequate medical insurance and that any equipment, such as a wheelchair, is covered, especially if going abroad
- Check the voltage of the country you're visiting as you may need to take/hire a transformer
- Under EU regulations only containers of 100mls or less of liquids, gels, pastes, lotions and cosmetics may be brought through the passenger security screening points at all EU airports. In addition, these items must be presented at the passenger security screening point in a transparent re-sealable bag of no more than one litre capacity (20cm x 20cm). There are some exemptions to the restrictions. These include essential medicines and dietary requirements in liquid form, for example baby-food or food for people on special diets. Passengers are allowed to bring these items to the screening points in the quantities that they need during their trip. However, as a safeguard, passengers may be required to demonstrate that the product is real medicine or special food
- If you are taking medication or special feed with you, make sure that it is clearly labelled and carry a doctor's letter certifying that you are taking prescribed medication/feed. Keep these items separate in your hand luggage when approaching the airport security area
- Check that the airline will accept any equipment you are taking with you and if this will be included in your baggage allowance or if there will be an additional cost for this

→ See 'How The IMNDA And Other Organisations Can Help' section for important contact details.

Mobility around your home

If balance and mobility are problematic for you, you may be experiencing difficulties in and around your home. A tendency to fall can be a major concern and can happen without warning.

Some simple tips to reduce risks may help:

- Remove loose rugs and tape down any upturned edges on carpets
- Wear supportive and appropriate footwear to avoid slipping or tripping
- If carrying items safely is tricky – think about using a trolley. An Occupational Therapist can advise
- If you spend long periods on your own consider wearing a small portable alarm system which will alert a control centre to get help. These can be supplied by the IMNDA when requested by your Occupational Therapist, MND Nurse Specialist or Public Health Nurse.

Stairs and lifts

If you have difficulty climbing steps and stairs or getting to your toilet if it is located upstairs, then your Occupational Therapist can advise and may even be able to organise the provision of stair rails and grab rails. However, if climbing stairs is becoming impossible or unsafe, then alternatives are available.

It's worth pointing out here that local authorities differ greatly in their attitudes to installing lifts for disabled people and in particular when the nature of a disease is progressive, as with MND. You may be eligible for the Housing Adaptation Grant for People with a Disability towards the cost of works to be carried out. This is applied for through the housing department of your local authority. The Housing Adaptation Grant for People with a Disability is a means-tested grant. This means your total household income is assessed to find out if you qualify for the grant and the amount payable. → See 'Work, Benefits and Finance' section for more information.

The time frame for approval of grants varies with each local authority. It is important to think ahead and discuss the options early.

There are two major types of lift:

Stairlifts: A track is fixed to the staircase and a seat takes you up and down. One major consideration regarding suitability is how easily/safely a person can transfer off and on the seat - or will be able to in the future. For this reason, many local authorities take the view that a stairlift may not meet long-term needs and is therefore not the preferred option. In some instances stairlifts can be provided on loan from the IMNDA.

Vertical Lifts: These rise through the ceiling to the floor above and are designed to take a wheelchair. They take up considerable space both upstairs and down, but may prove the most practical way to give access to both bed and bathroom facilities.

One final point; if you decide to buy or hire a lift privately, then please talk to an Occupational Therapist first. They are very expensive items with little second hand value, and you need to know that they are safe for you to use.



Extensions and conversions

For some people, the most practical solution is a ground floor extension with the requisite facilities

→ See also **Bathing and showering in the 'Everyday Activities' section**

Whatever you plan, read the following information first.

- Talk to your Occupational Therapist. They can help you plan for your future. It can be difficult for you to foresee and ensure that the plans will suit your needs
- Consider applying for a grant from your local authority for the cost of structural alterations/extensions (The Housing Adaptations Grant For People with a Disability). But remember, processing this application can take time
- **Never** do the work first and then apply for a grant
- Check all the information on grants with your local Citizens Information Centre
- Check about VAT relief on building works from the Central Repayments Office of the Revenue Commissioners ph: 047 81425

If lifts and extensions are not practical, then converting existing ground floor accommodation may be sensible. For example, you might turn a dining room into a bedroom or reinstate a partition wall in a through lounge or install folding doors to provide private ground floor space.

Ramps

If you use a wheelchair you may require ramps to assist with getting in and out of your home. The Occupational Therapist can advise you about the options and larger ramps may also be grant aided. There are specific guidelines for ramp gradients to ensure safety so please get advice before you have a ramp installed.

Wheelchairs

"I never ever wanted to use a wheelchair, but I must admit I stayed indoors more than I wanted to, until I got my own."

Getting your head round the idea of using a wheelchair can be a hurdle. When we are fit and well it is difficult to imagine that we may ever have to use one. One in four people in this country use a wheelchair at some point in their life so it is not uncommon and they are becoming a normal tool of everyday life for many people.

Wheelchairs help people with MND to continue getting out and about.



Where can I get one?

IMNDA wheelchairs

These are supplied by IMNDA. You must be assessed for your individual needs by your Occupational Therapist. There are many different models of wheelchair so having an assessment to help you choose what fits your body and requirements is essential. Regular review of the suitability of your wheelchair is also recommended.

HSE wheelchairs

Your local Occupational Therapist or Public Health Nurse will have access to Health Service Executive stores that supply wheelchairs. They will be in a position to assess you before choosing the appropriate chair from their stores.

Shopmobility

Many of the large shopping centres and retail parks offer schemes where you can phone ahead and book a wheelchair - check in the telephone directory.

Wheelchair safety

- Never try to lift a chair with someone in it
- Never push a wheelchair forward down a step or kerb
- Check brakes and tyre pressure regularly
- Make sure the user is dressed safely and comfortably
- Move footplates clear and apply brakes when getting in and out of the chair
- Use a safety belt, particularly if you are being pushed over uneven ground

Comfort and positioning

Weakness of those muscles that help you with your posture, even when you are sitting or lying down, can cause tiredness and discomfort if you are poorly positioned and supported. More importantly, spending too long in the same position can increase the risk of developing pressure sores on the skin.

What can I do to improve my position and comfort?

Chairs

The height, stability and support of a chair are all important aspects.

- It may be possible to adapt your existing chair to make it more comfortable with chair blocks to raise the height
- Cushions can be used to support your head, back and neck. Using a V-shaped pillow, can be helpful in a chair or in bed. Filling a V-shaped pillowcase with polystyrene beads and sewing up the ends creates a lightweight arm support for the lap
- There are specially designed chairs such as a riser recliner chair that reclines to provide head and neck support and rises to help you to your feet - sometimes available through the HSE. The IMNDA equipment loan service can provide powered riser recliner chairs subject to advice from an Occupational Therapist
- Pressure relieving cushions will reduce the risk of soreness by alternating skin pressure and improving blood circulation. These are normally available through your Public Health Nurse, Occupational Therapist or through the IMNDA on referral from either of these healthcare professionals



Beds

The quality of rest for many people with MND depends on their comfort and position.

- Pressure relieving mattresses for the bed can usually be obtained through a Public Health Nurse
- A backrest for the bed, powered mattress variator, or pillow lifter to help sit you up in bed can also be arranged through an Occupational Therapist or Public Health Nurse
- Hospital style electric profiling beds are available through the Public Health Nurse or on their referral from IMNDA



Lifting and transferring

Helping someone to move or transfer is a skilled task and incorrect techniques can hurt both the person being moved and their helper. When getting up from sitting or lying is no longer possible without the help of another person, a Physiotherapist, Occupational Therapist or Public Health Nurse will be able to provide training in the correct methods. Anything to do with helping someone to transfer is called **manual handling or moving and handling**. There is clear government guidance on how to avoid or minimise risks associated with moving and handling people.

A healthcare professional will be able to help you decide when it is no longer safe to try to transfer without equipment to help. They can provide and train you or professional carers in the use of the appropriate equipment from the huge range available. If you receive help from a nurse or caring agency, the use of equipment may be necessary to meet legal requirements for manual handling.

Environmental controls

These are devices that enable people with little movement to control a range of practical operations in the home at the touch of a switch. These might include opening doors; opening and closing curtains; turning the radio or TV on and off or calling for assistance. It is possible to obtain environmental control units through the IMNDA following an assessment carried out by an assistive technology advisor. This assessment is organised by IMNDA or your Occupational Therapist.

Environmental control systems should be considered before they are required because they may take some weeks to get installed. They are often highly valued because of the independence and choice they offer.