



Introduction

A progressive decrease in mobility is a feature of Motor Neurone Disease and people affected by the illness can take steps to prepare for it. There are many ways to maintain your mobility and this factsheet suggests just a few ideas. Your MND Care Team Specialist is an essential link with other professionals who can help offer advice in this area.

Your Physiotherapist

It is important that you tell your MND Care Team Specialist or GP about any problems you are having in order that they can decide whether a referral to a physiotherapist would be appropriate or not.

Physiotherapists can give guidance, support and advice regarding:

- Exercise
- Posture and Co-ordination
- Muscle and Joint pain relief
- Walking Aids
- Physical Support Equipment.

Your Occupational Therapist (OT)

A referral to an OT can usually be arranged through your MND Care Team Specialist or your G.P. The OT provides advice to help you:

- Change your way of doing things
- Improve your balance and co-ordination
- Reduce muscle and joint pain
- Choose equipment that will maintain your independence

- Adapt your home for safety and comfort

Dealing with Symptoms

Joint and Muscle Pain

Careful attention to an exercise programme may help eliminate much potential joint pain.

If your arms are weak and hang unsupported from the shoulder, there is a tendency for the shoulder joint to become painful. It is helpful to support weak arms whenever possible on pillows, armrests or on a table. A shoulder sling will also give the arm some support and decrease strain on the shoulder joint while you are walking. Hip pain can result from prolonged sitting in a sagging seat or chair. A firm seat on a chair or wheelchair can help relieve strain on the hip joints.

Leg and Foot Swelling

Mild leg and foot swelling is not uncommon and is best reduced by moving the toes and ankle if possible. Your physiotherapist can help by showing you and your carer both active and passive exercises that can help reduce swelling. Elevating the leg and/or using elastic stockings can also help to reduce swelling.

Muscle Cramping

Cramps are not uncommon in people with MND. They can be alleviated to some extent by keeping the affected

MND Scotland is the working name of the Scottish Motor Neurone Disease Association, the only charity funding research and providing care and information for those affected by MND in Scotland.

muscle warm and by stretching and contracting it or having your carer stretch and relax it until the pain is eased. Severe or frequent cramps should be discussed with your physiotherapist or doctor. There are a number of medications which may reduce cramping.

Posture Changes

If the muscles that maintain your posture weaken, you may have discomfort in your lower back, neck and shoulder blade region. Special cushions, chair backs, and supports called “rolls” are available to help you to maintain correct sitting posture and to support your lower back and neck. It may be necessary for you to sit in a reclined position or to use a neck collar to maintain proper positioning. Your physiotherapist can assist you in choosing the right device.

Walking

As leg and ankle muscles weaken, unexpected fatigue, tripping and falling could become problems. Many people benefit from using a stick or stroller as soon as they experience unexpected falls. Various leg and ankle splint devices are available to provide added support to weakened muscles. (See Orthotic Devices, below).

Gripping and Holding

People with MND may eventually lose strength in the hand and wrist muscles, losing the ability to manage small hand movements like holding a pen to write or cutlery to eat, turning a key to start a car or turning a handle to open a door. There are products designed to assist you with a weakened grip.

As these weaknesses develop, you may lose your ability to hold even lighter weight articles.

Getting dressed and undressed can become increasingly difficult, and then impossible to do alone. As this process occurs, dressing can be made easier with Velcro-type fasteners, elastic waistbands, and other features that make clothing easier to put on and take off.

Cold or hot hands can weaken the grip of most people, for people with MND, however, this is even more pronounced. If your fingers get cold you will probably be surprised by how much harder it is to do such things as undo buttons, or turn a doorknob.

Useful Devices

Walking sticks and Strollers

Many MND patients will require a stick or stroller sooner or later. The choice of a stick or a stroller should be made in consultation with your doctor and physiotherapist.

Orthotic Devices

Orthotic devices are aids that are attached to your body. They help to support your joints in certain positions when your muscles no longer can. Your doctor usually prescribes such devices, and your occupational therapist will fit and instruct you in its proper use.

Foot and Ankle Supports

When weakened muscles cause “foot drop,” leading to stumbling on stairs or kerbs, a lightweight ankle splint,

usually made of plastic or metal, can be a big help.

Hand and Wrist Supports

The “universal cuff” may be the most familiar orthotic aid. This straps over the hand and allows you to grasp such objects as cutlery, hairbrushes and other small personal objects.

A wrist splint can help you to grasp eating utensils and other objects. Additional supports can be added for positioning the fingers, enabling you to make finer movements with weakened fingers, such as are required for writing. For those in wheelchairs, there are more sophisticated supporting devices that can be used to help a person with MND eat. This requires adapting these devices to each person's individual situation.

Shoulder and Neck Supports

Weakened shoulder muscles can cause the arms to “hang” more than normal, which can become very painful. A shoulder sling can support the arm, reducing the pressure on arm muscles and ligaments. There are also neck collars that can support the head when neck muscles are weak.

Supply of assistive equipment for your physical and environmental needs can be arranged through your MND Care Team Specialist, occupational therapist, physiotherapist or social services.

Exercising to Maintain Mobility

Exercising can also help maintain mobility by preventing joints from stiffening up and maintaining a full range of movements,

see factsheet 5B Getting the Best from Physiotherapy for more on this.

Some Exercising Tips

Exercises should be done daily and should become a routine. You may wish to break up your exercise routine into parts to avoid fatigue. If you experience fatigue, consult your therapist for a change in your programme.

Do as many active exercises as you can. Later-on it may be necessary to switch to active-assisted or passive exercises. Your therapist can help you to make decisions about the correct limits of your exercise. Ask your physiotherapist which exercises are the most important ones to do if you have a busy day ahead of you.

Some exercises can be done while you either sit or lie down. Passive exercises are usually performed while you lie down. Your therapist can advise you on which exercise positions are best for you. Stop doing any exercise that hurts, and consult your therapist if this happens.

It is important to realise that exercise will not strengthen muscles that have been weakened by MND. Once the supply of motor neurons that control a particular muscle has degenerated, it cannot be regenerated by exercise or anything else. The right exercise program can minimise joint and muscle stiffness.

Recreational Exercise

If you enjoy such activities as walking, stationary bicycling and especially swimming, keep them up for as long as you can do them

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safely. If you experience cramping or fatigue, do not continue the exercise until you have consulted your doctor or therapist.

Swimming and hydrotherapy can be particularly beneficial to people with MND as the water helps take the weight of limbs that are otherwise too heavy for the muscles to move. Movements that might not otherwise be possible can suddenly be accomplished with the support of the water.

Wheelchairs

Many people with MND will find themselves in need of a wheelchair at some point in time. Some will use it only for long excursions outside the home, some for activities only, and some people will spend most of their day in a wheelchair. When and how often you need to use a chair and the type of chair you need will change overtime.

The decision about when to acquire a wheelchair is one that you will make with your doctor and/or occupational therapist.

Questions you need to answer include:

- Do you always need another person to help you to rise from a seated position?
- Do you stumble and fall a lot?
- Are you fatigued when you walk?
- Do you avoid outings because you are afraid of injuring yourself?

No one is eager to use a wheelchair and this is natural, but a wheelchair should be viewed as an opportunity to increase your independence and your ability to get around. It will also help you to conserve your energy. A therapist can help you decide on and obtain the most appropriate chair.

In the UK the NHS provides wheelchairs through their Disablement Service Centres (DSC) where you can be assessed for your individual needs following a referral by your GP, Physiotherapist or Occupational Therapist.

There are many different models of wheelchair so having an assessment to help you choose is always a good idea. Regular review of the suitability of your wheelchair is also recommended. The local DSC can also assess you for powered indoor or indoor/outdoor wheelchairs, although the criteria are strict and there may be a long wait. Get advice from a Physiotherapist or Occupational Therapist if you are going to buy a wheelchair privately. People with MND often need special features added to their chairs as the disease progresses. There may be a Disabled Living Centre near to you who can offer fast independent advice and a range of wheelchairs to try.

Selecting a chair will depend on your own personal needs which will require much input from an OT, PT, or rehabilitation specialist to assess your needs and determine required customization for fit and accessories. Because MND is progressive, you may need different types of wheelchairs for varying periods of time. Try to borrow some of the types of chairs you may not need on an ongoing basis to save your resources for more expensive equipment later on.

Wheelchairs range in type with the major two categories being manual and power. Manual chairs are most appropriate for someone who still has some ability to move themselves, power chairs are most appropriate for someone who cannot. Before purchasing a power chair you

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need to make sure your home is wheelchair accessible and it can be taken apart to fit in a vehicle.

Not only can a chair help you get around, many of the things you need to do in a day can be done from your wheelchair with adaptations. This makes for fewer transfers and reduces the risk of injury. For example, trays can be fixed for eating or holding a laptop computer. Electronic switches used to operate the computer or any other environmental controls in your home can also be attached.

Whichever type of wheelchair you use, it is critical to have it customised to best fit you and your mobility needs.

Ramps

If you use a wheelchair you may require ramps to assist with getting in and out of your home. Your Occupational Therapist can advise you about the options available including sources of funding to help pay for their installation. There are specific guidelines for ramp gradients to ensure safety so please get advice particularly if you intend to have one made.

Further Reading

Factsheet 5A	Assistive Equipment
Factsheet 5C	Getting the best from Physiotherapy
Factsheet 5D	Aids to Maintain Mobility

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