



Assistive equipment plays a major role in the lives of people with Motor Neurone Disease (MND). Since MND is a progressive condition physical changes occur with time, often leading to the need to use assistive equipment.

MND affects everyone differently. The assistive equipment used by one person might not be needed by someone else and could actually be dangerous if used by yet another. This factsheet attempts to give you an overview of some of the many types of equipment that could be used by people with MND. Not everyone will need all of it, and certainly not all at once.

In general if you are having difficulties with daily activities your occupational therapist (OT) or your MND Care Team Specialist are both great sources of practical advice and possible solutions. In particular your occupational therapist can assess your own circumstances and needs and suggest both practical solutions and equipment that might help to maintain independence. In many cases the OT will be able to provide this equipment too. In some areas it may be a physiotherapist who assesses whether someone needs specialist equipment to help with mobility, or not.

Choosing the best solution for your situation involves many considerations, including an understanding of your longer-term needs. Your OT will consider what you can do as well as what you can't do and make suggestions based on your abilities as well as disabilities.

Before purchasing equipment

Many of the more commonly used pieces of equipment are available for extended loan from your local council's social work department or your local health board.

Equipment can be expensive, so you need to make wise choices if you or your family decide to purchase your own, rather than rely on what can be supplied. It is important to discuss your needs with an appropriate professional before making a purchase. Some devices are reasonably priced and some are expensive. Some will assist you for a long period of time, whereas others may only be useful in the short-term.

As a broad rule of thumb it is the therapist who deals with that aspect of your care who needs to agree that you would benefit from a certain piece of equipment and recommend it for you. For example, riser-recliner chairs and household or mobility aids, generally come on the recommendation of OTs, while communication aids usually come from speech and language therapists (SLTs)

Although the rules vary across different councils, most would expect you to purchase relatively low-priced items yourself.

MND Scotland also has an equipment loan service that may fill the gap between a need being identified and your own equipment arriving from the supplier. To access these short-term loans your MND Clinical Specialist and the relevant therapist need to countersign a request form which is sent to our HQ in Glasgow.

MND Scotland is the only charity funding research and providing care and information for those affected by MND in Scotland.

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You may also want to visit local suppliers to test out various equipment options before you borrow or buy. Find out from healthcare professionals, in particular social workers, what financial assistance might be available if home adaptations are necessary

Types of Equipment

Assistive Tools for Activities of Daily Living

Many people with MND develop trouble with gripping and manipulating objects. It is often possible to modify everyday tools or to substitute specially designed versions of such tools to compensate for weakness in the muscles of the fingers, hands and wrists. For example, a knife, fork and spoon with extra-thick handles can make eating much easier. These could be purchased, or the thickness of your existing cutlery can be artificially increased by pushing it into thick tubular foam similar to pipe-lagging foam. There are also sets of cutlery available with thick, long handles that compensate to some extent for impaired shoulder movement.



Right and left "one handed eating" forks and a spoon adapted for poor grip.

Mugs with oversized, or open-bottomed, handles will allow you to slip all fingers under the handle, reducing the danger of spills. A plate guard gives a slight vertical edge to a plate so that food can be pushed against it onto a spoon or fork.

Plates with large rims can prevent food being pushed off your plate, while placing the plate on some rubber mat (e.g. Dycem) can stop the plate moving around.



Dycem can be purchased in rolls to be cut to size

If you have problems carrying things around the house try using an apron with big pockets or a bag slung diagonally across the body or around your waist. Use a tray with a non-slip rubberised surface such as Dycem.

A purpose built four-wheeled trolley can be useful for transporting items if you are unsteady while carrying a tray.



Electronic control systems, known as "environmental controllers," can be installed in the home to enable a person with MND to control lights, radios, televisions, open and close doors, start a kettle, etc. with the palm of the hand, a head movement, or even a puff of breath. The double action of gripping and turning a doorknob may also be a problem for you. A doorknob adapter could be the answer since it allows the door to be opened by pushing down or pulling up the lever. Environmental control systems can

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be adapted to include electrical door-entry systems while a fat wooden or plastic handle attached to your door key can help with the turning motion necessary to turn a key in the lock.



Large handle key turners can be very useful if your grip is weak,

To assist with written communication, use thick-barrelled pens or pencils that are easier to grasp than the usual thin variety, or use a writing aid that consists of a block for holding a pen or pencil.



A wide range of environmental controllers is available

Clothing fasteners can be difficult to use if your hands and fingers are weak. There are devices to assist in fastening buttons. Velcro is a popular replacement for both buttons and zippers on clothing. Shoes can have buckles or laces replaced with

Velcro closures by a cobbler. Items such as trousers or skirts with elastic waistbands, which need no fasteners at all are very useful. Pullover tops usually have no fasteners, but they can be some of the hardest clothes to get on and off.



The Click-to-Phone enables a person who cannot press the keys of a mobile phone to operate the phone with a single switch, a 5 switch device or the joystick on their powered wheelchair.

Telephones that do not require the use of hands are also available.

Body Supports

Items like ankle or wrist supports you might be offered at a hospital are called "orthoses." Orthoses can help to support your joints in certain positions when your muscles weaken, can prevent contractures if spasticity is a problem, enhance comfort, and aid in function.

Orthoses may be recommended by your doctor or physiotherapist. There are more orthoses available than we can discuss in this brief overview, but some of the major ones are described.

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Foot and Ankle Supports



Many people with MND experience "foot drop" which is caused by weakened muscles supporting the ankle joint. This can lead to stumbling on

stairs or kerbs or tripping while walking. The answer may be a simple ankle-foot splint made of plastic that is inconspicuous under trousers or slacks. These devices are often referred to as "ankle and foot orthoses" (AFOs). For more information on AFOs, talk to your doctor.

Hand and Wrist Supports

A wrist and thumb splint can stabilise the wrist and thumb, helping 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.

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

small personal objects. A thumb splint helps in supporting the thumb in opposition to the fingers and makes it easier to grasp and hold an object for use.

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 pull the arm up, reducing the tension on arm muscles and ligaments. There are also collars that can support the head when neck muscles are weak. A new collar has been developed which may be more appropriate for you. Ask your MND Clinical Specialist for more information.



Walking Equipment Aids

Sticks and Walkers

Many people with MND will require a stick or walker at some point. Walking sticks are especially useful when one leg is stronger than the other. Sticks



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should always be used on the stronger side, with the stick moving forward with the weaker leg. There are single or multi-legged sticks, so discuss with your physiotherapist which type of aid might work best for you. Another type of stick extends up the lower arm, almost to the elbow, with a ring that fits around the arm for added support.

Walkers and strollers provide maximum support because they spread the weight over a wide area. The choice of stick or walker should be made in consultation with your doctor and physiotherapist and you should not try to use it until you have received instruction from your therapist.

Wheelchairs

The decision about whether to get a wheelchair is one that you will make with your doctor or OT. A wheelchair can be prescribed for you by your occupational therapist.

Choosing the right wheelchair requires careful consideration and professional advice. Many factors will have to be considered, such as:

- Your size, this will determine the height, depth and width of seat, as well as the height and width of the back.
- Your physical abilities now and what they might be in the future,
- Available support from family and friends, and
- the sorts of services your community provides for transport, e.g. "Dial-A-Bus" services or wheelchair capable taxis.

There are different types of wheelchairs and wheelchair features that require consideration. Depending on which muscles are weakened, straps may be

needed to hold in arms and feet, and a seat belt is also a good idea. Hand-rim pegs are helpful if you have trouble gripping with your fingers, but have strength in your arms. There are wheelchairs that have a double hand rim for operating from one side which is useful if you have strength on one side only, although under these circumstances a motorised chair might be better.

Anti-tipping bars may be extended out the front or back to prevent the wheelchair from tipping forward or backward. A commode attachment is available on some wheelchairs, but not all, for when you are alone for long periods. Tray or table-like platforms should be a standard feature that can be attached to your wheelchair. Folding wheelchairs are useful because they can be put in a car.

Ask the professionals who help you with your wheelchair decision about other available features that are likely to be of benefit to you.

For the more advanced stages of MND, a battery-powered wheelchair may be required. These can be operated using a joystick or other switching device that can be controlled by almost any part of the body that you can move. Control switches can be modified to operate with even very small muscle movements.

Wheelchairs are expensive and if one is to enhance your life now and in the future, it must be a careful choice.

Manual Wheelchairs

Lightweight manual wheelchairs are often used by people who retain trunk stability and the ability to sit upright in the chair. These chairs are light to push and may be easily transported by car. Since MND is progressive, it is usually more cost effective to borrow this type of chair..

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Power Wheelchairs

Power wheelchairs allow a person to remain mobile and independent for a longer period of time than manual wheelchairs do. A standard power chair (or scooter if muscles are relatively unimpaired) will increase your outdoor mobility while reducing overall fatigue. Because the progression of the disease will necessitate ongoing changes, borrowing this type of chair from your local NHS wheelchair services unit will always be more cost-effective than buying it as these chairs are extremely expensive.

If you weaken and more support and better positioning are required, a scooter will no longer be a viable option. Wheelchairs with manual or electric tilt-and-recline functions should then be considered.

Many people with MND find breathing is easier when in a reclining position. This type of chair positions the body in ways that use gravity, instead of working against it. The tilt feature allows gravity to pull the hips to the back of the chair to prevent a continual forward sliding movement, which is a common problem with a reclining chair. The wheelchair should support your back and head. Specialty backs provide pressure relief and lateral support, which improves stability and positioning. Headrests are available in a variety of sizes and styles. The tilt feature also relieves pressure on the tailbone, preventing pressure sores from forming.

No matter what type of chair is used, skin breakdown is more likely to occur if regular repositioning techniques are not used. Cushions should be chosen for comfort and pressure relief, as many positions demanded by prolonged

wheelchair use can cause skin breakdown. If you can independently reposition every 30 minutes, a high-density foam cushion should be adequate to relieve pressure. As physical mobility decreases, more pressure-relieving cushions will be necessary. Many people with MND report that gel cushions are uncomfortable, while air-filled cushions seem to provide more comfort and pressure relief. More than one type of cushion is usually required since no cushion will provide both comfort and relief all the time. Wheelchairs can be controlled using many different methods. A therapist can help you determine what method best meets your needs.

Hoists, Lifts and Stair Lifts

This type of equipment can be expensive and requires much consideration and pre-planning to determine what is the best solution for your home-setting and longer-term situation. The types of lifting equipment to consider include stair glides, portable lifts, ceiling-track lifts and wheelchair lifts. Some devices could be positively dangerous if you were to slip out of them while in use, so it is best to get a trained professional and not a salesman to assess your home and circumstances if you think lifting devices are the answer to your problems.

Chairs

A chair should be supportive and comfortable and at an appropriate height to allow you to move easily,



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especially if you rely on help. People with weakened legs may find it difficult to get up out of chairs. Higher chairs with arms to push on should make it easier. Ultimately, an automated riser/recliner chair may be required. Riser-recliner armchairs have electrically operated motors installed that can change your position from almost horizontal (reclining) into an almost standing position. Ask your MND Clinical Specialist or occupational therapist if you feel you might benefit from the loan of a riser recliner. More expensive models come with heaters, massage devices and other features. These would need to be purchased by you as social work budgets are very unlikely to stretch that far.

Ceiling Lifts

Ceiling lifts are usually installed to move a person between the bedroom, bathroom and living areas. In this case a rail is installed in the ceiling, and the person is lifted in a sling, similar to the sling used on a portable lift. There are also turntable tracks that allow the running tracks to intersect or cross. Installing a ceiling lift system is a major project that requires professional advice and installation.

Portable Lifts

Portable hoists or lifts, which use a sling to lift a person up, can be rolled around on one floor level. A common type of sling lift is the Hoyer Lift. Most of these kinds of lifts are light, can be broken down into two pieces, and easily moved to a different level, or put in a car. The



minimum door size for moving a person through in a portable lift is about 26". Using a portable lift requires training, during which both you and your carer should be lifted, so that the carer can understand what you are experiencing.

Stair lifts

Most stair lifts use a track that is fastened securely to the wall side of a stairway. An automated chair can then be moved up and down the track. Stair lifts can go on curving stairs, and even around corners.



However, there must be adequate room and help at the top and at the bottom of the stairway for assisting you on and off. Stair lifts should only be installed by a professional familiar with the safety aspects of this equipment. It is these same safety aspects that can make a stair lift unsuitable for some people with MND, particularly when they have difficulty sitting upright.

Wheelchair Lifts

Portable wheelchair lifts are the most economical solution, and can be used on various stairways. Built-in wheelchair lifts are often used when it is not practical to have a wheelchair ramp from an outside door to ground level. Again, installing a wheelchair lift system is a major project which requires advice and installation by a professional who is familiar with the safety aspects of wheelchair lifts. (An

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amateur installation of a wheelchair lift was once responsible for the death of a small child.)

Through-Floor Lifts

Through floor lifts are sometimes installed in suitable properties to permit someone with serious mobility problems access to rooms, such as a bathroom, on an upper floor. Consideration should be given to the both the benefits and drawbacks of such a major installation before proceeding. Firstly, the layout of the house itself, where would a lift be accommodated, how would cut floor joists be supported where the lift passes through the floor? Are the costs involved cheaper than alternatives such as converting a downstairs room to a bedroom or building an extension to house a new bathroom or wet room? You might also want to consider what effect such an adaptation might have on the value or saleability of your house if you own your own home?

Bathroom Equipment

There are several devices to help people with disabilities in the bathroom. Raised toilet seats or commode chairs are a standard requirement for those with weakened leg muscles. Raised seats can range from homemade and low-cost seats to more expensive models. Another option is to have a plumber raise the level of the toilet by putting it on a low platform.

Attachments to give a standard toilet a bidet function are also available. Some people with MND, who have little



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lower body disability, but have problems with their arms and hands find using a bidet enables them to retain total independence with toileting.

When it comes to bathing, there are a number of simple remedies to common problems, as well as assistive devices. Liquid soap is easier to manage than bars of soap and a shower seat can be a large help towards maintaining independence while bathing or showering. When shampooing hair it is worth remembering that baby shampoo does not sting the eyes. If getting in and out of the bath becomes difficult ask your OT to assess your needs and provide appropriate aids or adaptations, such as a bath-lift. A grab-rail and non-slip mat can increase confidence and safety.

For those with mobility problems special trays are available to help wash hair in bed.

There are several models of bathtub seats and lifting equipment that can assist you in sliding or rotating over the tub for showering.

Retail stores that handle equipment for the disabled often have a variety of bathroom aids on display. Check with your occupational therapist or other healthcare professional for their advice and assistance in choosing these aids.

Tap turners can help retain independence



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Beds and Mattresses



Some people with breathing difficulties find it useful to sleep in a slightly upright position for which electrically operated beds (above) are ideal.

A common problem during the advanced stages of MND is being unable to roll over in bed. Lying in one position can become intolerably painful, or requires a carer to move you every few hours. Satin sheets or silk pyjamas can make turning easier. There are now specially segmented, air filled mattresses, a PVC- (Poly Vinyl Chloride) mattress, which are attached to an electronic pumping device which continually changes the air levels in different cells in the mattress, thereby relieving pressure during the night.

A bed with an incline feature can be helpful with breathing and comfort. Devices from foam wedges to fully automatic hospital beds are used. Hospital beds are often advantageous when lifts (e.g., Hoyer lift) are used because of the extra clearance required underneath.

Augmentative and Alternative Communication (AAC) Equipment

There are many different types of assistive devices available to help the speaking impaired communicate. These devices range from communication letter boards based on tracing the person's eye movements (low-tech), to speaking

valves for those on a respirator, to small hand held electronic speaking devices, to computer based systems with sophisticated software and speech synthesizers (high-tech).

Keep in mind that assistive technology is continually improving. MND Scotland has some types of AAC equipment for loan. Acquiring AAC equipment is only half of the equation. It is critical that you are properly assessed by an assistive technology expert, who may be a speech and language therapist and trained in how to use the devices. It is important for your family carers to also be trained.

Home Modifications

Listed below are some considerations to keep in mind when making home modifications to accommodate wheelchair users:

- **Rearrange furniture** to make wheelchair access and movement easier
- **Install ramps** (12:1 in slope) and guardrails or lifts in place of stairs
- **Doorways** should be at least 76 cm (30 in.) wide. They can be widened by removing the door and hinges, or removing inner mouldings and installing a sliding door or curtain.
- **Hallways** should be 92 cm (36 in.) wide to accommodate the chair's turning radius. A cleared turning space of 1.6m² (five sq.ft.) is necessary for safe and easy turns
- **Space under sinks and worktops** to accommodate wheelchairs can be made by removing cupboards, any exposed pipes must be insulated
- **Thick carpets can hinder** the movement of a wheelchair; Berber carpet, wood, laminate, or linoleum are good choices for wheelchair users

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- **Shower renovations or conversion to a wet room** for wheelchair access

Lights and Power Sockets

Dimmer, Rocker and touch pad switches can be an alternative to conventional switches and usually just replace the existing light switch. Extension leads fixed to the wall can be used to raise the height of electrical sockets (ask your OT).



Some families might choose to make extensive home modifications while others will not. The financial cost is a major consideration. However, it is important to note that while it may seem like a good idea to make modifications well in advance of needing them, given your expectations of the disease process, keep in mind MND is very individual. Your disease may progress slowly and spending money on a wet room now may not be something you need for several years if ever. The more expensive the modification, the more consultation you will need with your occupational therapist. It is also a good idea to talk to other families who have been affected by MND to share their thoughts, opinions, and experiences.

Local authority social work departments may help with costs as can a grant from MND Scotland. Ask your MND Care Team Specialist should you wish to apply for a grant.

The most important messages to remember when it comes to assistive equipment are to:

- Think about both short- and long-term needs
- Consult with appropriate healthcare professionals about your equipment options and how to use what you select
- Learn from others who have come up with creative, simple solutions
- Seek information on financial assistance and equipment loan programs to minimise your out of pocket expenses

These are just a few suggestions of the modified or special tools available to make everyday life easier for you. There are many more such tools that your occupational therapist can tell you about. Remember, though, none of your professional carers are mind readers, so you need to tell them what you are having trouble in doing and ask them to think about a solution for you.

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Other Sources of Information

There are many on-line retailers of “accessible” equipment, the following links are only a very small sample of some useful sites that might give you ideas.

<https://www.pattersonmedical.co.uk/>

<http://www.portaramp.co.uk/>

<http://www.clos-o-mat.com/>

<http://www.nrs-uk.co.uk/>

<https://www.talarmade.com/products/headup-collar/headup-collar/>

Funding Equipment Purchases

Purchasing equipment can be expensive. You may be eligible for a grant from MND Scotland towards the cost of some such purchases.

Details can be found on our website

<http://www.mndscotland.org.uk/how-we-can-help/grants/equipment-and-adaptations-grant/>

There are other Charitable Trusts which can assist with funding, so please ask our Information Officer to look for any Trusts which might offer some financial support towards the costs of equipment purchases.

RICA (Research Institute for Consumer Affairs)

Rica (formerly Ricability) is the trading name of the national research charity Research Institute for Consumer Affairs. They focus specifically on issues of concern to disabled and older consumers. Rica was founded through Consumers Association, publishers of Which? but is now an independent charity. Their website contains many helpful guides to equipment aids for use around the home. It also includes reports on Mobility equipment such as scooters and wheelchairs and very good information about accessible Public Transport

<http://www.rica.org.uk>

Factsheet 5B Maintaining Mobility

Factsheet 5C Getting the Best from Physiotherapy

Factsheet 5D Aids to maintain Mobility

Factsheet 21 Specialist Clothing

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