

Everyday Activities

“We were assigned an Occupational Therapist who worked so hard on our behalf. She did her utmost to acquire things for us and organised for us to have equipment, which proved invaluable around the house.”

We take for granted the work done by our hands and arms and also the store of ‘energy’ we have that makes every day activities like washing and dressing ourselves seem effortless. The muscle weakness and fatigue caused by MND can make everyday tasks feel difficult and it may be necessary to change the way you do things, or look for labour saving devices to help overcome the problems. It may be worth using these for mundane tasks, or, consider accepting help from others in order to save your energy for more interesting activities. Some people actually prefer the independence that certain equipment gives them, while others would rather have help from another person. → See ‘Living with MND’ section for further information.

The topics covered in this section are:

- Where to go for help and advice
- Bathing and showering
- Using the toilet
- Sexuality
- Clothing/Dressing
- Oral hygiene
- Grooming
- Eating and drinking
- Comfort
- Around the house
- Cooking
- Telephones
- Alarms
- Environmental controls



Where to get help and advice

Before making any decisions about using equipment, you will need to seek advice from an expert.

Occupational Therapists (OTs) can advise on alternative ways of doing everyday tasks and on the wide range of available equipment. Most equipment can be provided on loan from the IMNDA on referral from your OT. You can contact your OT either through your local health centre or your local hospital. They will also be able to give you advice about any grants that may be available for adapting your home.

Technical Advisor can also advise on alternative ways of doing everyday tasks using the assistance of environmental controls or assistive technology. This refers to the use of technology to operate devices around your home, or your wheelchair or to assist with communication. To set up a visit or an assessment by a technical advisor, contact the IMNDA and they will organise this for you.

Physiotherapist can give you advice on appropriate exercise, posture and balance and ways of helping you to move about. Your Doctor can arrange a referral. In some areas, there are Community Physiotherapists who do home visits.

Public Health Nurses offer nursing care and advice on equipment in your own home and can be contacted through your local health centre or your local GP's surgery.

Social Services will be able to offer advice and information on all services available to you and your family/carer. Services provided will vary from area to area, so you will need to make enquiries locally about what is on offer.

The IMNDA is always on hand to provide help and advice and will be familiar with any difficulties you are facing.

For people who tire easily

- Prioritise your tasks - non-essential ones can be done less or not at all!
- Plan your week and spread out strenuous activities
- Take frequent rests during tasks
- Organise your home so that important items are easily to hand
- Carry out tasks while sitting
- Use labour-saving gadgets

Bathing and showering

Anyone experiencing muscle weakness may begin to find bathing and showering very tiring. There is a wide range of equipment available to help, but do ensure you get advice as not everything will suit your bathroom. The guide below covers some of the most common problems with possible solutions as well as where to go for advice.

Bath

Potential Difficulties	Possible Solutions	Who To Consult
At risk getting in/out of the bath	Non-slip mat Grab rails - to increase safety	Occupational Therapist
Getting in/out of the bath	Bath Board - fitted across the bath. Bath seat - to assist getting up Powered bath seat - raises up and down	Occupational Therapist
Getting tired standing at the sink	Perching stool – forward tilted seat helps you sit close to the sink (also useful in the kitchen)	Occupational Therapist
Unable to get in/out of the bath	Ceiling mounted hoist - with sling Shower facility	Occupational Therapist

Shower

Showering usually requires less effort. The best type of shower to install is one without a shower tray, often referred to as a level access shower. Equipment for an over bath shower can include:

- Slatted bath board
- Grab rails

And for a shower cubicle:

- Grab rails
- Wall fixed shower seat
- Shower stool

An Occupational Therapist will be able to talk to you about all these and advise about any specialised equipment needed for a level entry shower. Grab rails can be bought in DIY stores.

Top Tips

- Rather than using a hand-held shower while sitting on a bath board, fill the bath in the normal way and scoop water in a lightweight plastic jug. Hair can be washed in this way
- Instead of towelling dry, put on a towelling bathrobe, lie on the bed and relax for 10 minutes (wrap your feet in a towel too).
- Fit tap turners (available from DIY stores or mail order)
- Use a flannel mit/long-handled sponges or lambswool pads (to reach your back and feet)
- Buy a soap on the rope/liquid soap on a dispenser/magnetic or suction soap holder/tip-up soap dispenser (the latter two by mail order)

Using the toilet

Equipment to help with toileting is assessed by the Occupational Therapist and is generally regarded as essential by social services departments and health authorities. In addition, people with weak hands may have particular difficulties undoing and doing up clothing → see **Clothing/Dressing chapter in this section** and cleansing.

Potential Difficulties	Possible Solutions	Who To Consult
Getting on/off the toilet	A raised toilet seat, rails or toilet surround	Occupational Therapist
Going to the WC at night	Bedside commode	Occupational Therapist or Public Health Nurse
Hygiene	'Bottom wiper' with long, looped handle and paper grip portable bidet which fits into the toilet Closomat or Medic-Loo: a unit connected to electrical/water supplies, providing a spray washer and warm air dryer operated by either a hand or foot switch	Occupational Therapist
Out and about	Portable urine bottles (men) or urine pans (women) can be discreetly carried when away from home	Mail order or Public Health Nurse

Your Occupational Therapist will be able to advise on the Closomat option and raised toilet seats/rails. All the other items are available by mail order.

Top Tips

- French knickers - wide, elastic-free legs can be pulled to one side
- “Crotchless” knickers - especially useful for wheelchair users
- Attach a tab or key ring to fly zippers

Periods

If this is posing particular difficulties, the following suggestions may help:

Potential Difficulties	Possible Solutions	Who To Consult
Weak grip	Self adhesive pads adapted applicators	Local shop/chemist
Menstruation	The possibility of chemically induced menopause contraceptives that stop periods	GP

Sexuality

Your sexual needs may be a very important part of your relationship and should not be ignored. MND does not affect sexual ability or the ability to have an erection, and orgasm will remain unchanged. Most of us need to express our sexuality and show our feelings towards those we love. Armed with a desire to maintain your loving relationship and a sense of humour, you can experiment and explore new positions that are comfortable for you both. Talk to each other about any difficulties, and don't be afraid to ask your Doctor, Nurse or Therapist for advice. We all know that sex is a normal function of any loving relationship. Sex itself may become less of an issue for some couples, but do continue to show your love in other ways. Even if sex is not on the agenda, you can still cuddle and kiss. Touch is very important to most people, but so is a kind word or a loving look.



Clothing/Dressing

Comfortable, easy-fitting clothes are the ideal combination for everyone. Many people with MND spend a good deal of time sitting and so styles of clothes should be chosen with this in mind. Changing the fastenings can also make clothes easier to manage - an important consideration as dressing and undressing can become tiring. In addition, many feel the cold acutely (particularly in the hands and feet) while others can suddenly feel incredibly hot.

Keeping cool

- Choose light-fitting garments
- Wear a cardigan/waistcoat - something that is easily removable - over a cotton shirt/blouse
- Wear something cotton-rich at night
- Choose your fabric - cotton or cotton-rich mixtures are the best. Avoid nylon and polyester

Outdoors

It is wind chill that can really make you feel the cold. The best plan is to start out warm and cover up well, including your head. Again, layers of lightweight clothes will provide the best insulation. Ski shops are a good source of lightweight but warm trousers and quilted windproof jackets as well as long-sleeved vests and long johns. For hands, try sheepskin, fur-lined or quilted mitts.

Keeping warm

- At home, sitting in a quilted bag is better than a blanket which can slip
- Layers of loose-fitting lightweight clothing make the best insulation
- Insulate the whole body to keep hands and feet warm
- Start off warm - warm your clothes before putting them on
- Know your fabric - quilted fabrics, wool or acrylic materials trap air

For wheelchair users, the range of special shower proof capes and sitting bags give the best protection against the cold.

Potential Difficulties	Possible Solutions
Tops	<ul style="list-style-type: none"> • A good choice is tops which can be worn outside skirts/trousers • Large neck openings/easy-fitting sleeves make dressing easier • Look for casual styles in men's shirts which stretch more easily
Skirts and dresses	<ul style="list-style-type: none"> • Choose a skirt long-enough to allow you to cover the knees when sitting • Those with elasticated waists are easier to put on and 'give' when sitting • Full skirts of light-weight material are comfortable to sit in and easy to lift out of the way when using the toilet • A front wrap-over or button-through style may suit wheelchair users best • Velcro can prove a good replacement for awkward fastenings on a skirt
Trousers	<ul style="list-style-type: none"> • Hooking a key-ring through the eye of a zip makes it easier to pull up and down • Narrow leg trousers can make dressing difficult • Many people find track suits comfortable and practical • Trousers with an elasticated waistband may be the easiest to manage • A button-through night shirt can replace pyjama trousers • If movement in bed is difficult, fabrics such as satin or polyester can help
Underwear	<ul style="list-style-type: none"> • Cotton underwear is the most comfortable and cooler in hot weather • Boxer shorts and slip briefs are easier to manage than Y-fronts • French Knickers are a good idea - if the leg is wide enough, the crotch can be pulled to one side to use the toilet
Footwear	<ul style="list-style-type: none"> • Slip-on shoes are easy and practical • Many shoe and slipper styles now have Velcro fastenings • Slipper socks are warm for people who are not walking • Wide shoes and those with very long openings are also useful
Fastenings	<ul style="list-style-type: none"> • Buttons can be replaced by small squares of Velcro - sewing a button back on top of the buttonhole will restore the normal appearance • Mantle hooks and toggles are very useful on outdoor clothing • Popper sets are available for attaching poppers neatly to clothing • Velcro is good for replacing other fastenings • Remember to close the Velcro fastening before washing

Dressing Aids

Your Occupational Therapist will be able to offer more advice on alternative ways of getting clothes on and off if needed. There are a number of simple aids available by mail order including such items as elastic shoelaces and other aids for putting on shoes and stockings.

Oral Hygiene

Oral hygiene is an important part of general health. It contributes to a feeling of well-being and confidence and may help with eating and speaking well. General fatigue and a weak grip can cause problems. Your dentists will be able to offer specialist advice, but here are a few tips:

Tips on Oral Hygiene

- Use an electric toothbrush
- Make the toothbrush handle thicker by pushing it into sponge tubing
- Swab the mouth with a solution of bicarbonate of soda and water (half a teaspoon to a glass of water) using a cotton bud
- Clean dentures over a basin of water to avoid breaking if dropped
- Clean dentures with a nailbrush attached to suction cups
- Using an artificial saliva spray can help ease a persistently dry mouth

→ See 'Eating and Drinking' section for further information

Grooming

How you look and feel about yourself can add to your feeling of health and well-being. It is worth the effort, looking good can help you feel good about yourself.

Potential Difficulties	Possible Solutions
Nail care	<ul style="list-style-type: none">• It is best to keep toe and fingernails short• Extra length nail clippers and scissors with easy grip handles are available• See a Chiropodist if necessary
Shaving	<ul style="list-style-type: none">• Electric razors are usually easier to grip. If someone is helping, there are fewer casualties.• How you look is important to you, so consider using a mobile beautician to assist with eyebrow/nose/ear plucking or other depilation.
Hair and beauty	<ul style="list-style-type: none">• Use a long handled comb or hairbrush if your grip is weak• Inflatable hair washing trays can be used whilst in bed• Fit a loop to the back of a brush for easier grip• Ask a mobile beautician or close friend to teach your partner how to apply your makeup and skin care products

Eating and Drinking

Some people with MND develop symptoms that affect their ability to eat and drink. In this case, the Speech & Language Therapist will be able to give advice on particular difficulties → see 'Eating and Drinking' section for further information. However, weakness in the arms and grip can also make eating a very tiring activity.

So do talk to your Occupational Therapist for further advice on the following suggestions:

- Try to sit upright in a well-supported position
- Supporting forearms on a high(er) table reduces the need to bend your head over the plate
- For one-handed use, try using cutlery that combines a knife, fork and spoon in one item
- Choose lightweight cutlery with large, angled or swivelling grips
- “Dycem” mats stop plates from sliding on the table surface
- Keep food warm on an insulated hollow plate that is filled with hot water
- Try using lightweight plastic cups with large or two handles
- If lifting cups is a problem, a straw is a good alternative
- A ‘Pat Saunders’ straw has a non-return valve making sucking easier

Comfort

People who have lost weight and are less active need to think about avoiding pressure sores

→ see ‘Symptoms’ section for further information.

These happen when the blood supply is cut off from the underlying skin, fat and muscle and can be caused by sitting or lying for long periods in one position. Your MND Nurse or Public Health Nurse is able to provide expert advice, but in the meantime:

- Ensure that skin is clean and dry
- Change position frequently
- Put a spare blanket or underblanket between the mattress and sheet

→ For more information on beds and chairs, see ‘Movement and Mobility’ section.

Around the house

For people who have a reduced grip

- Don’t carry/lift heavy things, perhaps use a household trolley
- To spread the load, use both hands
- Use lightweight equipment and appliances
- Use devices with improved hand grips, e.g. key turners or enlarged handles (available by mail order)
- Use devices to help open jars/cans/bottles (available by mail order)
- Think about using labour-saving devices wherever possible

Cooking

There is a range of labour-saving gadgets around but check how easy they are to operate before buying. Lightweight bowls and utensils are on the whole easier to manage, and if you haven’t yet considered a microwave oven, now might be the time. Specialist mail order companies (information on suppliers is available from the IMNDA or your Occupational therapist) produce a number of items for specific problems, for example:

- A variety of jar openers
- Clamps or non-slip “Dycem” material to stabilise things
- Peelers and graters
- Boards to help with buttering bread
- Kettle tippers

Alternative knobs for cookers can be obtained from manufacturers of electric and gas cookers.

Potential Difficulties	Possible Solutions
Carrying things	Apron with big pockets a bag slung diagonally over the shoulder a freehand tray (carried in one hand) trolleys
Electrical Fittings	Rocker or touch pad switches plugs with plastic loop handles use extensions to bring sockets up to a convenient height
Door Knobs and Locks	A multi-purpose knob turner a plastic “enlarger” to fit over knobs on Yale locks enlarged key grips

Telephones

A number of relevant features to consider are:

- Hands free operation (a built in microphone and loudspeaker allows you to talk without lifting the handset)
- Memory - which allows you to store frequently used phone numbers. They can be dialled automatically by pressing just one button
- Mobile phones - now small and lightweight and with the useful text facility for those with speech difficulties
- Answering machines - good value if it takes time to get to the phone or if there are speech problems

Alarms

Some people need to be able to alert others in the house. In this case, special beepers are available or intercoms which can be plugged into 13 amp sockets (an Occupational Therapist or Technical Advisor can advise on these). You could simply use something that can be homemade, such as a doorbell wired to a light-touch switch or pressure pad if it is difficult to work an ordinary button control.

For when you are alone, telephone systems can be activated by a small alarm button worn around the neck or on a wrist band. The system would automatically contact emergency services/family/friends (ask your Occupational Therapist or the IMNDA for details).

Environmental Controls

These enable people to control electrical devices (TV, lights etc) at the touch of a switch. A huge range of switches are available and can be modified to your needs. The IMNDA can refer you to an assistive technology advisor who will assess your individual requirements.

Plug-in timers can be used to control heaters and other appliances or switch on lights at set times.

→ **Telephones, alarms and environmental controls are also covered in the ‘Speech and Communications’ section.**

