



7: Everyday activities and personal care

This section will help you find ways to prolong independence with daily tasks.

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**

7: Everyday activities and personal care

This section will help you find ways to prolong independence with daily tasks.

Muscle weakness and fatigue can make tasks more difficult. You may be reluctant to use assistive equipment at first, but it can help you and your carers save energy for things you really want to do.

If you tire easily:

- plan, pace and prioritise tasks – what can be done less, or not at all?
- carry out tasks while sitting and take rests
- keep important items to hand
- use labour-saving gadgets
- adjust posture and positioning, and stop if an activity causes pain
- consider relaxation and mindfulness techniques, as advised by your health and social care team
- think about your future care needs and plan ahead.

“ We had no idea what MND is, what to expect or what equipment may help.”

Where to go for help and advice on equipment and aids

Assistive equipment may not always suit your needs and mistakes can be costly. Some equipment is also available through statutory services (provided free or on loan by health or social care services).



Ask your GP or health and social care team for referral to the following professionals as appropriate. They can help assess your equipment needs.

See also Section 10: Finance, work and social care.

“ At first I didn’t think I needed help and advice, but I learned that professionals have lots of hints and tips that are really useful.”

Occupational therapists (OTs) advise on assistive equipment, alternative ways of doing tasks and Disabled Facilities Grants (DFGs) for home adaptations (where you qualify for funding).

Physiotherapists advise on appropriate exercise, posture, balance and ways to help you to move about. In some areas, community physiotherapists make home visits. A neuro physiotherapist has experience of working with neurological conditions.

Community or district nurses provide nursing care, advice about equipment in your own home and communicate with your doctor or consultant.

Specialist suppliers offer product demonstrations. Some may do home visits or have showrooms where you can try out equipment. However, there may be pressure to buy certain products, so ask an occupational therapist first – they can assess your needs and home, then advise on your current and likely future needs.

Contact your local adult social care services for advice about equipment provision in your area. They can direct you to the nearest independent Disabled Living Centre to try out products and speak to trained advisers. They will also have lists of services and suppliers.

If an item is not supplied by social services or the NHS, you can source products through specialist suppliers, mail order, the internet or various general stores.

“ Our occupational therapist has been excellent, providing a good and timely service. However, for professional reasons she can only advise, not necessarily recommend things.”

See Section 2: *Managing symptoms* for more about the professionals that can help you.

Bathing and showering

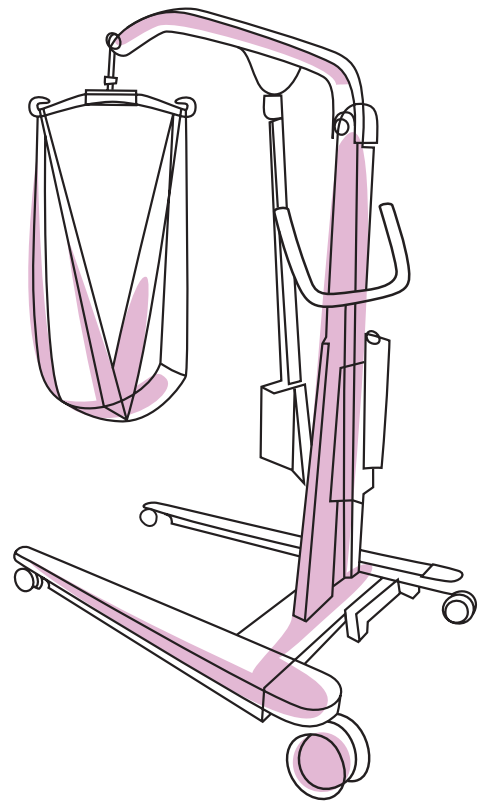
If you decide to adapt your bathroom or buy new equipment, ask your occupational therapist for guidance. The following may help your discussions.

I feel at risk getting in and out of the bath, or need help:

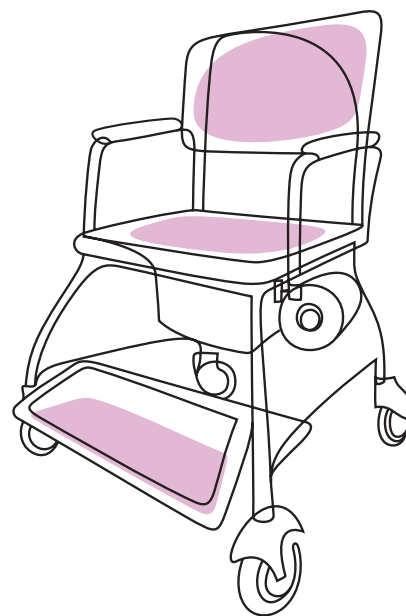
For safety, try non-slip mats and grab rails. A bath seat or bath board can help with transfer (some bath seats are powered). If you need more help, think about a mobile or ceiling track hoist - some are powered.

I find it difficult to stand under the shower:

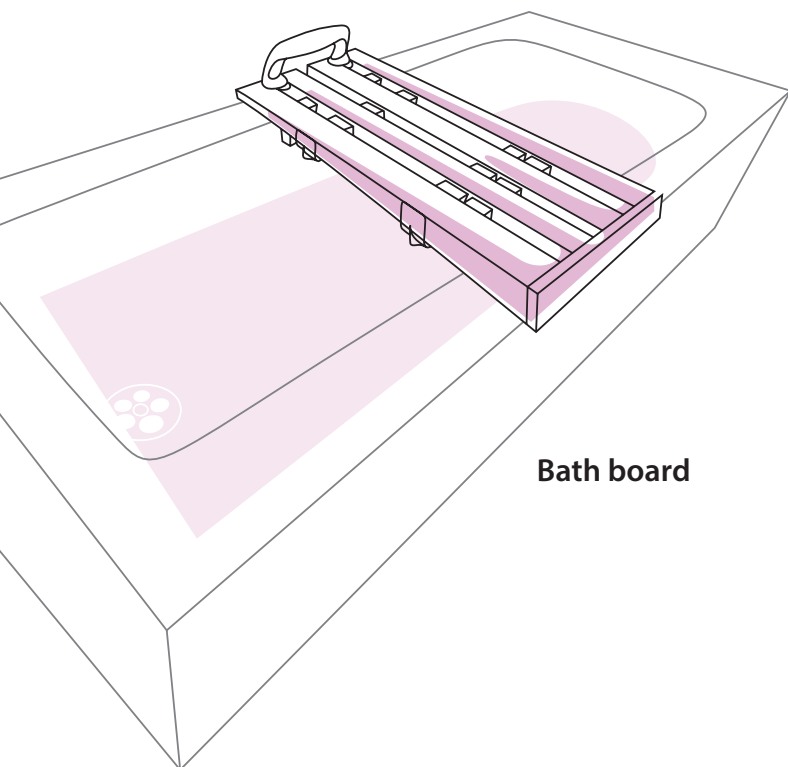
Showering usually requires less effort than a bath. If you find it difficult to stand you can use slatted bath boards and grab rails for over-bath showers. In shower cubicles, grab rails, wall-fixed seats and shower stools can help. For level access showers, use a wheeled shower chair.



Mobile hoist



Wheeled shower chair



Bath board

I have difficulty directing 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 also be washed in this way. Long-handled sponges can help you reach your back and feet.

I have difficulty gripping:

Fit tap turners and use soap on a rope or a hanging soap dispenser. A flannel mitt may be better than using a hand held flannel or sponge.

I get tired standing at the sink:

A perching stool with a forward tilting seat helps to provide good positioning for arm function and reduces the energy needed for standing.

Getting dry is so tiring:

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).

Using the toilet

MND does not usually affect the bladder, but problems with mobility can make it difficult to get to the toilet. Equipment to access your toilet is generally regarded as essential by health authorities, so ask an occupational therapist for advice. There may be help available. Some items, such as commodes, may be available through a community nurse.

I feel at risk getting on and off the toilet:

A raised toilet seat, toilet surround and grab rails give support. Wheeled shower chairs often fit across washer dryer toilets to help. A ceiling track may be required with a hoist, as some adapted toilets can be too high for mobile hoists.

I worry about getting to the toilet in time or at night:

A commode provides a portable toilet unit. If you have problems with mobility in and out of bed, incontinence pads, urine bottles (men) and urine pans (women) may help ease anxiety. Some people with MND choose to have a catheter fitted, to collect urine in a bag – this will need discussion with your doctor.

“ We may not generally need incontinence pads, but if you can't access a toilet for a long time, it's better to be safe than sorry.”

I worry about personal hygiene:

A 'bottom wiper' with a long looped handle and paper grip can help. Portable bidets, or wash and dry toilets, can fit into a standard toilet. A full replacement washer-dryer toilet can also be fitted. These powered toilet options can help prolong independence, with spray washers and a warm air dryer that you operate with hand or foot switches.

What do I do when away from home or if I use a wheelchair?

Incontinence pads can remove anxiety when travelling. Portable urine bottles (men) or urine pans (women) can be discreetly carried. Various other portable devices are available to assist. You can also gain entry to thousands of accessible public toilets using a RADAR key, which is available to disabled people.

See Disability Rights UK, as listed in *Further information* at the end of this section, for more about RADAR keys.

“ Some accessible toilets are locked (we found this happens at motorway service stations) so make sure you have a Radar key to unlock them.”

I have difficulty adjusting my clothes to use the toilet:

Attach a tab or key ring to fly zippers, wear loose clothing and underwear that can be pulled to one side. Adapted clothing is available through specialist suppliers.

I find it difficult to manage when I have my period:

Self adhesive pads and adapted applicators are available from chemists if you have a weak grip. If menstruation is difficult to manage, ask your doctor about contraceptives to stop periods. A coil or implant may be helpful if you cannot swallow pills.

It is possible to have a chemically induced menopause, but discuss the possible impact of this with your doctor.

Clothing and getting ready

If your grip is affected, it can be difficult and tiring getting in and out of clothes. You may also need to think about comfort and temperature control if sitting for long periods. Many people with MND find creative solutions with clothing.

“ A friend with MND struggles with buttons and zips due to impaired hand function. He started to wear a kilt to make visits to the toilet easier.”

It can be helpful to:

- adapt fastenings, eg with velcro, larger zip pulls, elastic waistbands or replace shoelaces with elastic ones
- use dressing aids like button hooks
- try different materials for temperature control (cotton or cottonrich is helpful), and wear loose layers to trap heat or remove if hot
- warm your clothes before putting them on and cover up well if out in the cold, including your head
- use a cape, poncho or wrap rather than a coat or jacket with sleeves
- sit in a quilted bag for warmth, rather than a blanket which can slip, and use special shower-proof capes or sitting bags if outside in a wheelchair.

Clothing is also about self expression and style may be important to you. With MND, you may spend a lot of time sitting, so think about:

- how people may focus more on the upper part of your body
- clothes riding up when sitting, which may affect the length you choose.

See our list of *Further information* at the end of this section.

If you need adapted footwear or orthotics (supports for your feet and ankles), ask your GP for referral to a specialist in this area – usually a podiatrist or chiropodist.

Mouth care

Mouth care is an important part of general health, but fatigue, weak grip and swallowing difficulties may cause problems.

“ My bad gagging reflex can cause problems, but my dentist at the dental hospital was very patient and gave me relaxation techniques to help control it.”

It may help to:

- use an electric toothbrush
- make the toothbrush handle thicker by pushing it into sponge tubing
- rinse the mouth with a fluoride mouthwash
- use a non-foaming toothpaste if normal toothpaste makes you cough
- scrub dentures against a nailbrush attached to a surface by suction cups, and over a basin of water if worried about dropping them
- use an artificial saliva spray to ease a persistently dry mouth
- try a soft baby toothbrush for tongue care.

See our list of *Further information* at the end of this section.

“ One of the best tips is buying an electric toothbrush, to help while you can still use it, but also to help your carer to clean your teeth.”

Personal appearance

How you look and feel can improve your sense of wellbeing. Many hairdressers and beauty therapists offer a mobile service and home visits, and some palliative and hospice services too. Equipment can help on a daily basis, such as a mobile arm support, but these can be expensive. An occupational therapist can advise and help you avoid costly mistakes.

I find it harder to take care of my nails:

Try extra length nail clippers and gadgets with easy grip handles. If you need support, a manicurist can assist. If you enjoy wearing nail varnish, they can apply gel polish which lasts for several weeks. See a chiropodist or podiatrist for support with your feet if necessary.

I'm worried about shaving:

Electric razors are usually easier to grip and safer for someone else to use if you need support with this. Beauty therapists can help with shaving and depilation, including for eyebrows, nose and ear.

I find it difficult to wash, brush or comb my hair:

Inflatable hair washing trays can be used while you lay on a bed. No-rinse shampoo can extend time between washes. If holding a hairdryer is difficult, try a hairdrying stand. If you have a weak grip, use a long-handled comb or hairbrush, or fit a loop to the back of a brush for easier hold.

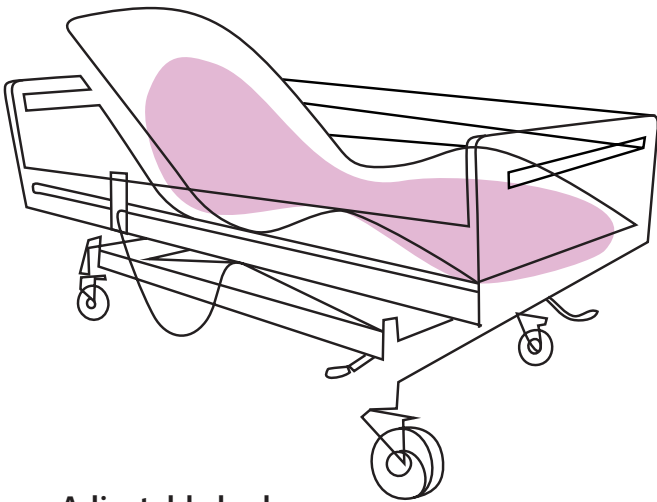
I find it difficult to apply make-up:

Try different approaches at first. For example, if you have weak shoulders and arms, place your elbow on a pressure pad and use the other hand to support your wrist. If you need more support, your partner may be able to help. If new for them, they could ask a beauty therapist or friend to show them how to apply make-up and skin care.

Comfort

If you are less active you may need to think about:

- how to keep skin clean and dry
- assisted exercise to increase flexibility, following assessment with a physiotherapist
- getting into a comfortable position and changing this frequently
- using a riser recliner chair or a powered adjustable bed (where your back or legs can be raised)
- using extra cushioning, pressure relief cushions, and an underblanket or duvet between your mattress and bed sheet.



Adjustable bed

Ask your occupational therapist or community nurse about seating and beds, as you need the right measurements for comfort. Some items may be available through statutory services (through healthcare or social care), which means you have a right to access them if you qualify.

“ Getting the bed right is important for everyone involved. Too wide, high or low causes difficulties for carers. Too narrow or high creates more risk of falls if you have MND.”

Around the house

If you have a reduced grip, doing things at home can become difficult. Ask an occupational therapist to assess your needs and likely future needs. They can advise on equipment that will suit.

“ I get very frustrated not being able to do things for myself. In my head I can do it, but I find it hard when I try, even though I used to be a very energetic.”

Wherever possible try to:

- fit improved hand grips or enlarged handles
- use labour-saving devices, such as gadgets to open jars, cans and bottles, plastic levers on taps, key grips for opening locks and plastic enlargers to fit over some locks
- avoid lifting heavy objects or slide items along surfaces, where safe to do so
- use equipment such as a rollator (a wheeled walking frame) which has a carrying shelf.



Rollator, or wheeled walking frame

Environmental controls can be installed to operate electrical devices, such as the television, lights and powered curtains or doors. Ask your occupational therapist for guidance. Adapted switches and remote controls can be operated from where you are sitting or lying, by different parts of your body.

Voice activated support is available from household virtual assistants, with systems such as Siri, Google Assistant, Alexa or Cortana.

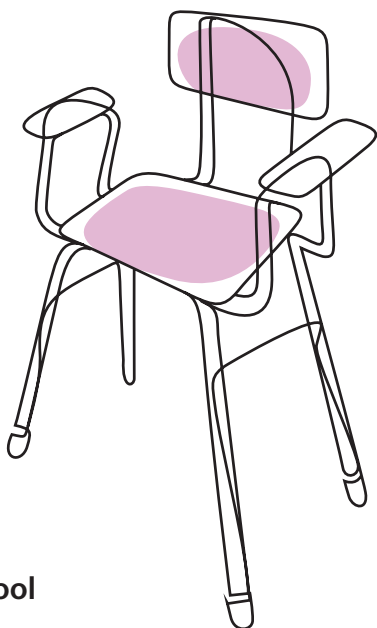
Simple plug-in timers can also be used to control heaters, appliances or lighting.

Pendant and wrist alarms connect you to emergency support and telecare through telephone systems. Home communication devices, simple baby alarms or doorbells can alert someone in a different room that you need help.

See Section 8: *Speech and communication for more on communication systems and alarms.*

Cooking

Labour-saving kitchen gadgets are available through shops, mail order or the internet, but check how easy they are to use before buying. Adapted aids can also be sourced through specialist suppliers, but talk to your occupational therapist to discuss what will be suitable.



Perching stool

I get very tired trying to cook:

A microwave oven can be useful for heating pre-prepared food to save time and effort. It can help to have meals cooked in batches and frozen, so you have a selection readily available. When preparing food, use a perching stool for support. Over time, you may need someone to help prepare food and drink.

I worry about carrying items in the kitchen:

Try an apron with big pockets or a bag slung diagonally over the shoulder to access small items. A rollator or walking frame with a carrying tray may help. Avoid using heavy pans.

I find it difficult to use electrical fittings:

Rocker or touch pad switches can be fitted, which can be operated by muscle movement, as with the head, knee or foot. Plugs with plastic loop handles are easier to push and pull. Plug sockets can also be moved to a convenient height or use an extension cable where safe to do so.

I find it difficult to open cupboard doors and drawers:

Use a multi-purpose knob turner, which can usually operate taps too, or open jars and bottles. Adhesive velcro loops can also be attached to cupboard doors.

I have difficulties eating and drinking:

We provide detailed information on eating, drinking and tube feeding.

See Section 9: *Eating and drinking or Further information at the end of this section.*

How do I get my care needs assessed?

You may not need help immediately, but find out how to get this so you're prepared when symptoms progress. Contact your local authority about a needs assessment in England and Wales, or your local health and social care trust in Northern Ireland.

You have the right to a needs assessment with MND and your carer has the right to a carer's assessment. Assessment is usually carried out by adult social care services and may lead to a care plan with agreed services and support.

Assessment provides an opportunity to get advice and information. This will help you feel better prepared, by exploring possible needs for personal care, respite care and emergency care support (should your carer be unable to support at any point).



“ Do everything possible to save on effort for the person with MND and the carer.”

At your assessment, give as much detail as you can, to gain appropriate support in return. With MND, ability can vary daily, including levels of tiredness. Explain the support you need on a bad day. It helps to keep a diary leading up to assessment, to track when you need help and how long it takes. This can also show how symptoms progress, so future needs can be considered.

A financial assessment works out if you need to pay towards agreed services, and how much you will receive. Services can be arranged, or you can receive direct payments to choose services yourself. With direct payments, you need to keep financial records.

See Section 10: *Finance, work and social care* for more about needs assessment and *Further information* at the end of this section.

Urgent or emergency care cover

If your carer is unable to provide support for any reason, contact your local adult social care services department. A limited out-of-hours Emergency Duty Team (EDT) may be able to arrange assistance, including bank holidays and weekends. It is worth keeping contact details for your local EDT to hand.

If you are in touch with one of our Association visitors, they may know about local care support, or contact our helpline MND Connect.

See Section 11: *Planning ahead for advance care planning and resources*.

NHS continuing healthcare (CHC)

If your health needs become complex, ask your GP about NHS continuing healthcare (CHC). If you meet the criteria at assessment, the NHS will fully fund all your care needs, including personal care. This is a complicated application process, involving members of your health and social care team. Before applying, explore carefully to get the best outcome. We provide detailed information on this subject.

There are no guidelines for NHS continuing healthcare in Northern Ireland. If you are resident there and need increased support, please contact your local health and social care trust.

Key points

- Before buying equipment and aids, seek assessment from an occupational therapist. Items can be costly and may not suit your changing needs, or your home.
- Discuss the way you do things when being assessed, as your occupational therapist may have lots of tips. Knowing how to adapt can prolong independence.
- Homemade solutions can be very effective, but check their safety with your occupational therapist.
- Your needs will change with MND – if a gadget or aid doesn't feel necessary at first, it may be worth trying again at a later date.
- If you have care workers coming into your home, let them know how best to help – for example, by using different colour towels for face and body. You can also use our *Understanding my needs* booklet to write down your preferences, so they have guidance.

“ It’s very important to think properly before buying lots of things.”

Further information:

From our range of information sheets:

1A: *NICE guideline on motor neurone disease*

6A: *Physiotherapy*

6C: *Managing pain*

10A to 10G:

Our range of sheets on benefits, social care and NHS continuing healthcare

11A: *Clothing*

11B: *Mouth care*

11C: *Equipment and wheelchairs*

11D: *Managing fatigue*

12A: *Driving*

12B: *Choosing the right vehicle*

12C: *Travel and transport*

From our guides and other publications:

Making the most of life with MND: a booklet about how to maintain interests and adapt.

MND Checklist: a questionnaire that helps you think about your condition and how to plan and prepare for your care needs.

Understanding my needs: a booklet in which you record your needs and preferences to guide all those involved in your care.

Caring and MND: support for you: a comprehensive guide focused on the wellbeing of family and unpaid carers.

Caring and MND: quick guide: a booklet to help someone new to the caring role.

Telling people about MND: our guide to help open conversations about the disease with family, children, friends, colleagues and professionals.

Information to pass to your health or social care professionals:

P1: Head supports

P11: Pain in MND

*Caring for a person with MND –
a guide for care workers*

*Occupational therapy for motor
neurone disease*

*Motor neurone disease for dental
professionals*

*Supporting children and young people close
to someone with MND*

Download our publications at:

www.mndassociation.org/publications

Or order them from **MND Connect**, our
support and information helpline:

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Email: **mndconnect@mndassociation.org**.

MND Connect can also help you find external services and providers, and introduce you to our services, where available in your area, including your local branch, group, Association visitor or regional care staff contact.

See Section 12: How we can help you.

Online forum:

A safe place to share information and support with others affected by MND at:

<https://forum.mndassociation.org>

Age UK:

You can ask their incontinence advisers about suitability of different toilet access products.

Telephone: **0800 849 8032**

Disability Rights UK:

For guidance and support when living with disability. They enable purchase of RADAR keys to gain entry to accessible public toilet facilities across the UK.

Telephone: **0203 687 0790**

or see website at: **<http://bit.ly/radar-key>**

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**This resource has been evidenced,
user tested and reviewed by experts.**

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

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