



7: Everyday activities and personal care

This section will help you find ways to prolong independence with everyday activities and personal care.

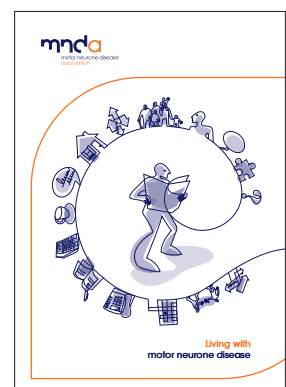
The following information is an extracted section from our full guide *Living with motor neurone disease*.

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 everyday activities and personal care.

Muscle weakness and fatigue can make everyday tasks difficult. At first, you may feel reluctant to change the way you manage routine activities or to use equipment or aids to assist. Yet this type of support can help you and those close to you to save energy for the things you really want to do.

If you tire easily

- prioritise your tasks – what can be done less or not at all?
- plan your week and pace yourself and any activities
- carry out tasks while sitting and take frequent rests
- organise your home so that important items are to hand
- use labour-saving gadgets
- think about your posture and positioning and if an activity causes you pain, stop doing the task
- consider your future care needs and plan ahead.

Where to go for help and advice on equipment and aids

There are many ways of adapting everyday tasks to maximise independence, including the use of equipment and aids.

However, before buying equipment always seek advice from an expert. Not all aids are suitable for every individual and mistakes can be costly. You may even be able to obtain equipment on loan or through statutory services (those provided free by health or social care services).

See Section 12: How statutory services can help you.

Relevant professionals can help to assess your needs:

Occupational therapists (OTs) for advice on assistive equipment, alternative ways of doing tasks and the possibility of a Disabled Facilities Grant (DFG) for adapting your home. You can contact OTs through social services, your health and social care team or your local hospital.

“ We have a good occupational therapist and physiotherapist who organise the equipment required and a good palliative care team who look after our needs.”

Physiotherapists for advice on appropriate exercise, posture, balance and ways to help you to move about. Your doctor can arrange a referral. In some areas, community physiotherapists make home visits.

Community/district nurses for nursing care, advice about equipment in your own home and liaison with your doctor or consultant. They can be contacted through your doctor’s surgery.

Specialist suppliers for product demonstrations, although there is a risk of commercial bias. Some have showrooms where you can try a range of equipment and some may visit your home with selected items. See an occupational therapist first, for advice on what will suit your home and current/future needs.

“ I think the most important thing is where to get advice and to try to meet other people with MND.”

Contact your local adult social care services for advice about provision in your area. They can direct you to the nearest independent Disabled Living Centre to try out equipment 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.

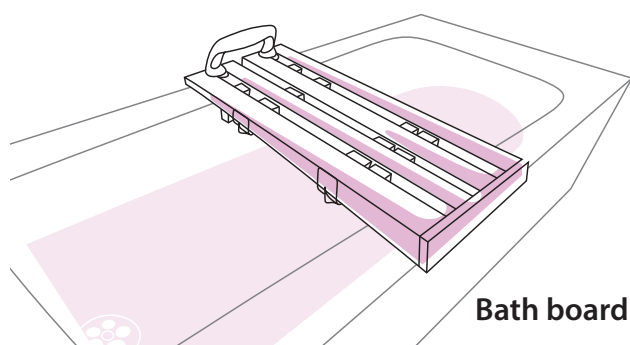
See Further information at the end of this section and Section 14: How we can help you for details about MND Association support services including local branch and group support meetings.

Bathing and showering

Bathing and showering may begin to feel tiring, although showering usually requires less effort. If you decide to install a new shower, consider a level access unit (without a shower tray) for ease of access. Your occupational therapist can advise about what will work in your bathroom.

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

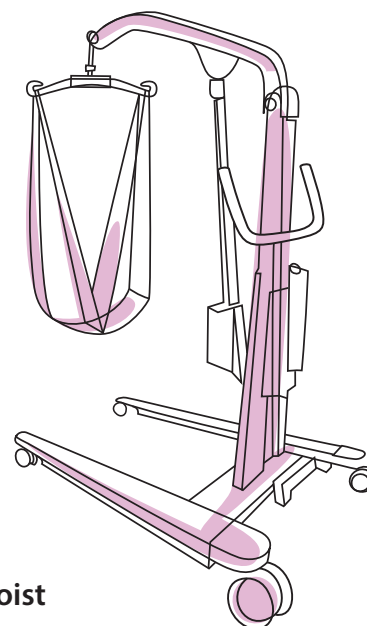
Non-slip mats and grab rails can help increase safety. Bath boards can be fitted across the bath for transfer. A bath seat can help you transfer in and out and some bath seats are powered.



Bath board

I am unable to get in and out of the bath:

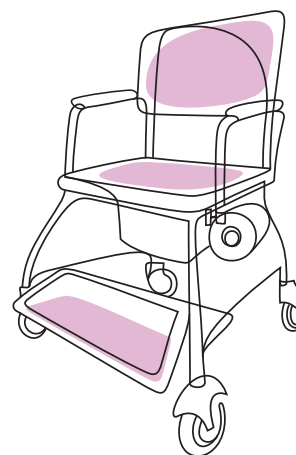
A mechanical or powered hoist or a level access shower facility can help.



Mobile hoist

I find it difficult to stand under the shower:

For over-bath showers, you can use slatted bath boards and grab rails for support. In shower cubicles, grab rails, wall-fixed seats and shower stools are helpful. For level access showers, use a wheeled shower chair.



Wheeled shower chair

I have difficulty directing the spray with 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 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

Equipment to access the toilet is generally regarded as essential by health authorities, so ask about available provision. An occupational therapist can advise, but some items such as commodes may be available through a district nurse.

I feel at risk getting on and off the toilet:

Try a raised toilet seat, toilet surround and grab rails to support you. Wheeled shower chairs are often designed to fit across washer dryer toilets offering dual purpose assistance. If you need to use a hoist, some adapted toilets can be too high for mobile hoists and a ceiling track may be required.

I worry about getting to the toilet at night:

A bedside commode provides a portable unit for close access.

I worry about personal hygiene:

A 'bottom wiper' with a long looped handle and paper grip may help and portable bidets can fit into a toilet. A powered washer/dryer toilet unit can be connected to your electric/water supplies, which enables a spray washer and warm air dryer to be operated by hand or foot switches.

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

Portable urine bottles (men) or urine pans (women) can be discreetly carried. Various other portable devices are available to assist.

I have difficulty adjusting my clothes to use the toilet:

Attach a tab or key ring to fly zippers. French knickers are loose around the leg and can be pulled to one side, or try adapted underwear.

*See **Clothing and dressing** and **Further information** later in this section.*

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 becomes very difficult to manage, ask your doctor about using contraceptives to stop periods. It is also possible to have a chemically induced menopause, but this needs discussion with your doctor to understand the possible impact of this treatment.

Clothing and dressing

With MND, getting dressed and undressed can be tiring, or difficult if your grip is affected. You may also need to think about comfort and temperature control. It can be helpful to:

- adapt fastenings to make them easier to manage, eg using velcro, larger zip pulls or elastic shoelaces
- use dressing aids like button hooks for assistance

- try different types of material for temperature control (cotton and cotton-rich fabric is usually best)
- wear loose fitting layers to help trap heat (remove layers if hot)
- start out feeling warm, if going outside in the cold, (warm your clothes before putting them on) and cover up well, including your head
- sit in a quilted bag for warmth, rather than a blanket which can slip. For wheelchair users, special shower-proof capes and sitting bags can protect against the cold.

For many people, clothing is not just a matter of comfort and ease, but something that enables you to present yourself in the way you wish. With MND you may spend a good deal of time sitting, which may be worth considering when thinking about style.

For example:

- visual impact may be more focused on the upper part of your body
- hemlines of trousers and skirts may become an important factor as clothes can ride up when sitting.

For an information sheet on clothing, see *Further information* later in this section.

Mouth care

Mouth care is an important part of general health, but fatigue and a weak grip may cause problems. Your dentist can advise, but it may help to:

- use an electric toothbrush if these feel comfortable
- make the toothbrush handle thicker by pushing it into sponge tubing
- rinse the mouth with a fluoride mouthwash (or swab the mouth with a lint free cloth soaked in the mouthwash)
- clean dentures over a basin of water to avoid breaking if dropped and try scrubbing them against a nailbrush attached to a surface using suction cups
- use an artificial saliva spray to ease a persistently dry mouth.

For an information sheet on mouth care, see *Further information* later in this section.

Personal appearance

How you look and feel about yourself can add to your sense of well-being. Many hairdressers and beauty therapists will visit you at home, but specialist equipment can help on a daily basis. As many tasks require you to raise your arms, a mobile arm support may be worth considering, but these can be expensive if purchased privately. An occupational therapist can advise on suitable solutions and help you avoid costly mistakes.

How can I take care of my nails more easily:

See a chiropodist or podiatrist for help with your feet if necessary. Extra length nail clippers and scissors with easy grip handles may help.

I'm worried about shaving:

Electric razors are usually easier to grip and safer for someone else to use if you need additional help. 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. If you have a weak grip, a long-handled comb or hairbrush may help or fit a loop to the back of a brush for easier hold. If holding a hairdryer is difficult, try a hairdrying stand.

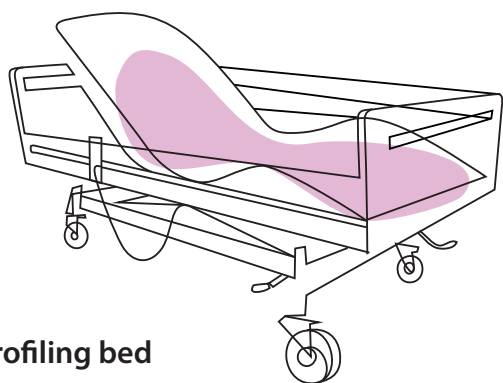
I find it difficult to apply make-up:

Supporting your dominant elbow on a pressure pad, and using the other hand to support your wrist, may help initially with applying make-up if your shoulders are weaker. If you find it particularly difficult or have a weak grip, a beauty therapist or close friend may be able to teach your partner how to apply your make-up and skin care products.

Comfort

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

- positioning yourself with care and changing position frequently
- ensuring skin is kept clean and dry
- asking your physiotherapist about assisted exercise to maximise flexibility
- exploring helpful options for seating, such as riser recliner chairs
- exploring helpful options for sleeping, such as profiling beds (where your back or legs can be elevated).



Profiling bed

Ask your occupational therapist and district nurse about adapted seating and beds. Some items may be available through statutory services, but it is really important to get the measurements right to maintain comfort.

See Section 12: How statutory services can help you.

Good positioning can help with pain relief, so take your time when settling into a chair or bed for long periods. Extra cushioning can also be helpful, such as an underblanket or duvet between the mattress and sheet.

“ I have my own single profiling bed and my wife has a standard single bed that we can push together or apart. Now I don't disturb her by adjusting position throughout the night.”

Around the house

If you have a reduced grip, general activities around the home can become difficult.

Wherever possible try to:

- avoid lifting heavy objects and slide items along surfaces where safe and possible to do so
- use both hands if you do need to carry items
- if carrying items is particularly difficult, rollators (wheeled walking frames) often have a carrying shelf, or you can use a household trolley if safe to do so



Rollator, or wheeled walking frame

- use lightweight equipment and appliances with improved hand grips or enlarged handles
- use labour-saving devices wherever possible, such as gadgets to help open jars, cans and bottles, or plastic levers on butterfly type taps. Enlarged key grips make opening locks easier and a plastic enlarger can be fitted over Yale locks.

You may find it useful to have environmental controls installed, which enable you to control electrical devices (such as the television, lights and powered curtains) with adapted switches. These switches can be accessed from where you are sitting or lying and are operated through muscle movement suited to your needs, such as the head, knee or foot. Talk to your occupational therapist for guidance. Many systems can now be operated by wireless technology, so you can access them from your laptop, tablet or smartphone.

Plug-in timers can also be used to control heaters, appliances or lighting at set times.

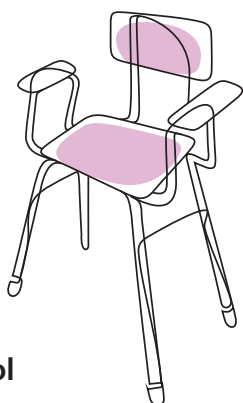
For information on telephones, communication systems and alarms, please see Section 8: *Speech and communication*.

Cooking

A wide range of labour-saving kitchen gadgets are available from general stores, mail order or the internet, but check how easy they are to operate before buying. Adapted aids can be sourced through specialist suppliers, but talk to your occupational therapist to discuss what will be suitable.

I get very tired trying to cook:

A microwave oven can be useful for heating pre-prepared food to save time and effort. When preparing food, use a perching stool for support.



Perching stool

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 freehand tray (carried in one hand) or a kitchen trolley may help. Avoid using heavy utensils if possible.

I find it difficult to use electrical fittings:

Rocker or touch pad switches can be fitted, which can be accessed through muscle movement to suit your needs, such as the head, knee or foot. Plugs with plastic loop handles are easier to push in and pull out. Plug sockets can be moved to a convenient height or use an extension.

I find it difficult to open cupboard doors and drawers:

Use a multi-purpose knob turner (these can usually be used to operate taps and open jars or bottles too), or try adhesive velcro loops attached to cupboard doors.

I have difficulties eating and drinking:

See Section 9: *Eating and drinking* for information on how to manage related issues.

How do I get my care needs assessed?

You may not feel you require any external help at the moment, but it is worth noting how to get help and guidance when needed.

This is normally done by asking adult social care services to provide you with a needs assessment. Ask your local authority about this in England and Wales, or your local health and social care trust in Northern Ireland.

If you have a carer, they can also request a carer's assessment of their needs. Both types of assessment provide advice and information and may lead to arrangements for services and support, either now or in the future.

These allow you to explore aspects of personal care, respite care, emergency support (eg should your carer be ill) and a variety of other needs.

“ You need to be as well informed as possible about how to access services.”

If you have an assessment, give as much detail as you can to ensure any resulting arrangements provide the best possible support. What you find physically possible can vary daily with MND, so it is important to let the assessor know what assistance you need on a bad day. It may help to keep a

diary before the appointment to track any progression. This may help you and the assessor to consider future needs.

A financial assessment will determine the amount you may need to contribute to any agreed services. Services can either be arranged or you can decide to receive direct payments as part of a personal budget, so you can choose services yourself. If you do select direct payments, you are responsible for the money received and will need to keep records.

You and your carer have the right to an assessment of your individual needs. Our publications include content about your rights, assessment and direct payments.

See *Further information at the end of this section for details about relevant publications.*

See *Further information at the end of this section for carer information.*

NHS continuing healthcare

If your primary health care needs become complex, you may wish to ask your GP about how to get assessed for NHS continuing healthcare. If you meet the criteria, this means the NHS will fully fund all your care needs. This is a complicated application process, involving members of your health and social care team. It is worth exploring the requirements carefully before applying. We provide an information sheet on this subject. There are no guidelines for NHS continuing healthcare in Northern Ireland. If you are resident there and need this type of support, please contact your local health and social care trust.

See *Further information at the end of this section and Section 12: How statutory services can help you regarding social care, direct payments and NHS continuing healthcare.*

Key points

- Before making any decisions about equipment and aids, seek an independent assessment from an occupational therapist. Private purchases can be costly and may not suit your needs, or your home.
- An independent assessment also enables you to discuss ways of adapting your routines and methods to help maximise independence.
- You may develop a wide range of homemade solutions and techniques, which can be very effective, but check with your occupational therapist for advice on safety, eg be careful not to overload plug extensions.
- If you have professional carers coming into your home, think of ways to help them help you, eg use colour coded towels for face and body to keep these separate and provide a quick reference list of any special requirements.
- As MND progresses, your needs will change. If something has not worked before, it may be worth trying again.

Further information:

We have a range of numbered information sheets, including:

- 1A:** *NICE guideline on motor neurone disease*
- 6A:** *Physiotherapy*
- 10A:** *Benefits and entitlements*
- 10B:** *Direct payments and personalisation*
- 10C:** *Disabled Facilities Grants*
- 10D:** *NHS continuing healthcare*
- 10E:** *Work and motor neurone disease*
- 10F:** *Your rights to social care*
- 11A:** *Clothing*
- 11B:** *Mouth care*
- 11C:** *Equipment and wheelchairs*
- 12A:** *Driving*
- 12B:** *Choosing the right vehicle*
- 12C:** *Travel and transport*

We also provide the following publications:

Caring and MND: support for you
a comprehensive guide for carers.

Caring and MND: quick guide
summary information for carers.

Most of our publications can be downloaded from our website: **www.mndassociation.org** or you can order them from **MND Connect**, our support and information helpline:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

MND Connect can also help you locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional care development adviser (RCDA).

See Section 14: How we can help you.

MND Association Support Services:

Email:

support.services@mndassociation.org

Telephone: **0808 802 6262** for guidance on our financial support and equipment loan services

Online forum:

<http://forum.mndassociation.org> hosted by the MND Association for you to share information and experiences with other people affected by MND.

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The MND Association has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org