

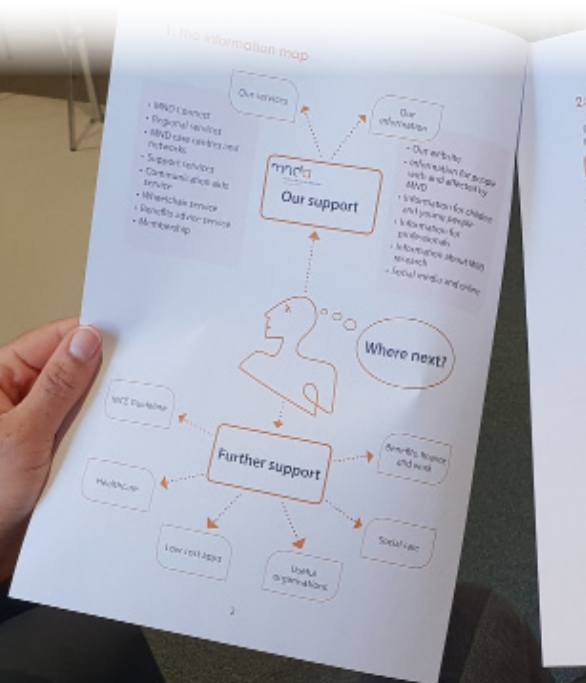
Personal care

for people with MND and their carers



“The thing about MND is the goalposts are constantly moving... But you just have to adapt as you change. It’s all about living life to the full.”

Person living with MND



Contents

How can this booklet help me?	4
1: What is personal care?	5
2: What can help me?	11
Washing and bathing	14
Dressing and getting ready	20
Toilet and intimate care	25
What else could I think about?	31
3: How do I get my needs assessed?	33
4: Who can help me?	37
5: How do I find out more?	39



This symbol highlights quotes from people living with or affected by MND.



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

How can this booklet help me?

Motor neurone disease (MND) affects everyone differently, but everyday tasks will become more challenging over time. This includes how you care for yourself.

This booklet looks at personal care such as bathing, dressing and toileting, and how you can adapt or find support when needed. This can help you prolong independence and may also assist your carers.

You may find the content useful if you are living with Kennedy's disease, which has similar symptoms to MND.

See Further information, section 5: How do I find out more? about our resources and how to order them.



1: What is personal care?

Personal care means different things to different people. In this guide, it means any regular task that you do to maintain your hygiene or appearance such as:

- washing and dressing
- getting ready and maintaining a sense of self
- going to the toilet or managing intimate care, such as shaving or managing your periods.

How can MND affect personal care?

MND affects the nerves that control movement (your motor neurones). This stops messages reaching your muscles, leading to muscle weakness. This can affect how you walk, talk, move, eat and drink. For some people with MND it can also affect thinking and behaviour. These symptoms progress and can all make everyday tasks more difficult. Activities can take longer and become tiring.

For more information about fatigue see later heading in this section: *Personal care and fatigue*

Learning how to adapt, by doing things differently, and using equipment to assist you, can help prolong independence.

In time you may need to seek some professional support, even if those close to you take on a caring role. Having the right assessments can help you and your carer get appropriate support, now and in the future.



“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.”

For more information on how to get an assessment see, section 3: *How do I get my needs assessed?*

You may find it embarrassing to seek support or discuss personal care, which is normal, as it involves intimate tasks. When providing support, family and friends may find it embarrassing too. Open conversations can help everyone feel informed, prepared, and better supported. We provide guidance on how to discuss all aspects of MND with carers, family members, children, friends, colleagues and professionals.

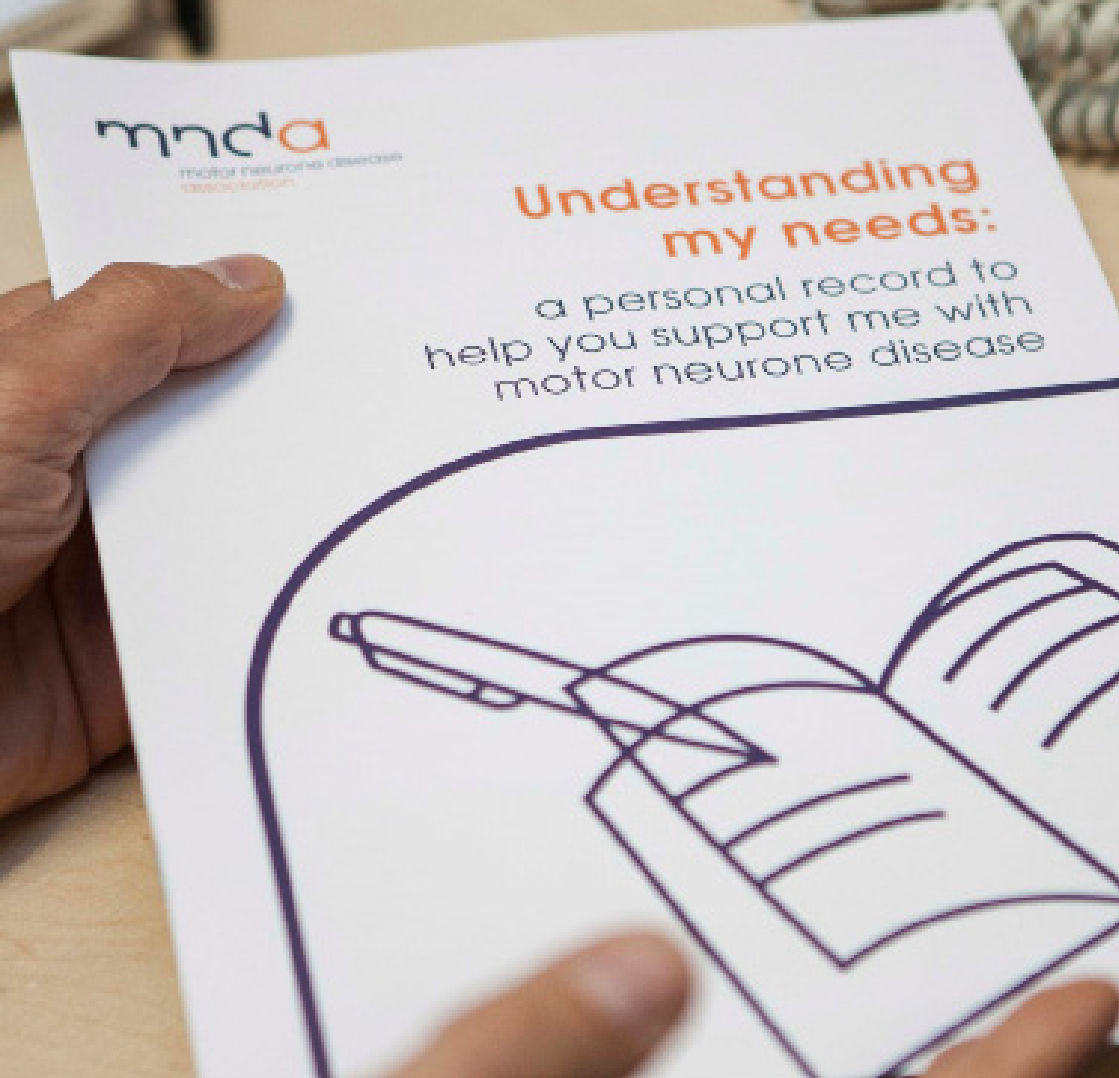
Try to raise awareness of any changes or needs as soon as you can, with those close to you. Conversations can become more difficult if MND affects speech and communication or thinking and behaviour. It can help you all to share any worries and work together.

See our booklets: *Telling people about MND and Changes to thinking and behaviour*. See also, Information sheet 7C – *Speech and communication support*.

Some people with MND also experience changes to the way they think and behave. This is usually mild but means having conversations early on can be helpful. Where these changes are more severe, additional support may be needed.

Use our *Understanding my needs* form to write down and explain your needs. This can be used as a guide by everyone involved in your care. It can also avoid having to repeat personal details at appointments.

See Further information in section 5: How do I find out more? for details about our resources.



Personal care and fatigue (feeling very tired)

Fatigue is common with MND and can make you feel:

- exhausted after being active or even when resting
- tired after a night of good sleep, feeling very drowsy and not able to concentrate
- heavy in body and limb, making it hard to do everyday tasks.

With MND, fatigue may be due to:

- reduced mobility and movement
- sleep problems
- breathing difficulties
- weight loss
- medications
- low mood or feelings of depression.

We have a range of resources on symptom management. See section 5: *How do I find out more?* and ask your health and social care team for advice.

How can I save my energy?

Think of your energy like a rechargeable battery. If you do a lot in one day, rest the next day. Try and plan 'proper' rest into your day, in bed or a comfy recliner, before you feel the need to stop.

Keep a log of activity and how it makes you feel. You may be able to plan activities around times you have more energy. Prioritise tasks and leave things that don't feel essential. This will help you keep energy for the things you really want to do.

Ask for help with chores and get a needs assessment to see how care services can support you.

Sit down to do tasks as much as possible. Place chairs for rest stops around your home or use a four wheeled walker with a seat.



“Listen to your body and perhaps do a task in two steps, rather than all at once. You achieve the task in the end, but without the frustration of tiredness.”

How can I maintain my wellbeing?

Eating a nutritious diet and maintaining fluid intake can maintain energy, prevent weight loss, and boost general mood and wellbeing. It may be tempting to change your diet and how much you drink, but dehydration can make you tired and lead to constipation.

For more information about nutrition and recipes, see our guide: *Eating and Drinking with MND.*

If you get bouts of constipation or diarrhoea, check any medication with your GP, in case adjusting levels can help.

Relaxation techniques, mindfulness, and breathing exercises such as breath stacking, can help wellbeing. For example, breath stacking helps you place additional air on top of the air already in your lungs, which can add extra force to your cough. Sometimes an inflatable bag with a mask is used to help. When the bag is squeezed, it gently encourages more air to be inhaled.

For more information about mindfulness, see our guide: *Emotional and psychological support*.

For more about breath stacking, see Information sheet, *8A – Support for breathing problems*.

See also, Information sheets *6A – Physiotherapy*, *6B – Complementary therapy*.

Ask your GP to refer you to specialists so they can assess any new, old or changing symptoms. For example, feeling more tired than has been usual for you could be down to another symptom such as a change in your breathing.

If you're following an exercise plan from a physiotherapist, don't overdo this to the point of fatigue. Although exercise can help boost your mood, maintain range of movement and strengthen unaffected muscles, it cannot reverse the effects of MND.



2: What can help me?

MND symptoms will progress in time. By adapting how you do things, you and your carer can find ways to make tasks easier and safer. You may feel this is a loss of independence, however accepting support and planning for expected changes can prolong your independence and reduce frustration. Using equipment can also help you and your carer conserve energy for the activities you really want to do.



“Do everything possible to save on effort for yourself and your carer.”

Before making any purchases, ask for an assessment by an occupational therapist, (OT), who can help you find new ways to do things. They can advise on your needs now and likely needs in the future, which can help you avoid costly mistakes and find equipment appropriate for your needs. An early assessment can be helpful, as certain items may take time to arrive. Some equipment may also be available free of charge or on loan through health or social care funding.

For information on getting assessed, see section 3: *How do I get my needs assessed?* For more about occupational therapists see section 4: *Who can help me?*



“Don’t assume something can be provided in a timely way. This is tough, but you’ll only know how long something will take by asking. The sooner you ask, the better.”

What if I'm caring for someone with MND?

If you're a close friend, or family member supporting someone with MND, you may not see yourself as a carer. However, it's important you get a carer's assessment.

See our guide: *Caring and MND – support for you*

See section 3: *How do I get my needs assessed?* of this booklet to see what support is available for the person you are caring for. Getting the support that is available for them can help you as a carer too.

Some carers find it difficult to ask for support from professionals, but extra help could free up more time and give you both quality time to be together. This may help you hold onto what was unique about your close relationship before MND, especially if you are their partner.

See our information about *Sex and relationships with MND* for suggestions on maintaining intimacy.

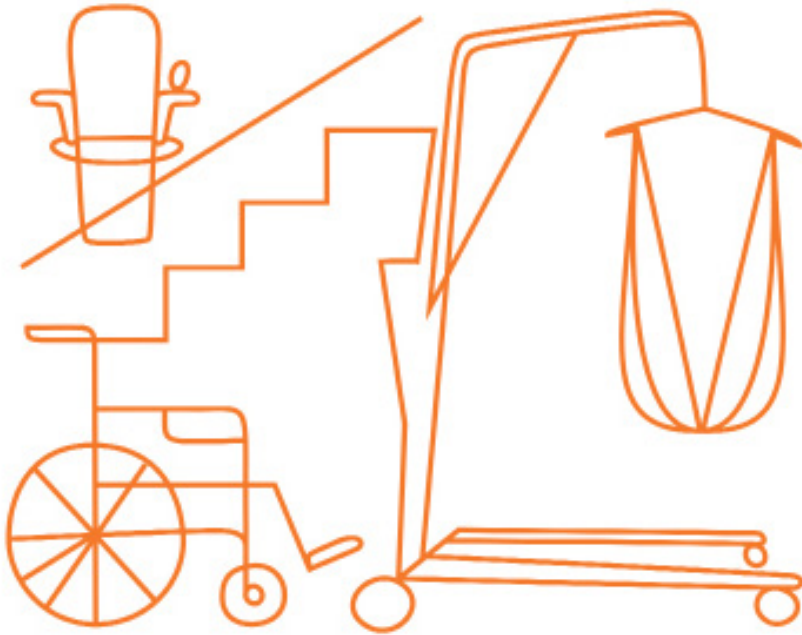
Tell your GP if you are a carer. Doing this can help you access regular health checks and flexible appointments. Your GP can also refer you to other support, such as an occupational therapist, who can advise on how to safely move and adjust the position of the person you are caring for, and how to safely manage falls.

See section 4: *Who can help me?* for more information about who can help. Also see *Further information* for details about our online forum, which is a safe space to share experiences with other people affected by MND.

What could make personal care easier?

The following suggestions in this booklet may help you think about how to adapt. However, a needs assessment looks in detail at your individual care needs to develop a personal care plan.

See section 3: *How do I get my needs assessed?*



Always seek advice from your GP, occupational therapist, physiotherapist, dentist or relevant health and social care professional, before using new equipment or trying new ways of doing things, to ensure it will be safe and suitable for your needs.

Washing and bathing

What might be changing?

I need help to:

- grip things like my toothbrush, taps and bottles
- get in and out of the bathroom, bath or shower
- keep my balance and avoid falls
- get washed and get dry.



“I find my current shower difficult to get in and out of and am considering getting a wet room or similar installed.”

What could make washing easier?

In the bathroom

If not using a wheelchair, put down a nonslip mat to help with stability. Keep the bathroom warm and comfortable so you can take your time.

Make reaching easier with aids like long handled sponges. Leave a foot cleaner or scrubber in place in the bath or shower so you don't have to reach down to wash your feet.

Use perching stools to provide stability at a sink.

Try strip washing

Colour co-ordinate your flannels and towels if others help you to wash. For strip washes have different flannels for your top half, bottom half and face.

Try environmentally friendly cleaning wipes if you need something portable and quick, or for taking out and about.

When showering

Use a nonslip mat in your shower and install grab rails to make you feel safer with more support.

A fixed seat can be installed in the shower cubicle or use a corner shower stool to sit on.

Wheeled shower chairs can help provide stability if you have a level access shower cubicle. Some have a *tilt in space* function to help with positioning.

Wet rooms are waterproof rooms where the shower is on one level. They allow easy access and no hard shower screens.

Soft shower curtains can be used for privacy, and a half height fixed screen can be used to help keep carers dry when helping you wash.

Portable shower units allow you to use the shower head anywhere you can hang the compact unit. Hang it over a sink or inflatable bath tray making every day washing tasks more accessible.

When bathing

Simple bath seats or a mechanical bathing seat can reduce the effort needed to lower and raise yourself in the bath.

Bath boards go across the top of your bath to sit on, useful if you have a shower above your bath.

If you don't have a shower above your bath, try using a lightweight plastic jug to scoop water over yourself, in amounts you, or your carer can manage easily.

Walk in baths allow you access over a very low step. You close the door, then fill up the bath. When the water has emptied, the door can be opened to help you get out.

Ceiling track hoists can help your carer lift you in and out of a bath.

To get dry

A towelling dressing gown can help you get dry with little effort. Wrap your feet in a separate towel. You can lay down to rest at the same time.

When washing your hair

Long handled hair washers have a secure grip to help you shampoo, massage, and wash your hair if you have limited arm movement. Using a long shower head hose attachment on taps can help extend reach.

Hair washing trays range from solid plastic trays or flexible, softer trays. They fix to sinks so you can have your hair washed while sitting down.

Inflatable trays can be used comfortably, lying down in bed.

No rinse shampoo caps can be warmed up carefully in a microwave. Once checked for level of warmth, these can be put over your hair and massaged until your hair is saturated. Afterwards hair can be towel dried and styled with no need for rinsing.

Hands free hairdryer holders have suction cups that fix the holder to a surface. Insert your hairdryer and bend the flexible stand to the right position for you to dry your hair.

Dry shampoo sprays can refresh hair between washes, but they may not be suitable if you have breathing problems.

Hair salons usually offer hair washing and drying services, without the need for a haircut too.

What could make mouthcare easier?

As many people with MND are advised to eat a lot of calories to maintain weight, there could be an increased risk of tooth decay from eating sugary foods. It's important to brush your teeth last thing at night and at one other time during the day, using a fluoride toothpaste.

Maintaining good oral hygiene is still important if you use a feeding tube, as bacteria will still be present.

For more on tube feeding, see Information sheet 7B - Tube feeding.

Using an electric toothbrush will help do a lot of the brushing work for you and you can buy lightweight ones.



“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.”

With limited arm movement, try propping your arm up on the side of a chair or table, then move your head gently from side to side instead of moving the toothbrush.

Multi-sided toothbrushes let you clean with less brush strokes and large handled toothbrushes increase grip area.

Gripper aids like polystyrene balls can be pushed onto the handle of existing toothbrushes to increase the surface area.

Non-foaming toothpastes can reduce worries about toothpaste or mouthwash ‘going down the wrong way’. Ask your GP if they can offer these on prescription, or look for toothpastes without sodium laureth sulphate.

If your carer helps brush your teeth, a mouth rest on one side of your mouth can help keep your jaw open.

Scrub dentures against a nailbrush attached to a surface by suction cups, and over a basin of water if you’re worried you might drop them.

How do I prevent gagging when brushing?

Try keeping your chin in a level or downward position and ask your carer to use slower, gentle movements, so you know what to expect. Keep your airways open by sitting upright with your head turned slightly to one side.

If you find a normal sized toothbrush makes you gag, try using a soft washcloth soaked in dental gel or fluoride mouthwash. This may not work long-term, as it's not as effective as brushing and can irritate the soft parts of your mouth. However, once you get used to someone helping to clean your mouth, a soft baby toothbrush may feel acceptable.

If you use a suction machine because of excess saliva, this can be used while brushing. A specialist toothbrush accessory can also be attached.



“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.”

For more information about saliva and swallowing, see Information sheet 7A - *Swallowing difficulties*.

Try to make regular visits to your dentist. If it becomes difficult to travel, a community dental service may be able to arrange home visits.

In Wales and Northern Ireland ask for a referral from your dentist or health and social care team. In England you can ask for a referral or, for more information see, **www.communitydentalservices.co.uk**

Dressing and getting ready

What might be changing?

I need help to:

- do up fastenings on clothes and shoes
- dress and undress
- maintain my temperature and comfort
- keep my sense of self and style.



“With MND and getting dressed, we need to think about how to make life easier for our carers too.”

What could make dressing easier?

Use different fastenings

Lightweight, looser fitting or partially fastened clothes can make it easier to get dressed or undressed.

Replace fastenings on your existing clothes with Velcro (hook and loop tape) or choose belts with large, wide D rings.

Choose adapted clothing, like side-opening underwear, or elasticated clothing with no fastenings at all.

Choose looser, lighter fabrics and styles which allow for easy handling and access when going to the toilet.

Use dressing aids

Dressing sticks can pull up, push down, and help move clothing around while getting dressed.

Hoop leg lifters are a strap with a stiffened loop at one end to lift your leg. It might help in any daily task where you have difficulty lifting your legs. If you have weak grip place the loop over your wrist to lift.

Bra dressing aids are designed to 'hold' one side of your bra for you so you can hook the other side in with just one hand.

Zip pullers and button hooks can help with fastenings and sock aids can help when putting on socks.



Shoehorns can help extend reach when putting shoes on, and boot jacks can be left in place on the floor to help with taking shoes off, so you don't have to bend down.

Check the care instructions on any new items and look for anti-crease labels. It can help reduce laundry time if the fabric is easy to wash, dry and iron.

Think about comfort

Think about the material. Is it slippery, rough, or itchy?
Will it be comfortable if you're sat down for a long time?

Layers of loose, lightweight clothing provide good insulation to keep warm, but allow you to take something off if you get hot.

Whether indoors or outdoors, try a sleeping bag if you feel the cold as blankets can slip and let the heat escape.

Absorbent materials such as cotton, viscose and modal can help reduce getting too hot. Avoid nylon and polyester, as they can make you sweat.

Wearing dark patterned fabric, neck scarves, adult bibs and tabards can help disguise splashes, spills, or problems with saliva.

Look at how long clothing items are, will hemlines ride up in a wheelchair? Keep a covering handy for your lap, like a wrap scarf or blanket in case they do.

Think about safety, check nothing could trail and get caught in wheelchairs or hoists.

Check with your doctor before using heated products like heated socks or foot warmers. Especially if you have swollen feet or circulation problems.

Choosing footwear and foot care

In general, shoes should:

- fit well, not pinch or rub your toes
- be fully enclosed, not be slip-on or backless
- have good grip, low heels and support your ankle
- fasten securely and easily.

Occupational therapists and physiotherapists can offer advice if you are worried about trips or falls.

Orthotics services can provide a foot support called a Foot up, as well as other foot support devices, such as splints, braces and insoles. Ask any health and social care professional about orthotics services.

Chiropodists or podiatrists can offer support with footcare in general and things like toenail cutting if you have limited mobility.

Swollen feet can be a problem if you are seated for long periods of time. If you have this problem, try:

- wide fitting or larger size footwear
- elastic or velcro fastenings to allow for adjustment
- fleece lined boots to allow for swelling (but give warmth if your feet get cold).

How can I keep my personal style?

Maintaining a sense of self through personal style can boost wellbeing. If you need help with this, provide written guidance for those involved in your care. This may include getting dressed according to your cultural or religious beliefs.

To make personal styling easier try:

- using electric shavers as they are easier to grip, and safer for someone else to help with
- propping your elbow on a pressure pad and holding your wrist with your other hand to help apply your makeup
- asking trained carers to help keep fingernails trimmed using nail clippers, or use adapted clippers that require less pressure to be used.
- asking someone to help with makeup (they can watch YouTube tutorials if not used to doing this and look at photos of you to see what style you like)
- asking a beautician to help with hair removal, eyebrow shaping, eyelash tinting or permanent tattoo makeup
- having your hair cut and styled by a hairdresser or barber
- finding a beautician, hairdresser or barber who offers home visits.



“When shaving with an electric razor, lying on the bed with pillows under my elbows to raise them up is ideal.”

Toilet and intimate care

What might be changing?

I need help to:

- get to the toilet in time
- grip and tear off toilet paper
- manage bouts of constipation and diarrhoea
- manage my periods.



“No-one talks about living with urine incontinence from MND muscle relaxant medication.”

Why are things changing?

MND does not usually affect the bowel and bladder. Some people with a rarer form of MND, called primary lateral sclerosis (PLS) experience bladder urgency, which is a sudden urge to pee.

For more information on PLS see, *Information sheet 2C - Primary lateral sclerosis.*

However reduced mobility can make it difficult to get to the toilet in time. You may be tempted to drink less to avoid the need to go to the loo. That can lead to dehydration and constipation, so try to maintain your fluid intake.

For guidance on maintaining a healthy diet see our guide, *Eating and drinking with MND.*

Constipation can also happen with, anxiety, medication, or due to reduced mobility and weakened abdominal muscles. If you have difficulty breathing, it can be hard to 'push' to empty your bowels. Discuss any changes with your health team as they can help, and changes may not be due to MND.

The following suggestions may help if you have difficulties with intimate personal care and toilet access.

How can I keep clean and comfortable?

Choose clothing that's easy to remove (see earlier content on clothing and fastenings.)

Use a long handled bottom wiper.

Cleaning foams and barrier creams leave a water repellent layer on the skin, helping to prevent skin problems and discomfort if you do have accidents.

Incontinence products are available for men or women, as disposable pads or padded pants, washable pants, bed pads, and pillow and mattress protectors. These can reduce discomfort and anxiety about accidents.



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

**For further support, Age UK have incontinence advisers.
Contact: 0800 849 8032.**

What could make using the toilet easier?

A raised toilet seat on top of your existing loo, or a frame fitted around the toilet may make it easier to sit and stand.

Support rails in the bathroom and around your home can help you maintain stability.

Toileting slings are compatible with most hoists and help transfer from seat to seat. This can help your carer too. They allow easy access to remove and adjust clothing so can be useful when dressing.

Some toilet adaptations may need ceiling track hoists installed to be used safely. Otherwise a mobile hoist can be used by carers to help.

Wheeled shower chairs sometimes fit across existing toilets for easier transfer, without having to repeatedly stand up. They can also help with stability.

For ease of cleaning a wash and dry toilet could be installed. A cheaper alternative is a wash and dry toilet seat that can often be placed over your existing loo.

What if I can't get to the toilet easily?

Commodes and bed pans can be used as a portable toilet if you find it difficult to get to a bathroom. Gels can be added to the pans to thicken fluids and prevent spillages or odours.

Urine bottles and bed pans are practical to take out and about, use during the night, and keep downstairs so you don't have to rush upstairs to use a toilet. You can add gels to thicken fluids and prevent spillages. Some have lids or screw caps.

Sheaths are a popular alternative to absorbent pads for men. Sometimes called condom catheters, uridomes or external catheters they are a non-invasive way to drain pee into a discreet bag day or night.

Catheters use a flexible tube to empty your bladder of pee. They are at increased risk of infection but can help make managing urine easier. Catheters come in two options:

- **urethral catheters** are inserted into the bladder by a doctor or nurse and can be temporary or left in place all the time. The urine drains into bags. Larger bags for at night and smaller, discreet bags for during the day.
- **suprapubic catheters** are inserted into a small opening made in the side of the stomach and left in place all the time. You can empty it by either allowing the urine to drain into a bag or by using a valve to open the tube when convenient.

Using a toilet away from home

Knowing where you can make toilet stops can help you feel more confident about travelling. Taking a portable toilet aid as previously described can be helpful too.

To gain access to thousands of accessible public toilets you can also purchase a RADAR key.



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



See useful organisations in section 5: *How do I find out more?* for Disability rights UK about RADAR keys. Also see, *Changing Places*, where you can search for accessible toilets.

How can I manage my periods?

It can be embarrassing to ask for help with periods, but you may need support with this now or in the future. Use this booklet to help open conversations with those involved in your care, and with your GP to find out about available options. You can also ask a practice nurse or family planning clinic for advice.

Period pains: can feel worse if you can't move around easily to help ease cramps or aching. Ask your GP if you experience painful periods. Warmth from a heat pad or appropriate over the counter pain relief may help.

Sanitary pads and tampons: are available if you can grip them easily yourself, as tampons should never be left in place for more than 8 hours.

Menstrual cups: can be worn for up to 12 hours, so need changing less than tampons or pads. It also means less waste and cheaper too, but you need to have enough grip and strength to insert and remove them yourself.

Period pants: are underwear designed to be worn during your period. They are becoming more popular, affordable and less taboo. These pull up pants are like normal pants and absorb fluids keeping you clean and comfortable. They are washable, easy to handle and are a good option if your cycle varies.

Contraceptives: may be an option if your periods become difficult to manage or if you do not have a predictable cycle. Ask your doctor about contraceptives to stop your periods.

If pills are difficult to swallow ask about having a coil or implant fitted, as these can be left in longer term. Or ask about the contraceptive injection.

Chemically induced menopause: It is possible to have a chemically induced menopause to permanently stop periods. However, this can have a significant impact. Discuss the possible results of this with your doctor. If your periods have begun to become irregular, ask to have your hormone levels tested to see if you are nearing menopause.

What else could I think about?

It is difficult to predict how your MND will progress, but your mobility is likely to reduce. This can make moving around your home to do personal care tasks more difficult.

Use these checklists to think about if your home environment is suitable for your needs, now and in the future.

When you're at home:

- Can your home support your changing needs?
- Do you need to change anything for safety in your home?
- Would environmental controls or personal alarms help?
- Does your home need adaptations now or in the future?
- Have you had your needs around the home assessed?
- Have you had your needs assessed for possible care support?



“My chair is compact and very easy to use. I can now stand up to my walking frame and sit down safely. I have put the back down and my feet up, and slept very comfortably.”

Eating and drinking:

- Could you have perching stools at worktops?
- Can you store everything you use most in easy reach?
- Could you have your shopping delivered?
- Could you use equipment such as adapted cutlery, crockery and plate guards?
- Can you arrange some batch cooking, so you can have nutritious meals but save on time and energy?



“Avoid combinations of different objects where one will do, such as a cup and saucer, or a knife and fork.”

For more information about nutrition and cooking, see our guide: *Eating and Drinking with MND*.

Moving around:

- Could using wheelchairs, rollator frames and ramps help?
- Do you need a riser-recliner chair or an adjustable bed?
- Would using a mobile hoist help provide support?
- Could you install environmental controls?
- Would a wet room, through floor lift or stairlift be suitable?
- Do doorframes need widening to fit equipment?
- Would creating wheelchair turning circles help?
- Would renovations such as home extensions be suitable?

Where there is space, a through floor lift or converting a downstairs room may be a longer-term solution than a stairlift. If using a wheelchair with a stairlift, you will need to transfer from seat to seat. You may need a wheelchair on each floor and possibly a hoist. If you use crutches, keep a spare pair upstairs.



“We’ve asked for a home visit survey by an occupational therapist, for advice regarding adaptations to the home and wheelchairs, for future use.”

For more about wheelchairs and home adaptations see, Information sheets:

10C – *Disabled Facilities Grants*

11C – *Equipment and wheelchairs*

11E – *Environmental controls*

3: How do I get my needs assessed?

Care needs will increase with MND, which means external support may be necessary. You might not need help immediately, but there are often delays in services. Finding out what is available early on could help you and your carer plan ahead and receive the support you need.

By law you are entitled to receive an assessment and for any resulting care needs to be met by the relevant authority.



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

How do I get my needs assessed?

Adult social services can provide a needs assessment if you have MND, or a carer’s assessment if you are providing support. The assessment will work out your needs, agree with you which support services could assist, and help you plan for emergencies.

To arrange an assessment, contact your local authority in England and Wales, or your local health and social care trust in Northern Ireland.

In England and Wales find your local authority at:
www.gov.uk/find-your-local-council

In Northern Ireland search for *health and social care trusts* at:
www.nidirect.gov.uk

Everyone will have a different outcome from assessment, depending on their situation, symptoms, and preferences. You may have to contribute to the costs of any agreed services, following a financial assessment.

You may be able to get funding through a Disabled Facilities Grant (DFG), to make adaptations to your home, but this can take time, along with the actual work of applying. Try to think about this as early as possible and ask an occupational therapist to assess your needs at home.

For more about assessments, your rights, social care support and how this is funded, see Information sheet 10B – *What is social care?*

You may also be entitled to a range of benefits and financial support such as Attendance Allowance (AA) if you are of state pension age, or Personal Independence Payment (PIP), if you are of working age. PIP is designed to help with some of the extra living and mobility costs of long-term illness or disability. For government information, look on **www.gov.uk** for England and Wales, or **www.nidirect.gov.uk** for Northern Ireland.

In Northern Ireland you can contact the Make The Call Team, who can check if you're getting the benefits, services and support you're entitled to:

www.nidirect.gov.uk/contacts/contacts-az/make-call-service

For more, see our range of benefits and support information in Information sheets: 10A – 10G and see *Further information* at the end of this booklet for details about our MND Association Benefits Advice Service.

What if I'm not happy with the support offered?

If you're unhappy with the support you receive, discuss this at first with the following:

- **needs assessment** - contact your social worker from adult social care services
- **care service or support** – contact the relevant care worker or care provider
- **benefit claim** – the authority that made the decision (this is called asking for a 'mandatory reconsideration').

If this does not solve the issue, the following may help:

To challenge the result of a needs assessment contact:

- **England** – Local Government and Social Care Ombudsman
- **Wales** – Public Services Ombudsman in Wales
- **Northern Ireland** – Northern Ireland Public Services Ombudsman.

To challenge the support that you receive from a care provider, contact:

- **England** – Care Quality Commission (CQC)
- **Wales** – Care Inspectorate Wales (CSSIW)
- **Northern Ireland** – The Regulation and Quality Improvement Authority (RQIA)

**Find contact details in Useful Organisations, in section 5:
*How do I find out more?***

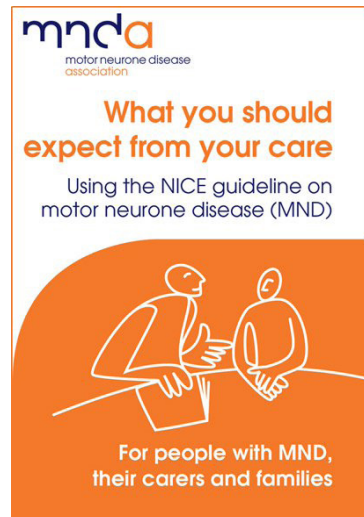
To challenge a decision for a benefit claim (after the mandatory reconsideration), find details about the appeals process at:

- **England and Wales** – search *benefits appeals* at:
www.gov.uk
- **Northern Ireland** – search *appeals* at:
www.nidirect.gov.uk

NICE Guideline on MND

This set of recommendations for health and social care professionals is provided by the National Institute for Health and Care Excellence. Being informed about the guideline can help you open discussions with health and social care providers. This may help you access more suitable support.

See *Further information* for details about our resources on the NICE Guideline for MND.



4: Who can help me?

There is a wide range of health and social care support available, and different specialists for symptoms, but with personal care your main contacts may be:

GP: for guidance, symptom management and medication if needed. They are also a good first point of contact for referral to other services and specialists such as a speech therapist.

Occupational therapist (OT): for assessment and support to prolong independence, safety in the home, equipment, adaptations, and different ways to do everyday activities.

Physiotherapist: for assessment and guidance specifically tailored for your needs. They can offer advice on posturing and positioning, (for you and your carer), breathing exercises, managing falls, adapting and exercises to help maintain range of movement and comfort for as long as possible.

District Nursing Teams: work closely with GPs and other health professionals to provide a service tailored to your individual care needs.

Adult social care services: for needs assessments, information and help to arrange care services.

NHS Continuing Healthcare: for a package of nursing and personal care fully funded by the NHS. This is only provided where healthcare needs are severe, difficult to manage or changing quickly. Continuing healthcare works in a similar way in England and Wales.

There is no formal guidance in Northern Ireland, but health and social care trusts are encouraged to refer to the same criteria.

See information sheet 10D: *NHS Continuing Healthcare*.

You can ask for written guidance or information in a format or language that is accessible for you. In England, this is a legal duty for the NHS and adult social care, governed by the *Accessible Information Standard*:

www.england.nhs.uk/ourwork/accessibleinfo

In Wales, see also the *All Wales Standards for Accessible Communication and Information for People with Sensory Loss*:

bit.ly/3wcKBjV which may be helpful.



5: How do I find out more?

Useful organisations

We cannot endorse organisations, but the following may help your search for further support. Find more links at: **www.mndassociation.org/usefulorgs** Contact details may change between revisions. Our MND Connect helpline can help you find services,(see *Further information* in this section).

Adult social cares services

To arrange a needs assessment or a carers assessment, contact your local authority in England or Wales. Search for *find your local council* at: **www.gov.uk**

In Northern Ireland search for *health and social care trusts* at: **www.nidirect.gov.uk**

British Red Cross

For a variety of disability living aids and equipment hire.

Telephone: 0344 871 11 11

Website: **www.redcross.org.uk**

Changing Places

Find your nearest accessible toilet.

Telephone: 0207 803 2876

Email: changingplaces@muscular dystrophyuk.org

Website: **www.changing-places.org/find_a_toilet**

The College of Occupational Therapists

Sets professional standards and includes a search facility to find registered occupational therapists.

Telephone: 020 7357 6480

Website: **www.cot.co.uk**

Disability Rights UK

Information on how to purchase a RADAR key

Telephone: 0203 687 0790

website at: **bit.ly/radar-key**

MND Scotland

Providing support for people affected by MND in Scotland.

Telephone: 0141 332 3903

Website: **www.mndscotland.org.uk**

NHS UK

Online health information according to need.

Website: **www.nhs.uk**

NHS 111

Health information and support for Wales.

Telephone: 111 where available or 0845 46447

Website: **111.wales.nhs.uk**

NHS Health in Wales

For healthcare information in Wales

Telephone: 0300 060 4400

Website: **www.wales.nhs.uk**

NHS Northern Ireland

Online information and NHS services in Northern Ireland.

Website: **www.online.hscni.net**

RiDC

Information to help disabled and older people live more independently.

Telephone: 020 7427 2460

Website: www.ridc.org.uk

Acknowledgments

Thank you to the following for their kind assistance in the development of this booklet:

Diane Aldridge, Social Worker, Salford Royal NHS Foundation Trust

Shane Elliott, Housing and Health Liaison Officer, Department of Health, Northern Ireland.

Anna Rutherford, Specialist Neurological Physiotherapist, Salford Royal NHS Foundation Trust

Gemma Spedding, Occupational Therapist, Salford Royal NHS Foundation Trust

References

References used to support this information are available on request. Email us at: infofeedback@mndassociation.org

Or, write to us at:

Care information feedback, MND Association,
Francis Crick House, 6 Summerhouse Road,
Moulton Park, Northampton, NN3 6BJ.

Further information

For more support, see our following resources:

Information sheets:

2C – *Primary Lateral Sclerosis (PLS)*

3A – *MND Care centres and networks*

6A – *Physiotherapy*

6B – *Hospice and palliative care*

11C – *Equipment and wheelchairs*

11E – *Environmental controls*

See also our sheet ranges:

7A–7D on swallowing, tube feeding and communication

10A–10G on benefits, financial support and social care

Guides and booklets:

Living with motor neurone disease (MND)

Caring and MND – Support for you

Eating and drinking with MND

Telling people about MND

Changes to thinking and behaviour with MND

Sex and relationships with MND

Understanding my needs

What you should expect from your care: using the NICE guideline on motor neurone disease (MND) - Pocket guide

We have a web area for children, young people, parents and guardians at: **www.mndassociation.org/cyp**

You can download most of our publications at:

www.mndassociation.org/publications or order printed copies from our helpline team, MND Connect.

MND Connect

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

MND Association online forum

Our online forum is a safe place to share experiences and ideas with other people living with or affected by MND. You can access the forum at: **<https://forum.mndassociation.org>**

Equipment loans and MND Support Grants

If statutory funding is not available, or is taking too long, we may be able to provide a support grant or some equipment on loan. Applications need to be made by a relevant health or social care professional.

Telephone: **0808 802 6262**

Email: **support.services@mndassociation.org**

Website: **www.mndassociation.org/getting-support**

Benefits Advice Service

Find current contact details for England, Wales and Northern Ireland at: **www.mndassociation.org/benefitsadvice** or contact our MND Connect helpline for guidance: **0808 802 6262**

We welcome your feedback

We'd love to hear your thoughts on this booklet at: **www.smartsurvey.co.uk/s/personalcarewithMND**

Your anonymous comments can also help raise awareness, by sharing your experience in our resources, campaigns or applications for funding.

You can also email your comments to us at: **infofeedback@mndassociation.org** or contact *Care information feedback* by post, to the address on the back cover.

MND Association,
Francis Crick House,
6 Summerhouse Road,
Moulton Park,
Northampton NN3 6BJ



Created: 06/21
Next Review: 06/24
Version: 2

Registered Charity No. 294354
Company Limited by
Guarantee No. 2007023
© MND Association 2021