

# Personal care

for people with motor neurone disease (MND)  
or Kennedy's disease, and their carers



**“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

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Patient Information Forum

**This information has been evidenced, user tested and reviewed by experts.**  
<https://piftick.org.uk>

## How can this booklet help me?

Motor neurone disease (MND) and Kennedy's disease share similar symptoms. The MND Association supports people affected by both conditions.

Although the way symptoms progress can vary, everyday tasks do get more challenging. This booklet explores how to look after your personal care and seek support when needed.

Finding ways to adapt can help prolong independence and assist your carers too. This can feel emotional, but thinking ahead can help you find appropriate and timely services. Extra support may be needed, even with help from people close to you.



See *Further information*, section 6: *How do I find out more?* about ordering our resources.



This symbol highlights quotes from people living with or affected by MND, or Kennedy's disease.



# 1: What do I need to think about with my personal care?

Personal care means any routine task to help maintain your wellbeing, hygiene and appearance. This includes tasks 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 or Kennedy's disease affect personal care?

Both conditions affect your motor neurones, which are nerves that control movement. When these nerves are damaged, it leads to muscle weakness that can affect how you walk, talk, move, eat and drink. As symptoms progress, everyday tasks take longer, become more difficult and feel very tiring.



See later heading in this section:  
*Personal care and fatigue (feeling very tired).*

Adapting how you do things, such as using assistive equipment, can help prolong independence. This can feel difficult to accept at first, but can be of great benefit. In time, some professional support may be needed, even if family and friends already help.



**“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.”**

Having your needs assessed can help you and your carers work out a care plan for support.



See section 4: *How do I get my needs assessed?*

## **Early conversations to help plan personal care**

You may find it embarrassing to seek help for personal care. This is normal and family and friends may worry about it too.

Open conversations can help everyone feel informed, prepared, and better supported. This can get more difficult if your speech and communication are affected, so sharing worries as early as possible can help you find solutions together.



See our resources:

- *Telling people about MND*
- *Changes to thinking and behaviour*
- *7C – Speech and communication support.*

Some people with MND experience changes in thinking and behaviour. Having early conversations about how this affects your individual care needs can be helpful, as support can be tailored. With more severe changes, extra help may be needed.

Use our *MND Checklist* to think about your care needs and our *Understanding my needs* form to explain your needs and guide those involved in your care. It can also help you provide your personal details at appointments, so you don't have to keep repeating these.



See *Further information*, section 6: *How do I find out more?* for details about our resources.

## Personal care and fatigue (feeling very tired)

Tasks become much harder if you feel very tired. MND and Kennedy's disease can cause fatigue due to:

- reduced mobility and movement
- sleep problems
- breathing difficulties (milder for Kennedy's disease)
- weight loss
- medications
- low mood or feelings of depression.

You may feel:

- exhausted after being active or even when resting
- tired or drowsy after sleep and not able to concentrate
- a sense of heaviness in body, arms and legs.





## How can I save my energy?

Ask your GP to refer you to specialists for assessment of any changes. For example, feeling more tired. See our resources on symptom management and ask your healthcare team for advice.



See section 6: *How do I find out more?* about resources.

Think of your energy like a rechargeable battery. If you do a lot in one day, rest the next. Take breaks when you can and keep a diary of how you feel, to work out your best times for activity.



**“If I have a two hour rest in the afternoon, I feel better in the evening.”**

It can help to do tasks that matter most to you and let go of tasks that aren't essential. Assistive equipment can make activities easier. Place chairs around your home to rest and if you use a walker, some have a built-in seat to help you take a break.



**“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?

Balanced nutrition can maintain energy, prevent weight loss, boost mood and wellbeing. It may be tempting to drink less if mobility makes it hard to get to the toilet, but dehydration is tiring and risks constipation.



For more on diet and easy-swallow recipes, see our guide: *Eating and Drinking with MND*.



If you do get constipation or diarrhoea, check any medications with your GP, as you may be able to alter the dosage.

To manage energy levels, you may want to try the following:

- referral to a relevant specialist for assessment, such as a respiratory team for breathing therapies
- relaxation and mindfulness techniques
- an exercise or assisted exercise programme following assessment with a physiotherapist
- complementary therapies, which some people find helpful to ease symptoms and stress.



**“Hydrotherapy, acupuncture and massage at my local hospice help me relax and feel a little better.”**



Try not to overdo exercise to the point of fatigue.

Exercise cannot reverse motor neurone damage with MND or Kennedy's disease, but it can help your sense of wellbeing, range of movement and strengthen unaffected muscles.



For more guidance, see:

- 6A – *Physiotherapy*
- 6B – *Complementary therapies*
- 8A – *Support for breathing problems*

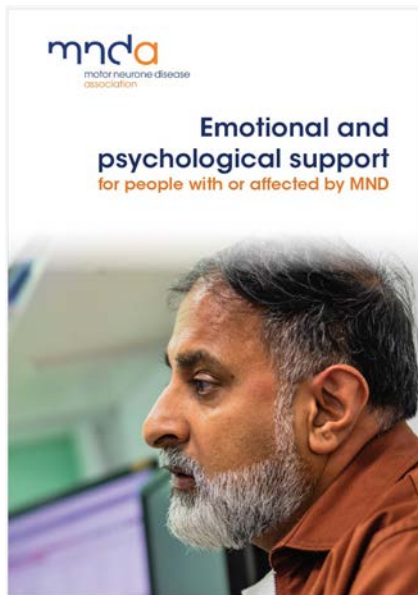


**“While I am restricted in the activities I can pursue, there are many things I can still do to give myself a good quality of life.”**

Taking positive action can bring a sense of control and lift mood. Various therapies are also available.



See our booklet, *Emotional and psychological support*



## 2: What do I need to think about if I'm a carer?

If you're supporting a partner, relative, or friend after an MND or Kennedy's disease diagnosis, you may not think of yourself as a carer. However, recognising yourself as a 'carer' can help you access valuable support.



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

A needs assessment for the person with MND or Kennedy's disease helps you both, but a carer's assessment helps you find information and possible services to support your caring role.



See section 4: *How do I get my needs assessed?*

You may want to cope without professional support, but some extra care can help you rest, get other things done or maintain the relationship you had with the person before their diagnosis. This is especially valuable when supporting your partner.



See our booklet, *Sex and relationships with MND* for suggestions on maintaining intimacy.

Let your GP know that you are a carer, as this can help you access regular and flexible health checks, along with referrals.

For example, you may be referred to an occupational therapist for guidance on safely positioning and moving the person you support, or how to assist if they fall.



See section 5: *Who can help me?*

Our online forum is a safe space to share experiences with other carers: <https://forum.mndassociation.org>

Our comprehensive information resources provide guidance on symptoms and care, for both the person diagnosed and to help you when providing support.



Use our *Care information finder* to search by need at:  
[www.mndassociation.org/careinfinder](http://www.mndassociation.org/careinfinder)



## 3: What can help with my personal care?

### How can I make things easier?



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

MND symptoms do get worse, but planning ahead can reduce frustration and help prolong independence.

Assistive equipment can make tasks easier and safer. Accepting support can save energy for you and your carer.

Seek assessment by an occupational therapist (OT) before buying assistive equipment. They can advise on your needs now and in the likely future to help you avoid costly mistakes.

Do this early, as equipment and adaptations take time to arrive.

Some items may also be free of charge or on loan from health or social care.



See section 4: *How do I get my needs assessed?* and section 5: *Who can help me?*



**“This is tough, but you only know how long things will take by asking. The sooner you ask, the better.”**

These changes can feel emotional at the beginning. The first step may be to think about why and how you need to adapt, in a way that feels right for you.

The following may help you plan ways to adapt. Always seek advice from your health and social care professionals before trying new equipment or new ways of doing things. They can help you explore safe and suitable choices for your needs.



See section 4: *How do I get my needs assessed?*

## Washing and bathing

You may need help to access your bathroom, grip items, keep your balance and feel comfortable when washing, bathing and getting dry.



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

### Improve access to your bathroom with:

- wheeled shower chairs for entry into a level access shower cubicle (some can *tilt in space* for positioning)
- a wet room installation, to make your bathroom waterproof and one level, with no screen in your way
- a sit on bath board or movable bath seat to lower and raise yourself in the bath
- a lightweight plastic jug, for you or your carer to scoop water over you in the bath
- a walk in bath, where you step in through a door that closes, fill the bath and step out after it empties
- ceiling track hoists to help your carer lift and move you
- portable shower units to use anywhere, such as over a sink or an inflatable bathing tray.

## **Grip and reach items more easily in your bathroom with:**

- long handles to give more reach
- adapted items or sponging around handles for grip
- a foot cleaner or scrubber left in the bath or shower, so you don't have to reach down to wash your feet.

## **If not using a wheelchair, keep your balance better with:**

- a perching stool to perch at your sink
- nonslip mats at your sink, in the bath and in the shower
- grab rails to make you feel safer with more support
- a fixed seat or a shower stool to sit on.





## **For comfort and convenience, try:**

- keeping the bathroom warm so you can take your time
- using different colour flannels and towels for top half, bottom half and face if you need others to help you
- environmentally friendly cleaning wipes if you need something portable and quick
- a half-height screen to keep carers dry when they help
- a towelling dressing gown to dry off by wrapping and resting (wrap your feet and hair in separate towels).

## **Make it easier to wash and style your hair with:**

- long handled hair washers to help you wash your hair if you have limited arm movement
- a shower head and hose attached to taps
- a hair washing tray fixed to a sink, for someone to wash your hair while you sit, or an inflatable tray for them to wash your hair while you lie on a bed
- no rinse shampoo caps - these can be gently warmed and fit over your hair for massage until your hair is saturated (towel dry your hair with no need for rinsing)
- a hairdryer holder that fixes to a surface with suction cups, to help you angle your hairdryer and dry your hair hands free
- dry shampoo sprays to refresh your hair between washes (these may not be suitable with breathing problems)
- help from a hairdresser, as they usually offer hair washing and drying services, without the need for a haircut.



## Mouthcare

To protect against decay, it helps to brush your teeth last thing at night and another time in the day, with fluoride toothpaste.

If you have MND and you've been losing weight, you may also have been advised to eat more calories to reduce that loss. This may increase risk of tooth decay from eating sugary foods.

Even when you're using a feeding tube, mouthcare is essential as bacteria are still present.



See: information sheet 7B - *Tube feeding*.



**“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.”**

### **Make it easier to clean your teeth with:**

- a lightweight electric toothbrush or multi-sided toothbrush to clean with less effort
- a large handled toothbrush or polystyrene ball on the handle for grip
- non-foaming toothpaste if you worry it may 'go down the wrong way' - look for toothpaste without sodium laureth sulphate or ask your GP if you can get this on prescription
- a mouth rest placed on one side of your mouth to keep your jaw open, if someone helps brush your teeth
- a nailbrush fixed to a surface by suction cups to clean dentures (over a basin of water in case you drop them).

If you have 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.

## Prevent gagging when brushing by:

- sitting upright with your head turned slightly to one side
- keeping your chin in a downward or level position and ask your carer to use slow, gentle movement, so you know what to expect
- soaking a soft washcloth in dental gel or fluoride mouthwash to get used to someone helping to clean your mouth (this isn't as effective as brushing and may irritate the soft parts of your mouth)
- using a soft baby toothbrush
- using your suction machine if you have one for excess saliva, as this can be used while brushing your teeth and a specialist toothbrush accessory can 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.”**



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 offer home visits. In England, ask your dentist for a referral or find out more at: **[www.communitydentalservices.co.uk](http://www.communitydentalservices.co.uk)** In Wales and Northern Ireland ask your dentist for a referral or seek guidance from your health and social care team.

## Dressing and getting ready

You may need help when getting dressed or undressed, and with fastenings. Think about practical ways to make this easier, but maintaining your own style can support your wellbeing and sense of self.



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

Check the care instructions on new items and reduce laundry time with easy-care fabrics.

### Make dressing easier with:

- lightweight, looser fitting or partially fastened clothes (these allow for easier access when going to the toilet)
- velcro (hook and loop tape) to replace fastenings
- belts with large, wide D rings instead of buckles
- adapted clothing, like side-opening underwear or elasticated clothing with no fastenings
- a dressing stick to pull up, push down and move clothing while getting dressed
- a hoop leg lifter, where you lift your leg using a strap with a stiffened loop at one end
- a bra dressing aid to hold one side of your bra so you can hook the other side with just one hand.
- zip pullers and button hooks can help with fastenings.

Focus on your top half more for style if you're seated a lot.



## **Maintain comfort by:**

- avoiding slippery, rough or itchy fabrics, but choosing absorbent fabrics such as cotton, viscose and modal, as these are less likely to make you sweat
- wearing clothes that are comfortable if seated for a long time, such as items that don't 'ride up' or loose-fitting trousers with an elasticated waistband
- using layers to keep warm but take off if you get hot
- wearing dark patterns, scarves, tabards or adult bibs to disguise splashes, spills, or problems with saliva
- checking your clothes or accessories won't get caught if you use a wheelchair or hoist.

## **Keep a sense of personal style by:**

- giving written guidance to those helping about how you want to be dressed, (such as clothing for cultural or religious beliefs)
- 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
- using adapted nail clippers that need less pressure or ask trained carers to help
- asking for help with your makeup.

Those helping you can watch YouTube clips on applying makeup or look at past photos of your style. Ask a beautician about hair removal, eyebrow shaping, eyelash tinting or permanent tattoo makeup. They often do home visits.





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

## Foot care

Shoes should always fit well, without pinching or rubbing.

With MND or Kennedy’s disease it can also help if they:

- are fully enclosed (not slip-on or backless)
- have good grip, low heels and support your ankle
- fasten securely and easily.

Sock aids help when putting on socks and shoehorns extend reach when putting on shoes.

Boot jacks on the floor help you take off shoes without bending.

## Find specialist help from:

- occupational therapists and physiotherapists for guidance if you’re worried about trips or falls
- orthotics services for guidance on foot support devices, such as splints, braces and insoles
- chiropodists or podiatrists for guidance and help with personal care tasks like like toenail cutting if needed.

Ask your GP or any health professional about referrals and find out about other help in a needs assessment from adult social care services.

Swollen feet can be a problem if seated for long periods of time.

### **Manage swollen feet with:**

- 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).

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

### **Toilet and intimate care**

MND does not usually affect the bowel and bladder, but getting to the toilet in time can be difficult if your mobility is affected.

With Kennedy's disease and the rare form of MND known as primary lateral sclerosis (PLS), you may also experience a sense of urgency to pee.



See our booklet *Kennedy's disease* and information sheet 2C - *Primary lateral sclerosis*.

Medications may also affect the way your bladder works.



**"No-one talks about living with urine incontinence from MND muscle relaxant medication."**

Even if there are no direct effects, you may be tempted to drink less to avoid the need to go to the loo. This can lead to dehydration and constipation.



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

You may find anxiety, medication, reduced mobility or weakened abdominal muscles lead to constipation. If you have difficulty breathing, it can also get harder to 'push' to empty your bowels.

Discuss any changes with your health team to find out about support. Some changes may not be due to MND and need checking, but could also have a remedy.

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

### **Keep clean and comfortable with:**

- clothing that's easy to remove (see earlier content on fastenings)
- a long handled bottom wiper
- cleaning foams and barrier creams that leave a water resistant layer on the skin, as this helps prevent skin problems and discomfort if you have an accident
- disposable pads, padded pants, bed pads, and pillow and mattress protectors, to help reduce anxiety about accidents and any discomfort.



**"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."**



## **Make using the toilet easier with:**

- guidance from an occupational therapist on toilet adaptations
- a raised toilet seat on top of your existing loo
- a frame around the toilet to make it easier to sit and stand
- grab rails in the bathroom, for stability
- a wash-and-dry toilet installation, or more affordable wash-and-dry seat that fits over your existing toilet
- a ceiling track hoist installation, so that your carer can help you transfer safely (ask your occupational therapist for advice about using a mobile hoist)
- a toileting sling to use with a hoist for transfer, which helps your carer (and can help when you're dressing too)
- a wheeled shower chair that fits across your existing toilet for stability and access.

## **Get to the toilet more easily with:**

- a portable toilet, such as a commode or bed pan, or a urine bottle or pan if you're out and about
- gels to thicken fluids and prevent spills or odours when using portable toilet items
- an outer sheath to drain pee into a bag, which can be used as a male alternative to absorbent pads (often called condom catheters, uridomes or external catheters)
- a catheter, which places a flexible tube into your urethra (the part of your body that empties your bladder of pee).

Catheters carry a risk of infection, but can help make managing urine easier and come in two options:

- **a urethral catheter** is inserted into the bladder by a doctor or nurse and usually changed by them when needed too. It drains your pee into a larger bag at night or a smaller, more private bag in the day, which you then empty as needed.
- **a suprapubic catheter** is inserted by a doctor into a small opening made in the side of the abdomen and then drains into a bag. It has a shorter tube, which can be changed more easily.

With a suprapubic catheter, you can still have sex as a male (not possible with a urethral catheter). Sex is usually more comfortable for females with this type of catheter.



For more about sexual expression, see our booklet: *Sex and relationships: for people with MND or Kennedy's disease, and their partners.*

## Using public toilets

Using portable devices can be helpful (see previous heading) but there may be times when you need to use a public toilet.

Knowing where to make toilet stops can help your confidence when travelling. Plan your journeys ahead to avoid anxiety.

Most places that offer a public toilet also offer an accessible toilet. You may need a RADAR key to access some of these.



## 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.”**

You can purchase a RADAR key to access the thousands of accessible toilets that are locked to protect their use.



See Useful organisations in section 6:

*How do I find out more?* for:

- Disability Rights UK, who provide details about RADAR keys
- Changing Places, for help to search for accessible toilets.



## How can I manage my periods?

You may feel embarrassed to ask for support with your periods, but this information can help open conversations with your GP and those involved in your care. A practice nurse or family planning clinic can also give advice.

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

**Sanitary pads and tampons:** you may need help to replace and dispose of these and 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 cost too, but you need to insert and remove them.

**Period pants:** are washable pull up pants that absorb fluids during your period to keep you clean and comfortable. These are becoming popular and more affordable.

**Contraceptives:** to stop your periods may be an option if your periods become difficult to manage. Ask your doctor for guidance. If pills are difficult to swallow, you may be able to have a coil or implant fitted, or a contraceptive injection.

**Chemically induced menopause:** permanently stops periods, but can have a significant impact. Your doctor can provide guidance. If your periods have become irregular, ask to have your hormone levels tested as you may be nearing menopause.

## What else can affect personal care?

You may find it helpful to think about safety, mobility and eating and drinking. Use these checklists to think about your needs now and what you are likely to need 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 personal alarms help?
- Does your home need adaptations now or in the future?
- Have you had your needs assessed for possible care support?



**“My chair is easy to use. I can now stand 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 for some batch cooking of nutritious meals to 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.”**



See our guide: *Eating and Drinking with MND*.

## Moving around:

- ❑ Do you need a riser-recliner chair, adjustable bed or hoist to help your carer provide support?
- ❑ Could environmental controls help you access things in your home through remote control?
- ❑ Would a wet room, through floor lift or stairlift be suitable?
- ❑ Could a wheelchair, walking frame or ramps help?
- ❑ If you use a wheelchair, would creating turning circles or having doorframes widened help you with access?
- ❑ Would converting rooms downstairs be more suitable?

If using a wheelchair with a stairlift, you need to transfer from seat to seat. You may need a wheelchair on each floor and possibly a hoist. If you use a walking aid, such as crutches or a frame, keep a spare upstairs.



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



See our resources on Disabled Facilities Grants, equipment, wheelchairs and environmental controls.



## 4: How do I get my needs assessed?

You and your carer may need some external help, as your symptoms progress and care needs increase.



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

Services can take time to arrange. Early planning can help you and your carer get the timely support you need.

### How do I get my needs assessed?

By law you are entitled to receive an assessment and for any agreed care needs to be met by the relevant authority. You may have to contribute to the cost of agreed services, following a financial assessment.

Adult social care services can provide a needs assessment if you have MND or Kennedy’s disease, or a carer’s assessment if you provide care. The assessment helps you work out your needs, support services and how to plan for emergencies.

To arrange an assessment in England and Wales, contact your local authority. See: **[www.gov.uk/find-your-local-council](http://www.gov.uk/find-your-local-council)**

To arrange an assessment in Northern Ireland, contact your local health and social care trust. Search for *health and social care trusts* at: **[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

To arrange an assessment in Scotland, contact your local council. See: **[www.careinfoscotland.scot/find-my-council](http://www.careinfoscotland.scot/find-my-council)**

Everyone will have a different outcome from assessment, depending on their situation, symptoms, and preferences.

Funding may be available through a Disabled Facilities Grant (DFG), to make home adaptations, but this can take time.

Think about applying for a DFG as early as possible and ask an occupational therapist to assess your needs at home.

You may be entitled to a range of benefits and financial support such as Attendance Allowance (AA) at state pension age or Personal Independence Payment (PIP) at working age. Both help with the extra living costs of long-term illness or disability. PIP may also help with mobility costs.

For government information on benefits and social care, see **[www.gov.uk](http://www.gov.uk)** for England and Wales, **[www.nidirect.gov.uk](http://www.nidirect.gov.uk)** for Northern Ireland or **[www.mygov.scot/browse/benefits](http://www.mygov.scot/browse/benefits)** for Scotland.

In Northern Ireland you can also contact Make The Call, to check if you're getting the benefits and support you're entitled to: **[www.nidirect.gov.uk/contacts/contacts-az/make-call-service](http://www.nidirect.gov.uk/contacts/contacts-az/make-call-service)**



See our information sheets 10A - 10G on benefits and social support.

See *Further information* about our MND Association Benefits Advice Service at the end of this booklet.

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

Discuss any problem with the service provider first. For example, adult social care services, a care agency or the authority making a decision about a benefit claim. For benefit claims, this first step is known as a mandatory reconsideration. If this fails to solve the issue, the following may help.

Challenge the result of a needs assessment by contacting:

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

Challenge the care support you receive from a provider, by contacting:

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



Find current contact details and more at:  
**[www.mndassociation.org/mycare](http://www.mndassociation.org/mycare)**

To challenge a decision for a benefit claim (after mandatory reconsideration), see:

- England and Wales, search *benefits appeals* at:  
**[www.gov.uk](http://www.gov.uk)**
- Northern Ireland, search *appeals* at:  
**[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**
- Scotland: **[www.mygov.scot/disagree-decision](http://www.mygov.scot/disagree-decision)**

## NICE Guideline on MND

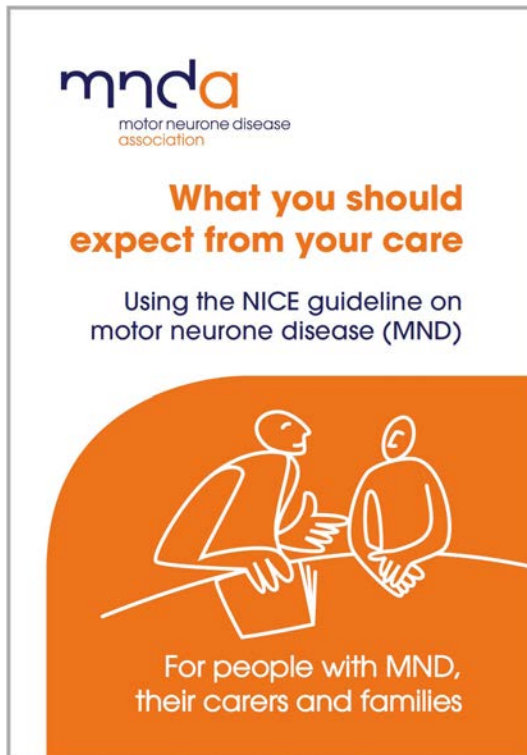
NICE guideline NG42 sets out recommendations about the management of motor neurone disease (MND):

[www.nice.org.uk/guidance/ng42](http://www.nice.org.uk/guidance/ng42)

It's provided by the National Institute for Health and Care Excellence to help health and social care professionals provide appropriate care.



See our pocket guide based on the guideline, *What you should expect from your care*. This may help you at appointments to get the right care outcomes.





## 5: Who can help me?

With personal care, your main contacts will likely include your:

**GP:** for guidance, symptom management and medication, and referral to specialist services, such as speech therapy.

**Occupational therapist (OT):** for assessment of your needs, guidance on managing daily tasks, safety at home, maintaining independence, assistive equipment and home adaptations.

**Physiotherapist:** for assessment and advice on positioning, managing falls and exercises to help maintain range of movement and comfort, including assisted exercise.

**District or community nurse:** for help to meet your health needs at home, working with your GP and healthcare team.

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

**NHS Continuing Healthcare:** for a package of nursing and social care. This is fully funded by the NHS in England and Wales, where healthcare needs are assessed as urgent and severe.

There is no formal guidance for NHS Continuing Healthcare in Northern Ireland, but health and social care trusts often refer to the criteria. In Scotland, you may qualify for Hospital Based Complex Clinical Care if your needs must be met in hospital.



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

## How do I get information in the format I need?

Everyone in the UK has the right to health and social care information in a way they can access and understand. If you are disabled, health and social care services funded by the government or the NHS must provide information in a format to help you make decisions. Ask for support before an appointment or assessment, to give them time to arrange this.

In England, Wales and Scotland this is governed by the *Accessible Information Standard*:

**[www.england.nhs.uk/ourwork/accessibleinfo](http://www.england.nhs.uk/ourwork/accessibleinfo)**

In Wales, see also the *All Wales Standards for Accessible Communication and Information for People with Sensory Loss*: **[www.gov.wales/accessible-communication-and-information-standards-healthcare](http://www.gov.wales/accessible-communication-and-information-standards-healthcare)**

In Northern Ireland, accessible information is governed in various ways, including by the *Disability Discrimination Act 1995* and by *Quality Standards for Health and Social Care* from the Department of Health, Social Services and Public Safety 2006.

## Can the MND Association help?

We offer information in a range of formats and languages. Use our *Care information finder* to search for resources by need at: **[www.mndassociation.org/careinfofinder](http://www.mndassociation.org/careinfofinder)**



See also our information sheet 1B - *Health information in other languages and formats* and guidance in other languages at: **[www.mndassociation.org/languages](http://www.mndassociation.org/languages)**

## 6: How do I find out more?

### Useful organisations

We don't endorse organisations, but these may help your search or see: [www.mndassociation.org/usefulorgs](http://www.mndassociation.org/usefulorgs). If you need help to find services where details have changed, contact our MND Connect helpline (see *Further information* in this section).

### Adult social care services

Contact your local authority or council in England, Wales or Scotland, or your health and social care trust in Northern Ireland.

### Age UK

Guidance for older people, including topics like incontinence.

Telephone: 0800 055 6112

Website: [www.ageuk.org.uk](http://www.ageuk.org.uk)

### British Red Cross

For a variety of disability living aids and equipment hire.

Telephone: 0344 871 11 11

Website: [www.redcross.org.uk](http://www.redcross.org.uk)

### Changing Places

Use their find-a-toilet to search for accessible facilities.

Telephone: 020 7803 4814

Website: [www.changing-places.org](http://www.changing-places.org)

### The Royal College of Occupational Therapists

For a search facility of registered occupational therapists.

Website: [www.rcot.co.uk](http://www.rcot.co.uk)

## **Disability Rights UK**

Search for *RADAR* key to find out how to purchase one.

Telephone: 0203 687 0790

website at: [www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)

## **MND Scotland**

Providing support for people affected by MND in Scotland.

Telephone: 0141 332 3903

Website: [www.mndscotland.org.uk](http://www.mndscotland.org.uk)

## **NHS and UK healthcare**

Information about NHS services and healthcare across the UK

Website: [www.nhs.uk](http://www.nhs.uk)

### **For England**

Telephone: 111 (for urgent medical advice, available 24/7)

Website: <https://111.nhs.uk>

### **For Wales**

Telephone: 111 (for urgent medical advice, available 24/7)

Website: <https://111.wales.nhs.uk>

### **For Northern Ireland**

Telephone: through each Trust's website contact page

Website: [www.hscni.net](http://www.hscni.net)

### **For Scotland**

Telephone: 111 (for urgent medical advice, available 24/7)

Website: [www.nhs24.scot](http://www.nhs24.scot)

## **RiDC**

Information on living independently with disability.

Telephone: 020 7427 2460

Website: [www.ridc.org.uk](http://www.ridc.org.uk)

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## References

References supporting this content are available. Email to:

**[infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)** or write to:

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

## Further information

### Information sheets:

6A *Physiotherapy*

6B *Complementary therapies*

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

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

We also provide guidance on equipment, wheelchairs and environmental controls.

## **Guides and booklets:**

*Living with motor neurone disease (MND)*  
*Living alone with MND or Kennedy's disease*  
*Caring and MND – Support for you*  
*Eating and drinking with MND*  
*Types of care*  
*Getting around*  
*Telling people about MND*  
*Emotional and psychological support*  
*Changes to thinking and behaviour with MND*  
*Sex and relationships with MND*  
*MND Checklist*  
*Understanding my needs*  
*What you should expect from your care*

For children, young people, parents and guardians:  
**[www.mndassociation.org/cyp](http://www.mndassociation.org/cyp)**

Search for our information by need at:  
**[www.mndassociation.org/careinfofinder](http://www.mndassociation.org/careinfofinder)**

Download at: **[www.mndassociation.org/publications](http://www.mndassociation.org/publications)**  
Or order printed copies from our MND Connect helpline:

## **MND Connect**

Telephone: **0808 802 6262**

Email: **[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**

## **MND Association Benefits Advice Service**

Find details at: **[www.mndassociation.org/benefitsadvice](http://www.mndassociation.org/benefitsadvice)**  
or contact MND Connect.

## **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>**

## Our financial support

We provide a range of financial support for care needs, quality of life, carers and young people. Some 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/financialsupport**

## We welcome your feedback

We'd love to hear your thoughts on this booklet at: **www.smartsurvey.co.uk/s/personal-care** or email your comments to: **infofeedback@mndassociation.org** or post to *Infofeedback* at the address shown below. Your anonymous comments help us improve our content and raise awareness by sharing your experience in our resources, campaigns or applications for funding.

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



*Patient Information Forum*

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