



11C

# Equipment and wheelchairs

## Information for people with or affected by motor neurone disease, or Kennedy's disease

With MND, you may experience problems with movement and strength in your arms, hands and legs. This can make everyday tasks difficult. Equipment to prolong independence can improve your quality of life. If you are living with Kennedy's disease, you may have similar symptoms and also find this information helpful.

This information sheet looks at ways to make daily life easier by using a range of equipment, including wheelchairs, and how to access this support.

Always get individual advice from your occupational therapist to ensure that equipment or installations are right for you.

The information is split into the following sections:

- 1: **Do I need to use equipment?**
- 2: **What types of equipment can help with MND?**
- 3: **Where do I get equipment from?**
- 4: **How do I access a wheelchair?**
- 5: **How do I find out more?**



This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.



This symbol is used to highlight **quotes** from other people with or affected by MND.


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




# 1: Do I need to use equipment?

At first, you may not need any support with MND. As your symptoms progress, you may find new ways of doing things, but in time you will need more help.

Accepting you have to find new ways of doing things can be difficult for you and those close to you. However, equipment designed to assist with disability can help you remain independent for longer. You may need to use different types of equipment as your needs change. Equipment can also help you and your carer to save energy for activities you really want or need to do.

 *“For my wife’s peace of mind, it’s better for me to use walking aids as I’m not balanced enough to risk not using them.”*


The impact of MND on your mobility and independence can be frustrating and upsetting, but support can make these changes feel easier. Ask your GP or another member of your health and social care team for advice.


 For more information about coping with the emotional impact of MND, see our guides: *Emotional and psychological support* and *Changes to thinking and behaviour with MND*

## What if I’m just tired?

With MND, you may feel tired if:

- your muscles have weakened and it takes more effort to complete everyday tasks
- your breathing is affected and this causes fatigue
- you are finding it more difficult to eat and drink the amounts you need.

 For more information about breathing with MND, see: Information sheets 8A to 8D

 For more information about swallowing with MND, see: Information sheet 7A – *Swallowing difficulties*

It may help to ask your GP for a referral to the following specialists:

- a respiratory team if you think your breathing is affected
- a speech and language therapist and a dietitian if your swallowing is affected
- an occupational therapist who can give you advice on managing tiredness (fatigue) and different ways to do activities which are important to you.

Equipment can also help with fatigue, particularly if doing things begin to take longer. If you can find ways to do tasks more easily, you can save energy.

It can help to think about energy like a 'bank account'. If you overspend one day, you may feel extremely tired the next. Plan what you really want or need to do first. Delay or get help with other tasks as needed.



*"I prefer to think of fatigue in terms of my batteries running low and needing to recharge them".*

Try to:

- listen to your body and pace yourself
- prioritise tasks, manage your time and be flexible with routines
- ask your physiotherapist, occupational therapist and dietitian about ways to manage your fatigue
- plan a rest day before and after a particularly busy time, such as a day out
- carry out tasks while sitting and take frequent breaks
- organise your home so that important items are close at hand.



*"I would endorse taking advantage of any help that's available."*






For information about fatigue see our booklet [Personal care](#).




## 2: What types of equipment can help with MND?

The following overview looks at the types of equipment that may help with MND, depending on your symptoms. See also section 3: *Where do I get equipment from?*

<b>Difficulty</b>	<b>Examples of equipment or aids that may help</b>
<b><i>Getting around</i></b>	<ul style="list-style-type: none"> <li>• splints and braces to support vulnerable joints</li> <li>• walking sticks, crutches, grab rails and walking frames or rollators to give support and help balance when walking</li> <li>• wheelchairs to help with mobility or if you find it difficult to walk far without getting tired. See section 4: <i>How do I access a wheelchair?</i></li> <li>• manual handling aids such as hoists – either powered or manual – to help transfer, such as from chair to bed</li> <li>• ramps and widened doorways to allow wheelchair access</li> </ul>
<b><i>Getting upstairs or downstairs</i></b>	<ul style="list-style-type: none"> <li>• handrails on both sides of the stairs</li> <li>• stair lift – although you need to think about getting on and off the stairlift and what equipment you need on each floor, for example a wheelchair. A stair lift may only be helpful for a short amount of time</li> <li>• through floor lift that a wheelchair can fit into, to enable getting up and down different floors</li> </ul>
<b><i>Feeling safe on your own</i></b>	<ul style="list-style-type: none"> <li>• cordless or mobile phone close at hand to call for help</li> <li>• personal alarm which automatically contacts emergency services or other people of your choice, should you need urgent help. These can be worn as a pendant around the neck or on the wrist</li> </ul>
<b><i>Independence around the home</i></b>	<ul style="list-style-type: none"> <li>• environmental controls to operate TV, lighting, door entry etc</li> <li>• smart devices including smartphones, tablets or smart speakers such as Amazon Echo, Google Home or Apple HomePod. These can be used to control other devices around your home</li> </ul>

Difficulty	Examples of equipment or aids that may help
<b><i>Eating and drinking</i></b>	<ul style="list-style-type: none"> <li>• adapted cutlery, crockery and cups to help with grip and control</li> <li>• mobile arm supports to help move your arms and reach your mouth</li> <li>• different height and shaped tables</li> <li>• head supports to keep your head and neck in a comfortable position</li> <li>• portable suction unit to help clear the mouth</li> </ul> <p> For more information about swallowing see: Information sheet 7A – <i>Swallowing difficulties</i></p>
<b><i>Showering</i></b>	<ul style="list-style-type: none"> <li>• non-slip mats for grip and safety</li> <li>• grab rails to help support balance</li> <li>• level access shower or a wet room to make it easier to access the shower</li> <li>• wall-fixed seat, shower stool, wheeled shower chair to enable you to sit down in the shower</li> </ul>
<b><i>Bathing</i></b>	<ul style="list-style-type: none"> <li>• non-slip mats for grip and safety</li> <li>• grab rails to help support balance</li> <li>• bath boards or mechanical bath seat to make it easier to get in and out of the bath</li> <li>• hoist – either powered or manual to transfer in and out of the bath</li> </ul>
<b><i>Using the toilet</i></b>	<ul style="list-style-type: none"> <li>• a 'bottom wiper' with a long looped handle and paper grip or a powered washer/dryer toilet to support you to clean yourself after using the toilet</li> <li>• raised toilet seat, grab rails, toilet frame or commode to make it easier to get on and off the toilet</li> <li>• wash and dry toilets could be installed, a cheaper alternative is a wash and dry toilet seat which may fit over your existing toilet</li> </ul>

Difficulty	Examples of equipment or aids that may help
<b>Getting dressed and personal care</b>	<ul style="list-style-type: none"> <li>• leg lifters, sock aids and shoe horns can make getting dressed easier</li> <li>• button hooks and zip pullers to make managing clothing fastenings easier</li> <li>• long handled hairbrushes and hands free hairdryers to make grooming yourself easier</li> <li>• adapted clothing</li> </ul> <p> For details about getting dressed and feeling comfortable in your clothes, see our booklet: <i>Personal care</i></p>
<b>Mouth care</b>	<ul style="list-style-type: none"> <li>• lightweight electric toothbrush, extra long handled toothbrush, three-sided toothbrush, easy-grip toothbrush if you have limited arm strength or movement</li> <li>• non-foaming toothpaste to help if you have swallowing difficulties and worry about choking on toothpaste</li> <li>• portable suction units with a tooth brush attachment can be used to help clear the mouth of toothpaste and saliva</li> </ul> <p> For more information about caring for your teeth and mouth with MND, see our booklet: <i>Personal care</i></p>
<b>Bed</b>	<ul style="list-style-type: none"> <li>• bed raisers to increase the height of your bed, or grab rails to make it easier to get into bed</li> <li>• slide sheets to help you transfer and make it easier for carers to move you in bed</li> <li>• powered adjustable bed to support your positioning, particularly if you have difficulties breathing and cannot lie flat, including a mattress or pillow lift</li> </ul>
<b>Comfort</b>	<ul style="list-style-type: none"> <li>• cushions to make chairs more comfortable and relieve pressure</li> <li>• riser recliner chairs to help you to sit down and stand up and improve your comfort</li> <li>• head supports to keep your head and neck in a comfortable position</li> </ul>

Difficulty	Examples of equipment or aids that may help
<b><i>Driving or being a passenger</i></b>	<ul style="list-style-type: none"> <li>• leg lifters, hand holds, transfer boards, hoists and swivel cushions to make it easier to get in and out of the car</li> <li>• adapted car controls to help you continue driving if you find standard controls difficult to manage</li> <li>• wheelchair accessible vehicles to travel without transferring in and out of your wheelchair</li> </ul> <p> For further information about driving, travel and transport, see our booklet: <i>Getting around</i></p>
<b><i>Communication</i></b>	<ul style="list-style-type: none"> <li>• communication boards or books to enable you to point or signal to letters or words to create your message</li> <li>• eye-pointing frames to indicate a letter, word or symbol by directing your gaze at the appropriate section</li> <li>• voice amplifier to make your voice louder if it has become faint</li> <li>• voice output communication aids to store words or phrases electronically that can be played back</li> <li>• voice banking and message banking</li> <li>• tablet with text-to-speech app</li> <li>• assistive technology such as eyegaze</li> </ul> <p> For more information about communication aids, see information sheets: 7C – <i>Speech and communication support</i> 7D – <i>Voice banking</i></p>
<b><i>Sex and intimacy</i></b>	<ul style="list-style-type: none"> <li>• slings, harnesses and positioning pillows to support positioning and comfort</li> <li>• sexual aids for both men and women if tiredness or movement are an issue</li> <li>• adjustable beds to help with transfers and positioning</li> </ul> <p> For more details about sex and relationships with MND, see our booklet: <i>Sex and relationships</i></p>

### 3: Where do I get equipment from?

Before buying equipment seek an assessment with an occupational therapist, as not all equipment is suitable for everyone. Mistakes can be costly and frustrating. An occupational therapist can also help you think about your future needs. As some items may take time to arrange, it is best to arrange them early.

Your needs should be regularly reviewed to ensure equipment is suitable for you.

The types of equipment you need will depend on how MND affects you. It may be helpful to ask other people with MND about equipment they use and find helpful. Our online forum provides a safe place for you to communicate openly with other people affected by MND. You can view the forum conversations without joining if you prefer. Visit the forum at: <https://forum.mndassociation.org>

Our branches and groups run informal support meetings for people living with MND and their carers. Contact MND Connect to find your local branch or group. See section 5: *How do I find out more?* for contact details.

#### Who can help me?

**Physiotherapist:** for advice on exercise, passive or assisted, to help maintain flexibility and movement in muscles not yet affected by MND. They can offer guidance on muscle stiffness (spasticity), cramps, fatigue and positioning to maximise your comfort. They can also advise on mobility aids, such as walking frames.



For more information about physiotherapy for MND, see: Information sheet 6A – *Physiotherapy*

**Speech and language therapist (SLT):** for advice and assessment on speech and swallowing difficulties. An independent assessment with a speech and language therapist is recommended if you are considering purchasing any communication aids.

**District or community nurse:** for medical services, such as assistance with medication and monitoring symptoms. They can support you to get nursing equipment at home such as a hospital bed, pressure relieving mattresses and commodes. (In some areas an occupational therapist can assess for and supply a commode, as these can help with fatigue.)

**Dietitian:** works closely with your speech and language therapist to advise on the most appropriate diet to help you maintain a healthy weight and offer advice on nutrition where swallowing may be difficult.



**Occupational therapist (also referred to as an OT):** for advice on posture and equipment, to help you continue daily routines with as much independence as possible. They can advise how to maintain independence in all aspects of self-care and daily living. In terms of equipment and aids, they are usually the main professional contact. If you do not currently have an occupational therapist, ask a member of your health and social care team for a referral.

Occupational therapists can also:

- provide guidance on preventing falls
- recommend how to maintain posture, minimise pain and reduce discomfort
- advise about adapting your home environment for wheelchair accessibility or for equipment to help you with mobility or tasks
- provide advice to you and your carer on moving and handling
- suggest ways to budget your energy to help manage fatigue
- provide guidance on how to maintain work or social activity and personal hobbies or interests
- advise you about using equipment to control your environment
- support the psychological and emotional impact of MND and using new equipment.

## **Will I need to pay for any equipment supplied?**


**Home or personal equipment through your occupational therapist:** If you are assessed by an occupational therapist who agrees you need equipment, it is usually loaned to you free of charge. However, your local authority in England and Wales may charge for certain pieces of equipment. In Northern Ireland, you will not be charged for pieces of equipment.

**Nursing equipment through your community nurse:** If a district or community nurse provides home nursing equipment, this is usually free of charge, but larger items may be provided on loan, such as a powered bed.

**Servicing and maintenance:** Check with the service providing the equipment whether they will pay for any servicing the equipment may need. If the equipment was provided following an assessment, this will usually be the case.

**Home adaptations or installations:** For larger adaptations or installations, a Disabled Facilities Grant (DFG) may be available from your local authority or, in Northern Ireland, the Northern Ireland Housing Executive (NIHE), if you qualify. You may still need to contribute towards the costs. Some people choose to fund the work themselves or seek funding from charities, which may help to get the work completed more quickly.

It is important to try and think ahead, rather than waiting until you need the adaptation, as a grant can take a long time to be agreed.

 For more information about Disabled Facilities Grants, see:  
*10C - Disabled Facilities Grants and home accessibility (DFGs)*

Always seek assessment from an occupational therapist first to ensure any adaptation will suit your needs. Your local authority or the NIHE can usually advise on how to check if a building contractor is reputable and has appropriate certifications.

## Can the MND Association help?

The MND Association may be able to help you access the equipment you need if you are unable to get it from your local adult social care services or the NHS (known together as statutory services).

### Equipment loan

We are able to provide a limited range of equipment that can be borrowed where statutory funding is not available or is not timely.

This includes:

- communication aids
- portable suction units.

Requests for equipment loan need to be made by a relevant health or social care professional. For more information on equipment loan, contact our Support Services team on: 0808 802 6262 or email: [support.services@mndassociation.org](mailto:support.services@mndassociation.org)

### MND support grants

We offer various types of support grant to help you and those close to you:

**MND support (care) grant:** may be able to help you fund equipment if it is not available from adult social care services or the NHS, or if there are large delays in accessing the equipment. You will need to have been assessed by a health and social care professional.

**Quality of life grant:** can be used for things that improve your quality of life such as household repairs, a holiday, complementary therapies etc.

**Carer's and young carer's grant:** specifically to help main unpaid carers aged over 16 to take a break, such as respite, a spa day etc.

**Young person's grant:** for those aged 18 and under who either live with the person with MND, or their parent or guardian is living with MND. It can support young people to fund things that they may miss out on due to the impact of MND on their family, such as driving lessons or school trips.

If you would like further information about our grants or would like to discuss an application, contact our Support Services team on 0808 802 6262 or email: [support.services@mndassociation.org](mailto:support.services@mndassociation.org)

## **What if I need to source equipment for myself?**

You can source products through specialist suppliers, mail order, the internet or various general stores. However, it is still worth having an assessment with an occupational therapist before purchasing any items to ensure they meet your needs.

Some key things to consider when purchasing equipment:

- Can I get spare parts easily if needed?
- Does it need to be serviced?
- Can it be returned if I am not happy with it?
- Does it come with a warranty?
- Would hiring the equipment be a better option?
- Will it meet my needs in the future, as my symptoms progress?

You may be able to get VAT exemption on products designed for people with disabilities if you qualify. The supplier should sell you the goods or services with the VAT already discounted, so discuss this in advance.

## **What if I need equipment to be able to continue working?**

The Access to Work scheme helps employers get grants to provide equipment, adaptations or support to enable disabled employees and carers to continue working if they wish to. For England and Wales, contact Access to Work to apply. For Northern Ireland, contact your local job centre or social security office. See *Useful organisations* in section 5: *How do I find out more?* for contact details.



For more information about support to help you continue working, see: Information sheet 10E – *Work and MND*

## 4: How do I access a wheelchair?

MND can cause muscle wasting and fatigue. This can lead to mobility problems, including difficulty walking. Initially, equipment such as walking sticks and frames can help, however you may need to consider a wheelchair as your symptoms progress.

The thought of using a wheelchair may feel upsetting. Discuss any concerns about using a wheelchair with your occupational therapist or wheelchair service, as they are experienced in supporting people to adjust to new equipment and can answer any questions.

Using a wheelchair can improve your quality of life by helping you to:

- maintain your mobility and independence
- continue community and social activities
- preserve your energy
- avoid falls.



*"My wheelchair has really changed my life."*

Local wheelchair services are provided by the NHS in England and Wales. In Northern Ireland, they are provided by your local health and social care trust. A member of your health and social care team can refer you to your local service.

You will have an assessment to determine whether you need a wheelchair and which type would be most suitable for you. Getting a wheelchair provided can be a lengthy process. However, the NICE guideline on MND says that, if needed, you should be able to get a wheelchair that is right for you quickly.



For more about the NICE Guideline on MND, see: Information sheet 1A – *About the NICE Guideline on MND*

### What types of wheelchair are there?

#### Manual wheelchairs

There are two main types of manual wheelchair:

**A standard wheelchair:** These can be useful and convenient if you are starting to need help with your mobility. This type of chair is generally easy to use and can be folded up to transport in a car boot.

**A highly supportive manual wheelchair:** These are most often used if you need more support with your posture than can be offered by a standard wheelchair. These are larger than standard wheelchairs and may not fit into a car boot.

Tilt-in-space is a mechanism that will tilt the whole seat and back backwards. This is helpful if you have weakness in your trunk, shoulders and neck, as it can help prevent you sliding down the wheelchair, and can also relieve the effects of fatigue.

## Powered wheelchairs

These wheelchairs offer more independence if you are unable to self-propel a manual wheelchair. Powered wheelchairs are usually driven using a hand-operated joystick controller but a wheelchair therapist or rehabilitation engineer will assess you for the most suitable control system. Powered wheelchairs usually include a powered tilt-in-space mechanism.

There are many different types of powered wheelchairs, which may be suitable for indoor or outdoor use only. Some can be used both indoors and outdoors. The NHS will only provide wheelchairs that can be used either indoors only, or indoors and outdoors. It is not advisable to lift a powered wheelchair into a car due to the weight of the wheelchair, but a boot hoist might be an option if an existing car is big enough. A wheelchair accessible vehicle (WAV) is an alternative option, especially if transferring into a car seat is difficult.



For more information about suitable vehicles with MND, see our booklet: *Getting around*.

If you are travelling by air, powered wheelchairs can be taken on a plane. However, airlines may require them to be immobilised while flying. An 'airsafe' plug can be bought to inhibit powered wheelchairs on flights. This device is compatible with most powered wheelchairs. It plugs into the charging socket to immobilise the chair. This can prevent costly damage to wheelchairs, such as wires being cut or taking the chair apart to remove the battery. Search for *airsafe wheelchair plug* online to purchase, as may be available from various suppliers.



For more information on travelling with MND, see our booklet: *Getting around*

## Powered Neuro Wheelchair

The MND Association has worked with three wheelchair manufacturers to create different models of Powered Neuro Wheelchair. These wheelchairs are specifically designed to meet the needs of people with MND and other similar conditions.

Each of the Powered Neuro Wheelchairs is suitable for indoor and outdoor use and has features that can adapt as your needs change.

Each wheelchair has been designed to be affordable by local NHS wheelchair services, so it is worth discussing this option during your assessment. Features of the Powered Neuro Wheelchair include:

- powered tilt-in-space, to help prevent slumping or sliding
- a cushioned, adjustable backrest
- a seat board that can be supplied with the most appropriate cushion
- different headrest options
- padded arm rests
- options for adding different controls and switches
- independent angle-adjustable foot rests.

## **How will I be assessed for a wheelchair?**

**England:** assessments are offered by the NHS through its wheelchair services.

**Wales:** assessments may be provided by an OT, or if you need a specialist wheelchair, the Artificial Limb and Appliance Service via three Artificial Limb and Appliance Centres.

**Northern Ireland:** assessments are carried out through the occupational therapy service in your local health and social care trust.

An assessment will consider:

- your posture and mobility
- your living environment and local surroundings, for example, will the chosen wheelchair fit through doorways in your home?
- how the wheelchair will be transported
- your family and carers needs
- the activities you wish to do
- your skill level, particularly with safe control of a powered wheelchair
- relieving pressure and also prevention of pressure sores
- how your needs may change in future.

The assessment may include an eye test for a powered wheelchair, although not every wheelchair service will need to do this.

## **Will I need to fund the wheelchair?**

Once you have been assessed, the wheelchair service will advise which type of wheelchair they can provide to you on loan. The loan of the chair is free of charge. They will also be responsible for cost of servicing, maintenance and repairs.

If you choose to purchase a wheelchair privately, you should still have your needs properly assessed by a relevant professional. You can request a copy of your assessment and use this to help you choose an appropriate wheelchair. Purchasing a wheelchair privately without an assessment can lead to costly mistakes and a chair that may not meet your needs.

## **Personal wheelchair budgets (England only)**

In England, the aim of a personal wheelchair budget (PWB) is to help you choose a wheelchair suited to your needs and preferences, with support from your wheelchair therapist.


Personal wheelchair budget schemes vary depending on where you live, but you will still need to be assessed for a suitable wheelchair by your local NHS wheelchair service. This assessment will help develop your wheelchair support plan.


You may wish to ask the following during your assessment:

- Is a personal wheelchair budget available?
- Can I have the details of my local personal wheelchair budget scheme?
- Who will own the wheelchair?
- Who will maintain or repair the wheelchair?
- What happens if I need a reassessment?
- What happens if my needs change and my equipment is no longer suitable?

There are three personal wheelchair budget options:

- **Notional PWB (within the NHS)**, where you access a wheelchair from the NHS range of the wheelchair service. Your budget will cover what it would cost the NHS to provide an appropriate wheelchair. You can then add features to this wheelchair using money from another source. If you choose this option, the NHS will own the wheelchair, and will repair and maintain it for you.
- **Third party PWB (outside the NHS)**, where you can use your budget to contribute to buying a wheelchair from an independent provider, in agreement with your wheelchair therapist. Your budget will not cover the whole cost of the wheelchair, so you will need to top up the rest from another source of funding. Your budget will help with the cost of repairs and maintenance of the wheelchair, which you will need to organise. With this option, you may be able to own the wheelchair, following a decision from your local wheelchair service.
- **Direct payments**, where you can receive your budget in direct payments to your bank account. This option is only available for people who currently receive a personal budget for other needs, such as social care or continuing healthcare. You can use your budget to contribute to buying a wheelchair, and pay for repairs and maintenance from an independent provider. The rest of the cost of the wheelchair must come from your other personal budget. You may be able to own the wheelchair, following a decision from your local wheelchair service.

 For more information on direct payments and personal budgets, see: Information sheet 10B – *What is social care?*

 For more information on NHS Continuing Healthcare, see: Information sheet 10D – *NHS Continuing Healthcare*

PWBs are being introduced gradually in England and are not yet available everywhere.

## **What happens when the wheelchair arrives?**

This will depend on the type of wheelchair you are getting and how services work in your area. Your wheelchair may be issued from the stock available at the wheelchair service. However, it may need to be ordered from a supplier, which can take longer.

Once it arrives, your wheelchair will be adjusted to suit you and then you will be shown how to use it. For powered wheelchairs, you will be given opportunity to practice using it to ensure your safety. You should also be given advice about insurance.

Waiting times will depend on whether your chair is a standard order or made to measure. The Powered Neuro Wheelchairs have been designed to come as standard order chairs that are adjusted to your needs on arrival, so the wait is reduced.

## **How do I maintain and repair my wheelchair?**

The wheelchair service should tell you who to contact if there is a problem with your wheelchair. Most often, this will be an external service provider. Any wheelchair provided by a local wheelchair service will be serviced and maintained by the service. This may not be the case where a Personal Wheelchair Budget has been used in England, so ensure that you ask.

## **What if my needs change?**

If the wheelchair no longer meets your needs, contact the wheelchair service for a reassessment, adaptations such as seat risers, attendant controls, power packs and leg elevators may help, or a change from a manual to a powered wheelchair might be needed. Ensuring that your wheelchair and any other aids meet your changing needs can help to improve your quality of life and prolong your independence. 'Ask professionals involved in your care if an item is no longer helpful, as alternatives may be available.



## 5: How do I find out more?

### Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information. The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation or have any questions, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

#### Adult social care services (sometimes called social services)

For adult social care contact your local authority through your area telephone directory, or search for local authorities at GOV.UK

Website: **www.gov.uk**  
**www.nidirect.gov.uk** (for Northern Ireland. Search for health and social care trusts.)

#### The Royal College of Occupational Therapists (RCOT)

Sets the professional and educational standards for the occupational therapy profession and represents the profession at the national and international levels. You can search the site for a registered occupational therapist.

Telephone: 020 3141 4600  
Email: [hello@rcot.co.uk](mailto:hello@rcot.co.uk)  
Website: **www.rcot.co.uk**

#### Living made easy

Provide impartial advice, information and training on independent living.

Address: Unit 1, 34 Chatfield Road, Wandsworth, London SW11 3SE  
Telephone: 0300 999 0004  
Email: [info@dlf.org.uk](mailto:info@dlf.org.uk)  
Website: **www.livingmadeeasy.org.uk**

#### GOV.UK

Online government advice on a variety of welfare topics, including support for disabled people.

Email: email addresses are provided on the website, related to each enquiry  
Website: **www.gov.uk**

#### Health and Social Care Northern Ireland (NHS Northern Ireland)

Information on NHS services in Northern Ireland. This is an online service only.

Email: through the website contact page  
Website: **http://online.hscni.net/**

### Health in Wales

Information on NHS services in Wales, including a directory of the Welsh health boards.

Email: through the website contact page

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

### Local wheelchair services

To find your local wheelchair service contact details, visit the National Wheelchair Managers Forum (NWMF). You should be able to get local advice on local provision.

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

### MND Scotland

MND Scotland provides care, information and research funding for people affected by motor neurone disease in Scotland.

Address: Unit 8, 76 Firhill road Glasgow G20 7BA

Telephone: 0141 332 3903

Email: [info@mndscotland.org.uk](mailto:info@mndscotland.org.uk)

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

### NHS 111

The NHS telephone service if you need urgent, but not life-threatening medical help or advice. Available 24-hours a day, 365 days a year.

Telephone: 111 (England and some areas of Wales)

### NHS UK

The main online reference for the NHS.

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

### NI Direct

Providing government information for Northern Ireland on a variety of welfare subjects, including health services and support for disabled people.

Email: through the website contact page

Website: [www.nidirect.gov.uk](http://www.nidirect.gov.uk)

### Research Institute for Disabled Consumers (RIDC)

Carries out research and publishes information to enable disabled and older people to live more independently.

Address: Ground Floor, Unit 10, Blenheim Court, 62 Brewery Road, London N7 9NY

Telephone: 020 7427 2460

Email: [mail@ridc.org.uk](mailto:mail@ridc.org.uk)

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

## References

References used to support this information are available on request from

Email: [infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)

or write to:

Care Information Feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,  
Moulton Park, Northampton NN3 6BJ

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## Further information

You may find these information sheets from the MND Association helpful:

6A – *Physiotherapy*

7A – *Swallowing difficulties*

10C – *Disabled Facilities Grants and home accessibility (DFGs)*

10E – *Work and MND*

We also provide the following guides and other resources that you may find useful:

*Living with motor neurone disease* – our main guide containing an overview of MND

*Personal care with MND* – information on prolonging independence with daily routines

*Getting around with MND* – information on transport, driving and travelling with MND

*Making the most of life with MND* – ways to continue doing things you enjoy

*Sex and relationships* - information about maintaining intimacy with MND

*Caring and MND: support for you* – practical and emotional support for unpaid carers

*Caring and MND: quick guide* – the summary version of our information for carers

*Understanding my needs* – A tool to assist health and social care professionals to understand your needs

*MND alert card* – to carry in your pocket, purse or wallet that states you have MND and provides details of your emergency contacts

*MND checklist* - to help you manage your condition and think ahead

*What you should expect from your care* –notes to help at appointments.

You can download most of our publications from our website at:

**[www.mndassociation.org/publications](http://www.mndassociation.org/publications)** or order in print from the MND Connect helpline, who can provide further information and support.

MND Connect can also help locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional MND Association staff.

### **MND Connect**

Telephone: 0808 802 6262

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

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

### **MND Association website and online forum**

Website: **[www.mndassociation.org](http://www.mndassociation.org)**

Online forum: **<https://forum.mndassociation.org>** or through the website

## **We welcome your views**

We'd love to know what you think we're doing well and where we can improve our information for people with or affected by MND, or Kennedy's disease. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

To feedback on any of our information sheets, access our online form at:

**[www.smartsurvey.co.uk/s/infosheets\\_1-25](http://www.smartsurvey.co.uk/s/infosheets_1-25)**

You can request a paper version of the form or provide direct feedback by email:

[infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,  
Moulton Park, Northampton NN3 6BJ

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