



Living with
motor neurone disease



Living with

mnd

Contents

What people say about this guide	2
Foreword	3
How to use this guide	
Do you need to read it all?	4
How do I find the content I need?	4
What are the other resources in the folder for?	4
Further support	5

Part 1: What is MND?

Section 1: Motor neurone disease (MND)	7
Section 2: Managing symptoms	14
Section 3: What do I need to think about?	24

Part 2: Living with MND

Section 4: Emotional impact	29
Section 5: Family, children and friends	34
Section 6: Getting around	40
Section 7: Everyday activities and personal care	48
Section 8: Speech and communication	58
Section 9: Eating and drinking	66
Section 10: Finance, work and social care	74
Section 11: Planning ahead	84

Part 3: Accessing services and support

Section 12: How we can help you	93
Section 13: Useful organisations	98

Part 4: Helping you to keep track

Introduction	104
Personal details	105
Contact record	106
Appointment and communication record	113
Equipment record	117
Medication record	120
References	122
Acknowledgements	122
Index	123
What do you think?	129

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

What people say about this guide

From people living with or affected by MND:

“A useful guide to refer back to once the shock of diagnosis is overcome.”

“Knowing who you can contact and where to begin asking is a great advantage.”

“Glad to see you have emphasised the importance of planning ahead...also not buying equipment without appropriate advice.”

“Having the information to gain the resources you may need is invaluable and could save time, money, distress and confusion.”



The MND Association would like to thank the **Tesco Charity Trust**, and the **Evan Cornish Foundation** for their support which has made the production of *Living with motor neurone disease* possible.

From health and social care professionals:

“The best thing is the level at which this is pitched and the prompts to seek further advice on individual circumstances. If you had tried to cover every person’s experience, there would be far too much information and none of it would be accessible. I think the balance here is just right.”

Idris Baker, Consultant in Palliative Medicine
ABM University Health Board, South Wales

“Congratulations on an excellent, highly understandable and very readable information set.”

Pam Bostock, Consultant Occupational Therapist - Neurology, Adult Ability Team, Staffordshire and Stoke on Trent Partnership NHS Trust

“I found it a very easy to read document – I liked the ‘can do’ message it conveys and the regular personal quotes gives it ‘realness’ and validity.”

Alison Jinks, Specialist Palliative Care Occupational Therapist, Dudley Group Foundation Trust, Stourbridge Health and Social Care Centre



Foreword

My name is Gina Bellman. I'm an actress, a mother and the daughter of someone who is living with MND. If you are opening your copy of *Living with motor neurone disease*, right now, then you are having the exact same experience as I had several years ago when my own mother was diagnosed. Until that moment we had all been feeling a little bit windswept. We felt like we had been blown from pillar to post whilst various diagnoses were being discussed and explored.



Speaking to an adviser at the MND Association and opening my own copy of the guide felt like a well-earned moment of calm, where I could finally take some control and learn about what we were up against. *Living with motor neurone disease* provides a candid, but sensitive overview of MND and can direct you to where you can access support.

Engaging as early as you can with the variety of support on offer, may help you to make choices to ensure the best possible quality of life for you or your loved one. This guide enables you to read as much or as little as you want, when you feel ready to do so, with lists of further information if needed. MND is a complex condition. Each individual will have a different experience, depending on rate of progression, symptoms and their own circumstances.

Living with motor neurone disease has all the information you need and is carefully divided into sections so that you can refer to what is relevant to you as and when you need it.

It is simply written with bullet points and with refreshingly little medical jargon. When I received my copy, I highlighted the information that was relevant to us and forwarded it to our immediate family and support group.

This meant that we were all on the same page and could learn together moving forward. There is no question that MND can be totally overwhelming, but we have learned that if you take it one symptom at a time, it can lighten the load a little.

MND often feels very isolating, but support from people in similar circumstances can be very encouraging. The guide includes quotes, tips and experiences from others affected by the disease.

Please use this guide as a starting point to help you learn about MND and adjust to a different way of living, and remember that the MND Association is ready to listen, support and provide further direction as needed.

Wishing you all the best,

Gina Bellman

MND Association ambassador

How to use this guide

This guide is designed to help you achieve the best possible quality of life with motor neurone disease (MND).

Do you need to read it all?

Not all of the content will necessarily apply to you and certainly not all at once. You may find it helpful to scan through, so you know what to think about. Feedback from people with and affected by MND has been included to help you plan ahead. You can return for detailed information when needed.

If you have just been diagnosed and would prefer a short overview to start with, see our booklet *An introduction to motor neurone disease (MND)*.

How do I find what I need?

The guide uses plain English and clear headings. The sections are grouped into four parts, which are colour coded to help you find content easily:

Part 1 – What is MND?

The first part includes facts and what to think about when diagnosed.

Part 2 – Living with MND

The second part looks at how to manage everyday routines with MND.

Part 3 – Accessing services and support

The third part directs you to available services and support.

Part 4 – Helping you to keep track

The fourth part is designed to help you keep track of important details.

You will see the following features in each section:

- **Key points:** to highlight important things to think about
- **Further information:** to help you find other relevant resources
- **Quotations:** to share experiences from other people affected by MND.

What are the other resources in the folder for?

We provide other resources in the folder with this guide, including:

What you should expect from your care

Use this handy guide to open discussions about your care with health and social care professionals. The content is based on the NICE guideline for MND, which provides recommendations for appropriate treatment and care from the National Institute for Health and Care Excellence.

MND Alert Wristband

If you need urgent treatment, and you're unable to communicate for any reason, this wristband lets hospital staff know you have MND and may be at risk with oxygen. It directs professionals to further online information.

MND Alert Card

This card works in a similar way to the wristband and can be kept in a wallet or purse. It includes space to write down key contacts who understand your needs.

Understanding my needs

Use this booklet to record your needs and preferences to guide hospital staff, care workers and others involved in your care. It can also save having to repeat information at appointments.

Online forum and MND Connect helpline card

A reference card for our online forum, which provides a safe place to share experiences and support with others affected by MND, <https://forum.mndassociation.org>. The back of the card provides handy contact details for our MND Connect helpline.

Feedback form

We welcome your feedback on this guide to help us understand what we're doing well and where we can improve. Your comments and anonymous quotes can also help us raise awareness for our resources, campaigns and fundraising. A form is provided to reply by post – or feedback online at, www.smartsurvey.co.uk/s/LWMNDfeedback. You can also contact by email: infofeedback@mndassociation.org

Publications order form

Order printed copies of MND Association resources, as required. You can also download most publications at www.mndassociation.org/publications

Further support

See **Section 12: How we can help you** and **Section 13: Useful organisations**.

You can find out about our services, information and membership on our website, www.mndassociation.org

Contact our helpline, MND Connect with any questions, or to order printed publications. We also offer a selected range of resources in different formats and other languages.

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

If you are disabled, you can ask health and social care services for their information in a different format, if needed. For example, information in Braille or as an audio recording. In England, provision of accessible information is now mandatory for Government funded health and social care services - for more details, search for *accessible information standard* at: www.england.nhs.uk

If you live in England, Wales or Northern Ireland

The MND Association supports everybody affected by MND in England, Wales and Northern Ireland. We do all we can to ensure our information is relevant to all three nations, but NHS and local systems work sometimes work in different ways. Always check with local service providers for guidance on available support.

If you live in Scotland

Please contact MND Scotland for advice on support and services in Scotland.

See **Section 13: Useful organisations for contact details**.



Part 1: **What is MND?**

Section 1: Motor neurone disease (MND)

Section 2: Managing symptoms

Section 3: What do I need to think about?

1: Motor neurone disease (MND)



This section provides basic facts about motor neurone disease (MND) and its diagnosis.

What is MND?

Motor neurone disease (MND) is a condition that affects the motor neurones (sometimes called motor neurons). These are the nerves in the brain and spinal cord that control how your muscles work. This means that messages gradually stop reaching muscles, leading to weakness, stiffness and loss of muscle mass (wasting).

MND is progressive, which means symptoms get worse over time. It can affect how you walk, talk, eat, drink and breathe. In some cases, it can also change how you think and behave.

However, not all symptoms happen to everyone, or develop at the same time, or in any particular order. This means it is difficult to predict how the disease will affect you. Becoming informed about the possible changes can be daunting, but may help you feel more prepared.

“ Information helps me think ahead about what to do.”



Although MND is life shortening and there is currently no cure, symptoms can be managed to help maintain the best possible quality of life.

See [Section 2: Symptoms and management](#).

Who does it affect?

On average, six people per day are diagnosed with MND in the UK.

Studies show that the disease:

- can affect adults of any age, but usually when they are older than 40
- is most common in people aged 55–79 years
- affects up to 5,000 adults in the UK at any one time.

What does it affect?

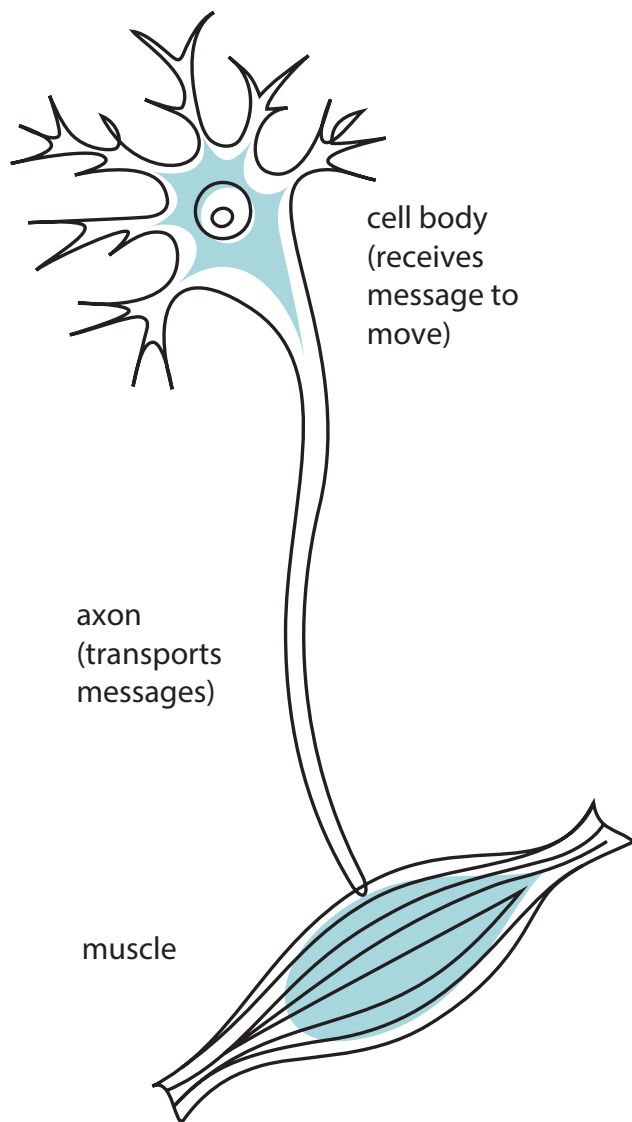
Your nervous system is made up of two main groups of nerves:

- those that control the senses, such as touch and sight, known as sensory neurones – these are **not** usually affected by MND, but other symptoms can impact on how you sense things
- those that control how our muscles move, known as the motor neurones – these **are** affected by MND.

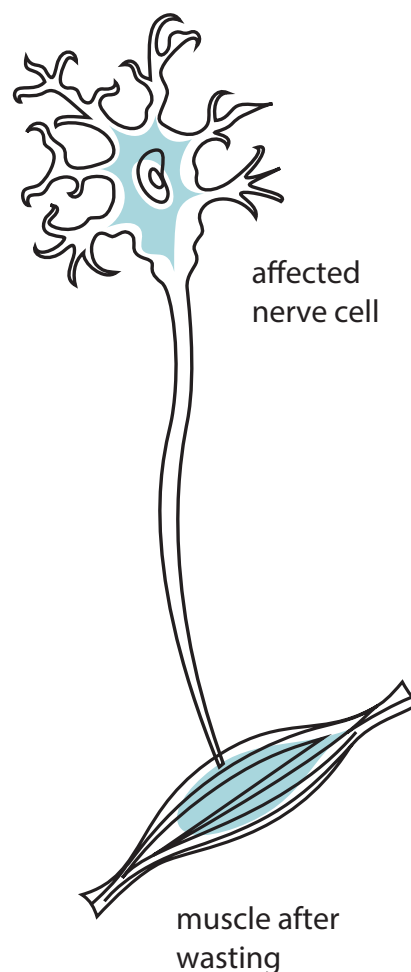
The motor neurones are split into two groups:

Upper motor neurones: these run from the brain into the spinal cord. They send instructions to the lower motor neurones, which then pass the messages to your muscles. Upper motor neurone damage tends to result in weak and stiff muscles.

Lower motor neurones: these run from the spinal cord to your muscles. They pass on the messages from the upper motor neurones to control movement. Lower motor neurone damage tends to result in weak and floppy muscles, and twitching sensations that ripple under the skin (known as fasciculations).



Healthy motor neurone



Motor neurone affected by MND

With MND, motor neurones become damaged and can no longer carry messages to the muscles. As this damage gets worse, it can cause difficulties with movement, mobility, speech, swallowing and breathing.

The muscles first affected tend to be those in the hands, feet or mouth. You may drop things, trip easily or slur words, but this can vary from person to person.

Up to half of people with MND also experience changes to their thinking and behaviour. In most cases, the changes are mild, but may be more severe for a small number of people.

MND does not usually have a direct affect on bladder and bowel, or sexual function. However, MND symptoms may impact on these.

You may have symptoms that are not related to MND, so always see your GP if you have any health problems.

See also [Section 2: Managing symptoms](#).

“ All I could feel was I had something wrong with my throat.”

How is MND diagnosed?

MND can be difficult to diagnose because:

- it is not a common disease
- it can take time before someone sees their GP, as they may think early symptoms are due to other causes (for example, clumsiness, mild weakness or slurred speech)
- the disease affects individuals in different ways, as they may not get all of the symptoms or in the same order
- there is no single test to prove someone has MND, so testing can only rule out other possible conditions.

Getting a confirmed diagnosis can take time.

“ I saw my GP on numerous occasions with different symptoms: cramps, loss of strength in right hand and arm, and general loss of core strength.”

Tests

If your doctor thinks you have a neurological problem, you will be referred to a neurologist for assessment and tests.

You normally attend any tests as an outpatient, but may need to spend a short stay in hospital.

Clinical examination: helps a neurological consultant recognise signs and determine which tests to use.

Blood tests: look for a rise in creatine kinase. This substance is produced when muscle breaks down. It is sometimes found in the blood of people with MND, but may indicate other medical conditions.

Electromyography (EMG): is sometimes called the needle test, as it uses fine needles to record natural nerve impulses within muscles. When muscles start to lose nerve supply, abnormal electrical activity can be measured, even if movement is not yet affected.

Nerve conduction tests: apply an electrical impulse through a small pad on the skin to measure the speed at which nerves carry electrical signals.

Transcranial magnetic stimulation (TMS): measures the activity of the upper motor neurones to assist diagnosis.

Magnetic resonance imaging (MRI) scans: involve being placed in a cylinder-like machine to take internal images of the body. These help rule out conditions such as stroke, Alzheimer’s disease, Parkinson’s disease, multiple sclerosis, tumours and trapped nerves, as well as injuries to spine or brain.

Other tests: may be requested by your neurologist if your symptoms mean they could be useful.

Are there different types of MND?

MND can be seen as one disease, with a range of symptoms. However, it can help to break it down into types, as each type may need different support.

There are four main types, each affecting people in different ways. However, overlapping symptoms can make it difficult to give an exact diagnosis.

The following definitions talk about life expectancy, so you may not want to read any more at this stage. If so, please move to the heading *What causes MND?*

Why include life expectancy here?

Information about life expectancy can be upsetting, but with MND, planning ahead is important. Understanding how types of MND usually progress can help with decision making on future care, treatments and finances.

Life expectancy for each type of MND is based on average results from clinical studies. However, the way MND progresses can be rapid for some and slower for others.

Amyotrophic lateral sclerosis (ALS): is the most common form. It involves both upper and lower motor neurones, leading to weakness, wasting of limbs, muscle stiffness and cramps. Early signs may include tripping up or dropping things. Average life expectancy is between two to five years from first symptoms.

Progressive bulbar palsy (PBP) – also known as bulbar onset ALS: affects a small number of those diagnosed with MND, and involves the upper and lower motor neurones, particularly those linked to the bulbar regions (muscles of the face, throat and tongue). Early symptoms may include slurring of speech or difficulty swallowing. Average life expectancy is between six months to three years from the point when symptoms begin.

Progressive muscular atrophy (PMA): affects a small number of those diagnosed with MND, mainly causing damage to the lower motor neurones. Early symptoms may show as weakness, diminished reflexes or clumsiness of the hands. Average life expectancy is usually more than five years. An email support group exists for people with this rare form.

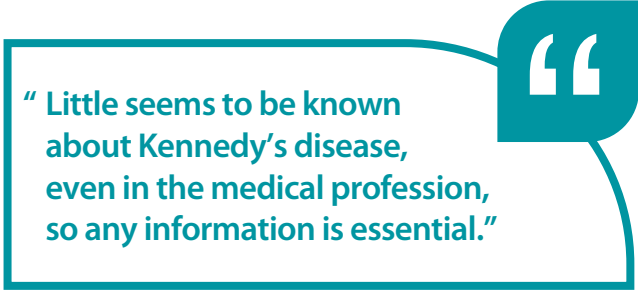
Primary lateral sclerosis (PLS): affects a small number of those diagnosed with MND, damaging the upper motor neurones only. This causes weakness in the lower limbs, although some people experience clumsiness in the hands or speech problems. Reflexes can become exaggerated. Average life expectancy may be 10 to 20 years, or more. An email support group exists for this rare form.

[See Further information at the end of this section about our resources on PMA and PLS.](#)

Please note that as symptoms progress, PBP, PMA and PLS are sometimes rediagnosed as ALS.

Kennedy's disease

Kennedy's disease is a rare neurological disease. As it causes increasing weakness and wasting of muscles, it can sometimes be confused with MND at diagnosis.



“ Little seems to be known about Kennedy's disease, even in the medical profession, so any information is essential.”

Most people with Kennedy's disease develop symptoms at 40-60 years old, but it can appear when older or younger. There is no known cure, but most people live an average life span with the disease. Symptoms can be managed to improve quality of life.

Kennedy's disease is caused by a genetic mutation, which can be diagnosed through gene testing. Usually, only men show symptoms, but women can carry the genetic mutation and may develop mild symptoms in rare cases. The MND Association offers support if you have Kennedy's disease and this guide may be useful where symptoms are similar.

[See also Further information at the end of this section.](#)

What causes MND?

It is still not possible to give a clear answer about the causes of MND. Each individual may be affected by a different combination of triggers. However, a neurological consultant will probably ask during diagnosis about any family history of MND or frontotemporal dementia (FTD). It is worth discussing family history with your neurologist, to help work out if an inherited gene is likely.

“ Many tears have been shed and we wondered why I had been ‘chosen’.”

MND with no apparent family history:

In most cases of MND there is no apparent family history of the disease and precise causes in these instances are not yet known. Multiple genetic and environmental triggers are thought to be involved, with genes playing a small role. The environmental triggers may be different for each individual, so there is no simple way of identifying how the disease began.

MND where there is a family history:

In a small number of cases, there is a family history and genes have more involvement. Where this happens, the disease is caused by a mistake in the genetic code, which can be passed down through the family. However, other triggers may still be necessary for the disease to begin.

If you are concerned about family history with MND, ask your neurologist about genetic counselling to find out more. Although sensitive to the emotions involved, genetic counselling is not a form of psychotherapy. A genetic counsellor explains the facts and relevant options as clearly as possible. This will include discussion about the possible impact on relatives, who may have inherited the genetic code.

You will be given accurate information about genetic testing and what is possible. Some of the genes that play a part in inherited MND have been discovered, but not all of them yet. This means test results may not be conclusive.

Being informed can help you decide whether genetic testing feels right for you. This can be a difficult decision, as it affects the wider family.

Your neurological consultant can advise on how to get genetic counselling for MND.

See *Further information* at the end of this section about our research sheets on **inherited MND and genetic counselling**.

Research into MND

A French doctor called Jean-Martin Charcot first described motor neurone disease (MND) in 1874, but very little was known about the condition.

Now, world-wide research into the disease and its causes is constantly advancing, with the aid of technology and data sharing. This includes projects funded by the MND Association. As a result, our understanding of MND and the way motor neurones function is growing rapidly. You can keep up to date with latest findings through the research pages on our website:

www.mndassociation.org/research

“ I am optimistic there will be a cure one day. It’s a challenge for the 21st century and I think science will find a way.”

Research projects and clinical trials often need people with MND to take part, and sometimes their families. If keen to help in this way, register your interest at:

www.mndassociation.org/researchlist or contact us to see if you qualify for a particular trial:

Telephone: **01604 611880**

Email: **research@mndassociation.org**

The MND Register

The MND Register of England, Wales and Northern Ireland aims to collect information about every person living with MND. The information gathered in this database will tell researchers more about what might be causing the disease and help improve care for people living with MND.

For example, the data will help us work out the number of people diagnosed with MND each year, how many people currently have the disease and how this changes over time. Information such as gender and ethnicity can be used to look for characteristics of people more likely to develop MND.

If you have MND, your local MND clinic may invite you to register, or join at: www.mndassociation.org/mndregister

Key points

- MND affects the motor neurones which we use to control movement. It does not usually affect the senses.
- There is no single test for MND. Testing is used to rule out other conditions.
- MND is thought to be caused by a mix of genetic and environmental triggers, but these can vary for each person.

Further information:

From our range of information sheets:

- 1A:** *NICE guideline on motor neurone disease*
- 1B:** *Health information in other languages or formats*
- 2B:** *Kennedy's disease*
- 2C:** *Primary lateral sclerosis (PLS)*
- 2D:** *Progressive muscular atrophy (PMA)*

Also research sheets:

- B1 – Inherited MND: Introduction**
- B2 – Inherited MND: Genetic testing and insurance**
- B3 – Inherited MND: Options when starting a family**

From our guides and other publications:

An introduction to motor neurone disease: a short summary of this larger guide.

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

What you should expect from your care: our pocket guide on questions to ask at appointments, based on the NICE guideline.

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

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

Changes to thinking and behaviour with MND: a booklet about support for these changes, if they happen.

Emotional and psychological support: a booklet about self-support and how to find professional support if needed.

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

Information to pass to your health or social care professionals:

Motor neurone disease – a guide for GPs and primary care workers

Download our publications at:

www.mndassociation.org/publications

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

Telephone: **0808 802 6262**

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

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

See Section 12: *How we can help you.*

Our research website pages:

www.mndassociation.org/research

Online forum:

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

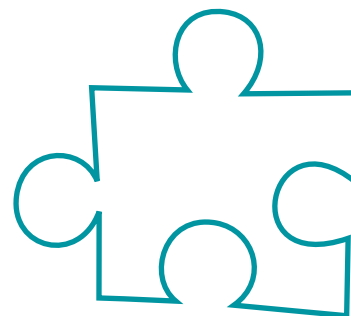
<https://forum.mndassociation.org>

PMA/PLS email support group:

This group is not hosted by the MND Association, but offers a place to share experiences with others affected by primary muscular atrophy and primary lateral sclerosis. If you would like to join, contact our MND Connect helpline as shown above.

2: Managing symptoms

This section looks at the likely symptoms of MND, how these can be managed and who can help.



What are the symptoms?

Not everyone will experience all of the likely symptoms, or in any particular order.

“ Things stay the same for several weeks, then one morning I find I can't do something I could the day before.”

As the disease can affect everyone differently, you may have symptoms not mentioned here. You may also have an unrelated problem that needs medical attention. Ask your GP about any concerns.

The following looks at what is happening and what can be done for MND symptoms. Health and social care professionals are described later in this section.

[See Further information at the end of this section for more resources.](#)

Muscle weakness

What is happening? When motor neurones stop delivering instructions from the brain, the affected muscle is used less and reduces in mass (wasting). This causes weakness and can affect balance and posture, with risk of falls.

What can be done? Ask your GP or health and social care team for a referral to a physiotherapist or neuro physiotherapist. They can recommend an exercise programme to suit your needs, including assisted or passive exercise where someone moves your limbs for you.

A dietitian can also suggest ways to maintain weight, through changes to diet.

[See Section 6: Getting around.](#)

Exercise cannot reverse muscle wasting caused by MND, but it can support flexibility, range of movement, strength of unaffected muscles, posture and balance.

Twitching (and fasciculations)

What is happening? Twitching and rippling sensations under the skin, called fasciculations, are often early and annoying symptoms. Some people feel a rippling effect in individual muscles, but it can be widespread.

What can be done? Talk to your GP, neurologist or specialist nurse, as medication can help. This symptom usually fades over time.

Muscle tightness and/or cramping

What is happening? You may feel general muscle tightness (spasticity) as messages stop reaching your muscles. This can impact on mobility and co-ordination of movement, which may cause pain or increase the risk of falls. Sudden muscle cramps or spasms are also common and can be very painful.

“ For me, relaxation is the answer to sudden stiffness or spasm. I'm getting better at relaxing, but over time, more things cause stiffness to happen.”

What can be done? Ask your health and social care team about physiotherapy or medication that may provide some relief. They can also advise you and your carers on managing falls. Appropriate positioning when sitting or lying down can help you feel more comfortable.

Breathing problems

What is happening? Problems with breathing may develop, often in the later stages of the illness. The internal respiratory process is not affected, but the muscles involved in the control of breathing can weaken.

What can be done? If you have shortness of breath, fatigue, disturbed sleep, morning headaches or daytime sleepiness, you may be referred to a respiratory consultant for assessment. Depending on your needs and preferences, assistance can include breathing exercises, physiotherapy, advice on careful positioning, guidance on effective coughing, medication and assisted ventilation (where a machine provides breathing support). There are two types of ventilation:

- non-invasive ventilation (NIV), where a machine supports your breathing by providing extra air through a mask
- tracheostomy ventilation (also known as invasive ventilation), where a machine supports your breathing by a tube, which is inserted into the windpipe through an opening made in the neck.

NIV has traditionally been more common with MND, but ask about both types of ventilation at your breathing assessment. It's important to find out what's available in your area, and the support needed if you decide to go ahead with either type of ventilation.

“ Despite general caution about tracheostomy ventilation, I decided to proceed after deliberations with my family and extensive reading of research papers.”

You may only need assisted ventilation for short periods at first, or overnight. As your breathing muscles continue to weaken, you are likely to become dependent on it if you continue to increase its use. It can help to ease breathing difficulties and prolong survival, but your symptoms and care needs will continue to progress. Being fully informed about ventilation options, benefits and risks, can help you make decisions that feel right for you and your future care.

You may decide not to increase use of ventilation as your muscles get weaker. If so, you can use medications to help with the feeling of breathlessness. The medications can't make your breathing muscles work better, but they do help to make breathing more comfortable. Ask your health care team if you want to know more, and if you wish to stop using ventilation at any stage of your illness. We have information to help.

See Further information at the end of this section.

“ I found wearing an NIV mask not as claustrophobic as expected. I practised for a short time each day for a couple of weeks. Then wearing it all night was easy.”

Oxygen: is not usually recommended as a treatment with MND, as it can upset the balance between oxygen and carbon dioxide in your body. However, controlled use in small amounts may be used if your oxygen levels are low.

In most cases, assisted ventilation uses normal air to help you breathe, not oxygen.

Our alert wristband lets hospital staff know you have MND and may be at risk with oxygen, as they may not be aware of the need for caution, especially with higher doses. It is your choice whether to wear the wristband or not, but it may help if you need emergency treatment and are unable to communicate for any reason. The wristband is included in the folder with this guide or can be ordered from our MND Connect Helpline.

[See Further information at the end of this section for contact details.](#)

Swallowing problems

What is happening? If your face, mouth and throat weaken (due to MND affecting your bulbar muscles), you may have problems with swallowing. Difficulty with swallowing is called dysphagia, and may mean you don't eat or drink as much as you need. You can lose weight from this and from muscle wasting.

What can be done? Discuss any issues with your health and social care team and ask to be referred to a speech and language therapist (SLT) and a dietitian. An SLT will assess your ability to swallow and advise on consistencies of food and drink. They can also provide guidance on how to manage coughing and choking if you experience these when eating and drinking. A dietitian will assess your weight and advise on whether to increase calorie intake. This can be helped with changes to diet, but also with supplements if needed. In time, if your swallowing difficulty gets worse, tube feeding can top up or replace meals.

[See Section 9: Eating and drinking.](#)

Tube feeding is a way of passing fluids and specially prepared liquid feed straight into your stomach, through a tube in your abdomen. This requires an operation in hospital, but the tube is easy to use once fitted.


Saliva and mucus problems

What is happening? If your swallowing is affected, saliva can gather in the mouth and throat, and lead to drooling, which many people find embarrassing. Saliva may be watery, or thick and sticky. If your mouth is dry, mucus secretions can thicken, which can be difficult to clear if your cough weakens. Dryness of the mouth can result from medication, thrush, dehydration or breathing through the mouth.

What can be done? Talk to your health care team as various options can be offered, depending on the circumstances. These can include advice on diet and fluid intake, the use of medication and suction machines for clearing out the mouth.

Speech and communication difficulties

What is happening? If muscles in the lower face and throat weaken (bulbar muscles), the way you speak and sound can be affected. This gets worse over time. Weakened breathing can also affect volume. Difficult or unclear speech is often referred to as dysarthria. Muscle weakness in your face, arms and hands can also affect gesture and expression.



“ I try to make people aware that I need time to communicate, otherwise I feel left out of conversations.”

What can be done? A speech and language therapist (SLT) can assess your communication needs, and suggest techniques and suitable communication aids. An occupational therapist (OT) can assess your physical needs for equipment or aids around the home. Speech and communication aids are often referred to as Augmentative and Alternative Communication (AAC).

AAC can range from low tech (gestures, notepads, alphabet boards, etc) to high tech (computer based). Voice and message banking can also help to preserve the sound of your own voice, for use with computer based communication aids.

See Section 8: *Speech and communication* for further details.

Fatigue

What is happening? Loss of physical function means that everyday routines take longer and become more tiring. Fatigue can also occur from breathing problems, breathlessness, low calorie intake and not drinking enough.

What can be done? Be flexible with daily routines to make the most of when you feel alert and then allow for rest. An occupational therapist (OT) can advise on fatigue management and aids to make daily tasks easier. A dietitian can advise you on calorie and fluid intake to maintain energy. A speech and language therapist can advise on swallowing techniques and consistencies of food and drink.

Pain

What is happening? Pain may be experienced due to muscle cramps, stiff muscles and joints, muscle spasms, skin pressure or constipation. You may also experience discomfort from fluid retention or swelling, caused by limited mobility (known as oedema). Some people experience intense itching.

What can be done? Always ask your GP or another health professional about any discomfort, pain or itching. It may not be connected to MND and needs checking. Something can usually be done to ease these symptoms. Ask your health and social care team for advice on careful positioning, support, pressure care and medication. If you have fluid retention or swelling, you may be referred to the lymphoedema service. If pain is persistent, ask for referral to a specialist palliative care team or pain clinic.

Emotional lability (also known as pseudobulbar affect)

What is happening? You may experience inappropriate laughing, crying or outbursts that are difficult to control and feel distressing. This does not affect everyone with MND and is an involuntary response.

What can be done? Talk to your health and social care team who can support. Medication may help. This can be alarming for those close to you or providing support, but once recognised as an MND symptom, it can be easier to manage.

See Section 4: *Emotional impact* for more on emotional lability.

Emotional reactions

What is happening? You may feel you are on an emotional roller coaster, experiencing multiple emotions, such as anxiety, fear, anger, sadness, depression and disbelief. These reactions are common and to be expected.

What can be done? Trying to understand what you are feeling can be the first step towards managing these emotions. If they are persistent and extreme, ask your health and social care team for support. You may need referral to an appropriate counsellor or psychologist. There is often a waiting list for this type of service, but there may be alternative services through specialist palliative care teams and hospice care. Medication may also be helpful.

See Section 4: *Emotional impact*.

Changes to thinking and behaviour

What is happening? You may find it harder to think, concentrate, interact and plan as easily as you used to. These changes to thinking and behaviour are known as cognitive change. Those close to you may notice the changes before you do.

Up to half of people with MND are thought to be affected, with mild effects in most cases. This number can increase in the later stages of MND. A few people experience more noticeable change and a very small percentage develop a type of dementia called frontotemporal dementia (FTD), which is more severe.

What can be done? Additional support is likely to be needed, including mental health and psychological services. If you or your carer have any concerns, ask your neurologist about the possibility of screening. This assessment process can help detect changes to thinking and behaviour, so that appropriate support can be arranged.

What is not affected by MND?

The following are usually unaffected, although each individual has a different experience. Talk to your GP or health and social care team if you have any concerns, as there may be an underlying condition.

Taste, sight, smell, touch and hearing

Senses are generally unaffected, but some people experience changes to taste, skin hypersensitivity or problems with temperature regulation. MND symptoms can also impact on your senses, such as muscle tightness causing pain.

Continence

Your bowel and bladder are not usually affected, but some people do report a sense of urgency to pee with MND. Getting to the toilet and using facilities may be harder if mobility is affected. Constipation may happen with changes to eating, dehydration, anxiety, medication or poor mobility. Persistent constipation may lead to diarrhoea. Discuss any changes with your health professionals. They can help and problems may not be due to MND.

Sexual function and expression

Sexual function is not usually affected, but MND will make movement and expression more difficult. Your sense of identity and sexual desire can also change. Physical changes can affect intimacy at all levels, from cuddling to having sex. Open discussion with your partner, and your health and social care team, can help you find ways to maintain intimacy.

Eye muscles (and head support)

Most people with MND retain the ability to move their eyes. If you do experience any changes, discuss these with your health and social care team to help work out the cause. Being able to use your eyes also depends on positioning of your head, which may be affected by weakness in your neck muscles. Appropriate head supports can help.

Who can help?

With MND, much can be done to help you manage symptoms, adjust to the emotional impact and maintain independence, for as long as possible.

Ask your GP for general advice on symptom management and medication, and for referral to other specialists. Other health and social care professionals can also make referrals.

In most areas, you can now access your GP records online. This can help you keep track and some surgeries allow you to book appointments online too.

Ask for information at appointments, when needed. If you are disabled and need information in a particular format, this should be provided by the health or social care service you are dealing with. This is now mandatory in England - for more details, search for *Accessible Information Standard* at: www.england.nhs.uk

“ Questions to ask the professionals are really useful when making decisions. Have some valid questions ready for appointments.”

The multidisciplinary team

With MND, you are likely to meet a wide range of health and social care professionals. As MND is not common, many have no experience of supporting people with this disease. They are more likely to have relevant expertise if they work through an MND care centre or network, or your local neurological service. You are likely to have access to a multidisciplinary team (MDT) through these clinics. This is where professionals work together to provide co-ordinated care and linked services, including some or all of the following:

Neurologist: a consultant who specialises in the brain and nervous system, for assessment, diagnosis, symptom management and advice on care management.

Consultant: depending on your symptoms, you may be referred to other consultants who may specialise in areas such as respiratory medicine or palliative care.

Neurology or MND specialist nurse: for specialist advice and information about neurological conditions such as MND. However, this role is not always available in every region.

MND care co-ordinator: sometimes a specialist nurse or other discipline, such as an occupational therapist or physiotherapist, who provides assistance at an MND care centre or network. They act as a link between you, the multidisciplinary team, community services and the MND Association. A similar role is sometimes available through local neurological services.

Community or district nurse: for help with medication, monitoring of symptoms, skin pressure, provision of home nursing equipment and advice on local services. A community or district nurse works closely with your GP and can make home visits if needed.

Specialist palliative care services: including symptom management, counselling, emotional and spiritual support, complementary therapies, practical guidance, support groups and information resources. You may receive this support as an outpatient or through home visits. Short stay admissions may sometimes be needed for assessment or support, often in a hospice setting. Palliative and hospice care is designed to help you achieve the best possible quality of life throughout a life-shortening illness. Once you have been referred, these services are available for your family and main carers too.

“ Get all the help you can. Your local branch of the MND Association is a good start...and don't be afraid to contact your local hospice, as their services can help at every stage of MND.”

Wheelchair services: for assessment of seating needs and provision, as appropriate. Please be aware that there are often waiting lists.

Occupational therapist (OT): for advice on posture, equipment and home adaptation, to help you continue daily routines with as much independence as possible.

Physiotherapist: for guidance on managing symptoms, such as cramps and stiffness. They can advise on positioning and appropriate exercise, including assisted exercise. While exercise cannot delay the progression of the disease, it may help maximise use of unaffected muscles and increase your flexibility.

Speech and language therapists (SLT):

for assessment and help with speech and swallowing difficulties. Assessment is recommended before purchasing any communication aids, as these can be expensive and not all solutions suit everyone. An SLT often works closely with a dietitian for swallowing difficulties.

Dietitian: for help with nutrition, maintaining a healthy weight and guidance about tube feeding.

Pharmacist: for advice on the best types of medication in particular circumstances. For example, many drugs can be dispensed as a liquid for ease of swallowing.

Counselling and psychology services: for emotional and psychological support. Your GP can usually refer you to an appropriate service, counsellor or psychologist, but there may be a waiting list. Hospices and specialist palliative care teams usually offer counselling as part of their support.

Complementary therapist: for therapies that may help ease symptoms and reduce anxiety, such as massage, reflexology or acupuncture. These therapies cannot reverse the progress of MND. Rather than replacing conventional medicine, they work alongside it. Contact your GP before any complementary therapy, to check it will not conflict with current treatment, and ask to be referred to a registered practitioner. Many hospices also offer selected complementary therapies as part of their service and may include this service for carers too.

“ My physiotherapist suggested acupuncture to relieve stiffness in my neck. I was sceptical at first but it made an amazing difference.”

Social worker or care manager: for assessment of your daily needs and those of your carer. These professionals work for adult social care services or other related local services. They can provide information about local care services and support.

Benefits adviser: for help with benefit claims and enquiries. They may seek medical evidence from your health and social care team to support a claim. You can also search for government online information about benefits at: www.gov.uk or for Northern Ireland at: www.nidirect.gov.uk

See [Section 12: How we can help you for details about our services through the MND Association.](#)

Are there any medications for MND?

Depending on your symptoms, various types of medication may be prescribed to help. At first sign of a developing symptom, ask your GP first. You will be referred to a specialist if necessary.

Riluzole

Only one drug is currently licensed and approved for use with MND in the UK, called riluzole. It's available through the NHS under more than one brand name. It can be taken as tablets or a liquid and is the first medicine to show a modest impact on survival with MND, of a few months.

Ask your neurologist for assessment and details about riluzole, but your GP is likely to be the prescribing doctor. If you have any problems in obtaining this drug, let our MND Connect helpline know.

See [Further information](#) at the end of this section for contact details.

New medications

Researchers continue to investigate other drugs to help people living with MND. Several clinical trials are underway, where people meet the qualifying criteria. We have a research list to register those who might be interested in taking part in future trials:

www.mndassociation.org/researchlist

Telephone: **01604 611880**

Email: **research@mndassociation.org**

Making a complaint

If you feel that you're not receiving appropriate treatment or social care support, you have the right to complain. Try to discuss your concerns first with the service involved, as this may solve the problem. If not, you can take the matter further and there are organisations that help patients with queries and complaints.

See *Further information* at the end of this section for details about patient councils that can assist with complaints. See Section 13: *Useful organisations* for more contacts.

The NICE guideline on MND (from the National Institute for Health and Care Excellence) gives recommendations for the treatment and care of MND. This is not a legal document, but health and social care professionals are encouraged to follow these guidelines. This may support you when making a complaint - see our information sheet 1A: ***NICE guideline on motor neurone disease.***

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

Key points

- Not everyone gets the same symptoms in the same order, or at the same speed.
- Not all health and social care professionals are familiar with MND and may not be aware of every symptom. Ask for referrals as soon as you develop symptoms that require specialist help.
- Ask for a referral to a hospice or specialist palliative care team as soon as possible after diagnosis. There is much they can do to improve your quality of life. Their detailed knowledge of your case may also help you spend less time in hospital, if a stay is needed.
- If planning to buy equipment or aids, ask for an assessment of your needs by an occupational therapist to avoid unnecessary expense.
- If you have any difficulties with the supply of riluzole, please contact MND Connect, as shown next in *Further information*.

Further information:

From our range of information sheets:

- 1A:** *NICE guideline on motor neurone disease*
- 1B:** *Health information in other languages and formats*
- 2B:** *Kennedy's disease*
- 5A:** *Riluzole*
- 6A:** *Physiotherapy*
- 6B:** *Complementary therapies*
- 6C:** *Managing pain*
- 7A:** *Swallowing difficulties*
- 7B:** *Tube feeding*
- 7C:** *Speech and communication support*
- 7D:** *Voice banking*
- 8A:** *Support for breathing problems*
- 8B:** *Ventilation for motor neurone disease*
- 11C:** *Equipment and wheelchairs*

From our guides and other publications:

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

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

What you should expect from your care: our pocket guide on questions to ask at appointments, based on the NICE guideline.

Personal care: a booklet about how to get support for your everyday needs.

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

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

Changes to thinking and behaviour with MND: a booklet about support for these changes, if they happen.

Emotional and psychological support: a booklet about self-support and how to find professional support if needed.

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

Information to pass to your health or social care professionals:

P1: *Head supports*

P3: *Managing saliva*

P6: *Evaluation and management of respiratory symptoms*

P8: *Managing dysphagia in motor neurone disease*

P10: *Voice banking*

P11: *Pain in MND*

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

Cognitive change, frontotemporal dementia and MND

Occupational therapy for motor neurone disease

Motor neurone disease – a guide for GPs and primary care workers

Multidisciplinary team working for MND

Download our publications at:

www.mndassociation.org/publications

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

Telephone: **0808 802 6262**

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

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

See Section 12: *How we can help you.*

MND Association Support Services:

For guidance on our MND support grants and equipment loan services:

Telephone: **0808 802 6262**

Email:

support.services@mndassociation.org

Online forum:

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

<https://forum.mndassociation.org>

Health and social care in Northern Ireland:

Online information about health and social care services in Northern Ireland at

<https://online.hscni.net>

Health in Wales:

Online information about NHS services in Wales at **www.wales.nhs.uk**

Health Professions Council (HPC):

A register of qualified health professionals at

www.hcpc-uk.org

Telephone: **0300 500 6184**

NHS information:

Health information and NHS services.

www.nhs.uk

NHS 111:

NHS 24-hour help, for urgent, but non-emergency medical advice. **www.nhs.uk**

or contact Helpline: **111**

NHS 111 Wales:

Similar to NHS 111, but particular to Wales.

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

Telephone: **111**

Local authorities or health and social care trusts:

Contact your local authority in England or Wales, or your local health and social care trust in Northern Ireland, about adult social care services, needs assessment and complaints on social care.

Confidential advice and making a complaint about healthcare:**England:**

Contact the Patient Advice and Liaison Service (PALS). Search for PALS on the NHS website: **www.nhs.uk**

Northern Ireland:

See the Patient and Client Council at:

<https://pcc-ni.net>

Wales:

Find your local Community Health Council.

www.wales.nhs.uk/ourservices/directory/CommunityHealthCouncils

3: What do I need to think about?

This section looks at some of the things you may need to consider when diagnosed with MND.



It can take time to accept and adjust to a diagnosis of MND. However, once you know why symptoms are happening, you can look at available options to make informed decisions.

With MND, there is a lot to think about. The following list covers 'things I wish I had known at the start' based on feedback from others affected by the disease.

Not all of these suggestions will apply to your own situation, but they may help you feel more prepared for the challenges ahead. We have also shown which sections of this guide provide further detail.

“ This is the first situation in my life where I can't control the outcome. It's a waiting game to anticipate 'what will happen next'.”

1. Don't rush into purchasing equipment

Before buying equipment or assistive aids, have your needs assessed by a relevant professional, such as an occupational therapist. Equipment may not always suit everyone and mistakes can be costly. You can also get certain items free or on loan through the NHS or social services. Assessment will also consider your future needs. For example, if you plan to install a stairlift and you use a wheelchair, you may need a second wheelchair upstairs and a hoist for transfer.

A through-floor lift or downstairs conversion may provide another option, and funding may be available to help with costs.

See Section 6: Getting around, Section 7: Everyday activities and personal care and Section 10: Finance, work and social care.

2. Seek an assessment of your care needs

Adult social care services can provide a needs assessment for yourself – known as a community care assessment in Northern Ireland – and a carer's assessment for carers. Assessment can help you identify needs, get support and plan for emergencies. Support can vary between regions, so explore what's available during your assessment. These assessments are free, but a financial assessment works out if you need to pay towards agreed services.

See Section 10: Finance, work and social care.

3. Provide a full picture of your needs

If you are being assessed for care needs or benefits, give lots of detail when describing how MND affects you. This is important to get appropriate support. Keep a diary, so you can give examples of your symptoms, the support you need and how long tasks take.

See Section 10: Finance, work and social care.

4. Check out the benefits system

If you have not accessed benefits before, it may feel uncomfortable and confusing. However, it's important to find out what you may be entitled to – this is your right.

See Section 10: Finance, work and social care and Further information at the end of this section for details about our Benefits Advice Service.

5. Take advice on financial decisions

Try not to rush decisions that could affect finance or work. Seek advice from an independent financial adviser and a benefits adviser. For example, early retirement payments may affect access to certain benefits.

See Section 10: Finance, work and social care.

6. Ask about managing your bank account

Ask your bank for advice on managing your bank account if you feel you may need help to continue doing this. There may be different ways to set up shared access with a spouse, partner or trusted friend.

See Section 10: Finance, work and social care.

7. Think about home adaptations early

As your symptoms progress, you may need to adapt your home for disabled access. This can take time and you may need to seek funding, which can also be a lengthy process. Explore adaptations and funding as soon as you think it may be necessary. An occupational therapist (OT) can help assess your current and possible future needs. This assessment is free, unless arranged with an independent OT who charges.

See Section 6: Getting around.

8. Keep a list of questions and contacts

Keep a list of questions you want to ask at appointments, so you don't miss anything. Note down any answers to read again later. You can also ask to record the conversation – most mobile phones allow you to do this.

See the notes pages at the end of this guide to help you keep track, including the Contact record and the Appointment and communication record.

9. Find out as much as you can about treatments

Ask your health care team as soon as possible about available treatments to manage symptoms. Knowing what each option could mean for you (even before you need it), will help you make informed decisions as symptoms progress. In all cases, the choice is yours, but timing is important for some interventions.


See Section 11: Planning ahead.

10. Find out about voice banking

Over time, you may experience difficulties with speech and communication, but simple aids can help, such as alphabet boards and communication charts. Some high-tech devices use spoken voices, such as communication apps on smartphones, tablets and computers. You can create an electronic version of your own voice by recording a bank of phrases. This can help you preserve a sense of identity and is known as voice banking. For best results, voice banking needs to be completed before any changes to your voice, so explore this option as early as possible if you'd like to consider it. If your voice is already changing, you can ask a family member or friend to record their voice for you, if this feels appropriate.

For example, they may sound similar to you or have the same accent. Ask a speech and language therapist for advice.

See Section 8: *Speech and communication* for more details.



“ It was too late to bank my voice by the time I realised I could.”

11. Have difficult conversations as early as possible

When planning ahead, it may feel difficult to discuss the later stages of MND with your health and social care team, and those close to you. Yet making your wishes known about future care can help guide everyone involved. If your speech and communication are affected, it may be easier to discuss plans earlier rather than later. Some people with MND also experience changes to the way they think and process information, so early conversations can be helpful.

See Section 11: *Planning ahead*.

12. Find out about specialist palliative care and hospice care

Palliative and hospice care is about achieving the best possible quality of life for you and those close to you. This is done by managing symptoms, but also wider emotional, practical or spiritual support, as required. You may not need this support immediately, but ask your GP when a local referral is possible. The earlier you can link in to these services, the more benefit they can bring. Their detailed records of your needs can also help reduce any time spent in hospital.

See Section 11: *Planning ahead*.

13. Help your professionals become more aware about MND

MND isn't common and your health and social care professionals may not always have experience of working with the disease. We provide information, education and support services for professionals. They can find out more at: www.mndassociation.org/professionals or through our MND Connect helpline: **0808 802 6262** or email:

mndconnect@mndassociation.org

Professionals can find recommendations about MND treatment and care in the NICE guideline on MND. The guideline is produced by the National Institute for Health and Care Excellence. Our pocket book *What you should expect from your care* is supplied in the folder with this guide or download at www.mndassociation.org/mycare. You can use the prompts inside this handy guide to ask questions at appointments, based on the NICE guideline.

See Section 2: *Managing symptoms* and Section 10: *Finance, work and social care*.

If you are disabled and need information in a particular format from your health and social care professionals, this should be provided. Let them know your needs. This is now mandatory for NHS and social care services in England – for more details, search for *accessible information standard* at: www.england.nhs.uk.

14. You are not alone

Support from others affected by MND can help reduce any feelings of isolation. Our local branch and group support meetings can be a good way to connect, or you may prefer our online forum, which provides a safe place to share experiences:

<https://forum.mndassociation.org>

Even if this type of support doesn't feel right for you now, you can always explore this at another time.

See Section 12: *How we can help you.*



“ I find it really helpful meeting new friends in the same position as myself, and being able to discuss problems and hear their solutions.”

15. We are here to support you

If you have questions or just need support, contact our MND Connect helpline: **0808 802 6262** or email: **mndconnect@mndassociation.org**

The team can guide you to our information resources, our services (including branches and groups) and external services.

See Section 12: *How we can help you.*

Further information:

From our range of information sheets:

1A: NICE guideline on motor neurone disease

From our guides and other publications:

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

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

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

Information to pass to your health or social care professionals:

Motor neurone disease – a guide for GPs and primary care teams

Download our publications at: **www.mndassociation.org/publications**
Or order them from **MND Connect**, our support and information helpline:
Telephone: **0808 802 6262**
Email: **mndconnect@mndassociation.org**

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

See Section 12: *How we can help you.*

MND Association Benefits Advice Service:

We can provide free, confidential and impartial advice on any benefits you may be entitled to. Find current contact details for England, Wales and Northern Ireland at: **www.mndassociation.org/benefitsadvice** or contact our MND Connect helpline for guidance.

Online forum:

We host this forum for you to share information and support with others affected by MND, **<https://forum.mndassociation.org>**



Part 2: Living with MND

Section 4: Emotional impact

Section 5: Family, children and friends

Section 6: Getting around

Section 7: Everyday activities and personal care

Section 8: Speech and communication

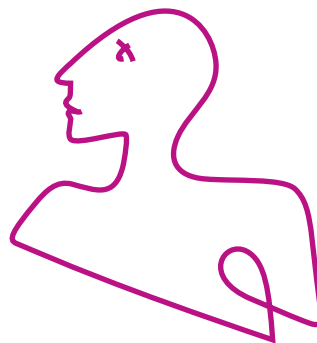
Section 9: Eating and drinking

Section 10: Finance, work and social care

Section 11: Planning ahead

4: Emotional impact

This section will help you identify and manage emotional responses you may feel following diagnosis.



Your emotions will be influenced by your own situation, culture and beliefs. Whatever responses you feel in the weeks and months following diagnosis, you are not alone. Seek help and support, in a way that works for you.

Expected reactions

For most, the diagnosis of MND comes as a shock and it's natural to feel distress. For some there is a sense of relief in finally getting an answer. Once you know what is happening, you can find appropriate support when needed.

As you adjust to diagnosis and what this means, your emotional responses may feel confusing.

- guilt that you may be the cause of stress for others
- anger at the medical profession, or family and friends
- isolation because you suddenly feel different from others
- relief that you finally know what is happening to you.

Feeling overwhelmed

First, give yourself permission to be emotional. A diagnosis of MND is not easy to hear, so work through your feelings at your own pace. You may need time to adjust before seeking support or information, but at some point you may wish to review your life and plans.

It can be difficult to find a positive approach when facing such a challenge. You may feel determined to face the disease head on and fight it, or you may prefer to deal with it one day at a time.

“ I find myself wondering about my own identity. I feel as though I'm in conflict with another individual inside me, but not part of me.

Feelings can be mixed, as you can experience more than one distinct emotion at a time, such as anger and guilt.

You may experience:

- shock
- intense sadness
- fear for the future
- disbelief and denial
- anxiety for family, children and friends
- grief for the loss of the future you expected

“ I've only just started to accept my condition and read more...For a long time I believed it would go away or that I'd been wrongly diagnosed.”

Learning to accept that you have a life-shortening disease is not easy. You may even find that family and friends seek information and support services before you do. They will have their own questions about what is happening and taking action can help them adjust.

When you feel ready, discussing your feelings with those close to you is vital. MND affects them too, and sharing highs and lows means you can support each other.

See Section 5: Family, children and friends for help on managing conversations about MND.

We also have resources for family, carers and friends. While there are ways to prolong your independence, you will need more help over time. Our resources for carers include emotional guidance to support their wellbeing too.

See Further information at the end of this section, about resources for carers and our guide, *Telling people about MND*.

Emotional lability

You may find you laugh or cry at inappropriate times. This can be difficult to stop and hard for others to understand. If it happens, it may feel distressing for yourself and those close to you.

“ It doesn’t help when people say things like ‘Get control of yourself’. The more I try to do that, the harder it gets. It feels as though something is using my body against my will.”

Known as emotional lability (also pseudobulbar affect), this symptom can happen with MND, but is not experienced by everyone with the disease.

Despite the way it makes you feel, emotional lability is a physical reaction rather than emotional. It’s an abnormal motor response, which can be caused by MND. The disease affects the pathway between the outer layer of the brain and the brain stem, resulting in emotional responses that don’t always match how you feel. For example, you may laugh uncontrollably when you feel sad, or you may cry when you feel happy.

This symptom usually reduces over time. Understanding the cause can help you and your family adjust, and manage the impact.

“ I have an advice sheet with me that I can give to people if I break down, as when this happens I cannot speak or communicate.”

If emotional lability is severe and begins to limit what you do, medication or therapy may help. Ask your GP for advice. If they are not familiar with emotional lability, ask for referral to a specialist with experience of neurological conditions.

Some people with MND experience changes to thinking and behaviour (called cognitive change). In these instances, it’s more common to experience emotional lability. However, emotional lability is not in itself a sign of changes to thinking.

See Section 2: *Managing symptoms* for more detail on changes to thinking and behaviour.

Depression

With any serious illness, low moods are to be expected at times. If you find it difficult to recover from these lows, it may be time to seek some help. Watch for physical signs, such as:

- difficulty sleeping
- loss of interest
- loss of appetite
- lack of energy.

These can be signs of other symptoms, rather than depression, so ask your health care team for guidance. Discuss any ongoing distress, including:

- feelings of hopelessness
- sadness that you cannot shake off
- loss of interest in activity
- difficulty finding pleasure or enjoyment in anything
- suicidal thoughts.

Discuss any feelings of low mood with your health care team.

Sometimes changes to behaviour may be a sign of changes to the way you think. Those close to you may be the first to notice and you can be screened to work out if there are likely changes to your thinking and how you process information. Your neurologist can advise if this is the case.

See Further information at the end of this section about our resources on emotions, and changes to thinking and behaviour.

“ Online programmes like mindfulness (cost-free) can be helpful, but you have to be willing to use such initiatives. Meeting people socially can help you remain positive and alternative therapies such as reflexology can be beneficial. Social media can play a part too.”

Intimacy and sexuality

For many of us, physical intimacy is very important. Touch and being close to those you care for shows affection and enables you to share emotional support. It can help to work out different ways to express how you feel.

“ I used to be able to indicate emotion, especially love and care for others, by use of my hands... when this means of communication is lost, misunderstandings happen, with loss of rapport.”

Intimacy with a partner does not have to include sex, but sex may be a significant part of your emotional life. You may worry about the impact of MND on sex.

MND does not affect sexual function, but impaired movement can make sexual expression more difficult. Open discussion with your partner or potential partners can be very helpful. Some people find it difficult to ask questions about intimacy at health and social care appointments, but this can be useful. There may be simple answers to many concerns. We also provide candid information on sex and relationships.

See Further information at the end of the section about our booklet on Sex and relationships.

Rethinking and planning

With MND, things can change quickly. This means plans have to change too.

The urge to deny the diagnosis can be strong and often people ask ‘Why me?’ This is to be expected, but acceptance that life has changed can help you take control and adapt. Becoming informed about the disease will help you make decisions and find support when needed. This can help you achieve the best possible quality of life.

“ It really can’t be emphasised enough to listen to professionals who have helped people go through this before... Please listen, I know it is hard, but it could save you pain and keep you well that bit longer.”

Accepting change:

- means recognising and accepting what is, in comparison to what was
- means adapting to make life easier for yourself and your carers, for example, using assistive equipment
- does not mean giving up or giving in
- turns ‘Why me?’ into ‘What can I do?’

“ The easiest way to feel positive is to do something positive...ask an MND forum or Facebook group for ideas.”

Decision making:

- can include people involved in your care, but you have the final say
- can be reviewed as your symptoms change.

Staying in control:

- means trying to stay involved in the world around you, as MND can feel very isolating
- means giving yourself permission to laugh when needed, as humour can help ease difficult moments
- is about planning ahead to ensure support is already in place when needed
- means being aware of your future needs, while managing the disease one day at a time.

“ I have explained my symptoms in detail to those who help me. They have been better able to understand and respond to my needs.”

Emotional support and guidance

Ask your GP, and your health and social care team for guidance if needed. They can help you manage difficult emotions and medication may ease certain symptoms.

If you feel overwhelmed, ask your GP to be referred to a counsellor, psychologist or neuro psychologist for guidance. There can be long waiting lists for these services. However, specialist palliative or hospice care usually includes some counselling. If wanted, they offer practical and spiritual guidance too, for yourself and those close to you.

Complementary therapies may also be offered through palliative or hospice care, such as massage. These therapies may help relieve anxiety and certain symptoms. If you are not yet linked to a palliative care team, but wish to try complementary therapies, ask your GP how to seek registered practitioners in your area.

See Section 11: *Planning ahead for more information on palliative care.*

“ It helps put emotions in some sort of order by knowing support is there.”

Our helpline MND Connect provides information and emotional support. The team can also introduce you to our services and external services, as appropriate.

If you have access to one of our Association visitors in your area, they can support by telephone, email or through face to face visits.

Our local branches and groups offer a warm welcome if you would like to meet others affected by MND and share support. If this doesn't feel right yet, you can always attend a gathering at another time.

See Section 12: *How we can help you.*

“ It is comforting to be with people who understand, without explanations.”

Our online forum at **<https://forum.mndassociation.org>** also provides a safe place for you to share experiences, practical tips and support, with others affected by MND. You can read the forum posts without joining conversations if you prefer.

Key points

- Open conversations with those close to you can help you all understand each other's emotions and anxieties. This can help you find ways to manage how you feel and cope with challenges.
- Whatever emotions you experience, you are not alone and these feelings are usually a natural response to difficult circumstances. If overwhelmed, seek support from your health and social care team. You can also contact our MND Connect helpline (details provided next, in *Further information*).

Further information:

From our range of information sheets:

- 1A:** *NICE guideline on motor neurone disease*
- 6A:** *Physiotherapy*
- 6B:** *Complementary therapies*

From our guides and other publications:

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

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

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

Changes to thinking and behaviour with MND: a booklet about support for these changes, if they happen.

Emotional and psychological support: a booklet about self-support and how to find professional support if needed.

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

Sex and relationships: a booklet with guidance on ways to maintain intimacy.

Information to pass to your health or social care professionals:

Motor neurone disease: a guide for GPs and primary care teams

Cognitive change, frontotemporal dementia and MND

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

Supporting children and young people close to someone with MND

Download our publications at:

www.mndassociation.org/publications

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

Telephone: **0808 802 6262**

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

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

See Section 12: *How we can help you.*

Online forum:

A safe place to share information and support with others affected by MND at: **<https://forum.mndassociation.org>**

Samaritans:

A listening service for confidential support. **www.samaritans.org**
Telephone: **116 123**

5: Family, children and friends

This section can help you manage difficult conversations about MND, with those close to you.

Sharing news of your diagnosis may feel difficult, as it brings change and emotional impact. Reactions will vary too, depending on each person's own circumstances and relationship with you, their age and the way they respond to situations.

How do I tell people about this?

You should do what feels right for you. Following diagnosis, you may:

- need time to adjust before telling anyone else
- only wish to tell your immediate family for now
- want all close contacts to be aware.

As MND progresses, the effects will be visible. The more people know, the easier it is for them to adjust and offer support.

“ Tell your friends and colleagues when you feel able...give them something positive to do, so they have a sense of helping.”

If you find it stressful to keep explaining the situation, ask a close friend to help tell your wider circle. They could attach information to messages.

Find our short animation, *What is MND?* at: www.mndassociation.org/MNDfacts
We also have a booklet to help you open conversations called, *Telling people about MND*.



It may help to keep early conversations simple in case you or those close to you feel overwhelmed. You can offer more detail over time, so that people know how to support you and your changing needs.

You may find people try to hide their emotions to protect you, which can prevent open communication. If you sense someone needs to share their feelings, encourage conversation.

“ My way of telling my workmates was to use a humorous approach with the ‘good news, bad news’ idea. The good news is we finally know what’s wrong and the bad news is there’s no cure yet. I found it broke the ice nicely.”

Changing roles

Living with MND can result in your routines and lifestyle being turned upside down. There can be significant changes for everyone in your immediate circle.

You may find that:

- someone else has to take on tasks that you can no longer do
- your own sense of purpose and family roles begin to change
- you may need to think about whether to continue working
- money worries can increase.

None of this is easy. Unwanted change can take time for everyone to accept, but it can help if you find ways to work like a team.

It's also essential to help your main carer consider their own wellbeing, as care demands with MND will increase.

See *Further information* at the end of this section about our resources for carers.

See Section 12: *How we can help you about our MND Support Grants, including grants for carers.*

“ We feel for our carers as they do us. We are all sharing a terrible situation. The idea of sharing helps – it gives a feeling of togetherness.”

Accepting external support for some of your care can be valuable. It can:

- help you hold on to what was unique about close relationships before you had MND
- provide rest for your main carer, as the care demands increase
- allow your main carer time for activities beyond the caring role.

If your main carer is your partner, the demands of MND may strain your relationship. It can also bring you closer, but you may both have concerns about the effect on intimacy and sexual expression.

“ I have feelings when I’m with those I love, but I cannot express them actively.”

You may have similar concerns if you are single and would like to begin a relationship or find a sexual partner.

If you have any worries about sex and relationships following your diagnosis, ask your health and social care team for guidance.

See *Further information* at the end of this section about our booklet on *Sex and relationships*.

Feelings of isolation

People with MND and their main carers often talk about a sense of growing isolation. This can happen for various reasons:

Social networks may grow smaller:

As MND symptoms progress, hobbies and job roles can become more difficult to do.

You may want to think about equipment and other ways to prolong independence, for activities you'd like to continue. Staying involved helps maintain social contacts, but explore new interests too.

Speech and communication may become affected:

MND can make communication more difficult, but there are therapies and communication aids to assist. You may need to explain to others how they can best support you in conversation.

See Section 8: *Speech and communication*.

Wider family members and friends may retreat:

People sometimes stop contacting someone who is ill. This can be through fear of saying or doing 'the wrong thing'. They may also lack understanding.

Where people do keep in contact, it can help to:

- keep them informed of changes so they know what to expect when they see you
- let them know when to visit and how long to stay, if you feel more energised at certain times
- keep a list of tasks they can help with if they offer support (a list gives choice and saves trying to think of instant tasks)
- open conversations that give them permission to share concerns
- try to join social gatherings for as long as this feels right for you.

“ Be flexible with routine, as things can change from day to day and night to night.”

Meeting people going through similar experiences can also help you and your family, and ease any sense of isolation. Not everyone wants this at first, but you can join one of our MND Association branches or groups at any time.

If you have access to an Association visitor in your area, they can contact you by telephone, email or visit face to face, to provide support and helpful information.

See Section 12: How we can help you.

Our online forum also provides a safe place share to share support and tips with others affected by MND. You can just view or join forum conversations, at:

<https://forum.mndassociation.org>

See Further information at the end of this section for contact details.

“ I have had a one-to-one conversation with someone else with MND. This was very useful at a low time.”

Communicating about MND to children and young people

Protecting children from distress or worry is a natural instinct, but even young children notice more than we realise. MND will become more visible as time goes on and without explanation, children may:

- feel isolated and forgotten
- use imagination to find answers, which can be more distressing than reality
- think their thoughts or actions can influence the wider world and feel they are to blame
- try to find out information on their own, which may not come from an accurate or sensitive source.

When communicating about MND with children, start with things the child has already noticed. For example, if leg muscles are affected, explain how this makes it more difficult to walk. If facial muscles have been affected, explain how this makes it more difficult to smile, but that doesn't mean you're angry.

You may worry about getting upset in front of children and young people, but this can give them permission to release their own emotions. Openly discussing MND means it's not taboo and can help children feel safe enough to ask questions.

“ I wish we had talked more when Dad was diagnosed, because a lot of my worries would have been dealt with.”

There is no need to give information all at once. How much and how often depends on a child's age and the speed at which your symptoms progress.

However, it's important to be clear and avoid misunderstanding. This includes asking questions to check how much they understand.

“ We told them we would explain everything, but we needed to be honest. As you can imagine there were floods and floods of tears...When they were ready, I gave them information. They asked a few questions, and I could answer them because I had read the content.”

As they get older, young people develop greater understanding. They may seek information on their own and know more than you realise, but still need discussions with you.

See *Further information* at the end of this section for our resources to help communicate about MND with children and young people.

Teachers can also be a source of support if they know what's happening. If a child or young person takes on responsibility at home as a young carer, they may feel torn between home and student life. In this situation, it can really help to keep their school or college informed.

However, keeping children and young people involved in care support can be helpful. It enables them to feel included, maintain a strong relationship, build good memories and to contribute. This can help them build resilience.

“ The balance of care and support is not always perfect in our house, and for our teenage children, dealing with daddy's illness is a tricky landscape.”

If the care demands are overwhelming, external support may be needed. Where children and young people live in the same household, any needs assessment considers the whole family. Care plans should include the needs of young carers.

See Section 10: *Finances, work and social care* on needs assessment.

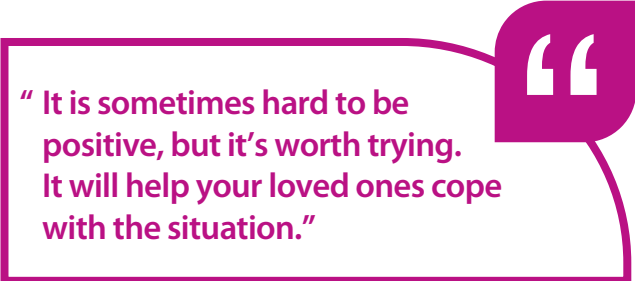
Encourage young people to maintain links with the outside world. Reassure them that their friends and activities are essential to maintain a balanced life. This can help them have time, where they can just be themselves.

See Section 12: *How we can help you about grants for young people affected by MND.*

Key points

- Try to find out what children think is happening, so you can help them understand.
- When children and young people are included in discussions and care tasks, it can help them build good memories and strengthen their resilience.
- There are specialist services and organisations that can help you, your family and those close to you to work through sensitive and difficult issues.

See **Further information next or Section 13: Useful organisations.**



“ It is sometimes hard to be positive, but it’s worth trying. It will help your loved ones cope with the situation.”

Further information:

From our range of information sheets:

1A: NICE guideline on motor neurone disease

10G: Support for families with children

11D: Managing fatigue

From our guides and other publications:

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

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

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

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

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

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

Personal care: guidance about support for daily routines.

Sex and relationships: a booklet with guidance on ways to maintain intimacy.

Information for children and young people:

MND Buddies: our online activity hub to help young children find out about MND through games, stories and things to do.

Why is everything changing? a storybook for young children about families affected by MND.

Online: See our pages for children aged 4 to 10 and young people aged 11 to 18 at: www.mndassociation.org/cyp

When someone close has MND: an activity workbook for children aged 4 to 10, to help a trusted adult communicate about MND at a pace they feel is appropriate for the child and for the child to explore ways of coping.

So what is MND anyway? a publication for young people and young carers, with input from young people who have been affected by MND.

Find out more about our services for children and young people affected by MND by emailing: cyp@mndassociation.org

Information to pass to your health or social care professionals:

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

Supporting children and young people close to someone with MND

Download our publications at: www.mndassociation.org/publications
Or order them from **MND Connect**, our support and information helpline:
Telephone: **0808 802 6262**
Email: mndconnect@mndassociation.org.

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

See Section 12: How we can help you.

Online forum:

A safe place to share information and support with others affected by MND at:
<https://forum.mndassociation.org>

Samaritans:

A listening service for confidential support.
www.samaritans.org
Telephone: **116 123**

Childline:

A free, confidential helpline for anyone under the age of 19 at **www.childline.org.uk**
Telephone: **0800 1111**

The Carers Trust:

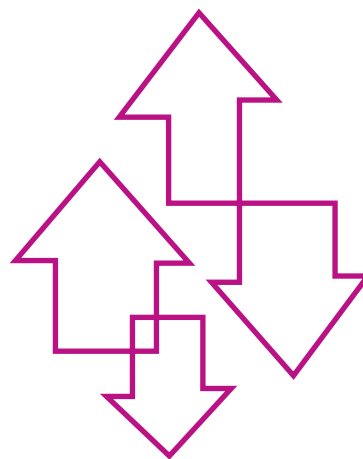
Information and advice for all family carers at
<https://carers.org>
Telephone: **0300 772 9600** (England)
Telephone: **0300 772 9702** (Wales)

Carers UK:

Information and advice for all family carers at
www.carersuk.org
Telephone: **0808 808 7777**

6: Getting around

This section can help you find safe ways to prolong independence and mobility.



MND is likely to affect your movement, mobility and posture as the disease progresses. This can be extremely frustrating, as you may need help to do things and get around. You may also be at risk of falls and injury.

Having to change the way you do things can feel difficult. However, accepting support can improve quality of life, and make a real difference for yourself and those close to you.

“ I find inactivity hard – being unable to do daily tasks, drive, travel independently or go mountain walking, which was my passion.”

Who can help me with mobility?

A physiotherapist can:

- assess your needs regarding mobility equipment and walking aids
- recommend a suitable exercise programme
- advise carers on assisted or passive exercise (where they move your limbs)
- provide guidance on positioning for comfort
- advise you and your carer on safe moving and handling
- advise on how to manage falls
- suggest ways to manage fatigue.

Respiratory physiotherapists can also advise on breathing techniques.

An occupational therapist can:

- suggest ways to prolong independence with self care and daily routines
- assess and advise on equipment and technological solutions to promote independence
- assess your home environment for possible adaptation, wheelchair accessibility or assistive equipment, such as grab rails
- advise on prevention of falls
- provide guidance on posture, and how to reduce any pain or discomfort
- advise you and your carer on safe moving and handling
- suggest ways to manage fatigue
- explore ways to maintain social activity, hobbies or interests
- support the psychological and emotional impact of having to adapt to change.

A district or community nurse can:

- help monitor and advise on pain control and medication
- advise on how to manage falls
- advise you and your carer on who can provide guidance on moving and handling
- provide guidance on care for swollen hands or feet.

Will exercise help?

It is the nerves supplying the muscle, rather than the muscles themselves that are damaged with MND. This means excessive exercise is not usually recommended, as it can cause fatigue.

General exercise such as walking and swimming are fine, but try not to push beyond your natural limits. Try to conserve energy for activities you really want to do.

A physiotherapist can advise on exercises and review these as your needs change.

“ I can’t thank my physiotherapists enough for helping to maintain my quality of life. They had full knowledge of MND and tailored my treatment.”

Exercise cannot reverse damage to muscle groups already weakened by MND. However, it can help to:

- maintain muscles not already affected by MND
- extend range of movement in joints
- prevent or ease stiffness and pain
- support your posture.

Assisted exercise (or passive exercise where someone else moves your limbs) can help to relieve stiffness and pain. This type of exercise can also ease any discomfort if lack of mobility causes poor circulation or swollen limbs.

How do I manage fatigue?

You may feel extremely tired (known as fatigue) due to:

- using extra effort because of weakened muscles
- problems with your breathing
- poor sleep
- not eating enough if you have swallowing difficulties.

You may not have all these issues, but think of your energy like a battery – when the power runs low, it needs time to recharge. If you use a lot of energy one day, you may feel extremely tired the next and need rest time.

Try to:

- listen to your body, pace yourself and be flexible with routines
- do the tasks you really want or need to do, and leave or get assistance for others
- use equipment to help you and your carer do things more easily
- manage your time, for example, let people know the best time to visit
- plan a rest day both before and after a busy time, such as a family event
- ask your physiotherapist and occupational therapist how to manage fatigue
- consider relaxation techniques, as advised by your health and social care team
- ask your GP for a referral to a respiratory team if you have any breathing problems (respiratory physiotherapists can also help manage breathing problems).

“ 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.”

What practical support is available?

You need to be assessed for appropriate equipment and aids. This includes looking ahead at your changing needs, as some equipment may no longer be helpful by the time it arrives.

In most cases an occupational therapist is your first contact for advice, assessment and arrangements for equipment. Depending on your needs, other professionals may be involved, such as a physiotherapist or community nurse.

For balance, walking or personal mobility:

- use splints or braces to support joints or problems such as foot drop, where muscles in the foot weaken
- try walking aids like sticks, crutches, a walking frame or a rollator (a frame with wheels), but these may be difficult to use if arms and hands weaken
- ask for a wheelchair assessment if needed (see later heading)



Rollator, or wheeled walking frame

“

“ Having someone bend and straighten my fingers and toes eases discomfort if they clench or become rigid.”

If experiencing pain, cramps and/or stiffness:

- ask your GP, physiotherapist or occupational therapist what may be causing the problem, or ask for referral to a neurological specialist
- explore changes to seating and positioning, including use of a riser recliner chair, a riser on a toilet for height and a powered bed
- use pressure relieving cushions and mattresses if you tend to stay in one position for a long time
- use splints, braces or a support collar if helpful
- ask about pain control and medication.

See *Further information* at the end of this section about our resources on managing pain.

“

“ When I try too hard to do anything, my muscles become stiff. If I continue to fight, I become stiff all over.”

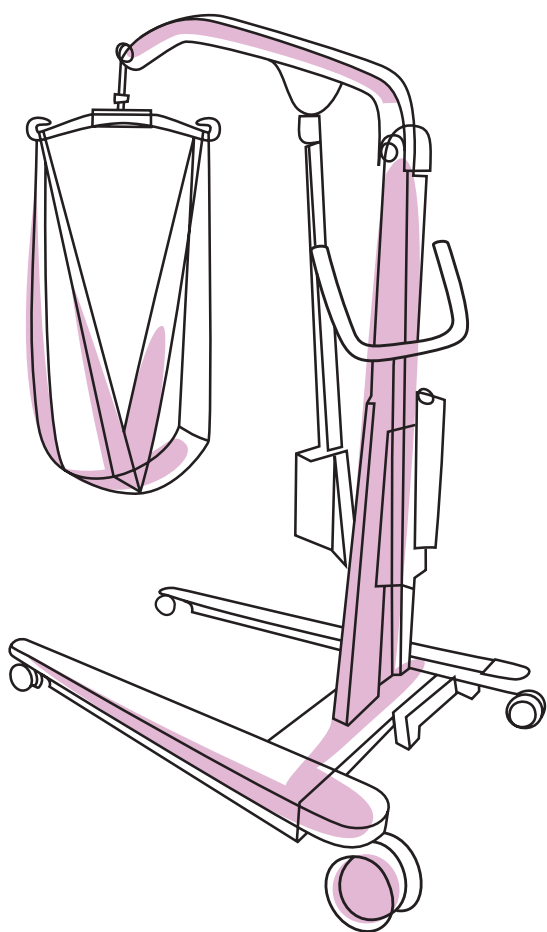
“ When helping someone with MND to move, do it in stages. For example, when getting out of bed, help them sit up, then relax. Help them stand, then relax. Sit them in a nearby chair, then relax.”

To move from chair to bed, bath or toilet:

Ask your occupational therapist, physiotherapist or community nurse about:

- available equipment, such as grab rails, frames around toilets, hoists, riser recliner chairs, adjustable beds, sliding boards and rotating transfer frames
- adapting the bathroom to a level access shower with a wheel-in shower chair
- safe moving and handling techniques for you and your carer to use, including how to manage falls (this guidance may need to be reviewed over time).

A memory foam mattress can make it more difficult to move in bed. Slippery materials may help you slide, but could risk falls.



Mobile hoist

“ When helping someone with MND to move around, don’t leave them unsupported. Even a momentary lapse can make me lose confidence and affects my balance.”

To get in and out of the house:

- use ramps and widen doors
- consider home adaptations, such as door systems that can be opened using environmental controls (these can also control appliances, such as the television).

To move between floors:


- use stair rails and grab rails if safe to do so
- have a rollator on each floor if you find it helpful for balance
- consider if a stairlift will be suitable, as you will need transfer to and from the seat, and possibly a wheelchair on both floors
- install a through-floor lift, which can take a wheelchair up and down
- adapt your home to enable you to live downstairs (and be wheelchair accessible)
- plan any conversions or extensions as early as possible, as these can often take a year or more.

You may be eligible for a Disabled Facilities Grant (DFG) for adaptations or major installations. Ask your occupational therapist to advise, but it can be a lengthy process to get a grant, so explore options as early as you can. You will be financially assessed to work out how much you may need to contribute.

See *Further information* at the end of this section for more on DFGs and adaptations.

If you decide to make adaptations privately, get an assessment through an occupational therapist to work out your needs and what will be safe to use. This also applies to stair lifts and through floor lifts, which are also expensive items with little second-hand value.

Some building adaptations are VAT exempt, so find out as much as you can before any discussions with providers.



“ When deciding to adapt or move to a more accessible home, get information on costs, accessibility and time scales to make a balanced decision. The best technical solution may not be what you want.”

To get in and out of a car:

- ask your occupational therapist for advice, such as using a lever in the door catch for grip or a swivel cushion to help turn into the car
- try a long strap under the feet to help lift them into the car if your carer finds bending difficult
- think about adapting your car or change to a wheelchair adapted vehicle (WAV), which may be accessible through the Motability scheme
- ask a driving assessment centre for guidance.

If you drive and receive a diagnosis of MND, you must notify your car insurer and the DVLA immediately. You may be asked to take a driving assessment if you wish to continue driving. Adapted controls can help you prolong your driving ability.

You may also want to explore the Blue Badge scheme for disabled parking. This can help you park close to your destination and use disabled parking bays. Find information through GOV.UK at

www.gov.uk/apply-blue-badge

See *Further information* at the end of this section for resources on driving, vehicles and general transport.

How do I apply for a wheelchair?

Wheelchairs range from simple manual versions to specialised chairs for posture, and powered chairs for indoor and outdoor use.

A posture and mobility assessment is essential to work out which type of wheelchair will meet your needs. The service providing the wheelchair should review your needs if they change.

Who provides the assessment and funding?

Your GP, physiotherapist or occupational therapist can refer you for assessment, as follows:

- **In England:** through your local NHS wheelchair service
- **In Wales:** through the Artificial Limb and Appliance Service
- **In Northern Ireland:** by the Department of Health, Social Services and Public Safety (DHSSPS) Wheelchair Service.

We provide information about equipment and wheelchairs, which covers options on funding, including personal wheelchair budgets in England to choose your own chair after assessment.

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

Powered neuro wheelchairs

Several years ago, the MND Association worked with wheelchair manufacturers to create a range of powered neuro wheelchairs for people living with MND.

Since then, wheelchair design has progressed even further and wheelchair services can assess you for the most suitable option. Your position can be changed in these powered chairs and add ons can be attached, such as communication devices and adapted controls.

“ My husband’s powered wheelchair gave him an enormous amount of independence. It enabled him to travel much more easily than a manual chair, and for a longer period of time.”

See *Further information* at the end of this section about our resources on equipment and wheelchairs.

Private hire or purchase

If you decide to buy privately, seek assessment from a qualified health professional to ensure you purchase the right chair for your needs. This should consider:

- your size, shape and posture
- any pressure relief needs
- how, when and where the chair will be used
- your environment where you live, to check accessibility.

If you are assessed by a local wheelchair service, ask for a copy of your assessment. This can help a local dealer or distributor advise on the most suitable wheelchairs for you to test.

Motorised scooters

Some people may find a scooter useful for a while. Seek an assessment with your occupational therapist, as they can be costly and have limited use. Look online for your nearest Disabled Living Centre, where you can get advice (some offer scooter training). You may need insurance to use a scooter away from the home environment.

See *Further information* for information on choosing the right vehicle and useful organisations.

Wheelchair and scooter safety:

- check brakes and tyre pressure regularly
- carry extra layers of clothing, as temperature control can be more difficult with MND
- ensure clothing and covers are tucked in to avoid getting caught in the wheels
- a wheelchair should never be lifted with someone in it
- a wheelchair should not be pushed forward down a step or kerb
- apply brakes when getting in and out of a wheelchair or a scooter
- move footplates clear when getting in and out of a wheelchair
- use a safety belt, particularly over uneven ground.


Splints and collars may offer extra comfort and security if needed. These can provide hand, foot, neck and chin supports. Talk to your health and social care team to explore suitable options.

Transport and travel

Our information resources include detailed content about:

- driving
- adapted vehicles and the Motability scheme
- Blue Badge
- public transport
- scooters
- disability transport schemes
- holiday and long distance travel
- the ‘fit to fly’ assessment.

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



“ We went on holiday as soon as my husband was diagnosed, but he found he couldn’t walk far. I had to organise help at the airport both ends before going home. All was done with no problem.”

It may be more difficult to get insurance cover for a holiday following diagnosis. It’s worth exploring this as soon as possible when trying to book your travel, as insurance offers and policies change frequently. Our MND Connect helpline cannot recommend one company above another, but may know of existing offers for holiday insurance.

See Section 10: Finance, work and social care for an overview about health and life insurance cover.

Key points

- Always get assessed by an appropriate health or social care professional before deciding on equipment or home adaptations. This will help you make informed choices, based on your likely needs now and in the future.
- If you use a wheelchair and you have a stairlift installed, you will probably need two wheelchairs – one for transfer on each floor.
- If you drive and receive a diagnosis of MND, you must notify your car insurer and the DVLA immediately. You may be able to continue driving, but an assessment is usually needed.

See Further information for resources on driving and choosing a vehicle.

Further information:

From our range of information sheets:

- 1A:** *NICE guideline on motor neurone disease*
- 6A:** *Physiotherapy*
- 6C:** *Managing pain*
- 8D:** *Air travel and ventilation for motor neurone disease*
- 10C:** *Disabled Facilities Grants*
- 11C:** *Equipment and wheelchairs*

From our guides and other publications:

Getting around: our booklet about driving, transport and travelling.

Making the most of life with motor neurone disease: our guide on how to adapt and find ways to continue your hobbies and interests for as long as possible.

MND checklist: our form to help you think about support planning when first diagnosed.

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

Caring and MND: quick guide: a summary guide for carers.

Information to pass to your health or social care professionals:

- P1:** *Head supports*
- P2:** *Wheelchairs for people with MND*
- P11:** *Pain in MND*
- Occupational therapy for motor neurone disease**

Download our publications at:

www.mndassociation.org/publications

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

Telephone: **0808 802 6262**

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

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

See Section 12: *How we can help you.*

Online forum:

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

<https://forum.mndassociation.org>

Motability scheme:

An affordable way for disabled people to lease a car, scooter or powered wheelchair in exchange for their mobility allowance.

Telephone: **0300 456 4566**

Textphone: **0300 037 0100**

Website: **www.motability.co.uk**

The British Red Cross:

The Red Cross can help with short term hire of manual wheelchairs.

Telephone: **0344 871 1111**

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

Shopmobility:

Many large centres and retail parks offer schemes where you can book a wheelchair for use while shopping. Search for Shopmobility online to find your local contacts.

7: Everyday activities and personal care

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

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

If you tire easily:

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

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

Where to go for help and advice on equipment and aids

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



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

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

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

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

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

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

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

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

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

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

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

Bathing and showering

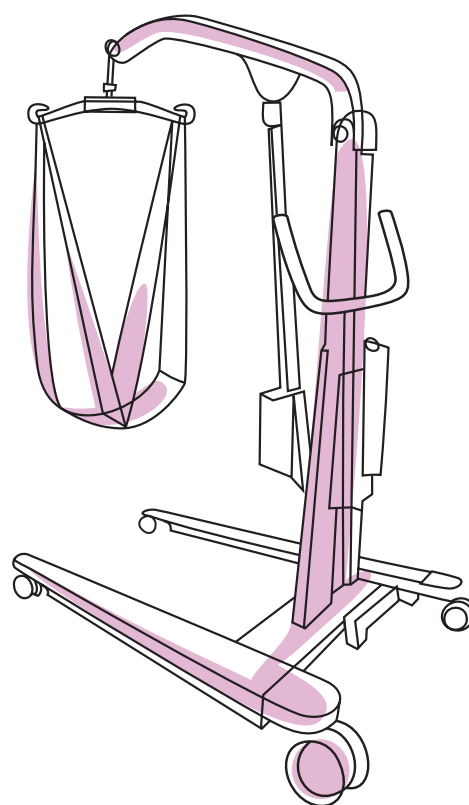
If you decide to adapt your bathroom or buy new equipment, ask your occupational therapist for guidance. The following may help your discussions.

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

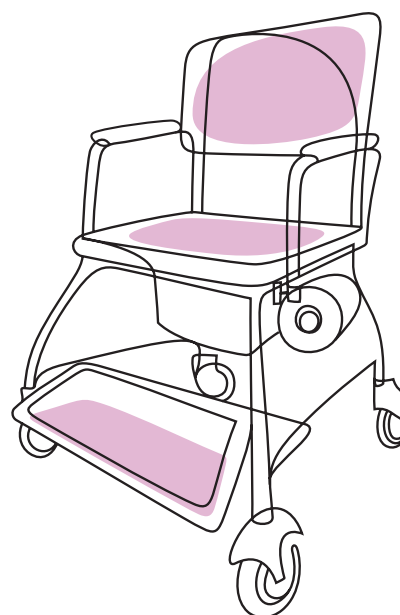
For safety, try non-slip mats and grab rails. A bath seat or bath board can help with transfer (some bath seats are powered). If you need more help, think about a mobile or ceiling track hoist - some are powered.

I find it difficult to stand under the shower:

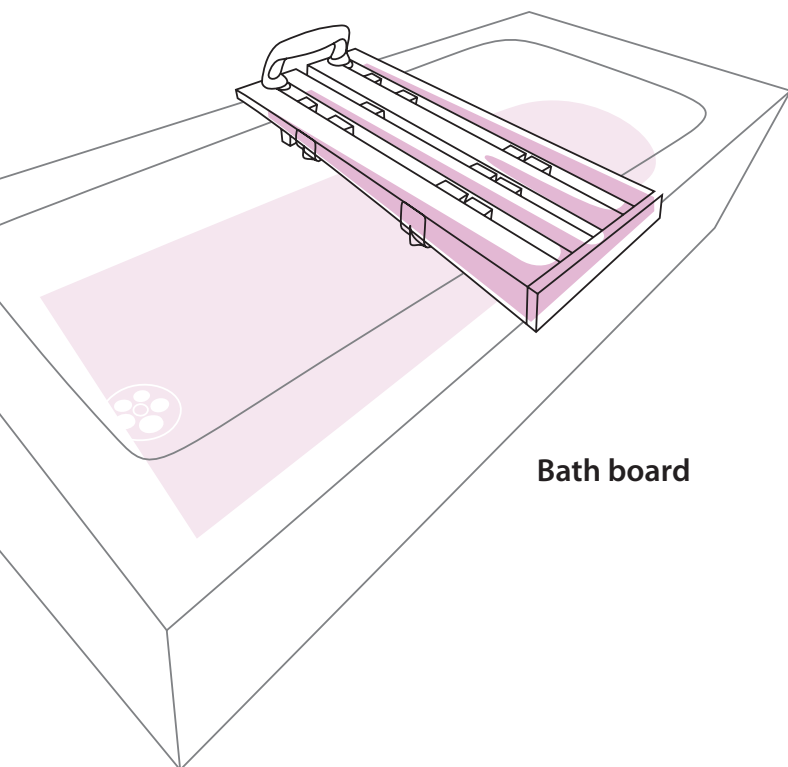
Showering usually requires less effort than a bath. If you find it difficult to stand you can use slatted bath boards and grab rails for over-bath showers. In shower cubicles, grab rails, wall-fixed seats and shower stools can help. For level access showers, use a wheeled shower chair.



Mobile hoist



Wheeled shower chair



Bath board

I have difficulty directing a hand-held shower:

While sitting on a bath board, fill the bath in the normal way and scoop water in a lightweight plastic jug. Hair can also be washed in this way. Long-handled sponges can help you reach your back and feet.

I have difficulty gripping:

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

I get tired standing at the sink:

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

Getting dry is so tiring:

Instead of towelling dry, put on a towelling bathrobe, lie on the bed and relax for 10 minutes (wrap your feet in a towel too).

Using the toilet

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

I feel at risk getting on and off the toilet:

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

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

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

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

I worry about personal hygiene:

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

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

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

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

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

I have difficulty adjusting my clothes to use the toilet:

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

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

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

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

Clothing and getting ready

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

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

It can be helpful to:

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

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

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

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

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

Mouth care

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

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

It may help to:

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

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

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

Personal appearance

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

I find it harder to take care of my nails:

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

I'm worried about shaving:

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

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

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

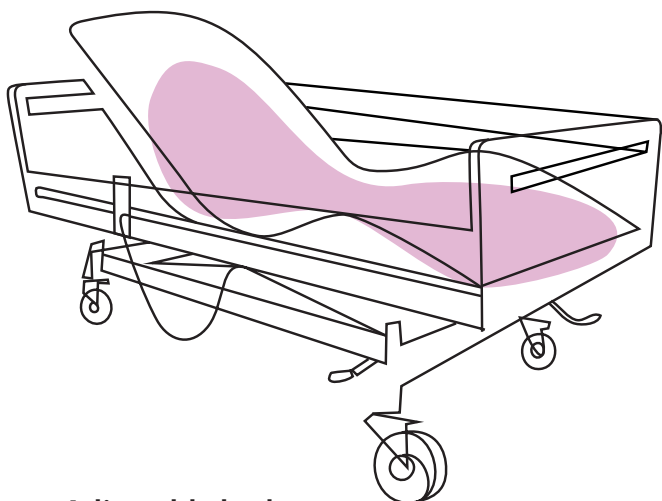
I find it difficult to apply make-up:

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

Comfort

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

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



Adjustable bed

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

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

Around the house

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

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

Wherever possible try to:

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



Rollator, or wheeled walking frame

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

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

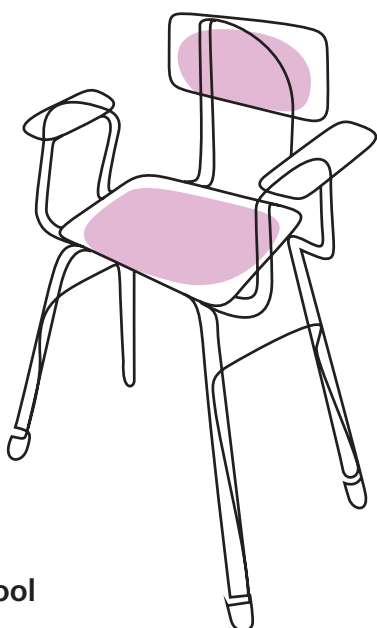
Simple plug-in timers can also be used to control heaters, appliances or lighting.

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

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

Cooking

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



Perching stool

I get very tired trying to cook:

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

I worry about carrying items in the kitchen:

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

I find it difficult to use electrical fittings:

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

I find it difficult to open cupboard doors and drawers:

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

I have difficulties eating and drinking:

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

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

How do I get my care needs assessed?

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

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

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

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

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

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

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

Urgent or emergency care cover

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

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

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

NHS continuing healthcare (CHC)

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

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

Key points

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

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

Further information:

From our range of information sheets:

1A: *NICE guideline on motor neurone disease*

6A: *Physiotherapy*

6C: *Managing pain*

10A to 10G:

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

11C: *Equipment and wheelchairs*

From our guides and other publications:

Personal care: guidance about support for daily routines.

Getting around: our booklet about driving, transport and travelling.

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

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

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

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

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

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

Information to pass to your health or social care professionals:

P1: Head supports

P11: Pain in MND

P12: Information for dental teams

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

Occupational therapy for motor neurone disease

Supporting children and young people close to someone with MND

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

Telephone: **0808 802 6262**

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

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

See Section 12: How we can help you.

Online forum:

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

<https://forum.mndassociation.org>

Age UK:

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

Telephone: **0800 055 6112**

or see website at: **www.ageuk.org.uk**

Disability Rights UK:

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

Telephone: **0203 687 0790**

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

8: Speech and communication

This section explores how MND can affect your ability to communicate and what can help.

We communicate for many reasons – to get things done, access what we need and take part in social activities. Also, to share our thoughts and feelings. Speech and writing are the main ways we do this, but we also use gesture, facial expression, laughter and tears. MND can affect your ability to do all these things. One of the challenges with MND is to find ways to overcome these problems and be able to communicate your needs.

As problems with speech and communication get worse over time, try to have open conversations about your wishes for future care as soon as you feel ready.

See Further information at the end of this section for more resources.

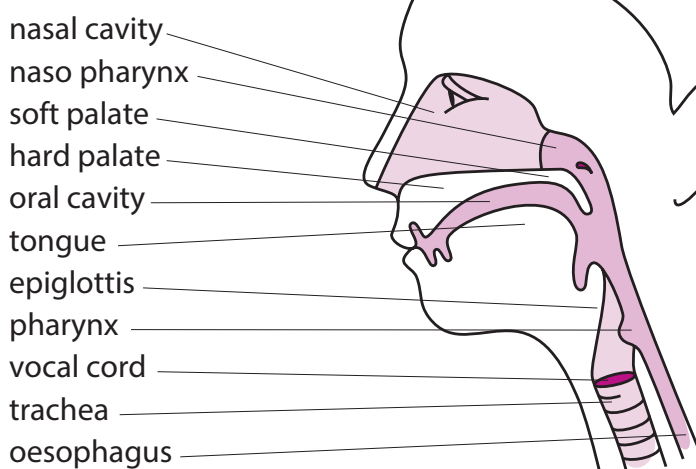


“ I can still talk but find it hard to concentrate or hold complex discussions. The advice on having these difficult discussions as early as possible is crucial.”

What happens when we talk?

When we speak, air from the lungs passes up the windpipe and through the vocal cords, which vibrate to produce sound. We shape this sound by using muscles to control movement of the tongue, lips, teeth and roof of mouth (palate).

How we speak



How does MND affect speech?

Most people with MND will experience some difficulties with speech, although not everyone. When muscles in the mouth, throat and chest are affected, it can cause:

- weakness in the muscles of the tongue and lips, causing slow, slurred and unclear speech that may be difficult for others to understand
- weakness in your soft palate (at the back of the roof of your mouth), allowing air to leak out of the nose and giving your voice a nasal quality
- weak vocal cords, which can make your voice sound hoarse
- weakened breathing or breath support, making your voice soft and faint.

“ Family and friends tell me they need time to tune into my speech, so it is important not to give up too easily.”

Who can help?

Your GP can refer you to a speech and language therapist (SLT), who can advise on how best to use your voice, ways to help your speech or any communication aids that may help you communicate.

How can I improve my speech, unaided?

You may find it helpful to:

- speak more slowly
- pause frequently to take a breath or clear your mouth of saliva
- over emphasise words and break them into distinct syllables
- save energy by using short sentences
- get your meaning across quickly by starting with a key word

- avoid background noise
- make sure your listener is actively listening and watching for non verbal clues
- use gestures to emphasise or replace speech.

What can I do if my speech gets worse?

- work out hand signals for frequently used phrases with those involved in your care
- establish a ‘yes’ or ‘no’ signal, which could be a sound, a movement, blinking or eyebrow raising
- list things you often need, so your partner can go through the items until you indicate yes or no.

A speech and language therapist (SLT) would be able to work with you to develop these skills, as needed.

“ Try new ways to communicate as physical ability changes. For example, turning your head right can mean ‘yes’, to the left ‘no’ and looking straight ahead ‘don’t mind’ or ‘don’t know’.”

People close to you are more likely to understand your speech if it becomes affected, but often strangers can’t. People can get the wrong impression or misunderstand. For example, strangers may think you’re drunk, which can be hurtful and embarrassing. Other common mistakes are people thinking you have a hearing impairment or that you’re emotional.

“ When trying to say thank you, I sound as if I’m cursing... if people say things like ‘Don’t get upset’ or ‘I’m being as quick as I can’, I know my attempts to speak have been misunderstood.”

It can help to:

- carry a message to help you avoid having to explain what's happening all the time (we supply pocket sized notepads and cards that do this)
- keep a pen and pad handy or a wipe clean 'magic slate' for quick messages – some people type text on phones or computer tablets to show what they want to say.

It is important to remember that you will need to deal with different situations and environments. What works in a quiet sitting room with friends may not work in a noisy shop. It's worth practising different tactics to use in a range of situations.

Communication can become more difficult if your arms and hands are also affected. However, there are aids to support you with this.

See later heading *Are there other ways to communicate?*

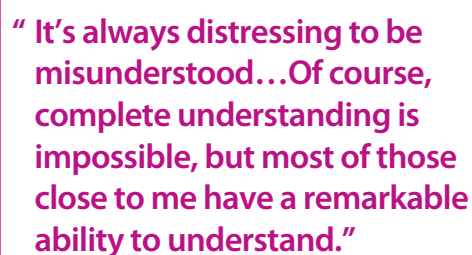
Is there any advice for families and carers about communication problems?

Share your frustration and challenges with your main carer, family and friends. Involve them in finding ways to help you communicate.

You can also show them the following tips.

- Don't change the speed or volume of your speech, unless the person with MND has hearing loss.
- Impaired speech does not necessarily mean impaired understanding, so don't feel you have to simplify the way you speak.
- Be patient if the person with MND speaks slowly, as it takes them a lot of effort and allow for pauses or moments to rest.
- Encourage over-articulation of speech to make speech clearer and watch the person's face and lips.

- For longer conversations, sit in a quiet room facing each other and avoid distractions.
- Keep a pencil and paper or communication board handy and, if speech is tiring, encourage the person with MND to gesture or use eye pointing.
- Try not to finish sentences for them, as this can cause confusion if wrong – unless you have asked and they agreed for you to support in this way.
- Ask questions that can be answered with yes or no. For example 'Would you like a cup of tea?' rather than 'would you like tea, coffee or a cold drink?'
- Try not to mix yes and no questions together, which can confuse. For example, 'Are you warm enough or shall I put the heating on?'



"It's always distressing to be misunderstood...Of course, complete understanding is impossible, but most of those close to me have a remarkable ability to understand."

Are there other ways to communicate?

Communication is usually described in two main groups:

- **Unaided communication:** also known as total communication, includes body language, gesture, pointing, signing, and facial expression. These may become difficult with MND, depending on your symptoms.
- **Aided communication:** from simple non-electronic systems to electronic systems using software technology.

Where techniques or communication aids replace speech, they are known as Augmentative and Alternative Communication (AAC). Each solution has pros and cons, depending on your preferences and abilities.

Ask your speech and language therapist for advice, as not all technologies suit everyone and can be expensive.

Non-electronic communication aids

Communication aids without a power source are usually known as low tech, and include:

- pen and paper
- writing boards, wipe boards, magnetic sketch boards or digital writing slates
- communication charts and image boards
- alphabet or word boards and booklets, including eye-pointing frames (E-Tran frames) on transparent plastic where you indicate a letter, word or symbol with eye movement.

With alphabet boards, you point to letters or words to create a message. The person you're communicating with can also scan their finger across the board, until you signal they have made the correct choice. The alphabet can be handled in sections such as A-K or L-Z, to speed up this process. There are different designs or you can create your own.

“ Electronic aids are not for me – at this stage a notepad and pen are much easier.”

Electronic communication aids

Communication aids that use a powered device are usually known as high tech, and include:

- voice amplifiers if you need help with the volume of your speech
- voice activated computer applications if you have difficulty typing
- voice output communication aids if you have difficulty speaking
- other computer based systems, from general email to systems that rely on movement from eye tracking.

These can be used on personal computers, laptops, tablets and smartphones, including apps (software applications you download for a specific purpose).

“ I have a smartphone and haven't looked back. I intend to get a tablet later, to ensure it is the most up to date.”

See Further information at the end of this section about our resources on speech and communication.

How do I find out about voice and message banking?

A wide range of realistic voices are now available with speech software, including voices with regional accents. You may be happy to use these, but they won't sound like you. If you want to preserve a sense of identity, there are ways to record or 'bank' your own voice for use with speech software.

See Further information at the end of this section for resources, and watch our voice and message banking animation at: www.mndassociation.org/speech

Voice banking

When you bank your own voice, you record a set number of phrases. These are used to create a version of your voice that enables speech software to 'speak' any message you want.

You need to do this as early as possible for the process to work, before speech problems progress. If your voice has already changed, a friend or relative may be willing to bank their voice for you, so that you can use a voice or accent that feels familiar.

“ Voice banking was mentioned, but we didn’t comprehend how useful it could have been...I think the more voice banking is talked about, the more it will become a vital tool for people with MND and their carers.”

The final result may feel a little robotic, but it will sound more like you than a supplied voice. Prolonging the use of your voice in this way can help you and those close to you, but ask a speech and language therapist for guidance. Voice banking can be expensive, depending on the software used. It takes time to record the words and phrases needed, but the process is getting quicker as software continues to develop.

“ With new voice banking software, I only had to record a few hundred phrases.”

Message banking

As well as creating a version of your voice to form new messages, you can record common questions, responses or messages to simply replay. In this way, the messages will sound exactly as you recorded them. They can be programmed into speech software, so they are easily available in the communication aid of your choice.

You may find message banking particularly useful for expression. For example, to record the sound of your laugh or affectionate responses for use with your family and friends.

“ I didn’t want MND to define me. I wasn’t in denial, but wanted to still be me for as long as possible.”

What else do I need to think about with communication aids?

A speech and language therapist, with relevant experience of MND, can assess your current and future needs. The following may be useful:

I want to use computerised speech, but have never used a computer:

If you have never used a computer before, you may feel wary. However, it is worth asking someone to show you how to use the controls and try to explore. A portable electronic communication aid may be an easier option than a computer or laptop. Powered by rechargeable batteries, you can operate the keyboard and display screen with an adapted switch if you have limited hand movement. You type a sentence, then press a button for the machine to speak it, from a selection of voices. Frequent words and phrases can be pre-set and text prediction can speed up communication.

Is using a computer to communicate worth the effort?

Computers, laptops, tablets and smartphones can all help you to communicate, join social groups, find information and services, and be entertained. This can include synthesised speech, the internet, music and video online, email, online forums, social networks, office software, creative software and games.

Using my computer or electronic aid is difficult with restricted hand and arm function:

If your speech is unaffected, you can operate a computer by speaking commands into a voice recognition system. If not, try using adapted switches or more complex eye tracking systems, where you select items on screen through eye or head movement.

Assessment by a speech and language therapist is needed, as this type of system may not suit everyone and they can be expensive.

“ I use a computer controlled by my eye movements to surf the web, read and write emails, and even use spreadsheets... I lead an active life thanks to this new technology which is improving all the time.”

If you have problems with arm or hand movement, ask to be assessed by an occupational therapist. They can help advise on other equipment, such as arm supports, clamps to hold hardware in place or an adjustable table.

What if I cannot use my computer or electronic aid for any reason?

Try to use a combination of high and low-tech options. This ensures you have a simple means of communication should your system break down, run out of power or for situations when you cannot use this type of aid.

I'd like a smartphone or tablet to make use of the latest apps:

Wireless technology enables internet access and apps, through the use of a computer, laptop, tablet, smartphone or other portable device. You may find a touch screen helpful, but if you have restricted hand function, a keyboard or adapted controls may be easier to use.

“ Apps give ease of use for today's way of life!”

I find it hard to lift my head, which makes using aids difficult:

You may need to be assessed for a head support, to raise your eye level. This will make it easier for you to use a range of communication aids.

I have started to have trouble with spelling and word recognition:

With MND, some people experience changes to thinking and the way they process information. For example, spelling may become an issue. If this makes word grids or text based software difficult to use, you may find symbols and images quicker to identify. If you are being assessed for communication aids, explore this type of difficulty with your speech and language therapist to ensure your needs are met.

“ New formats generally need to be got used to.”

Where can I try out different communication aids?

A speech and language therapist, with relevant experience of MND, can advise on solutions suited to your needs. They may demonstrate some of them or refer you to a specialist centre to try out a variety of equipment, with advice about how it can be funded.

Speech and language therapists who are unfamiliar with MND, may find our *AAC Pathway* useful. This helps them identify likely communication needs and appropriate solutions to suit each individual. This is available to professionals through our Communication Aids Service.

See Section 12: *How we can help you for contact details.*

Is there funding for communication equipment?

Try not to rush into private purchases before being assessed, as communication aids can be expensive and your needs are likely to change as MND progresses. You may be able to access support and funding for communication aids from:

The NHS: your speech and language therapist is your main contact to find out what is available.

The MND Association: we may be able to offer a limited amount of financial support or equipment loan for communication needs, where health or social care services cannot supply. This can only be given following an assessment by a speech and language therapist.

See Further information at the end of this section for details about our Communication Aids Service.

Other charities: some organisations will fund communication systems. If employed, your employer may also be able to apply to these organisations for support at your place of work.

Access to Work scheme: this scheme offers advice, support and information for you and your employer. The scheme may help with costs for assistance to enable you to continue working, including communication aids. Contact your local Jobcentre Plus or see: www.gov.uk/access-to-work

See Section 10: Finance, work and social care.

Home communication systems

Seek guidance from your occupational therapist on communication aids around the home.

These include:

Telephones:

If you still have the ability to speak, but have weak arms and hands, try a hands-free system. This will have a built in microphone and loudspeaker so that you can talk without lifting the handset.

Smartphones enable texting, storage of contact numbers, internet access and wider functionality. This includes the ability to download apps or speech software (you can also do all of these with tablet computers and laptops if you need a bigger screen).

Alarms and telecare:

You can wear a small alarm button, usually around the neck or on a wristband. If you are in difficulty and need urgent help, you press the button. A signal passes down a telephone line to alert an emergency service and personal contact of your choice. These are known as telecare assistive technologies. Ask your local adult social care service about systems and costs.

If you just need assistance from someone else in the house, beepers or intercoms are available. You can also use a simple solution, such as a doorbell connected to a switch or pressure pad.

Environmental controls:

You can control electrical devices around the home using remote control to prolong independence. This can include items such as doors and curtains if they have a connecting device fitted. Adapted switches can help you do this, using different parts of your body.

Even if you don't need this immediately, it helps to find out how to access these systems in case your situation changes. Ask about environmental controls if you have a needs assessment with adult social care services. Your occupational therapist can also advise.

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

If your speech is unaffected, voice activated support from virtual household assistants can help, using systems such as Siri, Google Assistant, Amazon Alexa or Cortana. These can be operated from a smartphone, computer device or a separate 'pod' and other brands are likely to be developed.

Key points

- If you would like to explore voice banking, look at the options as soon as possible. Your voice has to be recorded before speech problems develop, for the technology to work well.
- If you have speech problems, take your time and say the important things first to make your needs known.
- To avoid wasting time and money on unsuitable aids, get advice from your speech and language therapist first and try out devices before purchase.
- Have regular reviews with your speech and language therapist as your needs change.
- Keep a low tech aid to hand, in case communication devices break down.
- If your speech is becoming affected, try to have important discussions about future planning before it becomes more difficult to question and communicate.

See also [Section 5: Family, children and friends](#) and, [Section 11: Planning ahead](#).

Further information:

From our range of information sheets:

- 1A: *Nice guideline on MND*
- 1B: *Health information in other languages and formats*
- 7A: *Swallowing difficulties*
- 7C: *Speech and communication support*
- 7D: *Voice banking*

From our guides and other publications:

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

MND Alert Card: a card to carry in a purse or wallet that alerts medical staff that you have MND if you are unable to communicate. You can add key contacts onto the card.

MND Alert Wristband: a wristband that alerts medical staff that you have MND if you are unable to communicate. It includes a warning that you may be at risk with oxygen and a web link for professionals if they need more detail.

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

Information to pass to your health or social care professionals:

P10 Voice banking

MND Association AAC pathway: our full and summary guidance for professionals providing support on communication aids.

Download our publications at:

www.mndassociation.org/publications

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

Telephone: **0808 802 6262**

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

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

See [Section 12: How we can help you](#).

Communication Aids Service:

For guidance about speech and communication support contact **0808 802 6262** or email:

communicationaids@mndassociation.org

Online forum:

A safe place to share information and support with others affected by MND at: **<https://forum.mndassociation.org>**

9: Eating and drinking



This section can help you adjust if you have problems eating and drinking.

Not everyone has the same symptoms with MND, but it can become more difficult to eat and drink enough if you have:

- swallowing difficulties (called dysphagia)
- problems with head and neck support
- problems with hand and arm control
- reduced mobility, which makes food preparation difficult
- fatigue, and eating or drinking takes a lot of effort.

This can lead to weight loss and affect your wellbeing. Weight loss can also happen in MND where muscles weaken and begin to waste.

You may also enjoy eating and drinking as a social activity. Yet, if it becomes harder to eat or drink with your usual control, you may feel self-conscious where food is involved.

“ Eating out is currently a major part of our lives and I would like to continue doing so, for as long as possible.”

Adapting the way you eat and drink can help you maintain a good diet and reduce anxiety.

Who can help me?

Your contacts are likely to include a:

Speech and language therapist (SLT) for assessment and guidance on eating and drinking techniques, and food consistencies for ease of swallowing (they often work closely with your dietitian).

Dietitian for guidance on food types, diet and how to stay nourished.

Occupational therapist (OT) for advice on posture and equipment if you develop weakness in your arms and hands.

Physiotherapist for advice on posture, exercise and assisted exercise.

GP for general medical advice, prescriptions and referrals.

Pharmacist for guidance if tablets are difficult to swallow, as medication may be available in liquid, soluble form or as patches.

Consultant gastroenterologist to discuss support such as tube feeding, for topping up or replacing meals and fluids.

See Tube feeding later in this section.

How will MND affect my eating and drinking?

MND can affect:

- how well you chew and swallow
- how much you are able to drink if this becomes difficult (or if you try to reduce how often you go to the toilet)
- how much you eat, if this becomes difficult or your appetite reduces.

Over a period of time, these effects may lead to a series of problems, such as:

- weight loss, feeling tired and loss of strength
- constipation from dehydration, change of diet or poor mobility
- loose dentures, or loose, dry and flaky skin, with a risk of developing pressure sores.

Some of these issues are directly linked to MND, so improving your diet will not eliminate them entirely. However, maintaining nutrition can help and is important for wellbeing.

“ I have difficulty opening my mouth wide enough to eat. Also, when I get food to my mouth, my tongue sometimes gets in the way.”

“ Drinking water was the first thing I noticed that triggered coughing. Now I have prescribed thickener in drinks.”

We provide an *MND Just in Case Kit* to help with breathlessness, anxiety and choking. This can be ordered by your GP, who prescribes medication to go inside the box to meet your likely needs. This is kept at your home in case a medical professional is called out of hours. Information is provided in the kit for visiting health professionals – and family carers, who may also be able to give you some of the medication. The kit can provide reassurance and many find it comforting to know it's there, even though an emergency may never happen.

See [Further information at the end of this section about our resources.](#)

Swallowing

We rarely think about the way we swallow. It is a complex process, partly under our voluntary control and partly automatic.

Dysphagia is the medical term that describes problems with swallowing. With MND, this happens if muscles around the mouth and throat weaken.

This can cause some or all of the following problems:

- food and liquid may dribble out of the mouth
- poor chewing means food is not ready to swallow or positioned at the back of the mouth for swallowing
- each mouthful of food can take several attempts to clear
- a gag reflex, due to muscles not working well together
- food or liquid may 'go down the wrong way' into the lungs. This is called aspiration and may lead to a chest infection or pneumonia.

Some people also experience either thin saliva that pools in the mouth or thick stringy saliva that is difficult to clear. Combined with a weak cough this can be distressing, as saliva, food or liquids may cause coughing or choking. However, your physiotherapist, speech and language therapist and district nurse can advise on how to manage choking.

What should I eat and drink?

We are generally encouraged to eat less fat and sugar in our diets. However, with MND you may need food with higher calories. This is because MND can cause weight loss from muscle wasting or eating difficulties. Sometimes MND can also cause you to burn energy more quickly.

A dietitian can advise on supplements or how to fortify food if you need to increase calories. Often this can be done simply, by adding oils, fats or cream, but depends on your dietary needs. If you have another medical condition such as diabetes, or problems with thickened saliva, it is especially important to consult a dietitian.

There is no specific diet for MND, but a balanced diet includes a mix of:

Protein: for repair and regrowth

Eggs, milk, cheese, meat, fish, pulses, tofu, grains (such as oats or quinoa).

Carbohydrates: for energy and maintaining weight

Starch through: bread, rice, cereals, pasta, potatoes. Sugar through: jam, honey, syrup, chocolate.

Fat: for energy and to help the body absorb other nutrients

Butter, margarine, oil, dairy products, meat.

Vitamins and minerals: for healthy skin, eyes, bones, teeth and hair

Fruit, vegetables, milk, meat.

Fibre: for a healthy digestive system

Wholegrain cereals, wholemeal bread, fruit, vegetables.

Water: to prevent dehydration

Tea, soft drinks, fruit, vegetables, sauces, ice lollies, sorbets.

Alcohol

There is no reason to stop enjoying alcohol, if you wish to. It may cause coughing, but diluting drinks can help - you may need to add a thickener. In large amounts, alcohol can dehydrate the body or affect your balance. When taking any medication, ask your doctor if it is safe to continue drinking alcohol.

“ My husband liked his pint when going out and got really good at ways of drinking when he lost the use of his hands and arms.”

Consistency of food and drinks

Swallowing problems vary with MND. What may be easy for one person to eat, may be difficult for another.

Foods most likely to cause problems include:

- mixed consistencies, as with some soups or cereals
- foods that need a lot of chewing, such as raw vegetables and some meats
- stringy food, such as runner beans
- coarse hard food, such as nuts
- foods that get sticky in the mouth, like bread or mashed potato
- vegetable skins, which can be difficult to clear from the roof of the mouth
- crumbly foods like biscuits, cakes and crunchy cereals.

Spicy or sharp foods can help stimulate saliva to ease swallowing, but can make you cough.

“ Any food that’s flaky, powdery, crunchy, or that needs to be chewed a lot, is a food to avoid.”

Experiment and try to:

- select foods that are the right consistency for you
- cook meat and vegetables until tender, and break up or mash
- moisten food with gravy, custard and sauces (sweet and savoury)
- soften hard foods (dunk biscuits or spread butter thickly on hot toast)
- peel and stew hard fruits like apples
- use a blender to change the consistency of foods.

“ Some companies deliver ready meals to people’s homes, including puréed meals which look attractive and appetising. Once you discover these, it saves a lot of preparation time. They may seem expensive, but there’s no waste involved.”

However, try not to mash or purée foods sooner than necessary. Your ability may vary on different days and it’s important to keep biting and chewing as long as you can. This helps keep the tongue mobile.

You can be assessed by a speech and language therapist, for advice on food and drink that will enable you to swallow most safely.

Using thickeners

The Eatwell Guide, by Public Health England, recommends we drink 6-8 glasses of fluid every day.

However, liquids can cause more difficulty than solids, as thin drinks are hard to control. Semi-solid foods (like porridge) are the easiest to swallow.

An early sign of swallowing difficulties may be coughing when drinking. Even a tiny amount ‘going the wrong way’ can make you cough. If this is happening, ask your GP for a referral to be assessed by a speech and language therapist. They can advise and may recommend thickened fluids.

Try thicker fluids or foods with a high fluid content such as:

- milk shakes, fruit purées and homemade or bought ‘smoothies’
- yoghurt, custard, mousses, jelly or ice cream
- smooth soups.

Add thickeners to food and drink, such as:

- flour, cornflour, arrowroot, rice flour, ground rice or semolina
- instant mash potato
- breadcrumbs or crushed cereal that mixes easily (eg powdered oats or wheat biscuits)
- powder prescribed by your GP to add texture or thicken.

Water adds moisture to food, but thin juices can be tricky to swallow. Add oil, butter, cream or yoghurt to moisten food and add calories too.

“ Lots of cream, yoghurt, creme fraiche, sauces or gravy make foods easier to swallow.”

What can I do to make eating and drinking easier?

Always talk to your health and social care team about any problems with eating and drinking. The following suggests some potential solutions to common concerns:

I tend to regurgitate food or experience reflux (acid or heartburn):

Eat small portions more often, rather than large meals. Try to sit upright for half an hour after eating. Avoid foods that tend to cause acid, such as spicy or acidic foods. Ask your GP about medication.

I find it difficult to eat and socialise at the same time:

It can be tempting to rush through food in order to join a conversation, but take your time if you have swallowing difficulties. Some people prefer to eat separately and just share a few mouthfuls with others, so they can focus on being sociable.

I get very tired and eating takes a long time:

Try several small meals rather than one large one. If it takes a long time to eat, an insulated plate helps keep food warm.

“ I divide his meal between two plates, one of which is covered and kept in a warm oven, so that his food won't get too cold.”

Chewing and swallowing are becoming more difficult:

Small mouthfuls are usually easier to manage. Swallow each one before taking the next, as the swallow clears the throat as well as the mouth. Sometimes you may need several swallows to clear each mouthful.

Straws are useful for drinking, but it's more difficult to suck:

Ask your speech and language therapist and your dietitian about adapted straws with one way suction, where a valve prevents the fluid from slipping back down the straw. However, with swallowing difficulties using a straw may increase risk of aspiration (fluid 'going down the wrong way' into your airway or lungs).

I like food to look good:

Attractively presented meals can help stimulate the appetite. If food needs to be blended, keep flavours and colours separate (rather than combining everything). Shaped food moulds can be bought from shops and online, to make puréed food look more appetising.

I find it difficult to grip utensils and sit correctly:

Your occupational therapist and speech and language therapist can advise about posture and equipment, such as arm supports and adapted utensils.

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

Taking medication is very difficult:

Some tablets can be crushed and mixed with soft foods to make them easier to swallow, but not all. Check with your GP or pharmacist. They can also advise on liquid medications, patches, suppositories or drugs that dissolve under the tongue.

My sense of taste has altered or disappeared:

This happens for a small number of people with MND. Strong, spicy or acidic flavours can help, unless they make you cough. Taste can be affected by thrush or sticky saliva coating the mouth. Ask your GP for advice.

I have a very dry mouth:

Discuss with your GP, as some medications can cause a dry mouth. Artificial saliva sprays and gels may help. You can get dehydrated if you don't drink enough, so increase your fluid intake, with thickeners if necessary. Small sips of very cold water or ice cubes on sticks can help.

I keep hurting my cheeks, mouth and tongue:

If your facial muscles weaken, you may bite or burn the insides of your mouth by accident. Seek advice from your speech and language therapist for guidance on techniques to avoid this.

“ Avoid serving food that is very hot. If you cannot move food about easily, it can burn the tongue, gums or roof of the mouth.”

We eat at different times, or separately:

Discuss this with your partner or family to clear concerns. You may be anxious about changes to the way you eat. Those close to you may feel guilty about eating things that you find difficult. It is important that you all eat well, including your carer, as they may neglect their own needs when focused on supporting you. Maintaining social contact over meals can be valuable.

“ We ate at different times. When I was trying to eat mine at the same time, he would tap the table to say that he was ready for the next mouthful, so in the end it was easier to have mine after his.”

I worry about mouth care:

Ensure that all food has been cleared from the mouth at the end of a meal. Clean teeth thoroughly, at least twice a day. If this becomes difficult to do, an electric or long angle-headed toothbrush may help, with a small amount of low foaming toothpaste. Electric toothbrushes also make it easier for carers to support you with this.

Have regular dental checkups and ask about alternative ways to clean your teeth if needed (some dentists may make home visits).

See *Further information* at the end of this section about our resources on mouth care and dental support.

Tube feeding

If you begin to have problems with eating and drinking, ask your health and social care team for a referral to a specialist in tube feeding (known as enteral feeding). They can assess your needs and discuss the options. You can then make an informed decision whether or not you wish to use this.

Two methods of tube feeding can be used:

- nasogastric, where a narrow feeding tube is passed through the nostrils, down the back of the throat and into the stomach
- gastrostomy, where a feeding tube is inserted directly into the stomach through the abdomen.

The most popular method for long term use is a gastrostomy, which is offered in three forms:

- PEG (Percutaneous Endoscopic Gastrostomy)
- RIG (Radiologically Inserted Gastrostomy)
- PIG (Per-oral Image Guided Gastrostomy).

The difference is how the tubes are inserted, but the end result is the same. Once the tube is fitted, you can use it to have specially prepared liquid feeds.

“ Tube feeding can be helpful for taking medication.”

With a gastrostomy:

- the feeding tube is hidden under your clothes
- you can still eat and drink by mouth after having a tube fitted, for as long as you feel safe or wish to do so
- you can either top up your diet, or receive all food and fluids through the tube
- the special feeds are provided on prescription and delivered to your home, including high calorie feeds if you have lost weight
- your dietitian can assess your needs, prescribe feeds and advise on timings

- you may have an improved sense of wellbeing as your energy levels increase
- each tube generally lasts up to 12 months and can be easily replaced, some types of tube can last much longer.

Always ask a relevant member of your health care team before using anything other than a fluid or special feed through a tube. This is to avoid risk of blocking.

Anxiety about meals should lessen with tube feeding. Your carer or partner is also likely to feel more confident that you are receiving the food and fluids you need.

“ With a feeding tube, I’m feeling much better now I don’t have to struggle (or eat more yoghurt than I ever imagined to get my pills down). I had no idea how easy tube feeding would be and how difficult it was to stay hydrated without it...my appetite has returned now that I’m hydrated.”

If you use tube feeding for most or all of your food and drink, it reduces the risk of food or drink entering the airway when swallowing, which can cause chest infections.

Whether to have a feeding tube is your choice, but works best before any major weight loss. You may prefer to carry on as you are, with advice from your dietitian and speech and language therapist. Discuss the options with them, and with your family.

This can be a good time to talk through other treatment decisions, even if not needed yet, so you can make informed choices in a timely way.

Sometimes your wishes may be different to those of your family or friends. Open conversation will hopefully bring you to a shared understanding and views can change over time.

You may have a tube fitted later, or decide to stop using one at some point. Again, discuss this with your carers, family and healthcare team.

See *Further information at the end of this section for resources and, when ready, Section 11: Planning ahead.*

Changes in bladder and bowel habits

You may find it more difficult to get to the toilet or remove clothing if you have mobility problems. However, in most cases, MND does not directly affect the muscles that control the bladder or bowel. This means any changes should be investigated, as they may not be due to MND.

You may experience changes due to:

- not having enough food, liquid or fibre
- some types of medication
- reduced mobility, leading to weakness of the pelvic floor, abdominal muscles or diaphragm
- weakened breathing, which can reduce the strength of ‘push’ needed when you try to poo
- tube feeding, which may cause constipation or diarrhoea until you adjust.

It may help to:

- eat more foods containing fibre
- increase your liquid intake
- talk to a physiotherapist about assisted exercise
- ask your dietitian, GP, district nurse or pharmacist for advice.

If your bladder or the way you pee is affected, it may be due to irritation from:

- concentrated pee, due to drinking less
- citrus drinks, such as orange and pineapple juice
- alcohol or caffeine (tea and coffee).

It may be tempting to reduce the amount you drink if it takes effort and time to get to the toilet, but it is important to keep well hydrated.

Key points

- Even if you feel tube feeding may not be right for you, find out about it as soon as you can. Your views may change as you find out more, or as your needs progress.
- Discussions on eating and drinking can be quite detailed, so try to explore all options early in case you experience any problems with speech and communication later on.
- Good nutrition is important, but eating and drinking are about enjoyment as well as health. Select the flavours, amounts of food and times of meals that suit you best.

Further information:

From our range of information sheets:

1A: *Nice guideline on MND*

7A: *Swallowing difficulties*

7B: *Tube feeding*

11C: *Equipment and wheelchairs*

From our guides and other publications:

Eating and drinking for people with motor neurone disease: guidance on problems with eating and drinking and a range of easy swallow recipes.

Personal care: guidance about support for daily routines.

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

Caring and MND: quick guide: summary information for carers.

Information to pass to your health or social care professionals:

P3: *Managing saliva problems in motor neurone disease*

P8: *Dysphagia in motor neurone disease*

P12: *Information for dental teams*

Download our publications at:

www.mndassociation.org/publications

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

Telephone: **0808 802 6262**

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

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

See Section 12: *How we can help you.*

Online forum:

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

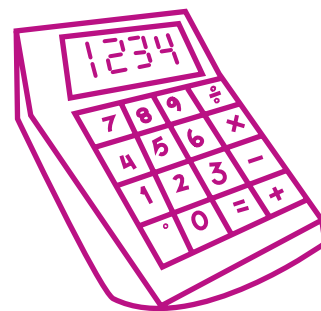
<https://forum.mndassociation.org>

myTube:

For information and video content about tube feeding, featuring people with MND and their family and carers, see

<https://mytube.mymnd.org.uk>

10: Finance, work and social care



This section will help you identify financial support, work options and how to get your needs assessed for social care.

You may want to act quickly following a diagnosis of MND, but gather as much information as you can before making financial decisions. Some options can affect finances in unexpected ways.

Thinking about your financial needs is important and this section can help. However, this information does not represent legal advice and individual circumstances can vary.

We recommend asking qualified experts for advice, such as legal experts or benefits advisers, as relevant.

The financial impact of MND and getting help

With MND, your daily life has to adapt, which creates personal and emotional challenges. Over time, you may need increasing levels of care support and equipment. This can be costly.

“ We had to have our property converted at our own expense. We couldn't get help from our local council as we had savings, which we used up on this.”

If you work, you may also be thinking about whether to continue and how to manage your income. The financial impact of MND can feel overwhelming at first, but it helps to know where to seek guidance.

See Further information at the end of this section for resources and contacts.

Practical or financial support is available from:

- **Your place of work:** for changes to help you in the workplace, such as assistive equipment, flexible working, sick leave or early retirement.
- **Adult social care services:** for care support and services, following a needs assessment, or direct payments to select your own services.
- **Benefits and entitlements:** for financial support, where you qualify, often claimed through your local authority in England and Wales, or your local health and social care trust in Northern Ireland.
- **NHS continuing healthcare:** for fully funded health and social care support from the NHS, where primary health care needs have become complex and urgent.
- **Voluntary organisations and Trusts:** for possible grants, particularly those relevant to disabilities.
- **The MND Association:** for a range of support, including our Benefits Advice Service, and MND Support Grants. We also provide grants for carers, and children and young people who have a diagnosed parent or live in the same household as a diagnosed person.

The following information explores these types of support, but we provide other resources when you need more detail.

See Further information at the end of this section for other resources and Section 12: How we can help you, for details about our services.

In the United Kingdom, statutory services are those provided through health and social care. You have a legal right to their support if you qualify.

Your place of work

Can I take a break?

Taking time out after diagnosis may give you space to think about your options. However, paid and unpaid leave is at the discretion of your employer.

If you are an employee you may be entitled to take periods of sick leave, depending on your symptoms. If your employer does not operate their own sickness scheme, they still have a duty to pay you Statutory Sick Pay (SSP) if you qualify.

Will I have to leave work?

If you work, you may worry about continuing employment with MND. Your care needs will increase over time. This can be unsettling, but leaving work is a personal choice and everyone's experience is different.

" I miss getting up early to go to work and spending all day with other people."

Many people with MND find ways to adapt how they work and continue for as long as possible.

If your partner is your main carer and employed, juggling work and care can also be very challenging.

" Being a full-time carer deprived me of opportunities to earn money."

Both of you may need to consider your work options, which can affect your:

- sense of purpose and identity
- standard of living
- social network
- daily routines
- approach to accepting financial support.

MND symptoms can vary widely, but as physical tasks become harder, you may also feel increasing levels of tiredness. It may not be safe or legal to continue some types of work, such as driving heavy vehicles.

If you drive at work or socially, you are legally required to contact your car insurer and the DVLA to inform them of your diagnosis. You may be asked to take a driving assessment if you wish to continue driving. Adapted controls can help you prolong your driving ability.

It may be useful to discuss your employment options with:

- your partner, family and friends, especially your main carer
- your employer can apply for help to the Access to Work scheme if you need support to continue working, see www.gov.uk/access-to-work/apply
- a social worker from your local authority – or health and social care trust in Northern Ireland – and a benefits adviser at your local Jobcentre Plus
- your local Disability and Carers Service, Department of Work and Pensions (DWP) local service or, in Northern Ireland, your local social security office (for help with claim applications if MND means you need assistance)
- local care services and organisations
- an independent financial or benefits adviser about the impact on your income, entitlements and pension
- our MND Connect helpline and Benefits Advice Service.

See Further information at the end of this section.

Some of the options to consider are:

- shorter or flexible working hours, including home working and teleworking
- adapting your work environment (the Access to Work scheme may be able to help your employer with this and some occupational therapists too)
- voluntary redundancy, leaving work or early retirement
- a needs assessment by adult social care services to work out your current and future care needs.

Always take advice from a pensions adviser before making any decisions. For example, taking your pension through early retirement may affect your ability to claim certain benefits.

See *What about insurance and life cover?* later in this section.

Carers may also be able to get help from their employer, with flexible working, unpaid leave and other options.

“ I can still work part time, but due to my wage I cannot claim carers allowance.”

What if I'm self-employed?

You may be working:

- as a sole trader or freelance consultant
- in a partnership
- as a limited company
- through an agency as self-employed
- by contracting or sub-contracting.

“ I was always very fit, and I owned and worked in my own business about 60 hours a week. I continued with this for two years after diagnosis, then sold the business. I continued to work for the new owner for a while, but found it hard when it wasn't mine.”

You should seek advice from an independent financial adviser who can review your income, tax liabilities and any financial investments. They may be able to advise on the impact of any decisions which affect other financial matters. You may also need to seek advice from:

- a benefits adviser to look at possible entitlements, which may depend on the level of National Insurance you have been paying
- a legal expert specialising in self-employment or company law, if you are subject to any contracts or legal accountabilities.

What about insurance and life cover?

If you work, investigate your contract of employment, as you may be entitled to a death-in-service payment. If offered, this employee benefit pays out a tax-free lump sum if you are employed by the company at the time of your death. The pay out is usually between two and four times your annual salary.

If you are repaying a mortgage or other loans, these can also include life cover. Check your policy documents or contact the provider to find out.

“ With queries regarding critical illness cover, I had two small policies - one that has paid out a quarter of what I thought and the other still pending. I’m not an expert on these things but I didn’t realise that as my mortgage decreased, so did the projected sum. I had taken loans out to cover my kids’ university costs and the cover didn’t include those. We’re always wise after the event. My advice is to apply as quickly as you can after receiving confirmation of diagnosis. Some clinical consultants may be reluctant to complete forms sent from the insurance company and that may hold up proceedings.”

If you have any existing health-related insurance policies, explore these too. Find out if you qualify for an award following a diagnosis of MND. As with early retirement, take independent advice to check how any payment received could affect other options, such as benefit claims.

It may be difficult to get cover following diagnosis for health care, critical illness or life insurance. Some insurance companies may consider this, but it could be more expensive than expected and the potential award smaller than hoped. However, it’s worth exploring insurance as soon as you can.

Insurance offers and policies change frequently. Current offers that include MND may not be available for very long. However, new offers can also appear unexpectedly, so it may be worth rechecking companies at a later date.

See Section 6: *Getting around* for details about holiday insurance cover.

Adult social care services

Following a needs assessment – or community care assessment in Northern Ireland – you may qualify for care support arranged by adult social care services. You can also receive direct payments, which enable you to choose the support and services you prefer.

You have the legal right to apply for this type of support. If you meet the qualifying criteria, it is also your right to receive the support agreed in your care plan.

Your care needs will increase over time and you may wish to explore what is available. This can be done through a needs assessment for yourself and a carer’s assessment for your carer.

“ Being supported by a care company brings its stresses and challenges, but provision of committed compassionate care workers can help families immensely.”

For an assessment, contact adult social care services through your local authority in England and Wales, or your local health and social care trust in Northern Ireland.

“ Could examples be given of what type of support would be included within a care plan? I know everybody’s symptoms are different, but it may put it into context.”

Your needs assessment will result in a personal care plan, for agreed services. What’s included in the plan could be different to that of someone else with MND, as your needs will be determined by your personal situation.

Your care plan will need to be reviewed over time, to ensure it still meets your needs.

However, the assessment is an opportunity to explore available options. Try to find out about:

- what can be included in your care plan in terms of personal care or household support (as this may vary across regions)
- what support can be offered for you and what support can be offered for your carer (a joint assessment can be helpful if this feels right for you both)
- local care services and agencies, and what to expect
- community palliative care, day therapy units and hospice day care
- counselling and psychological support
- support to maintain interests and hobbies that are important to you
- respite services and emergency care cover if your carer is unable to support for any reason
- financial support and benefits advice
- useful local or national charities.

Ask for a separate assessment by an occupational therapist, who can look at how to prolong independence through:

- lifting, bathing and other aids to assist daily living
- appropriate seating
- advice about disabled facilities grants if you need to adapt your home.

Services agreed in your care plan are means tested. This means your finances are assessed to work out how much you may have to pay towards any costs. Some or all of the cost may be paid for you, depending on your finances. In Northern Ireland domestic care services are not charged, but there are exceptions such as meals on wheels, and a financial assessment may still be carried out.

You can choose to receive direct payments to allow you to choose your own services instead of having these arranged.

If you do this, you are responsible for keeping financial records. This may include employer records if you employ someone to help you with your care. There are agencies and brokers who can manage this process for you – ask about this at your needs assessment when discussing direct payments.



“ We have a problem recruiting as we are in a rural area... with social service carers we knew we would always have cover.”

Urgent or emergency care cover

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

Making a complaint

If you feel that you are not receiving appropriate treatment or social care, you have the right to complain. In most cases, discuss your concerns first with the service or professional involved, as this may help to solve the problem. If not, you can take the matter further and there are organisations set up to help patients with queries and complaints.

The NICE guideline on MND is provided by the National Institute for Health and Care Excellence. It sets out recommendations for health and social care professionals on MND treatment and care, including guidance for carers. While not legally binding, professionals are expected to follow the recommendations. The guideline may support you when making a complaint and we provide information to help.

See *Further information* at the end of this section for details about patient councils, that can help with queries about care.

Benefits and entitlements

It is your right to claim benefits or other entitlements for financial support, where you qualify. These are usually provided by the Government, your local authority or Trust, to help you and your carer. Some of these benefits or entitlements are means tested, which means your income and savings are assessed to see if you qualify.

“ It seems to be very hard nowadays to get benefits and we certainly didn't know very much about claiming.”

If you are living with MND or Kennedy's disease, or a carer, our Benefits Advice Service can help. Trained advisers can identify benefits you may be able to claim if you live in England, Wales or Northern Ireland.

They can also advise on which benefits can be fast tracked, where you may be able to avoid a more lengthy assessment.

See Further information at the end of this section for more about this service and contact details.

Universal Credit

Various benefits can help with low income and housing. The main one is means tested and called Universal Credit. You may qualify if you have a low income (whether in or out of work). For new claims, Universal Credit has replaced the following benefits:

- Income Support
- Job Seekers Allowance (income-based)
- Employment Support Allowance (income-based)
- Housing Benefit
- Child Tax Credit
- Working Tax Credit

Disability and carer benefits

It's useful to be aware of the following:

Attendance Allowance: Not means tested. Available when you reach state pension age to help support with care costs. Attendance Allowance is not affected by the introduction of the Personal Independence Payment (PIP) – see later heading.

Carer's Allowance: Not means tested, as savings are not taken into account, but your earnings may affect your entitlement. For carers providing 35 hours or more of unpaid care a week to someone who gets Attendance Allowance, the middle/higher rate care component of Disability Living Allowance or the daily living component of Personal Independence Payment (PIP).

Carer's Credit: If caring creates gaps in a carer's work history, this credit protects their National Insurance to build qualifying years for state pension. Also available to those who cannot claim Carer's Allowance if their earnings are too high.

Carer Premium: A top-up to assist carers on a low income, who receive certain benefits. See also Universal Credit, which is gradually replacing various benefits, but will include a similar top-up called the Carer Element.

Council Tax Discounts: The following discounts only apply in England and Wales. For Northern Ireland, see Disabled Persons Allowance – Rates.

- **Disabled Band Reduction Scheme:** If you live in a bigger or adapted property due to disability, you may be able to avoid paying more in Council Tax.
- **Single Person Discount:** If there is only one person living in your home who qualifies for Council Tax purposes, a 25% discount may apply (someone with a confirmed diagnosis of frontotemporal dementia or FTD may be considered exempt for Council Tax purposes, along with children full-time students and some carers). If no-one living in your home qualifies for Council Tax, a 50% discount may apply.

Disability Living Allowance (DLA): Not means tested. This used to be provided to help people under 65, when assessed with care or mobility needs from disability. Personal Independence Payment (PIP) has now replaced DLA for new claims. Most existing DLA claims are gradually being transferred to PIP (you will remain on DLA if you were born on or before 8 April 1948).

Disabled Facilities Grant (DFG): Means tested. This local authority grant may be available towards adaptations to enable a disabled person to continue living in their home.

Disabled Persons Allowance – Rates: If additions or adaptations have been made to your home due to disability, you may qualify for this reduction in rates in Northern Ireland. For England and Wales, see Disabled Band Reduction Scheme.

Employment and Support Allowance (ESA): An allowance if your ability to work is limited by ill-health or disability. If you have paid enough National Insurance you may be able to claim contribution-based ESA, which is not means tested. Universal Credit is replacing income-based ESA.

Personal Independence Payment (PIP): Not means tested. This is designed to help with some of the extra living and mobility costs of long-term illness or disability. PIP has now replaced Disability Living Allowance (DLA) for new claimants of working age and existing DLA claimants are gradually being reassessed and transferred to PIP (unless you are over 65 and applied for DLA before you were 65, in which case you will remain on DLA). Attendance Allowance (AA) will continue and is not affected by the change to PIP.

Rate Relief: Means tested. You may qualify for help to pay rates in Northern Ireland if you own your own property and are on a low income. For England and Wales, see Disabled Band Reduction Scheme.


NHS continuing healthcare and personal health budgets

NHS services for primary or emergency healthcare are free.

With a long term condition in England, you may be able to get a personal health budget agreed to select the health services you prefer. For example, you may wish to have regular complementary therapies to reduce anxiety. To find out what the NHS can provide, talk to your GP or health team. All primary and emergency health care remains free of charge.

In time, you may need more intensive support and become eligible for NHS continuing healthcare. Your primary need must be healthcare, and your needs complex and urgent. If you qualify, your social care and healthcare needs will be arranged and fully funded by the NHS in England. This type of funded care works in a similar way in Wales.

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



“ I’ve heard that people struggle to get these care packages and have to really battle to get help?”

We provide information to help you, as the assessment process can be complicated.

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

Voluntary organisations and trusts

Many charities, voluntary organisations and trusts provide one or more of the following:

- guidance on financial matters
- funding or grants if you qualify against their criteria
- practical help in specific circumstances.

Ask your local authority for advice about organisations in your region in England and Wales, or your local health and social care trust in Northern Ireland.

“ Funding and grants can make the difference between being homebound and being able to get out.”

Our MND Connect helpline can also help you find relevant support and services.

How the MND Association can help you

Where statutory funding and services are not available or timely, we offer a limited amount of financial support, through care support and quality of life grants. These grants are available to people with MND or Kennedy’s disease, and their carers. We also offer grants to support children and young people who live with someone who has been diagnosed or have a parent with the disease.

We consider a variety of needs such as respite care, adaptations and equipment rental, following an independent assessment of need and an application from a health and social care professional. We also loan certain items of equipment and aids, following similar criteria.

We can help direct you to appropriate services. You may also find it useful to contact your local authority or council about local services and discounts for people affected by disability, for example, local parking concessions through the Blue Badge scheme.

“ With funding, you can get help to take a break from home and the daily struggles of life with MND.”

What else do I need to think about?

When you feel ready to do so, you may want to:

- get your general financial affairs in order
- think about writing a will
- consider other options about future welfare, such as power of attorney to enable someone to make decisions on your behalf if you become unable to do so.

MND can affect speech and communication, and in some cases how you think and process information. It can be helpful to open sensitive or complex discussions as soon as you can. We provide information to support you and your family.

See Further information at the end of this section for resources and Section 11: Planning ahead.

Key points

- Try not to rush any financial decisions. Gather as much information as you can, before taking any action, as certain choices can have hidden consequences. For example, early retirement payments may affect benefit claims.
- When completing claim forms, give lots of details and try not to make light of any help you need. This will help you receive the level of support you really require. Emphasise the way MND progresses, as your needs will increase over time.
- Detailed examples of your challenges can improve applications. For example, 'Getting dressed can be difficult' is not very clear, but 'Getting dressed takes at least two hours, as I have to rest frequently and can't manage fastenings' gives a more complete picture.
- Regional support varies, so explore what is available during your needs assessment. We recommend asking about urgent or emergency care support.
- Ask for information from health or social care services, as needed. If you are disabled, it should be provided to you in a format that is accessible.
- If money problems occur, a reputable financial adviser or debt counsellor may be able to advise. Let your bank know what is happening and your mortgage company if you own property. They can help, but only if they know about your concerns.
- Ask your bank for guidance if you need a trusted carer, relative or friend to help manage your account. There may be procedures to follow or other help the bank can offer.
- You may also wish to consider setting up power of attorney for a trusted carer or relative.

See Section 11: *Planning ahead for more on Power of Attorney.*

Further information:

From our range of information sheets:

1A: *Nice guideline on MND*

10A to 10G:

Our range of sheets on benefits, social care, DFGs, work and MND, NHS continuing healthcare and family support

From our guides and other publications:

Personal care: guidance about support for daily routines.

Getting around: our booklet about driving, transport and travelling.

What you should expect from your care: our pocket guide on questions to ask at appointments, based on the NICE guideline.

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

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

End of life – a guide for people with motor neurone disease: our comprehensive guide to planning ahead for future care, including information on finance and wills.

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

Caring and MND: quick guide: summary information for carers.

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

Information to pass to your health or social care professionals:

P5: Providing medical evidence for benefit applications made by people with MND

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

Supporting children and young people close to someone with MND

Download our publications at:

www.mndassociation.org/publications

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

Telephone: **0808 802 6262**

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

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

See Section 12: *How we can help you.*

MND Association Benefits Advice Service:

We can provide free, confidential and impartial advice on any benefits you may be entitled to. Find current contact details for England, Wales and Northern Ireland at: **www.mndassociation.org/benefitsadvice** or contact our MND Connect helpline for guidance.

Online forum:

A safe place to share information and support with others affected by MND at: **<https://forum.mndassociation.org>**

Further sources of help can be found in Section 13: *Useful organisations or try these contacts:*

Government online information:

www.gov.uk for current details about benefits, entitlements and your state pension. For Northern Ireland visit **www.nidirect.gov.uk**

Local authority/health and social care trust:

Contact your local authority in England or Wales, or your local health and social care trust in Northern Ireland, for details about adult social care services and regional support organisations.

Working Families:

Advice on employment and work/life balance for parents and carers.

Telephone: **0300 012 0312**

Website: **www.workingfamilies.org.uk**

11: Planning ahead

This section will help you to plan ahead for the later stages of MND.

The following includes information about end of life decision making. Read when you feel ready to do so.



“ I’m still in the early stages, but find qualified information helpful. It’s less frightening than looking on the internet.”

Why has this section been included?

People with and affected by MND have told us they want more opportunities for sensitive discussions. This includes conversations about the later stages of the disease and end of life decisions.

“ When supported, you feel less daunted about what lies ahead.”

We aim to help by:

- training our own staff and volunteers
- providing relevant education opportunities for health and social care professionals
- providing clear information to enable you to have more effective discussions with professionals.

We provide detailed publications on symptoms, treatments and end of life decisions, so that you can find guidance when you need it.

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

“ I’ve always preferred to be told straight... I appreciate not everyone wants hard facts, but I think you have a duty not to shield us from the reality of MND.”

The following will highlight what to consider and why.

Why would I need to plan ahead?

Discussions about late stage symptoms and end of life decisions can feel overwhelming. Some prefer not to think about this at all, while others prepare for the later stages of MND as soon as they can.

It can help to prepare as soon as you feel able to do so. This is because:

- speech and communication are likely to be affected as the disease progresses, making complex and difficult discussions more challenging
- fatigue with MND can make conversations very tiring
- some people also experience changes to the way they think with MND, making it harder to process information.

“ At first, when I couldn’t speak, I could still gesture with my hands and arms, so the difficulties were not as great.”

“ Even with the best care in the world and maximum co-operation with your carer, the bigger problems of MND cannot be avoided.”

Being prepared ensures your wishes can be fully considered. This can also ease worries, so you can focus on the things you really want to do.

See Section 2: *Symptoms and management* and Section 8: *Speech and communication*.

Most people have wishes they want to share about the end of their lives and are naturally concerned for those they love.

You may have wishes based on:

- personal preferences
- family needs
- cultural choices
- religious or spiritual beliefs.

These wishes may impact on:

- how medical treatment is provided and in what circumstances
- how your finances will be arranged and managed
- how legal arrangements are handled, eg Lasting Power of Attorney (or Enduring Power of Attorney in Northern Ireland) or your will
- guidance for your family and carer, to help them support you in the way you would prefer and to help support them in return.

“ You worry about what will happen to your family after you’ve gone. It is therefore reassuring for everyone concerned to plan ahead and feel prepared for what is to come.”

MND symptoms do progress. Although the speed of this can vary, it is sometimes rapid. You may find it gets harder to make and express choices, so it can be a good idea to think about what you might want in the future, as early as you feel ready to do this. For example, think about what you want to happen as your care needs increase. It can help to discuss this with your:

- family
- carer
- health and social care team
- legal adviser
- spiritual or religious representative, where needed.

Our MND Connect helpline can help if you find it difficult to know where to start. If you are in touch with one of our Association visitors, regional staff, or a branch or group, they can also offer local information and support.

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

You may all find this hard at first, but having difficult conversations gives everyone a chance to share feelings. This can help you better understand how to support each other.

Children also have things they need to ask, say and do at this time. However, sensitive conversations can feel even more difficult with children and young people. There is a natural desire to protect children from distress, but they can sense tension and become insecure if not included. They may try to seek out information on their own or even blame themselves.

“ We found a ‘post box’ useful for questions about the disease, as children and young people don’t always want a face to face discussion about the illness.”

We provide publications to help you support children and young people. We also provide information on bereavement to support family members, friends and carers.

See Further information at the end of this section and Section 5: Family, children and friends.

“ As soon as I got the children’s resources, I read through them. It was a bit like, you know, when you give your daughters or sons the book of life and think ‘I will just check this out first’. I read it front to back and it answered so many questions... probably every question that I’d never thought of was in this book, in such a way that it wasn’t as scary as I’d thought...this was reassuring even though honest. That’s what you want. We wanted honesty – how is it going to be? What do we do if this happens...?”

Palliative and hospice care

Many people with a life-shortening illness are fearful of receiving palliative or hospice care. It raises the question, ‘Does this mean I’m at the end of my life?’. However, this is not necessarily true.

Palliative care is very much concerned with quality of life, from the point of diagnosis onwards. It is designed to help you receive the best possible medical, practical and emotional support, according to your wishes. The earlier you can access this care, the more benefit it can bring.

If hospice services are limited in your area, palliative care teams can also be accessed through hospitals and clinics.

“ I’ve been to a hospice for MND support meetings, which made me quickly realise a hospice offers much more than a place to die. But when the time comes I also feel it will be handled with so much dignity that it banishes fear about the end.”

Depending on your needs, you can receive palliative care at home, in hospital, in a nursing care home or at a hospice.

Where available, palliative care can be particularly beneficial for people with MND. As the disease progresses and care needs become more complex, much can be done to relieve symptoms and provide guidance. This does not necessarily mean admittance to a hospice or hospital.

Palliative care also extends to immediate family. For example, once the person with MND has been referred, counselling may be available for the whole family.

We advise asking your GP if you can be referred to a palliative care team as soon as you have been diagnosed. If you have a slower progressing type of MND, this may not be necessary yet, but try to get as much information as possible.

There may be a waiting list, but it is better to be on the list than asking for referral at point of need. The knowledge a palliative care team or hospice can build about the individual may also help to reduce time in hospital if urgent or emergency treatment is required.

“ At the hospice, it’s reassuring to meet with staff who seem to have more time to build a rapport.”

What else do I need to consider?

Planning ahead can be complicated. Your specific symptoms, personal circumstances and beliefs will all influence your wishes. Over time, you may change your mind about the choices you make, but you can review and amend any plans you put in place.

“ There is a sense of relief it’s all in place and not something still to be tackled.”

Ensuring your wishes and preferences are known can help to reduce anxiety. Keep all important documents safe, but easy to access when needed. Provide up to date copies to those involved in your care, as appropriate. This may include sharing passwords to computer files with your family.

When you feel ready, we recommend exploring the following in more detail, so that you can make informed and timely decisions.

See Further Information at the end of this section for resources with more detail.

Late stage symptoms: as your needs become more complex, your health and social care team will be able to advise. Options such as assisted ventilation to help with breathing, or tube feeding to support eating and drinking can be discussed. Ask for guidance as soon as you begin to experience any symptoms, as some interventions may be difficult to introduce in later stages. You may also want to discuss what will happen if you wish to have treatments withdrawn in the future.


MND Just in Case Kit: a box containing medication prescribed by your GP, that you keep at home for emergency use. This can help with breathlessness and anxiety, and having the box at hand can be reassuring.

Your GP can request the kit, free of charge, from the MND Association. There is a section with medication that visiting health professionals can use. There is also a section with medication and instructions that a carer can use, as explained by the GP, or a community or district nurse.

Advance Care Plan: a document in which you record preferences about your care in case you become unable to make your wishes known. It is not a legal document, but health teams will take note of your choices. These could include where you wish your care to take place, how you would like care provided, or aspects of your faith or beliefs. You can’t use it to insist on a treatment that isn’t right for you, but it can say what things you’d accept in the future, as well as those you’d prefer to avoid. Making people aware of wishes can be important if gets more difficult to explain, and you can change the wording at any time.

“ I hated fussiness. Now I’m the most finicky fusspot you could imagine – or so it must seem to anyone who makes my bed or prepares my food.”

Advance Decision to Refuse Treatment (ADRT): a document that lists any treatments you do not wish to receive and in what circumstances. When completed correctly and witnessed, an ADRT is legally binding in England and Wales, but not in Northern Ireland or Scotland (although it must still be taken into account by the health and social care team and anyone making decisions on your behalf). It only becomes valid if you lose the ability to make or communicate decisions for yourself. It is important to create an ADRT with your doctor or health team, so that you have a full understanding of your options and the implications. Such decisions also need to be communicated to all appropriate members of your care team and family.



“ If my husband had left instructions in an ADRT, we wouldn't have undergone the stress that we did.”

An ADRT cannot be used to request any form of treatment to deliberately hasten death, but it can include the right to refuse life-sustaining treatment. You can review and change your ADRT at any time.

A will: a legally binding document where you state what will happen to your possessions and money after your death. If you die without a will (known as dying intestate), your possessions will be distributed amongst members of your family as defined by law, which may not be what you want. This can make it difficult for loved ones to manage your estate - more so if not legally related to you. For example, cohabiting partners will not have the same legal standing as a spouse.

Power of Attorney: a legal document to let someone you trust make decisions, if you become unable to communicate or make decisions for yourself (known as lacking mental capacity).

In England and Wales this is called a Lasting Power of Attorney (LPA), which is registered with the Office of the Public Guardian (OPG). You will be charged a fee. There are two types of LPA:

- for property and finance (which can also be used by the appointed person if you still have capacity, should you agree)
- for health and personal welfare, where the appointed person makes decisions on your behalf if you lack capacity. This can invalidate any previous ADRT.

In Northern Ireland this is called an Enduring Power of Attorney (EPA), which is registered through the Office of Care and Protection. An EPA only enables decisions on your behalf concerning property and finance, not personal welfare or care related matters.

NHS continuing healthcare (CHC):

describes a package of health and social care, arranged and fully funded by the NHS to meet complex health needs. The primary need must be for healthcare, following assessment to see if you qualify. CHC works in a similar way in England and Wales. In Northern Ireland there is no guidance on CHC, but health and social care trusts are encouraged to refer to the criteria used in the rest of the UK.

Where you wish to receive care and preferred place of death:

where you wish to receive care and your preferred place of death should be respected. It may not always be possible to ensure your wishes are carried out, as this depends on circumstances and your health needs. However, it is easier to make arrangements if planned ahead of time. Location choices include a nursing care home, a hospice, a hospital or remaining at home. It is really important that the person with MND, their family, carer and health team are all involved in discussions. Such decisions often change with time and should be regularly reviewed.

Funeral arrangements: you may want your funeral arranged in a specific way. If so, it can be helpful to leave instructions for those close to you or to discuss your wishes with them. This may involve messages, chosen words or music, or things you would like included because of belief or faith. If you are concerned about the cost, a pre-paid plan might be possible, or the person arranging the funeral may be entitled to a benefit payment to help with this. A funeral director will be able to provide guidance about arrangements.

Organ and tissue donation: if you are interested in organ or tissue donation, we recommend exploring possible arrangements for this at the earliest opportunity. This can be more complex to arrange with MND, but we provide information to help.

See Further information at the end of this section.

MND alerts

If you become unable to communicate for any reason, a range of tools can help alert hospital staff and care workers that you have MND. These can be used in urgent or emergency situations, or for general care. These alerts are important, as not all health and social care professionals are experienced with MND.

Our alerts

Our own alerts are MND specific and most warn that you may be at risk with oxygen. Prolonged use of oxygen with MND can upset the balance of gases in your blood. It may still be used in certain circumstances if your levels are low, but with caution and monitoring.

MND alert card: our small card for you to carry in a purse, wallet or pocket (this includes the oxygen alert). It tells professionals that you need specialist help and has space for you to record key contacts.

MND alert wristband: this has a similar purpose to the MND alert card (including the oxygen alert), but can be worn all the time. It states that you have MND, with a web page address for professionals about urgent MND care.

Understanding my needs: our write-on booklet to help you record your needs and personal background (this includes the oxygen alert). Once completed, keep this with you to help inform anyone involved in your treatment or care.

MND checklist: our form to alert you on what to think about, when first diagnosed. This may help you better manage your condition and arrange for appropriate support.

Our alert card, wristband and Understanding my needs booklet are all included in the folder with this guide. All of our resources can also be ordered through our MND Connect helpline.

See Further information at the end of this section for details.

Message in a bottle: a sticker on your fridge and the inside of your front door tells paramedics that an alert bottle can be found in the fridge. You can use this to store essential personal and medical details. The bottle is not large enough to hold items such as an ADRT, but you could add a note about where to find such documents. Bottles are free of charge from your local chemist. You can also contact the Lions Club for details – see their contact page at:

<https://lionsclubs.co>

MedicAlert: this registered charity provides an identification system for individuals with medical conditions or allergies. Usually in the form of a bracelet or necklet, which you purchase, the scheme is supported by a 24-hour emergency telephone service. You can find details at: **www.medicalert.org.uk**

Carer emergency card: a card that carers can carry in case they are involved in an emergency and unable to communicate. Usually linked to a registration service, the card alerts authorities, so you can be supported if your carer is unable to help. Ask your local authority in England or Wales if they have a carer card scheme. Ask your local health and social care trust in Northern Ireland about emergency and out of hours care support.

Telecare and telehealth: enables you to use an automated alarm system through a telephone line. These systems can help if you have a fall or need urgent assistance. Ask your GP or adult social care services about how to access equipment. There may be a charge for this service.

Texting emergency calls to 999: you can download an app for the Relay service, which enables text calls to emergency services through 999. See more information at **www.relayuk.bt.com/how-to-use-relay-uk/contact-999-using-relay-uk.html**

Key points

- If you begin to have problems with speech and communication, try to get your wishes for future care written down in an advance care plan or ADRT. You may also wish to get your affairs in order, such as making a will. The later you leave these arrangements, the harder it may be to have detailed conversations.
- Keep copies of important documents like your ADRT in a safe place, but easy to access when needed. Ensure someone you trust knows passwords for access to computer files, where appropriate.
- Your views may change over time, in surprising ways. Don't worry about expressing this. You have the right to change instructions, and for your views and wishes to be respected.

Further information:

From our range of information sheets:

- 1A: *Nice guideline on MND*
- 6C: *Managing pain*
- 7A: *Swallowing difficulties*
- 7B: *Tube feeding*
- 7C: *Speech and communication support*
- 8A to 8D:
our range of sheets on breathing and ventilation support for MND, including withdrawal of ventilation
- 10D: *NHS continuing healthcare*
- 11C: *Equipment and wheelchairs*
- 14A: *Advance Decision to Refuse Treatment (ADRT) and advance care planning*

From our guides and other publications:

End of life – a guide for people with motor neurone disease: our comprehensive guide to end of life discussions, advance decisions, future care, getting affairs in order, organ and tissue donation, wills and other planning.

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

MND checklist: our form to help you think about support planning when first diagnosed.

What you should expect from your care: our pocket guide on questions to ask at appointments, based on the NICE guideline.

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

Finding your way with bereavement: our guide to help with grieving when someone dies, including anticipatory grief before death.

When someone close has MND: a workbook for children aged 4 to 10 to help a trusted adult communicate with them about MND.

So what is MND, anyway?: a publication about MND and its impact for young people and young carers up to the age of 18.

Research information sheet I: Tissue donation: explains how donated tissue may be used and how to go about arranging for donation.

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

Information to pass to your health or social care professionals:

P4A: MND Just in Case Kit (introductory sheet)

P11: Pain in MND

A professional's guide to end of life care in motor neurone disease

MND in acute, urgent and emergency care

Supporting children and young people close to someone with MND

Download our publications at:
www.mndassociation.org/publications
 Or order them from **MND Connect**, our support and information helpline:
 Telephone: **0808 802 6262**
 Email: **mndconnect@mndassociation.org**.

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

See Section 12: *How we can help you.*

Online forum:

A safe place to share information and support with others affected by MND at:
<https://forum.mndassociation.org>

Samaritans:

A listening service for confidential support.
www.samaritans.org
 Telephone: **116 123**

Office of the Public Guardian:

Search for lasting power of attorney at
www.gov.uk for information about power of attorney in England and Wales.
 Telephone: **0300 456 0300**
 or textphone: **0115 934 2778**

Office of Care and Protection:

Search for EPA at: **www.courtsni.gov.uk**
 for information about Enduring Power of Attorney in Northern Ireland.
 Telephone: **0300 200 7812**

Government online information:

For advice about benefits and other matters, such as NHS continuing healthcare.
www.gov.uk in England and Wales
www.nidirect.gov.uk in Northern Ireland.

Record Me Now

A downloadable free app to leave video messages for your family and children at:
www.recordmenow.org

Digital Legacy Association

Online help about what to do with any online records that may be left in your name at:
<https://digitallegacyassociation.org/for-the-public/>



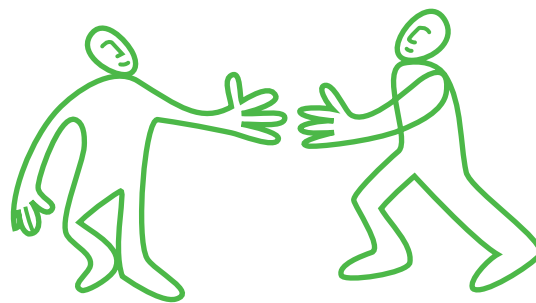
Part 3: Accessing services and support

Section 12: How we can help you

Section 13: Useful organisations

12: How we can help you

This section explains how to access help from the MND Association.



We are a charity dedicated to improving the lives of people affected by MND in England, Wales and Northern Ireland. Scotland is supported by a different organisation called MND Scotland.

See Section 13: *Useful organisations for contact details.*

The earlier we can help you, the more we can accomplish on your behalf. You may at times feel very isolated, but you are not alone in this.

See the following for our service details.

MND Connect helpline

Our helpline provides support and information for:

- people living with MND or Kennedy's disease
- their carers and families
- our volunteers
- health and social care professionals.

The team can provide emotional support, information and direct you to our own services and appropriate external organisations.

The service is available Monday to Friday, from 9am to 5pm and 7pm to 10.30pm.

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Association visitors (AVs)

AVs are trained volunteers who provide free and confidential guidance to people with MND or Kennedy's disease, their carers, close family and friends.

An AV can help you identify problems as they arise, answer questions and discuss how you might get support.

All AVs are carefully selected and undergo a Disclosure and Barring Service (DBS) check. They are based in the local community and can contact you by phone, email or through home visits.

If you would like to be supported by an AV, a member of our regional care staff or our MND Connect helpline can help arrange this, where an AV is available.

If an AV is not available in your area, we can offer ongoing support and help through our helpline or your local branch or group. Please see other headings in this list for details.

Regional staff for local support

Our regional staff for local support have knowledge about the management and care of people with MND.

They work with volunteers and affected families, or help to influence local service providers.

Their aim is to help ensure care and support is made available at the right time.

Find out more about our services and local support on our website at www.mndassociation.org/support-and-information or contact our MND Connect helpline, as shown in this list.

Local branches and support groups

We have a network of more than 85 branches and groups, throughout England, Wales and Northern Ireland. These are run by volunteers and provide a warm welcome and the opportunity to meet others affected by MND.

Our branches and groups offer guidance, information and get-togethers where people can share experience and support. These meetings sometimes include gatherings specifically for carers.

Our branches are listed on our website at www.mndassociation.org/branchesandgroups or contact our MND Connect helpline for help, as shown in this list.

MND Association Benefits Advice Service:

We can provide free, confidential and impartial advice on any benefits you may be entitled to. Find current contact details for England, Wales and Northern Ireland at: www.mndassociation.org/benefitsadvice or contact our MND Connect helpline for guidance.

Equipment loan and grants

We may be able to provide certain items of equipment and communication aids on loan, or consider requests for financial support through grants.

All statutory funding and services should be explored first. However, loaned items can be provided if you have to wait for health and social care services to arrange equipment or if they are unable to provide an item.

The following types of grant are available:

MND support (care) grant

Provided to: people living with MND or Kennedy's disease, of any age.

Amount provided: depends on the type of spend and the value of any previous grants provided.

Application: by a health or social care professional following assessment of need, where this need cannot be met through the services they link to, or where provision will be delayed.

Can be used for: a variety of purposes, such as home adaptations, equipment or respite care.

MND quality of life grant

Provided to: people living with MND or Kennedy's disease, of any age.

Amount provided: depends on the type of spend and the value of any previous grants provided, up to £500 in any one grant.

Application: by any family member, Association visitor, health or social care professional or a regional care staff contact.

Can be used for: improving quality of life for the person diagnosed, or for equipment that does not require a health or social care assessment.

MND carer's and young carer's grant

Provided to: family or non-professional carers, who are 16 or older.

Amount provided: up to £500 is available in any one year.

Application: by the carer, or on their behalf by one of our Association visitors or a health and social care professional.

Can be used for: a break from caring, as with a pamper day, a short break or to support a hobby.

Young person's grant

Provided to: a child or young person aged 18 or under, who has a parent with MND or Kennedy's disease, or who lives in the same household with someone who has been diagnosed.

Amount provided: up to £250 is available in any one year.

Application: by a family member for the young person, or on their behalf by one of our Association visitors, a regional care staff contact or a health or social care professional.

Can be used for: a variety of purposes, such as decorating their room at home, a family day out or for equipment to help the young person, such as a laptop.

If you have any queries about grants or equipment loans, please contact our MND Connect helpline, as shown in this list.

Communication Aids Service

Our Communication Aids Service helps people with MND, carers, families, and health and social care professionals, with queries about communication aids. The service provides limited financial support for communication aids or some items on loan, if unavailable or delayed through health and social care services.

Our aim is to improve provision and information on a local and national level, through collaboration with health and social care professionals.

Telephone: **0808 802 6262**

Email:

communicationaids@mndassociation.org

MND care centres and networks

We part-fund MND care centres and networks across the UK. These offer specialist help to support people with MND, their carers and families.

MND care centres and networks bring together a range of health and social care professionals to provide co-ordinated care. They are usually referred to as a multidisciplinary team (MDT).

If you cannot get to a care centre or network easily, you can still receive co-ordinated care through regional neurological services and local specialist palliative care services.

MND care centres are not 'buildings', but usually take place in an established clinic in one place, such as a hospital.

MND networks provide similar services, but do not have a fixed location, as they cover a wide geographical area.

Care centres and networks sometimes run clinical drug trials and undertake clinical research about MND. They also help to educate colleagues in the community and share good practice to improve MND care and support.

To find your nearest MND care centre or network, contact our MND Connect helpline, as shown in this list.

Our website

Please visit the MND Association website to find our information resources online and more about our services and the MND Association. Find our site at **www.mndassociation.org** which includes news about our research, volunteering, fundraising and campaigning activities.

Care information and publications

We provide a wide range of care information resources and publications. Our information is developed and revised under an accreditation through PIF Tick

<https://piftick.org.uk>

This means it is evidence checked, user tested and reviewed by experts.



Patient Information Forum

Online forum

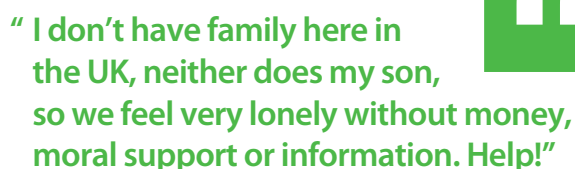
Our online forum is a safe place to share experiences, ideas and a wealth of information, with other people affected by MND. You can access the forum on our website or at

<https://forum.mndassociation.org>

Inclusion

We are here for everyone living with or affected by MND or Kennedy's disease in England, Wales and Northern Ireland. We acknowledge that people have differing needs, backgrounds, culture and faiths. Other aspects of diversity may also influence the way care and support should be offered and provided.

The MND Association supports equality in all of its services. Please ask the service you are dealing with if you have any particular preferences or needs that you wish to be taken into consideration.

A green speech bubble containing a quote. The quote is in green text and reads: "I don't have family here in the UK, neither does my son, so we feel very lonely without money, moral support or information. Help!"

" I don't have family here in the UK, neither does my son, so we feel very lonely without money, moral support or information. Help!"

Information in other languages and accessible formats

We provide introductory information in languages other than English and a limited service for further translations of care publications. We also have alternative formats for some resources, such as audio or easy read.

Find out more at

www.mndassociation.org/languages

or contact our MND Connect helpline. If needed on first enquiry, ask someone to contact the team on your behalf. They can help answer your questions or direct you to appropriate support.

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Membership

Membership of the MND Association enables you to join a community of people living with MND, their spouses, partners and carers. A community of people who all share the same vision of a world free from MND. As a unified force, our membership creates a powerful voice to support lobbying and campaigns on behalf of all people affected by MND.

By becoming a member, you will:

- have opportunities to influence the work of the Association
- be sent a welcome pack, including a membership card
- be able to link to your nearest branch or group
- receive Thumb Print, our quarterly magazine for our members
- be able to attend and vote at our AGMs
- have invitations to our conferences and events
- have access to a collectible pin badge every year.

To become a member, contact us by:

Telephone: **01604 611860**

Email: **membership@mndassociation.org**

Getting involved

Many people with or affected by MND or Kennedy's disease ask how they can get involved with our activities. If you would like to know more, see the following web pages:

Volunteering:

www.mndassociation.org/volunteering

Fundraising:

www.mndassociation.org/fundraising

Campaigning:

www.mndassociation.org/campaigning

Research:

www.mndassociation.org/research

Or contact enquiries:

Telephone: **01604 250505**

Email: **enquiries@mndassociation.org**

We work alongside people with MND or Kennedy's disease, and their carers, to develop and improve our information. If you would like to get involved, you will have opportunities to feed into a range of different content and formats.

You can pick and choose which tasks you want to work on and make a difference from the comfort of your own home. To find out more, contact:

infofeedback@mndassociation.org

Key points

- We support everyone with or affected by MND or Kennedy's disease in England, Wales and Northern Ireland (support is provided in Scotland by MND Scotland).
- Our services are free for people with MND or Kennedy's disease, their partners and carers.
- If you need assistance to contact any of our services or external services, contact our MND Connect helpline, as listed in this section.

Further information:

A list of other contacts can be found in Section 13: Useful organisations.

A *Publications order form* is included in the folder with this guide. You can order further copies of this form or any of our resources from our MND Connect helpline, as listed in this section.

13: Useful organisations



This section will help you identify some of the organisations that can provide further information or support.

Access more links to useful organisations at: www.mndassociation.org/usefulorgs. We also list relevant organisations in our information sheets.

Contact your local authority in England and Wales, or your local health and social care trust in Northern Ireland, to find out about services in your area. They may offer a directory on their website.

See the Contact record in Part 4: Helping you to keep track, to group details.

If you would like to know more about organisations that support carers, children or young people affected by MND, we provide publications to meet their needs:

See Further information at the end of Section 5: Family, children and friends.

Organisations

We do not necessarily endorse the organisations listed here and cannot be held responsible for anything stated on their website or supplied as a service or a product.

We keep this information updated, but the contact details may change before the next revision. If you need help locating an organisation, contact our helpline, MND Connect:

Telephone: **0808 802 6262**
Email: mndconnect@mndassociation.org

The helpline team can also direct you to our services and local support.

Access to Work

To help you and your employer support your work routines.

Telephone: **0800 121 7479**
Textphone: **0800 121 7579**
Website: search for *access to work* at www.gov.uk or for Northern Ireland at: www.nidirect.gov.uk

Adult Social Care Services

Contact your local authority for a needs assessment, carer's assessment or social care advice. For Northern Ireland, search for health and social care trusts at www.nidirect.gov.uk

Advicenow

Online information on rights and legal issues.
Website: www.advicenow.org.uk

Age UK

Information, advice and advocacy for people in later life, including guidance on benefits.
Telephone: **0800 055 6112** (England)
0300 303 44 98 (Wales)
0808 808 7575 (Northern Ireland)
Email: through website contact page
Website: www.ageuk.org.uk

Asian Health Agency

Information and support for Asian elders, disabled people and carers across the UK, with care services across many London boroughs.

Email: through website contact page
Website: www.taha.org.uk

Blue Badge Scheme

A blue badge enables access to a range of parking benefits and other motoring concessions for people with severe mobility difficulties. Contact your local authority or look online at GOV.UK

Website: search for *blue badge* at: www.gov.uk or in Northern Ireland at: www.nidirect.gov.uk

BME Health Forum

An organisation helping to improve health services for black and minority ethnic groups. Their work is based in London, but their site includes patient information on rights for healthcare and how to access support.

BME Health Forum, Church Street
Neighbourhood Centre, Cherwell House,
Penfold Street, London NW8 8PT
Telephone: **07958 479 217**
Email: through website contact page
Website: www.bmehf.org.uk

BACP (British Association for Counselling and Psychotherapy)

A body representing counselling and psychotherapy in the UK who can direct you to trained practitioners.

BACP, BACP House, 15 St John's Business
Park, Lutterworth LE17 4HB
Telephone: **01455 883300**
Email: bacp@bacp.co.uk
Website: www.bacp.co.uk

British Red Cross

For health and social care assistance, equipment hire (eg standard wheelchairs) and various disability living aids for purchase.

British Red Cross, 44 Moorfields,
London EC2Y 9AL
Telephone: **0344 871 11 11**
Email: contactus@redcross.org.uk
Website: www.redcross.org.uk

Carers Trust

Support for carers.

Carers Trust, Unit 101, 164-180 Union Street,
London SE1 0LH
Telephone: **0300 772 9600** (England)
0300 772 9702 (Wales)
Email: info@carers.org (England)
wales@carers.org (Wales)
Website: <https://carers.org>

Carers UK

Information, advice and campaigning for the rights of carers.

Carers UK, 20 Great Dover Street,
London SE1 4LX
Telephone: **0808 808 7777**
Email: through the website contact page
Website: www.carersuk.org

Childline

Counselling and a free 24-hour helpline for children or young people in distress or danger.

Childline, Via NSPCC, Weston House,
42 Curtain Road, London EC2A 3NH
Telephone: **0800 1111**
Email: through the website contact page
Website: www.childline.org.uk

Citizens Advice

Free information and advice on legal, money and other problems. Search for your local branch on their website.

Telephone: **0800 144 8848** (for England or contact your local branch)
0800 702 2020 (for Wales)

Website: **www.citizensadvice.org.uk**

For Northern Ireland, search on the website for your local Community Advice.

Community Law Service

Independent advice and representation, including welfare benefits, debt and housing. Contact your local service through your telephone directory or by searching for *community law service* online.

Disability Law Service

Contact the DLS for assistance on disability law.

Disability Law Service, The Foundry,
17-19 Oval Way, Vauxhall, London SE11 5RR

Telephone: **0207 791 9800**

Email: **advice@dls.org.uk**

Website: **https://dls.org.uk**

Disability Rights UK

Information, products and services designed by and for disabled people.

Disability Rights UK, Plexal, 14 East Bay Lane,
Here East, Queen Elizabeth Olympic Park,
Stratford, London E20 3BS

Telephone: **0330 995 0400**

Email: see website for contact details

Website: **www.disabilityrightsuk.org**

The Disabled Living Foundation

See entry for *Living Made Easy*.

GOV.UK

Online government information about financial help and benefits.

Website: **www.gov.uk** (England and Wales)
www.nidirect.gov.uk (Northern Ireland)

Health in Wales

Online information about NHS services in Wales including a directory of the Welsh health boards. (See also NHS Direct Wales).

Email: through the website contact page

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

Health and Care Professions Council (HCPC)

A register of health professionals who meet HCPC standards of practice, with a search facility to find professionals, including psychologists, physiotherapists, occupational therapists and speech and language therapists.

Health Professions Council, Park House,
184-186 Kennington Park Road,
London SE11 4BU

Telephone: **0300 500 6184**

Website: **www.hcpc-uk.org**

Health and Social Care Online (Northern Ireland)

Online information about health and social care services in Northern Ireland.

Email: through the website contact page

Website: **https://online.hscni.net**

Healthtalk.org

A website of personal health experiences, including a series of interviews with people affected by or living with MND.

Website: search for motor neurone disease at: **www.healthtalk.org**

Independent Age

Independent advice on a range of care issues, including assessments, getting help at home, paying for care, benefits and hospital discharge.

Independent Age, 18 Avonmore Road,
London W14 8RR

Telephone: **0800 319 6789**

Email: **advice@independentage.org**

Website: **www.independentage.org**

Jobcentre Plus

Contact your local Jobcentre Plus for advice about employment and some benefit claims.

Website: search for **jobcentre plus** at:

www.gov.uk to find your local office. This will also link you to *jobs and benefits* offices for Northern Ireland, or search for these at:

www.nidirect.gov.uk

Lesbian and Gay Foundation

Information and advice for lesbian, gay and bisexual people.

LGBT Foundation, Fairbairn House
(2nd Floor), 72 Sackville Street,
Manchester M1 3NJ

Telephone: **0345 3 30 30 30**

Email: **info@lgbt.foundation** or through website contact page

Website: **https://lgbt.foundation**

Lions Clubs International (British Isles and Ireland)

A community service organisation, helping to promote the Message in a Bottle scheme to assist paramedics in case of emergencies.

Lions Clubs International, 257 Alcester Road
South, Kings Heath, Birmingham B14 6DT

Telephone: **0121 441 4544**

Email: **enquiries@lionsclubs.co** or through website contact page

Website: **https://lionsclubs.co/Public**

Living made easy

Previously known as the Disabled Living Foundation. An organisation providing products to support disabled people in their daily lives.

Email: **info@dfl.org.uk**

Website: **https://livingmadeeasy.org.uk**

Medic Alert

An identification system for individuals with medical conditions, usually in the form of bracelets or necklets, supported by a 24 hour emergency telephone service.

MedicAlert, Suite 1, Liscombe South,
Liscombe Park, Soulbury LU7 0JL

Telephone: **01908 951045**

Email: **info@medicalert.org.uk**

or through website contact page

Website: **www.medicalert.org.uk**

Motability

For details about vehicle leasing or hire purchase through the Motability scheme.

Telephone: **0300 456 4566**

Textphone: **0300 037 0100**

Email: through website contact page

Website: **www.motability.co.uk**

MND Scotland

Support for people affected by MND in Scotland.

MND Scotland, 6th Floor, Merchant
Exchange, 20 Bell Street, Glasgow G1 1LG

Telephone: **0141 332 3903**

Email: **info@mndscotland.org.uk**

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

NHS (online information)

Health information according to need. For Wales, see *NHS Direct Wales*. For Northern Ireland, see *Health and Social Care Online*.

Website: **www.nhs.uk**

NHS 111

The NHS online/telephone help and support service, providing health advice and information, 24-hours a day, 365 days a year.

Telephone: **111** for urgent, but non-emergency medical advice

Email: through the website contact page

Website: **https://111.nhs.uk**

NHS 111 Wales

Similar to NHS 111 for England, but for Wales.

Telephone: **111**

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

Office of Care and Protection

Information about Enduring Power of Attorney for Northern Ireland. For Lasting Power of Attorney in England and Wales, see Public Guardianship Office.

Office of Care and Protection, Room 2.02,
First Floor, Royal Courts of Justice, Chichester
Street, Belfast, BT1 3JF

Telephone: **0300 200 7812**

Email: epa@courtsni.gov.uk

Website: bit.ly/EPAttorney

Office of the Public Guardian

Information about Lasting Power of Attorney and the Mental Capacity Act. For Enduring Power of Attorney in Northern Ireland, see Office of Care and Protection.

Public Guardianship Office, PO Box 16185,
Birmingham B2 2WH

Telephone: **0300 456 0300**

Textphone: **0115 934 2778**

Email:

customerservices@publicguardian.gov.uk

Website: www.gov.uk/power-of-attorney

Outsiders Club

Support on relationships and sexuality for disabled people.

Outsiders Trust, WestEnd, Redwood Farm,
Barrow Gurney, Avon, BS48 3RE

Telephone: **07900 957 393** or
01997 421 019

Email: members@outsiders.org.uk

Website: <https://outsiders.org.uk>

The Patient Advice and Liaison Service (PALS)

Confidential advice about NHS services and complaints.

Telephone: contact your local hospital, GP or health clinic

Website: search for *PALS* at: www.nhs.uk

For Northern Ireland:

Patient and Client Council

Freephone: **0800 917 0222**

Email: info.pcc@pcc-ni.net

Website: <https://pcc-ni.net>

For Wales:

Refer to your local Community Health Council (CHC):

www.wales.nhs.uk/ourservices/directory/CommunityHealthCouncils

Pension Service

For queries and claims regarding pensions and pension credit.

Telephone: **0800 731 7898**

Textphone: **0800 731 7339**

Website:

www.gov.uk/contact-pension-service

For Northern Ireland:

Telephone: **0800 587 0892**

Website: www.nidirect.gov.uk/contacts/northern-ireland-pension-centre

REMAP

A charity of volunteers who make bespoke aids for disabled people.

Remap Head Office, D9 Chaucer Business Park, Kemsing, Sevenoaks, Kent TN15 6YU

Telephone: **01732 760209**

Email: through the website contact page

Website: www.remap.org.uk

Scope

This charity offers local disability advice, having combined with Disability Information and Advice Line services (previously known as DIAL).

Helpline: **0808 800 3333**

Email: **helpline@scope.org.uk**

Website: **www.scope.org.uk**

Samaritans

Confidential 24-hour emotional support by telephone, email, letter or face-to-face in most branches.

Freepost SAMARITANS LETTERS

Telephone: **116 123** (or contact your local branch)

Email: **jo@samaritans.org**

Website: **www.samaritans.org**

Shopmobility

A scheme in many towns and shopping centres, providing manual or powered wheelchairs or scooters, for loan or hire.

Telephone: **07984 740 271** (urgent enquiries only)

Email: through website contact page

Website: **www.shopmobilityuk.org**

Turn2us

Online help about financial support, grants or funding, including a benefits calculator.

Website: **www.turn2us.org.uk**

Working Families

Helping people and employers find a better balance between work and home.

Working Families c/o Buzzacott LLP,
130 Wood Street, London EC2V 6DL

Helpline: **0300 012 0312**

Email: through website contact page

Website: **www.workingfamilies.org.uk**

Key points

- Before selecting or purchasing any specialist equipment or aids, have your needs assessed by an appropriate health or social care professional, as items may not be suitable for everyone and mistakes can be costly.
- You can note details of local organisations on the contact record, in the *Helping you to keep track* pages at the back of this guide.

Further information:

We offer a range of publications to help you manage life with MND. Each resource lists organisations relevant to the subject being covered.

Download our publications at:

www.mndassociation.org/publications

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

Telephone: **0808 802 6262**

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

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

See Section 12: How we can help you.

Online forum:

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

https://forum.mndassociation.org

Part 4: Helping you to keep track

Introduction

Personal details

Contact record

Appointment and communication record

Equipment record

Medication record

References

Acknowledgements

Index

We welcome your views

Introduction

The five forms on the following pages have been developed to help you keep important information in one place. It is your choice if you wish to use these pages or not, but they may help if you meet a wide variety of health and social care professionals.

You can also download and print these forms to carry around as separate sheets.

See *Helping you to keep track* at www.mndassociation.org/lwmnd

The five forms are:

1. Personal details:

to record basic information about yourself to save time at appointments.

We also supply a form in the folder of this guide, called, *Understanding my needs*.

This is designed to help hospital staff and care workers provide you with suitable support

2. Contact record:

to keep a central list of key people and services with their contact details.

3. Appointment and communication record:

to help you prepare for appointments and keep notes.

4. Equipment record:

to note the equipment you receive and contacts for support.

5. Medication record:

to note when and how much to take of any medication, nutritional supplement or tube feed.

Personal details

By recording your details here, you can use this page to show health and social care professionals if they need your basic information. This can be very helpful as you are likely to meet a wide span of professionals. Keep the guide safe if you complete this page, as it will contain confidential data.

My information:

Name:

Home Tel:

Mobile:

Address:

Email:

NHS number:

Date of birth:

My main contacts are:

Next of kin - Name:

Telephone:

Email:

Main carer - Name:

Telephone:

Email:

MND Association contact - Name:

Telephone:

Email:

GP - Name:

Telephone:

Address:

Name of my MND care centre, network or neurological service:

Telephone:

Address:

Contact record

This will help you keep a central record of all contacts for easy reference.

MND Association services

Name or organisation	Contact details
MND Connect	0808 802 6262 mndconnect@mndassociation.org
Association visitor	
Branch or group	
Regional care staff contact	
Support services (MND support grants and equipment loan)	0808 802 6262 support.services@mndassociation.org MND Association, Francis Crick House (2nd Floor), 6 Summerhouse Road, Moulton Park, Northampton NN3 6BJ
Switchboard	01604 250505 enquiries@mndassociation.org
Membership enquiries	01604 611855 membership@mndassociation.org

MND Association services (continued)

Name or organisation	Contact details
MND Association Benefits Advice Service	Free, confidential and impartial advice on any benefits you may be entitled to. Find current contact details for England, Wales and Northern Ireland at: www.mndassociation.org/benefitsadvice or contact our MND Connect helpline for guidance.
Communication Aids Service	0808 802 6262 communicationaids@mndassociation.org MND Association, Francis Crick House (2nd Floor), 6 Summerhouse Road, Moulton Park, Northampton NN3 6BJ
Online forum	https://forum.mndassociation.org
Website	www.mndassociation.org
MND Association publications	www.mndassociation.org/publications or contact the MND Connect helpline (see earlier in list)
MND Association information feedback	infofeedback@mndassociation.org

Healthcare services

Name or organisation	Contact details
NHS 111	Telephone 111 if you need urgent, but non-emergency medical help.
999 or Relay UK	Telephone 999 for emergency help. If you have speech difficulties, use Relay UK for emergency contact: https://www.relayuk.bt.com/how-to-use-relay-uk/contact-999-using-relay-uk.html
MND care centre or network	
Neurology clinic	
Consultant	
GP	
District nurse	
MND specialist nurse	

Healthcare services (continued)

Name or organisation	Contact details
Palliative care nurse	
Occupational therapist (OT)	
Speech and language therapist (SLT)	
Physiotherapist	
Dietitian	
Pharmacist	
Counsellor	
Psychologist	

Social care and related services

Name or organisation	Contact details
Adult social care services (local)	
Local authority (England and Wales) or local health and social care trust (Northern Ireland)	
NHS Wheelchair service (local)	
Jobcentre Plus (local branch)	
Carer's Allowance Unit	0800 731 0297 or textphone: 0800 731 0317 www.gov.uk/carers-allowance-unit
Citizen's Advice Bureau (local branch)	
The Pension Service	0800 731 7898 or textphone 0800 731 7339 www.gov.uk/contact-pension-service
Religious or spiritual guidance	

Appointment and communication record

You may find this helpful to prepare for appointments and keep a record of what was said. List any questions beforehand and either make notes during the meeting or ask the health and social care professional to write down the answers for you. If you begin to attend a lot of appointments, you may wish to use this layout in a notebook instead.

Day, date & time	Who with	Questions you want to ask	Notes
<p>Example: Monday 25 July 2022 11.30am</p>	<p>My GP, Dr Smith</p>	<p>My joints feel stiff. What can I do to maintain flexibility?</p>	<p>Dr Smith recommended specific assisted exercises and will refer me to a physiotherapist with experience of MND.</p>

Day, date & time	Who with	Questions you want to ask	Notes

Day, date & time	Who with	Questions you want to ask	Notes

Day, date & time	Who with	Questions you want to ask	Notes

If you have a great many appointments, you may wish to use this layout in a notebook instead.

Equipment record

You can use this form to record any equipment you receive and who will be your main contact in case you need support.

Date	Item	Person or provider to contact	Contact number or email address
Example: 25 July 2022	Rollator walking frame	Anne Jones A Made-up Equipment Service	Add contact details as appropriate

Date	Item	Person or provider to contact	Contact number or email address

Date	Item	Person or provider to contact	Contact number or email address

References

An extensive reference list of the evidence used to support this guide is available on request. Please make your request by email to: infofeedback@mndassociation.org or write to us at:

Information feedback, MND Association, Francis Crick House (2nd Floor)
6 Summerhouse Road, Moulton Park, Northampton NN3 6BJ

Acknowledgements

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Index

- AAC Pathway 63
- abdomen 16, 17
- accepting change 31
- Access to Work scheme 64, **75**, 76
- Accessible Information Standard 5, 18, **26**
- acupuncture 20
- adapted switches 54, 62, 64
- adapted utensils 70
- adapted vehicles 44, 45
- adapting your work environment 76
- adapting your home 19, 25, **43**, 46
- adult social care services 20, 23, 24, 49, 55, 64, **74-78**, 83, 89
- advance care plans **87**, 90
- Advance Decisions to Refuse Treatment (ADRT) **87**, 90
- alcohol **68**, 72
- Alert wristband 4, 16, 65, **89**
- alphabet board 17, 25, **61**
- alternative communication 16, **60**
- Amyotrophic lateral sclerosis (ALS) 10
- appetite 30, **66**, 70, 72
- appliances 43, 54, 64
- Appointment and communication record 113
- apps 25, 61, **63**
- aspiration 67, 70
- assisted exercise 19, **41**, 53, 66, 72
- Association visitors (AVs) 32, 36, 55, 85, **93**
- Attendance Allowance (AA) 79-80
- Augmentative and Alternative Communication (AAC) 16, 17, 60, 63
- balance 14, **42**, 43, 48, 68
- balanced diet 67
- bank account 25
- bath boards 49, 50
- bath seat 49
- bathing aids 49, 78
- bathing and showering 49
- bathroom 43, 49
- beliefs 29, 85, 87, 88
- Benefits Advice Service 25, 27, 74, 75, **79**, **94**
- benefits 20, 25, 27, **74-80**
- benefits adviser 20, 25, **74-76**
- bladder 8, 18, 50, **72**
- bladder irritants 72
- blood tests 9
- Blue Badge scheme **44**, 45, 81, 99
- bowel 8, **18**, **72**
- braces 42
- branch or group 19, 26, 27, 32, 36, 93, **94**, 97
- breathing 8, **15**, 16, 17, 41, 59, 72, 87
- breathlessness **15**, 17, **67**, 87
- bulbar muscles 10, **16**
- caffeine 72
- calories **67**, 69
- car insurer 44
- care information and publications 96
- care needs 15, 24, 48, **55**, **74-77**, 80, 85, 86
- care services and agencies 48, 49, 55, 64, **74-82**, 89, 94, 95
- carer 15, 18-20, 24, 30, 31, **34-44**, 48, 55, 60, 67, 72, **74-82**, **93-97**
- carer emergency card 89
- Carer's Allowance 79, 110
- carer's assessment 24, **55**, **77**
- Carer's Credit 79
- Carer Premium 79
- carrying items 53, 54
- causes 9-11
- changing roles 34
- charitable funding 48, 64, 74, **81**
- chest infection 67, 72
- chewing 66-70
- children 36-38, 74, 79, 81, 85, 86, **95**
- chiropodist 52
- choking 16, 67
- citrus drinks 72
- claiming benefits 20, 27
- clinical examination 9

Index (continued)

clinical trials	11, 21	dietitian	14, 16, 17, 20, 66-73
clothing	45, 51 , 71, 72	difficult conversations	26, 34, 85
cognitive change	17, 30	difficulty sleeping	15, 30 , 41
comfort	15, 17, 40, 41, 45, 51, 53	direct payments	55, 74, 77-78
commode	50	Disability and Carers Service	75
communication	34, 35, 44, 54, 58-65 , 73, 81, 84, 90, 94, 95 , 104	Disability Living Allowance (DLA)	79, 80
Communication Aids Service	63, 64, 95	disability transport schemes	45
Community or district nurse	19 , 40-43, 48, 50, 53, 67, 72, 87	Disabled Band Reduction Scheme	79
Complaints	21, 78	Disabled Facilities Grant (DFG)	43, 48, 78, 80
complementary therapies	19, 20 , 32, 80	Disabled Living Centre	45, 49
concentrated pee or urine	72	Disabled Persons Allowance – Rates (Northern Ireland)	80
consistency of food and drink	68	district or community nurse	19 , 40-43, 48, 50, 53, 67, 72, 87
constipation	17, 18, 66, 72	disturbed sleep	15, 30 , 41
contact record	106	dressing and dressing aids	51
conversions (home)	24, 43	drinking	16, 17, 66-73 , 87
cooking	54	driving	44-47 , 75
coughing	15, 16, 52, 67-70	drooling	16
Council Tax discounts	79	drugs or medication	14-21 , 30, 32, 40, 42, 66-72 , 87, 120
counselling and psychology services	11, 19, 20, 32 , 78, 86	dry mouth	52, 70
cramp	10, 14 , 17, 19, 42	DVLA	46, 75
cultural choices	29, 85, 96	dysarthria	16
cushioning	42 , 44, 53	dysphagia	16, 66, 67
day therapy units	78	early retirement	25, 76-77 , 82
daytime sleepiness	15	early symptoms	9-10
debt counselling	82	eating	16, 18, 66-73
decision making	9, 11, 15, 24-27 , 31, 32, 71, 72, 74, 76, 81, 82, 84-90	electric toothbrush	52, 71
dehydration	16, 18, 66, 68	Electromyography (EMG)	9
dental care	71	Emergency Duty Team (EDT)	55, 78
dentures	52, 66	emergency support	54, 55, 78
Department of Work and Pensions (DWP)	75	emotional lability	17, 30
depilation (hair removal)	52	emotions and support	11, 17-20, 26, 29-33 , 34, 36, 40, 86, 93
diagnosis	7-10 , 19, 21, 24, 29 , 31, 34 , 35, 44, 46, 74, 75	employment	75-76
diaphragm	72	Employment and Support Allowance (ESA)	80
diarrhoea	18, 72	end of life concerns	84-91
diet	14, 16, 66-73	energy	17 , 30, 41 , 48, 59, 67-72

- entitlements 74-83
- environmental controls 43, 54, **64**
- equipment 24, 35, **40-47, 48-57, 60-65,**
70, 71, 81, 94, 95, 117
- equipment loan (MND Association) 64, 94
- Equipment record 117
- exercise 14, 15, 19, **40-41,** 48, 53, 72
- eyes **18,** 59, 61, 62, 68
- eye-pointing frames 61
- eye tracking systems 61, 62
- facial expressions 58, 60
- falls 14, 15, **40,** 43
- family 19, 25, 29-33, **34-39,** 41, 60,
62, 71-73, 75, **85-91**
- family history of MND 10-11
- fasciculations 7, 14
- fastenings **51,** 82
- fatigue 15, **17,** 40, 41, 48, 52, 66, 84
- finances and support 24-27, **74-83,** 85, 88
- financial assessment 24, 55, 78
- flexibility **14, 19,** 53
- flexible working hours 74, 76
- friends 29-30, **34-39,** 60, 62
- Frontotemporal Dementia (FTD) 10, **18,** 79
- funeral arrangements 88
- gag reflex 52, 67
- gastrostomy 71
- genes 10-12
- genetic counselling 11
- genetic testing 10-12
- gestures 17, 59
- GP (general practitioner) 8-23, 26, 30, 32,
44, 55, 66-69, 72, 80, 87, 89
- grab rails 40, 43, 49, 50
- grants 48, 74, 78, 81, **94-95**
- grip 44, **50-53,** 70
- hair washing and drying 50, **52,** 68
- head support 18, 63
- health and social care professionals **18-20,** 26, 78, 95
- hearing **18,** 59, 60
- hobbies 35, 40, **78**
- hoist 24, 43, **49-50**
- home adaptations **25,** 43, 46, 48, 94
- home working 76
- hospice care 17, **19,** 20, 21, 32, 52, 78, **86**
- hospital 9, 16, 21, 26, **86-89,** 95
- Housing Benefit 79
- Income Support 79
- incontinence 50-51
- independence 40-46, 48-56, 64, 78-80
- independent financial adviser 25, 75, 76
- information in other languages or formats 96
- inherited MND 10-11
- injury 40
- installations 43
- intimacy **18, 31,** 35
- invasive ventilation 15
- isolation 26, 29, **35,** 36
- Jean-Martin Charcot 11
- Kennedy's disease **10,** 93, 97
- Lasting Power of Attorney (LPA) 85, **88**
- late stage symptoms 84, 87
- leaving work 75, 76
- legal issues 74-78, 85-88
- lifts 44
- lips 58-60
- liquid feed 16, 71
- loss of interest 30
- lower motor neurones 7, 10
- lymphodema service 17
- Magnetic Resonance Imaging (MRI) scans 9
- make-up 52
- making a complaint 21, 78
- mask 15
- massage 20, 32
- mattresses 34, 42-43, 53
- means tested **11, 78-80**
- MedicAlert 89
- Medication record 120

Index (continued)

membership of the MND Association	97	online forum	5, 26, 32, 36, 96
menstruation	51	organ donation	88
Message in a bottle	89	oxygen	4, 15 , 65, 89
minority and ethnic groups	96	pain	14, 17 , 18, 40-42, 48
MND Association website	96	palliative care	17-21, 26 , 32, 52, 78, 86
MND care centres and networks	95	partner	18, 25, 31, 35, 52, 59, 71, 72, 75, 88, 97
MND checklist	89	passwords	87, 90
MND Connect helpline	93	PEG (Percutaneous Endoscopic Gastrostomy)	71
MND Just in Case Kit (JIC Kit)	67, 87	pelvic floor	72
MND specialist nurse	19	perching stool	50, 54
MND support grants	81, 94	personal appearance	52
mobile arm support	52	personal care plan	77-78
mobile hoist	43, 49	Personal details form	105
mobility	8, 14, 17, 18, 40-47 , 50, 66, 72, 80	personal health budget	80
Motability scheme	44-47	Personal Independence Payment (PIP)	79-80
motor neurones	7-11	pharmacist	20 , 70, 72
mouth care	52 , 71	physiotherapist	14, 19, 40-44 , 48, 53, 66, 67, 72
movement	7-18 , 31, 40-47 , 48-56 , 58, 61-63	physiotherapy	15
mucus	13	PIG (Per-oral Image Guided Gastrostomy)	71
multi-disciplinary team (MDT)	19 , 95	planning ahead	9, 26, 32, 84-91
muscle spasms	14, 17	podiatrist	52
muscle wasting	7-9, 16	positioning	15-19, 40, 42, 44, 48, 50, 53
muscle weakness	7-9, 14, 36, 41, 42, 48, 59, 67, 70, 72	posture	14, 19, 40-48 , 66, 70
nasogastric feeding	71	Power of Attorney	81-91
neck	15, 18, 45, 64, 66	powered bed	42
needs assessment	24, 37, 55 , 64, 74, 76-78, 82	preferred place of care	71
Nerve Conduction Tests	9	pressure relief	17 , 19, 42, 45, 53, 66
neurological services	19, 95	Primary lateral sclerosis (PLS)	10
neurologist	9-11, 18-20, 31	Progressive bulbar palsy (PBP)	10
NHS continuing healthcare	55, 74, 80 , 88	Progressive muscular atrophy (PMA)	10
NICE guideline on MND	4, 21, 26 , 78	pseudobulbar affect	17, 30
non-invasive ventilation (NIV)	15	psychologist	17, 20, 32
Northern Ireland	12, 20, 24, 27, 44, 55, 74-83 , 85-89	quality of life	7, 10, 19 , 21, 26 , 31, 40, 81, 86, 95
nursing/care home	86, 88	ramps	43
nutrition	20, 66-73	referral	18, 21
occupational therapist (OT)	16-19, 21-25, 40 , 41-45, 48-57, 63-66, 70, 78	reflexology	20
oedema	17	reflux	69

- Regional care staff contact 94
- research **11-12**, 21, 96, 97
- respiratory care **15**, 19, 40, 41
- respite care 55, 81, 94
- RIG (Radiologically Inserted Gastrostomy) 71
- riluzole **20**, 21
- riser recliner chairs 42, 43, 53
- rollator 42, 43, 53, 54
- saliva 16, 52, 59, **67**, 68, 70
- school 37
- scooters 45
- Scotland 5, 87, 93
- self-employment 76
- senses 7, **18**
- sensory neurones 7
- sex and intimacy **8, 18, 31**, 35
- shaving 52
- Shopmobility 47
- shortness of breath 15
- showers 43, **49-50**
- shower stools 43, **49-50**
- sight 7, **18**
- skin and sensitivity 7, **14, 17-19**, 52-53, 66, 68
- smartphones 25, **61-65**
- smell 18
- social care 20, 21, 24, 26, 49, **55**, 64, **74-83**
- social contact 35, 71
- social networks 35, 62, 75
- soft palate 58-59
- spasticity 14
- specialist palliative care services **17-20**, 26, 32, 95
- specialist suppliers **48-49**, 51, 54
- speech and communication 34, 35, 44, 54, **58-65**, 73, 81, 84, 90, 94, **95**, 104
- speech and language therapist (SLT) 16, 17, **20, 58-65, 66-83**
- spiritual or religious beliefs 26, 32, 85
- splints 42, 45
- stair rails 43
- stairlift 24, **43**, 46
- statutory services 48, 53, **75**, 81, 94
- Statutory Sick Pay (SSP) 75
- stiffness 7, 10, **14**, 17, 19, **41-42**
- suction machines 16
- supplements 16, **67**, 120
- support collar 18, 42, 63
- support groups 10, 13, 19, **94**
- swallowing 8, 10, **16**, 17, 20, 41, 51, 52, **66-83**
- switches 50, **54**, 62, 64
- swollen hands, feet or limbs 40-41
- symptom management 14-21
- synthesised or electronic speech 25, 61-62
- taking medication **70**, 71, 120
- tap turners 50
- taste 18, 70
- Tax Credits 79
- teachers 37
- telecare 54, **64**, 89
- teleworking 76
- temperature regulation 18, 45, **51**
- tests 9-12
- thick stringy saliva 16, 67
- thin saliva 16, 67
- through-floor lift 24, 43
- tissue donation 88
- toilet 18, 42, 43, **50-51**, 66, **72**
- tongue 10, 52, 58, 59, 69, **70**
- touch 7, **18**, 31
- tracheostomy 15
- Transcranial Magnetic Stimulation (TMS) 9
- translation service 96
- transport and travel 45
- treatments 16, 20, 21, **25**, 26, 78, 84-90
- tube feeding 16, **71-73**, 87
- twitching 7, 14
- types of MND 9-10
- unaided communication 60
- Understanding my needs (booklet) 5, 56, **89**
- Universal Credit 79

Index (continued)

upper motor neurones	7-10
urine bottles and pans	50-51
useful organisations	98-103
vehicles	44, 45, 75
ventilation to support breathing	15, 87
vocal cords	58-59
voice activated	
computer applications	54, 61, 65
voice amplifiers	61
voice banking	25, 61, 62
voice output communication aids	61
voluntary redundancy	76
Wales	5, 12, 27, 44, 55, 74, 77-83, 87-91
walking	40-42, 53-54
washer-dryer toilet	50
weak cough	15, 16 , 67
weight loss	14, 16, 20, 66-72
wellbeing	30, 35, 52, 66, 67, 72
wheelchairs	19, 24, 40-43, 44-47
wheelchair accessibility	40, 43
wheelchair and scooter safety	45
Wheelchair Service	44
wheeled shower chair	43, 49-50
Wills	88
word recognition	63
wristband	4, 16, 64, 89
young carers	37, 95
young people	36-39 , 81, 85, 95 , 98

What do you think?

Let us know what you think of this *Living with motor neurone disease* guide. We'd love to hear what you think we did well and where we can improve the content for people with or affected by MND.

Your anonymous comments may also be used to support and influence, as they help us share real MND experience and raise awareness in our resources, campaigns and applications for funding.

Please use our online feedback form at: **www.smartsurvey.co.uk/s/LWMNDfeedback** or you can complete and return the paper feedback form included in the folder.

To find out more about how you can help shape our information, contact us at **infofeedback@mndassociation.org**

Or write to *Care information feedback* at the address shown below.

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