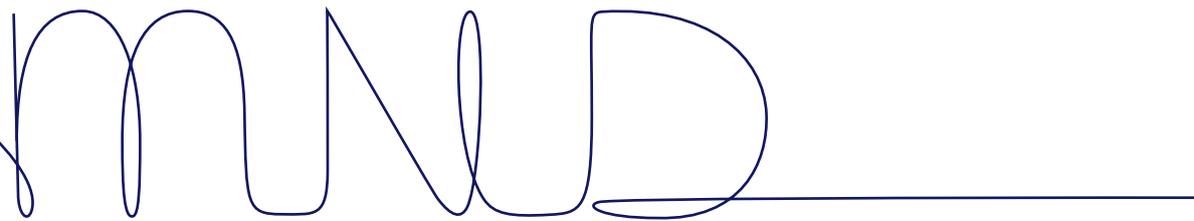




Living with
motor neurone disease



Living with



mnd

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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."

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



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.



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

www.theinformationstandard.org

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

If you have been diagnosed with motor neurone disease (MND), this guide will help you to find out more about this condition and its likely impact. The aim is to help you plan for the practical, emotional and financial challenges ahead and maintain the best possible quality of life.

Do I need to read it all?

Not all of the content will necessarily apply to you and certainly not all at once. The individual experience will always be unique. For that reason, each section acts like an overview for a particular subject, with directions to further information should you need more detail. The choice is yours.

As MND is progressive, it may be useful to scan through so you know where to find appropriate guidance in the future.

Finding the content you need

The pack is divided into three main parts, with clear sections to help you find the subject matter you need easily:

Part 1 – What is MND?

The first part explores the facts about the disease and what to consider when you are first diagnosed.

Part 2 – Living with MND

The second part looks at how to cope with the challenges of the disease in your everyday routines.

Part 3 – Accessing services and support

The third part directs you to available services and support for specific assistance.

We have also included the following features to assist you:

- **Top tips:** to emphasise key points that you might need to consider
- **A list of further information at the end of each section:** to help you order or download our additional information as appropriate to the subject, if it is relevant to your personal needs
- **Quotations:** to share feedback from other people affected by MND.

What is the *Understanding My Needs* booklet for?

This guide is accompanied by the *Understanding My Needs* leaflet, to help you to record your own preferences, needs and wishes.

It is designed to help you communicate your needs, whether at an appointment, or whilst receiving treatment or professional care. Due to its rarity, not all health professionals have experience of MND, so this leaflet can help to inform your health and social care team. They may be able to help by adding notes for you, when appropriate.

In some regions, hospitals/clinics may have their own version which they prefer you to use. The use of 'patient records' to which you can add your own comments is increasing. Talk to your health and social care team to discuss the best way forward, but the *Understanding My Needs* booklet is specifically designed to support someone with MND.

Responding to your views

Your expectations about information really matter to us and we greatly value your input. Our approach to *Living with motor neurone disease* is based on feedback from other people living with or affected by MND, which indicated the following preferences:

- to build information at your own pace to suit individual needs
- to ensure information received just after diagnosis is simple and concise to avoid feeling overwhelmed
- to make it easy to find the subject matter you need with clear references to further information
- to provide directions to services and support, so you know where to go for specific help
- to include tips to help you plan ahead more effectively
- to make it easier to tackle difficult conversations about the disease with health and social care professionals, and family and friends.

Further support

Part 3: Accessing services and support explains both our services and appropriate external support. If you have any specific questions, please contact our information and support service MND Connect:

MND Connect
MND Association
 PO Box 246
 Northampton NN1 2PR

Telephone: 08457 626262
 Email: mndconnect@mndassociation.org
 Website: www.mndassociation.org

If you live in England, Wales or Northern Ireland

While the MND Association is keen to help everybody affected by MND, our charity supports those living in England, Wales and Northern Ireland. We endeavour to ensure our information is relevant to all three and to indicate major differences between England, Wales or Northern Ireland. However, as the NHS and government structures work in slightly different ways, the terms and processes they use can vary. Always check with your local service providers for guidance on specific types of support.

Please note, to avoid cumbersome repetition, the term used in England has been applied for the following in this guide:

England

Local authority, council or social services

Wales

Local authority, council or social services

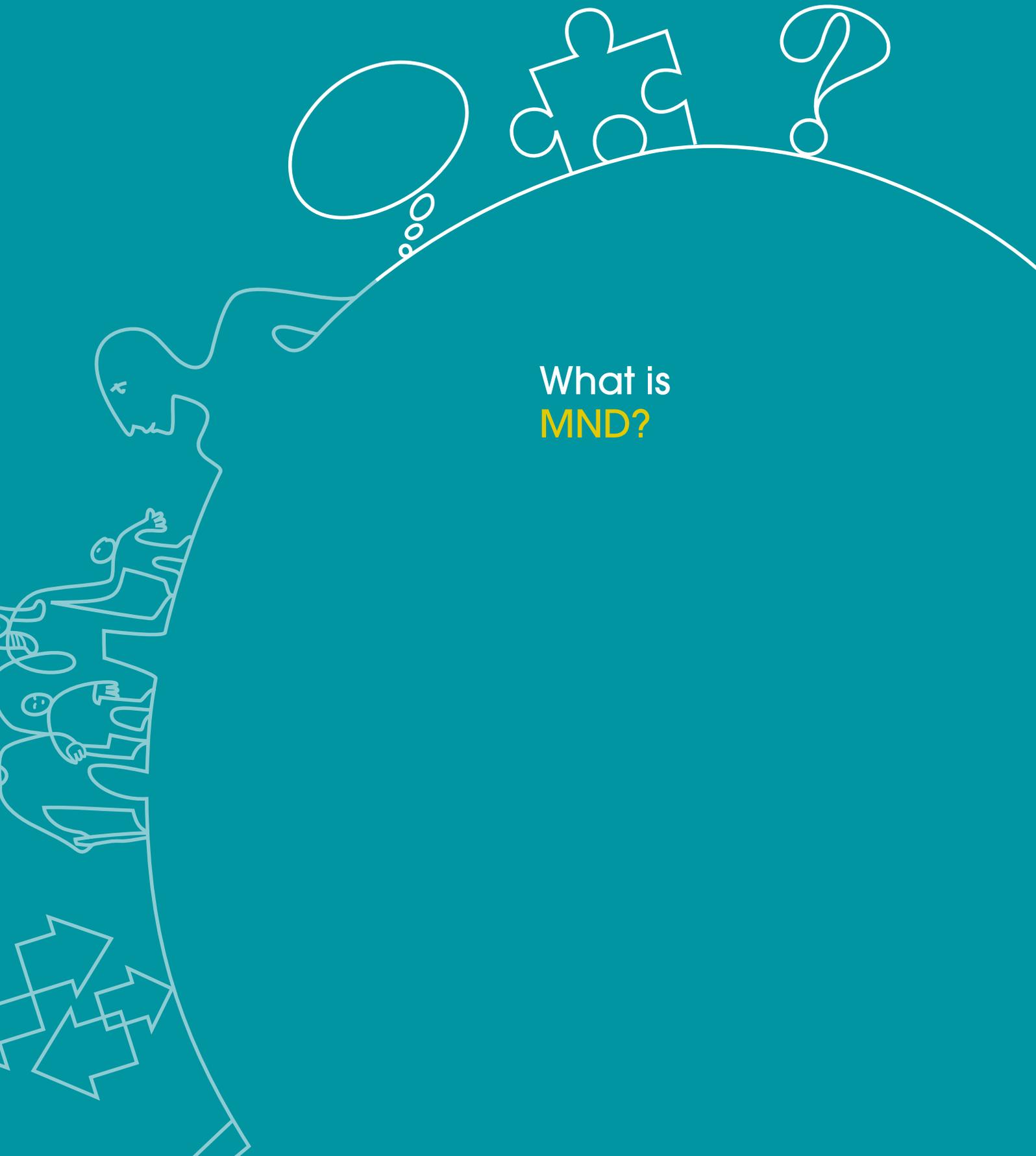
Northern Ireland

Health and Social Care Trust or social services

If you live in Scotland

If you live in Scotland please contact MND Scotland for advice on specific support and services.

See Section 15: *Useful organisations for contact details.*



What is
MND?

1: Motor neurone disease (MND)

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

What is MND?

A French doctor called Jean-Martin Charcot first described motor neurone disease (MND) in 1874.

The term covers a group of related diseases that attack the motor neurones (sometimes referred to as 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 wasting.

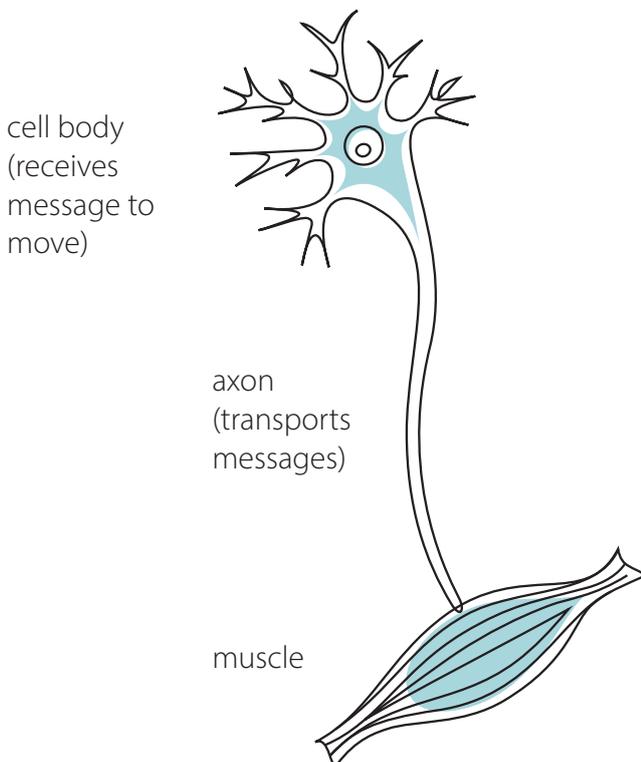


MND is a progressive life limiting condition that can affect how you walk, talk, eat, drink and breathe. However, not all symptoms necessarily happen to everyone and it is unlikely they will all develop at the same time, or in any specific order.

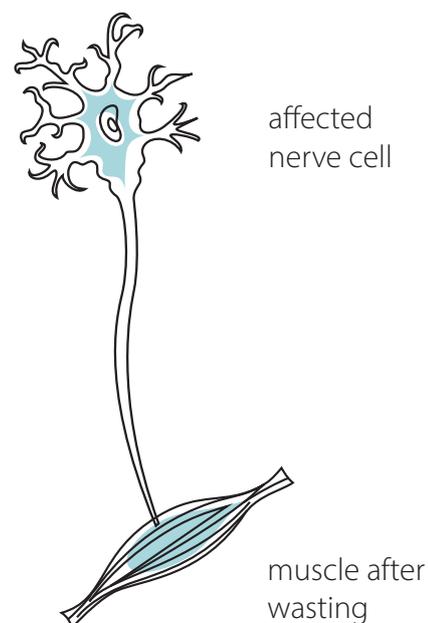
“ I hadn't a clue what motor neurone disease was.”

Although there is currently no cure for MND, symptoms can be managed to help improve quality of life.

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



Healthy motor neurone



Motor neurone affected by MND

Who does it affect?

It is difficult to be exact, but international studies of MND indicate that:

- it can affect adults at any age, but most people diagnosed with the disease are over the age of 40, with the highest incidence occurring between the ages of 50 and 70
- men are affected approximately twice as often as women, but this can vary depending on the type of MND and evens out with age at about 70
- the incidence or number of people who will develop MND each year is about two people in every 100,000 of the general population
- the prevalence or number of people living with MND at any one time is approximately seven in every 100,000.

What does it affect?

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

- nerves controlling the senses, such as touch and sight, known as sensory neurones (not generally affected by MND)
- nerves controlling the way our muscles move, known as the motor neurones (affected by MND).

The motor neurones are split into two groups:

Upper motor neurones: which run from the brain into the spinal cord carrying instructions to the lower motor neurones. Upper motor neurone damage tends to result in weak and stiff muscles.

Lower motor neurones: which run from the spinal cord and control muscles using the instructions received from the upper motor neurones. Lower motor neurone damage tends to result in weak and floppy muscles, and a twitching sensation that ripples under the skin (known as fasciculation).

MND is a progressive neurodegenerative disease. As the motor neurones deteriorate, this causes increasing loss of mobility in the limbs, and difficulties with speech, swallowing

and breathing. The muscles first affected tend to be those in the hands, feet or mouth.

Some people may experience changes in thinking and behaviour, often referred to as cognitive impairment, but only a very few will experience severe cognitive changes.

MND does not usually affect the senses, bladder and bowel, or sexual function.

The effects of MND can vary enormously from person to person. Each individual will have a very different experience, from symptoms and disease progression, to the length of survival time after diagnosis.

How is MND diagnosed?

MND can be extremely difficult to diagnose for several reasons:

- it is a comparatively rare disease
- the early symptoms can be quite slight, such as clumsiness, mild weakness or slightly slurred speech, all of which may have been attributed to a variety of other causes. It can be some time before someone feels it necessary to see a GP
- the disease affects each individual in different ways, as not all symptoms may be experienced or appear in the same sequence
- there is no specific test to prove someone has MND, which means diagnosis requires the elimination of other potential conditions.



“ After nearly a year of tests, visits to my GP and hospital, MND was finally confirmed.”

Tests

If your doctor feels you may have a neurological problem, he will refer you to a neurologist at your local neurology department, who may arrange for a series of tests. You normally attend these as an outpatient, but in some cases you may be required to spend a short stay in hospital.

Clinical examination: helps a neurological consultant to determine a great deal from the initial examination. Their experience of a wide span of neurological disorders enables them to recognise signs and determine which tests are appropriate. Depending on your current symptoms, it is not always essential to conduct all of the following.

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

Electromyography (EMG): is sometimes called the needle test, as fine needles are used to record the naturally-occurring nerve impulses within certain muscles. Muscles which have lost their nerve supply can be detected by abnormal electrical activity. Abnormalities can show even if a muscle is as yet unaffected, so it is a very important diagnostic tool.

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 and can help in the diagnostic process.

Magnetic Resonance Imaging (MRI) scans: involve being placed in a cylinder-like machine to take internal images of the body. These do not diagnose MND, but help to rule out other conditions by revealing damage that has been caused, for example, by stroke, Alzheimer's disease, Parkinson's disease, multiple sclerosis, tumours and trapped nerves, as well as injury damage to the spine and the brain.

Other tests: may be requested by your neurologist, such as a lumbar puncture or muscle biopsy, if clinical findings indicate they could be useful. However, these are not always used as diagnostic tools for MND.

Are there different types of MND?

There are four main types of MND, each affecting people in different ways. However, it is difficult to give a precise diagnosis, as the group of diseases covered by the term motor neurone disease can have overlapping symptoms.

The most common form is amyotrophic lateral sclerosis (ALS). Although other forms may be diagnosed, it is possible they will progress into the more typical form of ALS.

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?

Please note, when we talk about life expectancy, this is determined by average expectations according to clinical studies. It is not an exact figure and the experience of MND can differ. For some people the progression of the disease is more rapid and for others it is slower.

Amyotrophic lateral sclerosis (ALS): is the most common form, involving both upper and lower motor neurones. It is characterised by weakness and wasting in the limbs, muscle stiffness and cramps. Someone may notice they are tripping when walking or dropping things. Average life expectancy is between two to five years from onset of symptoms.

Progressive bulbar palsy (PBP): affects only a small proportion of those diagnosed with MND, and involves the upper and lower motor neurones, particularly those linked to the bulbar regions in the early stages (muscles of the face, throat and tongue). Symptoms may include slurring of speech or difficulty swallowing. Average life expectancy is between six months to three years from onset of symptoms.

Progressive muscular atrophy (PMA): affects only a small proportion 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.

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

Primary lateral sclerosis (PLS): affects only a small proportion of those diagnosed with MND, damaging only the upper motor neurones. 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 more than 10 years. An email support group exists for this rare form.

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

Kennedy's disease

Kennedy's disease is a slowly progressive disorder of the motor neurones.

This rare form of muscular atrophy leads to weakness, but people with Kennedy's disease often have a normal life span. Although not classed as a type of MND, it is supported by the MND Association.

As it bears similar traits to MND, Kennedy's disease can cause confusion during diagnosis. However, it is caused by a genetic mutation and gene testing can determine an accurate diagnosis. Kennedy's disease only affects men, but women may carry the genetic mutation.

What causes MND?

It is still not possible to give a clear answer about the precise causes of MND as each individual may be affected by a different combination of triggers. However, when you are being diagnosed, a neurological consultant will probably ask you about any family history of MND or of frontal temporal dementia (FTD). If not, it is worth asking the consultant to discuss family history, as this may help determine if an inherited gene is one of the likely factors.



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

MND with no apparent family history:

Most cases of MND occur with no apparent family history of the disease and the 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 what may have played a role in the onset of the disease.

MND where there is a family history:

In a small number of cases, there is a family history and the genetic input is more significant. Where this occurs, the disease is caused by a mistake in the genetic code which can be passed down, although other triggers may still be necessary for the disease to emerge.

If you are concerned about the possibility of a family history of MND and what that could mean for those close to you (in terms of inheriting the genetic code), you may wish to seek genetic counselling. Although sensitive to the emotional aspects of the situation, genetic counselling is not a form of psychotherapy. A genetic counsellor explains the facts as clearly as possible, and gives you accurate information on the implications for your family.

This will include information about options such as genetic testing, to help you make up your own mind if this is a choice you wish to make. Some genetic testing is possible, but not everyone with a family history would benefit. Currently, testing is only available for four of the genes that play a part in inherited MND and results are not necessarily conclusive.

Choosing to be tested can be a very difficult decision, as it affects the wider family. We would advise genetic counselling from a neurological expert experienced in MND. In the

first instance talk to your neurological consultant for advice.

For more information about inherited MND and genetic counselling see *Further information* at the end of this section and our research sheets on inherited motor neurone disease.

“ 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.”

There has been an acceleration of world-wide research into the disease and its causes, including projects funded by the MND Association. As a result, our understanding of MND and the way motor neurones function is constantly advancing.

Top tips

- Some research projects and clinical trials need the participation of people with MND and occasionally their families. We know how keen some people are to help in this way and have developed a research register to help record this interest. If you would like to find out if you meet the qualifying criteria to join the register, contact us on **01604 611812** or by email: regionaladmins@mindassociation.org

Further information:

We have a range of numbered information sheets, including:

- 2: *Kennedy’s Disease*
- 15: *Primary Lateral Sclerosis*
- 17: *Progressive Muscular Atrophy*
- 23: *Cognitive impairment in MND: information for carers*

Also research sheet B:

- Part one – *Introduction to inherited motor neurone disease*
- Part two – *Genetic testing and insurance*
- Part three – *The options available when starting a family*

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

Telephone: **08457 626262**

Email: mndconnect@mndassociation.org

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

See Section 14: How we can help you.

Our research website pages:

www.mndassociation.org/research

Online forum:

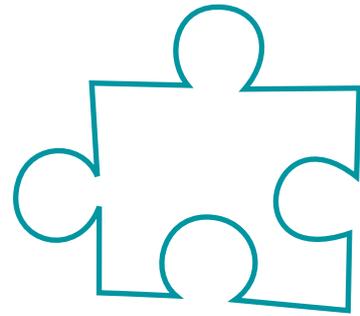
<http://forum.mndassociation.org> hosted by the MND Association for you to share information and experiences with other people affected by MND.

PMA/PLS email support group:

if you wish to join the email support group for primary muscular atrophy and primary lateral sclerosis, please email your details to care@mndassociation.org

2: Symptoms and management

This section will help you to find out about the likely symptoms of motor neurone disease (MND) and how these can be managed.



What are the symptoms?

Not everyone will experience all of the following symptoms, or in any particular order. You may even have symptoms that are not mentioned here, as the disease can affect everyone differently, or you could have another unrelated problem which also requires medical attention, so please speak to your GP about any concerns.

“ At the moment the disease has only affected my left arm.”

See *Further information* at the end of this section for detailed publications linked to some of the symptoms listed here.

Muscle weakness

What is happening? When the messages from the motor neurones reduce, the muscle they connect to is used less and tends to decrease in mass (to waste). This causes weakness and can affect balance and posture, with the risk of falls.

What can be done? Muscle wasting cannot be reversed by exercise, as the progression of the disease cannot be undone. What exercise can do is to assist flexibility and range of movement in your joints, help to maintain unaffected muscles, and support posture and balance. Ask your GP or health and social care team for a referral to a relevant physiotherapist, who can recommend an exercise programme appropriate to your needs. You can also ask for a referral to a dietitian to discuss ways of

maintaining your weight, to prevent any further muscle breakdown through weight loss.

See *Swallowing problems* later in this list of symptoms.

Twitching (and fasciculations)

What is happening? Twitching, and the rippling sensations under the skin called fasciculations, are often among the first and most annoying of symptoms. Some people feel the rippling effect in individual muscles, but this can be more widespread.

What can be done? Talk to your GP, consultant or specialist nurse, as medication may help to relieve this symptom. In many cases, this symptom fades over time.

Muscle tightness and/or cramping

What is happening? Due to the breakdown of messages from the motor neurones, general muscle tightness or spasticity can impact on mobility, affect coordination of movement and may cause pain or increase the risk of falls. Sudden muscle cramps are also common and can be very painful.

“ My limbs became unusually stiff in the middle of a climb I had made several times before. I dismissed the problem as paranoia for my approaching 40th birthday.”

What can be done? Talk to your health and social care team as physiotherapy or medication may provide some relief and they can advise on managing falls. Appropriate positioning when seated or lying down can also help you feel more comfortable.

Breathing difficulties

What is happening? Respiratory problems may develop, usually in the later stages of the illness. The internal respiratory process is not affected, but the muscles involved in the voluntary control of breathing can become impaired.

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 specialist equipment for assistive ventilation.

See heading *Respiratory management* later in this section.

Swallowing problems

What is happening? If the bulbar muscles weaken (those in the face, mouth and throat), swallowing can be affected. Disruption of the normal eating and swallowing process is referred to as dysphagia, which can result in inadequate food and fluid intake. Weight loss may occur, but this can also be due to 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. They will assess your ability to swallow and your weight and advise on managing choking episodes, should they occur. Calorie and protein content can be increased with changes to supplements and/or diet. Alternative feeding options, such as a gastrostomy (using a tube inserted into the abdomen) can supplement or replace meals.

See Section 9: *Eating and drinking* for more details about nutrition and the types of gastrostomy available, such as PEG.

Saliva and mucus problems

What is happening? If swallowing is impaired, saliva can gather in the mouth and throat, and lead to drooling, which many find embarrassing. Saliva may be watery or thick and ropy. Decreased fluid intake can make mucus secretions thicker which may be more difficult to clear due to reduced coughing pressure. Dryness of the mouth can occur 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 occasionally suction machines for clearing out the mouth.

Speech and communication difficulties

What is happening? With weakening of the bulbar muscles (those in the lower face and throat), speech can be affected and poor respiratory support can also weaken the voice. Difficulty with speech is often referred to as dysarthria.

What can be done? A speech and language therapist (SLT) can assess your needs, provide therapy techniques and advise on suitable communication aids. An occupational therapist (OT) can assess your requirements regarding how you physically access any equipment or aids. Speech and communication aids are often referred to as Augmentative and Alternative Communication (AAC) and can range from low tech (gestures, notepads, alphabet boards, etc) to high tech (computer based).

See Section 8: *Speech and communication*.

Fatigue

What is happening? Loss of physical function means that everyday routines become more tiring. Fatigue can also occur from breathing problems and breathlessness, low calorie intake and dehydration.

What can be done? Develop flexible routines to make the most of the times you feel alert and to allow for rest. Your occupational therapist (OT) can advise on fatigue management and aids to make daily tasks easier and your dietitian can advise you on increasing your calorie and fluid intake.

See also [Breathing difficulties and Swallowing problems](#) as listed above.

Pain

What is happening? Pain may be experienced due to muscle cramps, spasticity, stiff joints, muscle spasms, skin pressure or constipation. It is important that the cause of the pain is assessed, as it may not be connected to MND.

What can be done? Talk to your health and social care team for advice on careful positioning, support and pressure care, and suitable medication. If pain is persistent, you can be referred to a palliative care or pain clinic.

Emotional lability (also known as pseudo-bulbar effect)

What is happening? You may experience inappropriate laughing and/or crying, which can be difficult to control and feels 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 to relieve this symptom. This can also be alarming for those close to you or providing support, but if it is recognised as a part of MND, it can be easier to manage.

See [Section 4: Emotional impact](#) for more detail 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 normal.

What can be done? Trying to understand what you are feeling can be the first step towards managing these emotions. If these feelings are persistent and extreme, you may find it helpful to talk to your health and social care team. In some instances medication can help and/or a referral to an appropriate counsellor or psychologist.

See [Section 4: Emotional impact](#).



“ It’s nice when I’m treated as a whole person and not just an illness.”

Cognitive changes

What is happening? You may find it harder to think, concentrate, interact with others and plan things as easily as you used to. This is commonly referred to as cognitive change. Up to 35% of people with MND are thought to be affected, with mild effects in most cases. A few people experience more noticeable change and a very small percentage develop a type of dementia called Frontal Temporal Dementia (FTD), which involves severe cognitive change.

What can be done? Help is available, requiring a multidisciplinary team approach, including mental health and psychological services.

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

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.

Incontinence

Bowel and bladder functions are not usually affected by MND, but mobility problems can make it more difficult to access and use toilet facilities. Constipation may occur due to changes in eating, dehydration, anxiety, medication and poor mobility. Diarrhoea can occur as a result of persistent constipation. Any changes to bladder and bowel function should be investigated and may not be due to MND.

Sexual function and expression

Sexual function is not usually affected, but a person's perception of their own sexuality may change. Physical changes can affect intimacy at all levels from cuddling to sexual expression. Open discussion with your partner, and possibly the help of your health and social care team, can help you to maintain intimacy if this is important to you.

Eye muscles

Most people with MND retain the ability to move their eyes. If neck muscles are affected, the use of appropriate head supports can help.

Heart muscles

The heart is not directly affected by MND.

“ It’s very difficult to assess future needs as we all progress differently with MND and it is impossible to say how long it will take for conditions to change.”

Are there any specific treatments for MND?

Much can be done to manage symptoms, to enable you to maintain independence for as long as possible and to help you deal with the emotional impact of MND. Through MND Care Centres and neurological centres, a wide range of health and social care professionals are likely to be involved with you and your family, which is often referred to as a multi-disciplinary team (MDT). MDT expert care, combined with treatments or therapies as featured below (when relevant to your needs), may help you to maintain the best possible quality of life, for as long as possible, when living with the condition.

See Section 13: How health and social care professionals can help you.

Depending on your symptoms and progression, discussions with your health and social care team are likely to include the following:

Riluzole

Currently, there is no treatment that will halt the progress of the disease, although one drug, riluzole, has shown a modest benefit for some people. Researchers continue to investigate other drugs in the laboratory and through clinical trials, with the help of people living with MND.

Riluzole is licensed for the treatment of MND and has been approved for use on the NHS. It is not a cure, but it is the first medicine to show a modest impact on survival, of a few months.

See Further information at the end of this section.

Respiratory management

If you experience breathing difficulties, there are a number of treatments and therapies to help.

“ Wearing my [NIV] ventilator 24 hours a day allows me to lead what I call a ‘normal’ life and doesn’t stop me from doing anything I want to do.”

Ask your health and social care team for a referral to a respiratory consultant for guidance. This will include discussion about supported breathing, which is your decision to make. This generally involves two options:

- Non-invasive ventilation (NIV), where a portable machine supports your own breathing by providing extra air through a mask.
- Full ventilation (tracheostomy), where a machine takes over your breathing through a tube inserted into the windpipe through the neck.

Some people choose full ventilation to avoid the need for a mask. However, full ventilation can raise serious questions about quality of life when life is extended in this way, as other disabilities caused by MND will continue to progress.

See *Further information* at the end of this section for information sheets on breathing and ventilation.

Alternative feeding methods

See Section 9: *Eating and drinking* for general advice on nutrition, swallowing and alternative ways to ensure you receive the food and fluids you need, should you experience difficulties with eating and drinking.

Physiotherapy

See Section 6: *Getting around* for guidance on physiotherapy, exercise and assisted exercise.

Complementary therapy

Many people living with MND find that some use of complementary therapies can help to relieve some symptoms and reduce stress. However, it is important to recognise these therapies are not a treatment or cure for MND.

Complementary therapy is not considered to be part of conventional medicine, but it is felt to ‘complement’ conventional treatments if used in combination.

A wide variety of complementary therapies exist, such as massage, acupuncture and reflexology. These therapies are increasingly available on the NHS and some general practices now provide access to them. Hospices usually offer a selection of complementary therapies as part of their service.

“ A reflexologist kindly massages my feet, hands and arms, which helps with circulation and generally feels good. These appointments were facilitated by the local hospital.”

Top tips

- Not all health and social care professionals are familiar with MND due to its rarity. They may not be aware of every sign or symptom, so do not feel wary of asking questions or requesting referrals should you see signs of early symptoms that require specialist help.
- Not everyone gets the same symptoms at the same time or in the same order. If planning ahead for equipment or aids, ask for an independent assessment of your needs by a relevant member of your health and social care team to avoid any unnecessary expense.
- Contact your GP before undertaking a complementary therapy, to check it will not conflict with any current treatment and ask to be referred to a registered practitioner.
- If you have any difficulties with the supply of riluzole, please contact MND Connect.

[See Further information for contact details.](#)

Further information:

We have a range of numbered information sheets, including:

- 9: *Riluzole*
- 10: *Swallowing difficulties*
- 11: *PEG feeding – making the decision*
- 13: *Complementary therapies*
- 14A: *Understanding how MND might affect your breathing*
- 14B: *Ventilation in MND*
- 14C: *NICE Guidelines for non-invasive ventilation (NIV)*
- 14D: *Troubleshooting when using non-invasive ventilation*
- 14E: *Air travel and non-invasive ventilation (NIV)*
- 20A: *Sex and relationships for people living with MND*
- 20B: *Sex and relationships for partners of people living with MND*
- 21: *Physiotherapy for people with MND*
- 23: *Cognitive impairment in MND: information for carers*

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

Telephone: **08457 626262**

Email: mndconnect@mndassociation.org

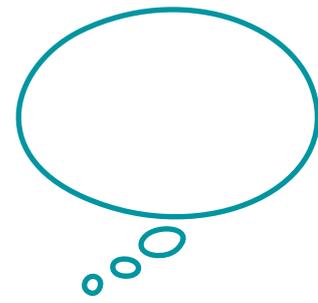
MND Connect can also help you locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional care development adviser (RCDA).

[See Section 14: How we can help you.](#)

Online forum:

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

3: What do I need to think about?



This section will help you to consider some of the things you can do to maintain the best possible quality of life with motor neurone disease (MND).

As traumatic as diagnosis can be, once you know why symptoms are occurring, you can make informed decisions to make life more comfortable.

MND is a complex condition that requires a wide range of support from a variety of health and social care professionals. There is a huge amount to think about and this can begin to feel overwhelming. However, this section features the top 15 tips based on repeated feedback from other people affected by MND. In other words, 'things I wish I had known at the start.'

“ The problem with MND is that it is always moving on while you play catch up.”



You will find further detail throughout the remainder of this guide, but the following tips provide simple starting points. Whether these will all apply to you depends on your individual circumstances, but they may help you to approach the future with more knowledge and confidence.

The top 15 tips

1. Don't rush into purchasing equipment:

Before making decisions about equipment or aids, have your needs assessed by the relevant professional, eg an occupational therapist or speech and language therapist. Equipment may not always be suitable for everyone and mistakes can be costly. You may be able to obtain certain items through the NHS or social services.

See Section 7: [Everyday activities and personal care.](#)

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

2. Financial choices can have hidden consequences:

For example, early retirement payments may affect access to certain benefits. Don't rush decisions that will affect finance or work and seek advice from an independent financial adviser and a benefits adviser.

See Section 10: [Your finances.](#)

3. Think about home adaptations as early as possible:

Adapting your home can take time and you may need to seek assistance with funding, which can also be a lengthy process. Investigate this as soon as possible if you think it may be necessary. An occupational therapist can help advise about your future needs.

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

4. Make sure major equipment will continue to work for you:

Try to consider your future needs when looking at equipment, particularly installations, such as mobility aids. Seek assessment from your occupational therapist. For example, a stairlift may not be effective later on if you need a wheelchair, as this requires two wheelchairs, one for each floor, and transition between chair and stairlift. A through-floor lift or downstairs conversion may allow for easier access and there may be statutory or charitable funding to assist.

See Section 6: *Getting around*.

5. Seek assessment if you need assistance with care:

Social services can provide a Community Care Assessment for yourself, and a Carer's Assessment for your main carer, to identify needs, plan for emergencies and help provide social care assistance. Support can vary between different regions, local authorities and councils, so explore what's available to you during assessment.

See Section 12: *How statutory services can help you*.

6. Provide a full picture of your care needs:

If you are being assessed for care needs or making a claim for benefits (eg Personal Independence Payment), give lots of detail and always describe your worst day, not your best, to obtain the appropriate level of support. Keep a diary of your progression, to provide real examples of how long tasks take and the impact of the disease on your routines.

7. Keep a log of questions:

If you have queries for your health and social care team, make notes so you don't miss anything out when you meet. If you feel tired or overwhelmed at an appointment, written notes can be very helpful.

See the *Appointment and communication record* towards the end of this guide to help you keep a note of queries and answers.

8. Managing bank accounts:

If you live with a spouse, partner or related carer, it can be helpful to add their name to your bank account, as a joint account. This means they can help to manage finance should this become difficult for you to access.

See Section 10: *Your finances*.

9. Check out the benefits system:

if you have not previously accessed benefits, this can feel uncomfortable and bewildering, but it is important to find out what you are entitled to. It is your right.

See Section 10: *Your finances*.

10. Find out what the local specialist palliative care team or hospice can do:

Palliative care is about achieving the best possible quality of life for you, and those close to you, through symptom management and support services. Palliative care teams and hospices can do a great deal to improve your well-being. If you build a relationship with them, it may decrease any time spent in hospital, as their knowledge of your case can be extremely helpful. Not everyone needs this straight away, but talk to your neurologist or GP about a palliative approach and whether a specialist referral would help, whether this is immediately after diagnosis or later on. Some hospices take self-referrals.

See Section 13: How health and social care professionals can help you.

11. Find out as much as you can about treatments:

Decisions about treatment or medical intervention with MND can be difficult, due to the unpredictable nature of its progression. Discuss options with your health and social care team, so that you know what is possible, what it could mean for you and optimum timing for specific interventions. In all instances the choice of whether to accept what is on offer is yours, but try to make decisions based on clear information. Your health and social care team can advise.

12. Have difficult conversations as early as possible:

Planning ahead for the later stages of MND can feel intimidating and means having difficult conversations with your health and social care team and your family. If your speech and communication are affected, you may find it easier to discuss plans earlier rather than later. Many people report that having made their wishes known, they feel calmer.

See Section 11: Planning ahead.



“ The regular support meetings held by my local branch are invaluable – people affected by MND are the only ones who can really ‘tell it as it is’.”

13. Remember MND is rare:

Your GP and your health and social care contacts may not have previous experience of working with MND, so publications like this can help equip you with the knowledge to make the most of your relationships with these professionals. We provide information, education and support services about MND to professionals, through our regional care development advisers and our MND Connect helpline contact details for professionals:
Telephone: **01604 611870**
Email: **mndconnect@mndassociation.org**

14. You are not alone:

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

<http://forum.mndassociation.org>

See Section 14: *How we can help you.*



“ The MND Association provides a bridge to direct people to access care and support through its publications and helpline.”

15. If you have questions, concerns or just need a listening ear:

You can also contact our helpline
MND Connect:

Telephone: **08457 626262**

Email: mndconnect@mndassociation.org

They can direct you to all our services, branches, groups, your local regional care development adviser and relevant external organisations for support.

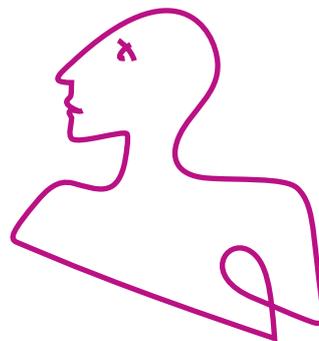
See Section 14: *How we can help you.*

Living with MND



4: Emotional impact

This section will help you to identify and manage some of the more difficult emotional responses you may feel after diagnosis.



Every individual is different and your emotions will be influenced by your own particular circumstances, culture and beliefs. Whatever responses you feel in the weeks and months following diagnosis, it is important to remember these reactions are normal and shared by many. You are not alone. There is help and support available.

Normal reactions

For most people, a diagnosis of MND can feel devastating, although for some there can also be a sense of relief after a period of great uncertainty. Once you know what is happening, you can take action to make life as comfortable as possible.

Yet, as you begin to deal with the diagnosis and what it will mean, the range of emotional responses can feel very confusing. It is not uncommon to feel mixed emotions, as you can experience more than one distinct feeling at a time, such as anger and guilt.

You may experience:

- shock
- fear for the future
- disbelief at the diagnosis, and denial
- anxiety for family, children and friends
- grief for the loss of the future you expected
- anger at the medical profession or family and friends
- isolation because you suddenly feel different from others
- intense sadness
- guilt that you may be the cause of stress for others
- relief that you finally know what is happening to you.

Feeling overwhelmed

Some or all of these reactions may feel overwhelming for a while and you need to work through them at your own pace. You may need to get the situation straight in your own mind before seeking support or information. Gradually though, you may wish to review your life and plans.

One of the most difficult things at this time is to get a balance between keeping a positive mental attitude and accepting that you have a life-shortening illness. 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 think a lot about living and not about dying. I may not be around a year from now, but on the other hand neither might anyone else. Why spend time worrying about the worst scenario?”

Discussing and acknowledging feelings with those close to you is vital. MND affects them too and sharing highs and lows means you can all support each other. They may even wish to access information on the disease and support services before you feel ready to do so. They will have personal questions about what is happening and seeking information can help them to adjust.

See Section 5: Family, children and friends for help on how to handle these sensitive conversations.

If your partner or a family member helps to support you, we also provide information specifically for family carers. This includes emotional and practical guidance to help them cope, particularly as they face the challenges of the caring role.

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

Emotional lability

You may find you tend to laugh or cry at inappropriate times. This can be difficult to stop and you may feel out of control, which is often distressing for yourself, but also for those close to you, who may not understand.

This is called emotional lability (also known as pseudo-bulbar effect) and is a symptom of MND, though it is not necessarily experienced by everyone with the disease.

It is an abnormal motor response caused by the effects of MND on the pathway between the outer layer of the brain and the brain stem. This means your responses may not match how you feel. For example, you may laugh uncontrollably, but feel sad, or you may cry, but feel happy.

In many cases this is a temporary symptom that reduces over time, but if the responses are persistent and causing distress, talk to your GP. If your GP is not familiar with emotional lability, try to talk to an appropriate member of your health and social care team with experience of neurological conditions.

You may find that understanding the symptom is enough to help you and your family to manage the impact. Others find emotional lability limits where they go and what they do, and that medication or other assistance helps.

“ 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. It is very alarming for people around me.”

Some people with MND experience changes to thinking and reasoning (called cognitive impairment/change). In these instances, it is more common to experience emotional lability. However, it is very important to be aware that emotional lability is not in itself a sign of other cognitive change.

Depression

With any serious illness, it is quite normal to experience low moods at times.

“ You really need to be kind to yourself...It's ok to feel 'Poor me!'”

If you find it particularly difficult to recover from feeling low, it may be time to seek some help. Try to be aware of signs such as:

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

Bear in mind that there could be other underlying causes for these effects which may be due to physical symptoms rather than depression. Whatever the cause, if they persist or feel overwhelming, you can seek help. There is no reason why you should have to go through them alone and there are effective treatments available. Speak to your health and social care team for guidance.

See Section 13: How health and social care professionals can help you.

Intimacy and sexuality

For many of us, physical intimacy is very important. Touch and being close to your partner can be an essential part of showing affection and sharing emotional support. Intimacy does not necessarily always include sex, but sex may be a significant part of your emotional life. Many people affected by MND worry about the impact of the disease on sexual expression.

“ It is easy for the person with MND to withdraw and for the carer to be preoccupied with caring. It is important to take time to remember to show the other that you still care. I can't stress how important this is.”

MND does not affect sexual function, but impaired movement can make sexual expression more difficult. However, open discussion with your partner can be very helpful. You may also find it useful to talk to someone from your health and social care team for guidance should you have specific questions.

You and your partner may have questions about how MND will affect intimacy and how you can solve these issues. We provide helpful and candid information if you have concerns.

See Further information at the end of the section for information sheets on sex and relationships.

Rethinking and planning

A diagnosis of MND may alter the direction you expected your life to take, but it should not stop you making new plans. By becoming as informed about the disease as you can, you can learn to manage it and find support. This will help you to 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.”

The urge to deny the impact of the diagnosis can be strong, followed by 'Why me?' This is normal and understandable, but too much focus on this may delay how you take control of managing the illness. Although different for each individual, MND is always one step ahead. It is unpredictable and, for some, the progression is rapid. It is important to become informed about the types of decision you are likely to face in the future.

The following may help you find a positive way to deal with the diagnosis:

Accommodating and accepting change:

- means adapting to change and being able to recognise what is now, in comparison to what was
- means using available support to make life easier, for example, using a walker or wheelchair for safer mobility when required
- does not mean giving up or giving in
- is proactive, turning 'Why me?' into 'What can I do?'

Decision making:

- can be better supported through discussion with those close to you and your health and social care team, but ultimately, you have the final say
- should be flexible, as you may need to revise or reverse decisions as your symptoms change.

Staying in control:

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



“ It’s important to stress that although people may not want to discuss things immediately, they can always seek help at a later stage.”

Emotional support and guidance

For professional guidance please talk to your GP and your health and social care team. They can offer a range of assistance, from how to manage difficult emotions, to medication for specific symptoms.

If you are feeling particularly overwhelmed, ask your GP to be referred to a counsellor or psychologist for guidance, although there may be a waiting list. Palliative care teams and hospices usually offer counselling and spiritual guidance as part of the palliative care approach.

When you feel ready, you can read more about palliative care in Section 11: *Planning ahead.*

Some people affected by MND find complementary therapies help relieve stress and can be very calming. These should always be taken with a qualified and registered practitioner.

The MND Association is here to help you in any way we can, with advice, information and support. Our helpline MND Connect can direct you to services or just provide a listening ear. For many, joining a local branch or group of the MND Association to meet other people affected by the disease can be supportive. If you decide this is not for you, it may be something to consider at another time.

If you have access to an Association visitor in your area, they can support by telephone, email or through face to face visits.

See Section 14: *How we can help you.*

The MND Association online forum also provides a safe place for you to communicate openly with other people who are living with or affected by the disease. You can also view the forum conversations without joining if you prefer. Although your particular experience of MND is unique to you, there will be many examples of shared issues and practical tips.

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



“ The MND Association is the cushion from the falling sensation you get when you are diagnosed.”

Top tips

- Whatever emotions you experience, you are not alone and these feelings are usually a normal response to difficult circumstances. If overwhelmed, do seek support from your health and social care team.
- Talking to those close to you, and to your health and social care team, is an essential part of finding ways to manage how you feel and enable you to cope with the challenges ahead.

See Section 5: Family, children and friends for help on how to handle sensitive conversations with those close to you.

- If you feel persistently low and unable to manage, do seek help from your health and social care team.

Further information:

We have a range of numbered information sheets, including:

- 13:** *Complementary therapies*
- 20A:** *Sex and relationships for people living with MND*
- 20B:** *Sex and relationships for partners of people living with MND*
- 21:** *Physiotherapy for people with MND*

We also provide the following publications:

Caring and MND: support for you
a comprehensive pack focused on the well-being of family and unpaid carers

Caring and MND: quick guide
a small A5 booklet to help someone new to the caring role become aware of available support

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

Telephone: **08457 626262**

Email: mndconnect@mndassociation.org.

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

See Section 14: How we can help you.

Online forum:

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

Samaritans:

08457 909090

5: Family, children and friends



This section will help you to manage difficult conversations as people close to you adjust to your diagnosis of MND.

A diagnosis of MND can be shocking to receive and sharing this news can be very difficult.

The reactions of other people to your diagnosis will vary greatly, influenced by their own circumstances, their relationship with you, their age and the way they respond to crises. These reactions are natural responses to troubling news that will bring change and emotional impact.

How do I tell people about this?

How and when you inform others about your diagnosis is up to you. You should do what feels right for you. You may feel that:

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

MND is progressive and the effects will be visible to others. The more people know, the easier it is for them to adjust too. It can also help them to understand how to offer support in ways that suit you.

“ 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.”

You may not want to explain the situation over and over again if this feels stressful. If you are married, or in a relationship, this may also be true for your partner. A close friend may be prepared to communicate on your behalf to reach a wider circle. There are many ways they can do this, perhaps by email or sending information about MND with their message.

It may help to keep any initial conversations quite simple in case people feel overwhelmed. As time goes on, you may wish to give more detail about how the disease is affecting you, so that people know how to support you.

Changing roles

Living with MND can result in normal routines and lifestyles being turned upside down. This can lead to significant emotional changes for everyone in your immediate circle.

Tasks that were traditionally yours may be taken on by someone else, careers may be put on hold and money worries can increase. Your own sense of purpose may need to adapt rapidly, but family roles can all change, and this is not always easy.

If your main carer is also your partner, this may cause strain, although some people find it strengthens their relationship. However, it cannot be emphasised enough how important it is for your carer to consider their own well-being, as MND is progressive and your need for support will increase.

See *Further information* at the end of this section for publications designed to support family carers.

“ There never really seems to be time to shift from talking about symptoms to the emotions that come up.”

Many will try to hide their own feelings to protect you and it may take time to develop open communication. Try to recognise when people close to you need to share their feelings and encourage this to help open conversations. This will enable understanding and help you all to develop better ways of coping as a team.

Accepting external support for some of your care can be very beneficial. This may help you to hold on to what was unique about close relationships before you had MND. It can also provide a rest for your main carer, as their well-being can come under pressure through fatigue and worry.

If your main carer is your partner, you may each have concerns about how MND will affect intimacy and sexual expression. Again, open communication is very helpful and you may find it beneficial to talk to your health and social care team about specific worries.

See Further information at the end of the section for information sheets on sex and relationships.

Feelings of isolation

People with MND, and their main carers, often talk about a sense of growing isolation, for various reasons:

Social networks may grow smaller:

Physical hobbies and certain types of employment may become difficult as the disease progresses. There may be ways to do things differently, if you wish to remain involved. This can help to maintain relationships based on these activities.

Speech and communication may become affected:

This can make social interaction more difficult. There are therapies and communication aids to assist, but you may need to explain to others how to listen and respond to you in different ways.

See Section 8: *Speech and communication.*

Some friends may retreat:

There could be many reasons for this, including fear of saying or doing ‘the wrong thing’. It is also possible they lack understanding, for example, if you are affected by emotional lability and they are unaware of this symptom.

See Section 4: *Emotional impact.*

“ We made a strategic decision to relocate, to be closer to our relations and our family roots.”

Where people do continue to visit and maintain contact, you may find it helpful to:

- keep them informed of changes so they know what to expect (MND is rare and they may not fully appreciate the impact of the disease)
- let them know the best times of day to visit, as your routines may change and you may feel more energised at certain times
- let them know how long to stay, to help you avoid fatigue
- make a list of tasks that others might be able to help with (people like to offer practical support and a ready list gives them choice and saves you trying to think of instant tasks)
- open difficult conversations to give them ‘permission’ to ask about things that may concern them
- encourage your inclusion at social gatherings for as long as you feel this is right for you.

You may find new ways to develop social contacts by exploring different types of social activity. This could include new hobbies, or joining a local branch or group of the MND Association. Meeting other people in a similar situation and sharing experiences can help to remove the feeling of isolation for both you and your carer. Not everyone feels this is appropriate for them at first, but you can join a branch or group at any point.

“ I have had a one-to-one conversation with someone else with MND. This was very useful at a low 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 14: *How we can help you.*

The MND Association online forum also provides a safe place for you to communicate openly with other people who are living with or affected by the disease. You can also view the forum conversations without joining if you prefer. This can still help to reduce isolation. Although your particular experience of MND is unique to you, there will be many examples of shared issues and practical tips.

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

Communicating about MND to children and young people

It is natural for any parent to want to protect their children from distress or worry. Yet even young children notice far more than we realise. Without information and explanations, children may:

- feel isolated and forgotten
- rely on their imagination to provide answers, which can be far more damaging and distressing than reality

- think their thoughts or actions can influence the wider world and, seeing someone they love gradually get worse, they may feel it is somehow their fault
- try to find out more information on their own, which may not be from an accurate source.

When communicating sensitive issues to children, start by talking about things the child will already have noticed. For example, if leg muscles are affected, explain how this will make it increasingly difficult to walk. If facial muscles have been affected, explain how it may be difficult to smile, but this does not mean you are angry.

You may be worried about getting upset, but this can give children and young people permission to release some of their own emotions. By talking about MND you are clearly demonstrating it is not a taboo subject, but one that is safe to discuss.

“ Although we were a close family, we didn’t talk much about what was happening or what might happen in the future. I wish we had talked more because a lot of my worries would have been dealt with.”

There is no need to give all the information at once. How much and how often you should talk to children will depend on their age and how quickly the disease is progressing. However, it is important to be clear in your explanations to avoid confusion or misunderstanding.

It may help to use information about MND specifically for young people:

See *Further information at the end of this section for publications we have produced to help adults and children communicate about MND.*

Teachers at your child’s school should be told if someone in the family has MND. If they have the information and know how the disease is affecting the family, they can be a real source of support for the child.

As they get older, children have more mature perceptions and a different level of understanding. Often, they will seek information on their own and may know more than you realise, but still need to talk to you. They may shoulder a heavy responsibility as a young carer, or they may be at college and feel torn between home and student life.

Encouraging young people to maintain their links with the outside world is vital. Reassure them that their friends and activities are essential in maintaining a balanced life.

Top tips

- 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 at the end of this section for examples and for contact details of MND Connect who can direct you to a wide range of support
- Try to find out what children think is happening, as it may be worse than you expect and you can help them to understand.
- Working together to keep things as open and positive as possible can really help to improve quality of life.

Further information:

We have a range of numbered information sheets, including:

- 20A:** *Sex and relationships for people living with MND*
- 20B:** *Sex and relationships for partners of people living with MND*
- 24:** *Communicating about MND to children and young people*

Publications specifically to help children and young people:

When someone close has MND

an activity workbook for children aged four to ten, 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

We also provide the following publications:

Caring and MND: support for you

a comprehensive pack focused on the well being of family and unpaid carers

Caring and MND: quick guide

a small A5 booklet to help someone new to the caring role become aware of available support

Most of our publications can be downloaded from our website: www.mndassociation.org or you can order them from **MND Connect**, our support and information helpline: Telephone: **08457 626262** Email: mndconnect@mndassociation.org MND Connect can also help you locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional care development adviser (RCDA).

See Section 14: How we can help you.

Online forum:

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

Samaritans:

08457 909090

Childline:

0800 1111

The Carers Trust:

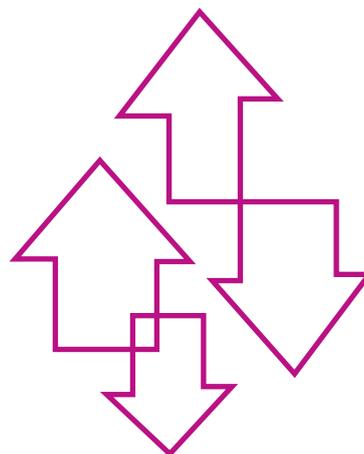
provides an interactive online facility for young carers at: www.youngcarers.net and support for all family carers at: www.carers.org **0844 800 4361** (England, Northern Ireland and Wales)

Carers UK:

provides information and advice for all family carers at: www.carersuk.org and through their advice lines:
0808 808 7777 (England)
02890 439 843 (Northern Ireland)
02920 811 370 (Wales)

6: Getting around

This section will help you to find safe ways to maintain movement and mobility in your everyday life, to prolong independence and support social contact.



MND affects everyone in different ways, but impact on movement, mobility and posture is to be expected as the disease progresses. This can be extremely frustrating and, for some, may result in falls and injury. It can also restrict living independently at home.

Accepting that you may have to find new ways of doing things can be difficult. However, there are many ways to find support and this can genuinely improve quality of life for yourself and for those close to you.

“ The ability to adapt to change can make such a difference to the experience of living with MND.”

Who can help me maintain mobility?

A physiotherapist can:

- help maximise your movement and mobility, and maintain good balance and posture
- assess your needs regarding appropriate walking aids
- recommend an exercise programme appropriate for you and advise carers on passive exercise (where they move your limbs)
- advise you and your carer on moving and handling
- provide guidance on positioning for comfort

- provide advice on how to manage falls
- suggest ways to manage fatigue
- provide advice on respiratory care, which may help relieve fatigue.

An occupational therapist can:

- advise how to maintain independence in all aspects of self care and daily living activities
- provide guidance on falls prevention
- recommend how to retain posture, minimise pain and reduce discomfort
- advise about adapting your home environment for wheelchair accessibility or for equipment to help you with mobility or tasks
- provide advice to you and your carer on moving and handling
- suggest ways to manage fatigue
- provide guidance on how to maintain social activity and personal hobbies or interests
- support the psychological and emotional impact of having to manage the changes being experienced.

A district nurse can:

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

Will exercise help?

It is the nerves supplying the muscle, rather than the muscles themselves that are damaged in MND, so excessive exercise is not usually recommended and can cause fatigue. General exercise such as walking and swimming are fine, but don't push yourself beyond your natural limits.

Try to conserve energy for activities that are important to you. A physiotherapist can advise you and your carer on exercises that will suit you and these exercises need to be tailored to your individual needs. What may suit one person with MND may not be ideal for another.

It is also important to get advice as your condition changes and exercise routines may need to adjust.

“ Physiotherapy has helped me feel proactive rather than a helpless victim.”

Initially exercise will help to:

- maintain muscles not already affected by the MND
- maintain range of movement in joints to help prevent stiffness and pain.

Assisted or 'passive' exercise (where someone else moves your limbs) can help to relieve stiffness and pain. This type of exercise can also help ease discomfort if poor circulation occurs and limbs are swollen. Again, a physiotherapist can advise on a programme that will be appropriate.

How do I manage fatigue?

You may find that fatigue is a persistent issue. This may be due to a variety of reasons, such as:

- the extra effort required to complete common tasks due to the weakening of the affected muscles
- a decrease in respiratory function, should breathing problems occur

- a reduction in food intake if you experience eating problems.

Not everyone will necessarily experience all of these issues, but fatigue may still be felt.

It might be helpful to take on the idea that you have a 'bank account' of energy to spend each day. Plan to do valued and essential tasks first and either leave or get assistance for others. If you overspend on energy one day, you may feel extremely tired the next. Try to:

- listen to your body and pace yourself
- prioritise tasks, manage your time and be flexible with routines
- use equipment to help you do things more easily
- talk to your physiotherapist, occupational therapist and dietitian about ways to manage fatigue
- talk to your health and social care team about any breathing problems
- plan a rest day both before and after a particularly busy time, such as a family event.

What support is available?

You will need to be assessed for any equipment or aids to determine the most suitable provision. In most cases an occupational therapist is your first contact for advice and arrangements regarding equipment, but other members of the health and social care team may also be involved. The following indicates the type of support that may be available to help with movement and mobility.

For balance, walking or personal mobility:

- use devices such as splints or braces to support vulnerable joints and assist with problems such as foot drop, where the muscles in the foot become less responsive

- use walking aids like sticks, crutches, a walking frame or a rollator (a frame with wheels). Sometimes this can be difficult if the arms and hands are weak
- consider if a wheelchair may be useful (see later heading).



Rollator, or wheeled walking frame

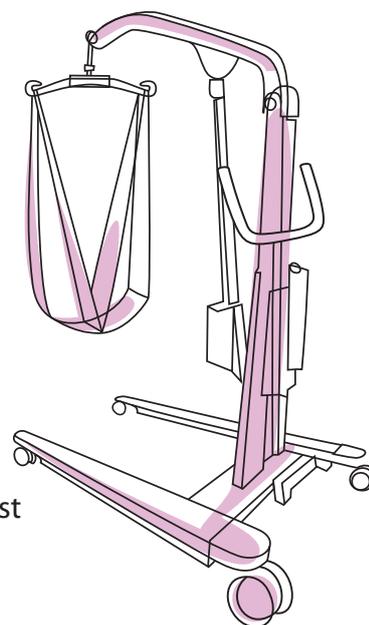
If experiencing pain, cramps and/or stiffness:

- talk to your health and social care team to assess what may be causing the problem
- a physiotherapist or occupational therapist may be able to help
- explore changes to seating and positioning and whether splints, braces or a support collar may be helpful
- use a specialist chair and bed, walking aids and pressure relieving cushions and mattresses
- ask about pain control and medication.

To move from chair to bed, bath or toilet:

- you and your carer need to be shown safe moving and handling techniques and how to use any equipment and aids – ask your occupational therapist, district nurse or physiotherapist for advice (if they are not able to give direct instruction, they may be able to refer you to an appropriate source of qualified help)

- use equipment such as hoists, riser recliner chairs, sliding boards and rotating transfer frames



Mobile hoist

- consider adapting the bathroom to a level access shower and use a wheel-in shower chair
- slippery materials may also assist the ability to move around and slide, eg when in bed, but care must be taken to avoid falls
- a memory foam mattress may make it more difficult to move in bed.

To get in and out of the house:

- use ramps and widen doors
- install environmental controls to open doors and control appliances, such as the television.

To move between floors:

- use stair rails and grab rails if safe to do so
- consider if a stairlift will be suitable – where a track is fixed to the staircase and a seat takes you up and down. Suitability may depend on how easily/safely a person can transfer off and on the seat, both now and in the future
- consider if a through-floor vertical lift will be suitable - these rise through the ceiling to the floor above and are designed to take a wheelchair. They take up considerable space, but may prove the most practical way to access bed and bathroom facilities

- adapt your home to enable you to live downstairs or to be wheelchair accessible. Plan any conversions or extensions as early as possible, as these can often take a year or more.

Local authorities differ greatly in their approaches to assisting people with disabilities with home adaptations such as stairlifts and lifts. This is particularly true with a progressive disease like MND where needs can change. However, if you decide to buy or hire a lift privately, please talk to an occupational therapist first. These expensive items have little second-hand value and you need to know if they are safe for you to use.

You may be eligible for a Disabled Facilities Grant (DFG) towards the cost of lifts, conversions and extensions. This is normally arranged by an occupational therapist employed by social services. It is means tested and can be a very lengthy process, so explore the options as early as you can.

See Further information at the end of this section.

To get in and out of a car:

- ask your occupational therapist for advice on equipment and techniques to help, such as a lever in the door catch to help with grip or a cloth swivel cushion to help turn the upper body into the car
- if your carer finds bending and stretching difficult, try a long strap under the feet to help lift them into the car
- think about adapting your car or consider changing to a wheelchair adapted vehicle (WAV), which may be accessible through the Motability scheme.

See Further information at the end of this section for publications on motoring, 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.

NHS wheelchairs

Currently these are supplied by local health authorities through the Wheelchair Service, where you can be assessed for your individual needs following a referral by your GP, physiotherapist or occupational therapist.

A posture and mobility assessment is essential to help you choose the most suitable option to meet your needs, from a wide variety of models and adaptations. As your needs are likely to change, regular review of the suitability of your wheelchair is also recommended.

“ I remain determined to get on with my modified life... my outlook, by necessity, is having to change.”

You may be eligible for the NHS voucher scheme that will help you pay for an alternative wheelchair to the one the NHS Wheelchair Service has available. The NHS criteria for the provision of a powered indoor or indoor/outdoor wheelchair can be very strict and there may be a long wait.

Wheelchair support from the MND Association

If all enquiries for statutory support regarding a wheelchair have failed, we may be able to help. We have worked hard to gain grant funding to move towards national coverage of wheelchair services to help more people living with MND. For more information about our David Carleton Paget wheelchair service, please contact MND Connect or our Support Services team.

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

Private hire or purchase

If you decide to buy privately, get advice from a physiotherapist or occupational therapist to ensure you purchase the right chair for your needs. An assessment should take into consideration not only your size, shape and postural needs, but how, when and where the chair will be used, with an environmental assessment too (to check accessibility). It is essential to get this right, as an ill-fitting chair can be very uncomfortable. There may be a Wheelchair Service near to you who can offer fast independent advice and a range of wheelchairs to try.

The British Red Cross

This independent charity lends or hires manual wheelchairs for short periods.

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

Shopmobility

Many large shopping centres and retail parks offer schemes where you can phone ahead and book a wheelchair. Look for your local contact in the telephone directory or search for *Shopmobility* online.

Scooters

Some people may find a scooter useful for a while, but an assessment should be undertaken with your occupational therapist, as they can be costly and have limited usefulness. Your nearest Disabled Living Centre can offer advice and some centres 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 for you.

Wheelchair and scooter safety:

- check brakes and tyre pressure regularly
- carry extra layers for warmth if likely to be in cold conditions for long periods, 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 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.

“ The Motability car has given Dad a new lease of life and so much freedom, so the benefits really do outweigh the costs.”

Transport and travel

We provide a range of information sheets to answer your concerns about:

- driving
- adapted vehicles and the Motability scheme
- Blue Badge
- public transport
- scooters
- disability transport schemes
- holiday and long distance travel.

See Further information at the end of this section.

Top tips

- If you are a driver who has been diagnosed with MND, you must notify your car insurer and the DVLA immediately. This does not necessarily mean you will have to stop driving, but you may need to be assessed.

See *Further information for information on motoring and MND*

- Always get an independent assessment by an appropriate health and social care professional before making major decisions about aids or home adaptations. The professional will be able to help you consider both present and future needs to help you make an informed choice.
- Bear in mind that if you use a wheelchair and you have a stairlift installed, you will probably need to purchase another wheelchair – one for transfer on each floor.

Further information:

We have a range of numbered information sheets, including:

- 3: *Holiday information*
- 7: *Motoring and MND*
- 8: *Choosing the right vehicle for you*
- 14E: *Air travel and non-invasive ventilation (NIV)*
- 21: *Physiotherapy for people with MND*
- 22C: *Disabled Facilities Grants and housing issues*
- 25: *Travel and transport considerations*

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Email: mndconnect@mndassociation.org

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

See *Section 14: How we can help you.*

MND Association Support Services:

Email:

equiploanandfinsupp@mndassociation.org

Telephone: **01604 611802** for guidance on our financial support and equipment loan services

Online forum:

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

The British Red Cross:

www.redcross.org.uk or telephone

0844 871 1111 to find out about short term hire of manual wheelchairs.

7: Everyday activities and personal care

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

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

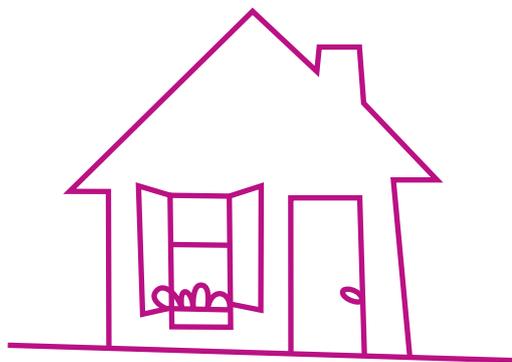
If you tire easily

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

Where to go for help and advice on equipment and aids

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

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



See Section 12: *How statutory services can help you.*

Relevant professionals can help to assess your needs:

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

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

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

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

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

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

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

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

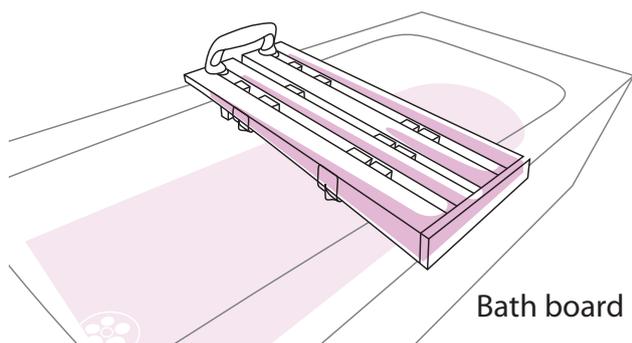
See Further information at the end of this section and Section 14: How we can help you for details about MND Association support services including local branch and group support meetings.

Bathing and showering

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

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

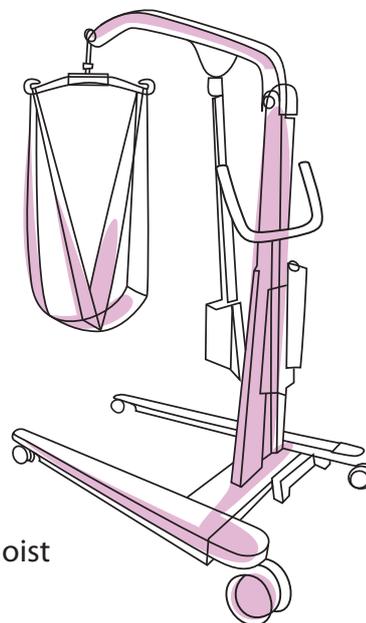
Non-slip mats and grab rails can help increase safety. Bath boards can be fitted across the bath for transfer. A bath seat can help you transfer in and out and some bath seats are powered.



Bath board

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

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



Mobile hoist

I find it difficult to stand under the shower:

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



Wheeled shower chair

I have difficulty directing the spray with a hand-held shower:

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

I have difficulty gripping:

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

I get tired standing at the sink:

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

Getting dry is so tiring:

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

Using the toilet

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

I feel at risk getting on and off the toilet:

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

I worry about getting to the toilet at night:

A bedside commode provides a portable unit for close access.

I worry about personal hygiene:

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

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

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

I have difficulty adjusting my clothes to use the toilet:

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

See [Clothing and dressing and Further information](#) later in this section.

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

Self adhesive pads and adapted applicators are available from chemists, to help if you have a weak grip. If menstruation is particularly problematic, you may wish to talk to your doctor about using contraceptives to stop periods or the possibility of a chemically induced menopause.

Clothing and dressing

With MND, comfort and ease of dressing can become issues. Getting dressed and undressed can be tiring or problematic if your grip is affected, and the way you react to temperature may change. It may be helpful to:

- adapt fastenings to make them easier to manage, eg using velcro, larger zip pulls or elastic shoelaces
- use dressing aids like button hooks for assistance
- try different types of material for temperature control (cotton and cotton-rich fabric is usually best)

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

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

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

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

Oral hygiene

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

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

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

Personal appearance

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

How can I take care of my nails more easily:

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

I'm worried about shaving:

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

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

Inflatable hair washing trays can be used while you lay on a bed. If you have a weak grip, a long-handled comb or hairbrush may help or fit a loop to the back of a brush for easier hold. If holding a hairdryer is difficult, try a hairdrying stand.

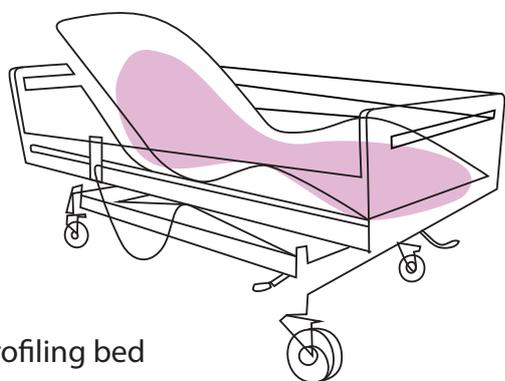
I find it difficult to apply make-up:

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

Comfort

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

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



Profiling bed

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

See Section 12: How statutory services can help you.

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

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

Around the house

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

Wherever possible try to:

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



Rollator, or wheeled walking frame

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

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

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

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

Cooking

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

I get very tired trying to cook:

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



Perching stool

I worry about carrying items in the kitchen:

Try an apron with big pockets or a bag slung diagonally over the shoulder to access small items. A freehand tray (carried in one hand) or a kitchen trolley may help. Avoid using heavy utensils if possible.

I find it difficult to use electrical fittings:

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

I find it difficult to open cupboard doors and drawers:

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

I have difficulties eating and drinking:

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

How do I get my care needs assessed?

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

This is normally done by asking social services to provide you with a Community Care Assessment. If you have a carer, they can also request a Carer's Assessment of their needs. Both assessments provide advice and information and may lead to arrangements for services and support, either now or in the future.

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

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

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

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

In England and Wales, you have the right to request an assessment from your local social services. If your care needs are identified as critical or substantial, they have a duty to meet your needs. Carers also have a right to request a Carer's Assessment, but the decision to provide services for carers is discretionary.

Northern Ireland uses a slightly different approach, through local health and social care trusts. If you are assessed as having care needs, they have a duty to meet those needs. Where a Carer's Assessment establishes needs, they have power to provide services directly to the carer.

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

NHS Continuing Healthcare

If your primary health care needs become complex, you may wish to consider requesting an assessment for NHS Continuing Healthcare where, if you meet certain criteria, the NHS fully funds your care needs. This is a complicated application process, involving members of your health and social care team, and you are advised to explore the requirements carefully. We provide an information sheet on this subject. There is no guidance regarding NHS Continuing Healthcare in Northern Ireland. If you are resident there and in need of this arrangement, please contact your local health and social care trust.

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

Top tips

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

Further information:

We have a range of numbered information sheets, including:

- 1: *Clothing ideas*
- 7: *Motoring and MND*
- 8: *Choosing the right vehicle for you*
- 12: *Oral hygiene*
- 21: *Physiotherapy for people with MND*
- 22A: *Benefits and entitlements*
- 22B: *Direct payments and personalisation*
- 22C: *Disabled Facilities Grants and housing issues*
- 22D: *NHS Continuing Healthcare*
- 22E: *Work and MND*
- 25: *Travel and transport considerations*

We also provide the following publications:

Caring and MND: support for you
a comprehensive pack for carers

Caring and MND: quick guide
summary information for carers

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

Telephone: **08457 626262**

Email: mndconnect@mndassociation.org

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

See Section 14: *How we can help you.*

MND Association Support Services:

Email:

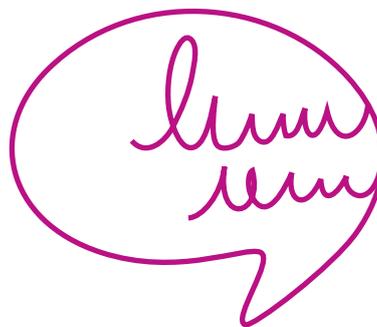
equiploanandfinsupp@mndassociation.org

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Online forum:

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

8: Speech and communication



This section will help you understand how MND can affect your ability to communicate and what can help.

We all need to get things done and to share our thoughts and feelings with others. Communication is not just about speech and writing. We express things to others by gestures, facial expressions, laughter and tears.

MND may affect your ability to do all these things. One of the main challenges of living with MND is to overcome these problems, if they occur.

What is happening when we talk?

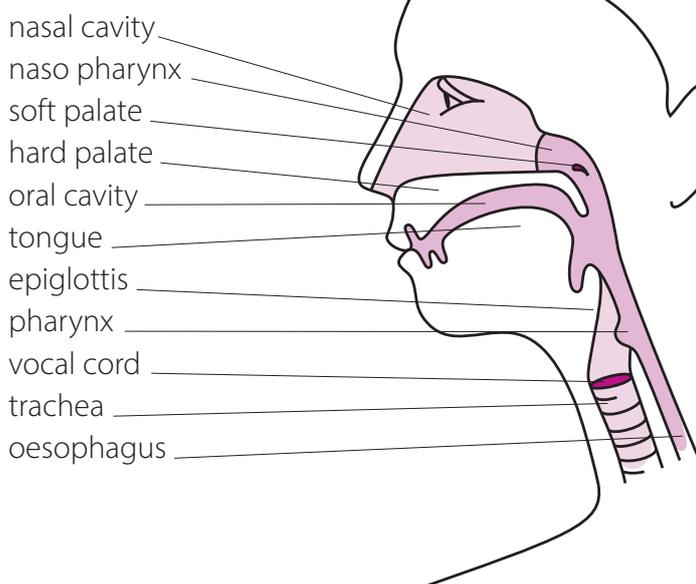
When we speak, air from the lungs passes up the windpipe and through the vocal cords, which vibrate and produce sound. Shaping this sound with the muscles of the tongue, lips, teeth and palate produces speech.

How MND can affect speech

Not everyone with MND experiences problems with speech, but for some people muscles in the mouth, throat and chest are affected, which can cause:

- weakness in the muscles of the tongue and lips, making it difficult to speak clearly
- difficulty with sounds such as consonants 'p', 'b', 't', 'd', 'k', 'g'
- weakness of the soft palate, allowing air to leak out of the nose giving your voice a nasal quality
- weak vocal cords, which can make your voice sound hoarse, low pitched and monotonous

How we speak



- speech to become slow, slurred and indistinct, making it difficult to produce intelligible speech
- problems with muscles in your chest, which can affect your breathing so that your voice becomes soft and faint.

Who can help?

Your GP can refer you to a speech and language therapist (SLT), who can provide advice and show you how to modify your speech. They can also recommend equipment for alternative ways of communicating.

Extending your ability to speak, unaided

You may find it helpful to:

- speak more slowly
- pause more frequently to take a breath and clear your mouth of saliva
- over emphasise words and break them into distinct syllables
- save energy by using short sentences
- get your meaning over early in a sentence 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.

“ If I cannot say as much as I used to say, I have to say it better. So the choice of words becomes crucial.”

If speech problems are increasing

- work out some hand signals for frequently used phrases with your immediate family and other carers
- establish a ‘yes’ or ‘no’ signal, which could be a particular sound, slight head movement, limb movement or blinks/eyebrow raising
- compile a list of regular questions/requests so your partner can go through the list until you indicate yes/no by an agreed signal.

You may not realise how your voice sounds to others. People close to you are more likely to understand what you’re saying, but often strangers can’t. Strangers may think that you are drunk, which can be hurtful and embarrassing, or that you have a hearing impairment. It can help to:

- carry a message to explain to strangers and to help you avoid repeating explanations (we can supply pocket sized notepads and a card with an explanation from the MND Association)
- keep a pen and pad handy or a wipe clean ‘magic slate’ – some people use text phones or computer tablets to type and show what they want to say, but this can become difficult if your arms and hands are affected.

When you know that you are going to be seeing your doctor or other professional, you may find it helpful to prepare a written list of the main things that you want to say or ask.

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 so that you can cope in a wider range of situations.

Advice for families and carers

Share your frustration and challenges with your main carer, family and friends. Involve them in finding ways to help. It may be useful to show them the following tips:

- impaired speech does not mean impaired understanding, so don't feel you have to simplify statements for someone with MND
- don't change the speed or volume of your speech, unless the person with MND has a hearing loss
- be patient if the person with MND speaks slowly, as it may be taking a lot of effort
- encourage the speaker with MND to pause between phrases and rest often
- encourage over-articulation of speech to make up for slower and weaker movements as this will help make speech clearer
- face one another and watch the person's face and lips
- for longer conversations, sit in a quiet room, turn the television off and avoid distractions
- keep a pencil and paper or a communication board handy
- if speech is becoming tiring for the person with MND, encourage them to use eye pointing or gesture
- use questions that only need a yes or no answer. For example 'Would you like a cup of tea?' rather than 'Would you like tea or coffee?'

Alternative ways of communicating

There are a huge range of techniques and aids to support or replace spoken communication. The term used to describe these is Augmentative and Alternative Communication (AAC).

There is no 'best' type of AAC system for someone with MND. Each solution has pros and cons and the most suitable one for an individual will depend on their personal preferences, abilities and needs.

Specialist assessment, with a speech and language therapist, is necessary to help you identify the most appropriate solutions by considering both current and future needs. This is important as some technologies can be very expensive and will not suit everyone.

There are two main types of AAC system:

Unaided communication: such as body language, gesture, pointing, signing, and facial expression. These may become difficult with MND, depending on your symptoms.

Aided communication: from simple tools (non-electronic) to electronic systems and software technology.

Simple tools include:

- pen and paper
- writing boards, wipe boards, magnetic sketch boards or slates
- communication charts
- letter, word or image boards and books, such as an alphabet board where you point to correct letters or words to create your message. If need be, someone else can scan their finger across the board until you signal 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 available or you can create your own.
- Eye-pointing frames (E-Tran frames) on stiff, transparent plastic allow you to indicate a letter, word or symbol with eye movement.

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

Electronic and software communication aids include:

- voice amplifiers if your speech is clear, but faint
- voice activated computer applications where you have difficulty typing
- voice output communication aids where you have difficulty speaking

- computer based systems, which can range from general email to sophisticated eye gaze systems.

Depending on the system requirements, electronic and software communication aids can be operated on a variety of equipment, including personal computers, laptops, tablets and smartphones. Some solutions are now available as an app (an app is a special software 'application' that can be quickly downloaded and used on portable devices like smartphones and tablets).

“ 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.”

What do I need to consider?

A speech and language therapist with relevant experience of MND can assess your current/future needs and suggest specific solutions, but the following may be useful:

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

A portable electronic communication aid may be an easier option. Powered by rechargeable batteries, with a keyboard and display screen, these can be operated by a single switch if you have limited hand movement. You type a sentence and press a button for the machine to speak it, and you can select from a range of voices. Frequently used words and phrases can be pre-set and text prediction can be used to speed up communication.

“ My progress in learning voice recognition gives me hope that I can still negotiate the internet and suchlike without the use of my limbs.”

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

If your speech is unaffected, voice recognition systems allow you to operate a computer by speaking commands. If not, you may be able to use adapted switches or more complex eye-gaze systems to continue operating a computer independently. Eye gaze and similar tracking systems allow you to select items on the screen through eye or head movement. You need to be assessed by a speech and language therapist, as these do not suit everyone and can be very expensive. Other equipment may be needed, such as arm supports, clamps to hold equipment steady or an adjustable table. An occupational therapist can advise about physical aids.

I don't like the synthetic voices on voice output systems:

Advances in voice banking software are beginning to enable more representative segments of recorded speech to be used, to create a unique synthetic voice which can be accessed via a keyboard. Your own voice may be able to be used if 'banked' before speech problems have advanced. A speech and language therapist may be able to advise, as these systems are relatively new.

I don't currently use a computer – is it worth the effort?

If you have never used a computer before, you may feel wary. However, computers, laptops, tablets and smartphones enable access to a range of communication solutions, including synthesised speech and facilities such as the internet, email, online forums, social networks, office software, creative software and games.

What happens if I cannot use my 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 electronic systems break down, or for situations when the system may not be portable.

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

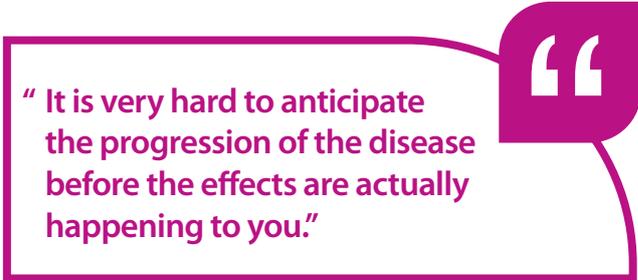
Wireless technology can offer a range of solutions through internet access and apps. Try various options before purchase to find what suits you. For example, some people find touch screens helpful, but if you have restricted hand function a keyboard or alternative method of access may be easier to operate.

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

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

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

With MND, some people experience mild changes to the way they process information, which can impact on communication. If word grids or text based software are 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 the speech and language therapist to ensure your needs are met.



“ It is very hard to anticipate the progression of the disease before the effects are actually happening to you.”

Will I need to change to a different communication aid in the future?

What you use is likely to change as your MND progresses. Also technology is advancing rapidly in this arena, so improved solutions may become available as your needs change. What may not have been suitable at one point may become relevant in the future, so always be prepared to try something again.

Where can I try out different communication aids?

A speech and language therapist with relevant experience of MND, can advise on the solutions most suited to your needs and will be able to demonstrate most of them. You may be referred to a specialist assistive Communication Aids Centre (CAC) or an Access to Communication Technology centre (ACT) where you can try out a wide variety of equipment and get advice about how it can be funded.

For speech and language therapists who are unfamiliar with MND, we have produced guidance (our AAC Pathway) to help them identify likely communication needs and how to determine an appropriate solution for you. This is available to professionals through our Support Services team.

See Section 14: *How we can help you for contact details.*

Is there any funding available to help with the cost of communication equipment?

Try not to rush into private purchases before being assessed, as communication aids are sometimes very 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: you are strongly recommended to consult your speech and language therapist to find out what is available.

The MND Association: we may be able to offer a limited amount of financial support where statutory services cannot supply. This can only be given following an assessment by a speech and language therapist.

Other charities: some organisations will fund communication systems. If you work, these sources of help can sometimes be sought through your employer.

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 look for further detail at: www.gov.uk/access-to-work

For more on work related matters and other financial support, see [Section 10: Your finances](#).

Other communication systems

Most of the following solutions are generally available, or seek guidance from your occupational therapist.

Telephones:

It may be helpful to use:

- a hands-free system with a built in microphone and loudspeaker to enable you to talk without lifting the handset

- a telephone with memory, to store frequently-used phone numbers, which can be dialled automatically by pressing one button
- mobile phones or smartphones, which are lightweight and portable outside of the home, and enable texting if you have speech difficulties
- mobile phone technology designed to help people with disabilities, eg simple functions, larger buttons, etc
- answering machines, to record messages if it takes time to get to the phone or if there are speech problems.

Alarms:

For when you are alone, telephone systems can be activated by a small alarm button worn around the neck or on a wristband. These are known as telecare assistive technologies and your local social services may be able to provide a system. This would automatically contact emergency services or other people of your choice, should you need urgent help.

You may also need to alert others in the house if you need assistance. Special beepers are available or intercoms which can be plugged into 13 amp sockets. You can also use a simple solution, such as a doorbell connected to a switch or pressure pad.

Environmental controls:

These allow you to control electrical facilities around the home, such as the TV, using a remote device. This means you don't have to keep asking for help and can maintain independence for longer.

Top tips

- If you have speech problems, take your time, say the important things and ensure you make your thoughts and wishes known.
- If you sense that your speech is becoming affected, you may wish to have difficult discussions while it is still relatively easy to question and communicate.

See also Section 5: Family, children and friends and if you are ready to think about the later stages of MND, Section 11: Planning ahead.

- To avoid wasting time and money on unsuitable aids, get specialist advice from your speech and language therapist even if buying your own communication aids. Always try out devices before purchase.
- Always have a simple method of communication available, especially if you tend to use electronic aids that may break down.
- Try to have regular reviews with your speech and language therapist as your needs are likely to change.

Further information:

We have a range of numbered information sheets, including:

- 10:** *Swallowing difficulties*
- 13:** *Complementary therapies*
- 20A:** *Sex and relationships for people living with MND*
- 20B:** *Sex and relationships for partners of people living with MND*
- 21:** *Physiotherapy for people with MND*

We also provide the following publications:

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

Caring and MND: quick guide
a small A5 booklet to help someone new to the caring role become aware of available support

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9: Eating and drinking



This section will help you to find ways to adjust to any problems with eating and drinking.

Not everyone has the same symptoms, but it can be difficult to eat and drink as much as you need, should you experience:

- swallowing difficulties
- problems with hand and arm control
- reduced mobility (making food preparation difficult)
- muscle wasting (leading to weight loss)
- fatigue (when eating and drinking may feel very tiring).

For many of us, eating and drinking is not just about wellbeing, but about social activity. When swallowing goes wrong you cannot eat, drink or even swallow saliva with your usual control. You may feel like avoiding food-related social events for fear of embarrassment. Modifying your eating and drinking techniques may help you to feel less anxious, maintain a nutritious diet and join in.

Who can help me?

Your primary contacts are likely to be:

Speech and language therapist (SLT) for expert assessment and advice about eating and drinking techniques to ensure a safe swallow.

Dietitian for guidance on food types and consistencies to keep you nourished (they usually work closely with the SLT).

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

Physiotherapist for advice on posture, exercise, assisted exercise and how to deal with any experience of choking.

GP for general medical advice, prescriptions and referrals.

Pharmacist for guidance on types of medication for particular circumstances, eg liquid or soluble form.

How will MND affect my eating and drinking?

MND affects nutrition in several ways:

- problems with chewing and swallowing, resulting in loss of body fat as less food is taken in
- where nerves are affected, unused muscles begin to waste and more energy is needed by healthy muscles to compensate
- if swallowing becomes difficult, you may be tempted to eat and drink less and to avoid foods which cause problems
- if your mobility is affected you might be tempted to cut down on drinks to reduce the number of trips to the toilet
- your appetite may reduce.

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

- weight loss, feeling tired and loss of strength
- constipation (from dehydration, change of diet and poor mobility)
- dentures can become loose
- skin may become loose, dry and flaky 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, but maintaining adequate nutrition will lead to greater wellbeing.

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 used when the normal eating and swallowing process goes wrong. With MND, this happens when muscles around the mouth and throat weaken and become difficult to coordinate.

See Further information at the end of this section for information on swallowing difficulties.

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
- the gag reflex occurs due to lack of muscle coordination
- food/liquid may trickle into the lungs due to a delayed swallow reflex. This is called aspiration and may lead to chest infection.

Some people also experience either very thin saliva that pools in the mouth or thick stringy saliva that is very difficult to clear. Combined with a weak cough this can be distressing, where saliva, food or liquids may cause choking. However, there are ways to help avoid experiences of choking and to control them if they happen. Your physiotherapist, speech and language therapist and district nurse can advise.

For detailed guidance on swallowing difficulties, including saliva problems, coughing and choking, see Further information at the end of this section.

With all these issues, talk to your wider health and social care team as a variety of help, advice, equipment, aids and in some instances, medication can be offered.

The MND Association provides a *MND Just in Case Kit* (JIC Kit) to help with respiratory

problems, saliva issues and choking. This can be ordered by your GP who determines your needs and prescribes any medication for the kit. This is then kept at your home for instant access, eg if a doctor is called out of hours. Information is provided in the kit both for health professionals and family carers. The JIC Kit can provide reassurance and many people find it comforting to plan in this way, even though an emergency may never happen.

What should I eat and drink?

We are generally encouraged to eat less fat and sugar to reduce the risk of obesity, heart disease and cancer. However, with MND, weight loss from muscle wasting or eating problems can occur and you may need to consider foods with higher calories.

“ I was aware I had lost weight. Continuing on a low fat, low sugar diet was not the name of the game.”

A dietitian can advise on this and tell you whether supplements or fortified foods may be suitable. This may vary depending 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 should include:

Protein: for repair and regrowth

Eggs, milk, cheese, meat, fish, pulses

Carbohydrates: for energy and maintaining weight

Starch: bread, rice, cereals, pasta, potatoes

Sugar: 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

There is no specific reason why you cannot still enjoy alcohol if you wish to, but some people with MND find it can cause coughing. Diluting may help with this. Bear in mind that alcohol can dehydrate the body and in excessive amounts may affect balance. When taking any type of medication, always check with your doctor if it is safe to continue drinking alcohol.

Consistency of foods

Swallowing problems vary widely and what one person finds easy to eat may be difficult for another. In general, liquids cause more difficulty than solids, and food of a semi-solid consistency (like porridge) is the easiest to swallow. Experiment to find what suits you best and try to:

- select foods that are already the right consistency for you
- cook meat and vegetables until tender so they can be broken up and chewed more easily
- 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 hand or electric blender to change the consistency of foods.

Don't be tempted to mash or purée foods sooner than necessary. You may cope with different consistencies on different days. It is important to keep biting and chewing as long as you can to help keep the tongue mobile and play its part in helping you to swallow.

It is important to remember that adding water to food will only increase its volume. It will not increase the energy, protein, vitamins and minerals.

Foods most likely to cause problems include:

- mixed textures and liquids with bits in, such as minestrone soup
- foods that need a lot of chewing, such as fresh bread, vegetable skins, raw vegetables and some meats
- stringy food, such as bacon or old green beans
- coarse hard food, such as nuts or hard toast
- foods that get sticky in the mouth like bread, mashed potato or white rice
- some cooked vegetable skins can be difficult to clear from the roof of the mouth, such as tomato
- crumbly foods like biscuits, cakes and crunchy cereals.

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

Consistency of liquids

The Department of Health recommends that we should drink about 1.2 litres of fluid every day (about six 200ml or eight 150ml full glasses). However, swallowing muscles need to be finely tuned to cope with fast flowing clear liquid. An early sign of swallowing difficulties may be coughing when drinking. Even a tiny amount 'going the wrong way' will make you cough.

Try thicker fluids or foods high in fluid such as:

- milk shakes, fruit purees and homemade or bought 'smoothies'
- yoghurt, custard, mousses, jelly or ice cream
- soups.

Thickeners can be added to food and drinks, such as:

- flour, cornflour, arrowroot, rice flour, ground rice or semolina
- instant mash potato

- breadcrumbs or cereal (eg Weetabix)
- powder prescribed by your GP to add texture or thicken.

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 smaller portions more often, rather than larger meals. It can help to remain sitting upright for half an hour after a meal. Avoid foods that tend to repeat or cause acid, eg spicy foods, acidic foods and caffeine, and talk to your GP about medication that may help.

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 will keep food warm.

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 my suction ability has reduced:

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.

I like food to look good:

Attractively presented meals can help stimulate the appetite. If food needs to be liquidised it can help to keep flavours and colours separate, rather than combining everything together.

I find it difficult to grip utensils and sit correctly:

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

Taking medication is very difficult:

Some can be crushed and mixed with soft foods to make them easier to swallow. Ask your GP or pharmacist for advice, as some medication can be provided in another form, eg as a liquid, patches, suppositories or a drug that dissolves easily under the tongue.

My sense of taste has altered or disappeared:

This happens for a small proportion of people with MND. Strong, spicy or acidic flavours may help, but some people find these cause coughing. Taste may be affected by thrush or sticky saliva, which can coat the mouth, so talk to your GP who may be able to help.

I have a very dry mouth:

Discuss with your GP, as some medications can cause a dry mouth and artificial saliva sprays and gels may help. You may be dehydrated if the amount you drink has reduced. Increase your fluids, thickened if necessary. Sips of very cold water or ice cubes on sticks may help. Fill a small spray bottle with water and cool it in the fridge.

I keep biting my cheeks and tongue:

Seek advice from your speech and language therapist for guidance on techniques to avoid this.

My partner or carer seems to eat at different times, or separately:

If this happens and worries you, your partner or carer may need reassurance that it is okay to eat with you, even if they are eating different types of food. They may feel a sense of guilt about this and open communication may be needed to clear any concerns. It is important that your carer eats well, as they may neglect their own needs when focused on support.

I worry about mouth care:

Ensure that all food has been cleared from the mouth at the end of a meal. If swilling the mouth out is difficult, use a lint-free cloth to wipe out the mouth with mouthwash. Clean teeth thoroughly, at least twice a day. An electric or long angle-headed toothbrush may help, with a small amount of low foaming toothpaste. Have regular dental checkups (some dentists may make home visits).

*For more on oral hygiene, see **Further information** at the end of this section.*

Alternative feeding methods

If eating and drinking are likely to become a problem, other ways of feeding may be discussed with you by your health and social care team. There are two frequently used methods:

- nasogastric feeding, where a narrow tube is passed through the nostrils, down the back of the throat and into the stomach
- feeding by gastrostomy, where a tube is inserted directly into the stomach through the abdomen.

The most popular method for long term use is a gastrostomy, where a tube is inserted through the abdominal wall by a minor

operation, so you can receive specially prepared liquid feeds.

“ I wanted to fight the disease, and not accept defeat. I believed that a liquid feed through a tube couldn’t be as beneficial as a ‘healthy diet’. This proved to be wrong on both counts.”

This is offered in three forms known as PEG (Percutaneous Endoscopic Gastrostomy), RIG (Radiologically Inserted Gastrostomy) or PIG (Per-oral Image Guided Gastrostomy). The difference is in how the tubes are inserted, but the end result is the same.

Important facts about a gastrostomy:

- the tube can be discreetly hidden under your clothes
- you can continue to take some foods and/or drinks by mouth, so you can enjoy foods you like without worrying about eating large amounts
- you will receive all the nutrients and fluids you need and your dietitian will advise on feeds and timings
- the special feed is provided on prescription and delivered to your home

“ Pouring liquid feed down the tube and flushing with water and cleaning very quickly became part of the daily routine. It doesn’t disrupt or prevent any activity.”

- anxiety about meals should lessen, for you and for your carer/partner who is reassured that you are receiving what you need
- your dietitian may prescribe a high calorie liquid feed to help you regain lost weight, then adjust the feeds to help keep your weight at the right level for you

- a gastrostomy can reduce the risk of chest infections caused by small amounts of food and/or fluid entering the airway during swallowing
- a gastrostomy tube generally lasts for one to two years and can be replaced easily if necessary
- you should have an improved sense of wellbeing as your energy levels increase.

The decision is yours. You may prefer not to be fed by tube and to continue the way you are, with advice from your dietitian and speech and language therapist.

However, if you do wish to go ahead, it is better to think about a gastrostomy before considerable weight loss has occurred and before the risk of chest infection increases, due to inhalation of food or drink into the airway.

Before making a decision, discuss the options with your family, dietitian, speech and language therapist and doctor to be as informed as possible.

This can be a good time to talk through the choices available to you regarding feeding in the later stages of the disease.

When you have made up your mind, you may find that the decision you make is not the one that relatives and carers would prefer you to make. Talking together will hopefully bring you to a shared understanding.

As your MND progresses you may change your views on feeding. You may then wish to have a tube inserted or, if you have had one, you may decide to discontinue using it. Again, discuss this with your carers, family and health and social care team.

For detailed information on alternative feeding and making the decision, see *Further information* at the end of this section.

If you are concerned about treatment decisions during the later stages, you can refer to Section 11: *Planning ahead, when you feel ready*.

Changes in bladder and bowel habits

While mobility problems can make it more difficult to access and use toilet facilities, MND does not usually affect the muscles that control bladder or bowel action. Any changes should be investigated, as they may not be due to MND.

However, you may experience changes due to:

- not having enough food, liquid or fibre
- some types of medication
- reduced mobility and weakness of the pelvic floor, abdominal muscles or diaphragm
- adjustment to gastrostomy feeds, which may cause constipation or diarrhoea in the early stages.

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 normal pattern of passing urine has changed, it may be linked to your diet. Bladder irritants can include:

- alcohol
- citrus drinks, such as orange and pineapple juice
- caffeine (tea and coffee)
- concentrated urine, due to drinking less.

It may be tempting to reduce the amount you drink if it takes more effort and time to get to the toilet, but it is important to keep well hydrated.

Top tips

- Even if you feel alternative feeding methods may not be right for you, find out about these as soon as you can. Your views may change as you become more informed or as your needs progress.
- Discussions on eating and drinking can be quite detailed and you may wish 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:

We have a range of numbered information sheets, including:

10: *Swallowing difficulties*

11: *PEG and alternative feeding – making the decision*

12: *Oral hygiene*

We also provide the following publications:

MND Association Recipe Collection

easy swallow meals

Caring and MND: support for you

a comprehensive pack for carers

Caring and MND: quick guide

summary information for carers

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

Telephone: **08457 626262**

Email: mndconnect@mndassociation.org

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

See Section 14: How we can help you.

MND Association Support Services:

Email:

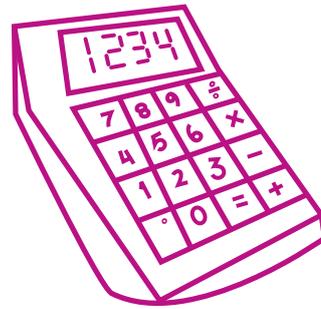
equiploanandfinsupp@mndassociation.org

Telephone: **01604 611802** for guidance on our financial support and equipment loan services

Online forum:

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

10: Your finances



This section will help you identify options regarding financial support, entitlements and employment, if you have been diagnosed with MND.

While you may feel you need to act quickly following a diagnosis of MND, try not to make any hurried financial decisions. Consider all options and gather as much information as you can first.

Please note: this information does not represent legal advice. Each individual has different circumstances and we advise contacting a qualified expert for specific queries, such as a benefits adviser.

The financial impact of MND and where to get help

MND affects everyone in different ways and the rate of progression can vary, but your daily life will need to adapt.

“ Dependent on individual circumstances, each person affected has different worries or concerns.”

This can create many pressures. Not only will you face personal and emotional challenges, but additional financial costs to help you maintain mobility and physical independence for as long as possible. While facing these challenges, you may also need to consider whether to continue your employment if you work.

This can all feel overwhelming at first, but you can find advice from various sources.

See Further information at the end of this section for helpful publications and key contacts relevant to financial support.

Practical financial support is available from:

- statutory services (those provided free by social services and the NHS)
- the Government, in the form of benefits and entitlements
- voluntary organisations and grants, particularly those relevant to disabilities
- the MND Association.

See the later heading in this section: *What are statutory services?* and the sections in Part 3 of this guide: *Accessing services and support.*

Where statutory funding and services are not available, we offer a limited amount of financial support from the MND Association. 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.

Taking a break from work

If you are an employee you may be entitled to take 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) should you meet the criteria.

Taking a period of leave after diagnosis may give you time to consider your options, but paid or unpaid leave is at the discretion of your employer.

A campaigning charity called Working Families provides information on work issues, such as paid and unpaid leave.

See Further information for contact details.

Will I have to leave work?

If you work, one of the first major concerns following diagnosis is how living with MND will affect your employment. This can be very unsettling, but when to leave work is a personal choice and everyone's experience with MND is different.

It is important to recognise that as the disease progresses, your care needs will increase. If your partner is your main carer and employed, juggling work and care can be very challenging. So both of you may need to consider your work options. These decisions may affect your:

- sense of purpose
- standard of living
- social network
- daily routines
- approach to accepting financial support.

“ I was determined to carry on teaching and I believe my pupils benefit from having me as a teacher and a positive role model. It's an opportunity for the children to realise that being disabled is not a negative thing.”

Your options will depend on your symptoms, which can vary widely. However, as MND is progressive, you are likely to experience increasing fatigue. Physical tasks will become more challenging and it may not be safe or legal to continue certain types of work, eg driving heavy vehicles.

Please note: If you drive at work or socially, you are legally required to contact your car insurer and the DVLA to inform them following diagnosis. You may be able to continue driving, but will need a medical assessment.

You will need to consider all possibilities and it may be useful to discuss options with:

- your partner, family and friends
- your employer
- the person who is likely to become your carer
- a social worker from your local authority

“ Trade unions have funds and access to other areas too and can help as mediators.”

- an adviser for the Access to Work scheme, should you want support to continue working (ask for details from your regional Access to Work contact centre or your local Jobcentre Plus)
- 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 your disability 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 advice information and support team, MND Connect.

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

Some of the options to consider are:

- shorter or flexible working hours
- home working and teleworking
- a community care assessment by a social worker or health worker to help determine your current and future care needs
- adapting the work environment to prolong your ability to work, for as long as it is safe to do so (help may be available from the Access to Work scheme)
- voluntary redundancy or leaving work

- early retirement (always take advice from a pensions adviser before making any decisions, as taking your pension early can impact on other financial aspects, such as benefits).

“ In some cases, private insurances take your last 12 months of earnings to determine how much they will pay you, which may affect you if you go part-time.”

What should I do 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.

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 review any 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.

Benefits and entitlements

There are various benefits and entitlements specific to your needs and those of your carer. Many are means tested, where your income and savings are assessed to see if you qualify or need to contribute.

It is useful to be aware of at least the following:

See information sheet 22A – *Benefits and entitlements* for details on who qualifies, how to apply and various other benefits, as listed in *Further information* at the end of this section.

Attendance Allowance (AA): Not means tested. Provided for people over 65 to help support their assessed care needs. AA is not affected by the introduction of the Personal Independence Payment (PIP) – see later heading.

Carer’s Allowance: Not means tested (savings are not taken into account, but your earnings may affect your entitlement). Available to carers who provide 35 hours or more of unpaid care per week to someone receiving Attendance Allowance or the middle/higher rate care component of Disability Living Allowance.

Carer’s Credit: If caring creates gaps in a carer’s work history, this credit protects your National Insurance to build qualifying years for state pension.

“ I was in work when diagnosed and found it difficult to know what benefits I was entitled to.”

Carer’s Premium: A top-up to assist carers receiving Income Support, income-related Employment and Support Allowance (ESA), income-based Jobseeker’s Allowance, Pension Credit, Housing Benefit or Council Tax Benefit. See also Universal Credit for changes happening in 2013.

Council Tax Benefit: Means tested. If you need help to pay your Council Tax bill on a low income, you may be able to get Council Tax Benefit (or Rate Relief in Northern Ireland). From April 2013 Council Tax Benefit will be administered by local councils and may be renamed.

Council Tax Reduction: This may be available if your disability means living in a larger property, with an additional bathroom or kitchen, or you have a room used predominantly by the disabled person, or extra space has been provided to allow for indoor wheelchair use.

Disability Living Allowance (DLA): Not means tested. Provided to help support people under 65, who have assessed care needs/mobility issues resulting from disability. See also Personal Independence Payment (PIP) for changes happening in 2013.

Disabled Facilities Grant (DFG): Means tested. A local authority grant which may be available to help towards adapting a home to enable someone with disabilities to continue living there.

Disabled Persons Allowance (Northern Ireland only): Not means tested. If a property has been suitably adapted or has additional features to meet the special needs of a resident disabled person, a 25% reduction is available on your rates.

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. If not, you may still be able to claim income-based ESA, which is means tested. See also Universal Credit for changes happening in 2013.

Housing Benefit: Means tested. If you're on a low income, whether working or not, and need help to pay all or part of your rent, you may be able to get housing benefit (or a rate rebate in Northern Ireland). See also Universal Credit for changes happening in 2013.

Income Support: Means tested. If you're over 18 and under state pension age and do not have enough money to live on, you may qualify for Income Support. If you receive this, you qualify for certain other entitlements. If over state pension age, you can claim Pension Credit instead. See also Universal Credit for changes happening in 2013.

Pension Credit: Means tested. There are two parts: the Guarantee Credit, designed to top-up your income to a guaranteed minimum level, and Savings Credit, to help people with retirement provision in addition to their state pension. You may get one or both of these elements.

Personal Independence Payment (PIP): Not means tested. This will replace Disability Living Allowance (DLA) for new claimants of working age, from April 2013 in the North West and North East of England. This will expand to the rest of the UK for new claimants and some existing claimants from October 2013. Other existing DLA claimants will be reassessed and transferred from April 2014 (unless you are over 65 and applied for DLA before you were 65, in which case you will remain on DLA). PIP works in a similar way to DLA. Attendance Allowance (AA) will continue and is not affected by the change to PIP.

The Social Fund: Means tested. The Social Fund may help with one-off expenses, such as interest-free crisis loans which you pay back over a period of time. This will be subject to reform in 2013.

Tax Credits: If you are responsible for at least one child or young person, you may qualify for Child Tax Credit. If you work, but are on a low income, you may also qualify for Working Tax Credit. See also Universal Credit for changes happening in 2013.

Universal Credit: Means tested. This will be introduced from October 2013 to new claimants and from April 2014 to existing claimants, to provide a single, simple, integrated benefit for people in or out of work. It will replace: Income Support, Job Seekers Allowance (Income Based), Employment Support Allowance (Income Based), Housing Benefit, Child Tax Credit and Working Tax Credit.

Will statutory services help me financially?

Statutory services are those provided by the Government, usually through social services or the NHS, to provide support to people with social care or health needs. If you qualify, you can select to have services arranged for you or to receive payments to choose services for yourself.

You have the legal right to apply for this type of support and to receive it, as long as you meet the qualifying criteria.

Your care needs will increase over time and you may wish to explore what is available through your local social services. This can be done through a Community Care Assessment for yourself and a Carer's Assessment for your carer.

For more detail about statutory services and assessments see the sections in Part 3: *Accessing services and support.*

To find out what the NHS can provide, talk to your GP or health team.

Top tips

- Try not to rush any decisions - it is particularly important to gather as much information as you can, before choosing any course of action that will impact on your finances
 - Financial choices can have hidden consequences. For example, early retirement payments may affect access to other benefits
 - When completing claim forms, describe your worst day, not your best, to help you receive the level of support you really require and emphasise the progressive nature of MND to indicate the increasing impact over time
 - Detailed examples of your challenges will improve your 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 I can no longer handle fastenings' gives a more complete picture
 - If you live with a spouse, partner or related carer, it can be helpful to add their name to your bank account, as a joint account, to ensure they have ease of access to help manage finances
 - You may also wish to consider setting up Power of Attorney for a trusted carer
- See Section 11: *Planning ahead***
- 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.

Further information:

We have a range of numbered information sheets, including:

- 7: *Motoring and MND*
- 8: *Choosing the right vehicle for you*
- 22A: *Benefits and entitlements*
- 22B: *Direct payments and personalisation*
- 22C: *Disabled Facilities Grants and housing issues*
- 22E: *Work and MND*
- 25: *Travel and transport considerations*

We also provide the following publications:

Don't DeLAy

a leaflet about claiming Disability Living Allowance (DLA)

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

Telephone: **08457 626262**

Email: mndconnect@mndassociation.org

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

See Section 14: *How we can help you.*

MND Association Support Services:

Email:

equiploanandfinsupp@mndassociation.org

Telephone: **01604 611802** for guidance on our financial support and equipment loan services

Online forum:

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

Further sources of help can be found in **Section 15: *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

Benefit Enquiry Line:

For queries on benefits and how to claim:
0800 88 22 00 (England and Wales)
0800 220 674 (Northern Ireland)

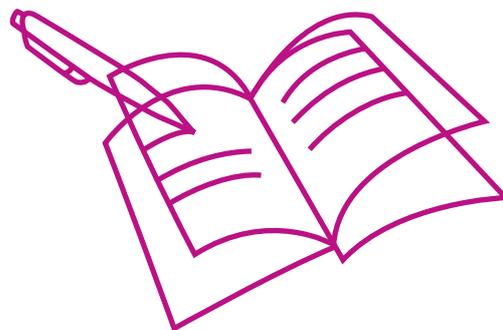
Local authority/councils:

Contact your local authority or council to find out contact details for social services and regional support organisations

Working Families:

Advice on employment and work/life balance for parents and carers. Freephone helpline **0300 012 0312** or visit 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 concerns, so you may not want to read any more at this stage. Refer to this section when you feel ready.

Why has this been included?

Recent studies have revealed that we need to work harder to provide opportunities for people living with or affected by MND to discuss the later stages of the disease, including end of life issues.

Our aim is to improve these conversations, as and when appropriate, by:

- providing training to our staff and volunteers
- redeveloping our information
- calling for and providing better training and education for health and social care professionals involved with MND

“ I think it is vitally important for the person and those around them...to ensure their individual wishes are actually carried out, rather than what others may think they are.”

Planning for end of life can be complicated. We provide more detail in other publications so that you can find guidance when you need it.

The following will highlight what to consider and why.

See Further information at the end of this section for additional publications, when you feel ready to access more detail.

Why would I need to plan ahead?

Discussions about later stage symptoms or end of life concerns 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.

“ I must thank you for focusing my mind on this matter which I had ignored.”

If your speech and communication abilities are affected during the course of the disease, complex and difficult discussions will become even more challenging. A small proportion of people with MND experience cognitive changes, which can make decision making and planning more difficult. Preparing early ensures your wishes and preferences are fully considered. This can also help to reduce concern, so that you can focus on things you really want to do.

See Section 2: Symptoms and management and Section 8: Speech and communication

Most people do have wishes they want to communicate 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
- 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) and/or your will
- guidance for your family and/or carer, to help them support you in the way you would prefer and to help support them in return.

“ Main concerns are probably for my wife and my son... How she is going to be in the future is obviously a great concern to me.”

When ready, try to consider what you want to happen when your care needs become more complex and if you would like professional guidance. We would advise talking to your:

- family
- carer
- health and social care team
- legal adviser
- spiritual or religious representative (if relevant).

We are also here to help you gather information or identify options if you need us, through our MND Connect helpline. This may help you to start tackling this area if you find it particularly difficult. If you are in touch with an Association visitor or a branch or group, they can offer local information and support.

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

“ When is the right time to talk about it? Maybe we ought to talk about these things more, probably just to make sure they’re clear in everybody’s mind as to what’s going to happen.”

Family and children

When someone is near the end of life, it is important that concerns and fears are talked through. This can help the person with MND, but can also reassure those they are close to. Often, understanding the practical aspects of what is involved at end of life can reduce fear.

This can take time, which can become very precious. Having these difficult conversations as early as possible can be very positive, giving everyone a chance to talk and share their feelings more easily.

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. Children also have things they need to say and do at this time. Yet, if talking to your wider family about sensitive issues is difficult, it can be even more so with children and young people. We provide publications to help you with this and to help children and young people explore ways to cope with the situation.

See also Section 5: *Family, children and friends* for more detailed guidance on difficult conversations.

Further information at the end of this section provides details of publications about MND for children and young people.

Palliative and hospice care

Many people are fearful of palliative and hospice care, in the belief that attending such care means they have reached the very final stages of a life limiting condition. On the contrary, palliative care is very much concerned with quality of life from the point of diagnosis onwards, to ensure you receive the best possible symptom, emotional and spiritual support, according to your preferences.

You can receive palliative care at home, in hospital, in a nursing/care home or at a hospice.

“ Things have improved dramatically since my local hospice has become involved...they have stepped in and fought my corner for me and pushed for situations to be resolved. I didn't realise that their remit was as wide as it is and they have really lessened our burden.”

Where available, a relationship with a palliative care team may be an option. This can be particularly beneficial for people with MND and for those close to them. As the disease progresses and the 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.

We advise asking your GP if you can be considered for referral to a palliative care team as soon as you have been diagnosed. The knowledge a palliative care team or hospice can build about the individual may help to reduce time spent in hospital if any emergency treatment is required.

You may find that hospice services are restricted in your area, but palliative care teams can also be accessed through hospitals and clinics.

What else do I need to consider?

Planning ahead can be complex and will be influenced by your specific symptoms, personal circumstances and beliefs. Your preferences may also change over time.

The following is designed as a simple checklist to help you identify aspects you may need to review. When you are ready, we advise you to explore in detail to ensure your wishes are feasible and within the law.

See *Further information* at the end of this section for relevant publications and contacts to help you explore further.

Late stage symptoms: as your needs become more complex, your health team will be able to advise. There are options such as non-invasive ventilation (NIV), to help with breathing, and alternative feeding (through an abdominal or nasal tube), to support with nutrition and hydration. We advise asking your health team about planning for future care as soon as you begin to experience related symptoms, as some interventions may not be suitable for introduction in later stages.

See *Section 2: Symptoms and management, Section 9: Eating and drinking, and Further Information* at the end of this section.

MND Just in Case Kit (JIC Kit): a kit containing medication prescribed by your GP to be kept at home for emergency use with breathlessness or an inability to clear saliva. Many people with MND find this very reassuring as it means help is instantly available. If your GP agrees the JIC Kit would help, it is supplied free by the MND Association. Your GP can then prescribe appropriate medication and tell your carer and health team how it should be used.

Advance Care Plans: 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 choices about where you wish your care to take place, spiritual or religious beliefs, and how you would like care provided (eg shower or bath).

See also *Advance Decisions to Refuse Treatment* later in this list.

“ Doing my ADRT took a huge weight off my shoulders because I’ve got some sort of guidance for people – it does give me a degree of control!”

Advance Decisions to Refuse Treatment

(ADRT): a document that states which treatments you do not wish to receive and in what circumstances. It only becomes valid if you lose the ability to make or communicate those decisions. 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. An ADRT cannot be used to request any form of treatment to deliberately accelerate death, but it can include the right to refuse life sustaining treatment. 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). An ADRT can be reviewed and amended at any time should your wishes change.

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

A will: a legally binding document that states your decisions about what will happen to your possessions and money after your death. There

is usually a cost associated with making a will, but this is something we should all do. 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 can make managing your affairs more difficult for your loved ones, particularly if they are not legally related to you, eg cohabiting partners will not have the same legal standing as a married partner.

Lasting Power of Attorney (LPA): a legal document registered with the Office of the Public Guardian (OPG), for which you will be charged a fee. An LPA allows a trusted friend or relative to make decisions on your behalf if you are unable to communicate your wishes, or lack capacity to make decisions. 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 known as an Enduring Power of Attorney (EPA) and is registered through the Office of Care and Protection. EPA only enables decisions on your behalf concerning property and finance, not personal welfare or care related matters.

NHS Continuing Healthcare: describes a package of care arranged and fully funded by the NHS to meet complex health needs. The primary need must be a healthcare need for the package of care to be agreed, following assessment to determine if you are eligible and what level of funding and care would be appropriate. Continuing Healthcare works in a similar way in England and Wales. In Northern Ireland there is no guidance on NHS-funded healthcare, but the health and social care trusts are encouraged to refer to the criteria used in the rest of the UK.

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

Preferred place of care: one of the biggest concerns people have about the end of their life is where they would prefer to be, including where they may prefer to die. Depending on your circumstances, preferences and health needs, this could be at home, in a nursing or care home, in a hospice or in a hospital. It is really important that the person with MND, their family, carer and health team are all involved in any discussions or arrangements, to help ensure the best possible support. Such decisions often change with time and should be regularly reviewed.

Funeral arrangements: many people wish to discuss their funeral arrangements as there may be particular elements they would like incorporated, or they may be guided by a religious affiliation. Many worry about whether it will be affordable for their loved ones. A pre-paid plan might be possible, or the person arranging the funeral may be entitled to a benefit payment to help with the cost. A funeral director will be able to provide guidance about the arrangements.

Tissue donation: if you are interested in tissue donation to assist research, it is always best to make any arrangements well in advance. Always ensure your family and health and social care team are aware of your wishes.

See *Further information* at the end of this section for a research information sheet on tissue donation.

Top tips

- As difficult as it may be to have discussions about later stages, some people with MND experience increasing problems with speech and communication. The later you leave these arrangements, the harder it may be to have detailed conversations.
- Ensure your family know passwords for computer access to important files and where to find all important documents.
- Your views may change over time, in surprising ways. Don't worry about expressing this. If you feel differently about anything, you have the right to change instructions and to have your views and wishes respected.

Further information:

We have a range of numbered information sheets, including:

- 11:** *PEG feeding – making the decision*
- 14A to 14E:** *various sheets on breathing and non-invasive ventilation*
- 19:** *Advance Decisions to Refuse Treatment (ADRT) explained*
- 22D:** *NHS Continuing Healthcare*
- P4A:** *MND Just in Case (JIC) Kit*

We also provide the following publications:

End of life decisions

a booklet covering end of life concerns

Advance Decision to Refuse Treatment Pack

includes proforma

How will I die?

a booklet answering questions about dying and MND

Tissue donation for motor neurone disease research

research sheet L

Someone close has MND

a workbook for children aged 4 to 10 to help a trusted adult communicate with them about MND

What is MND anyway?

a publication about MND and its impact for young people and young carers up to the age of 18

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

Telephone: **08457 626262**

Email: mndconnect@mndassociation.org

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

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Online forum:

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

Office of the Public Guardian:

0300 456 0300 or textphone **0115 934 2778**

www.justice.gov.uk/about/opg - for advice about Lasting Power of Attorney (LPA)

Office of Care and Protection:

028 9072 4733 or search for power of attorney

at www.courtsni.gov.uk for information on Enduring Power of Attorney (EPA) in Northern Ireland

Government online information:

www.gov.uk - which includes advice about relevant benefits or www.nidirect.gov.uk in Northern Ireland



Accessing
services and support

12: How statutory services can help you



This section will help you identify some of the services and support to which you may be legally entitled.

*Please note: we use the term **social services** in this section, which is still common to many local authorities as the department responsible for assessing needs and providing support for care. However, some authorities may refer to this as Adult Care Services or Adult Services.*

What are statutory services?

Statutory services are those agreed by statute (in law) as your legal entitlement, as long as you qualify for the particular service.

These services include:

- care support
- benefits and entitlements
- a range of equipment and aids
- NHS services.

Try to explore what is available through statutory means before applying for other support or funding. In many cases, voluntary organisations and charities will only provide where statutory services fail to supply.

See Further information at the end of this section for helpful publications and key contacts relevant to statutory services.

Local authority and social services support

Your local authority or social services department will be able to direct you to local support and services. They can also refer you for an assessment of your needs, which is usually done by a social worker or care manager. This might include:

- a community care assessment (of your care needs)

- a carer's assessment (of the support they might need)
- an occupational therapy assessment (of your physical needs to help maintain your independence).

“ Your financial support needs change as the illness progresses. This is difficult to get across to social services.”

Assessment for you or your carer might lead to advice on benefits and the co-ordination of support and services. This may include care in the home, or referral to other local support services such as:

- relevant health professionals
- relevant social care professionals
- care services and agencies
- community palliative care
- day therapy units (often linked to hospices)
- counselling
- respite services
- financial and benefits advice
- useful local or national charities.

An occupational therapist will assess your needs for equipment and services to enable independence. This might include access to:

- lifting aids
- bathing aids
- other aids to assist daily living
- appropriate seating
- disabled facilities advice
- access to grants where appropriate.

Please be aware that services co-ordinated by social services may be subject to means testing, and you may be asked to pay for, or to contribute towards, any services arranged.

“ I’m able to employ people I know and trust... If I had different help all the time, they wouldn’t get used to what I need.”

You can choose to receive direct payments to allow you to choose your own services instead of having these arranged. This does mean being responsible for the money received and keeping records.

“ We have a problem recruiting as we are in a rural area... with social services carers we knew we would always have cover.”

You will also be seen as the ‘employer’ if you hire someone as a personal assistant, unless you hire them through an agency who will deal with this side for you. However, it does enable you to have choice and to build a relationship with those who provide a service.

Social services will be able to advise on all aspects of direct payments and how they work.

For more details on direct payments and personalisation see *Further information* at the end of this section.

“ It works very well for me. I have a very good care manager who helps me a lot, who has known me for years now.”

“ Most external carers know nothing about MND and I have to explain my condition to them.”

Emergency care

Should an urgent need for care assistance arise (eg your carer may be unwell), please contact your local social services department.

Social services also run a limited out-of-hours Emergency Duty Team (EDT), including bank holidays and weekends. It is worth keeping the telephone number of your local contact in your records.

If you are in touch with an Association visitor (AV), try to talk through these issues before they are likely to arise. If you do not have access to an AV, and would like to discuss any concerns, please contact our helpline MND Connect.

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

Benefits and entitlements

There may be certain benefits and entitlements that you are immediately eligible to claim following diagnosis. It is strongly recommended that you explore what is available as soon as possible. There may be qualifying periods for claims or you may need to appeal.

See Section 10: *Your finances* for details about the types of claims you can make and *Further information* at the end of this section for other publications and contacts.

NHS services

NHS services to support your healthcare needs are free and will involve a variety of health professionals to help manage the complexity of MND.

See Section 13: *How health and social care professionals can help you* to explore the types of professional you are likely to meet.

Personal budgets for certain services are currently being piloted. This means that in the future you may be allowed to use an agreed budget to select the service provider you prefer.

MND is progressive and there may come a time when you need more intensive healthcare support. You may become eligible for NHS Continuing Healthcare, which is a package of care arranged by and fully funded by the NHS, to meet complex care needs. The primary need must be a healthcare need and you will be assessed to see if you qualify.

Top tips

- When completing claim forms, explain your worst day, not your best, to help you receive the level of support you really require
- Detailed examples of your challenges will improve your 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 I can no longer handle fastenings' gives a more complete picture
- Support can vary between different regions, local authorities and councils, so explore what is available to you during assessment, eg equipment and aids to support your daily living are often available through statutory services and do not have to be bought
- 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
- Think about whether your home might need to be adapted as early as possible, as this can take time and you may need to seek assistance with funding. An occupational therapist (OT) can help to advise on your future needs.

Further information:

You may find these information sheets helpful:

22A: *Benefits and entitlements*

22B: *Direct payments and personalisation*

22C: *Disabled Facilities Grants and housing issues*

22D: *NHS Continuing Healthcare*

22E: *Work and MND*

We also provide the following publications:

Don't DeLAy

a leaflet about claiming Disability Living Allowance (DLA)

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

Telephone: **08457 626262**

Email: mndconnect@mndassociation.org

Further sources of help can be found in Section 15: Useful organisations or try these contacts:

Government online information:

www.gov.uk which includes advice about relevant benefits or www.nidirect.gov.uk in Northern Ireland.

Benefit Enquiry Line:

For queries on benefits and how to claim:

0800 88 22 00 (England and Wales)

0800 220 674 (Northern Ireland)

Local authority/councils:

contact your local authority or council to find out contact details for social services and emergency care

MND Association Support Services:

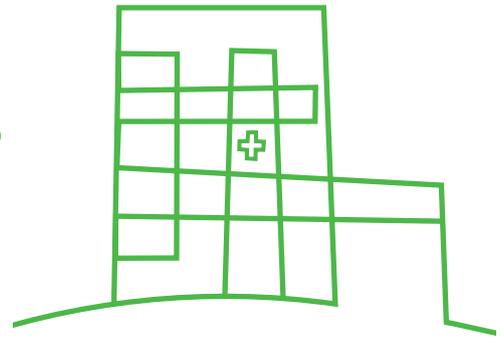
for guidance on our financial support and equipment loan services **01604 611802**, equiploanandfinsupp@mndassociation.org www.mndassociation.org/financialsupport

Online forum:

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

13: How health and social care professionals can help you

This section will help you to identify the range of health and social care professionals that may become involved in your care.



Most health services are first accessed via your general practitioner (GP).

They might include direct support from your GP such as advice on symptom management, medication or referral on to other services, such as a specialist consultant, local neurological services, MND Care Centre (see section 14) or NHS Continuing Healthcare.

Please note: as MND is a rare disease, many GPs will never come into contact with MND, or will see very few cases. An MND Care Centre or local neurological service can provide support from health and social care professionals with extensive experience in the disease.

The variety of health professionals involved in your care are often referred to as a multidisciplinary team or MDT, particularly where their services are linked, as at an MND Care Centre or neurological centre.

See Further information at the end of this section for helpful publications and key contacts relevant to this section.

The multidisciplinary team

The multidisciplinary team supporting you and your carer will probably include some or all of the following:

Consultant: usually a neurologist for assessment, diagnosis, symptom management and advice on care management. Depending on symptoms, you may be referred to other consultants, such as a consultant specialising in respiratory medicine, palliative care or the digestive system.

District nurse: for medical services, such as assistance with medication and monitoring of symptoms.

Neurology or MND specialist nurse: for specialist advice and information about neurological conditions such as MND. Nurses may offer home visits, clinic appointments or a combination of both and will make referrals on your behalf as and when the need arises. Please be aware that not all areas may support this specialist nursing staff.

Palliative care nurse: for information, counselling and support, to help you, your family and your carers cope with the impact of a life limiting illness. Their focus is to ensure the best quality of life possible through appropriate symptom control and other services, as the disease progresses.

Specialist palliative care services: including symptom management, advice and support, counselling, emotional and spiritual support, complementary therapies and information resources. This is often through a hospice as an

outpatient, but short stay admissions may be needed for assessment or palliative care support. Hospice care is specialist care, designed to support the best possible quality of life during a chronic or progressive illness. Many hospice services are available for your family and your carer, as well as yourself, and these can be provided at home.

Wheelchair services: for assessment of seating needs and co-ordination of provision for a wheelchair, as appropriate. Please be aware that there are often waiting lists for this provision. If you find this is the case in your area, please call our Support Services team for advice.

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

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

Physiotherapist: for guidance on managing symptoms, such as fatigue, cramps and spasticity in muscles. They can advise on appropriate exercise, passive or assisted exercise and positioning to maximise comfort. Please be aware that physiotherapy and exercise cannot delay the progression of the disease. They may help to maximise the use of muscles that are not yet affected and increase flexibility by maintaining movement of your joints.

Speech and language therapists (SLT): for advice and assessment on speech and swallowing difficulties. An independent assessment with a SLT is recommended if you consider purchasing any communication aids. These can be very expensive, and not all solutions suit all people, as everyone with MND follows a unique path.

Dietitians: work closely with your SLT to advise on the most appropriate diet, to help you maintain a healthy weight and offer advice on diet where swallowing may be difficult.

Pharmacist: for advice on the best types of medication in particular circumstances, eg

many medicines can be dispensed in liquid form 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. Your local hospice will usually be able to offer counselling as part of their palliative care support.

Social care services: for assessments, advice, information and social care arrangements.

See Section 12: How statutory services can help you for more detail.

Top tips

- You can ask about referral to a local hospice or palliative care team immediately after diagnosis. There is much they can do to improve your quality of life. This relationship tends to decrease any time spent in hospital, as their knowledge of your case can be extremely helpful.
- MND is rare and your GP may not have seen it before. We can help guide health professionals through our support and information team, **MND Connect: 01604 611870, mndconnect@mndassociation.org**

Further information:

You may find these information sheets helpful with regard to how health professionals can assist you:

- 9: *Riluzole*
- 11: *PEG feeding – making the decision*
- 13: *Complementary therapies*
- 14A to 14E: *various sheets on non-invasive ventilation*
- 16: *Care Centre Programme*
- 19: *Advance Decision to Refuse Treatment explained*
- 20A: *Sex and relationships for people living with MND*
- 20B: *Sex and relationships for partners of people with MND*
- 21: *Physiotherapy for people with MND*
- 22D: *NHS Continuing Healthcare*

Most of our publications can be downloaded from our website: www.mndassociation.org or you can order them from **MND Connect**, our support and information helpline:
Telephone: 08457 626262
Email: mndconnect@mndassociation.org

Further sources of help can be found in Section 15: Useful organisations or try these contacts:

Health in Wales:

online information about NHS services in Wales, www.wales.nhs.uk

Health Professions Council (HPC):

a register of qualified health professionals
020 7582 0866 www.hpc-uk.org

NHS Choices:

online information about health choices for specific conditions with an Information Prescription Service www.nhs.uk

NHS Direct:

The NHS online/telephone help and support service, 24 hours a day, 365 days a year, **0845 4647** (number changing to 111)
www.nhsdirect.nhs.uk

NHS Direct Wales:

similar to NHS Direct, but particular to Wales
0845 46 47 (number changing to 111)
www.nhsdirect.wales.nhs.uk

NHS Northern Ireland:

online information about NHS services in Northern Ireland www.hscni.net

The Patient Advice and Liaison Service (PALS):

confidential advice and support regarding NHS and health matters, www.pals.nhs.uk

Northern Ireland:

Patient and Client Council **0800 917 0222**
www.patientclientcouncil.hscni.net

Wales:

Please refer to your local Community Health Council (CHC)

MND Association Support Services:

for guidance on our financial support and equipment loan services, **01604 611802**,
equiploanandfinsupp@mndassociation.org

Online forum:

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

14: How we can help you

This section will help you access the services and support we offer at the MND Association.

We are a charity dedicated to improving the lives of people affected by MND in England, Wales and Northern Ireland. The following explains how you can access our support, as and when needed.

“ When I was diagnosed, I had no knowledge of MND. A friend gave me your telephone number. It was the most important call of my life.”

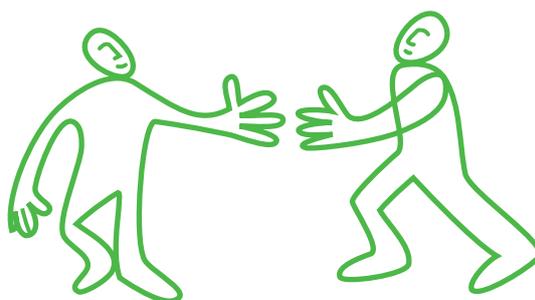
Our overall vision is a world free of MND. We help fund research to bring about an end to MND and assist people living with the disease to achieve the highest possible quality of life. We also strive to do all that we can to support their families and carers.

Please do contact us if you need help. At times, you may feel very isolated, but you are not alone.

MND Connect

MND Connect is our advice, support and information service for people living with MND, their families, their carers and health and social care professionals.

“ The MND Connect service gives helpful and positive advice at times when we feel hopelessly out of our depth.”



If you are concerned about any aspect of MND, the team will be happy to listen and advise in any way they can. The service is available Monday to Friday, from 9am to 5pm and 7pm to 10.30pm.

Telephone: **08457 626262**

Email: mndconnect@mndassociation.org

MND Association

PO Box 246, Northampton NN1 2PR

Association visitors (AVs)

AVs are volunteers who provide free and confidential personal support to people living with MND, their carers, their family and close friends. An AV can help you to identify problems as they arise and discuss your choices for how these might be managed.

“ ...when my husband got MND, we didn't know what it was, so to have someone with knowledge about it, to be able to sit and talk about it was so important.”

All AVs are carefully selected, undergo a thorough training programme and a Criminal Records Bureau (CRB) check. They can make contact with you by phone, email or home visit.

If you would like to be supported by an AV, please contact your local regional care development adviser (RCDA). If an AV is not available in your area, we can offer ongoing support and help through regular contact with our advice, information and support service, MND Connect, or your local branch or group. Please see other listed services in this section for details.

Local branches and support groups

We have a network of over 90 branches and groups, run by volunteers, throughout England, Wales and Northern Ireland. They provide a warm welcome, friendship and the opportunity to meet others affected by MND.

“ They answered many questions, understood problems that we were encountering and offered advice on how to overcome these.”

Our branches and groups offer advice and support, including newsletters and regular meetings. Our branches are listed on our website, or you can contact MND Connect to help you find the nearest location (see previous MND Connect heading for contact details).

Regional care development advisers (RCDAs)

Our regional care development advisers (RCDAs) all have a professional health or social care background. They have expert knowledge of the management and care of people with MND and work closely with local service providers to ensure care and support is available at the right time. A key part of their role is to influence statutory services and to advise in complex situations. They also manage our regional teams of Association visitors (AVs). Our RCDAs are listed on our website, or you can contact MND Connect (see previous MND Connect heading for contact details).

Membership

Membership of the MND Association is free for people living with MND, their spouses, partners and carers. It enables you to join a community of people who share the same vision of a world free of MND, creating a powerful voice to support campaigns on behalf of all those affected. Members can access the following benefits:

- a welcome pack, including membership card, choice of literature and awareness items
- an optional link to your nearest branch or group
- a quarterly members' magazine, with features on care and research as well as inspirational stories from people affected by MND
- a choice of e-communications
- attendance and voting at our AGMs
- invitation to our conferences and events.

To become a member, you can contact us on **01604 611855**, or if preferred by email: **membership@mndassociation.org**

MND Care Centres

MND Care Centres can offer the specialist help you may need, to cope with the complexity of the disease. If you are not close to an MND Care Centre, you can still access coordinated support through regional neurological services. In this instance, you can still access a second opinion if needed through an appointment with the nearest MND Care Centre, for confirmation of diagnosis.

The MND Association has been helping to establish and part-fund MND care and research centres across the UK for many years. There are now 19 MND Care Centres based in large hospitals with two networks of outreach teams, all with specialist doctors and nurses coordinating the care of people with MND.

“ The Care Centre staff are all brilliant. It’s a great place to go to solve medical problems and it’s good meeting other people with MND as well.”

MND Care Centres:

- are based in Regional Neuroscience Centres with a dedicated MND clinic and a dedicated single point of contact for people with MND
- enable access to a multi-disciplinary team with expertise in the management of MND and strong links with the MND Association and local community services
- spread expertise through education and by sharing good practice with colleagues in the community
- are the location for clinical drug trials and undertake clinical research.

To find your nearest MND Care Centre, contact MND Connect (see previous MND Connect heading for details).

Equipment loan and financial support

Following a diagnosis of MND, the MND Association may be able to provide certain items of equipment and communication aids on loan, or consider financial support requests for a variety of needs, such as respite care, adaptations or equipment rental.

All statutory funding and services must have been explored first.

“ Due to a combination of the complexities of the disease and the way the health and social care system is set up, people will almost certainly benefit from the support the MND Association can give.”

Loaned items can be provided while you wait for statutory services to arrange equipment or where statutory services do not supply the item.

All initial requests must be made through a health and social care professional, following an assessment of individual need. If you have any queries, please contact the Support Services team at our national office:

Telephone: **01604 611802**

Email:

equiploanandfinsupp@mndassociation.org

MND Association

PO Box 246, Northampton NN1 2PR

Care information and publications

We provide a wide variety of care information and publications.

“ I felt I was no longer alone in my fight.”

You can download the majority of our information from our website, including our publications list, using the following address: **www.mndassociation.org/publications** or contact MND Connect to order printed copies (see previous MND Connect heading for details).

Our website

Please visit the MND Association website to find out more about MND, our services and the Association: **www.mndassociation.org** including our research, volunteering, fundraising and campaigning activities.

“ If I’d gone to the MND Association site first, it would have saved me a lot of stress.”

Our online forum

The forum is a safe place to share experiences, advice and a wealth of information with other people who have been affected by MND.



“ This can be such a help to those people who may feel isolated in everyday life...This can really support those with MND and their families as well as carers.”

You can access the forum from our website or by using the following internet address:

<http://forum.mndassociation.org>

Support for minority and ethnic groups

We are aware that not everyone will have the same needs, as everyone’s experience of MND will be unique. Culture and religion may also influence the way care and support should be provided and the MND Association supports diversity and 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.

Top tips

- The MND Connect helpline is not just here to provide information and practical advice, the team can also offer a listening ear if you just need to talk. MND Connect supports people living with MND, their families, carers and health and social care professionals
- Before contacting us about equipment loan or financial support, try to gain an independent assessment of your needs by an appropriate health and social care professional.

Further information:

A list of other contacts can be found in Section 15: *Useful organisations.*

15: Useful organisations



This section will help you identify some of the organisations that are likely to become frequent sources of information or service.

You can access a wider list of useful organisations on the *Getting help* page of our website at: www.mndassociation.org/getting-support and we list subject-related organisations at the end of all our information sheets.

You may also wish to contact your local branch or group, an Association visitor or our helpline **MND Connect**, to ask about external services and advice about local support.

See Further information at the end of this section for contact details and publications with lists of organisations for family carers.

Your local authority or council will also have lists of regional providers and may offer a directory of services on their website.

Organisations

Please note, 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 product.

Access to Work

For advice on how your employer can support your working routines.

London centre: for South East England, London, East of England

Jobcentre Plus, Access to Work Operational Support Unit, Nine Elms Lane, London SW95 9BH
Telephone: **020 8426 3110**
Email:
atwosu.london@jobcentreplus.gsi.gov.uk

Cardiff centre: for South West England, Wales, West and East Midlands

Jobcentre Plus, Access to Work Operational Support Unit, Alexandra House, 377 Cowbridge Road East, Cardiff CF5 1WU
Telephone: **02920 423 291**
Email:
atwosu.cardiff@jobcentreplus.gsi.gov.uk

Glasgow centre: for Scotland, North West and North East England, Yorkshire, Humberside

Jobcentre Plus, Access to Work Operational Support Unit, Anniesland JCP, Baird Street, Glasgow G90 8AN
Telephone: **0141 950 5327**
Email:
atwosu.glasgow@jobcentreplus.gsi.gov.uk

Northern Ireland:

Contact an Employment Service Adviser in your local Jobs & Benefits office or JobCentre for advice on Access to Work. Locate your nearest branch by:

Telephone: **0800 353 530 (free phone)**
Website: www.nidirect.gov.uk (search for jobs and benefits offices)

Age UK

Services for people in later life throughout the UK, with advice, information and advocacy, including support on benefits.

Age UK, York House, 207-221 Pentonville Road, London N1 9UZ
Telephone: **0800 169 6565**
Email: through the website contact page
Website: www.ageuk.org.uk

Benefit Enquiry Line

The Benefit Enquiry Line does not have access to personal details, but is available for queries and help, eg advice on how to fill out a form. Open 8am to 6pm Monday to Friday.

Telephone: **0800 88 22 00**

Textphone: **0800 24 33 55** (England and Wales)
0800 220 674 (Northern Ireland)

Website: www.gov.uk/benefit-enquiry-line

Childline

A counselling service for children and young people, with a free 24 hour helpline for children in distress or danger.

Childline, Via NSPCC, Weston House,
42 Curtain Road, London EC2A 3NH

Telephone: **0800 111 111**

Email: through website and confidential login

Website: www.childline.org.uk

Citizens Advice Bureau

Free guidance to resolve legal, money and other problems from over 3,200 locations. Search for your local branch on the *Get Advice* page of the website.

Telephone: **08444 111 444** (England)
0844 477 2020 (Wales)

Website: www.citizensadvice.org.uk (main site)
www.adviceguide.org.uk/ (online help site)
www.citizensadvice.co.uk/en/Where-We-Are
(Northern Ireland)

Community Law Service

Independent advice and representation, including help on welfare benefits, debt and housing. Find your local service through your telephone directory or online.

DIAL UK (Disability Information and Advice Line)

A network of approximately 120 local Disability Information and Advice Line services (DIALs) run by and for disabled people.

DIAL UK, St Catherine's, Tickhill Road,
Doncaster, South Yorkshire DN4 8QN
Telephone: **01302 310 123**

Website: www.dialuk.info

GOV.UK

Online government advice, including information on benefits and related entitlements such as the Blue Badge scheme. You can access associated claim forms through the website:

Email: all email addresses can be found on the website, as related to the type of enquiry

Website: www.gov.uk

www.nidirect.gov.uk (Northern Ireland)

Disability Law Service

Assistance on disability law.

Disability Law Service
39-45 Cavell Street, London, E1 2BP

Telephone: **020 7791 9800**

Email: advice@dls.org.uk

Website: www.dls.org.uk

The Disabled Living Foundation

A wide range of support and advice for people with disabilities, including demonstration centres where you can try different aids.

The Disabled Living Foundation
380-384 Harrow Road, London W9 2HU

Telephone: **0207 289 6111**

Email: info@dlf.org.uk

Website: www.dlf.org.uk

Health and Care Professions Council (HCPC)

A regulatory body with a register of health professionals who meet their standards of practice, including psychologists, physiotherapists, occupational therapists and speech and language therapists.

Health Professions Council, Park House
184 Kennington Park Road, London SE11 4BU
Telephone: **0845 300 6184**
Website: **www.hpc-uk.org**

Healthtalkonline

A website database of personal and patient experiences, including a series of interviews with people affected by or living with MND.

Healthtalkonline, DIPEX, PO Box 428
Witney, Oxon OX28 9EU
Telephone: **01865 201330**
Email: **info@healthtalkonline.org**
Website: **www.healthtalkonline.org** (search for motor neurone disease)

MND Scotland

Formerly the Scottish Motor Neurone Disease Association, providing care, information and research funding for people affected by MND in Scotland.

MND Scotland, 76 Firhill Road
Glasgow G20 7BA
Telephone: **0141 945 1077**
Email: **info@mndscotland.org.uk**
Website: **www.mndscotland.org.uk**

NHS Choices

Online information to help you make informed choices about health. NHS Choices also hosts an Information Prescription Service, for trustworthy healthcare information according to need or condition.

Telephone: see NHS Direct for helpline
Email: through the website contact page
Website: **www.nhs.uk**

NHS Direct

The NHS online/telephone help and support service, providing health advice and information, 24-hours a day, 365 days a year.

Telephone: **0845 4647** (number changing to 111)
Email: through the website contact page
Website: **www.nhsdirect.nhs.uk**

NHS Direct Wales

Similar to NHS Direct, but particular to Wales and the Welsh NHS structure.

Telephone: **0845 4647** (number changing to 111)
Website: **www.nhsdirect.wales.nhs.uk**

NHS Northern Ireland

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

Email: through the website contact page
Website: **www.hscni.net**

The Patient Advice and Liaison Service (PALS)

PALS is a local service in all NHS Trusts in England, providing confidential advice and support to families and carers, and information on the NHS and health matters. Contact your local hospital, GP or health clinic for details of a local branch.

Website: **www.pals.nhs.uk**

Northern Ireland:

Patient and Client Council
Freephone: **0800 917 0222**
Email: **info.pcc@hscni.net**
Website: **www.patientclientcouncil.hscni.net**

Wales:

Please refer to your local Community Health Council (CHC)

The Pension Service

For all queries and claims regarding pensions. An adviser can help you apply for pension credit.

Telephone: **0800 731 7898** (pension claims)
0800 99 1234 (pension credit claims/queries)
 Website: **www.gov.uk** (search for pensions)

Northern Ireland:

Pension Service Enquiry Line
 Telephone: **0845 601 8821**
 Website: **www.nidirect.gov.uk** (search for pensions)

Samaritans

Samaritans provides confidential non-judgemental emotional support, 24 hours a day, for people experiencing feelings of distress or despair. Their service is available by telephone, email, letter or face-to-face in most of their branches. Contact your local branch or:

Samaritans, P.O. Box 9090, Stirling, FK8 2SA
 Telephone: **08457 90 90 90**
 Email: **jo@samaritans.org**
 Website: **www.samaritans.org**

Top tips

- Always try to obtain an independent assessment of your needs before approaching commercial companies for products or services. For example, see an occupational therapist before purchasing any costly equipment or aids. You need to be aware of what will be usable for you and whether your needs are likely to change to ensure that items are suitable.
- You can use the contact record at the back of this guide to list details of useful local organisations.

Further information:

We have a range of information sheets, relevant to the management of MND. Each of these will list relevant organisations. We also provide many other publications.

If you are a carer, you may find it helpful to order our comprehensive carer's pack, *Caring and MND: support for you*, which includes a list of organisations relevant to the challenges of the caring role, or the smaller introductory version *Caring and MND: quick guide*.

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

Telephone: **08457 626262**

Email: **mndconnect@mndassociation.org**

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

See Section 14: How we can help you.

MND Association Support Services:

01604 611802,
equiploanandfinsupp@mndassociation.org
 for guidance on our financial support and equipment loan services

Online forum:

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

Helping you to keep track

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.

The five forms are:

- 1. Personal details:**
to record basic information about yourself to save time at appointments.
- 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:

Address:

Main carer - Name:

Telephone:

Address:

MND Association contact - Name:

Telephone:

Address:

GP - Name:

Telephone:

Address:

MND Care Centre or neurological service - Name:

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	08457 626262 mndconnect@mndassociation.org MND Association, PO Box 246, Northampton NN1 2PR
Association visitor	
Branch or group	
Regional care development adviser	
Support services (equipment loan and financial support)	01604 611802 equiploanandfinsupp@mndassociation.org MND Association, PO Box 246, Northampton NN1 2PR
Switchboard	01604 250505 enquiries@mndassociation.org MND Association, PO Box 246, Northampton NN1 2PR
Membership enquiries	01604 611855 membership@mndassociation.org MND Association, PO Box 246, Northampton NN1 2PR

MND Association services (continued)

Name or organisation	Contact details
Online forum	http://forum.mndassociation.org
Website	www.mndassociation.org

Healthcare services

MND Care Centre	
-----------------	--

Healthcare services (continued)

Name or organisation	Contact details
Neurology clinic	
Consultant	
GP	
District nurse	
MND specialist nurse	
Palliative care nurse	
Occupational therapist (OT)	
Speech and language therapist (SLT)	

Healthcare services (continued)

Name or organisation	Contact details
Physiotherapist	
Dietitian	
Pharmacist	
Counsellor	
Psychologist	

Social care and related services

Name or organisation	Contact details
Social services (local)	
Local authority main switchboard	
Benefit enquiry line	Freephone: 0800 882 200
NHS Wheelchair service (local)	
Jobcentre Plus (local branch)	
Carer's Allowance Unit	0845 6084321 cau.customer-services@dwp.gsi.gov.uk
Citizen's Advice Bureau (local branch)	
The Pension Service	0800 731 7898 for first claims 08456 060 265 for enquiries

Social care and related services (continued)

Name or organisation	Contact details
Religious or spiritual guidance	

Appointment and communication record

You may find this helpful to prepare for appointments or communications. 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
Example: Monday 25 July 2013 11.30am	My GP, Dr Smith	My joints feel stiff. What can I do to maintain flexibility?	Dr Smith recommended specific assisted exercises and will refer me to a physiotherapist with experience of MND.

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

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 2013	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

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:

Care information feedback
MND Association
PO Box 246
Northampton NN1 2PR

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We welcome your views

The MND Association encourages feedback about any aspect of the information we produce.

If you would like to provide feedback about *Living with motor neurone disease*, please use our online feedback form at:

www.surveymonkey.com/s/lwmnd or alternatively, the printed feedback form included in the pack.

Your feedback is really important, as it helps us to develop new materials and improve our existing information, for the benefit of people living with MND and those who care for them.

To find out more about how you can help shape our information, please contact us at infofeedback@mndassociation.org or write to us at:

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