MND Association

Introduction to Motor Neurone Disease

Guidance for people with MND and for their family.

Every day, helping you feel informed, matters.

Contents

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How can this booklet help me?

If you have been diagnosed with MND, this booklet provides a simple introduction for you, your family and anyone offering support.

It explains:

- the disease and who it affects
- how MND is diagnosed
- the likely symptoms
- the different forms of MND
- what is known about the causes
- the type of support available
- treatments you may receive
- tips to help manage the disease
- how to find further information and support.

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

ℹ This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in section 5: **How do I find out more?**

A diagnosis of MND can feel overwhelming. You and everyone close to you may need time to adjust.

When you feel ready, find out as much as you can.

Feeling informed and having open conversations can help everyone share concerns, now and in the future.

> **“Prepare yourself... listen to as much guidance as you can because every bit helps. But you meet a lot of great people that have your best interests at heart.”**

1. What is MND?

You have nerves called motor neurones in your brain and spinal cord. These nerves help you control how your muscles work. MND is a disease that affects motor neurones.

With MND, motor neurones gradually stop telling your muscles how to move. When muscles no longer move, they become weak, which can also lead to stiffness and loss of muscle mass (wasting).

MND is a life-shortening illness that can affect how you walk, talk, eat, drink, breathe, think and behave. This is usually different for each individual. You may not get all of the symptoms and there is no set order in which they happen.

> **“It’s just realising that you have to do things differently. I think that’s the thing that has really helped him.”**

The disease will progress, which means symptoms get worse over time. For some people with MND this can be rapid, for others it is slower.

There is currently no cure for MND, but your doctors and other health and social care professionals can help you manage symptoms and remain independent for as long as possible.

Who does MND affect?

MND is not a common disease. It affects adults and sometimes younger adults. You are likely to be more than 40 years old at diagnosis, and most people with MND are aged between 50 and 70.

How is MND diagnosed?

If your doctor thinks you have a neurological problem (to do with the brain and nervous system), you will be referred to a neurologist. They usually work in the neurology department of a hospital, or as part of the team at an MND care centre or network.

> **“We weren’t aware of the symptoms of MND and so we didn’t spot them early on. And I think actually my dad had it for a year before he was diagnosed.”**

MND is difficult to diagnose as:

— early symptoms, such as clumsiness, weakness or slightly slurred speech could have other causes

— it can be some time before you go to see your GP

— not all symptoms happen to everyone or in the same order

— there is no direct test for MND, which means testing can only prove you don’t have other conditions.

You will have tests to check if your symptoms are caused by anything else. These tests can range from blood samples to various nerve tests. You normally attend as an outpatient. In some cases you may need to spend a short stay in hospital or need further tests.

Following your test results, you may get a diagnosis of MND, but it can take time before doctors feel sure about the likely cause of your symptoms.

> **“It can be overwhelming... just give yourself some time to absorb it. It takes a while to process things. And then just see where you go from there.”**

Will there be a follow-up appointment?

If diagnosed with MND, you should be offered a follow-up appointment with your neurologist or with a specialist nurse.

You may need some time to adjust, but this next visit is a valuable opportunity to find out about the ongoing support you will need.

> **“We didn’t have to ask for support. The support was there, which was a great relief.”**

Are there different forms of MND?

MND affects people in different ways in four main forms. It can take time to diagnose which one at first, as they share some symptoms.

Amyotrophic lateral sclerosis (ALS)
This is the most common form, with weakness and wasting in your limbs, muscle stiffness and cramps. In the early stages you may trip or drop things.

Progressive bulbar palsy (PBP)
This form usually appears first in the muscles of your face, throat and tongue. You may notice slurred speech or difficulty swallowing.

Progressive muscular atrophy (PMA)
This form is usually slower to get worse than ALS. You may notice weakness, diminished reflexes or clumsiness with your hands.

Primary lateral sclerosis (PLS)
This form is usually slower to get worse than ALS. At first, you may notice weakness in your lower limbs, but sometimes problems with your hands or speech.

Is Kennedy's disease a form of MND?

Kennedy's disease is different to MND, but the two conditions can be confused. They both affect your motor neurones with similar symptoms, resulting in muscle weakness. Kennedy's disease progresses slowly, usually with a normal life span.

Caused by a genetic mutation, Kennedy's disease can be identified by gene testing.

Kennedy's disease normally affects males. Females can carry the genetic mutation, but only develop mild symptoms in rare cases.

See our booklet: **Kennedy's disease**.

At the MND Association, we provide support if you are affected by either MND or Kennedy's disease.

What causes MND?

It is not yet possible to be clear on why or exactly how MND begins. This is because each person may be affected by different things.

> **"The problem with MND is it's just very individual. So there is no clear timeline for anyone. It just varies so much from person to person. "**

MND usually occurs with no apparent family history of the disease. In these cases, a mix of genetic and environmental triggers are thought to be involved, although genes may play a smaller role.

Environmental triggers could be things that you eat, drink, touch or breathe, or a mix of these.

These may be different for each individual, so there is no simple way to find out how the disease started.

In a small number of cases, there is a family history of MND, where it is passed down.

This means there is a mistake in the genetic code that has been inherited, although other triggers may still be necessary for the disease to actually begin.

See our booklet:
Inherited MND and genetic testing.

Research into the disease is progressing, including projects funded by the MND Association.

Understanding about the way motor neurones work is constantly moving on. As a result, clinical trials for new treatments have been funded and are advancing.

2. What are the symptoms?

> **“ You know your own body, so listen to it... At first, I just had twitches, problems with my voice and falling occasionally, and I knew they weren’t to do with stress.”**

MND can cause:

- weakness and increasing loss of movement in your limbs
- twitching and rippling sensations under your skin (known as fasciculations)
- muscle tightness and cramping, which may cause you pain
- problems with breathing and extreme tiredness
- difficulties with your speech, swallowing and saliva.

Muscles in your hands, feet or mouth are usually affected first, but not necessarily all at once.

Some people may have changes in thinking, reasoning and behaviour, known as cognitive change, but this is usually mild. A few experience a more severe form called frontotemporal dementia (FTD) and more care support may be needed.

You may have unexpected emotional reactions with MND. You may cry when happy, or laugh when sad.

This is called emotional lability and can be distressing, but your health and social care team can provide support. It doesn't happen to everyone with MND.

MND does not usually affect:

- your senses: sight, hearing, smell, touch and taste
- your bladder and bowel, but mobility problems can make it slower to get to the toilet in time and some people feel a sense of urgency
- your bowel, although lack of mobility and breathing problems can make it harder to push
- sexual function, but sexual expression may be more difficult due to feeling tired, loss of movement and the emotional impact of an MND diagnosis.

See section 5: **How do I find out more?** for details about our information, which includes guidance on symptoms.

"They reassured me that I wasn't going to wake up the next day with my life changed totally... One day I can't do something but the next day I can. So it gives some hope."

3. What help is available?

> **“Being diagnosed with MND might seem like the end of the world, but you go home, go to bed, you get up... It’s not running into a wall. It’s a thing that you can gradually deal with.”**

When needed, support can be given to help you:

- manage symptoms and feel more comfortable
- cope with the emotional impact of MND
- remain independent for as long as possible
- claim for financial support
- get help with mobility, daily activities and personal care
- plan ahead for future care.

Who can help?

Support is likely to come from three main sources:

Health and social care professionals

Not all health and social care professionals know about MND in depth. However, MND care centres and networks (which we help fund), and local neurological services, have experience with MND support.

You are likely to meet a wide variety of specialists this way, such as your neurologist, MND co-ordinator, a range of therapists, specialist nurses and palliative care professionals.

See section 4: **What do I need to think about?** for more about the benefits of palliative and hospice care for ongoing emotional, practical and symptom support.

Your professionals all work as a team, usually called a multi-disciplinary team (MDT). This includes contact with community support, such as district nurses and your GP.

Your GP and most of your healthcare professionals can refer you to specialists. Your team will help you find therapies, treatments, counselling, equipment, help with care and assistive aids.

Adult social care services

Adult social care services can assess your needs and those of your carer. They advise on home and personal care services, and emergency support.

Contact your local authority to arrange assessments. In Northern Ireland, contact your local health and social care trust. Local care services vary, so ask about these at your assessment.

A range of equipment and services may be agreed with you. Depending on your finances, you may need to pay an amount towards these.

“I had to kind of swallow my pride and say, it needs to be done... Let them in. Let the care services help. And after the first two visits, I had more energy to do what I wanted to do.”

Any care services at home can be arranged for you. You can also select services of your own choice by receiving direct payments from an agreed budget.

“With direct payments, it was then up to us to find our own care services, which we did. The carers we use are great.”

If you choose direct payments, you have to account for that money and the employment of any personal assistants to help with care. However, you can get support with this.

See section 5: **How do I find out more?** on how to access our information, which includes benefits and social care guidance.

The MND Association

We provide a range of guidance and financial support for anyone with MND or Kennedy's disease, and their families and carers.

Our MND Connect helpline can help you access our services, regional support and specialist services with other organisations.

ℹ See section 5: **How do I find out more?** for contact details.

Are there any treatments?

Find out as much as you can about appropriate treatments, therapies and medication so that you can make informed decisions when needed.

ℹ See section 5: **How do I find out more?** for access to our information, including how to search for topics by need or by symptom using our: **Care information finder**.

Depending on your symptoms, your health and social care team are likely to discuss the topics on the following pages.

Riluzole

There is currently no treatment to cure or halt the disease, but a drug called riluzole has shown some benefit in slowing down the progress of the disease (by a few months).

Riluzole is licensed for the treatment of MND and has been approved for use in the NHS. Ask your GP or neurologist to find out whether riluzole is suitable for you to take.

Other drugs that may help slow the progress of MND are becoming available.

Other medication

You may be offered a variety of medicines to help ease your symptoms. These will be prescribed by your GP or the specialists you meet. If you find it gets harder to swallow tablets, medicines are often available as liquids or patches.

Physiotherapy

Exercise cannot reverse damage to muscles affected by MND, but it can strengthen unaffected muscle, reduce stiffness and improve range of movement.

A physiotherapist can assess your needs and review them as your symptoms change. They sometimes specialise, such as respiratory physiotherapists for breathing support.

Occupational therapy

Although not a therapy in the sense of receiving treatment, an occupational therapist looks at how you can adapt to stay independant for as long as possible.

“Our occupational therapist is always getting us to trial different aids to see what can help.”

They can also assess your needs at home for daily living, adaptations and equipment, including the needs of your partner or main carer.

Speech and communication therapy

If your speech, expression or ability to gesture are affected by MND, ask a member of your healthcare team for a referral to a speech and language therapist.

They can help you maintain your voice for as long as possible with therapy, and advise on communication aids and voice banking. With voice banking, you record phrases that can be made into a version of your voice, for use on a communication device or phone app.

“I find it amazing they have technology that will allow Dad to communicate with a copy of his own voice.”

Eating, drinking and swallowing support

If you have swallowing problems or weight loss, ask your healthcare team for referral to a dietitian about nutrition. A speech and language therapist can also help with swallowing, saliva and mucus.

> **“I have regular visits from the dietitian for advice on what to eat and the speech and language therapist to assess my swallow.”**

These specialists can help you maintain food, fluids and medicines as needed, and provide guidance on safe swallowing techniques.

This may include easy-swallow meals, therapies, supplements, fortified foods or other ways to receive food and drink.

See our guide:
Eating and drinking with Motor Neurone Disease
for guidance, food preparation and recipes that can be easily adapted to your needs.

Breathing support

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

Ask your healthcare team for referral to a respiratory consultant for guidance, so that you can make timely decisions. You may be offered options for mechanical breathing support (assisted ventilation).

> **"I'd already flagged up that my breathing wasn't very good. I was becoming short of breath... and it triggered that chain reaction of getting help and support."**

Complementary therapies

Although not a treatment for MND, you may find complementary therapies feel relaxing and help to ease symptoms. These therapies, including massage, acupuncture and reflexology, are often used alongside traditional healthcare.

Some palliative care teams and hospices include a limited range of complementary therapies as part of their service.

4. What do I need to think about?

If you or someone close to you has been diagnosed with MND, there is a huge amount to think about. These tips are based on things that people affected by MND told us they wished they'd known at the start.

> **"Make sure you have enough information about the condition and what's coming. It helps you prepare mentally and physically."**

Explore before buying equipment

Have your needs assessed by a relevant specialist, such as an occupational therapist or speech and language therapist, before buying equipment or aids.

Items may not always suit everyone and mistakes can be costly. You may be able to get certain items free or on loan, from the NHS or adult social care services.

Adapt your home as early as possible

Investigate what your future needs may be, as major changes to your home can take time. An occupational therapist can help assess your environment.

You may be able to seek funding through a Disabled Facilities Grant, but this can also be a lengthy process.

Prepare questions and record their answers

Appointments can be tiring and you may miss an important question, so take a list. Note or record any answers, or ask the professional to do this for you.

You can use these notes later if you have to make a choice or decision. Mobile phones and computer tablets usually have an option to record.

Think about how your finances may be affected

You may find it useful to ask your bank how a trusted carer or partner can help manage your account, if you need help with this.

Also seek guidance from an independent financial adviser and a benefits adviser. For example, if you take early retirement, these payments may affect which benefits you can claim.

Find out what you may be entitled to, even if you have never claimed benefits before. We have an MND Association Benefits Advice Service to help you identify where you may qualify for support.

See section 5: **How do I find out more?** for contact details.

Provide detail if you are being assessed

Try not to simplify. Give detailed answers if being assessed for care needs or a benefit claim. Be honest about how you're affected to get the level of support you need, as your symptoms will increase.

Keep a diary to show how long tasks take, the impact on your routines and how quickly things are changing. This means your future needs can be considered.

Find out about treatments

Discuss treatment options with your healthcare team. You need to know what's possible, what it could mean for you, the best timing to introduce treatments and what is likely to happen if you wish to withdraw them.

Each treatment is your choice, but being informed helps you choose what feels right for you.

> **"Information and knowledge is better than lack of."**

Seek out palliative care and hospice services

People often feel wary about palliative care, but this support can be of huge benefit. It can help you and those close to you achieve the best possible quality of life with a life-shortening condition like MND.

It can help you manage symptoms, but also gives wider support for practical, financial, emotional, spiritual, religious or psychological needs.

You may be able to receive this care from diagnosis and mostly attend as an outpatient. This can be at a day centre, hospital, hospice or sometimes at home. Ask your neurologist or GP for guidance.

Building a relationship with specialist palliative care professionals can help reduce time spent in hospital. Their knowledge of your case helps other professionals understand your needs.

Plan ahead as early as possible

Planning future care with MND usually means having emotional conversations with loved ones and your professionals. However, if your communication is affected or you have any changes to thinking, it may be less tiring to discuss plans earlier rather than later.

This could include decisions about finance, family and how you want to receive future care. Your health and social care team can help with these discussions.

Many people with MND tell us that having made their wishes known, they feel calmer and a greater sense of control.

5. How do I find out more?

Other organisations

We cannot endorse organisations, but we provide lists of contacts in many of our resources. These are relevant to the topic being explored to help you search for further information.

Our MND Connect helpline can also help you find organisations. See contact details later in this section, under the heading: Our support.

Find a wide range of specialist organisations, that offer guidance, services or products at:
mndassociation.org/usefulorgs

References

References used to support this resource are available on request. Email: **infofeedback@mndassociation.org**

Or write to:

Information feedback,
Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road
Moulton Park
Northampton NN3 6BJ

Acknowledgments

With thanks to our User Review Group for kindly sharing their experiences.

Thank you also to the following for their kind review during the development or revision of this booklet.

Pauline Callagher, MND Specialist Nurse and Care Centre Co-ordinator, Preston MND Care Centre, Royal Preston Hospital

Emma Chapman, Advanced Nurse Practitioner, Douglas Macmillan Hospice, Stoke on Trent

Emma Husbands, Palliative Medicine Consultant, Gloucestershire Hospitals NHS Trust

Kevin Ilsley, Medical Advisor, Herefordshire Clinical Commissioning Group and former GP, Herefordshire

Elizabeth Ilsley, Speech and Language Therapist, Rotherham NHS Trust, Rotherham

Amanda Mobley, Consultant Clinical Neuropsychologist, Worcestershire Health and Care NHS Trust

Dorinda Moffatt, Specialist Neuro-Respiratory Physiotherapist and Frailty Therapist, Prospect Hospice, Swindon

Gabrielle Tilley, Interim Neighbourhood Team Leader, Great Western Hospitals NHS Foundation Trust, Calne

Further information

We offer a wide range of information about MND and Kennedy's disease. You may find the following resources helpful, relating to this booklet.

Information sheets

For help with managing symptoms.

Booklets

What you should expect from your care
Types of care
Telling other people about MND
Caring and MND: quick guide

Large guides

Living with MND
Caring and MND - support for you

Search for information:

By need: **mndassociation.org/careinfofinder**
In other languages: **mndassociation.org/languages**
In animations: **mndassociation.org/animations**
As video content: **mndassociation.org/mndviews**
Professionals: **mndassociation.org/professionals**
On research: **mndassociation.org/research**
For all resources: **mndassociation.org/publications**
Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

MND Connect
Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at:
mndassociation.org/mndconnect
Tel: 0808 802 6262
Email: mndconnect@mndassociation.org

Support services
Find out about our support services at:
mndassociation.org/our-services

Local and regional support
Find out about our branches and groups at:
mndassociation.org/local-support

MND Association Benefits Advice Service
For help to identify claims and how to apply, visit:
mndassociation.org/benefitsadvice
or call our MND Connect helpline.
Tel: 0808 802 6262

MND Association website and online forum
Website: **mndassociation.org**
Online forum: **forum.mndassociation.org**

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with MND or Kennedy's disease, their families and carers.

Your anonymous comments may also help us raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on this booklet, access our online form at: **smartsurvey.co.uk/s/IntroMND**

You can request a paper version of the form or provide direct feedback by email:
infofeedback@mndassociation.org

Or write to:
Information feedback
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton NN3 6BJ

Want to help review our information?

If you are living with MND or Kennedy's disease, or you are a carer, contact us at:
infofeedback@mndassociation.org

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Registered Charity no. 294354

Revised: May 2026
Next review: May 2029
Version: 1