



1: Motor neurone disease (MND)

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

The following information is an extracted section from our full guide *Living with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: **www.mndassociation.org/publications**

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**



**Living with
motor neurone disease**

1: Motor neurone disease (MND)



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

What is MND?

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

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

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

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



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

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

Who does it affect?

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

Studies show that the disease:

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

What does it affect?

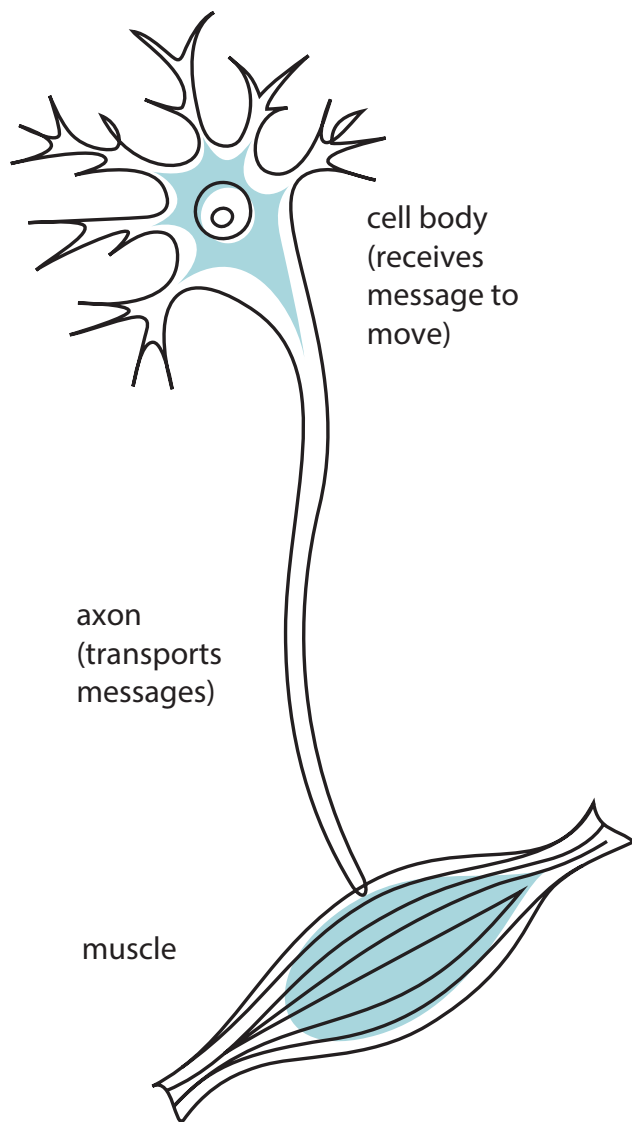
Your nervous system is made up of two main groups of nerves:

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

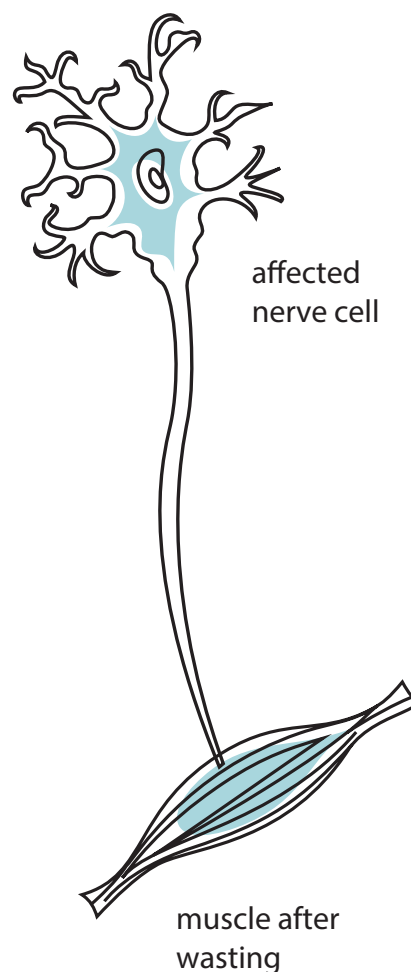
The motor neurones are split into two groups:

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

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



Healthy motor neurone



Motor neurone affected by MND

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

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

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

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

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

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

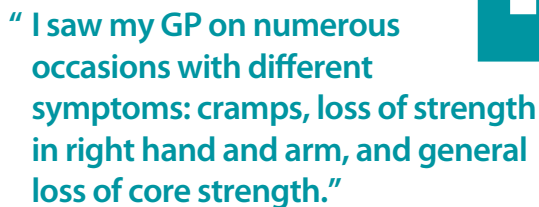
See also [Section 2: Managing symptoms](#).

How is MND diagnosed?

MND can be difficult to diagnose because:

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

Getting a confirmed diagnosis can take time.



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

Tests

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

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

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

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

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

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

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

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

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

Are there different types of MND?

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

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

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

Why include life expectancy here?

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

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

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

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

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

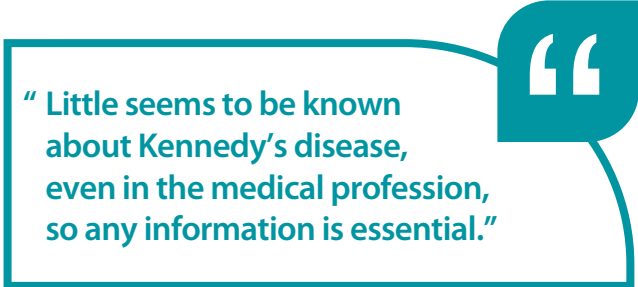
Primary lateral sclerosis (PLS): affects a small number of those diagnosed with MND, damaging the upper motor neurones only. This causes weakness in the lower limbs, although some people experience clumsiness in the hands or speech problems. Reflexes can become exaggerated. Average life expectancy may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

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

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

Kennedy's disease

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



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


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

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

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

What causes MND?

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



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

MND with no apparent family history:

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

MND where there is a family history:

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

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

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

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

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


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

Research into MND

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

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

www.mndassociation.org/research



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

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

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

Telephone: **01604 611880**

Email: **research@mndassociation.org**

The MND Register

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

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

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

Key points

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

Further information:

From our range of information sheets:

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

Also research sheets:

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

From our guides and other publications:

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

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

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

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

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

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

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

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

Information to pass to your health or social care professionals:

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

Download our publications at:

www.mndassociation.org/publications

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

Telephone: **0808 802 6262**

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

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

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

Our research website pages:

www.mndassociation.org/research

Online forum:

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

<https://forum.mndassociation.org>

PMA/PLS email support group:

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

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

For references and acknowledgements please refer to the full guide, *Living with motor neurone disease*.

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