

mnda

motor neurone disease
association



An introduction to
motor neurone disease (MND)

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Patient Information Forum

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

How will this information help me?



If you have just been diagnosed or someone close to you has MND, this booklet provides a simple introduction to the disease.

It explains:

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

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


Even if it feels difficult at first, open conversations about the diagnosis can make it easier for everyone to share concerns, now and in the future.

When you are ready to read more about the disease, we have a wide range of publications to help you, including our main guide, *Living with motor neurone disease*.

See *How do I get more information?* at the end of this booklet for details about our other publications and how to contact our helpline, MND Connect.

All quotes are from people living with or affected by MND.

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



What is MND?



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

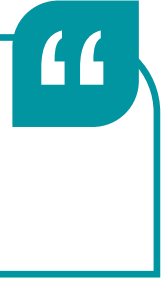
With MND, motor neurones gradually stop telling your muscles how to move. When muscles no longer move, they become weak, which can also lead to stiffness and loss of muscle mass (wasting).

MND is a life-shortening illness that can affect how you walk, talk, eat, drink and breathe. 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.

The disease will progress, which means your symptoms will get worse over time. For some people 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 to manage symptoms and remain independent for as long as possible.

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



Who does MND affect?

MND is a rare disease that affects adults. Although younger adults are diagnosed, in most cases, you are likely to be over 40 years old. Most people with MND are aged between 50 and 70.

Men are affected almost twice as often as women, but this varies. It depends on the type of MND you have and evens out with people who are 70 or older.

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 with an MND care centre or network.

These tests can range from blood samples to various nerve tests to check your symptoms are not being caused by anything else. You normally attend as an outpatient. In some cases you may need to spend a short stay in hospital or have further tests at a later date.

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

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



MND is difficult to diagnose as:

- it is a rare disease and 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
- testing can only prove you don't have other conditions, as there is no direct test 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 be exact, as they share some of the symptoms.

Amyotrophic lateral sclerosis (ALS): 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): affects fewer people than ALS, and in the early stages tends to appear in the muscles of your face, throat and tongue. You may notice slurred speech or difficulty swallowing.

Progressive muscular atrophy (PMA): affects fewer people than ALS and is usually slower to get worse. You may notice weakness, diminished reflexes or clumsiness in your hands.

Primary lateral sclerosis (PLS): affects fewer people than ALS and is usually slower to get worse. This causes weakness in the lower limbs, although you may also experience clumsiness in the hands or speech problems.

Is Kennedy's disease a type of MND?

Kennedy's disease is different to MND, but the two conditions can be confused. They both affect the motor neurones, with similar symptoms and muscle weakness. The MND Association provides support if you are affected by either disease.

Kennedy's disease progresses slowly, usually with a normal life span. Caused by a genetic mutation that can be found through gene testing, it normally affects men. Women only tend to carry the genetic mutation, but in rare cases may develop mild symptoms.

We provide information sheet 2B - *Kennedy's disease*. See *How do I get more information?* at the end of this booklet.

What causes MND?

It is still not possible to be clear about what causes MND, as each person may be affected by different triggers. 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. The triggers 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. 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.

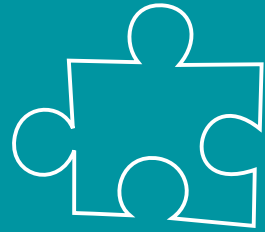
See [How do I get more information?](#) at the end of this booklet for details about our research information sheets on inherited motor neurone disease.

Research into the disease and its causes is progressing, including projects funded by the MND Association. As a result, our understanding of how motor neurones work is constantly advancing.

“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.”



What are the symptoms?



“ I think it’s important for me to understand, broadly speaking, what will happen.”



MND can cause:

- weakness and increasing loss of movement in your limbs
- twitching and rippling sensations under your skin
- 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. Very few will experience severe changes to reasoning.

You may have unexpected emotional reactions, where you cry when happy, or laugh when sad. This is called emotional lability and can feel distressing, but your health and social care team can provide support. It does not happen to everyone with MND.

MND does not usually affect:

- the senses – sight, hearing, smell, touch and taste
- the bladder and bowel, although mobility problems can make it more difficult to get to the toilet. Reduced mobility may also cause constipation (as movement helps the bowel to work)
- sexual function, but sexual expression may be more difficult due to feeling tired, loss of movement and the emotional impact of dealing with the disease.

See *How do I get more information?* for details about our other publications which cover symptoms in depth.

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



What help is available?



When needed, support can be given to help you:

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

This 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, due to its rarity. However, MND care centres and networks (which we help to fund) and local neurological centres offer a wide range of help from professionals with experience of supporting people with MND.

You are likely to meet a wide variety of specialists, such as a neurologist, MND co-ordinator, specialist nurses and therapists. These professionals tend to work as a team, often called a multi-disciplinary team (MDT), including community team members such as district

nurses and your GP. Any member of this team can refer you to another specialist, but many referrals happen through your GP.

“ It really can’t be emphasised enough to listen to professionals who have helped people go through this before.”



The team can help you and your family access expert care, treatments, therapies, counselling and equipment or aids. This can help you to maintain the best possible quality of life, for as long as possible, when living with MND.

Adult social care services: can assess your needs and those of your main carer. They will help identify any home help required, and advise on services and emergency support. Contact your local authority to ask for an assessment – in Northern Ireland this would be done through a local health and social care trust. Local services can vary, so explore what is available during your assessment.

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



A variety of aids, equipment and care services may be agreed for you, although you may need to make a financial contribution. Help with your care can be arranged for you or you may be able to buy services yourself by receiving direct payments.

See [How do I get more information?](#) for details about our publications, which include guidance on claiming for benefits and social care.

The MND Association: we provide support in a variety of ways to anyone living with or affected by MND. Our MND Connect helpline can provide support, information or a listening ear if you need to talk. The team can help you find external services, and introduce you to our services as available, including your local branch, group or Association visitor. This includes our regional staff for care, who help influence wider services in your area to improve MND care.

We may be able to provide certain items of equipment on loan or support grants for people living with or affected by MND. Requests for equipment will need to come through a health or social care professional.

See [How do I get more information?](#) at the end of this booklet for contact details.

Are there any treatments?

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

Riluzole: there is currently no treatment to cure or halt the disease, but one drug, riluzole has shown a modest 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 medication: there are a variety of medicines to help you with individual symptoms. These may be offered by your GP or the specialists that you meet. If you find it difficult to swallow tablets, many medicines can be provided in other forms, such as liquids and patches.

Physiotherapy: this cannot reverse damage to muscles weakened by MND, but can help to reduce discomfort, stiffness and improve flexibility. Your individual needs should be assessed by a physiotherapist and reviewed if your needs change. Try not to over-exercise, even when assisted, as this is not helpful with MND and can make you very tired. Physiotherapists often specialise, for example a respiratory physiotherapist can assist with breathing support and how to manage any problems with saliva and mucus (see later heading for *Breathing support*).

Speech and communication support: ask for a referral to a speech and language therapist for guidance on speech and communication. If your voice is affected, they can help you maintain it for as long as possible, and advise on whether voice banking and message banking will be suitable (to use as spoken phrases through a computer device). If your voice is affected by MND, they can assess your needs for therapy or aids to help you communicate. A speech and language therapist can also advise on managing swallowing problems, saliva and mucus.

Breathing support: if you experience breathing difficulties, there are a number of treatments and therapies to help. Ask your health and social care team for a referral to a respiratory consultant for guidance. This will include discussion about whether to use mechanical support for your breathing (known as ventilation). Try to find out about this, so that you can make an informed decision if needed.

Diet, nutrition and swallowing support: if you have problems with swallowing you may wish to seek advice about nutrition. This will help you maintain the food, fluids and medicines you need, as well as how to swallow safely and comfortably. This may include easy-swallow meals, therapies, supplements, fortified foods or discussing alternative ways to receive food and drink. Ask your health and social care team for a referral to a dietitian and a speech and language therapist for guidance.



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

See *How do I get more information?* for details about our publications with guidance on how to manage difficulties with mobility, communication, swallowing and breathing.

Complementary therapies: some people find that complementary therapies can help to relieve symptoms and reduce stress. Although not a treatment or cure for MND, this type of therapy can be used to ‘complement’ conventional treatments if used in combination. A wide variety of complementary therapies exist, such as massage, acupuncture and reflexology. Some local specialist palliative care services and hospices offer complementary therapies, as well as other forms of support to improve quality of life.



“ 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.”

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. This can feel overwhelming. These tips are based on things that people affected by MND have said they 'wished they'd known at the start'.

You can find more in our main guide, *Living with motor neurone disease*. See *How do I get more information?* at the end of this booklet for details of how to access our other publications.

Don't rush into buying equipment: have your needs assessed by an occupational therapist or speech and language therapist, before buying equipment or aids. Items may not always be suitable for everyone and mistakes can be costly. You may be able to get certain items free, or on loan to try out, from the NHS or adult social care services.

Think about how your finances may be affected: seek advice from an independent financial adviser and a benefits adviser. For example, early retirement payments may affect which benefits you can claim. If you have not claimed benefits before, it can feel

uncomfortable and complex, but it is important to find out what you are entitled to. You may find it useful to ask your bank how a trusted carer or partner can help manage your account, in case this becomes difficult for you to do.

Adapting your home can take time: investigate this as soon as possible if you think it may be necessary, as it can take time to make major changes to your home. An occupational therapist can help advise about your future needs. If you are eligible, you may be able to seek funding through a Disabled Facilities Grant, but this can also be a lengthy process.

Provide good evidence if you are being assessed: give plenty of detail if you are being assessed for care needs or a benefit claim (such as Personal Independence Payment to help live with a disability). Be honest about how the condition affects you to obtain the level of support you need – even if something only feels difficult now and then. If you keep a diary of how your symptoms progress, it can help you to provide examples of how long tasks take and the impact of the disease on your routines. It may also help to demonstrate the speed at which changes are happening, so that your future needs can be considered.

Note down any questions: appointments can be tiring and you may forget to ask something important, so prepare a list of questions to take with you. Note down the answers or ask the health or social care professional to do this for you in case you need to read them later. Most mobile phones and computer tablets can record discussions if this is easier.

Seek out palliative care services: palliative care aims to help you (and those close to you) achieve the best possible quality of life, when you have a life-shortening condition. It provides symptom management and wider support to include practical, financial, emotional, spiritual, religious or psychological needs. A relationship with specialist palliative care professionals may help reduce any time spent in hospital, as their knowledge of your case can help other professionals to quickly understand your needs.

“ From our experience, it is better to be in a position where you feel as prepared as you can be.”



Palliative care services may be able to provide support early on following diagnosis. Ask your neurologist or GP for guidance on how and when to be referred to these services. These may be available at home, or in a hospice, hospital or day centre.

Find out as much as possible about treatments: discuss treatment options with your health and social care team. You need to know what is possible, what it could mean for you and the best timing to introduce any treatments. Whether to accept any treatment is your choice, but try to make decisions based on clear information.

“I wanted to know everything.”



Plan ahead as early as possible: planning ahead for the later stages of MND can feel intimidating. It means having difficult conversations with those close to you and your health and social care team. However, if your speech and communication are affected, or you experience any changes to thinking and reasoning, you may find it easier to discuss plans earlier rather than later. Planning may include decisions about finance, family and your future care. Your health and social care team can help with these discussions. Many people report that having made their wishes for the future known, they feel calmer and more in control.

“Once you’ve done it, you can put it away in a cupboard. You can relax... and you feel better for doing it.”



How do I get more information?



We provide:

- *Living with motor neurone disease* – our main guide to help people with MND manage daily life with the disease
- a wide range of information sheets, including information on symptoms, benefits and social care
- information for carers to help them manage their own well being and find out about available support
- an easy read guide for people with learning or reading difficulties
- a series of research information sheets, including information on inherited MND
- other publications and items to help you with decision making about MND.

Most of our publications can be downloaded from our website at www.mndassociation.org/publications or ordered in printed format from our helpline.

MND Connect helpline

MND Connect can provide support, information or a listening ear if you need to talk.

They can also help you find external services, and introduce you to our services as available, including your local branch, group, Association visitor or regional staff contact.

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

MND Association Benefits Advice Service

We can provide free, confidential and impartial advice on any benefits you may be entitled to.

Telephone: **0808 801 0620** (England & Wales)

0808 802 0020 (Northern Ireland)

Email: through the website contact page, at:
www.mndassociation.org/benefitsadvice

MND Support Grants and equipment loan

You can read more about these at **www.mndassociation.org/getting-support** or contact us as follows:

Telephone: **0808 802 6262**

Email: **support.services@mndassociation.org**

Online forum

Our online forum enables you to share information and experiences with other people affected by MND:

<https://forum.mndassociation.org>

PMA/PLS email support group

You may wish to join this email support group if you have been diagnosed with primary muscular atrophy (PMA) or primary lateral sclerosis (PLS). For details, contact our MND Connect helpline, as shown earlier in this list of services.

Helping professionals to support you

Due to its rarity, not all health and social care professionals have previous experience of working with MND. We provide information, education and support services to professionals, through our regional staff for care and our MND Connect helpline. The helpline contact details for professionals are:

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

Information: **www.mndassociation.org/professionals**

References

References used to support this information are available on request from:

Email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association
Francis Crick House (2nd Floor), 6 Summerhouse Road,
Moulton Park, Northampton NN3 6BJ

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We welcome your views

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.

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

If you would like to provide feedback about our *An introduction to motor neurone disease (MND)*, please use our online feedback form at:
www.surveymonkey.co.uk/r/IntroMND

or alternatively, please contact us at:
infofeedback@mndassociation.org

Or post to us, using the address on the following page.

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