

An Introduction to Motor Neurone Disease (MND)



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1. Introduction

The Irish Motor Neurone Disease Association (IMNDA) is here to help once you or someone you know has been diagnosed with MND. We are dedicated to working on behalf of and supporting people living with MND, their families and caregivers.

MND is a life-changing illness, and we are here every step of the way to help you and your loved ones navigate any difficulties MND may present.

This booklet provides a simple introduction to MND. It explains in brief:

- MND and who it affects
- How MND is diagnosed and symptoms
- Causes of MND
- Support available
- How to manage a diagnosis of MND
- Where to get further information and support

2. What is Motor Neurone Disease (MND)?

Motor Neurone Disease (MND) was first identified in the 1850's by French Neurologists.

In 1874 Physician, J M Charcot called it Amyotrophic Lateral Sclerosis (ALS) the common name by which it is referred to in the USA. Despite extensive research, the cause remains unknown.

Motor Neurone Disease (MND) is a progressive neurological condition that attacks the motor neurones, or nerves, in the brain and spinal cord. This means messages gradually stop reaching the muscles, which leads to weakness and wasting.

MND can affect how you walk, talk, eat, drink and breathe. Some people may also experience changes to their thinking and behaviour. 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.

MND affects people of all ages and currently there is no cure, however symptoms can be managed to help the person achieve the best possible quality of life. There are many research projects underway to find the cause of MND.

3. Who gets MND?

The cause of MND is unknown. It is a rare disease that generally affects adults. Most people with MND are aged 50 years or older but occasionally it affects people under 50. More men than women are diagnosed with MND in Ireland. Approximately 155 people are diagnosed with MND each year and there are about 470 people living with the disease in Ireland.

4. How is it Diagnosed?

I became more and more convinced I was developing some sort of problem. Almost a year after the first signs I began falling over my feet and enough was enough. When I was told, after two days of tests, that it was probable I had MND, the news came as something of a relief.

Some of the early signs of MND may be difficult to identify because many other conditions start in a similar way. Your GP will have referred you to a consultant neurologist who will carry out various tests to eliminate other possible causes of your symptoms. As there is no specific test for MND, your consultant may well have waited to see how your condition progressed before giving you the diagnosis. This can be a frustrating and draining time for everyone concerned.



MND can be difficult to diagnose for several reasons:

- It is not a common disease
- The early symptoms may be quite mild such as clumsiness, weakness in the legs or slurred speech. It may be some time before someone even considers reporting the changes to their GP
- In the early stages, many of the symptoms are like those of other, more common, medical problems that will need to be eliminated
- The nature of the disease is that it affects different people in different ways. There are many symptoms that indicate a diagnosis of MND
- MND is a serious disease that has many implications, a definite diagnosis is needed to confirm MND

Tests to diagnose MND

- Blood Tests
- Lumbar puncture - a lumbar puncture (also called a spinal tap) is a procedure to collect and look at the fluid (cerebrospinal fluid, or CSF) surrounding the brain and spinal cord
- Electromyography (EMG) - is sometimes called the needle test, as fine needles record the natural nerve impulses within certain muscles. When muscles start to lose their nerve supply, this can be detected, even if the muscle activity still seems normal
- MRI scan (Magnetic Resonance Imaging scan)

Your Diagnosis

How individuals react to the diagnosis of MND varies greatly from person to person. For some, the fact that there is a clear cause of their symptoms comes as a relief; for others, it can come as a shock. You will receive a lot of information which can be hard to take in all at once. Don't be afraid to ask questions, we are here for you from the moment you are diagnosed. When someone is diagnosed with MND they may want to learn as much as they can about it. We recommend always consulting a reliable source, like your IMNDA nurse or our website www.imnda.ie. We can also provide information to other Healthcare Professionals.

Are there different types of MND?

There are different types of MND, and it affects people in different ways. Please check with your consultant for further details on your type of MND and how it might impact you. For more detail, please see the About MND section of our website www.imnda.ie.

Prognosis

It is not possible to give an exact timeline for how long someone will live with their type of MND. This can be very upsetting and will need support from your MND nurse and wider health care team.

5. What causes MND?

Generally, MND is believed to be caused because of a combination of environmental, lifestyle and genetic factors. Most cases of MND develop without an obvious cause.

A combination of these factors may contribute to the development of MND. This is called “sporadic MND” because the disease appears for no apparent reason. Up to 85 % of MND is sporadic. 15% of MND cases are thought to be genetic, this is often referred to as ‘familial MND’. This means there may be a gene in the family that may make a person more prone to MND compared to someone with no family history of MND. This does not mean a person will get MND.



6. What are the Symptoms of MND?

MND presents in various ways, depending on the particular groups of muscle fibers which weaken first.

- Wasting and weakness of muscles of the hands, sometimes one side at first
- Weakness or stiffness in the legs, sometimes one side at first
- Dragging one leg or marked weakness in both legs
- Weakness of muscles of the tongue causing difficulty swallowing or coughing
- Slurring of speech

The disease may not cause any changes for some time or may develop quickly affecting the muscles in other limbs, the tongue and breathing muscles.

MND can cause:

- Weakness and loss of movement in your limbs
- Twitching and rippling sensations under your skin
- Muscle tightness and cramping (which may cause pain)
- Problems with breathing and severe tiredness
- Difficulties with speech and swallow

Cognitive (Thinking) Changes

Some people may also experience changes in thinking, reasoning and behaviour, known as cognitive change. These changes are generally mild, however, a small number of people may suffer severe changes in their thinking and reasoning.

Psychological (Emotional) Changes

You may also have unexpected emotional reactions, where you cry when you are happy, or laugh when you are sad. This is called 'emotional lability' and can feel distressing, but your MND nurse and healthcare team can provide support. This does not happen to everyone with MND but can be difficult to come to terms with for you and your family.

“IMNDA has been supporting me for over 8 years. Their help is huge and without it, I probably wouldn't exist. Thank you very much for your great heart and for your patience.”

7. Support Available from IMNDA?

Some people with MND don't ask for help upon diagnosis. Some people feel a sense of despair because there is no cure for MND. However, there are many options to manage the symptoms of MND. The team in the IMNDA are experts in supporting people with MND and their families. We can identify which symptoms can be prevented and which others can be successfully managed. Our services are evidence based to help overcome practical problems and to maintain independence for as long as possible.

IMNDA

IMNDA is here to help once you or someone you know has been diagnosed with MND. We are dedicated to supporting people living with MND, their families and caregivers. We work closely with local service providers to ensure you get the care and support you need. Register with us to access the support available from IMNDA from the moment of diagnosis.

You can register yourself or a healthcare professional or a family member can register on your behalf once your consent is given. Registration is free and details are completely confidential.

To register you can contact the IMNDA on Freefone **1800 403 403**, online on **www.imnda.ie/new-imnda-registration/** or you can send us an email to **services@imnda.ie**.

Once this is completed, one of our IMNDA nurses will contact you within 2 weeks.



IMNDA services are free of charge.

Our key services include:

- Nursing support: our nationwide outreach IMNDA nurses will visit you in your home, link you in with local services and provide the practical, caring, and experienced support for all those living with MND and their families
- Information and support online: we provide the latest most up-to-date information on MND. We also have an online community hub where people can connect and share their experience of life with MND
- Practical support: access to specialised equipment on a loan basis to all all living with MND once recommended by your OT, SLT, PHN, MND Nurse
- Financial support: the IMNDA offers several grants that help with the costs associated with home care, travel to medical appointments and offers a recharge grant for families in need of a break. More on these grants are available on our website or through your IMNDA nurse
- Psychological support: as requested by your IMNDA Nurse, counselling sessions with the professional of your choice for you and your loved ones
- Everybody's requirements vary but we are here regardless of when and how we are needed.



This battle is tough, but we could not imagine going through it without the IMNDA. For anybody reading this that is feeling a bit lost or helpless, pick up the phone and call the IMNDA for help and they will either provide it for you or guide you in the right direction.

IMNDA Nursing Service

The IMNDA nurses, work alongside the MND consultant Neurologists throughout the country. They attend MND clinics, and travel nationwide providing nursing support to people and their families who have been diagnosed with MND. The nurses are experts in the area of MND and supporting people living with the disease. They also work closely with health care professionals in the community. Once you are registered with IMNDA one of the nurses will make contact with you.

IMNDA Nursing Service focuses on enhancing quality of life and includes the management of distressing symptoms and provision of support and care throughout the journey of MND.

Equipment Loan Service

The IMNDA provide a range of specialised pieces of equipment on loan to all those who are registered with us, when the equipment is not available through the HSE or will take too long to get from the HSE. The equipment includes but is not limited to: wheelchairs (powered and manual), hoists, riser recliners chairs, shower chairs, profiling beds (single & double), communication aids and environmental controls.

We can only accept requests for equipment from the relevant health care professional.

Home Care Grant

IMNDA can provide funding towards home care. This payment is designed to act as a top up to HSE funded home care hours, when the HSE hours are not sufficient to provide the level of care that is required for the person living with MND. This service must be approved by one of our IMNDA nurses.

Psychological Support

A diagnosis of MND can lead to stress for you and your family. IMNDA provide funding for counselling with the professional of your choice for you and your loved ones, to help alleviate any fears or anxieties which may be experienced upon diagnosis. For more information, speak with your MND nurse.

Caregiver programme

This recurring online programme was set up in response to a survey where we looked at the needs of our MND caregivers. Funded by the Charlie Bird Development Fund, the programme is designed for family caregivers who are looking after a person living with MND. These sessions are facilitated by a psychotherapist, and cover a variety of areas including trauma and anxiety, relationships, conflict and the process of change among others. More information is available on the IMNDA website.

Support group for People with MND

In 2025, we launched our peer support groups for people living with MND. These provide a fantastic opportunity to meet with other people who are going through a similar journey but also meet healthcare specialists. Following a great response to our first group session, we will introduce more of these over the coming months. Keep an eye on our website to register your interest.

8. Is there a cure or treatment for MND?

As yet, there is no specific treatment that will stop the progression of the disease. However, there is a lot that can be done for symptom management of the disease. There have been some promising lines of research and one drug in particular, Riluzole (Rilutek™), has been shown to have a modest benefit.

9. Living with MND

Coping with a diagnosis of MND

You are likely to experience a wide range of emotions when diagnosed with MND. Shock, anger, sadness, sorrow, denial, guilt and anxiety are all very normal feelings. Recognising these feelings will help you to cope better and feel more in control of your illness.

Normal reactions to a diagnosis of MND

- Shock
- Fear for the future
- Disbelief at the diagnosis
- Anxiety for yourself, loved ones and friends
- Grief for the future you expected to have
- Anger at the medical profession or family and friends
- Isolation because you feel 'different' from those around you
- Intense sadness
- Relief that you finally know what is happening to you
- Denial

Feeling very up and down, as if you are on a roller-coaster ride, does not mean you are not coping. Understanding your feelings and emotions can help you learn to cope better. You may also feel more in control of your illness. It can take time to come to terms with your emotions, but most people learn to cope.

Taking a Positive Approach

Living with MND means continuous change and personal challenge. Accepting the fact that you have a serious disabling illness that is not yet curable does not mean giving up and doing nothing. Rather, it means continuing to do as much as you can and channelling your time and energy into maintaining the best quality of life and independence.

The physical effects of MND vary from one person to another, as does the rate of progression. There will be times when you feel frustrated if you can't do all the things you used to but it does help to keep as normal a lifestyle as possible. Its important that everyone in the family keeps their separate roles, even if everyday jobs need to be shared out differently.

Feelings and Concerns

It can sometimes be difficult to talk openly to those you are closest to without feeling you are worrying them. You may find it helps to talk through any feelings or worries with someone outside the immediate family, like your MND nurse, GP, social worker or a professional counsellor.

They are present in that moment of need, have empathy and understanding of the impact of MND. Good with information and signposting to relevant services. Readiness to help eg Equipment, advice through the helpline, accessibility.

Emotions

You might laugh and/or cry a lot more, or what seems like the wrong time and you are unable to control it. This may be due to how you are feeling but commonly it is because a part of your brain that is affected by the disease is causing this to happen. This may seem embarrassing to you and disturbing to others but be reassured that this is a symptom of MND. Talk to your MND nurse or doctor to discuss medication to help with these symptoms.

Sharing the Diagnosis with Others

Almost certainly, you will have undergone a variety of tests before the diagnosis is made. You may have involved those closest to you in every stage, or it may simply not have been possible for someone to be with you at every doctor's appointment or hospital visit. Either way, those closest to you will be concerned and it is important that at some point they know what is going on.

It can be very helpful to make an appointment to see your consultant neurologist together so that your partner, close friends or family can ask their own questions and settle their own concerns as well as sharing the experience with you.

It does not follow that, just because someone is close to you, that they will experience the same feelings as you at the same time. It may be that you are feeling anxious and distressed; your loved one is not and vice versa. Open, honest communication is vital to avoid possible friction or misunderstanding. Never make assumptions about how others are feeling.

Advice for Friends & Family

While feelings of anger, disbelief and anxiety are normal for someone diagnosed with MND, they are equally normal reactions for those closest to them. Family and friends may feel guilty because they have reacted negatively or because someone they love and care about has been diagnosed instead of them. At the same time, they are trying to offer as much support and understanding as they can.

It may be that the person with MND is rejecting any attempt at support – their anger may be directed at family and friends. It may feel as though any help that is being offered is simply not enough. Equally, they may feel some level of resentment that their lives and expectations have changed also.

It is important that friends, family and caregivers:

- Accept their own reaction as normal and that they too need to find a source of support and help, whether from professionals or friends
- Try not to over-react to any anger or frustration that may seem directed at them
- Know that any negative reactions from someone diagnosed with MND are usually temporary. Though there may be periods in the months and years ahead when these negative feelings may overwhelm them again, these are normal, natural and understandable and usually transient.

10. Where do I get more information

To find out more talk to your MND Nurse. On our website we have a lot of very useful information so please visit www.imnda.ie

To register with IMNDA please Freephone **1800 403 403** or register www.imnda.ie/register



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