Irish
Motor
Neurone
Disease
Association

AN INTRODUCTION TO MOTOR NEURONE DISEASE (MND)

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1. INTRODUCTION

If you or someone in your family has recently been diagnosed with Motor Neurone Disease (MND) it is likely that you are experiencing many confusing and conflicting emotions. Good quality information and support from people who understand MND is vital at this time. The MND community is extensive, committed and immensely supportive.

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

- The disease and who it affects
- How MND is diagnosed and likely symptoms
- What is known about the causes of MND
- The type of support that is available
- How to manage a diagnosis
- Where to get further information

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 strikes 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. The drug Riluzole (Rilutek) has shown to be helpful in slowing down the progress of the disease.

3. WHO GETS MND?

MND is a rare disease that generally affects adults. Most people with MND are aged 50 years or older but occasionally people in their 20s, 30s and 40's develop MND. In Ireland approximately 155 people are diagnosed with MND each year and there are about 400 people living with the disease.

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 have used 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 particularly 'common' disease
- The early symptoms may be quite slight, such as clumsiness, weakness in the legs or mildly slurred speech. Indeed, it may be some time before someone even considers the changes worthy of visiting their GP
- In the early stages, many of the symptoms are similar to 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. In other words, there are no clear cut definitive symptoms that immediately indicate diagnosis
- MND is a serious disease that has many implications, so the consultant needs to be certain of diagnosis

Likely Tests:

- 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
- Electomyography (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

How individuals react to the final diagnosis 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.

Getting More Information

Whatever your reaction, the moment of diagnosis does tend to shock people with the result that they find it difficult to take on board all the other information immediately. So don't be afraid to ask questions every time you see your doctor. As MND is fairly uncommon, your GP may not have much experience of helping someone who has been diagnosed. The Irish Motor Neurone Disease Association (IMNDA) can provide GPs and other Healthcare Professionals with as much information as required.

Almost certainly, anyone diagnosed with MND will want to find out more about it - whether from professionals, the library or the internet. It is vital, however, that wherever someone goes for this information, it is a reliable source. The internet, particularly, can be the source of much unreliable and unprofessional information that could only serve to either increase anxiety or give unfounded hopes of a 'cure'.

One of the key things a lot of people want to know – how and at what rate the disease will progress – is something that is almost impossible to answer. Life expectancy can vary greatly depending on what form of MND is diagnosed. For more information on life expectancy please talk to your consultant, our Services team on **services@imnda.ie** or see our website **www.imnda.ie**

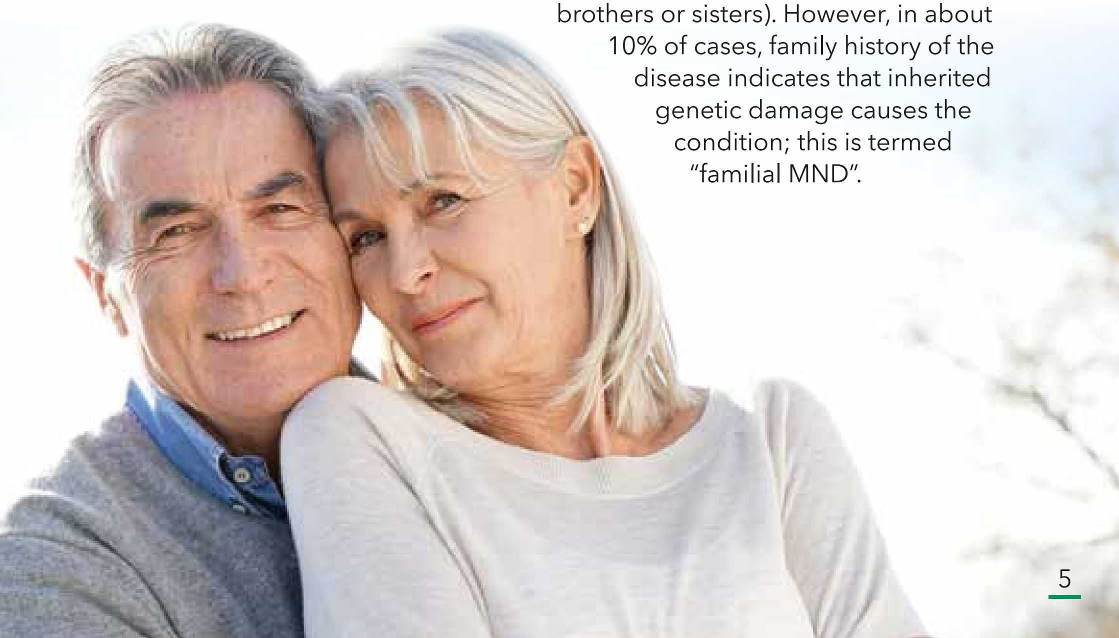
Are there different types of MND?

There are different types of MND, each affecting people in different ways. There can be a great deal of overlap between all of these forms, so, while it is useful to separate the various types of the disease, in practise it is not always possible to be so specific. Please check with your consultant for further details on your form of MND and how it might impact on you. For more detail, please see the About MND section of our website.

5. WHAT CAUSES MND?

Many theories have been proposed – viral infection, environmental poisons, metabolic disturbance and genetic defects. While the cause or causes remain unknown, it is quite possible that some combination of the factors above may jointly contribute to the development of MND. This is called "sporadic MND", because the disease appears for no apparent reason.

In the vast majority of cases of MND, there is no history of the disease in any of the immediate family members (grandparents, parents, brothers or sisters). However, in about 10% of cases, family history of the disease indicates that inherited genetic damage causes the condition; this is termed "familial MND".



6. WHAT ARE THE SYMPTOMS OF MND?

MND presents itself in various ways, depending on the particular groups of muscle fibres which degenerate initially. Wasting and weakness of muscles of the hands, sometimes one side at first, stiffness in the legs with dragging of one leg or the development of marked weakness in the legs may be the initial symptom. Sometimes the muscles of the tongue and swallowing mechanism are affected early, with slurring of speech, difficulty in swallowing and coughing.

The disease may remain relatively stationary for some time or may progress to other limbs, to the tongue and to the breathing muscles.

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 pain)
- Problems with breathing and extreme tiredness
- Difficulties with speech and swallow

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

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 healthcare team can provide support. This does not happen to everyone with MND.

MND does not usually affect:

- The senses – sight, hearing, smell, touch or taste
- The bladder and bowel
- Sexual function

7. WHAT HELP IS AVAILABLE?

Some people with MND hesitate to seek or accept help and advice, asking 'what's the point' if the condition cannot be cured – but much can be done to overcome and manage the symptoms experienced. A range of healthcare professionals are employed by the HSE as well as MND Nurses employed by the IMNDA. These people are available to help people with MND and their families to live with the condition. Also some symptoms can be prevented and others successfully managed. A great deal can be done to overcome practical problems and to maintain independence for as long as possible.

It may be beneficial to talk through feelings and anxieties with someone outside your immediate family perhaps a close friend, understanding relative, counsellor or your GP.

The IMNDA

The 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 carers. Whether yourself or someone you know has been diagnosed with MND our information services can make a real difference in how you cope going forward. We work closely with local service providers to ensure you get the care and support you need.

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**. We will ask for a small amount of detail for our registration form which will include: contact details, date and place of diagnosis and symptoms.

Once this is completed, one of our MND nurses will aim to contact you within 2 weeks unless you request no contact.

When you register with the IMNDA you can automatically avail of the below services free of charge:

- Access to 4 MND Nurses directly employed by the association
- Access to specialised equipment on a loan basis to all clients once recommended by your OT, SLT, PHN, MND Nurse
- Access to a home care grant once recommended by the MND Nurse and where a HSE home care package is already in place
- Counselling sessions for the person with MND and one other member of their family

The IMNDA Nursing Service

Louise, Eithne, Katie and Fidelma are the IMNDA nurses, who work alongside the IMNDA and consultant Neurologists throughout the country. As well as attending MND clinics, the nurses travel nationwide providing nursing support to people who have been diagnosed with MND. They provide support to their families and carers by means of home visits, a help line and on-line contact. All 4 nurses have a vast level of experience working within the field of neurology and all 4 previously worked together on a neurological ward in Beaumont hospital.

Being nurses that specialise in Motor Neurone Disease means that they play an active role in both patient and health care professional education to ensure the highest level of patient care is being delivered at all times.

The nursing service is active in its total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the person living with MND and support for the family and includes the management of distressing symptoms and provision of support and care throughout the journey of MND.

The MND nurses are central to the person living with MND and their family. They also act as a link between services and health care professionals. They endeavour to co-ordinate a service that provides continuity of care for those living with MND in collaboration with local health care professionals and carers, especially those with specific palliative care needs. The role applies to acute and community care settings. The nurses act as an informed resource for health and social care professionals, involved in the care of the people living with MND.

The nurses have designated areas to ensure a continuity of care and equitable service throughout the country.

The Multi-Disciplinary Team (MDT)

The IMNDA Services Team and Nursing Staff work very closely with Multi-Disciplinary Teams across the country. The Multi-Disciplinary Team (MDT) comprises of a group of clinical professionals who work in a hospital and community setting. The IMNDA links in with these healthcare professionals but they are not employed by us.

They include; Neurologist, Occupational Therapist (OT), Public Health Nurse (PHN), Social Worker, Physiotherapist, Speech & Language Therapist (SLT) Dietician, Counsellor and GP. They work as an integrated unit and their aim is to provide flexible and accessible care for people with MND, their families and carers. The type of multidisciplinary expertise required by people with MND will vary depending on the stage of the illness. They can help with difficulties with everyday things such as personal care, climbing the stairs, mobility support etc.

Counselling

Diagnosis of a fatal illness with a shortened life expectancy can lead to significant stress. Appropriate referral to a qualified counselling service is essential for people with MND and families experiencing such difficulties. Difficulties can arise in relationships between partners, siblings, parents or children.

The IMNDA provides funding for counselling sessions for registered patients. For more information, contact the office on Freefone **1800 403 403** or email **services@imnda.ie**.

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 in the way of symptom management and to slow the progression 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. WHAT NEXT?

Normal Reactions

The diagnosis of MND inevitably means the beginning of a new journey – one that in all likelihood you did not expect to be making but one that, in fact, you have already begun.

'Normal' reactions to learning that you or someone close to you has a serious illness can include:

- Shock
- Fear for the future
- Disbelief at the diagnosis
- Anxiety for 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

Some or all of these feelings may be overwhelming for a while and you need to work through them at your own pace. You may also find that you need to get to the reality of the situation straight in your own mind first before turning to people for support. Others may find it easier to involve friends and family immediately. Gradually, though, most people will begin to 'rethink' and review their life plans.

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.
Although it is difficult not to, there is little to be gained from worrying about the future, and much to be gained from enjoying today.

Clearly 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. Particularly important is to ensure that everyone in the family maintains their individual 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 adding to their emotional burden. You may find it helps to talk through any feelings or worries with someone outside the immediate family. Your GP or a counsellor or an understanding listener could all be useful support. Social workers attached to your hospital are also available to help.

> ***"Through the amazing generosity of the IMNDA I have been able to receive all the aids and appliances that I have required to live a normal life."***

Emotions

You may find that you are laughing and/or crying at what might seem 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 normal. Some people have found that taking certain medication helps with these symptoms so you may want to talk to your GP or Neurologist.

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 or 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 carers:

- 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 or to talk to our Services Team please
Freephone **1800 403 403** or email **services@imnda.ie**
On our website we have a lot of very useful information
so please visit **www.imnda.ie**

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