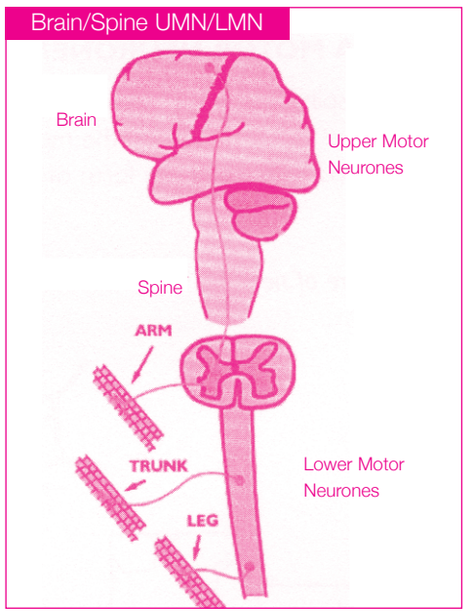
The topics covered in this section are:

- The different names for MND
- Who gets MND?
- Causes of MND
- Treatments available
- The effects of MND



The different names for MND

In the USA, MND is referred to as Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig Disease. MND can be sub-divided into different clinical forms although there is considerable overlap between the different types.

"Classical" Spinal Onset MND

- The upper and lower motor neurones of the arms and legs are damaged leading to a combination of weakness and stiffness
- The life expectancy is usually between 3 and 5 years from the first symptom, although there is considerable variability
- This form is slightly more common in men

Bulbar Onset Disease

- The upper and lower motor neurones supplying muscles of speech and swallowing are affected first, leading to difficulties with chewing, swallowing and speech
- Early symptoms are likely to be slurred speech and difficulty with fluids
- The life expectancy of bulbar onset disease is slightly lower than for spinal onset disease, although there is considerable variability

Pure Lower Motor Neurone Disease (Progressive Muscular Atrophy)

- In some instances, only lower motor neurones are affected. This leads to weakness and wasting of muscles, without stiffness
- This form is rare and is more common in men
- The life expectancy of this form is longer than for "classical" MND

Pure Upper Motor Neurone Disease (Primary Lateral Sclerosis)

- The form affects only upper motor neurones. Onset is with stiffness in the legs, with progression to involve the arms, and speech and swallowing
- Diagnosis is difficult, and requires observation for at least 3 years
- The life expectancy is 10-15 years

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Sporadic and Familial MND

- **Sporadic MND:** This accounts for 90-95% of all cases. Sporadic MND is the term used for cases of the disease where there is no family history. If you are not aware of anyone else in your family who has MND the chances are it is sporadic
- **Familial MND:** This accounts for just 5-10% of cases. Familial MND is the term used when more than one member of a family has been diagnosed with the disease. This may be within the same generation or passed from one generation to some members of the next. There is little difference between the symptoms and course of this disease and Sporadic MND

Who gets MND?

MND is not infectious or contagious. In the vast majority of cases the disease can affect anyone at any age. More specifically:

- The majority of people with MND are over the age of 40, with the highest incidence occurring between the ages of 50 and 70
- Men are affected slightly more often than women

How many people are affected

There is no strong evidence that the incidence of MND is increasing. The frequency of MND in Ireland has been studied in detail over 15 years and comparisons have been made with other countries and populations. The following is known:

- Between 80 and 85 people are diagnosed with MND in Ireland every year
- Approximately 250 people are living with MND in Ireland at any one time
- A similar incidence of MND occurs in other populations of European origin
- The incidence of MND seems to be lower in non-European or mixed populations

Causes of MND

The precise cause of MND is not yet known. There has been an acceleration of world-wide research into the disease and advances are being made in understanding both the disease itself and the way motor neurones function.

Possible causes

- In the familial form of MND, a number of different gene mutations have been identified
- Excitotoxicity - whereby excess glutamate (a single amino acid) becomes overactive in key areas of the brain and spinal cord and may cause nerve damage
- Excess Oxidation - whereby the oxygen free radicals produced by our energy cells overproduce or are not “mopped up” effectively. Both motor neurones and muscle cells have a high energy requirement
- Deficient neuronal blood supply - a relatively new theory looking at subtle changes in blood supply causing damage to nerves
- Deficiencies in the “machinery” of motor neurones, including proteins that transport vital cargo along the nerve fibres

The IMNDA funds research projects in many different fields as well as initiatives to improve the care and comfort of people with MND.

International Symposium

The International Symposium, organised by the International Alliance of ALS/MND on an annual basis has become a major forum for the presentation of new research into the condition. Its aim is to provide an opportunity for researchers and practitioners from all over the world to share information on current progress in the research and management of MND, in order to achieve greater understanding and stimulate improvement in the quality of life for people living with the disease.
Information about each Symposium is available from the IMNDA.

World Federation of Neurology Research Group on MND

The WFN RG is comprised of the international scientific community of researchers in MND. The Journal Amyotrophic Lateral Sclerosis, is the official organ of the WFN Research Group, and publishes scholarly articles on MND.

Treatments available

Riluzole

Riluzole (Rilutek™) is the only drug to be licensed for the treatment of MND. Riluzole is not a cure but it is the first medicine to show a modest impact on survival for people with MND.

Riluzole – the facts

- Riluzole is an anti-glutamate agent
- Riluzole inhibits the amount of glutamate released into the synapse
- Trial results indicate that survival is increased by 3-6 months for those taking Riluzole as compared to those on a placebo
- Riluzole is taken in tablet form twice a day

Many other drug therapies are under investigation in the laboratory and a number of clinical trials are underway around the world.
To date no other effective therapy has been identified although many new compounds are being identified in the laboratory.

Complementary therapies

Many people living with MND find that using complementary therapies can help make them more comfortable and reduce stress, although none affect life expectancy.
The most popular therapies are acupuncture, massage, aromatherapy and reflexology.

While some people do report an increase in well-being and comfort, it is very important to recognise that such therapies are not a treatment or cure.

Equally important is to get medical advice before embarking on any 'alternative' or 'complementary' therapy and only to use those therapists who have been recommended by a trustworthy source. Some health centres, GPs and hospices have a list of therapists they are happy to recommend.

- **Acupuncture –** where needles are inserted into key parts of the body. It is said to help the body, mind and spirit to heal itself. Acupuncture is now used regularly alongside conventional medicine. Ensure that a practitioner is fully aware of your condition and preferably that they are members of the Acupuncture Council of Ireland
- **Massage –** is one of the most popular therapies for people with MND. For many, the benefits can be considerable, including feelings of deep relaxation; improved muscle tone and circulation; improved digestion; the release of tensions and renewed energy
- **Aromatherapy –** is used to reduce stress, aid relaxation and relieve anxiety. It is important to ensure that the practitioner is well qualified and personally recommended
- **Reflexology –** is used to help with numerous disorders, including digestive and circulatory problems, back pain, tension and stress. Treatment generally takes the form of massaging the reflex areas of the feet, each of which corresponds to a particular part of the body

The effects of MND

"I think a lot about living and not about dying. I may not be around a year from now but that is the case for a lot of people. Why spend time worrying about the worst scenario."

Progression of the disease

Most people measure the progression of the disease in terms of the difficulties they experience in doing everyday things. Everyone's experience is different but, realistically, once a diagnosis has been made, there is no doubt that the disease will steadily progress.

So how will it be for you?

The truth is no-one can say but some of the difficulties you are likely to experience are:

- The legs – walking may become more difficult as the legs weaken
- The arms – as the arms get weaker, it may be increasingly difficult to perform everyday tasks
- The neck – as muscles to the neck become weaker, it becomes increasingly difficult to keep the head upright
- Speech and swallowing – as speech and swallowing muscles become weaker, difficulties may be experienced in speaking and/or eating and drinking
- Breathing – if the respiratory muscles are affected, there may be difficulties with breathing
- Emotions – emotional responses may be affected, leading to someone laughing or crying involuntarily. It is important to remember though, that this has a physical rather than mental cause

Remember, help is available with all of these symptoms.

What is not affected

"I may have a few mechanical problems but I feel so well. I can hear distinctly, see sharply, think clearly, and my libido is not a thing of the past."

- In the vast majority of cases, MND does not affect the core **senses** of touch, taste, sight, smell and hearing. MND does not directly affect **bowel** functions, although immobility and changes to diet in later stages may lead to changes in bowel movement
- **Bladder** function can be affected later in the condition but symptoms can be controlled with medication
- In most cases, **sexual** function is unaffected until the later stages of the disease
- **Eye** muscles are generally not affected
- **Heart muscles** are not affected

Unusual features

Cognitive change – there is increasing evidence that MND can lead to mild changes in thinking, ability to concentrate and planning in up to 50% of those affected. In some cases, these changes can progress to a more severe form, known as Fronto-temporal dementia. This affects up to 10% of people with MND.

Prognosis

As with so many other aspects of MND, it is difficult to be precise about the longer-term prognosis of anyone diagnosed with the disease.

While there have been rare occasions when someone with MND has survived for over 30 years and others have died within months, the average life expectancy is between two and five years. Approximately 40% of those diagnosed live for five years, and between eight and 16% of people live for 10 years.

Research in Ireland

The IMNDA is dedicated to funding and promoting research into the causes, types and treatment of MND in Ireland. There are a variety of research projects that you and your family can become involved in. You can discuss the various projects and decide which project you would like to become involved in with the relevant research team.

Research is carried out at:
The Clinical Research Centre
Beaumont Hospital
Beaumont
Dublin 9
Ireland
Phone: 01 8093874
Fax: 01 809 3809

The MND Register

The Irish Register of MND, (www.mnd.ie), is the point from where all Irish MND Research can evolve. The register includes all known patients diagnosed with MND each year. It dates back to 1994 and it now has clinical information from over 1,400 patients. The register is one of the largest and most complete in the world and was made possible by support from the IMNDA.

The continued success of Irish MND research depends heavily on the constant collaboration of the relevant people. The register must be constantly updated, and it is hoped that the register would, if possible, continue to include everybody in Ireland with MND.

Using the Irish register, and more recently the DNA bank the team at Beaumont Hospital have made a number of significant breakthroughs in MND research, including the discovery of a new gene that might help to find new treatments. This finding was made possible by the support of people in Ireland with MND, their families and their general practitioners.

How you can help with research

If you would like to find out more details about the research clinic or the Irish MND/ALS Register or if you have any questions or concerns with regard to research, please do not hesitate to contact the IMNDA at Freephone 1800 403 403 or 01 873 0422 or email info@imnda.ie

Alternatively you can contact the register directly at 01 809 3874 or clynch@rcsi.ie