

## Multiple Sclerosis & MS Ireland Media Fact Sheet

**This fact sheet gives a summary of the main facts and issues relating to Multiple Sclerosis and gives an overview of the services offered by MS Ireland. For more detailed information please visit our website [www.ms-society.ie](http://www.ms-society.ie)**

MS is one of the most prevalent diseases of the central nervous system and directly affects an estimated 2.5 million people worldwide including approximately 8,000 people in Ireland. It is the most common disabling neurological disorder amongst young people but it can occur at any age.

### Stats and facts

- ▶ Approximately, 250 people are diagnosed with MS every year in Ireland. In the North West the prevalence rate for MS can be as high as 1 in 400.
- ▶ Women develop MS more frequently than men, Caucasians develop MS more frequently than non-Caucasians, and people living further from the equator are more likely to develop MS.
- ▶ MS does not significantly reduce life expectancy, but quality of life can be affected greatly.
- ▶ Most people are diagnosed between the ages of 20 and 40, when most are planning families and careers.
- ▶ **Ireland:** 20 Neurologists **Northern Ireland:** 30 Neurologists **Czech Republic:** 335 Neurologists
- ▶ It is estimated that over 50% of those diagnosed with MS are unemployed

Multiple Sclerosis can be a very disabling condition although many people experience mild disability or none at all. Living as comfortably and healthily as possible can be managed through adequate medical, social and emotional support from family, friends and health professionals.

### What is MS?

Multiple Sclerosis is a disease of the brain and spinal cord (central nervous system). The central nervous system acts like a switchboard sending electrical messages along the nerves to various parts of the body. Most healthy fibres are insulated by Myelin, a fatty substance which aids the flow of messages. In MS, the myelin breaks down or becomes scarred. This distorts or even blocks the flow of messages. It is like a damaged electrical cable where the flex is broken and the wires are exposed.

### What causes MS?

There is no known cause of MS but it is generally held that it is a combination of factors such as genetics, environment and your immune system. MS is not hereditary but the risk factors are increased if a family member has MS.

### What are the Symptoms?

There is no set pattern to MS and everyone affected by it has a different set of symptoms that vary from time to time and can change in severity and duration.

Common symptoms include:

- ▶ Visual disturbances including blurring of vision/double vision
- ▶ Lack of co-ordination and mobility

- ▶ Altered feelings in arms or legs such as tingling/pins and needles, numbness
- ▶ Speech problems such as slurring words
- ▶ Fatigue which is unpredicted or out of proportion to what you have done
- ▶ Cognitive difficulties such as loss of concentration and/or short term memory
- ▶ Bladder and bowel dysfunction

## **How is MS diagnosed?**

MS is very difficult to diagnose as there is no one test; neurologists usually have to eliminate other conditions and diseases first. Also symptoms of MS are most often intermittent and appear and disappear over long periods of time. Many people with MS would usually experience seemingly unconnected symptoms for months of most often years before a diagnosis is confirmed. A medical history, MRI scans and lumbar punctures are common tests used to gradually diagnosis MS.

## **Types of MS.**

There are 4 main types of Multiple Sclerosis, each characterized differently:

***Relapsing – Remitting:*** This is the most common type of MS. It is characterized by attacks (relapses) and remissions (recovery). During remissions a person would have fewer or no symptoms. Relapses tend to be unpredictable and their causes are unclear. During a relapse new symptoms may occur or previous symptoms may return. A relapse is usually defined as the appearance of new symptoms lasting more than 48 hours. They can last any length of time. In 85 % of people with MS, it starts with a relapsing – remitting phase.

***Primary Progressive:*** Some people with MS never have distinct relapses and remissions. From the start they experience steadily worsening symptoms and progressive disability. This may level off at any time, or may continue to get worse. Around 15% of people with MS have the primary progressive form of the disease, which is also known chronic progressive.

***Secondary Progressive:*** This type starts in the same way as relapsing – remitting MS but after repeated attacks the remissions stop and the MS moves into what is known as a progressive phase. Around 40% of people develop secondary progressive MS. The time it takes to move into the secondary progressive phase varies. It usually happens within 15 to 20 years of the first onset of MS.

***Benign MS:*** This type of MS generally starts with mild attacks followed by a recovery. It does not worsen over time and there is rarely permanent disability. The first symptoms are usually sensory. It is only possible to classify people as having benign MS when they have little or no sign of disability 10 to 15 years after the onset of the disease. However, occasionally disability may develop even after many years of the disease remaining inactive. Around 15 - 20 per cent of people with MS have the benign form.

## **What treatments are available?**

As there is no cure for MS, medicinal treatments usually fall into 3 categories:

- Drugs that help to relieve specific symptoms such as pain, spasms etc
- Drugs that ease relapses – usually steroids

- Drugs that modify the course of the disease in some way. Standard drugs include Copaxone, Rebif, Avonex and Betaferon. Tysabri is also a new treatment in this category.

Many people with MS use various types of complementary therapies to help with symptom relief and increase a greater sense of well-being. As with many diseases and conditions there are a number of treatments and interventions that even though people have reported benefits, there is little scientific proof.

### **What is it like Living with MS?**

The time surrounding diagnosis can be a very emotional period. Prior to diagnosis there can be a lot of frustration due to unexplainable symptoms. Once a diagnosis is confirmed there can be so many mixed feelings; anger, shock, relief, loss. MS, as an incurable, often progressive disease, can change the course of a person's life and around the time of diagnosis the person and family have much to come to terms with.

MS can affect many aspects of a person life, particularly if the disease becomes more progressed. Maintaining health and well being can be a challenge as symptoms are unpredictable and the progression of the disease varies. Social aspects like employment and transport can be affected due to increased disability. Financial problems may also be experienced due the high cost of medications, adaptations and loss of earnings.

MS is unique to each individual person. The presence, severity and duration of symptoms can vary drastically from person to person. For this reason, there is no typical way to cope with MS. There are no generic steps to take to help day to day living. Understanding how MS affects your mind and body, availing of services and resources and building a supportive environment are all elements a person needs to consider when developing coping mechanisms for living with MS.

Living from day-to-day with MS is a combination of many things. Medically, it is about working with health professional to find suitable treatments and interventions that can keep you healthy. Socially, it is about finding ways to maintain participation in society through your home life, work, leisure pursuits and community activity. Emotionally, it is about finding ways to cope with challenges and maintain good mental health.

### **MS the Issues:**

As a complex neurological condition MS can present a number of health, social and welfare related challenges. MS Ireland, as a representative organisation, has prioritised 7 issues that we feel, if addressed adequately, would make the most difference for people and families living with MS.

1. An increase in the number of **Neurologists and associated multi-disciplinary teams** to be brought to the recommended EU level of 39, within a 3 year timeframe
2. The provision of the required staff and facilities for the delivery of **approved treatments** on an equitable basis throughout the country
3. The introduction of a **Cost of Disability payment** of €40 per week for all people with MS
4. A significant increase in the **Disabled Persons Housing Grant** and a higher mean test

threshold

5. The issuing of a **Medical Card** to every person diagnosed with MS
6. The assurance that the necessary **physiotherapy services** are made available to people with MS on an equitable basis throughout the country
7. A review of the current criteria for **drivers tax concessions**, so that anyone diagnosed with Multiple Sclerosis automatically becomes eligible for these rebates.
8. To provide additional **personal assistants** who can assist family carers to provide adequate care for people with MS.

## **Multiple Sclerosis Ireland**

Mission Statement:

'...to enable and empower those affected by MS  
to live the life of their choice to their fullest potential...'

MS Ireland is the only national organisation working solely on behalf of people living with Multiple Sclerosis and the many thousands of people who share their lives. MS Ireland offers professional services to people with MS, their families and carers.

The Society provides a wide range of services and programmes designed specifically to meet the needs of the MS community.

### **Individual and Family Support**

Through our case work service our teams of professional Regional Community Workers support the person with MS through the transitional changes that MS, as a disease, presents. Support is also available to the family members in dealing with the challenges they may face as a family unit.

### **Living with MS programmes**

A range of living with MS programmes, workshops and activities are organised throughout the country that are targeted at various groups such as those newly diagnosed, carers, children of parents with MS and health professionals. Programmes include symptom management, information/education seminars and a range of therapeutic interventions.

Getting The Balance Right is one of our main programmes, providing physiotherapy and exercise programmes to people with MS. All levels of mobility are catered for and people can expect to take part in a number of group or individual activities such as yoga or physiotherapy.

### **Confidential Information Line, 1850 233 233**

The MS Information Line provides people with Multiple Sclerosis, their families, friends and colleague's information and support on all aspects of living with the condition. The Helpline is staffed by a team of trained professionals who are on hand to talk, or more importantly, listen to anyone concerned about or with MS. The information Line is open Monday to Friday, 10am–2pm.

### **MS Care Centre**

The centre offers short-term respite care for people with MS and also provides an opportunity for residents to access a multidisciplinary team assessment. The Occupational Therapist, the Physiotherapist and the MS nurses can explore issues relating to symptoms, treatments etc and provide guidance on appropriate management at home and in the community.

#### **41 Voluntary Branches, nationwide**

Our voluntary Branches are a support network for people and families living with MS in local communities. The services of the Branch differ depending on the needs of the MS community; however common services include social events, therapeutic sessions, self help groups and befriending visits. Branches also fundraise extensively in fund their welfare service, which offers financial assistance to members.

#### **Professional counselling**

Our team of independent, professional Counsellors assist those diagnosed with MS to come to terms with the changes MS brings into their lives and the lives of their family.

#### **Advocacy and lobbying**

MS Ireland represents the views and needs of the MS community at local, regional and national level. Working with statutory agencies, representative bodies and the government, MS Ireland aims to lessen the challenges faced when living with MS. Our Regional Community Workers also advocate in behalf of clients to ensure their needs are being met.

#### **Publications and Fact Sheets**

MS Ireland produces a number of publications and fact sheets exploring many facets of MS. From understanding MS as a condition to coping with various symptoms, our publications are available in hard copy or online on our website.

#### **MSnews magazine and e-newsletter**

Our MSnews has a readership of nearly 10,000 and it is a useful to keep up-to-date with new developments in MS and MS Ireland. Our eNews is an electronic newsletter delivered directly to your email with news and events from all around the world.

#### **Website [www.ms-society.ie](http://www.ms-society.ie)**

Over 900 people a day visit our website, which provides lots of information about MS, our services, resources and events taking place all around the country.

#### **Information and research**

Each year MS Ireland funds medical and/or social research into various facets of MS. We also work in partnership with other organisations. Updates and reports are disseminated through our various communication tools. MS Ireland information service provides accurate, up-to-date sensitive information on many aspects of MS.

#### **National Conferences**

In addition to regional events, MS Ireland organises various national conferences focusing on certain aspects of MS. Guests speakers, exhibitors and social events make our conferences informative and relaxed events.

#### **For more information about MS or MS Ireland contact:**

**MS Ireland, 80 Northumberland Rd, Dublin 4**

**Tel: 01 678 1600 Fax: 01 678 1601**

**Help Line: 1850 233 233**

**[www.ms-society.ie](http://www.ms-society.ie)**

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