

# CONTENTS

3	INTRODUCTION		
4	WHAT IS MS?		
5	Who develops MS?		
5	What causes MS?		
6	Types of MS		
9	Diagnosing MS		
10	Symptoms		
13	AD ILICTING TO MC		
	ADJUSTING TO MS		
14	Telling people		
17	TREATMENTS AND INTERVENTIONS		
17	Medical treatments and interventions		
19	Non-medical treatments and interventions		
21	Emerging therapies		
23	LIVING WITH MS		
23	A healthy lifestyle		
25	Life events		
29	HELP AND SUPPORT		
29	Health care team		
29	Multiple Sclerosis Ireland		
32	Benefits and Entitlements		
34	Helpful Organisations		

# INTRODUCTION

If you are reading this booklet you have probably been recently told you have Multiple Sclerosis (MS). You may be experiencing a range of emotions; shock, anger, denial or relief, to name a few. You possibly have lots of questions.

This booklet is aimed at those newly diagnosed, clearly explaining what MS is, how you may experience it, treatments and interventions, aspects of living with MS and sources of help and support available. We have also included contributions and insights from people living with MS. Each person's journey with MS is unique. Symptoms differ from person to person and everyone has their own personal coping strategies and support systems. Therefore when reading information or listening to others with MS remember that your experience of MS may be very different.

We hope this booklet answers any questions you may have. We also hope it helps you to come to terms with your MS.

#### If you have further queries about MS we recommend the following resources:

### Our website

#### www.ms-society.ie

We particularly recommend our MS & Me Blog where various people with MS write about their experiences of all facets of MS. We also recommend our range of information booklets and fact sheets which can be found at

www.ms-society.ie/pages/living-with-ms/information-centre

### Our information Line

#### 1850 233 233

Open from 10am - 2pm, Monday to Friday.

### Our local services

Check our website or call (01) 678 1600 for local contact information.

Our trained staff members can visit or meet you or your family to talk through any queries you may have about MS. This one-to-one meeting can occur anytime at a location convenient to you. Our staff can answer your questions, give you information and refer you to other helpful services and resources.

Our regional community workers also organise various Living with MS programmes and activities you can take part in. Newly diagnosed days, symptom management seminars and a whole range of physiotherapy and exercise programmes are just a few that could be available near you.

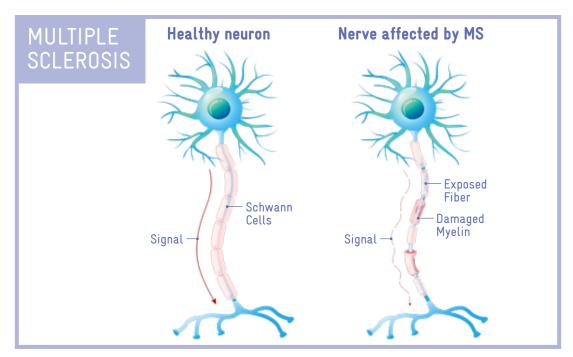
There are many other sources of information about MS. However, not all of them are accurate or helpful. We suggest you visit websites operated by MS societies or well-known organisations to ensure you obtain accurate information. A list of helpful organisations and websites is listed at the back of this booklet.

# WHAT IS MS?

Multiple Sclerosis is a disease affecting the central nervous system (CNS), which consists of the brain and the spinal cord. The CNS controls the motor, sensory and cognitive functioning of the body by processing and transmitting messages through a network of nerves. These nerves are covered by a fatty substance called myelin, which helps to conduct the messages. MS develops when the body's immune system mistakenly attacks this myelin, thinking that it is a foreign substance. This is why MS is often referred to as an autoimmune disease.

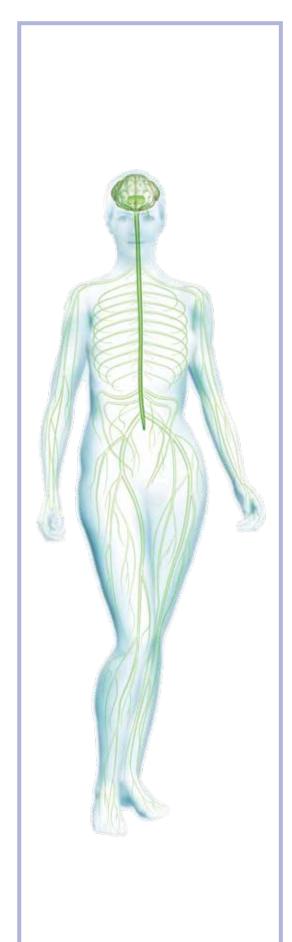
The purpose of our immune system is to protect the body from infection. A variety of cells (macrophages, T-cells, B-cells, and others) work together to destroy the invading cells and the cells it has infected. In normal circumstances the body is able to distinguish between the body's own cells and those that have invaded the immune system. However, in some circumstances the body is unable to recognise one from the other and begins to attack the body's healthy cells. This is what happens in autoimmune disease such as MS.

In MS, when the immune system attacks the nerves it damages or destroys the myelin sheath, causing inflammation in the area of attack. This process is knows as demyelination. It causes the messages being sent by the CNS to slow down or become blocked. While the initial attack may not last long, scar tissue forms over the area. This scar tissue can be viewed as the white spots on an MRI scan, commonly referred to as plaques or lesions.



In many cases, the body is able to repair some of the damage caused by the attack. This process is known as remyelination. However, if the cells that produce myelin are damaged remyelination may not occur. Remyelinated myelin is often not as strong and after repeated attacks remyelination may not occur at all. In addition to repairing damage the body can sometimes find alternative routes to transmit messages, therefore lessening the impact of demyelination. This process is known as plasticity.

The frequency and extent of the attacks differs from person to person and also by the type of MS. Primary progressive MS is associated with much less inflammation or attacks than relapsing-remitting MS, although damage can be greater in the spinal cord area. As attacks differ so do the presence of symptoms as the location of lesions and the extent of the scarring determine the nature of the symptoms associated with MS.



# Who develops MS?

MS is usually diagnosed between the ages of 20 and 40 but can be diagnosed in older age groups and less frequently in younger age groups. More than twice as many women than men have MS and those living in cooler climates are more susceptible to developing MS. Generally, those closer to the equator have a lower risk of developing MS.

MS is not a hereditary disease as there is no one defective gene passed on from parent to child. However, there is a greater risk of developing MS if someone in your family has the disease. Risk factors in Ireland are generally held as follows:

- General population risk is 1:500
- The lifetime risk for women is 1:200 and for men it is 1:400
- The risk of a child of someone with MS developing MS is 1:50
- The risk of a brother/sister of someone with MS developing MS is 1:35
- The risk of second degree relatives (cousins, aunts, nephews etc) is 1:100

This risk is small and the majority of people with MS do not have family members living with MS.

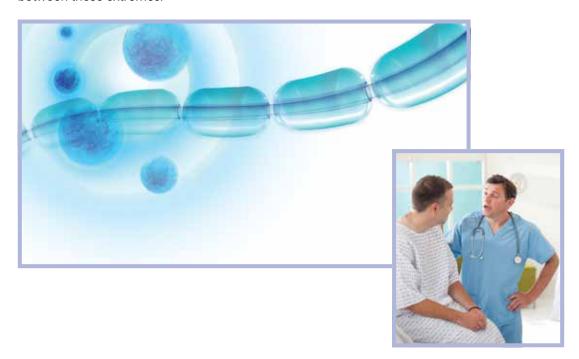
# What causes MS?

The cause of MS is still unknown. Even though MS is most often considered an autoimmune disease, the reason or triggers causing the body to attack itself is still a mystery. Scientists believe there may be a genetic factor involved. Some diseases are caused by a defect in one particular gene, but in MS it is thought that a number of genes are involved. Researchers have identified a number of genes that seem to contribute to a person's risk of developing MS but the identification process is unfortunately slow. Research in this area is ongoing.

External or environmental factors may also contribute to the risk of developing MS. There has been research done to explore if the presence of a particular infection or virus, or a combination of them, may trigger a faulty immune response. Lower levels of vitamin D may also be linked to development of MS as research looks at why people in sunnier climates have a lower risk of developing MS then those living in cooler climates.

# Types of MS

MS is a complicated and unpredictable condition that varies from person to person and does not follow a set pattern. Some people may be only mildly affected throughout their lives while, for others, progression happens more quickly. Most people with MS experience something in between these extremes.



It is important to note that it is not usually possible to diagnose which type of MS you have when you are first diagnosed. This will only become apparent over time when you and your health care team can look at the presence and frequency of relapses and the development of disability.

#### MS is often divided into four different categories:

### 1 Relapsing-remitting

6

Approximately 85% of people are first diagnosed with relapsing-remitting MS. This means they experience a relapse or flare up of symptoms followed by remission (a period of recovery).

A relapse is a significant worsening or a re-occurrence of a symptom, or a group of symptoms, lasting for more than 24 hours in the absence of infection or a change in core body temperature.

Relapses occur when inflammatory cells attack the myelin of specific nerves, interfering with the job the nerve normally does. For example, inflammation of the optic nerve may cause vision problems. Relapses usually occur over a short period of time (hours or days), but can last for anywhere between a few days to many months. The severity of a relapse can also vary from mild to severe.

Remission occurs when the inflammation subsides and symptoms become less severe or disappear altogether. In the early stages of relapsing-remitting MS, symptoms may disappear completely during remission. However, after several years of relapses there may be residual damage to the myelin sheath which can result in partial recovery.

### 2 Secondary progressive

It is estimated that approximately 60% of people who start off with relapsing-remitting MS may later develop a progressive form of the condition, known as secondary progressive MS. In this case people will experience a decrease in the number of relapses but an increase in the level of disability. Like all forms of MS the emergence of disability varies from person to person.

Secondary progressive MS generally occurs 15-20 years after diagnosis. In some cases, people with secondary progressive MS continue to experience relapses.

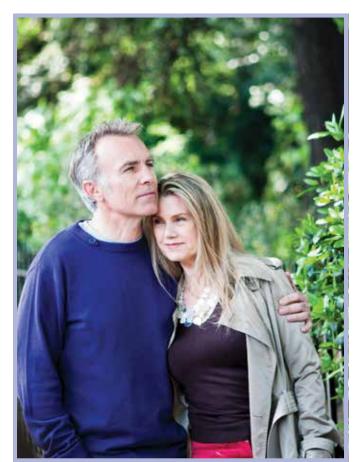
### 3 Primary progressive

About 10% of people experience persistent symptoms right from the start that become progressively worse over a period of years. Relapse and remission is not a feature of primary progressive MS. The average age of onset is ten years older than relapsing-remitting MS and it affects men and women in the same ratio.

The rate of progression varies from person to person.

### 4 Clinically Isolated Syndrome

Clinically Isolated Syndrome (CIS) is a term often used by the medical community to describe the first 'attack' (relapse) of MS symptoms i.e. the presence of a typical MS symptom such as optic neuritis. The 'attack' may be accompanied by the formation of lesions in the brain, although not always. Experiencing CIS does not always lead to a diagnosis of MS. However, the presence of lesions does increase the person's risk of developing MS.



Approximately 85% of people are first diagnosed with relapsing-remitting MS. This means they experience a relapse or flare up of symptoms followed by remission (a period of recovery)

8

# Grace Kavanagh



"I am still me, I am still capable of a lot of things and life can still be fun and fulfilling, it just takes more work and consideration than it used to"

11 years ago I was diagnosed with relapsing-remitting MS. My diagnosis left me numb, which is ironic as that was my first symptom too, I didn't know much about MS or what to expect so I bought a book and took it from there. I was working in the UK when diagnosed and didn't find much support at the time, but that was fine with me as I mostly pretended it wasn't happening.

My numbness progressed to difficulties with walking and 10 years down the road pretending MS is not an issue isn't an option anymore. It's certainly not all doom and gloom though as I returned to Ireland a few years ago so am surrounded by family and friends who can't do enough for me and I am gradually learning to let them!

Just because they want to help doesn't mean I'm a burden – it has taken a lot of mindfulness practice for me to be able to say that and mean it!

Also after several tries my care team and I have found the right drug for me which thankfully no longer involves injections and my MRIs have been stable recently. I have regular physiotherapy and support from my Occupational Therapist and MS nurse. I attend weekly yoga classes at the MS Care Centre, which is just the friendliest group. So from being someone who hid MS at all costs I no longer feel the need to hide.

My 10 years with MS has involved lots of changes, moving home from the UK, getting married, going to Hawaii with my sisters, decreased mobility and lots of drugs to mention a few. Some changes I have enjoyed, others I have not, some I have stuck with and others I really should go back to, like my healthy diet but no one is good all the time.

I have retrained twice since my diagnosis. Firstly, I trained as an adult learning tutor in computing and have had a lot of fun volunteering to help get older people online. Most recently I studied for a Post Graduate Diploma in Digital Marketing thanks to the scholarship offered by the Digital Marketing Institute via MS Ireland. I really enjoy learning and would happily study for the rest of my life. I completed the course and graduated so it is nice to get a reminder that MS and my mobility issues haven't changed me completely. I am still me, I am still capable of a lot of things and life can still be fun and fulfilling, it just takes more work and consideration than it used to.

### **Grace, Dublin**

# **Diagnosing MS**

There is no one test or procedure which can be used to diagnose MS on its own. The symptoms may be caused by something other than MS so your healthcare professional will have to rule this out first. This can take time which can be stressful for the person and their family. Some people describe it as 'limbo land', the struggle knowing something is wrong but no confirmation on what it could be.

Diagnosis is generally based on the results of some of the tests below and a history of symptoms. Some people describe this process as 'joining the dots' as they begin to connect seemingly connected falls, ill health or other symptoms.

#### Common tests and procedures in MS:

### Medical history

Your doctor will ask you about your medical history and symptoms and will carry out some simple physical examinations.

### **Neurological Examination**

The nervous system can be systematically examined by testing reflex pathways (the knee jerk), and measuring sensation to stimulus (especially a pin prick). By carrying out a full neurological examination a doctor is able to establish any abnormalities in the nerve pathways. However, this examination cannot conclude what is causing the abnormality and so other possible causes of illness which produce similar symptoms to MS must be eliminated.

### MRI scanning

Magnetic Resonance Imaging (MRI) is a technique that produces detailed images of inside of the brain and spinal cord. It is used to identify any areas of scarring (plaques or lesions). These show up as areas of white or lighter shades of grey.

### Lumbar puncture

This procedure involves drawing off a sample of fluid from around the spine and testing for abnormalities that can indicate MS.

### VER (Visually Evoked Responses)

These are simple electrical tests, carried out on vision, which can detect a delay in messages between the eyes and the brain.

The neurologist will use a number of these tests and procedures to determine if you have MS or not.

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9

# **Symptoms**

The location and the extent of the scarring within the central nervous system will determine the type and severity of symptoms any person will experience. For example the optic nerve is responsible for bringing information from the eye to the brain for processing. If scarring occurs in this area, a person's eyesight may be affected. Equally, if damage occurs in the area of the brain responsible for cognition a person's memory or perception may be affected.

No two people with MS will have exactly the same set of symptoms. The presence, severity and duration of all symptoms of MS vary considerably from person to person. Some are more common than others and they may also change through time.

#### **Common symptoms include:**

- Fatigue Extreme tiredness not related to the level of activity or sleep/ rest
- Optic Neuritis Blurred vision or whole or partial loss of vision. Eye pain is often associated. This is often the most common symptom at the onset of MS
- Weakness of limbs Particularly in the legs where people feel they are 'dragging' their foot or in their hands where gripping things becomes difficult
- Balance problems Often experienced as veering off to one side when walking, bumping into things or falling
- Sensory Altered feelings in the body, particularly the limbs.
   Numbness, pins and needles, burning pain or skin sensitivity are common
- Cognition Affecting such functions as memory, reason, problem solving, concentration
- Spasticity Includes muscle spasms, stiffness and tremors
- Bladder or bowel problems Urgency to pass urine, leakage, or difficulties passing urine. Constipation
- Speech and swallowing difficulties Slurred speech or problems swallowing
- Sexual Affecting arousal, stimulation and impotence

Some of the symptoms of MS are immediately obvious. Reduced mobility is often the most obvious symptom to onlookers. However, it is often the 'hidden' symptoms such as fatigue, bladder problems or sensory problems such as neuropathic pain that can be difficult to see and explain.

The presence of a new symptom or the worsening of an existing symptom may be a relapse so it is important to alert your GP or neurologist when a new symptom appears of if an existing symptom changes. Many people find it helpful to keep an MS diary to record symptoms as they happen. This can be a great help when meeting with your health care team.



Many people notice triggers and patterns to their symptoms. Stress often brings on symptoms and some people find that high temperatures unduly affect them. (Known as Uhthoff's phenomenon) Being aware of your body and its reaction to events is good.

Anxiety, emotional issues, stress and depression are not necessarily symptoms of MS but they often accompany symptoms. Trying to come to terms with emerging symptoms and managing their impact can be difficult and challenging to your mental health. Be patient, seek advice and learn more about adopting relaxation techniques.

Managing symptoms is part of the overall management of MS. It is important that you look at your everyday life and look at what adjustments you can make that will help you manage your MS as successfully as possible.

Many symptoms have associated treatments that may be suitable. Physiotherapy and other rehabilitation techniques are used by many as are complementary and alternative therapies. There are a range of medications that can help with certain symptoms such as pain and bladder problems.

MS Ireland has a range of information booklets available on different symptoms of MS and how to manage them. Visit our website **www.ms-society.ie** or contact our National Office or your local regional office to find out more (see page 31).



12

# Colm Sharkey



"Life likes to throw curve balls at us and it's up to us to move forward and not let it stop us"

It all started around the end of 2003 with pins and needle sensations in my hands and feet. I went to my GP as it kept coming and going. He checked me out and said if it was still bothering me in the New Year to come back to him. In early 2004, the pins and needles were getting worse, I started to drop items like pens, the power in my hands was weaker and I started developing a nasty taste on the left side of my mouth. I went back to my GP and he referred me to a neurologist as he had a hunch.

About two weeks later I got up one Wednesday morning to go to work and it felt like someone had poured the contents of a pub into me. I couldn't walk, had slurred speech, my eyesight was a bit blurry, the bad taste in my mouth was worse and I had other random aches. I saw my GP and he phoned the neurologist to tell him I had to be seen today. I saw the neurologist, got sent for an MRI scan two days later and went back to neurologist to be handed the news of MS..... I felt like I got hit with a sledge hammer.

He pointed out to me that all the different things going wrong with my body were all related to this MS. That was some nice news after that harsh blow. I got put onto treatment a week later and I haven't looked back since. It took a good year to fully feel back to almost normal after that.

Having got that sort of diagnosis I don't take things for granted as even the simple things like walking were a massive challenge for me back then. Thankfully I've been having a good run since that whirlwind ride and hopefully will continue to do so. Some days I have to take it easy as I just don't have the energy to do much, but having young kids doesn't give you much chances for that. As one of my friends said to me after my diagnosis "Nice to see you've still got your f\*\*\* it attitude to life". Made me think when he said that to me that I do approach things in life with that attitude. Life likes to throw curve balls at us and it's up to us to move forward and not let it stop us.

Colm, Co. Meath

# ADJUSTING TO MS

The time surrounding diagnosis can be a difficult and emotional period. Prior to diagnosis there can be a lot of frustration due to unexplainable symptoms. You may have gone to the doctors with something you think can be treated easily. Instead, a long agonising wait and a batch of tests confirm MS. You may have put 'multiple sclerosis' into an internet search engine and read lots of information that may have increased your anxiety. You may also have done this all on your own and now are now wondering who to turn to for support.

Discovering that you have MS can give rise to many feelings. Some people are shocked or angered, wondering how and why they are affected. Some feel relived that they know why they have been unwell and are able to start dealing with it. Some deny that they have MS and try to carry on as if nothing needs to be addressed.

All these feelings are normal; it is part of coming to terms with the diagnosis. Go with the feelings and take your time to let your diagnosis settle in your head. However, many of these feelings and reactions can be damaging in the long run so at some stage you may need to find a way to accept your MS and decide how you can manage it. This process may take weeks, months or for some, years.

Coming to terms with your MS can be helped by getting the right information and talking to your partner, family or friends. Some people seek help from professional organisations like MS Ireland, rely on their healthcare team or seek help through counselling.

People will react differently to the diagnosis; some may wish to find out everything about the condition and talk about it straight away. Others may wish to spend time alone to take time to accept the diagnosis before they ask questions or talk to anyone. Whatever your reaction, it is important to realise that you are not alone; there are many people around to support you.

When your MS is diagnosed, your neurologist, MS nurse or neurology team will be able to answer many of your questions and give you appropriate information. They may also refer you to other healthcare professionals in the hospital or your community. They may also put you in touch with MS Ireland. We provide many individual and group supports for people with MS and their families. Both your neurology team and MS Ireland can help you to manage the affects of your MS now and in the future.

See page 30 for a list of services and contact details for MS Ireland.

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13

# Telling people

In the initial stages you may only wish to tell those who are very close to you. Once you have had time to adjust and you have learned more about MS, you may wish to tell a wider circle of people.

Telling your family and friends for the first time can be daunting but it can often be a great relief to get it out in the open and know that you can then rely on them for support.

There is no right or wrong way to tell people, there is also no ideal time, you just need to make sure that you are ready to tell people and that it feels right to you.

Your MS will impact on people around you so be prepared for different reactions from people; some may experience a mixture of emotions and may need some time to adjust to the situation, just as you did.

It is important to encourage those around you to build up their understanding of what MS is and the issues that are of concern to you. Building up their understanding of MS will help avoid misconception and put some of their fears to rest.

# Telling your children

14

Deciding when to tell your children you have MS can be particularly difficult. It is up to you how much information you want to tell them and when you want to tell them, this will all depend on their age and how you think they will react. It might help to give small amounts of information first and then give more information as they ask.

MS Ireland has a range of books geared towards telling children and teenagers about MS. They include games, puzzles and stories from other young people with parents who have MS. Visit our website **www.ms-society.ie** or contact one of our offices to get copies.



### Telling your employer

Many people continue to work full-time for many years after their MS has been diagnosed. You will probably want to tell your employer and your colleagues at some stage about your MS.

There is no legal obligation to inform your employer unless there is a heath and safety risk. Some people feel comfortable disclosing early while others feel that they may be treated unfavourably, so they wait. Others may choose never to disclose their MS.

If you do decide to tell your employer, gather together as much information as possible to educate them on MS. Explain how MS impacts you and your work situation. Where possible offer solutions to difficulties you may encounter. These can often be simple things like moving your desk nearer the toilet or working from home one day a week.



Many employers are extremely supportive and will show flexibility should you need to change your working patterns. There are financial supports available to employers from the Department of Social Protection to help them accommodate your needs.

Unfortunately, some employers discriminate against employees who have disabilities or long-term illnesses like MS. Employees with disabilities and illnesses like MS can use legislation to safeguard their rights and protect their employment.

Career planning often becomes a facet of MS as people look more strategically at what work might suit their life down the line. Some people opt for less stressful or manual jobs and some people retrain or go back to college.

MS Ireland has an information booklet available 'Working with MS' which provides detailed information on employment rights and options for people with MS, including advice on telling your employer and what to do if you feel you have been treated unfairly by an employer. MS Ireland also has a practical toolkit available for employers which provides examples of reasonable adjustments in the workplace and details the various financial supports that are available to employers. Both booklets are available on our website **www.ms-society.ie** or from our offices.

16

# Sara-Jane Tracy



I am a professional show jumper and I experienced my first MS symptoms when I was 21. I was at a horse show in Cavan and I was bending down to pick something up and I got this weird shock sensation going down my spine and into my legs. Over the next few years the sensation from my neck down into my legs grew worse and from time to time I lost feeling in my legs. Then in the summer of 2014 I began to lose sight in my right eye. From the beginning of 2015 my condition was getting worse. I had a lot of international shows coming up and I was so worried and afraid because it got to the point where I could not even get on a horse by myself never mind jump big fences.

When I was told I had MS all I could think about was when I could ride again and then I was told this would realistically probably not happen. However, even though I could not shower myself, dress myself, walk unaided, feed myself, go to the bathroom alone or write I refused to accept that this was my fate.

For the next month I worked as hard as I could in rehab and in November 2015 I started an aggressive disease modifying therapy (DMT). MS nearly took everything from me but I refused to let it. I am now back riding horses and I competed in my first show in April 2016. Although I have a long way to go I feel like piece by piece and bit by bit I am getting control of my body again.

I have no idea what the future holds for me but one thing I know for sure is there is no way I am going to let MS stop me from doing what I love to do and I will continue fighting and working as hard as I can to do all the things that I love doing.

Sara-Jane, Kildare

# TREATMENTS AND INTERVENTIONS

Managing the symptoms and effects of MS can often be achieved using a variety of medical and non-medical interventions. In addition, a healthy lifestyle including a balanced diet, regular exercise and the reduction of stress can also help. It is extremely important that all treatments or interventions are discussed with your neurologist as they can best advise on what is most suitable to the individual.

# **Medical Treatments & Interventions**

#### Medical treatments for MS concentrate on:

- Managing symptoms
- Reducing inflammation during relapses (steroids)
- Changing the course of the disease (disease modifying therapies)

Disease modifying therapies (DMTs) are generally only used in relapsing-remitting MS. Progressive forms of MS don't respond to most currently licenced disease modifying therapies, though one drug has now been licensed to treat primary progressive MS and other treatment options may become available in the near future.

# **Managing Symptoms**

Symptoms are treated as and when they appear. The use and benefit of these treatments differ from person to person due to the unpredictable nature of MS and the variance in the presence, severity, and duration of symptoms. It is therefore very important to seek advice from a neurologist before starting any treatment.

# **Reducing Inflammation**

Inflammation is caused during demyelination when the immune system attacks the myelin sheath. This causes new symptoms to develop or exacerbates existing symptoms, which is defined as a relapse. Corticosteroids (or steroids) are the standard treatment for a relapse in MS and can be given orally or by infusion.

It is still unclear how steroids work exactly but it is thought that they act by suppressing the immune system or by reducing fluid around the site of the nerve damage. Studies have shown that steroids can speed up recovery from a relapse. However they do not have an affect on the degree of recovery or the long-term progression of the condition.

# Changing the course of the disease (Disease Modifying Therapies)

Disease-modifying therapies (DMT) act to reduce the number and severity of MS relapses and slow down the rate of progression of the condition. They are not a cure and may not be suitable for everyone. However, they are a standard treatment for relapsing-remitting MS.

There are a number of different DMTs available in Ireland. DMTs can be categorised as either first-line or second-line treatments. First-line treatments are prescribed to those with relapsing-remitting MS who have experienced one or more relapses. People with secondary progressive MS who are still experiencing relapses can also be prescribed first-line therapies. Second-line therapies are prescribed in people with very active MS from the outset or in people who have failed treatment with first-line drugs.

DMTs are administered differently, some are self-injected once to several times per week, some are oral tablets, some by monthly infusion and some are administered in two or more treatment cycles. The efficacy and safety of these drugs has been established through a series of clinical trials and they have all met the required regulatory requirements for use in Ireland.

### How do disease modifying therapies work?

Different DMTs work in different ways and each is associated with a particular set of benefits and possible side effects. The drugs currently available interact with different parts of the immune system to calm down the inflammation that causes MS.

### Choosing a DMT

Choosing the right therapy can make a big difference in successfully managing your MS. Be sure to read all the information available to you in order to make an informed decision. Once you have read about all the therapies available to you, it is important to discuss the following considerations with your doctor.

#### **Consider the following:**

- What are the known side effects that I should expect?
- How well can I tolerate the side effects?
- How effective is the therapy?
- How can I introduce it into my lifestyle?

MS Ireland's booklet 'MS Treatment Decisions' aims to empower and equip people with MS or suspected MS to explain to healthcare professionals what is most important to them and what their treatment goals are, so they can make fully informed decisions about what medication is right for them. 'MS Treatment Decisions' is available on our website www.ms-society.ie or from our offices.



MS Ireland also has a range of impartial information sheets with more detailed information on each of the DMTs that are currently available. These can be found on our website **www.ms-society.ie** 

### Deciding when to start using a DMT

Recent research now strongly suggests that long-term outcomes for people with relapsing forms of MS are improved by starting treatment with an appropriate DMT as soon as possible after diagnosis. Many neurologists therefore now advise people with MS to start treatment early, even if their symptoms are mild.

### Choosing not to use a DMT

Some people with MS decide not to use a DMT even if their neurologist believes it would suit their MS. Often people wish to manage their MS by changing their lifestyle or by using alternative therapies and remedies. Some people do not wish to take drugs at all or want to wait until they feel they need them.

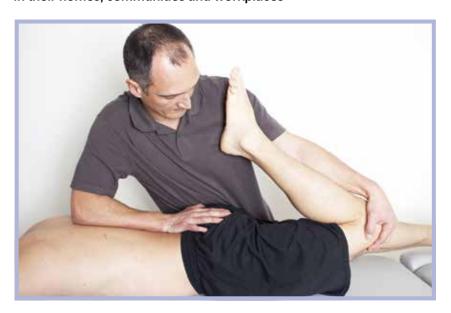
If you decide not to start treatment with a DMT or discontinue treatment, make sure you have discussed this fully with your healthcare professionals and ensure that there is a monitoring plan in place.

# Non-Medical Treatments and Interventions

### Rehabilitation

A number of non-medical interventions can help to manage MS greatly. Rehabilitation is a collective term used to describe a number of therapies that can help to maintain, restore or improve physical and cognitive functioning of the body. The three most common rehabilitative therapies used by people with MS are:

- Physiotherapy plays a significant role in the physical functioning of the body by working on muscle strength, mobility, balance and flexibility
- Speech and language therapy can help with speech and swallowing difficulties
- Occupational therapy focuses on independent living by advising on techniques, aids and appliances, energy conservation and modifications that can better sustain people in their homes, communities and workplaces



These and other therapies and rehabilitation processes can help to maintain and promote independence and help to achieve a healthy lifestyle. Speak to your GP or neurologist to find out how you can be referred for access to rehabilitation.

While access to rehabilitation services is limited, there are many community out-patient services available to people living with MS. MS Ireland also run a number of physiotherapy and other exercise related programmes for people of all levels of ability. Contact your local office for more details.

### Complementary and Alternative Medicines (CAMs)

Many people with MS use complementary and alternative medicines (CAMs) as a way of relieving symptoms or improving wellbeing. These include yoga, touch therapies (for example, reflexology or aromatherapy), homeopathy, acupuncture, relaxation and meditation techniques.



It is estimated that between 50 and 75% of people with MS have used complementary or alternative medicines as part of their lifestyle. This may be because people with MS feel that conventional medicine no longer has all the answers. Some may feel they have more control over their health and well-being when they use complementary and alternative medicines. Others may find the 'holistic' approach to treatment appealing because it may look beyond the physical and take the emotional and spiritual issues into account too. Whatever the reason behind this treatment choice, many people with MS report that complementary and alternative therapies help them to feel better.

Unfortunately there is little research to show how effective or safe many of these treatments may be. Despite this, conventional healthcare professionals' attitudes to complementary and alternative medicines are changing and becoming more positive. It is important to do some background research, and talk over the idea with your doctor who can check that it is appropriate, taking into consideration your medical history and current medication. It is also very important to find a properly trained and qualified practitioner to provide the treatment.

### Unconventional treatments

The therapies and interventions above outline the more conventional ways to treat and manage MS. However, there are other methods some people use to find relief or help. Many of these are not recommended by the medical community as they have not undergone rigorous testing or trials to ascertain their safety or effectiveness.

MS Ireland advises caution when deciding to try these therapies and always recommends seeking medical advice before starting any treatment or intervention. Examples of therapies that are of no proven benefit include Low Dose Naltraxone (LDN), snake or bee venom, hyperbaric oxygen and CCSVI.

# **Emerging and potential treatments**

There are a number of potential therapies and interventions for MS that have showed some promising results in scientific testing but haven't yet reached the required standard of evidence to be considered as mainstream treatment options. These include stem cell therapy, medicinal cannabis, high-dose vitamin D, Biotin (a form of vitamin B) and various 'repurposed' medications that have already been licensed for other conditions such as cancer and are now being tested to see if they are also effective in treating MS.

MS Ireland encourages a person to be cautious about any treatment or technique that has not yet been proven to be safe or effective in the treatment of MS. Generally unless a potential treatment is being offered as part of an authorized clinical trial then it is not possible to be sure that it is being used safely and that proper monitoring conditions are in place. Stem cell treatment in particular attracts a lot of attention and a number of centers internationally offer stem cell treatment for a substantial fee. MS Ireland advises that these centers should be avoided. People with MS should always seek the advice of their neurologist before embarking on any treatment course. Your neurologist can also advise if there are any clinical trials operating in Ireland that you may be suitable for.

22

# Mark Mitchell



"I keep myself very busy. I can honestly say I have never been happier"

I was 44 when I was diagnosed with MS. Prior to being diagnosed, I had read up on MS extensively and pretty much knew that I had MS as I had all the classic symptoms, i.e. heavy fatigue, so bad at times it would wipe me out for days, and my right leg no longer responded voluntarily. But I was devastated to be told I had primary progressive MS. Only 10% of people with MS have the primary progressive form.

It takes a number of years for your body and your mind-set to adjust to MS.I carried on working for a number of years, running my own recruitment business. I had spent 30 years in recruitment and I absolutely loved every day of it. However, by 2006 I took the decision to sell my business and I retired.

Since then I got involved with MS Ireland and became the East Wicklow Branch chairman for seven years. I work very closely with the current CEO and I was a board member for three years. I also work very closely with the Fundraising department among other things.

I keep myself very busy between playing bridge three to four times a week and I am a member of a creative writers' workshop which I love. My wife Ros is my main support – she is an angel.

I can honestly say I have never been happier!

Mark, Wicklow

# LIVING WITH MS

MS will always be a factor in your life so finding ways to manage the physical, emotional, cognitive and practical effects of MS is vital. There are many things you can do to help your mind and body cope better with the challenges that you meet and the challenges that may face your family.

# Healthy lifestyle

A healthy lifestyle is an important part of anyone's life. A good diet, exercise, relationships and social interaction are some of the facets of lifestyle that can help anyone keep their mind and body healthy. For people with MS a good lifestyle is very important too. Keeping yourself as healthy as possible can alleviate some of the symptoms, delay disability and sustain your mental well being.

Staying healthy is about recognising the way MS affects you and making choices that have a positive impact on your life and on the lives around you.

Smoking should be avoided as it can aggravate autoimmune conditions as well as having multiple other negative health effects.

#### Diet

You might find that symptoms of MS affect what you can eat or how you prepare meals. Learning new ways of cooking or using energy-saving tips can help you carry on eating what you enjoy. Adjusting to MS will not always mean changing your diet, but sometimes it can help. With careful planning, perhaps with the help of a dietician, you can make sure you meet your dietary needs, even if they change over time. Many people with MS report that they feel better when they eat well.

There is no particular MS diet although there are many regimes that have been popularised over the years. The SWANK diet revolves around increasing the amount of polyunsaturated fats and reducing the amount of saturated fats taken into the body. The BEST BET diet is based on the notion that a leaky gut contributes to the cause and symptoms of MS and that by eliminating dairy, grains and red meat the leaky gut will improve. The Overcoming MS diet advocates cutting out dairy and meat, and reducing fat intake – particularly saturated fat. It also recommends supplementation, particularly with omega 3 (in the form of fish oil or flaxseed oil) and vitamin D. There is little evidence available on any of these diets, although if followed sensibly they are unlikely to be harmful.

Some of the key minerals that may have an added benefit to people with MS include essential fatty acids and vitamin D. Fatty acids – particularly omega 3 and omega 6 – are found in oily fish, nuts and seeds and certain vegetables. Essential fatty acids have immunosuppressive and anti-inflammatory properties and have a role in our central nervous system and therefore play a role in protecting the myelin.

Preliminary research about vitamin D suggests that there may be an association between reduced levels of vitamin D and MS. Often referred to the 'sunshine vitamin', it can be produced naturally in the body when the skin becomes exposed to ultraviolet rays in sunshine. As MS is less prevalent in sunny climates, where vitamin D levels are higher, researchers are now exploring how it affects the risk of developing MS and also if it may have potential as a treatment for MS.

### **Exercise**

Everyone benefits from being physically fit, including people with MS. However if MS affects you, there are specific exercises that can be targeted at certain problem areas to help keep you as fit and healthy as possible. All kinds of physical movement can be of benefit. It may be beneficial to get advice from a chartered physiotherapist with experience in treating people with MS to find an appropriate exercise programme that will best suit your needs. You can ask your neurologist or GP to refer you to your local physiotherapy service or access physiotherapy through your local MS Ireland branch if available.

Getting The Balance Right is MS Ireland's physiotherapy and exercise programme designed for people with MS. We have carried out extensive research with the Physiotherapy Department of the University of Limerick and developed physiotherapy programmes that are beneficial and effective for people with MS. The research arm of the programme was accompanied by hundreds of physiotherapy and exercise sessions for people with all levels of ability. The programme is still operating and classes can be accessed through your local regional office of MS Ireland. Toolkits are also available for physiotherapists to use in their own local area.

#### **Positive Attitude**

Keeping positive is an important part of everyone's life as the stresses of balancing all our commitments takes its toll. For someone with MS the normal challenges can often be added to as the symptoms of MS can make even the easiest task more complicated.

Like medications, physiotherapy or any other tool you use to manage your MS, keeping positive can become an important part of the way you live your life with MS. Indeed, many people with MS say that keeping positive is the most important tool in their arsenal. A positive attitude is free, you can access it whenever you want and it is infectious!

Not everyone is born with a positive attitude and even at the best of times keeping a smile on your face can be hard. However, you have the ability to adopt new attitudes and reinforce those that can be most helpful.

#### **Staying Positive:**

- Write a list of your talents and skills and focus on the ones that you can revisit
- Take up a new hobby
- Think about the things you are grateful for
- Laugh
- Pamper and treat yourself every now and again
- Enjoy the company of others
- Challenge yourself to achieve something you have always said you would do
- Talk to other people with MS
- 'Don't sweat the small stuff'
- Take time out to relax
- Surround yourself with positive people
- Seek professional information and advice

### **Stress**

Stress is a normal part of everyday life. Not all stress is bad; getting married, having friends over for a meal or having a baby can all be sources of stress and yet are happy occasions that most of us would look forward to. However, too much stress can make it hard to cope with normal day-to-day tasks. Stress can also aggravate many of the symptoms of MS. If your body is working hard to fight the effects of MS it is less able to fight stress too.

#### Some suggestions for managing stress include:

- Learn to recognise what you can and can't control
- Set realistic goals and plan ahead
- Keep a 'stress diary'
- Exercise and complementary therapies
- Relaxation and breathing techniques

# Life Events

MS may have an impact on some of the decisions you make about your life or the lives of your family. For some people this means changing priorities (being healthy is more important than being the best sales person), compromising (doing art with the kids instead of running around the playground) or deciding to take a new path in life (travelling around the world now while I'm able to).

#### Significant key events:

#### **Parenthood**

MS does not have an effect on fertility in men or women and having MS should not prevent anyone from having children. Caring for children can be tiring with or without MS, so you may need to make allowances for fatigue levels or mobility problems. For the period immediately after the birth, you may wish to ensure you have the support of your family and close friends to help you adjust. Like the general population parenthood is not for everyone. Some people with MS choose not to have children as they believe their health may have a negative effect on their child's life.

Pregnancy has no long term effect on the course of MS. With MS, pregnancy, birth and breastfeeding should be normal, although MS treatments may need adjusting. If you are planning to start a family, you should talk to your neurologist about your symptoms and medications. Most DMT treatments cannot be used during pregnancy and will have to be stopped.

Studies have shown that there can be a reduction in relapse rate during pregnancy and can be a marked increase in relapse rates in the first three months after delivery (these are when compared with the pre-pregnancy year). Again, ensuring you have family and friends around will help you cope.

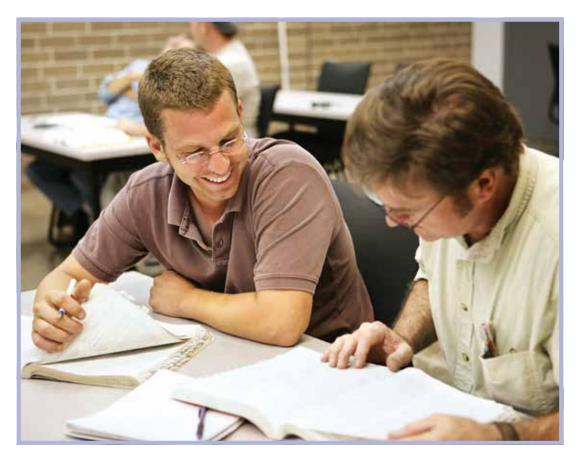
### Relationships and sexuality

MS can put a strain on partnerships as both parties try to deal with the short-term and long-term effects of MS. Various roles may change and if this isn't acknowledged or communicated frustrations can arise. Open, honest, communications are import to help keep the partnership healthy.

MS can affect sexual functioning in both men and women. This may be as a direct result of damage to the nerves affecting signals that produce sexual arousal, or it may be as a result of symptoms such as fatigue and pain. As with many symptoms of MS, sexual dysfunction may come and go. Understanding of MS-related sexual problems has improved greatly in recent years and various treatments are now available. Getting accurate information and communicating openly with partners and healthcare professionals can help minimise problems.

### **Education and training**

MS should not stop you from undertaking a training course or further education. Education or retraining can allow you to enjoy a career or new career better suited to living with MS. There are a number of courses available online now making it easier to tailor education to your particular requirements and schedule. Many colleges and universities have dedicated access offices which specialise in providing assistance to students with disabilities. They can provide support such as physical access, extra exam time, classroom assistance and special equipment. There may be funding that universities and colleges can access to support students with disabilities.



### **Employment**

Depending on how MS affects you, certain types of jobs may be more or less suitable. You may find over time that your current job can become more challenging. However, there can be simple ways to make it more comfortable including changing your working hours, moving you desk closer to a bathroom or getting your employer to put a ramp into the building. Employers have a responsibility to make adjustments to try and keep you in the workplace and there are grants available to employers to help with costs. MS Ireland has information resources on employment for both people with MS and their employers; visit our website **www.ms-society.ie** or contact one of our offices for further details.

# **Driving and Transport**

Public transport, particularly around and into the larger cities, has improved with the introduction and development of low-floor buses and extra designated wheelchair space on trains. (Check **www.cie.ie**) However, much of rural Ireland has limited public transport options.

Specially adapted cars are quite common now and can modify to your specific needs e.g. hand controls, transfer seating etc. Financial assistance is available on VRT and fuel costs. Disabled drivers are also entitled to reduced charges regarding tolls and may be entitled to a disabled parking permit. Contact the Disabled Drivers Association of Ireland, the Irish Wheelchair Association or MS Ireland for more details.

#### The Future

MS does not have to stop you from doing the things you always wanted to do, you may have to compromise and make some alterations but ultimately MS does not mean your life has to stop. The most important thing to do is to take into account your desires and your abilities. Finding ways to meet in the middle will be the important aspect of living the life you are happy with.



28

# **Judith Percy**



"I try to treat each day as it comes"

The first sign of MS for me was difficulty keeping my footing when out hillwalking. Then another sign, more significant - I used to run but had not done much training recently. One Sunday morning, while out on a training run, it felt like my legs were on fire. After that I had recurring tingling sensations round my hips every time I walked. I ignored this for a while but in the end went to my GP followed by a neurologist referral and, to cut a long story short, ended up with a diagnosis of MS. Enough to stop anyone in their tracks but as symptoms were mild and manageable and relatively benign, life carried on without too much interruption. I joined MS Ireland, attended the "Newly Diagnosed" day and got to know a bit more of what MS might be all about.

Life was busy; full time work, part-time study and client counselling as a student counsellor. There was lots to engage and distract me from the prospect of dealing with anything that MS might bring. After my first relapse I started on a DMT. This began a period of trying one DMT after another, when my body didn't respond well to the medications. Yet life continued and so did the MS!

So where am I now on my MS journey? I have adjusted and made changes (part-time work, automatic car, mobility aids, diet and lifestyle) but have learnt a lot along the way. I am now a qualified counsellor and able to support others on the emotional rollercoaster of chronic long term illness with the benefit of my own personal experience.

The mental challenge that this disease presents is immense, not just on diagnosis but continually throughout the MS journey. Yet it can be dealt with by positive attitudes, determination, support from those around you and constantly being aware of how you are. I try to treat each day as it comes, being mindful of how I am, the good things in life and appreciating all that my experience as someone with MS brings.

Judith, Co. Kildare

# HELP AND SUPPORT

# Friends and Family

With or without MS those closest to you will give you the most support. It can be difficult asking for help. You may feel like you are imposing on people or it may seem like you are admitting that you can't cope. These feelings are natural but they will not help you in the long run. Your family and friends are probably happy to help, given the right direction.

Be realistic and practical with you family and friends. Think of the everyday things they could help with – picking up the kids from school, making your lunch for college, hanging the clothes on the line, having a night in rather than a night out etc.

Including your family and friends in managing your MS will give you time to prioritise the important things in your life. If you allow others to help it means you will have more time or be better able to do things you really want or need.

# Your Health Care Team

There are many health professionals you and your family may encounter during your journey with MS. Who you will meet often depends on the symptoms you experience and the assistance you need.

Your GP will often be the person you have most contact with regarding your health in general but also your MS. They often advise on symptom management and general health issues associated with MS. Also, they will probably be more accessible than your neurologist or MS nurse.

Your neurologist and MS nurse will be invaluable to you throughout your journey with MS. They will have the best information about your MS and will be able to advise on all matters, particularly around treatments.

Other health care professionals may include the physiotherapist, occupational therapist, speech and language therapist, dietician, continence advisor, pain specialist, urologist, psychologist, public health nurse, rehabilitation team, home care support team and many of the staff from MS Ireland.

# MS Ireland

MS Ireland is the only national organisation providing information and support services to people with MS and their families and carers. Our staff work in every region in Ireland and are supported by dedicated volunteers. We are available to listen, talk and advise when and if people need support.

We provide services all around the country and while these may differ slightly from region to region our core services include:

### **Individual and Family Support**

Individual and family support, often called casework, is a one-to-one service provided by our Regional Community Workers. They work with you or/and your family to address any issues or concerns. These issues may include those related to health and wellbeing, emotional factors, available services or welfare needs.

They are there to listen to your concerns, provide you with information you may need, support you in coming to terms with your diagnosis and refer you to other services and organizations if needed.

### Living with MS Programmes

A range of groups, programmes and activities are organized for people and families living with MS. These include information seminars, newly diagnosed days, symptom management seminars, carers support groups and a range of exercise and physiotherapy based sessions.

#### **MS Care Centre**

The MS Care Centre is the only dedicated respite and therapy centre for people with MS in Ireland. It offers short-term respite care, therapeutic services, neurological assessments and many social activities in a homely environment in Rathgar, Dublin.

### **Information**

Information delivered by our staff through various services is complemented by a range of information booklets, our website, MS News magazine, local newsletters, our Information Line, our social media tools and our monthly eNews.

Information on research developments is shared via our website and social media and also in our bi-annual research eZine, MS Research. Information is available on various aspects of managing MS including symptom management, treatment options and employment as well as information on available services and supports. Information is also provided to health professionals and students.

### **Voluntary Branches**

Our voluntary Branches are a support network for people and families living with MS in local communities. They organise many social events, therapeutic sessions and support groups. Branches also fundraise extensively to fund their welfare service, which can offer financial assistance to people with MS.

### Advocacy and Lobbying

MS Ireland represents the views and needs of the MS community at a local, regional, national and international level. Working with statutory agencies, representative bodies and the government, MS Ireland aims to lessen the challenges people face when living with MS. Our regional teams also advocate locally on behalf of clients.

### Research

MS Ireland invests in and supports a range of research projects and activities. We assist many researchers and students in their research work and use our many communication tools to disseminate research information and developments and inform the MS community of opportunities to participate in research.

For more information on our services, supports and activities visit our website or call one of our offices. We would be delighted to help you find the right services to support you or your family.

NATIONWIDE **01 678 1600** 







31

REGION	AREAS COVERED	EMAIL	TELEPHONE
Midlands	Laois, Offaly, Longford and Westmeath	midlands@ms-society.ie	090 647 1137
Mid West	Clare, Limerick, and Tipperary North	midwest@ms-society.ie	061 303 802
North East	Cavan, Monaghan, Louth, and Meath	northeast@ms-society.ie	042 975 4304
North West	Donegal, Sligo and Leitrim	northwest@ms-society.ie	074 918 9027
Southern	Cork and Kerry	southern@ms-society.ie	021 430 0001
South East	Kilkenny, Wexford, Carlow, Waterford and Tipperary South	southeast@ms-society.ie	056 77 77771
Western	Galway, Mayo and Roscommon	western@ms-society.ie	091 768 630
Dublin North and Fingal	North Dublin City and Fingal County	na@ms-society.ie	01 490 5933
South Dublin and Wicklow	South East Dublin and East Wicklow	eca@ms-society.ie	01 678 1600
South West Dublin, Kildare and West Wicklow	South West Dublin, Kildare and West Wicklow	swa@ms-society.ie	01 490 5933

# **Benefits and Entitlements**

The State and many of its agencies assist with the financial cost of living with MS, both for the person with MS and the carer. The list below is just a brief overview of some of the entitlements and benefits a person with MS/Carer may be entitled to.

The terms and conditions of benefits and entitlements change frequently. Visit **www.citizensinformation.ie** for the latest information.

#### Please note:

People with MS may be entitled to some of the following benefits (many are means tested).

### Payments for the Sick and those with Disabilities

### Overview of benefits to people who are sick or have a disability:

- Long Term Illness Scheme Multiple Sclerosis is one of the conditions covered by the
  Long Term Illness Scheme. Under the scheme, people affected by certain conditions can
  get free drugs, medicines and medical and surgical appliances for the treatment of that
  condition. This scheme is administered by the Health Service Executive (HSE) and does
  not depend on your income or other circumstances
- Disability Allowance Is a weekly allowance paid to people with a disability who are aged 16 or over and under age 66. Your disability must be expected to last for at least one year and as a result you must be substantially restricted in undertaking work that would otherwise be suitable for a person of your age, experience and qualifications. The allowance is subject to both a medical suitability and a means test
- Disability payments and work You may be able to work and either keep all or some of your disability payment
- Illness Benefit Is a payment for insured people who cannot work due to illness. You
  may qualify for Illness Benefit if you are unable to work due to illness, satisfy the PRSI
  conditions and are under age 66
- Disabled Person's Parking Card (Also known as European Parking Cards or Disabled Parking Badge) are available to people living in Ireland with certain disabilities and those who are registered blind, whether they are drivers or passengers. The parking card can be used by a disabled person in any vehicle in which he or she is travelling
- Housing Adaptation Grant Housing adaptation grants may be available where changes need to be made to a home to make it suitable for a person with a physical, sensory or intellectual disability or mental health difficulty to live in. These grants are means tested
- Medical Cards/GP Visit Card To qualify for a Medical Card your weekly income must be below a certain figure for your family size. If you do not qualify for a Medical Card, you may still meet the criteria for a GP Visit Card. A Medical Card may also be awarded where someone's income is above the means test threshold, but it is determined that to not award the card would result in undue financial hardship (this is sometimes referred to as a 'discretionary Medical Card')
- Occupational Injuries Scheme Provides benefits for people injured or incapacitated by an accident at work or while travelling directly to or from work. The scheme also covers people who have contracted a disease as a result of the type of work they do. There are a number of benefits available and there are different conditions attached to each benefit
- Treatment Benefit Scheme Is a scheme run by the Department of Social Protection that provides dental, optical and aural services to qualifying people

### **Payments for Carers**

### Overview of Benefits to people who care for the sick or disabled:

- Carer's Allowance Is a payment to people on low incomes who are looking after a
  person who needs support because of age, disability or illness (including mental illness)
- Carer's Benefit Is a payment made to insured persons who leave the workforce to care for a person(s) in need of full-time care and attention
- Half rate Carer's Allowance If you are getting certain social welfare payments and you
  are providing full-time care and attention to another person, you can keep your main
  social welfare payment and get a half-rate Carer's Allowance as well
- Carer's Support Grant (Formerly called the Respite Care Grant) is an annual payment made to carers by the Department of Social Protection. Carers can use the grant in whatever way they wish. You can use the grant to pay for respite care if you wish, but you do not have to do so

#### Other Benefits and Entitlements

#### You may be entitled to a number of additional benefits and entitlements such as:

- Back to Education Allowance If you are unemployed, parenting alone or have a
  disability and are getting certain payments from the Department of Social Protection, you
  may take part in a second-or third-level education course and get a Back to Education
  Allowance (BTEA)
- Benefits and entitlements following a death After a bereavement you may need financial support. The Department of Social Protection provides certain once-off payments to help out families during this difficult time. Your local Department of Social Protection's representative (formerly known as the Community Welfare Officer) deals with some of these payments
- Blind Pension Is a means tested payment paid to blind and visually impaired people
- Blind Welfare Allowance Is a means tested payment made to certain people who are blind or visually impaired
- Day centres and day care Day centres and day care centres in Ireland provide a range of social and rehabilitative services for older people and people with disabilities
- Facilities for Voters with Disabilities There are a variety of arrangements in place to assist those with certain disabilities in Ireland to exercise their voting rights
- Fuel Allowance A Fuel Allowance is a payment under the National Fuel Scheme to help
  with the cost of heating your home during the winter months. It is paid to people who are
  dependent on long-term social welfare payments and who are unable to provide for their
  own heating needs. Only one Fuel Allowance is paid to a household
- Household Benefit Package Is a package of allowances which help you with the costs
  of running your household. The package is available to everyone aged over 70 and to
  people under age 70 in certain circumstances
- Free Travel Scheme Everyone aged 66 and over living permanently in Ireland is entitled to travel free of charge on State public transport (bus, rail and Dublin LUAS)
- Disabled Drivers and Passengers Tax Relief The Disabled Drivers and Disabled
  Passengers Scheme provides a range of tax reliefs linked to the purchase and use of
  specially constructed or adapted vehicles by drivers and passengers with a disability.
- Fund for Students With Disabilities Allocates funding to further and higher education colleges for the provision of services and supports to full-time students with disabilities, such as special equipment and personal assistants

For further information contact your local Citizens Information Centre, call the national telephone service on **0761 07 4000** (Monday to Friday, 9am to 8pm), log on to **www.citizensinformation.ie** or contact your local MS Ireland Regional Community Worker.

# Helpful Organisations

#### The Health Services Executive (HSE)

The HSE is the national health service agency, providing hospital and community care and services nationwide.

Website - www.hse.ie

Contact the HSE infoline from 8am to 8pm, Monday to Saturday.

Callsave - 1850 241 850 or 041 685 0300

Email - infoline1@hse.ie

#### **Citizens Information Service (CIS)**

The CIS help people to access information and support services throughout the country. They provide impartial information on social services, benefits and entitlements, employment rights and a host of other information relating to health and social affairs.

Website - www.citizensinformation.ie

Phone - 0761 074 000

#### Irish Wheelchair Association (IWA)

The IWA provide a range of information and support services for those using a wheelchair or living with reduced mobility.

Website - www.iwa.ie Phone - 01 818 6400 Email - info@iwa.ie

#### **Family Carers Ireland**

Family Carers Ireland provides a variety of supports and services to family carers. These include training for carers; home care services; information on carers' rights and entitlements; free legal advice; and both one-to-one counselling and personal advocacy services.

Website - www.familycarers.ie

Phone - 1800 240724

Email - info@familycarers.ie

#### **Assist Ireland**

Assistireland.ie contains information on daily living aids, mobility aids and assistive technology. It includes a directory of products available from suppliers for people with disabilities and older people.

Website - www.assistireland.ie

Phone - 0761 07 9200 9am-1pm and 2pm-5pm.

#### **Disabled Drivers Association of Ireland**

The Disabled Drivers Association delivers its services to members and to persons with disabilities generally through the Association itself and its two subsidiary companies, Ability Enterprises and Shopmobility Ireland.

Website - www.ddai.ie Email - info@ddai.ie Phone - 094 936 4054

#### **National Learning Network**

National Learning Network provides a range of flexible training programmes and support services for people who need specialist support (job seekers, unemployed, people with an illness or disability) in 50 centres around the country.

Website - www.nln.ie Email - info@nln.ie Phone - 1890 283 000

# AUTHORS AND ACKNOWLEDGEMENTS

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**Disclaimer** - We have made every effort to ensure that information in this publication is correct. We do not accept liability for any errors or omissions and policy and practice may change. Seek advice from health professionals and sources mentioned.

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Multiple Sclerosis Ireland, 80 Northumberland Road, Dublin 4

> T (01) 678 1600 F (01) 678 1601 MS Info Line 1850 233 233 E info@ms-society.ie

> > www.ms-society.ie

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