

DIAGNOSED with *MS?*

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INTRODUCTION

When you are first told that you have MS, you are likely to feel shocked and bewildered. There are so many questions that you want answered.

Most people have heard of MS, but any real knowledge of it is likely to be based on someone you know who has it, or things you have heard through the media or press.

Many people feel they do not know what questions to ask their doctor to help them understand and live with MS and “not knowing” can be frightening in itself.

This booklet aims to explain accurately and honestly what MS is and hopefully will answer some initial questions you may have.

You will find details of the Society’s **HELPLINE** at the back of this booklet should you wish to talk, or are looking for further information after reading this booklet.

Michèle Kerrigan

Cert HSC (Open).

M.S.I. National Office

WHAT IS MS?

Multiple Sclerosis is the most common disabling neurological condition of young adults, affecting approximately 85,000 people in the United Kingdom, 250,000 in the USA and 6,000 in Ireland.

It has been recognised for the past century and a half, being known as disseminated sclerosis and although considerable research has been carried out, the exact cause remains unknown.

MS is a chronic condition of the central nervous system. The central nervous system consists of the brain and spinal cord.

The most common age of diagnosis is late twenties to mid-thirties. Onset is rare before the age of 12 and after the age of 50.

It is a condition which affects more women than men on a ratio of 3:2.

MS tends to be a condition of temperate climates and is rare in tropical countries.

The symptoms experienced with MS are caused by patchworks of demyelination, or scarring, in the central nervous system. It is not yet known what actually triggers the process of scarring.

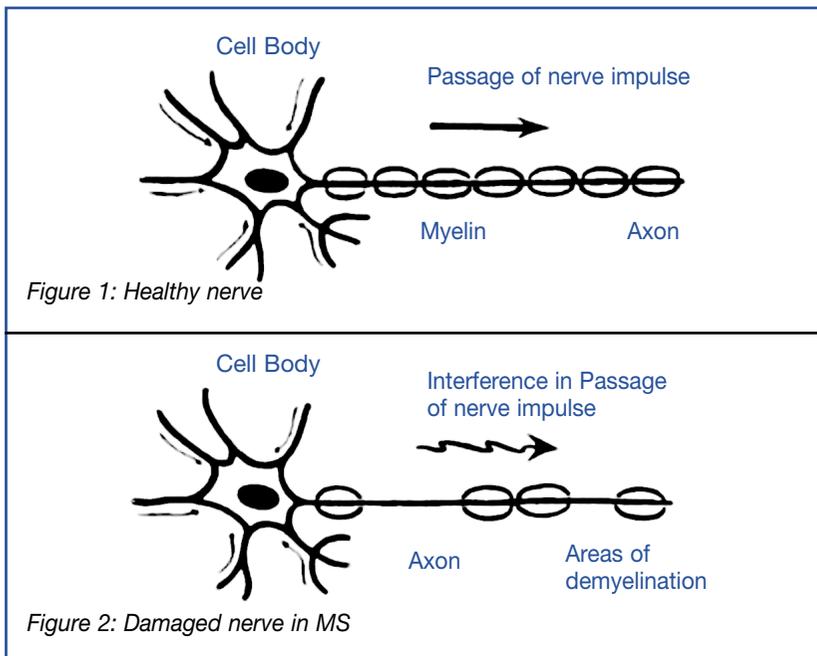
Nerve fibres are covered by a fatty substance called the myelin sheath. The myelin, as well as protecting the nerves, assists the passage of messages along the nerves between the brain and all parts of the body. With MS, the myelin sheath covering the nerves in the brain and spinal cord become scarred. The scarring occurs in scattered patches, distorting or preventing the smooth flow of messages from the brain and spinal cord to parts of the body. **We need to emphasise here that there is no typical MS. It is individual to each person, so one general description and certain prognosis is not possible.**

- MS used to be known as disseminated sclerosis
- MS is not infectious
- MS is not a psychiatric or “nervous” disorder
- MS is not hereditary

THE CENTRAL NERVOUS SYSTEM

The function of the brain is to interpret sensations and initiate movements and other responses to these sensations. This activity depends upon a complex communication system of nerves running from the brain to every part of the body via the spinal cord.

Each nerve of this communication system can be compared to an electric cable. The inner part of the nerve, the axon, is made of conductive tissue and carries messages or impulses throughout the body ~ like the wires in an electric cable. The axon is surrounded by a layer of fatty substance, the myelin sheath, like the insulating cover on an electric cable (Fig 1).



THE DIAGRAM SHOWS HOW MYELIN BECOMES DAMAGED IN MS

The myelin helps the conduction of messages along the nerves as well as insulating and protecting the nerve.

Demyelination

In Multiple Sclerosis parts of the myelin sheath are attacked and become inflamed. This inflammation may die down leaving no permanent damage. If the scarring process continues, the myelin sheath is destroyed at the point of attack leaving fibrous scar tissue known as plaques or sclerosis (Fig 2). This process is known as demyelination and as scarring usually occurs in more than one place in the brain and/or spinal cord, the condition is known as Multiple Sclerosis.

WHAT CAUSES MULTIPLE SCLEROSIS?

Three common theories are :-

Virus attack

When VIRUSES enter the body, they multiply rapidly inside body cells.

Most viruses cause symptoms quickly. Certain SLOW-ACTING VIRUSES also reappear later, causing new symptoms. Other SLOW-ACTING VIRUSES stay inside the body for months or years before triggering illness.

MS might be caused by some slow-acting viruses, or might be a delayed reaction to a common virus.

Immune Reaction

Our bodies have a built-in DEFENCE SYSTEM which destroys “invaders” like viruses and bacteria.

This defence system can “backfire” and start attacking the body’s own cells: this is called an AUTOIMMUNE reaction.

MS might involve an auto-immune reaction in which the body attacks its own tissues by mistake.

Combination

MS might involve both viruses and immune reaction:
When viruses invade the body, they take over body cells.

The body’s defence system might become confused because some viruses take over parts of cells, and it might attack both host cells and virus.

SYMPTOMS OF MS

Multiple Sclerosis is a very variable condition. Demyelination can affect both the motor and sensory nerves affecting movement, touch and sensations. Symptoms may vary considerably depending on which nerves are affected.

There is no set pattern to MS and some people will experience symptoms which others will not. Each person's symptoms can vary from time to time.

Whilst some of these symptoms are immediately obvious, others such as fatigue, changes in sensation, memory and concentration problems are often "hidden" symptoms and can be very difficult to describe to others.

There is no typical MS. It is individual to you and therefore one general description and one certain prognosis is not possible. However, there are some symptoms which are common for many people:

- Blurring of vision, double vision
- Weakness or clumsiness of a limb
- Altered feelings in arms or legs such as tingling numbness – this is often described as "walking on cotton wool"
- Giddiness or lack of balance
- Fatigue which is out of proportion to what you have done, or unpredictable fatigue
- The need to pass water frequently and/ or urgently.

There are four main types of MS, and a great deal of variability within each of them.

Benign MS

This type starts with a small number of mild attacks followed by complete recovery. It does not worsen over time and there is no permanent disability. The first symptoms are usually sensory. It is only possible to classify people as having benign MS when they have little 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 20 per cent of people with MS have the benign form.

Relapsing-remission MS

Most people with MS start with the relapsing-remission type. This means they have attacks followed by remissions. During remission they have fewer or no symptoms.

Relapses (also known as attacks or exacerbations) tend to be unpredictable and their causes are unclear. During a relapse new symptoms may occur or previous symptoms may return. A relapse may last for hours, days, weeks or months and vary from mild to severe. At their worst, acute relapses may require hospital treatment.

Remissions are periods of recovery. They can last any length of time – often years. No one knows exactly what makes the disease process go into remission. Even during remission there will still be plaques visible on MRI scans.

In the early stages of relapsing-remission MS, people are generally symptom-free during remissions. However, after several attacks, and as demyelination progresses, there may be some residual damage, resulting in the person being slightly more affected than before the relapse. In 85% of people with MS, it starts with a relapsing-remission phase.

Secondary progressive MS

This type starts in the same way as relapsing remission MS but after repeated attacks the remissions stop and the MS moves into what is known as the progressive phase.

Around 40 per cent 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.

Primary progressive MS

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 per cent of people with MS have the primary progressive form of the disease, which is also known as chronic progressive.

DETECTION AND DIAGNOSIS

MS can be difficult to diagnose as there is no conclusive diagnostic test for MS.

The history of symptoms is often vague with varying signs that could be symptoms of a number of conditions. Therefore, a long period of time may elapse before a suggestion of MS is made. This whole diagnostic process can cause anxiety and uncertainty. The tests which are conducted will eliminate the possibility of other conditions and show if there is an abnormality in the nervous system that could point towards MS. There are several ways in which the possibility of MS can be investigated:

Medical history

A doctor will usually ask for a medical history of your symptoms. A description of their onset and pattern may be a diagnosis of MS. Physical examination and medical tests will be needed to support a suggestion of MS.

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 Multiple Sclerosis must also be eliminated.

Visual and auditory evoked potentials test

When demyelination (scarring) occurs the conduction of messages along the nerves may be slow. Using this test the time taken for the brain to receive and interpret a message can be measured. This is done by placing small electrodes on the head which monitor brain waves in response to visual and auditory (hearing) stimuli. Normally the brain's reaction is almost instant to such stimuli but if there are scars in the central nervous system a delay may occur. This test is not invasive or painful and therefore does not require a stay in hospital. By testing such specific areas of the central nervous system the doctor may be able to identify where the scars are situated. However, this test cannot identify the cause of the scarring.

Lumbar puncture

In this test, cerebrospinal fluid (the fluid which flows around the brain and spinal cord) is tested for the presence of antibodies. Antibodies can occur with MS but they can also indicate one of a number of other neurological conditions. The fluid is taken from the spinal cord by inserting a needle into the small of the back and withdrawing a small amount. This test does require the person to lie flat for a number of hours and people are usually requested to stay in hospital overnight. A local anaesthetic is given to numb the skin and therefore whilst it is uncomfortable it is not usually painful. This test may indicate MS but is not in itself conclusive.

Myelogram

This is an X-ray examination of the spinal cord. An opaque dye is injected into the spinal column and its movement along the spinal cord can be seen on X-ray. Any obstructions along the nerves will show up on the X-ray and therefore will help to identify any other causes of the symptoms and will support a possibility of MS. Like the lumbar puncture, a short hospital stay will probably be required but the test is more uncomfortable than painful.

Magnetic Resonance Imagery

The MRI scanner is a more recent diagnostic test and takes X-ray type pictures of the brain and spinal cord, showing any existing areas of sclerosis. Whilst this is the only test in which Multiple Sclerosis can be seen, it cannot be claimed to be totally conclusive as not all areas of sclerosis may be picked up by the scanner. It cannot prove that these areas of sclerosis are in fact caused by MS but it can give a strong indication together with the medical history and examination.

DIAGNOSIS

Initial symptoms may be vague and confusing to both the person and his/her doctor. Invisible or subjective symptoms such as fatigue and visual or sensory disturbances are often difficult to communicate to doctors and other health care professionals. Sometimes people at first may be dismissed as being “neurotic” or a hypochondriac. Following your first episode of illness your doctor may not have told you that he/ she suspected MS. This delay may be reasonable because while one symptom can be suggestive of MS, it could also be a symptom of a number of other conditions and therefore may never reoccur.

Honesty with and from your doctor at the time of diagnosis will enhance the doctor/ patient relationship. Many people who have MS speak of their relief at knowing their diagnosis. Regular follow-up visits are important so that the person with MS and his/her relatives can ask questions, obtain information and work through their feelings.

HOW IS MS TREATED?

Symptoms of MS can often be successfully managed if they are treated individually, if and when they arise. MS can only be treated as a whole with steroids, and these are often given to treat a relapse when inflammation and symptoms are acute. Steroids dampen down inflammation and therefore can promote a remission or stabilise symptoms.

Various medications may be prescribed to help manage individual symptoms: muscle relaxants can ease cramps or spasms; analgesics may be prescribed if pain is experienced as a symptom. Any form of medication or treatment should be openly and fully discussed with your doctor, reviewed regularly to check its effectiveness and your feelings about it.

Many people find supportive therapy, such as physiotherapy and reflexology, an important part of treating and managing MS. If you have any concerns over symptoms, treatments or worries over distinguishing what is and is not MS, you should feel free always to discuss them with your GP or neurologist.

WHAT IS INTERFERON?

Interferons are proteins that are released by the body when inflammation occurs and which can either slow down or stimulate the inflammation.

There are three groups of interferons:

Alpha, beta and gamma. Beta-interferon seems to be the best at slowing down inflammatory activity in MS.

There are two types of beta-interferon: interferon beta-1a and interferon beta-1b. As yet no studies have been performed to compare the effectiveness of these two types, but both seem to reduce the risk of MS relapse by about 30%. On average the severity of any relapse is less and the defects in the white matter, as observed in MRI, are reduced. Studies carried out with interferon beta-1 also show that there is a favourable effect on the progression of disability: it is slowed down.

How is interferon taken?

Both types of interferon have to be administered by injection. Interferon beta-1b has been tested in doses that have to be injected every other day under the skin (subcutaneous injection – drug injected below fatty layer beneath the skin – short needle). Interferon beta-1a has been tested in two ways: weekly injections into muscle tissue (intra-muscular – drug injected into muscle – long needle) or three times a week subcutaneously. If the treating physician feels it is appropriate, then the injections can be performed by yourself or by your partner after receiving the appropriate training.

What are the side effects?

The side effects produced by beta-interferon can be divided into those at the place where the injection is given and general side effects. At the site of injection the skin can react (with redness, and /or swelling). Intramuscular injections are associated with fewer local side effects. This localised reaction to the injections disappears in most people (but not all) after some time. A general reaction to injection with interferon can be “flu-like” – shivering, muscle pain, pain in the joints – as if a flu is coming on. This type of reaction usually occurs in the first few hours after the injection or occurs

in the first few weeks or months after the beginning of treatment. Your physician may advise you take some fever-reducing medicine. If paracetamol, or some similar medication (aspirin or ibuprofen) is taken at the same time, these flu-like reactions can be suppressed. It can also help to perform the injection in the evening, which helps you to avoid feeling “flu-ey” during the day.

There are some differences between the various types of beta interferons available: some have to be kept cool (between 8 degrees and 15 degrees Celsius). At the moment various kinds of beta interferons have already been registered in most European countries and can be obtained via your neurologist.

Who should not receive beta interferon?

It is likely that pregnancy or the possibility of pregnancy will prevent the prescribing of beta interferon because of the unknown effects the drug may have on the developing baby. Certain other existing medical conditions, including severe depression, may prevent the use of beta interferon.

How to obtain further information?

This booklet attempts only to answer matters of a general nature in relation to beta interferon. As there are several forms of the disease, the Society is unable to give advice on a particular case; this is purely a matter for each person’s consultant. A neurologist will be a source of further information pertinent to an individual patient’s condition.

YOU AND YOUR FAMILY

A diagnosis such as MS may well throw a strain on family relationships. However, if you and your partner are able to speak openly and honestly with each other, you will probably find you are brought closer together and are able to help each other through difficult times.

You may find it difficult to accept help when you need it, or your partner may feel that he/she cannot give that help or become over protective towards you. It is difficult to carry on family life as if nothing has happened – an understanding approach from yourself, your partner and your family can often be the answer with the result that the family bond is strengthened.

CHILDREN AND ADOLESCENTS

How much and what exactly should you tell your children? Young children need to be told little but it is important that their questions are answered as and when they occur. Instinctively children are aware that something is wrong and that you are worried. You need to be aware of this and understand that their behaviour can sometimes be disturbed. The truth is hardly ever as frightening as their fears.

A booklet which is designed for children approximately 8yrs-12yrs explains the facts about MS and the feelings they might be experiencing. The booklet was put together after delicate and careful consultation.

Older children and adolescents are different and may require a careful approach. Although they can appear outwardly calm and possibly even indifferent, they can become acutely anxious. Their anxiety can be helped by information, a little at a time. Questions answered as they come up may be more helpful than just one talk, and they need to know they can ask you questions without upsetting you.

Adolescents feel that they should be treated as adults and if they are not allowed to play a responsible part in a family problem they can feel both hurt and resentful. They may behave in a destructive way. If, however, their co-operation is encouraged they can become surprisingly mature and a source of strength. Trying to keep your problems to yourself will not spare them any anxiety.

FRIENDS AND FAMILY

When you first learn that you have MS you may feel able to discuss it with your family but after that you may want to keep it to yourself. Should you tell neighbours or the people at work? Reticence is natural and you don't want to become a medical bore! However, curiosity and concern are natural and your friends will probably want to help. If you can be honest with your friends and let them know that you will accept help when you need it, you will allay their worries and probably find them very supportive. This is not a one-way system and you will be able to repay their help, in ways which would not have occurred to you before.

YOU AND YOUR DOCTOR

Perhaps the most important way in which your doctor can help is to listen to you and discuss any problems or anxieties you may have. It is important to build a good relationship with your doctor, as you will have to consult him/her on different health matters in the future.

Help from your doctor

As yet there is no cure for MS but frequently so-called “miracle” cures are given a lot of publicity. Many of these claims have no medical or scientific research to support them and may prove costly or disappointing. Whilst some people may find alternative or non-medical treatments beneficial for themselves, they may not prove so for everyone. Before embarking on any “alternative” therapies it is important to seek advice from your doctor, neurologist or the MS Society to save you from unnecessary harm, expense or bitter disappointment. Your doctor, neurologist or the MS Society will be able to advise you when an effective form of treatment, that has been medically proven, becomes available.

Although there is not one overall treatment for MS, there is much that your doctor can do to help. Many problems, some of them temporary, such as upsets with vision, giddiness and urinary disturbances may be helped with medication or supportive therapy such as physiotherapy.

THE UPS AND DOWNS OF MS

Multiple Sclerosis may follow a pattern of relapses and remissions or a more gradual increase in symptoms. During a relapse new symptoms may occur, or old symptoms which had previously subsided may reoccur. This may be caused by inflammation of the nerves, the development of either a new area of demyelination or the extension of an old one.

Relapses can last from a few days to many months and may be relatively slight or quite severe. Relapses sometimes occur for no apparent reason, but may also be triggered by infection, trauma or stress. People can also experience temporary exacerbations of MS when the appearance or exaggeration of an old symptom occurs for a short period, e.g., minutes or days.

A remission occurs when the symptoms experienced during the relapse disappear either partially or completely for a period of time which may last for weeks, months or even years.

It is impossible to predict with certainty how MS is going to affect an individual in the future. The pattern of relapses and remissions varies greatly from person to person. Try to accept this variability without getting too worried about it. A period of relapse can be disturbing but many people make some recovery, followed by a long period of remission.

MS does not always have these patterns of being “better” and “worse”; sometimes symptoms can gradually increase over a period of many years. The form of multiple sclerosis where symptoms can come and go is often referred to as “relapsing-remitting” MS.

People who do not experience “better” times, but have a developing number of symptoms over the years are referred to as having “progressive” MS. In some cases, people who start off with “relapsing-remitting” MS have less periods with reduced symptoms over time; they are referred to as having “secondary progressive” MS. For some people, the first period of symptoms may be followed by decades without any “worse” periods – this form of MS is sometimes called “benign” MS.

THE SENSE OF LOSS

You will probably feel upset when you are first told that you have MS. In the past you will probably have had good health and it is difficult to believe that health has, in some way, been taken away from you. This feeling of loss may be similar to that after the death of a relative or a close friend. It can take a long while to understand its full significance. This reaction is entirely normal; some people will suffer it more acutely, but without doubt everyone will react in some measure. You will probably need to allow yourself and your loved ones time to grieve the loss of health.

Your first response to being told that you have MS is probably shock and bewilderment. You may also feel angry about it and possibly want to deny it, carrying on as though nothing has happened.

When these feelings settle and you become adjusted to any necessary changes in your lifestyle you will probably begin to feel more secure in yourself and more able to cope. You may find it helpful to talk to someone outside your situation in understanding your changing feelings. Many people find a good friend, family doctor or counsellor good people with whom to share their feelings. You may also wish to telephone the Society's Helpline to talk to someone in confidence, who is more removed from your close circle of friends or family.

A chronic condition such as MS, despite the nature of the symptoms, may have to be accepted a number of times and there may be times when you feel help from a professional counsellor would be most supportive. By building a relationship of trust with a counsellor, he/ she may be able to help you realise your worries and guide you through them. You can ask your doctor to refer you to a counsellor.

The Society has a national network of trained, professional counsellors. Referral to a counsellor can be made through MS Contact 1850 233 233 or your community worker within your area. A list of Community Workers is given on Page 40 of this booklet.

ATTITUDE TO LIFE

It is not just our physical condition that undermines our health; our emotional and psychological attitudes play a big part in keeping us healthy and mentally active.

It is possible that your symptoms of MS mean you can no longer follow the same lifestyle or do all the things you used to. It is natural to mourn the loss of these abilities and you may need time to do so. However, when possible think positive! For everything we can no longer do there is something new to take up. This takes a great deal of effort, determination and often courage but it is essential to turn ourselves to our capabilities rather than our inabilities. You may have to shift your priorities in life and in a sense redefine individual limits and capabilities.

If you are willing to adapt and apply your capabilities and strengths to the fullest you will find an emotional peace that can only help to keep you healthy and give a good feeling of well-being. It is far better to achieve the possible than fail the impossible.

KEY POINTS TO HELP YOU MANAGE YOUR MS

MS does not mean your life has come to a stop. It may mean that you have to adapt to a different lifestyle that suits your own capabilities and limits. The golden rule is to follow as healthy a lifestyle as possible. This will help prevent other illnesses and you will be in a healthy state to cope with your MS.

Diet

A nutritionally balanced diet will ensure you are getting all the vitamins and minerals you require, keeping you feeling fit and healthy. A diet low in animal fats is advisable, as it is the polyunsaturated fats which contain essential fatty acids that nourish the nervous system.

The MS Society has a booklet available, giving information about the theoretical link between diet and MS along with 10 recipes.

Exercise

Regular exercise is important for overall health and should be taken according to individual limits and capabilities. Over-exertion may cause fatigue. However, a little regular exercise will ensure you maintain muscle tone and give you a good feeling of well-being.

Any form of exercise that you enjoy and can comfortably follow will prove beneficial. A physiotherapist will be able to advise you on suitable exercises that can be followed as part of an exercise programme at home.

Rest/Relaxation

Adequate rest periods are essential to avoid fatigue and enable you to cope with your daily routine. Stress and tension have been known to irritate symptoms of MS and therefore relaxation will allow you to unwind and “recharge”. Yoga is often found to be beneficial as it combines gentle exercise with relaxation.

FOR YOUR INFORMATION

MS Society information publications – a range of information available. Information may also be found on our website at www.ms-society.ie.

MS News is a lifestyle magazine for members of the MS Society. You will receive a copy on joining the Society either at branch or national level. The magazine includes features on different aspects of living with MS and information on current trends in medical research and welfare services.

The Multiple Sclerosis Society of Ireland provides the following services:

- The Society have a number of information days and seminars about MS.
- The Society provides a network of community workers who offer professional support to people with MS.
- A network of professional counsellors.
- Research programmes.
- A network of voluntary branches provides locally based social, recreational, educational and visiting services.

SOURCES OF HELP

General Practitioners (GPs)

Your GP or family doctor should be consulted if you are at all worried about your health, or are trying to get help in managing your MS.

Neurologists

Neurologists are the specialists who diagnose and treat conditions of the nervous system. The initial referral to your neurologist is made through your GP, unless you are being treated as a private patient, and subsequent appointments will be made direct with you from the Neurology Department.

Physiotherapists

Physiotherapists are based within hospital services and in the community health service. They can help with mobility, balance and movement problems. Referral to a physiotherapist is usually made through your GP or neurologist.

Occupational Therapists

OTs are based in the hospital and community services. They make home visits to assess needs within the community and advise on practical living aids and home adaptations to enhance independence.

Speech Therapists

Speech therapists have the skill and experience to assess and treat people who are having speech, swallowing or communication difficulties. They can also advise on suitable communication aids. Referral to a speech therapist is usually made through your GP or neurologist or other health professional such as an occupational therapist.

Community Workers

Community Workers are a very important function of the Society's community services and are often the first point of contact for a newly diagnosed person. They are flexible, multiskilled people providing service on a number of fronts. Each worker operates in a defined region and generally has 400 or more people with MS in that area.

They are a local source of information about MS, welfare rights, entitlements, statutory services from health boards and government departments. They provide direct personal support in crisis situations and will act as an advocate on a member's behalf.

The Society through its services organises and arranges workshops, seminars and educational events for people with MS, their families, carers and for the public. They provide support for volunteers by arranging recruitment and training in the work of the Society. They also work with the branches to help them develop their services to members, and liaise with other voluntary and statutory agencies to improve and develop services.

Community Workers form a link between members, the national society and its branches, and act as the catalyst for services based on local need.

Continence Advisors

Most Health Authorities now employ specialist nurses as continence advisors. They are able to determine the nature of continence problems and advise on suitable methods of treatment and management. In most instances a GP or other health professional will make a referral on your behalf, but you may be able to contact them direct for further details about arranging an appointment.

Counsellors

Counselling gives you an opportunity to explore what it means for you to live with M.S. You may find the existence and symptoms of M.S. intrusive and frightening. Talking through in confidence with a trained counsellor will allow you to face the experience of M.S. and discover the resources within yourself. Through counselling you can choose to face and learn to like yourself. As each person's needs are different, the counsellor uses his/her skills to focus on you and create the right environment for you to discover

for yourself in your own way and time what contributes to or blocks your coping well with M.S.

- Work with a counsellor can re-establish the ability to enjoy life. The counsellor can help you deal with the anger which is preventing recognition of real pleasures and abilities.
- Counselling can uncover hidden love. Resentment and anger arising out of M.S. can cover up and bury real love and affection. Counselling can help you find, recognise and express your love again.
- Counselling can sometimes help lift depression.

A counselling session usually lasts for one hour once a week over an agreed period of time.

Your GP will be able to refer you to a counsellor or clinical psychologist, or you can contact the [MS Contact Helpline](#) at **1850 233 233**.

Respite Care

The National M.S. Care Centre opened in 1989, and provides short-term respite care and therapy services to people with Multiple Sclerosis and other neurological conditions.

Care staff that have a wide variety of physical and emotional care skills meets resident care needs. Members of care staff, who are nurses, provide 24 hour a day cover and a doctor is always on call, if required. The therapy services offered by the Care Centre are available by appointment, made following an information session soon after arrival. Services available at the Centre include counselling, massage, physiotherapy, disability management advice, yoga, art therapy.

Residents usually stay at the centre for one or two weeks at a time running from Saturday to Saturday. For people without a medical card or private health insurance, the cost of stay is £30 per day. This covers all therapies, meals etc. Medical cardholders can apply through their Area Health Board for assistance towards the cost of their stay. This should be done before coming to the centre. VHI or other private health subscribers are advised to confirm with their insurers that they are covered to stay at the Centre.

Applications are assessed entirely on the basis of need and no application will be refused because of an inability to pay.

Forms and details available from the Centre at:

National MS Care Centre,
65 Bushy Park Road, Rathgar, Dublin 6.
Telephone: 01 490 6234
Fax: 01 490 6724
E-mail: mscontact@ms-society.ie
Website: www.ms-society.ie

Health Boards

Health Board are responsible for providing services in the community to support people in their own homes and enables them to live independent lives. Services vary from one Health Board area to another.

Eastern Regional Health Authority
Canal House, Canal Road, Dublin 6.
Tel (01) 406 5600
Website: www.erha.ie

North Western Health Board
Manorhamilton, Co. Leitrim.
Tel (072) 55123
www.nwhb.ie

Midland Health Board
Arden Road, Tullamore, Co. Offaly.
Central Offices
Tel (0506) 21501
Website: www.mhb.ie

South Eastern Health Board
Lacken, Dublin Road, Kilkenny.
Tel (056) 51702
www.sehb.ie

Mid-Western Health Board
31/33 Catherine Street, Limerick.
Tel (061) 483286
www.mnhb.ie

Southern Health Board
Cork Farm Centre, Wilton, Cork.
Tel (021) 545011
www.shb.ie

**North Eastern Health Board
Regional Disabilities**
Dublin Rd, Dundalk, Co. Louth.
Tel (042) 932 9320
www.nwhb.ie

Western Health Board
Merlin Park Regional Hospital,
Galway.
Tel (091) 751131
www.mayo-cs.ie

DRIVING

Do you have to inform the Motor Taxation about your diagnosis?

The Road Traffic Act, 1961, Section 48-(1) states:

“A person shall not drive or attempt to drive a mechanically propelled vehicle in a public place when he is to his knowledge suffering from any disease or physical or mental disability which would be likely to cause the driving of the vehicle by him in a public place to be a source of danger to the public”.

Any person who qualifies for Motor Taxation exemption under the Disabled Drivers and Disabled Passengers (Tax Concessions) Regulations 1994, is required to produce a driving licence when taxing the vehicle. Details of disability must be endorsed on licence before an exempt tax disc may be issued.

EMPLOYMENT

Do you have to tell your employer about your diagnosis?

There is no law to say that you must, but it would be wise to check any contract of employment you have. The exception is if your symptoms could cause accident or injury either to yourself or others.

The Safety, Health and Welfare at Work Act, 1989 Section 9-(1a) states 9.-(1) *It shall be the duty of every employee while at work:*

(a) to take reasonable care for his own safety, health and welfare and that of any other person who may be affected by his acts or omissions while at work.

SUPPORT

When you are first told that you have MS you may feel upset. You have probably had good health in the past and may find it difficult to believe that your health has been taken away from you.

You may feel a sense of loss, like that following the death of a close relative or friend, and it may take some time to understand the full significance of this feeling. You may experience shock or bewilderment and feel angry and want to deny the diagnosis, carrying on as though nothing has happened. All these reactions are normal, but some people will experience them more acutely than others.

You may find it helpful to talk through your emotions or have questions answered. The [MS Contact Helpline](#) at **1850 233 233** is a direct confidential service and provides you with support and further information.

GLOSSARY OF TERMS

In this booklet and in other material you might be reading, you will come across terms which are defined below.

Aetiology

The study of the cause of disease.

Antibodies

Protein substances produced by the human body in response to antigens (see next definition). The most significant antibodies produced in cases of MS are those made by B-lymphocytes.

Antigen

The protein part of an organism or cell which the body recognises, rightly or wrongly, as foreign, and which therefore stimulates the production of antibodies to mount a defensive immune action. Viruses and bacteria are examples of external antigens. When an antigen comes from part of the body, the reaction is known as auto-immunity. MS may be the result of either an external antigen or an auto-immune response.

Astrocytes

Spidery or star-shaped cells which hold together the structures in the central nervous system. Astrocytes control the blood-brain barrier and are responsible for producing scar tissue when myelin sheaths have been irreparably damaged.

Anti-viral agents

Drugs and other substances which are used to counteract viruses.

Auto-immune

A disease occurring when the body mis-recognises part of its own tissue as foreign and attacks that tissue causing damage.

Axons

The fibres which carry messages in the nervous system. They are protected and insulated by myelin sheaths.

Benign

In the medical sense, this term means mild or not causing serious damage.

Blood-brain barrier

A type of filter which prevents some substances but not others from moving into the central nervous system from the bloodstream.

B-lymphocytes (B-cells)

A major family of white blood cells which are produced in the bone marrow and circulate in the bloodstream. They are one of the immune system's weapons in attacking invading organisms, through their production of antibodies.

CAT scan (CT scan)

An x-ray technique which produces images of the body in thin slices rather than presenting a flat view from one perspective.

Caucasian

A member of the "white" or light skinned races of humankind.

Central nervous system (CNS)

Defined as the brain, optic nerves and spinal cord, the CNS is the body's main control system. MS occurs only within this system.

Cerebrospinal fluid (CSF)

The special fluid which bathes the Central Nervous System. It can be tapped for analysis using a lumbar puncture – a procedure in which a needle is inserted between lumbar vertebrae and fluid is drawn off.

Chronic

Long lasting – MS is a chronic condition. The opposite medical term is acute, meaning a condition which is marked by a crisis or sudden onset.

Cognitive function

To do with thought processes and intellectual functions such as memory, problem solving, goal setting rather than the emotions.

Demyelination

The disease process, in which the myelin sheaths around nerve fibres in the CNS are attacked, damaged and replaced by scar tissue. There are a number of demyelinating diseases in humans and animals but MS is the most common in- humans and does not occur in animals.

Dormant

Inactive. Some viruses are known to lie dormant in the body for long periods of time, subsequently becoming activated. A possible role of viral infections in MS still has not been excluded.

EAE (Experimental allergic encephalomyelitis)

An auto-immune demyelinating disease of mice and other small animals which closely resembles MS in its processes and effects and is therefore used for laboratory study in MS research. However it is not identical to MS.

Epidemiology

The science of studying diseases in whole populations – a word derived from “epidemic”.

Evoked responses

Nerve conduction can be assessed by testing the body’s response to outside stimulation, usually through the eyes or by touch. Such tests can sometimes show evidence of damage to the CNS when there are no obvious symptoms. They measure the magnitude and speed of the condition by detecting small electrical output of nerves.

Exacerbation (bout, attack)

In MS, an acute recurrence of previous symptoms or the relatively sudden development of new symptoms; both are the result of renewed disease activity in the CNS.

Idiopathic

The cause is unknown.

Immunoglobulin (Gamma) (IgG)

A protein made by B-cells and normally found in the bloodstream, IgG contains antibodies. Raised levels in the CSF are additional evidence in diagnosing MS.

Immunosuppressive Agents (Drugs)

Able to suppress some or all of the functions of the immune system. Drugs which can do this are given to people who have organ transplants so the body does not reject the new component. Most of these drugs have been tested for the treatment of MS with little success.

Immune system

The complex system by which the body recognises and destroys antigens. It uses various families of white blood cells made in such organs as the bone marrow and the thymus gland. The study of this system (immunology) is now a very important part of medical science.

Incidence

In epidemiological terms, the number of new cases of a disease or condition occurring in a given population in a given period – usually a year. It is often mistakenly used instead of the term prevalence. E.g. 2 per 100,000 per year.

Inflammation

The body's response to injury, infection or other attacks. On the skin, this can be seen as redness and swelling. In the CNS an attack on the myelin sheath results in accumulation of white blood cells and fluid, called oedema (swelling).

Interferons

A group of proteins which are made by cells when infected with a virus, and which can prevent nearby cells from being infected. Different interferons are being tested for their possible ability to halt the progression of MS. Previously interferons for research had to be extracted from human blood; they can now be made in the laboratory using genetic engineering techniques. Types of interferons are alpha, beta or gamma. The Beta-interferons are used widely in relapsing-remitting MS and some patients with progressive MS.

Longitudinal

Of length or duration, implying ongoing or long-term.

Lymphocytes

Families of white blood cells with different functions in the body's immune system (see B- and T-lymphocytes, natural killer cells).

Macrophage

A white blood cell which literally eats and disposes of debris in the CNS following tissue damage. The macrophage is made in the bone marrow.

Microglia

A component cell of the CNS, it helps the macrophage remove damaged tissues after an attack.

Motor nerves

Nerves which the brain uses to control movement of muscles.

MRI (Magnetic resonance imaging)

A scanning technique for producing images of the body's internal tissues. Like CAT scanners, MRI scanners provide a picture of a thin slice of the body – but by using magnetic fields and radio waves rather than x-rays. MRI Scanning shows the lesions (plaques) of MS; the cat scan does not.

Myelin

The many-layered sheath, composed mainly of fats and protein, which are wrapped around nerve fibres. They insulate the fibres from one another and aid conduction. Myelin is damaged in MS thus interfering with nerve impulses.

Myelin basic protein

A protein which forms an important part of the myelin sheath. It has proved significant in both inducing and protection again EAE, but this effect has not yet been demonstrated in MS in humans.

Natural killer (NK) cells

A group of lymphocytes made in the bone marrow. As their name implies, they destroy other cells which have been identified as faulty. They are part of the body's immune defence system.

Nerve Cells (neurone)

Tiny structures which form the main component of grey matter. The billions of nerve cells in the brain are the starting point for messages carried along nerve axons (fibres), and both cell and fibre are part of the same structure.

Nervous system

The body's complex message system, made up of the CNS, the peripheral nerves (e.g. those leading from the CNS to the limbs) and the autonomic nerves (which control the heart beat, blood pressure and other functions not under conscious control).

Neurogenic

Arising from, or with a neurological basis.

Neurologist

A physician specialising in disease of the nervous system and usually the clinician who will make the definitive diagnosis of MS.

Oedema (or Edema)

A medical term to describe an abnormal build up of fluid in body tissues usually after injury or infection. Sometimes oedema is visible as swelling in the skin. It is also part of the inflammatory process in MS.

Oligodendrocytes (oligodendroglia)

Cells in the CNS which are responsible for making and then maintaining the myelin sheath.

Relapsing

A term used to describe a disease in which symptoms come (relapse) and then go (remissions). Most people with MS experience such a pattern of symptoms in the early stages of the disease.

Pathogen

An agent causing disease.

Plaques

The essential lesion in the brain in MS caused by loss of myelin in a small zone of nervous tissue.

Prevalence

In epidemiology, the number of cases in a given population at a given time. Often confused with incidence. E.g. incidence might be 2 per 100,000 per year and prevalence 60 per 100,000 population.

The prevalence of MS in Ireland is at least 100 per 100,000 population.

Progressive

Used in medicine to describe a condition or disease which gets worse over time. In MS, there is the primary progressive form, that is progressive from the outset, and the secondary progressive form in which progression follows relapsing/remitting MS.

Remyelination

The opposite process to demyelination. Some evidence exists to show that myelin can be repaired in the CNS by a process not yet understood. Remyelination (and even regrowth of fibres) is commonly observed in the peripheral nerves and the possibility of encouraging this in the CNS is being actively explored for its obvious potential to correct some of the damage caused by MS.

Sclerosis

Scarring of tissue within the body.

Sensory nerves

Those nerves which convey information back to the brain about the environment outside and inside the body.

Symptomatic

Of or related to symptoms. Some researchers are trying to find ways to ease the symptoms of MS; that is, to provide successful symptomatic treatments which do not, however, alter the disease process itself.

T-lymphocytes (T-cells)

White blood cells produced by the thymus gland in the upper chest. There are many different types of T-cells, all with different jobs in the immune system.

Trigeminal neuralgia

Brief attacks of severe pain involving the trigeminal nerve. Pain is usually felt in the region of the cheek or jaw.

Virus

A tiny organism which can exist only in other living cells and is capable of causing disease.

RECOMMENDED READING

- **Diagnosed with MS**
MSI Production
- **What everybody should know about MS**
MSI Production
- **Taking Control of your emotions**
MSI Production
- **Sexuality and Multiple Sclerosis**
Mary Leonard/MSI
- **Coping with MS**
Judy Graham/Faber
- **Multiple Sclerosis: A Personal Exploration**
Alexander Burnfield/Human Horizons Series. Souvenir Press
- **Living Multiple Sclerosis**
Elizabeth Forsythe
- **A Manual on Multiple Sclerosis**
Helmut J Bauer
- **Multiple Sclerosis: Guide for newly diagnosed**
Nancy Holland, T. Jock Murray, Stephen Theingold
- **Incontinence: What you should know about Incontinence**
M.S.I.
- **Depression: What you should know about Depression**
M.S.I.



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