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**BEGINNERS'  
GUIDE TO  
MULTIPLE  
SCLEROSIS**

3RD EDITION

**ms.**

**Multiple Sclerosis Society of New Zealand**



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## **AUTHOR**

Written by Lynne Roberts with the assistance of Dr Tom Miller.

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Multiple Sclerosis Society of New Zealand Incorporated  
PO Box 2627  
Wellington 6140  
NEW ZEALAND

Phone           0800 MS LINE or 0800 675 463  
                  or 64 4 499 4677  
Fax             64 4 499 4675  
Email          info@msnz.org.nz  
Website       www.msnz.org.nz

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# INTRODUCTION

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We have a very important message for you: **Don't Panic.**

Multiple Sclerosis does not necessarily produce serious disability. With a new generation of drug therapies becoming available, it's a potentially treatable disorder. The future for those newly diagnosed is looking more favourable with each new development, although available therapies are only partially effective at present.

This booklet will answer many of your commonly-asked questions and, while some matters are only briefly touched on here, other information booklets in this series deal with particular issues in more depth. All are available on request from your local field officer or from the MS Society of NZ.

In addition, our National Information Centre and most Regional MS Societies have a comprehensive library of books and videos available, written and produced by people from a range of viewpoints from health professionals to people with MS.

Please make the most of these opportunities to learn about MS as education is empowering on so many levels. We trust you find these NZ produced booklets helpful.

# WHAT IS MULTIPLE SCLEROSIS?

Multiple sclerosis (or MS as it is often called) is a disorder of the central nervous system (CNS) - the brain, spinal cord and optic nerves.

The central nervous system is responsible for our conscious and unconscious functioning including movement and the response to sensations such as sight, touch and hearing. It directs these functions by sending its instructions in the form of electrical impulses to the appropriate sites along nerve fibres. Nerve fibres are coated in a protective insulating covering called the myelin sheath that serves a very similar function to the coating around electrical wires. Myelin is important in speeding electrical conduction along nerve fibres and in insulating nerve fibres from one another.

The term multiple sclerosis refers to multiple areas of scarring (sclerosis) scattered through the brain and spinal cord. The scars are the result of healing patches of inflammation. These are the basic cause of damage to nerve fibres and of the suddenly appearing symptoms that are referred to as an attack or relapse. Patches of inflammation heal

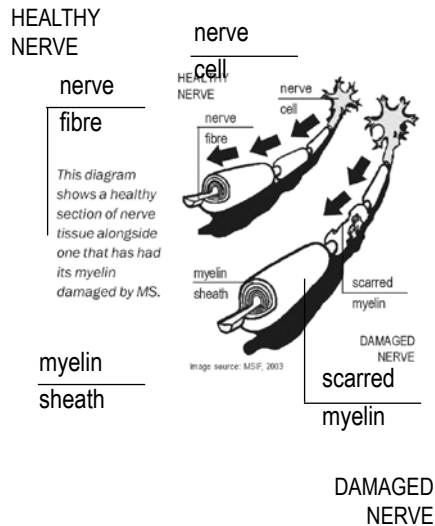


Image source: MSIF, 2003

spontaneously over several weeks or months when symptoms may resolve completely or residual impairment may result.

The inflammation causes damage particularly to the insulating myelin sheath covering nerve fibres but also damages the nerve fibres (axons) themselves. In MS the typical damage is often referred to as “demyelinating”. The nature of the symptoms and their severity depends partly on the site of the patch of inflammation (or lesion) and partly on its nature and intensity.

The course of MS varies widely from person to person. Some people will only ever experience mild symptoms over their lifetime while others will have relapses followed by incomplete remission when disability may worsen in a stepwise fashion with each relapse experienced. A number of persons experience slowly progressive worsening of disability over many months or years. There is uncertainty how much of this progressive process is due to low-grade inflammation and how much to loss of previously damaged nerve fibres.

### **In general three typical patterns of MS can be**

**RELAPSING-REMITTING MS:** relapses with a flare up of old symptoms or the development of new symptoms (over several days or weeks) are followed by a remission with resolution or reduction of symptoms.

**SECONDARY-PROGRESSIVE MS:** after an initial course of relapsing/ remitting MS there is the development of slowly progressive disability (over many years). In this phase relapses may also still occur.

**PRIMARY-PROGRESSIVE MS:** in about 10% of cases, from the beginning, there is slow progressive worsening of symptoms and disability without distinct attacks.

## SYMPTOMS OF MS

In MS the condition and symptoms are unpredictable and vary from person to person. Symptoms are not only different in different people but typically vary in the same person from time to time as different areas of the central nervous system become inflamed and scarred.

Common symptoms include:

- Weakness or in-coordination of the limbs
- Impaired balance or instability walking
- Sensory disturbances
- Blurred or double vision
- Impaired urinary or sexual function
- Cognitive dysfunction such as impaired memory or concentration
- General fatigue

NOTE: a person with MS will usually experience more than one symptom but NOT necessarily all of them.



# WHO GETS MULTIPLE SCLEROSIS?

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In New Zealand, about one in every 1,000 to 2,000 develops MS with approximately 2500 people affected.

It is more common in:

**YOUNG ADULTS:** symptoms usually appear between the ages of 20 and 50 with a peak in the early 30's.

**WOMEN:** Women are affected approximately twice as often as men.

**CAUCASIANS:** MS is more prevalent in Caucasians (people with ancestry from Northern Europe), than any other racial group. It is rarely found in Maori and Polynesian people and is uncommon in Asian people

**NEAR RELATIVES** of those with MS have an increased risk. Having a first-degree relative, (mother, father, sibling,) with MS increases the chances of having it from approximately one in every thousand people to 30 in every thousand, but it is important to note that the great majority of people with an affected first-degree relative do not develop MS.

MS is not contagious or infectious; it is not possible to contract it from close contact with a person with MS.

# WHAT CAUSES MULTIPLE SCLEROSIS?

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The cause of MS is still not known. Both genetic and environmental factors are important but how they interact to produce episodes of localised inflammation over many years is not clear. MS is widely regarded as an autoimmune disease in which the body produces a misdirected immune system attack on its own tissue (in this case, the myelin sheath that protects the axons), but that has never been firmly established. A reaction to a virus hidden in the central nervous system has been long suspected but also not proven. In persons with MS the immune system appears to be normal in all other respects.

MS is not a hereditary disorder in the sense of being passed directly from parent to child. The increased risk in close family members is not attributable to a single gene but is related to several genes whose function is not well understood – some probably influence immune reactions.

A striking environmental feature is the increase in prevalence of MS in higher latitudes both above and below the equator. In NZ, for example, the prevalence in the South Island is approximately twice that in the upper half of the North Island. The pattern of migration from Northern Europe may contribute to that distribution but undetermined environmental factors are most important. Among many possibilities, exposure early in life to a virus infection that has a long-term effect on immune responses is thought most likely. However, none of the numerous viruses suspected can be directly linked at present.

# HOW IS MULTIPLE SCLEROSIS DIAGNOSED?

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Ideally, a neurologist or specialist physician should confirm the diagnosis of MS. The basis of a diagnosis of MS remains a careful neurological assessment including analysis of symptoms and physical examination. It depends on the demonstration of typical features and exclusion of other disorders that may produce similar symptoms.

Diagnostic tests have an important role and include:

- Magnetic Resonance (MR) scanning of the brain and spinal cord. This has been a major advance in the diagnosis of MS but the changes seen are not specific for MS and age-related changes may cause confusion.
- Lumbar Puncture to examine the cerebrospinal fluid (CSF).
- Evoked Potentials which measure electrical conduction through CNS pathways are not commonly used now that MR scanning is widely available.

# WHAT TREATMENTS ARE AVAILABLE?

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While there currently is no 'cure' for MS, treatments are available to deal with different aspects of the disease. These can be considered in four main categories.

## 1. TREATMENT OF RELAPSES

Acute flare-ups or relapses are usually managed by the administration of corticosteroids (eg: methylprednisolone or prednisone), which can shorten the duration of an attack and lesson its severity. These can be taken either orally or intravenously.

## 2. DISEASE MODIFYING THERAPY – PREVENTING RELAPSES

A number of agents generally classed as 'disease modifying agents' are now capable of reducing the number of relapses and the development of new brain lesions seen on MR scans. The most widely used are described as immunomodulating agents and include beta-interferon (Avonex®, Betaferon®, and Rebif®), and glatiramer acetate (Copaxone®). These treatments are expensive, must be given by regular injection and must be continued indefinitely to maintain effect. Immune suppressing agents such as mitoxantrone (Novantrone) also have a place. In New Zealand only Betaferon® and Avonex® are currently funded by Pharmac and access to treatment is restricted to persons with frequent relapses and significant residual disability. Your neurologist can advise you if you qualify for this treatment.

### **3. MANAGEMENT OF SYMPTOMS**

Therapy is available to relieve many of the symptoms associated with MS. Treatment options can include physiotherapy and medication.

### **4. REHABILITATION**

While it may not be possible to improve all lost function, persons with MS should try to optimise their physical, mental and social condition. After an exacerbation there may be the need for rehabilitation. During remission periods people with MS should participate in a maintenance therapy programme to achieve and sustain their optimum physical condition. This may involve physiotherapy, stretching, coordination exercises, speech and swallowing instruction. It may also include medication, good nutrition and counselling. There may be the need for lifestyle changes (both social and occupational).

# COMPLEMENTARY AND ALTERNATIVE MEDICINE

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Some people believe that if conventional medicine cannot provide a cure for MS, then perhaps alternative medicine will do so. Others find that seeking more holistic therapies allows them to feel they are controlling their MS.

Caution should be the keyword, particularly when the use of herbal remedies is being contemplated. A number of these remedies have been shown to interact with prescribed drugs and adverse effects are not uncommon. Specifically a number of these remedies claim to 'enhance' the immune system. As the principal problem in MS is an already over enhanced immune response it is particularly important to tell your doctor if you are taking or contemplating taking any 'natural' or 'herbal' remedies. Some of these can react badly with prescribed drugs and are often promoted by people with little or no understanding of the disease. Some cautions and incompatibilities associated with herbal products have been widely publicised recently and reputable reference sources can be consulted.

Medsafe is the New Zealand Medicines and Medical Devices Safety Authority. It is a business unit of the Ministry of Health and is the authority responsible for the regulation of therapeutic products in New Zealand.

Medsafe regulates products used for a therapeutic purpose. This includes:

- ➔ Medicines
- ➔ Related products
- ➔ Herbal remedies
- ➔ Medical devices
- ➔ Controlled drugs used as medicines

Medsafe can provide useful information about particular products and therapies. Contact details for Medsafe and the Ministry of Health are located in the section Sources of Support. The Rocky Mountain MS Centre CAM website can also be helpful if you have internet access, and the MS Society can provide information on specific topics.

Be aware that information you read on the Internet or in a newspaper may not necessarily be correct. Be particularly wary of any product or information that claims to be a cure for MS; if it's genuine and has been scientifically proven, your neurologist will know of it. Don't forget that MS can go into remission suddenly and 'miraculously,' for no apparent reason, so apportioning success to any particular treatment can be misleading.

# ADJUSTING TO THE DIAGNOSIS

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In coming to terms with a diagnosis of MS one of the most difficult aspects is its unpredictability. Receiving a diagnosis of MS can alter the way you look at life. It may make you feel that you have lost control or that your future is uncertain. Don't despair. Everyone goes through stages of adjusting to major life changes and these processes are entirely normal, although the intensity of feeling and length of those stages will vary from person to person.

Some people will feel relief at finally having a diagnosis. Finally they will have an explanation for the puzzling and sometimes frightening symptoms they have been experiencing. More than that they may be relieved to find their symptoms are not caused by a life threatening disease.

Others may react differently, becoming fearful of what life will hold. Do they give up their job, alter any plans to start a family or have more children? They may fear the reaction of their partner and family and grieve for their perceived altered relationships. All these feelings are very natural and will become less overwhelming with time and support.

## SPREADING THE NEWS

Don't be afraid to tell those closest to you about your MS; they will be your strongest supporters. Acknowledge though that they will pass



through their own stages of acceptance, just as you will, so try to also be aware of their needs. If you share your feelings about having MS you will find it easier to accept their support and you can grow together in strength and understanding.

Children should be told at a level they can understand and this may need to be repeated and expanded on as they grow older. It's very important that children are reassured that their behaviour has not caused your MS and that it's not contagious - they can't catch it from you. You'll find children tend to be very accepting and love you for who you are.

The same can be said for friends. They can do what they do best, be supportive and loving when they know what's going on. They may have witnessed your symptoms and be already worried about the cause. Remember, everyone's imagination is almost invariably worse than the reality so put those closest to you out of their misery and confide in them. It's the relationships in our lives that get us through not only the good times but the difficult, as well.

You may have concerns about telling your employers, worrying it could affect your employment. Remember, they are obliged to respect your privacy and not tell others about it. By law you cannot be fired just because you have developed an illness. In many cases employers are very understanding and with consultation may make small but significant changes to your work environment to allow you to keep working productively.

# WHAT CAN I DO?

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The best thing you can do for yourself is to live a healthy life style that gives you good quality of life. You may be tempted to fall into the trap of thinking that just because there is currently no cure for MS then it doesn't matter what else you do. It's simply not true. If you smoke or drink to excess, then you are just as likely to suffer from a range of adverse health effects, regardless of whether you have MS or not. Maintaining a healthy body gives you the best chance of living long and well.

## REST AND EXERCISE

Stay active, with reasonable rest. Recognise fatigue and rest when you need to. This may be short periods with your feet up or one specific time period set aside each day. If you are working it may mean taking an extended break mid-morning and mid-afternoon at your employer's discretion. Try to avoid pushing yourself too hard as this may make your symptoms temporarily worse. You don't have to belong to a gym to exercise. Walk, swim, move to music, join an exercise class - whatever you enjoy. There is good evidence that regular exercise improves overall health and energy levels.

## DIET

While there is widespread belief that diet can alter the course of MS there is no scientific proof to back this up. Eat a sensible diet and you will feel better within yourself but don't expect it to cure you. Don't fall into the trap of thinking that you need to swallow bottles of vitamins. In a healthy diet there is no evidence to suggest additional

vitamins are necessary or of any benefit; as for any healthy lifestyle, limiting alcohol and caffeine intake is also recommended.

## **TEMPERATURE**

Be cautious of overheating, as this could increase fatigue and may make your symptoms temporarily worse. Bear in mind that heat could be a factor in a worsening of your symptoms and avoid activities such as saunas or hot baths if heat affects you.

## **BE POSITIVE**

The best way to deal with your life with MS is to be flexible. Try something new; there are many things you can enjoy in life, so concentrate on what you can do rather than what you can't. Some people may say *'It's just not fair!'* No, it's not, but no one said life has to be. In time you will be able to find a place where MS can fit into your life without allowing it to dominate. You may not believe this to be possible so soon after a diagnosis but it does come with time. Remember, MS can only change you if you allow it to; you're still the same person today as you were the day before the diagnosis.

# THE FUTURE

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Your life with MS will be what you make of it. Just as everyone is unique, everyone's MS is also unique to them. Neurologists are unable to predict the future as it may take years for a pattern to evolve; in many cases this is only evident after looking back with retrospective evaluation.

Although the progress of the disease in any one person cannot be predicted with any accuracy, the statistics are encouraging:

- ➔ Many people with relapsing remitting MS have many years between attacks.
- ➔ Long term disability is more likely to occur in those with secondary progressive MS rather than relapsing remitting MS.

## MAKING DECISIONS

Think carefully before making any major decisions about your life when you are newly diagnosed with MS. This is when you need time to come to terms with it and should try to live as normal a life as possible.

Decisions about starting a family or having more children need to be well thought out when you have had time to consider your options.

# PREGNANCY AND MULTIPLE SCLEROSIS

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Because of the typical age of onset of MS, this is often a time when women are starting a family or contemplating having more children. MS should be taken in account just as you would any other factors in this decision.

Several issues arise when people with MS plan to have children.

- A person with MS has an increased risk of having a child who will develop MS but the risk is small and not usually sufficient to dissuade couples from starting a family.
- Relapses are less likely to occur while pregnant, but there is an increased risk of a relapse in the three months following a pregnancy.
- Overall, pregnancy does not have a significant effect on the course of MS.
- Pregnancy is best avoided while taking disease modifying therapies.
- Consult your GP about family planning and pregnancy, particularly if you are taking any medication for your MS.

# SOURCES OF SUPPORT

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The MS Society may put you in contact with a regional field officer who can offer support and information. They can give advice on all matters concerning MS and arrange social groups, exercise classes, support meetings and referrals. The range of services offered varies between regional societies. Contact details for your local society are located at the end of this book. Meeting people through the MS Society can be very reassuring, as you may be surprised to find how many people have MS that you were unaware of. A lot of people with MS have 'invisible' symptoms and lead normal lives. Some people find support groups helpful as an occasion where they can share their experiences and learn how others deal with MS.

Your GP is your main health care provider, so do your best to locate a GP with an interest in MS. It's important to communicate your worries and symptoms as clearly as possible so you can get appropriate assistance. Your GP will be able to refer you to a neurologist or other specialist (eg. physiotherapist) if there are questions and concerns. Ideally, the diagnosis of MS should be confirmed by a neurologist or specialist physician.

The following information and referrals are available from your local GP. These are invaluable sources of help, supplies, and governmental funding should you require their services. Not only are they very important; they're completely free.

## **COMMUNITY OCCUPATIONAL THERAPIST**

A Community OT knows how to minimise the difficulties a person with MS may encounter, and how to access funding from regional agencies for aids such as handrails or tools for ease of living and safety around the home. They are able to submit applications to do with mobility and make referrals for vehicle modifications and to Disability Support Link (DSL) who assess and fund personal care and housekeeping hours.

## **COMMUNITY DRIVING ASSESSOR**

This person will discuss and approve vehicle adaptations should you require any. If necessary they can arrange for trials of different hand or foot controls and can assist in overcoming a host of vehicle-related difficulties.

## **COMMUNITY PHYSIOTHERAPIST**

Available to provide home visits to help with issues relating to changes in the body. They can advise on exercises and ways of reducing the strain on weakening muscles.

Referrals to Speech Therapists, Urology Clinics and any other support services can also be accessed through your GP.

## **INTERNET RESOURCES**

The Internet provides a great deal of information about MS, but the quality and accuracy of the information can vary. Some useful websites are listed below.

## **MS Societies**

MS Society of New Zealand: [www.msnz.org.nz](http://www.msnz.org.nz)

Multiple Sclerosis International Federation: [www.msif.org](http://www.msif.org)

Australia: [www.mssociety.com.au](http://www.mssociety.com.au)

United Kingdom: [www.mssociety.org.uk](http://www.mssociety.org.uk)

United States: [www.nmss.org](http://www.nmss.org)

## **Medication**

Medsafe: [www.medsafe.govt.nz](http://www.medsafe.govt.nz)

PHARMAC: [www.pharmac.govt.nz](http://www.pharmac.govt.nz)

## **Work and Income**

[www.workandincome.govt.nz](http://www.workandincome.govt.nz)

## **Carers**

Carers.net – the online resource for carers: [www.carers.net.nz](http://www.carers.net.nz)

## **Disability**

Weka, What Everyone Keeps Asking – about disability

(contact by phone - 0800 17 1981): [www.weka.net.nz](http://www.weka.net.nz)

## **Complementary and Alternative Therapy**

Rocky Mountain MS Centre: [www.ms-cam.org](http://www.ms-cam.org)



# GLOSSARY

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## Aa

**Acute** Having rapid onset, usually with recovery; not chronic or long lasting.

**Antibodies** Proteins produced by the immune system in response to antigens on foreign organisms or other substances. Antibodies attach selectively to their specific antigens as part of the process by which foreign material is cleared from the body by the immune system.

**Antigen** A substance that stimulates the production of an antibody. Common antigens include protein components of viruses and bacteria, and other foreign substances.

**Ataxia** The incoordination and unsteadiness that results from the brain's failure to regulate the body's posture and the strength and direction of limb movements. Ataxia is most often caused by damage to the cerebellum.

**Autoimmune disease** A process in which the body's immune system causes illness by inappropriately attacking healthy cells, or tissues in the body. Multiple sclerosis is widely believed to be an autoimmune disease, but that is not firmly established.

**Avonex** trade name for Interferon beta 1-a.

**Axon** The core nerve fibre that transmits

electrical signals from a nerve cell to other nerve cells or to muscles. It is covered by the myelin sheath which speeds electrical conduction and insulates the axon from other nerve fibres.

## Bb

**Babinski sign** A neurological sign, common in MS in which stroking the outside sole of the foot with a pointed object causes an upward (extensor) movement of the big toe rather than the normal downward (flexor) movement of the big toe. It results from damage to motor pathways in the CNS.

**Benign MS** Some people with relapsing/remitting MS are described as having a benign form of the disease. It is not possible to diagnose someone initially as having this form of MS, as it is only by looking at the disease ten or fifteen years after its onset that the pattern is evident. Benign multiple sclerosis has little impact on daily living. Individuals may experience a number of mild attacks or relapses, but little or no ongoing disability.

**Betaferon** Trade name for Interferon beta 1-b.

**Beta-interferons** (See also *Interferons and Immune-Modulating Therapy*) Type of interferons which are produced using

genetic engineering techniques and are used for treatment in MS.

**Blood-brain barrier** A semi-permeable layer around blood vessels in the brain and spinal cord that prevents large molecules, immune cells, and disease-causing organisms (eg viruses) from passing out of the blood stream into the central nervous system (brain and spinal cord). A temporary break in the blood-brain barrier occurs as part of the inflammatory process in MS.

**Brain stem** The part of the central nervous system which houses the nerve centres of the head as well as the centres for respiration and heart control. It extends from the base of the brain to the spinal cord.

## Cc

**Catheter** A hollow, flexible tube, made of plastic or rubber, that can be inserted through the urinary opening into the bladder to drain urine that cannot be excreted normally.

**Central nervous system** The central nervous system (CNS) consists of the brain and spinal cord, and includes the optic nerves but not other peripheral nerves.

**Cerebrospinal fluid (CSF)** A watery, colourless, clear fluid that bathes and protects the brain and spinal cord. It can be sampled by a lumbar puncture (spinal

tap). The composition of this fluid be altered by a variety of diseases. Including MS where there is characteristically an increase in proteins produced by immune cells (immunoglobulins).

**Chronic** Of long duration, not acute; a term often used to describe a disease showing gradual worsening over months or years.

**Cognition** High level intellectual functions carried out by the human brain, including comprehension, speech, visual perception, calculation ability, attention (information processing), memory, and executive functions such as planning, problem-solving, and self-monitoring.

**Cognitive impairment** Changes in cognitive function caused by injury or disease process. Some degree of cognitive impairment occurs in many people with MS, with memory, information processing, and executive functions being the most commonly affected functions.

**Coordination** An organised working together of muscles and groups of muscles aimed at bringing about a purposeful movement such as walking or standing.

**Copaxone** Trade name for glatiramer acetate. See also Immune-Modulating Therapy.

**Corticosteroids** Natural hormones produced by the adrenal glands that have anti-inflammatory and immune-system

suppressing properties. Prednisone and methylprednisolone are synthetic steroids used to treat acute MS relapses.

## Dd

**Demyelination** A loss of myelin with relative sparing of axons characteristic of the inflammatory process in MS.

**Diplopia** Double vision, or the simultaneous awareness of two images of the same object resulting from a failure of the two eyes to work in a coordinated fashion. Covering one eye will erase one of the images.

**Disability** As defined by the World Health Organization, a disability (resulting from an impairment) is a restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being.

**Double-blind clinical study** A study in which none of the participants, including experimental subjects, examining doctors, attending nurses, or any other research staff, know who is taking the test drug and who is taking a control or placebo agent. The purpose of this research design is to avoid inadvertent bias of the test results. In all studies, procedures are designed to “break the blind” if medical circumstances require it.

**Dysarthria** Poorly articulated (slurred) speech resulting from dysfunction of the

muscles controlling speech. The content and meaning of the spoken words remain normal.

Dysphagia Difficulty in swallowing.

## Ee

**EDSS** See *Expanded Disability Status Scale*.

**Etiology** The study of all factors that may be involved in the development of a disease, including the patient’s susceptibility, the nature of the disease-causing agent, and the way in which the person’s body is invaded by the agent.

**Evoked potentials (EPs)** Recordings of the nervous system’s electrical response to the stimulation of specific sensory pathways (eg visual, auditory, general sensory). Demyelination in MS results in a slowing of response time. EPs can demonstrate lesions along nerve pathways whether or not they are producing symptoms. EPs are infrequently used for the diagnosis of MS now that MR scanning is widely available.

**Exacerbation** (see *Relapse*) The appearance of new symptoms or the aggravation of old ones, lasting at least 24 hours (synonymous with attack, replace, flare-up, or worsening); usually associated with inflammation and demyelination in the brain or spinal cord.

**Expanded Disability Status Scale (EDSS)**

A scale used to measure a patient's level of disability due to MS. The score ranges from 0 (no disability) to 10 (death) in 20 ½ point steps. It is determined using a standard neurological examination and assessment of walking ability.

## Gg

**Glia** The central nervous system consists of neurons and glial cells. Neurons constitute about half the volume of the central nervous system and glial cells make up the rest. Glial cells provide support and protection for neurons. They are thus known as the “supporting cells” of the nervous system. The four main functions of glial cells are: to surround neurons and hold them in place, to supply nutrients and oxygen to neurons, to insulate one neuron from another, and to destroy and remove the carcasses of dead neurons (clean up). The three types of glial cells are: astrocytes, oligodendrocytes, and microglia.

## Hh

**Handicap** As defined by the World Health Organization, a handicap is a disadvantage, resulting from an impairment or a disability, that interferes with a person's efforts to fulfill a role that is normal for that person. Handicap is therefore a social

concept, representing the social and environmental consequences of a person's impairments and disabilities.

**Hemiparesis** Weakness of one side of the body, including one arm and one leg.

**Hemiplegia** Total paralysis of one side of the body, including one arm and one leg.

**Hyperbaric oxygen** A procedure in which the person breathes oxygen under greater than atmospheric pressure in a specially constructed chamber. Once thought to be a potential treatment for MS, it has been evaluated in several controlled, double-blind studies and found to be ineffective for this purpose.

## Ii

**Immune system** A complex system of various types of cells that protects the body against disease producing organisms and other foreign substances.

**Immune-Modulating Therapy** Medication that changes the response of the immune system without producing general immune suppression. Includes beta-interferons and glatiramer acetate (Copaxone) which have a similar, partial effect in MS in reducing the frequency of relapses by about a third, and reducing the patches of inflammation seen on MR scans. The therapy must be given by regular injections and must be continued

indefinitely to maintain the effect. It is expensive and its availability in NZ is limited by PHARMAC to MS patients with frequent relapses and significant residual disability. (see PHARMAC and MSTAC). In NZ the beta-interferons Avonex (beta-interferon 1a) and Betaferon (beta-interferon 1b) are funded by PHARMAC but not Rebif (interferon beta-1a) or Copaxone, which is a different, non-interferon medication.

**Immunosuppression** A form of treatment which slows or inhibits the body's natural immune responses, including those directed against the body's own tissues. Examples used in MS include cyclophosphamide, methotrexate, azathioprine and mitoxantrone.

**Impairment** As defined by the World Health Organization, an impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function. It represents a deviation from the person's usual biomedical state. An impairment is thus any loss of function directly resulting from injury or disease.

**Incidence** The number of new cases of a disease in a specified population over a defined period of time.

**Incontinence** Also called spontaneous voiding; the inability to control passage of urine or bowel movements.

**Inflammation** A tissue's immunologic response to injury, characterized

by mobilization of white blood cells and antibodies, swelling, and fluid accumulation.

**Intention tremor** Rhythmic shaking which occurs in the course of a purposeful movement, such as reaching to pick something up or bringing an outstretched finger in to touch one's nose.

**Interferons** A group of immune system proteins that are produced naturally in response to viral infections. They restrict the spread of infection and also modulate immune reactions. There are three main types: alpha, beta and gamma interferon. Beta interferon is used as therapy in MS.

## LI

**Lumbar puncture** A diagnostic procedure that uses a hollow needle to enter the spinal canal in the lower (lumbar) spine to remove cerebrospinal fluid (CSF) for analysis.

**Lymphocytes** Type of white blood cells that are major components of the immune system. The main types are T and B-lymphocytes and there are many sub-types with different functions in immune reactions.

## Mm

**Magnetic Resonance Imaging (MRI)**

A diagnostic procedure which produces images of different body parts without

the use of X-rays. Nuclei of atoms are influenced by a high frequency electromagnetic impulse inside a strong magnetic field. The nuclei then give off resonating signals, which differ in different types of body tissue. MR scanning is very sensitive to the inflammatory changes and scarring that occur in MS and is an important in diagnosis and in assessing the effects of new treatments.

**Monoclonal antibodies** Laboratory-produced antibodies, which can be developed to react selectively against a specific antigen in order to suppress a particular response, usually to modify immune reactions.

**MSTAC** Multiple Sclerosis Treatment Assessment Committee, which assesses applications for funding for beta-interferon for PHARMAC in NZ

**Myelin** A coating (sheath) of nerve fibres that is composed of lipids (fats) and protein. Myelin serves as insulation and as an aid to efficient nerve fibre conduction. When myelin is damaged in MS, nerve fibre conduction is faulty or absent, with impaired bodily functions or altered sensations the result.

**Myelin basic protein (MBP)** A major protein component of myelin that may be the target of an autoimmune reaction. The possibility of using oral MBP as MS treatment has led to the controversial development in NZ of genetically modified cows that produce

human MBP in their milk.

**Myelitis** Inflammation of the spinal cord. A common manifestation of an MS relapse.

## Nn

**Nerve** A bundle of nerve fibres (axons). The fibres are either afferent - leading toward the brain and serving in the perception of sensory stimuli of the skin, joints, muscles, and inner organs; or efferent - leading away from the brain and mediating contractions of muscles or organs.

**Nervous system** Includes all of the neural structures in the body: the central nervous system consists of the brain, spinal cord, and optic nerves; the peripheral nervous system consists of the nerve roots, nerve plexuses, and nerves throughout the body.

**Neurogenic bladder** Bladder dysfunction associated with neurologic malfunction in the spinal cord in MS and characterized by a failure to empty, failure to store, or a combination of the two. Symptoms which result include urinary urgency, frequency, hesitancy, nocturia, and incontinence.

**Neurologist** Physician who specializes in the diagnosis and treatment of conditions related to the nervous system.

Neurology Study of the central, peripheral, and autonomic nervous system.

**Neuron** The basic nerve cell of the

nervous system. A neuron consists of a cell body containing a nucleus and one or more processes (extensions) called dendrites and axons.

**Nocturia** The need to urinate during the night.

**Nystagmus** Rapid, involuntary jerky movements of the eyes in the horizontal or the vertical direction.

## Oo

**Occupational therapist (OT)** Occupational therapists assess functioning in activities of everyday living, including dressing, bathing, grooming, meal preparation, writing, and driving, that are essential for independent living. In making treatment recommendations, the OT addresses: 1) fatigue management 2) upper body strength, movement, and coordination 3) adaptations to the home and work environment including both structural changes and specialized equipment for particular activities, and 4) compensatory strategies for impairments in thinking, sensation, or vision.

**Oligoclonal bands** An abnormal pattern of immune proteins (immunoglobulins) on electrophoresis of CSF. Common in MS and helpful diagnostically but not specific for MS.

**Oligodendrocytes** Glial cells that produce and support the myelin sheath, in the

CNS.

**Optic neuritis** Inflammation of the optic (visual) nerve which produces impairment of vision in the affected eye, often with pain on eye movement.

## Pp

**Paraparesis** A weakness, but not total paralysis, of the lower extremities (legs).

**Paraplegia** Total paralysis of both lower extremities (legs).

**Paresis** Partial or incomplete paralysis of a part of the body.

**Paresthesiae** Sensations of burning, prickling, tingling, or creeping on the skin, often with impairment of sensation.

**PHARMAC** The Pharmaceutical Management Agency of New Zealand, PHARMAC, manages a list of subsidised pharmaceuticals, the Pharmaceutical Schedule, on behalf of the Crown. Pharmaceutical suppliers may apply to PHARMAC to have a medicine listed on the Pharmaceutical Schedule for subsidy. Decisions on listing, subsidy levels and prescribing guidelines and conditions are made by the PHARMAC Board with input from independent medical experts who sit on the Pharmacology and Therapeutics Advisory Committee (PTAC) and its specialist

sub-committees, as well as PHARMAC staff. Patients and consumers also have input into PHARMAC's decision-making processes through the Consumer Advisory Committee. PHARMAC also has functions to promote the responsible use of pharmaceuticals and to manage the purchasing of hospital pharmaceuticals on behalf of District Health Boards.

**Physiotherapist (PT)** Physiotherapists are trained to evaluate and improve movement and function of the body, with particular attention to physical mobility, balance, posture, fatigue, and pain. The physical therapy program typically involves (1) educating the person with MS about the physical problems caused by the disease, (2) designing an individualized exercise program to address the problems, and (3) enhancing mobility and energy conservation through the use of a variety of mobility aids and adaptive equipment.

**Placebo** An inactive, non-drug compound that is designed to look just like the test drug. It is administered to control group subjects in double-blind clinical trials (in which neither the researchers nor the subjects know who is getting the drug and who is getting the placebo) as a means of assessing the benefits and liabilities of the test drug taken by experimental group subjects.

**Placebo effect** An apparently beneficial result of inactive therapy that occurs because of the patient's expectation that

the therapy will help.

**Plantar reflex** See Babinski sign

**Plaque** An area of scarring in CNS in MS resulting from a patch of inflammation.

**Prevalence** The number of all new and existing cases of a disease in a defined population at a particular point in time.

**Primary progressive MS** In most cases, people with multiple sclerosis will experience a relapsing/remitting form of the disease. For some people, however, the symptoms will increase over time with no periods of remission. The degree of progression and the time over which it takes place will vary from one person to another.

**Prognosis** Prediction of the future course of a disease.

**Pseudo-exacerbation** A temporary aggravation of symptoms, resulting from an elevation in body temperature or other physiological change such as exercise.

**PTAC** Pharmacology and Therapeutics Advisory Committee.

**PwMS** People or person with multiple sclerosis.

## Rr

**Rebif** Trade name for Interferon beta 1-a.

**Relapse** Sudden deterioration of current symptoms or development of new symptoms resulting from an area of active



inflammation in the CNS in MS.

**Relapsing/remitting MS** The pattern which multiple sclerosis follows differs for different people. The relapsing/remitting form of MS follows a course of relapses (also known as “attacks”) where there is an increased level of symptoms, followed by remissions in which there are less, or no, evident symptoms. The frequency and severity of relapses varies. In a few cases, people with relapsing/remitting MS may go on to develop secondary progressive MS.

**Remission** A lessening in the severity of symptoms or their disappearance following a relapse.

**Remyelination** The repair of damaged myelin. Myelin repair occurs spontaneously in MS but to a limited degree. Research is currently under way to find a way to speed the healing process.

## Ss

**Sclerosis** Hardening or scarring of tissue. In MS, sclerosis is the result of healing of a patch of inflammation.

**Secondary progressive multiple sclerosis** In some instances, people who begin with a relapsing/remitting form of MS may find that over time the symptoms they are experiencing increase. This may be a case of the remaining symptoms after each attack increasing over time, or

the relapsing/remitting pattern may be replaced by a progressive pattern.

**Sensory** Related to bodily sensations such as pain, smell, taste, temperature, vision, hearing, acceleration and position in space.

**Spasticity** A type of increased tone (resistance to passive movement) in the limbs that results from damage to motor pathways in the CNS. May be associated with involuntary spasms of the muscles.

**Spinal Tap** See lumbar puncture.

**Symptom** A subjectively perceived problem or complaint reported by the patient.

## Tt

**T-cell** See Lymphocytes.

**Transverse myelitis** A severe form of myelitis that involves both sides of the spinal cord. The spinal cord loses its ability to transmit nerve impulses up and down. Paralysis and numbness are experienced in the limbs and trunk below the level of the inflammation with loss of urinary function.

**Trigeminal neuralgia** Lightning-like, brief severe pain in the face caused by demyelination of nerve fibres at the site where the sensory (trigeminal) nerve root for that part of the face enters the brainstem.

**Tremor** Uncontrolled trembling or

shaking.

## Uu

**Urethra** Duct or tube that drains the urinary bladder.

**Urinary sphincter** The muscle closing the urethra at the base of the bladder, which in a state of flaccid paralysis causes urinary incontinence and in a state of spastic paralysis results in an inability to urinate.

**Urologist** A physician who specialises in the branch of medicine (urology) concerned with disorders, and care of the male and female urinary tract, as well as the male genital tract.

**Urology** A medical specialty that deals with disturbances of the urinary (male and female) and reproductive organs.

## Vv

**Vertigo** A dizzying sensation of the environment spinning, often accompanied by nausea and vomiting.

**Vibration sense** The ability to feel vibrations against various parts of the body. Vibration sense is tested (with a tuning fork) as part of the sensory portion of the neurological exam.

**Videofluoroscopy** A radiographic study of a person's swallowing mechanism that is recorded on videotape.

**Videofluoroscopy** shows the physiology of the pharynx, the location of the swallowing difficulty, and confirms

whether or not food particles or fluids are being aspirated into the airway.

**Visual acuity** Clarity of vision. Acuity is measured as a fraction of normal vision. 20/20 vision indicates an eye that sees at 20 feet what a normal eye should see at 20 feet; 20/400 vision indicates an eye that sees at 20 feet what a normal eye sees at 400 feet.

**Visual evoked potential** A test in which the brain's electrical activity in response to visual stimuli (e.g. a flashing checkerboard) is recorded by an electroencephalograph and analysed by computer. Demyelination results in a slowing of response time. Because this test is able to confirm the presence of a suspected brain lesion (area of demyelination) as well as identify the presence of an unsuspected lesion which has produced no symptoms, it is extremely useful in diagnosing MS. VEP's are abnormal in approximately 90% of people with MS.

## Ww

**White matter** That part of the brain which contains myelinated nerve fibres and appears white, in contrast to the cortex of the brain which contains nerve cell bodies and appears grey.

## THE MS SOCIETY OF NEW ZEALAND

MSNZ

PO Box 2627 Wellington 6140 NEW ZEALAND

Phone 0800 MS LINE or 0800 675 463

OR 04 499 4677

Email [info@msnz.org.nz](mailto:info@msnz.org.nz)

Website [www.msnz.org.nz](http://www.msnz.org.nz)

## REGIONAL MS SOCIETIES

Northland	09 438 3945	Manawatu	06 357 3188
Auckland & North Shore	09 845 5921	Wellington	04 388 8127
Waikato	07 834 4740	Marlborough	03 578 4058
Bay of Plenty	07 571 6898	Nelson	03 544 6386
Rotorua	07 346 1830	West Coast	03 768 7007
Gisborne	06 868 8842	Canterbury	03 366 2857
Hawkes Bay	06 843 5002	South Canterbury	03 684 7834
Taranaki	06 751 2330	Otago	03 455 5894
Wanganui	06 345 2336	Southland	03 218 3975

## OTHER SOURCES OF SUPPORT

**weka:** *What Everyone keeps Asking* - about disability

website [www.weka.net.nz](http://www.weka.net.nz) phone 0800 17 1981

### Enable NZ

website [www.enable.co.nz](http://www.enable.co.nz) phone 0800 362 253

**Carer's New Zealand** - NZ's national organisation for carers

website [www.carers.net.nz](http://www.carers.net.nz) email [info@carers.net.nz](mailto:info@carers.net.nz)

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