

# MS *in focus*

July 2012

**Is it MS?**



multiple sclerosis  
international federation

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### Multiple Sclerosis International Federation (MSIF)

MSIF's mission is to lead the global MS movement to improve the quality of life of people affected by MS, and to support better understanding and treatment of MS by facilitating international cooperation between MS societies, the international research community and other stakeholders.

Our objectives are to:

- Stimulate and facilitate international cooperation and collaboration in research into the understanding, treatment and cure of MS
- Support the development of effective national MS societies
- Communicate knowledge, experience and information about MS
- Advocate globally for the international MS community

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## Letter from the Editor



MS is a disease surrounded by questions. From the first disturbing symptom, through to the process of confirming (or not) a diagnosis, the experience may be associated with fear, confusion and doubt.

For some people, the diagnosis can be straightforward, perhaps only requiring days or weeks. Others have a prolonged process, perhaps due to presentation of uncommon symptoms, an unclear clinical history or difficulty accessing MS clinicians or diagnostic tests, such as MRI, that today are fundamental for assuring an accurate diagnosis.

Once a person has been diagnosed with definite MS, and the initial questions of “What is happening to me?” and “What is causing my symptoms?” are answered, other questions may take their place. For a person with a chronic illness like MS, other health issues may be attributed to the disease, when in fact they are due to something else.

Advanced research in MS is on-going in many parts of the world, which will contribute to finding answers to many questions. While research is vital to reaching the goal of a world free of MS, there are millions of people living daily with a disease that can be confusing, frightening and unpredictable. *MS in focus* now reaches 100 countries and we hope that this issue will provide answers to at least some of the questions health care professionals and people with MS face.

A big thank you to Dr Elizabeth McDonald, a member of our Editorial Board since 2002, for co-editing this issue of *MS in focus* and for playing an active role in putting together the outstanding authors and content. As the Medical Director of MS Australia, Liz has years of experience in MS, and we are fortunate to have her expert input.

We hope every reader of *MS in focus* will help to disseminate information to others in the MS community by encouraging them to subscribe for paper or e-editions at [www.msif.org/subscribe](http://www.msif.org/subscribe).

**Michele Messmer Uccelli**, Editor

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The next issue of *MS in focus* will be about young people and MS. Please send questions and letters to [michele@aism.it](mailto:michele@aism.it) or marked for the attention of Michele Messmer Uccelli at the Italian MS Society, Via Operai 40, Genoa, Italy 16149.

## Editorial statement

The content of *MS in focus* is based on professional knowledge and experience. The Editor and authors endeavour to provide relevant and up-to-date information at the time of publication. The views and opinions expressed may not be the views of MSIF. Information provided through *MS in focus* is not intended as a substitute for advice, prescription or recommendation from a physician or other health care professional. For specific, personalised information, consult your health care provider. MSIF does not approve, endorse or recommend specific products or services, but provides information to assist people in making their own decisions.

# Introduction to “Is it MS?”

Elizabeth McDonald, MBBS, FAFRM, RACP, Medical Director, MS Australia (ACT/NSW/VIC), Melbourne, Australia

## Is it MS?

This is a question asked by people presenting with neurological symptoms and being investigated for a diagnosis, as well as by people living with MS who are experiencing new or varied symptoms.

“Is it MS?” is also a question asked by primary care doctors, neurologists and health professionals involved in the care of people with MS, both from the time of presentation and diagnosis, and continuing over the entire course of the disease as new symptoms arise.

MS is a complex and chronic disease which can be difficult to diagnose. It is variable and does not follow a predictable course on an individual basis. MS frequently presents with fluctuating symptoms and these symptoms alone may be due to a variety of other different diseases or even stress or low mood. Conversely, people may be diagnosed with stress or depression when it is actually MS. All this makes the topic “Is it MS?” important to address, and highlights the need to look at the issues and necessary factors that should be considered.

Having an unexplained symptom and not knowing what is causing it can create distress, anxiety and uncertainty. Armed with correct information we are able to make informed decisions and choices. It is important to know if it is MS for treatment and management and, importantly, for support and reassurance of the person affected. It is also important to know if it is not MS so that the right diagnosis is made and management of other conditions is not neglected.

## Evolution of MS

Our understanding of MS has increased exponentially in recent times. Where it was once considered to be inactive for prolonged periods when those with the disease were not experiencing

any changes, it is now known to be a dynamic disease and demyelination can occur within the central nervous system (CNS – which is made up of the brain, spinal cord and optic nerve) even at times when the person is not experiencing any new or changing symptoms. This is referred to as the subclinical phase. The use of magnetic resonance imaging (MRI) has helped us to understand and see the changes taking place during this phase. The use of the MRI in both assisting with diagnosis and following disease progression is now widely accepted. This is important, as recent studies have shown that earlier treatment for the relapsing-remitting form of MS has a more positive and beneficial outcome in the longer term.

We also now know that the nerve fibre or “axon”, which carries the nerve messages of the CNS, can be damaged early in the course of the disease. It is this damage which leads to the permanent disability that can occur with MS. Previously, axonal damage was thought to be a late stage of the disease process. This important new understanding of MS has led to research in the new fields of neuroprotection, neurorepair and prevention, which is particularly vital in the progressive forms of MS.

Increasing the understanding of the underlying pathological processes of MS allows for more and varied research that can lead to specific and targeted treatments. We know that the immune system plays a significant role in MS and this has led to the development of drugs that modify the immune system: the immunotherapy drugs that are now available. Further drugs are currently in clinical trials and more are in the development phase.

Improved awareness of who gets MS and where it is more prevalent has also led to development in the fields of genetics and environmental studies. International, collaborative studies are helping to



define the genetic profile of those with MS, with many genes being found that seem more common in those with MS. Further research is needed to define the roles of these genes. The latitudinal gradient seen with MS – that it is more common in areas further from the Equator – has led to current research into the role of ultraviolet radiation and Vitamin D. This is very important work and clinical trials using Vitamin D in early MS are currently underway and should provide answers to questions about early management.

### **“Is it MS” – the personal perspective**

Not knowing if it is MS or not can be very difficult and challenging, with a range of emotions being experienced. These include fear and anxiety, uncertainty about the future, anger and grief. Support by way of understanding and information from MS societies and MS nurses can be very helpful at this time.

Once a person does know, they can start to adjust to it. Having an understanding of what MS is, what investigations are done and why, and how the diagnosis is made, helps the doctor and the individual focus on what is happening realistically, rather than developing unnecessary anxiety and envisaging negative, catastrophic-like scenarios.

Family and friends also need to have appropriate information about what the person with MS is experiencing in order that they can themselves understand and seek support, as well as be supportive. The time around diagnosis can be difficult and protracted with symptoms coming and going, perhaps with no apparent physical changes.

Sometimes receiving the diagnosis of MS is accompanied by a feeling of relief. There really was something wrong, the symptoms were real and it was not something imagined. Having an opportunity to discuss one’s fears can help a person to come to terms with these changes.

### **“Is it MS” – the medical perspective**

The primary care doctor or family physician also has a very important role to play. Unfortunately having the diagnosis of MS does not protect an individual from other illnesses. Maintaining general health and attending regular checkups is important whether one has MS or not. The primary care doctor looks more at the whole person and not just MS.

“Is it MS?” is an important question and the following articles will present helpful information to assist in providing the answer.

# How do I know if it is MS?

<b>Pre-diagnosis</b>	<b>Is it MS?</b>	<ul style="list-style-type: none"> <li>• The emergence of neurological symptoms</li> </ul>
	<b>Diagnosis of MS</b>	<ul style="list-style-type: none"> <li>• Multiple in time – symptoms occurring over time</li> <li>• Multiple in place – due to alterations in different parts of CNS</li> <li>• Exclude other neurological conditions</li> <li>• No single test gives the answer</li> </ul>
<b>During the course of MS</b>	<b>Relapse</b>	<ul style="list-style-type: none"> <li>• New or worsening symptoms for over 24 hours, without obvious cause</li> </ul>
	<b>Pseudo relapse</b>	<ul style="list-style-type: none"> <li>• MS symptoms exacerbated by rise in body temperature or other non-MS factors</li> </ul>
	<b>What to do if experience relapse</b>	<ul style="list-style-type: none"> <li>• Be prepared and in control</li> <li>• Have a “relapse plan”</li> <li>• Discuss with doctor</li> <li>• Exclude pseudo relapse</li> <li>• Depending on symptoms steroid treatment may be prescribed</li> <li>• Know who to contact for physical and psychological support, for example, MS Nurse, MS Clinic, MS Society</li> </ul>
	<b>MS does not exclude other conditions</b>	<ul style="list-style-type: none"> <li>• Do not put everything down to MS</li> <li>• Have regular health checks</li> <li>• Seek assessment of new symptoms</li> </ul>
	<b>Importance of MS Nurse</b>	<ul style="list-style-type: none"> <li>• Source of information and support</li> <li>• Offer advice if things change</li> <li>• Understand local support (medical) systems</li> <li>• Link with all members of the MS team</li> </ul>

# Who gets MS?

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MS is primarily an inflammatory disease of the brain and spinal cord, leading to demyelination and axonal degeneration. Initially, inflammation is transient and resolves itself spontaneously, so demyelination is followed by remyelination, but with time, the degenerative changes become dominant. Thus the most common pattern of presentation is of transient episodes of neurological loss, followed by recovery, and later, accruing disability.

## Presentations

Eighty-five percent of people with MS first present with an acute episode known as a clinically isolated syndrome. This may affect one or, less frequently, several areas of the body. Following this, further acute episodes occur. In the early stages, recovery from each episode may be complete, but with time, recovery becomes incomplete and disability accrues. This period with relapses and recovery is known as relapsing-remitting MS. In time, the majority of people with MS (about 65 percent) enter the secondary progressive phase with progressive disability. In ten percent, disability is progressive from onset, known as primary progressive MS.

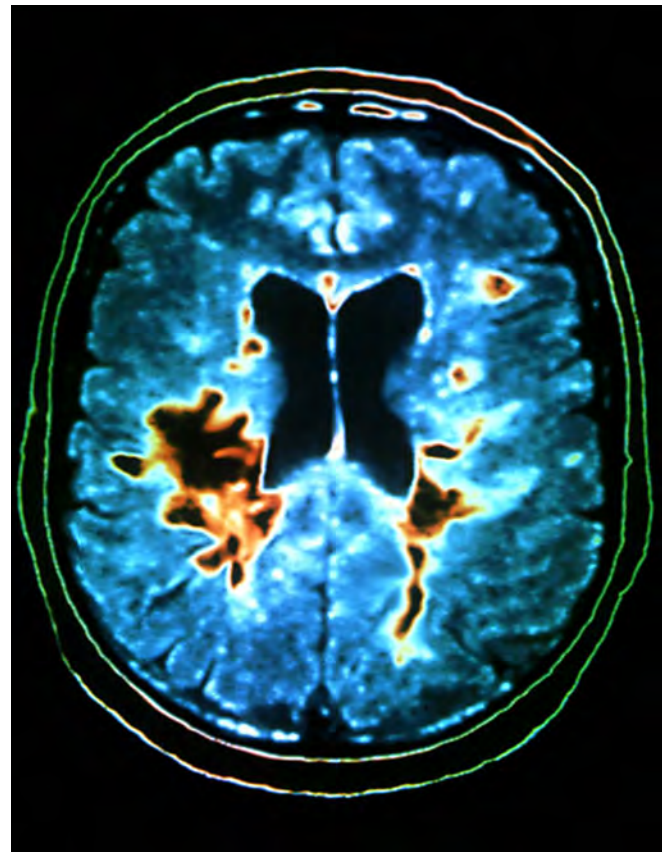
The most common first presentation is with sensory abnormalities (about 30 percent) or with optic neuritis in one eye, which occurs in 20 percent of individuals. Optic neuritis is inflammation of the optic nerve that can be painful upon eye movement, and which can reduce visual sharpness and colour vision.

Brain stem and cerebellar presentations include ataxia (lack of coordinated muscle control) and gaze evoked nystagmus (drift of the eye when looking in certain directions). Spinal cord lesions result in incomplete transverse myelitis (inflammation of the spinal cord) with asymmetric limb weakness, Lhermitte's phenomenon (an

electrical sensation that runs down the back and into the limbs), and urinary frequency and urgency. Lesions in the brain hemispheres can result in weakness and loss of sensation on one side of the body.

## Diagnosis

The diagnosis of MS may be made on clinical grounds when there is evidence of two or more attacks in different parts of the nervous system disseminated over time. However, many people present with a clinically isolated lesion and this is when an MRI may be used to help inform an individual about the risk of conversion to definite MS.



An MRI scan of the brain showing lesions.



Around 50-70 percent of adults with a clinically isolated syndrome will have multiple lesions visible on MRI that do not cause symptoms. Of these people, 60-80 percent will develop clinically definite MS. If a person has optic neuritis, a negative MRI, and a cerebrospinal fluid (CSF) analysis negative for oligoclonal bands, the risk of developing MS is low.

Certain symptoms occur regularly in MS and, despite advances in treatment, symptomatic management remains important. Symptoms reported include fatigue, low mood and anxiety, bladder and bowel dysfunction, cognitive impairment, pain and sexual dysfunction. These symptoms all have a marked impact on daily life, which may lead to decreased participation in family, social, leisure and work activities, and therefore on quality of life.

Many of these symptoms interact. For example, fatigue may be exacerbated by low mood, the use of drugs for increased spasticity or increased physical effort caused by weakness and cardiovascular de-conditioning. Urinary frequency combined with poor mobility may result in incontinence.

Therefore treatment needs careful analysis of the underlying causes of symptoms, and may be best managed by a multidisciplinary team working together.

## Causes of MS

### Gender, including female-to-male ratio

MS is an auto-immune disease, which is characterised by a person's immune system mistakenly attacking and destroying healthy body tissue. Like other auto-immune disorders, MS is more common in women than men, with typical ratios being reported as 2:1. However, evidence from a number of countries suggests this ratio is increasing, with recent studies reporting ratios as high as 3:1. The reasons for this increasing female-to-male ratio remains unclear.

### Genetics and environmental factors

MS occurs in genetically susceptible people affected by an unknown environmental factor – possibly a virus – that triggers an abnormal immune process. MS is therefore caused by an interplay of genetic and environmental factors.



It is well known that the prevalence of MS increases with latitude, which suggests environmental factors. The country of birth also appears to be important. People migrating before their teenage years acquire the risk of the areas they migrate to, but people migrating in adult life retain the risk of the country they were brought up in. People with MS report being infected with mumps, measles, rubella, and Epstein–Barr virus at a later age than other people. It is also more common in higher socio-economic groups. Both these factors are consistent with the so-called hygiene hypothesis, which suggests lack of normal exposure to childhood infectious diseases may predispose susceptible individuals to allergic and autoimmune diseases later in life.

MS is more common in areas populated by Northern Europeans, but the risk to indigenous populations in countries to which Northern Europeans have migrated is lower. For example, in Australia, the risk for MS is higher in the European migrants than the Aboriginal and Torres Islander populations. These findings suggest a genetic component. Differences in the human leukocyte antigen (HLA) system (a group

of genes related to immune-system function in humans) increase the probability of developing MS. The association between sun exposure (latitude), HLA types and Vitamin D status is currently being explored and our understanding of this relationship is evolving.

Given the genetic findings, it is not surprising that MS has a higher recurrence rate within affected families. Twin studies show higher concordance in identical than non-identical twins, with identical twins having a 25 percent rate and non-identical having the same as any other sibling, at five percent. Adopted children to families with a family history of MS have the same risk as the rest of the population; children where both parents have a family history have a higher risk. All this suggests genetic factors are important in susceptibility to MS.

In summary, the causes of MS remain to be fully elucidated and understood. Numerous risk factors have been examined but growing numbers of studies around the world and new technologies will allow the interplay between genetic and environmental factors to be investigated further.

### Prevalence of MS globally



# Unravelling the complexities of MS

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## Introduction

“How do you know that I have MS?” People who are newly diagnosed, as well as some of those who have had the disease for many years, continue to ask this question. Despite the many advances in neuro-imaging and genetic testing, the cause of MS remains elusive. It is much easier to definitively diagnose a disease if we have a definite cause such as a gene mutation. The use of MRI has assisted in the recognition and treatment of MS at much earlier stages, although MS remains a clinical diagnosis. There is no single test, but diagnosis is based on the person’s history of symptoms, physical examination findings and supportive evidence from MRI, cerebrospinal fluid (CSF) analysis and visual evoked potential testing.

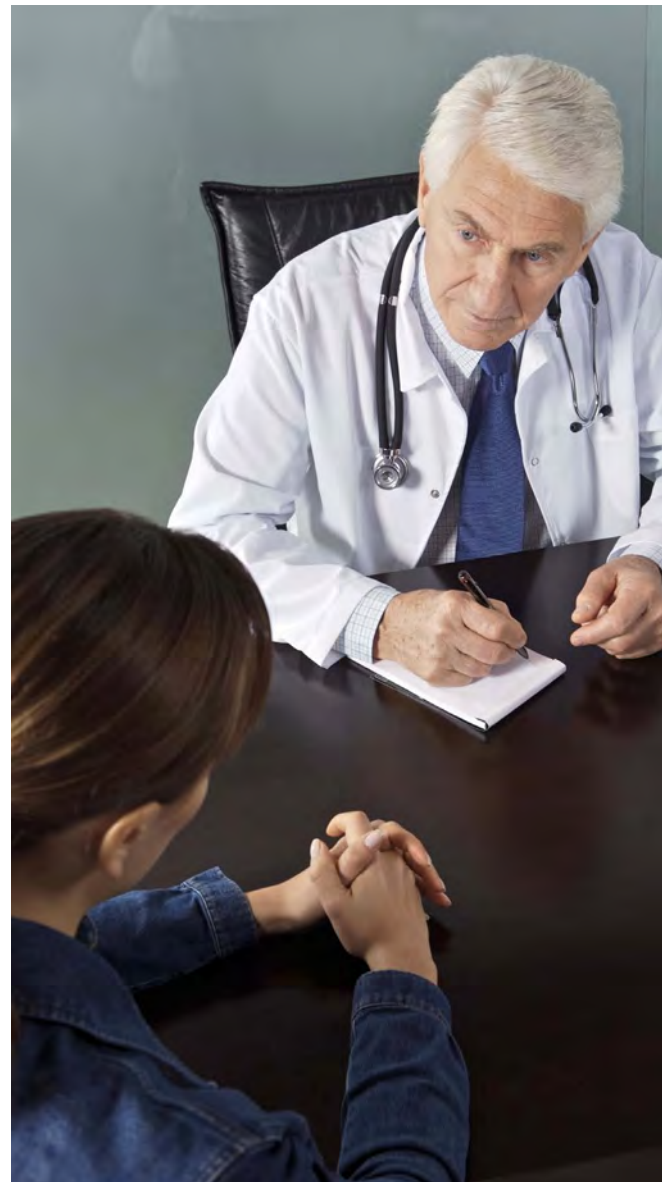
## Diagnosis: Why is it so difficult?

A 24-year-old woman presents with a loss of vision in her left eye and pain with eye movement, which developed over two days. Her ophthalmologist diagnoses her with optic neuritis and arranges an MRI scan. Her MRI of the brain reveals three white spots, or “lesions”, in addition to an enhancing lesion in her left optic nerve. She is then referred to a neurologist for an evaluation of possible MS.

Classic diagnostic criteria for relapsing-remitting MS (RRMS) requires neurological symptoms to be separated in time (at least 30 days) and to involve more than one area of the CNS (brain and spinal cord). Neurologists used to wait until a second symptom occurred to diagnose clinically definite multiple sclerosis (CDMS) and start treatment. This became problematic because the second attack could be many months or years later. Clinical trials for MS treatment clearly show that

earlier treatment is better in terms of lessening disability progression and improving prognosis.

Clinically isolated syndrome (CIS) is a term used to describe a sentinel event that will lead to a future diagnosis of MS. This term implies that



The person’s clinical history is an important part in diagnosing MS.

the individual has no recollection of a previous neurological event. However, if they have evidence of demyelinating lesions consistent with MS in areas outside of the one causing their current neurologic dysfunction, studies have shown that they are likely to have future events and meet the diagnostic criteria for RRMS. The woman in the case would be classified as having CIS.

### **Why is a brain MRI with lesions not sufficient to make a diagnosis of MS?**

Not every abnormal MRI with “white matter lesions” means the person has MS, and neither does every constellation of multiple neurologic symptoms. Vascular disease, migraines and malignancy can all be associated with different patterns of white matter lesions in the brain and possibly in the spine. Additionally, there are other diseases in the spectrum of “demyelinating disease” such as acute demyelinating encephalomyelitis (ADEM), which usually occurs in children and is not recurrent, so does not require long-term treatment. Another disease in the spectrum of demyelinating disease is neuromyelitis optica (Devic’s Disease), which primarily involves the optic nerves and spinal cord. The treatments for this disease are different from MS so it is important to distinguish between the two.

MRI of the spine can be helpful to assess for evidence of demyelination or other lesions that may explain neurological dysfunction. Degenerative disc disease or other structural defects causing spinal cord compression or nerve root compression, can present with signs of MS.

### **How could other tests such as cerebrospinal fluid analysis (CSF) and visual evoked response testing help with diagnosis?**

Abnormal CSF shows evidence of increased immune activity such as oligoclonal bands, elevated IgG index and/or elevated IgG synthesis rate. Nearly 80 percent of those diagnosed with MS will have at least one of these spinal fluid abnormalities, but normal results do not exclude

the diagnosis, especially early on in the disease. In other words, if CSF is abnormal it supports a diagnosis, but if it is normal, it does not rule out the diagnosis. CSF studies are also helpful to rule out infection and evidence of malignancy, which can also cause neurological symptoms. Visual evoked response testing (an electrical potential recorded from the nervous system following a stimulus of light) can reveal evidence of demyelination in the optic nerves, which cannot always be identified on MRI.

In the case of the 24-year-old woman discussed earlier, she may, for example, later recall an episode of right-arm weakness that lasted for two weeks, which she attributed to a pinched nerve in her neck. If there is objective evidence of dysfunction on her neurological examination, such as increased reflexes in the right arm and leg, the goal of the evaluation is to support the diagnosis of MS, so the criteria of symptoms separated in time and space is now fulfilled. It is still important to look for further support of the diagnosis and to ensure that there is no alternate diagnosis that better explains the symptoms.

An evaluation for MS is targeted not only at finding evidence of demyelination, but also at ruling out other potential causes of neurologic dysfunction. Several categories of disease can mimic symptoms of MS including vascular disease, infection, vitamin deficiencies and rheumatologic disease. Other physicians such as rheumatologists and ophthalmologists may be consulted to rule out other causes of the symptoms. Difficulties also arise in people who cannot have an MRI because of implanted devices, such as a pace-maker. In some cases, lesions may be extremely difficult to distinguish from tumours and a brain biopsy may be needed to make a definitive diagnosis.

Finally, in some cases, even after all diagnostic tests have been exhausted, the diagnosis may still be unclear. In these instances, a person may need regular follow up, with repeated clinical assessment and MRI, before diagnosis can be made definitively.



## Primary progressive MS

What if the 24-year-old individual was instead 55 and had presented with a one-year history of progressive leg weakness and falling? She is referred by her primary care physician because she has had MRIs of her complete spine that have found no degenerative disease which would explain her symptoms. However, she did have some lesions in her cervical spine that are suspicious for demyelination and CSF that is positive for oligoclonal bands. How would this change the diagnosis? Although 85 percent of people are diagnosed with the relapsing-remitting form of the disease, a small proportion of people (10 percent), such as this individual, have primary progressive MS at onset.

Diagnosis of primary progressive MS requires at least one year of progression, along with at least two other neurological symptoms in different parts of the body, with one or more characteristic brain lesions, two or more typical spinal cord lesions or positive CSF analysis.

For this person, the investigation would proceed with a brain MRI, and, to rule out infection and

malignancy, other CSF testing and laboratory tests. Unfortunately, there are no approved treatments for progressive forms of MS, but symptomatic treatment and rehabilitation are important interventions that can improve quality of life.

## Looking ahead

There are now disease-modifying therapies that are approved for the treatment of both clinically definite MS (CDMS) as well as clinically isolated syndrome (CIS). In addition, the most recent revised diagnostic criteria permit a diagnosis of MS in one visit. If the individual has neurologic symptoms, plus MRI evidence of old white matter lesions, in conjunction with new ones, a diagnosis of CDMS can be made, and treatment started immediately. This is important because lesions can accumulate in the absence of clinical symptoms and early treatment can decrease lesion burden and long-term disability.

Disease-modifying therapies have changed the natural history of MS, so many of the figures for periods of time used to describe disability and conversion from relapsing-remitting MS to secondary MS may be changed in the future.

# The course of MS and changes to expect over time

Marcelo Kremenchutzky, MD, Multiple Sclerosis Clinic in London, Ontario, Canada

MS is an inflammatory, demyelinating, degenerative, complex neurological disease with wide variation from person to person. Symptoms sometimes come and go as a reminder that a person does have MS, sometimes with minimal physical impairment and, at other times, symptoms may develop into more severe disability.

This variability is one of the hallmarks of MS and it creates a large source of uncertainty in people's lives. There are many reasons for this, but in part, it is because of how MS affects each person's central nervous system (CNS).

In relapsing-remitting MS (RRMS) the damage to the CNS is a process of periodic relapses. These MS lesions can be seen on MRI scans and evolve in different ways; some quickly settle down, as the body repairs the damage. Months or years can pass between relapses with no new symptoms because the body has time to heal itself through remyelination (a process of mending nerve fibres by growing new myelin to protect the nerves).

Over time, some lesions are harder to repair due to repeated relapses, which can result in permanent damage or scarring, leading to continued and gradual worsening (progression). These lesions persist as areas of permanent nerve damage that appear dark on MRI (black holes) and become more significant as the illness progresses.

It is very important to have a neurologist with experience in MS, as conventional MRI has a poor correlation with clinical outcomes and most MS lesions produce no symptoms at all. Thus MS is best monitored clinically with regular follow-up visits.

It has been estimated that only 10 percent of MS lesions result in some type of symptom. Whether a given lesion produces symptoms or not will depend, in part, on the area of the CNS that is affected, and the severity of the damage. The electric-current-like sensations that a person with MS may experience down their back or arms when bending their neck forward (called Lhermitte's sign) appears to be caused by a lesion in the upper spinal cord. Bowel and bladder symptoms often occur with lesions in the spinal cord. Lesions in the mid-pons (part of the brain stem) can cause intense facial pain (trigeminal neuralgia).

Relapses can be unpredictable and people with RRMS often need help to cope with this uncertainty, as symptoms are as variable as the course of the disease. Some individuals may experience only one or two symptoms throughout

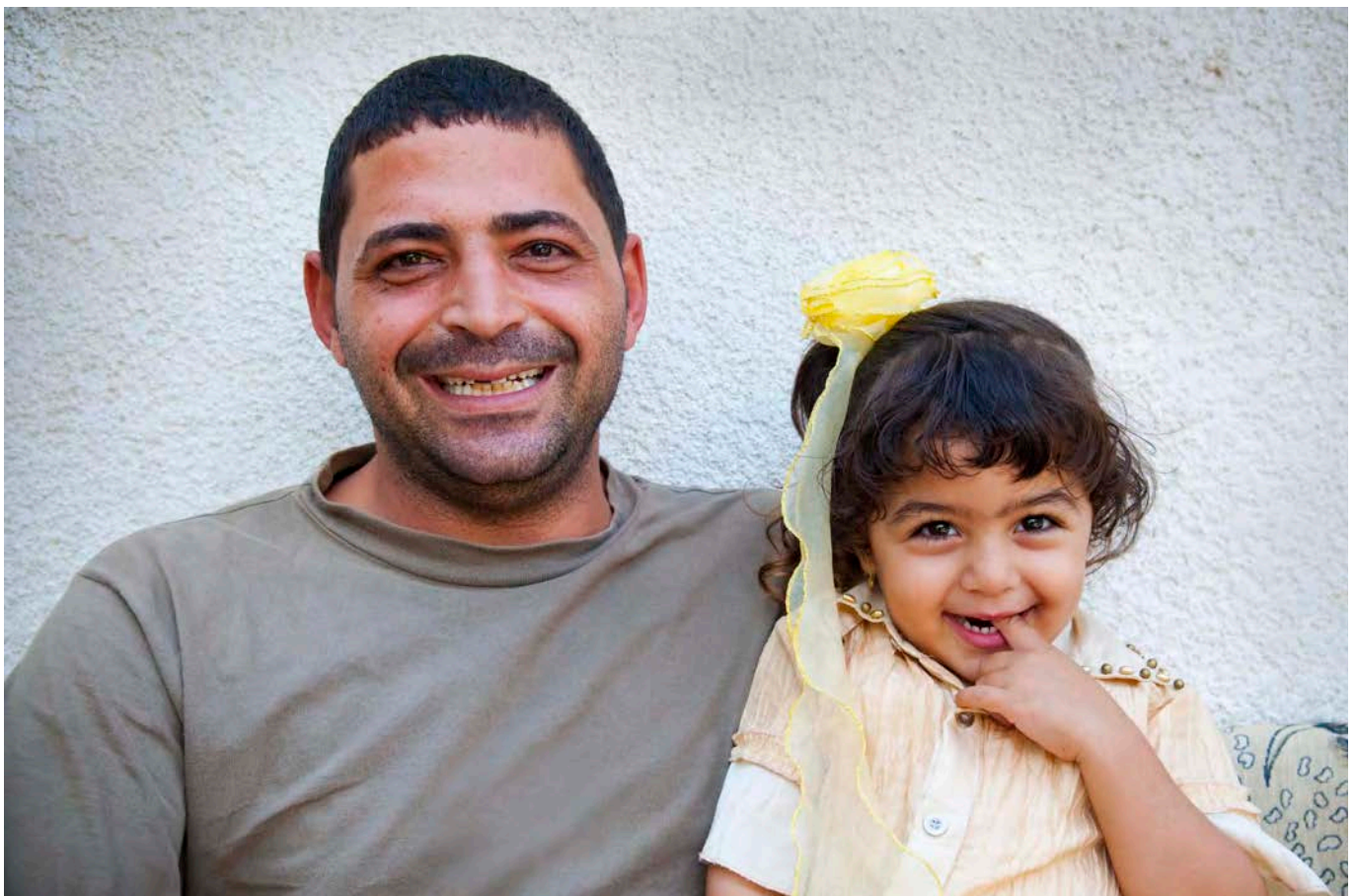


the course of their disease, while other people may accumulate disabling symptoms quite rapidly. In addition, symptoms can come and go with relapses, fluctuate in intensity from day to day or gradually increase over time.

Many people only start to worsen several years after diagnosis, with increasing levels of disability without remission. This is known as the secondary progressive type of MS. Less common is the primary progressive type of MS (10 percent of people at the onset of MS), with a nearly continuous worsening of symptoms from the beginning of the illness, usually without relapses or remissions at all. People with progressive types of MS may sometimes feel they can adapt better, as their disease course is more predictable than the relapsing types. Nowadays people with RRMS can feel optimistic as there are several approved therapies to prevent relapses. People with progressive MS lack these options and rely primarily on symptomatic management and supportive care.

The available treatments help to reduce or modify disease activity and are more effective earlier for people with the relapsing type of MS. By decreasing the episodes of inflammation and demyelination (relapses), the aim is to slow down the accumulation of disability or progression over time. However, scientific proof is still being evaluated. It is therefore best to initiate treatments early in the course of MS, before progressive disability begins, in order to reduce the frequency of relapses. There are a number of clinical trials looking at the efficacy of current treatments for all types of MS.

A relapse is a worsening of symptoms in the absence of a trigger, better explanation or an underlying cause, such as another illness, an infection, over-heating or increased stress. Should there be a trigger, such as a bladder infection, it is called a “pseudo-relapse” and it is important to treat or manage this underlying cause first – the MS symptoms may then improve and return to what they were before the infection occurred.





A multidisciplinary team may include physicians, nurses, physiotherapists, occupational therapists, counsellors, dietitians and speech language pathologists.

However, when a relapse does occur, depending on the severity or impact on one's ability to function, a physician sometimes prescribes corticosteroids to help reduce CNS inflammation and hopefully promote a faster recovery. It is important that people with MS educate themselves about the disease and that they contact their doctor promptly if they think they may be having a relapse. Corticosteroids do not have a significant impact on the long-term course of MS but can reduce the duration and severity of the relapse.

If you have MS, contact your doctor if:

- you experience new neurological symptoms that last longer than 24 hours  
OR a significant change in your MS symptoms lasting more than 48 hours
- AND no excess heat or stress, infection or other illness.

### Monitoring and support

Treatment of MS symptoms is arguably the most important aspect of MS therapeutics. Alongside medications, aids (for example canes or grab bars), coping strategies and lifestyle modifications will help improve quality of life. All these aspects of MS are ideally monitored regularly by a neurologist, MS nurse or other appropriate health

care professional. Regular review of a patient-centred treatment plan can also help reduce the severity of symptoms and improve function, and is best carried out by a multidisciplinary team (including physicians, nurses, physiotherapists, occupational therapists, counsellors, dietitians and speech language pathologists) at an MS clinic where available. This team can evaluate and recommend strategies to improve the management plan for a person with MS.

A specialised MS clinic can also provide information about local programmes available to people with MS and may provide other services such as:

- support and counselling to people with MS and their family on being diagnosed with MS and living with a chronic disease
- information to people with MS and their families about appropriate community resources
- support for financial, employment and career issues.

MS clinics are recognised internationally for their pioneering role in MS research as well as their care of people with MS. People with MS can check with their doctor or MS society if this kind of support is available in their area.

# Living and ageing well with MS

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With advances in health and medical care, people are living longer – including people with MS. While the symptoms and complications of MS may reduce life expectancy for a small proportion of people, the majority will generally live as long as their friends and family who do not have MS.

With increasing age, the risk of age-related health issues becomes greater; these include heart disease, osteoarthritis, changes in vision, hearing, sleep, sensation, the ability to metabolise medications and muscle atrophy. These normal changes may partially explain research findings that show that the progression of MS is both age-related and age-accelerated.

The combination of normal ageing changes and MS progression means that people with the disease and their health care providers must thoroughly consider a range of possible causes when new health or activity-related limitations emerge.

By drawing on and combining knowledge and strategies from both MS care and geriatric care, the challenges associated with ageing with MS can be effectively managed. Effective management can, in turn, promote health and quality of life, and allow people to live and age well despite health challenges and accumulating disability caused by MS.

## Managing changes in mobility

As people age, muscle strength and reaction times tend to decline. Pain, swelling and reduced range of joint motion can occur as a result of osteoarthritis and general years of use. There are normal declines in vision and hearing. Information processing can also slow. Even if a person does not have MS, these changes can make it more

difficult to safely walk around, climb stairs, and transfer in and out of a chair, a vehicle or a bath.

For both older adults and people with MS, mobility changes can increase the risk of falls and fall-related injuries. Fear of falling, even among people who have not experienced a fall, can lead to reduced activity, physical de-conditioning and increased fall risk. Fatigue and depression can further complicate matters and lead to social isolation and loneliness.

Because falls are a leading cause of accidental death among older people, practice guidelines from the American and British Geriatrics Societies (AGS/BGS) encourage health care providers to regularly ask their patients about falls so that targeted interventions can be put in place to address relevant risk factors. Until comprehensive, MS-specific information is available, members of the MS care team can draw on the AGS/BGS guidelines to ensure that their approach to mobility changes and fall risk management is comprehensive.

These guidelines recommend that all older adults who have gait or balance problems, or who present with a fall, be assessed for all of the following factors:

- Fall history and circumstances
- Medications and their side-effects
- Vision
- Strength and balance
- Blood pressure and heart rate and rhythm
- Activities of daily living, including the use and fit of adaptive equipment mobility aids
- Fear of falling
- Feet and footwear
- Safety of the person's home environment.



Since people with MS may experience age-related changes sooner than their similar-aged peers, health care providers should consider conducting fall risk assessments with people with MS well before they turn 65 years of age.

### Driving, ageing and MS

For people with MS who are limited in their walking abilities, being able to continue to drive may be particularly important in order to conduct daily activities and remain socially active. Since many normal age-related changes can negatively impact driving and driving safety, significant attention is being paid to the issue of older adult driving in many countries.

In addition to normal age-related physical changes, such as a reduction in strength, vision and range of motion, the ability to drive is also influenced by cognitive changes, for example, attending to multiple stimuli, multi-tasking and information processing speed.

Driving related issues and challenges have not been well studied among people with MS. Yet, there are many resources for older adult drivers that people with MS and their health care providers may find useful through websites such as the US Centers for Disease Control and Prevention.

These resources suggest that key strategies for addressing driving safety include:

- Reviewing medications and their side effects, and planning driving activities to accommodate side-effects when needed
- Having regular vision assessment
- Using cognitive compensatory strategies such as reducing distractions – such as talking with others, listening to music, talking on the phone or eating – when driving and planning routes in advance
- Taking older driver safety courses
- Having car checked and adjusted to ensure optimal positioning when driving (for example, positioning of the seat and steering column).



Check with the driving authority in your country for any further guidelines or regulations.

### Managing changes in life situations

Research has shown that people who are ageing with MS are concerned about becoming a burden on family and friends if their care needs become greater. They also worry that their care needs may exceed what others can provide, which would necessitate a move to an assisted living or nursing facility.

These concerns are also shared by people who are growing older without MS. The major difference is that people with MS often have these concerns and worries much earlier in their lives, often beginning in early middle age. Retiring from work, having children move out, or losing a spouse, life partner or other close family member or friend can further exacerbate these worries and add to underlying depression, feelings of fatigue and social isolation.

As a result, health care providers need to ask people who are ageing with MS about broader wellbeing issues and changes in general life situations. Where available, referrals to community

support services, social workers or case managers may provide the necessary support to individuals who are simultaneously coping with normal age-related changes in life situations as they also cope with MS symptoms and activity limitations.

## Ageing well with MS

Not all challenges and limitations experienced by people ageing with MS will be due to their disease or its progression. Normal age-related changes in physical and cognitive abilities, physiological functioning and life situations can also occur.

Taking a holistic and comprehensive perspective and drawing on diverse knowledge (MS, geriatric and chronic illness management, for example) can provide guidance for health care professionals with regard to screening, assessment and the selection of intervention options.

Research on chronic illness self-management suggests that developing partnerships between people and providers, and supporting individuals to develop skills for problem-solving, decision making, goal setting, and finding and using resources, will facilitate improved quality of life and better health outcomes. Supporting self-management can help support people with MS to live and age well.



# Keeping yourself healthy

Regular monitoring of a person's general health status is very important. Often people with MS and their carers spend so much time coping with the disease that they have little time to dedicate to preventive health.

This table lists screening examinations that a person should have regularly, based on advice from their doctor. The need for and frequency of these examinations may depend on age, medical history, ethnic group and family history. Since internationally accepted recommendations are not available for most of these procedures, a primary care doctor should be consulted.

**Blood pressure check** A procedure that uses a small, portable instrument called a blood pressure cuff (sphygmomanometer), which registers the blood pressure in units called millimetres of mercury (mm Hg).

**Breast self-examination** A visual and physical examination of the breasts to detect changes in colour, the appearance of dimples, lumps and other abnormalities.

**Chest X-ray** A safe radiology test that involves exposing the chest briefly to radiation to produce an image of the chest and the internal organs of the chest.

**Colonoscopy** A procedure using a viewing tube that enables an examiner to evaluate the appearance of the inside of the colon (large bowel).

**Complete blood count** A calculation of the cellular elements of blood, a major portion of which measures the concentration of white blood cells, red blood cells and platelets in the blood.

**Complete skin examination** A procedure performed by both the health care professional and the individual, to detect new growths, sores that do

not heal, changes in the size, shape, or colour of any moles, or any other changes on the skin.

**Coronary artery disease screening (CAD tests)**

A screening procedure to detect blood-flow limiting blockages in the coronary arteries that involves stressing the heart under controlled conditions.

**Digital rectal exam** An examination to detect abnormalities that can be felt from within the rectum – the health care professional inserts a lubricated, gloved finger into the rectum and feels for anything that is not normal.

**Dual X-ray absorptiometry or DEXA (bone density scan)** A test that uses a machine (DX scanner) that produces two X-ray beams, each with different energy levels. One beam is high energy while the other is low energy. The amount of X-rays that pass through the bone is measured for each beam and depends on the thickness of the bone. Based on the difference between the two beams, the bone density can be measured.

**Electrocardiogram (ECG/EKG)** A non-invasive test that positions electrical sensing devices on the body to reflect underlying heart conditions by measuring the electrical activity of the heart.

**Faecal occult blood tests** Special chemical tests performed on stool samples to detect traces of blood (undetectable to the naked eye) that may be due to slow bleeding from colon polyps or cancers.

**Fasting blood glucose** A method for learning how much glucose (sugar) there is in a blood sample taken after not having eaten for a period of time, usually overnight, commonly used in the detection of diabetes mellitus.

**Flexible sigmoidoscopy** A procedure to examine the rectum and the lower colon for rectal bleeding or other abnormalities, using a flexible tube gently inserted into the anus and advanced slowly into the rectum and then the lower colon.

**Liver blood enzymes** A blood test that determines the presence of certain liver enzymes in the blood stream rather than only in the cells of the liver.

**Mammogram** An X-ray test that produces an image of the inner breast tissue on film, visualising normal and abnormal structures within the breasts.

**Oral examination** A procedure to detect changes in the colour of the lips, gums, tongue or inner cheeks, and for scabs, cracks, sores, white patches, swelling or bleeding.

**Cervical smear (Pap test)** A procedure in which a sample of cells from a woman's cervix (the end of the uterus that extends into the vagina) is collected and smeared on a microscope slide. The cells are examined under a microscope in order to look for changes that may indicate cancer.

**Prostate specific antigen (PSA)** A blood test that measures the amount of PSA (a protein produced by the prostate gland) present in the blood stream, which is used to screen for cancer of the prostate.

**Testicular self-examination** A procedure for detecting the early signs of testicular cancer that involves checking the testes visually and physically for new swelling or other changes.

**Thyroid scan** A nuclear medicine procedure that takes an image of the thyroid gland as it accumulates radioactive material that is ingested by mouth.

**Tuberculosis Skin Test (PPD Skin Test)** A procedure that injects a purified derivative of tuberculosis into the skin to determine if there has been prior infection, which is confirmed when a hard, raised area at and around the injection site appears.

**Urinalysis** An analysis of the urine that can detect evidence of diseases, even some that have not caused significant symptoms.

**Visual field test** A method of measuring an individual's entire scope of vision, mapping the visual fields of each eye, in order to detect any signs of glaucoma, damage to the optic nerve and/or damage to the retina.

*This table was first used in the Health Living edition of MS in focus. Download or read this edition at [www.msif.org/msinfocus](http://www.msif.org/msinfocus)*

# Providing support during the uncertainties of MS in Australia

Gayle Homann, Peer Support Program Leader, MS Australia – ACT/NSW/VIC

## Programme description

Since 1956, MS Australia has been assisting people living with MS, as well as their family members and carers, through the provision of specialised services and programmes, such as the Peer Support Program (PSP).

The organisation's integrated approach to chronic disease management includes enabling people with MS to meet and connect for practical and emotional support. The PSP is flexible and responsive to the needs of individuals and the framework is designed to empower people with MS to use their personal experience to support others.

The programme provides the opportunity for people living with MS, their families and carers to be supported by others who also live with MS and have undertaken specific training to provide practical and emotional support through their "lived experience". The programme offers three modes of support via telephone, online and face-to-face. People are able to choose the type of support which best meets their particular circumstances.

**Telephone support** No matter where a person with MS lives, telephone support provides the opportunity for that person to be matched with a trained Peer Support Volunteer for one-to-one telephone support.

**Online support** Our online communities provide a forum and chat-room, and more recently a Facebook group established specifically for younger carers aged 13-21. This is moderated by a young carer who is a trained Peer Support Volunteer.

## Lisa, a Peer Support Volunteer

Lisa started volunteering because she believes that "everyone needs support and friendship. When I was diagnosed with MS in 1996, I was turning 30 and pregnant with the second of my four children. I found the staff at MS Australia supportive, but I needed to speak to a person living with MS. So 11 years ago I volunteered to provide telephone support to other mums with MS. Speaking to people living with MS is a positive experience. Peer support helps people to move forward with their lives from the moment they are diagnosed. It also helps to have support during all the challenges MS and life brings. It's about supporting each other through whatever we are facing."



**Face-to-face support groups** There are currently a range of support groups which provide the opportunity for people to share information and experiences for mutual support. These groups are led by trained Peer Support Volunteers and meet at various locations throughout the community and are established according to an identified need within the area for people to meet and connect.

## Background

The PSP was introduced into the state of Victoria in Australia in 2001. The main factor leading to its development was feedback via consumer focus groups and surveys of people with MS. A consistent message articulated by people living with MS and their families and carers was the need for a structured peer programme whereby people were supported by others with a shared "lived experience".

## Training and volunteer support

Trainee Peer Support Volunteers are selected from various backgrounds and circumstances. They have indicated a desire to support others, believe they have the capacity to do this effectively, and demonstrate the required skills, behaviours and attitudes for an effective Peer Support Volunteer. Those wishing to become involved in the programme and undertake the training must have lived with MS for at least two years.

MS Australia Peer Support Programme staff train the Peer Support Volunteers. There are currently 180 trained Peer Support Volunteers working across the three modes of support. The special qualities, experience and commitment of Peer Support Volunteers, combined with ongoing training, supervision and continual assessment and support, contributes to the programme's success. Staff are available to provide mentor support or debrief Peer Support Volunteers, and they can go "on hold" at any stage if they are not able to meet their commitments either due to their MS or for personal reasons.

## Reviewing the programme

The PSP is currently servicing more than 500 people per month across the various modes of support. The programme has a well-developed framework with policies, procedures and training manuals, and is regularly audited. The programme

has an ongoing strategic commitment to strengthening and adding value to existing PSP services, including a focus on rural/regional areas and cultural and linguistically diverse communities.

## Future of the programme

With the ongoing need and expansion of the PSP, it has become clear that mentor support is necessary to build capacity and support the transition of newly trained volunteers across the programme. MS Australia hopes to develop this mentor programme in the near future with specialised training and support given to existing experienced volunteers. There is also an increasing need to train more carers and family members to work across the programme.

## Conclusion

The PSP is a vital service that provides people living with a chronic illness the opportunity to meet and connect. The programme enables those seeking support and encouragement to receive it in a way that helps them to make sense of their experiences, to feel less isolated and fearful, and to come to terms with the changes and challenges in their life journey with MS. Peer support programmes come in many forms. They may be broad or specific, but all aim to assist participants to rebuild their self-esteem and sense of identity, and enable a greater confidence in the future, providing much needed hope!

### Anna\*, Victoria, Australia

It has been two years since I was diagnosed with MS. During the first year I was confused, frightened and very scared of what might lie ahead. I read all I could about MS but still felt very alone and that my family and friends didn't understand what was happening to me, no matter how hard they tried or cared.

But 12 months ago I made contact with MS Australia and they asked if I would like to talk to someone through the Peer Support Program. I agreed, and was matched with my telephone Peer Support Volunteer. It was like talking to someone I had known my entire life; we talked about family, work, life and about our MS. It was great to talk to someone who understood what I was going

through. When I said "some days I just feel unwell" she knew exactly what I meant. I felt relieved after speaking to her, especially when we discussed how her partner, family and even friends and work colleagues coped with her MS. I had this great sense of relief that it is not only me that is angry about having MS or that my family doesn't understand what I am going through.

After our telephone conversations, I felt so much better within myself and I began to understand my MS so much more. I felt that finally someone understood! I shall never forget my Peer Support Volunteer and how she gave me hope at such a difficult time in my life.

\* Real name withheld

# Two personal journeys to a diagnosis: Poland and India

## Zuzanna, Warsaw, Poland

I am 27 years old and work as a neuropsychologist, an anthropologist of culture and a journalist. I live in Warsaw with two cats, Mia and Ganesia.

I was diagnosed with MS two years ago, but I think it started in high school. It was not until 2009 that there was a turning point. I was walking in the Tatra Mountains with my best friend, Monica, and amid the extraordinary landscape, at a height of 2,000 metres, I felt as if hundreds of small ants had passed over my body. I also realised that I could not control my gait. The strange feeling passed after a while.

Once I was home, more symptoms appeared – a strange shiver along my spine that would come and go, and my neck itched terribly. But, most disturbing, was my problem with concentration, attention and memory. My friends and family used to say I had a memory like an elephant, so when I started to forget the simplest things I felt like I ceased to know who I was. My other main symptom is depression which, unfortunately, has not yet been treated with any success. Sometimes I am better, sometimes worse. This is the life that I have learned to live.

My diagnosis came about after visiting my GP, who referred me to an orthopaedic specialist because of the feelings in my spine. The orthopaedic surgeon arranged an X-ray and I waited for the results. “The X-ray is clear”, said the orthopaedic surgeon, “there is no problem with your spine”. “What about the numbness?” I asked. I was worried and confused but did not want to be a hyperchondriac. The doctor asked my age and then handed me a referral for a neurological consultation.

At my appointment with the neurologist, I was asked to close my eyes and to touch the tip of my nose with my right index finger, and then the left. I knew where my finger should go, but I touched my



cheekbone instead of my nose. The neurologist then arranged for an MRI scan. I noticed words on the notes about MS and became very frightened.

At the MRI the radiologist said, “Do not move. Once it starts it is quite loud, but you will get used to it. Good luck”. I was left alone in a deafening and unpleasant tube. After a while, I heard a series of repetitive high-frequency sounds which sounded like 1980’s electronic music; a mix of synthesizer and bass guitar. Being in a closed, claustrophobic space seemed to make the time pass even more slowly.

I left the hospital feeling full of fear. Fortunately, I was not alone. My friend Irena was waiting for me. “Well, how was it?” she asked. I saw scientific curiosity in her eyes. “Sorry,” she said, “What did the doctor say? Do you have the result?” I replied “The result will be ready in an hour. I’m so hungry. Let’s go and eat”.

An hour later, Irena stood beside me and we watched the pictures of my brain. “At least you can see that I have a brain” I said to her, stifling fear with black humour. We smiled at each other but then I felt tears well up in my eyes. “Now what?” I asked.

For some, the diagnosis of MS is the end of the world. I would be lying if I said that I had no such thoughts. The fear that accompanied me in the first moments was enormous. I had just turned 25. Paradoxically however, MS started a new stage of my life. I started the battle for myself and so far I am winning. My perspective has been changed by knowing other people with MS, gathering information about treatments and taking part in an experimental drug trial. The therapy is working, making me feel positive and that life is not meaningless.

Thanks to organisations such as the Polish National Multiple Sclerosis Society, people with MS have an opportunity to establish a personal bank account, and the right to collect funds for treatment and rehabilitation. Donations from friends, acquaintances and even strangers means that I have enough money for treatment for six months.

It is not easy to open up and announce that you are sick. Most people do not know what MS is. However, I recommend that people with MS be completely open. "Coming out" helps you feel free from unnecessary tension and stress. Some of the people I told drifted away, but nature hates a vacuum, so in a short time, there were plenty of people who wanted to help and just be my friend. This is a sign of sincerity above all.

It is also important to acknowledge and seek help for depression and cognitive problems caused by MS. I now use simple but effective strategies to focus attention on what is in the here-and-now.

I remember words from a seminar: "Let us live beautifully, live actively, wisely, open ourselves to new experiences, gain new skills, try to act and if it fails to get established, then try something else. Do not perceive life as a to-do list". Thanks to these words, I see life with a chronic disease as a challenge but it is not the focus of my life. I'm sick, but I choose if I give up or make friends in spite of the difficulties of MS. Good luck!

**Contact the Polskie Towarzystwo Stwardnienia Rozsianego at [biuro@ptsr.org.pl](mailto:biuro@ptsr.org.pl) or [www.ptsr.org.pl](http://www.ptsr.org.pl)**

## Prabal, New Delhi, India

I am 56 years old and a retired Group Captain of the Indian Airforce. I served in the fighter stream and am a qualified flying instructor and an experimental test pilot. I was diagnosed with primary progressive MS in 1998 while in service and was permanently downgraded medically from flying duties. As a consequence I was not eligible for further promotions on medical grounds. Presently, I am the Honorary Chairperson of the MS Society of India Delhi Chapter.

I live in New Delhi with my wife Renuka, who is an entrepreneur and consultant in the social development sector, as well as an active member of the MS Society of India. We have two sons Gaurav, who is 27 and an electronic music producer, and Aditya, who is a 25-year-old industrial designer.

I have had MS for the past 16 years. I have a high degree of spasticity in my right leg as well as mild incontinence. The initial symptoms manifested in mid-1995 but I was not diagnosed until August 1998.

In 1995, I realised that I was having problems running so I started doing long walks instead. My right leg would become stiff after about 2-3km and would



begin to drag. After rest it would become better again. I visited my GP who advised me to see an orthopaedic specialist. He diagnosed the problem as osteoarthritis. I carried on with this diagnosis and changed my exercise to cycling. I also noticed that gradually my walking distance was progressively reduced. In mid-1998 I had an episode of viral fever and the doctor noticed that I was dragging my foot. He immediately recommended a visit to a medical specialist who, in turn, forwarded my case to a neurologist in Mumbai. I was then diagnosed with MS at the Naval Hospital in Mumbai in August 1998.

Until the diagnosis, ignorance was bliss, as the saying goes. I had no understanding of MS, and at the time, knowledge of MS in India amongst the public was limited and the internet was in its infancy. In a way this protected me mentally, so as I became gradually more aware of the disease, I was able to handle it psychologically. My wife, however, was devastated as she was aware of the consequences – one of her relatives had MS and needed a wheelchair.

My family and friends have been extremely supportive. I came to know of the MS Society of India in 1999 and I am now an active member. The MS Society has provided emotional and material support. My personal advice to all people affected with MS is to keep strong mentally and to try to live life to the extent possible. Although I use a wheelchair, I am not completely wheelchair bound. I still swim and go to the gym. I also climb 49 steps each day to get to my room, as my apartment complex has no lift. I know that in time these activities may not be possible, but as long as I can manage them, I will continue to do so.

As a test pilot, my job was to progressively expand the operational “envelope” (range) of a new aircraft and thereafter clear it for use. In MS we start with a full operational range of movement which gradually contracts as the disease progresses. Our endeavour is to stop or delay the rate of contraction. My movements may be restricted but not my spirit.

Contact the MS Society of India at [www.mssocietyindia.org](http://www.mssocietyindia.org)

# Results of the online survey about diagnosis

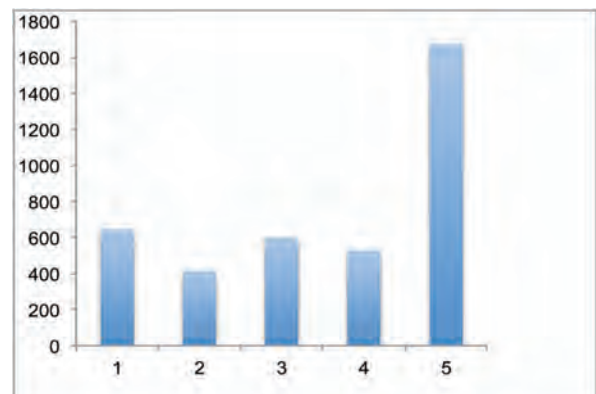
4,367 people from 90 countries took part in our survey about the experience of being diagnosed with MS.

More than 80% of respondents to the survey were female and 53% were in the age group 40-59 (36% were younger and 11% were older). Almost two-thirds had relapsing-remitting MS, 21% had a progressive type of MS and 16% were unsure or said “other type”.

More than half of those who took the survey (58%) waited less than six months to see a doctor after experiencing MS symptoms. When asked about the earliest symptoms that had alerted them to a potential health problem, 58% said numbness, 43% said blurred vision or vision problems and 34% said fatigue or weakness. Interestingly, 78% said they did not have any idea that it might be MS, and many attributed the symptoms to stress, tiredness or an acute condition such as a trapped nerve.

Significantly, 43% reported to have a very supportive doctor. Other ratings can be seen in the graph below. After first seeking medical help, 70% were

When you did seek medical help, how supportive was your doctor?  
1 = not supportive, 5 = very supportive





referred to a neurologist. When asked if they had received other diagnoses for their symptoms prior to their MS diagnosis, 38% said yes and 56% said no (6% were unsure).

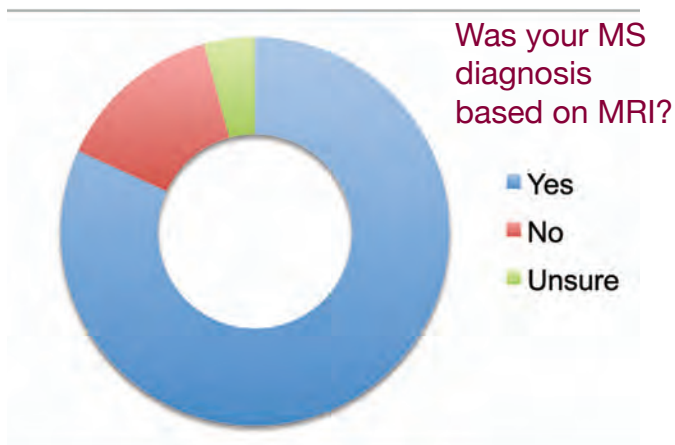
***“No-one wanted to commit themselves as very little was known in 1954.”***

Those that had received an incorrect diagnosis were asked how it made them feel once they were correctly diagnosed and many said “relieved” while others were “angry”, “shocked” or “scared”.

The majority of respondents (73%) had not been treated for an incorrect diagnosis but a significant proportion (22%) had, and some mentioned the side effects caused by these medications.

When asked how long it was between going to the doctor for the first time and being diagnosed with MS, responses were widely spread, with the largest group saying 1-6 months (28%). 82% of respondents said their diagnosis was based on an MRI, which shows its wide use today.

Most respondents (79%) were given information about MS after their diagnosis, but less than half



***“With the MRI, the diagnosis itself was straightforward. How to deal with it was not.”***

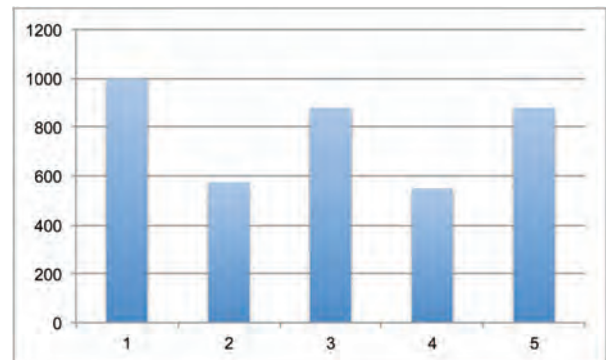
***“Wish it was not such a clinical diagnostic process. This causes tremendous anxiety for patients.”***

(47%) were given the contact details for a local or national MS organisation.

***“For myself and many other cases it is a process of elimination.”***

Respondents were asked to rate the process of getting a diagnosis of MS, where 1 meant straightforward and 5 meant very difficult. Interestingly, a quarter answered 1 and just less than a quarter (22%) answered 5, giving extreme views (as shown in the graph below).

**Overall, how would you rate the process of getting a diagnosis of MS, where 1=straightforward and 5=very difficult?**



When we looked closely at the data by country, only 4% were from developing countries (as defined by the World Bank). However, the percentages for key diagnosis resources such as their diagnosis being based on an MRI were similar. Interestingly, the proportions were also similar when asked about the overall process.

The results of this survey could indicate that the ease of the diagnosis process may relate more to the nature of symptoms and how they present for each individual, rather than the particular resources available across the world.

***“I hope with the improvements in MRI technology, the length of time from first symptoms to diagnosis is shorter now. I would hate to think other people out there are going through what I had to go through.”***

# Your questions answered

Dr Elizabeth McDonald, Medical Director for MS Australia (ACT/NSW/VIC), answers your questions.

**Q. I am a physiotherapist and run a weekly exercise programme for people with MS. One participant has had a recent change in his mobility and is complaining of pain around his hip. Is this part of the normal deterioration of MS?**



**A.** You are right to question whether such changes are part of the progression of MS. Certainly mobility is a common disability associated with MS, and

altered gait patterns can cause musculoskeletal pain, but other things also need to be considered and ruled out. Is the deterioration in the person's mobility due to degenerative changes in the hip or lower back? Has there been a history of a fall? A referral for full examination and X-ray is warranted and then appropriate management prescribed.

**Q. I have had MS for 15 years and have always had a problem with constipation. I have been able to manage this with attention to my diet and drinking plenty of fluid, but recently it has become more difficult. I have also experienced some embarrassing episodes of incontinence. Is this just due to the progression of my MS?**

**A.** While bowel problems are common in MS, in particular constipation, any change in usual bowel habits should be investigated. These changes may be due to MS but other causes need to be ruled out. I would suggest that you make an appointment to see your doctor for an examination and advice on the most appropriate course of action.

**Q. I have MS and understand it is a type of autoimmune disease. Does this mean I am more likely to have other autoimmune diseases as well? Are autoimmune diseases more common in families of people with MS?**

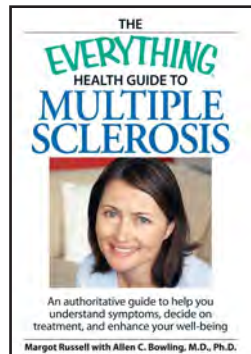
**A.** The link between MS and other autoimmune diseases is weak. Most studies indicate only a small increase in risk of other autoimmune diseases, such as ulcerative colitis and Grave's disease. The issue of autoimmune disease frequency in families of people with MS is also complex, with numerous contradictory studies. If there is a family association with other autoimmune diseases, the risk is certainly low.

**Q. Before I was diagnosed with MS, my doctor ordered many tests to try and find out what the problem was, as I was experiencing many symptoms. One of these tests was for Anti-ds DNA. I subsequently found out that this is a test for systemic lupus erythematosus. Is this related to MS?**

Systemic lupus erythematosus (SLE) is a chronic inflammatory disease which can display many similar symptoms to MS, but is not related to MS. SLE most commonly affects the skin, joints, blood and kidneys, and is associated with fatigue and rashes. It can also affect the central nervous system. SLE is known as the great imitator because of the many parts of the body it can affect and the variety of symptoms it can produce. The Anti-ds DNA test is a blood test looking for the presence of antibodies which are fairly specific for SLE. Often, doctors perform these blood tests while they are checking for MS, even though the probability of SLE is low. Usually, MS and SLE are easily differentiated.

# Resource reviews

## ***The Everything Health Guide to Multiple Sclerosis*** by Margot Russell & Allen C Bowling, 2009, Adams Media Publishing



Margot Russell was diagnosed with MS in 1998. It is a testament to her determination to embrace lifestyle-based therapies and resources that encourages the reader to feel that, with courage, persistence and hope, MS can be controlled, giving the opportunity to live a fulfilling life in the knowledge that you are not alone.

This book is easy to navigate, with good clinical information and a wealth of practical advice. The introduction is excellent, painting a comprehensive picture of the process and presentation of MS. An important point covered, which affects the majority of people with MS, is the presence of invisible symptoms which can themselves present significant problems.

The chapters are divided into convenient subheadings with boxed "trigger factors" giving

important snippets of information, urgent warnings, handy tips and answers. The chapters cover everything from what MS is, through information on signs, symptoms and diagnosis, the effect on the family unit, employers, carers, support network and current research, to drugs and potential therapies which point towards a hopeful future.

I would thoroughly recommend this book to the newly diagnosed, and anyone at any stage of the disease, who needs practical, accurate and positive information while trying to come to terms with the illness. It is also a useful tool for health care professionals, outlining essential medical advice and how the progression of the disease can also be modified by lifestyle changes. The only drawback I found was the lack of any colour images, which are especially important for a good first impression.

All in all, no person with MS should be without a copy of this well thumbed MS bible, offering everything one needs to know about understanding and managing MS.

*Reviewed by Kate Renesto, Editor of "Keep in Touch" newsletters, Buckinghamshire, UK*

## **Review of [www.msdiscovery.org](http://www.msdiscovery.org)**

The main purpose of this website is to provide comprehensive and accurate information for health care professionals interested in MS. The website connects and captures all the issues related to MS health care professionals by its design, language and pathways. It is very easy to use and could add wide knowledge to a health care professional looking for information on aspects of MS.

The website covers a range of subjects and fields for health care professionals. From its first page, it clearly shows the content the website contains.

It loads very quickly and is constantly evolving, providing updated information to meet the needs of its users.

As an international health professional I wanted to know more about chances for scholarships or educational opportunities worldwide. It would also be great if forums for different specialities could be added, to create a connection point between countries and a chance to share many experiences and practices worldwide.

*Reviewed by Samira Al-Rasbi, Sultan Qaboos University Hospital, Oman*

## **MSIF Member Society contact details**

**Argentina:** Esclerosis Múltiple Argentina  
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**Australia:** Multiple Sclerosis Australia  
info@mssociety.com.au www.msaustralia.org.au

**Austria:** Multiple Sklerose Gesellschaft Österreich  
msgoe@gmx.net www.msgoe.at

**Belgium:** Ligue Nationale Belge de la Sclérose en Plaques/Nationale Belgische Multiple Sclerose Liga  
ms.sep@ms-sep.be www.ms-sep.be

**Brazil:** Associação Brasileira de Esclerose Múltipla  
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**Canada:** MS Society of Canada /Société canadienne de la sclérose en plaques  
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www.scleroseenplaques.ca

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**Netherlands:** Stichting MS Research  
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epost@ms.no www.ms.no

**Poland:** Polskie Towarzystwo Stwardnienia Rozsianego  
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**Portugal:** Sociedade Portuguesa de Esclerose Múltipla  
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**Romania:** Societatea de Scleroza Multipla din România  
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**Russia:** The All-Russian MS Society  
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**Slovakia:** Slovenský Zväz Sclerosis Multiplex  
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**USA:** National MS Society  
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# MS *in focus*



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