

# Living well with MS

**A resource for anyone  
impacted by MS**



## Acknowledgements

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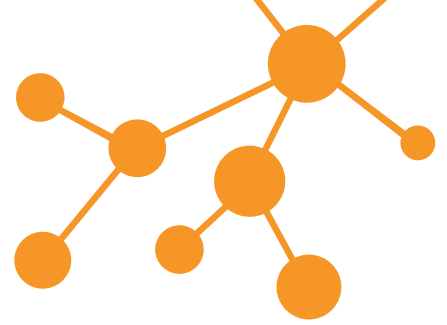
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The information provided in this booklet should not be considered as a substitute for health or medical advice. You should always take specific and individual advice from a qualified healthcare or medical professional. Any links provided do not imply that MSNZ has endorsed the information, or the accuracy of the information provided in such links and that Multiple Sclerosis Society of New Zealand cannot be liable for the content. [Please see our full disclaimer.](#)

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## Kia ora,

**You may be reading this as someone who has recently been diagnosed with multiple sclerosis (MS), going through diagnosis, or supporting a loved one who has. We hope the information in this booklet and that available on our website is helpful now, and in the long-term as you navigate life with MS.**

Multiple Sclerosis New Zealand (MSNZ) is a non-profit organisation, established in 1967. We are striving towards our vision of being the National Leader for Service Excellence for people impacted by multiple sclerosis. To achieve this, we are on a mission to coordinate and lead the advances in best practice multiple sclerosis care. We do this by providing national leadership, advocacy, information, education and raising awareness. We work with 18 member organisations nationally to meet the needs of people with multiple sclerosis, their families and carers across Aotearoa.

MSNZ and our MS regional societies acknowledge and respect Te Tiriti o Waitangi, the Treaty of Waitangi, as Aotearoa's founding document and our obligations to meet this. We aim to deliver services which are culturally respectful, person-centred,

and inclusive of the wider whānau. As MS impacts people of all cultures and ethnicities, we endeavour to be culturally aware that everyone has different cultures, values, beliefs, languages, and life experiences and all are acknowledged and respected.

MSNZ endorse and promote internationally recognised MS Brain Health principles and recommendations for living well with MS. We encourage resiliency, self-management, preventative services. By providing evidence-based information and advocacy we encourage people to take control of their diagnosis and condition. Positive attitudes and lifestyle modifications, which we encourage, can have a profound effect on symptom management and maximising opportunities for long-term health and brain health outcomes.

It's natural to feel overwhelmed or upset if you or someone you know has been diagnosed with MS. Having some knowledge about the condition, what the future may look like, and what support is available can be helpful at this time.

This booklet will provide answers to most of your initial queries regarding MS. Although certain topics are covered briefly, you can find in-depth information about them in our other informational resources, available online, or you can request them from your [Regional Society](#) (local organisations that offer support to people with MS in their area) or from MSNZ.

In addition, we and most regional societies have a comprehensive library of books and resources available, written and produced by people from a range of viewpoints from health professionals to people with MS.

Education can be an empowering way to deal with an MS diagnosis, and we trust you find these NZ produced resources helpful. If you want to talk about any of the topics

raised here, contact your [regional society](#), who have experienced community advisors ready to help.

The take-away we hope to leave you with is that while MS is a chronic condition, well-researched therapies and lifestyle changes can help reduce the impact of MS on your life. New research and medications are consistently improving outcomes for people with MS. People diagnosed with MS, like you, are continuing in their careers, building families, and living long and healthy lives. We're here to help you make that happen.

*Tukuna ngā roimata kia heke, whiua te hūpē, ka haruru te tapuwae ki te marae, ka ea, ka ea.*

*Express your emotions, let tears flow and mucus run and gather together for support and recovery.*

*MSNZ Team*



# Tēnā koutou e te Whānau,

**Welcome to your journey with multiple sclerosis (MS). As a person with MS I would like to acknowledge that everyone has a different pathway and experience. If you are on a learning and possible diagnosis direction, a newly diagnosed person, family, friend, or medical professional, remember, we are all in this together.**

My journey to diagnosis was a very unexpected and emotional path. While lucky in the short timeframe from significant relapse, to MRI, neurologist review and formal diagnosis, looking back my symptoms were around for a couple of years prior. My initial thoughts and understanding of what MS meant included, my life is over, and I would never be the same again. As a very active person, with goals including long distance triathlon and, a busy and physical job as a flight paramedic, my life came crashing down.

By educating myself and selecting a wonderful support crew, I now see my diagnosis as a blessing. I have a different understanding with increased depth and appreciation of life. I appreciate the small things, have a wonderful life, continue to work, and exercise, and can give back so much more than I ever expected.

Specifically, for those who are newly diagnosed, I wish for you the best on this journey. Please reach out to those who you feel safe with, find the hope and positives to move into the future. Look after yourself both physically and mentally. Connect with those who have MS, contact your local MS society, talk to all the medical professionals who can, or may help, now and into the future. Learn, ask questions, try different tips and tricks from those who live with or intimately know what having MS is like. Take the time for you, relax, process, accept and then work out what is going to work for you.

*Hurihia tō aroaro ki te rā, tukuna tō ātārangi kia taka ki muri i a koe*

*Turn your face to the sun and the shadows fall behind you*

*Prue*

# What is multiple sclerosis?

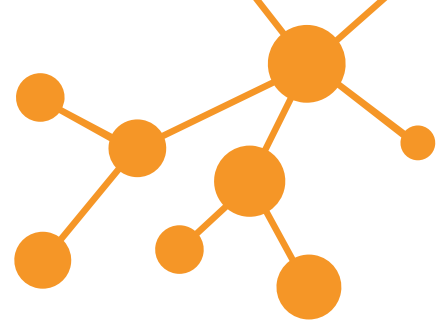
**Multiple sclerosis (or MS as it is often called) is an autoimmune disease that affects the central nervous system (CNS) - the brain and the spinal cord. The term multiple sclerosis refers to multiple areas of scarring (sclerosis) that develops throughout the brain and spinal cord.**

The central nervous system controls conscious and unconscious functions, including walking, talking,

and responding to sensations such as sight, touch, and sound. It does this by sending instructions in the form of electrical pulses along nerve fibres. Healthy nerve fibres are coated in a protective insulating covering called the myelin sheath, which is like the coating around electrical wires. Myelin speeds up electrical conduction along nerve fibres and insulates nerve fibres from one another.

In people with MS, the immune system attacks the myelin sheath, wearing it down. This is called demyelination which causes the patches of scarring that make it harder to send messages along nerves.

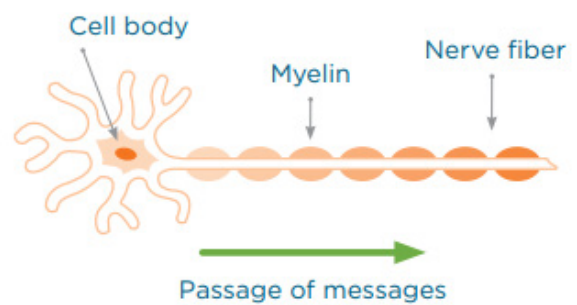
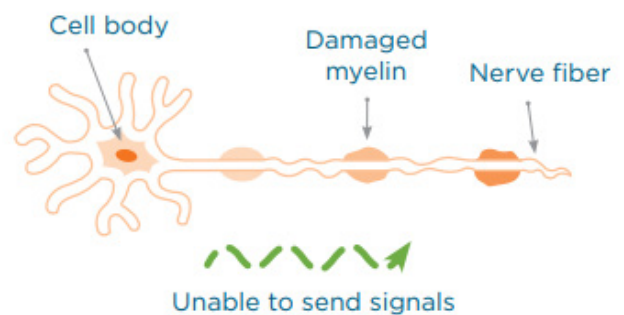
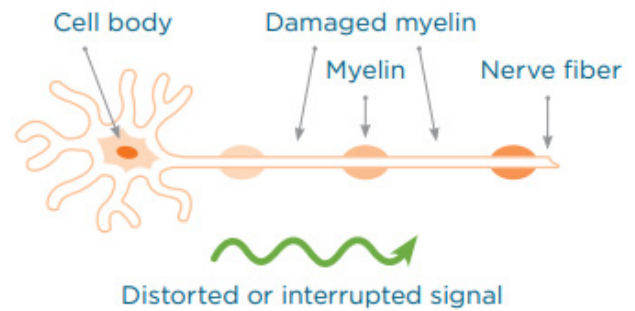




After an attack, these patches of scarring start to heal, to some extent. This process is called remyelination where your body replaces the damaged myelin, although it tends to be thinner than unaffected myelin. The symptoms the scarring cause may go away completely, or some symptoms may remain. Your brain can also reroute the messages to avoid a damaged area, this is known as plasticity.

The nature of the symptoms and their severity depends on the scarring location and intensity. Because the central nervous system controls so many functions, the symptoms caused by MS are wide ranging, and experienced differently by everyone.

Just like the symptoms, the progression of MS varies widely from person to person. The good news is that some people will only experience mild symptoms over their lifetime and have long periods of remission. Some will have relapses that don't completely heal, and as a result disability may get a little worse with each relapse. About 15% of people experience slow, progressive worsening of disability over many years.



[Read more: Understanding MS](#)



## There are four types of MS:

**RELAPSING MS:** This is the most common type of MS, affecting about 75% of people diagnosed. Relapses occur sporadically, where old symptoms may flare up or new symptoms may be developed over several days or weeks. This is followed by remission, where symptoms may go away completely, or may be reduced. Some people who have relapsing MS will go on to develop secondary-progressive MS.

**SECONDARY-PROGRESSIVE MS:** After an initial period of relapsing MS, some people develop secondary-progressive MS. In this type of MS, disability may increase slowly over many years or decades. Occasionally, relapses may also still occur. The latest research is showing that about 10% of patients convert to SPMS within 10 years, 50% at 20 years and 93% at 30 years. Earlier use of high efficacy treatments and positive lifestyle modifications can help delay this progression.

**PRIMARY-PROGRESSIVE MS:** About 10% of people diagnosed with MS have this type, and experience slow progressive worsening of symptoms and disability without distinct relapses.

**PROGRESSIVE-RELAPSING MS:** This is the least common type of MS, where disability slowly worsens over many years, with some distinct relapses.



# What causes multiple sclerosis?

**Although the exact cause of MS remains unknown, identified factors, whether genetic or environmental, contribute to its onset. These factors, while not individually guaranteeing MS development, collectively increase the likelihood of its occurrence.**

## Genetics, ethnicity, and family history.

MS is not passed directly from parents to children, but it does occur more frequently in people who have a family member with MS. No single gene has been identified as the “cause” of MS, but researchers have identified over 110 different genetic factors that are associated with MS. It’s been estimated that about half of the risk of getting MS is related to genes. That said, most people with a relative with MS will not develop the disease.

## Gender

In Aotearoa New Zealand, three times more women are diagnosed with MS than men. Research has shown that this gender difference is not apparent in cases of MS that occur before puberty or after menopause, suggesting it is likely to be the sex hormones influencing the immune system in a way that contributes to the development of MS.

## Environment

Where you are born and grow up may affect your risk of getting MS. MS is more common as you get closer to the North and South poles. For example, the prevalence and incidence MS is roughly twice as common in the South Island than in the upper North Island. This could be related to UV light and Vitamin D exposure, and research is ongoing in this area.

The latest research from Australia and Aotearoa New Zealand is indicating that there is no direct link between Vitamin D supplementation and the development of relapsing MS or in reducing the disease activity once established.

## **Viruses**

Some researchers believe that exposure to certain viral infections as a young person may have long-term effects on the immune system that can lead to MS. Epstein-Barr virus is thought to increase the likelihood of someone developing MS. However, Epstein-Barr virus does affect a large proportion of the population, and only a small fraction of those who get Epstein-Barr will go on to develop MS. There is ongoing research into this area.

## **Smoking**

The evidence is clear that smoking has a significant impact on the progression of MS. Smoking is

known to cause inflammation, and can alter the function of some immune cells, which could contribute to MS. For people who already have MS, there is good evidence that stopping smoking can slow down progression of the disease. Research shows that relapse rates are increased in people with MS (PwMS) who smoke, even in those taking DMT's. For the best possible outcome, the recommendation is that those diagnosed, and their immediate family, quit smoking. MS community advisors and GP's can connect you with services aimed at supporting you throughout this process.



# Who gets multiple sclerosis?

**Over 4,100 people in Aotearoa New Zealand have multiple sclerosis. That means approximately 1 in every 1,000 people in Aotearoa New Zealand have MS, and anywhere from 2-5 people per 100,000 will be diagnosed with MS each year.**

Near relatives of those with MS have an increased risk. Having a first-degree relative, (mother, father, or 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 vast 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.

## **It is more common in:**

### **Young adults**

Symptoms usually first appear between the ages of 20 and 50, and the most common age to develop MS is the early 30s.

### **Women**

In Aotearoa New Zealand, 75% of people with MS are women.

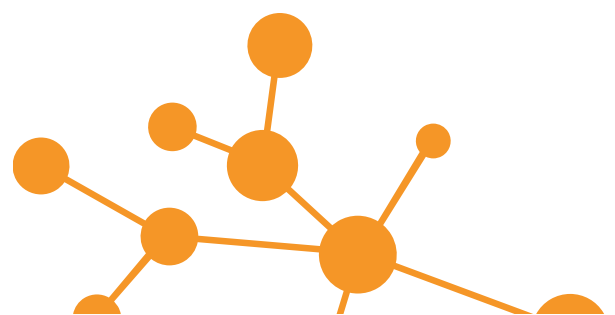
### **Caucasians**

MS is more prevalent in Caucasians (people with ancestry from Northern Europe), than any other racial group.

The incidence of MS is much lower in Māori and Polynesian people, and the disease is uncommon in people of Asian ancestry. Further information can be found in the 2006 [MS Prevalence Study](#), and the 2012-14 [MS Incidence Study](#).

It is well documented that Māori statistically are underrepresented when it comes to other health conditions due to lack of access to health care services. We are mindful that Māori may also be underrepresented in the numbers of people with MS due to these same issues. MS is a complex condition, and a clear connection is not always made between the symptoms.

Culturally sensitive support is provided to all those impacted by MSNZ and our 18 regional society members across the country as required.



# Symptoms of MS

The symptoms of MS are unpredictable and vary from person to person. They also vary in one person over time due to changes in inflammation activity.

Scarring in MS often heals. This means you may experience a symptom for a while, followed by months or years without experiencing that symptom again.

## Common symptoms include:

- Weakness or a lack of coordination of the limbs
- Impaired balance or instability walking

- Sensory disturbances
- Blurred or double vision
- Impaired urinary, bowel or sexual function
- Muscle stiffness and spasms
- Cognitive dysfunction such as impaired memory or concentration
- General fatigue

People with MS usually experience multiple symptoms over the duration of their condition, but it is unusual to experience them all.

## MSNZ Information Sheets

Our comprehensive information sheets offer additional insights into each symptom associated with MS. You have the option to download the information sheet relating to the symptoms you are currently experiencing or request them from your regional society or community advisor. You may wish to create a folder containing the information sheets that are relevant to your specific symptoms. By doing so, you can conveniently refer to the information whenever needed, and if you encounter a new symptom, you can easily add the corresponding information sheet to your folder for quick access.



[View information sheets here](#)

# What is an MS relapse?

A relapse in MS occurs when new symptoms emerge temporarily, or existing symptoms worsen for a period of time. It's important to note that relapses can vary in their intensity and duration. While some may be mild, others can be severe, and they can last for varying lengths of time, ranging from days to months. Even mild relapses have the potential to cause nerve damage, so it's important to alert your medical team about any relapses you experience.

“I have had excruciating pain in my feet for well over 15 years. When I have a relapse, the night before my foot pain is absolutely unbearable. Then when I wake up in the morning I have no foot pain at all. That’s when I realise it is because I can’t actually move my legs.”

Hannah, PwMS



# How do I know if I'm having a relapse?

## **NEW OR WORSENING SYMPTOMS**

If you experience the onset of new symptoms or significant exacerbation of symptoms, you have previously experienced, in the absence of infection it could be indicative of a relapse. These symptoms might include numbness or tingling in limbs, muscle weakness, fatigue, difficulty with coordination or balance, visual disturbances, bladder or bowel changes, or problems with cognition.

## **DURATION AND PERSISTENCE**

A relapse typically lasts for at least 24 hours and persists for several days or even weeks. If your symptoms persist or worsen over this duration, it's advisable to consult with your healthcare provider.

## **FUNCTIONAL IMPACT**

Assess how the symptoms affect your daily life and activities. If the symptoms significantly interfere with your ability to perform routine tasks or impact your overall well-being, it's important to consider the possibility of a relapse and report it to your healthcare provider.

## **RULE OUT OTHER CAUSES**

Rule out other factors that could mimic or contribute to your symptoms, such as infections, side effects from medication, temperature changes, increased stress, fatigue, menstruation, menopause, or other medical conditions. It's essential to consult with your healthcare provider to determine the underlying cause of your symptoms.

## **TEMPERATURE CHANGES / UHTHOFF'S PHENOMENON**

Uhthoff's phenomenon or Pseudo-exacerbation is the worsening of neurologic symptoms in multiple sclerosis and other demyelinating diseases when the body is overheated. This may occur due to hot weather, exercise, fever, saunas, hot tubs, hot baths and hot food and drink.

## MEDICAL EVALUATION

Reach out to your healthcare team, including your GP, neurologist, or MS nurse, to discuss your symptoms and any changes you have noticed. They will evaluate your condition and determine if a relapse is occurring.

Remember, the diagnosis and management of relapses should be overseen by healthcare professionals familiar with your medical history and experienced in managing MS. It's crucial to maintain open communication with your healthcare team to ensure proper evaluation and appropriate treatment, if necessary. Even if you think you don't require any change in medication, alerting your healthcare provider to your potential relapse helps to build up a picture of how active your MS is.





# How is MS diagnosed?

**There is still no single test for diagnosing MS, as the disease looks different in each person. MS is usually diagnosed by reviewing medical history, observing symptoms over time, and combining those observations with the results of medical tests. Other diseases of the central nervous system produce similar symptoms, and therefore need to be ruled out before an MS diagnosis can be confirmed. For these reasons, MS can take some time to diagnose.**

In Aotearoa New Zealand, the 2017 McDonald Criteria are used by neurologists to diagnose MS and differentiate from similar neurological conditions. This is an internationally accepted guide which is periodically updated in line with the latest research.

The McDonald criteria require a history of one or relapses (a clinical attack of neurological symptoms) with supporting evidence of two or more MRI lesions in different areas of the brain or spinal cord. Symptoms often go unreported. Depending

on the MRI findings, sometimes a lumbar puncture may be performed, looking for evidence of antibody formation in the cerebrospinal fluid (known as oligoclonal bands).

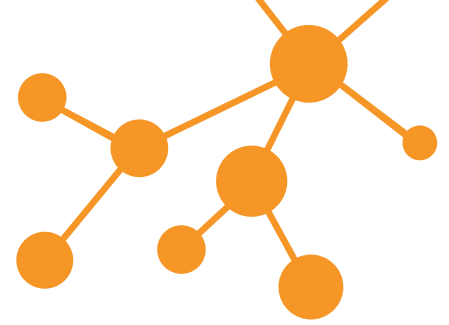
## What is Clinically Isolated Syndrome

If there is not enough evidence to confirm MS, you may receive a diagnosis of Clinically Isolated Syndrome (CIS). In cases of CIS, you may, or may not convert to MS. It is recommended that you monitor for any new or worsening of symptoms and report these to your primary health care provider as soon as possible.

## I think I have MS - who should I see?

If you think you may have MS, see your General Practitioner (GP), and talk to them about your concerns.

It can help to keep a diary of the symptoms you experience over weeks or months. Note the symptoms, what they feel like, what time of day you experience them,



how severe they are, and how long they last. This information is very important and will help your GP get a full picture of what's going on and will help them decide whether to refer you to a neurologist (a doctor specialising in disorders of the nervous system).

Your GP will also talk to you about your medical history and family history. If your GP thinks you could have MS, they will arrange for you to see a neurologist.

## Tests for MS

**A neurologist may carry out the following tests:**

**MRI - MRI (magnetic resonance imaging)** is a medical imaging procedure used to create pictures of different organs in the body. For people with MS, MRI scans can reveal areas of inflammation and scarring in the brain, and they can be used to monitor changes over time.

**Lumbar Puncture** - A lumbar puncture involves inserting a needle into the lower back to take a sample of the fluid that surrounds the brain and spinal cord. People with MS may have specific changes in protein patterns and white blood cell counts, which could be used to diagnose MS.

**Evoked Potentials** - These measure the time it takes for the brain to receive and interpret messages from the body. Small electrodes are placed on the head to monitor the brain's response to certain types of signals. If the myelin sheath is damaged, signals will take longer to get to the brain.

“A diagnosis of MS may usually be made based on the story of someone's symptoms, the findings on examination and the results of MRI. In some cases, additional tests, including CSF examination are also needed.”

**Dr. John Mottershead,  
Neurologist**

## If it's not MS, what could it be?

If you have only experienced one episode of symptoms, and other tests don't show any evidence of past attacks, then you may be diagnosed with Clinically Isolated Syndrome.

Another variation of this is Radiologically Isolated Syndrome (RIS), where scarring, like the kind that occurs in MS, can be seen on an MRI, but the person doesn't

experience any symptoms. This is usually only diagnosed in people who are having an MRI for another reason. Some people who are diagnosed with RIS go on to develop MS, but not all.

Severe migraines can also produce symptoms similar to MS, as do other autoimmune diseases and some brain infections. Another disease called neuromyelitis optica (NMO) causes similar symptoms to MS but is much rarer.



# Coming to terms with an MS diagnosis

**Coming to terms with an MS diagnosis may take some time. It's normal to experience emotions such as shock, fear, sadness or anger, and everyone handles these emotions differently. Some people feel relief at finally receiving an explanation for the symptoms they've been experiencing, and to hear that their symptoms are not being caused by a life-threatening disease.**

One of the most difficult things about MS is its unpredictability. You may feel uncertainty, and a loss of control, and it might take a while before the implications of the diagnosis are clear to you.

Don't be afraid to tell those closest to you; they will become a strong source of help and comfort in the coming months and years. You can also talk to your neurologist, MS nurse or a counsellor about your concerns, and they can help you make a plan to manage your MS, and the challenging emotions you may have around it.

Although there is no cure for MS, there are several highly effective preventative treatments that can help reduce relapses and slow the development of any potential disability. Your neurologist can also suggest medicines to help manage your symptoms on a daily basis.

**“I wouldn't say I'm glad I've got MS. But if you asked me to give it and everything it's taught me up, I'm not sure I would.”**

**Blake, PwMS**



# What could the future look like?

**Neurologists are unable to predict the future, and it may take years for any patterns of symptoms to evolve. Although the progress of MS cannot be predicted with any accuracy, the statistics are encouraging:**

- Many people with relapsing remitting MS have years between attacks.
- Between 2014 and 2020, five new MS treatments became available in Aotearoa New Zealand.
- These new treatments, many more people with MS have a good quality of life.

- Every year, ongoing research on MS brings us new insights into the disease and enhances our understanding of how to effectively manage it.
- In addition to advancing treatments, researchers are consistently discovering innovative non-medical approaches to help individuals with MS maintain optimal health and well-being.

You don't have to face this journey alone. Our network of [regional societies](#) has dedicated community advisors who are ready to provide guidance, support, and facilitate connections with others affected by multiple sclerosis. It's essential to remember that MS cannot define or alter who you are as a person. You remain the same individual today as you were before diagnosis, and with the right support, you can navigate through this condition and continue living a fulfilling life.



# Treatments for MS

**There is no cure for MS, but treatments have been developed to slow the course of the disease, help manage symptoms, and increase quality of life. Treatments for MS can be divided into four main groups:**

## Disease Modifying Therapies

There are several 'disease modifying therapies' (DMTs), which are treatments designed to reduce the frequency of relapses and slow the progression of new areas of inflammation (lesions).

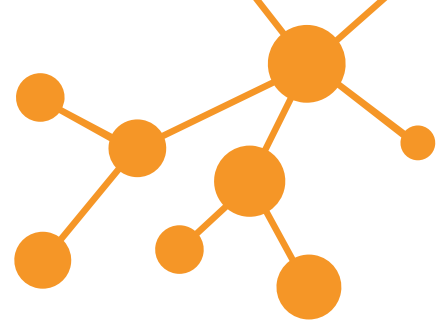
Eight disease modifying therapies are available in Aotearoa New Zealand and funded through PHARMAC for people who qualify. Most are for the treatment of Relapsing-Remitting MS, the most common type of MS.

The initial treatments your doctor will consider are called first-line treatments. These are: dimethyl fumarate (Tecfidera®), fingolimod (Gilenya®), natalizumab (Tysabri®),

ocrelizumab (Ocrevus®) and teriflunomide (Aubagio®). If these are not suitable, then there are second-line treatments that are less frequently used due to a lower efficacy: beta-interferons (Avonex®, Betaferon®), and glatiramer acetate (Copaxone®).

Disease-modifying treatments are available in various forms. Some come in the form of tablets that can be taken at home, while others involve injections that can initially be administered by a healthcare professional and later taught for self-administration at home. Additionally, certain treatments are administered intravenously, requiring visits to a medical centre or hospital. Typically, these intravenous treatments are given every six weeks (natalizumab) or every 6 months (ocrelizumab). As MS varies in everyone, your neurologist is best equipped to determine the suitability and effectiveness of these treatments for your specific case.

There are a few other disease-modifying treatments for MS available in Aotearoa New Zealand, although they are not covered by



PHARMAC funding. If you opt for these treatments, you will need to cover the costs yourself. It's best to discuss with your neurologist whether these treatments might be beneficial for you.

There is only one medicine, Ocrevus® (ocrelizumab), that has been approved by Medsafe to treat primary progressive MS (PPMS). Criteria for access requires a neurologist confirmed diagnosis of PPMS with no history of relapsing remitting MS. You must also have an Expanded Disability Status Scale (EDSS) score between 2.0 and 6.5 inclusive. This means, you must be able to walk 20 metres with one or two aids (crutches, sticks or walkers) without stopping for rests.

Data shows that for some people with PPMS Ocrevus can improve quality of life and slow progression and enable people to live more independently for longer. Ocrevus is not a cure, but has been shown to effectively slow the worsening of PPMS and helps manage symptoms. However, Ocrevus is not suitable for everyone, so it is important that you discuss with your doctor or nurse whether this medicine is right for you based on your individual circumstances. Before talking with your MS nurse or neurologist we recommend

considering what your treatment goals are so that you can be clear around what you would consider to be treatment success or otherwise. Other medications and rehabilitation strategies are used to manage symptoms of PPMS which we encourage you to discuss with your health care team.

Visit our website for the latest information about unfunded but registered treatments:

[MS Treatments](#)



[Read more about Disease Modifying Treatments on our website](#)

## Management of Symptoms

Both medication and various types of therapy can help to relieve the symptoms associated with MS and are good topics to discuss with your neurologist.

Steroids are commonly prescribed to help relieve the symptoms of relapses. While steroids can help



your relapse pass quicker, they don't affect your overall level of recovery, or the course of your disease over many years. For this reason, steroids are typically administered when a relapse is severe, whereas in milder cases, it may be advisable to wait for the relapse to naturally subside.

There are other treatments and lifestyle modifications that can help you when you're having a relapse.



[To read more about treatment of symptoms, download 'Treatment of Symptoms' info sheet, or read the info sheet on the symptoms you're experiencing.](#)

## Rehabilitation

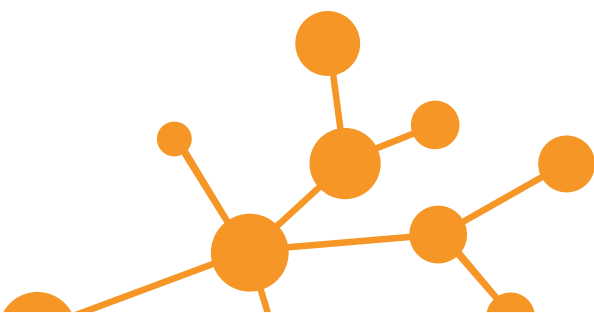
While it may not be possible to improve all lost function, people with MS can reduce the impact of the disease by optimising their physical, mental, and social well-being. Rehabilitation can help improve quality of life, particularly after a flare up of symptoms. By focusing on these aspects, individuals with MS can actively work towards optimising their overall health and embrace a fulfilling life.

During remission periods people with MS should participate in a maintenance therapy programme to re-achieve and maintain good physical and mental health. Depending on symptoms, this may involve physiotherapy, stretching, coordination exercises, speech, and swallowing instruction. It may also include medication, good nutrition, counselling, and lifestyle changes (both social and occupational).

## Alternative or complementary medicine

Some believe that if conventional medicine cannot provide a cure, then perhaps alternative medicine will. Others find that seeking more holistic therapies allows them to feel in control of their MS. Caution should be key, 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.

Several of these remedies claim to 'enhance' the immune system. However, in people with MS, the immune response is already over-enhanced. It is important to tell your doctor if you are taking or thinking



of taking any 'natural' or 'herbal' remedies as some of these can react negatively with prescribed drugs and are often promoted by people with little or no understanding of MS.

Medsafe is the New Zealand Medicines and Medical Devices Safety Authority. It is part of the Ministry of Health and is responsible for the regulation of therapeutic products in Aotearoa New Zealand. Medsafe regulates products used for therapeutic purposes.

This includes:

- Medicines
- Related products
- Medical devices
- Controlled drugs used as medicines

Medsafe can provide useful information about products and therapies. Contact details for Medsafe and the Ministry of Health are located at the end of this guide.

Keep in mind that information found on the internet or in newspapers may not always be accurate. It's important to exercise caution, especially when encountering products or information claiming to be a cure for MS. Your neurologist is your best source of reliable and scientifically proven treatments. It's essential to remember that MS can enter remission unexpectedly and seemingly miraculously, without any apparent cause. Therefore, attributing success to a specific treatment can be misleading.



# Living well with MS

**Naturally, receiving an MS diagnosis may create a sense of lost control over your health. However, it's important to recognise that there are several evidence-based measures you can adopt to proactively influence your MS through lifestyle modifications. By prioritising your well-being, you not only enhance your overall health but also improve your MS journey, increasing your chances of leading a long and fulfilling life. Embracing these steps empowers you to take an active role in your health and well-being, with the potential to make a positive impact on your experience with MS.**

We encourage resiliency, self-management, and utilising preventative services. With this in mind, we follow the MS Brain Health principles and recommendations for living well with MS.



[Read more about MS Brain Health on our website](#)

## Diet

Prioritising a healthy diet holds significant value for everyone, but it is critical for those with MS. Ensuring adequate intake of essential vitamins and minerals becomes even more vital as deficiencies in these nutrients can exacerbate certain symptoms. Consuming an insufficient amount of food or relying heavily on unhealthy junk food may contribute to fatigue, a commonly experienced symptom of MS. By making mindful dietary choices, you can support your overall well-being and potentially alleviate the impact of MS symptoms.

You might hear about specific “MS Diets”. The most prominent share some similarity: low to no sugar, reduced intake of dairy or meat, and no processed foods. However, there is not enough evidence to recommend any specific diet to help with MS.

A few studies have shown that low fat, plant-based diets can reduce BMI in those who are overweight or obese, with slight improvements in mood. One small study on the Palaeolithic (Paleo) diet showed an

improvement in MS related disability. Both require further investigation, with large study groups, before any reliable conclusions can be reached. In the absence of definitive evidence supporting specific diets, we advise maintaining a diverse and nutritious diet that includes a wide variety of fruits, vegetables, legumes, and lean meats. It is also important to stay adequately hydrated, limit the consumption of foods high in saturated fat, added sugar, and salt, and moderate alcohol intake.



[Read more about MS and Diet on our website](#)

## **Exercise**

Evidence supports regular exercise is beneficial for both physical and mental well-being, for everyone. It can improve balance, coordination, fatigue levels, and sleep quality, while also enhancing cognitive function, mood, and protecting against depression.

When experiencing fatigue, it's important to find a balance between rest and physical activity. For individuals in good overall health, it is generally recommended to engage in moderate aerobic exercise two to three times a week, along with strength exercises two

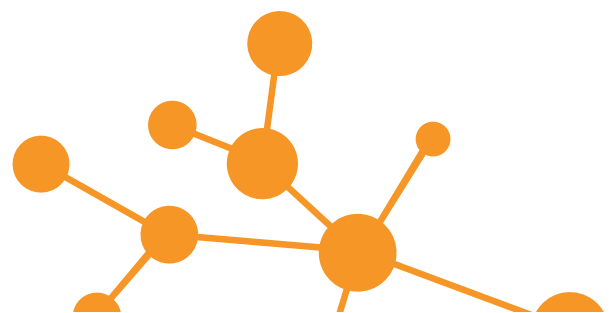
to three times per week. However, it's important to tailor these recommendations to suit individual needs. Remember, even a little activity each day is better than none.

“Exercise has been a vital aspect of my MS journey. Joining in aqua jogging and aqua aerobics classes in the early days was great. Not only did I keep moving, this allowed regulation of my temperature and prevented symptom exacerbation, while exercising in a controlled environment where if I felt I wasn't going to hurt myself. Dancing in the pool with supportive friends provided some wonderful giggles and definitely raised my spirits to keep going.”

## **Prue, PwMS**



[Read more about MS and Exercise on our website](#)



## **Embracing a smoke-free life**

Making the decision to quit smoking can have a profound positive impact on your MS journey. Research consistently shows that smoking increases the risk of MS progression, worsens symptoms, and diminishes overall quality of life. By quitting smoking, you have the power to reduce these risks and improve your well-being.

The sooner you quit smoking after an MS diagnosis, the better. Studies reveal that persistent smokers reach the progressive stage of MS eight years earlier than those who quit smoking upon diagnosis. For every decade of not smoking, the risk of increased MS disability diminishes

by 30%. No matter how long you've smoked, quitting now can bring tremendous benefits to your life.

Quitting smoking not only benefits your own health, but also creates a healthier environment for those around you. Passive smoking, especially in children, has been linked to an increased risk of MS. Creating a smoke-free household can contribute to a healthier future for everyone.

Remember, the journey to quit smoking may have its challenges, but you're not alone. Reach out to medical professionals, friends, and whānau for support. [Smokefree.org.nz](https://www.smokefree.org.nz) offers valuable resources and guidance to help you on your smoke-free journey.



## **Maintaining a healthy weight**

Maintaining a healthy weight is a key aspect of overall well-being, including managing MS. Encouraging studies have highlighted the significance of maintaining a healthy weight, particularly during childhood and adolescence, as it can reduce the risk of developing MS.

Furthermore, maintaining an optimal weight is associated with better management of MS-related symptoms. By avoiding obesity and excess weight, you can minimise the risk of other conditions, such as diabetes and high cholesterol, which can exacerbate MS symptoms and impact your quality of life. It is believed that maintaining a healthy weight helps reduce inflammation in the body, which can contribute to alleviating MS symptoms.

Taking a proactive approach to achieving and maintaining a healthy weight can positively influence your MS journey, supporting overall well-being and potentially reducing the occurrence of relapses. Remember, adopting a healthy lifestyle with balanced nutrition and regular physical activity can contribute to your overall health and enhance your experience with MS.



[Read more about MS and Nutrition on our website](#)

## **The effects of temperature**

Overheating, or being too cold, can exacerbate symptoms for individuals with MS. The effects are temporary but can be unpleasant. You may notice changes with your vision, balance or you may feel more fatigued.



To mitigate the impact of temperature on your symptoms, it's advisable to be mindful of your surroundings and consider avoiding physical activities during the hottest times of the day, or to wear extra layers in the cold. Additionally, if heat sensitivity affects you, it's beneficial to refrain from activities such as saunas or hot baths.

Implementing pre-cooling techniques before engaging in exercise or activities that may increase your body temperature can be an effective strategy to combat overheating. There are various cooling equipment options that can assist in maintaining a comfortable body temperature.

By understanding and managing heat sensitivity in MS, you can take proactive steps to minimise symptom exacerbation and enhance your overall well-being.



[Read more about MS and Temperature on our website](#)

## **Cognition**

MS can affect cognitive functions, including memory. Individuals can experience 'Brain Fog', a state of reduced mental clarity and a feeling of being less organised or as sharp

as before. It can help to keep diaries and lists to record appointments and commitments. It's also beneficial to communicate with your loved ones about your memory-related concerns, allowing them to provide assistance when needed.

If you find that everyday tasks are becoming more difficult, consult your GP, MS nurse or one of our regional societies community advisors. They can provide valuable guidance and support, helping you navigate any cognitive challenges that arise.



[Read more about MS and Changes to Thinking and Memory on our website](#)

## **Mental Health**

It's common to feel overwhelmed by the challenges of living with multiple sclerosis. Embracing flexibility is key to navigating life with MS. Focus on exploring new things and finding joy in what you can do rather than focussing on limitations. Over time, you'll discover how to incorporate MS into your life without it taking over. While it may be hard to believe early after diagnosis, this balance can be achieved with time.

Openly discussing MS with those around you, including your medical team, can be beneficial. Support groups provide an opportunity to share experiences and connect with others facing similar challenges. Seeking guidance from counsellors and mental health professionals can help you develop effective coping strategies. Additionally, maintaining social connections and seeking support from friends, family and Whānau is important.



[Read more and MS and Mental Health on our website](#)

## **MS and Pregnancy**

The typical age of onset of multiple sclerosis means that many women who are diagnosed with MS are starting a family or contemplating having more children. A person with MS has an increased risk of having a child who will develop MS, however, the risk is small.

### **There are a few factors you might consider when making your family / Whānau plans:**

- Relapses are less likely to occur while pregnant, but there is an increased risk of a relapse in the three to six months following a pregnancy.
- Overall, pregnancy does not have a significant effect on the course of MS.
- Pregnancy is best avoided while taking most disease modifying therapies.





- Consult your GP, neurologist or MS nurse about family planning and pregnancy, particularly if you are taking any medication for your MS.

Watch the MS and Pregnancy webinar below, where one of the world's leading researchers in MS, women's health, fertility, and pregnancy discusses how MS affects these issues. Visit the online version of this document to access the webinar.

[www.msnz.org.nz/nzmsrt-webinar-ms-and-pregnancy/](http://www.msnz.org.nz/nzmsrt-webinar-ms-and-pregnancy/)



[Read more about MS and pregnancy on our website](#)

## MS and Menopause

The effects of the menopause can feel similar to many MS symptoms. Couple this with hot flushes and difficulty sleeping and you might feel our MS symptoms appear worse. Finding ways to manage the menopause symptoms could help with your MS symptoms too. Some women find their MS changes around the time of menopause.

When experiencing symptoms like brain fog and fatigue, it's not always easy to know if it's MS or menopause causing them, so let your neurologist or MS nurse know what you are experiencing, and they can help you find the best way to manage it.



[Read more about MS and menopause on our website](#)

“Since having the girls it has been a matter of managing my energy levels and trying to get enough rest so I can keep my symptoms at bay.”

[Tanya, PwMS](#)

# Your Friends, Family and Whānau

**Confide in your loved ones about your MS diagnosis, as they will undoubtedly be your biggest supporters on this journey. It's important to remember that just as it took time for you to process the news, it may also take them some time to adjust. Being mindful of their needs and emotions can go a long way in strengthening your bond.**

Don't hesitate to openly share your thoughts and feelings about your condition with your loved ones and encourage them to do the same with you. By keeping them informed about your physical and emotional well-being, you can create a sense of comfort and understanding for everyone involved. Sometimes, our minds tend to paint worst-case scenarios when left in the dark, so keeping the lines of communication open is key.

Remember, our relationships have the power to carry us through not only the good times, but also the challenging ones. Your loved ones are there to support you, so let them in and allow them to be a source of strength and encouragement along this journey.

## For your partner:

- Talk to your partner about their feelings and anxieties about your condition
- Talk with a counsellor or social worker if you are worried about the effect MS is having on your relationship, especially if you are concerned about the burden this places on your partner
- Encourage your partner to take time out for themselves, even if this means getting help from others



[Read more about MS for Carers on our website](#)



[Read more about MS and Dating on our website](#)



[Read more about MS and Sex on our website](#)



## For your children:

- Explain your diagnosis to your children at a level they can understand; increasing the detail as they get older
- Listen to your children's questions, and take time to answer them
- Don't hide the truth from them
- Consider how your child will be absorb information about MS - some might prefer to read books alone, while others might want to sit with you and watch videos about MS

- Involve your child by asking them to help around the house
- Consider family counselling



[Read more about MS for kids on our website](#)

## MS and Work

Maintaining employment and earning a living holds great importance for many individuals, and the presence of MS doesn't necessarily have to hinder your ability to work. While you may need to make adjustments to accommodate symptoms such as fatigue and pain, people with MS can continue pursuing their chosen careers even after their diagnosis.



## Here are some positive considerations to help you navigate work and MS:

- Arrange your work schedule in a way that allows you to tackle demanding tasks in the mornings when you feel more energised, and reserve easier tasks for the afternoons when fatigue might be more pronounced.
- Take short breaks and engage in light exercise if you start feeling tired. It can help rejuvenate your energy levels.
- If parking is available, try to secure a spot close to your building for easier accessibility.
- Opt for a chair with armrests and good back support to ensure comfort during your work hours.
- Remember that your employer is legally obligated to make reasonable accommodations to assist you in continuing your work. This could involve making physical adjustments to your workspace, redistributing tasks if certain aspects of your job pose challenges, or even allowing you to work remotely on occasion.

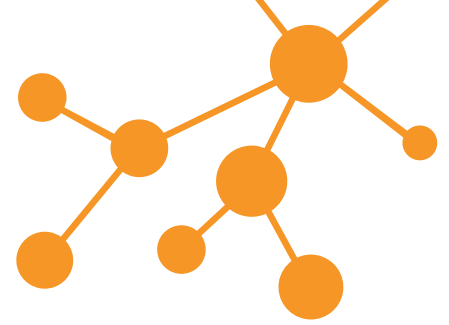
- Reach out to your [regional societies](#) community advisors for guidance and assistance. They possess valuable experience in helping individuals manage workplace changes following an MS diagnosis and can serve as effective advocates if you encounter any issues with your employer.

By adopting these positive strategies and seeking support, you can proactively manage your work and MS, allowing you to thrive in your chosen career while prioritising your well-being.



[Read more about MS and Work on our website](#)

# Your Home and Environment



You may not require any modifications to your home, but if in time your symptoms interfere with your ability to move around easily and safely, making some small changes can make a big difference.

## **Around your home:**

- Ensure your floor surfaces are slip-resistant and free from any potential trip hazards.
- Store frequently used items in easy to reach locations to avoid unnecessary strain.
- Talk to an occupational therapist for expert advice on specific changes you can make to your home to improve accessibility and convenience, such as handrails, if necessary.

## **For safety:**

- Keep a portable or mobile phone within easy reach, ensuring it is always accessible in case of an emergency.

- Establish a network of friends, family and Whānau whom you can call upon when needed. Having a support system is invaluable.
- Install night lights around your home to provide better visibility and reduce the risk of accidents.
- If you have trouble hearing, consider installing a smoke detector with a visual signal to ensure your safety in case of a fire.
- Personal alarms are small devices that feature an audible alarm to alert people to your need. Some are programmable to contact pre-set mobile numbers.

By implementing these small adjustments, you can create a home environment that promotes ease, accessibility, and peace of mind. Remember, your safety and comfort are paramount, and taking proactive steps to address any challenges will help you enjoy your home to the fullest.



# Sources of Support for People with MS

## **MS Regional Societies and Community Advisors**

Regional Societies provide an extensive range of support and services for individuals with MS, their families, whānau, carers, and employers.

**Trained community advisors are employed by most regional societies to offer guidance and assistance on a diverse range of matters, including:**

- Advice and information on multiple sclerosis symptoms and management
- Access to information resources developed and provided by MSNZ
- Networking with others with MS in your area

- Advice on local services and supports
- Support with applications and grants
- Advocacy and support for dealing with employers, support services and your medical team

Find your local regional society here:

[www.msnz.org.nz/contact-your-regional-society/](http://www.msnz.org.nz/contact-your-regional-society/)

## **Your Medical Team**

You will work with a range of health specialists during your journey with MS.

### **Your GP**

Your primary point of contact for various health concerns will be your General Practitioner (GP). GPs possess broad knowledge about a wide range of illnesses, but they may not necessarily have specialised expertise in multiple sclerosis. In such cases, you can request that they familiarise themselves with the condition by reading up on it or enquire if there are other GPs within your practice who do possess specialist MS knowledge.



## Neurologist

Your GP will guide you towards the next step by referring you to a neurologist, a specialist who focuses on addressing issues concerning the nervous system. It is beneficial to request a referral to a neurologist with specialised knowledge in multiple sclerosis, if available. The neurologist will conduct a thorough assessment, discussing your symptoms with you, and may recommend additional tests such as MRIs and lumbar punctures for further evaluation.

## MS Nurse

Depending on your location, you may have access to specialist MS nurses. These nurses are trained to provide valuable support and assistance to individuals living with MS. They can offer essential education about your condition,

assist you with medication management, help alleviate symptoms, and provide valuable information regarding the impact of MS on various aspects of your life. Having access to specialised MS nurses can be a valuable resource in your journey of managing MS and promoting overall well-being.

## MS Community Advisors

Your local MS Society can arrange regular meetings with a community advisor, who will address your MS questions, and assist in arranging any additional support you may require. These dedicated professionals are equipped to offer guidance, information, and practical assistance tailored to your specific needs.



You might also connect with other health professionals depending on your symptoms, like speech and language therapists, counsellors, ophthalmologists, and physiotherapists.

By tapping into the support provided by MS community advisor and collaborating with other healthcare experts, you'll have a comprehensive network of professionals to enhance your wellbeing and address the unique challenges posed by multiple sclerosis.

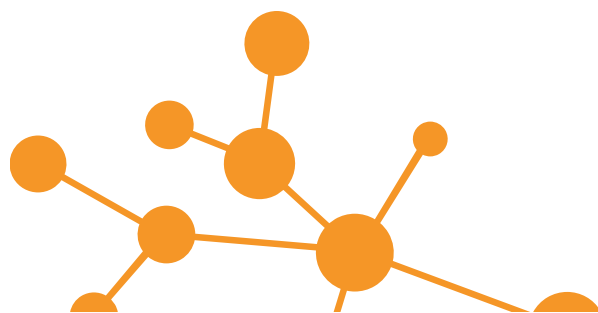
### **Support Groups**

It can be useful to talk to other people with MS, to share experiences, ideas, and helpful tips. Talk to the community advisor at your local MS society - they can recommend support groups with people in similar situations to you or set you up with one-to-one peer support.

Online support groups can also be a useful resource, but it's important to note that people often find it easier to share negative experiences rather than positive ones. Therefore, exercise caution and actively seek out the helpful or positive stories.

### **Many people with MS in Aotearoa New Zealand find the following helpful:**

- Shift MS <https://shift.ms/join>



# Using MSNZ Resources

We hope this introductory booklet has given you a good overview of multiple sclerosis, and valuable insights into living well with this condition. We encourage you to explore our additional resources for more detailed information on many aspects of MS. By delving into these supplementary resources, you can expand your knowledge and equip yourself with a wealth of information to further assist you in navigating your journey. Remember, knowledge is power, and the more you educate yourself, the better equipped you will be to make informed decisions and actively manage your well-being.

## Info Sheets

Our collection of concise and user-friendly guides covers a variety of topics related to MS, such as symptoms, treatments, and practical suggestions for leading a fulfilling and joyful life with MS. You can read through the information sheets that are relevant to you at any time. We encourage you to download or print them. Having these resources readily

available will empower you to access the information you need, precisely when you need it.



[Take a look at the MSNZ info sheets on our website](#)

## What's available for people with MS?

Within this guide, you will find a range of resources at your fingertips. From organisations to assist in modifying your home to enhance accessibility, to transportation services ensuring you can easily reach your appointments, and groups to help you navigate the challenges of employment while managing MS – the guide covers a wealth of support opportunities.

## MS for Carers

This booklet is designed to help individuals supporting loved ones with MS. It offers practical insights and strategies for friends, family and Whānau to effectively support their loved one while also taking care of themselves. By sharing this resource, you can empower your support network with valuable information

on understanding MS, offering assistance, and maintaining their own well-being. Together, you can foster a strong support system that promotes the well-being of both you and your caregivers.

### **MS and Work**

Designed with your needs, as well as those of your co-workers and employers, in mind, this booklet provides valuable insights on effectively adapting your workplace and job to meet any specific requirements you may have. It offers guidance and practical suggestions to navigate the process of creating a more accommodating work environment.

“I have found that full disclosure of my illness to my workplace has meant that they have supported and helped me on my journey.”

**Bryce, PwMS**



## Contacts and useful websites

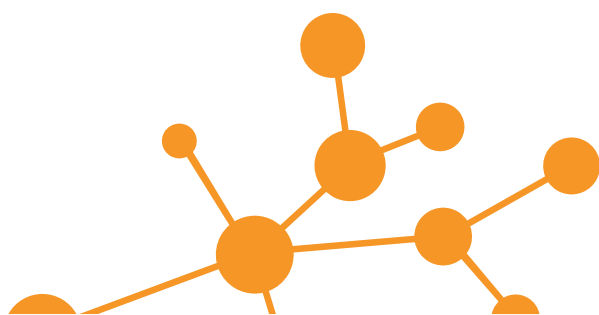
The Internet provides a great deal of information about MS, but the quality and accuracy of the information can vary.

Some useful websites are listed below:

- Multiple Sclerosis New Zealand: [www.msnz.org.nz](http://www.msnz.org.nz)
- MS Regional Societies: [www.msnz.org.nz/contact-your-regional-society](http://www.msnz.org.nz/contact-your-regional-society)
- MS International Federation: [www.msif.org](http://www.msif.org)
- MS Australia: [www.msaustralia.org.au](http://www.msaustralia.org.au)
- MS Society UK: [www.mssociety.org.uk](http://www.mssociety.org.uk)
- National Multiple Sclerosis Society (USA): [www.nationalmssociety.org](http://www.nationalmssociety.org)
- Rocky Mountain MS Center: [www.mscenter.org](http://www.mscenter.org)
- MS Trust: [www.mstrust.org.uk](http://www.mstrust.org.uk)
- MS Brain Health: [www.msbrainhealth.org/people-with-ms](http://www.msbrainhealth.org/people-with-ms)

**Aotearoa, New Zealand resources:**

- Whaikaha (Ministry of Disabled People): [www.whaikaha.govt.nz](http://www.whaikaha.govt.nz)
- Carers NZ (an online resource for Carers): [www.carers.net.nz](http://www.carers.net.nz)
- Medsafe: [www.medsafe.govt.nz](http://www.medsafe.govt.nz)
- Ministry of Health: [www.health.govt.nz](http://www.health.govt.nz)



# Glossary

## 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.

**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

**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 several 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.

**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

**Central nervous system:** The central nervous system (CNS) consists of the brain and spinal cord and includes the optic nerves but no other peripheral nerves.

**Cholesterol:** A substance your body needs to make hormones, vitamin D, and substances that help you digest foods. If you have too much cholesterol in your blood, it can combine with other substances in the blood to form plaque, which can lead to problems like atherosclerosis and heart disease.

**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 could 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.

**Corticosteroids:** Natural hormones produced by the adrenal glands that have anti-inflammatory and immune system suppressing properties. The medicines prednisone and methylprednisolone are synthetic steroids used to treat acute MS relapses.

## Dd

**Demyelination:** A loss of myelin seen in the inflammatory process of MS.

**Diabetes:** A chronic disease characterised by high levels of blood glucose, which can lead over time to serious damage to the heart, blood vessels, eyes, kidneys, and nerves.

**Disease modifying treatment (DMT):** Treatments that aim to reduce the number of relapses and slow the development of new patches of inflammation for people with MS.

## Ee

**Epstein-Barr Virus (EBV):** One of the most common viruses in the world. It spreads primarily through saliva. Most people will get infected with EBV at some point in their life, and it usually has very few symptoms.

**Evoked potentials (EPs):** Recordings of the nervous system's electrical response to the stimulation of specific sensory pathways (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, relapse, flare-up, or worsening); usually associated with inflammation and demyelination in the brain or spinal cord.

## Gg

**Genetic:** Relating to the genes, which pass heritable traits from parents to children.



## Ii

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

**Immunosuppression:** When the immune system is not fully functioning, and this may affect the body's ability to fight infections. This can also be a form of treatment which slows or inhibits the body's natural immune responses to reduce inflammation, including immune responses directed against the body's own tissues (see autoimmune disease). Examples used in MS include cyclophosphamide, methotrexate, azathioprine and mitoxantrone.

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

**Inflammation:** A tissue's immune response to injury with signs such as swelling and redness, and in blood test showing extra white blood cells and antibodies.

**Interferons:** A group of immune system proteins that are produced naturally in response to viral infections. They restrict the spread of infection and moderate 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 performed by a specialist doctor that uses a hollow needle to enter the spinal canal in the lower (lumbar) spine to remove cerebrospinal fluid (CSF) for analysis.

## Mm

**Magnetic Resonance Imaging (MRI or MR scans):** A diagnostic procedure which produces images of different body parts without the use of radiation. MRI 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.

**MSTAC:** Multiple Sclerosis Treatment Assessment Committee, which works with PHARMAC to assess applications for funding of MS medication in NZ.

**Myelin:** A coating (sheath) around nerves 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.

## 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 influencing contractions of muscles or organs.

**Nervous system:** Includes all 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 network, and nerves throughout the body.

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

**Neurology:** Study of the 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.

## Oo

**Occupational therapist (OT):** OTs evaluate and enhance the ability to perform daily activities necessary for independent living, such as dressing, bathing, meal preparation, writing, and driving. They address various aspects, including managing fatigue, improving upper body strength and coordination, suggesting home and work environment modifications, and providing strategies to compensate for cognitive, sensory, or visual impairments.

## Pp

**Paraparesis:** A weakness, but not total paralysis, of the legs.

**Paraplegia:** Total paralysis of both legs.

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

**PHARMAC:** The Pharmaceutical Management Agency of New Zealand, PHARMAC, which manages a list of subsidised pharmaceuticals, the Pharmaceutical Schedule, on behalf of the Crown.

**Physiotherapist:** Physiotherapists assess and enhance body movement and function, focusing on mobility, balance, posture, fatigue, and pain. Their program involves educating individuals with MS about the disease's physical impact, creating personalised exercise plans, and utilising mobility aids and adaptive equipment to improve mobility and conserve energy.

**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.

**Progressive relapsing MS:** A type of MS characterised by gradual deterioration, with some distinct relapses.

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

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

## Rr

**Relapse:** A temporary period of new or aggravated existing symptoms, varying in intensity and duration from mild to severe, with some lasting days and others extending to months.

**Relapsing MS:** The pattern which multiple sclerosis follows differs for each person. The relapsing form of MS follows a course of relapses where there is an increased level of signs and symptoms, followed by periods in which there are fewer or no symptoms. The frequency and severity of relapses varies. People with relapsing 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, touch, smell, taste, temperature, vision, hearing, acceleration, and position in space.

**Steroid:** A type of anti-inflammatory medication that can help relieve symptoms of an MS relapse. See corticosteroid.

**Symptom:** A physical or mental experience that a person experiences that may indicate a condition or disease. It is 'felt' by the person but not seen by the doctor (the latter is called a 'sign').

## Tt

**Tremor:** Uncontrolled trembling or shaking.

## Vv

**Visual evoked potential (VEP):** A test that measures the brain's electrical response to visual stimuli (e.g. a flashing checkerboard). The test is recorded by an electroencephalograph (EEG) and analysed by computer. EEG is a non-invasive test that measures and records the electrical activity of the brain. As the VEP test can 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 established 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 Multiple Sclerosis Society of New Zealand (MSNZ)

PO Box 1192, Christchurch 8140

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 0800 MS LINE (0800 675 463)

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

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

## Regional MS Societies

### Northland

09 4383945  
[nthlndms@xtra.co.nz](mailto:nthlndms@xtra.co.nz)

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### Auckland

09 845 5921  
[info@msakl.org.nz](mailto:info@msakl.org.nz)

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### Waikato

07 834 4740  
[mswaikato@mswaikato.org.nz](mailto:mswaikato@mswaikato.org.nz)

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### Bay of Plenty

022 638 7015  
[admin@bopms.co.nz](mailto:admin@bopms.co.nz)

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### Rotorua

022 314 0212  
[msrotoruardistricts@gmail.com](mailto:msrotoruardistricts@gmail.com)

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### Gisborne

06 868 8842  
[office.ms.gisborne.eastcoast@gmail.com](mailto:office.ms.gisborne.eastcoast@gmail.com)

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### Hawkes Bay

06 835 8542  
[info@mshawkesbay.org.nz](mailto:info@mshawkesbay.org.nz)

---

### Taranaki

021 985 285  
[secretary@mstaranaki.co.nz](mailto:secretary@mstaranaki.co.nz)

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### Wanganui

06 345 2336  
[info@mswanganui.org.nz](mailto:info@mswanganui.org.nz)

---

### Manawatu

06 357 3188  
[mmss@inspire.net.nz](mailto:mmss@inspire.net.nz)

---

### Wellington

04 388 8127  
[info@mswellington.org.nz](mailto:info@mswellington.org.nz)

---

### Marlborough

03 578 4058  
[mmss@xtra.co.nz](mailto:mmss@xtra.co.nz)

---

### Nelson

021 174 3298  
[admin@msnelson.org.nz](mailto:admin@msnelson.org.nz)

---

### West Coast

03 768 7007  
[mspdwestcoast@gmail.com](mailto:mspdwestcoast@gmail.com)

---

### Canterbury

03 366 2857  
[support@ms-pd.org.nz](mailto:support@ms-pd.org.nz)

---

### South Canterbury

03 687 7375  
[office@mssouthcant.org.nz](mailto:office@mssouthcant.org.nz)

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### Otago

03 455 5894 / 027 88 99 035  
[info@msotago.org.nz](mailto:info@msotago.org.nz)

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### Southland

03 218 3975  
[info@mssouthland.org.nz](mailto:info@mssouthland.org.nz)

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**ms.**  
Multiple Sclerosis  
New Zealand

**Together, we're stronger**