

Symptoms

Managing a relapse

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People living with multiple sclerosis may experience relapses – the frequency, severity and longevity varies from person to person. With the right information and support, relapses can be managed effectively to maintain a healthy and active lifestyle.

What is a relapse?

A relapse is a relatively sudden (over hours or days) episode of new, or worsening of existing, multiple sclerosis symptoms. Other names for relapse include an attack, episode, exacerbation, a flare up or blip. Another frequent term 'pseudorelapse' is used when multiple sclerosis symptoms increase or become apparent while you are experiencing a concurrent/parallel illness.

When the immune system attacks the myelin covering of nerves, it causes inflammation and damage to the myelin (demyelination). Messages pass along a demyelinated nerve more slowly or are blocked. This can give rise to a variety of symptoms, depending on the part of the brain or spinal cord that is affected.

When the inflammation lessens, it's possible for damaged myelin to be replaced, a process known as remyelination. Messages can pass along the affected nerves more easily and symptoms gradually improve. Although the new myelin can work effectively, it tends to be thinner than unaffected myelin and so messages through the affected nerves may not be as fast as before the relapse.

Inflammation doesn't always result in a relapse. It can occur in a part of the brain not associated with symptoms, or the brain may be able to adapt rapidly and re-route messages around an area of inflammation. These are known as silent lesions and can only be seen using MRI scans. Increasingly, these silent lesions are being seen as both an important marker of multiple sclerosis activity and one of the measures which make up the NEDA (no evidence of disease activity) treatment goal.

To be medically defined as a new relapse:

- it must last for at least 24 hours but more commonly for a number of weeks
- it must occur at least 30 days after the start of a previous relapse
- there must be no other explanation for the onset of symptoms such as an infection or a rise in body temperature

With the right advice, you can manage relapses and prevent complications or associated illnesses.



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Your neurologist or MS nurse may be the first point of contact

What should I do if I experience a relapse?

If you have relapse concerns talk to your MS nurse or GP as soon as possible. Relapses can be a sign that your multiple sclerosis is active so it's important to report each one, even if you don't think you need medical treatment. If your multiple sclerosis is becoming active, it may be necessary to consider starting a disease modifying therapy or switching to a different one. Tell your neurologist about new and/or persistent symptoms.

Different centres have different approaches to reporting and managing relapses. For many people, their neurologist or MS nurse will be the first point of contact but for others, it could be their GP.

Some MS nurses will discuss your concerns by phone or email, or they may book an appointment to see you. Some MS teams have relapse clinics that you can attend at fairly short notice.

Your MS nurse will ask about the symptoms you're experiencing, when they started, what's changed and how these symptoms are affecting you on a day to day basis. Your MS nurse will also want to know if there's anything happening that could be making your symptoms worse such as signs of infection – this will often include a urinary tract infection test. Some women find that their multiple sclerosis symptoms worsen around the time of their period, so an MS nurse may ask about a patient's menstrual cycle.

Your MS nurse may ask:

- When did your symptoms start to change and what's been the pattern of this change?
- What symptoms are you experiencing?
- Which part of your body is affected, for example if you have numbness, where is this?
- Have the symptoms stopped you doing anything that you can normally manage, such as preparing meals, driving, getting up and down stairs, working etc?
- Have you been ill lately or had any symptoms of infection, for example unexplained shivering?
- What medication are you taking and has your medication recently changed?

It'll be easier to answer these questions if you've been keeping track of your symptoms and any drugs you are taking.

It can be worrying when you experience a relapse, but try not to panic. It's important to bear in mind that it will usually settle down of its own accord. You know yourself best, so listen to your body. If you need a rest then do your best to take one.



What else can I do to manage a relapse?

Once your neurologist or MS nurse has confirmed you're having a relapse, they should discuss your symptoms with you and decide whether you need treatment for the relapse itself or the symptoms.

Not all relapses need treatment. The symptoms of a relapse will generally improve on their own.

Steroids

If your relapse is having a significant effect on your daily life, your MS team or GP may suggest you take a short course of steroids. Your MS nurse or neurologist should discuss with you the pros and cons of taking steroids, to help determine the best course of action for your particular situation.

Steroids speed up recovery from a relapse by reducing inflammation and ideally, should be started as soon as possible after your relapse has been confirmed. However, taking steroids won't affect how well you recover in the long term and won't affect the course of your multiple sclerosis.

You usually take steroids as tablets or through an intravenous infusion (drip) in a hospital clinic/infusion centre.

Disease modifying therapies

Disease modifying therapies are a group of treatments for people with relapsing remitting multiple sclerosis (RRMS), which help reduce the frequency/number and severity of relapses.

Rehabilitation

Whether or not you decide to take steroids, there may be other treatments to help you cope with your symptoms. These might include medication for multiple sclerosis symptoms, physiotherapy, occupational therapy to support you at home or at work, neuropsychology, speech and language therapy. Depending on the severity of your relapse you may be offered rehabilitation – at a day rehabilitation centre or as an inpatient at a hospital.

For more severe relapses, you may need help from community care services, for instance with aspects of your personal care or meal preparation.

Follow-up appointment

A follow-up appointment with your neurologist or MS nurse is usually arranged about two months after the start of your relapse. This may be face-to-face or a phone appointment and enables them to check on how you are, and for you to discuss other treatment options if things are still difficult. Your MS nurse should also make a record of your relapse and pass this on to your neurologist, so that your MS medical team has a full record of your relapses and symptoms.

Recovering from a relapse (home and work life)

If you're going through a relapse, it's important to remember that it will usually settle down of its own accord. It's likely that you will feel unwell and more tired while you're recovering from your relapse. This can have an impact both at home and at work so ask for help, make adjustments or take an extended break if suitable, or shorter breaks during your day.



General information and assistance

There is support available to help you manage your multiple sclerosis:

- Contact your state MS organisation (details below) to access services such as MS nurses, peer support and other resources.
- Speak to your neurologist and other healthcare providers about the best approach to treatment management for your individual circumstances.

 For information about multiple sclerosis and multiple sclerosis treatments, visit www.msplus.org.au

State MS organisations

MS Plus (Victoria, NSW, ACT and Tasmania)



1800 042 138 connect@msplus.org.au www.msplus.org.au

MSWA (Western Australia)



1300 097 989 communications@mswa.org.au www.mswa.org.au

MS Society SA & NT (South Australia and NT)



1800 812 311 msassist@ms.asn.au www.ms.asn.au

MS Queensland



1800 177 591 info@msqld.org.au www.msqld.org.au

The following support services may be able to provide wellbeing or other advice

• Carers Australia 1800 242 636

www.carersaustralia.com.au

Information and advice to carers, their friends and families about carer support and services.

Independent Living Centres Australia 1300 885 886

www.ilcaustralia.org.au

Information about products and services to help people remain independent and improve their quality of life.

Sources

This fact sheet comprises material from previously published Australian MS organisation leaflets plus Multiple Sclerosis (MS) UK Trust online resources. The Brain Health Guide (and associated references), and has been endorsed by a medical expert, an MS Nurse and a person living with multiple sclerosis.

Disclaime

Information prepared by MS Australia. It is intended to provide useful and accurate information of a general nature and is not a substitute for medical advice.