

Relapses and relapse management

Approximately 85% to 90% of people diagnosed with multiple sclerosis (MS) have relapsing-remitting MS. This type of MS is characterized by unpredictable but clearly defined periods (relapses) during which symptoms are apparent, followed by periods of partial or complete recovery (remission). Relapses are also known as *attacks*, *exacerbations*, or *flare-ups*.

What is a relapse?

A relapse is defined as the appearance of new symptoms or the reappearance of existing symptoms for a period of at least 24 to 48 hours in absence of infection or illness. The average duration of a relapse is eight weeks, but it can be longer or shorter. Individuals are considered to be in remission once symptoms begin to subside. If symptoms worsen within the same month, it is considered to be the same relapse.

Why do relapses occur?

It is believed that relapses occur when the immune system mistakenly attacks myelin, the protective covering that surrounds the nerve fibres. The attack causes inflammation and subsequent scarring, also called plaques or *lesions*. Lesions interfere with the normal transmission of nerve impulses and can result in a variety of symptoms. It is impossible to predict the time, intensity, duration or accompanying symptoms of a relapse. Relapses may vary from one attack to another and symptoms may continue even during the remission period.

When does remission begin?

Remission is a period of partial or complete recovery and starts when the symptoms begin to subside after a relapse. Recovery is dependent on the severity of the lesions. In general, people recover quite well but residual effects are experienced in about half of all cases. Remission usually lasts for several weeks, but may continue for a year or more.

During remission, the body is usually able to either partially or fully repair the damaged myelin. Generally, a scar appears on the nerve tissue and remains visible to magnetic resonance imaging (MRI), even if the symptoms of the relapse have disappeared completely. Recovery is incomplete if the myelin isn't sufficiently repaired or nerve fibres have been destroyed.

Different levels of relapse severity

Relapses can be mild, moderate or severe and they often differ from one time to the next, both in their intensity and in their symptoms. Their duration also varies, as does the time between relapses. An intense relapse one time does not mean that the following relapse will also be severe.

What to do during a relapse

Relapses often appear gradually. During these times, you need to rest as much as possible, especially if it is a severe relapse. When you feel better, you can gradually resume your activities however it is important to listen to your body. Experience will help you to learn how best to take care of yourself. You should consult your neurologist if:

- you aren't sure if your symptoms are caused by a relapse,
- the symptoms get worse, or
- they interfere with your daily activities.

Relapse management – treating relapses

Steroids (corticosteroids) administered intravenously and orally, are currently the most effective treatment for MS relapses. Corticosteroids reduce inflammation in the central nervous system during a relapse. They are powerful and can cause serious side-effects, so they should only be used on a short-term basis. Generally, only moderate or severe relapses, resulting in painful or disabling symptoms, are treated. Your doctor may choose to act if your vision or mobility is affected. The goal is to lessen the severity of the relapse and speed recovery, especially in the early stages of the disease. It is important to note that a lack of treatment or a delay before starting treatment with corticosteroids will **not** have long term consequences for the course of the disease.

Although each individual case will be assessed differently, corticosteroids are administered in one of two ways: high-dose **intravenous (IV) methylprednisolone** for 3-5 days which may or may not be followed by a tapering dose of oral steroids, or high-dose **oral prednisone**, also for 3-5 days. The benefit of taking oral steroids is that the individual does not need to be hospitalized, or have the IV administered in an outpatient department. Studies indicate that there is no difference in efficacy between the high-dose IV and oral administrations, although symptom relief is typically faster with IV administration.

Side effects of corticosteroids

As with all medications, corticosteroids carry side effects, some more adverse than others. *Short-term* side effects can include: allergic reaction, insomnia, mood alterations, stomach ache, fluid retention, increased appetite, acne, increased susceptibility to opportunistic infections and although rarely, bone damage. With the use of intravenous methylprednisolone there are also the side effects of a metallic taste to

the mouth and flushing of the face. Long-term side effects can include: weight gain, high blood pressure, cataracts, hardening of the arteries, diabetes, life-threatening infections, osteoporosis or other bone damage and risk to fetus (heart defects or cleft palate).¹

Corticosteroids may diminish the effect of vaccines. If vaccinated during steroid therapy a re-vaccination should be completed within three months.

There can be complications of getting pregnant while on steroids so birth control should be utilized. Steroids are excreted in breast milk and therefore not recommended in women who are breastfeeding.

Pseudo-relapse

People with MS may sometimes experience pseudo-relapses (or pseudo-exacerbations). A pseudo-exacerbation is a temporary worsening of MS symptoms that have occurred before. The episode usually results from a trigger such as a rise in body temperature (*Uhthoff's phenomenon*) or other stressor (e.g., infection, fatigue, constipation). A pseudo-exacerbation is not related to new inflammation or disease activity within the central nervous system and does not require treatment. Symptoms will subside as the body temperature regulates.

MS Disease-Modifying Therapies

There are a number of treatments currently available to manage relapsing forms of multiple sclerosis (relapsing-remitting and secondary-progressive *with* relapses). Known as immunomodulators or disease-modifying therapies, they reduce the frequency and severity of MS relapses and slow disability progression. They can also reduce the number and volume of lesions visible with MRI. If you have repeated relapses, your neurologist may suggest that you change treatments if the one you're currently taking seems to be ineffective.

Symptom Management

Symptom management medications help ease many MS-related symptoms such as fatigue, spasticity and pain. These medications are available to people with all types of MS. In addition, there are important non-medicinal strategies to improve quality of life for people living with MS, including appropriate exercise, physiotherapy, rehabilitation, massage, stress reduction techniques, among other wellness approaches.

Rehabilitation

The goal of rehabilitation is to improve and/or maintain function. If symptoms begin to interfere with everyday activities, a rehabilitation team can address problems with mobility, dressing and personal care, role performance at home and work, and overall fitness. Types of rehabilitation may include physical therapy, occupational therapy or speech therapy.

¹ Multiple Sclerosis: The Facts You Need, 5th ed. Dr. Paul O'Connor (2014)

Keeping a Health Journal

A journal is your personal record of what is happening with your health and it will help you communicate with doctors about what has happened since your last visit. The journal can be a written booklet or there are several smart phone apps available to assist with tracking and maintaining personal health information.

Things to keep track of in your journal:

- when symptoms started/ended
- what the symptoms were (and if you have had them before)
- did you have a fever
- how was your life affected by the relapse
- when symptoms ended, were there any deficits in your abilities (i.e. vision did not recover to previous state or status)
- record medications, including dose and potential side effects
- record energy levels, e.g. best in the morning, worse in the late afternoon
- results of doctors' appointments
- exercise programs and results
- dates and results of any medical tests
- complementary and alternative therapies tried and results
- difficulties with activities of daily living

In addition to pharmacological and complementary therapies, living a healthy lifestyle will help maximize your sense of wellbeing. Balanced nutrition, adequate rest, stress reduction, abstaining from smoking, taking measures to protect yourself from infections or other illnesses and regular exercise can equip your body with what it needs to feel your best.

SYMPTOMS CHECKLIST

Visual symptoms	Yes	No
Loss of vision		
Double vision		
Eye pain		
Flashes of light		
Other:		
Abnormal Sensations		
Abnormal Sensations	Yes	No
Numbness or tingling		
If yes, please list location(s) on body of abnormal sensations:		
Other:		
Muscle Spasms and Spasticity		
Muscle Spasms and Spasticity	Yes	No
Muscles may contract tightly and painfully (spasms)		
Muscles may be stiff and resistant to movement (spasticity)		
Other:		
Pain		
Pain	Yes	No
Stabbing pain		
Extreme skin sensitivity		
Burning sensation		
Other:		
Mobility Problems		
Mobility Problems	Yes	No
Problems with coordination		
Tremor (shaking of limbs)		
Dizziness		
Muscle weakness (arms and legs)		
Other:		
Fatigue		
Fatigue		
Cognitive Issues (problems with thinking, learning, planning)		
Cognitive Issues (problems with thinking, learning, planning)	Yes	No
Difficulty understanding and using language		
A short attention span		
Problems remembering and learning new things		
Other:		
Mental Health		
Mental Health	Yes	No
Depression		
Anxiety		
Mood swings		
Other:		

Sexual Dysfunction	Yes	No
Erectile problems		
Difficulty achieving orgasm		
Other:		
Bladder Issues	Yes	No
Difficulty emptying the bladder		
Frequent urination		
Incontinence		
Frequent urination during the night		
Bowel Problems	Yes	No
Constipation		
Infrequent bowel movements		
Bowel incontinence		
Other:		

Please describe any other symptoms below:

Symptoms Checklist Adapted from 'Relapse: Solutions for every day matters. Teva Canada Innovation. 2013

Connect with an MS Navigator today by calling 1-844-859-6789

Email: msnavigators@mssociety.ca

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