



# Understanding MS

As a person living with MS, you may have many questions about your condition. Having a better understanding of what MS is can help you adapt to your life with MS.

This booklet aims to answer some of the common questions about MS. You may find it provides useful discussion points to speak about with your doctor or MS team.

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# Glossary

You may find that some of the language that doctors and care providers use when talking to you about your MS and its treatment is difficult to understand. This glossary explains some of the words and terms that may be unfamiliar to you.

More information on the different types of MS (RRMS, SPMS, PRMS, and PPMS) can be found later on in this booklet.

<b>Axon</b>	The long, thread-like part of a nerve cell
<b>Central nervous system</b>	This is the brain and the spinal cord. They send messages to the body that allow you to move, think, and use your senses.
<b>Diagnosis</b>	Identifying a condition based on the results of tests and/or symptoms
<b>Disease-modifying therapies</b>	Medicines that can reduce how many relapses someone with MS has. They can also slow down the damage caused by MS.
<b>EDSS (Expanded Disability Status Scale)</b>	A test measuring the impact of MS on physical ability carried out by a neurologist
<b>Immune system</b>	The body's natural protection against harmful substances, such as germs

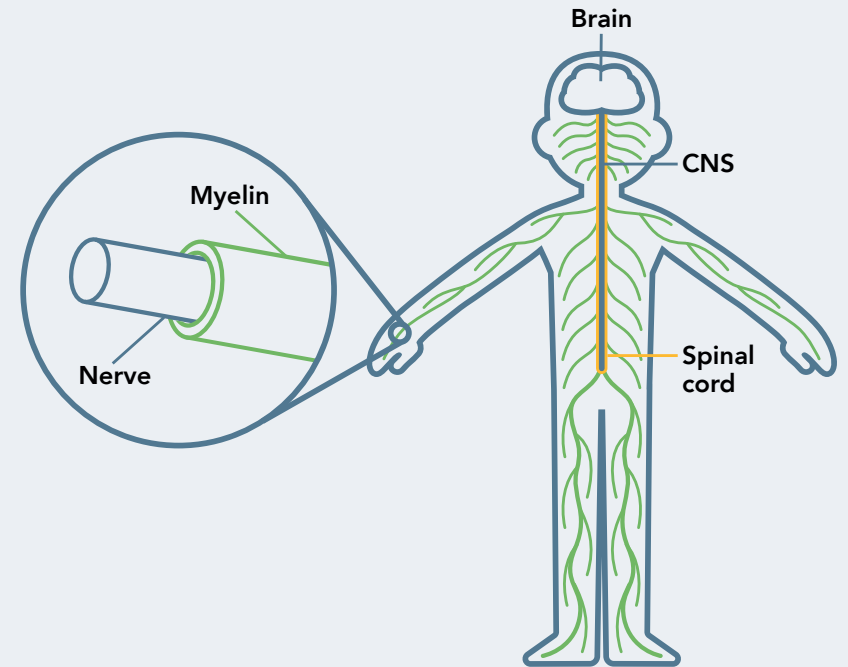
<b>MRI (magnetic resonance imaging)</b>	A type of body scan that provides detailed images of inside the body. It can be used to both diagnose and monitor MS.
<b>Myelin</b>	A fatty material that wraps around the outside of nerve cells and helps them send messages quickly
<b>Nerve cell</b>	A type of building block in the body that helps to carry messages between the body and brain; sometimes called 'neurons'
<b>Neurologist</b>	A doctor who specialises in conditions that involve nerves
<b>Relapse</b>	Any new MS symptom, or a worsening of an existing MS symptom, that lasts for 24 hours or more
<b>Remission</b>	The time of recovery following an MS relapse where there are no or few MS symptoms
<b>Spinal cord</b>	The part of the central nervous system located in the spine. It contains lots of nerve cells carrying messages to and from the brain.

# What is MS?

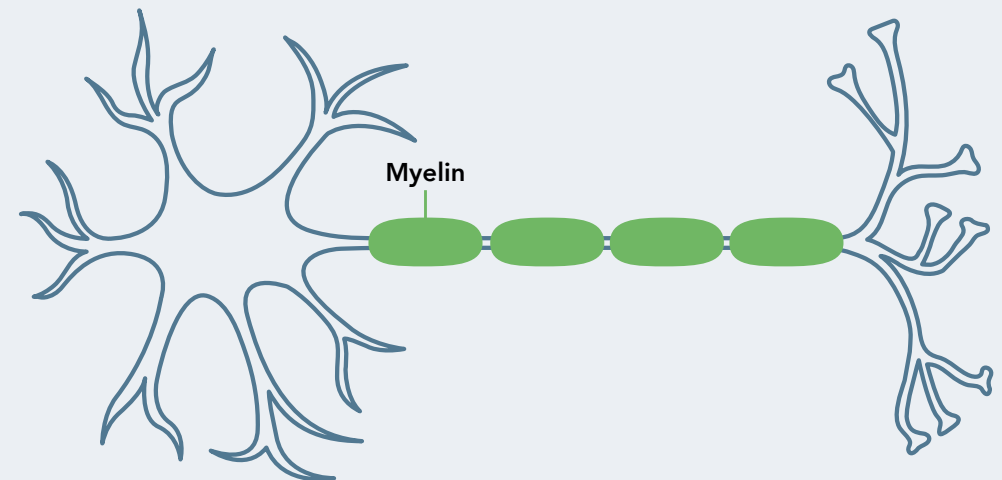
To understand MS, it is helpful to understand how the parts of the body involved in MS work.

Your brain and spinal cord – called your central nervous system (CNS) – send messages between your brain and the rest of your body that allow you to move, think, and use your senses.

- Imagine your central nervous system as a large network of electrical cables, with your brain as the central 'hub.'
- These cables are made of nerve cells, a type of building block.
- Most nerve cells are wrapped in a fatty layer called myelin.
- Myelin is like the insulating tape on a cable (axon) – it protects nerve cells and allows messages to travel along them quickly.
- This is important, as millions of messages are being sent between the brain and other parts of the body every second.



**Nerve cell**

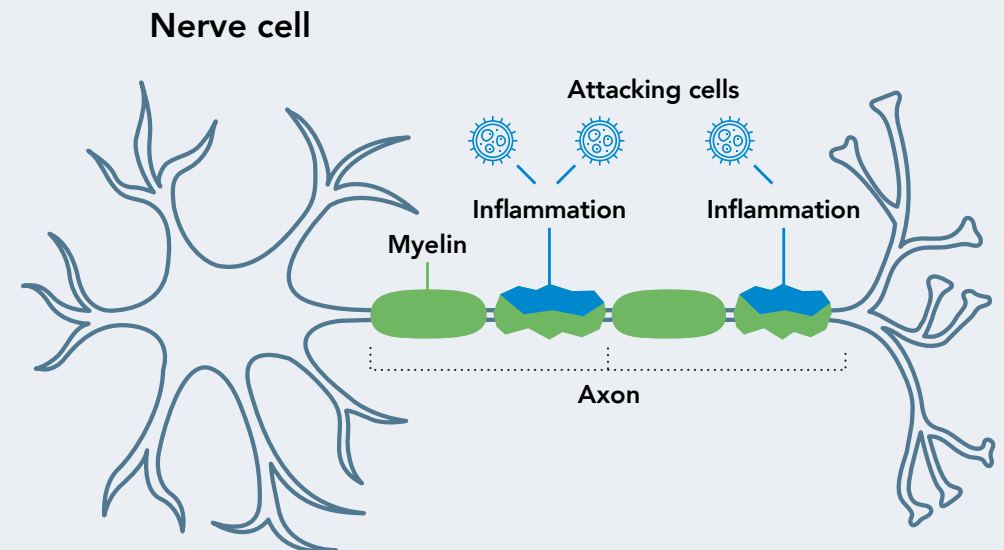
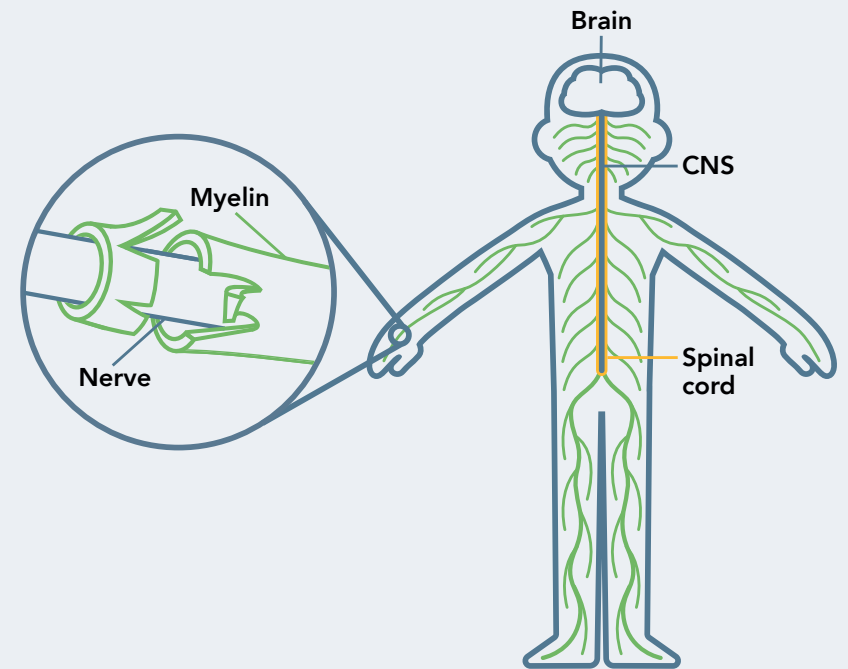


## What happens in MS?

- Our body's immune system naturally helps protect us against harmful substances, like germs.
- In MS, the immune system damages the protective myelin by creating substances that attack it. This is because the body starts to see myelin as harmful.
- Because of this, the nerve cells are not as well protected. They can become inflamed and damaged, just like a fraying cable.
- This damage can slow down the movement of messages between the brain and other parts of the body. This causes the symptoms of MS.<sup>1,2</sup>

**“Understanding is a journey with no correct path. I reached understanding and acceptance through a combination of patience, finding the support that worked for me, being open to a change in perspective, and crucially, by surrounding myself with like-minded people. It may not be today or tomorrow, or next month, but everything will be OK. Understanding and acceptance will follow.”**

**— Daniel L.**



# What do we know about MS?

## Why do some people get MS?

Our understanding of MS has come a long way over the past few decades. However, the reason why some people develop MS is still not entirely clear. There are a number of possible reasons, and it may also be a combination of reasons.

People with MS are most commonly diagnosed between the ages of 20 and 40, although it can happen to people of any age. MS also affects around twice as many women as men.<sup>3</sup>



### Family history

MS is not passed directly from parent to child. However, it does occur more often in people who have a family member with MS. Even if one of your family members has MS, the risk of developing MS is still very low.<sup>4</sup>

*You can read more about MS and family in our 'MS and Family Planning' booklet.*



### Environment

Where you grow up can affect your chance of getting MS. MS is more common the further away you are from the equator.<sup>5,6</sup> People exposed to less sun as a child and teenager are more likely to get MS than those who had more exposure.<sup>7</sup>

This is thought to be linked to vitamin D. Our body's main source of vitamin D is the sun, and not getting enough vitamin D is linked to a higher chance of having MS.<sup>8</sup>



### Smoking

Smoking can increase the chance of getting MS. It can also lead to more damage in the brain and to worse disability.<sup>9</sup>

If you smoke or vape, talk with your doctor or MS nurse about ways to give up smoking.



### Infections

It is possible that certain viral and bacterial infections can damage myelin, and these events may trigger MS.<sup>10,11</sup>

It is thought that infections may also play a role in making MS relapses worse, however researchers have not yet confirmed this link.<sup>12</sup>



### Diet and exercise

There is no proof that diet and exercise are linked to getting MS, but healthy eating and regular exercise can have a positive effect on MS symptoms.

## REMINDER







The reasons why some people get MS are still not entirely clear. Researchers continue to work on finding answers.





# What are the symptoms of MS?


Everyone is unique and will experience MS differently. However, there are some common symptoms.


You may not experience all of these symptoms, and the ones you do have may change over time. Symptoms can also improve or worsen. Some examples of symptoms include:<sup>1,13</sup>


-  Feeling off-balance or light-headed, loss of coordination and clumsiness, walking problems ('foot drop')
-  Stiffness and muscle spasms
-  Numbness or tingling in the face, arms, legs, hands, or feet ('pins and needles')
-  Fatigue
-  Acute or chronic pain
-  Bladder and/or bowel problems

 Problems around sex

 Problems with speech

 Problems with vision

 Difficulty thinking and concentrating, memory lapses ('cog fog')

 Depression, anxiety, mood changes

## THINGS TO CONSIDER

Sometimes you may feel that MS is affecting your mental wellbeing. If things are getting to you, do try to open up to someone, like your doctor. You may have access to experts, such as psychologists, who can also support you.

If you find yourself getting fatigued easily, try planning your day to save energy and making notes of any particular times that you feel fatigued. That way you can do the things you need to without getting too fatigued to do the things you enjoy.





## What tests are there for MS?

### How is MS diagnosed?

Diagnosing MS can be difficult as there is no specific test, and symptoms vary from person to person. MS symptoms can also be similar to those seen with other conditions.

Your own MS diagnosis may have been quick, or it may have taken some time. Your doctor will have most likely kept an eye on your symptoms over time and also carried out some tests to help confirm MS.

These tests may have included body scans (MRI), physical exams, blood tests, and eye tests.

“I found some great information online when I was first diagnosed. It’s about knowing where to look and remembering people who have a good experience with their MS won’t have the need to talk about it on social media platform.”

— Ellen M.



## What tests could I have after my diagnosis?

After your diagnosis, you will have ongoing tests to keep track of your MS to see whether it is stable or progressing.

These are likely to include:



### MRI (magnetic resonance imaging) scans

- MRI scans are used to help diagnose MS and also to keep track of MS after diagnosis.
- An MRI scan creates detailed pictures of your brain and spinal cord.
- These pictures help to see if there are any new areas of inflammation or damage.
- Results from MRI scans can help with treatment decisions.



### Physical ability tests, such as the EDSS (Expanded Disability Status Scale)

- Some healthcare teams use the EDSS to keep track of MS.
- EDSS measures changes in physical ability, such as how well you can move.
- A neurologist will carry out the test and will score a number on a scale.
- This number tells you how much MS has impacted your body's function.

## What can I do to keep track of my MS?

You can also track your MS. For example, using a monthly calendar or diary to track your own symptoms. This can be helpful for both you and your doctor.

Don't be afraid to speak up about how you are feeling. If you want to know more about your tests, you can ask your doctor questions. For example, how your results compare to previous visits, if there is anything you should keep an eye out for, and whether your treatment is working for you.



### REMINDER

Coming to terms with an MS diagnosis can take time – it is common to feel shock, fear, or anxiety.

Don't be afraid to share your questions or concerns with your doctor or MS team. They are there to help you.

**“During an MRI, close your eyes, and try and forget where you are. Take yourself out of the situation. In your head, you are in your favourite place. Envision your hopes and dreams for the future. But remember that some days life is just about putting one foot in front of the other. And that is OK.”**  
— Daniel L.

# What are the different types of MS?

Although MS may be spoken about as one condition, there are actually three different types. They differ in how MS behaves over time.

## How do I know which type of MS I have?

By monitoring your MS symptoms and any changes, your MS team will determine the type of MS you have and the best way to manage it.

### 1. RELAPSING REMITTING MS (RRMS)

#### What is RRMS?

- People with RRMS experience relapses. A relapse is any new MS symptom, or a worsening of an existing MS symptom, that lasts for 24 hours or more.<sup>3,13</sup>
- Relapses are followed by a time of recovery (also called 'remission') where there are no or few symptoms.
- There may not always be an increase in disability after every relapse. Some relapses result in full recovery, others in partial recovery.
- In RRMS, disability can rise gradually over time as a result of relapses.

#### How common is RRMS?

- RRMS is the most common form of MS.
- About 85 to 90% of people with MS have it when they are diagnosed.<sup>2,14</sup>

## Why do relapses happen?

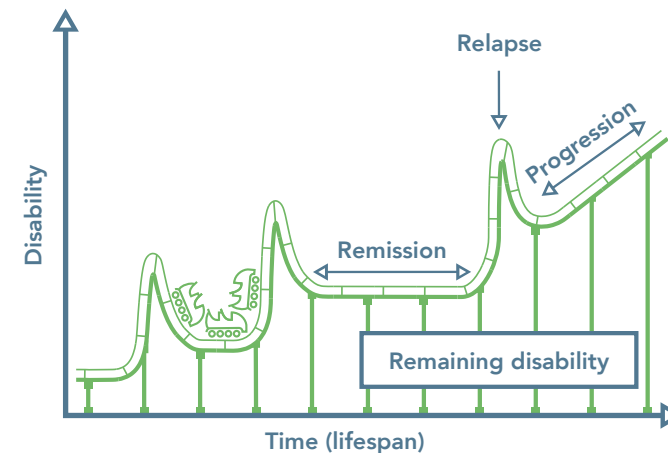
Relapses may occur for no apparent reason, or they may be triggered by something, like an infection.

## What are relapses like?

- Some relapses are mild while others can be worse.
- A relapse may last for days, weeks or months.

You can read more about MS relapses in the next section.

If we compare this to a roller-coaster, where height of the track relates to the level of disability and the length of the track increases with time, the relapses are like bumps in the track. These bumps increase the height of the track over time.



## 2. SECONDARY PROGRESSIVE MS (SPMS)

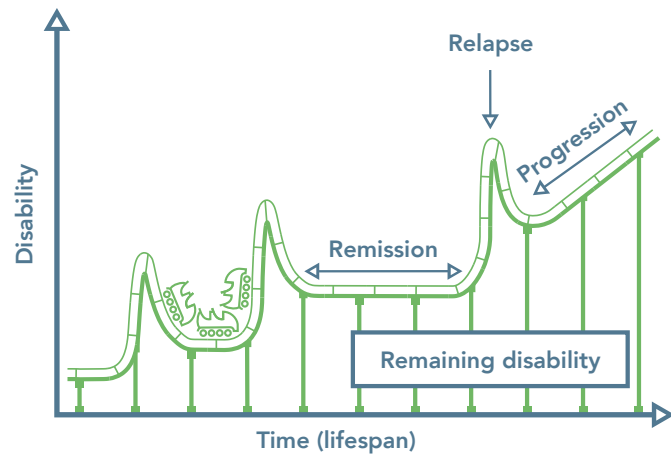
### What is SPMS?

- Some people with RRMS may develop SPMS.
- This is when MS starts to become gradually worse between relapses.

### How common is SPMS?

Without treatment, around half of people with RRMS will develop SPMS within 10 years and most after 25 years.<sup>14,15</sup>

If we compare this to a rollercoaster, the relapses are like bumps in the track, but between bumps the track increases in height.



## 3. PRIMARY PROGRESSIVE MS (PPMS)

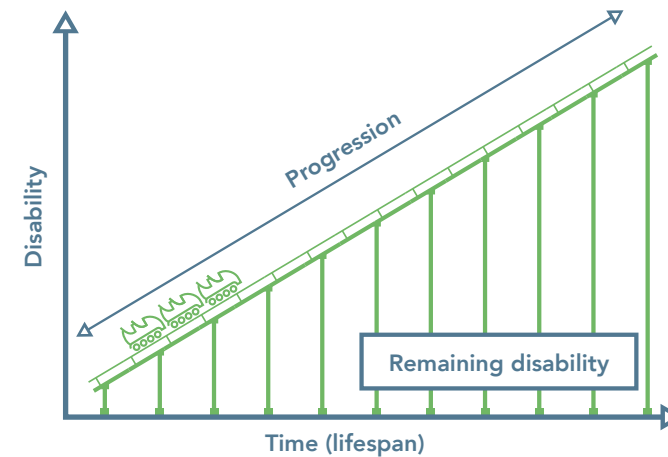
### What is PPMS?

- In PPMS, people do not experience relapses.
- MS symptoms may remain the same or gradually worsen over time.

### How common is PPMS?

Around 10 to 15% of people with MS have PPMS.<sup>2,14</sup>

This is the equivalent of a rollercoaster without any bumps that gradually gets higher with time.



# What is an MS relapse?

People with relapsing remitting MS (RRMS) may have periods when their MS is not apparent in between the relapses because there are few or no symptoms.

Sometimes, you may have a hard time telling whether you are having a relapse, but it is still important to let your doctor know. There are benefits to letting your doctor and MS team know even if you are not sure. Having a relapse may be a sign to start or change your MS treatment.

## REMINDER

A relapse is any new MS symptom, or a worsening of an existing MS symptom, that lasts for 24 hours or more.<sup>3,13</sup>

If you have not let your doctor know you've had a relapse, you are not alone – up to 30% of people with MS have not reported their most recent relapse.<sup>16</sup>

This is likely because it can be difficult to tell when a relapse is happening.



## When is a relapse not a relapse?

When symptoms are caused by other factors, such as:



Tiredness



Heat



Premenstrual stress



Stress



Infection

## REMINDER

The important thing to remember is that an MS relapse is often followed by some level of recovery, with symptoms either completely or partly disappearing.

If you think you are having a relapse, contact your doctor or nurse as soon as possible – you will not be bothering them.

# How is MS treated?

Over the past 30 years there have been improvements in MS diagnosis and the variety of MS medicines that have been developed.

Today, there are many research teams worldwide dedicated to better understanding MS and finding new treatment options.

Although there isn't a cure at the moment, there are treatments that can help you live better with MS.

You will have an opportunity to discuss the best treatment options with your doctor and the best order to receive them in.

## What types of MS treatments are there?

There are two types of medicines for MS:<sup>17</sup>

### Symptomatic treatments

- Improve symptoms
- Help you cope with MS relapses

### Disease-modifying therapies

- Improve symptoms
- Work to reduce the number of relapses and to slow MS progression

For each type of medicine, there are different options, and the number of options is growing. In the 1990s, the first disease-modifying therapy was approved to treat MS. Now there are more than a dozen.

## REMINDER

Different medicines are suited for different people and their lifestyles.

Discuss with your doctor and MS nurse which treatment might be the best for you. Remember, because there are different options, the order may change based on your choices or as your MS progresses.



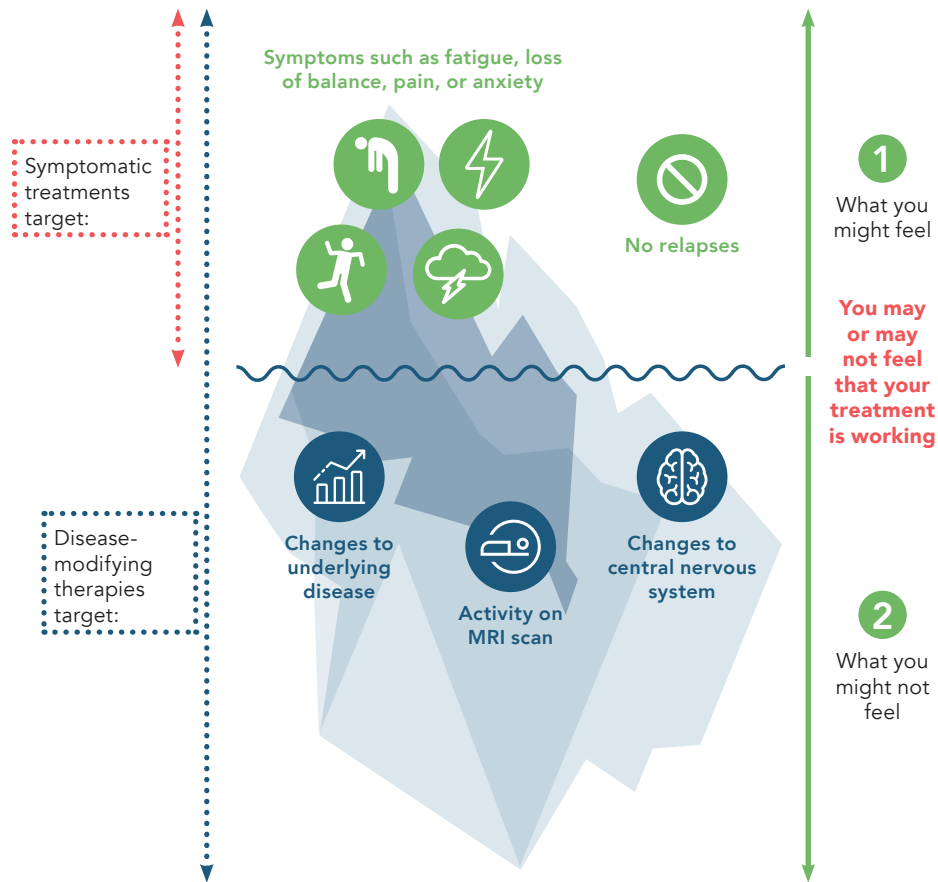
## How do disease-modifying therapies treat MS?

Disease-modifying therapies can reduce the number of MS relapses you experience. They can also help to reduce the underlying damage caused by MS even when you feel well and your MS seems to be stable.

Because of this, it is important to keep taking these medicines through periods of feeling well, unless your doctor advises you to stop.

## It might help to think of your MS in two parts:

- 1 What you feel happening, which is visible on the surface
- 2 Changes to your central nervous system caused by MS, which you may not feel and are hidden under the surface



## Is it safe to take disease-modifying therapies with other medicines?

Let your MS team know if you are taking any other prescribed or over-the-counter medicines, herbal preparations, or supplements.

If you see a doctor or nurse who isn't part of your MS team, let them know what MS medicines you are taking. This is because MS medicines may affect how other medicines work and can change the results of blood tests.

## How will MS treatment fit into my lifestyle?

Although it is important that your medicine treats MS, it should also fit into your lifestyle too. Things to consider are how often the medicine has to be taken and the way in which it is taken.

You can speak with your doctor or MS team if you are struggling with adding your treatment into your daily routine, family life, work, hobbies, or travel.







## References:

1. Brain Foundation. Multiple sclerosis. Available at: [www.brainfoundation.org.au/disorders/multiple-sclerosis](http://www.brainfoundation.org.au/disorders/multiple-sclerosis). Accessed September 2019.
2. Tullman MJ. Overview of the epidemiology, diagnosis, and disease progression associated with multiple sclerosis. *Am J Manag Care*. 2013;19(2 Suppl):S15–S20.
3. Confavreux C and Vukusic S. Natural history of multiple sclerosis: a unifying concept. *Brain*. 2006;129:606–616.
4. O’Gorman C, et al. Modelling genetic susceptibility to multiple sclerosis with family data. *Neuroepidemiology*. 2013;40(1):1–12.
5. Health Union. MS Statistics. Available at: [www.multiplesclerosis.net/what-is-ms/statistics](http://www.multiplesclerosis.net/what-is-ms/statistics). Accessed September 2019.
6. Wade BJ. Spatial analysis of global prevalence of multiple sclerosis suggests need for an updated prevalence scale. *Mult Scler Int*. 2014;2014:124578.
7. Tremlett H, et al. Sun exposure over the life-course and associations with multiple sclerosis. *Neurology*. 2018;90(14):e1191–1199.
8. Alharbi FM. Update in vitamin D and multiple sclerosis. *Neurosciences (Riyadh)*. 2015;20(4):329–335.
9. Zivadinov R, et al. Smoking is associated with increased lesion volumes and brain atrophy in multiple sclerosis. *Neurology*. 2009;73(7):504–510.
10. Pawate S and Sriram S. The role of infections in the pathogenesis and course of multiple sclerosis. *Ann Indian Acad Neurol*. 2010;13(2):80–86.
11. The National Multiple Sclerosis Society. Viruses. Available at: <https://www.nationalmssociety.org/What-is-MS/What-Causes-MS/Viruses>. Accessed September 2019.
12. Steelman A. Infection as an environmental trigger of multiple sclerosis disease exacerbation. *Front Immunol*. 2015;6(520).
13. Compston A and Coles A. Multiple sclerosis. *Lancet*. 2002;359(9313):1221–1231.
14. Hurwitz BJ. The diagnosis of multiple sclerosis and the clinical subtypes. *Ann Indian Acad Neurol*. 2009;12(4):226–230.
15. Gross HJ and Watson C. Characteristics, burden of illness, and physical functioning of patients with relapsing-remitting and secondary progressive multiple sclerosis: a cross-sectional US survey. *Neuropsychiatr Dis Treat*. 2017;13:1349–1357.
16. Duddy M, et al. The UK patient experience of relapse in Multiple Sclerosis treated with first disease modifying therapies. *Mult Scler Relat Disord*. 2014;3(4):450–456.
17. National Multiple Sclerosis Society. Medications. <https://www.nationalmssociety.org/Treating-MS-Medications>. Accessed February 19, 2020.
18. Giovannoni G, et al. Brain health: Time matters in multiple sclerosis. <https://www.msbrainhealth.org/perch/resources/brain-health-time-matters-in-multiple-sclerosis-policy-report.pdf>. Accessed February 19, 2020.