

# Choices



## Types of MS



Read me...

## Types of MS

Although multiple sclerosis affects individuals very differently, there are four broad groups into which MS is categorised.

### Clinically Isolated Syndrome

Clinically Isolated Syndrome (CIS) is used to describe the first neurologic episode that lasts at least 24 hours, and is caused by inflammation or demyelination in one or more sites in the central nervous system. CIS is often diagnosed before a formal diagnosis of MS can be made. Around 60 - 80 percent of people with CIS, who present with brain lesions, will go on to develop MS within ten years (1).

Those with CIS who show abnormalities on MRI scans within one year, may be offered treatment with a disease modifying therapy.

For more information, see our Choices leaflet on Disease Modifying Therapies.

### Relapsing remitting MS

The majority of people with MS are diagnosed as having the relapsing remitting form – perhaps as many as 85 percent (2). People with relapsing remitting MS (RRMS) experience relapses periodically – often months or years apart. When a relapse resolves, the person moves into remission, hence ‘relapsing-remitting’.

The severity and type of relapse can vary between people, but may also vary for an individual – affecting vision or mobility, or causing pain. New symptoms can appear, or symptoms experienced previously may worsen.

It can often be difficult to determine if you are having a relapse. It is important to let your GP and MS nurse know if you think you are experiencing a change in symptoms so they can determine if it is a clinical relapse and therefore if treatment is required.

Your MS nurse may advise steroid treatment to reduce inflammation in the body to help aid recovery from a relapse.

The National Institution for Health and Care Excellence (NICE) published guidelines in October 2014 for the management of multiple sclerosis. In these guidelines a relapse can be diagnosed by a GP or neurologist if:

‘The person with MS has developed new symptoms or has a worsening of existing symptoms, and these symptoms have lasted for more than 24 hours in the absence of infection or any other cause after a stable period of at least one month.’ (2)

Some people with RRMS are eligible for disease modifying therapies (DMT’s), which can reduce the number of relapses. Talk to your neurologist or MS nurse about what disease modifying therapy you may be eligible for.

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For more information, see our Choices leaflet on Disease Modifying Therapies.

**‘I went from possible MS quickly to RRMS. Just confirmed that in fact I wasn’t going crazy or lazy, I was really not feeling great for a reason.’**

There are other sub-categories of RRMS used by neurologists, these can include the following:

### **Benign MS**

Benign MS is a form of RRMS. Benign MS is used to describe a person’s experience of RRMS after many years – it cannot be diagnosed from the outset. A person will be initially diagnosed with RRMS and it is only after time – perhaps 10 to 15 years - that a neurologist may suggest that their MS is benign.

People diagnosed retrospectively with benign MS will have exhibited mild symptoms with infrequent relapses. After a relapse, there is complete recovery. People with benign MS will have little or no disability after ten years of being initially diagnosed as RRMS.

A person with benign MS can still experience relapses and symptoms, and their MS may change as they grow older.

Around 10 to 15 percent of people with RRMS will be diagnosed retrospectively with benign MS. (3)

### **Rapidly evolving severe relapsing remitting MS**

Also called highly active or severe RRMS, rapidly evolving severe RRMS (RES-RRMS) is categorised as having two disabling relapses in one year, as well as MS activity in the brain showing up as lesions in an MRI.

People with rapidly evolving severe RRMS may be eligible for treatment with the disease modifying therapy – Tysabri. Talk to your neurologist or MS nurse about the disease modifying therapies you may be eligible for.

For more information, see our Choices leaflets on Disease Modifying Therapies.

### **Secondary progressive MS**

People who are initially diagnosed with relapsing remitting MS (RRMS) may then, in the future, transition to secondary progressive MS (SPMS).

Secondary progressive MS is characterised by fewer or no relapses and a gradual worsening of symptoms.

Some people with SPMS may still experience relapses, but remission following a relapse is less complete, or there is less time between relapses.

Only a neurologist can diagnose SPMS after careful observation of MS symptoms over time. A small number of people are diagnosed with SPMS from the outset.

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This is because looking back it becomes apparent that the person has experienced MS relapses for a number of years prior to seeing a neurologist.

Around two thirds of people diagnosed with RRMS, will develop SPMS approximately fifteen years after initial diagnosis (2). SPMS varies between individuals with some people experiencing a gradual worsening of symptoms, and others becoming more disabled more quickly.

There are many medications, complementary therapies and strategies to manage the symptoms of SPMS.

A few disease modifying therapies can be prescribed for SPMS, if you are still experiencing relapses. Talk to your neurologist or MS nurse about the disease modifying therapies you may be eligible for.

For more information, see our Choices leaflets on Disease Modifying Therapies, Complementary Therapies, Drug Therapies and Diet & Nutrition.

## Primary progressive MS

Around ten to fifteen percent of people are diagnosed with primary progressive MS (PPMS). (2) PPMS begins with a slow progression of neurological symptoms. Some people with PPMS experience a steady worsening of symptoms, and others find they become disabled more quickly.

It can take many months or years for a neurologist to arrive at a definitive diagnosis of PPMS as changes can be subtle over an extended time. MRI scans can prove inconclusive.

Most people with PPMS will not have relapses, but a few do. If relapses are part of your PPMS, this is called progressive relapsing MS.

For more detailed information, see our Choices leaflets on Primary progressive Multiple Sclerosis, Disease Modifying Therapies, Complementary Therapies, and Diet & Nutrition.

“Definitions make explaining my MS to people much easier.”

There is a sub-category of PPMS used by neurologists, this is:

### Progressive relapsing MS

Around 5 percent of people affected by MS have the progressive relapsing form (PRMS). (4)

A person will have progressive symptoms that continue to worsen over time at varying rates dependant on the individual. A relapse in PRMS is an exacerbation of symptoms that have already been occurring.

PRMS can be difficult to diagnose.

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## Further reading

What is MS?

[www.ms-uk.org/choiceswhatisms](http://www.ms-uk.org/choiceswhatisms)

Is it MS?

[www.ms-uk.org/choiceswhatisms](http://www.ms-uk.org/choiceswhatisms)

Diagnosis

[www.ms-uk.org/choicesdiagnosis](http://www.ms-uk.org/choicesdiagnosis)

Primary progressive multiple sclerosis  
(PPMS)

[www.ms-uk.org/choiceswhatisms](http://www.ms-uk.org/choiceswhatisms)

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# How we create our Choices leaflets

MS-UK believes we must listen to the voices of people affected by multiple sclerosis to shape the information and support we provide. It is these people that bring us perspectives that no one else can give.

For every Choices leaflet we produce, MS-UK consults the wider MS community to gather feedback, and uses this to inform content. All of our Choices leaflets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

Thank you to everyone affected by MS who made this leaflet possible.

## Sources

- (1) National Center for Biotechnology Information (NCBI). Updates on Clinically Isolated Syndrome and Diagnostic Criteria for Multiple Sclerosis. 03 April 2013. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3726117/>
- (2) National Institute for Health and Care Excellence (NICE). Multiple Sclerosis – Management of multiple sclerosis in primary and secondary care. Clinical guideline 186. Methods, evidence and recommendations – October 2014. © National Clinical Guideline Centre, 2014. <https://www.nice.org.uk/guidance/cg186/evidence/full-guideline-193254301>
- (3) Journal of Neurology, Neurosurgery & Psychiatry. Benign multiple sclerosis? Clinical course, long term follow up, and assessment of prognostic factors. S A Hawkins, G V McDonnell. 20 January 1999. <http://jnnp.bmj.com/content/67/2/148.full>
- (4) Kristeen Cherney, Healthline. Progressive-Relapsing MS: Symptoms, Progression, and More. Medically reviewed by George T Krucik, MD, MSA. 10 July 2014. Accessed 26 October 2016. <http://www.healthline.com/health/progressive-relapsing-ms-symptoms-progression-and-more#ReadThisNext7>

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