

Choices

Types of MS



Multiple sclerosis information

Welcome to this Choices booklet about types of MS

MS-UK listens to the voices of people affected by multiple sclerosis (MS) 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 booklet we produce, MS-UK consults the wider MS community to gather feedback and uses this to inform our content. All of our Choices booklets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

This Choices booklet has been designed with you in mind and we hope it will answer some of your questions about MS.

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Types of MS

Everyone who has a diagnosis of multiple sclerosis (MS), will be different. Even those with the same type of MS will experience it very differently. There are so many symptoms of MS, and they affect everyone in a variety of ways. No two people are the same.

There are three main broad groups into which MS is categorised and we will explore these more throughout the booklet.

Relapsing remitting MS

The majority of people with MS are diagnosed as having the relapsing remitting form – perhaps as many as 85 per cent (1). 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 and to help aid recovery from a relapse.

The National Institution for Health and Care Excellence (NICE)

published guidelines in June 2022 for the management of MS. In these guidelines a relapse can be diagnosed if the person with MS has

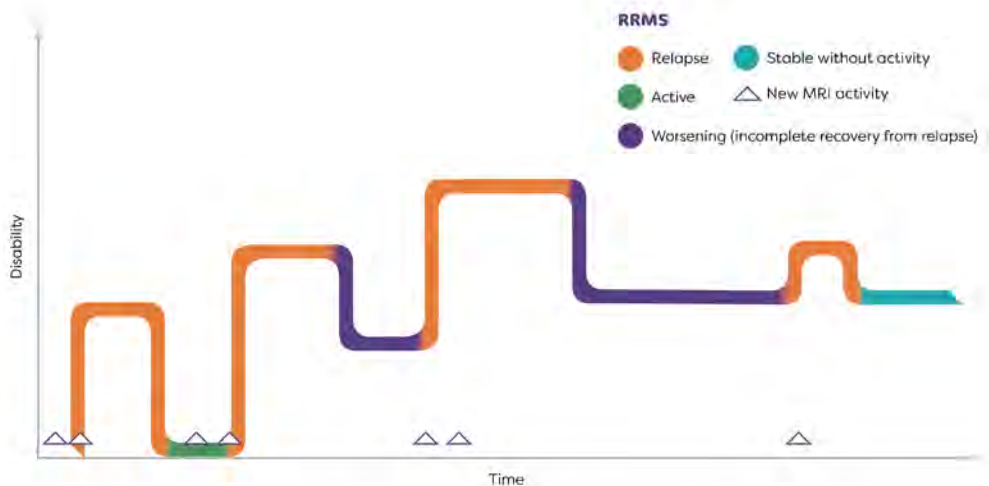
- developed new symptoms
- or has a worsening of existing symptoms

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 (DMTs), which can reduce the number of relapses. There are a number of different types of DMT available depending on if you are eligible and fit the criteria. Talk to your neurologist or MS nurse about what DMT you may be eligible for.

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



Benign MS

A person will initially be diagnosed with RRMS and it is only after several years of living with a mild form of RRMS, that a neurologist may suggest that their MS is benign.

Studies show that people with benign MS (BMS) will have little or no disability, equal to two or three on the Expanded Disability Status Scale (EDSS), at ten years after onset (3).

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

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 new MS activity in the brain showing up as lesions on an MRI (4).

People with rapidly evolving severe RRMS may be eligible for treatment with a DMT. Talk to your neurologist or MS nurse about the DMTs you may be eligible for.

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.

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. 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 (1). 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.

There is one main DMT licensed specifically for people with active SPMS. Meaning, people who continue to experience relapses or are showing MS activity on a magnetic resonance imaging (MRI) scan. A few other DMTs can be prescribed for SPMS, if you are still experiencing relapses. Talk to your neurologist or MS nurse about the DMTs you may be eligible for.

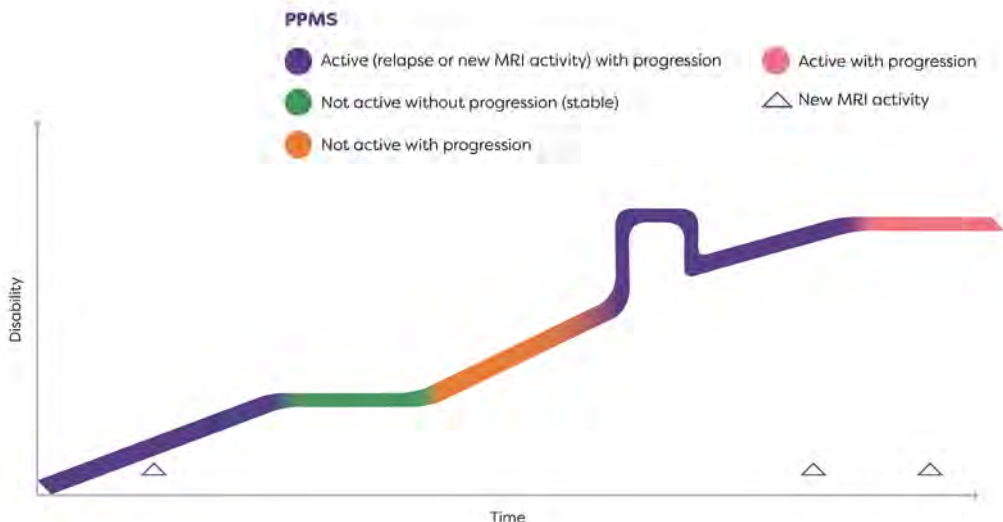


Primary progressive MS

Around 10 to 15 per cent of people are diagnosed with primary progressive MS (PPMS) (1). 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.

PPMS is mostly diagnosed in people over 40 years. 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. It is commonly a diagnosis of exclusion before reaching the point of confirming PPMS officially (5).

Most people with PPMS will not have relapses, but a few do. If relapses are part of your PPMS, your neurologist may use the sub-category 'progressive relapsing MS'.



Progressive relapsing MS

Around five per cent of people affected by MS have the progressive relapsing form (PRMS) (6).

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

Other

Clinically Isolated Syndrome

Although not technically a classification of MS, it is important to include this within this booklet. 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 diagnosed before a formal diagnosis of MS can be made. Around 60 - 80 per cent 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 (DMT).

Advanced MS

The term Advanced MS is not about the type of MS a person has, but rather about the level of impact and difficulties MS is causing.

This terminology is used when MS has progressed and is having

a greater impact, with significant physical symptoms or cognitive impairment that does not improve. This is most typical in the later stages of SPMS or PPMS. A person is more highly affected by their symptoms and requires additional support from carers and/or family members (2).

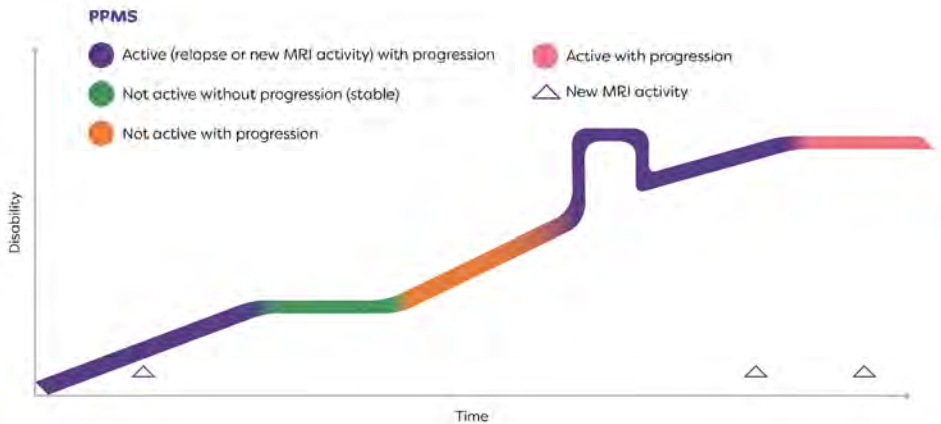
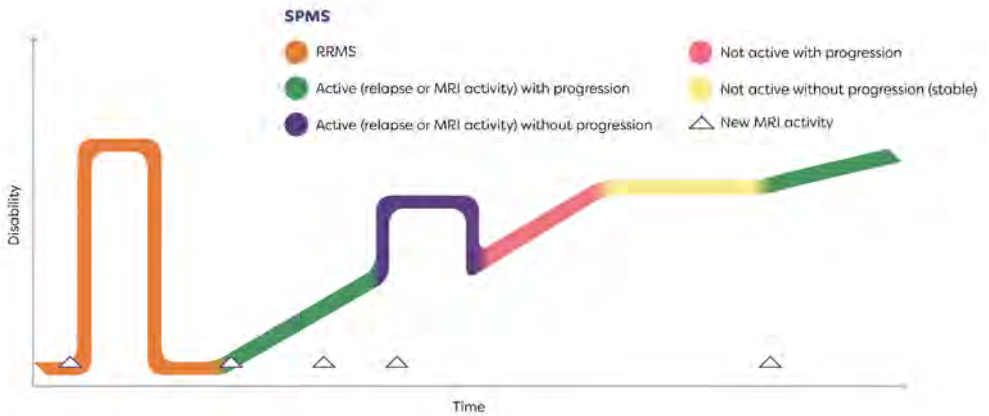
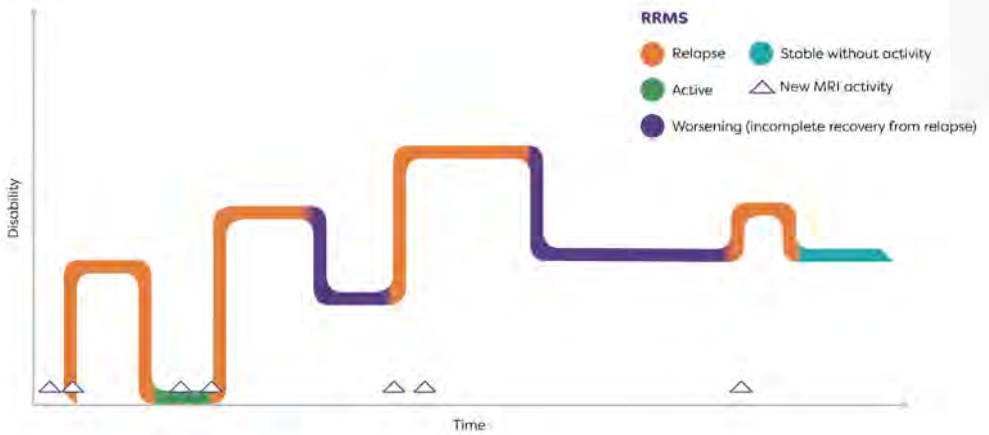
The level of impact of these symptoms means they can be complex and difficult to treat. A person living with advanced MS is still entitled to an annual neurology review and may need referrals to a wider variety of health professionals in order to find the best ways to manage symptoms and maintain a good quality of life (2).

Further information

MS-UK Choices booklets

Disease modifying therapies, What is MS?, Is it MS?, Diagnosis, Complementary and other therapies, Diet and supplements

www.ms-uk.org



About MS-UK

MS-UK is a national charity formed in 1993 supporting anyone affected by multiple sclerosis. Our hope for the future is a world where people affected by MS live healthier and happier lives.

MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis, whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

We will always respect people's rights to make informed decisions for themselves.

The MS-UK Helpline

We believe that nobody should face multiple sclerosis alone and our helpline staff are here to support you every step of the way.

Our service is informed by the lived experience of real people living with MS, so we can discuss any treatments and lifestyle choices that are of benefit, whether they are clinically evidenced or not.



New Pathways

Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

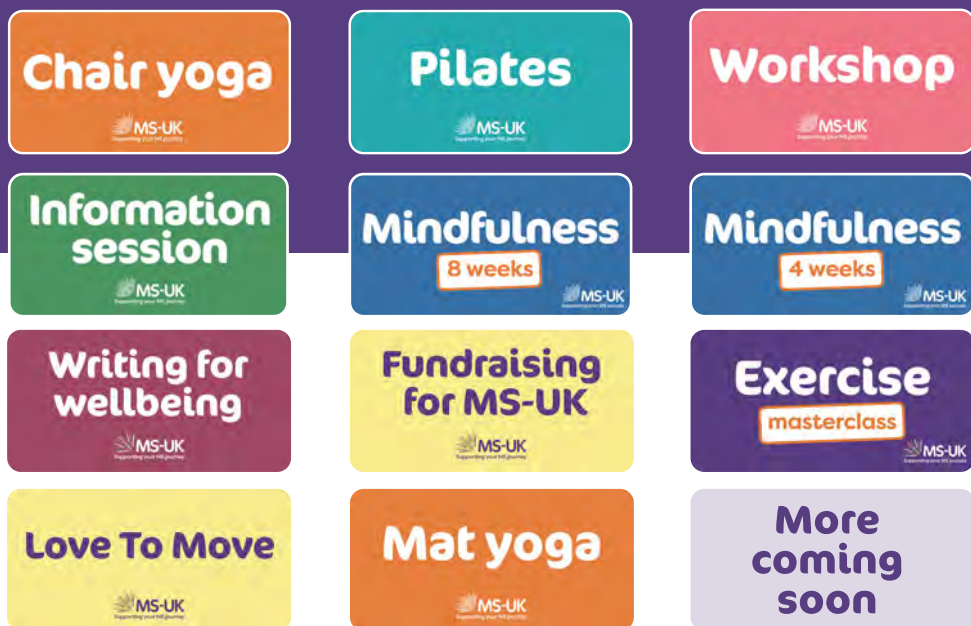
Available in print, audio version, large print and digitally.

About MS-UK

Peer Support Service

Our Peer Support Service enables people to connect with others in a safe space and share experiences on topics of interest. Our Peer Pods take place regularly and are all volunteer led. Please visit the website to find out more www.ms-uk.org/peer-support-service or email peersupport@ms-uk.org.





Online activities

MS-UK offers a variety of online activities to stay active and connected for those affected by MS and manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. Visit our website to explore and find out more.

E-learning

Do you work with or support someone living with MS and want to increase your understanding and knowledge of this long-term health condition? Professionals at MS-UK have created accredited Learning courses that can help you do this. Visit <https://ms-uk.org/excellence-ms/> to find out more.

Sources

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Call the MS-UK Helpline

You're not alone in your journey. the MS-UK Helpline can support you emotionally every step of the way. You can contact us about anything, whether it is about managing your multiple sclerosis symptoms, accessing benefits or simply just to chat.

Laura, Ryan and Shaun are here
to take your call



We're here to help

Call free on **0800 783 0518**
weekdays 10am to 4pm

 **MS-UK**
Supporting your MS journey

Stay in touch

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