

## Types of MS



Multiple sclerosis information

# Welcome to this Choices booklet about types of MS

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

This Choices leaflet has been designed with you in mind. We hope it will answer some of your questions and also provide some first-hand experience from those who have been in your position - people who can truly understand and empathise with your current thoughts and feelings.

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## 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 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.

### Relapsing remitting MS

The majority of people with MS are diagnosed as having the relapsing remitting form – perhaps as many as 85 per cent (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 MS. 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 (DMTs), which can reduce the number of relapses. Talk to your neurologist or MS nurse about what disease modifying therapy you may be eligible for.

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 per cent 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 a disease modifying therapy. Talk to your neurologist or MS nurse about the disease modifying therapies 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.

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. 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 15 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.

## Primary progressive MS

Around 10 to 15 per cent 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.

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

## **Progressive relapsing MS**

Around five per cent 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 dependent on the individual. A relapse in PRMS is an exacerbation of symptoms that have already been occurring.

PRMS can be difficult to diagnose.

## **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](http://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.

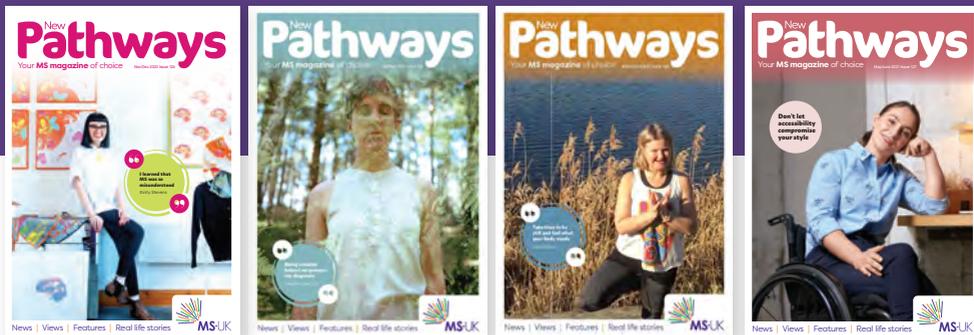
MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis; whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

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.

## MS-UK Counselling

MS-UK Counselling is open to anyone living with MS and is the only service of its kind available in the UK. Whether you want support coming to terms with a diagnosis or to improve your mental wellbeing, our counselling service is focused on helping you.

All of our MS-UK counsellors are BACP registered or accredited with an in depth knowledge of MS.

# 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](http://www.ms-uk.org/peer-support-service) or email [peersupport@ms-uk.org](mailto:peersupport@ms-uk.org).





## MS-UK Online

MS-UK Online offers a range of activities for people living with multiple sclerosis (MS). Our aim is to help people manage their wellbeing independently through exercise, information and connecting with others.

The activities offered online have been chosen by the MS community and future activities are guided by the feedback we receive.

Our current online activities include exercise classes, chair yoga, information sessions, interactive workshops and courses such as mindfulness and poetry.

To get involved, please visit the website [www.ms-uk.org/ms-uk-online-exercise](http://www.ms-uk.org/ms-uk-online-exercise) or email [register@ms-uk.org](mailto:register@ms-uk.org).

## Sources

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All links accessed July 2016

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## Stay in touch

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 [www.facebook.com/MultipleSclerosisUK](http://www.facebook.com/MultipleSclerosisUK)

 [www.youtube.com/c/ms-ukorg](http://www.youtube.com/c/ms-ukorg)

 [www.linkedin.com/company/ms-uk](http://www.linkedin.com/company/ms-uk)

 [www.instagram.com/multiplesclerosis\\_uk](http://www.instagram.com/multiplesclerosis_uk)

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