

## Managing a relapse

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## About this booklet

Most people with multiple sclerosis (MS) are diagnosed with ‘relapsing remitting’ MS – where symptoms arrive unexpectedly (a relapse) and are followed by periods of improvement (remission). For nearly all people with MS, this is how their MS begins. The exception is for people who have ‘primary progressive’ MS, where from the start symptoms gradually get worse over time.

This booklet explains what a relapse is, and how relapses can be treated and managed. It also includes space at the back to record details if you have a relapse, and to note the key contacts who can help with your treatment. For more about living with relapsing remitting MS, self management, disease modifying drugs and rehabilitation, you might also want to read the MS Society booklet *What is relapsing remitting MS?*

Some people with ‘secondary progressive’ MS also experience relapses. We also publish *What is secondary progressive MS?* Information about primary progressive MS is also available. For any of these booklets, or for further information, visit our website or get in touch with the Information Team (see Further information). 

## What is a relapse?

A relapse is an episode of neurological symptoms (caused by inflammation or demyelination) that happens at least 30 days after any previous episode began, lasts at least 24 hours and is not caused by an infection or other cause.<sup>1</sup> A relapse is often described by other names, including an attack, exacerbation, flare-up, acute episode or clinical event.

## How do I know if I am having a relapse?

New symptoms appear, or old symptoms re-appear, either gradually or suddenly. Symptoms usually come on over a short period of time – hours or days. They often stay for a number of weeks, usually four to six, though this can vary from only a few days to many months.

Typical MS symptoms in a relapse include weakness, unsteadiness, bladder disturbance or double vision. Other symptoms of MS, like fatigue or pain, can be more difficult to categorise as a relapse because they may not have a clear-cut beginning or end.

Some people may have symptoms that come and go, such as a shock-like sensation when they bend their neck. This can be considered a relapse if over a period of at least 24 hours it occurs every time they bend their neck.

Remember that even if you have MS, not all symptoms will necessarily be caused by MS. Speak to your doctor if you feel unwell, just as you would have before the diagnosis. For example, there might be an easily treatable reason for fatigue such as anaemia.

## Pseudo-relapses

Sometimes you might experience a flare-up of symptoms which is not a relapse. For example, a cold or a bladder infection could raise your body temperature and make symptoms temporarily worse. These 'pseudo-relapses' can be treated by tackling the cause of the fever – the cold or infection. Exercise or hot baths can also raise the body's temperature, but any temporary symptoms that it causes (such as fatigue, or usual symptoms) are not a sign of a relapse.

## Uncertainty

No-one can say when – or if – you will ever have another relapse, or what part of your body will be affected if you do. It varies from person to person. This uncertainty can be difficult to deal with, but there are people who can help you manage it, such as MS nurses, neurologists or your GP.

More information is available in the MS Society booklet *Living with the effects of MS*. [i](#)

## What do I do if I think I am having a relapse?

If you think you are having a relapse, you need to contact your MS nurse or GP as soon as possible. Tell them about the symptoms you are experiencing, how you are feeling in general and any difficulties you are having as a result of your symptoms.

It is important that other possible causes of symptoms are not missed, so you will probably be asked lots of questions about your symptoms, your general health and your activity over the last few days. You may be asked to take a specimen of urine to the surgery or clinic to be checked for infection. If you are in regular contact with an MS nurse or neurologist, an appointment may be arranged for you at the clinic.

It is important for future treatment options that your neurologist is aware that you are having a relapse.

If you are not in regular contact with a neurologist or MS nurse, you should still make an appointment to see your GP. Your GP will then decide, in discussion with you, whether to refer you back to a neurologist.

### **What happens in a relapse in the central nervous system?**

In MS, relapses are caused by inflammation in the central nervous system (the brain and spinal cord). This inflammation is the body's reaction when immune cells mistakenly attack the protective layer (myelin) that surrounds nerve fibres.

When messages are blocked in an area with a specific function (for vision, movement or sensation, for example) then symptoms occur. When inflammation dies down, so too can the symptoms.

Inflammation may also damage some of the nerve fibres (axons) themselves. Although it does not always happen, studies have shown that axons can be damaged even in the earliest stages of MS.<sup>2</sup> The central nervous system can repair by itself some of the damage done to myelin (this is known as remyelination). Even when there is not complete remyelination, people can still recover from the symptoms of a relapse.

## If I have a relapse, how will it be treated?

The options for managing an MS relapse are:

- treatment with high-dose steroids, either as an in-patient, a 'day-case' or at home
- rehabilitation – after steroids, or without steroids being given
- no treatment

### Steroids

Steroids are also known as 'corticosteroids' and 'glucocorticoids'. Different types of steroid include 'prednisolone', 'cortisone' and 'methylprednisolone'.

Steroids are powerful drugs. They often get a bad name in the media because of their association with athletes and body-builders who use 'anabolic steroids' to boost their performance and ability. These are not the same as steroids used to treat MS.

Used correctly, steroids can be a very good treatment for different conditions, including relapses in MS.<sup>3</sup>

In MS relapses, the way that steroids work is not fully understood.

However, we expect them to:

- reduce the inflammation
- shorten the duration of the relapse
- speed up recovery from the relapse

It is important to note that steroids do not affect the outcome of a relapse – for example, any difficulty or disability that might result from a relapse will occur irrespective of steroids being taken.

## **Side effects of steroids**

There are a number of side effects of steroids – as there are with all drug treatments. The possible effects of the drug must be weighed against the possible side effects.

This should ideally be done in discussion with your MS nurse, GP or neurologist so that you are able to make a fully informed choice.

Occasionally there are reasons why steroids are not prescribed and these should be discussed with you. Steroids can make urinary infections worse, so many professionals recommend testing for infection before starting high dose steroids.

Side effects can include:<sup>4,5</sup>

- mood alteration (up or down)
- altered sleep pattern (often difficulty in falling asleep)
- upset stomach or gut – including feeling nauseous
- palpitations (faster than normal heart rate)
- metallic taste in the mouth
- increased appetite
- weight gain (usually short-term)
- flushing/reddening of the face
- ankle swelling
- acne (temporary)

With regular or prolonged use of steroids, longer-term side effects can include:<sup>4,5,6</sup>

- thinning of the skin
- thinning of bones (osteoporosis)
- increased blood pressure
- diabetes
- very rarely, some people can experience severe damage to the hip (known as avascular necrosis of the hip)

### **Long-term steroid use**

It is not recommended to use steroids on a regular ('pulsed') basis or in progressive forms of MS. Studies have shown a lack of positive effect.<sup>4</sup>

However, steroids are generally well tolerated when given to treat relapses, and side effects are normally short-lived, but anyone who is prescribed a course of steroids should be aware of the possible side effects and should be monitored by a health care professional.

### **How are steroids given?**

Steroids can be given orally (usually in tablet form) or intravenously (in a drip). If you have difficulty swallowing, you may prefer a liquid steroid treatment. Although there have been trials comparing different doses and different steroids, and trials comparing the use of oral and intravenous steroids, treatment regimes vary between MS centres. Sometimes a tapering dose is given, meaning the dose is reduced every few days.



## What does NICE say about the use of steroids in relapse management?

NICE, the organisation which makes recommendations for health care in England and Wales, says:<sup>7</sup>

*Any individual who experiences an acute episode (including optic neuritis) sufficient to cause distressing symptoms or an increased limitation on activities should be offered a course of high-dose corticosteroids. The course should be started as soon as possible after onset of the relapse and should be either:*

- *intravenous methylprednisolone, 500mg – 1g daily, for between 3 and 5 days*
- or
- *high-dose oral methylprednisolone, 500mg – 2g daily, for between 3 and 5 days*

NICE also recommends:

- steroids should not be given more than three times in any year
- a course of steroids should last no longer than three weeks

## Do I have to go into hospital to have steroids?

There is no straightforward answer to this – like the dosage of steroids, different centres have different arrangements. Usually when people choose to have intravenous methylprednisolone (given through a drip), the treatment is given in hospital, either as an in-patient (you stay in the hospital overnight) or as a day-patient (you come into hospital for the treatment then go home, returning each day).

Occasionally, intravenous methylprednisolone is given in the GP surgery or at home.<sup>8</sup> Your MS nurse or GP will know the procedure in your area.

If you are prescribed oral methylprednisolone (taken as a tablet or sometimes liquid), you will not usually have to attend hospital. Other services, such as physiotherapy and occupational therapy, which can be offered together with steroid treatment, can be given at home or in hospital – services vary from area to area.

## Rehabilitation

Rehabilitation can combine many different approaches to managing MS – physiotherapy, occupational therapy, dietary advice, employment services, support for care at home, and so on. Whatever services are involved, the aim is to lessen the impact of MS on someone's life.

You might benefit from rehabilitation after a relapse, whether or not you had steroids.

There is some evidence to show that recovery from a relapse is improved by having rehabilitation as well as steroids.<sup>9</sup>

An MS nurse, district nurse or GP sometimes acts as a central point of contact for you. They can help ensure referrals are made to other professionals and answer your questions about rehabilitation services.

## What does NICE say about the use of rehabilitation in relapse management?

The guidance says:<sup>7</sup>

*When a person with MS experiences a sudden increase in disability or dependence the individual should be:*

- *Given support, as required and as soon as practical, both in terms of equipment and personal care.*
- *Referred to a specialist neurological rehabilitation service.*

*The urgency of the referral should be judged at the time, and this referral should be in parallel with any other medical treatment required.*

## What if I choose not to have any treatment for my relapse?

This decision should only be made after careful consideration of all the pros and cons of treatment and in discussion with your GP, MS nurse or neurologist.<sup>10</sup>

Although the NICE guideline for MS does not say anything specific about the 'No treatment' option, this is an option that anyone can choose.

For milder, sensory relapses (such as tingling or numbness), this is often the preferred option.

As we mention above, any difficulties or disability resulting from a relapse will occur whether or not you have treatment with steroids. However, the relapse might last longer if you don't have steroids.

Rehabilitation can help you back to your optimal functioning and activity, so this is something you and your health care team should consider whether or not you decide to take steroids.

## **Should I rest or exercise when I am having a relapse?**


There is no straightforward answer to this question. The benefits of exercise have not been studied in relation to relapses (and it would be very difficult to carry out a study). But fatigue is usually much worse with relapses, and resting would often be recommended.

In MS, studies have shown that exercise is beneficial in relation to levels of fatigue and fitness, as well as muscle strength and psychological well-being (feeling good).<sup>11,12,13,14</sup> However, it is important to prevent your core temperature from rising as this can temporarily make you feel worse or experience symptoms.


It is advisable to discuss exercising with your physiotherapist. If you don't have a physiotherapist, speak to your MS nurse or GP who should be able to refer you.

## **After a relapse – what do I do now?**

Recovery from a relapse can take time – weeks or possibly months. Symptoms from early relapses can disappear completely, but sometimes you might be left with symptoms or some difficulty. This is more likely with later relapses. It is important that you speak to your MS nurse or GP about this, as there may be treatments, such as physiotherapy, rehabilitation or medication that can help. Unfortunately current treatments cannot reduce or prevent this lasting damage occurring, but they can help you manage the effects.

If your situation has changed, you may be entitled to further support from social care services. See the MS Society booklets *Getting the best from social care services* and *Getting the best from social work in Scotland*. 


It is important that your neurologist knows that you have had a relapse, as you might now be eligible for one of the disease modifying treatments (glatiramer acetate, beta interferon 1a, beta interferon 1b, or natalizumab). If you have not had contact previously with a neurologist, or haven't seen one for a long time, speak to your MS nurse or GP about being referred.

For more about these approaches to managing relapsing remitting MS, see the MS Society booklets *What is relapsing remitting MS?* and *Disease modifying drugs*. 

## Planning ahead

Relapses are unpredictable, and it's true that you may never have another. But most people will at some time, and putting a few simple things in place while you are in remission could make things easier for you and those around you if a relapse happens.

Some of the things you might want to think about:

- Do my friends or family know who to contact and what to say if I am taken ill? This might include informing your workplace or school as well as health or social care professionals.
- In case I go into hospital, have I got a list of drugs that I usually take (for MS or any other condition), or any other details that might affect how I receive care? A *Personal details card* for this is available from the MS Society. 

## Relapse record

The table below might be helpful for you to keep a record of any relapses.

Symptoms

Seen by GP, MS NURSE, NEUROLOGIST	Treatment	Date

## Contact details

<b>GP</b>	
Name	
Address	
Phone	
Email	

<b>Neurologist</b>	
Name	
Address	
Phone	
Email	

**MS nurse**

Name

Address

Phone

Email

**Social worker**

Name

Address

Phone

Email



## Further information

### **MS Society publications**

The MS Society has publications on a wide variety of topics, including information for people just diagnosed, types of MS, managing relapses, and social care services. For a publications list and order form visit the website [www.mssociety.org.uk](http://www.mssociety.org.uk) or call 020 8438 0799 (weekdays 9am-4pm).

### **MS Society website and members' magazine**

Keep up to date with news relating to MS with the MS Society website [www.mssociety.org.uk](http://www.mssociety.org.uk) and members' magazine, MS Matters. Details about membership are on the website and in the Society's publications list.

### **MS Helpline**

The award-winning MS Helpline offers confidential emotional support and information to anyone affected by MS, including family, friends, carers, newly diagnosed or those who have lived with the condition for many years. Information about MS is available in over 150 different languages by speaking to a Helpline worker via an interpreter. Call freephone **0808 800 8000** (weekdays 9am-9pm, except bank holidays) or email [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)

### **MS Society National Centre, Information Centre**


Based at the MS National Centre in London, the Information Centre is equipped for visitors to read or locate books and journals or view videos and DVDs. To request publications, research articles or other information about MS, visit [www.mssociety.org.uk/library](http://www.mssociety.org.uk/library) or call 020 8438 0799.

### **Local information centres**

There are MS Society local information and support centres in many locations around the country. These centres are staffed by volunteers who can help you with information about MS and services in your area. Call 020 8438 0799 for the details of your nearest centre.

## Local branches

The MS Society has a network of over 300 local branches across the UK. The branches – run by trained volunteers – provide information about MS and local services, a chance to meet others affected by MS and take part in a range of activities. For more information check the MS Society website or call 020 8438 0944.

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**Disclaimer:** We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. The law and government regulations may change. Be sure to seek local advice from the sources listed.

Suggestions for improvement in future editions are welcomed. Please send them to [infoteam@mssociety.org.uk](mailto:infoteam@mssociety.org.uk)

## **MS Society**

Multiple sclerosis (MS) is the most common disabling neurological disorder affecting young adults and we estimate that around 100,000 people in the UK have MS. MS is the result of damage to myelin – the protective sheath surrounding nerve fibres of the central nervous system. This damage interferes with messages between the brain and other parts of the body.

For some people, MS is characterised by periods of relapse and remission while, for others, it has a progressive pattern. For everyone, it makes life unpredictable.

The MS Society is the UK's largest charity dedicated to supporting everyone whose life is touched by MS. It provides respite care, a freephone MS Helpline, grants for home adaptations and mobility aids, education and training, specialist MS nurses and a wide range of information.

Local branches cater for people of all ages and interests and are run by people with direct experience of MS.

The MS Society also funds around 80 vital MS research projects in the UK.

Membership is open to people with MS, their families, carers, friends and supporters. You can help the work of the MS Society by:

- becoming a member
- making a donation
- offering your time as a volunteer

The Multiple Sclerosis Society of Great Britain and Northern Ireland is a charity registered in England and Wales (207495) and Scotland (SC016433)

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