

First edition
December 2008



What is
relapsing remitting
MS?



Multiple Sclerosis Society

This booklet is available in large print and audio CD. For either of these formats, contact the MS Society information team: 020 8438 0799 (Weekdays 9am-4pm, except Tuesday, 9am-3pm) or infoteam@mssociety.org.uk

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Where this symbol  appears in the booklet, the MS Society or another organisation can provide more information on a particular subject – more details are in the ‘Further information’ section at the back of this booklet.

If you have just been diagnosed with multiple sclerosis (MS), you may also have been told something about the type of MS you appear to have. 'Relapsing remitting' MS is the most common type of MS. It affects around 85 per cent of all people diagnosed.

'Relapsing remitting' is a label for your MS which, when it's understood, can help to explain it to others and help you to find the best treatments. But it is still a broad label, which cannot predict exactly how MS will affect you. MS is only one aspect of your life and how you manage it will depend as much on you and your circumstances as on which 'type' you have.

You might want to find out everything you can straight away, or you might feel like taking it slowly. There's no 'right way' to react, but knowing a little about your type of MS and what it might bring can be helpful for planning ahead, recognising and managing the symptoms and adapting to changes over the years.

As well as this booklet, you might want to read *Just diagnosed – an introduction to MS* or *What is MS?* We also have free booklets about two other types of MS: *What is primary progressive MS?* and *What is secondary progressive MS?* For any of these free booklets or for further information, visit our website or get in touch with the MS Society information team. 

You can contact the national MS Helpline to talk to someone about any aspect of living with MS. Freephone 0808 800 8000 (Monday to Friday, 9am-9pm) or email helpline@mssociety.org.uk

What is relapsing remitting MS?

MS is nearly always described as a relapsing remitting condition – meaning that symptoms appear (a relapse), and then fade away, either partially or completely (remission).

For most people with MS, this is the way their MS begins, except for the small group of people who have primary progressive MS (about 15 per cent of all people with MS).¹

Relapses can be mild or severe and can last for a matter of days, or for as long as several months. Equally, remission can last for many months or many years. Any symptom of MS can occur as a relapse, and all of this uncertainty can be one of the most worrying and frustrating aspects of MS. This hidden issue might not be obvious to others but can feel very real to you and your close family.

Explaining the uncertainty of relapsing remitting MS to others might help them to understand some of your concerns even if you may look and sometimes even feel very well. Get in touch with the MS Society information team if you'd like more copies of this booklet to give to family, close friends or colleagues. 

It is not uncommon to experience some 'on-off' symptoms even during remission – for example, fatigue or balance problems. New symptoms can be shocking or distressing at any time, but not every symptom will be a sign that a relapse is beginning.

We explain a little more about what exactly a relapse is in the next section.

‘Benign’ MS?

If, after 10 to 20 years, your condition hasn’t worsened and you have very little or no disability, you might then be said to have ‘benign’ MS. It is difficult to give exact figures, but probably between 10 and 30 per cent of people with MS fit this broad description and have had many years without major disability. But using the word ‘benign’ can be misleading. ‘Benign’ MS doesn’t mean that someone’s condition has been completely problem-free; and a relapse can occur after many years of inactive MS. Unfortunately, it’s still difficult to predict future MS symptoms, even by looking at the symptoms someone has already had.

Secondary progressive

Most people with relapsing remitting MS eventually develop ‘secondary progressive’ MS – around 65 per cent have developed it after 15 years.²

Secondary progressive MS, as the name suggests, sees a progressive increase in people’s symptoms, but this progression can be very slow. Changes might be so slight that they are hard to notice for a long time.

Remember that whatever name is given to your MS, how you best manage it will be a personal thing – any name for MS is only a guide to help you and your care team find the best treatments. You can read more about this in our booklet *What is secondary progressive MS?* 

What is a relapse?

A relapse is when new MS symptoms appear, or old ones re-appear or get markedly worse. Symptoms you have experienced before, or perhaps grown used to dealing with, might appear in a different part of the body.

Medical staff would usually define a relapse as an episode of neurological symptoms that happens at least 30 days after any previous episode began. This episode lasts at least 24 hours. Other possible causes for the appearance of these symptoms also have to be ruled out before deciding it is an MS relapse. Other causes could include infection or something else that raises the body's temperature and makes symptoms worse.³

Symptoms which come and go can sometimes be considered a relapse – they don't always have to be continuous. For example, some people experience a shock-like sensation when they bend their neck. This can be considered a relapse if it occurs every time they bend their neck for at least 24 hours.³

In relapses, symptoms usually come on over a short period of time – over hours or days. They often stay for a number of weeks, usually four to six, though this can vary from very short periods of only a few days to many months. Relapses can vary from mild to severe. At their worst, acute relapses may need hospital treatment, but many relapses are managed at home, with the support of the GP, MS specialist nurse, and other care professionals.

Other names for relapses

Many other names are used for 'relapse', and you might hear different ones used at health appointments, in information such as this and in the wider media. A lot of people with MS – and many care professionals – use the word 'attack' instead of relapse. Others might talk about a 'flare-up', an 'exacerbation' or even an 'acute episode' or 'clinical event'.

What isn't a relapse?

Not all symptoms you notice will necessarily be relapses, but it's often difficult, especially in the first few years, to know what is and what isn't a relapse. Living with MS is a different experience for each person, but speaking to experienced professionals and others with MS can help. Over time, you will get more confident in understanding the symptoms as you get to know your MS. You might find it helpful to keep a diary of symptoms when they change significantly, or if new ones appear. This could be helpful when meeting your doctor or MS nurse. It could also help you to learn more about your own MS.

Sometimes, symptoms may get worse for a short time without MS activity increasing in the brain and spinal cord. This is sometimes known as a 'pseudo-relapse'.

Pseudo-relapses are caused most commonly by a rise in body temperature, either because of an infection or after exercise. An increase in body temperature slows down the way messages travel along the nerves. If those nerves have been damaged in the past, then this slowing may mean symptoms re-appear.

Although you may want to take precautions to stay as cool as possible when exercising, symptoms usually go back to how they were as the body cools down. It needn't be a reason to stop exercising altogether.^{4,5}

What's happening in the brain or spinal cord?

In MS, relapses are caused by inflammatory cells attacking nerve fibres in the central nervous system (the brain and the spinal cord). This attack results in fluid collecting around the nerve fibre, compressing the nerve and preventing messages getting through, or distorting them.

When messages are blocked in an area that has a specific function, such as the optic nerve, or motor (movement) or sensory fibres in the spinal cord, then symptoms occur.

When the fluid disappears and no longer compresses the nerve fibres, then there is remission. This inflammation can also, but not always, damage myelin – the protective sheath that surrounds nerve fibres in the central nervous system. Inflammation may also damage some of the nerve fibres themselves. Recent studies have shown that nerve fibres can be damaged even in the earliest stages of MS.

Once the inflammation dies down and the fluid disappears, the central nervous system can remyelinate, repairing some of the damage done to myelin. It is important to realise that people can fully recover from symptoms when there is some demyelination (myelin damage). Even if some nerve fibres themselves are damaged, people can still recover completely from relapses.

Will I make a complete recovery?

People often make a very good recovery from a relapse, with complete remission. However, this is not always the case and around half of all relapses may leave some lingering problems, however slight.⁶

Why does this happen?

If the damage to myelin is severe, then some symptoms remain, though they may still improve over the following months if there is further effective repair to myelin.

There can also be incomplete recovery when a critical number of nerve fibres are damaged or destroyed. This kind of damage may be irreversible. We can all lose quite a lot of nerve fibres in the brain and spinal cord without this affecting the way the body functions. It is thought, however, there may be a threshold effect – a certain point where any further loss has an effect on function. From then on, each time more nerve fibres are lost, symptoms get worse.

Are there things that bring on or prevent relapses?

Many people with MS feel they can identify things that trigger a relapse for them. Unfortunately, what appears to affect one person doesn't always apply to someone else, and research has not yet found what it is in the body that triggers a relapse. This makes it hard to give definite strategies for reducing the risk of relapses.

Stress

Over the years, many studies have looked at whether there is a link between psychological stress and MS getting worse. The evidence is not absolutely clear, but many experts believe that stress might be one of many factors which could increase the risk of a relapse.⁷

Infections

As mentioned on page 5, infections can cause the body temperature to rise and cause symptoms similar to a relapse

(a ‘pseudo-relapse’). But some infections, for example a bladder infection, may also make an attack more likely.⁸ For this reason, people with MS are encouraged to treat bacterial infections early.

Vaccinations

Research has indicated that most vaccines are safe for people with MS. It is generally felt that if a person is going to an area where a serious infectious disease is prevalent, or might be at risk of catching a particular infection, it would be far better to have the vaccination than to get the illness – which could have worse consequences.⁹ There are certain exceptions – for example live vaccines should be avoided in people whose immune system is compromised by medication or another condition. Our website, www.mssociety.org.uk, has more information.

Pregnancy

It is well established that pregnancy results in a reduced risk of having a relapse, notably during the last three months, when it is reduced by 60 per cent. However, there is an almost identical increase in relapse rate in the three months following the birth. In short, having a baby does not generally alter the course of a woman’s MS, though of course the practical issues of looking after the baby need to be carefully considered.¹⁰ 

Managing relapsing remitting MS

There is no cure yet for MS, and there is no single drug which has been shown to control MS one hundred per cent for everyone, but there are many treatments and therapies available that people find helpful. Finding what works for

you can be a matter of trial and error, learning – with the support of your health care team – what suits you best at different times.

But you might also come across suggested therapies which have not even been tested to make sure they are safe, let alone effective. You should always discuss any treatment options, whether ‘traditional’, ‘complementary’ or ‘alternative’, with your GP, neurologist or another qualified health care professional. When a prescription medicine is discussed with you, there should be a clear explanation of the potential risks, side effects and benefits. The same discussion should take place when other therapies are being considered. Anything which might have the potential to improve symptoms might also be potent enough to cause side effects.

Managing your MS is part of living your life – it is not only a medical condition to be treated. Having the support and understanding of family, friends and colleagues can help you to manage things more effectively. They might like to read this booklet, or other information produced by the MS Society. The freephone MS Helpline is for anyone affected by MS – including family, friends and colleagues. 

You may need to make some changes to your lifestyle because of MS, but remember that MS is only a part of your life – there are all the other things still going on that you want or need to do. Health care, social care, support from those around you, and your own self management should all help you live your life to the fullest. The MS Society has more information and support available. 

Self management

Over time, you will find your own ways of managing symptoms and of keeping as fit and healthy as possible. These might change over time, if the effects of your MS change, and it is helpful to stay in touch with your health care team to be confident you are finding the most effective combinations of lifestyle and treatments for you. Exercise and diet are two

areas of life which many people find helpful to control. The MS Society booklets, *Exercise and physiotherapy*, *Diet and nutrition* and *Complementary and alternative medicine* have more information you might find helpful. 

Some people with MS find it helpful to attend the Expert Patient Programme – a six-week course to help people gain skills for living with a long-term condition. 

Multi-disciplinary support

The team which supports you to manage your MS might involve many different specialist areas of expertise, including MS specialist nursing, physiotherapy, dietary advice, fatigue management or pain control. Not everywhere in the country has these formal ‘multi-disciplinary’ teams, but you should be able to access help in these different areas through a central point of contact – through your GP, MS nurse or social worker, for example. Any health or social care professional should be able to refer you to someone with expertise in another area, so do ask if you feel you need more advice or support.

Treating relapses

Relapses can be treated with steroids – either orally (usually as a tablet) or intravenously (in a drip).

Even if you have not benefited from steroids previously, you may still benefit on another occasion, particularly if the attack is affecting a different part of the nervous system. You can usually take oral steroids at home. Intravenous steroids are normally given during a day or overnight visit to hospital, though occasionally at a GP surgery or at home.¹¹

Whether or not you have steroid treatment for a relapse will depend on you and your doctor weighing the potential benefits against the possible side effects. If your relapse is relatively mild, for example, you might decide it's better to let it recover without steroids.

Steroids do not have long-term benefits for treating MS¹² and to avoid possible side effects such as osteoporosis (weakening of the bones), steroids are not generally given more than three times a year.⁹

Whether you have steroid treatment for a relapse or not, you might benefit from 'rehabilitation', to help you get your health and fitness back as the symptoms start to improve. Different members of the multi-disciplinary team could be involved in this, depending on the symptoms of your relapse and the speed of your recovery. There is no 'one size fits all' treatment for MS. It should always be a case of discussion between you, your health care team and those around you – the most effective rehabilitation involves everyone, including close family.

For more information on managing relapses, see our free publications *Essentials 01: Managing relapses* and *Managing MS relapses – a pocket guide*. 

Disease modifying drugs

Disease modifying drugs can affect or modify the course of MS. They are thought to suppress the immune system's activity in the brain and spinal cord. Although not a cure for MS, disease modifying drugs can reduce the number and severity of relapses.

Guidelines produced by the Association of British Neurologists say that the disease modifying drugs beta interferon and glatiramer acetate should be available for people with relapsing remitting MS if they have had two or more relapses in the last two years, or one 'disabling' relapse in the last year.¹³

If you think this may be the case for you, ask your neurologist, MS nurse, GP or the MS Society information team for more details. 

More recently, the disease modifying drug natalizumab (trade name Tysabri), has been licensed for MS. As well as reducing the number of relapses, some people taking natalizumab in a two-year clinical trial developed less disability than expected. It should be noted that Tysabri has been associated with a rare, but potentially serious, side effect.¹⁴

NICE, the organisation that assesses the benefits of all new treatments on the NHS, says natalizumab should be available for people with highly active relapsing remitting MS – those who have two or more disabling relapses a year and where MRI scans show evidence of new MS damage.

Again, if you think this applies to you, contact your neurologist, MS nurse, GP or the MS Society information team for more details. 

Disease modifying drugs are not a cure and they do not help everyone, but they are a helpful addition to the ways that people manage relapsing types of MS. Research continues into finding more effective drugs and more specific ways to target MS in the brain and spinal cord. The MS Society website can keep you up to date: www.mssociety.org.uk

i Further information

Further reading

Coping with Multiple Sclerosis: a practical guide to understanding and living with MS by Cynthia Benz and Richard Reynolds. Published by Vermillion (Second edition 2005). An informative and encouraging book to help people find ways to manage their MS.

Multiple Sclerosis: the questions you have – the answers you need by Rosalind C. Kalb. Published by Demos Medical Publishing (Fourth edition 2008). This American book looks into many of the topics people affected by MS raise, and offers information about what MS is, how to treat it, self management and practical solutions.

www.mssociety.org.uk/pieces – A website designed for anyone aged 18-40 who is affected by MS.

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 services. For a publications list and order form visit the website www.mssociety.org.uk or call 020 8438 0799 (Weekdays 9am-4pm, except Tuesday, 9am-3pm). A range of Factsheets are also available to download from our website, or call the information team.

MS Society website and magazine

Keep up to date with news relating to MS with the MS Society website www.mssociety.org.uk and members' magazine, *MS Matters*. Details about *MS Matters* are on the web 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** (Monday to Friday, 9am-9pm, except bank holidays), or email **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. The Information Centre also runs an information line 020 8438 0799 (Weekdays 9am-4pm, except Tuesday, 9am-3pm), which you can call to request publications, research articles or other information about MS. Search our library database at www.mssociety.org.uk/library

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 0759.

Other organisations

Expert Patients Programme

Six-week courses to help people with a long-term condition maintain their health and improve their quality of life. Led by people who themselves live with a long-term condition. To find out about courses in your area, go to www.expertpatients.co.uk or ask your GP or MS nurse for details.

National MS Therapy Centres

A federation of therapy centres around the UK. They offer a variety of therapies, often including physiotherapy.

PO Box 126
Whitchurch SY14 7WL
Telephone 0845 367 0977
www.ms-selfhelp.org

Useful contacts



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Useful contacts



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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

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Multiple Sclerosis Society

Multiple sclerosis (MS) is the most common disabling neurological disorder affecting young adults and we estimate that around 85,000 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 70 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

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National Office
Ratho Park
88 Glasgow Road
Ratho Station
Newbridge EH28 8PP
Telephone 0131 335 4050

MS Society Northern Ireland
The Resource Centre
34 Annadale Avenue
Belfast BT7 3JJ
Telephone 028 9080 2802

MS Society Cymru
Temple Court
Cathedral Road
Cardiff CF11 9HA
Telephone 029 2078 6676

National MS Helpline
Freephone 0808 800 8000
(Monday to Friday, 9am-9pm)
Website www.mssociety.org.uk

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