Understanding Relapse in Multiple Sclerosis

A guide for people with MS and their families
Introduction

You have been given this booklet because you have been diagnosed with Multiple Sclerosis (MS) and have either already experienced a relapse, or because your MS nurse or neurologist thinks that you might be at risk of experiencing a relapse at some time in the future.

Relapses are very common in MS and largely unpredictable in terms of how often they occur, how severe the symptoms are and how long they last. However, whatever form your relapse takes the symptoms will most likely subside over time and though they may be worrying for you and those around you at the time, there is help available.

The aim of this guide is to help you understand what relapses are, to give you more information about what to look for and what to do if you think you might be having a relapse and to explain the sort of help that you should be able to access. Understanding what a relapse is and what can be done about it can help you feel much more in control if you do experience one.
This guide will help you to understand:

- What a relapse is and how it differs from more general fluctuations in your MS symptoms
- What to do if you think you are experiencing a relapse
- What you can expect from your MS team in terms of possible treatment options and support.

What is a relapse?

Approximately 85% of people with MS will experience relapses at some stage during the course of the disease (Lublin et al 1996). They happen most commonly in the first few years after diagnosis, though people can experience a relapse at any time. You will probably hear different terms used to describe relapses such as ‘attacks’, ‘exacerbations’ or ‘flare ups’, all of which mean the same thing.

One of the features of a relapse is its unpredictability – no two people will experience the same symptoms in the same way and even the same person will often find that each relapse is different to previous ones.

No warning

Relapses typically happen ‘out of the blue’ with little or no warning, though sometimes people can tell when a relapse is ‘coming on’. The range of symptoms experienced often varies from one person to another and from one relapse to another. These symptoms may be new ones that you haven’t previously experienced, or they may be old symptoms which have reappeared or which become significantly worse.

Symptoms

Relapses are clinically defined as the appearance of new symptoms or the return of old symptoms which last for at least 24 hours in the absence of any signs of infection or increased body temperature and after a period of relative stability lasting at least a month (Lublin et al 1996). However they are often not as clear cut as this definition makes them sound.

Symptoms can be many and varied and some examples are listed on page five. Generally you may find that you are either unable to do the same things that you could do a week or two before or that it is just more difficult to do these things. Whatever symptoms you experience they are likely to get gradually worse over the initial period of a few of days, or longer, and then level off. After a time, (typically weeks, though this varies) the symptoms will usually subside and you will start to gradually recover again. Some people will experience a full recovery from the relapse, whilst for others the symptoms will improve but may not fully disappear.
Examples of symptoms...

- Blurred vision
- Double vision
- Dizziness
- Balance and coordination problems
- Weakness in a leg or arm
- Areas of numbness, pins and needles or pain
- Bladder or bowel problems
- Sexual dysfunction
- Loss of balance
- Increased spasm and stiffness
- Sustained and increased fatigue
- Cognitive problems (for example attention, thinking and memory problems)

Typically you would experience onset or changes in two or more different symptoms during a relapse.

Day to day fluctuations in symptoms

Many people with MS find that their symptoms fluctuate all the time and they can find it confusing to know when they are experiencing a relapse and when it is just ‘part and parcel’ of their MS.

The severity of your MS symptoms does tend to change all the time. Sometimes there is no obvious reason for this, whilst at other times it is clear why you are feeling a bit worse than usual. For example you may find that your symptoms get worse when you are tired or if you are feeling very stressed or worked-up about something. Some people find that excessive heat can also bring on their MS symptoms but these settle down again once you have cooled down.

Generally, the worsening in these instances lasts just a few hours and things start to improve again once you have had a rest or cooled down. With a relapse you will find that the deterioration in your symptoms continues despite rest and that things don’t immediately start to improve.

Infection

It’s important also to be aware that if you are unwell – for example if you have a cold or a urine infection – you will often find that your MS symptoms get worse. Usually your symptoms will settle down again once you have recovered from your cold or the infection has been treated. This would not be classed as a relapse.
Sometimes the MS symptoms don’t settle down once the infection has resolved and then it’s important to contact your MS nurse, as you may be having a relapse. Whether you are having a relapse or not, your MS nurse should also be able to give you some advice on how to manage your symptoms more effectively and it is always worth letting your MS nurse know if you are feeling unwell.

Speak to your MS nurse

All this can be very confusing and the important thing is to try not to worry. Don’t feel that you have to decide yourself whether or not what you are experiencing is a relapse – it can be difficult for your MS nurse or neurologist to be sure sometimes!

If you think you are experiencing a relapse, or you are worried about any of your symptoms, then it is best to speak to your MS nurse and together you can decide what you should do next.

If in doubt – shout!

What to do if you think you are having a relapse

Relapses can be a sign that your MS is more active which is why it’s important to contact your MS nurse whenever you think you might be experiencing one, even if you don’t feel the relapse itself needs treating. Sometimes people know they are having a relapse but feel that their symptoms are too mild to bother about, or that it is just part of the MS and there is nothing anyone can do anyway. However, it is still worth letting your MS nurse know about your symptoms so that they can make a record in your medical notes. This allows the MS nurse and neurologist to work with you to ensure your MS is managed as well as possible.

Contact your MS nurse

Even if you feel that you don’t want anything to be done because you know that the relapse symptoms will go away on their own, it is important that you tell a member of your MS specialist team what is happening. Once you let your MS team know you are experiencing a possible relapse they should then be able to help you manage your current symptoms, as well as review whether you would be helped by a disease modifying medication (or a different disease modifying medication if you are already being treated). By reducing the number and severity of relapses, some of these medications have also been shown to slow the build up of disability (MS Trust 2012).
In the first instance most people find it easiest to phone their MS nurse and chat about their concerns. MS nurses know you and your history, as well as having a thorough understanding of MS.

**What will the MS nurse want to know?**

Your MS nurse will ask you about the symptoms you are experiencing, when they started and what has changed – how are these symptoms affecting you on a day to day basis? What could you do a couple of weeks ago that you either can’t do now or that is more difficult to do now? The MS nurse may also want to know if there is anything happening that could be making your symptoms worse such as signs of infection. It is also worth noting that some women find their MS symptoms worsen around the time of their period and you may find that the MS nurse asks you about your menstrual cycle.

Sometimes when you are in the middle of a relapse it can be difficult to remember everything you want to say or ask, or you may just feel you don’t have as much confidence as usual, making it more difficult for you to explain. Don’t let this put you off contacting your MS team. Write a list of the things you want to talk about, or ask a friend or family member to help. Alternatively ask someone close to you to be there when you speak to the nurse, so they can take over if you get stuck with what you want to say.

Sometimes it can help to keep a record of your changing symptoms which you can share with your MS nurse at your next appointment – this can be done online (for example by using a simple mobile app such as SymTrac™ which helps you to keep track of your MS symptoms over time) or by making a note on your calendar or in your diary.

When you speak to your MS nurse they should discuss your symptoms with you and decide whether you are experiencing a relapse and if so, whether you need any treatment for the relapse itself or for the symptoms you are experiencing. The MS nurse and your neurologist might also consider whether or not you need to start or change a disease modifying treatment (DMT). These are medications which reduce the frequency, duration and severity of relapses over time.

If required, a follow-up appointment will be arranged – this may be face to face or over the phone and usually takes place within six to eight weeks. A follow-up appointment can be very useful for you and your MS nurse in order to make sure that you are improving and to discuss other treatment options with you if things are still difficult. Your MS nurse should also make a record of your relapse and pass this on to your neurologist, so that the MS specialist team has as a full record of your relapses and symptoms. This is very helpful when deciding which (if any) of the disease modifying treatments will be right for you.
How to manage a relapse

Rest
Whatever symptoms you experience during a relapse, the chances are that you will be much more tired than usual. You know yourself best, so listen to your body. If you need a rest then do your best to take one. It is also really important to ask for help. This can be one of the hardest things for some people to do but the chances are that your friends and family really want to help and perhaps they just aren’t sure what they can do – so talk to them!

If you need additional support, have a chat with your MS nurse. If you are struggling more than usual it may be possible to arrange some social services support, just to help in the short term.

Work
Taking time off work is not easy and not always possible and some people with MS have no alternative but to continue to work during a relapse, which can be difficult. It may help to let a manager that you trust know you are having a relapse as it may be possible to arrange for you to do some work from home or for you to take some flexi-time or have longer or more flexible breaks depending on your needs.

Your employers have a duty to make ‘reasonable adjustments’ within the work place to help you when you need it (as laid down in the Equality at Work Act which legally protects against discrimination in the workplace).

Driving
Anyone with MS has to notify DVLA (see www.gov.uk) of their diagnosis but most people are able to continue driving (there is more information on the MS Society and MS Trust websites). If you experience a relapse and therefore a worsening of your MS symptoms you should use your common sense to decide whether or not you should continue to drive during the relapse and when you feel able to start driving again.

Keep a record
Keep a note of what is happening. This doesn’t need to be daily or lengthy but keep a note of any changes and how they are affecting you, along with the date. These notes will be useful for you as a record of your MS symptoms and they will also be helpful for your MS team. You can either do this via an App (such as SymTrac™) or by making a note in your diary.
Below is a list of the sort of questions the MS nurse may ask you:

- When did your symptoms start to change and what has been the pattern of this change?
- What symptoms are you experiencing?
- Which part of your body is affected, for example if you have numbness, where is this?
- Have the symptoms stopped you doing anything that you can normally manage, such as preparing meals, driving, getting up and down stairs, working etc.?
- Have you been ill lately or had any symptoms of infection, for example unexplained shivering?
- What medication are you taking?

What are the treatment options for an MS relapse?

Not all relapses need treatment. The symptoms of a relapse will generally improve on their own, although how long that will take and the full extent of recovery is unpredictable.

As steroids (which are used to treat the short term effects of relapses – see below) make no long term difference with respect to disease progression, some people prefer not to take anything, however other people experience a lot of problems connected with their relapse and do choose to take medication. Your MS nurse or neurologist should discuss the pros and cons of taking steroids with you so that you can decide together on the best course of action in your particular situation.

**Steroids**

The treatment for relapse is high dose methylprednisolone – a type of steroid. High-dose steroids are given in high doses over a three to five day period (NICE 2003b). Taking steroids in this way can reduce the duration and severity of the relapse, but they make no difference to the long term outcome.

Steroids can be given either as a course of tablets or by infusion (a drip). If you have the steroids by infusion you will probably need to go into hospital each day for your treatment.

There are downsides to taking steroids and these can include some unpleasant side-effects (Burgess 2011). About half the people who take steroids feel unwell while taking them and many choose not to use them. Others take steroids and feel much better, so it’s a very mixed picture. It’s not possible to predict how you will react to steroids if you haven’t tried them before. Your MS nurse and neurologist should discuss the pros and cons of the treatment with you and help you make a decision about whether or not to take steroids, if appropriate. There are things that you can do to minimise any side-effects and your MS nurse or neurologist should be able to give you more information about these.
If a relapse is not causing too many problems, steroids will probably not be prescribed. This is because the more courses of steroids you take, the greater the chances of developing long term problems, such as diabetes. The nature of relapse is such that you will experience an improvement in your symptoms over time whether or not you are prescribed steroids; steroids simply reduce the severity and duration of a relapse.

**Physiotherapy**

Specialist neurological physiotherapy (neuro-physio) has been shown to be very helpful for people experiencing a relapse (Craig et al 2003). It can be difficult to get timely access to physiotherapy treatment but if you can it may well be helpful. Your MS nurse should be able to refer you to the local neuro-physiotherapist, if they feel this would be beneficial.

If you are experiencing a relapse, or just think you might be, it is important that you let your MS team know. They can then help you cope with the immediate problems you are experiencing and they may also review your overall medication and consider whether there is any need to prescribe a disease modifying therapy (or change your current DMT) which can reduce your chances of experiencing further relapses in the future and possibly slow the build up of disability.

It is important to remember, relapses are a sign of active disease and getting the right help as early as possible may help to reduce any long term effects/damage. The range of treatment options is increasing and your MS team should be able to discuss the relevant options with you.

Your MS team is there to help. They would rather you called; even if it turns out that you’re not having a relapse, than hear you have struggled on your own.

**If in doubt – shout!**

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Understanding relapse in multiple sclerosis
Sources of further information

- DVLA driving advice: www.gov.uk/driving-medical-conditions
- Equality at Work Act: www.gov.uk/equality-act-2010-guidance
- MS International Federation: www.msif.org
- MS Research, Barts and The London: A blog for people with MS and their families: www.multiple-sclerosis-research.blogspot.ch
- Information about a mobile symptom tracking App for MS: www.symtrac.com
- MS Trust information: Relapse: www.mstrust.org.uk/atoz/relapse.jsp
- MS Trust information: Driving: www.mstrust.org.uk/information/livingwithms/driving.jsp

References

Recognise

Look out for changing symptoms lasting more than 24 hours\(^1\)

Record

Keep track of changing symptoms to build up a clear picture

Report

Talk to your MS team if you notice a change that affects daily life

Review

Consider treatment or a change in treatment

\(^1\)http://www.mstrust.org.uk/information/opendoor/articles/1105_10_11.jsp

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