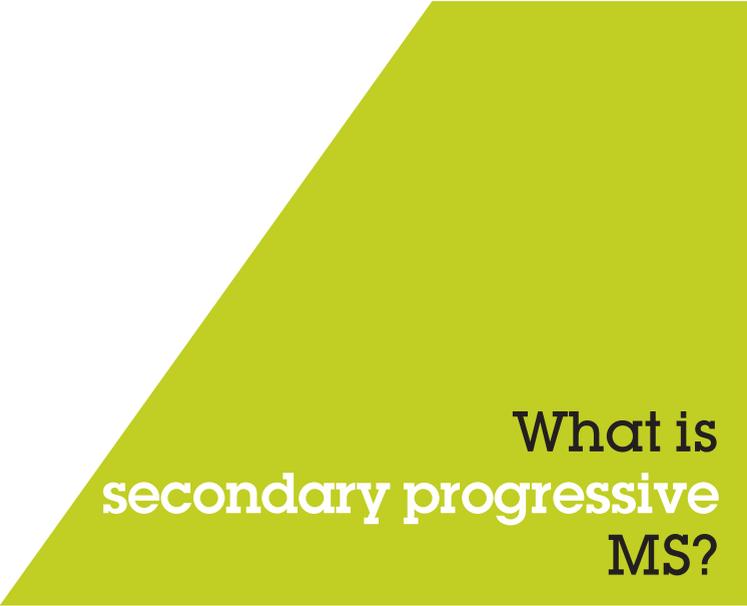


First edition
December 2008



What is
secondary progressive
MS?

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.

What is secondary progressive MS?

Secondary progressive multiple sclerosis (MS) is a stage of the condition which comes after – is secondary to – relapsing remitting MS. In other words, secondary progressive MS only occurs in people who have already had relapsing remitting MS.

It is possible to be diagnosed with this type of MS when you are first diagnosed with the condition – if the relapsing remitting phase of MS had never been identified – but this is rare.

Like any label for MS, being told you have ‘secondary progressive’ might be a shock, or it might confirm what you have suspected for some time. There’s no ‘right way’ to react. However you feel, you might have as many questions or concerns about this new label as when you were first diagnosed. Your neurologist will be able to answer some of your questions – about treatments and therapies, for example – but you might also want to speak to an MS specialist nurse, or the MS Society freephone Helpline on 0808 800 8000. You can also email the Helpline: helpline@mssociety.org.uk. Friends, family and colleagues can also contact the Helpline. All calls are confidential.

How do I know if I have developed secondary progressive MS?

It is not always easy to say that someone’s MS has become secondary progressive. Neurologists generally agree that MS can be called secondary progressive when there is a sustained

build up of disability, completely independent of any relapses.¹ In other words, the MS gets noticeably worse whether or not there are relapses having a more dramatic effect. Most neurologists will look for at least six months of clear progression before they use the term secondary progressive.

You, or others close to you, might have noticed more difficulties with getting around than before, or other symptoms might have become a little worse. Changes can happen very slowly though, so if there is progression it may not be clear for some time. Remember that with or without progression you might still get good days and bad days. If there is progression, the speed of change can vary. At times, things may almost seem to stand still, with no obvious changes. These are some of the reasons why it's hard to be sure if progression is happening.

Your MS – the symptoms you experience and how they affect you – might still be very different to that of someone else with secondary progressive MS. Managing it will still be a personal thing – and one which involves not only treatments for symptoms, but also learning and adjusting to how MS fits into your life.

How is this different to primary progressive MS?

Secondary progressive MS follows relapsing remitting MS. Primary progressive MS is progressive from the beginning and does not start with a relapsing remitting phase. You can read more about this in our booklet *What is primary progressive MS?* 

Difficulties diagnosing secondary progressive MS

The differences between someone with relapsing remitting MS and someone with secondary progressive MS are not always obvious. The neurologist has to try and decide if there has been a change in the underlying process of MS in the central nervous system (the brain and spinal cord).

In MS, two things can lead to a build up of disability:

- 1 incomplete recovery from relapses
- 2 gradual progression of the condition

In relapsing remitting MS, lasting symptoms result only from relapses.

In secondary progressive MS, lasting symptoms can result from relapses and progression.

Relapses

Not everyone continues to have relapses with secondary progressive MS, but when there are still relapses it can make it harder to diagnose the type of MS. Although many people recover from relapses within three months, in some cases it can take up to six months, or even longer, before full recovery takes place. This makes it hard to tell whether symptoms are due to progression or the lingering effect of a relapse.

Other confusing factors

Relapses and progression are not the only things that can cause noticeable changes in symptoms.

For example, one symptom of MS might have knock-on effects for others (such as fatigue making walking more difficult at certain times). Issues not directly caused by the

MS might also make your MS feel worse – such as being less physically fit, menopausal symptoms or changes in mood.

Any of these factors can make it difficult to determine if there is truly a progression in the MS.

What's happening in the central nervous system (the brain and spinal cord)?

There appear to be three key processes going on in the brain and spinal cord of someone with MS:

- inflammation (caused by a rush of 'activated' white blood cells)
- damage to the protective 'myelin sheath' around the nerve fibre
- sometimes there is damage to the nerve fibre itself

When people with MS have a relapse, the main process going on is inflammation. However, it is likely that during most relapses some damage also occurs to the myelin sheath and to the nerve fibre (called the axon). Severe damage to the axon can cause it to die. If this happens, it cannot repair itself.

Fortunately, each of us can afford to lose quite a lot of axons (perhaps up to 40 per cent) without having a noticeable effect on what we can do. However, once the damage to axons reaches a certain level it does have an effect on function. From then on, a gradual loss of axons causes a gradual progression of the MS, with symptoms becoming worse. There are still many unanswered questions around the processes of MS, but this may explain why it takes many years before secondary progressive MS develops.

Does everyone with relapsing remitting MS develop secondary progressive MS?

Most people with relapsing remitting MS will eventually develop secondary progressive MS, though the time it takes for this to occur from the beginning of the condition varies from person to person – in keeping with the unpredictable and variable nature of MS.

On average, 15 years after being diagnosed, around 65 per cent of people with relapsing remitting MS will have developed secondary progressive MS.²

As with all averages, individual experience can be different. Some people develop secondary progressive MS sooner than this, while others never do, even after many decades.

At the moment, we don't have a clear idea why some people develop secondary progressive MS and others don't. It may, for example, be influenced by our genes. Knowing more about this would be a major breakthrough in understanding MS and might provide a potential target for treatment.

Managing your MS

Managing your MS will mean you need to make adjustments and adapt to changes. 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. Unfortunately, services can vary around the UK, but knowing what to ask for and who to ask can sometimes make the difference. The MS Society has more information about managing particular symptoms, health and social care services. 

Self management

Over time, you will have found your own ways of managing your symptoms and of keeping as fit and healthy as possible. These might change, 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. The MS Society has more information on aspects of self management that many people find helpful, in booklets such as *Exercise and physiotherapy*, *Diet and nutrition* and *Complementary and alternative medicine*. 

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

For symptoms

There are drug treatments which can help people manage many different MS symptoms, including muscle stiffness, bladder problems and pain. Speak to your MS nurse, GP or neurologist about any symptoms you have as there may be a treatment that can help. Remember that symptoms might not always be due to MS and a health care professional can investigate further to make sure the appropriate course of action is taken.

Often, drug treatments work best if accompanied by ‘rehabilitation’, involving the expertise of different health and social care professionals, including physiotherapists and MS specialist nurses. There’s more about rehabilitation on page 9.

For relapses

If you have secondary progressive MS with relapses, then these 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. Steroid treatment may

need to be followed by further therapy or rehabilitation. There's more about rehabilitation on page 9.

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 drug beta interferon should be available for people with secondary progressive MS if they are still having relapses and if it is clear these relapses are the main cause of increasing disability.⁴

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

Can disease modifying drugs delay the start of secondary progressive MS?

In relapsing remitting MS, the disease modifying drugs beta interferon and glatiramer acetate reduce both the frequency and severity of relapses for some people. Another drug, natalizumab, can also reduce the number of relapses. In addition, some people taking natalizumab in a two-year clinical trial developed less disability than expected.⁵

It might seem logical to think that taking these drugs before the secondary progressive stage of MS would delay it. However, reducing relapses is only part of the process in MS so we cannot assume that they would have this long-term benefit. At the moment, we do not have results from long-term studies to show this possible benefit.

Mitoxantrone

Research has shown that mitoxantrone, a strong drug that suppresses the immune system, may also be effective in treating secondary progressive MS, particularly for those who have relapses; it appears to be much less effective for those who do not still have relapses.⁶ It is currently licensed in the US for secondary progressive MS and worsening relapsing remitting MS. Although it is not licensed in the UK for MS, you can ask your doctor to prescribe it on a 'named-patient basis'. There is an overall limit to the amount of mitoxantrone that someone can safely be given. It is usually only prescribed for between six months and two years.

Research into new drugs

In recent years, research has started to focus on three key areas which could bring benefits for progressive MS:

- neuro-protection: drugs that might protect nerve fibres (such as 'sodium channel blockers')
- approaches that encourage nerve-fibre repair or regeneration (such as stem cell therapy)
- research into drugs for other progressive neurological conditions (such as eliprotil and riluzole)

These approaches are still in their early stages and more research is needed before their potential benefits for MS and safety can be known. The MS Society is investing in research into stem cells and neuro-protection. For the latest news on research, including trials that are recruiting for participants, visit www.mssociety.org.uk/research or contact the research team on 020 8438 0822.

Rehabilitation

Drug treatments are not the only way to manage the effects of MS. Another approach, which should go hand in hand with any drug treatments given, is rehabilitation.⁷ This helps people make the best of their abilities, and can involve many different skills. 'Multi-disciplinary rehabilitation' can include nursing, occupational therapy, physiotherapy, and many other specialist disciplines. This team can give advice and treatment to manage ongoing changes to symptoms as well as help aid recovery from relapses. For example, a physiotherapist and an occupational therapist might help with weakness or unsteadiness.

Rehabilitation is a team approach which includes you and those close to you. For rehabilitation to work best, everyone needs to play an active part – learning about the most effective ways to manage MS. Of course, you will already have ways you manage things. The expert team can help you build on these strategies and make them as effective as possible for you and your life.

Specialist multi-disciplinary teams to treat people with MS are beginning to be established in the UK. For example, the MS Society is helping to place MS specialists throughout the UK and develop multi-disciplinary teams for MS.

For details of services in your area, speak to your MS nurse, GP, neurologist or the MS Society information team.

i Further information

Further reading

Living with progressive multiple sclerosis: overcoming the challenges by Patricia K. Coyle and June Halper. Published by Demos Medical Publishing (Second edition 2008). This American book includes chapters on managing the social, economic and medical aspects of progressive MS.

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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References

- 1 Lublin F. D. and Reingold, S. C. (1996) Defining the clinical course of multiple sclerosis: results of an international survey. *Neurology*, 46, 907-11.
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- 4 Association of British Neurologists (2007) *ABN guidelines for treatment of multiple sclerosis with beta interferon and glatiramer acetate*. London, ABN.
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- 6 Hartung, H. *et al.* (2002) Mitoxantrone in progressive multiple sclerosis: a placebo-controlled, double-blind, randomised, multicentre trial. *The Lancet*, 360, 2018-25.
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Authors and contributors

With thanks to Professor Alan Thompson and all the people affected by MS who contributed to this publication.

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

Contact information

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372 Edgware Road
London NW2 6ND
Telephone 020 8438 0700

MS Society Scotland
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)