

MS Essentials

For people living with MS

This booklet is available in a larger print and audio CD
Call 020 8438 0799 or email shop@mssociety.org.uk

Vision and MS

Many people with MS have a problem with their vision at one time or another. It's often an early symptom, although problems can occur at any time.

The most common cause of problems with vision in MS is an inflammation of the optic nerve, known as optic neuritis. MS can also cause problems with eye movement, although these are less common. This booklet looks at the effect these problems can have on your sight, and how to manage them.

It's important to remember that there are many different possible causes of sight problems, not all of which are MS-related. But if your optician can't correct your vision with glasses, ask your GP for a referral to an eye specialist (an ophthalmologist), or a neurologist, who can investigate further.

i Where you see this symbol turn to pages 15–16 for contact details.

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Gilenya

There is a rare side effect of the disease modifying drug Gilenya (fingolimod) that can cause problems with your sight. If you are taking this drug and notice changes to your eyesight, tell your MS nurse or neurologist immediately. There's more about Gilenya in our booklet *Disease modifying drugs*.

Optic neuritis

“ I had it in one eye and it started with blurred vision which eventually decreased to almost total loss of vision in that eye, couldn't see light or colour and a sharp pain when I moved my eye. – *Aisling* ”

Optic neuritis is the name for inflammation (swelling) of the optic nerve. This is the nerve that carries messages from your eyes to your brain.

Symptoms

The effect that optic neuritis can have on your sight varies. It can range from blurred vision to a complete loss of sight. It often affects just one eye, although it can affect both, either at the same time or one after the other.

Some people notice a blurring or blind spot in the centre of their vision. Colour vision is usually affected: colours might appear darker, or washed out. Some people have light flashes, called 'phosphenes' when they move their eyes.

In some cases optic neuritis can be painful, particularly when you move your eyes. The pain usually lasts for a few days, and shouldn't be severe enough to affect your sleep. If it does, there may be something else causing it.

The worsening of vision tends to progress over a few days to a week, although for some people it can be much quicker – a few hours, or overnight.

Optic neuritis and MS

Although optic neuritis is associated with MS, not everyone who has optic neuritis will have, or go on to develop, MS. Many people have optic neuritis with no further symptoms.

Because of this association between optic neuritis and MS, if it is your first MS-like symptom then you may be referred for further tests. This can obviously be a worrying time. If you want to talk through any of the issues you're experiencing, you can call the freephone MS Society Helpline on 0808 800 8000 from 9am to 9pm, Monday to Friday. There is also a message board on our website for people who are going through the diagnostic process: www.mssociety.org.uk/forum

Diagnosis

Optic neuritis is diagnosed by an ophthalmologist or neurologist. In order to reach a diagnosis, they will want to know how your vision is affected, when your symptoms came on and whether you've had any previous neurological symptoms.

They may also carry out some tests. These may include blood tests and 'visual evoked potentials'. This tests how well your optic nerve is working, by checking how long it takes your brain to react to a visual signal. They may also carry out an MRI scan of the optic nerve, to look for signs of inflammation.

If this is your first MS-like symptom, you may also be referred to a neurologist for further tests, including an MRI scan of your brain. There's more information about the different diagnostic tests for MS in our booklet, *What is MS?*

Other eye conditions can mimic optic neuritis so, depending on your symptoms, you may need to have further tests. This is more likely if your symptoms aren't typical – for example: if you have very severe pain that disturbs your sleep or limits how much you can move your eyes; if you lose your sight completely in the affected eye; or if your sight hasn't started to improve after three or four weeks.

Treatment

Optic neuritis will often improve on its own, usually within a few weeks, so you may not need any treatment.

However, if your symptoms are particularly severe – for example, if it's affecting both eyes – or if you want a faster recovery, you may be prescribed a course of steroids. These are given either as a tablet or as a drip. Steroids have been shown to speed up recovery from optic neuritis, but they don't affect how well your eyes recover.

Recovery

Most people's sight recovers well from optic neuritis.

The early stages of recovery can happen quite quickly, probably due to the inflammation of the optic nerve going down. In one of the key clinical trials for optic neuritis, 79 per cent of people showed signs of improvement within three weeks, and 93 per cent began to recover within five weeks.

A fuller recovery can take longer, and you may find that your sight continues to improve for up to a year after your first symptoms.

Although your sight may recover to normal levels in terms of standard visual acuity charts, you may notice some subtle, lasting changes to your

vision. For example, you may find it harder to pick out colours, or distinguish between different colours. Your depth perception may also be affected, and things may not appear as sharp as they used to. You may also find that certain triggers, such as heat, exercise or fatigue, make your vision temporarily worse, or that it varies during the day or from one day to the next.

What if my sight doesn't recover?

While most people's sight recovers well from optic neuritis, for some people it doesn't. If the nerve fibres within the optic nerve are significantly damaged then this can cause more lasting sight problems.

At the moment, there are no treatments that can repair this damage. However, research – including some funded by the MS Society – is underway to find treatments that can halt this damage. For more about the latest research, see our website: www.mssociety.org.uk/research or contact the MS Society Helpline on 0808 800 8000.

There's more on living with lasting sight problems on page 11.

Eye movement problems

In some people with MS, the nerve pathways that control the movement of their eyes can be affected. As a result, their eyes may not move smoothly, or the two eyes may be out of alignment.

The two most common eye movement problems in MS are double vision (diplopia) and involuntary eye movements (nystagmus).

Double vision (diplopia)

“ Double vision is really annoying but it makes watching some sports such as snowboarding, surfing etc, twice as fun. Scary as a passenger in a car though when it looks as if there are two cars driving towards you, one in each lane. Aaaargh!!!! – Jo ”

If your eyes aren't working perfectly together, then you may see double – a single object may appear as two objects. They may be side by side or one on top of another. Sometimes one of the images may appear tilted.

You may notice that the double vision only occurs when you're looking in certain directions, for example, all the way to one side, or straight ahead.

Some people with double vision can also have problems with nausea (feeling sick), vertigo (a spinning sensation) or a lack of coordination, which can affect your balance. There's more on how visual problems can affect balance in the MS Society booklet *Balance and MS*.

• Treatment

As with optic neuritis, if your double vision is related to a relapse it often improves on its own. A course of steroids, either as a drip or a tablet, may help to speed up recovery.

If your double vision is particularly troubling, there are things you can do to reduce the impact of it. Patching one eye blocks out one of the two images and can provide some relief. If you wear glasses, you can get these fitted with special prisms to realign the two images. These help to ease the imbalance caused by double vision, by making your brain think your eyes are working together.

Involuntary eye movement (nystagmus)

“When I change the direction that I am looking in, for example go to look over my shoulder, it feels like my eyes are wobbling everywhere until they get to the thing I was going to look at, then they settle. – Tom”

Nystagmus is the name for an uncontrolled movement of the eyes. They can move in any direction: side to side, around, or up and down.

Many people with MS who have nystagmus don't realise they have it, as the movement has little or no effect on their vision. It's often something doctors will pick up on when they're testing eye movements. However, some people do notice a significant effect on their vision. Objects may seem to move back and forth, to jerk or to wiggle (oscillopsia).

As with other MS-related eye problems, visual problems caused by nystagmus can vary; for example, some people notice their vision can get worse when they are stressed, tired or hot.

- **Treatment**

Drugs, such as gabapentin, baclofen or clonazepam, can help to reduce the jerky movements, and improve your vision. However, they don't work for everyone. Research is underway into other possible treatments. Information about the latest research into nystagmus, as well as support for living with the condition, is available from the Nystagmus Network. [i](#)

Living with sight problems

“ I think one of the biggest things for me is that when I have problems with my sight I know I have to ask for help. That was a major issue for me. Especially when I am so affected and can't drive, so even getting my daughter to school is a problem. I know it is very hard for other people to understand why that happens. – *Lorraine* ”

Changes to vision – whether they're temporary or longer lasting – can have a major impact on your life. They can affect almost all aspects of daily life, including work, driving, and leisure activities such as reading or watching TV. You may find it's harder to do the things you normally do, or you may have to ask someone else to help you.

However your vision is affected, there are usually things you can do to make it easier for you to carry out your normal activities. These range from simple things like using overhead lights rather than lamps to make your home brighter, to gadgets that can help you around the home and at work. These include: screen readers, to convert computer text to speech; magnifying glasses; big button telephones; and talking kitchen equipment. Contact the RNIB or the Disabled Living Foundation for more information, and to find out about the wide range of equipment you can use to make the most of your sight. [i](#)

Many of these items, as well as other practical suggestions for managing around the home, are available through social care services (social work in Scotland) following an assessment by an occupational therapist. For more information about assessments see our booklets, *Getting the*

best from social care services, Getting the best from social work in Scotland and Getting the best from social care services in Wales.

Identifying triggers

“ I don't drive even longish distances so that any potential eye problems related to fatigue aren't going to crop up unexpectedly. I rest before I take the short drive home from our local shopping centre. A good excuse for a nice posh coffee! – *Ellen* ”

Many people with MS who have problems with their vision find certain triggers, such as heat or fatigue, can make their sight temporarily worse. If that's the case for you, then you may need to plan around it, so you can avoid potential triggers at times when it's especially critical that you can see well. For example, if you know fatigue makes your sight worse, you may plan not to drive at times when you're likely to be fatigued, or you may give yourself extra time to allow for breaks in your journey.

As with everything to do with MS, it's very individual. It may take some time to work out what affects your vision, and what changes you can make to tackle it.

Of course, it's not always possible to predict when your vision will be affected. If you do develop problems unexpectedly, it can sometimes be difficult to ask other people for help. The MS Society has produced a credit-card-sized *Assistance Card* which you may find useful in these situations. It lists some of the common symptoms of MS, including difficulties with eyesight, and can help you to explain why you need assistance.

More lasting sight problems

While most people with MS don't have any lasting problems with their vision, a small minority do.

If you have problems with your sight that can't be corrected by glasses or contact lenses, you can be referred to a low vision service. These services are normally located in hospital eye departments, and their aim is to help you make the most of your remaining eyesight.

Rehabilitation workers will work with you to solve practical problems, such as getting about safely, and can teach you daily living skills. They may, for example, suggest magnifying devices or other equipment that can help you, or they may give you advice on using different techniques, such as specific eye movements.

The RNIB has more information about low vision services and how to access them, as well as the various different professionals involved in eye care. [i](#)

Coping with the impact of sight problems

Coming to terms with a long-term sight problem can be difficult. Changes to your vision can have a major impact on you both practically and emotionally, and this can sometimes be overwhelming. If you want to talk through any of the issues you're experiencing, you can call the freephone MS Society Helpline on 0808 800 8000 from 9am to 9pm, Monday to Friday. There's also information on coping with the emotional impact of MS and its symptoms in our booklets, *Living with effects of MS* and *Mood, depression and emotions*.

The RNIB also offers a telephone service for people who are experiencing emotional difficulties because of sight loss. You don't need to be blind to get support from the RNIB – they can help anyone with any degree of sight loss. [i](#)

Further information

Read more

Our free booklets help explain MS, look at its practical and emotional effects, and help you find your own ways to manage life with MS. Titles are available in large print, audio format and a number of languages. For copies, email shop@mssociety.org.uk or call 020 8438 0799.

We can help you find and borrow other books, research articles and DVDs about living with MS. Search online or call the librarian on 020 8438 0900.

Find out more online

Get the latest on research, campaigns and MS news. Chat online with our message boards and Facebook. Follow us on Twitter, see the MS community at Flickr and watch us on YouTube.

Join us

Receive local and national magazines and newsletters, and get involved locally and nationally. Be as involved as you like. Just by being a member you strengthen the voice of all people with MS, and help us continue our vital work. Join online, or call 020 8438 0759 or your national office (see back cover).

Get in touch

The freephone MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers. Information is available in over 150 languages through an interpreter service. **0808 800 8000 (weekdays 9am-9pm) or helpline@mssociety.org.uk.**

Near you

Our volunteers run over 300 local branches and support groups. They provide information about MS and local services, and a chance to meet others affected by MS and take part in a range of activities.

In many parts of the country, you can pick up our booklets at MS Society Info Points. Larger information centres – including ones in our national offices in London, Belfast, Cardiff and Edinburgh (Newbridge) – can help you with information about MS and services in your area.

Or come along to our local and national events and learn more about MS from expert care professionals, researchers and other people with the condition. Find out more online or call your national office.

Useful organisations

Ability Net

Ability Net is a registered charity with over 20 years' experience helping people adapt and adjust their information and communications technology (ICT).

Telephone 0800 269 545

www.abilitynet.org.uk

Action for Blind People

Action for Blind People is a national charity with local reach, providing practical help and support to blind and partially sighted people of all ages. They have a network of local action teams across England.

Contact them through the RNIB Helpline on 0303 123 9999

www.actionforblindpeople.org.uk

Disabled Living Foundation (DLF)

Provides information and advice on equipment to enhance independence.

380-384 Harrow Road
London W9 2HU

Helpline 0300 999 0004

(Monday to Friday, 10am-4pm)

Textphone 020 7432 8009

www.dlf.org.uk

NHS services and information

England

NHS Choices

www.nhs.uk

Telephone 111

(for medical help, but not for emergencies)

Scotland

NHS Inform

Telephone 0800 22 44 88

www.nhsinform.co.uk

Wales

NHS Direct Wales

Telephone 0845 4647

www.nhsdirect.wales.nhs.uk

Northern Ireland

NI Direct

www.nidirect.gov.uk

Nystagmus Network

A self-help group offering information and support for people with nystagmus.

Telephone 0845 634 2630

www.nystagmusnet.org

RNIB – Royal National Institute of Blind People

Offers information and support for people with sight problems.

105 Judd Street

London WC1H 9NE

Helpline 0303 123 9999

(Monday to Friday, 9am-5pm)

www.rnib.org.uk

Visionary

Supporting local sight loss charities. Contact them for details of your nearest independent sight loss charity.

www.visionary.org.uk

References

A list of references is available on request, and all cited articles are available to borrow from the MS Society library (there may be a small charge). Contact the librarian on 020 8438 0900, or visit www.mssociety.org.uk/library

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With thanks to Dr Simon Hickman, Dr Susan Blakeney and Dr Catherine Dalton, Bernadette Porter, Lisa Black and all the people affected by MS who contributed to this booklet.

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.

Suggestion for improvement in future editions are welcomed. Please send them to infoteam@mssociety.org.uk

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First edition, June 2003

Third edition, August 2013

This title will be reviewed within three years of publication.

The MS Society provides this information free of charge but if you would like to help cover the cost, which will help towards our essential work, please call 0845 481 1577 or visit the fundraising section of our website to make a donation. Anything you can give will be greatly appreciated.

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. We provide a freephone MS Helpline; grants for home adaptations, respite care and mobility aids; education and training; support for 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 is also the biggest charitable funder of MS research 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

MS National Centre
372 Edgware Road
London NW2 6ND
Telephone 020 8438 0700
info@mssociety.org.uk

MS Society Scotland
National Office, Ratho Park
88 Glasgow Road
Ratho Station
Newbridge EH28 8PP
Telephone 0131 335 4050
msscotland@mssociety.org.uk

MS Society Northern Ireland
The Resource Centre
34 Annadale Avenue
Belfast BT7 3JJ
Telephone 028 9080 2802
information@mssociety.org.uk

MS Society Cymru
Temple Court
Cathedral Road
Cardiff CF11 9HA
Telephone 029 2078 6676
mscymru@mssociety.org.uk

National MS Helpline
Freephone 0808 800 8000
(weekdays 9am-9pm)
www.mssociety.org.uk

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Registered as a limited company in England
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