MS and your eyes

Large print version

We're the MS Society. Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to stop MS.

We rely on the generosity of people like you to fund our vital work. If you would like to make a donation, you can do so by:

- Calling us on: **0300 500 8084**.
  Lines are open Monday to Friday, 9am – 5pm
- Visiting us at: **mssociety.org.uk/donate**
- Posting your donation to: MS Society, National Centre, 372 Edgware Road, London NW2 6ND. Please make cheques payable to the 'MS Society.'

Contents

A word from Martin, whose eyes are affected by MS

Apart from extreme fatigue, it was only after I lost my sight in my right eye for a second time that I saw a neurologist. I was then diagnosed with MS, at just 26.

Of all the limitations of my many symptoms, the main feature of my relationship with MS has been its effects on my eyes, balance and coordination.

As a writer, this affects how I make a living, attend meetings and drive. I've lost some of my independence.

Yet given all the restrictions that come with living with MS for over 30 years, I tolerate it by following a simple mantra: live a life, not the illness.

My eyesight issues, like my other MS symptoms, aren't going to get better. But by 'living a life and not the illness', I feel I'm coping and managing far better than anyone who lives the illness and not a life.

However MS affects your eyes, I hope you'll find the information in this booklet useful

Martin

Five things to know

1. For lots of people their MS causes them an eye problem at some time or other

2. MS can affect how well you can see. It can also affect how your eyes move

3. Most people make a good recovery from their eye problem

4. If the problem doesn't get better, there are places and people to turn to for support and practical help

5. If you take the MS drug fingolimod (Gilenya), there's a very small chance of a side effect that affects your eyes

About this booklet

When you have multiple sclerosis (MS), it won't be the reason for every eye problem you get. But it's very common for MS to cause eye problems.

In fact, for many people the first sign they had MS was when they suddenly couldn't see properly.

In this booklet you'll read about how MS can affect your eyes, and what treatments are available.

If your problem can't be treated, you'll find tips on how to manage better with it.

Where you see a word in bold it means you can turn to the back of the booklet and find it explained.

There you'll also find where you can get more information and support, such as from the MS Helpline on **0808 800 8000.**

> **"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'm so affected and can't drive."**
> **Lorraine**

How MS can affect your eyes

If MS affects your sight as part of a relapse, you often get over it quite quickly.

But for about 1 in 3 people MS causes some sort of lasting problem with their eyes. You'll learn about these in this booklet.

About half of people with MS at some time or other get a particular problem called **optic neuritis.** This is when your optic nerve becomes inflamed.

MS can also have an effect on parts of your brain that control how your eyes move. This can cause symptoms of double vision or wobbly vision (see page 15).

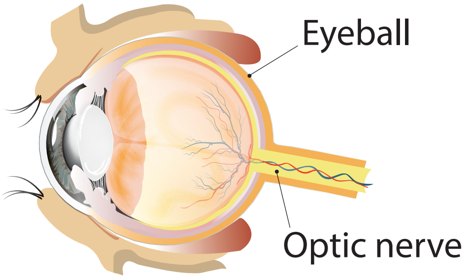
Around 1 in 3 people with MS at some point find their eyes don't move as they should.

These effects may so small that your vision isn't affected. But your neurologist may see that your eye movements aren't normal.

Your optic nerve

This nerve joins your eyes to your brain. When you look at something, the back of your eye (the retina) changes the light that lands on it into an electrical signal.

Your optic nerve sends these signals from your eye to your brain. Your brain then decodes this signal into what you 'see'.



The damage MS can do

Your body's immune system protects you from infections. It kills viruses and bacteria that get into your body.

But when you have MS, this system can attack your optic nerve and nerves in your brain or spinal cord by mistake.

A **relapse** is one sign this is happening. It's caused by inflammation in the nerve.

Inflammation can directly affect how your nerves work. It can also cause problems by damaging the nerve fibres and the covering of the nerves.

This covering is made of a fatty substance called **myelin.** If the myelin covering gets damaged, the nerve won't work how it should. This can affect your sight or how your eyes move.

Your body can usually repair much of the damage MS causes to your nerves, including your optic nerve.

That's why your sight often goes back to normal after a relapse. But there might be some lasting changes afterwards.

Eye tests

An eye test at least every two years is recommended for everyone, whether you have MS or not.

This will make sure you have the right glasses or contact lenses, and check the health of your eyes.

What if anything unusual is found during a routine eye test?

Then your doctor (GP) can be asked to refer you to an eye specialist in a hospital (**ophthalmologist**) or to your neurologist.

If you notice anything wrong with your eyes yourself, get them looked at straight away. Waiting could lead to lasting damage.

It'll be quickest if you go to an optician, to your GP or to a hospital Accident and Emergency department.

Optic neuritis

Optic neuritis is the name for inflammation of your optic nerve. What this nerve does is explained on page 8.

It's the most common way MS affects people's sight. Around half of people with MS might get this at some time in their life.

Symptoms

Optic neuritis usually affects just one eye. But it can sometimes affect both eyes at the same time (or one after another).

You might get any of these:

- blurred vision
- a blind or blurred spot in the middle of your vision
- changes to how you see colours. They become darker or 'washed out', especially reds
- flashes of light when you move your eyes (called 'phosphenes')
- pain for a few days around your eyes when you move them
- for a while you might not be able to see through your eye to some degree (or maybe completely)

With optic neuritis your vision tends to get worse over a few days to a couple of weeks.

It's very rare for optic neuritis to leave you with serious, lasting loss of sight in both eyes. But some people are left with reduced vision. Read more about this in the 'Getting better' section.

Lots of people with MS have optic neuritis once, then never get it again. But about half do get it again within five years.

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

Tests

Optic neuritis is usually diagnosed by:

- an **ophthalmologist.** This a doctor who specialises in problems that affect your eyes

or

- a neurologist. This a doctor who specialises in problems that affect your nerves (such as MS)

Your doctor will talk to you about what's happened to your eyes and will examine you.

This may be enough to diagnose optic neuritis. If not, you may need further tests, such as a blood test, brain scan and a **visual evoked potential test**.

MRI scan

You may have an MRI scan. It looks for inflammation in your optic nerve.

This is painless but the MRI scanner can be noisy, and you might feel a bit claustrophobic. Ear plugs help and you can be given something to relax you.

A visual evoked potential test

This is a painless test where you watch patterns on a screen and it measures how fast messages go from your eye to your brain.

Treatment

When MS causes optic neuritis, it usually gets better on its own within a few weeks, so doesn't need treatment.

But that doesn't mean you should leave an eye problem days or weeks before having it checked.

Always get a problem looked at straight away. If you leave it, you might be left with permanent damage to your sight.

You can be given steroids if your optic neuritis symptoms are especially bad; for example, you can't work properly or drive. You can have them in tablets or as an infusion (known as a 'drip'), or both.

Usually you'll get steroids through an intravenous (IV) drip for three days, going to the hospital each day. The steroid goes down a needle into a vein in your hand or arm. This takes about an hour. Then you'll go home and take steroid tablets for the next 11 days.

Steroids dampen down inflammation in your optic nerve.

Whether you take them or not makes no difference to your how good your final recovery will be. But they do speed up how fast your symptoms will ease off.

Taking steroids can cause short-lived side effects such as :

- upset stomach
- poor sleep
- going red in the face
- a metallic taste in the mouth
- some people can get quite severe mood swings

Take steroids too often and they can cause things like:

- diabetes
- weight gain
- acne
- stomach ulcers
- or make your bones weaker and more likely to break

For this reason doctors prefer not to give people steroids more than three times a year.

That's why steroids are often only used if optic neuritis symptoms are very bad – or they stop you functioning, for example, at work.

Read more about steroids in our booklet 'Managing a relapse'.

Getting better

Most people's sight recovers well from optic neuritis. Given time it often goes back to normal.

About 8 in 10 people start to get better in the first three weeks. Around 9 in 10 people have started to get better within five weeks.

It could take longer to make a fuller recovery. Up to a year afterwards your sight may still be getting better.

Around 6 in 10 people still find they have some mild disturbances in their vision up to a year after they first got optic neuritis.

Five years later most patients' sight is good or excellent. That's true even if they have another bout of optic neuritis during that time.

Around half of people with MS who get optic neuritis will get it again within five years.

For between 1 in 10 and 1 in 20 people their sight never gets back to exactly how it was. So you might notice small, lasting changes.

You may find it harder to pick out colours, or tell the difference between colours.

Things might not be as sharp as before. Or you might be less good at judging what you see at a distance.

After optic neuritis your vision can change a little from one day to the next. Fatigue can make it worse.

Your eyesight might get worse when you get hot, too. This could be after exercise, a hot bath or shower, or when your temperature goes up during an infection.

This happens because nerves find it harder to pass on signals whenyour body's hot. Your sight should get better when you cool down.

What if my sight doesn't get better?

For some people the damage to their optic nerve leaves them with sight problems that don't go away. Pages 23 to 27 have more on living with lasting sight problems.

Tips:

- **mssociety.org.uk/forum** is a message board where people who've had optic neuritis can answer your questions
- think you might be in the early stages of optic neuritis? Urgently see an optician or your GP. If it's out of hours, call the 24 hour NHS helpline on 111 for emergency advice. Or go to an Accident and Emergency department
- for less urgent questions about optic neuritis, the MS Helpline has information or just someone to talk to. Call **0808 800 8000**.

If you notice anything wrong with your eyes yourself, get them looked at straight away. Waiting could lead to lasting damage.

It'll be quickest if you go to an optician, to your GP or to a hospital Accident and Emergency department.

Problems with how your eyes move

MS can affect nerves in the parts of your brain that control how your eyes move. They might not move smoothly. They might not both look in exactly the same direction.

The two most common eye movement problems caused by MS are:

- double vision, known as ‘diplopia’ (pronounced ‘dipp-PLOH-pia’)
- to-and-fro movements that you can’t control, known as ‘nystagmus’ (pronounced niss-STAG-mus)

Double vision (diplopia)

Nerves that control the muscles around your eyes can become inflamed because of MS.

This can mean your eyes don’t work perfectly together, so you see double. You see two of something when there’s only one. Things may be side by side, or one on top of another. Sometimes one of them may seem tilted to one side.

This double vision might only happen when you look in certain directions. This could be when you look down, all the way to one side, or straight ahead.

You might get nausea (feel sick), vertigo (a feeling that things around you are spinning), or lose your balance.

There's more on how visual problems can affect balance in our booklet 'Balance and MS'.

> **"Heat, hunger, thirst, fatigue ... all make my double vision even worse!"**
> **Sonika**

Treatment

If you get double vision as part of a relapse, it often gets better on its own. A course of steroids, either as a drip or a tablet (or both), can speed this up.

If you wear glasses, you can get a special kind of lens called a 'prism' fitted on to them for a while.

A prism is plastic and makes sure that what both eyes are seeing is lined up properly. This stops the double vision.

If you don't normally wear glasses, you have this prism fitted to a pair of glasses that's got clear (non-prescription) lenses in them. This stops you seeing double while your eyes get back to normal.

Tip:

- if double vision is affecting you a lot, you might be given an eye patch over one eye. This will block out the second image
- be aware that an eye

patch will make it harder for you to see in 3D and judge distances

Nystagmus

Nystagmus is a to-and-fro movement of your eyes that you can't control and that won't stop. They can move from side to side, around, or up and down.

A doctor might notice nystagmus when testing your eyes. Many people don't realise they have it because the movement may have little or no effect on their vision.

But some people do notice things moving back and forth, jerking or wiggling. This is called oscillopsia (pronounced 'ossi-LOPP-sia'). That can trigger vertigo, the feeling that everything is spinning around you. This can affect your balance and make you feel sick.

Nystagmus can vary. It may happen when you look straight ahead or when looking in a particular direction.

Treatment

Four drugs may help reduce these jerky movements and make your vision better.

They are gabapentin, baclofen, clonazepam and memantine. They don't work for everyone but research is looking for other treatments.

Other things that might help are:

- advice on changing your day to day activities so that you avoid the worst of the ‘jumpy’ vision. This can be things like where you put your television or the position you read in
- prism lenses can keep your eyes in an area of steady vision
- surgery on your eye muscles or Botox injections can dampen down the random eye movements
- if you have nystagmus only in one eye, a special contact lens can cloud out the jumpy images

Tip:

- the Nystagmus Network (see page 33) has information about research into treatment, as well as support with living with nystagmus

If your sight problem doesn't get better

For some people their sight problem won't clear up. If that happens, you'll get help to make the most of the sight you have, and to cope with these changes.

If your sight can't be put right with glasses or contact lenses, you can be referred to a low vision service or clinic.

Low vision services

These are normally in a hospital's eye department. They help you make the most of your eyesight. You'll have an assessment and they can lend you equipment, all free of charge.

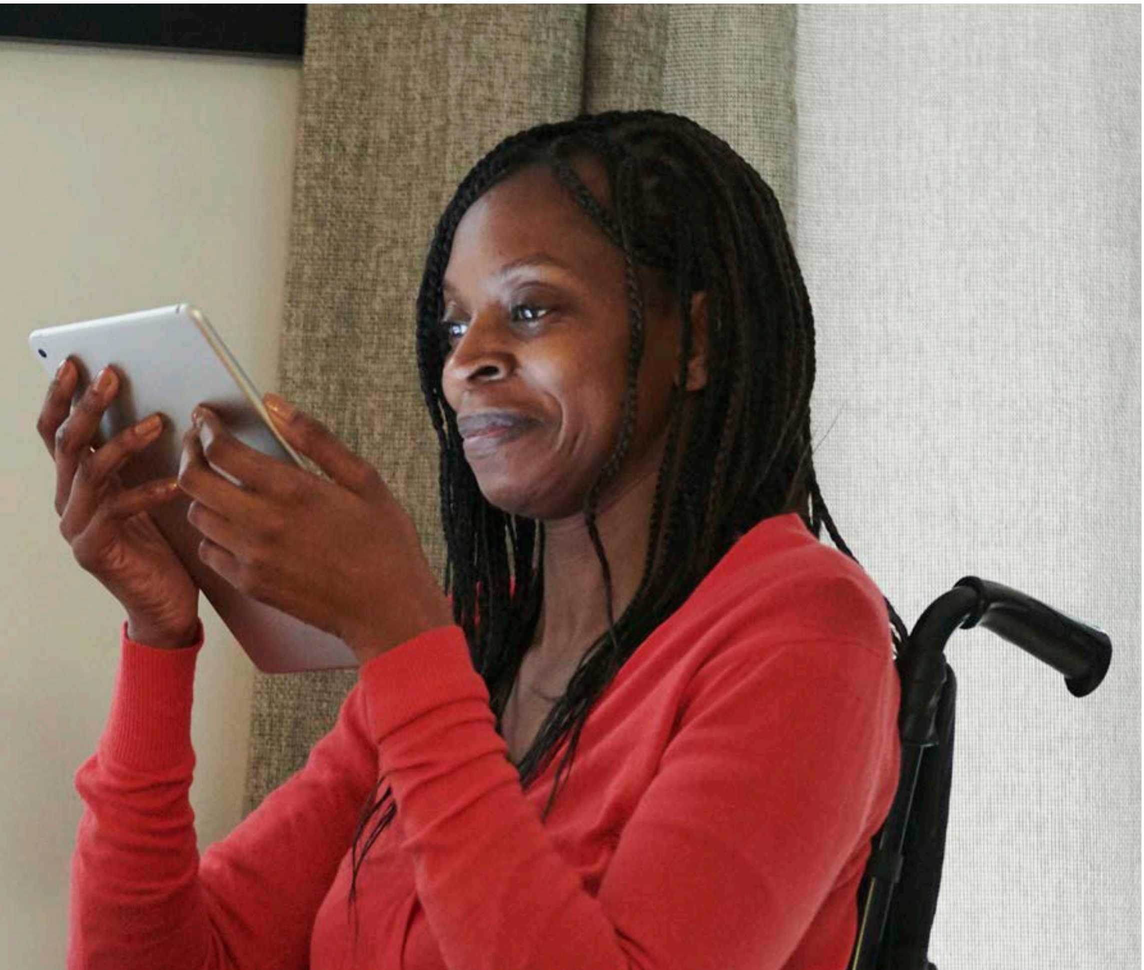
Rehabilitation workers work with you to solve practical problems, such as getting about safely.

They teach skills to help with everyday life (such as cooking) or suggest useful equipment. They might give advice on using different techniques, such as specific eye movements.

Tips:

- find your local low vision service by asking your doctor (GP) or contacting a local hospital eye department
- your council's social services department also know where it is

- if your council has a visual impairment team, ask them. In Northern Ireland ask your Health and Social Care Trust
- the RNIB (Royal National Institute of Blind People) can tell you about local low vision services, and their own shops and groups near you. Visit **help.rnib.org.uk/help/products-services/online-shop/nearest-shop**



Practical tips

A problem with your eyesight can affect so much of life, from work and driving, to reading, watching TV and enjoying your free time.

Changing the lighting can make things easier. There are gadgets to help around the home and at work, too.

You can get many of the gadgets and devices we're about to mention through the social care services of your local council. If you're in Northern Ireland this will be your Health and Social Care Trust instead.

First you'll need to be assessed by their visual impairment team or sensory impairment team. Our booklet 'Social care – getting support from your council' has more details about these assessments. The booklet comes in different versions for each country of the UK.

Tips:

- use specially designed kitchen equipment (like measuring spoons and jugs). They have easier to read markings or displays or ones you can touch
- use talking equipment like weighing scales, measuring jugs, timers, even talking microwave ovens

- make your home brighter by using overhead LED lights instead of lamps
- have an anglepoise lamp shining its light over your shoulder on to where you need to see
- carry a magnifying glass. A low vision service or clinic can recommend one for you
- use the magnifier app on your smartphone. Learn how at **learningenglish.voanews.com/a/magnifying-glass-phones/4024864.html**
- change the font size on things like tablets, mobile phones and computer screens
- install free software on your computer that makes what's on the screen bigger. Examples are Lightning Express, Windows Magnifier or Desktop Zoom
- try screen readers (like ClaroRead) that turn words on screen, emails, and so on, into speech
- use voice recognition software (like Dragon) that turns what you say into text on your screen
- change to a big button telephone

What makes things worse

Some things can make your sight worse for a while. MS fatigue is one. Getting hot is another. You may need to plan around this.

At times when it's more important than usual to see well, avoid what triggers your symptoms.

For example, if your fatigue affects your sight, you might avoid driving when fatigue's likely to be worse. Or you might give yourself extra time for breaks during the journey.

More tips:

- when driving at night, it can help if you wear antiglare glasses
- for tips on making banking easier, including cash machines and cards, check out: **choose.co.uk/guide/accessible-banking-for-blind-partially-sighted.html**
- there's a BBC guide to making the internet easier at **bbc.co.uk/accessibility/guides/vision_index.shtml**
- contact the RNIB or the Disabled Living Foundation (DLF) for more ideas (details are at the back of this booklet)
- check out the useful products on the DLF's website **livingmadeeasy.org.uk**

Driving

As soon as you're diagnosed with MS, you must tell the Driver and Vehicle Licensing Agency (DVLA). In Northern Ireland tell the Driver and Vehicle Agency (DVA). They'll judge if you're fit to drive.
You don't have to tell them about a problem in just one eye. But you must tell them about any problem that affects **both** eyes, including double vision.

If you've lost your sight in one eye, you must tell them if you get a problem with the other one. You must tell your insurance company about your condition.
Find out more about how good your eyesight must be at **gov.uk/driving-eyesight-rules**

Coping emotionally

Eye problems, such as suddenly losing some of your sight, can be a shock. It can mean a very worrying time, waiting to see if and when your sight will go back to normal.

What if your problem turns out to be long term? It can have a major impact on how you're feeling, and how you go about your daily life.

It can be frightening, and feel sometimes almost too much to deal with.

Find information on the emotional impact of MS in our booklets 'Living with the effects of MS' and 'MS and your emotions'.

People often find it helpful to talk about how they feel about the effect MS is having on their eyes.

Tips:

- call the MS Helpline on **0808 800 8000**
- it's staffed by people trained to give emotional support. Many have MS. They have lots of information about eye problems and what help is out there
- the RNIB has a telephone service with information, support, iand counselling. This service isn't only for people who are blind. Details on page 34

Advice if you take fingolimod (Gilenya)

If you have relapses with your MS, you can take a disease modifying therapy (DMT). This can mean fewer relapses, and ones you do get could be less serious. That could mean MS affects your eyes less.

One DMT called fingolimod (its brand name is Gilenya) can cause a serious but rare side effect that involves the eyes. It's called macular oedema (pronounced 'MACK-you-ler oh-DEE-mer).

Between 1 in 100 and 1 in 200 people who take fingolimod (Gilenya) get this side effect.

It's most likely to happen during the first three to four months after starting the drug. You're more likely to get it if you also have diabetes.

In macular oedema fluid builds up at the back of your eye. This can give you blurred or distorted vision. These are a lot like common MS-related eye symptoms. So you might mistake macular oedema for your usual symptoms.

You can also have macular oedema but not notice anything wrong. So you'll have your eyes checked a few months after you start this drug.

You'll be checked more often if you're diabetic. You'll also be checked more often if you've ever had an inflammation of the eye called uveitis.

If you get macular oedema, you'll be told to stop taking the drug. Your eyes should go back to normal. Your doctor will talk to you about starting a different DMT.

Tip:

- if you're on fingolimod (Gilenya) and notice changes in your sight, tell your neurologist or MS nurse straight away

Useful organisations

AbilityNet

AbilityNet is a charity that helps people with a disability use computers and the internet to achieve their goals at home, at work and in education.

0800 269 545

abilitynet.org.uk

Disabled Living Foundation (DLF)

Information and advice on equipment that helps you live more independently.

Helpline 0300 999 0004 (Monday to Friday, 10am-4pm)

dlf.org.uk

They have a website called Living Made Easy. It has products that help with vision and reading. Find them in the 'communication' section of their website.

You'll find a factsheet there called 'Communication and vision'.

livingmadeeasy.org.uk

Disability Scotland

Helps to guide people through the the maze of disability information in Scotland.

0300 323 9961

disabilityscot.org.uk

Nystagmus Network

A charity offering information and support for people with nystagmus. It also funds research into treatments.

Contact them through their website.

nystagmusnet.org

BIPOSA

Association of Ophthalmologists and Orthoptists with a special interest in eye movement disorders.

Their website has a directory of specialists around the UK.

biposa.org

RNIB

RNIB (Royal National Institute of Blind People) offers information and practical and emotional support for everyone affected by sight loss.

Helpline **0303 123 9999**

(Mon to Fri, 8.45am-5.30pm, Saturday, 9.30am to 1pm)

Email: **helpline@rnib.org.uk**

rnib.org.uk

RNIB Scotland

Helpline: see above

Email: **rnibscotland@rnib.org.uk**

rnib.org.uk/scotland

New words explained

depth perception – when both eyes work together so you can judge distances between things accurately and see in '3-D'. This can be measured in tests

diplopia – double vision

field test – see **'visual field test'**

inflammation – when your immune system reacts to an attack or damage to a part of your body, it sends more blood and immune cells to the damaged area. This makes it swollen.

When MS inflames the optic nerve or muscles that control how your eyes move, it starts to cause damage. This leads to symptoms that affect your eyes

lesion (or **'plaque'**) – area of damage caused by MS in your central nervous system (brain, spinal cord or optic nerve). This slows down or stops messages travelling down nerves, affecting your control of parts of your body. Lesions are seen on **MRI scans**

low vision – problems with sight that can't be corrected with glasses or contact lenses

macular oedema – the macula is an area at the back of your eye. It helps you see things clearly in the centre of your vision. Oedema means a build-up of fluid.

Macular oedema causes things to be blurred in the centre of your vision and you see colours differently. It happens to about 1% of people who take the MS drug fingolimod (Gilenya)

MRI scan – a picture of inside your brain made by 'magnetic resonance imaging'. It can show where MS is causing inflammation and damage to the myelin around the nerves

myelin – a fatty covering around your optic nerve (and other nerves) that protects it. In MS it becomes damaged by your immune system. This interrupts messages that travel along your nerves, causing the symptoms of MS, including vision problems

nystagmus – a to-and-fro movement of your eyes that you can't control

optic nerve – a bundle of nerve fibres going from the back of each eye to your brain. It sends signals to your brain which turns them into the image you see. In MS this nerve can become inflamed

optic neuritis – when your **optic nerve** gets **inflamed**

ophthalmologist – a doctor, usually in a hospital, who specialises in diseases, conditions or injuries that affect your eyes

orthoptist – a hospital-based specialist in how eyes work together as a pair. They treat eye movement problems such as **double vision,**

nystagmus or difficulty with **depth perception**

optometrist/ophthalmic optician – ‘optometrist’ is what opticians are now called. It’s someone who’s not a doctor but who is trained to examine eyes and find sight problems, injuries, diseases or anything wrong with your health that shows in the eye. If they notice a problem, they can ask your GP to refer you to an eye specialist or neurologist

relapse – a flare-up of new MS symptoms, or when old ones get worse. This can involve your eyes. Symptoms then ease off, go away completely or may become permanent

visual acuity – a measure of how good your central vision is. This can be measured by how well you can read the smallest letters on an eye test chart

visual evoked potential test – a painless test where you watch patterns on a screen. Electrodes placed on your head measure how fast your brain is reacting

visual fatigue – how your vision can get blurred when you’re tired. This can happen after optic neuritis

visual field test (or ‘field test’) – a test that measures how wide an area your eye can see. It can show if your optic nerve is damaged or if you have missing areas of vision. It’s normally tested by asking you to push a button each time you see a light flash

Further information

Resources

Our award winning information resources cover every aspect of living with MS.

To order them email **shop@mssociety.org.uk** or visit **mssociety.org.uk/publications**

MS Helpline

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
(closed on weekends and bank holidays)

helpline@mssociety.org.uk

About this resource

With thanks to all the people affected by MS and professionals who contributed to this booklet, in particular Simon Hickman and Valerie Trimble.

If you have any comments on this information, please send them to: **resources@mssociety.org.uk**

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. Seek advice from the sources listed.

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Eye illustration: Damion Mulrain

This booklet is also available in standard print.

Call **0300 500 8084** or email **shop@mssociety.org.uk**

Contact us

MS Society

MS Helpline

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MS National Centre

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twitter.com/mssocietyuk

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This title will be reviewed within three years of publication.