

### What is MS?

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.'

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### A word from Eiona, who has MS

After my own diagnosis, I sought out all the information I needed from trusted and reliable sources. After all, knowledge is power.

The information in MS Society booklets and publications has been invaluable throughout my life with MS, as have their website discussion forums. DVDs and books that I borrowed from the MS Society Library were a great help, with their personal accounts of life with MS. People on the MS Helpline were equally helpful in answering my questions and directing me to the relevant information.

I discovered early on that my MS could be a source of concern, bewilderment and fear of the unknown for close family and other relatives and friends. I attended local awareness events. I came away from them with enough information to set everyone's mind at rest, and to help us all adapt to living with MS.

These days I also follow the MS Society on Facebook and Twitter, for the latest on potential new treatments and research into MS.

A life with MS may take a lot of time in adjusting to, but ultimately it's possible to live a full life and a very happy life. We face the future with what we have got, not with what we haven't got.



### Five things to know

No-one has to face MS alone. There's lots of support out there

Everyone's MS is different

5

Research is making progress all the time

4 Treatment can make a real difference to many people's MS, especially if treatment starts early

5 If you have MS it may mean making some changes but you can still achieve what you always wanted to



### **About this booklet**

Perhaps you've recently been told you have multiple sclerosis (MS). Or maybe someone you know has it and you'd like to know more. We hope this booklet goes some way to answering your questions.

Knowing more about MS can help you feel more in control of what's happening. Hopefully it'll make you less uncertain or worried.

Living with MS can bring real challenges but a lot has changed since the first effective treatments became available in the nineties. What we know about MS is growing all the time. Research into even better treatments is making progress, new ones keep being launched, and recently we've seen some major breakthroughs. Life with MS these days is less about what you can't do, but more about what you can do. At the MS Society we're here to help you or the person you know with MS find ways to live out your plans and hopes.

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

"I was just sent away with my diagnosis. No-one gave me any information or help then, which made things worse and made me worry more. Thankfully I contacted the MS Society for information and the MS Helpline for some much-needed help." Carole

### What is MS?

Multiple sclerosis, or MS, is a neurological condition. That means it affects your **nerves**. The specialist doctors who look after people with MS are called neurologists.

You can't catch MS from someone. You get it when your **immune system** isn't working properly. Your immune system normally protects you by fighting off infections. In MS it attacks your nerves by mistake.

> "MS is a significant part of me, but it's far from the most interesting part." Helen

These nerves control lots of different parts of your body and how they work. That's why, if you have MS, you can get its symptoms in many parts of your body and it can affect lots of things your body does. This is why everyone's MS is different.

> "Yes, MS is serious and, yes, it does change your life. But you can still enjoy your life." Louisa

### What's happening in MS?

# Your brain and spinal cord make up your **central nervous system**.

Your spinal cord connects nearly all parts of your body to your brain. Messages go between your brain and spinal cord, travelling along the nerves. These signals control how parts of your body move or work and let you feel things like pain, touch and so on.

Your immune system protects you from infections. It does this by attacking and killing viruses and bacteria that get into your body. But in MS your immune system attacks nerves in your brain and spinal cord by mistake. This damages the covering around your nerves.

This covering is made of a fatty coating called **myelin**. This protects each nerve from harm and helps messages



Messages travel along nerves between your brain and spinal cord, controlling how parts of your body work. travel along it. When myelin becomes damaged, messages find it harder to get through – or can't get through at all. That's when symptoms of MS begin. Eventually so much damage takes place that it can't be repaired and the nerve dies.

Think of this being like an electric cable. The wire inside it is like your nerve. Electricity travels down the wire so the machine at the other end will work. This is like when your brain sends a signal down your nerve to tell a part of your body what to do.

A cable has a plastic covering around the wire to protect it from damage. If the cable's covering gets broken it can mean electricity won't get through like it should and the machine won't work properly. Myelin protects your nerves in the same way.



Myelin as it should be. Messages travel smoothly



Myelin damaged. Messages are disrupted

# Why do some people get MS?

In the UK around 1 in 500 of us has MS. That's over 130,000 people. Each week over 100 people are told they have it. Nearly three times as many women have MS than men. We don't know why yet.

## **ŧŧŧŧŧŧ**

In the UK people are most likely to find out they have MS in their thirties, forties and fifties. But the first signs of MS often start years earlier. It's rare that children get MS.

Nobody knows for sure why MS happens to some people. What we know is growing all the time. Slowly we're putting together more pieces of the puzzle.

Certain things seem to play a part in triggering MS. It's probably not just one thing but a combination of:

- your genes
- the environment
- your lifestyle

#### Genes

MS isn't directly passed on from a parent to their child. There's no one gene that causes MS. In fact, over 200 genes might affect your chances of getting it. Genes alone don't decide who gets MS.

Identical twins have the same genes. But when one gets MS, the other usually doesn't get it. That twin does have a higher risk of getting MS but most don't get it. This shows genes play a part but that's far from the whole story.

If you have a close relative with MS, the chances you'll get it are a bit higher, but the risk is still low. Researchers have come up with figures for the risk of getting MS.

#### **Risk of MS in your lifetime** If you have:

a parent with MS	1.5% chance (1 in 67 get it)	
a brother or sister with MS	2.7% chance (1 in 37 get it)	
a child with MS	2.1% chance (1 in 48 get it)	
an identical twin with MS	18% chance (1 in five get it)	
The risk is around 1% if an aunt, uncle, cousin, nephew or niece has MS.		

If you have MS and you want a child, there's only a 1 in 67 chance he or she will get it too.

In 2014 a very big study found that MS may be even less likely to be passed on than these figures suggest.

You can find more information on genes in our factsheet 'Genes and MS'.

#### Environment

There are things in the world around you that might affect your risk of getting MS, such as:

- some infections
- sunshine and vitamin D

#### Infections

There's growing evidence that some viruses, and maybe bacteria, can help trigger MS, especially the Epstein Barr virus. This is the virus that causes glandular fever. This doesn't mean you'll get MS if you've had glandular fever. Most of us have had this virus but very few of us get MS.

The link isn't totally understood but infections could act together with other things to trigger MS.



#### Vitamin D

Years ago it was noticed that more people have MS the further away you go from tropical countries near the equator with a lot of sun. This is true no matter what your ethnic background is. Researchers started to look at a lack of vitamin D, the 'sunshine vitamin', as a possible cause of MS.

More and more studies are pointing to a link between MS and vitamin D. The risk seems highest if you're low in this vitamin before you become an adult.

Lots of us in less sunny countries like the UK become low in vitamin D, especially when it's not summer.

We get some vitamin D from food (oily fish, eggs, spreads and breakfast cereals with added vitamin D, for example). But most of it comes from sunshine. Our skin makes this vitamin when we're in the sun.

Within the UK, there are higher rates of MS in Scotland and Northern Ireland. This could be because this far north people are even more likely to be low in vitamin D.

Other reasons you might not have enough of this vitamin are:

- you have genes that make it harder for your body to make it
- you're a pregnant woman
- you have dark skin (then it's harder for your skin to make vitamin D)

Guidelines say people in Britain should think about taking extra vitamin D, especially from September to April. But that advice is to keep your bones healthy. There's no proof yet that extra vitamin D protects against getting MS. Researchers are looking into that.

If you already have MS, studies have found a link between levels of vitamin D and how bad people's MS is. Many people with MS take extra vitamin D. There's no hard evidence yet that doing this slows down MS or helps with symptoms but studies are looking into this, too.

If you want to know if you're low in vitamin D, your GP (family doctor) or MS specialist can check your levels with a blood test. If your levels are low, get medical advice about boosting them. But taking too much can be harmful.

You can read more about MS and what you eat, including vitamin D, in our booklet 'Diet and nutrition'. Check out our web pages on vitamin D, too.

#### Lifestyle

Two lifestyle factors have been linked to MS:

- smoking
- being very overweight (obese)

#### Smoking

Studies show you're more likely to get MS if you smoke. Chemicals in cigarette smoke might affect your immune system, helping to trigger MS. Passive smoking – breathing other people's smoke - is also linked to a higher risk of getting MS.

Studies show that stopping smoking could slow down how fast you go from having relapsing MS to secondary progressive MS. You can read more about these different types of MS on page 24.

If you want to stop smoking your GP can suggest things to help. This website has ideas and support, from nicotine gum and patches to e-cigarettes.

#### www.nhs.uk/smokefree

#### Obesity

Studies have found that being very overweight (obese), especially when a child or young adult, is linked to MS. This could be because being very overweight can:

- make you low in vitamin D
- make your immune system overactive and cause inflammation inside your body
- there may be other reasons we don't yet understand

Of course, not everyone who's obese gets MS and not everyone who has MS is or was very overweight. But if the risk of getting MS is on your mind, for example, because a close relative has it, your weight is a risk factor you can change.

#### MS is no-one's fault

Hearing about things that may cause MS might make you ask: 'Could I have done something to avoid it?' The answer's no, because no-one knows for sure which things came together to cause MS in each person. And in the past we all knew much less about what might cause MS. So you weren't in a position to do anything to stop it.



### What are the symptoms?

MS damages nerves in different parts of your brain and spinal cord. Where this damage is will affect which part of your body gets symptoms.

Symptoms can be unpredictable. They can change from day to day, even hour to hour. They could last days, weeks or months. Depending on the type of MS, these symptoms could stay, ease off or go away completely.

Some people find getting hot, tired or stressed, or exerting themselves can make symptoms worse or trigger a **relapse** (a flare up of your MS symptoms). Everyone has their own symptoms and they won't be the same as other people's. And how MS develops over time is unique to each person.

#### Types of MS symptoms

No-one is likely to get all the symptoms of MS. But here are the more common ones.

- 'Fatigue'. This feeling of being exhausted isn't like normal tiredness. It can make doing things (even thinking) very hard or impossible
- Strange feelings. You may get numbness or tingling in your arms, legs, hands or feet
- Eye problems. Your sight might become blurred or you may see double. For a while you might not see through one or both eyes
- Feeling dizzy and having problems with your balance
- Pain
- Problems walking
- Problems with talking or swallowing

- Muscle stiffness and spasms (sudden movements you can't control)
- Your bladder or bowels not working properly
- Shaking in your arms or legs (called 'tremor')
- Forgetting things and difficulties with your thinking
- Sexual problems
- Emotional issues. Feeling depressed or crying a lot can be a normal reaction to being told you have MS but it can also be one way MS affects your brain

We have information on all the symptoms of MS. Find them at:

#### mssociety.org.uk/ms-resources/ key-publications

#### Symptoms you can't see

If people see someone has a symptom of MS they can understand and offer help. But some symptoms you can't see.

Things that aren't obvious include pain, bladder or bowel problems, fatigue and difficulties with your balance, memory or thinking. It might not be easy to explain these to people.

When you have MS it can be frustrating if someone says 'you look so well'. It can feel like your very real but invisible symptoms are being overlooked. This can be even more of an issue at work.

"I manage my time carefully due to fatigue but I sometimes have a day where I sail through without much difficulty at all. Those days are precious and I really appreciate them. People without MS would just take that for granted!" Ellie

If you don't have MS, bear these invisible symptoms in mind. Someone might not want to do something because their MS is making them feel exhausted, for example. It's not because they're being lazy or can't be bothered.

### What can be done about symptoms?

If your MS has **relapses** treating it early with a **disease modifying therapy (DMT)** can make a real difference. It can mean you get fewer relapses and you see a slow down in how fast your symptoms or disability get worse. This can mean fewer symptoms to deal with. But when symptoms do happen there are ways of managing them. Turn to page 30 to learn more.



### How is MS diagnosed?

Diagnosing MS isn't easy. Symptoms can be confused with more common problems. Doctors must rule these out first before they look for signs of MS. It can take a long time from when you first notice something's wrong to when you're officially told you have MS.

There's no simple test, like a blood test, for MS. Only a neurologist can diagnose it, not your GP. If your GP thinks MS could be causing your symptoms they'll send you to a neurologist for tests.

You can learn more in our factsheet 'Have I got MS? And why is it taking so long to find out?'

#### Seeing the neurologist

When you see a neurologist it can take a few tests and several months before you have a final diagnosis. This can be a frustrating time. Four types of tests are used to diagnose MS:

- a neurological examination
- MRI scans
- 'evoked potentials' tests
- a lumbar puncture

### What are the tests looking for?

A neurologist looks for signs of how much damage has happened to your **central nervous system**. They need to know that damage happened at different times and in at least two different parts of your brain or spinal cord. In most cases MRI scans are used to help show this.

#### **Neurological examination**

A neurologist will ask about your 'history', meaning your health problems and symptoms, now and in the past. A physical examination will check your movements, reflexes and senses, such as your eyesight. Even if a neurologist suspects MS other tests are needed to be sure.

### MRI (magnetic resonance imaging)

A machine called an **MRI** scanner takes pictures of your brain or spinal cord. You lie on a bed that slides into the scanner where you stay for a few minutes to up to an hour.

Using strong magnetic fields and radio waves it builds up a picture of the inside of your brain or spinal cord. On the scan an MS specialist can see any **inflammation** and damage MS has caused. These areas of damage are called **lesions** or **plaques**. Having a scan is painless but can be a bit noisy and feel a little claustrophobic.

MRI scans are the most accurate way of diagnosing MS. Over 90% of people have their MS confirmed this this way.

#### Lumbar puncture

During a lumbar puncture (or 'spinal tap') a needle is put into your lower back, into the space around your spinal cord. A little bit of fluid is taken out and checked for signs that your immune system has been active in your brain and spinal cord (which doesn't happen if you don't have MS). These signs, which can include '**antibodies'**, show that you're very likely to have MS.

You're given something to numb where the needle goes in. It can still be uncomfortable and might give you a headache. Now we have MRI scans, lumbar punctures aren't used so often.

#### 'Evoked potentials' test

This test measures how fast messages travel between your brain and your eyes, ears and skin. If MS has damaged the myelin around your nerves in these parts of your body your reactions will be slower.

To measure your eyes, you're shown patterns on a screen. Electrodes measure how your brain reacts to what you see. To test your hearing you'll listen to clicks through headphones. In another test you're given tiny shocks on your skin (it feels like 'pins and needles'), and the reactions of your muscles are measured.

### When you're told you have MS

Finding out you have MS can bring up strong feelings. It's natural to feel afraid, confused, upset or overwhelmed. But you may feel relieved. You might have feared you had something fatal like a brain tumour. Finally you know what's wrong and that you're not imagining it. And you can take steps to look after yourself and think about treatment.

Whatever the reaction, we're here to support you. There's our MS Helpline, our online and printed information and our local groups and the forum on our website.

- MS Helpline 0808 800 8000 (Closed weekends and bank holidays)
- Find your nearest group, MS centre or specialist at mssociety.org.uk/near-me

 Chat to people with MS on our forum at mssociety.org.uk/ forum

People who've recently found out they have MS may find two of our booklets useful: 'Just diagnosed' and 'Living with the Effects of MS'.

"I felt relieved when I was told. A big weight off my shoulders. Nothing had changed within those split seconds. So I went off on holiday and decided to throw myself wholeheartedly into learning about it when I got home." Eleanor



### The different types of MS

#### Everyone's MS is different. That said, we can put MS into two broad types.

Most people have MS that has **relapses**, with **inflammation** in the brain or spinal cord. This is called 'relapsing MS'. There are drugs that can help with this.

A smaller number of people have MS that gets steadily worse over time without relapses or inflammation. This is 'progressive MS' and it's been much harder to find treatments that help with this type.

You can further divide MS into these main types:

- relapsing remitting MS
- primary progressive MS
- secondary progressive MS

Sometimes the lines between the different types aren't clear, even to MS specialists.

A big difference between them is whether you get 'relapses'.

#### **Relapses**

Most people diagnosed with MS get relapses to begin with. A relapse is when, after a period when your MS was stable, your immune system attacks your nerves. This causes **inflammation** to the **myelin** coating around them. This damage stops signals travelling along the nerves like they should and causes symptoms of MS.

For days, weeks or months the symptoms you had already may get worse or new ones appear. Your body does its best to repair the damaged myelin. Then symptoms can get better or go completely. This recovery is called 'remission'. You might be left with some symptoms, disability or damage to the nerves. As time goes on it gets harder for your body to repair the damage after each relapse. Doctors used to believe that during remission MS wasn't causing any harm. We now know that even when you're not having a relapse, MS can be damaging your nerves.

#### Why are relapses important?

If your MS has relapses it means inflammation is happening in your brain and spinal cord. MS treatments we have at the moment can make a difference to this inflammation and the relapses that go with it. These treatments include **disease modifying therapies (DMTs)**. Taking one can mean fewer and less serious relapses, and it could slow down how fast your disability or symptoms get worse.

MS without relapses is much harder to treat. Until very recently there was no drug for this type of MS (progressive MS). This is changing, with the first one hoped to be licensed in 2018, that can help with some parts of progressive MS.

You'll find more on treating MS on page 29.

#### **Relapsing remitting MS**

With this type of MS you have a pattern of relapses (symptoms getting worse) followed by recovery ('remission'). Your disability or symptoms don't get worse between relapses but after each relapse it can end up worse than before. As time goes on your body finds it harder to repair the damage each relapse brings. So your disability or symptoms are likely to get worse, especially if you don't start treatment.



About 85% of people diagnosed with MS have this type of MS to begin with. It's mostly diagnosed when people are in their twenties to fifties. Women get it more than men for reasons we don't yet understand. There are now over a dozen **disease modifying**  therapies (DMTs) that can help with relapsing MS.

Read more in our booklet 'Understanding relapsing remitting MS'.

#### **Primary progressive MS**

From the start, with primary progressive MS you usually don't have relapses. That's because there's much less **inflammation** with this type of MS. Instead it attacks the nerves directly, causing a build-up of disability or symptoms that's usually quite slow.



About 10-15% of people with MS have this type. Men are just as likely as women to get it. People tend to be diagnosed in their 40s or older. Because the DMTs we have right now reduce inflammation, they don't work against progressive MS.

For some people (about 1 in 20) their MS gets steadily worse but they have relapses on top of that. This is 'progressive relapsing MS'. Treatments can help with the inflammation that comes with the relapsing part of this type but not with the progressive part.

For more on primary progressive MS read our booklet 'Understanding progressive MS'.

#### Secondary progressive MS

You only get this MS if you've already had relapsing remitting MS. Your body can't repair the myelin anymore, so the pattern of relapses followed by recovery comes to an end. Inflammation and relapses usually stop or happen less often.

Instead your MS is now directly damaging the nerves itself. Up until now your disability or symptoms were stable between relapses. Now it gradually gets worse. In the past, it usually took around 20 years for relapsing MS to change into secondary progressive MS. Thanks to DMTs this is changing:

- fewer people are likely to go on to secondary progressive MS
- for those that do this will take longer to happen

It's not always easy for doctors to know when your MS has become secondary progressive. If your disability or symptoms get steadily worse over at least six months, then it's likely your relapsing MS has become secondary progressive.



No-one's MS starts out as secondary progressive MS. You might be diagnosed with it without first going through a diagnosis of relapsing MS. This happens if earlier you had symptoms of relapsing MS but they were overlooked or misdiagnosed.

Read more on secondary progressive MS in our booklet 'Understanding progressive MS'.

#### **Benign MS?**

Some people are told they have 'benign MS'. 'Benign' usually means it doesn't cause harm. Symptoms can be very mild, with few or no relapses. Up to 30% of people with MS might fit this description.

Calling MS 'benign' can be misleading. It doesn't mean your MS isn't affecting you. You might not have lots of relapses or much disability or many symptoms but you could suffer from fatigue or problems with your thinking or memory.

We can see from **MRI scans** that even when MS seems mild it doesn't mean it's no longer active. It can still be doing damage to your brain and spinal cord even when you're not having relapses. In fact, most of the damage MS causes goes unnoticed and can only be seen on scans.

'Benign' MS can suddenly become more active. You only know if your MS is really benign if you can look back after 15 years or so and see that MS hasn't caused you a lot of problems. "This condition will not define me any more than the colour of my hair. I want to be described as a husband, a father, bright, witty, knowledgeable and kind. That's all." Martin



### **Treating MS**

There's no cure for MS yet but it can be treated in different ways. There are treatments for the many symptoms of MS. These include medicines, physiotherapy and or alternative or complementary therapies.

### Slowing down MS and cutting relapses

The biggest long-term difference people can make to their MS is to take a **disease modifying therapy** (DMT). They're called 'disease modifying' because they change the course of MS, not just tackle symptoms.

They can:

- slow down how fast your disability or symptoms get worse
- reduce how many relapses you get and make the ones you have less serious

For some people these drugs can work so well that there are no signs that their MS is still active at the moment.

DMTs we have right now only work against MS that has relapses. Happily, it's hoped that a drug that also works for progressive MS, called ocrelizumab, will be available in 2019.

For more on DMTs check out our booklet 'Disease modifying therapies (DMTs) for MS' and the factsheets for each drug you'll find at **mssociety.org.uk/dmts** 

#### **Treating relapses**

Some milder relapses won't need any special treatment (just keep on taking your DMT if you're on one). You can speed up how fast you get over more serious relapses with a short course of steroids. These are taken as a pill or through a 'drip' that goes into a vein. Whether a relapse is treated or not doesn't make any difference to how much permanent disability it could leave you with. Rehabilitation after a relapse can help get you over it. This includes physiotherapy, occupational therapy, advice on what you eat and support at work and with help in your home.

There's more on all this in our booklet 'Managing a relapse'.

"My life had another big change a few months after my diagnosis. I met my future husband and although in some respects the brakes were put on in my life, in others I did the things I had always hoped for." Rachel

#### **Managing symptoms**

There are lots of drugs and therapies for dealing with MS symptoms. They might not be able to get rid of a symptom totally but can make them easier to live with.

Physiotherapy can help with muscle stiffness. Occupational therapy might help with something like tremor (shaking that you can't control).

Occupational therapy means, at home or at work, making adjustments and finding practical solutions or techniques for a particular symptom.

Some people with MS use complementary and alternative therapies. Massage, reflexology, yoga, acupuncture and t'ai chi are some examples. For a lot of these kinds of treatments there's not much evidence showing they have an effect. Some people say they can help with symptoms or just make them feel better in general.

Our booklet 'Complementary and alternative medicines' goes into these therapies in detail. Check out our booklet on 'Exercise and physiotherapy', too.

#### **Stress**

Many people with MS say stress affects how they feel and makes their MS worse. Lowering your stress levels can definitely improve your overall health and how you feel. Some studies show a link between MS and stress but others don't. Some show stress over a long time can trigger a relapse.

Our website has a page on stress, anxiety and how to better manage it.

#### What you eat

A healthy, balanced diet is good for all of us. Eating healthily is all the more important if you have to cope with a long-term condition like MS.

A lot of people with MS take care about what they eat. They hope it will make a difference to their MS, its symptoms and how many relapses they get. Some follow special 'MS diets' but there's little evidence these have an effect.

We have a booklet called 'Diet and nutrition' that looks at food,

cooking and MS, including vitamins and the special 'MS diets' you might hear about.

#### **Exercise**

Staying physically active has real health benefits if you have MS. This doesn't have to mean sport if you don't feel that's right for you. It could be any activity that suits you such as gardening, walking or exercises you do at home.

Regular exercise has been shown to help with some MS symptoms such as fatigue, bladder and bowel problems and muscle stiffness or spasms. It can help keep you mobile if you have some disability, by making your muscles stronger or improving your posture. It can boost your mood and keep your memory and thinking sharp. This is important as MS can affect all these.

You'll find information and tips in our 'Exercising with MS' DVD, our booklet 'Exercise and physiotherapy' and the 'exercise' pages on our website.



### Who can help with symptoms?

Lots of different health and social care specialist can help. These include speech and language therapists, continence advisors (for problems with your bladder or bowels), physiotherapists, psychologists and occupational therapists.

These are just some of the booklets we have on treating

symptoms: 'Exercise and physiotherapy', 'Speech difficulties', 'Fatigue', 'Muscle spasms and stiffness', 'Managing bladder problems' and 'Managing the bowel in MS'.

Our website and MS Helpline have details of them all. Find them and others at: mssociety.org.uk/msresources/key-publications

#### **Pregnancy and MS**

MS often affects women at an age when they're thinking about having children. You can still do this. MS doesn't make it harder to get pregnant. You're less likely to have relapses while pregnant. But you're more likely to have one after you've given birth if you don't take a DMT. In the long run getting pregnant doesn't make MS worse.

If you get pregnant it doesn't always mean you must stop taking your MS drugs. You mustn't take some DMTs during pregnancy but others you can. Tell your MS specialist if you're thinking of starting a family and they'll advise you.

Read more in our booklet 'Women's health' and in our factsheets for each DMT.

### How can the MS Society help?

We support thousands of people with MS and their families, carers and friends. We have local groups across the country offering support and information. Find ones close to you at: **mssociety.org.uk/near-me** 

You can get confidential support and information from the freephone MS Helpline on 0808 800 8000 or email them on helpline@mssociety.org.uk

You can check out our booklets and factsheets covering every part of living with MS at: mssociety.org.uk/ms-resources/ key-publications

Order them from the MS Helpline for free.

You'll find lots of people with or affected by MS on our online forum, a part of our website. There's a section for people who've recently found out they have MS.

mssociety.org.uk/forum

#### Research

Research is seeing great progress against MS and making a real difference to the lives of those of us with MS. We are funding new research into why MS happens and treatments to stop or slow it down. We're helping to find better treatments for symptoms, too. We're also developing services to make people's lives better. Find out what we're funding, the latest scientific breakthroughs and ways you can help at **mssociety.org.uk/ research** 

#### **Get involved!**

Why not become a member of the MS Society? To find out more call our Supporter Care Team on **0300 500 8084** or visit our website at **mssociety.org.uk** 

#### Help us raise vital funds

www.mssociety.org.uk/ fundraising

#### Volunteer

mssociety.org.uk/volunteering 0300 500 8084

### Campaign with us, locally and nationally

campaigns@mssociety.org.uk 0300 500 8084

#### Join the MS register

The UK MS Register is a unique



project aiming to revolutionise our understanding of MS and

the impact it has on the lives of people with MS. There are many things we know about MS, but so much more that only people with MS can tell us. How many people are there with each type of MS? How does it affect them? What services are most needed?

That's where the UK MS Register comes in. This ground-breaking work combines clinical and

NHS data with the first-hand experiences of people with MS, to build a picture of what it's like to live with MS. Knowing this could transform the development and delivery of research, care and services for people with MS.

Anyone over the age of 18 with a confirmed diagnosis of MS and an email address can join the UK MS Register at **msregister.org** 

### New words explained

Antibodies – these are made by your immune system to kill things like viruses and bacteria that get into your body. If antibodies can be found in the fluid around your spinal cord it's a strong sign that you have MS

**Central nervous system** – your brain and spinal cord. Nerves carry messages between the two. These signals control how parts of your body work

#### Disease modifying therapy (DMT)

drugs that can be used if your
 MS has relapses. They reduce
 how many relapses you get or
 make them less serious. They
 can also slow down how fast
 your symptoms or disability
 get worse. DMTs available at
 the moment don't work against
 progressive MS

Immune system – how your body defends you against things that give you infections or diseases (like viruses and bacteria). In MS this system goes wrong and it attacks your central nervous system

Inflammation – when your immune system reacts to attack or damage it sends more blood and immune cells to the damaged area, making it swollen. When inflammation of the brain and spinal cord is left untreated it starts to damage it, leading to MS symptoms

Lesions (also called 'plaques') – areas of damage caused by MS in your brain or spinal cord. They slow down or stop messages travelling down nerves, affecting your control of parts of your body. Lesions can be seen on MRI scans

MRI scans – pictures of inside your brain or spinal cord made by 'magnetic resonance imaging'. They show where MS is causing damage through inflammation and damage to the myelin around the nerves Myelin – a fatty covering that protects parts of your nerves. When you have MS myelin is attacked by mistake by your immune system. This interrupts messages that travel along your nerves and that control parts of your body, causing the symptoms of MS

Nerves – bundles of fibres along which signals travel from your brain or spinal cord. These nerve signals control how parts of your body work and make sure your thinking and memory work correctly

**Obese** – being very overweight. Defined by the NHS as a body mass index (BMI) over 30 and over. Find out your BMI at www.nhs.uk/Tools/Pages/ Healthyweightcalculator.aspx

Plaques - see lesions

**Relapse** – a flare up or attack of your MS when you get new symptoms or old ones get worse. Symptoms then go away, get less noticeable or they can become permanent

### **Further information**

#### Resources

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

0300 500 8084 or email shop@mssociety.org.uk mssociety.org.uk/ publications

#### **MS Helpline**

The free 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 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 Alan Izat, Maureen Ennis, Audrey Owen and Carmel Wilkinson.

If you have any comments on this information, please send them to: resources@mssociety.org.uk or you can complete our short online survey at surveymonkey.com/s/ MSresources

**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.

#### References

A list of references is available on request. Call **0300 500 8084**.

#### Photography

Credit for photography belongs to Simon Rawles (cover, p13, 16, 23 and 28), Alex Grace (p6), Davie Dunne (p32) and Amit Lennon (p19).

This resource is also available in large print.

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

#### **Contact us**

#### **MS Helpline**

Freephone 0808 800 8000 (closed weekends and bank holidays) helpline@mssociety.org.uk

#### **MS National Centre**

0300 500 8084 info@mssociety.org.uk supportercare@mssociety.org.uk

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#### BK17WE

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