Just diagnosed
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](http://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 Cath, who has MS

It took about four years for me to be diagnosed. Right up to the final test, I was being reassured by the doctors that my symptoms were due to a spinal cord injury in my neck. So when the diagnosis was confirmed, I was in a state of shock. I didn’t want to tell my family, especially my daughter.

I don’t know where I’d have been without the forums – they’ve become like friendship groups. People there understand the condition better than medics because they have first-hand experience of it and can give tips that doctors aren’t taught, especially with some of the unusual symptoms.

But it’s not all doom and gloom. You also talk about hobbies and other things. You don’t feel alone anymore and it’s all very supportive.

I now know that there are lots of different treatments for symptoms and if one doesn’t work or has side effects, there are usually other options. There are lots of health professionals who can help such as your MS nurse, continence nurses, physiotherapists, dietitians and your GP.

Oddly, I feel less stressed now. I’d always had high expectations of myself in my career and was a stickler for a clean, tidy home. Now if I’ve made someone smile today, I feel that I’ve achieved something. What I can’t do today I do tomorrow. I look at things in a totally different way now.
Five things to know

1. If you’ve been diagnosed with relapsing MS, it’s recommended that you start taking a disease modifying therapy (DMT) as soon as possible after you’re diagnosed.

2. Most people are diagnosed with relapsing remitting MS, and 10-15% are diagnosed with progressive MS.

3. MS these days is about what you can do, not what you can’t.

4. Among the people involved in your care are you, your GP, your neurologist and, for many people, an MS nurse.

5. We are here to support you, through our MS Helpline, local groups, forums and information.
About this booklet

This booklet is for you if you’re going through diagnosis of MS, or have already been diagnosed. It’s also relevant if you’re the partner, relative or friend of someone who’s been diagnosed with MS.

Whatever your situation, you may be going through a huge range of emotions, among them anger, shock, fear or even relief (especially if it has taken some time to be diagnosed). It’s likely that you have lots of questions, many of which you don’t know who – or how – to ask.

This booklet will give you an introduction to MS and help direct you to other information and support if you need it.

One last thing. Where you see a word in bold in this booklet, it means you can turn to the back and find it explained.
What is MS?

Multiple sclerosis (MS) affects the nerves in your brain and spinal cord (also known as your central nervous system or CNS).

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.

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.

**What’s happening in MS?**

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.

Myelin as it should be. Messages travel smoothly

Myelin damaged. Messages are disrupted
This covering is made of a fatty coating called myelin. This protects each nerve from harm and helps messages 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.

**Types of MS**

While everyone’s MS is different, most people will get one of these main diagnoses:

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

We explain these three diagnoses below. It’s important to remember that knowing what type of MS you have will not tell you how your MS will turn out. MS is an unpredictable condition, and no two people will be affected in the same way.

**Relapsing remitting MS**

Most people with MS – around 85% – are diagnosed with this type. If you have relapsing remitting MS, you have relapses, or attacks, of symptoms that happen for a period of time – days, weeks or possibly months – and then mostly or completely get better.
In the early stages of relapsing remitting MS, your symptoms may go away completely between relapses – this is known as remission. But, sometimes there may be left over damage to the myelin, or even to the nerve itself. This damage can mean that your symptoms don’t always disappear completely.

**Primary progressive MS**

If you have primary progressive MS, you have a steady build-up – or progression – of symptoms over time with no periods of remission. You usually don’t have relapses.

Primary progressive MS is less common than relapsing remitting MS, affecting around 10 to 15% of people with MS.

Some people (about 1 in 20) who have progressive MS from the start also have relapses on top of clear progression. This is called progressive relapsing MS.

**Secondary progressive MS**

Many people with relapsing remitting MS go on to have secondary progressive MS.

It’s hard to tell when you move to this type of MS, but it’s usually diagnosed once your symptoms have got worse over a period of at least six months, regardless of any relapses.

No-one’s MS starts out as secondary progressive. But, it’s possible you’re told you have this type when you’re diagnosed if you’ve had unexplained symptoms for some time.

You can read more about MS in our booklet ‘What is MS?’.

“It doesn’t have to mean a life sentence. Yes, it’s serious and yes, it does change your life... but you can still enjoy your life.”

Louisa
First questions

Why did I get it?
We still don’t know what the exact cause of MS is.

What we do know is that there’s not just one single reason why you got MS. Instead, there are probably a number of different reasons, or factors, involved – your genes, your environment and your lifestyle.

Your genes
MS is not directly inherited like some conditions. Although we don’t know exactly what causes MS, there are likely to be a combination of factors involved – one of which is genes. As a result, the child of someone with MS has a slightly higher chance of developing the condition themselves, compared to the child of someone who doesn’t have MS.

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<td>a parent with MS</td>
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<td>a brother or sister with MS</td>
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<td>a child with MS</td>
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The risk is around 1% if an aunt, uncle, cousin, nephew or niece has MS.
MS isn’t directly passed on from a parent to their child. There’s no one gene that causes MS. In fact, over 100 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.

Your environment
We know that you’re more likely to get MS if you live further away from the equator. There are fewer people with MS in places like Malaysia or Ecuador, but many more in the UK, northern USA, Canada, Scandinavia, southern Australia and New Zealand.

This tells us there’s something in the environment that plays a role in MS.

More and more evidence shows that low levels of vitamin D before you become an adult may increase your chances of developing MS. Vitamin D is known as the sunshine vitamin. Our bodies produce it when sunlight shines on our skin.

Research has also looked into whether an infection, such as the Epstein Barr virus (also known as the kissing disease or mononucleosis, which can cause glandular fever), can trigger MS. It seems that infections do have a role to play, but it’s not clear exactly what. And just because you’ve had the Epstein Barr virus doesn’t mean you’ll get MS.

Your lifestyle
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. So, just as for
everyone else, it’s a good idea to stop if you do.

**Diet and nutrition**

More recently, research tells us that if you’re obese (very overweight) before your 20s you’re more likely to develop MS, as are people that do not have enough vitamin D in their bodies. We know now that it’s important to stick to a balanced diet, such as the one recommended by NHS Choices, and to take in more vitamin D if your body doesn’t have enough of it – either through sitting in the sun or through taking supplements.

For more support on stopping smoking, advice on vitamin D and healthy nutrition, talk to your GP. They can refer you to specialist support.

**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?’ But you couldn’t because we don’t know for sure which things come together to cause MS in each person. 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’s going to happen now?**

The short answer is that nobody knows.

MS is unpredictable and no two people are affected by MS in the same way. There’s no standard pattern that your MS will follow. Even knowing what type of MS you have won’t tell you how it will develop.

It’s impossible to tell when your next relapse will be (if you get relapses), how quickly your MS will progress or what part of your body will be affected. Symptoms can occur randomly – at any time, in any order. Being tired, stressed, ill – for example, having a cold – or feeling too hot can make you feel worse. These feelings affect how you experience your symptoms and don’t necessarily mean that your MS is progressing.
Your symptoms can change from day to day, or hour to hour, for no obvious reason. You may also find you have days, weeks, months and sometimes years when you feel fine, with no real symptoms.

This unpredictability, and not knowing what the future holds, can be one of the hardest parts of living with MS. It can take some time to come to terms with it, but there’s support available.

If you want to talk to someone, the MS Helpline is available weekdays from 9am to 9pm on 0808 800 8000 (closed at weekends and on bank holidays). Our local groups also offer direct access to a support network of experienced volunteers.

You can read more about the emotional effects of MS in our booklet, ‘MS and your emotions’.

**Am I going to die from MS?**

People don’t die directly from MS. If you have advanced MS and have many complex symptoms you may be more likely to pick up infections or get ill, which can be serious. But studies have shown that, on average, someone with MS is expected to live only a few years less than most people.

And some research shows that because our health care and MS treatments keep improving, this gap or difference in life expectancy seems to be getting smaller and smaller.

**Can MS be cured?**

At the moment, there’s no cure for MS. Once you’ve been diagnosed with MS, you have it for life.

Research is ongoing to try to find ways to stop MS. Until then, there are ways to manage your condition. This includes disease modifying therapies (DMTs). If you have relapsing MS a DMT can curb how many relapses you have or how bad they are. And it can also slow down how fast you become disabled. The dozen existing DMTs only work for relapsing MS but it’s hoped that for progressive MS the first DMT will become available by 2017 or 2018.
Will I have to use a wheelchair?

This is a question that a lot of people with MS ask in the beginning, when they are first diagnosed. Because we don’t know how your MS will affect you, it’s impossible to answer.

Some people with MS will need to use a wheelchair at some point, either all or some of the time. Symptoms, such as fatigue, weakness, balance problems or when your muscles contract and feel stiff and tight (spasticity), can make walking safely difficult or impossible. Most people with MS will never need to use a wheelchair. And those that do find it lets them lead productive lives.

Using a wheelchair isn’t a bad thing. If you have problems with walking, using a wheelchair can help you carry on with your everyday activities. It helps you do things you otherwise wouldn’t be able to do.

Can I still have children?

Yes. Having MS doesn’t mean you can’t get pregnant or father a child. So it shouldn’t stop you from having children.

If you’re a woman, having a baby won’t affect your MS. The general view these days is that pregnancies make no difference to the overall course of your MS. Relapses are more common within a few months after giving birth if you don’t take a DMT.

However, if you’re on medication, such as a disease modifying therapy (DMT), it’s better to get specialist advice from your neurologist or MS nurse before getting pregnant or deciding to stop treatment.

We don’t yet know for sure which DMTs are totally safe to take during pregnancy. Some DMTs might harm unborn babies. But others seem far less risky to use.

If you’re a woman of childbearing age, discuss with your MS specialist using reliable contraception (the ‘pill’ or
condoms) while on these drugs. This is true while you’re on the drug and for up to three months after you stop taking it.

“My main questions were about how it was going to affect me – it was a bit of a blow to learn there’s no cure, but good to know there was something to control it and someone to support me.”

Penny

Men and women with MS who would like to have a child should discuss this with their MS specialist. Talk to your MS specialist if you’re a woman and you think you may be pregnant.

See our booklet ‘Disease modifying therapies (DMTs)’ and our individual DMT factsheets for a detailed description of each drug and how it might affect a pregnancy.

Will my children get MS as well?

Many people with MS worry that their children will get it as well. There’s a small chance that this will happen, but there’s a much bigger chance that it won’t.

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.

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

Will I have to give up work?

Being told you have MS can make the future seem uncertain. It’s natural to worry about the effects on your job, home and money. Over time, you’re likely to reassess things and adjust, but it’s important not to rush into any major decisions.

Because MS is unpredictable and people do all kinds of different jobs, it can make the workplace situation difficult. Although some people do find that work – or the kind of work
they had been doing – is no longer possible, many people are able to carry on working.

You may find that you need to make changes, perhaps to your workplace, the work you do or how you do it, so that you can continue working. These are known as reasonable adjustments, and the Equality Act and, in Northern Ireland, the Disability Discrimination Act entitle you to ask for them. These laws also protect you from being treated unfairly by your employer as a result of your MS.

You can read more about working when you have MS in our booklet ‘Work and MS: an employee’s guide’.

“I still had a lot of unanswered questions. Am I disabled now? Am I going to be able to look after my children? Am I going to be able to continue in the job I love? But no two people with MS are the same so nobody could tell me what was going to happen.”

Sonia
Emotions and MS

There’s no right or wrong way to react when you’re diagnosed with MS.

You might burst into tears or feel stunned into silence. You could feel sorry for yourself and ask, why me? You could feel angry and want to lash out at other people. Or you might feel grief because you don’t see yourself as a healthy, carefree person anymore. You might go into denial, and try to shut out your diagnosis. It might also be a relief to hear you have MS – especially if you’ve had unexplained symptoms for a long time. Perhaps you felt you had a terminal illness like a brain tumour.

All of these reactions are perfectly normal when you’re diagnosed with MS.

You may find that your reaction varies from day to day, perhaps changing from fear to anger to sadness, to relief. This is perfectly normal. Many people with MS compare their emotional reaction to a rollercoaster ride, with its many ups and downs.

If you’re finding it difficult, there’s support available. If you want to talk to someone, you can call the MS Helpline. They’re available from 9am to 9pm, Monday to Friday, on 0808 800 8000 (closed on bank holidays and weekends). You can also connect with other people with MS through the forums on our website, or through your local MS Society group.

You may also want to read our booklet, ‘MS and your emotions’.

You can find more about how MS can affect your emotions at mssociety.org.uk/emotions
Telling people

At some point you’re likely to want to tell people you have MS.

This can feel like a scary thing to do. But it can help you to feel less alone with your MS, and to get the support you need from those around you.

You may want to tell everyone about your diagnosis – particularly if you’ve been unwell for some time. Or you may want to only tell the people closest to you or people who need to know.

Whoever you decide to tell and however you feel about telling people, you may find it helpful to plan what you’re going to say. Many people don’t know about MS, or they may have their own ideas about it. They may feel, for example, that everyone with MS needs to use a wheelchair, so you’ll have to be prepared to answer their questions.

The information in this booklet can help. You may also want to have copies of our booklet ‘What is MS?’ for people to read in their own time, or you could signpost them to our website.

Before you tell people, be aware that they might not react as you’d expect, however well you know them. They could feel more upset than you anticipate or even be surprisingly calm about it. Although you’re the one with MS, it’s important not to forget that your diagnosis will affect their lives, too.

You can find more on telling people you have MS at mssociety.org.uk/telling-people-you-have-ms

Do I have to tell my employer?

Depending on what you do, you may also have to tell your employer – for example, if you’re in the armed forces. Even if you
don’t need to tell your employer, you may still want to tell them, so they can give you any support you need in the workplace.

We also have a booklet for employers, ‘MS in the workplace’. This includes basic information about MS, and outlines what they can do to support you as well as what the law says they have to do.

As well as these guides, there are other resources available on our website. On here you’ll find a number of sample forms that you and your employer can use, along with case studies from people with MS and best practice examples. You can find this toolkit at mssociety.org.uk/work

**Is there anyone I have to tell?**

Yes, there are a few people you must tell.

If you drive, you have to tell the DVLA about your diagnosis. You’ll also have to declare your MS when you’re buying certain types of insurance. You should also check all of your existing policies, to make sure you’re still covered. Read more about driving and insurance in our booklets, ‘Motoring with MS’ and ‘Insurance and MS’.

“Once I had a diagnosis I told everyone at work, and I never found it difficult to talk to colleagues about my MS. They were very sympathetic. I worked from home for two months, and am slowly building up my hours.”

Jane
What treatments are there for MS?

There are several disease modifying therapies (DMTs) that vary in effectiveness, side-effects and how you take them.

What are DMTs?

Disease modifying therapies or DMTs are drugs used to treat relapsing forms of MS. They’re not a cure, but taking a DMT can have a significant impact on the course of your MS.

DMTs reduce inflammation, prevent damage caused by MS and lower the severity and number of relapses you may have. They give you a chance to take greater control of your condition and your life.

Unfortunately existing DMTs can’t help people with a non-relapsing type of MS. But it’s hoped that the first DMT for progressive MS will be available in 2017 or 2018.

The benefits of starting treatment early

Evidence shows that DMTs work better, the earlier you start taking them.

Damage caused by MS builds up (accumulates) over time. So the earlier you begin treatment, the less damage will have built up before the treatment starts to take effect.

How early is early treatment?

The Association of British Neurologists (ABN) updated their guidance on how MS should be treated in 2015. They recommend treatment starting as close to diagnosis as possible. In order to do this, they state that you should have a six-week follow-
up appointment after you are diagnosed.

They also recommend regular reviews with a neurologist who specialises in MS and they say that MRI scanning is useful to check how active your MS is.

MRI is the most accurate way of seeing how active your MS is, and which treatment to take should be a decision between you and your specialist. Scans and your checkup with your MS specialist will help you decide about treatment.

Our booklet and factsheets on disease modifying therapies look at the different drugs available, as well as things to consider when making a decision.

**Are there any treatments for progressive MS that doesn’t relapse?**

Until very recently, there were no DMTs that worked for progressive types of MS that didn’t also cause relapses. If you have primary progressive MS,
How can I manage my symptoms?

Whether you’ve taken a DMT in the past or not, taking a DMT can mean you get fewer relapses and/or less disability in the long run. There are also many treatments to help you manage your MS symptoms. These treatments don’t always make the symptom go away, but they can often make it easier to deal with.

Managing symptoms

Sometimes the first treatment you try may not work, or you might find the side effects too much to deal with. If you do, it’s important to tell the health care professional who prescribed it that it’s not right for you. There will usually be another treatment you can try, and it may be a matter of trying a few before you find the right one for you.

As well as drug treatments there are other ways to manage your symptoms – such as physiotherapy for muscle stiffness, or occupational therapy for tremor.

Depending on what symptoms you have, you may see many different health and social care professionals. These can include occupational therapists, physiotherapists, continence advisers, psychologists, and speech and language therapists. For an overview of all the professionals that may be involved with your care have a look at our who’s who page, mssociety.org.uk/ms-support/practical-and-financial-help/care/healthcare/whos-who

Our website also has information on how to manage each of your symptoms. You can also read detailed information on
Managing relapses

If you have a particularly disabling, distressing or painful relapse, you might be prescribed steroids. Steroids can help you to speed up recovery from a relapse. They are usually taken as tablets.

You don’t have to take steroids for every relapse. If it’s a fairly mild relapse, for example, or if you decide the side effects are too much for you, you can decide not to take them. The outcome of the relapse will be the same whether or not you take steroids.

Once a relapse is over, you may also need support to help you to recover from it.

This is known as rehabilitation. Rehabilitation can combine many different approaches including physiotherapy, occupational therapy, dietary advice, support at work or at home, and so on.

There’s more on managing relapses in our booklet ‘Managing a relapse’.
Who will be looking after me?

You may have a number of different people looking after you, so it’s worth knowing who can do what, and where to get the help you need.

You
As the person with MS, you get to know more about your condition than anybody else. You understand how individual symptoms affect you, both mentally and physically, and you’re best placed to monitor any changes in your condition and to avoid triggers that make your symptoms worse.

Remember, too, that having the right information about MS will mean you’ll be in a position to make better decisions for yourself. The more you know, the more you can help the professionals you deal with to help you.

Your GP
GPs aren’t MS specialists – many will only ever see one or two people with MS in their careers, so don’t expect them to understand MS fully.

Your GP can help you deal with many of your symptoms, referring you on to more specialist help when you need it. They can also contact your neurologist or MS nurse when necessary, for example to let them know if you’re having a relapse.

Your MS nurse
MS nurses are qualified nurses with specialist training in MS. They are a great source of information and advice. They may also act as a link between hospital, community services and social services.

You should be referred to an MS nurse as soon as you’re diagnosed. They often are the first point of contact for any concerns you might have about your MS.
If you haven’t already been offered an appointment with an MS nurse, you can ask your GP or neurologist for a referral. Sometimes, MS nurses take self-referrals, which means you can ring them directly and ask for an appointment.

Not all areas have an MS nurse. If there isn’t an MS nurse in your area, it’s worth asking if you can be referred to a specialist neurological nurse or someone else with an understanding of MS who can act as a central point of contact.

If you would like to find MS nurse services in your area, the MS Trust has a service finder on their website, at www.mstrust.org.uk/understanding-ms/who-can-help/map-ms-services

**Your neurologist**

Neurologists are doctors who specialise in treating conditions that affect the brain, spinal cord and nerves. You will have seen a neurologist when you were diagnosed with MS, as only a neurologist can make the diagnosis.

Your neurologist will be interested in the overall course of your MS, rather than the day-to-day management of it. Most people with MS will only see their neurologist once or twice a year, although you can ask to see them more often if you need to.

A neurologist can:

- prescribe DMTs
- arrange for scans and any other tests to check how active your MS is
- talk over any new symptoms with you and ways to manage them

**Your multi-disciplinary team**

The multi-disciplinary team (or MDT for short) is the group of health care specialists that work together to help you manage your MS.

As well as your neurologist and MS nurse, your multi-disciplinary team could be made up of the following people who you might
want or need to see at some point in the future:

• a physiotherapist, for advice and treatment of mobility and other physical problems
• an occupational therapist, to help you deal with fatigue and provide practical solutions for any problems that affect your daily life at work and home
• a social worker, for information and help with such things as applying for benefits and housing
• a counsellor, to help you and the people close to you to deal with the impact of MS on your life and relationships

Your GP or MS nurse should be able to refer you to any of the above, or to other experts, such as continence advisers, dietitians and specialists in pain management.

There’s more on our website about the professionals who may be included in your MDT.
What can I do to look after myself?

The treatments you get from your health care team are only part of managing MS. There’s a lot you can do to help look after yourself.

Finding the right information

Having the right information about MS can mean you’ll be more able to make better decisions for yourself.

There’s so much MS information around, particularly on the internet, that it can be hard to know where to start. It’s important that the information you read is accurate, unbiased and up to date, so you can use it to make the right choices. Be wary of anything that claims to be a miracle cure. Many companies try to cash in on conditions like MS by trying to sell unproven supplements, therapies and equipment.

You can get reliable information on managing MS from your health care team, from us, NHS Choices and the MS charities listed on page 31.

Eat well

If you eat a healthy, balanced diet your general health and quality of life will improve, which is particularly important when living with a long-term condition like MS.

Some people say that following a specific diet makes a difference to how they feel. Perhaps it can help you feel more in control of your life, perhaps it feels like it reduces the number of relapses you have, or makes you feel your overall quality of life is better. But not everybody feels this way. There’s no good evidence that special diets are effective at managing MS. For most people with MS, the best diet is a healthy, varied one.

Read more about eating well in our ‘Diet and nutrition booklet’.

Exercise

Regular exercise helps with managing many symptoms and makes you feel better mentally.
Being active doesn’t have to mean going out and playing a sport – it’s all about finding the right activities to suit you and your abilities. It includes things like gardening, yoga and swimming.

There is also information about exercise and MS in our booklet ‘Exercise and physiotherapy’.

**Complementary therapies**

Many people with MS use complementary therapies to help with particular symptoms, or to feel better. The kinds of therapies used by people with MS include acupuncture, yoga, meditation, massage, hyperbaric oxygen therapy, homeopathy and osteopathy – although this doesn’t list all of them.

There’s not a lot of evidence behind many complementary therapies in MS, and there can be risks involved. It’s always a good idea to check with a health care professional before trying out a complementary therapy.

Read more in our ‘Complementary and alternative medicine’ booklet or read ‘I’ve got nothing to lose by trying it’, a free guide by charity Sense about Science, which you can download from their website [www.senseaboutscience.org/](http://www.senseaboutscience.org/) for reliable information on unlicensed treatments.

“It’s a matter of trial and error. I’ve just started a treatment that works for some people so I’m giving it a try. I’m also following a diet plan written by a doctor who has MS, and I feel I’ve improved as a result – I definitely notice a difference if I eat junk food.”

Chris
Where can I get support?

The MS Helpline offers confidential emotional support and information to anyone affected by MS. It’s available from 9am to 9pm, Monday to Friday, on 0808 800 8000 (closed at the weekend and on bank holidays).

**MS Society groups**
A network of around 300 MS Society groups offers support and information across the UK. Through your local group, you can meet other people with MS in your area, find out about local services for people with MS and get support to help you deal with your MS. Find your nearest group: mssociety.org.uk/near-me

**MS Society forums**
The message boards on our website offer the chance to connect with other people affected by MS. There’s a board specifically for people who are newly diagnosed or going through the process of being diagnosed: mssociety.org.uk/forum

**Other MS organisations**

**Shift MS**
Shift MS is an online community for people affected by MS. Users can share, support and interact with each other throughout the site: [www.shift.ms](http://www.shift.ms)

**MS National Therapy Centres**
A network of centres across the UK for people with MS, offering a range of therapies including physiotherapy and counselling: [www.msntc.org.uk](http://www.msntc.org.uk)

**MS Trust**
A charity offering information for anyone affected by MS: [www.mstrust.org.uk](http://www.mstrust.org.uk)
New words explained

Central nervous system or CNS – your brain and spinal cord. Nerves carry messages between the two that control how parts of your body work.

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) of 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

Scientific or clinical evidence – we use the term evidence to describe when tests have been done to prove a (medical) claim does or doesn’t work. Usually, the larger the test, the more reliable the proof is. When we say there is ‘little evidence’ we mean that there have been few tests and/or tests with a small number of people

Steroids – are used to reduce inflammation and make your immune system less active. They’re man-made versions of the hormones you normally produce in your adrenal glands
Further information

**Library**
For more information, research articles and DVDs about MS contact our librarian.

020 8438 0900  
librarian@mssociety.org.uk  
mssociety.org.uk/library

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

020 8438 0999  
shop@mssociety.org.uk  
mssociety.org.uk/publications

**MS Helpline**
Our 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  
(weekdays 9am-9pm, closed bank holidays)  
helpline@mssociety.org.uk
With thanks to all the people affected by MS and professionals who contributed to this booklet.

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.Availability and prescribing criteria for drugs in various parts of the UK may change. Seek advice from the sources listed.

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 mssociety.org.uk/library

Photography
Credit for photography belongs to Simon Rawles (cover, p6, p25 and p28), Amit Lennon (p11) and Tronkantor (p18).

This resource is also available in large print.

Call 020 8438 0999 or email shop@mssociety.org.uk
Contact us

MS Helpline
Freephone 0808 800 8000
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MS National Centre
0300 500 8084
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