

The logo for MS Society, featuring the text "MS Society" in white on an orange triangle pointing to the right.

**MS** Society

A photograph of a family of three standing in front of a building entrance. On the left is a woman with long brown hair and glasses, wearing a grey cardigan. In the center is a young girl with long brown hair, wearing a grey t-shirt. On the right is a man with short brown hair and glasses, wearing a dark blue jacket over a green t-shirt. The building behind them has a sign that says "WELCOME" and "STREET CHILDREN".

# My child has MS

a guide for parents

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
- Visiting us at: **[mssociety.org.uk/donate](https://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 Conor, whose child has MS

It's a very tough time for you and for your family. It really is an awful diagnosis for a child, and awful for the parents, who can feel helpless. I know. We went through it a few years ago when my boy, now 12, was diagnosed.

He's probably had the condition since seven, when he had his first episode. We were initially told it was ADEM, which is a similar condition but one that's supposed to involve only a single episode!

First off, stop torturing yourself over vitamin D or food. These things happen. It's not your fault.

In terms of therapy, your neurologist is probably best placed to advise. Our young lad was put on Rebif (interferon), which is injected using a special injector, three times a week.

It might be worth considering a counsellor for your child at some point. It's a difficult diagnosis for them (and you) to come to terms with. Having a professional to talk to can be helpful.

Thankfully he's had no episodes now for about four years and he lives a perfectly normal life. As he is hitting late teens some difficult life choices are beginning to surface - compatible choice of career, where he can live/travel, and so on. But for now life is fine.

A handwritten signature in black ink that reads "CONOR". The letters are slightly slanted and connected, with a casual, personal feel.

# Five things to know

1

No one knows for sure what causes MS in children.  
MS is no one's fault

2

MS isn't directly passed on from a parent to a child.  
There is no single gene that causes MS

3

Children are more likely to get involved and stick to therapies and medications when they're included in the planning of their treatment

4

As a parent you can make a difference to your child's MS through activity, complementary therapies and healthy eating

5

The MS Society is here to help you find the support you and your child may need



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# About this booklet

If your child's been diagnosed with multiple sclerosis (MS), or it's been suggested as a cause for your child's symptoms, you may have lots of questions.

What caused it? How will it affect my child? Can it be cured? What will the future look like?

This booklet helps to give you answers to some of these questions. It should help you to understand more about MS, the care your child should receive, and the kind of support you're entitled to receive in order to manage the changes MS can bring.

If you have any more questions about MS, you can call our freephone MS Helpline on **0808 800 8000**. They're available from Monday to Friday (closed weekends and bank holidays).

You can find more contact details in the 'Useful organisations' section at the end of this booklet.

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.

**“There are so many disease modifying drugs nowadays. The neurologist will be wanting to get her on a good DMD as soon as possible. And it's likely she'll be able to get fitter and stay fit and healthy for as long as possible”**

**Sue**

# What is childhood (paediatric) MS?

People usually think MS is an adult condition, but children and teenagers can get childhood (paediatric) MS too.

In fact, the youngest person to have been diagnosed with MS was two years old.

There are estimated to be over 130,000 people with MS in the UK. It's not clear how many are under the age of 16.

Perhaps as many as 2-10% of people with MS experience their first symptoms before the age of 16.

MS is a neurological condition. That means it affects your **nerves**. Specialist doctors who look after people with MS are called neurologists.

MS isn't contagious. You can't catch it from someone. You get it when your **immune system** isn't working properly.

Your immune system normally protects you by fighting off infections. But when someone has MS it attacks their 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.

**“My daughter was diagnosed just over a year ago with relapsing remitting MS. I try to help as much as I can and be strong for her. We're trying to focus on what she can do, rather than the difficulties.”**  
**toughascustard**



GREAT ORMOND STREET  
HOSPITAL FOR CHILDREN

WELCOME



# What's happening in MS?

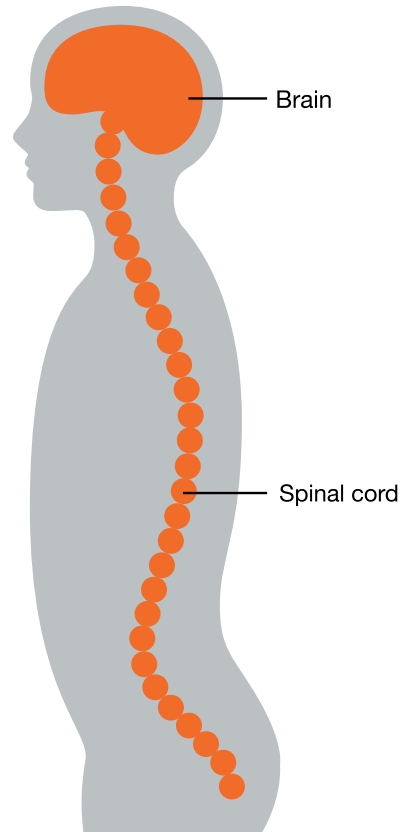
Your brain and spinal cord make up your **central nervous system (CNS)**.

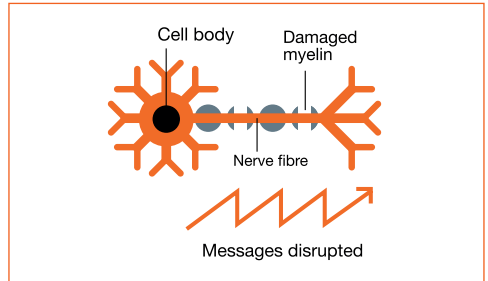
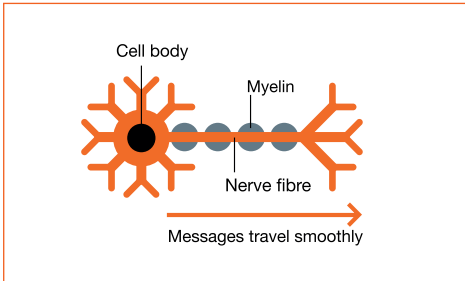
Your spinal cord connects nearly all parts of your body to your brain. Messages go between your brain and spinal cord, travelling along the **nerves**. These signals control how parts of your body move or work and let you feel things like pain, touch and so on.

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 fatty covering (**myelin**) around your nerves.

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.





In time, 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 that 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.

# Why do some children get MS?

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

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. It's rare that children get it.

Of all the people that have MS 2-10% are children. When under the age of 10, just as many girls and boys are diagnosed with it.

In their teenage years though, nearly three times as many girls have MS than boys. We don't know why yet.

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

- genes
- the environment
- 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 child's 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 someone has a close relative with MS, the chances they'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 want a child, there's only a **1 in 67** chance he or she will get it too.



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In 2014 a large study found that MS may be even less likely to be passed on than that figure suggests.

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

## Environment

There are things in the world around us that might affect the 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 virus causes glandular fever. That doesn't mean everyone who gets glandular fever will get MS. 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 people are low in this vitamin before they 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. Examples include oily fish, eggs, spreads and breakfast cereals with added vitamin D. 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 someone might not have enough of this vitamin are:

- they have genes that make it harder for their body to make it
- they're a pregnant woman
- they have dark skin (then it's harder for their 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 our bones healthy. There's no proof yet that extra vitamin D protects against getting MS. Researchers are looking into that.

If someone already has MS, studies have found a link between levels of vitamin D and how bad their 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 tend to show people are more likely to get MS if they smoke - and maybe breathe in other people's smoke (passive smoking).



Chemicals in cigarette smoke might affect the **immune system**, helping to trigger MS.

Studies show that stopping smoking could slow down how fast someone goes from having relapsing MS to secondary progressive MS. You can read more about these different types of MS on page 26.

If anyone wants to stop smoking, their GP can suggest things to help. This website has ideas and support, from nicotine gum and patches to e-cigarettes: [nhs.uk/smokefree](https://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 people low in vitamin D
- make their immune system overactive and cause inflammation inside their body

- and 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, 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.

# How is my child's MS diagnosed?

Diagnosing MS in children isn't easy. Your child should be examined by a (paediatric) neurologist. That's a doctor who specialises in conditions of the central nervous system.

Symptoms of MS can be confused with more common problems. Doctors must rule these out first before they look for signs of MS.

There's no single test to diagnose MS. It can take a long time from when you first notice something's wrong to when your child is officially diagnosed with MS.

Paediatric neurologists use different ways to diagnose MS in children. But some paediatric neurologists may be unfamiliar with MS, and may need to get advice from a paediatric neurologist with a special interest in MS.

Sometimes it can feel as if you and your child are stuck in 'limbo land' – waiting for a

diagnosis so that you know what you're dealing with.

To reach a diagnosis of MS, there needs to be evidence of MS activity in two or more parts of the brain or spinal cord and on at least two occasions.

If your child's had a single episode of symptoms, they're less likely to be diagnosed with MS, unless the specialists see specific signs on the **MRI** scan.

You may have been told that your child has 'ADEM' (acute disseminated encephalomyelitis), 'optic neuritis' or has had a 'clinically isolated syndrome' (CIS).

These can all show symptoms like MS, but might happen only once and not come back. If they do, then MS might be diagnosed.

Great Ormond Street Hospital has more information on ADEM:

**[gosh.nhs.uk/medical-information/acute-disseminated-encephalomyelitis-adem](https://www.gosh.nhs.uk/medical-information/acute-disseminated-encephalomyelitis-adem)**



## Seeing the neurologist

When you see a neurologist with your child, 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
- a lumbar puncture
- 'evoked potentials' tests

You will be able to stay with your child during most of these procedures.

## What are the tests looking for?

A neurologist looks for signs of how much damage has happened

to your child's **CNS**. They need to know that damage happened at different times and in at least two different parts of your child's brain or spinal cord. In most cases **MRI** scans are used to help show this.

### Neurological examination

A neurologist will ask you or your child (depending on their age) about their 'history', meaning their health problems and symptoms, now and in the past.

A physical examination will check their movements, reflexes and senses, such as their eyesight. They will also do a physical examination to check for small changes in your child's movement, reflexes or sensation.

These tests can pick up tiny changes which you and your child might not be aware of.

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 child's brain

or spinal cord. They lie on a bed that slides into the scanner where they stay for 20 minutes to up to an hour.

It's important for your child to lie still in the scanner. If it's likely your child won't be able to lie still long enough to capture the high quality images, they may need a general anaesthetic for the scan.

Using strong magnetic fields and radio waves, the scanner builds up a picture of the inside of the 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.

Your child might feel nervous about the scan – it's a large, noisy machine in quite an unfamiliar setting. But you're allowed in the room to reassure them. And they can usually wear headphones and play their own music while they're in the scanner.



Great Ormond Street Hospital has a downloadable factsheet, video and podcast explaining **MRI** scans for children.

[gosh.nhs.uk/medical-information/procedures-and-treatments/mri-scans](https://www.gosh.nhs.uk/medical-information/procedures-and-treatments/mri-scans)

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

## Lumbar puncture

During a lumbar puncture (or ‘spinal tap’) a needle is put into your child’s lower back, into the space around the spinal cord. Fluid is taken out and checked for signs that your child’s **immune system** has been active in their brain and spinal cord (which only happens when someone has MS).

These signs, which can include ‘antibodies’, will show that your child is very likely to have MS. Not all children need this test. This can be done under sedation or a local or general anaesthetic.

You can usually stay with your child to comfort them. They’ll be asked to lie on the bed on his or her side and to curl up into a ball. The nurse will help them to keep in the correct position. The doctor will feel your child’s lower back and locate the correct space between the vertebrae (the bones of the spine).

The doctor will then wash the skin around this area and cover the surrounding parts of the back with a sterile towel before inserting the needle. If under a local anaesthetic, this will be given by a small injection. The fluid obtained will be sent to the laboratories to be examined. In some cases the fluid pressure will be measured.

Some people get headaches after a lumbar puncture. This is a known side effect and the neurologist can advise you on how best to manage this. Bed rest and fluids may help.

Now we have MRI scans, lumbar punctures aren’t used so often.

Great Ormond Street Hospital have a downloadable factsheet on lumbar punctures:

[gosh.nhs.uk/medical-information-0/procedures-and-treatments/lumbar-puncture](https://www.gosh.nhs.uk/medical-information-0/procedures-and-treatments/lumbar-puncture)

### **‘Evoked potentials’ test**

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

The neurologist will place small electrodes on your child’s head to monitor their reactions to what they see or hear while looking at a screen. These electrodes measure tiny electrical impulses. They’re not painful for your child.

To measure their eyes, your child will be shown patterns on a screen. The electrodes measure how their brain reacts to what they see.

To test their hearing they’ll listen to clicks through headphones.

In another test they’ll be given tiny shocks on their skin (it feels like ‘pins and needles’), and the reactions of their muscles are measured.

If your child has MS or a similar condition these tests can detect messages to and from the brain travelling more slowly than usual.

Great Ormond Street Hospital has a downloadable factsheet for more information on these tests:

[gosh.nhs.uk/medical-information-0/procedures-and-treatments/visual-evoked-potential-vep-and-electroretinogram-erg-tests](https://www.gosh.nhs.uk/medical-information-0/procedures-and-treatments/visual-evoked-potential-vep-and-electroretinogram-erg-tests)

### **Telling your child**

‘Should I tell my child about their diagnosis?’ All parents will ask themselves this question and will be keen to get it right.

It’s usually best to give your child honest information about their diagnosis. It can be very helpful to tell them directly that they don’t have cancer, that they’re not dying and that MS is not their

fault. These are all things that children with MS tell neurologists and paediatric teams that they're afraid of.

There are good reasons for telling your child about their diagnosis, but it's an individual choice. It depends upon their maturity and ability to take in the information.

For children between six and 12, the Barts MS Research Team at the Queen Mary hospital in London developed an online tool to help explain MS. See more at [digestingscience.co.uk](http://digestingscience.co.uk). It could help you explain MS to your child.

We also have a series of videos that help explain MS to children under 10. You can find these at: [mssociety.org.uk/ms-resources/annie-and-dan-talk-about-ms](http://mssociety.org.uk/ms-resources/annie-and-dan-talk-about-ms)

### Remember:

- when you start talking about your child's diagnosis, you'll be giving them permission to talk about their feelings

- they'll be dealing with health care professionals a lot and need to be OK about this. You can give them the vocabulary they need to do this
- Children will often take their lead from you about how to act in a situation. If you can talk to them about their concerns and questions, they may be able to deal with the situation more calmly

### When you're told that your child has MS

Finding out your child has MS can bring up strong feelings. It's natural to feel afraid, confused, upset or overwhelmed.

You may feel relieved. You might have feared that your child had something fatal, like a brain tumour.

Finally you know what's wrong and that you're not imagining it. And you can now take steps to look after your child and think about treatment.



Whatever your reaction, we're here to support you.

There's the MS Helpline on **0808 800 8000**. They have lots of information and are trained in giving emotional support

There's our online and printed information and our local groups.

You can chat to people on the forums on our website. Find it at: [mssociety.org.uk/forum](https://mssociety.org.uk/forum)

Find your nearest MS Society group, centre or specialist at: [mssociety.org.uk/near-me](https://mssociety.org.uk/near-me)



# How will MS affect my child?

MS affects people very differently. It's unpredictable. So you'll often not know which symptoms might flare up, how long they'll last or when they'll go.

## The different types of MS

Every child's MS is different. That said, we can put MS into two broad types: MS that has relapses and MS that doesn't.

Most children 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. See page 36 for more information.

A smaller number of children have MS that gets steadily worse over time, without relapses or inflammation. This is 'progressive MS'. 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 someone gets 'relapses'.

## Relapses

Most children diagnosed with MS get relapses to begin with.

A relapse is when, after a period when your child's MS was stable, their **immune system** attacks their **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 they had already may get worse or new ones appear.

Your child's body does its best to repair the damaged myelin. If it can, the symptoms can get better



or go completely. This recovery is called 'remission'.

Your child might be left with some symptoms, disability or damage to the nerves. As time goes on it gets harder for the 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

someone's not having a relapse, MS can be damaging their nerves.

### **Why are relapses important?**

The MS drugs we have at the moment can make a difference to relapses and to the inflammation of the nerves that go with relapses.

These drugs are called disease modifying therapies (DMTs). Taking one can mean fewer relapses and less serious ones. A DMT could help with symptoms



and slow down how fast your child's disability gets 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 that can help with some types of progressive MS expected by 2019.

### **Relapsing 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 that 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. Women get it more than men for reasons we don't yet understand.

There are now around a dozen disease modifying therapies (DMTs) that can help with relapsing remitting MS.

Read more about this type of MS 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 to 15% of adults with MS have the primary progressive form. But primary progressive MS is very rare in children. Less than 5% of children with MS have this type. Boys are just as likely as girls to get it. Because the DMTs we have right now reduce inflammation, they don't work against progressive MS (but one is expected for early primary progressive MS by 2019),

For a small number of people (about one in 20) their MS gets steadily worse but they have relapses on top of that. This is called 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**

People only get this MS if they've already had relapsing remitting MS. The 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 the MS is now directly damaging the nerves themselves. Between relapses the person's disability or symptoms were stable. 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 MS has become secondary progressive. If someone's disability or symptoms get steadily worse over at least six months, then it's likely their relapsing MS has become secondary progressive.

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

Read more in 'Understanding progressive MS'.

## Symptoms

There are many possible symptoms of MS – few people experience them all. At times there might be several symptoms together, at other times there may be no outward symptoms.

Sometimes it seems children cope easily and don't complain of symptoms because they've found a way to manage despite them, or because they've noticed that some other symptoms clear up on their own.

Problems with memory and thinking are common symptoms of childhood MS. Problems with movement, such as poor coordination and tremor, are common as well. But MS is unpredictable and every child's MS is different.

Children can have different symptoms at different times. Although some are very common, there's no pattern that applies to everyone.

Some common symptoms include:

- fatigue: an overwhelming sense of tiredness making body or mind activity difficult
- balance problems and dizziness
- walking difficulties, problems with coordination
- visual problems: blurred or double vision, temporary loss of sight in one eye or both
- numbness or tingling: commonly in the hands or feet
- pain: sometimes mild, occasionally severe
- loss of muscle strength and how well your fingers work
- muscle spasms and stiffness
- anxiety, depression or mood swings
- cognitive problems: difficulty with memory and concentration
- speech problems: slurring, slowing of speech, or changes in pitch or tone

- incontinence: little or no control over bladder or bowel functions

Some symptoms, such as walking difficulties, are obvious to other people. Others, such as pain or fatigue, aren't and are often called hidden, invisible or silent symptoms. Hidden symptoms may be more difficult for people to understand, especially when they're not familiar with MS.

### What will the future hold?

As mentioned already, MS is difficult to predict and varies from person to person, so predicting exactly how it will affect each child is not possible.

Most children have relapsing remitting MS, with periods of good, but unpredictable, recovery. Some get more severe symptoms, but it's unlikely their MS will get much worse very quickly.

MS isn't a terminal illness. Like diabetes, it's known as a chronic

or long-term condition which needs to be managed for life.

Many people with MS live a normal life span. But on average people with MS die seven years earlier.

Of course averages aren't always helpful and everyone's MS is different. With recent advances in medicine, the gap in life expectancy is getting smaller.

There are many information resources from the MS Society that can help with things as they come up.

You can get these from our website or call our freephone MS Helpline on **0808 800 8000**. There's more information on the MS Society website on the latest research and news.

There are now drugs that can modify both the course of MS and many of the symptoms. There's also ongoing research into new treatments and better care.

You can find out more from the MS Society Helpline or from our website.

Some drug treatments commonly used for MS may not be licensed specifically for the condition. Many may be licensed for MS but not be licensed specifically for children. But this doesn't mean they won't be useful or can't be used for children, with careful monitoring.

There are many MS drugs used in adults that are now being formally trialled in children. Your child may be asked to join a trial to help gather further information on them and get the medication licensed for young people.

As with adult MS, choosing the best drug can be a process of trial and error. The first drug might not be the one that's effective, or the dose may need to be adjusted before the right amount is found.

Your child's neurologist, GP, MS nurse or **paediatric** nurse will monitor the effects the drugs are having and can alter the dosage.





Drug treatments for particular symptoms are often most effective when combined with other approaches, such as

physiotherapy or occupational therapy (OT). OT looks at how everyday activities can be done most effectively.

We have a range of information booklets about treatments for specific symptoms, such as fatigue, pain, or muscle stiffness.



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## Children in control

When children are included in planning their own treatment, they're more likely to get involved and stick to therapies and medications.

Having choice and a say in treatments helps anyone feel more in control. For example, if a child takes a disease modifying drug that needs to be injected (see page 36 for more details), they can be involved in the injection and preparing for it. This will give them a sense of control.

They might want to mark where the injection is given, or prepare the medication or apply pre-medication cream. All this helps give 'ownership' of the process to the child.

As children get older, they may want to take more control of their care. You might monitor that medication is being taken, without actually being involved in the process.

Whatever their age, it's vital to be honest, to present them with clear information, and involve them in the decision making process. See page 51 for more on teenagers and MS.

# Disease modifying therapies (DMTs) and managing 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, too. These include medicines, physiotherapy and or alternative or complementary therapies.

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 its symptoms.

DMTs can:

- slow down how fast your child's disability or symptoms get worse
- reduce how many relapses your child may get and make the ones they do 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.

The DMTs we have right now only work against MS that has relapses. It's expected that a drug that also works for progressive MS, called ocrelizumab, will be available in the UK by 2019.

Much of the information and guidance for doctors on DMTs relates to adults. But some DMTs are prescribed for children and adolescents by paediatric neurologists. Studies have shown that beta interferons and glatiramer acetate (Copaxone) are safe to treat children with.

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](http://mssociety.org.uk/dmts)



The most common DMTs used with children are the beta interferons:

- Avonex
- Rebif
- Betaferon
- Extavia
- and glatiramer acetate (Copaxone)

These are all given by injection, at home, either under the skin or into a muscle. Depending on the drug, these injections are weekly, daily, three times a week or every other day.

This means there's a routine to get into for any child taking DMTs. This is something they and you will want to discuss in detail with an MS or paediatric nurse, neurologist or paediatrician.

An MS nurse will be able to help you and your child with learning about injecting and can answer your questions. Your GP will be able to refer you to these specialists, who may be working in partnership to help your child.

These five drugs are available on the NHS to anyone who meets the criteria for them. These are set down in guidelines by the Association of British

Neurologists (ABN). These guidelines were updated in 2015. They now state neurologists can use DMTs for 16–18 year olds following the guidelines used with adults. Children under 16 should be treated in specialist clinics, preferably by a team that includes adult and paediatric neurologists with an interest in MS.

Among other DMTs available are natalizumab (Tysabri) and



fingolimod (Gilenya). Both are given to people with very active relapsing MS, especially if other DMTs haven't controlled it.

Neither natalizumab or fingolimod have been licensed for use in children or young people but are often used by specialists. There haven't been any formal studies of the use of natalizumab in children and young people but there has been a trial of fingolimod. This study showed clear benefit over the interferons, and showed to be just as safe and effective for children as it is for adults.

## Steroid therapy

Steroids are most often used to treat an attack of MS symptoms – either the first time, or later relapses. Steroids don't change the way your child's MS will run its course. They can reduce the inflammation in the nerves of the brain and spinal cord and speed up your child's recovery.

These steroids, known as 'corticosteroids', aren't the same as the 'anabolic steroids' sometimes used by athletes to build muscle.

A short course of high-dose **intravenous** steroids works just as well in children as in adults when given during the course of a relapse. The best dose to give for children will vary.

Steroids don't affect how your child recovers. So if there are still some symptoms several months later, steroid treatment most likely won't clear these up. And although they speed up your child's recovery, how well they work can vary.

Your child's neurologist will most likely choose intravenous methylprednisolone (IVMP) as the steroid to treat severe MS relapses. Large doses are usually given over a few days via a drip that goes into a vein and this is usually done in the hospital.

All drugs can have unwanted effects, and steroids are no exception. There are short-term and long-term side effects.

Possible side effects of prescribing steroids in the

long-term are diabetes and osteoporosis.

Other possible short-term side effects of steroids include:

- a metallic taste in the mouth
- faster heart rate
- hot flushes or a red face
- sleeping problems
- using the toilet often, particularly at night
- weight gain

Great Ormond Street Hospital has a downloadable factsheet on steroids for more information.

[gosh.nhs.uk/medical-information-0/medicines-information/steroids-children-neuromuscular-disorders](https://www.gosh.nhs.uk/medical-information-0/medicines-information/steroids-children-neuromuscular-disorders)

## Treating relapses

Some milder relapses won't need any special treatment (your child will just keep on taking their DMT if they're on one). How fast your child gets over more serious relapses can be speeded up 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 your child with.

Rehabilitation after a relapse can help them get over it. This includes physiotherapy, occupational therapy, advice on what to eat and support at home or school.

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

## Physiotherapy and exercise

However MS affects your child, there are exercises that can help them to stay as healthy and fit as possible and to improve symptoms and their effects.

Exercising regularly will help keep their growing body working to its full potential. To make it easier, it's important to find exercise that suits them – something they enjoy and find worthwhile. All kinds of physical movement can be of benefit. MS affects each person





differently and they will have their own likes and dislikes.

Although MS will sometimes make certain sports or activities more difficult, children with MS shouldn't feel they need to stop being active and must rest all the time. Of course, there'll be times when they need to take it easy. But people find their own limits and learn to listen to their bodies.

Your child's GP, neurologist or paediatric or MS nurse can make a referral to a physiotherapist. The can work with you and your child to find the best exercises for them.

A physiotherapist might suggest exercises that concentrate on a particular area of the body that they wish to improve, or help manage a specific effect of MS.

A physiotherapist can also help you find accessible sports facilities and suitable classes for football, netball, yoga, swimming, and a whole range of other activities your child might enjoy. Organisations like Get Kids Going could give you some ideas.

See our booklet 'Moving more with MS' for more information.

## Complementary therapies

Many people say they get benefits from therapies which aren't prescribed by their doctor called 'complementary therapies'. These therapies include medicine, yoga, acupuncture and massage.

The evidence for the safety and effectiveness of complementary therapies varies. Some are regulated by reputable national bodies, others aren't. It can be hard to tell what is a safe, potentially effective therapy and what might cause harm.

It'd be wise to approach cautiously anything making grand claims for a cure or miraculous recovery. You should always speak to a doctor or other appropriate health care professional before going ahead with any therapy, just as you would with a drug treatment.

See our booklet 'Complementary and alternative medicine' for more information.

## Healthy eating

A healthy diet is important for anyone. There are many special diets claiming to treat MS. But there's no evidence any one of them prevents or can have an effect on your child's MS.

Children can usually get the nutrients they need through a well-balanced diet. With careful planning, perhaps with the help of a dietitian, you can make sure you meet their dietary needs – even if they change over time.

Persuading any child to eat well, of course, may not be a simple task! If you have a young child or teenager, the following might help:

- have regular family meals
- serve a variety of healthy foods and snacks
- be a role model by eating healthy foods yourself
- avoid battles over food
- involve children in the process of preparing food

The NHS Choices website and our booklet 'Diet and nutrition' have more information.

## Managing mood changes and depression

Everyone with MS feels down from time to time. But for some people these lows become more frequent or longer lasting. This is when sadness and feeling low might be classed as 'depression'. Depression is very common with MS and

there are treatments available.

If your child feels depressed, health professionals should work with you to identify and change anything that might be making the depression worse.

They should also consider whether there might be other things affecting their quality of life. These could be anxiety about their diagnosis, trouble at school or fears for the future.



# School, college and university

Having MS can disrupt schooling. But there's support available to help your child to continue to study.

There's more information about the support available in our factsheet 'Education and MS: a factsheet for students, teachers and parents'. This covers education in England, Wales and Northern Ireland. Our factsheet for Scotland is called 'Education and MS in Scotland'.

## Fatigue

If your child is affected by fatigue, early mornings or late afternoons might be bad times for concentrating or doing active things at school.

They may not have to stay at school all day. That's the kind of adjustment a school might make. Help your child to choose a time when he or she will be at their best. Maybe they could choose lessons they like most to start with.

Checking where the lessons will physically be is important. They may be up long flights of stairs or at the end of long corridors.

Changing some classrooms could be another reasonable adjustment. Similar adjustments can be made for other symptoms which might affect the school day. Your paediatric or MS nurse will be able to help your child with their fatigue.

## Bullying

If your child misses a lot of school, or is seen as different, they may be bullied. They're no different from other children in this respect. They may be badly behaved as they 'act out' their feelings of fear and being out of control. This could lead to them bullying others. If your child is bullied, there are organisations you or they can contact for support and advice.

**ChildLine**, **Bullies Out** and **Respect Me** (in Scotland) can help. See pages 69 and 72 for details.



# MS and the family

MS affects the whole family. It can affect communication, relationships, everyone's mood and daily life.

Symptoms such as extreme fatigue, weakness, bladder problems and changes in your child's memory and thinking affect his or her ability to take part in everyday things that kids do.

Your child may show a range of emotions and feel aggressive, depressed and anxious as a reaction to their diagnosis of MS.

Learning how to live with an unpredictable and changing condition can be hard on anyone. MS will bring about changes – and everyone in the family will be aware that things are different.

It's important to talk openly about your family's concerns. Not understanding MS, and how it can make your child feel, can add stress to your family. And MS relapses, fatigue and hospital

appointments can result in school being missed.

Brothers and sisters may feel resentful or jealous of the attention that the child with MS gets. This can lead to bad behaviour from them as they try to redress the balance.

As parents, you might not always get the understanding from friends that you need – however well-meaning their intentions. Also, you may come across health and social care professionals who aren't aware that MS can affect children. You're not alone if you feel you spend lots of time explaining the basics.

There are no hard and fast rules for the best way to deal with MS as a family. But parents in similar situations have found the following tips helpful:

- try to keep the lines of communication open. That's between everyone in the family, with friends and with health care professionals



- remember that not every change in the family, and every issue to be tackled, will be MS related. For example, moody teenagers are still moody teenagers, whether or not they, or their brother or sister, have MS
- use support groups for families. Talking to other parents and families going through a similar situation may be helpful
- health and social care professionals can help with caring for your child, and also with maintaining the family's health and happiness
- it's important you get time out for yourself as a parent. Respite care is sometimes available to give carers and the person with MS a break. You may be able to get help with the costs from the MS Society's Health and Wellbeing Grants Scheme

For more information, check out [mssociety.org.uk/grants](https://mssociety.org.uk/grants) or call our Supporter Care Team on **0300 500 8084**.

## Explaining things to brothers and sisters

Your family members may have as many questions as your child with MS has. You may have some of the same concerns: What will happen? Why us? Will I get MS? Will things ever get back to normal? Is it my fault?

They can also feel fear, resentment and guilt. All are perfectly normal reactions. They might be more or less easy to spot and might show in different ways.

To encourage your other children to ask the questions they have, it's a good idea to know the basic facts of MS. Visit the MS Society website together, or read our booklet 'What is MS?'

Call the MS Helpline on **0808 800 8000** with any concerns you may have. A paediatric MS nurse may be able to help explain MS to your other children.

A good place to start is talking to your children about how you can't 'catch' MS. Many young children and teenagers need to talk about those fears at the very start.



You can also help your other children feel less scared. Explain that their brother or sister with MS can be expected to live a long life, and that their own risk of getting MS is low.

Some practical tips for explaining MS to other children:

- choose a time of day when they're not tired or distracted
- make sure you can look them in the eye and sense their reactions
- give a sign of what you want to

discuss. Try: 'We've something important to talk about'

- don't feel you have to share all the details at once. Talk about the basics, then answer questions
- it's OK to say 'I don't know, but I'll try to find out' to any question
- explain what your child's MS may mean to the family routine: will someone else be caring for them while you take care of hospital visits?





- check in from time to time to make sure your children understand and feel supported
- let the important people in your children's world know – teachers and babysitters, for example – so they can watch out for signs of stress
- let brothers and sisters spend time with you alone so they don't feel left out or ignored
- use simple medical terms, and explain them. Show your confidence in the doctors
- we publish video, web and printed information to help you explain MS to children and young people

Our MS Helpline **0808 800 8000** is available to answer any questions you might have.

Brothers and sisters can join support groups and 'young carer' organisations, even though they probably think of themselves first as family, rather than 'carer'.

For more information see 'Useful organisations' on page 69.

## Teenagers and MS

Children grow up, but, as a parent, you may not even be aware of this because you're living with them every day.

When they become young adults they may need more information, and in more detail, than before. Knowledge is power, and it's very important for them to feel that they have some control over their illness.

After a diagnosis of MS, teenagers can withdraw from parents and not talk much about what's going on. They may even just pretend nothing's wrong. Although it's difficult to separate teenage behaviour from a reaction to having MS, it is possible.

Listen carefully to what your teenager says and look out for signs of depression or problems with their memory and thinking.

Help your teenager talk about what's bothering them. Often these conversations happen in the car or while running errands,

when teenagers might be more likely to open up. A favourite teacher, or someone your child trusts and respects, can also be people for your child to turn to.

It's important you don't try to control what your teenager should or shouldn't be feeling or how they react. Everyone's different. They may want to cry or they might just have nothing to say on the subject.

It's not unusual for teenagers to feel guilty or wonder what they've done to deserve MS. Or they may feel relief if they've had unexplained symptoms for a while – now they have an answer.

They may take some time to settle down and accept things. They may be in denial, especially if they're in remission. But these feelings may come back if they get new symptoms or their MS gets worse.

Adapting to life with MS can take time. In some ways it's an ongoing, life-long process. But a positive attitude from you and your child can help manage it well.

## Learning to drive

Learning to drive can be a lifeline, not only in helping young people get around more easily but as a boost to their independence.

Young people with disabilities on the enhanced rate of Personal Independence Payment (PIP) can obtain a provisional driving licence and drive a car at 16 (a year earlier than normal).

See our booklet 'Claiming PIP' for more information.

They can get advice on what kind of car they may need at an assessment centre. Motability customers aged between 16 and 29 may be able to get funding from Motability towards the cost of driving lessons.

## Cigarettes, alcohol and drugs

Some medications for your child's MS symptoms may interact with alcohol. And they might have dangerous side effects. If your child drinks, or you suspect they drink, it's important they



know about the risks of mixing alcohol and their medication. Your GP or pharmacist can give you information about side effects.

As well as being bad for health generally, smoking makes MS worse. Smoking could speed up how soon relapsing MS turns into the much harder to treat secondary progressive MS.

There's also growing evidence that smoking can stop some DMTs working, especially beta interferons.

Some people say cannabis can help ease their MS pain and spasticity (muscle spasms or stiffness). But smoking cannabis with tobacco can make MS worse. This risk can be removed by using cannabis oils, taken by mouth or by vaporising them.

Cannabis oils aren't illegal if they don't have in them the ingredient that gets you 'high' (called THC) But buying and possessing other types of cannabis is illegal, even if used for symptom relief.

Smoking cannabis can damage lungs, and lead to people becoming dependent on it. In young people smoking it has been linked with mental health problems. These include schizophrenia or bipolar disorder.

If you suspect your child is smoking cannabis, or taking any drug, it's important you talk to them. Get advice on how from Talk to Frank (see page 73).

There's an oral spray containing cannabis extract called Sativex licensed to treat spasticity in adults. It's currently only available on the NHS on a limited basis in Wales. It's not been approved for children or young people. There's no evidence that it's safe or works for this age group.

Our website has more information at [mssociety.org.uk/cannabis-and-ms](https://mssociety.org.uk/cannabis-and-ms)

## Relationships and sex

MS may affect how your son or daughter sees themselves. This may affect their relationships, both forming them and keeping them going. MS may also impact on their sex drive and sex life.

Some DMTs could harm an unborn baby. For that reason a woman will need to use reliable contraception (condoms or ‘the pill’) while on the DMT, and, if she stops taking the drug, for up to a few months afterwards.

MS drugs can have side effects that get in the way of people’s sex lives.

It can feel embarrassing to talk about these things. You or your son or daughter can talk in confidence to the MS Helpline, or to a doctor or MS nurse you or they feel comfortable with.

## Taking care of yourselves as parents

After a child is diagnosed with MS, parents often report feeling ‘lost’. When they tell others about the

news they can hear things like: “MS doesn’t happen to children.”

There may be few chances to meet others in the same situation. But establishing a relationship with other parents is helpful in coping with the diagnosis and in growing as a family.

Telephone conference calls like Skype and internet forums can be useful to make links with support groups for parents of children with long-term conditions and other people with MS.

Parents of children with chronic illnesses like MS often mourn for the loss of their healthy child. They also mourn the loss of dreams they had for their child’s future.

You’ll be the one comforting your child or your partner. But it’s important as a parent to deal with your feelings about your child’s MS. So, take time to acknowledge how you’re feeling, to yourself and those around you.





# Health and social care services

There are many ways health and social care services can help you and the family. Knowing who to contact and how to access them isn't always easy.

What follows is a very basic guide to a very complex area. Local sources of information, like your nearest MS Society group, Citizens Advice or other volunteer organisations, can offer pointers to what's available and how to get it.

## Social care services

Local councils (or HSCTs in Northern Ireland) provide social care services. Many have a 'one stop shop'. This is a single phone number to get in touch. It'll be on their website.

Social care services can provide short breaks or respite care, and help at home (for example, with personal care tasks like dressing or washing someone). They can also cover equipment and adaptations to your home and support for your child and you at home or school.

The services vary from place to place, so get in touch with your local council (or HSCT if you're in Northern Ireland) to find out what's available. Local carers' groups are often good sources of information about what you can get.

There's lots more information in our booklet 'Social care: getting support from your council'. There are separate versions for the different nations within the UK.

## Health care services

If you have questions, problems or concerns about the health care your child is receiving:

- in **England** speak to your local Patient Advice and Liaison Service (PALS)
- In **Wales** speak to your local Community Health Council
- In **Northern Ireland** speak to the Patient Client Council
- In **Scotland** speak to the organisation's senior staff member or Complaints Officer, or the Health Board

You can also get support from the Patient Advice and Support Service, provided by your local Citizens Advice.

To find information about the change from paediatric to adult services in England, search for 'Transition: moving on well' on the Department of Health website. In Scotland, information is available from the Coalition For Scotland's Disabled Children:

**[fsdc.org.uk/to-better-lives/transition](https://fsdc.org.uk/to-better-lives/transition)**

Information is also available from the Transition Information Network.

## Who's involved in your child's care?

There may be many different people involved from the outset, and they may change over the years.

There may be a combination of **paediatric** and adult services involved. This may seem confusing but different specialists can bring different expertise.

## Your child

He or she will know most about their own symptoms and their impact. They'll understand when regular therapies and treatments are needed and if they're working.

## You

You'll know more about your child than anyone else. You know how symptoms affect them mentally and physically.

## Your GP

Your first point of contact, your GP can supply repeat prescriptions for some of the medication. Other medication may need to be delivered to your home or collected from your paediatrician.

GPs can also help deal with some symptoms and refer to more specialist help when it's needed. They can also get in touch with MS nurse or paediatric neurologist. They will hold all your child's medical records.

## MS nurses

They are often brought in on a special contract to work with

children with MS. They can be a vital point of contact as they work closely with neurologists and have an in-depth knowledge of MS.

### Paediatric nurses

They specialise in children's illnesses and often work in partnership with MS nurses.

### Paediatric neurologists

Key in diagnosing, treating and prescribing appropriate treatments for children.

### Adult neurologists

Key in diagnosing, treating and prescribing treatment for adults.

### Paediatricians

These doctors, who specialise in children's illnesses, can often help deal with some MS symptoms.

They can also refer on to therapists or psychologists.

### Child psychologists

They specialise in working with children with problems with their behaviour or their memory and thinking.

They'll have experience of dealing with children going through difficult situations.

### Child psychiatrists

They specialise in working with children with behavioural and mental health problems, for example depression. They'll be able to prescribe medication and psychological 'talking therapies'.

### Occupational therapists

They can provide practical help for problems that affect daily life at home, for example dealing with fatigue.

### Physiotherapists

These can give advice and offer treatment for mobility issues and other physical problems.

### Educational psychologists

They tackle the problems young people come across in education. These might be learning difficulties and social or emotional problems. They regularly liaise with other professionals from the departments of education, health and social services.

## Social workers

They can give advice about other organisations and which benefits your family and child may be entitled to.

## Voluntary organisations

These offer support and information and include the MS Society. There are also the MS therapy centres.

### MS National Therapy Centres

01296 711699

[msntc.org.uk/](http://msntc.org.uk/)

## Respite care and short breaks

A short break gives a valuable chance for you and your child to rest and recharge your batteries.

You can get out and meet people, spend quality time with family and friends, or pursue a hobby. It could even be as simple as getting a change of scenery.

For information on getting a short break and to find out what's available in your area, you can contact the Short Breaks Network (if you're in England, Wales or

Northern Ireland) or Shared Care Scotland.

There's also grant funding available for short breaks or respite care from the MS Society's Health and Wellbeing Grants Scheme.

For more information, visit our website [mssociety.org.uk/grants](http://mssociety.org.uk/grants) or call our Supporter Care Team on **0300 500 8084**.

<p><b>11:04 Platform 13</b> <b>Ayr</b></p> <p>Paisley Gll St Johnstone Milliken Park Howwood Lochmichael Glangarnock Daisy Kilwinning Irvine Barassie Troon Prestwick Airport Prestwick Newton on Ayr &amp; Ayr</p> <p><b>CALLS AT PRESTWICK INTL. FR</b> <b>ScotRail</b></p>	<p><b>11:05</b>      <b>On time</b> <b>Neilston</b></p> <p>Pollokshields E Queens Park Glas Crosshill Mount Florida Cathcart Hulwood Williamwood Whitestrags Patterton &amp; Neilston</p> <p><b>MHETERRAINS FOR</b> <b>ScotRail</b></p>	<p><b>11:05</b>      <b>On time</b> <b>Gourock</b></p> <p>Cardonald Millington East Millington West Paisley Gll St Paisley St James Bishopton Langbank Woodhall Port Glasgow Bosaton Cartsdyke Greenock Central Greenock West Fort Matilda &amp; Gourock <b>CONNECTS ARGYLL FERRIES</b> <b>SAILING TO DUNOON</b> <b>ScotRail</b></p>	<p><b>11:09</b>      <b>On time</b> <b>Preston</b></p> <p>Lockerbie Carlisle Penrith Lancaster &amp; Preston</p> <p><b>URGENT TRAINS ONLY TICKETS</b> <b>NOT VALID ON THIS SERVICE</b> <b>TransPennine Ex</b></p>	<p><b>11:12</b>      <b>0</b> <b>Paisley Canal</b></p> <p>Dunbreck Corkerhill Hosspark Crookston Hawhead &amp; Paisley Canal</p> <p><b>ScotRail</b></p>
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# Money matters: benefits and grants

Having MS in the family can have a financial impact. You may be worried about how this will affect your finances.

As well as any added costs associated with the MS, you may be concerned that looking after your child will mean having to give up work, or reduce your hours.

There are several benefits that a child under 16 may be entitled to. It's best to look for local information from an organisation such as Citizens Advice or Jobcentre Plus office.

Our booklet, 'Benefits and MS', also has lots more information.

## Disability Living Allowance (DLA)

This is a tax-free benefit for children under the age of 16 who need help with personal care or have mobility difficulties.

It's made up of two components: care and mobility. Your child might receive either or both components, at different levels, depending on how their MS affects them.

DLA isn't means tested (you don't need to have a low income to qualify).

You may be able to get other help for your child if they get DLA. You may get an extra amount for your child's disability in income support, housing benefit, and council tax benefit or child tax credit. You may also be able to get a blue badge for your car.

For more information visit our website on [mssociety.org.uk/disability-benefits/disability-living-allowance-dla](https://mssociety.org.uk/disability-benefits/disability-living-allowance-dla)

## Personal Independence Payment (PIP)

Once your child turns 16, they can no longer claim DLA. Instead, they'll need to claim Personal Independence Payment (PIP). This is a new benefit that has replaced



DLA for adults of working age. It is a non-means-tested benefit that can help cover the extra costs your child may face if they need help doing everyday tasks or find it difficult to get around outside their home.

Like DLA, PIP is made up of two components – a daily living component and a mobility component. Both of these can be paid at either a standard or enhanced level.

There's more information in our booklet 'Claiming PIP (Personal Independence Payment)'.

## Changes to benefits

Most income-based benefits, such as housing benefit and income support, are being moved into one Universal Credit. There's more information about Universal Credit on the Citizens Advice website: [adviceguide.co.uk](http://adviceguide.co.uk)

For more information read our 'Benefits and MS' booklet.

## Disabled Facilities Grant (DFG)

The disabled facilities grant provides financial assistance to help with home adaptations. For families with disabled children under 18 it's not means-tested, so your earnings and savings don't affect what you're entitled to.

It's administered by local councils and the most you can get (as of April 2018) is £30,000 in England, £36,000 in Wales and £25,000 in Northern Ireland.

See our booklet 'Adaptations and your home' for more information.

In Scotland the amount you can get will depend on your local council. There's more information in a booklet from the Scottish Government called 'Help with adaptations to your home: A guide for disabled people in private housing in Scotland'.



## The Family Fund

The Family Fund can provide grants to families across the UK with children under the age of 17 who are disabled or who have a serious illness.

They can help with the cost of things like holidays and breaks, washing machines, tumble dryers, bedding and clothing.

## MS Society grants

The MS Society, through its local groups, considers grant requests to help people affected by MS pay for items they need because of their disability.

These can't be things the law says your council or the Health Service must give you.

We give grants that help people pay for things like aids and equipment, adaptations to the home or car, and to top up funds for respite care breaks.

You can find out more on our website [mssociety.org.uk/grants](https://mssociety.org.uk/grants) or call our Supporter Care Team on **0300 500 8084**.

# New words explained

**antibodies** – these are made by our immune system to kill things like viruses and bacteria that get into our body. If antibodies are found in the fluid around someone’s spinal cord it’s a strong sign they have MS

**central nervous system (or CNS)** – the brain and spinal cord. Nerves carry messages between the two. These signals control how parts of the body work

**cognitive problems** – we use the term ‘cognitive’ when we’re talking about our mind and how we think. Examples of cognitive problems are difficulties with learning, memory, perception and problem solving

**complementary therapies** – are used alongside, or in addition to, conventional medical treatments. People use them to boost their physical or emotional health. They might relieve symptoms or side effects. Tai Chi and Yoga are examples

**disease modifying therapy (DMT)** – drugs that can be used if someone’s MS has relapses. They reduce how many relapses they get or make them less serious. They can also slow down how fast symptoms or disability get worse. DMTs available at the moment don’t work against progressive MS

**evoked potentials** – tests that measures how fast messages travel between the brain and eyes, ears and skin. If MS is active, your child’s reaction may be slower

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

**inflammation** – when our immune system reacts to attack or damage it sends more blood and immune cells to the damaged area, making it swollen. With MS when inflammation of the brain and

spinal cord is left untreated it starts to damage them, leading to MS symptoms

**intravenous** – when a treatment is given directly in the vein. This can be done through an injection or a transfusion

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

**lumbar puncture** (or ‘**spinal tap**’) – a needle is put into the space around the spinal cord in your child’s lower back. Fluid is taken out and checked for signs that your child’s immune system has been active in their brain and spinal cord (this won’t happen if they don’t have MS)

**MRI scans** – pictures of inside the brain or spinal cord made by ‘magnetic resonance imaging’. These show where MS is causing damage through inflammation and destruction of **myelin** around nerves

**myelin** – a protective, fatty covering around nerves. When someone has MS their immune system attacks myelin by mistake. The damage caused interrupts messages that travel along these nerves and that control parts of the body. This causes the symptoms of MS

**nerves** – bundles of fibres along which signals travel from the brain or spinal cord. These nerve signals control how parts of the body work and make sure our thinking and memory work well

**neurological symptoms** – we talk about neurological symptoms when we want to describe symptoms you might have as a result of the effect your MS has on your nervous system. Some of these symptoms include blurred vision, difficulty walking, weak muscles and fatigue

**obesity** – when somebody is very overweight with a BMI (Body Mass Index) over 30. Find out your BMI at [nhs.uk/Tools/Pages/Healthyweightcalculator.aspx](https://www.nhs.uk/Tools/Pages/Healthyweightcalculator.aspx)

**osteoporosis** – when your bones are weak and break easily. It's usually discovered when you've had a fall or impact and your bones, such as your wrist or hip, fracture easily

**paediatric** – means 'to do with children'

**physiotherapy** – help to restore movement and function when you're affected by injury, illness or disability. A physiotherapist helps you to do this

**rehabilitation** – happens when a physiotherapist guides you to maintain muscle tone and mobility after you've had a relapse, and helps get you back into a routine as you recover

**relapse** – when MS symptoms flare-up or become worse. This lasts days, weeks or months and may include new symptoms. Symptoms then go away, get less noticeable or might become permanent

# Useful organisations

## Bullies Out

Through anti-bullying programmes in schools and their website, Bullies Out works with children and young people to stop bullying.

**bulliesout.com**

## Child Demyelination UK

Useful resource for families and health professionals. Includes a research update in childhood demyelination from the UK & Ireland Childhood CNS Inflammatory Demyelination Working Group.

**0121 333 8576**

**study@childdemyelination.org.uk**

**childdemyelination.org.uk**

## Childline

Free and confidential support online and by email or phone for children and young people.

**0800 1111**

**childline.org.uk**

## Child Law Advice Line

Specialist advice and information on child, family and education law to parents and carers in England.

**0300 330 5480**

**childlawadvice.org.uk**

## Citizens Advice

Provides advice on a range of topics, such as benefits, through a network of local offices and online.

England:

**03444 111**

**citizensadvice.org.uk**

Wales:

**03444 77 20 20**

**citizensadvice.org.uk**

Scotland:

**03454 04 05 06**

**cas.org.uk**

Northern Ireland

**028 9023 1120**

**citizensadvice.co.uk**

## Contact

Charity providing support and advice for families with disabled children.

**0808 808 3555**

**contact.org.uk**

## Coram Children's Legal Centre

Free legal advice on all aspects of English law affecting children and young people.

**01206 714 650** (general enquiries only, for legal advice see website)

**childrenslegalcentre.com**

## Disability Rights UK

The leading disabled people's organisation. Has information on a wide range of topics related to disability, including benefits.

**020 7250 3222**

**disabilityrightsuk.org**

## Disabled Living Foundation (DLF)

Free, impartial advice about all types of disability equipment and mobility products.

**0300 999 0004**

**dlf.org.uk**

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## Enquire

The Scottish advice service for additional support for learning.

**0345 123 2303**

**enquire.org.uk**

## Family Lives

Charity providing help and support in all aspects of family life for people in England and Wales.

**0808 800 2222**

**familylives.org.uk**

## The Family Fund

Gives grants to families across the UK who are raising disabled or seriously ill children 17 and under.

**01904 550055**

**familyfund.org.uk**

## For Scotland's Disabled Children

Coalition of organisations campaigning to secure rights and justice for Scottish disabled children, young people and their families.

**0131 659 2939**

**fsdc.org.uk**

## Forum of Mobility Centres

Network of centres covering England, Scotland, Wales and Northern Ireland offering professional, quality information, advice and driving assessments.

**01872 672520**

**[drivingmobility.org.uk](http://drivingmobility.org.uk)**

## Get kids going!

National charity that gives disabled children and young people the opportunity to participate in sport.

**020 7481 8110**

**[getkidsgoing.com](http://getkidsgoing.com)**

## Great Ormond Street Hospital

Dedicated to children's healthcare and to finding new and better ways to treat childhood illnesses. It has the UK's widest range of specialist health services for children on one site

**020 7405 9200**

**[gosh.nhs.uk](http://gosh.nhs.uk)**

## Information, Advice & Support Services Network (IASS)

National network of supporting IAS Services across England. Previously known as the National Parent Partnership Network (NPPN). Doesn't provide direct advice or support to children and parents but can help you find your local IAS Service and other organisations who help with advice and support.

**[lassn@ncb.org.uk](mailto:lassn@ncb.org.uk)**

**[councilfordisabledchildren.org.uk/  
information-advice-and-support-  
services-network](http://councilfordisabledchildren.org.uk/information-advice-and-support-services-network)**

## Independent Parental Special Education Advice (IPSEA)

Offers free and independent advice to parents of children with special educational needs in England and Wales.

**[ipsea.org.uk](http://ipsea.org.uk)**

## Kids Health

American website with ideas for healthy eating for children, and lots more.

**[kidshealth.org](http://kidshealth.org)**

## **Mind**

Information, advice and support on mental health issues, including specific information for children and young people.

**0300 123 3393**

**mind.org.uk**

## **Motability**

Provides cars, scooters and powered wheelchairs for disabled people and their families.

**0300 456 4566**

**motability.co.uk**

## **MS National Therapy Centres**

Network of centres across the UK offering a range of therapies for people with MS.

**01296 711699**

**msntc.org.uk**

## **Respect Me**

Scotland's anti-bullying service.

**0844 800 8600**

**respectme.org.uk**

## **Samaritans**

Confidential emotional support to anyone in distress, 24 hours a day.

**116 123**

**Jo@samaritans.org**

**samaritans.org**

## **SANE**

Provides emotional support, practical help and information.

**0300 304 7000**

**sane.org.uk**

## **Scottish Child Law Centre**

Provides a free legal advice service, by telephone, email and text message, on all aspects of Scots law relating to children and young people.

**0131 667 6333**

**sclc.org.uk**

## **Shared Care Scotland**

For information about short breaks and respite care in Scotland.

**01383 622 462**

**sharedcarescotland.org.uk**



## **Talk to Frank**

Friendly, confidential drugs advice,  
with information for parents.

**0300 123 6600**

**[talktofrank.com/worried-about-a-child](http://talktofrank.com/worried-about-a-child)**

## **Transition Information Network**

Information for parents about the  
transition from children's to adult  
services.

**[councilfordisabledchildren.org.uk/  
transition-information-network](http://councilfordisabledchildren.org.uk/transition-information-network)**

## **Update Scotland**

Scotland's national disability  
information service.

**0300 323 9961**

**[disabilityscot.org.uk](http://disabilityscot.org.uk)**

## **Young Minds**

Charity committed to improving  
the emotional wellbeing and  
mental health of children and  
young people.

**0808 802 5544**

**[youngminds.org.uk](http://youngminds.org.uk)**

# 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

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 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.

If you have any comments on this information, please send them to: [resources@mssociety.org.uk](mailto: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. 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](https://mssociety.org.uk/library)

## Photography

Photography: Rebecca Cresta (pages 6 to 43, except pages 37, 38 and 41 which are courtesy of Great Ormond Street Hospital), Simon Rawles (pages 45, 53 and 56), Paul Moane (pages 47, 49 and 50) and Davie Dunn (pages 61 and 63).

This resource is also available in large print.

Call **020 8438 0999**  
or email [shop@mssociety.org.uk](mailto:shop@mssociety.org.uk)

# Contact us



## MS Helpline

Freephone 0808 800 8000  
helpline@mssociety.org.uk

## MS National Centre

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

## Online

mssociety.org.uk  
facebook.com/MSSociety  
twitter.com/mssocietyuk

## MS Society Scotland

0131 335 4050  
msscotland@mssociety.org.uk

## MS Society Northern Ireland

028 9080 2802  
nireception@mssociety.org.uk

## MS Society Cymru

0300 500 8084  
mscymru@mssociety.org.uk

**BK27**

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This title will be reviewed within three years of publication.

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