

The young person's guide to MS

Multiple
Sclerosis
Trust

MS



**A book for
10 to 16 year
olds who have
a parent with
multiple
sclerosis**

Kerry Mutch
Alison Whittam



At the start of this project we were very lucky to receive encouragement and support from the Previté family. Andrew Previté was diagnosed with MS ten years before he got married and so for his wife, Antonia, and their three sons MS has always been part of the family. Adjusting to the change from walking to wheelchair has been difficult both for Andrew, his wife and his children.

Teddy who is 11, recently had to speak about someone who had influenced his outlook on life as part of a school project. He chose to speak not about someone in public life but about his father, and how he had managed to continue to participate actively in life despite advancing disability.

The Previté family hopes that this booklet provides some answers to questions young people may have about MS, and that it will ensure that other young people realise that they are not alone when facing the challenges posed by MS in the family.

The young person's guide to MS

Kerry Mutch, MS Specialist Nurse, Walton Centre for Neurology and Neurosurgery, Liverpool

Kerry has been an MS specialist nurse since 2002. The young person's guide to MS was inspired by a series of workshops organised by Kerry to enable youngsters affected by MS to learn more about the condition and to explore their thoughts, concerns and emotions around living with MS in their family.

Alison Whittam, Information Officer, MS Trust

The MS Trust is a leading independent UK charity for people with MS, their family and friends. The MS Trust Information Service offers a personalised enquiry service; produces a wide range of publications including Open Door, a quarterly newsletter; and provides web based information.

The MS Trust would also like to thank Dr Alasdair Coles, Consultant Neurologist, Addenbrookes Hospital, Cambridge, for his advice.

Kerry Mutch, Alison Whittam

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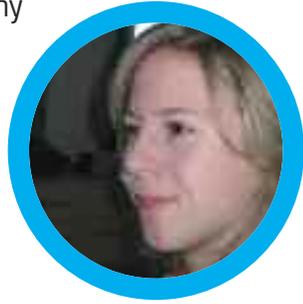
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Introduction

Hi. My name is Sarah, I'm 16 and my dad has MS. He was diagnosed in 2004 after years of uncertainty, so it was a relief to finally put a name to the cause of his symptoms. The last few years have been really eye opening for me as I have been faced with a lot to understand. Having a guide like this one would have been a great way to give me answers when I was too afraid to ask the questions.



Having a parent with MS can be stressful at times as MS affects the whole family, not just the person with it. However, it can help bring families like mine closer together - so it is not all bad! Having a parent with MS does not mean that your life is over, though you may have to make some changes. Your family and friends will always be there, no matter what happens.

Just remember, you're not alone and that it is your life to live too. So be confident in the fact that you are dealing with more than many people have to. It has definitely made me a more confident person!

This guide has been designed for YOU by other young people who have a parent with MS. I hope you will find it helpful!

SARAH BICKLEY

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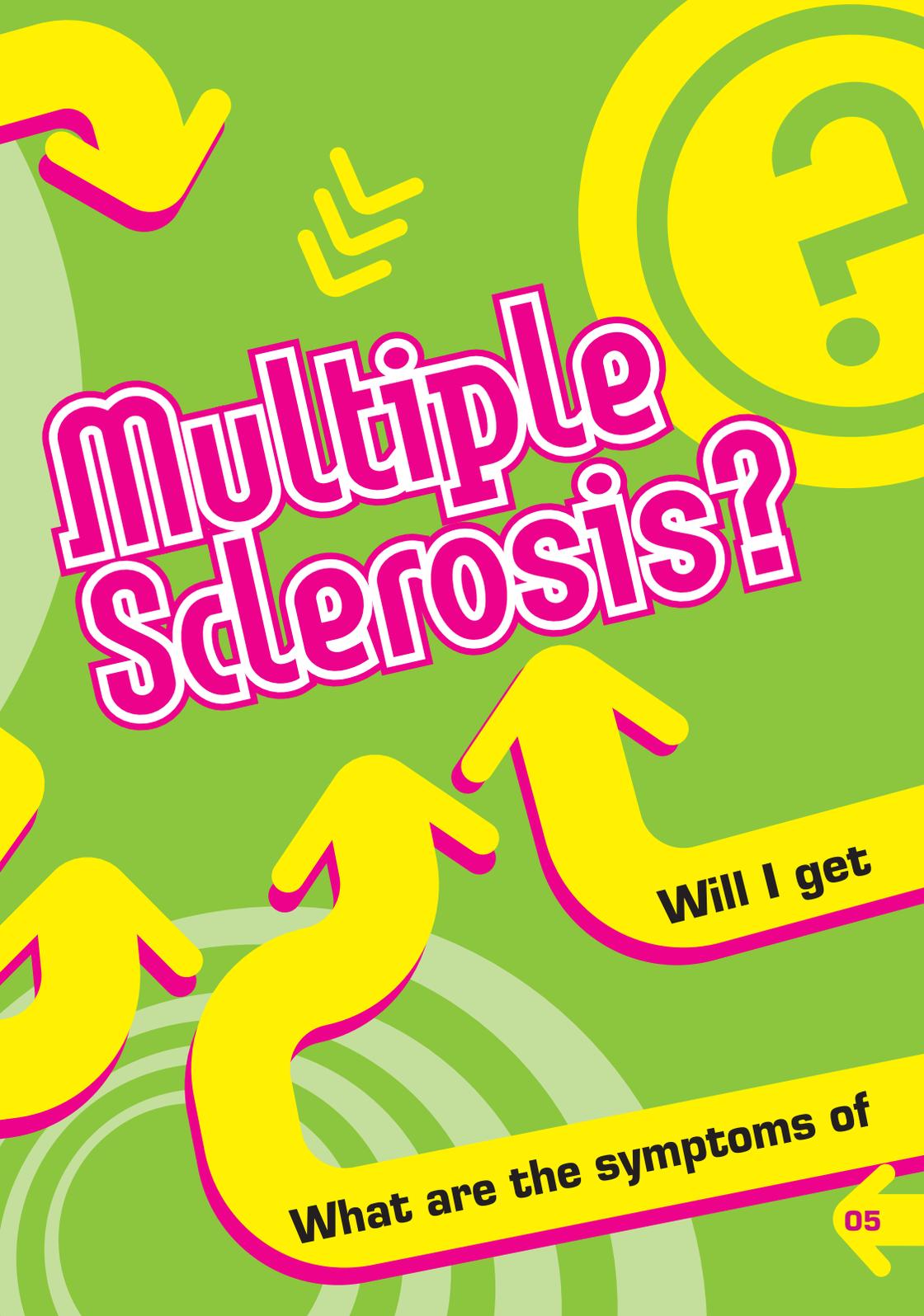
What is

What will happen with

Can you die from

How do you get

Is there a cure for



Multiple Sclerosis?

Will I get

What are the symptoms of

What is multiple sclerosis?

Multiple sclerosis, or MS for short, is a condition that damages the nerves in the brain and the spinal cord. Nerves carry messages between the brain and various parts of the body, via the spinal cord. For example, if you put your foot in a bath of very hot water, nerves in the skin send a message to the brain that the water is too hot and the brain sends a message back to the muscles in your leg and foot telling them to take your foot out of the water. Messages travel very quickly down the nerves as an electrical current.

WHAT GOES WRONG IN MS?

Our nerves are protected by a covering or sheath called myelin, which acts a bit like the insulating material around electrical wires. As well as protecting the nerves, myelin helps to speed the messages on their way. The body's immune system is designed to protect the body from outside attackers such as germs, but in MS, it attacks the myelin instead. Loss of the insulating effect of myelin means the electrical current escapes from the nerve and the messages may be slowed down or even be completely blocked. This leads to the different symptoms of MS. Perhaps the person with MS may not be able to see clearly or walk as fast as a healthy person. Their symptoms will depend on where in the brain or spinal cord the myelin has been damaged – so no two people with MS will have exactly the same set of symptoms.

CAN THE DAMAGE BE REPAIRED?

When the immune system stops attacking the myelin, in some cases the myelin is able to repair itself, either partially or completely. Scar tissue forms over parts of the damaged nerves, allowing them to begin working again. If this happens, the person with MS seems to stay the same – their symptoms don't get any worse. This is known as a period of remission. However, sometimes the scars may cause permanent damage to the nerves, leading to long-term problems.

WHERE DOES MS GET ITS NAME FROM?

It's because multiple means 'many' and sclerosis means 'scarring', so the name describes the various areas of scarring found on the myelin sheath.

MS is different for everybody. Nobody gets all the symptoms.

LIVING WITH MS IN YOUR FAMILY

Everyone adjusts differently to living with MS. Some changes may be small and easy to deal with, whilst others may be harder and take longer to get used to. Just as MS affects everybody who has it in a different way, the way a person copes when they hear about it varies too. There is no right or wrong way to react.

You might have lots of questions. You might feel you can ask your mum or dad about some things, but not others. Maybe you don't want to ask anything about MS at all, or maybe your parents have already explained it to you and it's just a normal part of your life.

It is also possible that your feelings will change over time. When you were younger, perhaps you only wanted some very basic information about MS, but as you grow older, you might decide that you want to have a more detailed understanding of the condition.

“When I first heard that mum had MS I got really upset, but they explained it to me using a hosepipe – without MS, water flows OK, with MS, there is a kink in the hose. That really helped.”
Matt, 11

“My dad was diagnosed when I was 6 months old. My parents told me early on, but I only started asking questions when I was about 8.”

Daniel, 12

“I don’t really ask questions because I like to think of her as my mum, not the something that is wrong with her.”

Lorna, 14

“I don’t need any questions answered about MS because I talk to my mum about it. It’s the best way. I ask her about all the concerns I have.”

Rachel, 12



How do you get MS?

What causes it?

Why does one person have it and not another?

What triggers it?

Can you catch it? Is it infectious?

How do you get MS?

Nobody knows exactly how MS is caused, but there is lots of research looking into it.

It is thought that your genes play a role in whether you might get MS or not. Your genes are inherited from your parents and they control a whole range of factors, including the colour of your eyes, whether you can roll your tongue or not and how tall you will be. Scientists think that having certain groups of genes may make a person more likely to develop MS. However, it is not just your genes that play a role, these are some of the other factors that scientists have investigated:

Where you live

MS is much more common in countries that are a long way north or south of the equator such as Britain, Canada and New Zealand. Nobody is 100% sure why this is so.

Viruses

Some experts think that the viruses that cause illnesses such as mumps, measles and chickenpox could be a trigger for MS in some people. However so far, no single virus has been identified as the trigger.

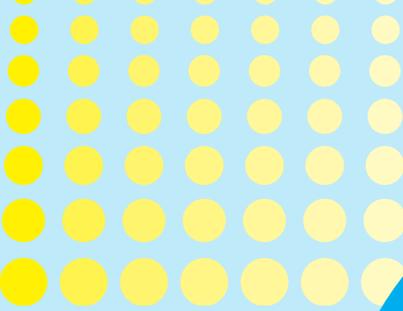
Other factors

Some research has looked at whether stress might be a trigger for MS, but no proof has been found. More women than men have MS so research is also being carried out to see if hormones have a role in MS.

Some facts about MS

- About 100,000 people in the UK have MS.
- It is most frequently diagnosed in people in their late 20s or 30s, although it can begin in people who are older than this. It is very rare in children.
- More women than men are diagnosed with MS.
- MS is not inherited.
- MS is not infectious. You can't catch it like you can illnesses such as colds or chickenpox, which are caused by a virus or bacteria.
- MS is not caused by stress or family disputes.
- MS was first recognised as a disease in the mid-1800s. The first identifiable case of MS was described by Augustus d'Este (1794-1848), a grandson of King George III. His MS wasn't diagnosed until after he died, but was recognised from a diary he kept describing his symptoms.

IT IS NOBODY'S FAULT THAT A PERSON HAS MS. NO ONE IS TO BLAME.



“My main thoughts are feeling sad and upset, but also angry because my mum has done nothing to deserve the illness she has.”

Patrick, 14

“I used to think that it was my fault that caused her to be ill, but when I talked to her, she said the attacks just come out of nowhere.”

Rachel, 12

“I think that it is not fair and why us, and why mum?”

Aimee, 12



Because my mum has MS is it likely my brother and I will get it in the future?

Does it run in families?

Will I get MS?

MS is not very common.

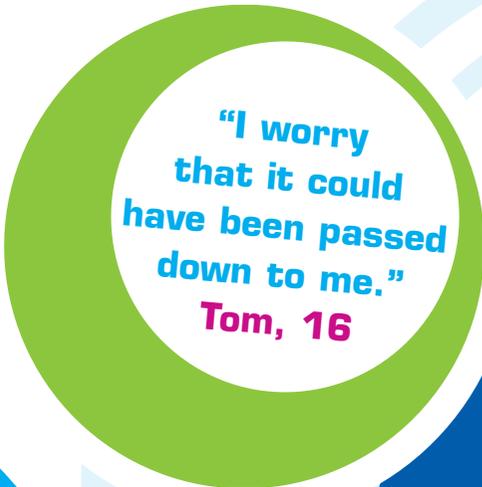
»» In the UK the chance of having MS is about 1 in 700.

»» As a comparison, around 1 in 200 people are allergic to nuts and 1 in 50 people are allergic to the antibiotic penicillin.

Usually a person with MS doesn't know anybody else in his or her whole family who has MS too. However, occasionally more than one member of the same family does have MS, but this is rare.

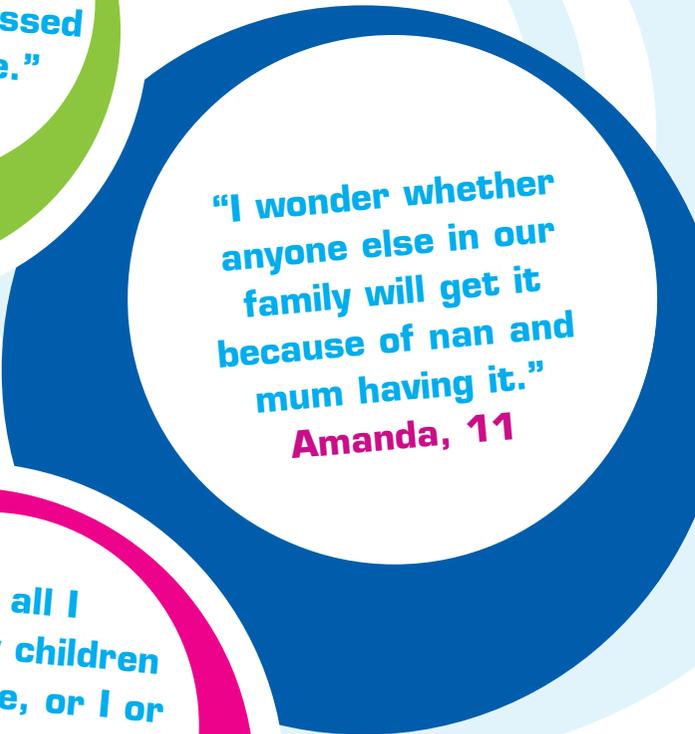
If your mum or dad has MS, there is a **slightly** higher risk of you getting MS than someone who does not have MS in his or her family – but remember, the increase in risk is very small.

“I now look for minor signs in my life and wonder if I'm developing MS, I look for symptoms my mum had.”
Leanne, 17



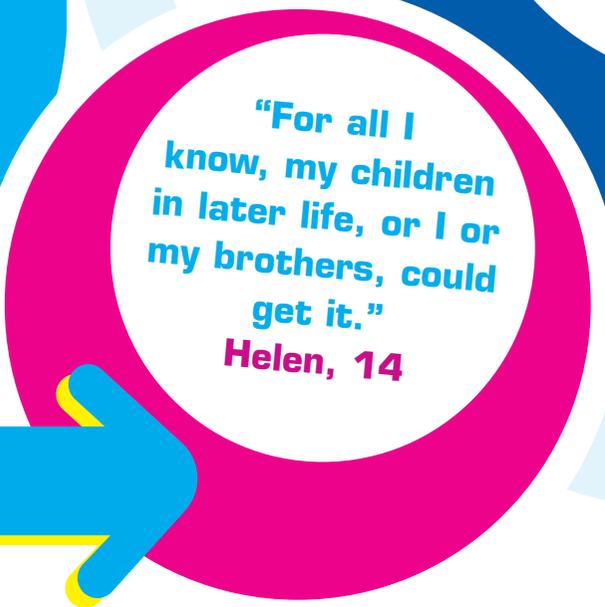
**“I worry
that it could
have been passed
down to me.”**

Tom, 16



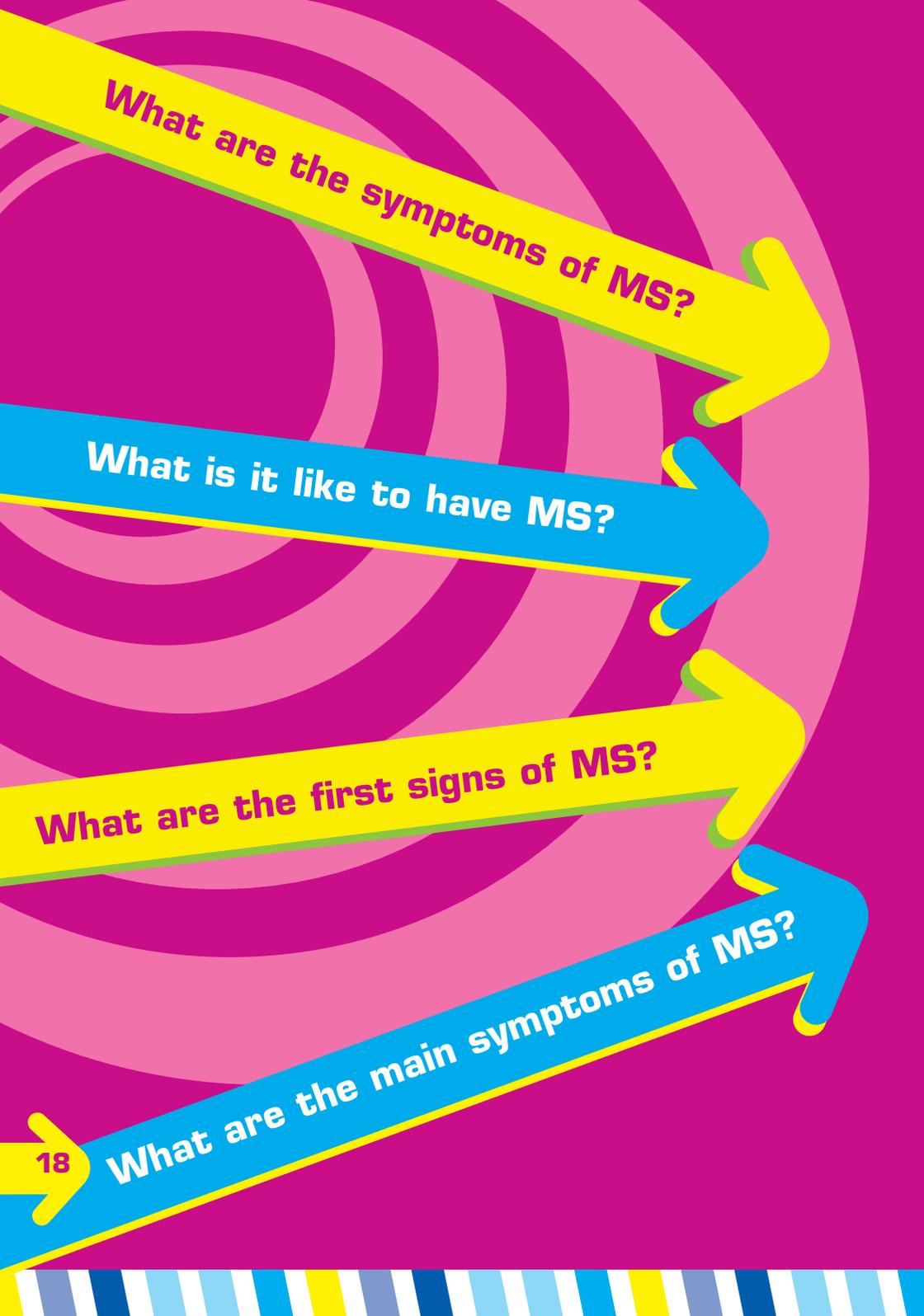
**“I wonder whether
anyone else in our
family will get it
because of nan and
mum having it.”**

Amanda, 11



**“For all I
know, my children
in later life, or I or
my brothers, could
get it.”**

Helen, 14



What are the symptoms of MS?

What is it like to have MS?

What are the first signs of MS?

What are the main symptoms of MS?

What are the symptoms of MS?

There are many different symptoms of MS. Some are 'hidden' or 'invisible', such as pain, extreme tiredness or fatigue, numbness, weakness, or problems affecting sight, memory or the bladder. Others are more visible and obvious, such as difficulties with moving or walking (mobility), stiffness, or speech problems.

The symptoms vary from person to person, according to where the scarring on the nerves has happened. For example, damage to the nerve that goes to the eye (the optic nerve) can cause visual problems, like double or blurry vision. If the nerves in the spinal cord are damaged this can cause difficulties with walking, stiffness and spasms in the legs, as well as bladder problems.

Symptoms can come and go and can even change on a daily basis, depending on different factors such as heat, mood, stress, tiredness or other illness such as an infection.

Nobody has, or will develop, every symptom of MS. Everybody is affected differently.



The next few pages of this book look at three symptoms that some young people particularly worry about – walking, tiredness and mood swings.

WALKING - MOBILITY

MS can cause unsteadiness, coordination problems and weakness – all of which may lead to difficulties with mobility. If your mum or dad has a problem with walking, they may sometimes need to use a stick or even a wheelchair to help them do more, for example, if they get tired very quickly when they go shopping, or if they can't stand for a long time at a football match. Most people with MS will not need a wheelchair permanently, but it is possible that if your mum or dad has a more progressive form of MS – a type that gets worse over time, they will have to use a wheelchair all the time.

“I worry that my mom won't be able to walk anymore.”

Emily, 13

“I worry that dad's going to trip over in a place that's dangerous. That he might not be able to defend himself.”

Connor, 12

“When my mum loses balance, I worry she may break a bone.”

Sean, 11

“Everyone cares for my mum, but people sometimes think she’s drunk when she’s got trouble walking, but to me she’s great. I’m fine with her, I don’t care I’ve got a mum with MS because I will look after her.”

Nathan, 12

“Sometimes mum finds it difficult to walk and so uses a wheelchair, this is good because it means we can go out for the day as a family.”

Hannah, 14

TIREDDNESS - FATIGUE

»»» What makes people with MS so tired all the time?

»»» Why does my dad get tired so quickly?

Everyone feels tired after exercise, if they're not sleeping properly or worrying about something. The fatigue that comes with MS is different. People with MS can get tired much more quickly, sometimes for no reason, and it also takes much longer to recover. This is because more energy is needed to send messages along nerves that have scars on them than nerves that haven't been damaged. Fatigue may be the only symptom a person with MS experiences, and it can be misunderstood as laziness.

When a person with MS is very tired, other symptoms can feel worse. For example the legs may feel heavier, making walking more difficult, people can be clumsier and drop things, or symptoms like pain or numbness may feel worse. These problems improve after rest - a bit like the way a mobile phone goes flat, but it is fine again once the battery has been recharged.

The fatigue can feel much worse if a person has an infection, is feeling stressed, if they are having a relapse, or even if it is a very hot day. Some people manage their fatigue by planning their day, getting the important things done first and leaving the less urgent ones for another time. Strangely, sensible exercise can actually **improve** fatigue and relaxation can also help.

"MS limits what a person can do before they get too tired. They're not being lazy."

Holly, 12

"Dad gets tired quickly so we have to decide carefully what we do and where we go on holiday, we have to ensure it's OK for him."

Sarah, 15

"I find it hard sometimes because if mum is really well she can manage to do quite a few things, but a few days later she can be really tired and her balance is bad and this affects her walking."

Jodie, 13

MOOD SWINGS AND STRESS

»»» **Why is he grumpy?**

»»» **Why does it cause people to have rapid mood swings?**

»»» **Why does it make you get more stressed?**

Sometimes MS can make it harder to do things. For example numbness in your hands can make it difficult to do something that should be simple like fastening a button, or doing up a zip. This can be frustrating for the person with MS and can make them grumpy or snappy. Also from time to time they may get sad and feel low because they are sorry that they can't do as much as they used to, or get out as much as they would like.

"I have to do anything to stop her shouting and make sure she is not stressed. I try to help by making tea/coffee/hot chocolate and I put my washing in the washing basket."
Oliver, 10

Usually it is not you that your mum or dad is angry with, they are angry with MS.

“My dad is boring because he can’t join in with things like football. We can’t go anywhere like theme parks because of the crowds. He is always tired and grumpy. Everything winds him up. He tells me off for everything. He seems older than he really is. He can’t go to work or do anything much. He doesn’t seem to be happy.”

Robert, 14

“It makes my mum stressed and she sometimes gets angry for the smallest thing.”

James, 13

“My mum has days that are worse than others, which makes her feel down and so do I sometimes.”

Emma, 13

Can you die from MS?

Does MS shorten your life?

Will my mum die earlier than other people without MS?

What is the worst scenario?

Can you die from MS?

Most people with MS will live just as long as anybody else. People don't die from MS itself, but sometimes people who are very badly affected get more infections, or pick up other illnesses more easily than healthy people and they can die from these.

MS does not kill.

“Before I found out what was wrong with my mum I was very frightened because I thought she might die. That was a few years ago and some people didn't believe she was ill.”

James, 13

**"I am
terrified that
it will bring my
mum to an
early grave."**

Emma, 14

**"Sometimes I
ask my mum if dad
will live 'til I'm 16, but
no one knows. I love
him, but he seems to
be hard work."**

Rachel, 11

**"I have
thought to myself
that MS could
cause death or
early death."**

Sam, 14

**"I am worried
that my dad
might die or his
problem might get
worse and worse."**

Marc, 14

**"Mum might
get really ill and go
into hospital. She might
collapse or faint. When
she is weak, she sleeps
all the time and I worry
if she doesn't open
her eyes."**

Sophie, 11



What will happen with MS?

How far will it deteriorate and how fast?

How badly can MS affect you?

Will it just get worse and worse?

Does everybody who gets MS end up in a wheelchair eventually?

Types of MS

There are different types of MS. Sometimes it can be difficult to decide what type of MS a person has, particularly when it is first diagnosed, and also how it might change over time.

RELAPSING REMITTING MS

Most people with MS are diagnosed with the relapsing remitting type. They have times when the symptoms flare up - known as a relapse, followed by periods of good or complete recovery – known as a remission.

It is impossible to know when, or how often, a person will have a relapse. However, **on average**, people with relapsing remitting MS have one or two attacks a year. Some people will have more than this and others will go for years without having an attack – so it is not possible to tell how long a person might be in remission. The length of time a relapse lasts differs as well. It might only be for a few days, or it could last for weeks or even months. We also have no way of knowing how bad the symptoms might be during a relapse.

BENIGN MS

Sometimes people can be described as having 'benign' MS. This term may be used if a person has had very mild attacks separated by very long periods with no symptoms. Benign MS can only be diagnosed if a person has had very few symptoms for at least 10 - 15 years.

You can't cause a relapse or stop one from happening.

Types of MS continued

PROGRESSIVE MS

With this type of MS, symptoms gradually get worse - or progress - over a period of time. For some people the worsening is very, very gradual with symptoms staying the same for many months or years, whilst for others it can occur more rapidly. Again, it is impossible to tell how quickly this might happen.

SECONDARY PROGRESSIVE MS

Many people who are at first diagnosed with relapsing remitting MS find over the years that their attacks become less frequent or stop completely, but that their symptoms gradually worsen and the MS becomes progressive. This is known as secondary progressive MS, because it has happened after having relapsing remitting MS.

“MS comes in lots of different forms, so it doesn't mean that your parent will end up in a wheelchair like my mum has.”
Ewan, 13

PRIMARY PROGRESSIVE MS

Some people never have relapses and have a progressive form of MS right from diagnosis. This is known as primary progressive MS.

Only a small number of people with MS will need to use a wheelchair on a regular basis.

“Dad has had it for my whole life but it does get worse the longer he has it. Some family members don’t understand that MS makes him what he is. At the moment nothing will make him get better so I am just going to have to watch him get worse.”

Peter, 14

“We have adapted to allowing for dad’s MS, but it keeps changing.”

Gemma, 12

“I worry that if my mum has a relapse at any time, will I be able to cope with the situation and what will I do? When will the next relapse happen?”

Ian, 13

Is there a cure for MS?

Is there a chance of finding a cure soon?

Why is it incurable? Why does it never go

**How can people treat
or even cure MS?**

**“Because
there is no cure,
it makes you think
that things are just
going to get worse -
but I try not to
think about it.”**

Lorna, 14

away?

Is there a cure for MS?

At the moment there is no cure for MS. MS is a chronic condition, which means that it is always there, even though the symptoms may come and go. Although there may be times when people with MS look perfectly well, this doesn't mean that the MS has gone away.

In the last 10 - 15 years researchers have learned a great deal more about MS and real progress is at last being made. Scientists all over the world are searching for better ways to treat symptoms, to slow the progression of MS and to repair the nervous system.

**"They
are searching
for a cure and
your parent may
never become
that unwell."**

Ruth, 15

**"It will never
go away; therefore
my mum will not be
able to do things that
she used to do with
me and my family."**

Tom, 14

Treatments that can help MS

Although there is no cure for MS, there are different types of treatment that may help. Treatment will depend on each individual and their symptoms.

TREATMENT FOR PARTICULAR SYMPTOMS OR FOR RELAPSES

Some medicines can be used to help symptoms on a daily basis, for example, to help reduce pain, improve bladder problems or reduce tiredness.

If a person with MS has an attack, or relapse, they may be treated with steroids, either in the form of tablets or sometimes through a drip into a vein. For this, they may need to go into hospital for a few days. Steroids are given to reduce the inflammation caused by the damage to the myelin, and can help to speed up recovery.

DISEASE MODIFYING DRUGS

These drugs are suitable for some people with MS and are used to reduce the number and severity of relapses. The drug is injected on a regular basis - either once a day, once a week or every few days.

PHYSIOTHERAPY AND OTHER THERAPIES

Some people with MS have treatment from a physiotherapist, who can help to improve mobility and give advice on exercises to help keep the joints and muscles working. Different people with MS find different things useful – for example, some find that therapies such as yoga, reflexology, meditation or a special diet help them to feel better.

“My mum is not well, sometimes for a day, sometimes for a week or two. My mum takes injections to make it better, which it definitely does. The injections worried me because they look painful, but now it’s fine and I feel OK about it.”

Charlie, 14

“Dad goes to see a physiotherapist sometimes.”

Daniel, 12

“Dad does yoga. He says he feels less tired and more relaxed afterwards.”

Chris, 15

“Mum’s MS affects her legs, but it has got better since she’s been using beta-interferon.”

Maddy, 11

"My mum went on a low fat diet. She also takes multivitamins and supplements."
Harriet, 10

"Mum is affected by relapses, which make her tired all day and she can't walk, but she takes a drug. The relapses don't occur very often."
Robert, 14

"My mum used to wet herself a lot, which was really embarrassing if we were out. She takes some tablets now which means it doesn't happen as often."
Chloe, 14

"I often have to cope with accepting drugs and medicines for my mother at the door and I have had to adapt my life in order to cope with her MS."
Ian, 13



**MS might
affect me**

emotionally

if it changes our social life

if I have extra responsibilities

why me? Why my family?

if we have less money

Life might have to change

When someone has MS, their whole family is affected and everybody will react in their own way. Having a parent with MS means life might have to change. Because MS is a very variable condition, the ways in which it might change will vary. Things may just carry on as normal. However, you may have to take on extra jobs at home. Perhaps going out or doing things as a family may be more difficult, so you have to find new things to do or new ways of doing favourite activities together. It could be that your mum or dad has to cut down on the number of hours that they work or stop working altogether.

You may also find that you are experiencing a wide range of feelings or emotions about the things that are happening in your family. Maybe nothing feels the same any more. Coping with these changes might be especially difficult in the beginning, but you will learn to adapt over time.

**“You just
have to learn
to take one day
at a time.”**

Ann, 14

**“It doesn’t
mean your whole life
has to change. It
shouldn’t stop you living
your life, going out,
having fun and meeting
new people.”**

Sarah, 15

**“I don’t
like to think
that it affects
me.”**

Lorna, 14

**“It’s not as bad
as you think. It’s
quite strange at first,
but as soon as you let
the news settle down
and you get used to it
a little bit, it is fine!”**

Maddy, 11



Angry

Helpless

Upset

Guilty

Embarrassed

Jealous

Worried

Frustrated

Isolated

Envious

Emotions

MS can be difficult to live with. It is **normal** to worry about what may happen in the future, or about a new symptom your mum or dad is experiencing. Sometimes roles or relationships may change at home and this can be difficult for everybody to adjust to. There may be a lot of tension and family members could be more short-tempered or irritable than usual.

As well as this you will probably still have the same everyday worries as your friends, such as the normal family squabbles, getting your homework done on time, or studying for exams. Below are some of the emotions you might identify with in more detail.

WORRY

MS can cause lots of worry because there are so many unknowns and at times it may leave you feeling helpless. It is natural to worry, but if you acknowledge these concerns, although they won't go away, it can make them easier to deal with.

ANGER

It is normal to be angry with MS. Sometimes it is difficult to separate MS from the person who has it – try to remember to be mad at MS, not your mum or dad. There may also be times that you get angry or upset with other people because they don't really understand what it is like to live with MS in the family.

Emotions continued

FRUSTRATION

Because MS is so unpredictable, it can make it hard to plan things, or plans may have to be changed at short notice. This can be really frustrating, especially if you were looking forward to doing something.

GUILT

Sometimes you might feel guilty that you can do things that your mum or dad can't, or because you don't want to do something they've asked you to do. At times you might get angry or impatient with them and then feel really bad about it later.

EMBARRASSMENT

A lot of young people are embarrassed by their parents at some point, for example if they do, say or wear the wrong thing. Some MS symptoms can make your mum or dad stand out. This might make you feel uncomfortable or isolated at a time when you don't want to appear to be different from your friends.

JEALOUSY

If your life has had to change because of MS, sometimes you may find yourself feeling jealous or envious of your friends whose parents don't have MS.

Everybody is different and will have different emotions at different times. This is natural.

"Nothing really worries me because ever since I was born my dad has had MS and nothing critical has ever really happened since then, so there is no reason why it should now."

Oliver, 12

"I worry about not knowing what could happen next. Could dad have another attack? Will it get worse? What will happen in the future?"

Sarah, 15

"I'm worried because I was told that one minute you can be totally fine and the next you could have problems with MS and I'm terrified that mummy might get bad. I know the tablets are helping, but I still can't help being scared."

Harriet, 10

"I can't go anywhere with my dad and when we do people are always staring at him and me and kids at my school keep asking what is wrong with him and they take the mick. I get worried when my dad goes to hospital because I don't know what will happen to him."

Melissa, 12

"My mum has MS and when I argue with her I sometimes forget."

Joe, 12

"It makes me sad because my mum has MS. I wish I could help her more. Other children make fun of my mum, which is hurtful to me."

Lily, 11

"My dad has been diagnosed with MS and I feel helpless."

Ruth, 15

"Our family can get into arguments, but this would happen anyway. Sometimes we can get annoyed because mum can't do things as fast as us."

Sarah, 12

"Sometimes it can be embarrassing like having your mates round and having to go and help your mum with her legs, or put her shoes on."

Joseph, 13

"I can't do all the things with my mum that my friends can do with theirs. It frustrates me."

Lorna, 13

I have extra responsibilities

Having a parent with MS may mean you have more responsibilities at home and less freedom than your friends have. You may only have to help when it's needed, or you may already have some everyday jobs like making your bed and keeping your room tidy. Sometimes you might have to do extra things like helping with the cooking, cleaning or doing the washing. But then, lots of young people have jobs to do in the house when their parents don't have MS. Some young people may have to spend some of their time helping to care for their parent.



"I have to help out a lot and sometimes find it hard to get to places and sometimes when I am asked for help I can struggle to do it. But I have got used to it now and I do feel good after helping out my mum. In fact sometimes I think I would miss it."

Sam, 14

"I have to help mum a lot more and she can't do as much stuff with me, but she helps me a lot so it's not so bad because after a while you get used to it."

Ben, 12

"I have more jobs to do and friends don't come round much because it causes stress."

Teresa, 12

"Mum can't drive me to school and I have to do her tablets every day. I have to know how to do more things in the house in case mum gets ill."

Claire, 11

It changes our social life

MS is unpredictable, which often means that your mum or dad won't know how they're going to feel from one week to another or even one day to the next. This can have an impact on your social life. If your parent is feeling really tired you might have to stay in and do some extra jobs, when really you want to be out with your friends. Occasionally plans for a day out with the family might have to be changed or even cancelled at short notice because your parent is having a 'bad day'. This can be really frustrating if it is something you've been looking forward to for ages.

Sometimes MS means that your mum or dad may not be able to do as many things with you as they used to do. Symptoms like numbness, especially in the hands or feet, might mean that they don't always feel very safe driving, so they might not be able to give you a lift to school or to the cinema like they normally do. If they get tired very quickly, they might not be able to stand for a long time at a football match or walk for hours around the shops.

"I can't have as much freedom. I can't have a friend round. I have to spend time caring for my dad. We can't go out as a family for a meal."

Ann, 14

"My dad has MS so he can't do all the normal dad stuff like play football in the garden."

Oliver, 12

"It affects me because mum can't do things sometimes, but it is more normal for her to be fine."

Rachel, 12

"It restricts certain parts of my life. I always have to think about things we could do together. It frustrates me because I knew my active mum before and now to see her limited frustrates me."

Eleanor, 15



We have less money

If your mum or dad has to work part-time or stop working because of MS, this could mean that there is less money for doing things like going to the cinema, shopping, day trips, or going on holiday.

“We can’t afford luxuries anymore because of mum losing her income so we have to economise. We can’t go on day trips out shopping like we used to or go out for long because she gets too fatigued (no long walks - if there is any walking we need a wheelchair for her). I do more chores and I help around the house without being asked sometimes because I feel I should be doing my bit to help. I worry about the financial situation.”

Charli, 17

**"It is really stressful, especially where money is concerned."
Rachel, 11**

**"It restricts our family on what we can do; we can't make plans for days out. Mom had to stop working so money is tight."
Samantha, 11**

**"My mum can't work and that means dad has to do more overtime, so we don't see him as much as we would like to."
Emma, 11**

Why me? Why my family?

Sometimes there will be days when life just doesn't seem fair. Maybe you can't go out with your mates because your help is needed at home, or you've had to cancel a family day out again because your parent isn't feeling well. At times like this, you might think why did it have to be you who has a parent with MS?

It is **natural** to feel like this occasionally. In fact you'll find that everybody feels like this when life isn't going quite how they planned it, or expected it to be.

**Danny wrote this poem
describing his feelings about MS:**

**Annoying monster
Cruel attacker
Outing stopper
Horrible geezer
Family splitter
Body spreader
Good feeling destroyer
Person hurter
Everyone hater
Worldwide heartbreaker
Seeing people preventer
Danny, 11**

**“It is hard.
The children who
make fun of my mum
don’t know how hard
it is. I want a miracle
cure for my mum.”**

Lily, 11

**“When I get
upset I don’t think
it is fair how my mum
is and all my friends’
parents are normal and
can do most things
they want.”**

Emma, 13

**“I sometimes
feel jealous of my
friends who have
parents that don’t
have MS.”**

Sophie, 12

Some tips for coping

If you are finding things difficult or upsetting, sometimes it can be a huge relief to talk to somebody else about your worries. This might be your parent with MS, another member of your family, a friend, teacher, young persons' group or helpline. Most towns have a young persons' group, and helplines are useful if you don't want to talk face-to-face with someone.

The contact details of some sources of information and support can be found at the back of this book.

Talking about your worries may make them easier to deal with, or someone might come up with an idea to help that you hadn't thought of. Over the next few pages some young people share their ideas and tips about what they do to help them cope.

“Try not to worry even though it is hard not to and if your mum is going through a difficult time leave her and don't get into an argument. Let her calm down and then talk to her about what has just happened.”

Sarah, 12

“I talk to a very close friend of mine whose dad has ME and knows what I’m going through.”

Laura, 12

“You’re not alone. There are lots of other people who have parents or relatives with the illness. There are many organisations that you can talk to and MS isn’t as bad as some other illnesses.”

Jonny, 13

“I talk to my mum about things and say I’m finding it hard. She is great and really listens to my problems; we try to work together to solve them. I had to do a lot of the housework, but mum listened and now we have a cleaner who comes once a week. I feel so much happier and our house is so much tidier.”

Jodie, 13

"I talk to my friends or mum. I leave dad for a while because I'll only get angry, then I talk to him. Life's too short to be angry with or without MS."

Peter, 14

"If you are upset don't bottle it up, be brave and tell the parent who has it the way you feel and they can reassure you."

Teresa, 12

"I have a cuddle with my mum and we cry together. I could also talk to people who come to our school every Wednesday, but I haven't as yet."

Jessica, 12

Make time for yourself

MS will have an impact on your life, but it is also important to make sure that you have some time to yourself and that you don't allow MS to dominate everything. Try to find the time to do something that you enjoy, whether this is reading a book, listening to music, drawing, singing, playing an instrument or computer games.

Physical activity is especially great when you feel down, frustrated or stressed. As well as being good for you and getting you fit, it can be a good way of meeting new people and spending some time away from the house. If sport isn't your thing, you might be interested in joining a drama, dance or photography group.

"I go out and see my friends. That often takes my mind away from things for a while and I can have a sociable time with my mates or ring either of my older sisters."

Sam, 14

"I talk about it to my friends Kelly and Becky, my grandma and dad."

Mollie, 11

"I go out with my friends and have a good time or even stay over at someone's house for a night and then come home and I can deal with it better as I have my head cleared and prepared."

Hayley, 13

"I write songs to help me express my emotions and it always makes me feel better."

Claire, 14

"When I go to my street dance classes I de-stress, let my hair down and focus my mind on other things."

Rachel, 11

"I batter my pillow."

Jack, 11

"I will either put on my playstation or I will go into my room and play my music."

Patrick, 14

"I make sure my mum is cosy and has everything she wants and leave her alone to rest whilst I play with my Lego that I love."

Nathan, 12

"I've recently joined a football team, so even though dad can't play any more he can still come and watch me. It's great fun, I've made a couple of new friends and giving the football a good kick is a great way to get rid of any frustrations."

Daniel, 12

It's not all bad – the positive side of MS

Having a parent with MS can make things difficult at home and unfortunately in some cases it can lead to families living apart, either as a result of separation, divorce, or because your mum or dad might need care that means they are no longer able to live in the family home. However, many families find that MS brings them closer together. Often they find they appreciate each other more and make more of an effort to do things together.

You are at a time in your life when you might feel under pressure to fit in with everybody else and you don't want to be different from your friends. Having a parent with MS might have taught you that it is OK to be different. It may have made you more thoughtful and more considerate of other people's feelings.

Although having extra jobs at home can seem like hard work at times, skills like being able to cook and do the washing are all things that will be really useful when you eventually leave home. You may also find, without even realising it, that you have become more mature or confident than your friends who haven't had to grow up with a parent who has a long-term condition, because you are used to being more independent.



“My mum is the best, most loving, caring person in the world. I don’t think life could be the same without her. Mum is affected badly I think, and it can affect the whole family, but everybody is so supportive it is unbelievable.”

Sam, 14

“My mum isn’t any different because she has MS. Everyone loves my mum. I think she’s GREAT.”

Scarlett, 13

“I treat my dad as a normal dad. I don’t look at him as being disabled.”

Melissa, 12

"I think it has made us realise how much we take for granted."

Jodie, 13

"When my mum was diagnosed she was upset and scared. Every time I cried she would cry, but there was no need because since then our life has just been normal."

Emma, 14

"It doesn't matter if your parent has MS. They are still the same person that they were before."

Stephanie, 11

"Life is hard but you learn to cope with it. There will be good days and bad days. Don't worry - be strong. It's not all bad because they are still capable of most things."

Rachael, 14



“Sometimes I get upset because of MS, but now I think ‘It’s not the end of the world’. I try to involve dad in things, so I talk to him a lot and read to him. When I make him laugh I get a warm feeling inside, like I’ve done something right.”

Rachel, 11

“It doesn’t mean life dramatically changes and can bring families closer together. It gives me a cause to help, something I can help with that relates to my life.”

Sarah, 15

“I feel good when I know I’m helping my mom. I want to be a research scientist and attempt to find the cure to MS and help all those with it.”

Damon, 10

"It's not all bad; my mum spends more time with me because she has MS."

Claire, 11

"Sometimes it can mean life is better than before - like when I get to see my dad a lot more and he can come to the school play and events."

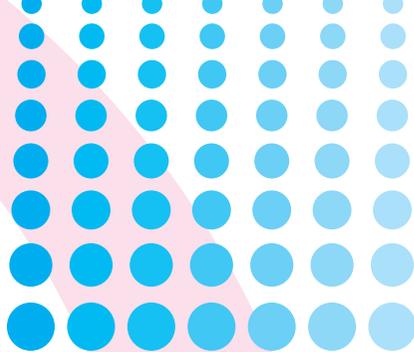
Gemma, 12

"It brings the family closer as you feel the need to make the most of life as anything could happen tomorrow."

Catherine, 12

"MS has brought my family closer together as my dad used to work away a lot, but now because of the MS, he only works for part of the week instead of 6/7 days. So it's not all bad!"

Sarah, 15



“With my dad working in London and my mum stuck at home most of the time, me and my brother are very independent and rely heavily on public transport to get everywhere.”
Jonathan, 17

“It has been a difficult journey since diagnosis and can be hard to see my mum going downhill, but I have grown up a lot and gained independence.”
Leanne, 17

“It sort of helps me to prepare for the future by making me do things that I will have to do if and when I move out.”
Emily, 13



The people who helped with this book

Firstly, we would like to thank **all** the young people who completed our questionnaire or participated in the 'MS in the family' workshops, without your help this book would not have been possible.

We would also like to thank the following young people, some of whom you can read more about later, who reviewed the book and provided invaluable comments:

Anna J, Ashleigh R, Ben G, Ben W, Eleanor R, Emma H, Harriet B, Jodie W, Laura C, Oliver W, Sam G, Sam N and Sarah B.

SAMANTHA GRAINGER

Hi my name is Samantha and I am 12. I live in Liverpool with my mum, dad and brother Ben.

We found out that my dad had MS when I was 9. We are a very musical family, I am a singer in a band, Ben and my dad play the guitar and my mum sings too.



Sam, Ben and their dad

BEN GRAINGER

Hi, my name is Ben and I'm 14.

My dad was diagnosed with MS about 3 years ago, so I was about 11. Samantha is my sister. One thing I would say about my family is that my mum is probably the glue that keeps us together because she does so much for us and looks after my dad when I can't.

LAURA CALDWELL

My name is Laura and I am 12. I live in Scotland in a lovely little village called Comrie. My dad was diagnosed with relapsing remitting MS when I was 6. I knew there was something wrong but was too confused to ask, and I only found out about the diagnosis when I was 9. I have two younger sisters Eve (11) and Juliet (9). My dad has been following a special diet for about 3 years; it helps keep him fit and healthy and helps me think positively about the future with my dad.



Laura

Laura's sisters

BEN WALLEN

My name is Ben and I am 13. I live in Ilford in Essex and I go to Ilford County High School, I enjoy it there. I was 7 when my mum was diagnosed with MS. I have a younger brother Oliver. My family love to go to antiques and boot sales together.



Oliver

Ben

OLIVER WALLEN

My name is Oliver and I am 10. Ben is my older brother. I was 4 when our mum was diagnosed with MS. Even though mum has MS my family still find lots of time to go to places together, it's amazing how much time we spend together.

Sources of information and support

We hope that this book has been helpful in answering the questions you had about MS and that you have picked up some useful tips from other young people who are in a similar situation to you. However, if you still have some questions that are unanswered, or if you want more information on MS or living with a parent with MS, below are the details of some organisations that may be able to help.

NATIONAL MS ORGANISATIONS

MS Trust

The MS Trust is a UK-based charity for people with multiple sclerosis, their family, friends and all health professionals. Their website provides information for anyone affected by MS.

www.mstrust.org.uk

Tel: 01462 476700

National MS Society

This is the website of the American MS Society. It contains two sections specifically for young people – Keep S'myelin and Teen InsideMS.

www.nmss.org

Canadian MS Society

This site contains lots of information and interactive activities for young people with a parent with MS.

www.mssociety.ca

MS Society

The MS Society is another UK-based charity that produces numerous publications on MS.

www.mssociety.org.uk

Tel: 0808 800 8000

YOUNG CARERS ORGANISATIONS

The Princess Royal Trust for Carers – Young Carers Site

This is an interactive website for young carers that includes discussion boards and live webchats.

www.youngcarers.net

Barnardos

Runs services throughout the country supporting young carers.

www.barnardos.org.uk

The Children's Society – Young Carers Initiative

A site for young carers, their families and those who work to support them across the UK.

www.youngcarer.com

This book has been produced with the help of lots of young people who know what it is like to have a parent with multiple sclerosis. Here they share their experiences, worries and emotions about living with MS in their family. In addition to answering some of the questions you may have about multiple sclerosis, we hope this book will enable you to explore your feelings about MS and how it affects you, as well as helping you realise that you are not alone in the feelings you may be experiencing.

Everybody's experience of multiple sclerosis is different and not everything in this book may be relevant to you at this moment, but it may be useful if you want to know more in the future.

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