



Multiple Sclerosis Society

First edition
February 2008

MS in your life – a guide for young carers

A stylized illustration of a hand in shades of blue and green, holding a white mobile phone. The phone screen displays the text 'Do you help look after someone with MS?'. In the background, there is a large white key with a blue ring, and a white pen with a blue band. The entire scene is set against a light green background with white geometric shapes.

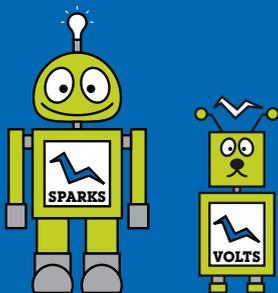
Do you
help look
after
someone
with MS?

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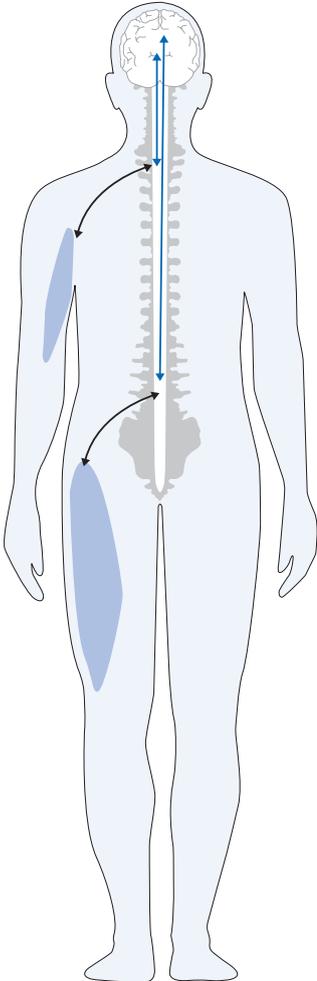
You might already know quite a lot about MS, but because it affects everyone differently, you might have questions even many years after you first heard the name 'MS'. This section answers some of the most common questions people have, but remember you can email or phone the MS Society if you have others. All our contact details are at the back of this booklet.

There is also an MS Society website for kids and teenagers affected by MS in their family. For online chat, information, advice and real stories from real people, go to **www.youngms.org.uk**



What is MS?

Multiple sclerosis (MS) is a condition which affects the central nervous system. *Sclerosis* comes from the Greek word meaning scars. As the condition causes lots of scarring in the central nervous system, it is known as *multiple sclerosis* meaning 'many scars'.



What is the central nervous system and how does it work?

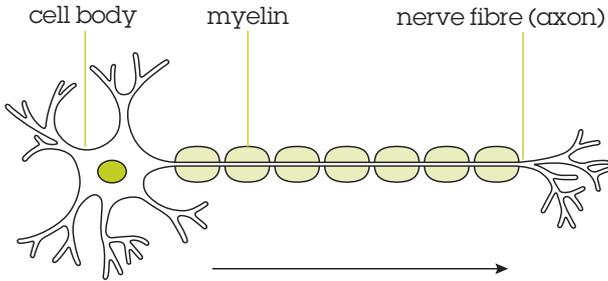
The central nervous system is made up of the brain and spinal cord. The brain controls the body's activities and the spinal cord passes messages between the brain and the rest of the body, through the nerve fibres.

For example, nerves in the hand send a message through the spinal cord to the brain. The brain thinks 'oh, the hand touching the fire is hot, let's move the hand away'. The spinal cord carries that message back to the muscles in the arm to pull the hand away from the fire.

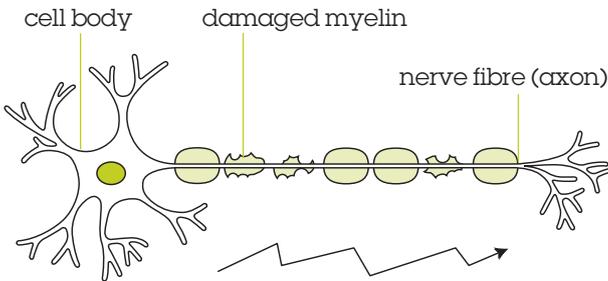
How does MS affect the central nervous system?

MS affects the nerve fibres in the brain and spinal cord and the protective layer around the outside of these fibres, called myelin. Myelin makes sure that the messages are carried smoothly and quickly.

Message carried smoothly and quickly



Disrupted message



But in MS the myelin is attacked and becomes damaged. Messages are slowed down or sometimes can't get through at all. This is what causes the symptoms of MS, such as slow movement or not being able to move certain parts of the body. It's a bit like when reception is bad on a mobile phone – the messages you say into your phone and the messages you hear from the other person can become distorted or cut out completely.

What are the symptoms of MS?

One of the difficult things with MS is that everyone's symptoms are different. They can come or go and will sometimes be better or worse from day to day. The following list includes some of the more common symptoms. Not everyone with MS will experience all of these:

Extreme tiredness – often called 'fatigue'

Balance problems

Problems with vision like blurry vision, temporary loss of sight

Numbness or tingling or 'pins and needles'

Pain

Loss of muscle strength – for example, not being able to carry heavy things like shopping bags

Muscle stiffness and spasms

Anxiety – worrying about lots of things

Depression or mood swings – feeling sad all the time, getting angry easily

Difficulty with memory and concentration (this is also known as cognitive problems)

Difficulty with speech such as slurring, slowing or changes in tone

Difficulty passing urine – needing to go to the toilet urgently or not feeling when they pass urine

Lots of other conditions have these same symptoms and that is why sometimes it takes a long time to get a diagnosis of MS. And some of these symptoms occur when nothing serious is wrong – it is quite common to get things like 'pins and needles' – it doesn't mean you are getting MS!

Types of MS

MS is different for each person, but it is usually described as a particular type of MS:

Relapsing remitting MS

This is when people have ‘relapses’ – when their MS symptoms are quite bad – and then recover for a while (called ‘remission’). People cannot predict how often they will have a relapse, or how exactly it will affect them. There can be years in between, or months, and there can be different symptoms with different relapses. This is the most common form of MS.

Secondary progressive MS

This is when someone started with relapsing remitting MS but over time has noticed that their symptoms are slowly getting worse and that some symptoms don't go away.

Primary progressive MS

People with this type of MS have symptoms that gradually, over time, get worse. They don't get relapses.

How is MS diagnosed?

MS is not easy to diagnose and it can be a long time before a person gets a definite diagnosis. There is no single test which gives the answer ‘yes’ or ‘no’. Doctors will always start by looking at the person's medical history and past illnesses. They will then follow up with further examinations. The following techniques are used to diagnose MS, and to rule out other conditions:

MRI scan

MRI stands for ‘magnetic resonance imaging’. The MRI scanner is a big tunnel-like machine which takes a photo of the brain and spinal cord. This photo is so detailed it can identify the scars on the brain and spinal cord and pinpoint the exact place where the myelin is damaged. The whole process takes around half an hour and does not cause the person any pain.

Visual evoked potentials

These are simple tests carried out on vision, to see how long it takes the brain to receive messages from the eyes.

Electrodes are placed on the head to monitor brain activity and how it responds to things that the person sees. If there is myelin damage, the responses will be slower. This test is also painless.

Lumbar puncture

The lumbar puncture is also called a spinal tap. This is carried out under local anaesthetic. A sample of the spinal fluid is taken by inserting a needle into the space around the spinal cord. This fluid is then tested to check for abnormalities. A lumbar puncture can be uncomfortable and people often get headaches straight after the test. Lumbar punctures tend to be used when other tests have not been able to give a confirmed diagnosis.

Who gets MS?

It is most often diagnosed between the ages of 20 and 40. Around 100,000 people in the UK have been diagnosed with MS, which is about one in every 600 people. Anyone can get MS but women are more likely to have MS than men – for every one man with MS, there are two to three women who have MS. Children can also be diagnosed with MS, although this is rare.

How do you get MS?

No one really knows what causes MS. There is lots of research going on to try and identify why people get MS, so you might hear things on the news or read them in the newspaper about the latest research. So far, most scientists think the following may affect who gets MS and who doesn't:

Genes

MS is not inherited, so it doesn't mean you will get it if your mum or dad has it. Scientists think that genes play a role in determining whether you can get MS or not. Genes are made of your DNA and control things like your eye and hair colour. Scientists think that some people have a specific group of genes that means they could develop MS. However, having genes that mean you *can* get MS does not mean that you *will* get MS. There are other factors which cause MS.

Where you live

Scientists have found that MS is more common in countries further away from the equator. This means it is quite common in colder areas like Britain and Scandinavia but is less common in hotter countries like Malaysia or Ecuador. They don't yet know why this is. There has been some research done that says that low levels of Vitamin D (that you can get from the sun) can have an impact on the likelihood of someone developing MS.

Triggers

Scientists are looking into viruses, such as mumps, measles and chickenpox, which might trigger MS. Other research has suggested that chemicals in the body called hormones may play a part. However, many people have these viruses and hormones inside them and never develop MS. Researchers still have a lot to discover about these possible triggers.

Is there a cure?

No, not yet. The MS Society spends around £2 million each year on research to try and find the causes of MS, work towards a cure and improve treatments and care for people with MS.

Will I get MS?

If your mum or dad has MS there is a slightly higher risk of you having it too. However the chances of you getting MS are still very small. MS is not inherited or caught and it is rare for more than one person in a family to have MS. If you have a parent with MS, there is only about a two per cent chance you will also develop it. In other words, there is a 98 per cent chance that you won't.

Can you die from MS?

Most people who have MS will live as long as anybody else. However, those people whose immune system has been badly affected (usually many years after developing MS) will find it harder to fight off infection or diseases and they can die from those.

Can it be treated?

Although there is no cure, MS can be treated by managing the symptoms and reducing relapses. These are the main types of treatment:

Drugs to help symptoms

Some medications may help improve the daily symptoms in MS such as pain, bladder problems or spasms.

Steroids for relapses

Steroids can be used to help someone recover more quickly from a relapse. They don't make the MS better but can make the recovery time quicker. Steroids are only usually given if a relapse is really bad or much worse than usual. These kind of steroids are not the same as anabolic steroids sometimes used by athletes.

Disease modifying drugs

These drugs help to reduce the number of relapses for some people. The most common disease modifying drugs are known as beta interferon and glatiramer acetate. The actual brand names that you may know are Avonex, Rebif, Betaferon, Extavia or Copaxone. These drugs are not suitable for everyone with MS so it is important that you ask advice from your family's MS nurse or neurologist. These drugs are all given by injection, at home.

Complementary and alternative therapies

Some complementary therapies may benefit the person with MS – for example reflexology, yoga and massage might all help. There is not yet a cure for MS so no therapy can honestly claim it is. And if a therapy is called 'alternative' or 'natural', this does not mean it is automatically safe or effective. Anything which is powerful enough to have a positive effect might also have a negative one. Just as with a prescription drug, before trying any new therapy the person with MS should speak to their GP, MS nurse or neurologist.

Practical steps

As well as this type of treatment, it can be helpful to manage symptoms. For example, if the person with MS feels poorly when they are hot, using an electric fan or air conditioning unit can help. Physiotherapy can help people find exercises to help their muscles stay supple, or improve their balance, for example.

When a member of your family is diagnosed with MS you will probably experience lots of changes. There may be lots of different professionals involved with your family and relationships between family members can change, even if only for a short while.



Changes in your family

After diagnosis, some people are glad to find out what is actually wrong with them. However, it is also usual for them, and their family, to have a whole range of feelings – such as shock, anger, sadness or fear – about MS. This may mean people are upset or are short tempered. Remember that even the people who haven't got MS have to live with it. So if it's your dad who has MS, your mum or dad may both be sad and scared.

Some of these changes can have a positive effect on a family. MS brings its difficulties, but you may find that your family gets on better, are closer and look after each other more. Living with someone with an illness or disability will also mean that you become more understanding towards others as you know not to judge people based on appearance or first impressions. If you are helping out around the house, you are learning new skills for the future. Many young carers find that they want a career that revolves around looking after people, such as nursing or teaching – and you will have already developed many of the qualities needed to do such a job well.

Who are all these new people...?

Lots of people can be involved with your family when you are living with MS. This can be really confusing as you might not know who they are, what they do or why they are visiting you. This list explains a little bit about the people who may be involved with your family:

GP (your doctor)

Neurologist

MS nurse

Physiotherapist

Occupational therapist (OT)

Social worker

Clinical psychologist

Counsellor

Local MS Society

Role	What they do	How will they help?
GP (your doctor)	Deals with general health and day-to-day treatment of MS.	The GP will be the first stop when the person with MS in your family is unwell. They can also refer on to other professionals like a neurologist or occupational therapist.
Neurologist	A neurologist is a special doctor, sometimes called a consultant, who deals with conditions, like MS, that affect the nervous system.	They would be the person who diagnosed the MS and they are responsible for prescribing treatment and/or medicines.
MS nurse	An MS nurse is a nurse specially trained to deal in MS.	They are often a very good source of support, information and guidance for people with MS and their families. They work with lots of other professionals and organisations to provide help to people affected by MS. If your family does not have an MS nurse they can ask their GP, neurologist or the MS Society to find out if there is one on your area.
Physiotherapist	This is someone who is trained to help people with their physical needs.	They may help after a relapse or if the person with MS has difficulty with mobility or fatigue by giving exercises to help strengthen the body.
Occupational therapist (OT)	This person's role is to help people with MS to be as independent as possible.	They will know lots about equipment that can help make life easier such as wheelchairs, or adaptations to your house.

Social worker Social workers are people who help with social difficulties – like everyday tasks such as cleaning or going to work.

The social worker will be able to arrange for short breaks, respite care and/or care workers to come into the house. They also provide support to help with everyday things like taking you or your brothers or sisters to school. They will look to help everyone in the family.

Clinical psychologist Clinical psychologists help with some symptoms of MS, such as memory function.

Clinical psychologists will work with the person with MS to help them with their memory and managing their moods.

Counsellor This is someone you can talk to about your feelings.

Counsellors can work with people on their own – particularly after a person has been diagnosed – or with you all as a family. You may also have a school counsellor that you can talk to on your own at school.

Local MS Society Your local branch of the MS Society. The MS Society is a national charity for MS.

The branch can provide lots of advice, help and support. It also gives you a chance to meet others living in families affected by MS. The branch could be a great way to meet new people.

Changes in relationships

Lots can change with MS. The person diagnosed may not be able to go to work anymore, or their role in the family – such as being the sporty one – may change.

Symptoms of MS can affect their behaviour. For example, fatigue can mean they are very tired and have to rest a lot. Fatigue can also make other symptoms worse, such as problems with walking. MS can also cause mood swings and make someone happy one minute and angry the next. You have to remember that they are often not angry at you – they are often angry at themselves and their MS, or the anger might be another symptom of the MS, which health care professionals like those mentioned above can help with.

Changes to your social life

Unfortunately, MS is very hard to predict – and this may mean it is difficult to plan activities as the person with MS may not know how they are going to feel. Trips out might have to be postponed or activities cancelled at short notice. This can be very frustrating.

MS might also mean they can't always drive, or they might not be comfortable driving as far as they used to – for example if they are feeling very tired, or have numbness in their feet, it is not very safe to drive. This means simple things like being taken to school or dropped round to a friend's house can become very difficult.

Where you go on holiday may be affected – for example the person with MS may not be able to go somewhere hot if the heat makes them feel unwell.

Less money

Sometimes the symptoms of MS mean the person has to give up work, or reduce their hours. This can mean the family has less money, which can affect things like going out, shopping and taking holidays.

More responsibility

You may have started helping out around the house more or helping the person with MS with daily activities. When young people have to help out at home due to illness or disability they are sometimes known as 'young carers'. There's more about being a young carer in the next section.

If MS gets worse

When someone has had MS for a long time, their symptoms may get worse over a period of time and they may need more care than before. Social care services can provide care workers but often another member of the family becomes the person's 'carer'. This can become quite a demanding role and the carer will need to have breaks. Usually social care services will be able to provide some sort of respite care. 'Respite' means 'break' and respite care aims to give carers a break by providing alternative support. This can be in the home or in a specialist centre.

If the person with MS develops mobility problems – for example, they find it hard to walk up stairs – the family home may need to be adapted. This can be done through your social worker and the council may help pay for some or all of the costs, depending on the family's income. An occupational therapist will come round to the house and discuss the adaptations needed.

Cars can also be adapted to make sure that the person with MS can continue driving safely, and easily get in and out of the car as a passenger.

If someone needs even more care

In some cases, the person with MS may need lots of extra care. This is often provided in the home, with care workers visiting to help in the mornings or at night for instance. For some, moving into a care home may be the best option. This is where someone would go to live, and trained staff provide the care they need 24 hours a day. This can be a very difficult time for your whole family as you can feel guilty about not being able to look after the person with MS anymore. If this happens,

it is important to make sure you show everyone in the family lots of love as everyone will be feeling quite sad. And remember that no-one is to blame for the way MS affects someone.

Nowadays, social care services will work hard to find ways to help people live at home for as long as possible. In most cases the person with MS and their family will know best about the support and care they need, and social care services can often provide 'Direct Payments' – money that allows the family to arrange care themselves. Most people say that this makes them feel much more in control.

If the worst happens...

Most people with MS live about as long as everyone else. But people who have MS very badly find it harder to fight off infection and diseases. If a parent dies, it is really important to speak to someone about how you are feeling and not to bottle it all up. Losing someone you love is always very difficult and you will need to give yourself time to grieve. It is OK to cry, scream and shout if you need to. But it is important to try not to take it out on those closest to you – they will be hurting as much as you. You may be able to speak to a school counsellor or get in touch with organisations such as RD4U or Winston's Wish. You can find their details at the back of this booklet.

It is important to remember that there is no right or wrong way to feel. However you feel is OK. It is also OK to have fun – you don't need to be sad all the time. In fact the person who died would want you to still have fun! Don't feel guilty if you enjoy things and have a good time with your friends – this is normal.

Being a young carer is much more common than you may think – in fact there are at least 175,000 young carers in the UK. They are helping to look after people with a whole range of illnesses and conditions. Some of you may be helping another adult look after the person with MS, others may be the only person caring for them. It is important that you are able to ask for help when you need it and that you say 'no' when you are not comfortable with doing something.

175
thousand

Becoming a young carer

Common tasks

Young carers often help with the following:

Housework

Household shopping

Cooking

Looking after brothers and sisters

Listening to the person with MS when they are sad, upset or lonely

Supporting other members of the family

Helping the person with MS get dressed

Helping the person with MS get washed or go to the toilet

What help is available

As well as extra support in the home, or a respite break for you and your family, your social worker may have ideas for how you can be better supported with your school work or helped to have a social life with your friends. Carers, including young carers, can usually get help from their social care services department (known as social work services in Scotland). Young carers often meet a social worker for an 'assessment'. Although this may sound scary, it is not like an assessment at school, it is a chance to tell the social worker what you are (and aren't) happy about. Social services can provide care workers to come in and help with the person with MS and can organise respite care – where the person with MS goes away for a short break.

In most places there are special support groups for young carers. These tend to be groups that do loads of fun activities or just give you a chance to meet other young people who are also helping to look after people they love. There are also a number of great websites, with online chat rooms for instance. Check out the Information and support section of this guide.

Saying no

If at any time you don't want to do something, tell your parents or your social worker. It is OK to say no. It does not make you selfish or a bad person, it makes you human! You should not be left to do caring tasks that you don't want to do and it is important that you tell someone.

It is also really important to talk to someone if your caring role is stopping you doing things you enjoy or that are important to you and your future. It is important for everyone to have a break and to enjoy themselves. It is also very important that you get the time and space you need to do well at school and to complete your homework. If caring affects your education, it really is time to say no! Social care services need to consider what's best for you as well, and they might arrange for extra help for you and the person you care for.

If you are trying to explain MS to your friends, you might want to explain it with a simple demonstration. You can explain MS by using a straw to suck up a drink. Show them what happens when the straw gets a hole and explain that it is the same as the messages in the body. And if you bend the straw completely it will show that messages can't get through, like a relapse, but when you straighten it up, the drink flows freely again which explains why MS symptoms aren't always permanent.



School and friends

Telling your friends

Some people find it easy to tell their friends about MS, others find it really difficult. It can be daunting to bring up a subject that may make you different from others around you. You might feel nervous telling them about MS as they may not understand it. Remember your friends are your friends because they like you and want to spend time with you.

Talking to your teacher

You can talk to your teacher about your family situation. They can be really supportive and help you out a lot. Sometimes the situation at home may affect your school life – being late or absent if you have to help out at home, not being able to get your homework done or just being upset making it hard to concentrate. Teachers can't help if you don't tell them! If you want to explain to your classmates about MS you could ask your teacher if you can talk about it within class during PSHE (Personal Social and Health Education) or Circle Time. You might be able to arrange for an MS nurse to visit the school to explain about the condition.

Being bullied

Some young people get bullied because their family is seen as 'different' – for example if you have to stay in to help look after someone or if your family can't afford the things that your friends have. If you are being bullied it is not your fault. Take practical steps to try and avoid the bullies – such as avoiding the places they hang out at break times. Try not to give them a reaction and pretend that it doesn't bother you. But most importantly you must tell an adult that it is happening. This can be scary but it will help things get better.

Being a bully

Sometimes you might feel that the only way to vent anger and frustration is to take it out on somebody else. If you feel like this, talk to someone about your concerns and how you feel – a friend, a relative, a teacher or an MS nurse, maybe. Everyone needs to get things off their chest at times, but taking it out on someone else at school or in the family can just make things more difficult for everyone.

ANGER

and frustration

guilt

worry

jealousy

L O N E L Y

sadness

embarrassment

Feelings and emotions

MS is a very frustrating condition to live with. It is unpredictable and different for each person. It is very normal to worry about the person with MS, what will happen in the future and how it will affect you. You will probably feel a whole range of emotions such as:

Anger and frustration

Worry

Guilt

Jealousy

Loneliness

Sadness

Embarrassment

How to deal with these emotions

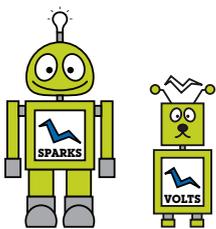
Anger is a normal emotion, but how you deal with it is important. Anger can cause you to say or do things that you don't mean. Next time you feel angry, think of a way to let it out while still being in control. Try punching a pillow, or screaming into a pillow to let it out. Play your music and jump about (so long as you don't annoy everyone else in the house!), go for a run or kick a football really hard at a wall. These are all ways of controlling your anger so you can let it out without it affecting anyone else.

If you are really **worried** about something then the best thing is to talk it over with someone. That could be an adult like your parents, teacher or counsellor or someone your own age like your friends. Sometimes the best thing is just to share that worry with someone else. If you get worried when you leave the person with MS, talk to school to see if you can call home at lunchtime to check everything is OK, or have a mobile phone with you when you go out with your friends.

If you feel **guilty** about things then again it is good to talk this over with someone. Sometimes you may feel guilty about being in good health, or because you feel angry at the person with MS. You might feel guilty for going out and having a good time without them. Remember it is important you have a break and have fun!

It is a perfectly normal human reaction to feel **jealous** of friends and family who don't live with a condition like MS. No one would choose to have a family member to be ill, so of course you sometimes wish that your family was different. When you feel jealous, think about all the good things you have in your life – maybe MS has brought your family closer together, maybe you've made new friends through the MS Society branch or a young carers project.

Sometimes you may feel like you are the only person going through this and you may feel really **lonely**. Again, many people feel lonely at one point or another in their lives. But there are lots of ways to help you feel better – you could join your local youth club or get involved with the MS Society branch. If you have access to a computer there are lots of websites where you can chat online – take a look at the MS Society message boards, the young carers site www.youngcarers.net, or www.youngms.org.uk. Just remember when talking online, don't give out personal details like your phone number or where you live.



Sadness is really hard to deal with – sometimes you can be so sad that it actually causes you physical pain! It is normal to feel sad some of the time. Sadness can show itself in a number of ways and can range from crying all the time to being very quiet and not wanting to do anything. It is fine to want to have time by yourself too, to think about things in your own way. However, it is really important that you don't shut yourself away from others – make sure you keep talking to the ones you love.

Sometimes it can be really hard to deal with people staring and asking questions about the person with MS. It is only natural to sometimes feel **embarrassed**. Unfortunately some people don't understand disability and will stare if they see someone in a wheelchair or having difficulty eating or speaking. Sometimes you have to act like you don't care if they stare. Hold your head high (even if you don't feel like it) and pretend it doesn't bother you. Sometimes people just genuinely don't know how to react to disability and don't realise that they might be embarrassing you and your family.



Looking after yourself

One of the most important things is to make sure that you are looking after yourself properly. This means making sure you are eating properly, taking exercise and listening to your body. The last thing the person with MS in your family would want is for you to make yourself ill or unhappy because of them. Plus, the better you are, the better you can make them feel!

Feeling stressed

When you feel stressed it is your body's way of ringing a warning bell – it is telling you that you need a break. There are lots of ways to help deal with stress:

Talk about how you are feeling with someone you trust

Go out with friends

Exercise

**Put aside time each day to do something you love
– like watching your favourite TV show or listening
to your favourite music**

**Write your feelings down – in a letter, diary,
poem or song**

Sometimes when people reach a very high level of stress they may need to find ways of letting out their feelings. Sometimes people hurt themselves on purpose – this is known as self harm. Sometimes people will also think of killing themselves. If you have feelings like this you must speak to someone like your teacher, school counsellor or GP. This shows that you may be depressed and this is a real medical condition which they can help with. Don't let it get to this point before asking for help.

Tiredness

Tiredness is a sign that you are doing too much. If you are having trouble sleeping it may be down to stress or worry. Here are some practical tips if you find it hard to get to sleep:

Keep a notebook next to your bed and write down everything that is worrying you before you go to sleep – this should help clear your head ready for sleep

Stick to regular bedtimes – your body will adjust to know the time it is supposed to sleep

Take a warm bath an hour before bed – it will relax you and the warmth will help you get sleepy

Have a hot, milky drink before bed

If you are sleeping well but still feel tired then you may be doing too much in a day and it really is time to take a break.

Having fun

One of the best things in life is to have fun! Just because there is MS in the family, it doesn't mean you are not entitled to have a good time with your friends and family. Make sure you take time out to have a laugh. After all, laughter is the best medicine!

Talking

Talking is one of the most powerful ways to make yourself feel better. Sharing your problems and anxieties is a way of 'offloading'. It doesn't have to be talking to an adult either – by getting involved with the MS Society or your local young carers project you will be meeting lots of other young people who understand your situation. You can talk to them about how you are feeling too.

Eating properly

To stay fit and healthy you need to eat a balanced diet. This means lots of fruit and vegetables and healthy proteins like lean meat and fish and carbohydrates such as pasta, potatoes and rice. You should eat at least five portions of fruit and veg a day. All this food gives us a good type of energy. Unhealthy foods, like crisps and chocolate, are packed full of fat and sugar so they will satisfy you for only a short period of time – after that you'll get hungry again. Slow releasing foods like pasta will keep you fuller for longer. A healthy diet will also keep the person with MS fit and ready to fight off any infection.

If you help out with the cooking and shopping at home, you may need some tips on healthy cooking.

Exercise

Exercise is a brilliant way of keeping fit and healthy. It keeps you looking your best and also helps fight against illness and stress. You should be aiming to exercise at least three times a week for 30 minutes at a time. Even if you don't like traditional exercise you could try:

**Getting off the bus a couple of stops early
and walking the rest of the way**

Dancing in your bedroom to your favourite music

Taking the dog out for a walk

Ice skating

Swimming

Street dancing

Maybe get a mini trampoline – they usually cost about £20

Almost the end...

So this is the last part of this booklet, where you will find a list of organisations and websites that you might find helpful. We hope that this information has helped you better understand MS and has answered some of the questions you may have had.

Let us know what you think of this guide and if there is any other information you want. You can write to us at:

MS Society Information Team

MS National Centre
372 Edgware Road
Cricklewood

London NW2 6ND

email infoteam@mssociety.org.uk

Don't forget to check out www.youngms.org.uk

We would love to hear from you!

Have a look on our fundraising website
www.mssociety.org.uk/events
it has lots of ideas under Community
Events that you could do at school
or in your free time.

Young Carers Organisations

The Children's Society – Young Carers Initiative

Find your local young carers group by logging on here:
www.youngcarer.com

The Princess Royal Trust for Carers Young Carers Website

For information, support, discussion boards and live web chats
log onto: www.youngcarers.net

Barnardo's

Barnardo's runs 14 young carers projects across the UK providing advice and emotional support as well as social events and opportunities to meet other young carers.

Telephone 020 8550 8822

www.barnardos.org.uk

MS Society

MS Society helpline

You can call the MS Society helpline between 9am and 9pm, Monday to Friday. It is free from landlines and from the following mobile phone providers: 3, O2, Orange, T-mobile, Virgin and Vodafone.

Telephone 0808 800 8000

Local MS Society branch

Look in your local phonebook or log onto the MS Society website and click on 'Around the UK: Local Branches'.

www.mssociety.org.uk

Young People's message board, MS Society website

Log onto the MS Society website and click on 'A Chance to Talk'.

www.mssociety.org.uk

Other Useful Organisations

Childline

The free 24-hour helpline for children and young people in the UK.

Telephone 0800 1111

www.childline.org.uk

Need 2 Know

Website for teenagers providing advice on all sorts of issues such as bullying, family and relationships.

www.need2know.co.uk

Winston's Wish

A charity to set up to support families and young people who are bereaved.

Telephone 08452 03 04 05

www.winstonswish.org.uk

RD4U

A website designed for young people dealing with the loss of a loved one.

www.rd4u.org.uk

Carers Connect

Social networking for carers.

www.carersconnect.com

MS National Centre
372 Edgware Road
London NW2 6ND
Telephone 020 8438 0700

**MS Society Scotland
National Office**
Ratho Park
88 Glasgow Road
Ratho Station
Newbridge EH28 8PP
Telephone 0131 335 4050

MS Society Northern Ireland
The Resource Centre
34 Annadale Avenue
Belfast BT7 3JJ
Telephone 028 9080 2802

MS Society Cymru
Temple Court
Cathedral Road
Cardiff CF11 9HA
Telephone 029 2078 6676

National MS Helpline
Freephone 0808 800 8000
(weekdays 9am-9pm)
Website www.mssociety.org.uk

The Multiple Sclerosis Society of Great Britain and Northern Ireland is a charity registered in England and Wales (207495) and Scotland (SC016433)

Disclaimer: We have made every effort to ensure that information in this publication is correct. We do not accept liability for any errors or omissions, and policy and practice may change. Seek advice from the sources listed.

Suggestions for improvement in future editions are welcomed. Please send them to infoteam@mssociety.org.uk

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