


A photograph of two young women standing outdoors and smiling at the camera. The woman on the left has long brown hair and is wearing a dark brown jacket. The woman on the right has short dark hair, wears glasses, and has a bright orange scarf wrapped around her neck. She is wearing a green parka. They are standing in front of a stone wall.

**For family
and friends**
when someone close
to you has MS

An orange diagonal graphic that starts from the top left corner and extends towards the middle of the right edge, creating a triangular shape in the top left of the page.

We're the MS Society. Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to stop MS.

We rely on the generosity of people like you to fund our vital work. If you would like to make a donation, you can do so by:

- Calling us on: **0300 500 8084**.
Lines are open Monday to Friday, 9am – 5pm
- Visiting us at: **mssociety.org.uk/donate**
- Posting your donation to: MS Society, National Centre, 372 Edgware Road, London NW2 6ND. Please make cheques payable to the 'MS Society.'

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A word from Nick, whose partner has MS

Before my girlfriend and I started dating, I knew she had MS. In the back of my mind I knew it was a serious condition. But it had never seemed to affect her life or behaviour, so I never gave it much thought. When we first started going out I began to learn a bit more about MS, through my own research and direct experience when she was ill.

Sometimes I'd feel sad and afraid, thinking about what this could mean for her. She told me that when she was first diagnosed she cried, and it was meant to be like a grieving process. This shocked me, as she is such a positive person. It upset me to picture her like that.

When her MS is making her ill, which thankfully isn't that often, I try to make her laugh and be patient with her, to show that I care. I think this booklet

will be valuable for people like me coming to terms with their partner's diagnosis. It covers the different feelings it involves and helpful and unhelpful things to say.

Great advances are being made in treating the condition and my girlfriend is on a DMT (disease modifying therapy) which is helping stabilise her relapses. I find it heartening that people with MS are leading fulfilling lives. And I'm glad my girlfriend is one of them.

A handwritten signature in black ink that reads "Nick". The signature is written in a cursive, slightly stylized font. The first letter 'N' is large and prominent, with a long vertical stroke. The rest of the name is written in a more fluid, connected script.

Five things to know

- 1 It can really help to talk honestly – and often – to each other
- 2 Lots of progress is being made in treating MS
- 3 People with MS can still live out hopes and plans they had before their diagnosis
- 4 Life goes on but some changes may need to be made
- 5 There's a lot of support out there for people with MS, their families and friends



About this booklet

This booklet is for you if someone you know has multiple sclerosis (MS). It could be your partner, friend or someone in the family. You might find it especially helpful if they recently found out they have MS.

Two things can often help:

- **information** – especially about treatments and what might happen in the years ahead
- **hearing from people in the same position**

This booklet has both. It'll hopefully make it easier for you to understand this new situation you're in, and get support if you need it.

In the pages that follow you'll see and hear from people with MS and those close to them. They want to share with you what they've learned. They want you

to know how, after a diagnosis of MS, life still goes on.

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.

“I never want to be defined by my MS. It's just a small part of me, and nothing more. I think some friends and family were afraid to ask about my MS. After I'd assured them it was OK, the questions started flowing, which I love!”
Steph

MS: what do I need to know?

First of all, you can't 'catch' MS from someone. People get it when their **immune system** isn't working properly. Your immune system is how your body fights off infections. But in MS it attacks **nerves** in your brain or spinal cord by mistake. These nerves control lots of different things your body does.

Over time the damage MS causes stops signals travelling along these nerves like they should. This can cause problems with, among other things, walking, balance, your sight or control over your muscles. Other things it can cause include extreme tiredness ('fatigue'), unusual feelings in your arms and legs or problems with your thinking and memory.

There are different types of MS. The main difference is that with some you get **relapses** and with

others you don't. A **relapse** is when symptoms suddenly get worse, but then usually get better. This is 'relapsing MS' and it's what most people are diagnosed with.

With other types of MS you don't get relapses. Instead your MS gets steadily worse over the years. This is 'progressive MS'.

But everyone's MS is different. No two people have the same symptoms. These may come and go or change from day to day. And how someone's MS will develop over the years is unique to them.

There's no cure for MS, but research is making progress all the time. Treatment keeps getting better and there have been big breakthroughs in the last few years.

After their diagnosis the person you know with MS can still live out their plans and hopes. It just might mean finding new ways

to make it happen. This booklet has plenty of ideas and ways of getting support with this.

There's more about MS, including the different types, in our booklet What is MS? and on our website. You can also call or email the MS Helpline with questions about MS. Details are at the back of this booklet.

**“With forward
planning we can
still do everything
we want to do.
MS doesn't get
in the way, as long
as we don't let it.”**

Alex

Why us?

You may be asking: why has MS happened to us? We don't know for sure why some people get MS. It's likely to be a mix of:

- genes that get passed on in a family
- things in our environment
- some things about our lifestyles

Two things about our environment that are thought to play a part are:

- certain infections
- a lack of sunshine (this makes you low in vitamin D)

Risks to do with our lifestyles include smoking and being very overweight (**obese**), especially before you become an adult.

You might ask: could we have done something to stop MS happening? No, because we can never know for sure what mix of things triggered MS in each person. So you can't know what might have made a difference in the past. Back then we also knew a lot less about what makes MS more likely. So, when someone gets MS, it's no-one's fault.

Will others in the family get MS?

MS isn't directly passed on between parents and children. It's not passed on through one gene. In fact, over two hundred genes might affect your chances of getting MS.

If someone in your family has MS the risk that someone else in the family will get it too is low. But it's slightly higher than for people in general.

If your brother or sister has MS there's about a 1 in 37 (2.7%) chance you might get it. If your mother or father has MS the chances are around 1 in 67 (1.5%). With other relatives your risk isn't much more than for people with no MS in the family. A recent

study suggests the risks could be even smaller than these figures.

So, genes do play a part in MS, but it's far from the whole story. If you're a close relative of someone with MS, and you're keen to lower your risk, there are things you can do. These are keeping a healthy weight, not smoking and not getting low in vitamin D. Check out pages 31 and 32 for more on this.



What do we do next?

After an MS diagnosis you or the person with it might do lots of reading about it. But some people go into denial and avoid facing up to it. That's how some people try to cope.

Learn about MS. Get information that you can trust. It'll help you to understand better what the future may hold and to feel more in control.

MS can put relationships to the test, including with friends and family. You might not feel like talking if you're worried or uncertain. But now's the time when good communication can help you both find a way through this. We'll come back to this later.

“Don't google! Go to quality, reputable organisations that have well-researched information.”

Ranjit

Tips:

- There's no right or wrong way to react
- Good quality information from MS organisations should help

It feels like we've lost something

Following the diagnosis you and the person in your life with MS can feel a big sense of loss. You both might feel you've lost who you once were. Hopes and dreams may seem over. Maybe you're grieving for how things used to be and what you think you'll never have.

People often go on a journey through different reactions. One or both of you might feel any of these:

- shock or denial
- guilt
- anger, anxiety, fear or panic
- bargaining (such as 'If I'm "good" the MS won't get worse')

- sadness or depression
- acceptance, relief, optimism and hope

There's no right order to this. You can go back and forth between these feelings. Each person goes through it in their own way. It may take time. But recognising this pattern to your feelings and knowing it gets better with time can help you cope.

Do you feel all your plans for the future have ended? They haven't. You might need to change them in some way, or work out a different way to make them happen. Lots of people with MS will tell you that they've managed to do what they always wanted to in life, from having children to climbing a mountain.

More tips:

- Rethink your plans if necessary. Be creative about how to get around things in the way
- Talking through your changing feelings with a counsellor can be helpful

“I’ve been able to go to festivals, concerts, operas and trips abroad, even when I’ve been hardly able to walk. That’s thanks to better access, helpful family and friends, and staying keen to try things.”

Yasmin

Feeling shut out

It takes time to get used to a diagnosis of MS. Before then some people go into denial. They shut you out, won't talk about their diagnosis, reject support or seem to give up. Maybe this is their way of giving their mind a break before facing up to reality. Everyone moves on from denial at their own pace. But some might need help to do this, for example, from a counsellor.

Some people push away those close to them. It can be their way of getting control over things, of trying to keep hold of their independence. Understanding

where this rejection, anger and frustration comes from may make it hurt less. Let them know you're there for them when they need you.

The person with MS might understand their condition, or not know much at all and be expecting the worst. If they pretend everything's fine, this can have serious consequences, especially if it means they won't talk about treatment. It'll take time for them to adjust, so long as they don't hide from the truth forever.

Tips:

- Offer to research information together – that can help steer them towards quality information relevant to them, not random scary stuff on the internet
- If they agree to it, suggest making an appointment with the team that looks after their MS
- Don't try and take over or pressure them. Gently nudge them instead

After their diagnosis people can feel isolated and worry they'll be treated differently. Some friends might drift away, leaving you both angry they're not around. Maybe friends are scared of saying or doing the wrong things.

You may feel guilty about having a social life of your own, so put all your time and energy into looking after the person in your life with MS instead. But no-one's social life has to stop because of MS. It might just mean you need to change a few things.

Tips:

- Let friends know how much their friendship means and that you're still up for having fun together
- Instead of going out, invite friends over for a meal or to watch TV or a film
- Keep the contact going through Skype, Face Time and social media

“I was afraid people would reject me because of my MS. I’ve been more than pleasantly surprised. People have been very kind when I explain my MS and how I may need help.”
Steph

Feeling guilty?

People close to someone with MS might feel guilty. Perhaps you feel you can’t do as much as you want for them or you’re not doing it well enough. Or you might feel guilty because you can still do things they can’t.

People with MS can feel guilty, too. That might be about the impact their MS is having on other people and how it’s changing their relationships. It can be hard to ask for support with this.

Guilt is understandable but it comes between you and the person who needs you. Talk about

these feelings to each other. And because a person’s MS is so changeable you’ll probably need to keep having these conversations.

It takes courage to talk frankly about the situation you’re both in and what support you need. But it can ease guilty feelings and help you both.

Another tip:

- Offload onto someone not closely involved, such as a counsellor or the MS Helpline

What do I say to someone with MS?

If you’re feeling awkward, why not say so? Ask the person how they’d like you to talk about things. But think twice about giving advice. They may have had enough of that. They may be happier to hear you say:

“So, how are you really feeling?”

“I’m here for you if you need me”

“Where can I learn more about MS?”

“Our daughter has already asked that we shouldn’t continually ask about her symptoms and how she’s coping. She says she wants to deal with things in her own way.”

Phil

People say things they think are helpful but often they irritate people with MS. Here are some examples:

“Well, things could be worse.”

This won’t make someone’s problems less real, go away or be easier to deal with.

Try instead:

“How are you feeling?
Anything I can do to help?”

“But you don’t look ill.”

Lots of symptoms you can’t see, such as fatigue, pain, heat sensitivity or problems with

balance, memory, bladder, bowel or eyes. Saying someone looks fine can overlook these and undermine how they feel.

Try instead:

“You’re looking good. But how are you feeling? If you want to talk about your symptoms, I’m listening.”

“Heard about the special diet that cures MS?”

There’s no quick fix or cure for MS. The person close to you with MS has probably looked into lots of ‘miracle cures’, and become sceptical about stories in the media.

Instead, encourage them to do what we know for a fact can make a real difference to their MS:

- starting treatment earlier rather than later
- keeping active
- not smoking

“I know someone with MS. And this happened to them...”

There are different types of MS and everybody has their own unique set of symptoms. MS for the person you know will be very different to how it is for someone else.

Instead say:

“I know someone with MS but I expect theirs is different to yours. Tell me how it is for you.”

“You’re tired? I get really tired, too.”

MS fatigue is a feeling of exhaustion so bad you can barely raise your head off the pillow or even think straight.

Avoid comparing everyday tiredness with fatigue. When you have MS you learn to make your energy last, for example, by keeping cool or resting during the day. You do things at times when you know you have enough energy. Make allowances for this or if someone with MS cancels plans.

What does someone with MS need?

Someone with MS knows best what they need. Keep doing things they don’t want and you might lose your connection with them. You can’t force them to open up or accept help. But you can talk about what’s on your mind, either with them, to friends and family or someone not so close to the situation.

You might worry about bringing up difficult subjects, stressing them out and making their MS worse. And it can be tricky knowing how much to do for them. You might worry they’ll tire themselves out by doing too much.

Find ways to share, communicate, adjust and offer support. Remind yourself that it’s natural for there to be times when one of you takes on more than the other.

Tip:

- Help someone hold on to their independence. Look into what special equipment or changes in the house they might need



These things helped

We asked some people with MS:
when you were first diagnosed
what helpful things did people say
or do?

Tom

“My wife asked me to be honest, to tell her how I was really feeling, and to stop saying ‘fine’ and leaving her guessing and thinking the worst. This way I know we’re dealing with my MS as a couple.”

Yasmin

“I just wanted people to treat me as the friend they knew before the diagnosis. Friends recognised I didn’t need the constant ‘poor you’. They offered help to get me out of the house and have fun.”



Ranjit

“The most precious thing that friends and family can do is to learn about MS, ask questions, call the MS Helpline or just simply ask us.”



Steph

“I really appreciate how my family and friends treated me no differently after my diagnosis.”



Helen

“Having a laugh together when times are really grim is a great safety valve.”

How we can communicate better

We need to keep working at our connections with other people. With MS it can be tough to keep communication open. Everyone's MS is different. There's no 'route map' to tell us what we should go through or how to manage it.

Support networks help you find solutions. Talk to others in a similar situation who'll understand:

- Check out your local MS Society group
- Use online forums from the MS Society, Shift MS and MS People UK (see page 41)

But how do you talk to someone without upsetting them or making them angry?

“What helps us get through it? Communication. I understand my wife's concerns and worries. We talk about MS relatively often.”
Peter

These might be helpful:

- An honest chat needs a safe place and time
- Don't have important conversations if you're angry, tired or in a bad mood
- Turn off the TV, your phone and other distractions
- Look the other person in the eye
- Listen how you'd like to be listened to
- Let them finish speaking before answering
- Say how you feel without either of you feeling guilty or

responsible. Here's an example:
"Today I'm feeling really angry
with MS, not with you"

You can get help from the experts:

- Counselling. Talk to someone on your own, as a couple or family. Or each of you can see a different counsellor. They can help you find solutions to issues MS can throw up
- The specialist MS team. If you and the person close to you with MS both agree, their medical team can often see you together. They'll help unpack the tensions or misunderstandings and put you in touch with counsellors and other support
- Call the MS Helpline. They're trained to give emotional support

More tips:

- Don't think you must manage without outside help
- Asking for help is a sign of strength, not weakness

"Keep talking, be honest about your feelings and try to forgive each other for being upsetting, difficult and constant hard work. Corny but it's true! Think about seeing a counsellor."

Yasmin

How MS might affect us

MS doesn't mean everything changes overnight. A person with MS often needs reassurance that they're basically still the same person they were before. You both just may need to make some changes.

Changing roles

In families, relationships and friendships we take on roles and responsibilities. MS can change these over time. The person with MS may need to cut back their work hours, change job or no longer do the more physical jobs at home. You might need to take over things they used to do but don't want to suggest this and hurt their feelings.

These changes can make you both feel disappointed, frustrated and like you've lost something.

Get around the table

One thing worth trying is a regular meeting or 'family time' when you're all encouraged to ask questions. That way everyone understands better what's going on. It might feel strange at first and you might worry people's feelings will get hurt. But with more of these 'family times' confidence often grows until you can talk about even very sensitive things.

"Focusing on what the person with MS can do, as opposed to what they can't, is a very positive message. It's about adjusting to the changes."

Paula

When plans fall through

MS symptoms such as fatigue mean that what a person could do

yesterday they might struggle with today. Planning can be tricky when you're not sure what the next day, week or month might bring.

Changes of plan like this often happen with little or no warning. You can lessen their impact if you talk about what you'd do if plans change. Build in flexibility. Encourage everyone to be creative about how to do what you planned but in a different way.

More tips:

- Arrange a 'family time' for honest chats to clear the air and let people get the answers they need
- Having back-up plans can prevent disappointment, anger or frustration

**"I found we all
got on OK if I
kept my kids
and family up
to date and informed
and was open to
talking about anything
related to my MS."
Shirlee**

When you're part of a couple

Being in a couple can be a real help with an MS diagnosis. Lots of us have really positive stories to tell. Relationships can become deeper. You might feel it's a privilege to support your partner in staying as active, fulfilled and in control of their life as possible.

Don't forget the things about you that can support your partner. It's not just practical stuff that helps them cope, but things like your sense of humour or positive attitude.

Changes

In a couple each partner often takes on certain roles. One might be the talker, the practical one, the planner, the provider, the one who looks after the other or the one who gets looked after. MS can change these roles. That can be a challenge.

You may notice changes in your partner's mood. They may become depressed or anxious, perhaps have difficulty thinking and doing certain tasks. This

could be a natural reaction to their diagnosis. Or it could be how MS is affecting their brain. Talk to their MS team to help work out what's going on.

Sex and intimacy

A couple's sex life can be affected by MS symptoms, its emotional impact or treatment side effects. If there are already communication barriers, talking about these personal things can be hard.

“My husband has been an absolute rock. I wouldn't be where I am today without his love and support.”

Steph

Don't wait until things get really bad before reaching out for support. You could speak to your doctor or find a therapist who specialises in sex and relationships. An MS nurse or neurologist can refer you to a counsellor or other kinds of help. This can build the confidence

you need to talk to each other about sensitive subjects. You can always talk to someone anonymously on the MS Helpline.

“Me and my partner share everything. It really helps me know how her symptoms are day to day and how I can help”.

Emily

More tips:

- Have positive things happening in the future for you both to look forward to
- We have a booklet, Sex, intimacy and relationships, that looks at this in more detail (see page 46 for details of how to order).



What about the kids?

When MS happens in the family you might ask: can children handle the truth? You may feel it's better to protect a child from knowing too much about a family member's MS. But they'll know something is wrong and MS in the family is likely to affect them to some extent.

It usually works better if kids are allowed to ask questions. When a parent has MS their children usually benefit from knowing more about it and how it affects Mum or Dad. This is true no matter how old the child is.

More tips:

- Things tend to work out better when kids are part of making important decisions and parents talk with them about future plans
- The MS Trust has a booklet, Talking with your kids about MS, on their website

“Children are worried you’re going to die from MS and they’ll get it. I always try to be positive by saying how research is finding lots of new treatments. Show them all the great things people with MS can still do.”

Yasmin

How much responsibility can kids take?

If Mum or Dad has MS children may take on things like washing, cleaning and shopping. This can affect school work and relationships with friends. That's when social services can be called in to do a 'Carers' Assessment'. This will find out what extra support the young person needs so that they don't do too much (more details are on page 30).

Doing more personal things for their mum or dad is often a challenge and might put them under some pressure. Where

possible it's better if someone else does these.

Not every young person ends up as a 'young carer'. All the same, they still need to understand MS. That way they can adjust to the changes in family life.

A child may feel different to other kids when they have MS in their family. They might believe other children won't understand how they feel. If you've been open with your child about MS this will help them answer questions that other kids ask about it.

Kids don't feel comfortable asking their parents about some things. So it can be reassuring when a child joins a local young carers group. Families say it also helps if teachers, schools or colleges are told that the young person is caring for someone with MS. School can then better understand your home life.

Young carers groups are great places for kids to find support. Find your nearest one by calling Carers Direct on **0300 123 1053**.

"It's much better to be honest because kids are probably already scared and thinking the worst. Use language they'll understand. We used to say 'yes, Mum has jelly legs and fiddly fingers'. As they grew older they learnt more about MS."

Lyndsey

More tips

- We have booklets for younger children whose mum or dad has MS (see page 46 for how to order)
- Check out our puppet videos for smaller children. Search for 'Annie and Dan' on our website

“The school introduced us to our young carers group and they’ve supported my children. It gave them someone to talk to and to realise other kids were in the same situation.”

Lyndsey

“Telling school helps to plan for school events such as parents’ evenings or school trips, so the school can help if necessary.”

Ben

What if your child has MS?

It’s rare for children to have MS. When it happens it brings up its own special issues. We have a booklet called ‘My Child has MS: a guide for parents’. It covers diagnosing and treating MS in children, telling your child they have MS, school and teenage life, finances, as well as dealing with health and social services.

You can download it from our website or call the MS Helpline for a copy.



Being a ‘carer’

‘Carers’ aren’t just people paid to look after someone. It also means anyone who, without being paid, looks after a friend or member of the family. Without this help they wouldn’t cope because of their disability or illness.

Quite a few of us wouldn’t call ourselves a ‘carer’ or we don’t really like the word. Instead we say we’re a partner, daughter, son, mother, father or friend. What we do for the person we look after grows out of that relationship. Most of us don’t plan on becoming a carer. It usually happens slowly, although sometimes it happens overnight.

We might take on a few responsibilities that put us under no extra pressure. But after a relapse or medical emergency we might give a lot more support. Then it’s good to know what help is available.

Calling yourself a carer can give you a way into lots of support. This can make it possible for you to carry on being a carer (if that’s what you want to do). The law says carers have a right to a Carers’ Assessment. This is when your local council looks at what help you need. In Northern Ireland your local Health and Social Care Trust does this. This could mean extra practical support or money.

More tips:

- Find out about Carers’ Assessments at www.carersuk.org
- If you’re a carer it helps if you let your GP know

“I found it difficult to identify as a carer. However it’s important to recognise that I am, and know that support is out there.”

Alex

Lifestyle changes

Reducing stress, keeping cool in the heat and physiotherapy can all help with MS. But there are two changes in particular that have been shown to help a lot: giving up smoking and being physically active.

Smoking

Smoking could make MS worse. People with relapsing MS who smoke are more likely to see their MS change to progressive MS faster.

Smoking and breathing in others' smoke can make people more likely to get MS, too.

If you're a close relative of someone with MS your chances of getting MS are already a bit higher. So you might want to take steps to keep the risk as low as possible by not smoking.

Another tip

- GPs can help people to stop smoking. This website has ideas and support, from nicotine gum and patches to e-cigarettes
www.nhs.uk/smokefree

Exercise

Studies show physical activity has a positive effect on MS-related bowel and bladder symptoms and fatigue. Exercise keeps people positive and makes their body stronger. That helps someone cope better with symptoms. Physical activity can include going for walks, gardening, even housework.

More tips

- Encourage the person you know with MS to keep active. Why not exercise together?
- Find out more at mssociety.org.uk/exercise and our exercise DVD that you'll find there

“Don’t beat yourself up if exercise is a bridge too far at times.”

Helen

Diet

There’s little evidence that special diets control MS. Some research suggests salt could make relapses more common, so a low-salt diet is worth thinking about.

Being **obese** (very overweight) when you’re young might increase the risk of getting MS. This is something to think about if the MS risk of you or other family members is on your mind.

Tip

- Check out our Diet and nutrition booklet (see page 46 for how to order)

Vitamin D

Most of our vitamin D comes from sunlight. Our skin makes this vitamin when our skin is in the sunshine. We get the rest from food, for example, oily fish, eggs, and spreads and cereal with added vitamin D.

Low levels of this vitamin before you become an adult have been linked to getting MS later on. In some (but not all) studies MS can get worse in people low in vitamin D.

Studies are looking at whether extra vitamin D can help with MS or stop close relatives getting it.

It’s recommended that women with MS of childbearing age take extra vitamin D, including if they get pregnant.

There are no official guidelines specifically for men with MS. Men should get advice from their neurologist on taking extra vitamin D.

People with MS often need a much higher dose of this vitamin than is recommended for the general population. Their neurologist can advise them.

Another tip:

- Worried about vitamin D levels? Talk to a doctor (an MS specialist is best) about whether to have this tested and whether taking extra vitamin D is a good idea



Hope for the future

When someone you care about is told they have MS certain questions are bound to come up:

“How sick might they get?
How fast?”

MS is hard to predict.

“Will they need a wheelchair?”

Most people don’t.

“Could they die from MS?”

That doesn’t usually happen.

By keeping questions and fears to yourself you might feel you’re protecting the person with MS or yourself. But bottling things up can lead to anger, resentment and guilt. You both might cut yourselves off emotionally. The issues you’re avoiding won’t go away.

MS affects each person differently. It’s unpredictable. It tends to get worse over time, especially if left untreated. But treatment can make a real difference to many people’s MS and it keeps getting better. Thanks to treatment

over the coming years we’re likely to see fewer people need wheelchairs or walking aids. Many people with MS already live as long as everyone else but we’re likely to see even more do this.

Another tip:

- Get worries out into the open. It can help you cope better with whatever MS might bring

“Honesty and finding out the truth about the prognosis was very important, and being able to talk honestly to each other and family members.”

Carolyn

Treating MS

If someone’s MS has relapses then treatment offers a chance to get more control over it. In the past people were often told to ‘wait and see’ before starting

treatment. Drugs have side effects, so perhaps it made sense to wait. This seemed sensible if a person didn't have serious flare-ups of symptoms (relapses).

But with **MRI scans** we can now see that MS can still cause damage even if a person isn't having a relapse at the moment. That's why now people with 'active' relapsing MS are recommended to start treatment soon after they're diagnosed.

Early treatment can mean:

- fewer and less severe relapses
- less brain and spinal cord damage
- a slow down in their disability getting worse

Treating early is best but starting later can still slow MS down.

No treatment yet can undo any permanent disability.

The drugs we have at the moment only work if someone's MS has relapses, or if active inflammation can be seen on their MRI scans. Some new drugs can work with progressive types of MS when

active inflammation can still be seen.

More tips:

- It's recommended that everyone with MS sees a specialist at least once a year to talk about treatment. This is whether or not they're on treatment and no matter what kind of MS they have
- Read more about treatment in our booklet Disease modifying therapies (DMTs) for MS

“Early treatment was invaluable to me. I became very ill and the medication allowed me to become myself again”
Steph

Can we beat MS?

Recent years have seen important treatment breakthroughs. We now have over a dozen drugs (**disease modifying therapies** or **DMTs**) for relapsing MS (the type that 85% of people are first

diagnosed with). We're seeing exciting stem cell treatments for some people with very active MS.

In 2019 the first drug became available on the NHS that can slow down early primary progressive MS. And a new drug to treat active secondary progressive MS will hopefully be available in 2020.

Lots of effort is going into research into progressive MS. We are helping to fund this

It may feel frustrating that things aren't moving faster. But the outlook has never been more promising.

Another tip:

- Read about drug research at mssociety.org.uk/ms-news-research/ms-research

"We've raised funds for MS. I run the London marathon. This helps us feel we're doing our bit to make a positive contribution to the lives of everyone with MS."

Phil



Look after yourself

If the person in your life with MS was diagnosed recently you may still feel shocked and find it hard to accept. Talking about how you're feeling is likely to make you feel better.

Some people react by keeping busy doing things. It can give a feeling of being more in control. But don't overdo it. Think about your health, not just theirs. Supporting someone can tire you out and take its toll emotionally. Get support through family or friends, if that's possible.

You might turn down help to keep up the appearance that everything's OK. Maybe you think friends and family won't understand about MS, or you don't want to be a burden. If you feel you're doing this, talk it through with them. Don't be scared to approach people again

for help. We all need a support network.

More tips:

- De-stress with things you enjoy: hobbies, exercise, being with family, walking the dog, cooking, yoga, music, and so on
- There's no shame in asking for support

Need a break?

If you want to go away for a break could you ask family or friends to take over? If you're feeling 'burnt out' speak to your GP or the MS nurse. They can put you in touch with a support group or someone to talk to, either for you alone or both of you.

Are you or the person you care for feeling down? Possibly depressed? Worried about how you're coping? Start by talking to someone. Your GP can help get



the help you need. Counselling can help.

If you have children and you're finding it hard to cope, talk to family and friends as well as the person in your life with MS. The social care team in your local council can give you advice and work out what support you need.

More tips:

- Contact the MS Helpline for emotional support
- Our grants fund can pay towards a short break for you or the person who has MS. The MS Helpline has details
- Check out our booklet Short breaks

MS nurses

MS nurses are a brilliant source of specialist advice and support for families and partners. For details of your local MS nurse call the neurologist who looks after the person you know with MS, their secretary or the hospital.

Not all parts of the UK have these nurses. If you can't get hold of one

a GP is usually the place to turn to. At the end of this booklet you'll find details of who else to contact for non-emergency care.

Another tip:

- Find your nearest MS nurse by searching for 'map of MS services' on the MS Trust website mstrust.org.uk

Money, benefits and social services

MS can hit finances hard but there's help. If you provide 'regular and substantial' care for a family member, partner or friend with MS, you have the right to ask for a Carers' Assessment from your local council's social services department. In Northern Ireland your local Health and Social Care Trust does this. You tell them what could make it easier for you.

You and the person you're supporting may be able to get welfare benefits. Our helpline can point you towards help with benefits and finances. We also have a booklet about benefits (see page 46). Our website has

benefits information, too. Search for 'benefits and money'. There's also help with filling out the forms when you apply.

MS Society grants

We give grants to pay for things people need to make daily life with MS easier, but also for short breaks, holidays and respite care. These can be for someone with MS or their carer. We give grants to carers to learn new skills or to help get back into work. Grants aren't loans. You don't pay the money back.

Find out more on our website by searching 'benefits and money' or call **0300 500 8084**.

Support for carers who work

Worried you'll have to cut down your work hours? Or your partner has MS and must stop working? As a working carer you may need support at work. The Carers UK website has more information support for working carers: **www.carersuk.org/help-and-advice/work-and-career**

Preparing for emergencies

What if you're suddenly taken ill or an emergency means you can't look after the person you care for? Free 'carers emergency card' schemes quickly put backup care in place if you're suddenly not there. You carry a card with a phone number for you or others to call in an emergency.

Contact your local council or Carers Centre to see if there's a scheme locally.

More tips:

- Get advice on benefits and money from your local Citizens Advice Bureau
- The organisation Turn2us helps people find the benefits and grants they qualify for. Details on page 42

Check out our booklets about getting the best from social care services. There are separate ones for England, Scotland, Northern Ireland and Wales (see page 46 for details of how to order).

Useful organisations

Support

Forums, blogs and discussion boards for people with MS or their families, partners and friends:

MS Society

[community.mssociety.org.uk/
forum](http://community.mssociety.org.uk/forum)

Shift MS

shift.ms/

MS People UK

ms-people.com/forum/index.php

MS Trust

Useful information about MS, including where the nearest MS nurse is (search 'map of MS services')

www.mstrust.org.uk

Carers UK

Information and support for carers

www.carersuk.org
0808 808 7777

Carers Trust

Information, advice and support through its carers' centres, website and online forum

0300 772 9600

www.carers.org

Counselling

British Association for Counselling and Psychotherapy

Details of counsellors can be found on their website

www.itsgoodtotalk.org.uk

College of Sexual and Relationship Therapists

COSRT
PO Box 13686
London SW20 9ZH
020 8543 2707
info@cosrt.org.uk
www.cosrt.org.uk/

Relate

Offers advice, relationship counselling, family counselling

and support face to face, by phone or through its website

England and Wales

www.relate.org.uk

Northern Ireland

028 9032 3454

www.relateni.org

The MS Society in Northern Ireland has a counselling service. Contact **028 9080 2802** for details.

Relationships Scotland

Similar service to Relate for people in Scotland

0345 119 2020

www.relationships-scotland.org.uk

Pink Therapy

Therapy organisation that has a directory of counsellors and therapists that work with lesbian, gay, bisexual and trans people

pinktherapy.mobi/

Money and benefits

Citizens Advice

Free, confidential information and advice to help people with their problems, including money

www.citizensadvice.org.uk

Turn2us

Charity that helps people in financial hardship gain access to welfare benefits, charitable grants and support services

www.turn2us.org.uk

Non-emergency NHS care services in:

England

When it's not an emergency call NHS 111 to speak to trained advisers and healthcare professionals. It's free and open all the time

Scotland

Dial 111 for NHS 24 or visit **www.nhsinform.scot/scotlands-service-directory** to find the right service if you're ill, injured or have a long-term condition

Wales

Call NHS Direct Wales on
0845 46 47

Across the UK call **999** for life-threatening situations and emergencies

Other things to read

We have information that friends, partners and families of someone with MS might find helpful. Among the topics are: diet, exercise, MS treatments, money, benefits, work, short breaks, booklets for children, genes, and sex and relationships. Our booklets *What is MS?* and *Just diagnosed* are available in 14 other languages.

See page 46 for how to order your free copies.

Also:

Multiple sclerosis: a guide for families (third edition), by Rosalind C. Kalb, Demos Medical Publishing (2006) ISBN 1-932603-10-7

New words explained

Disease modifying therapy (DMT)

– these drugs work if you have ‘active’ MS. This means you have relapses, or active inflammation can be seen on your MRI scans. DMTs can make you less likely to have more relapses or make them milder. They can also slow down how fast your disability gets worse.

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

MRI scans – pictures of inside your brain or spinal cord made by ‘magnetic resonance imaging’. They show where MS is causing damage through inflammation and damage to the nerves

Nerves – bundles of fibres along which signals travel from your brain or spinal cord. These nerve signals control how parts of

your body work and make sure your thinking and memory work correctly

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

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

Notes

Further information

Resources

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

To order email:

shop@mssociety.org.uk or visit
mssociety.org.uk/publications

MS Helpline

The free MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers.

Information is available in over 150 languages through an interpreter service.

0808 800 8000

(closed weekends and bank holidays)

helpline@mssociety.org.uk

A large orange triangle pointing upwards, located in the bottom right corner of the page.

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

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

References

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

Photography

Credit for photography belongs to Simon Rawles (cover, p6, 10, 17, 25, 29, 33 and 38) and Amit Lennon (p36).

This resource is also available in large print.

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

Contact us



MS Helpline

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

MS National Centre

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

Online

www.mssociety.org.uk
www.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

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This title will be reviewed within three years of publication.

