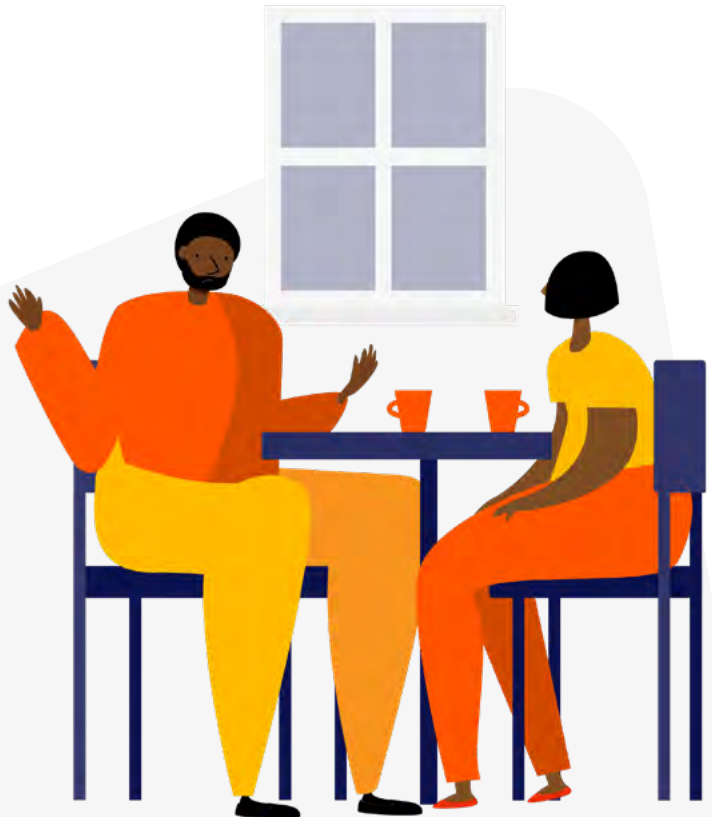


For family and friends

When someone tells
you they have MS



We're the MS Society and we're here for you. Funding world-leading research, sharing information, making voices heard and campaigning for everyone's rights.

Together we are a community.
And together we will 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: **donate.mssociety.org.uk**
- Posting your donation to: MS Society,
Carriage House, 8 City North Place,
London N4 3FU.
- 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.

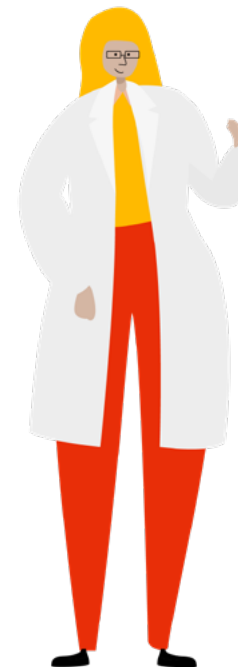
I think this booklet will be valuable for people like me coming to terms with their partner's diagnosis. It covers the different feelings it involves, and helpful and unhelpful things to say.

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.



Five things to know

1. People with MS can still live out hopes and plans they had before their diagnosis
2. You may need to make some changes, but life does go on
3. There's a lot of support out there for people with MS, their partners, families and friends
4. Treatments for MS keep getting better
5. Talking honestly and often to each other can be a big help





About this booklet

This booklet is for when someone close to you tells you they've been diagnosed with multiple sclerosis (MS). This might be your partner, a member of the family, or a friend.

There's a lot here to take in. But you can keep coming back to this booklet when you need the information. And you can share it with others. For a shorter read, you'll find information on our website. Search for 'supporting someone who has MS'.

When someone tells you they have MS, two things can help:

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

You'll find both in this booklet. People with MS, and those close to them, share what they've learned. They want you to know that, after a diagnosis of MS, life still goes on.

This is one of three booklets we have for family members, partners and carers. The other two are more about practical day to day support. You'll find more about those on page 38.

One last thing: if you see a word in **bold**, that means it's explained at the back of this booklet.

"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 like it should.

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. That's why the range of MS symptoms is so wide.

Over time MS causes damage that stops signals travelling along these nerves like they should. This can cause problems with, among other things, someone's walking, balance or sight. Or it might affect control over their muscles, including ones in their bladder or bowel.

Some MS symptoms you can see. Others you can't, like extreme tiredness ('fatigue') or problems with thinking and memory. Pain or unusual

feelings in the skin, arms and legs are other invisible symptoms.

When someone finds out they have MS, it doesn't mean they must give up all their hopes and plans. It might just mean finding new ways to make these happen. This booklet covers how to get support with this.

Types of MS

Active MS

The main difference in the types of MS is that some are 'active' and others aren't.

Active MS means doctors see signs of recent **inflammation** on **MRI scans** of someone's brain or spinal cord. Or they get **relapses**. That's when symptoms suddenly get worse, but later get better. This is 'relapsing MS'.

When people are first diagnosed with MS, around nine out of ten are diagnosed with an active type of MS like relapsing MS.

Progressive MS

MS that isn't active is called 'progressive'. This means it gets steadily worse over the years. Usually there are no signs of recent inflammation on scans. And no sudden flare ups of symptoms (relapses).

But a minority of people diagnosed with progressive MS also have an active side to it. Scans show new inflammation. The person might get an occasional relapse. These people have more treatment options than those with progressive MS with no signs of active inflammation.

Whatever type someone has, everyone's MS is different. No two people have the same symptoms. These may come and go, or change from day to day. How someone's MS will develop over the years is unique to them.

Unfortunately, there's no cure for MS. But research into treatments is making progress all the time. Treatments keep getting better. We've seen big breakthroughs in the last few years.

Read more about the different treatment options for the

different types of MS on pages 30-32.

There's more about MS, including the different types, in our booklet 'What is MS?' and on our website. You can call or message our MS Help Hub with questions about MS. Details are on page 35.

"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?

When someone close to you has MS, you may ask: why has this happened? Well, we don't know for sure why some people get MS. It's likely to be a mix of:

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

Environment

Experts think two things about our environment play a part:

- certain infections, especially Epstein Barr Virus, which causes glandular fever
- a lack of sunshine. This makes you low in vitamin D

Lifestyle

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

Genes

MS isn't automatically passed on from a parent to their child. But a parent can pass on genes that make the risk of getting MS higher.

There are over two hundred genes that might affect your chances of getting MS.

If you have a close relative with MS, the risk is low that you'll get it too. But that risk is a little 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 also 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 very large study in 2014 suggested these risks may be even smaller.

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, these things can lower your risk: keeping a healthy weight and not smoking. And don't let your levels of vitamin D get low. Check out pages 28 and 29 for more on this.

It's no one's fault

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 when someone gets MS, no one is to blame.

What next?

After an MS diagnosis some people do lots of reading about it. But some people with MS go into denial. They avoid facing up to it. That's how they try to cope.

Learn about MS, but avoid scary stuff on the internet. Instead seek out information that you can trust. It'll help you understand better what the future may hold. It can help you feel more in control.

MS can put relationships to the test. You or the person with MS 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 on page 19.

“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 trusted MS organisations should help. That includes us, the MS Trust or the American National MS Society.

What do I say to someone with MS?

If you're feeling awkward, just 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?”

Things not to say

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

What next?

“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 MS symptoms you can't see. This includes fatigue, pain, heat sensitivity or problems with balance, memory, bladder, bowel or eyesight. 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.”

“Have you heard about the special diet that cures MS?”

There's no quick fix or cure for MS. The person with MS has probably looked into lots of 'miracle cures'. They may have become sceptical about stories in the media.

Instead, encourage them to do things that we know make a real difference to MS:

- start treatment earlier rather than later
- keep active
- don't smoke

“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. So 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 being so exhausted that you can barely raise your head off the pillow. It can stop you thinking straight.

Avoid comparing everyday tiredness with fatigue. When you have MS, you learn to make your energy last.

You might keep yourself cool. You might rest 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.

“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

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. You can talk either with them, or to friends and family. Or to someone who's not close to the situation.

You might worry about bringing up difficult subjects. Will that stress them out and make their MS worse?

It can be tricky knowing how much to do for them. Will they do too much and tire themselves out?

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



What next?

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.”

Jasmin

“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 Help Hub, 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.”

”

It feels like we’ve lost something important

After a diagnosis of MS there can be a big feeling 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.

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 you need to. Be creative about how to get around things that are 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

What next?

Feeling shut out

It takes time to get used to a diagnosis of MS. Before then some people go into denial. They shut people out, won't talk about their diagnosis, reject support, or seem to give up. This could be their way of giving their mind a break before they face 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.

It may hurt less if you can understand where this rejection, anger and frustration come from. Let them know you're there for them when they need you.

The person with MS might not yet know much about their condition. So they might expect the worst to happen. But if they pretend everything's fine, this can have serious consequences too.

This is especially true if it means they won't think about starting

treatment. It'll take time for them to adjust. Just as long as they don't hide from the truth forever.

Tips

- Offer to research information together. This can steer them towards quality information that's relevant to them
- 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. They might worry people will treat them differently. Some friends can drift away. This can leave you both angry. Maybe these friends are scared of saying or doing the wrong things.

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

Tips

- Let friends know how much their friendship means. Tell them 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 social media and video call services like Skype, FaceTime, WhatsApp and Zoom

“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?

You might feel guilty because you can't do as much as you want for them. Or you worry you're not doing it well enough. 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.

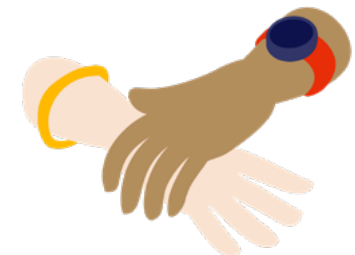
Guilt is understandable. But it comes between you and the person who needs you. Talk about these feelings to each other.

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 both need. But it can ease guilty feelings and help you both.

Another tip

- Offload onto someone not involved, like a counsellor or our MS Help Hub





How to communicate better

We need to keep working at our connections with other people. With MS it can be tough to keep communication open.

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

- Check out your nearest MS Society group. Search our website for 'local groups'
- Use online forums from the MS Society and Shift MS (see page 35)
- Talk things over with someone from our MS Help Hub

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

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

These tips might help:

- 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
- Body language makes a big impact. Avoid crossing your arms. It helps to look the other person in the eye
- Listen how you'd like to be listened to
- Give them space to answer. Let them finish speaking before you reply
- Don't be afraid of silences
- Use questions that start with 'why?', 'how?' and 'what?'. These 'open' questions need a full answer, and can't be answered with just 'yes' or 'no'.

How to communicate better

- Repeat and reword what the other person has said to check you've understood
- Say how you feel without either of you feeling guilty or responsible. For 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. They can put you in touch with counsellors and other support
- Call our MS Help Hub. They're trained to give emotional support

Family time

One thing worth trying is a regular meeting or 'family time'. Everyone is encouraged to ask questions, so they understand better what's going on.

It might feel strange at first. You might worry people's feelings will get hurt. But over time confidence often grows until you can talk about even very sensitive things.

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. Someone with MS often needs reassurance that they're still the same person they were before. You both just may need to make some changes.

Changing roles

Within a family, relationship or friendship people 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 and frustrated. You can feel you've lost something important to you.

When plans fall through

MS symptoms are hard to predict, especially fatigue. 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.

With little or no warning you may need a change of plan. Lessen the impact of that by talking about what you'll do if plans change. Build in flexibility. Encourage everyone to be creative about how to do what you planned but in a different way.

Tip

- Having back-up plans can prevent disappointment, anger or frustration

"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 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. Not just practical help, but 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. One of you may be the one who looks after the other, or the one who gets looked after. It can be a challenge if MS changes these roles.

You may notice changes in your partner's mood. They may become depressed or anxious. Perhaps they 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. The emotional impact or treatment side effects can also get in the way. If there are already communication barriers, it can be hard to talk about these personal things.

"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 GP. 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 our MS Help Hub.

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

Emily

Tips

- Have positive things happening in the future that you'll both look forward to
- Read about sex and intimacy on our website (search under 'sex and relationships')

What about the kids?

When an adult in the family has MS you might ask: can children handle the truth?

You might feel it's better to protect a child from knowing too much. 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 you let kids 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. It helps if parents talk with them about future plans
- The MS Trust has a booklet on their website called 'Talking with your kids about MS'.

"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 MS might affect us

How much responsibility can kids take?

If a child's mum or dad has MS, they may take on things like washing, cleaning and shopping. Too much of this can affect school work and relationships with friends.

That's when social services can be called in to do a 'Carers' Assessment'. This finds out what extra support the young person needs. That way they won't do too much. More details are on page 33.

Some children might find themselves giving someone 'personal care'. This covers things like bathing, or helping with someone's toilet needs.

Doing these kind of things is often a challenge and can put pressure on a child. It's better if another adult can look after personal care.

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

MS in their family can make a child feel different to other kids. 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.

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. They can ask these questions there.

Families say it helps if you tell teachers, schools or colleges that the young person is caring for someone with MS. School can then better understand your home life and make allowances.

"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

- Search our website for 'support for young carers' to get lots of useful information
- And search it for 'talking to children' for tips on discussing MS with kids. There you'll also find our puppet videos for very young children

"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

What if your child has MS?

It's rare for children to have MS. When it happens, it brings up its own special issues.

Search our website for 'MS in children'. You'll find information on how MS is diagnosed and treated in children. It also covers getting support and school issues.

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

Ben





Lifestyle changes

Reducing stress, keeping cool in the heat, and physiotherapy all help with MS symptoms. Two other changes have been proved to help a lot, too. These are giving up smoking and staying active.

Smoking

Smoking can make MS worse. People with relapsing MS who smoke are more likely to see it become progressive MS faster. Some DMTs work less well in people who smoke. They get more relapses.

Quitting can slow down how fast someone's disability gets worse. It can slow this down to the same rate seen in people who have never smoked.

Do you live with someone with MS who wants to give up? It should make it easier for them if you give up too.

Smoking makes people more likely to get MS. We need more studies but it seems that breathing in others' smoke might also increase this risk.

If you're a close relative of someone with MS, your chances of getting MS are already a bit higher. By not smoking, you help keep that risk as low as possible.

Tip

- GPs can help people quit. Find ideas and support at **[nhs.uk/smokefree](https://www.nhs.uk/smokefree)** from nicotine gum and patches, to vaping or e-cigarettes

Exercise

Studies show physical activity has a positive effect on bowel and bladder symptoms and fatigue. Exercise also keeps people positive and makes their body stronger. That helps people cope better with their symptoms. Physical activity includes walks, gardening, even housework.

Lifestyle changes

More tips

- Encourage the person you know with MS to keep active. Why not exercise together?
- Find out more at mssociety.org.uk/exercise
We have exercise and Pilates videos for all ranges of mobility. We have exercises for specific symptoms like bladder, muscle spasms and fatigue. We have yoga videos too.

“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. They might help with some symptoms.

A study from 2021 looked at 87 people with relapsing MS. They followed the Wahls or Swank diets. These diets are high in fruit and vegetables, low in processed food. They felt less fatigue, and were more positive about their quality of life.

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 38 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.

Experts say it’s sensible for people with MS to take some form of extra vitamin D all year round. And it’s officially recommended that women with MS of childbearing age take extra vitamin D.

Doctors often give people with MS a much higher dose of this than is recommended for the general population. Their neurologist can advise them.

Tip

- Want advice on vitamin D levels? Talk to a doctor (an MS specialist is best) about whether taking extra vitamin D is a good idea for you. And if so, how much to take.



Treatments and hope for the future

When someone you care about finds out they have MS, certain questions are bound to come up.

“How sick will they get? How fast?”

MS is hard to predict.

“Are there drugs to treat MS?”
For most people treatments can slow down their MS and reduce their relapses

“Will they need a wheelchair?”
Most people don’t.

“Will they die from MS?”
That doesn’t usually happen.

You might feel you’re protecting the person with MS or yourself if you keep questions and fears to 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. And it tends to get worse over time, especially if left untreated. But treatment can make a real difference for many people. And treatments keep getting better.

Over the coming years we’re likely to see fewer people need wheelchairs or walking aids. And thanks to treatment many people with MS already live as long as everyone else. We’re likely to see even more do this.

“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

Some treatments only help with the symptoms of MS. Others work on what causes these, the MS itself. We now have around 20 treatments that do this. They’re called DMTs (disease modifying therapies).

DMTs only work if someone’s MS is ‘active’. That means they get **relapses**. Or doctors see signs of new **inflammation** on scans of their brain or spinal cord.

When people are first diagnosed with MS, around 9 out of 10 have MS that is active. So DMTs can work for them.

In most cases a DMT can’t undo disability that’s already happened. But it should mean fewer and less severe relapses. It could also cause a slowdown in someone’s disability getting worse.

Waiting to start treatment isn’t a good idea. That’s because we know MS damages nerves even when no relapses are taking place. These drugs work best the sooner a person starts one after they’ve been diagnosed.

If someone’s MS isn’t active, they have ‘progressive’ MS. That means it gets steadily worse over time. There are usually none of the relapses or signs of new inflammation that you see with active MS.

DMTs don’t seem to help with progressive MS if there’s no inflammation. But there are now other drugs going through trials that might help. And we have treatments to help with the symptoms of MS.

Some people diagnosed with progressive MS still have an active side to it. New inflammation can be seen on their scans. They might have a relapse occasionally. They have ‘active progressive MS’. A few DMTs can work for them.

More tips:

- It’s recommended that patients see an MS 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

Treatments and hope for the future

- Read more on our website. Search 'treatments and therapies'

“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

Can we beat MS?

We’ve seen many breakthroughs for active MS (including relapsing MS). And if DMT drugs fail to control their MS, some people get good results with stem cell treatment (HSCT).

We have a small number of DMTs for people with progressive types of MS. But only if their MS also has an active side to it.

But lots of effort is going into research into drugs that will help all people with progressive MS. We at the MS Society are helping to fund this.

Trials have started that we hope will find drugs to fight progressive MS. It may feel frustrating that things aren’t moving faster. But the outlook has never been more promising.

Another tip:

- Read about the latest drug research by searching our website for ‘research news’



Caring for someone with MS

The word ‘carer’ covers anyone who, without being paid, looks after a friend, partner or family member. And without this help that person wouldn’t cope because of their disability or illness.

Many people do what a carer does, but don’t call themselves that. Some people don’t like the word. They prefer to be seen as someone’s partner, daughter, son, mother, father or friend. And what they do for that person grows out of that relationship

You might take on some caring responsibilities and feel under no extra pressure. But after a relapse or medical emergency, you might suddenly need to give a lot more support. Either way, it’s important to know what help is available.

If you accept the word ‘carer’, you can benefit from help that has that word attached to it. Don’t miss out on what carers organisations and local carers groups have to offer. On top of that:

- You might get the Carers Allowance benefit. For more on this search our site for ‘brief guide to benefits’
- The law says carers have the right to ask their local authority for a Carer’s Assessment. They’ll look at what help you need. For more details search our website for ‘getting help and support’
- If you work, from 2024 carers have the right in law to up to five days unpaid leave each year from their employer. This is to help them carry out their caring responsibilities. It also covers taking a break from caring. Find more details on our web site by searching for ‘carers leave law’.

MS nurses

MS nurses are a great source of specialist advice and support for families and partners. Get details of your local MS nurse from the neurologist, 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 who you should turn to.

Tip:

- Find your nearest MS nurse by searching for 'MS services near me' on the MS Trust website [mstrust.org.uk](https://www.mstrust.org.uk)
- There are MS nurses on our MS Help Hub who you can talk to or email

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? 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. Your local social services team can give you advice and work out what support you need.

More tips:

- Check our website for more on taking a short break or holiday and help with paying for this. Search for 'breaks and holidays'
- Our MS Help Hub can be a listening ear. They can help with your holiday options

Our other publications for carers

We have two other carers publications. They go into more detail about the practical side of supporting someone with MS, especially when it's having a bigger effect on them. Page 38 tells you how you can get them.

Useful organisations

Support

MS Society

Search our website for 'Support for carers' for lots of information all in one place. Chat to other carers at forum. [mssociety.org.uk](https://www.mssociety.org.uk)

MS Help Hub

Information and support for anyone with or affected by MS. Our operators include specialist legal and benefits advisors as well as MS nurses.

Freephone **0808 800 8000** 9am to 5pm (closed weekends and bank holidays). Email helphub@mssociety.org.uk

Or get in touch with webchat at [mssociety.org.uk](https://www.mssociety.org.uk)

Shift MS

Community and support for people with MS. [shift.ms](https://www.shift.ms)

MS Trust

Use their website to find your nearest MS nurse. Put 'MS services near me' in the search box. [mstrust.org.uk](https://www.mstrust.org.uk)

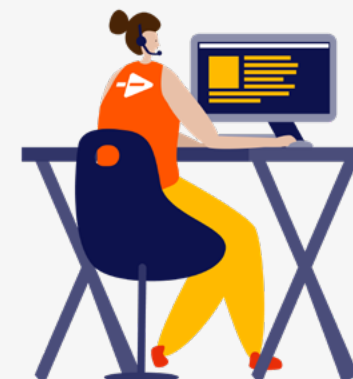
Carers UK

Information, advice and support for carers, including the Carers Connect forum [forum](https://www.carersuk.org). [carersuk.org](https://www.carersuk.org)
Helpline 0808 808 7777
advice@carersuk.org
[carersuk.org](https://www.carersuk.org)

Carers Trust

Support, advice and resources for carers to live a fulfilling life alongside caring. Its network of carer organisations provide funding, help, advice and breaks from caring.

Find your nearest Carers Trust Network Partner on: **0300 772 9600**
info@carers.org
[carers.org](https://www.carers.org)



Counselling

Mind

Learn about talking therapy and counselling by entering those words into their website's search box. It'll tell you how to find someone to talk to.

0208 215 2243

supporterrelations@mind.org.uk

mind.org.uk

British Association for Counselling and Psychotherapy

Find details of counsellors on their website.

01455 883300

bacp@bacp.co.uk

itsgoodtotalk.org.uk

College of Sexual and Relationship Therapists (COSRT)

Has a list of therapists.

020 8106 9635

info@cosrt.org.uk

cosrt.org.uk

Relate

Advice, relationship counselling, family counselling and support

face to face, by phone or through its website.

England and Wales

relate.org.uk

relateni.org

(Northern Ireland)

02890 323454

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

Relationships Scotland

Similar service to Relate for people in Scotland.

0845 119 2020

enquiries@relationships-scotland.org.uk

relationships-scotland.org.uk

Pink Therapy

Counsellors and therapists for lesbian, gay, bisexual and trans people.

pinktherapy.com



New words explained

Active MS – MS where you have **relapses** or your MRI scans show signs of recent **inflammation**. If your MS is active, you can be treated with **DMTs**. Relapsing MS, the most common type of MS, is a kind of active MS

Disease modifying therapy (DMT) – these drugs can make you less likely to have **relapses** or they make them less severe. They can slow down how fast your disability gets worse. They only work if you have **active MS**

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. It attacks the covering around nerves in your brain and spinal cord

Inflammation – a reaction that happens in MS when your **immune system** attacks nerves. Left untreated, inflammation damages nerves and leads to the symptoms of MS. Inflammation can be seen on **MRI scans** in the shape of lesions (areas of nerve damage)

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

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

Progressive MS – MS where you don't usually get **relapses** or signs of active **inflammation** on **MRI scans**. Instead you see a steady worsening (‘progression’) of your disability

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

Further information

MS Help Hub

Our MS Help Hub gives emotional support and information to anyone living with MS. And through the hub you can also access our:

- MS nurses
- MS benefits advisers
- MS legal advisers
- Physical activity service
- Short breaks service

We can provide information in different languages through an interpreter service. And by text relay and British Sign Language interpreters.

Find out more at mssociety.org.uk/ms-help

Call **0808 800 8000**
(Mon-Fri 9am to 5pm except Bank Holidays)

Email
helphub@mssociety.org.uk

Or get in touch with webchat at mssociety.org.uk

Resources

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

You can read them online or download at mssociety.org.uk/publications

You can order printed resources from onlineshop.mssociety.org.uk or call **0300 500 8084**, select option 4

Two more booklets for family members and carers

‘Supporting someone with MS - a guide for family and friends’ has more about the help available if you provide care and support to someone with MS.

‘Advanced MS – a carer’s handbook’ is for people who look after someone who is severely affected by their MS and need much more support.

Search our website using those titles to download them. Or order them free as explained above.

About this resource

With thanks to all the people affected by MS and professionals who contributed to this booklet.

We’d love to hear what you think about this information at mssociety.org.uk/yourviews

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

Email us if you’d like to know the references for this information at supportercare@mssociety.org.uk

Photography

Amit Lennon (p25, 28), Rebecca Cresta (p18), Alex Grace (p26) and Simon Rawles (p6)

This resource is also available in large print.

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





Contact us:

MS Help Hub

Freephone 0808 800 8000
(weekdays 9am-5pm)
helphub@mssociety.org.uk
Webchat at mssociety.org.uk

MS National Centre

020 8438 0700
supportercare@mssociety.org.uk

MS Society Scotland

0131 335 4050
enquiries-
scotland@mssociety.org.uk

MS Society Northern Ireland

028 9080 2802
nireception@mssociety.org.uk

MS Society Cymru

0208 438 0700
mscymru@mssociety.org.uk



Online

mssociety.org.uk

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This title will be reviewed within three years of publication
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