



Multiple Sclerosis Society

MS and your Emotions: Understanding and dealing with your feelings



The Multiple Sclerosis Society

More than 100,000 people live with multiple sclerosis in the UK. Every one of them shares the uncertainty of life with MS.

We're funding research and fighting for better treatment and care to help people with MS take control of their lives.

With your support, we will **beat MS**.

The MS Society provides this information free of charge but if you would like to help cover the cost, which will help towards our essential work, please call 0800 100 133 or visit the fundraising section of our website to make a donation. Anything you can give will be greatly appreciated.

Contents

Introduction	04
Why MS can affect your emotions	05
Understanding how you feel	09
Managing your feelings	11
Depression	24
What treatments can help?	30
Further information	32

Introduction

Living with a long-term condition such as MS can be challenging. Dealing with day-to-day unpredictability, along with wider uncertainty about the future, can take a toll on your emotions. You might be feeling sad, anxious, guilty, worried, frightened or angry – these are all normal reactions to living with any long-term condition and may come and go at various points.

This booklet looks at the different ways that MS can affect how you're feeling and offers suggestions for managing the emotional impact, whether you're coming to terms with a diagnosis or adapting to a change in your condition or circumstances. It also includes details about treatments that could help as well as sources of support.

Nobody can control every emotion and remain positive and happy all the time, and that is not what this booklet is aiming for. But many people find the suggestions described here helpful for managing the emotional effects of MS.

Why MS can affect your emotions

MS can make you feel emotional for a number of reasons. While much of how you're feeling is probably a reaction to the challenges of living with MS, emotional changes can also be symptoms of the condition.

They happen as a result of nerve damage to certain areas of the brain. Side effects of some drugs used to treat MS or its symptoms can also cause emotional changes.

It may be that changes to your emotions may not be down to one single cause. Whatever the cause, the suggestions in this book should help you feel more in control of them.

Impact of your condition

Being told that you have a long-term condition such as MS, whether or not you were expecting the diagnosis, can have a huge emotional impact. And as MS is a condition that changes over

time – and sometimes from day to day – adapting to those short- and long-term variations and the uncertainty they bring can be really hard to deal with.

If you have relapsing remitting MS, the most common type, it's impossible to know when you will have your next relapse, how it will affect you and how long it will last.

If you have progressive MS you may be upset that there are no treatments available for you. However, the time period to the transition from relapsing remitting to progressive can take years or even decades and the rate at which the condition worsens varies hugely between individuals. As yet, there is no way to predict how MS will affect one person. This can make planning for the future difficult and learning to live with this aspect is one of the biggest challenges for many people.

There is no right or wrong way to react. How you react will depend

Lyndsey, 45, a former research molecular biologist, has two children, aged 14 and 11.

“It took about a year to be diagnosed and I was expecting it to be MS so when the consultant finally said it, I was relieved at first. I felt numb for a while.

“Looking back, I think I was probably in denial for some time. I was in remission after being diagnosed. So it was only when I had more relapses that it started to seem more real.

“In 2007 I had a bad relapse that I didn’t fully recover from. Then in 2009 I had to give up work totally because I could no longer safely handle chemicals in the lab due to spasms.

“After that, I felt that I’d lost my identity. As a lot of my symptoms weren’t immediately obvious to other people, they’d ask why I wasn’t working, which was awkward.

“That’s when the depression started to take hold. I never felt able to speak to my family about it properly. It wasn’t fair to burden the children, and my ex-husband didn’t acknowledge or accept it. He didn’t even read the information I gave him about the condition and was annoyed with me for not being able to work. It was a contributory factor to our split.

“I’ve found both antidepressants and counselling helpful. The counsellor explained that all my emotions – anxiety, anger and depression – were part of a grieving process for my past life.

“I’m still finding it difficult but I do Pilates which is relaxing and I’ve joined a choir, which is therapeutic, partly because of the breathing but also because it’s a nice friendly group.”

on a combination of how MS affects you, your personality and the coping skills you already have.

There's more on understanding and taking control of your emotional reactions on pages 9 and 10.

Your circumstances

MS may also have an impact on your social, financial and domestic situation, which in turn can affect how you feel. For instance, if you've had to give up work as a result of having MS, your self-esteem may be low, and you may be feeling worried about money and guilty if you have people who depend on you.

If you live alone and don't have close friends or family nearby, you may feel isolated. But it can feel just as isolating if those around you don't understand your condition or if you feel unable to share your feelings with them. And if your partner is performing a caring role, this can alter the dynamics of your relationship.

MS and nerve damage

Different parts of your brain control different functions. A part of your brain called the frontal lobe is responsible for controlling emotions. If the nerves in this area of your brain have been affected, this can change how you feel and how you react.

Side effects of drugs

Certain drugs used to treat MS or its symptoms can cause changes in mood and behaviour, as follows:

- Steroids (to treat relapses) may cause mood swings, depression, hyperactivity (being more active than usual, easily distracted and poor concentration) or anxiety
- Interferon betas (disease modifying therapies) may sometimes cause depression
- Modafinil (for fatigue) may cause anxiety or depression
- Some drugs, including baclofen (to treat spasticity), can cause temporary mood and behaviour changes if you stop taking

MS and your emotions

them suddenly. For this reason, you will need to phase them out over a number of weeks. Your doctor will tell you if you need to do this with any of your medications.

If you think any of your medications may be affecting your emotions, speak to your GP, neurologist or MS nurse.

Other reasons

Not every issue you have with your health – whether emotional or physical – will be caused by MS. If you're experiencing changes

to your emotions and, there may be another reason for them, and some people are more prone to anxiety, depression or other emotional changes than others.

If you're concerned about any change to your emotions, speak to your GP, neurologist or MS nurse, who will be able to carry out a full assessment.

The rest of this booklet includes the feelings you might experience and guidance on how to cope with them, including what to do if you think you need professional support to help you manage them.

Understanding how you feel

One way of understanding your emotional responses to MS is to think of it in terms of grief. Although MS isn't fatal, it can lead to a number of losses – loss of your health, abilities, self-image and future plans, for instance. Grief is a natural response to any of these losses.

The grieving process

Although there are roughly five recognisable stages to grief, no two people will experience it in exactly the same way. The stages are:

1. Denial – You can't accept what's happening and can't face reading about your condition or seeking out any support or treatment. You may not realise you were in denial until you've moved past that stage.

2. Anger – You're angry about your condition but this feeling can be directed at anyone or anything, from your neurologist to yourself and those around you.

3. Bargaining – You try to make deals with fate, your doctors, or others: "If you help me through this, I will exercise more, or become a nicer person, and so on." However, changes made during this stage often don't last.

4. Deep sadness or depression – You feel overwhelmed by loss, weepy, distressed or withdrawn.

"The lesions on my neck mean I have chronic nerve pain down my arm every day, which is affected by everything I do. I try to manage it through exercise and posture, but sometimes it might be good to be able to see a specialist to assure me it's not something unrelated to the MS. It's a balancing act all the time – you have to be able to work out when you need to ask for help."

Anna 43, relapsing remitting MS

5. Acceptance – Finally, you feel you can accept what is happening. You know you can't replace what you've lost, and you start to recognise your new reality and move on.

Like MS itself, the different stages aren't predictable. You might find you don't go through them all in a neat order. You might spend more time on one or more of the stages than the rest, or even skip one stage completely. You might go back to a stage you've already been through, or even go through multiple stages at the same time.

Common grief triggers

Grief doesn't just occur after diagnosis. Any change in your condition can trigger an emotional reaction. Other common triggers may include a transition from relapsing remitting MS to secondary progressive MS when there are no longer periods of remission. Also, triggers such as an increase in disability, needing to use a wheelchair and having to make a lifestyle change such as reducing or stopping work can

trigger an emotional reaction. A loss of independence such as needing someone to help with an activity you used to do yourself such as housework, gardening or an aspect of personal care could also be the cause of an emotional reaction. The triggers will depend on what matters most to you.

📖 Find out more in our factsheet *Genes and MS*.

When you need extra help

However you're experiencing grief, remember that it's a natural process and that it will end. If you feel as though you're spending too much time on a particular stage, ask for help. This might be from your friends or family, your GP, MS nurse, another member of your health care team or a psychologist or counsellor.

Managing your feelings

As well as grief, living with MS can bring about a range of challenging emotions, including fear, anxiety, guilt, stress and low self-esteem, which at times may feel overwhelming. Here we look at the most common emotional responses and the different ways you can deal with them.

Fear and anxiety

Being fearful is normal when you're faced with the unknown, and living with MS means living with unpredictability. Besides worrying about what may happen on a day-to-day basis, such as when your next relapse is going to happen, you may have concerns about the future – for instance, whether you will need to give up work or use a wheelchair.

Schedule 'worry time'

Set aside just five minutes each morning and evening to concentrate on your worries.

Sit somewhere quiet, set an alarm clock to go off five minutes later and focus on your fears and anxieties. When the alarm goes off, get up and continue with your day. If a worry creeps into your head during the rest of the day, stop and tell yourself you'll think about it at your next appointment. This gives you space to acknowledge and address your problems while teaching you to switch off from them. After a while, you may find that your fears begin to fade.

Express your fears

Saying your fears aloud can help you to see them objectively, which may make them seem more manageable. You could also try sharing them with others. Telling other people what you are worried or anxious about allows those people – perhaps your family, or a close friend – to listen and to put your fears into perspective. However, it's important that you choose someone you trust to be supportive.

Try this exercise

If you feel yourself starting to get anxious or fearful, stop and pay attention to your thoughts. Could any of them be adding to your anxiety? If so, challenge some of those thoughts. One way to do that is to keep a thought diary, like the one opposite. When you recognise a negative thought, write it down – you can try in the one below. Then ask yourself the following:

- What's the evidence for this thought?
- How much do I believe this thought is true?
- Is there another way of thinking about this situation?

When you've done that, you can write an alternative thought to challenge the negative thought.

(This approach is one of the main ideas behind cognitive behavioural therapy (CBT). If you find it difficult to challenge negative thoughts, you may find it helpful to work with a CBT therapist. See page 30.)

Your thought:

.....

Is it the truth? Is there any proof? What would someone else say? Is it fact or opinion?

.....

How much do I believe this thought is true?

.....

Is there another way of thinking about this situation?

.....

An example thought

Your thought:

‘I felt exhausted all day and couldn’t concentrate at work. If it’s like this every day, I’m going to have to give up work.’

Is it the truth? Is there any proof? What would someone else say? Is it fact or opinion?

Perhaps I was able to get through most of the assignments on my to-do-list and my colleagues didn’t notice anything unusual about me today.

How much do I believe this thought is true?

I think it’s somewhat true – I did feel tired today, but I probably don’t have to give up work because of it.

Is there another way of thinking about this situation?

‘Today has been a bad day, but if I schedule in plenty of rest and pace myself then the rest of the week may be better. If fatigue continues to be a problem, there may be alternatives such as working some hours from home or staggering my work days.’

Managing your feelings

If you can't talk to a partner, friend or relative, you could call the MS Society helpline on 0808 800 8000, or ask your GP or MS nurse for help. See more about talking therapies on page 30.

■ You can read more about the emotional effects of MS in our booklet, *Living with the effects of MS*.

Write an anxiety rescue list

This is a list of what can help you to cope with anxiety. These might be things that you can do, for example, taking deep, calming breaths or going outside for some fresh air, or they might be positive messages that can help things seem less overwhelming. What you put in this list is entirely up to you. Keep it somewhere accessible such as on your phone, in your purse or on the fridge and take a look when you feel anxious.

Tackle thinking errors

How you think can make a big difference to how you feel and so-called 'thinking errors' can

make feelings of fear or anxiety worse. Here are some of the most common ones:

- 'Black and white' or 'all or nothing' thinking: You think in terms of extremes – only good or bad – with nothing in between. For example, if your fatigue is bad one day and you don't manage to do everything on your to-do list, you may see yourself as a failure, regardless of the things you did manage to achieve
- Exaggerated thinking: When you do something wrong, or something bad happens, you see it as worse than it is. For example, let's say you forgot to send an important email at work. Rather than accepting that everyone forgets things sometimes, you see it as a sign that you can no longer do your job well
- Negative bias: You concentrate solely on the negative and ignore anything positive. For example, you might focus on what you can no longer do

Lorraine, 45, a former lawyer and teacher, now writes fiction and lives with her partner and 14-year-old daughter

“I didn’t feel anything when I was diagnosed in 1999 with MS – no shock or anger or any of the grief cycle that’s often talked about.

“At first my GP thought I was in denial and sent me for counselling but after a couple of sessions, the counsellor said that she didn’t think that was the case.

“This doesn’t mean that I haven’t struggled with the symptoms and their consequences. One of the biggest challenges was when I had to give up formal work due to tiredness and some cognitive symptoms. I felt, and still feel to some extent, that I was no longer contributing to society.

“I do feel anxious sometimes, mainly about going out on my own. I have continence issues so worry about being near a toilet and I have balance and walking problems so worry about falling. Also I have to have a sat-nav in the car because I can suddenly forget the route due to cognitive problems.

“Yoga and relaxation exercises, such as breathing techniques, have been really helpful, as is having a regular doze every afternoon in front of the TV.

“I tend not to dwell on what may happen in future and I don’t feel the need to Google every symptom. It’s not denial – I know all the possibilities and my policy is to cope with things as they happen.

“I’m in a good place emotionally and I feel good about myself.”

Managing your feelings

because of your MS, ignoring everything you can still do and any positive changes you may have made since your diagnosis

- ‘Should’ or ‘ought’ thinking: You tell yourself you should or ought to be able to do something, such as walk your child to school. This isn’t helpful, as it only adds to feelings of guilt, anxiety or anger if your MS symptoms affect your ability to do certain tasks or activities
- Expecting the worst: You automatically expect the worst to happen. For instance, a relapse affects your legs and makes walking more difficult. Although relapses are temporary, you start to imagine that you’ll soon become severely disabled.

Stress

At a low level, stress can be positive, giving you the focus to meet a work deadline, for instance. But, besides normal

everyday pressures, you may have specific worries as a result of MS such as finding it more difficult to do your job and other activities.

Everyone has their own tolerance level to stress. Whatever the cause, problems come when that level exceeds your ability to cope over time. It can affect your emotions, leading to you feeling irritable, angry, depressed, anxious or overly negative.

But it can also affect your physical health, leading to a range of symptoms such as headaches, high blood pressure, muscle cramps, lowered immunity, sexual or sleeping difficulties and digestive problems. So it’s important to find ways to manage it.

To learn more about stress and MS and how to cope, visit our YouTube videos (www.youtube.com/watch?v=lyFgD-GgFkw). Dr Gail Kinmen presents a number of videos providing practical information on how to deal with stress and emotions. You may also want to try the following techniques:

Change what you can

When you feel yourself getting stressed, ask yourself if it's something you have any control over. If it is, take any action you know will help to relieve the stress. For example, if you've been asked to take on extra work when you're already busy, you could explain politely that you already have a full workload and don't have time to carry out the task effectively right now.

If this is an ongoing problem, either at work or in your personal life, it may be helpful to give information on the effects of MS to those involved.

Accept what you can't control

If you don't have any control over the situation, you can choose to 'let go'. For example, if you're waiting at your GP surgery for an appointment and the doctor is running behind schedule, you can choose to accept that the appointment is going to be late rather than get stressed over it.

If possible, use the time to catch up on some reading or listen to some music or a radio programme.

Keep a stress diary

This can help you identify the situations that cause you stress. Make a note of what happened, how you reacted and how you might have been able to avoid the situation. After three or four weeks, you will have enough information to understand what's causing you stress and how you can manage it. For example, if you've identified that you get stressed because you're fatigued after work and are cooking dinner for your family, you could manage that stress by asking others to do this task. If you live alone, you could re-heat pre-cooked food or ready meals sometimes.

Have back-up plans

With MS being so unpredictable, even the most carefully laid plans can be upset. So back-up plans can reduce stress when things don't happen as you'd hoped. For instance, you could keep a list of

Managing your feelings

friends or relatives who can take your child to the park if your MS symptoms flare up.

Manage expectations

Sometimes it's impossible to avoid the disappointment and frustration of a cancelled day out. That's why it's a good idea to manage people's expectations by letting them know that there's always a small chance you may need to cancel at the last minute.

Be patient


It's common to feel frustrated when you're finding it hard to do something that used to be easy. When you feel this happening, stop, relax for a moment then try again when you're feeling calmer.


Four stress-busting activities

Below are some suggestions to help you relax:


1. Exercise – It helps you let off steam, boosts energy and helps you sleep better, all of which can reduce stress. Short bursts of

exercise, like walking or cycling, have also been shown to help improve fatigue and quality of life in people with MS. Ask your GP or MS nurse to refer you to a physiotherapist who can advise on the best exercises for you.

 You can order our *Exercise and physiotherapy* booklet for tips on exercising.

 We teamed up with Sally Gunnall to create *Exercising with MS*, an exercise video for people with MS. Order the DVD from our shop or watch it online. We also have a library of exercise DVDs you can borrow.

2. Practise relaxation techniques – Symptoms of stress can be relieved through relaxation. It helps you take a step back from a stressful situation and can help calm you down. Relaxation techniques combine breathing more deeply with relaxing the muscles.

 Borrow relaxation CDs and books from our library for free.

3. Do something you love every day – This might be going for a walk, sitting outside, listening to music or reading – whatever helps you to switch off and unwind.

4. Consider complementary therapies – Such as massage, yoga, meditation, mindfulness or t'ai chi. All can help you to relax and feel less stressed.

You can read our booklet *Complementary and Alternative Medicine* for more information.

Is there a link between MS and stress?

Many people with MS say stress affects how they feel, and that when they're stressed their symptoms get worse. Although there does seem to be a link between stress and MS, it's not certain – partly because it's so difficult to define what we mean by stress, and partly because everyone reacts to stress in different ways.

Need more help?



Find out more about stress and how to deal with it at

www.mind.org.uk or call the Mind Infoline on 0300 123 3393

If you're still having difficulties, ask your GP or MS nurse what further support is available in your area.

Low self-esteem

Having MS can affect your self-esteem. Over time you may not be able to do all the things you used to do or do them in the same ways. If you fall into the trap of focusing on these negative aspects, you may begin to feel bad about yourself. However, MS doesn't have to destroy your self-esteem. Fight back with these confidence-boosters:

Challenge your 'inner critic'

Pay attention to your self-criticisms. Is what you're saying really true? What's the evidence, both for and against? For example, is it logical to feel like a bad parent just because your children have to help you do certain tasks? Think of all the other important things you may do for them, such as helping them with homework or providing

“I plan to get myself a good counsellor, do lots of yoga and reiki, I have booked myself in for a massage when/if my tingles die down a bit and I am going to move forward and treat this like a little blip in my life that has taught me to slow down, love myself and my body more, chill out and live life more fully, with more fun and adventure too.”

Amylytee, clinically isolated syndrome

sound advice or emotional support. And in the long run, helping out at home will help them learn essential life skills.

Thinking positive

Thinking positive statements to yourself or even saying them aloud can fight the negative messages from your ‘inner critic’. For example:

- I’m making the most of what I am able to do.

- There are still many things I’m able to enjoy such as...
- I have an amazing family, and with their support I can get through this
- Whatever the problem, I can find a solution with the right help.

If you can’t think of any, it might help to imagine what you’d say if a friend or relative were in your situation. Keep your list handy and make your positive statements part of your daily routine.

Jot down your talents and skills

Write down everything you know you’re good at, or hobbies you enjoy, even if you haven’t done them in a while. This can be a great way to remind yourself of what you can do, and to rediscover things that make you feel good about yourself. If there are things you used to enjoy but you’ve stopped doing, see if you can find a way to start doing them again.

If you’re struggling to do this, ask a relative or close friend to do it for

you. Seeing what someone else thinks you're good at can be a great boost to your self-esteem.

Be around supportive people

Where possible connect with people who make you feel good rather than critical people who may make you feel bad about yourself. If you always feel low after spending time with a particular person, it's likely that they are having a negative effect on you. Having a good support network of close friends and family helps boost your wellbeing, reinforce your sense of self-worth, and even have a positive influence on your health.

If those around you aren't as supportive as you'd like, you can find people who are in a similar situation to yourself through a local MS support group (www.mssociety.org.uk/ms-support/support-groups) or through the MS Society's forums (community.mssociety.org.uk/forum).

It may also help to give information about MS to family, colleagues

and friends so that they can better understand how the condition may affect you.

Guilt

It's quite common for people with MS to feel guilty, perhaps because of its impact on others. For instance, you might feel guilty if your partner has had to give up work to care for you, or your children have to help out around the house when they could be playing instead. Or simply because

"I used to love being fit before and did lots of exercise. I can still go to the gym but I have had to adapt what I do. I only work on my upper body now and always sitting down. I've also taken up Pilates and yoga, which I do at home with a DVD. I'll never be able to do all the exercises but it helps with core strength. I find yoga especially peaceful and relaxing."

Ronny, 29, primary progressive

Managing your feelings

you know that the people you care for are worried about you.

But MS is no one's fault and guilt can be an exhausting emotion, sapping what may already be limited energy supplies. So, for others' benefit as well as your own, it's important to find ways to address it. Try the following:

Assess why you feel guilty

Sometimes it may not be clear to you why you're feeling guilty – or

“You have to adapt your expectations. I'd planned to get a boat when I retired but that wasn't possible. Instead I've found other hobbies: photography, creative writing and sugar craft. I make and decorate wedding cakes, creating peonies, roses and orchids from icing. It's something I'd never have tried before.”

John, 74, secondary progressive MS

if there's something you feel guilty about, there may be another reason hidden underneath it. For example, if you've had to reduce your hours at work, you might feel guilty because your family has less money coming in. But underneath that, it might be that you feel guilty for having MS, and feel that you're a burden.

Adjust your expectations

If you've always taken pride in your garden or your DIY skills, for instance, you may feel guilty that you don't always have the energy to do the jobs that are needed. But it's not realistic to expect to be able to do everything in the way you could before having MS, so it makes sense to adjust your expectations. If you have relapsing remitting MS, you can probably save certain tasks for a remission period. If you have a progressive form of MS, some tasks may take longer and you may need help with them.

Talk to family and friends

If you're feeling guilty, it can really help to talk to those close to you

about it. They should be able to reassure you and help you to be kinder to yourself. You may discover you've been wasting

valuable energy feeling guilty about things that aren't important to your friends or family.

Notes:

Depression

Deep sadness, when you may feel overwhelmed, weepy, distressed or withdrawn, is a recognised part of the grief cycle. The danger is that if you deny or suppress this feeling, you won't deal with it and it may become harder to manage.

Allow yourself to experience it by crying, talking, or simply having a duvet day. This phase may last for several weeks and you will move forward with your life again.

However, if you get stuck, there's a risk it may develop into depression. As well as a constant low mood, other symptoms include loss of interest in activities you used to enjoy, feelings of worthlessness and excessive guilt, not being able to concentrate or make decisions and, in some cases, thoughts of death or suicide.

Depression can affect anyone, but it's more common in people with MS. In fact various studies have shown that up to 50% of people

with MS will have depression at some point during their lives.

If you think you might be depressed, it's important to speak to your GP or MS nurse. They will be able to carry out an assessment, and help you find the best ways to manage it (see page 30). In the meantime, the following strategies may help.

Do regular exercise

Regular exercise can improve your mood and some studies have found it to be at least as effective as antidepressants in treating mild to moderate depression. This doesn't have to mean working out in a gym or playing sport – activities such as brisk walking, swimming or cycling can help. See four stress-busting activities, page 18.

Eat healthily

A healthy, balanced diet and eating regularly will help maintain steady blood sugar, which can help control your mood and energy. A balanced diet includes at least five daily portions of fruit

Anne, 60, a retired librarian, is married with three grown-up children

“It may sound strange, but I was actually relieved to be diagnosed with MS in 2006. I’d had six years of unexplained symptoms, doctors’ visits, tests and uncertainty, and I’d suspected MS for some time. At last there was an official explanation.”

“At first, I hoped that I’d stay stable for a long time. I tried to carry on as normal but it got harder. I’d feel angry and frustrated when I couldn’t manage certain tasks and worried about the way things were going.”

“The real problems started at work. I started to feel increasingly useless and lost my confidence. My managers weren’t very understanding. An assessment recommended adaptations at work but this never happened and as a result I fell and broke my arm. In the end I had to retire early. I just sat there and cried. That was five years ago. To be honest, I’m less stressed now I’ve stopped working.”

“Sometimes I feel as though I’ve let other people and myself down, even though the condition isn’t my fault.”

“I’m still trying to make the most of what I can do. I go to an art group, a knitting group and a local MS group and find the social side therapeutic.”

“I’ve been taking antidepressants for a few years, which have helped, but I still worry about the future. If I get panicky, I try some calming breathing exercises that my occupational therapist taught me. I also sit and rest and empty my mind.”

“The thing that has helped most is having a good family and friends who keep me going. I’m very lucky to have them.”

Depression

and vegetables, some lean protein such as meat, fish, eggs or tofu and some complex carbohydrates such as whole grain bread, rice and pasta. Avoid too many refined foods, like pastries, cakes, white bread, white rice and white pasta, which can lead to blood sugar spikes and dips.

■ For more information, download Mind's booklet *Food and Mood* for free or order a printed copy for £1.

Rest regularly

Fatigue is a common MS symptom and can affect mood, so it's important to factor it in. Some people find it helpful to get into a routine that involves resting at the same time every day.

Ask for help

Sometimes people want to help but don't know how. So tell family and friends what you need. Also, having the right information about health and support services in your area can help you feel less overwhelmed and more in control.

Whether you've just been

diagnosed or you've had MS for some time, it's important to keep up-to-date on what health and support services are available in your area – as your condition changes, so will your needs. Ask your GP, MS nurse or local MS Society branch about services such as self-management programmes, rehabilitation, care services, shop mobility and transport and disability schemes.

Do activities you enjoy

Your MS symptoms may mean you're not able to do all the activities you used to do in exactly the same way, but putting a few adaptations in place may mean you can still do them. If there's something you aren't able to do any longer, why not try a new hobby? Many people with MS say they have had more time to try new hobbies they may not have considered before. Ask your local authority about education courses or classes.

Spend time with others


Spending time with others, as long as they are supportive, can help.


See Be around supportive people, page 21.

Develop a positive mindset

Making changes to your thinking style can also help you to feel better. See Tackling thinking errors, page 14. However, you may need professional help to be able to do this. See What treatments can help? on page 30.

Need more help?

 If you want to talk to someone about how you're feeling, call the MS Society Helpline on 0808 800 8000.

 Download a copy of charity Mind's free booklet, *Understanding depression*, or order a print copy for £1.

Anger

While anger is a natural part of the grief cycle, staying in this phase too long can be exhausting and damaging to relationships, especially if you direct your anger at your family, pushing them away when they try to comfort or

support you. Here are some ways to address it.

Remind yourself why

When you find yourself getting angry, it can help to remind yourself what you're really angry about: 'I am angry at the MS, not my partner.' Avoid taking it out on others as this will just damage your relationships.

"Because I sometimes get anxious and stressed so easily, I am more selective about what I do, where I go, who I meet etc.. Being stressed, anxious and depressed for me are all interlinked. I am thankful that I am going through a better patch at the moment"

Carole, 57, relapsing remitting MS

Depression

Explain how you're feeling

Talking to those close to you, especially those at the receiving end of your anger, can help them understand how you're feeling, which in turn can help them to better support you.

Spot the warning signs

When you feel those telltale signs that you're getting angry, such as muscle tension and faster heartbeat, get out of the situation if you think you're likely to lose control.

Calm down

Practise calming techniques such as slow breathing and counting to 10 to help you regain control.

Address stress

If you're feeling stressed a lot of the time, it will be harder to control your temper. Read about ways to manage stress on page 18.

If you're still having problems with anger, ask your GP or MS nurse about possible therapies. Anger management programmes, either

one to one with a counsellor or as part of a group, help you to develop techniques to deal with anger in a positive way.



The British Association of Anger Management (BAAM) runs programmes (www.angermanage.co.uk)

Denial

Someone in denial is unlikely to read this. But you may recognise the signs in someone close to you.

Denial is a common first reaction when something bad happens to someone – for example, being diagnosed with MS, or going through a change in their condition. A typical reaction to bad news would be to think: 'There must be some mistake' or 'It can't be happening'.

Bear in mind that denial is a coping mechanism, giving the person's mind a break before they have to deal with the reality. It can be helpful at first.

However, it becomes a problem if someone becomes stuck and

doesn't get the treatment or support they need, or doesn't make necessary lifestyle adjustments such as factoring in rest to avoid fatigue.


Avoid pushing someone to accept something as they may not be able to deal with the reality yet. But it's important not to encourage them by pretending there isn't a problem either. Instead, give them the opportunity to seek help when they need it by providing information and making them aware of what support is available.

Out of control emotions (emotional lability)

A small number of people experience extreme emotional reactions such as rapidly varying moods and a lack of control over their emotions or expressions

such as uncontrolled laughing or crying. Having an uncontrolled episode of crying, however intense it may seem does not necessarily mean you are depressed.

Sometimes MS can affect parts of the brain that control how we react. There are very effective treatments available to deal with these extreme emotions.

 Read more about out of control emotions on our website. You can also order or download our factsheet *Out of control emotions*.

Need more help?

If your feelings are completely overwhelming and the techniques above don't help, speak to your GP, MS nurse or another health care professional.

What treatments can help?

While all of the self-help strategies listed in the previous section can help many people to manage the emotional effects of MS, they don't work for everyone. You may need extra support, particularly if you think you may be depressed. This section looks at the kind of support that might be available for you.

Talking therapies

Therapies such as counselling and psychotherapy allow you to talk about your feelings in a safe environment with someone who is trained to help you to deal with them in a positive way. These therapies can help you to cope with a range of issues, including depression, anxiety and coming to terms with MS or a change in your condition.

The idea behind them is to help you tackle difficult situations in ways that make them seem more manageable. It can also be easier to speak to someone who isn't personally affected by

your situation. A professional won't judge you and isn't allowed to share anything you say with anyone else.

Counselling and psychotherapy

There's an overlap between counselling and psychotherapy as they both involve talking about difficulties with a view to helping you find a way to resolve them. However, psychotherapy tends to be more in-depth than counselling, often looking back at your childhood and past relationships to help you understand more about your feelings and how you react to particular situations. There are many types of psychotherapy but on the whole it tends to be a longer process than counselling.

Cognitive behavioural therapy

This type of therapy, also known as CBT, focuses on the present and uses practical, problem-solving techniques to help you change how you think and behave. It's based on the assumption that your

thoughts, feelings and actions are all connected, and that you can get trapped in a cycle of negative thoughts and behaviour.

The aim of CBT is to lift you out of this cycle by challenging negative thoughts or behaviour patterns and replacing them with positive ones. CBT can be carried out as a one-to-one therapy with a counsellor or therapist, as a group therapy, by telephone or even online.

Do talking therapies work?

NICE (National Institute for Health and Care Excellence), the government body that looks at the medical evidence for the effectiveness of treatments, recommends talking therapies for people with anxiety, depression, and some other mental health conditions. A small number of

studies have found that CBT can help improve mood and reduce stress and depression in people with MS.

Can you get it on the NHS?

The availability of talking therapies on the NHS varies according to where you live but access is gradually improving, thanks to the Improving Access to Psychological Therapies programme, which is putting thousands more trained therapists into GP surgeries in England. However, you may still have to wait before you can see someone and there is often a limit to how many therapy sessions you can have on the NHS – usually six to 12 sessions. Telephone or online CBT services may also be available on the NHS in certain areas.

Further information

If you can't access talking therapy on the NHS, you could pay to see a private therapist.

Other providers

Costs can vary greatly but some therapists will adjust their fees depending on what you can afford. However, it's important to make sure that your counsellor or therapist is qualified and listed on one of the registers of approved practitioners.

To find a good therapist:

- Ask your GP or MS nurse to recommend someone in your area
- Check if your local MS Society branch or nearest MS Therapy Centre has information on counselling services, runs a group or offers low-cost counselling
- If you work, check if your employer offers counselling through an employee assistance programme
- Ask a professional body such as the British Association for Counselling and Psychotherapy or The British Psychological

Society for details of qualified therapists in your area.

Need more help?


- 📖 Read *WHICH talking therapy for depression?* a free, downloadable booklet from the NHS's IAPT website (www.iapt.nhs.uk)
- 📞 Contact the mental health charity Mind.

Mindfulness

Most of us spend a lot of time thinking about the future or the past rather than concentrating on what we're doing at the time. This can be distracting and is thought to contribute to anxiety and stress. Mindfulness exercises help you be more aware of the present and become 100% engaged in whatever it is you're doing. The idea behind it is that if you become more aware of your thoughts, feelings and body sensations, you'll be better able to manage them. Exercises, which often involve breathing techniques as well as concentrating on details around you, can be combined with other practices

such as meditation, yoga, Tai Chi and CBT.

There is some evidence that mindfulness-based practices can help improve mood, including managing anxiety and depression, in people with MS. MCBT, a combination of meditation and CBT, is approved by NICE for depression. Other research suggests that mindful meditation can help reduce fatigue, anxiety and stress, and improve working memory, attention and planning abilities.

 The Mental Health Foundation charity has details of courses, including an online course that has been found to be effective in reducing stress, anxiety and depression.

Medication

You may be offered medication, usually antidepressants, to help with managing anxiety or depression. The most commonly prescribed antidepressant medications are known as SSRIs (selective serotonin reuptake inhibitors), which work by increasing the

levels of a brain chemical called serotonin, which is thought to have a good influence on mood, emotion and sleep. SSRIs are usually the first choice because they generally have fewer side effects than other types of antidepressants.

Be aware that antidepressants often don't have an immediate effect on your mood, so it's important to give them time to work. It can take up to eight weeks for them to take effect. If, after this time, you still aren't feeling the benefit, speak to your doctor about adjusting the dose, trying a different medication or if you are thinking about stopping your medication.

Other sources of support may also be helpful. They include:

- YMS Society website forums visit www.mssociety.org.uk/forum
- Self-help groups, also known as peer-support groups, where you can share your experiences and get support and encouragement from others in a similar situation.

Further information

Further information from the MS Society

Library

For more information, research articles and DVDs about MS, contact our librarian.

 020 8438 0900


 librarian@mssociety.org.uk

 www.mssociety.org.uk/library

Helpline

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

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

 0808 800 8000
(weekdays 9am-9pm)


 helpline@mssociety.org.uk

Resources

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

 020 8438 0999

 shop@mssociety.org.uk

 www.mssociety.org.uk/publications

About this resource

With thanks to Nicholas LaRocca and Anthony Feinstein and all the people affected by MS who contributed to this booklet.

First edition written by
Madeleine Bailey

If you have any comments on this information, please send them to resources@mssociety.org.uk or you can complete our short online survey at www.surveymonkey.com/s/MSresources

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. The law and government regulations may change. Be sure to seek local advice from the sources listed.

References

A list of references is available on request, and all cited articles are available to borrow from the MS Society library (there may be a small charge). Contact the librarian on 020 8438 0900, or visit www.mssociety.org.uk/library


This resource is also available in large print. Call 020 8438 0999 or email shop@mssociety.org.uk



Multiple Sclerosis Society

Contact us

MS National Centre

 Telephone 020 8438 0700

 info@mssociety.org.uk

MS Helpline

 Freephone 0808 800 8000

(weekdays 9am-9pm)

 helpline@mssociety.org.uk

Online

www.mssociety.org.uk

www.facebook.com/MSSociety

twitter.com/mssocietyuk

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