Making Sense of MS

Multiple Sclerosis Trust MS

MS and your feelings

Living with MS can affect your feelings

It's not unusual to experience a range of powerful emotions around your MS, especially at the time of diagnosis. However, due to the changing nature of MS, there may also be other points in your life with the condition where you find yourself living with challenging feelings.

In this information sheet we look at some of the common emotional reactions to diagnosis and life with MS, and how to take care of your emotional wellbeing.

I'm feeling emotional

Emotional reactions to diagnosis

There's no right or wrong way to react to the news of a diagnosis of MS. You could feel angry, anxious or upset. You may feel relief, especially if you've spent a long time trying to find the reason for what you've been experiencing. You might be in shock, particularly if the onset of your symptoms was very sudden and you were diagnosed almost immediately. You may feel numb, like it's unreal or happening to someone else. You may find you experience a complete lack of emotion.

Whatever you feel, it's OK.

Many people liken adjusting to the diagnosis of a long-term condition, such as MS, to the grieving process after a bereavement. During this process there are five stages of grief.

- **Denying that something has happened** – this allows you to isolate yourself from the cause of your pain and buffers you from the initial shock.
- **Feeling angry** – anger may be directed at other people or even inanimate objects, even though they're not to blame.
- **Bargaining** – this is when you look for a way to gain a sense of control and postpone the sadness. In this stage it's common to think about the 'What ifs?' such as "If only I'd gone to the doctors sooner" or "What if I'd got a second opinion".
- **Depression or low mood** – this is the stage where you might try to process and reflect upon your loss.
- **Acceptance** – when you become calmer and, though not necessarily happy, you feel more able to move on with life.

The stages of grief don't occur in a set order. It's common to go back and forth between stages and you might not experience them all. Your grief may not go away completely or it may resurface from time to time. This is completely normal.

My diagnosis was a mixture of sadness and relief. My MS was then quiet for a while, and I went into denial, so I could pretend it wasn't there.

Although the grief analogy is a reasonable one, there is a crucial difference. Unlike losing a loved one, being diagnosed with a condition like MS is not a one-time event. The unpredictable nature of MS can act as an unwelcome reminder of the changes, or losses, it has led to in your life. This can bring up fresh feelings of grief all over again. Although this can make it more difficult to work through your emotions, it doesn't mean you can't process your feelings and get to a better place. You might find it helpful to talk about the changes, any sense of loss, or the impact of your feelings with someone you trust.

Dealing with symptoms

Living with the symptoms of MS can be very draining, both physically and emotionally. Symptoms such as fatigue, pain, depression and anxiety can leave you feeling very fragile. If you're not sleeping well that can make things seem even more difficult. Often with MS your symptoms can vary from one day to another, which can take some getting used to; as can new or worsening symptoms.

It can be good to reflect on what might be causing you to feel emotional and whether there is anything you can do to improve things. Is it a particular symptom that's challenging you? Could you look at whether it could be better managed by starting or changing medication, or learning some management or relaxation techniques? Would improving your bedtime routine help improve your chances of a good night's rest? Are there things you can try yourself or is it time to ask for help from a health professional?

Concerned about the impact on family

You might be concerned about the impact of your MS on those closest to you, such as a partner, children, siblings or parents, especially if you're aware that MS is intruding into relationships or intimate moments. MS might mean you see yourself, or your partner, in a different light – especially if your roles within the relationship change. You may worry that some symptoms, such as pain, fatigue or continence issues, may impact on these relationships.

Keeping the communication channels open and being honest about how you feel and how MS is affecting you at any given time can be helpful. As can emphasising the unpredictable nature of MS, which might mean you can't always follow through on a promise to do something at a particular time. It's also good to encourage your family to be open with you about their own worries and frustrations.

However, this isn't always as easy as it sounds. These types of conversation can be tough for everyone involved. Sometimes it can be helpful to talk to someone outside the family to get an independent view. This might be a good friend, another person with MS or a health professional.

I was diagnosed two months into my marriage, and I was afraid of what it meant to conceive and be pregnant with MS. My anxiety was unfounded for the most part.

Apprehension about the future

You may be apprehensive about the future and what MS might mean for you in the longer term. This is a common and natural response to diagnosis or when things change. Perhaps you've had an episode of new or worsening symptoms, had a relapse, or a medication is no longer helping, and that's got you thinking more about what the future may hold. Learning to live with the unpredictable nature of MS, and the uncertainty this can bring, can be challenging. You might be worried about starting or adding to your family, or a particular concern for many people is what MS might mean for your career.

Life is never completely predictable, there are always unexpected or unwelcome hurdles thrown into the mix. However, significant events or changes can highlight uncertainties. It's important to try not to focus too much on what might happen or assume that MS will impact on a particular aspect of your life. Try to use this time and energy in a more positive way by focusing on the things that are important to you in the here and now.

Feeling down or anxious

Feeling down or anxious can happen for many reasons, whether this is dealing with your diagnosis, worrying about symptoms or the sheer unpredictability of living with a long-term condition. However, depression and anxiety can be symptoms of MS in their own right if an MS lesion is present in an area of the brain associated with mood.

Low mood, depression or anxiety can come on suddenly or creep up on you bit by bit without you realising. Talking things through with family, friends or in online or face-to-face support groups can help with low mood. However, if you continue to feel down or it feels like things are escalating, consider seeking professional advice about treatment options, such as counselling or medication, from your GP or MS nurse.

I'm not thinking straight

Not thinking clearly is common in MS. This might be due to the shock of your diagnosis, being confused about the different treatment options or simply being overburdened with everything else going on in your life. You may feel under pressure or not be sleeping well. If you're experiencing MS fatigue, which is an overwhelming feeling of mental and/or physical exhaustion out of all proportion to the task you've done, this can add to the issue.

Difficulties with slowed thinking, such as issues with memory, concentration or attention span, can also be symptoms of MS. They're collectively known as cognitive problems. Like fatigue, cognitive issues can affect how you feel so it's helpful to seek support from your MS team if needed.

Looking after your general health can help you keep a clear mind. Small lifestyle changes, such as eating more healthily, incorporating some exercise into your day and learning relaxation techniques such as breathing exercises or meditation to help you cope if you're feeling under pressure, can all be beneficial.

I began to understand the importance of self-care, to which I'd really not paid much mind previously. I was always in a rush, the diagnosis began a shift in mindset.

I don't see myself in the same way

How you see yourself as a person is probably intertwined with other factors which are important to you, such as your role within your family, your job or if you're particularly good at something, such as photography or a certain sport. If your life has to change, it can impact on your self-esteem and your sense of who you are can become lost or blurred.

You may feel a stronger sense of loss if your symptoms affect your ability to fulfil the roles which are most important to you. Physical symptoms may be more distressing if you're very active, whereas if you have a mentally demanding job or enjoy activities that rely on brain power, then cognitive difficulties may upset you more.

Although your symptoms may be restricting you at the moment, bear in mind that this can change. They may resolve if they've happened as part of a relapse, or you may find a treatment that helps. You might find a way to manage symptoms, such as strategies to reduce fatigue, which means you can do the things which are important to you more easily. Or you might adapt and find an alternative way to carry out activities.

Only you know what's most important to you. Try to find ways to reconnect with the roles and activities you valued before your diagnosis. This might be in a different way to before, so you might need to get creative – perhaps ask family or friends for ideas to help find ways to be yourself again!

What can I do to help myself if I'm struggling emotionally?

Look for the positives in your life

- Try to keep a sense of normality. Where possible, do the things you usually do and especially the things that you enjoy.
- Prioritise. Who, and what, is most important to you and your life? Focus your energy on them.
- Learn to say no. And don't beat yourself up afterwards! You don't have to do everything. Remember those priorities!
- Try something new. Take up a new hobby or challenge that you've always wanted to try – it can be good to have a new focus for your thoughts and something to look forward to.
- Reassure yourself that living with MS is a learning curve and that you're doing your best to manage your MS well.

Be kind to yourself

- Look after yourself and your body by eating more healthily, exercising sensibly, stopping smoking and avoiding drinking too much alcohol on a regular basis.
- Looking after your mind is important too. Practising relaxation techniques, mindfulness or meditation can be beneficial. Listen to soothing music or lose yourself in a good book. Whatever works best for you.
- Go outside. It could be for a gentle walk or run, or to simply sit and watch the world go by. Fresh air and connecting with the outdoors can help clear your head.
- Chill out. You're allowed to rest, relax, take a warm bath or pamper yourself, and just zone out sometimes.

Know that whilst change is likely to happen, you will adapt, learn how to be kind to yourself and how to make the best use of your energies.

- Don't be afraid to ask for, or accept offers of, support if you need it. Even if you're doing OK at the moment you can always let people know you'll get back to them if, and when, you need their support in the future.
- Set yourself realistic goals so you don't feel like you've failed if you try to take on too much.

These strategies can help you put worries to one side, even if it's only for an hour or two. Hopefully, they'll also leave you feeling better prepared to deal with life's challenges.

Express yourself!

- Find ways to release any tension. Thump a cushion, turn up the music and sing along – or scream, keep a diary, write a blog, exercise or simply cry and let it all out.
- Share your feelings with someone you trust.

Many people find that taking a problem solving approach can be helpful. Think about what's concerning you the most. Is it something you can deal with yourself or might you need the support of someone else? If the issue seems too overwhelming, can you break it down and tackle one small piece at a time? Sometimes there simply isn't a solution to a problem. If this is the case, can you find a way to learn to accept this and move on?

Who can I talk to?

You know yourself best and how you prefer to deal with your feelings. Sometimes you might feel that you need to keep strong and hide your emotions, but it's not always best to bottle up your feelings. Is there someone that you trust you can share them with?

Often this will be a family member, or a friend and hopefully they'll support you. However, do bear in mind that they may also be dealing with their own emotions and adjusting to your diagnosis.

You may prefer to talk to someone who is more removed from your day-to-day life. You may find you can be more open with people who aren't so close to you. You could talk to your MS nurse or GP about any concerns. They may suggest talking to a counsellor or neuropsychologist for a bit more support.

Alternatively, you might find it helpful to share your story with other people with MS, or read about their experiences to see if they're similar to your own and how they've dealt with their difficulties. There are online MS support groups, like the MS Trust Facebook group, or there are some groups which meet locally if you prefer to communicate face-to-face.

Going forward

We often feel we have to stay strong for others, but this can be more challenging when we're also trying to deal with our own rollercoaster of emotions. Remember, you don't have to be a superhero who deals with everything perfectly.

It's good to live in the here and now and make the most of today. Make a few plans, pick up the phone, and take action to make it happen. At the end of the day, you're a person who just happens to have MS – it's not your entire identity.

Got a question about MS?

Ask our Helpline Team on 0800 032 3839
or email ask@mstrust.org.uk

Scan to support the MS Trust

Further information

Making Sense of MS information sheets:

Making Sense of MS: introductory booklet *mstrust.org.uk/444*
Making Sense of MS: newly diagnosed with MS *mstrust.org.uk/448*
Telling people about your MS *mstrust.org.uk/454*
Someone I know has MS *mstrust.org.uk/441*
MS and life choices *mstrust.org.uk/446*
Treating MS symptoms *mstrust.org.uk/455*

Information on our website:

Anxiety *mstrust.org.uk/anxiety*
Depression *mstrust.org.uk/depression*
Stress *mstrust.org.uk/stress*
Cognitive symptoms *mstrust.org.uk/cognition*
Fatigue *mstrust.org.uk/fatigue*
Sleep *mstrust.org.uk/sleep*
Sexual problems for men with MS *mstrust.org.uk/men*
Sexual problems for women with MS *mstrust.org.uk/women*
Working life *mstrust.org.uk/work*
Talking with your kids about MS *mstrust.org.uk/family-t*
MS Trust Facebook group *mstrust.org.uk/fb-group*
Support groups *mstrust.org.uk/support*

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Multiple Sclerosis Trust
Spirella Building, Bridge Road
Letchworth Garden City
Hertfordshire SG6 4ET

T. **01462 476700**
T. **0800 032 3839**
E. **ask@mstrust.org.uk**
W. **mstrust.org.uk**

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Making Sense of MS

This information is part of a set of resources for people who are newly diagnosed with MS. You might like to look at our introductory resource, Making Sense of MS, which answers the questions most commonly asked around the time of diagnosis.

MS Trust Information Team
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