Multiple Sclerosis Society

Living with the effects of MS



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**.

As a charity, we rely on the generosity of people like you to fund our vital work. Thousands of people affected by MS turn to us for help and advice each year, and we want to make sure we are there for them whenever they need us. If you would like to make a donation, you can do so by:

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

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About this booklet

Multiple sclerosis (MS) is an unpredictable, uninvited guest that arrives in a person's life, and the lives of those around them, and is there to stay. Very few people are prepared for the emotional impact a diagnosis of MS brings to their lives. People's reactions to MS can be as varied, and as unpredictable, as the condition itself.

There is no 'right' way to react to a diagnosis, or to a change in symptoms, condition or circumstances. Whatever reaction you experience, it really will be 'normal'–you won't be alone in feeling the way you do, even if it seems different right now to those around you.

Everyone has different personalities, coping styles and strengths, and everyone will find different approaches helpful when dealing with the emotional impact of MS. These approaches might change over time.

This booklet outlines a number of ways that can help you to prepare for and manage the emotional impact of MS. Nobody can control every emotion and remain positive and happy all the time, and that isn't what this booklet is aiming for. But many people find the suggestions described here helpful for managing the emotional effects of MS.

Although some sections of this booklet are specifically for people who are newly diagnosed, other sections can be helpful for anyone at any stage of their MS. Some parts of this booklet will seem more relevant to you than others, so you might want to dip in and out, rather than read it straight through. Many of the ideas in this booklet can be explored more fully with a professional trained in dealing with emotional changes – a counsellor, psychiatrist or clinical psychologist, for example.

As well as this booklet, you might want to read our booklets *Just diagnosed – an introduction to MS* or *What is MS?*

The diagnosis

Receiving a diagnosis of MS can cause many different reactions. MS might have been discussed with you as a possible explanation for symptoms you have experienced, but it might equally have been a 'bolt from the blue'.

Getting the diagnosis could raise as many new questions as it answers, and people's reactions will vary – from person to person and over time. It's important to remember there's no right or wrong reaction.

Reactions vary

For some people, a diagnosis of MS can be overwhelming, frightening, confusing and distressing. For others it can be a relief, especially if they were wondering if they were going mad or they had symptoms for which no cause could be found. Some might even hear the diagnosis, leave the consultants room and return to normal daily life without giving it another thought until the next 'real' change in circumstances. Others might 'shut down' emotionally. For many, it's a combination of all the above.Ultimately, it's important to recognise that it's a unique process-there's no right way to react and whatever your reaction it's part of a normal process.

Remember, you're the same person you have always been. MS may require you to make adjustments to how you approach different aspects of your life over time, but you're the same person after diagnosis as you were before.

One way of understanding the initial reaction is to liken it to a roller coaster ride. At first there's a scary anticipation of the ride to follow, then once seated on the ride the realisation there's no turning back. The ride then begins and a significant number of emotions are experienced-there are highs and lows. And, like a roller coaster, some people are able to cope and others find it too frightening.

Reactions vary
Some of the initial reactions people can experience:

- shock
- denial
- optimism
- confusion
- isolation
- anxiety
- anger
- hope
- fear
- panic
- sadness
- relief

These reactions might be experienced not only by the person who is given the diagnosis, but also by those around them. It's possible that reactions will be different for each family member and close friend. For example, the person with MS might feel relief, while their partner is in denial. This experience is very common.

Questions?

A diagnosis can create emotional reactions. It can also raise many questions.Questions frequently asked include:

What did I do wrong? Could I have prevented this? Why me?

These are very natural questions. Whenever something bad happens we want to know why. The precise cause of MS is a mystery: there isn't anything you did to get MS and there isn't anything you could 've done to prevent it.

Will I need a wheelchair? Do I have to stop work? What will happen to me? How will my life change?

These are questions you will revisit time and time again, for the rest of your life. The truth is, no one can be certain how your MS will affect

you. Although many doctors agree that the first five to seven years of MS can be a good predictor of your future prognosis, many predictions made for MS are based on averages across many people. As with any average, people can be on either side of this 'average experience'-the average doesn't always accurately reflect the experiences of an individual.

Learning how to deal with unpredictability and being prepared to manage changes will help you take back the control you might feel MS has taken away.

Can I have children?

Having MS should not stop you from being a successful parent. MS doesn't affect fertility. Of course, a parent with MS may be faced with more day-to-day problems in looking after children than the average parent - but these are not insurmountable.

For more information about having children, read the MS Society booklets, *Sex, intimacy and relationships* and *Women's health*.

Many people worry that their children will also get MS. There's a genetic aspect to MS, but it's by no means the whole story and MS isn't directly inherited. There's only around a 2% chance of developing MS if one parent has MS.

There's more information in the MS Society factsheet *Genes and MS*.

Can I help myself?

The answer is yes! There are many ways of helping yourself and these might change at different times. Exercise can improve the overall health for people with MS, It can help those with more severe MS stay as mobile and active as possible.

Many people find prescribed medications and complementary therapies helpful. And your emotional health is also very important to living successfully with MS.

Strong links have been discovered in the past few years between emotions and health: they are a key element in self care. Some different techniques for emotional self care will be talked about in further sections in this booklet.

Do I need to tell my family, friends, people at work?

There's no rule for everyone to follow with this. Some people want to tell everyone, especially if they've been unwell for a time with no apparent reason. Others want to keep it a secret, telling only those they feel need to know.

Talking about your diagnosis can be a way of lessening the sense of feeling alone with your MS and gaining support from others.

One way of helping you decide who to tell is to draw a small circle on a piece of paper - that's you. Now draw another circle around it and write the names of those closest to you-family, close friends, and so on. Call that the 'inner circle'. Then draw another circle and write names of those people who are close but not as close as the inner circle - extended family or work colleagues.

You can continue drawing as many circles as you need, ending with a circle that includes names of people you might class as occasional acquaintances.

Most people find that they are happy to tell people in the inner circle and maybe the next circle, but decide that those on the outer circle are only given information on a need-to-know basis. You might use this exercise at different times of your life as people's roles in your life change.

There aren't always clear answers to the questions above, which can be frustrating. Partly, it's because of the unpredictability of the condition-but also because it's difficult to predict anything in life with certainty. This can increase distress and the sense of losing control.

Often these questions come from the emotions being experienced. Here's an example:

'Why did this happen to me?'

It's normal to want to know why things go wrong and as MS has no known cause it's easier to question yourself.

Asking 'What if...?' or 'What will...?' is a normal response to the unpredictability of MS. But getting stuck asking these questions can cause needless anxiety. Remember that life in general is unpredictable and you've probably dealt with unpredictable areas of life in the past. You can find ways to do the

Positive reactions

Receiving a diagnosis of MS can be negative, of course, but not all people react in a negative way. Some people find that the diagnosis provides an opportunity for change in their lives. There are many stories of people changing their career paths, changing their lifestyles, getting fit and so on. Receiving the diagnosis can be a 'turning point' and can be a time where the future is re-evaluated in a proactive way.

Early treatment

We're learning more about how MS affects people's bodies and the difference treatment can make. Experts used to think that when you had a 'relapse' it meant symptoms appeared and/or quickly got worse and then went away (or 'remitted').

Thanks to wider use of MRI scanning we now have new evidence that when symptoms get better, the damage that MS causes often doesn't stop. Even when you're not having a relapse, MS may carry on attacking your body, leading to nerve damage that can't be put right. This has changed what we understand about MS and how to treat it.

Starting treatment with a disease modifying therapy (DMT) gives you a chance to slow down this damage and reduce how many relapses you have.

Experts agree, treatment should be offered as close to diagnosis as possible. Your neurologist should begin talking about what kind of treatment is right for you as soon as you're diagnosed. This doesn't mean that starting treatment later won't have any benefits.

Everyone with a relapsing form of MS should speak to their neurologist about treatment options and make an active and informed choice about what is right for them.

Drugs for MS are developing all the time; for example, there are now 11 DMTs available for types of MS where you get relapses.

Unfortunately, the DMTs available now can't help people whose MS doesn't have relapses. But there are many clinical trials currently underway that are testing drugs for people with progressive forms of MS.

Managing a relapse

Around 85% of people with MS are diagnosed with relapsing MS. If you have this type of MS, you will have relapses (or attacks) of symptoms that occur for a period of time - days, weeks or months - and then improve, either partially or completely.

Some people with secondary progressive MS-a form of MS that many people with relapsing MS go on to develop-also have relapses. This booklet looks at what a relapse is, how relapses can be treated and managed, and what happens after a relapse.

What is a relapse?

A relapse is the collection of symptoms that arise because of new inflammation and nerve damage (demyelination) in the brain and/or spinal cord. An example of a relapse could be blurred or no vision or not being able to lift a leg.

A relapse may be called by other names, including an 'attack', 'exacerbation', 'flare-up', 'acute episode' or 'clinical event'.

How do I know if I'm having a relapse?

It can be difficult, particularly in the first few years after diagnosis, to know what is and isn't a relapse. It's quite common for MS symptoms to change from day to day, and having a cold or another infection can make your symptoms worse than usual.

If it's a relapse:

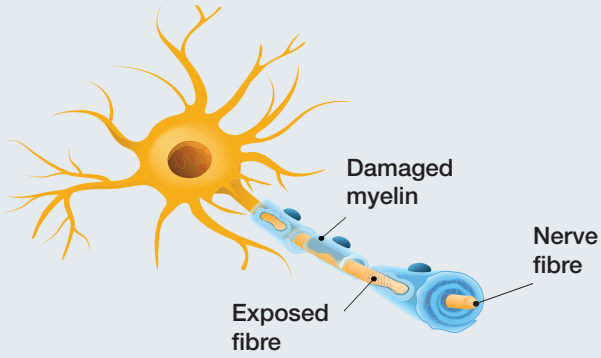
- you may find your symptoms come on over a short period of time -perhaps hours, or days
- they may be new symptoms, or they may be symptoms you've had before
- the symptoms will last for at least 24 or 48 hours (although most relapses last longer - often weeks, or sometimes months)

What's happening in the brain and spinal cord during a relapse?

In a relapse, cells from your immune system start to attack the myelin coating around the nerve fibres in your brain or spinal cord.

This causes inflammation around the nerve fibres.

This inflammation affects the way messages are able to travel along the affected nerve – they might slow down, be disrupted or not get through at all.



If you're unsure, you may find it helpful to speak to someone - perhaps your GP or MS nurse, or you can call the MS Society Helpline on 0808 800 8000. Please bear in mind we can't provide any medical advice. You may also find it helpful to ask other people with MS about your symptoms, via the forums on the MS Society website.

What should I do if I think I'm having a relapse?

If you think you're having a relapse, you should contact your GP or MS nurse (if you have one) as soon as you can.

Before your MS specialist can say your symptoms are definitely caused by a relapse, they will need to check for other possible causes for them. They'll probably ask you lots of questions about your symptoms and how they're affecting you, your general health and your activity over the last few days. They'll also need to test for possible infections, such as bladder infections.

It's important that your neurologist knows you're having a relapse, as it may affect your eligibility for disease modifying therapies (DMTs). If you're not in regular contact with a neurologist, you should still make an appointment to see your GP. They will be able to refer you back to a neurologist, if that's what you want.

What treatment can I have for a relapse?

If your relapse is particularly bad, and it's affecting what you're able to do - for example, if it's making it difficult for you to walk – you may be offered steroids. These can help to reduce the inflammation in your brain and spinal cord that's causing the symptoms of your relapse.

Dealing with loss

One way of thinking about people's reactions to the diagnosis of MS is to think about it in terms of 'bereavement.' For many people it's seen as a time of many losses – for example, loss of health, loss of self-image, loss of expectation and loss of employment. These losses lead to the experience of grief.

This section focuses on helping you understand and recognise emotions associated with grieving. It also suggests ways of grieving healthily – dealing effectively with very natural reactions to living with MS.

Why do I need to understand grieving?

Many people ask the question, 'Why do I need to understand grieving? MS isn't going to kill me.' That's true, but grieving is actually a normal response to any loss. Even though it's a very distressing and emotional experience, it's nevertheless an important and healthy part of life.

Grief allows us to survive change; it can help you to find new and creative ways to deal with change. In MS, grieving can be seen as a tool that helps in re-evaluating life, revising your view of life, changing your life where needed – with the goal of adapting to any losses you might experience. Grief can be a positive response to loss.

Being diagnosed with a long-term condition can force people to confront their own fears, limitations and vulnerabilities. While it might seem overwhelming to start with, healthy grieving enables you to let go of the past and grab hold of the future. It's also important to recognise that these feelings of grief can happen at different stages of life-not only at diagnosis. In other words, if your condition changes you might find you experience these grief feelings again.

The process of grief

The process of grief will be different for everyone, but it's widely recognised that there are five stages of grief. People experience

these stages to different degrees, and the whole process can last from a few days or weeks through to several months with intensity of emotions gradually decreasing.

Like MS, these stages are not predictable and you might find you don't go through them all in a neat order. You might find you skip one of the stages, revisit a previously experienced stage or even experience them at the same time.

These five stages are:

- denial
- anger
- bargaining
- depression or sadness
- acceptance

Let's look at these stages in more detail:

Denial

This is often experienced when the diagnosis of MS is first given. Often people think the consultant has made a mistake or think 'This can't be happening.' Denial is an effective coping mechanism allowing people to avoid thoughts and feelings which are too distressing to face. It might be a momentary flash in the mind, or it could last quite a bit longer. As a healthy coping mechanism, it gives your mind a break before needing to deal with reality – the diagnosis.

However, some people find themselves getting stuck in denial. This is when it can become a problem. Without accepting the diagnosis, it's hard to get the information you need to make decisions about treatments, support and so on.

Anger

The key to healthy anger is to direct the anger. You might be angry with the doctor for telling you the diagnosis, or at yourself, believing you could have stopped MS entering your life. You might be angry at your family – pushing them away when they try to comfort or support you. You might be angry at a higher power for

allowing you to have MS, or angry at the medical community for not having a cure or understanding MS.

In reality, this list can be very long and is as individual as MS is to each person. It's quite natural to feel all this anger, but it can be exhausting and stop you from moving forward. So the challenge is to find ways of using your anger in a positive way – make it work for you, rather than against you.

When you find yourself getting angry, ask yourself these questions: What is it that is making me angry? What is the real issue here? What am I thinking and feeling? What is it I want to accomplish? Who is responsible for what? What if I want to change? What things am I willing to do or unwilling to do?

These questions might help you think more clearly about the situation you're experiencing, and as a result enable you to make some conscious decisions. Anger can energise and help you find answers, solve problems and overcome obstacles.

One helpful way to deal with anger is to identify your triggers. If you can work out when you're more likely to lose your temper, you can take steps to control it. For example, if you recognise that being tired, hot or hungry makes you more irritable, then resting, cooling yourself down or eating will help you.

Being angry at the diagnosis of MS is normal, so verbalising these feelings to yourself, or those around you, can be helpful: 'I am angry at MS, but I am not angry at you.' Speaking the feeling can bring relief and allows others to support and encourage you.

Bargaining

In this stage people try to make deals with fate, with their doctors, or with their family: 'If you help me through this, I will change my lifestyle (or exercise more, or become a nicer person, and so on).' As time moves on, and symptoms lessen or emotions become more stable, any decisions people make in this

stage (for example, healthy eating or exercise) are often put to one side and unhealthy habits picked back up. This is the stage of attempting to avoid the inevitable.

Depression or sadness

This is the point in the process when the feelings of loss, both past and current, can appear to be overwhelming. This is the stage when people might be weepy, distressed or withdrawn.

Although the term 'depression' is often used here, this stage is perhaps best described as a feeling of deep sadness. Sadness can be defined as an appropriate reaction in proportion to an event you experience. The event could be receiving a diagnosis of MS or experiencing a relapse. And it's normal and appropriate for this to cause sadness.

Allow yourself to be sad: cry, talk, spoil yourself by having a duvet day, watch a movie – just give yourself permission to be sad. The best way to deal with sadness is to experience it. Usually, sadness soon passes and you will find yourself moving forward into life again. Occasionally people can move from sadness into depression and if you become concerned then speak to your GP, MS nurse or other health care professional. There's more about recognising depression later.

Acceptance

This is the stage where people feel they can accept what is happening and finally feel as though they can move forward. It's a time of stability. It can be a stage where you feel a void of emotion. This stage should not be mistaken for a 'happy phase'. Acceptance may be having more emotionally good days than bad days. You can't replace what has been lost, but this is the time when you start to recognise the new reality. You may no longer deny feelings but listen to them and use them to move, change, grow and evolve.

For information and strategies on how to deal with loss consult the resources listed in this booklet for more suggestions (see *Further reading* page 33).

Some final thoughts about the grieving process

- you might experience a wide range of emotions including anxiety, shock, avoidance, sadness, anger, apathy and despondency
- you may experience physical symptoms including crying, shortness of breath, restlessness, aches and pains, sleeplessness or fatigue
- grief can make you feel as though you're going crazy- remind yourself you're going through a natural process
- It's important to allow yourself to grieve otherwise you can get 'stuck'
- grieving might happen at the point of your diagnosis or at times of relapse or changes in your condition- this is normal
- the grief process may not go step by step; you may go from one stage to another and back again, or you may even miss a stage. The details of each person's experience will be different
- grief has been described as a gift, which has the power to heal. This may seem like a strangely positive description,but one leading psychologist says 'it transforms the wounded, broken soul'. It's a normal process that each human being experiences in life

How does MS affect emotions?

As well as leading to feelings of loss and grief, living with MS can bring about a wide range of other emotional changes. Some of these are a direct result of having MS, while others are the result of things related to MS – such as side effects of drugs.

If you're experiencing changes to your emotions, it may be difficult to pin down exactly what's causing them. Often these changes may be the result of a combination of factors. These factors are outlined below.

Factors directly related to MS

Psychological reaction to MS

Being diagnosed with MS and adapting to the changes and uncertainty it brings can be upsetting. It may lead to a whole array of emotions, such as grief, anxiety, guilt, fear, irritation and anger.

If you have relapsing MS, the uncertainty of not knowing when you will have your next relapse, or how it will affect you, can have a huge emotional impact. For some people, learning to live with this unpredictability is one of the hardest parts of coming to terms with having MS.

There's no right or wrong way to react – everyone's reaction is different. How you react will depend on how MS affects you, the symptoms you have and the coping skills you have already developed throughout your life.

There's more information on taking control of emotional reactions to MS in our booklet *Emotions and MS*.

MS-related nerve damage

Different parts of your brain control different things. The frontal lobe is responsible for controlling emotions, and how they're expressed. Regardless of your personality, if you have MS-related

nerve damage in this area of your brain it can affect how you feel and react.

Factors not directly related to MS

Side effects of drugs

Some drugs commonly used for treating MS and its symptoms can sometimes cause changes in mood and behaviour.

These include:

- Steroids (used to treat relapses) can cause mood swings, depression, hyperactivity or anxiety
- Beta interferons (a type of disease modifying drug) can sometimes cause depression
- Modafinil (sometimes used for fatigue) can cause anxiety or depression

Some drugs, including baclofen (used for treating spasticity), can cause temporary mood and behaviour changes if you stop taking them suddenly. For this reason, you'll 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, you should speak to your GP.

Social circumstances

Your social, financial and domestic situation can also affect how you feel. This may be a result of MS, or it could be due to something else going on in your life.

For example, if you live alone and don't have close friends or family nearby, you may feel isolated and unhappy. 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 anxious about money.

If you're feeling like this, you're not alone. The rest of this booklet includes guidance on how to cope with these feelings – including what to do if you think you need professional support to help you to manage them.

Other health conditions

Not every issue you have with your health – whether emotional or physical – will be caused by your MS. If you're experiencing changes to your emotions and behaviour, there may be another reason for them – such as another health condition. And some people, regardless of an MS diagnosis, are more prone to depression or other emotional changes.

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

Taking control of your emotional responses to MS

It's not surprising that at times you might feel overwhelmed by the emotions MS brings into play. The good news is you don't need to be bullied by them. There are ways to manage fear and anxiety, deal with stress, recognise and treat depression, and raise your self-esteem.

There's no 'right' coping strategy that works for everyone. Remember, you'll have your own way of dealing with difficult situations.

For more detailed information on managing fear and anxiety and for professional support and advice on dealing with stress consult our booklet *Emotions and MS* and factsheet *Anger, laughter and tears.*

Depression

Many people may loosely use the word depression to describe short periods of feeling down or low, but clinical depression is more than this.

Depression is characterised by a persistently low mood most of the time, lasting for a few weeks or more. It can cause distress and affect social and work abilities, with sadness and emptiness accompanying the low mood.

Up to 50% of people with MS will have clinical depression during their lifetime. For the general population, this figure is only 10%, so the odds are increased. But while it's known that depression is high in people with MS, it's often unrecognised by both them and health care professionals, and therefore frequently left untreated. This is a concern because although depression can be devastating it can often be successfully treated.

Symptoms of depression

It can be difficult to recognise depression in MS because some of the MS symptoms imitate symptoms of depression – for example, fatigue, loss of energy, sleeplessness, loss of libido or in how you think about or understand things (cognitive changes). Also, it can be difficult to decide whether the sadness experienced at times of grieving is actually depression.

The rule of thumb here would be that major depression lasts much longer than short-lived feelings of sadness. For an overview of the symptoms of depression (see page 20).

In order for a diagnosis of depression to be made, the doctor would expect to see at least five of the following symptoms being experienced daily for up to two weeks:

- loss of pleasure or interest in most daily activities
- feelings of hopelessness, sadness or despair
- significant weight loss or gain; or an increase or decrease in appetite
- persistent sleep problems, either insomnia or excessive sleep
- ongoing fatigue and loss of energy
- feelings of personal worthlessness
- inappropriate and excessive guilt
- inability to concentrate or make decisions
- observable restlessness or slowed movement
- recurrent thoughts of death, violence or suicide

Treatments for depression

If you think you may be depressed, the first step is to speak to your GP or another member of your health care team. They will be able to carry out an assessment, and work with you to find the best way to manage the depression.

Medication isn't the only way to treat depression. There's evidence to suggest that the best treatment is a combination of medication and therapy, as well as tackling the root causes – for example, treatable MS symptoms or social isolation.

You can access talking therapies through the NHS, or if you want to try a different therapy from the one you have been offered, you can also see a private therapist. If you've never seen a therapist before, it can be hard to find the right one. The following people and organisations can help:

- your GP or MS nurse may be able to recommend a therapist in your area
- many MS Therapy Centres offer low cost counselling to people with MS
- the British Association for Counselling and Psychotherapy has a directory of qualified therapists
- the British Psychological Society has a directory of psychologists

If you choose to see a private therapist, you'll have to pay for the service. Costs can vary from £10 to over £100 an hour. Some therapists will adjust their fees depending on what you can afford to pay.

Some employers also offer counselling to their employees through an employee assistance programme. You should speak to your HR department, if you have one, to find out if this is something you can access.

The impact of MS on others

MS affects family, friends and colleagues – in fact, anyone who is in contact with the person who has been diagnosed with MS. Those who are close to the person with MS frequently find they have the same emotions: grief, anxiety, anger, guilt, fear, isolation, and relief.

All the previously suggested strategies to deal with emotions are not only for a person with MS but can be effectively used by all those involved. If you're a family member or friend affected by MS, it's as important for you to look after yourself and recognise you can take control as well. This section looks at some of the different reactions the family can have, how to adjust to change, and tips for good communication.

Different reactions in the family

One of the difficult things to deal within families is that, often, people don't experience the same emotion at the same time. While the person diagnosed with MS might have moved through the grief process, their family members might still be grieving. It's not uncommon for one person to feel significant relief at the diagnosis and another to be very fearful. It's important to acknowledge that all emotions, both positive and negative, are important, and are normal emotions in the given circumstances.

Often many of the symptoms of MS are 'invisible', for example, fatigue and cognitive changes. If a person has their leg in plaster it's obvious to everyone that the leg isn't working properly, but symptoms like fatigue or cognitive changes can be subtle, and difficult to acknowledge and understand – which can make good communication particularly important.

Adjustment to change

There are many adjustments that frequently have to be made, not only by the person diagnosed with MS but also by the whole family, as the uninvited guest moves in.

These adjustments can lead to a number of different emotions, all of which are normal. It's important that each person gives themselves permission to experience these emotions and to acknowledge them – and to communicate or express them with their loved ones and those around who can help (such as a GP, or other health or social care professional).

Recognising the emotions you experience and dealing with them in a healthy way will help with the adjustment process. Asking for help isn't a failure but a positive step forward in coping with MS. The adjustments or changes MS might lead to, for partners, children, parents and friends of a person with MS, can include:

Change from partner or lover to carer

All relationships have hopes and plans for the future, a shared history and a shared commitment to making the relationship work. MS can cause shifts in these. A partner might, for example, have to provide intimate care, such as helping with bathing, dressing or toileting. The role appears to change. But this can be a change in role others place upon them. For example, health professionals might call the partner a 'full-time carer' and a lot of information uses the term 'carer' rather than parent, spouse, friend or colleague.

While this is a useful name for people wanting to access help and support in their caring role, it's rarely how the person wishes to be seen in day-to-day life. The caring role is only part of any relationship. All this can lead to frustration and confusion over their role.

Support is available for carers from both the Carers Trust and Carers UK (see page 31).

Changes in role

Sometimes partners or parents have to find different employment to fit around school hours (for example, if the person with MS isn't able to collect the children). For others, it's a case of working longer hours to help to keep finances in check. If the person with MS is experiencing a relapse

or struggles with fatigue, the partner, parent or child might find they are doing housework or other tasks the person with MS previously did. At times, this might lead to feelings of inequality or unfairness, anger, frustration and isolation.

Impact on children

Children who have a parent with MS can become confused and scared. Often this is due to lack of communication from the parents as they are worried about how to explain MS to the child. There's no right or wrong way to speak to your children about MS. How you tell them or how much you tell them is an individual decision – no two families are the same. You know your children best. However, it's important to recognise that children notice what goes on around them – they pick up on changes in atmosphere, emotions and what isn't being said.

This can lead to MS becoming a 'monster in the wardrobe' – the child knows it exists but the parents tell them it's their imagination. Children imagine the worst if things are not out in the open. Giving your child information about MS allows for questions to be asked and reassurances to be given.

There are books and DVDs to help you speak to your child about MS, available from the MS Society, the US and Canadian MS Societies and the MS Trust (see *Online resources* page 30).

Impact on adults with MS and their parents

Most parents have expectations, hopes and dreams for their children. They spend their lives preparing their children to become responsible, independent, self-supporting individuals, to leave home and to develop their own homes. Unfortunately, MS can sometimes interfere with these aspirations.

As MS is frequently diagnosed in young adulthood, adult children might find it more difficult to leave their parents' home, or they may have to return to the parental home. Adults with MS might need their parents' support financially,

or extra help with bringing up children. These situations can cause stress, anxiety and frustrations as the parent-child boundaries become blurred.

Parents, regardless of how old their child is when MS is diagnosed, experience the whole host of emotions mentioned previously. Frequently, the parents of the person diagnosed (regardless of age), and in particular the mother, believe it's their fault: 'Is it something I did wrong that caused MS?' This fear can lead to guilt-ridden behaviours.

Unfortunately, emotions being experienced aren't often recognised because parents of adult children don't often get the opportunity to express their concerns and ask questions of health care professionals, especially when the person with MS has a spouse. Frequently, parental protectiveness is reactivated and the person with MS can sometimes start to feel smothered. But, for many adult children with MS, having caring parents can be a positive experience, providing reassurance and emotional support.

Impact on friends and people at work

MS can affect all relationships and all too often the impact on work colleagues and friends can be forgotten. There are many resources available for helping families deal with MS, but there's very little recognition of the experience of friends and people at work. They too might find themselves facing strong emotions when they hear of the diagnosis of MS being given to someone close to them, or in watching them go through relapses or changing symptoms.

It's important for friends and colleagues to understand it's normal to experience their own emotions and to give themselves permission to express their feelings. Communicating well is the key to maintaining healthy friendships. The person with MS is still the same friend or colleague – MS might be a part of them

but it's not all of them. They have been diagnosed with MS – they aren't a diagnosis of MS! It can be difficult for the person with MS in knowing what to say to friends and colleagues – many people don't understand MS and so they find themselves having to 'educate.' They might find it hard to deal with constant questions of concern, such as 'How are you feeling today?,' especially at work where this concern can be perceived as 'You aren't capable of doing your job'.

This can lead to frustration on the part of the person with MS and to confusion for the colleague or friend expressing the concern.

Communication difficulties

Communication is a two-way street and a complex process. It's a skill we develop through life. It's important to remember that we don't only communicate through words but also through body language. Researchers suggest that up to 55% of communication is nonverbal – the way we present ourselves and body language.

Learning and practising good communication skills can help you better deal with difficult situations. A family member, friend or work colleague being diagnosed with MS can cause life to feel more unpredictable than it usually does. Together with emotions such as stress or fear, this can affect communication. There are a number of reasons for communication to become difficult. Understanding these will help you cope with communication problems and help each family member to express their own feelings.

Coping styles

Everyone has their own unique ways of coping. For example, one might want to talk, another to think long and hard. One might want to 'refuse' the diagnosis, the other to explore everything written about MS. This can cause conflicts, not only at the point of diagnosis but at different times in the future, especially if the MS changes.

Myths and misconceptions

When someone is diagnosed with MS it's amazing that everyone they speak to will know someone who has MS as well. This means there'll be as many ideas about MS and what it is as there are people you might speak to. This can lead to myths as to what MS is and misconceptions as to how MS affects people.

Protection

In families it's not uncommon for each member to want to protect other family members. This can lead to MS becoming the unmentioned guest that sits with you at each meal, watching the TV, and so on.

Uncomfortable subjects

There are many subjects families in general just don't talk about – for example, sex, bladder issues and bowel habits. They are just embarrassing subjects for a lot of us! Adding MS into this mix can cause even more embarrassment and make communication even more difficult.

Money, money, money

MS can be a costly condition so conflicts can arise over family finances. This isn't uncommon in families in general, where it's acknowledged that more couples argue about finances than anything else!

Communication is an important tool in all relationships and all of the above can be normal experiences in families and relationships, regardless of MS. MS might make communication more difficult, but it can also nudge families towards being better communicators.

A starting point to help with good communication is to recognise that everyone has different ways of communicating how they feel. Some are strong, silent types; others are talkative, fired-up types.

The goal is to find common ground for communication and then use this to begin to work through coping with the intrusion of MS in family life and relationships.

Here are some communication tips:

- be honest about your feelings. If it's hard for you to express yourself maybe say something like 'this is difficult for me to talk about'
- accept support and help when offered
- ask 'How can I help?'
- try to be a better listener than talker
- find the right time when an important thing needs to be communicated. If you're very tired or emotional it's probably not the best time to discuss something important
- turn the TV, computer or radio off –give the communicating person all your attention
- remember, it's all right to have different opinions. You might not always agree. The most important thing is to feel as though you've been listened to and your opinion matters
- try new ways to communicate –for example communication books, using white boards, Post-it notes,or by passing a teddy from one person to another (the person with the teddy does the talking, the other listens, and when the teddy is passed on the other person can communicate)
- recognise that everyone has a different style of communication, and that understanding these differences can help to improve communication between you

There are many good strategies to help you communicate. If you're struggling with this, ask your GP about a referral for family therapy or contact Relate for counselling advice (see page 32).

Getting the right support

Dealing with MS on your own isn't easy. Human beings are social creatures – we need connections, healthy relationships and social support structures.

Maintaining relationships and developing new ones after being diagnosed with a long-term condition such as MS can be a challenge. You might want to be alone or you might want people around you. You might want to do things on your own but also realise you might need others to help you.

As well as support from your family and friends, you might find groups such as MS Society branches helpful for information and support from others affected by MS in the area. Branches and other groups might also arrange for experts to visit the group and provide information or even services (such as physiotherapy). Not everyone wants to get heavily involved in an 'MS group', but there might be aspects of a group that you find helpful, so it can really be worth staying in touch with them.

You might prefer to explore internet support groups, discussion boards or chat rooms. There are also excellent resources on the internet – see the sites listed in '*Online resources*' on the next page. A word of caution: there are many internet sites and online adverts offering all kinds of treatments, such as very restrictive diets or un-proven therapies.

If there is a 'miracle cure' promoted and you want to find out more about it, the MS Society has a freephone MS Helpline you can call or email for information – or speak to your doctor, MS nurse or other health care professional.

Learning about your condition and how to manage it can also be a form of support: 'self-support.' You might do this through reading, going to MS Society information days, watching awareness talks on the MS Society website, or attending an Expert Patient Programme or self-management course (see *Useful organisations* page 31).

Online resources:

MS Society
- **www.mssociety.org.uk**

All our information booklets are available to download online. We also have discussion forums and links to social media.

National Multiple Sclerosis Society (USA)
- **www.nationalmssociety.org**

This American site is particularly strong on information for children and teenagers, whether they have MS themselves or live with someone who has the condition.

Multiple Sclerosis Society of Canada
- **www.mssociety.ca**

This Canadian site is also strong on information for children and teenagers.

MS Trust
- **www.mstrust.org.uk**

Provides information about MS.

Living Life to the Full
- **www.llttf.com**

Online self-help courses using Cognitive Behavioural Therapy (CBT) in everyday life.

Useful organisations

British Association for Behavioural and Cognitive Psychotherapies (BABCP)
Has details of accredited cognitive and behavioural psychotherapists – full directory available online.
0161 705 4304
www.babcp.com

British Association for Counselling and Psychotherapy
Has details of accredited counsellors, psychologists and therapists, via their 'It's good to talk' website.
01455 883300
www.itsgoodtotalk.org.uk

British Psychological Society
Has details of accredited psychologists.
0116 254 9568
www.bps.org.uk

Carers Trust
Provides information, advice and support through its network of independently managed carers' centres, as well as information and a forum for carers on their website.
0844 800 4361
www.carers.org

Carers UK
Provides information and support for carers.
0808 808 7777
www.carersuk.org

Mind
Provides information and support for anyone with mental health problems or emotional difficulties.
020 8519 2122
www.mind.org.uk

MS National Therapy Centres
A federation of centres offering a variety of therapies in England, Wales and Northern Ireland.
PO Box 2199
Buckingham, MK18 8AR
01296 711699
www.msntc.org.uk

MS Therapy centres in Scotland.
Duncrievie House
College Road
Methven
Perth PH1 3PB
01738 840 357
www.mstherapycentres.org.uk

Relate/ Relate NI
Offers advice, relationship counselling, family counselling, workshops, mediation, consultations and support, face to face, by phone and through the website.

In England and Wales:
0300 100 1234
www.relate.org.uk

In Northern Ireland:
028 9032 3454
www.relateni.org

Relationships Scotland
Offers a similar service to Relate for people in Scotland.
0845 119 2020
www.relationships-scotland.org.uk

Self-management courses
Self-management courses are designed for anyone with a long-term condition, like MS. They give people the tools and techniques to help them to manage their condition better. For information about self-management courses in your area, contact:

In England:
Self Management UK
03333 445 840
www.selfmanagementuk.org

In Wales:
The charity **Arthritis Care** runs free **Challenging your Condition** courses for people with any long term condition..
02920 444 155
www.arthritiscare.org.uk/in-your-area/wales

In Scotland:
The charity **Arthritis Care** runs free **Challenging your Condition** courses for people with any long term condition..
0141 954 7776
www.arthritiscare.org.uk/in-your-area/scotland

In Northern Ireland:
The charity **Arthritis Care** runs free **Challenging your Condition** courses for people with any long term condition.
028 9078 2940
www.arthritiscare.org.uk/

Further reading

The following books are all available to borrow from the MS Society library. Email **librarian@mssociety.org.uk**, call 020 8438 0900 or visit **www.mssociety.org.uk/library**

Overcoming anger and irritability by William Davies. Published by Robinson (2009), ISBN: 1849011311. Using cognitive behavioural therapy techniques, this self-help manual has been written to explain why bouts of anger and irritability can occur and suggests ways to overcome them.

Overcoming anxiety by Helen Kennerley. Published by Robinson (2009), ISBN: 1849010714. This book also uses cognitive behavioural therapy techniques to present a self-help programme for managing anxiety.

On grief and grieving. Finding the meaning of grief through the five stages of grief by Elisabeth Kubler-Ross and David Kessler. Published by Simon and Schuster (2005), ISBN: 0743263448. This book looks further at some of the concepts around healthy grieving introduced in this booklet.

Overcoming depression by Paul Gilbert. Published by Robinson (2009), ISBN: 1849010668. Another self-help book using a cognitive behavioural approach. This one suggests ways to help manage depression and low mood.

Overcoming low self-esteem by Melanie Fennell. Published by Robinson (2009), ISBN: 1849010684. A self-help book, again using a cognitive behavioural approach, which looks at ways to raise self-esteem.

Further reading

Self-esteem for women. A practical guide to love, intimacy and success by Lynda Field. Published by Vermilion (2001), ISBN: 009187632X. This guide uses a mixture of self-help techniques aimed at raising self-esteem and taking control.

'Teach Yourself' Managing stress by Terry Looker and Olga Gregson. Published by Teach Yourself (2003), ISBN: 0340860073. This self-help guide aims to help you assess and identify your own stress, then find ways to manage it.

Facing the cognitive challenges of MS (Second edition) by Jeffrey Gingold. Published by Demos Medical Publishing (2011), ISBN: 1936303205. An accessible look at the complex and often subtle ways in which MS can affect some people's memory and thinking.

Mental sharpening stones. Manage the cognitive challenges of multiple sclerosis by Jeffrey N. Gingold. Published by Demos Medical Publishing (2009), ISBN: 1932603654. This book includes practical strategies for managing changes in memory or thinking that some people with MS experience.

It's not all in your head: Anxiety, depression, mood swings and multiple sclerosis by Patricia Farrell, PhD. Published by Demos Medical Publishing (2011), ISBN: 1932603958. This book uses a cognitive behavioural approach to overcoming the depression, anxiety and stress that goes hand-in-hand with MS.

Further reading

Living with progressive multiple sclerosis. Overcoming the challenges by Patricia K. Coyle and June Halper. Published by Demos Medical Publishing (Second edition 2008), ISBN: 1932603476. This American book includes chapters on managing the social, economic and medical aspects of progressive MS.

Multiple Sclerosis: A self-care guide to wellness edited by Nancy J. Holland and June Halper. Published by Demos Medical Publishing (Second edition 2005), ISBN: 1932603077. This American book focuses on managing MS and living well. It contains many practical tips for keeping as healthy, fit and active as possible.

300 tips for making life easier with multiple sclerosis by Shelley Peterman Schwarz. Published by Demos Medical Publishing (2006), ISBN: 1932603212. This book has tips on many aspects of living with MS – for people with MS, their families, friends and carers.

Notes

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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 all the people affected by MS who contributed to this booklet. First edition written by Anita Rose.

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 don't 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

MS Society Scotland

Telephone 0131 335 4050

msscotland@mssociety.org.uk

MS Society Northern Ireland

Telephone 028 9080 2802

nireception@mssociety.org.uk

MS Society Cymru

Telephone 020 8438 0700

mscymru@mssociety.org.uk

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This title will be reviewed within three years of publication.

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