Mood, depression and emotions

Multiple sclerosis (MS) can affect your emotions as well as your body. These changes can be upsetting and sometimes difficult to understand. But there are many treatments that can help. Medication, talking therapies and self-help techniques can all make it easier to cope.

Mood, emotional and behavioural symptoms of MS – which can include depression – are sometimes overlooked, not fully acknowledged, or even dismissed as an understandable emotional reaction to the condition. If you experience any changes in mood, emotions or behaviour, do seek medical advice. Your health care team can provide help and support.

Emotional and behavioural symptoms are different from ‘cognitive’ symptoms, which affect how your mind processes information, although they can affect each other. You can read more about cognitive symptoms in the MS Society publication Memory and thinking.

This booklet contains information about a wide range of symptoms that can affect people with MS. You probably won’t need to read about them all. Some of them are very rare and only affect a small number of people.

There is also another MS Society publication you may find useful: Living with the effects of MS.

Through the booklet we refer to other organisations which can help with particular issues – just look for the [ ]. Their details are listed at the back of the booklet under ‘Useful organisations’ (page 21).
The causes of mood, emotional and behavioural changes in people with MS are not well understood, and a variety of factors can contribute to them. These factors fall into two broad categories – those that are directly related to MS, and those that are not directly related to MS. However, it is often difficult to pin down a specific cause for a specific symptom. It is more likely that a combination of factors is involved.

It is impossible to predict who will be affected by these symptoms or how. There is no set ‘MS personality’ and many people with MS do not experience changes in their mood, feelings and behaviour.²

Factors directly related to MS

MS-related nerve damage

The brain controls both conscious and unconscious actions by sending messages to all parts of the body. Different parts of the brain control different things, and the frontal lobe is responsible for the control of emotions and their outward expression. Regardless of your personality, nerve damage in this region of the brain can affect the way you feel or react, and can cause you to behave in a way that seems out of character.³

Psychological reaction to MS

Being diagnosed with MS, and adapting to the changes and uncertainty it brings, can be very unsettling. It may lead to a whole array of emotions such as grief, anxiety, guilt, fear, irritation and anger. There is no right or wrong way to react, and reactions to the condition will vary greatly from person to person. Your own reaction will be influenced by how MS affects you, the symptoms you are experiencing and how you usually cope with what life throws at you.

Factors not directly related to MS

Individual personality differences

Certain emotional and behavioural characteristics may have always been part of an individual’s personality and may have been obvious before their MS. Also, some people, regardless of an MS diagnosis, are more susceptible to depression and other emotional changes.
Other health conditions

It should not be assumed that all health issues – either emotional or physical – experienced by people with MS are related to MS. There could be other health conditions present that bring about changes in mood, behaviour or the way emotions are expressed. A doctor or MS nurse can ensure a medical assessment is completed, other conditions are not missed, and the most effective treatment is found.

Social circumstances

Social, financial and domestic circumstances can also influence emotional health. If this is the case, you may need to make some practical adjustments and seek additional help or support.

Side effects of drugs

Most drugs have potential side effects, and some drugs commonly used to treat MS and its related symptoms can cause temporary changes in mood or behaviour in some people. For example: steroids, used to treat relapses, can cause hyperactivity or depression – and a steroid ‘high’ often becomes a ‘low’ when treatment ends. A group of disease modifying drugs, known as beta interferons (Avonex, Rebif, Betaferon, Extavia), can sometimes cause depression and should be used with caution by people with a previous history of depression. Modafinil, sometimes used to treat fatigue, can cause anxiety or depression. Certain other drugs, such as baclofen, used for spasticity, can cause unpleasant hallucinogenic symptoms, agitation or altered moods if treatment is stopped suddenly. For this reason, when stopping medication some drugs need to be phased out over a few weeks.

Not everyone will experience these side effects, and many people successfully use these drugs to manage MS symptoms. If, however, you think you are experiencing side effects, consult your doctor who can reassess your medication.
A diagnosis of MS, the onset of new symptoms or increasing disability can all trigger a wide range of emotions, and it is impossible to describe a ‘typical reaction’. While there are some common emotional experiences, how each individual responds will depend on their character and personal history.

Response to loss

Life with MS can mean you experience losses, such as the ability to drive, do certain types of work, or take part in certain social activities. The process of grieving for these losses varies between individuals, but often includes periods of shock, fear and denial, followed by anger and frustration, which gives way to acknowledgement, accommodation and adaptation. This is sometimes referred to as the ‘cycle of grief’, though this term can be misleading as not everyone’s feelings will follow this exact cycle and people don’t necessarily experience all of these emotions. Whatever pattern these feelings follow, they are all a normal reaction to living with MS. And the period of grief is generally limited and resolves by itself over time.

However, a period of grief may follow every major loss, and no one will adapt to MS all at once. For example, you may feel you have adapted to living with MS and have grieved for the loss of your lifestyle before you had MS. Then, perhaps years later when new symptoms appear or disability progresses, you find these feelings of shock, fear, denial, anger and anxiety return to be worked through again. You may also find that while you have got used to symptoms that you have had for a few years, symptoms that appeared more recently still cause grief in one way or another.

Shock

A diagnosis of MS leaves many people overwhelmed and unable to connect to the news or to feelings they have about it. People often say things like ‘It hasn’t really sunk in yet’ or ‘I feel stunned’ or ‘numb’. People may experience similar feelings later in their MS if they are affected by very different or life-altering symptoms.

During this time, it can be difficult to absorb much information about the condition.

Fear and denial

It is a common human reaction to keep troubling or frightening issues at arm’s length. Many people delay fully confronting a diagnosis of MS by denying it is happening – others find it easier to take control by seeking information and help.
In the short-term denial can be positive ‘time-out’, giving the space needed to adapt, but it can become problematic if it persists. If symptoms are not acknowledged, it can become more difficult to make the practical, emotional or social adjustments that are needed to manage a situation successfully. This may result in your not being able to live life to the full, may jeopardise your own health and safety, and could have a negative impact on others. For example, if you develop a bladder problem – which you deny – you may go on to develop serious complications, which might have been avoided had you seen a health care professional.

People may also have unrealistic or exaggerated fears about MS, and these fears can make it harder to acknowledge and adapt. Talking about the things that are troubling you, preferably to someone who knows about MS, like an MS nurse or the MS Society Helpline, can be reassuring. Gathering information can also help you to make informed decisions and communicate effectively with health care professionals, so together you can establish the best ways of dealing with your particular situation.

**Anger and frustration**

The realisation that you are no longer able to do something you once could often leads to anger and frustration. Although these feelings are normal, they may also be a sign that you are resisting or fighting change. If the change can be acknowledged, and you begin to adjust to the new situation, you may find the anger goes away. However, it can take time – often a couple of years – to adapt and for these feelings to go completely.

**Acknowledgement, accommodation, adaptation**

Initially it can be hard to adapt to a condition that is as unpredictable as MS, may progress over time and carries a considerable risk of disability. Many people find the idea of ‘accepting’ or ‘embracing’ their MS difficult, but notice that, with time, they can acknowledge it and learn to live with it. This process may be emotionally difficult, but over time you will get to know your own MS and the way your body reacts to it. You will learn new ways of living with your symptoms and with the changes MS brings.

People often find there is a particularly difficult time between the appearance of a new symptom and finding a way of managing it, during which they become very aware of the things they can no longer do. Once a way of managing the symptom is found, people often report that they feel more comfortable with their new situation.
Guilt

Sometimes people with MS feel guilty, as if they have let their family and friends down or are somehow responsible for developing the condition. They may also feel guilty if they think they have burdened partners or children with a changing lifestyle or reduced income.

In addition, family members may blame the person with MS for difficulties that the condition has created, such as financial or relationship problems. This can make feelings of guilt worse – both for the person with MS and their family. It can help if everyone in the family understands MS, so they can identify when it is the MS, and not something else, that has caused the problem.

Stress and anxiety

Stress is defined as anything that disturbs a person’s emotional well-being, by creating tensions or strains. As MS is unpredictable and can bring about major physical, emotional, social and economic changes, it is understandable that living with the condition can be stressful. However, continued exposure to stress can lead to further emotional symptoms such as anxiety, and it is known that this is more common among people with MS than the general population.9 This anxiety can, in turn, cause physical symptoms such as headaches, palpitations, over-breathing (hyperventilation), increased blood pressure and muscle tension. Sometimes these physical symptoms may take the form of ‘panic attacks’.

The National Institute for Health and Clinical Excellence (NICE) guideline for MS, which sets out good practice for NHS health care in England and Wales, recommends that where a person is experiencing anxiety they should be offered specialist help.10 It says that for those with serious anxiety, psychologically based treatment should be given and, where appropriate, medication should be used. The charity Anxiety Care has information about coping with anxiety and panic attacks.

Research into the possible relationships between stress, the onset of MS, and relapses, has produced conflicting results. But there is currently little evidence to suggest that stress causes MS, relapses or an increase in relapse rate.11, 12

Stress is, however, a reality of life regardless of whether you have MS or not. Sometimes families try to avoid stressing the person with MS so much that they cause further stress, anxiety and guilt. This does not help anyone. In a life led to the full, stress cannot be avoided. The best approach is to learn how to manage and cope with stress. Talking therapies can help with this. Tips on managing the impact of fear and anxiety can be found in the MS Society publication Living with the effects of MS.
Help with adapting to MS

Self-management programmes can be very useful in helping you to adapt to life with MS. These can help you manage your symptoms and emotions, as well as helping you to develop the skills needed to continue with day-to-day activities. The NICE guideline states that within six months of diagnosis, people with MS should be offered the chance to participate in such a programme. For more information, ask your GP. To find a programme in your area visit www.expertpatients.co.uk in England, www.eppwales.co.uk in Wales, or contact the MS Society. The MS Society Scotland runs self-management courses north of the border.

Talking therapies and support groups can also help. The NICE guideline notes that people may benefit from emotional support and that, where possible, health care teams should provide this support or refer someone to a specialist.

You may also be offered a neuro-psychological assessment. This would use a number of tests to look at mood, cognitive function and behavioural issues, and offer strategies to help manage any issues. Availability of neuro-psychological assessments varies across the country, and would usually be via a referral from your GP or MS nurse. There is more about neuro-psychological assessment in the MS Society booklet Memory and thinking.

The MS Society Helpline also offers information and support to anyone with MS, their families, friends and carers. Helpline workers can also put you in touch with your local MS Society branch and send you further information about MS.

The emotional impact of MS on the family

A family member being diagnosed with MS is a bit like an uninvited guest coming to stay and not leaving again. Everyone has to deal with it and it may present an ongoing challenge to the family’s equilibrium.

Family members may also experience feelings of grief and loss as new symptoms appear or disability progresses. Often, this happens at the same time as family roles are changing to adjust to new symptoms or disability. For example, a child may be feeling the loss of playing football with their dad, whilst also having to consider how they can help care for a parent who is now less mobile. This can be emotionally difficult for everyone involved.
How each family member deals with this will vary according to their own personality, coping style, how they see MS and the direct effect it has on their own lives. This means that a family’s efforts to deal with MS is often not coherent. Instead, the ‘family’s reaction’ will be a combination of the varied, sometimes conflicting, coping mechanisms of the various individuals.

Open communication is the key to understanding everyone’s emotional needs, but talking about MS within a family can be difficult. Some people may not want to talk about painful emotions, feelings, questions or concerns. Others find it easier to cope with the physical aspects of MS, but more difficult to discuss the impact of symptoms which they cannot see and find hard to understand – such as those that affect mood, personality and behaviour.

If a family is finding it difficult to communicate, family therapy – a talking therapy done as a family group – may help. Alternatively, individual members of a family may find personal counselling or other talking therapies useful.

It can also be helpful to learn about the condition, perhaps through learning events where families can meet other people and share experience, or by joining a wider support network. The MS Society also has two publications, *My mum makes the best cakes* and *My dad makes the best boats*, which can help families with young children to understand MS.

**Talking therapies**

Cognitive behavioural therapy and other talking therapies can help you overcome depression and other emotional difficulties by providing an opportunity to talk in a way that helps you understand yourself better.13, 14

Using this understanding, you may be able to work out ways of taking positive and constructive steps towards improving the way you feel. You may also find you deal with situations in new ways that make them seem less stressful or difficult.

Talking therapies can also help all those affected by MS to feel less alone when dealing with distressing symptoms.
Types of talking therapies

Counselling: This allows you to talk about the difficulties or troubles you are experiencing in an environment that is confidential and without interruption. The counsellor should respect your viewpoint while helping you deal with specific problems, cope with crises, improve your relationships and develop better ways of living. Counselling can help you to gain insight into your feelings and behaviour, and, if necessary, help you to change your behaviour.

Psychotherapy: This is also a talking therapy and one that tries to help you understand why you feel the way you do, and what lies behind your responses to other people and things that happen to you. It goes deeper than counselling and you may look closely at your past, particularly your childhood, and your relationships with significant people in your life. Psychotherapy can be helpful with less severe depression. It can require a long-term commitment.

Cognitive behavioural therapy: This talking therapy focuses on specific, practical problem-solving techniques. It aims to help you to reassess situations that you may be misinterpreting. A small research study found cognitive behavioural therapy significantly improved mood for people with MS,¹ and other small studies have found that CBT can reduce depression in people with MS.¹⁵

Cognitive behavioural therapy can be delivered over the telephone and through self-help manuals as well as through face-to-face sessions. It can also be delivered in a group. It does not always suit people with cognitive difficulties (problems with memory or thinking), nor does it suit people who are severely depressed or suicidal.

Self-help groups: These groups, also known as peer support groups, are usually for people who want to overcome a shared problem. They allow people to share experiences, provide mutual support, and learn from and encourage each other. There are many self-help groups run by and for people with MS. Such groups can be valuable when adapting to life with MS, and can provide day-to-day support.

Professional help is, however, recommended when dealing with clinical depression, behavioural and emotional symptoms, difficult family adjustment or prolonged grief.

You can find out more about these different types of talking therapy from the mental health charity Mind, or ask your doctor. In Scotland, the Scottish Association for Mental Health has more information. [7]
Availability of talking therapies

If you feel you would benefit from counselling, psychotherapy, or cognitive behavioural therapy, consult your GP, MS nurse or neurologist, and request a referral to a specialist. Unfortunately, availability of such therapies on the NHS is limited, and varies from region to region. If you are referred, there may be a waiting list and you may find you are given very few appointments (generally six to twelve sessions). If your GP is unable to refer you, they may recommend a private counsellor or voluntary organisation.

Various organisations can recommend accredited practitioners. Costs can vary from £10 to over £100 an hour, although around £40-50 is typical. Some therapists will adjust their fees according to your income.

Access to talking therapies on the NHS should improve. In England, the 2005 National Service Framework for Long-term Conditions (NSF) – the government’s ten year plan that sets requirements for health and social care – recognises that people with MS can benefit from talking therapies and psychological support. The NSF also states that those living with long-term conditions should have access to psychologists as part of a multi-disciplinary team.16

In 2011, the Improving Access to Psychological Therapies (IAPT) programme was expanded to include people with long term physical conditions. The IAPT programme aims to make appropriate therapies more widely available on the NHS to people with depression and anxiety disorders.

Local support

Many MS Society local branches have regular support group meetings. Each branch also has a support officer or team who can provide support and offer guidance about other local services available. Counselling is also available from some regional MS Therapy Centres. In some areas, local branches are beginning to build relationships and links with local counsellors. You can find your local branch on the MS Society website or by calling the UK Information Team.
Many people may loosely use the word 'depression' to describe short periods of feeling down or low, but clinical depression is something much more severe, which prevents you from functioning normally and continues for more than a couple of weeks. Perhaps 50 per cent of people with MS experience this more serious depression at some point.1, 4, 17, 18

It's not clear why some people experience depression. Aside from physical damage to the brain, there are three main theories about what causes depression. One is that it is caused by a neuro-chemical or hormonal imbalance. Another view is that it is caused by certain styles of thinking. And a third view is that it is caused by a person's life experiences. Most people agree that it is generally some combination of these three.

You are considered clinically depressed if at least five of the following symptoms are present for at least two weeks.4, 18, 19

- Depressed mood, feelings of hopelessness and despair
- Significantly reduced interest or pleasure in most activities
- Changes in appetite and noticeable weight loss or gain
- Insomnia (inability to sleep) or hypersomnia (excessive sleeping)
- Feelings of excessive restlessness or sluggishness
- Fatigue or loss of energy
- Feelings of worthlessness, excessive or inappropriate guilt
- Reduced ability to think or concentrate, or indecisiveness
- Recurrent thoughts of death or suicide

These symptoms would need to be severe enough to upset a daily routine, interfere with relationships, or severely impair work. Health care professionals will also need to establish that the depression is not linked to another cause such as alcohol, drugs, medication or bereavement.

Depression is often misunderstood, and as a result a diagnosis may not be sought out by those affected, leaving this manageable symptom untreated. If you think you may be depressed, it is important to consult a health care professional as soon as possible. Depression is not something you can prevent, and it should not be considered embarrassing or shameful.

It is worth remembering that depression is something that affects people without MS as well. You may be experiencing depression for the same reasons that people without MS experience depression.
Carers and depression

It is not just the person with MS who is at greater risk of depression. Research has found that family members who care for someone with MS are more likely to experience depression, particularly as their caring role increases. Regular breaks from caring can reduce this risk of depression. A carer’s assessment by social care services (social work in Scotland) can help to find out what support they need in their caring role. Support is also available from local Carers’ Centres or Young Carers’ Projects – contact the Princess Royal Trust for Carers for details.

Depression and other MS symptoms

Some symptoms of depression are also symptoms of MS, and it can be difficult to identify what is causing them. For example, fatigue can be related to depression, or may be a direct result of MS, or a combination of the two. A specialist health care professional can ensure that all possible causes of symptoms are investigated fully and appropriate treatment provided.

Disability, progression of MS and depression

In some conditions there can be a link between being disabled and having depression, but in MS, depression does not seem to be related to how disabled a person is. For example, someone with little physical disability may experience severe depression and vice versa.

There is also no clear link between how long someone has had MS and the risk of being depressed. For example, someone who is recently diagnosed can be as depressed as someone who has had MS for many years.

One small study showed that depression rates are greater among people with relapsing remitting MS than those with primary progressive MS. It is thought this may be because primary progressive MS is generally diagnosed later in life when personal and social networks are more developed, and because people with primary progressive MS do not live with the uncertainty of unpredictable relapses.

Nerve damage and depression in MS

Research has also been carried out to see if depression can be directly linked to MS-related damage in particular areas of the brain. Some studies have suggested that there is a link, though they also suggest that MS-related nerve damage is only part of the equation. Other factors, including psychological reactions to living with MS, side effects of medication, individual situations and social circumstances, are also thought to play a part.
Treatment for depression

If your health care team believe you may be depressed, they should complete an assessment, and draw up a list of factors that may be contributing to it, for example, pain or social isolation. They should develop an appropriate depression management strategy, and give you further assessment, treatment and support to ease your problems.10

Self-management

The NICE guideline for MS encourages taking a self-management approach to tackling depression at first.10 Things like building or maintaining structure in your life, sleeping well, eating healthily, relaxation, having good relationships and using positive coping strategies – such as talking to someone about your feelings – can all help to improve low mood. Exercise is another important factor in triggering endorphins, the body’s natural antidepressants. There is an increasing amount of research to suggest that people with MS also benefit from exercise.26

Antidepressants

Various antidepressants are used to treat MS-related depression. Most common are SSRIs (selective serotonin reuptake inhibitors) such as fluoxetine or sertraline. Duloxetine, a serotonin and noradrenaline reuptake inhibitor, may also help. Tricyclic antidepressants such as amitriptyline and imipramine may also be used, though these are less common today as they tend to have more side effects which can make other MS symptoms feel worse.1, 4 Their side effects can include drowsiness, constipation or difficulty passing urine.5 If you are taking any of these and think you are experiencing side effects, ask your GP or MS nurse if you can try a different treatment. Always check with an appropriate health care professional before changing dose, or if you are thinking of stopping any drug treatment.

Be aware that antidepressants can take six to eight weeks to reach their full effect and it may take time for you to see the benefits.

Talking therapies

Talking therapies, including psychotherapy and cognitive behavioural therapy, might help you develop the ‘coping skills’ needed to deal with depression-related difficulties.9 For example, such therapy can help you to be assertive to get what you need, rather than giving up or getting excessively angry. For more information on talking therapies see page 9.

Research indicates that the most effective treatment for depression in MS is a combination of cognitive behavioural therapy or psychotherapy and drug treatment.6
**St John’s Wort**

Some people like to try complementary and alternative therapies. Research has suggested St John’s Wort (hypericum extract) might work as well as some antidepressants in mild depression. However, it is not an effective treatment for people with more severe depression. It is not known how St John’s Wort works, and the quality and strength of preparations vary significantly. As with all medicine it can have side effects.

St John’s Wort is known to react badly with some drugs, including other antidepressants, oral contraceptives and others. If you are thinking of taking St John’s Wort, you are strongly recommended to discuss it with your doctor as you would with any new medication or treatment.

**Suicide and MS**

While most people cope well with MS, not everyone does. Overall, the frequency of people with MS attempting suicide is around seven and a half times higher than for the general population. Research to date does not indicate that the level of disability is linked to the risk of suicide; instead, it appears to be related to depression and social isolation. If you are having suicidal thoughts, it is important to talk to someone. Your GP, MS nurse or other member of your healthcare team will have been trained in talking to people who are feeling suicidal, and they should ensure you get the support you need to deal with your feelings.

The Samaritans operates a 24-hour telephone helpline offering emotional support for people who are experiencing feelings of distress or despair.

**Bipolar disorder**

Bipolar disorder, sometimes known as ‘manic depression’, is much less common than clinical depression in people with MS.

It is a mood disorder where moods can swing from extremes – mania (very, very high) to depression (very, very low). Depressive symptoms are the same as those in depression, outlined above. Manic symptoms are a combination of over-activity, with a decreased need for sleep and racing thoughts, elevated or euphoric mood, and ‘grandiose’ thought content. For some people, euphoria may be replaced by irritability, and grandiose thoughts by beliefs of being persecuted.
Bipolar disorder affects around one per cent of the general population, but is perhaps twice this among people with MS. Again, the reasons are unclear.  

Research has shown that people with MS experiencing bipolar disorder react well to a mood stabiliser such as lithium. More extreme 'florid' symptoms, lasting seven days or more, may require hospitalisation and further drug treatment. When coming to terms with this symptom, talking therapies can help change the way you feel about it.

Other emotional and psychological symptoms

Some of the emotional and psychological symptoms of MS are much less common and only affect small numbers of people. Although they may never affect you, it is still important to be aware of these symptoms in case they do.

Psychosis

Psychosis is where people are unable to distinguish between what is real and what is imaginary. This may be more common in people with MS, but it's still very rare. Treatment with antipsychotic drugs may help. But if someone has psychosis and becomes violent or threatening to others, their family may become unable to care for them, and it may be necessary to arrange specialist residential care.

Mood swings and emotionalism

Some people living with MS describe mood swings, where moods switch rapidly from one state to another. Others describe emotional upheavals, like bouts of anger or heightened sensitivity, where they become very emotional very easily and seem unable to stop. These symptoms affect only a small minority of people with MS.

Unlike depression or bipolar disorder, which are common in other health conditions and have been studied for decades, these much rarer emotional symptoms have been little researched. As a result, there are few methods available to help healthcare professionals assess them, and they are harder to diagnose.

In recent years, researchers have begun to define specific categories for mood swings, emotionalism and ‘affective disorders’ that people with MS may experience. These are described on pages 16 to 19. If you do experience any of these symptoms, you may find that they do not neatly fit into these categories. Instead, you may recognise characteristics from one or more category, with certain aspects of some being stronger than others.
In the NICE guideline for MS, all these symptoms are grouped under the term ‘emotionalism’, highlighting the difficulty of trying to assign individuals to a specific box. It advises that individuals experiencing emotionalism should be offered a full assessment of their emotional state by a specialist. This is particularly important as specialists can identify other potential causes of the problem such as other health conditions or side effects of medication. The NICE guideline also states that if emotionalism is sufficient to be causing a person or their family concern, appropriate medication should be offered. Where someone is unwilling, or unable, to take medication, or does not respond to it, a suitable expert should offer advice on how they might adapt their behaviour to better manage these symptoms.

**Emotional lability**

Emotional lability describes a state where someone can no longer control their emotions and the way they are expressed. Instead, they experience rapid ups and downs in their feelings. They may find their emotions are easily aroused, freely expressed and tend to change quickly and spontaneously. For example, they may easily burst into tears or suddenly get very angry over something, in a way that seems exaggerated or out of proportion. Whether these outbursts involve crying, anger, laughter or anything else, they are usually brought on by a specific event.

Emotional lability is often referred to as ‘moodiness’ or ‘mood swings’. Emotional lability is, however, more severe and is thought to be caused by nerve damage in the brain. It can be difficult to separate moodiness that may affect a person under a great deal of stress from emotional lability. It is therefore important to seek advice from a health care professional to ensure appropriate diagnosis and treatment is given. A diagnosis can also help family and friends develop appropriate coping strategies.

Mood-stabilising drugs and antidepressants such as fluoxetine (Prozac), can be an effective treatment for emotional lability. Others find talking therapies are beneficial. Alternatively, a combination of both these approaches may work well.

**Uncontrollable laughing or crying**

Uncontrollable laughing or crying is also known as ‘affective release’ and ‘pseudobulbar affect’. This is different from emotional lability and probably affects about 10 per cent of people with MS. It is thought it might result from MS-related damage to nerves in the brain that control the formation, modification and expression of emotions (the limbic system).
People with this symptom can find themselves laughing when they are sad, or crying when they are happy. These involuntary outbursts are completely independent of their state of mind at the time, are unrelated to events going on around them, and cannot be controlled. This can be confusing, embarrassing and upsetting for all those affected, including family and carers. It can also mean that people do not recognise when someone with MS is really troubled (because they are laughing), and that real problems are not taken seriously.

There are mood stabilising drugs available that can help, such as amitriptyline or levodopa, and one small study showed fluoxetine (Prozac) to be particularly effective. A new drug, Nuedexta, was approved in the USA in 2010 for treating pseudobulbar affect. However, it has not yet been submitted for approval in the UK. For some people, symptoms may disappear completely with the right treatment.

**Emotional crescendo**

Emotional crescendo, sometimes referred to as increased sensitivity, lies somewhere between emotional lability and uncontrolled laughing and crying. With this symptom, people find that relatively unimportant or trivial issues can easily set off a very emotional response that seems uncontrollable and quickly reaches a ‘crescendo’. Unlike uncontrolled laughing and crying, the outward expression of emotions does reflect how the person is feeling.

This symptom can cause problems in relationships, as attempts to discuss and resolve even minor issues can quickly degenerate into tears, shouting matches and alienation. Again, it is not known what causes this symptom, and it is most likely to be a combination of factors including nerve damage, stress and psychological reaction to MS. Treatment is similar to that for emotional lability and uncontrolled laughing and crying.

**Euphoria**

Euphoria is characterised by persistently cheerful mood, particularly at times of difficulty. People may seem strangely unconcerned about their ongoing physical deterioration, and may have a sense of optimism that appears out of place, given their situation. In some people, both their mood and the way they express their feelings is euphoric. In others, their outward expression of optimism fails to give the true impression of their inner feelings of despair.

Euphoria is a different ‘high’ to the mania that is seen in people with bipolar disorder. It is a fixed rather than fluctuating state, and people with euphoria do not experience a flurry of new ideas and activities.
It is thought that euphoria affects about 10 per cent of people with MS, and that it is caused by nerve damage in the brain. Euphoria is more likely to affect those in more advanced stages of MS or those with significant cognitive problems.

While some people see euphoria as a ‘merciful symptom’ that prevents someone from being sad or unhappy, it is very important that it is recognised by those caring for a person with MS. Many problems may arise if euphoria is overlooked and those affected fail to get the necessary support. For example, if a person with euphoria does not acknowledge the symptoms they are experiencing, they may not receive appropriate care.

Unfortunately, there is no known treatment for euphoria. However, explaining the condition to family members, friends and carers can enhance their understanding, and make empathy and support that much easier.

There are also various behavioural symptoms associated with MS that are very rare and little researched. These symptoms overlap with ‘cognitive difficulties’, which can cause problems with concentration, and the way thoughts are processed, or plans are made.

**Disinhibition**

Disinhibition is a term used in psychology to describe a lack of restraint. This can show up in several ways, including disregard for social conventions, impulsivity, and poor risk assessment. Disinhibition is one of the rarest behavioural symptoms of MS and only a very small percentage of people are affected. It is linked to MS-related damage in the brain and is a common symptom following other physical injuries to the brain. In many cases, disinhibition can be quite mild, but it can also take a more severe form where people can lose control over their impulses leading to inappropriate behaviour and a loss of their sense of social rules. They may have little or no awareness of others’ feelings regarding their actions. For example, someone may make a hurtful or inappropriate comment, break into a rage, or behave in a sexually disinhibited manner – all of which they would have considered outrageous previously. It is important to recognise that people experiencing this symptom cannot control their behaviour.

Aggression or sexually inappropriate language or behaviour may be controlled with mood-stabilising drugs. In extreme cases, hospitalisation may be necessary for people to receive a more vigorous drug treatment. However, the need for this is extremely rare.
Disinhibition can leave family members, carers and friends feeling shocked and distraught. One small study has shown that cognitive behavioural therapy can help people with MS and their family cope with this difficult symptom. Family therapy and other talking therapies may also help.

Lack of insight

In certain situations, some people are unable to understand what is happening to or around them. Their judgement of safety may not be as good as it was, or they may have no insight into the way their behaviour affects others. Again, this only seems to affect a small percentage of people with MS. It may be linked to nerve damage in the brain.

This lack of insight can lead to problems, and family, friends or professionals may have to help the person affected to understand the situation better. Unfortunately, stepping in can be difficult – this is not because the person with MS does not want to understand, but because they cannot. Conflicts can arise, for instance, over driving a car or a motorised wheelchair if it is obvious to other people that the person with MS is not safe on the road.

All this can be very distressing for family carers. Family therapy and other talking therapies can help families to cope.

Lack of initiative

Initiating actions, for example, getting dressed, doing housework and getting involved in social or leisure activities, is controlled by a part of the brain called the frontal lobes. If someone has extensive nerve damage in this area, they may experience a lack of initiative. They may be fine to carry on doing something once they have begun, but unable to take the first steps towards doing it alone.

This lack of initiative is generally considered a cognitive problem rather than an emotional one. However, as apathy and a lack of motivation can also be a symptom of depression, this symptom is sometimes misunderstood.

It can help if family members understand the problem, as this will help prevent feelings of frustration and thoughts that the person is just being lazy, or is ‘always expecting someone else to do it’. Discussing the situation with a professional who knows about such problems (such as a psychologist or occupational therapist) can also help families and carers recognise what the person can and cannot do. This can lead to new ways of handling situations and can reduce some of the frustration involved.
Further information

UK Information Team
020 8438 0799
infoteam@mssociety.org.uk
National offices
– see back cover
www.mssociety.org.uk

Read more

Our free booklets help explain MS, look at its practical and emotional effects, and help you find your own ways to manage life with MS. Titles are available in large print, audio format and a number of languages.

We can help you find and borrow other books, research articles and DVDs about living with MS. Search online or call the UK Information Team.

Find out more online

Get the latest on research, campaigns and MS news. Chat online with our message boards and Facebook. Follow us on Twitter, see the MS community at Flickr and watch us on YouTube.

Children and teenagers can find out more and link up through our YoungMS site: www.youngms.org.uk

Join us

Receive local and national magazines and newsletters, and get involved locally and nationally. Be as involved as you like. Just by being a member you strengthen the voice of all people with MS, and help us continue our vital work. Join online, or call 020 8438 0759 or your national office.

Get in touch

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) or helpline@mssociety.org.uk

Contact the UK Information Team or your national office if you have any questions about MS.

Near you

Our volunteers run over 300 local branches and support groups. They provide information about MS and local services, and a chance to meet others affected by MS and take part in a range of activities.

In many parts of the country, you can pick up our booklets at MS Society Info Points. Larger information centres – including ones in our national offices in London, Belfast, Cardiff and Edinburgh (Newbridge) – can help you with information about MS and services in your area.

Or come along to our local and national events and learn more about MS from expert care professionals, researchers and other people with the condition. Find out more online or call your national office.
Further reading

**MS Essentials 02: Memory and thinking.** Not everyone who has MS will experience problems with memory and thinking, but mild difficulties are common. This publication looks at the kinds of problems there might be and the many ways to cope.

**MS Essentials 28: Living with the effects of MS.** This booklet suggests strategies for managing the emotional challenges that MS can bring. It includes ideas for managing the effects of MS on family and friends, as well as the person with MS.

**Shrinking the monster.** Published by the MS Society. Drawing on cognitive behavioural therapy and narrative therapy, this booklet can help you recognise, name and tame the ‘MS creature’ who takes up residence, uninvited.

**Our dad makes the best boats and Our mum makes the best cakes.** Published by the MS Society. These two illustrated booklets give a realistic but reassuring picture of how families deal with MS. They can be used to help young children to understand MS.

**MS and me.** Published by the MS Trust. A self-management guide to living with MS. Available to download from the MS Trust website: www.mstrust.org.uk

Useful organisations

**Anxiety Care**

Helps people deal with anxiety and offers support services in East London.

Telephone 020 8478 3400
(Mondays and Wednesdays 9.45am-3.45pm)
www.anxietycare.org.uk

**Bipolar Fellowship Scotland**

Local and national information and support for anyone affected by bipolar disorder.

Telephone 0141 560 2050
www.bipolarscotland.org.uk
**Bipolar UK**

Works to enable people affected by bipolar disorder (manic depression) to take control of their lives. In Scotland, see also the Bipolar Fellowship Scotland.

Telephone 020 7931 6480  
www.bipolaruk.org.uk

**Breathing Space**

Freephone service for anyone feeling low or depressed, worried or in need of someone to talk to. The website has a useful directory of support groups.

Telephone 0800 83 85 87  
(Monday to Thursday 6pm-2am, Friday 6pm to Monday 6am)  
www.breathingspacescotland.co.uk

**British Association for Behavioural and Cognitive Psychotherapies (BABCP)**

Supplies details of accredited cognitive and behavioural psychotherapists, full directory available online.

Telephone 0161 705 4304  
www.babcp.com

**British Association for Counselling & Psychotherapy (BACP)**

Supplies details of accredited counsellors, psychologists and therapists.

Telephone 0161 705 4304  
www.bacp.co.uk

**British Psychological Society**

Supplies details of accredited psychologists including neuropsychologists.

Telephone 0116 254 9568  
www.bps.org.uk

**Carers Trust**

Advice and support for carers. Runs a network of carers’ centres and young carers’ projects.

Telephone 0844 800 4361  
www.carers.org
**Clinical-Depression.co.uk**

Reliable, helpful and easy-to-absorb information on the most common psychological difficulties and mental health in general.

www.clinical-depression.co.uk

**Depression Alliance**

A group that provides support and understanding for people affected by depression.

Telephone 0845 123 2320 (information pack request line)

www.depressionalliance.org

**Depression Alliance Scotland**

Telephone 0808 802 2020
(Wednesdays, 2pm-4pm)

www.dascot.org

**Journeys**

Supports people in Wales to find their own route to recovery from depression.

Telephone 029 2069 2891

www.journeysonline.org.uk

**Living Life to the Full**

A free online skills course, which uses a cognitive behavioural therapy (CBT) approach.

www.livinglifetothefull.com

**Mind**

Works to create a better life for everyone experiencing mental distress. They can offer advice and have a series of publications available. In Scotland, see the Scottish Association for Mental Health.

Information line 0300 123 3393
(Monday to Friday, 9am-6pm)

www.mind.org.uk

**MS Therapy Centres**

A network of over 50 centres in the UK, offering support and various non-drug therapies, including counselling to people affected by MS.

Telephone 0845 367 0977

www.msntc.org.uk
No Panic
Provides a helpline and step-by-step programmes to support those dealing with anxiety.
Helpline 0800 138 8889 (every day, 10am-10pm)
www.nopanic.org.uk

Relate
In England, Wales and Northern Ireland, Relate offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face to face, by phone and through the website.
Telephone 0300 100 1234
www.relate.org.uk

Relationships Scotland
Offers similar services to Relate.
Telephone 0845 119 2020
www.relationships-scotland.org.uk

Samaritans
24-hour telephone helpline offering emotional support for people who are experiencing feelings of distress or despair.
Helpline 0845 7 909090 (every day, 24 hours)
www.samaritans.org

Scottish Association for Mental Health (SAMH)
Support and information for people with any mental health issues.
Telephone 0800 917 3466 (weekdays, 2pm-4.30pm)
www.samh.org.uk

United Kingdom Council for Psychotherapy (UKCP)
Umbrella organisation for psychotherapy in the UK. Regional lists of psychotherapists available.
Telephone 020 7014 9955
www.psychotherapy.org.uk
References


### Authors and contributors

Based on work by the Rehabilitation in Multiple Sclerosis (RIMS) Psychology and Neuropsychology Special Interest Group including: Päivi Hämäläinen (Finland), Agnete Jönsson (Denmark), Roberta Litta (Italy), Patricia Maguet (Spain), Bente Østerberg (Denmark), Michelle Pirard (Belgium), Sally Rigby (UK), Julia Segal (UK), Liina Sema (Estonia), Peter Thomson (UK), Rudi Vermote (Belgium), Luc Vleugels (Belgium).

Written by Chloe Neild

This edition edited by Jude Burke

With thanks to: Megan Burgess, Professor Anthony Feinstein, Jo Johnson, Dr Nicholas LaRocca, Dr Anita Rose, Dr Randolph Schiffer, Julia Segal.

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.

Suggestions for improvement in future editions are welcomed. Please send them to infoteam@mssociety.org.uk

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First edition, August 2005

Third edition, August 2009

Revised and reprinted, May 2011

This title will be reviewed within three years of publication.
MS Society

Multiple sclerosis (MS) is the most common disabling neurological disorder affecting young adults and we estimate that around 100,000 people in the UK have MS. MS is the result of damage to myelin – the protective sheath surrounding nerve fibres of the central nervous system. This damage interferes with messages between the brain and other parts of the body.

For some people, MS is characterised by periods of relapse and remission while, for others, it has a progressive pattern. For everyone, it makes life unpredictable.

The MS Society is the UK’s largest charity dedicated to supporting everyone whose life is touched by MS. We provide a freephone MS Helpline, grants for home adaptations, respite care and mobility aids, education and training, support for specialist MS nurses and a wide range of information.

Local branches cater for people of all ages and interests and are run by people with direct experience of MS.

The MS Society also funds around 80 vital MS research projects in the UK.

Membership is open to people with MS, their families, carers, friends and supporters. You can help the work of the MS Society by:

- becoming a member
- making a donation
- offering your time as a volunteer

Contact information

MS National Centre
372 Edgware Road
London NW2 6ND
Telephone 020 8438 0700
info@mssociety.org.uk

MS Society Scotland
National Office, Ratho Park
88 Glasgow Road
Ratho Station
Newbridge EH28 8PP
Telephone 0131 335 4050
msscotland@mssociety.org.uk

MS Society Northern Ireland
The Resource Centre
34 Annadale Avenue
Belfast BT7 3JJ
Telephone 028 9080 2802
information@mssociety.org.uk

MS Society Cymru
Temple Court
Cathedral Road
Cardiff CF11 9HA
Telephone 029 2078 6676
mscymru@mssociety.org.uk

National MS Helpline
Freephone 0808 800 8000
(weekdays 9am-9pm)
www.mssociety.org.uk

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Registered charity
nos 1139257 / SC041990.
Registered as a limited company in England and Wales 07451571.