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MS Essentials

For people living with MS

Mood, depression and emotions

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MS can affect your emotions as well as your body. Although this has been recognised since MS was first described in the 19th century, it is only more recently that we have begun to understand more about how MS can cause changes in mood and feelings.¹ There are now many treatments available to help manage these often upsetting and difficult aspects of MS. Medication, talking therapies and self-help techniques can all make it easier to cope.

Even so, 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.² If you experience any changes in mood, emotions or behaviour, do seek medical advice. Your healthcare 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 may not need to read about them all.

Causes of mood changes in people with MS

‘There is no set ‘MS personality’ and many people with MS do not experience changes in their mood, feeling and behaviour.’

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.³

Factors directly related to MS

- Psychological reaction to MS

Being diagnosed with MS, coping with, 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.

- 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.

‘Don’t assume all your symptoms are a result of your MS. Other conditions can also be present, which need to be treated separately.’

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 – both emotional and 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.^{4,5} Modafinil, used to treat fatigue, can cause anxiety or depression.⁶ Certain other drugs, such as Baclofen, used for spasticity, can cause unpleasant hallucinogenic symptoms, agitation or altered moods if treatment is stopped suddenly.⁶ 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.

Understanding emotional and psychological reactions to MS

‘MS affects everyone differently and there is no right or wrong way to react or feel.’

‘Feelings of shock, fear, apprehension, anxiety and stress are all a normal reactions to living with MS.’

A diagnosis of MS, the onset of new symptoms or increasing disability, can 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.

Grief

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.⁷ 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.

‘Some people react by pretending nothing is wrong; others seek help more easily.’

- 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.⁸ 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 healthcare 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 healthcare 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 find they 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 amongst people with MS than the general population.^{9,10} 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 Clinical Excellence (NICE) Guideline for MS, which sets out good practice for MS related NHS healthcare in England and Wales, recommends that where a person is experiencing anxiety they should be offered specialist help.¹¹ It says that for those with serious anxiety, psychologically based treatment should be given and, where appropriate, medication should be used.

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.^{10,12,13}

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.¹⁴ Talking therapies can help with this.

Help with adapting to MS

Self-management programmes such as those run by the MS Society and NHS Expert Patient Programme, 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.¹¹ For more information, ask your GP or contact the MS Society.

Talking therapies and support groups can also help. The NICE Guideline notes that people may benefit from emotional support and that, where possible, healthcare teams should provide this support or refer someone to a specialist.¹¹

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.

‘Talking therapies and support groups can be a great help when adapting to MS.’

Family members may also experience feelings of grief and loss as new symptoms appear or disability progresses. This grief often coincides with the need to reconsider family roles and dynamics so symptoms or disability can be accommodated. 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.

Talking therapies

‘Talking therapies can help you deal with situations in new ways that make them seem less stressful or difficult.’

Cognitive behaviour 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.^{15,16} 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 behaviour 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 behaviour therapy significantly improved mood for people with MS.⁴ 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 experience, 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 (see page 22) or ask your doctor.

Availability of talking therapies

If you feel you would benefit from counselling, psychotherapy, or cognitive behaviour therapy, consult your GP 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 (see page 21). Typically, this costs around £40-50 for an hour long session, though some will charge more and others less.

Access to talking therapies on the NHS should improve. The 2005 National Service Framework for Long-term Conditions (NSF) – the government's ten year plan that sets requirements for health and social care in England – 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.¹⁷

Local support

Many MS Society local branches have regular support group meetings. Each branch also has a fully trained welfare officer who can provide support and offer guidance about other local services available. Counselling is also available from some regional MS Therapy Centres (see page 22).

Emotional and psychological symptoms

'If you think you may be depressed, it is important to consult a healthcare professional as soon as possible.'

Depression

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. Approximately 50 per cent of people with MS experience this more serious depression at some point.^{2,4,18,19}

You are considered clinically depressed if at least five of the following symptoms are present for at least two weeks.^{4,18,20,21}

- 1 Depressed mood, feelings of hopelessness and despair
- 2 Significantly reduced interest or pleasure in most activities
- 3 Changes in appetite and noticeable weight loss or gain
- 4 Insomnia (inability to sleep) or hypersomnia (excessive sleeping)
- 5 Feelings of excessive restlessness or sluggishness
- 6 Fatigue or loss of energy
- 7 Feelings of worthlessness, excessive or inappropriate guilt
- 8 Reduced ability to think or concentrate, or indecisiveness
- 9 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. Healthcare 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 easily managed symptom untreated. If you think you may be depressed, it is important to consult a healthcare professional as soon as possible. Depression is something you cannot prevent, and it should not be considered embarrassing or shameful.

- 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.²² For example, fatigue can be related to depression, or may be a direct result of MS, or a combination of the two. A specialist healthcare 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.^{23,24} 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.^{24,4} 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 amongst 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.²⁵

- 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 recent studies have suggested that there is a link, though they also suggest that MS-related nerve damage is only part of the equation.^{5,26} 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.

'There are many treatments available for depression.'

Treatment for depression

Where depression is suspected healthcare teams should complete an assessment, and draw up a list of factors that may be contributing to it, for example, pain or social isolation. An appropriate depression management strategy should then be developed, and further assessment, treatment and support should be given to ease problems.¹¹

Antidepressants

Various antidepressants are used to treat MS-related depression. Most common are selective serotonin reuptake inhibitors (SSRIs) and research trials have shown good results with SSRIs such as Fluoxetine (Prozac), and Sertraline (Lustral).²² Tricyclic antidepressants such as Amitriptyline (Triptafen), Desipramine (Norpramin, Pertofrane), and Imipramine (Tofranil) 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, for example by causing drowsiness, constipation or difficulty passing urine.² 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.

Be aware that antidepressants can take six to eight weeks to reach their full effect.

Talking therapies

Talking therapies including psychotherapy and cognitive behaviour therapy can 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 behaviour therapy or psychotherapy and drug treatment.^{2,5}

Complementary therapies

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.^{27,4} 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 should not be taken with other antidepressants, and it is known to react badly with some other drugs. For example, it can make the contraceptive pill less effective.

You should always consult your doctor before trying any new treatment and before making any changes to your medication.

- Suicide and MS

While most people cope well with MS, there are some who lose the desire to live. 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.^{5,28} Overall, the frequency of people with MS attempting suicide is approximately seven times higher than it is for the general population.²² This highlights the importance of openly talking about MS-related depression and emotional difficulties with your doctor, MS nurse or other member of your healthcare team, and ensuring that it is addressed promptly and appropriately.

The Samaritans operates a 24-hour telephone helpline offering emotional support for people who are experiencing feelings of distress or despair (see page 23).

Bi-polar disorder

Bi-polar affective 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.

Bi-polar affective disorder affects around one per cent of the general population, but is perhaps twice this among people with MS. Again, the reasons are unclear.²¹

Research has shown that people with MS experiencing bi-polar disorder react well to mood stabilisers such as Lithium and Valproic Acid.^{3,22} 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.

Psychosis

Psychosis is where people are unable to distinguish between what is real and what is imaginary. This is very rare in MS, as it is in the rest of the population.²² Treatment with antipsychotic drugs may help.¹⁸ But if someone has psychosis and becomes violent or threatening to others, the 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 bi-polar 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.^{3,24} These are described on pages 16 to 19. Even so, you may experience changes that 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.¹¹ It advises that individuals experiencing emotionalism should be offered 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

‘The NICE Guideline sets good practice for NHS healthcare services and advises that individuals experiencing emotionalism should be offered full assessment of their emotional state by someone with suitable experience.’

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 is not responsive to them, a suitable expert should offer advice on how they might adapt their behaviour to better manage these symptoms.¹¹

- Emotional lability

Emotional lability describes a state where emotions and the way they are expressed can no longer be controlled as they once were. Instead, people experience rapid ups and downs in their feelings.²⁹ People may find their emotions are easily aroused, freely expressed and tend to change quickly and spontaneously. For example, you 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.⁴ It is therefore important to seek advice of a healthcare 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.³⁰ 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.^{2,9,18} It is thought to result from MS-related damage to nerves in the brain that control the formation, modification and expression of emotions (the limbic system).³¹

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, Levodopa, Desipramine, and one small study showed Fluoxetine (Prozac) to be particularly effective.^{2,32,33} 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.^{4,34} 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.² 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 bi-polar disorder.³ 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.^{4,17,31} Euphoria is more likely to affect those in more advanced stages of MS or those with significant cognitive problems.¹⁰

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.^{2,18} However, explaining the condition to family members, friends and carers can enhance their understanding, and make empathy and support that much easier.

Behavioural symptoms

There are also various behavioural symptoms associated with MS that are very rare and little researched. These symptoms overlap with cognitive difficulties that can cause problems with the way thoughts are processed, concentration, or the way plans are made.⁴

- Disinhibition

Disinhibition is one of the rarest behavioural symptoms of MS and only a very small percentage of people are affected.^{4,35} It is linked to MS-related damage in the brain.³⁶ People experiencing disinhibition 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.⁴ 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 behaviour therapy can help people with MS and their family cope with this difficult symptom.³⁷ 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 affects a small percentage of people with MS and may be linked to nerve damage in the brain.³⁵

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.³⁵ 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 lobe. 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

The MS Society has **publications** on a wide variety of topics, including information for people just diagnosed, on types of MS, managing relapses, and social services. For a publications list and order form visit the website www.mssociety.org.uk or write to MS Society Publications, PO Box 142, Bedford MK42 0FA. Please give your name and address details clearly, including postcode.

Keep up to date with all news relating to MS by checking the MS Society website **www.mssociety.org.uk** and the MS Society's magazine for members, *MS Matters*. Details about *MS Matters* are on the web and in the MS Society's publications list.

The **freephone MS Helpline** offers information and support to anyone with MS, their families, friends and carers. Trained helpline staff can answer questions about MS and related personal issues. All calls are treated in complete confidence. Freephone 0808 800 8000 (weekdays, 9am-9pm)

Information and advice on MS is available in other **languages**. People affected by MS can now discuss their concerns in 150 different languages by speaking to a helpline worker on freephone 0808 800 8000 via an interpreter.

Further reading

Memory and thinking, 02 in MS Essentials series published by MS Society, UK.

Useful organisations

Anxiety Care

Helps people deal with anxiety.

Cardinal Heenan Centre
326 High Road
Ilford
Essex IG1 1QP
Telephone 020 8478 3400

British Association for Behavioural and Cognitive Psychotherapies (BABCP)

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

The Globe Centre
PO Box 9
Accrington BB5 0XB
Telephone 01254 875277
www.babcp.com

British Association for Counselling & Psychotherapy (BACP)

Supplies details of accredited counsellors, psychologists and therapists.

BACP House
35-37 Albert St
Rugby CV21 2SG
Telephone 0870 443 5252
www.bacp.co.uk

Depression Alliance

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

35 Westminster Bridge Road
London SE1 7JB
Telephone 020 7633 0557
www.depressionalliance.org

The Manic Depression Fellowship (MDF)

An organisation that works to enable people affected by manic depression to take control of their lives.

Castle Works
21 St Georges Road
London SE1 6ES
Telephone 020 7793 2600
www.mdf.org.uk

Mind

Mind works to create a better life for everyone experiencing mental distress. They can offer advice and have a series of publications available.

15-19 Broadway
London E15 4BQ
Email: contact@mind.org.uk
Information line 0845 766 0163
(Monday-Friday, 9.15am-5.15pm)
www.mind.org.uk

MS Therapy Centres

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

MS Therapy Centres
Bradbury House
155 Barkers Lane
Bedford MK41 9RX
Telephone 01234 325781
www.ms-selfhelp.org

No Panic

Provides a helpline and step-by-step programmes to support those dealing with anxiety.

93 Brands Farm Way
Telford
Shropshire TF3 2JQ
Helpline 0808 808 0545 (everyday, 10am-10pm)
www.nopanic.org.uk

Relate

Offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face to face, by phone and through the website.

Telephone 01788 573241
www.relate.org.uk

Samaritans

24 hour telephone helpline offering emotional support for people who are experiencing feelings of distress or despair.

The Upper Mill
Kingston Road
Ewell
Surrey KT17 2AF
Helpline 08457 909090 (everyday, 24 hours)
www.samaritans.org

United Kingdom Council for Psychotherapy (UKCP)

Umbrella organisation for psychotherapy in the UK.
Regional lists of psychotherapists available.

167-169 Great Portland Street
London W1W 5PF
Telephone 020 7436 3002
www.psychotherapy.org.uk

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

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Multiple Sclerosis Society

Multiple sclerosis is the most common disabling neurological disorder among young adults in the UK and around 85,000 people in Britain have MS. MS is the result of damage to myelin – a protective sheath surrounding nerve fibres of the central nervous system. When myelin is damaged, this 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. It provides respite care, a freephone MS Helpline, grants for home adaptations and mobility aids, education and training, 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 over 55 vital MS research projects in the UK.

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 Rd
London NW2 6ND
Telephone 020 8438 0700

MS Society, Scotland
Ratho Park,
88 Glasgow Road
Ratho Station
Newbridge EH28 8PP
Telephone 0131 335 4050

MS Society, Northern Ireland
34 Annadale Avenue
Belfast BT7 3JJ
Telephone 028 9080 2802

National MS Helpline
Freephone 0808 800 8000

Website
www.mssociety.org.uk

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