

Choices



MS and mental health



Multiple sclerosis information

www.ms-uk.org

Welcome to this Choices booklet about MS and mental health

MS-UK believes we must listen to the voices of people affected by multiple sclerosis (MS) to shape the information and support we provide. It is these people that bring us perspectives that no one else can give.

For every Choices booklet we produce, MS-UK consults the wider MS community to gather feedback and uses this to inform our content. All of our Choices booklets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

This Choices booklet has been designed with you in mind. We hope it will answer some of your questions and also provide some first-hand experience from those who have been in your position - people who can truly understand and empathise with your current thoughts and feelings.

Every time you find bold text with quotation marks like this, it is a quote directly from someone affected by multiple sclerosis

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MS and mental health

A diagnosis of MS can have a huge impact on someone's mental health and emotional wellbeing. It can present in many different ways and can raise all sorts of thoughts and feelings around your future and how MS will play a part in it.

Dealing with the unpredictability of the condition can be hard and often takes its toll on a person's emotions. It can take time to adjust to a life with MS. These feelings shouldn't be dismissed and there is a variety of support available.

Mental Health issues are something that can effect anyone in life and that there is no reason to be embarrassed or ashamed

There is no right or wrong way of dealing with a diagnosis or the changes that MS can bring. This will depend on a variety of factors such as how the condition is presenting at that time, the individual coping skills and resilience of a person, different personality types, and what support is available from family, friends and health professionals.

What is important is recognising that MS may have an emotional impact to a certain degree and that is perfectly natural.

Emotional reactions can come as an 'indirect' response to being

diagnosed. Living with a long-term health condition, the changes it can bring to a person's life and the impact it can have on relationships, work or how a person sees themselves, for example, can spark a range of different emotions.



When I was forced to give up my career due to my worsening MS, I think it took me a couple of years to come to terms with it. My self-esteem was fully based upon my achievements at work and I found it hard to come to terms with



It can also be a 'direct' response given how MS can affect the brain. For example, the frontal lobe of the brain controls your emotions and if there is an MS lesion in that area it will most likely have some direct impact on your emotional responses.

It is estimated that one in four people living in the UK will experience a mental health problem each year (1). On a worldwide scale, a review of studies that focused on the impact of MS on mental health found that over one third of people with MS will develop clinically significant depressive or anxiety-related symptoms over time, with the prevalence of depression increasing significantly during relapses. It was also found that depression and anxiety affected over one third of people who had recently received an MS diagnosis (2).

This booklet relates specifically to the impact that an MS diagnosis and the condition itself can have on your mental health.

How can MS affect mental health?

It is not just the actual diagnosis of MS that can have an impact on a person's mental health but living with the condition and the changes that can come with it can affect wellbeing too. As already mentioned, the condition itself can have a negative impact on your emotions, so the effect on your mental health can be both a symptom of, and a reaction to, MS.



I was scared, frustrated, annoyed and impatient



MS is a fluctuating condition. There may be changes in symptoms and feelings of anxiety when a relapse occurs. The transition from relapsing remitting MS (RRMS) to secondary progressive MS (SPMS) can feel like a new diagnosis which can cause anxiety alongside varying rates of disease progression. All these things can have an impact, causing low mood, heightened anxiety levels and depression.

There might be anxiety about what the future may hold, in particular the uncertainty of not knowing what the future may be for yourself and your wider support network.

Below we explore low mood, depression and anxiety in more detail.

Low mood and depression

It can sometimes be difficult to know the difference between low

mood and depression. Symptoms of low mood can include

- Worry
- Feeling anxious or a sense of panic
- Sadness
- Tiredness
- Anger
- Frustration
- Low self-esteem

If a person notices that their low mood is starting to interfere drastically in their daily life and is lasting longer than a couple of weeks, this may be a sign of depression (3).

Depression can present in a variety of different ways and examples of how a person might think or feel include

- A sense of hopelessness and despair
- Feeling tired, lethargic or lacking in energy
- No self-esteem or confidence
- Isolated and unable to relate to other people
- Feeling guilt and worthlessness
- Being critical towards yourself
- Feeling empty or numb
- Changes to appetite
- Having little pleasure in life or having stopped enjoying the things you used to enjoy
- Frequent restlessness, irritability or agitation
- Having a sense of unreality
- Feeling down, upset or tearful
- Feeling suicidal



I take a day at a time. Sometimes I just aim to get through the next hour or a morning. Small steps



When a person is experiencing depression their behaviour may change too. Feeling tired all the time and therefore not doing as much during the day can be an indication of depression.

Other changes and physical body responses can include

- Loss of appetite leading to weight loss, or comfort eating leading to weight gain
- Physical aches and pains that perhaps do not correlate to physical activity
- Loss of interest in sex
- Avoiding social activities or events that are usually enjoyable
- Self-neglect - not washing frequently for example
- Lack of concentration, for example, whilst reading the newspaper or watching TV
- Changes in sleeping patterns or sleeping more than usual/waking up a lot
- Insomnia
- Finding it difficult to make decisions
- Difficulty speaking or thinking clearly

- Smoking more, drinking more alcohol than usual or using drugs more than usual
- Self-harming or suicidal behaviour

There is much debate about what causes depression with research suggesting that there is usually more than one single reason. We are all the sum of our personal life experiences, genetics, health issues and lifestyle, to name just a few of the factors that are cited to have an influence in the onset of depression (4). As individuals, our pathway to being depressed will usually be unique, sometimes very complex, and multifaceted.

The impact of MS as a cause of depression, in part, is the one constant that many people with MS share. That said, a source of confusion can be that some symptoms of depression can also be symptoms of MS, making it difficult to differentiate between the two. For example, fatigue may be an MS symptom, or it may be a symptom of depression. Or it could be both.

Fundamentally, depression can affect anybody, and it is important to note that an MS diagnosis does not mean you will automatically become depressed. However, around half of people living with MS will experience depression symptoms at some point in their lives, meaning it is more prevalent in people with MS than it is in the general public (5).

Interestingly, a recent study has shown evidence of an association between MS lesions appearing on what they term a 'specific brain circuit' that is linked to the onset of depression, and depression in people with MS (6).

The hope is that the more we learn about why people with MS are susceptible to low mood and depression, more specific treatments and therapies will become available.

If you think you may be depressed it is important to seek support and not sit in silence. Being affected by depression is nothing to be ashamed of and is often a natural reaction to a diagnosis, a relapse, and other changes that come with living with a long-term health condition. We explore ways of accessing different types of support later in this booklet.

Anxiety

Anxiety is something people can feel when they are worried, fearful, tense or afraid. Uncontrollable, sometimes racing thoughts about things going wrong can be consuming. Anxiety is a natural response when people perceive they are under threat. Most people will feel anxious at times particularly during periods that are stressful, such as the occurrence of major life events. If feelings of anxiety are very strong or last for some time, they can be overwhelming (7).

Anxiety is a term that covers a range of specific conditions, the most common being generalised anxiety disorder (GAD). Anxiety also covers phobias, panic disorders, adjustment disorder and stress reactions (8).

MS can cause anxiety within the brain itself. One reason that MS tends to cause anxiety is because the condition is unpredictable, which causes uncertainty. As we know that no one experiences MS in the same way and lesions can affect any part of the brain, some people may have generalised anxiety, whereas others may have panic disorder, and more.

MS can also cause anxiety as a result of the illness itself. MS inflames various parts of the brain, and when the brain experiences damage and stress, it's not uncommon for a person to experience anxiety. Depending on where the inflammation occurs, it may also provoke panic attacks.

Symptoms of MS can be triggers for those that already have anxiety. For example, many people with panic disorder have panic attacks as a result of changes in their body's sensations. MS can cause changes in sensations that trigger panic attacks. While MS isn't technically causing the panic attacks directly, it's creating an environment that makes them far more likely (9).

MS made me more self-conscious and anxious especially going to new places or meeting new people

Anxiety can cause the following symptoms

- Sleep problems
- Panic attacks
- Increased heartbeat
- Upset stomach
- Muscle tension
- Feeling shaky

What is the difference between anxiety and depression?

The main difference is that depression refers to a single illness, whereas anxiety refers to a group of conditions.

Anxiety and depression are experienced very differently despite them sharing some similarities. For example, anxiety causes worry about

the immediate or long-term future, whereas depression can cause assumptions that the future is hopeless.

The mental and physical characteristics differ between the two and the physical symptoms of both can be very exhausting for the person affected. Both have very different psychological features (10).

Anxiety and depression can also be a reaction to one another. People experiencing depression can often experience symptoms similar to people experiencing anxiety and vice versa. It is also possible for people to have them at the same time. They can have an overlap of symptoms and it is thought that around half of people with generalised anxiety disorder will also have depression (8).

Low levels of serotonin are thought to play a role in both, along with levels of other brain chemicals such as dopamine (10).



I manage my anxiety and depression through medication, meditation and making sure I exercise and spend time in nature regularly

While it is important for healthcare professionals to understand these distinctions so they can best support you, the most important thing for you is to know where to turn if you need help.

- Talk to somebody you trust about how you are feeling
- Speak to your MS nurse
- Book an appointment with your GP
- Contact the MS-UK Helpline. This service is confidential and is open to people living with MS. Our team can offer emotional support and signpost you further support, such as our Counselling Directory, which holds information of professional counsellors who have experience with clients that are affected by MS

More information


NHS Inform Scotland's website hosts some useful self-help guides designed for people experiencing mild to moderate anxiety and depression. These guides offer support that is underpinned by cognitive behavioural therapy (CBT) techniques.

Anxiety – www.nhsinform.scot/illnesses-and-conditions/mental-health/mental-health-self-help-guides/anxiety-self-help-guide


Depression – www.nhsinform.scot/illnesses-and-conditions/mental-health/mental-health-self-help-guides/depression-self-help-guide

MS and the impact on mental health

We are all individuals, with our own unique perspectives on life and ways of dealing with what it throws at us. Fundamentally the way we respond to situations that arise are shaped by our life experiences since birth and the issues affecting us in the present day. As such the way each of us deal with life-changing events will differ. This includes being diagnosed, and living with, long-term medical conditions such as MS.



Take time to grieve, accept and come to terms with the changes. When ready empower yourself by finding support



Acceptance and adjustment

Being diagnosed with MS may lead to some people starting to see themselves differently, otherwise known as an ‘altered sense of self’. It can be triggered by different things, such as the initial diagnosis to the impact of the condition over time. Others may see MS as being part of them, something that is not alien, a perspective which can foster a sense of ‘normality’ or ‘acceptance’. Often, receiving a confirmed diagnosis can take a long time, and as a result, the period from acknowledging initial symptoms to being diagnosed can take its toll.

Adjusting to a life with MS can take time. For some the process of adjustment and acceptance can take longer than it does for others, and that is perfectly natural.

A study in 2019 suggests that for people with MS, incorporating and accepting the condition as part of their ‘self-identity’ can have positive implications for seeking and receiving support (11).

The study looked at how MS can influence a person’s sense of self. For example, how a decline in body functions and performance can lead to feelings of loss of self and changes to identity. Each can have a negative impact on psychological wellbeing. It was suggested in the study that due to this impact, people with MS may

perceive that others view them differently because of their condition. This can lead to both anxiety and depression. It may also lead to social isolation as these thoughts may start to prevent a person from going out and socialising through fear of what others think of them.

Adjusting to life with MS can be difficult and accepting this may lead to feelings such as anger and resentment. Some may find it hard to incorporate this 'MS identity' into who they are. This could lead to negative effects and cause a person to not seek support from those around them, which can spark increasing levels of anxiety and depression.

A diagnosis does not automatically bring a person's sense of self into question, more so it is the level in which symptoms can impact a person's ability to fulfil roles that were fundamental to their pre-MS self (12). The symptoms that are more likely to contribute to emotional problems are the ones that threaten how a person sees themselves. It is therefore important to talk to healthcare professionals about these symptoms, this includes both the physical and emotional toll which they may be having on you. Your GP, MS nurse and neurologist can help find ways to manage these symptoms which in turn will help to maintain a positive sense of self. Additionally, identifying ways to reconnect with valued interests, roles and activities plays an important part in this process (12).

Studies have discovered there are certain themes experienced by people with MS. These themes include the idea of concealing the condition which can perhaps indicate feelings of denial towards a diagnosis. For some, not telling people about their MS diagnosis offers a sense of holding on to their pre-diagnosed self, perhaps thinking that once they tell people, they will be seen as different to whom they were (11).

Living with a long-term condition can provoke powerful emotions. Feelings of anger, sadness and adjusting to a diagnosis can feel like a grieving process. This is a natural reaction to such a life-changing event (13). Someone may be grieving for the person they were before MS started to have an impact, and also grieving for a life they thought they would have that may now change as a result of diagnosis.

Grief

In her book 'On Death and Dying' published in 1969, world renowned psychiatrist Elizabeth Kübler-Ross introduced her theory of the five stages of grief, also known as the 'Kübler-Ross model'. This model was initially devised as a result of her work with people who were affected by advanced illness but can be applied to understanding the concept of grief in many other circumstances.

Kübler-Ross has stressed that these stages of grief may not be experienced by everyone, and this is not a linear process (14). However, it is helpful to be aware of what each stage may entail.

- **Denial** - This process allows you to isolate yourself from the pain, as well as the initial shock of the diagnosis
- **Anger** - Feelings of anger may be directed at others, often taking anger out on those who are closest to us. Anger towards yourself, or the MS, or the world as a whole
- **Bargaining** - This helps you feel in control. You may find yourself thinking "if only I had had a second opinion", or "if only I had visited my GP earlier"
- **Depression** - Feelings of sadness are probably the most universally experienced symptom of grief. You may have feelings of emptiness, despair, yearning or deep loneliness. You may also feel your emotions at extremes. You could be laughing one minute and crying the next

- **Acceptance** - This stage allows you to feel calmer and able to carry on with life by accepting what is your new normal

Throughout varying stages of living with MS, some or even all of the above stages may be experienced at some point. Relapses, for example, may trigger this process a number of times. Living with increasing levels of progression can also trigger this process. It is important to note that as MS can fluctuate, so can a person's thoughts, feelings and emotions.

It is also key to remember that the process of handling grief is natural and unique to each person. Therefore, be kind to yourself, accepting that you may need time and space to heal (13).

Anger

Dealing with the unknown that living with a long-term health condition brings can be hard and it is common to feel anger for a number of reasons. Thoughts of 'why me' can create feelings of anger, grief and loss. A person may feel angry at what MS has taken from them or the way it has changed their life, or angry because it causes frustration. These are just a few examples. A mixture of emotions may be experienced, and all of those emotions are valid. If these emotions are not acknowledged in some way, they may manifest and merge into frustration and anger.

Most people view anger as a negative emotion and therefore try to push it away. This can result in negative consequences such as distancing from or pushing away the people we care about.

As anger is mostly thought of as a negative emotion, people learn to suppress it. Instead of finding ways to deal with the anger, people may choose to keep busy or withdraw from others in order to ignore it (15).

Anger can arise from feeling powerless or out of control and is

commonly seen as a way of hiding upset, shame and vulnerability, all of which are extremely valid responses for people with MS irrespective of what type of MS they have or how long a person has had it for.

In some cases, these strong emotions can be caused by nerve damage, or relapses in parts of the brain that control the emotions. Long-term damage can have a real impact and, in some cases, change personalities (15).

Anyone living with MS has the right to feel angry, but research suggests if not addressed it can result in a reduced quality of life, specifically for people with MS (16). By learning to understand and manage angry thoughts and feelings, better control can be achieved, resulting in a positive impact on both physical and mental health.

There are many ways to deal with anger, these include practicing mindfulness, or talking to a qualified counsellor. Anger is a complex emotion and what can seem like a small niggle can in fact come from a bigger root cause that should be dealt with. There are often many layers of emotions and simply talking about them can help relieve some of the angst and tension felt (15).


Frustration

Frustration is the experience of being upset or annoyed as a result of being unable to change or achieve something. Living with MS can create many frustrations. These may include things such as how long it took to receive a formal diagnosis, a feeling of not being listened to or heard by health professionals, frustration at dealing with the benefits system, and the list could go on.


Another source of frustration can be the impact the condition has on your quality of life. For example, fatigue can make daily tasks more difficult to perform, can make work commitments more difficult to fulfil and have an impact on taking part in the hobbies that you love to do.

Any kind of frustration can be unpleasant to experience and if

prolonged can lead to low mood causing unhappiness, poor sleep, negative thinking, worthlessness and self-pity. If left unchecked for too long, the impact can be debilitating and often have a ripple effect onto others.



I'm now much more aware of negative feelings associated with MS and I'll be watching out for them so I can take appropriate action such as mindfulness or phoning the MS-UK Helpline



One way of helping to overcome feelings of frustration is to try out what are known as distress tolerance skills, a type of dialectical behavioural therapy (DBT) which works using distraction and shifting focus. Distraction can help to divert attention and it works better when the diversion is to something that you can be fully absorbed into, something you may enjoy. Different things work for different people, so it is worth trying some out and seeing what may work for you.

Shifting focus helps by noticing the frustration and then deliberately choosing where to put your focus. Do you choose the frustration or a different focus? As you 'do' your chosen activity, you will notice thoughts, feelings and other distractions come into your awareness so just notice them, then gently bring your attention back to your chosen activity (17).

Examples of ways to distract yourself from frustration include things like thinking about what needs doing in your home or garden, and doing some work in bite-sized pieces to manage your energy levels.

Other things to try might include

Pampering yourself – try out aromatherapy or reflexology. You could watch tutorials online on how to massage reflexology points on the hands or feet. You could take a relaxing bath whilst listening to a podcast or a meditation, creating some space in the mind. Or watch a feel-good comedy movie, or a nature documentary.

Get out and about – join a leisure centre or health club or see what is going on at your local Neuro Therapy Centre. Take a walk or a jog, sit by the beach or in a park, take in your surroundings, and notice things around you that you may have not even thought of before. Take a bus ride to somewhere new, visit the library, or a museum. Find out what free classes are on in your area, visit a local garden, or go out for coffee or lunch.

Be creative – learn a new hobby, or a new language, write a story or poem, learn to meditate. Try out a yoga class, Qi Gong or Tai Chi. Try your hand at painting, or knitting, or sewing.

Make contact with others – phone someone you have not spoken to for a while, do some voluntary work, join a group of some kind, write a letter or email to a friend. You could also consider contacting the MS-UK Helpline or join one of our Peer Pods.

Express yourself physically – bang a drum, shout or sing loudly, dance.

Talk to yourself positively – it is so very important to be kind to yourself, encouraging and positive. Tell yourself ‘I can get through this – I can take one hour at a time and these feelings of frustration will pass’ (17).

Guilt

Guilt can be a part of the grieving process, when a person is searching for answers to their questions of why something is

happening to them and also the impact it can have on others. It can be a difficult emotion to identify and is often disguised by feelings of anger or resentment. When it is identified it can leave a person feeling quite low.

People living with MS may experience guilt for a number of reasons. These might include

- Feeling like they have let their family, friends, and colleagues down by being diagnosed with MS
- Their MS is a burden on their family life, for example, through a change of lifestyle or reduced household income
- Needing to reduce work hours, socialising, attendance at special occasions and hobbies
- A need to now rely on others in a way they didn't before
- Feeling personally responsible for developing MS because they didn't exercise enough, eat healthily enough, didn't take the right supplements, and didn't go to the GP early enough. Or guilt as they wish they had fought harder to be heard by health professionals
- Being punished for something they feel they did wrong at some point in their life

Guilt is experienced by most people at some point in their life, however, if you notice you are constantly apologising to yourself or others this could be a sign that you may be experiencing feelings of guilt. Communication is key in challenging these feelings. Talking to someone you trust, such as a family member, friend, colleague or health professional, can help you to start finding ways to alleviate these feelings.

If guilt is not recognised or processed it can impact your mental health and wellbeing. As well as talking to a trusted person, it may also be helpful to speak to an experienced mental health professional to discuss the feelings of guilt in a safe, supportive and non-judgemental setting. This could be through

- Counselling or cognitive behavioural therapy (CBT)
- Relationship or family therapy
- Mindfulness and meditation

More information about these types of therapy can be found later in this booklet.

Emotional impact on family and friends

Family members and close friends can also experience all or some of the emotions and feelings we have explored so far. MS can affect the wider family sometimes as much as it can the individual diagnosed. Family members and friends may feel upset and angry that someone so close to them, someone they love and care for, has received an MS diagnosis. They may feel angry, frustrated and helpless as they see the people they love deal with different symptoms, relapses and progression.

I have a good family network who tried to support me, but they too were trying to come to terms with it

Guilt can also be a particularly common feeling held by those close to you. They may feel that they are not caring enough, or that they don't have enough patience or compassion towards the person living with MS. Another potential issue is the feeling of guilt that it wasn't them diagnosed instead. Or they may blame the person for the challenges presented which can provoke guilt in the person living with MS (18).

Change as a result of MS

Change is something that every human being will encounter within their lifetime. This may be a change in age, relationship status, education, job, or home, and we all deal with the challenges that change thrusts upon us in many different ways.

For people living with MS, change can have a far greater impact from one day to the next. For example

- **Emotional changes** – mood and mental health
- **Physical changes** – fatigue levels, balance problems, bladder and bowel problems, foot drop, heat sensitivity, mobility issues and pain to name a few
- **Cognitive changes** – memory, information processing and concentration

Relationships

Emotional, physical and cognitive changes can have an impact on relationships. People may start to withdraw from family and friends. They may choose not to go to social events due to these changes. People might find they receive less invites to social events as a result which may cause lowered mood, anxiety and depression.

If a person finds they need to rely on others more, this can lead to feelings of guilt, shame or frustration which can start to impact relationships.

Other impacts on relationships might be

- Worry that MS is negatively affecting children
- Worry about how a partner may view your 'MS body' therefore having an effect on intimacy
- The experience of fear upon entering into a new relationship due to the uncertainty of what the other person may feel about your MS

Work

Emotional, physical or cognitive changes can impact a person's work life. People may feel hesitant to express what work adaptations and support may be required because they

- May not have told colleagues about their diagnosis
- Feel a sense that they need to come to terms with any changes experienced before sharing these changes with colleagues
- Feel fearful about talking about these changes - fear of being 'outed' as 'disabled' or a 'nuisance'
- May be hesitant to vocalise changing needs if, in the past, managers and/or colleagues have not been receptive to any requests



I have used my workplace Employee Assistance Scheme, through which I was able to get some telephone counselling a few years ago



Hobbies, interests and social activities

People may notice how emotional, physical or cognitive changes mean they

- May no longer be able to participate in
- Be asked to participate in
- Want to participate in hobbies, interests or social activities like they previously used to

While some people with MS may be able to accept these changes, others may find it far more difficult. They may feel a sense of guilt, upset, frustration, anxiety, grief, loss or sadness that things have changed and may feel stuck or unsure of how to move forward.

People may find themselves feeling overwhelmed by the emotional, physical or cognitive changes occurring. They may feel that life suddenly feels out of their control. Changes can highlight how different life looks to what it did a decade, a year, a month, a week or even a day ago. It is good to be able to find a way to talk about these changes and how they make you feel. Bottling up these thoughts and feelings can affect a person's mental health and wellbeing.

Talking to a trusted person about any changes experienced can really help. Counselling can help you process your thoughts and feelings in a supportive, professional and non-judgemental space (19). We provide more information about counselling later in this booklet.

Self-help and lifestyle

There are a number of ways to support your own mental health, and different techniques to practise at home, maybe alongside professional help or as an ongoing strategy to maintain a healthy mind.

It is important to realise that you need to take care of your mind in the same way as your body. For example, poor diet, smoking, or taking little or no exercise is going to result in poor physical health. The principle is the same for mental health

A friend who I met at a newly diagnosed talk is a great support. Although others try, it really helps when someone really understands

Talk to people you trust. It can really help to confide in someone close to you about how you are feeling. Sometimes people don't feel they want to talk to others through fear of burdening them or that it may just be too difficult to open up, even to good friends, about the challenges of MS.

Some friends may find it hard to listen, as they perhaps want to be able to do something to help. There may not be anything they can do except listen, but for many, a listening ear can provide so much support. Often people will feel flattered that you trust them enough to talk about your feelings. They may even have noticed something and feel relieved that you have spoken to them.

Support from others with MS has been vital

Talking to another person with MS can be helpful as there may be a mutual understanding of living with the condition and how it can impact. Joining a local group or online forum, visiting a local Neuro Therapy Centre, or getting involved with one of the many MS-UK Peer Support Pods can help you connect with the wider MS community.



I found great support in the MS-UK peer pods



More information

MS-UK Peer Support service
www.ms-uk.org/peer-support-service

MS-UK Finding support in your community
www.ms-uk.org/finding-support-in-your-community

MS-UK Forums and online support
www.ms-uk.org/online-forums-for-MS

Neuro Therapy Network website www.neurotherapynetwork.org.uk

The following is a list of suggestions of self-help and ways to help care for your mind.

Breathing

Many therapeutic approaches use breathing techniques to help calm the body and the mind. Breathing techniques produce a bodily response that helps to lower anxiety. Deep breathing, more specifically, slowing the out-breath, helps to decrease blood pressure, dilate your pupils and slow your heart rate. The theory is that by practising a breathing technique a few times per day, stress levels will reduce in the long term.

The longer out-breath stimulates the parasympathetic nervous system, therefore a technique with a longer out-breath than in-breath will be more effective (20).

A common technique is '7-11' breathing.

1 Breathe in for a count of 7

2 Breathe out for a count of 11

It is important to breathe in deeply, rather than a shallow, upper lung breath. A deep diaphragmatic breath where the diaphragm moves down and pushes your stomach out as you take a breath in is required.

If you find that is too long, you can reduce it and breathe in for three and out for five, in for five and out for seven or whatever is most comfortable, as long as the out-breath is longer than the in-breath. Focusing on breathing is not only relaxing but it is also a good distraction and can help take your mind off any immediate concerns.

Eating well

Research suggests that how we eat can have an impact on how we feel. By improving your diet it can help to improve mood, give more energy and help you think more clearly.

The mental health charity Mind provide some salient guidance on food and its impact on mental health (21). Below are some tips which they suggest could be areas of focus

- **Blood sugar levels** – it is important to eat regular meals, and more foods that release energy slowly, to help maintain blood sugar levels. If blood sugar drops it can cause a person to feel fatigued, irritable and depressed

- **Staying hydrated** – dehydration can impact levels of concentration and the ability to think clearly. Try to stay hydrated, focusing on fluids that do not contain caffeine or sugar
- **Getting your five a day** – fruit and vegetables contain lots of vitamins, minerals and fibre needed to stay physically and mentally healthy
- **Looking after your gut** – feeling stressed or anxious can have an impact on the gut. It can slow it down or speed it up. Try eating foods that are easy to digest such as fruits, vegetables and wholegrains and probiotics such as live yoghurt and kimchi
- **Getting enough protein** – protein contains amino acids which make up the chemicals your brain needs to regulate thoughts and feelings. Protein rich foods include nuts, seeds, eggs and lean meat
- **Managing caffeine** – caffeine is a stimulant, it provides a quick burst of energy but may then make you feel anxious or depressed. It can also negatively impact sleep
- **Healthy fats** – fatty acids such as Omega 3 and 6 are required to keep the brain working well. These can be found in oily fish such as sardines and mackerel
- **Alcohol** – too much alcohol can have a disruptive impact on the chemicals in the brain which are there to help maintain good mental health. Moderate alcohol intake where possible, support to do this is available if needed
- **Food intolerance and allergies** – intolerances and allergies to certain foods can have an impact on mental and physical health


More information

Our 'Diet and Supplements' Choices booklet provides further reading on the link between our diet and MS, including more information about gut health and the specific diets that have been developed and used by people with MS, with positive results. www.ms-uk.org/choices-diet-and-supplements-content


The NHS Live Well website offers guidance on a range of topics about healthy living including diet and exercise. www.nhs.uk/live-well

Exercise

Studies have shown that moderate exercise can improve mood and general wellbeing, provide stress relief, increase energy and stamina, reduce tiredness and increase mental alertness. It can also help you to feel better about yourself (22).



**I use yoga to help manage my anxiety,
I go swimming and walking, and
continue to read as much as I can**



Exercise helps to release endorphins. These are the body's own feel-good hormones. MS and some medications can make people less active - this may be due to fatigue, dizziness, poor mobility, or a lack of motivation. Doing short sessions of exercise can make a big difference to mental wellbeing as well as physical health. It helps to start with something small rather than set yourself unrealistic goals. Just ten minutes a week is better than nothing, increasing to ten

minutes a day to then 30 minutes a day dependant on your ability can really make a difference.

Exercise doesn't just mean going to the gym, or going for a run, it could be having a dance around your kitchen, hula hooping in the garden, some gentle seated yoga or Pilates. Finding the right type of exercise is important as you will be more motivated to continue doing something that you enjoy.


Contact your local Neuro Therapy Centre to see what exercise equipment and classes they have available. If you cannot find a therapy centre that is close to you, contact the MS-UK Helpline and they will look to see what alternatives are available in your area.

At MS-UK we host a variety of different forms of accessible online exercise classes that suit different levels of mobility. From our chair yoga and seated exercise classes to information workshops, our online activities are wide-ranging and inclusive.


More information

To find out more about the benefits of exercise in managing the impact of MS please read our dedicated 'Exercise' Choices booklet www.ms-uk.org/choices-exercise-content

MS-UK's online activities www.ms-uk.org/ms-uk-online



Get out every day, however difficult that may be, just to have the sky above your head and breathe fresh air will make you feel better



Gratitude

Gratitude is, quite simply, the human way of acknowledging the good things in life. It is a positive emotional response and is known as a natural stress detox for both the body and mind.

Research suggests that by practising gratitude, you can receive psychological, physical and social benefits. These include encouraging positive thoughts and emotions, enhanced mood, optimum blood pressure and cardiac functioning, better sleep/wake cycles, improved communication, more empathy and stronger interpersonal relationships (23).

Practising gratitude can reduce fear and anxiety. It can form new neural connections within the brain and enhance dopamine and serotonin – neurotransmitters responsible for happiness. When practised daily it can produce a feeling of long-lasting happiness and contentment (23).

Some ways to practise gratitude include

- **Appreciate yourself** – say out loud five good things to yourself. This could include past achievements, present efforts, compliment yourself with words like kind, loving, loyal
- **Gratitude journal** - include things like compliments you would like to give yourself today, current challenges and what you are learning from them, people you are grateful for
- **Gratitude buddy** – set aside some time each day to sit/talk with a friend, partner, or child and discuss the things you are thankful for
- **Gratitude jar** – keep a jar or box with small pieces of paper beside it. Each day write about one thing that you are grateful for today and put it in the jar. It is helpful to reflect on these thoughts at a later date

Research shows that by recognising the good things that are happening, it helps to strengthen the ability of the brain to focus on positive things. In his various studies that focus on the effects of gratitude, Dr Robert A Emmons PHD, psychologist and professor at the University of California, found that gratitude has a positive relationship with neurodegeneration and cardiac health, enhances mood, helps promote a healthy sleep-wake cycle and can help individuals manage anxiety and depression (23).

Grounding

This technique is a coping strategy that can help to reduce anxiety and shift attention away from frustrations, bringing the mind to the present moment by focusing the senses and saying/thinking to yourself. Grounding techniques can help separate you from the distress of your emotional state or situation, allowing your body to calm itself and recognise that the perceived threat is no longer present. In effect they are designed to help you better manage the sympathetic nervous system's 'fight or flight' responses (24).

Grounding uses different techniques that help with managing the impact of stress and trauma. There is no one size fits all approach and so what works for one person may not work for the other. It is about trying different approaches and finding what works for you.

Below are just three examples of grounding techniques (25)

The '5-4-3-2-1' method – This requires you to list senses that you feel at present, working backward from 5, counting down to 1, for example

- Five - things you can see
- Four - things you can feel
- Three - things you can hear
- Two - things you can smell
- One - thing you can taste

Focus technique – Choose a small item, could be anything that fits into a pocket, from a stone, coin, gem, or a piece of jewellery. Place it in your hand and close your eyes. Concentrate on different aspects of the item, such as

- Feel – Is it blunt, sharp, hard, soft?
- Temperature – Is the item warm or cold?
- Texture – Is the item smooth, lumpy, rounded?
- Weight – Is the item heavy or light?

Next open your eyes, look at the item, focusing on detail such as

- Colour – The colour/s of the item
- Pattern – Is the item patterned, is it plain?
- Other – What else do you notice about the object?

Using this process and the same object at times of increased anxiety can help you to focus on managing its impact.

Adrenaline refocus – Sometimes it can be difficult to connect with the more relaxing techniques such as the ones mentioned above. At such times, channelling the adrenaline that is pumping around your body into activities that will help to ‘burn off’ the energy that it brings, can then help you to refocus on other techniques afterwards. How you do this is entirely up to you, but some examples are

- Play some loud music – Via headphones is more socially acceptable!
- Singing and dancing – At the same time if you are multi-talented
- Dance – Have a dance, seated or standing, it doesn’t matter
- Go outside – Take brisk walk, a run, cycle, whatever is accessible to you


Practicing grounding techniques can help you take your focus away from sources of anxiety and in turn be an effective coping strategy.

Mindfulness


Mindfulness is a brain training meditation practice that originated in Buddhism 2,000 years ago. Mindfulness exercises are ways of paying attention to the present moment, using techniques like meditation, breathing, and yoga. Research has shown that it is effective at reducing stress and anxiety, increasing focus, reducing fatigue and pain, and it can help to boost the immune system and also increase a sense of acceptance (26).

Training helps people to become more aware of their thoughts, feelings, and body sensations so that instead of being overwhelmed by them, they're better able to manage them. Practising mindfulness can give more insight into emotions, boost attention and concentration, and improve relationships.

Prioritising relaxation as an essential part of health is a good first step to mindfulness. Setting time aside to practise daily will help to enable the brain to physically rewire itself and allow the mind and



I use mindfulness a lot. You only need a small amount of time to switch off from everything to help you feel calmer. I use mindfulness to get to sleep at night



body to be able to slip into states of relaxation more easily (26).

Mindfulness is also recommended by NICE as a preventative practice for people who experience recurrent depression (27).

You can speak to your GP or MS nurse to find out about any mindfulness courses in your area or call the MS-UK Helpline who will help you to find suitable options.

MS-UK also host four and eight week-long mindfulness courses which are available are part of our online activities programme.

More information

MS-UK online activities

www.ms-uk.org/ms-uk-online



**It won't do you any harm, give it a try.
It might just do some good**



Religion and spirituality

Both religion and spirituality can have a positive impact on mental health and for some can provide a sense of peace, purpose and forgiveness.

Religion and spirituality can offer you something to believe in, providing structure and connection with others over similar beliefs – a sense of community with likeminded individuals. If presented in a supportive way, both can help to improve mental health (28).

Apps to support mental health

Mobile phone or tablet apps can be really useful in supporting a healthy mind (29). They can be used alongside therapy, or in isolation and are seen as a step in the right direction of finding ways to support your mental health.

“
Headspace is a fantastic app and helps me get to a place of spaciousness, note any pain in my body then move on
”

Here are some suggestions that are all available as an app on android and iOS –

- **Aura** – helps people to manage mental wellness using a combination of techniques including breathwork, meditation and CBT
- **Breathe2Relax** – a useful app that teaches ‘diaphragmatic breathing’ to help reduce the impact of stress
- **Catch it** – a free app that uses CBT-based methods to help you manage feelings of anxiety and depression by turning negative thoughts into positive ones

- **Chill Panda** – this app uses different activities such as yoga and breathing techniques that are designed to help manage anxiety. Also available on Nintendo Switch.
- **Headspace** – its mindfulness and meditation-focused content is based on eight core authentic techniques that are proven to help people manage stress and anxiety. Also available via PC/ Mac desktop
- **Insight Timer** – an app that uses various techniques including yoga, meditation and breathwork designed to help people manage stress and anxiety
- **MyPossibleSelf** – an NHS-approved app that uses CBT interactive tools and techniques designed to help you identify sources of anxiety and how to manage them
- **Smiling Mind** – a tool, developed with the aid of psychologists, that uses meditation and mindfulness exercises designed to help promote mental wellness
- **What's Up?** – this wellbeing app uses tools to enable you to manage anxiety and calm an anxious mind and body
- **Worrytree** – using CBT and sensory practices, this app is designed to help you create a plan of action to help you cope with worries and concerns

More information

The mental health charity MIND provides a varied summary of online mental health tools, incorporating social media, blogs and podcasts

www.mind.org.uk/information-support/tips-for-everyday-living/online-mental-health/online-mental-health-tools

Professional help

Managing MS is, I find, about dealing with the physical problems it causes and the mental. Talking to a trained professional helps you explore and come to terms with MS

There are a number of health professionals who can help to support you if you are experiencing mental health issues. Here we explore some options

GP


Talking to your GP is a very good starting point. It can be difficult to start the conversation but try to be honest and open. Discussions around having trouble sleeping, feeling anxious, having little interest in hobbies or life in general will allow your GP to ask more questions and, where appropriate, refer on to more specialist mental health support perhaps through a social prescription service.

Try to focus on how you feel and use words that feel natural to you, not ones that you think the GP will want to hear. In some cases, it may be helpful to start medication first before seeking additional support.

Talking to your GP or practice nurse at an early stage can help you to stay well.

MS nurse

MS nurses will be aware of the challenges people with MS face on a daily basis. They may even spot signs of low mood or depression before you do as they recognise the symptoms and behaviours. Talk to your MS nurse about any current difficulties, they too may be able to help you seek appropriate support.




I was allocated a MS Specialist Nurse fairly early on - she was brilliant, and her successor is a real lifeline for me still




Counselling

Seeing a counsellor or therapist can give you a safe environment to talk about important issues in a confidential and non-judgemental way. This may help you to reflect on issues of concern and it can support you to develop coping strategies for the future.



Counselling has given me confidence to work on issues that were concerning me and a safe space to discuss my emotions and feelings



Counselling is a talking therapy and can help you to be open and honest about how you feel and how MS affects you. Counsellors do not offer advice or tell you what to do but help you to talk about your experiences to make it easier in finding a way forward.

There are various bodies that counsellors are likely to be registered with such as the British Association for Counselling and Psychotherapy (BACP), the UK Council for Psychotherapy (UKCP) or Counselling & Psychotherapy in Scotland (COSCA). Counsellors will usually be transparent and open about the body they are registered with.



I feel [the counsellor] has given me many skills to be able to manage the way I look at myself, they challenged my thinking and have helped me a great deal to find ways to come to terms with my struggles. I feel that I look at myself differently and am starting to be kinder to myself and less critical



Talk to your GP or MS nurse as there may be forms of talking therapies available from your local public health authority. Some of these services are accessible via self-referral.

There are also localised charities that provide access to free or low-cost counselling, however, the presence of these charities does vary from area to area.

You can also access counselling via other sources, such as your local Neuro Therapy Centre. Also, the MS Society in the UK has locally affiliated groups, some of which provide access to counselling.

MS-UK hold a directory of fully qualified, registered counsellors who have all undertaken our 'MS Awareness' and 'Counselling people with multiple sclerosis' eLearning course. These counsellors offer telephone or online counselling and some also provide access to face-to-face sessions depending on where you live. Each counsellor has stated their experience and costs within the directory, which is available on the MS-UK website, visit www.ms-uk.org/ms-counselling-directory/

More information

BACP

www.bacp.co.uk/search/Therapists

UKCP

www.psychotherapy.org.uk

COSCA

website www.cosca.org.uk

MS Society local group search

www.mssociety.org.uk/care-and-support/local-support

MS life coaching

Life coaches help you to identify and unlock your individual strengths, developing ways to use them in a positive sense to achieve set goals, overcome obstacles and generally live a healthier and more positive lifestyle.

Fundamentally, life coaches can specialise in helping you to develop strategies in many different areas of life, from careers, relationship building and general personal development. There are MS-focused

life coaches based in the UK and beyond whose aim is to empower people affected by MS to live healthier and happier lives.


Life coaching is currently not a regulated entity, and each coach will usually have their own approach and techniques, underpinned by their life and professional experience. Many coaches offer an initial consultation, usually at no cost, that will help you to gauge whether their approach, in terms of the tools they use, techniques and their personality, would be the right one for you (30). Additionally, most life coaches will have their own websites that provide information about their backgrounds and methods they use.

Cognitive Behavioural Therapy (CBT)


CBT is a talking therapy which focuses on how your thoughts, beliefs and attitudes can affect your feelings and behaviours. It teaches coping skills to help you deal with different problems (31). CBT combines cognitive therapy, which entails examining the things you think, and behaviour therapy, which examines the things you do, and is one of the more common types of therapy for anxiety and depression.

CBT is based on the idea that the way we think about situations affects the way we feel and behave. For example, if you react negatively to a situation, it is likely you will experience negative emotions as a result. Those feelings may lead you to behave in a certain way. Negative thinking patterns can start from childhood and if they go unchallenged can become part of a continuous cycle.

Fundamentally, CBT can help you to challenge negative thinking patterns, with an aim to change the way you feel about situations, enabling you to change your behaviour in the future. It can also help you find ways to cope with physical health problems, such as fatigue and pain (31). The tools and techniques learnt from CBT can often be applied to help you manage other problems in the future.



**MS has made me and my husband say
'yes' more. We live in the day and make
plans sooner rather than later**



CBT is recommended by NICE as a tool to manage depression and anxiety (27).

Referrals for CBT therapy via the NHS can be made by your GP, self-referral is available in some areas of the UK, or you can look for a private counsellor who offers this particular type of therapy through the BACP, UKCP or COSCA websites, to which we signposted to earlier in this booklet. Self-help books or online courses can also be accessed and may be useful whilst you are waiting.

More information

The NHS every mind matters website offers guides to self-help CBT techniques www.nhs.uk/every-mind-matters/mental-wellbeing-tips/self-help-cbt-technique

Living Life Scotland – A service powered by NHS 24 that offers telephone-based CBT courses. Available for people living in Scotland only www.breathingspace.scot/living-life

Silvercloud Wales – Powered by NHS Wales, this is an online therapy platform that uses CBT techniques to help people manage mild to moderate anxiety, depression and stress. Available to people living in Wales only www.bcuwb.nhs.wales/health-advice/mental-health-hub/silvercloud-free-online-mental-health-therapy

Acceptance and commitment therapy (ACT)

ACT aims to help people to explain their negative thoughts and feelings, enabling better self-management. It works towards living an active, valued life and increasing acceptance. Studies have shown that ACT reduces psychological distress and can help improve quality of life for people with MS (32, 33).

ACT encourages people to embrace their thoughts and feelings rather than fight against them or feel guilty for them.

There are six key elements to ACT which provide a framework for developing psychological flexibility (34). These are

- Acceptance – not the primary goal but a method of encouraging action to lead to positive results
- Cognitive defusion – techniques intended to change how an individual reacts to their thoughts and feelings
- Being present – the practice of being aware of the present moment without judgement
- Self as context – a process which offers the alternative concept that there is a self outside of the current experience
- Values – the qualities we choose to work towards
- Committed action – committing to actions that will assist in long-term goals, to live a life consistent with your values


ACT emphasises acceptance instead of avoidance.

Jo Johnson, Consultant Neuropsychologist, says that research is showing this is a helpful model of therapy for people with MS and for their partners. Also, that it may be more suitable for people with mild


cognitive problems, significant fatigue or for those going through a relapse, as it is an easier model to understand (35).

More information

ACT MySelf – This is a self-help support tool, underpinned by ACT principles, that is designed to help people living with MS to build an action plan aimed at improving their emotional wellbeing
www.actmyself.co.uk



I got some help from a neuropsychologist who applied the principles of ACT which worked well. I still get down sometimes but I now have a platform to get back up again



NHS Talking Therapies

NHS Talking Therapies formerly known as Improving Access to Psychological Therapies (IAPT) offers access to a range of evidence-based psychological therapies designed for the treatment of adult anxiety disorders and depression in England. Since its inception in 2008 this service has helped people to overcome their depression and anxiety, supporting them to manage their mental health more effectively.

NHS Talking Therapies can be accessed by self-referral, as well as via your health professionals. You can find out what services are available in your area by using the search facility on the NHS website.

Access to talking therapies is available in other areas of the UK, with referrals usually made via your GP or other health professionals.

More information

Find an NHS talking therapies service – England only www.nhs.uk/service-search/mental-health/find-an-nhs-talking-therapies-service

NHS Inform Scotland – Information about accessing talking therapies for those living in Scotland www.nhsinform.scot/healthy-living/mental-wellbeing/therapy-and-counselling/talking-therapies-explained

NI Direct – A guide to accessing mental health services for people living in Northern Ireland www.nidirect.gov.uk/articles/mental-health-services

NHS 111 Wales – Provides a summary of the mental health support available to people living in Wales, including Silvercloud, to which we refer previously in this booklet <https://111.wales.nhs.uk/encyclopaedia/m/article/mentalhealthandwellbeing>

Supporting someone with MS

Family and friends may find it difficult to know how best to support their loved one when MS affects a person's mental health. Here are five ways to support someone with MS (36)

Listen

Listening has great power. Listen actively by thinking about what the person is really saying rather than just the words that they are speaking. By listening, you will gain an understanding of what they are experiencing. Listening to someone does not mean that you have to do anything in particular to change their circumstances. Connect with what is being said rather than trying to put a positive spin on it.

Ask what you can do

If you feel able to help, ask what you can do rather than decide what the person needs. It is natural to feel over-protective to those close to us and to want to do as much as possible for them. However, think about how someone who is usually independent might experience extreme gestures of help and how this might affect their confidence. Equally, it is important to recognise that people might seem fine but still need some help. It might not be obvious that they are struggling physically or emotionally.

Recognise that the individual is unique

If you know more than one person with MS, think of them as unique individuals with their own experiences rather than trying to layer one person's experience over the other's. Just as no two people are the same, no two people will have the same experience of MS. Instead of second guessing what their lives are like with MS, invite them to talk about it.

Think about how their lives might have changed

Some people might have experienced radical changes to their lives. Their MS might have led to them having to give up work or change the type of work they do. This might have had a negative impact on their sense of self. Often our identity is closely linked to both personal and professional roles we hold. Changes to these can adversely affect how we see ourselves.

Try not to 'fix' it

As the relative or friend of a person with MS, you might feel helpless and try to do what you can to 'fix' the condition. MS cannot be fixed. It is here to stay. By learning to accept this you will be able to help the person with MS also come to terms with their condition.

Tips to cope with managing mental health in MS

We asked the MS community to share with us some tips on how they manage their mental health whilst living with MS.

- Mindfulness, physical exercises and maintaining as active a life as possible really helps me stay positive
- Problem solving on a daily basis gives me a sense of achievement!
- Talking things out. If you don't have someone to talk to, try talking to yourself. I've had some of my most successful problem-solving chats with myself and I don't get any disagreements!
- I manage my mental health by looking after myself and investing in my health through exercise and other therapies such as reflexology, keeping busy and having 'rules'.
- I try to keep busy at home and give my day structure which I really think helps me
- Don't be afraid of making new MSe friends - they'll really enrich your life!
- Write down a positive each day. Put it in a container. Review them whenever things seem too much
- When I was ready, I focused on taking steps to design a future life to include the things that were important to me and remove the things that weren't.

- Speak to your healthcare team or specialist nurse about what you are struggling with, they can signpost you to other services who can help
- Don't think about what you can't do, think about all the incredible things you can do
- I would advise people to do the opposite to me and ask for help
- Talking things through, especially with MS-UK can really help as they do understand the condition

[illegible]

About MS-UK

MS-UK is a national charity formed in 1993 supporting anyone affected by multiple sclerosis. Our hope for the future is a world where people affected by MS live healthier and happier lives.

MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis, whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

We will always respect people's rights to make informed decisions for themselves.

The MS-UK Helpline

We believe that nobody should face multiple sclerosis alone and our helpline staff are here to support you every step of the way.

Our service is informed by the lived experience of real people living with MS, so we can discuss any treatments and lifestyle choices that are of benefit, whether they are clinically evidenced or not.



New Pathways

Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

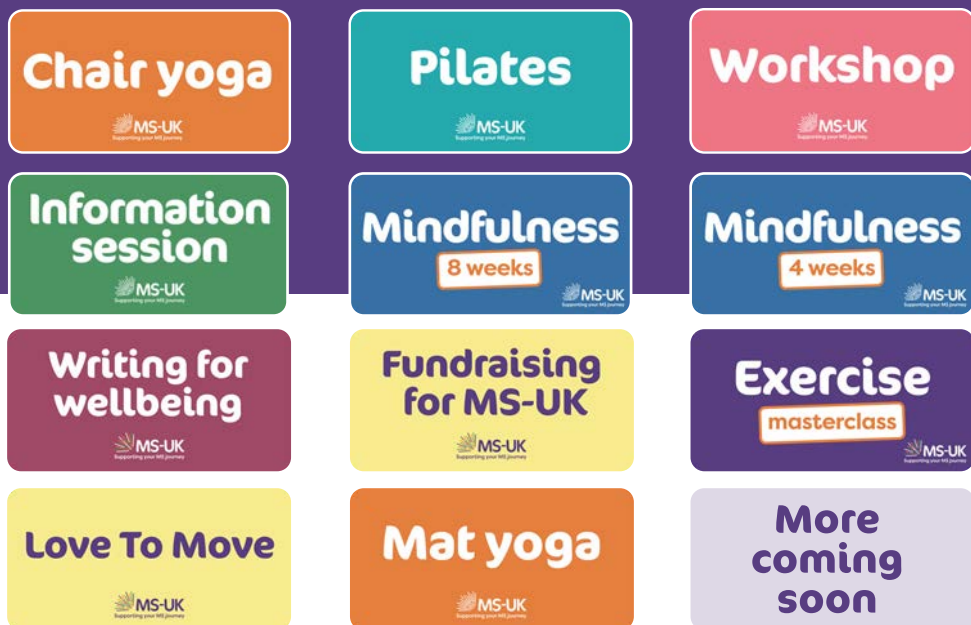
Available in print, audio version, large print and digitally.

About MS-UK

Peer support service

Our Peer Support Service enables people to connect with others in a safe space and share experiences on topics of interest. Our Peer Pods take place regularly and are all volunteer led. Please visit the website to find out more [ms-uk.org/peer-support-service](https://www.ms-uk.org/peer-support-service) or email peersupport@ms-uk.org.





MS-UK's online activities

MS-UK offers a variety of online activities for those affected by MS to stay active, connected with others and to manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. To get involved, please go to www.ms-uk.org or email register@ms-uk.org.

MS-UK elearning

Do you work with or support someone living with MS and want to increase your understanding and knowledge of this long-term health condition? Professionals at MS-UK have created an accredited eLearning course that can help you do this. Visit www.ms-uk.org/ms-awareness-e-learning to find out more.

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Last reviewed June 2023

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