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 empathize 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
# Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>MS and Mental Health</td>
<td>4</td>
</tr>
<tr>
<td>How can MS affect mental health</td>
<td>5</td>
</tr>
<tr>
<td>MS and the impact on mental health</td>
<td>12</td>
</tr>
<tr>
<td>Change as a result of MS</td>
<td>20</td>
</tr>
<tr>
<td>Self help</td>
<td>23</td>
</tr>
<tr>
<td>Apps to support mental health</td>
<td>29</td>
</tr>
<tr>
<td>Professional help</td>
<td>31</td>
</tr>
<tr>
<td>Supporting someone with MS</td>
<td>36</td>
</tr>
<tr>
<td>Tips to cope with managing mental health in MS</td>
<td>38</td>
</tr>
<tr>
<td>Further information</td>
<td>39</td>
</tr>
<tr>
<td>About MS-UK</td>
<td>40</td>
</tr>
<tr>
<td>Sources</td>
<td>42</td>
</tr>
</tbody>
</table>

Visit www.ms-uk.org to find out more
A diagnosis of MS can have a huge impact on someone’s mental health and emotional wellbeing. A diagnosis can present in many different ways and can raise all sorts of thoughts and feelings around a person’s future and how MS will play a part in it.

Dealing with the unpredictability of the condition can be hard and can often take 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.

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 will most likely have an emotional impact to a certain degree and that is perfectly normal. Emotional reactions can come as an ‘indirect’ response to being

“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
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 cause a range of different emotions.

It can also be a ‘direct’ response as a result of how the condition affects the brain. For example, the frontal lobe in the brain controls our emotions, if there is an MS lesion in that area it will have a direct impact to some degree.

It is estimated that one in four people living in the UK will experience a mental health problem each year (1). This booklet relates specifically to the impact that a diagnosis and experience of MS 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 emotional wellbeing, but living with the condition and the changes that can come with it too.

MS is a fluctuating condition. There may be changes in symptoms, and feelings of anxiety should a relapse occur. The transition from relapsing remitting MS (RRMS) to secondary progressive MS (SPMS) can also cause anxiety, as well as varying rates of disease progression. All these things can have an impact, causing lowered mood, heightened anxiety levels and depression.

There might be anxiety at what the future may hold – in particular the uncertainty of not knowing what the future may be.

In this booklet 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

The most important sign to recognise is 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 (2).

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 found enjoyable
• Self-neglect - not washing frequently for example
• Lack of concentration, for example, whilst reading the newspaper or watching TV
• Changes in sleeping patterns; 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 around what causes depression but there are three main perspectives

1. Depression links to certain ways of unhelpful thinking
2. Depression is a result of negative life experiences
3. Depression is caused by neuro-chemical or hormonal imbalances

It is however recognised that it is usually a combination of all three factors that link to why a person may be experiencing depression.

Depression can affect anybody. Having an MS diagnosis does not mean you will automatically become depressed. However, around 50 per cent of people living with MS will experience depression at some point in their life (3). This is three times higher than the general population. This higher rate could be due to MS damaging nerves in the brain that affect mood but also because the person is living with a complex disease.

What can also be confusing is that some symptoms of depression are also 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.

If you think you may be depressed, it 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. Below are a few suggestions that you may find helpful

• 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 Counselling service. This service is confidential and is open to people living with multiple sclerosis

**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 normal response when people perceive they are under threat. Most people will feel anxious at times and is very commonly felt during periods of time that are stressful, especially life events that have a big impact. If feelings of anxiety are very strong or last for some time, they can be overwhelming (4).

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 reaction too (5).

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 as well.

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 (6).

Anxiety can cause the following symptoms

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

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

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 (5).

Low levels of serotonin are thought to play a role in both, along with other brain chemicals such as dopamine. Both have very different psychological features (7).

Whilst it is important for healthcare professionals to understand these distinctions so they can best support you, the

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

Visit www.ms-uk.org to find out more
most important things 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 Counselling service. This service is confidential and is open to people living with multiple sclerosis

**MS and the impact on mental health**

Living with a long-term health condition can impact a person in many ways. Someone may start to see themselves differently, otherwise known as an ‘altered sense of self’. 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 (8).

Adjusting to a life with MS can take time. It is a normal reaction to at various points fear the worst and to worry about the future. It is a process that occurs over time and for some it may take longer than others to adjust and that is okay.

The study looked at how MS can have an effect on 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 also 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. Accepting a condition that you did not choose to have may lead to feelings of anger or 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. By not gaining support, levels of anxiety and depression can rise.

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 important to their pre-MS self. The symptoms that are more likely to contribute to emotional problems are the ones that threaten how a person sees themselves. It is important to talk to healthcare professionals about the symptoms which have the most affect. 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. Finding ways to reconnect with valued interests, roles and activities are important (9).

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. Often, receiving a confirmed diagnosis can take a long time. The time from acknowledging initial symptoms to being diagnosed can take its toll on a person. Some people may feel a sense of relief whereas others may struggle with the idea of having MS. Not telling people about the diagnosis can, in some cases, make people want to hold on to their pre-diagnosed self (8), perhaps thinking that once they tell people, they will be seen as different to whom they were.

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 (10). 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.

**There are five stages of grief**

- **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, it is likely that some or even all of the above stages will 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.

However, not everyone goes through every stage, and grief is not
always a linear process, therefore may not be experienced in the order listed above. Also, some people resolve their grief without going through any of these stages. It’s important to remember that this is a natural process and it is individual to each person. It is most important to be kind to yourself and give yourself the time and space to heal (10).

Maintaining a flexible approach to life is really important when adapting to a life with MS. It is important to express negative emotions openly without becoming overwhelmed by them, and to maintain a reasonable quality of life however the condition presents.

If life becomes too much and help is required to adjust to MS, this does not mean a person cannot cope, or that people should be able to deal with it on their own. Rather, it acknowledges that MS can cause difficulties and anyone would find them challenging.

**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. For example, a means to distance from or push 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 (11).

Anger can arise from feeling powerless or out of control. Anger is commonly seen as a way of hiding upset, shame and vulnerability. All of which are extremely valid experiences for people with MS irrespective of what type of MS 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 potentially change personalities (11).

Anyone living with MS has the right to feel angry but research suggests that keeping angry thoughts bottled up can result in a reduced quality of life (12). If anger is not dealt with it can impact relationships with others as well as the person experiencing it. 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 (11).

**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 like it taking a long time to reach a diagnosis, perhaps a feeling of not being listened to or heard by health professionals; symptoms getting in the way of living, for example fatigue making daily tasks more difficult, not being able to fulfil work commitments or maybe not being able to complete hobbies previously enjoyed; frustration at dealing with the
benefits system, the list could go on.

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 experienced for too long it 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 is known as distress tolerance skills – distraction and shifting focus. Distraction can help to divert attention and it works better when the diversion is to something that can be fully absorbed into. Different things work for different people so it is worth trying some out. 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 (13).

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.
**Others 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 MS 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 visit 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, 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.

**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’ (13).

**Guilt**

Guilt can be a difficult emotion to identify. It is often disguised by feelings of anger or resentment. When it is identified it can leave a person feeling quite low.
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.

**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 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 further in this booklet.

Family members can also experience all of the above feelings and emotions. 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 their friend or loved one has been diagnosed. They may feel frustrated and helpless as they see their friend or loved one deal with different symptoms, relapses and progression.

Guilt may also be felt by family members. They may not feel they are caring enough, or that they don’t have enough patience or compassion towards the person living with MS. They may feel 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 (14).

**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.
For people living with MS, change can have a far greater impact from one day to the next. People may experience emotional, physical or cognitive changes. 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 or 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

**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

Whilst 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 talk about any changes, help process them, and explore thoughts and feelings in a supportive, professional and non-judgemental space (15).

**Self help**

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.

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.

Often people will feel flattered as it is a sign you trust them enough to talk about your feelings. They may even have noticed something and feel relieved you are able to speak to them.

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. By joining a local group, visiting a local Therapy Centre or joining an online forum can be really help to meet other people.

Here 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. By practising a breathing technique a few times a 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 (16).

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 of any immediate concerns.

A friend who I met at a newly diagnosed talk is a great support. Although others try, it really helps when someone really understands
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 have eight tips on food and mood (17). They are

- **Eating regularly** – it is important to eat regular meals to 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. It is recommended to drink 6-8 glasses of liquid a day

- **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

- **Getting enough protein** – protein contains amino acids which make up the chemicals your brain needs to regulate thoughts and feelings

- **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 impact sleep

- **Eating the right fats** – fatty acids (such as Omega 3 and 6) are required to keep the brain working well. It is important to eat the right fats. Things like ‘trans-fats’ and ‘partially hydrogenated oils’ can be tempting when you feel low (found in things like shop-bought cakes and biscuits) but these kind of fats are not good for your mood
• Managing medication – some foods can have a real impact on certain medications. Always check with your health professionals if any foods should be avoided

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 (18).

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. It 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; there is no one that is better than another. It has to be something you enjoy and will want to continue with.

Contact your local MS Therapy Centre to see what exercise equipment and classes they have. If you do not have a therapy centre nearby, contact the MS-UK Helpline and they will look to see what else is in your area.

Gratitude

Gratitude is, quite simply, the human way of acknowledging the good things in life. It is a positive emotional response. Research suggests that by practising gratitude, you can receive psychological,
physical and social benefits. 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 are amongst the other benefits (19).

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 (19).

**Suggested ways to practise gratitude are**

- **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.

**Grounding**
This technique can help to reduce anxiety and help to shift attention
away from frustrations, bringing the mind to the present moment by focusing the senses and saying/thinking to yourself

• 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

Grounding can help take focus away from the anxiety felt about an uncertain future.

**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 (20).

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.

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"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."
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 body to be able to slip into states of relaxation more easily (20).

Mindfulness is also recommended by NICE as a preventative practice for people with experience of recurrent depression (21).

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 look into it for you.

"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. Both can provide a sense of peace, purpose and forgiveness.

Both religion and spirituality give a person 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 (22).

**Apps to support mental health**

Mobile phone or tablet apps can be really useful in supporting a healthy mind. They can be used alongside therapy and are seen as a step in the right direction of finding ways to support your mental health.
For those who may not feel ready to engage with professional help such as counselling, apps can be really useful (23).

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:

- **Aura** – Gives the option to subscribe, unlocking a wealth of personalised mindfulness exercises, from improving mood to lessening anxiety.

- **Breathe2Relax** – A useful app that teaches ‘diaphragmatic breathing’.

- **Calm** – Paid and unpaid access to mindfulness exercises for all levels of ability.

- **Chill Panda** – A free app that focuses on a game in which you navigate a panda around a virtual world, encouraging you to do breathing exercises and yoga stretching.

- **Elefriends** – A free app from Mind, the mental health charity.

- **Headspace** – A very popular app for mindfulness. You get ten free sessions or a one-year membership fee for access to the full practice.

- **Insight Timer** – A meditation app offering a free basic version and a paid version providing access to in-depth courses and additional services.
• MyPossibleSelf – A free in-depth eight-week cognitive behavioural therapy based course

• Smiling Mind – Track your mood for free and access targeted mindfulness practices

• What’s Up? – A free app with useful tools to enable you to manage anxiety and calm an anxious mind and body. Objective help and advice for anger, depression, self-esteem and stress

Professional help

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

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

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.

Visit www.ms-uk.org to find out more
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 can refer on when appropriate.

**Counselling**

Counselling is a talking therapy and can help you to be open and honest about how you feel and how MS affects you. It gives you the opportunity to talk and reflect in a confidential and supportive space with a qualified counsellor. Counsellors should be registered and accredited with a governing body such as the BACP.

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

Counsellors do not offer advice and will not tell you what to do but can help you to talk about your experiences to make it easier to find a way forward. MS is an unpredictable condition and learning to live
with this uncertainty can be challenging. Counsellors can help you to explore how MS may be affecting your wellbeing and how you are adapting emotionally. Relationship and family therapy can also be helpful. It can help to encourage your family to be open, too.

The MS-UK Counselling service is available to people with a diagnosis of MS. You can register online or a health professional can refer you. Your mental health and emotional wellbeing are linked to your experience of MS so our counsellors have had training about living with MS.

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 has 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

If more local face-to-face counselling is required, check if your local MS Therapy Centre or local MS Society group offers it. Otherwise you can search for a therapist through the BACP website, or online counselling directories.

**Cognitive Behavioural Therapy (CBT)**

CBT is a talking therapy which focuses on how your thoughts, beliefs and attitudes can affect your feelings and behaviours. CBT teaches coping skills for dealing with different problems (24).
CBT combines cognitive therapy (examining the things you think) and behaviour therapy (examining the things you do). It 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 about them. 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.

CBT can help to challenge these 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 to find ways to cope with physical health problems, such as fatigue and pain (24).

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 for depression and anxiety (21). Tools and techniques learnt can often be applied to other problems in the future.

Referrals for CBT can be made by your GP, or you can look for a private counsellor who offers this particular type of therapy through the BACP website or counselling directory. Self-help books or online courses can be accessed and useful whilst you are waiting for treatment.
Acceptance and commitment therapy (ACT)

ACT aims to help people be able to explain their negative thoughts and feelings and be able to manage them better. It works towards living an active, valued life and increasing acceptance. Studies have shown that ACT reduces psychological distress in patients with MS (25).

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 (26). 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

I got some help from a neuropsychologist who applied the principles of A.C.T. which worked well. I still get down sometimes but I now have a platform to get back up again.
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 (27).

**Improving Access to Psychological Therapies (IAPT)**

IAPT is an NHS programme developed in 2008. Its purpose is for the treatment of adult anxiety disorders and depression in England. It has helped people to overcome their depression and anxiety and therefore manage their mental health more effectively.

IAPT services can be accessed by self-referral, as well as via your health professionals. Services are not available in all areas but you can search your postcode or town via the NHS website. Please see link below.

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**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 (28).

**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 and in doing so you will be able to help the person with MS also come to terms with their MS.
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!

• Keep going. The longer you try the easier it is

• 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 MSer 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
Further information

MS-UK Counselling
www.ms-uk.org/counselling

British Association for Counselling and Psychotherapy (BACP)
www.bacp.co.uk/search/Therapists

Counselling Directory
www.counselling-directory.org.uk

Psychological therapies (IAPT)
www.nhs.uk/service-search/other-services/Psychological%20therapies%20(IAPT)/LocationSearch/10008

MS National Therapy Centres
www.msntc.org.uk

MS Society local group search
www.mssociety.org.uk/care-and-support/local-support
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.

MS-UK Counselling

MS-UK Counselling is open to anyone living with MS and is the only service of its kind available in the UK. Whether you want support coming to terms with a diagnosis or to improve your mental wellbeing, our counselling service is focused on helping you.

All of our MS-UK counsellors are BACP registered or accredited with an in depth knowledge of MS.
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 www.ms-uk.org/peer-support-service or email peersupport@ms-uk.org.
MS-UK Online

MS-UK’s online service is here to offer a range of activities to stay active and connected for those affected by MS and manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops.

MS-UK E-learning

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 e-learning course that can help you do this. Visit www.ms-uk.org/ms-awareness-e-learning to find out more.
Sources


4) Mind. Anxiety and panic attacks. Published 2017. Accessed April 2020 www.mind.org.uk/information-support/types-of-mental-health-problems/anxiety-and-panic-attacks/aboutanxiety/?gclid=EAIaIQobChMIlsfGNx5Hg6AIVKQBQ Bh2V6Qy_EAAAYAiAAEgIc3_D_BwE


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