

# Choices

## Newly diagnosed with multiple sclerosis



Multiple sclerosis information

# Welcome to this Choices booklet about your recent MS diagnosis...

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 our Choices booklets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

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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## Newly diagnosed with multiple sclerosis

You may be reading this booklet because you have recently been diagnosed with multiple sclerosis (MS). While it is perfectly natural to be feeling overwhelmed by your diagnosis, you may even feel a sense of relief that you now have answers about the causes of the symptoms you have been affected by.

At this time you may be experiencing a whole range of thoughts and feelings and are wondering what to do now and where to go from here. We hope this booklet will answer some of your initial questions or at the very least offer signposting to where you can find them.




**Diagnosis has been a blessing in disguise as it has encouraged me to get my life in perspective**




A diagnosis of MS can often make you think quite differently about your life. It is normal to worry about what is going to happen, if a little twinge is another sign or symptom, how the condition might progress and how it might affect your future. You may also be concerned about the effect MS will have on your family, friends, employment or hobbies.

It is important to know there is no right or wrong way to react to a diagnosis. How MS affects you will be unique to you. Do not be afraid to openly discuss your emotions with family, friends, healthcare professionals or charities like us.

Adjusting to a life with MS can take time. It is a normal reaction at various points to fear the worst and 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.



**I felt relieved by my diagnosis, as I had been told by many GPs that my symptoms were psychosomatic or that I was being a hypochondriac**



Accepting your new normal can enable a more positive approach to life and allow you to reach a point where you are empowered to do so. This will not happen overnight. Don't ever feel there is a time limit, as it will differ for everybody. Just remember to be kind to yourself and give yourself the time you need.

At MS-UK we have a great deal of experience and understanding of MS. We know that receiving a diagnosis of MS may be difficult to come to terms with, and that as individuals the way we reach this point will differ for each of us. Managing uncertainty can be made easier by knowing where to go for help and by having

someone to talk to. This booklet will provide you with a basic understanding of MS, and the next steps you may wish to take so you can choose the right pathway for you.



**It can be a shock to be given the news that you have MS. There is no right or wrong way to react to the news. It is very much a personal thing and everyone deals with it differently**




Please note that although this booklet covers a lot of different subjects relating to your MS diagnosis, not everything mentioned will happen to you all at once, immediately, or even at all. It is a guide to some of the possible things you may need to think about and discuss.

We are here to support you whenever you need us, in a way that is right for you.


## What is happening to me?

A diagnosis of MS can feel overwhelming, not least given that it may feel we have an abundance of information to try to take in and digest. Internet searches can provide pages upon pages of information that may or may not mean anything to you, some helpful, some not. In

this booklet we have tried to keep things simple and to the point - brief explanations rather than long sections that may be difficult to understand, with signposting to further reading. You can then choose what you want to research further.



**The initial diagnosis was hard and it takes a long time to come to terms with it. Two years later it's still on my mind but not all the time. You can come to accept it**



## **What is MS?**

MS is a disease of the central nervous system (your brain and spinal cord). The central nervous system cells are covered in a protective layer of fatty protein called the myelin sheath (a bit like the insulation on an electrical cable). MS is an auto-immune disease, where the immune system gets confused and instead of attacking an infection or virus, it turns on itself and attacks this protective sheath. This process is called demyelination. The demyelination disrupts the 'messages' being transmitted from and to the brain, causing them to slow down, become distorted or not get through at all.

It is important to know that MS is not directly inherited. There does appear to be genetic components (as well as environmental factors) to MS but this does not mean you will pass the condition on.

# Types of MS

Although MS affects individuals very differently, there are three broad groups into which it is categorised.

## Relapsing remitting MS

The majority of people with MS are diagnosed with relapsing remitting MS (RRMS). People with RRMS experience relapses periodically – often months or years apart. When a relapse resolves, the person moves into remission, hence ‘relapsing remitting’ (1).

There are sub-categories of RRMS used by neurologists, these include the following

### Benign MS

A person will initially be diagnosed with RRMS and it is only after several years of living with a mild form of RRMS that a neurologist may suggest that their MS is benign. Studies show that people with benign MS (BMS) will have little or no disability, equal to two or three on the Expanded Disability Status Scale (EDSS), at 10 years after onset (3).

### Rapidly evolving severe relapsing remitting MS (RES-RRMS)

Also called highly active or severe RRMS, RES-RRMS is categorised as having two disabling relapses in one year, as well as new MS activity in the brain showing up as lesions on an MRI (4).

## Secondary progressive MS

People who are initially diagnosed with relapsing remitting MS may then, in the future, transition to secondary progressive MS (SPMS). Secondary progressive MS is characterised by fewer or no relapses and a gradual worsening of symptoms. Some people with SPMS may



still experience relapses, but remission following a relapse is less complete, or there is less time between relapses (2).

## Primary progressive MS

Around 10 to 15 per cent of people are diagnosed with primary progressive MS (PPMS) (5). Some people with PPMS have a slow progression of neurological symptoms, whereas others find they progress more quickly. It can often take a long time for a neurologist to arrive at a definitive diagnosis of PPMS as changes can be subtle over an extended period. MRI scans can prove inconclusive (2).

Most people with PPMS will not have relapses, but a few do, approximately five per cent (6). If relapses are part of your PPMS, this is called progressive relapsing MS (PRMS).

## Other

### Clinically Isolated Syndrome

Clinically Isolated Syndrome (CIS) is used to describe the first neurologic episode that lasts at least 24 hours and is caused by inflammation or demyelination in one or more sites in the central nervous system. CIS is often diagnosed before a formal diagnosis of MS can be made (7).

### More Information

Our 'Types of MS' Choices booklet provides further reading on the different types of MS including links to recognised sources.  
[www.ms-uk.org/choices-types-ms-content](http://www.ms-uk.org/choices-types-ms-content)

## Symptoms

MS-UK has found that people cope best when they look at what is happening, rather than what might be. MS can cause many symptoms, and the most common are included here. This list is not exhaustive,

and it is extremely unlikely that any one person would experience all or even most of these symptoms. Additionally, the combination, severity and frequency will be different for everyone.

Symptoms can come and go - some are much more responsive to treatment whereas others can be more difficult to manage and may persist. Outside influences can exacerbate symptoms. For example, hot weather can make fatigue worse, an infection can cause a temporary worsening of existing symptoms or give rise to a symptom previously not experienced.

New symptoms may not always be down to your MS. It is important to remember that not every ache or pain is connected to MS and, if a new symptom persists, you should seek medical advice.

### **Some of the more common symptoms include**

- Issues with vision
- Problems with balance
- Cognition difficulties
- Fatigue
- Sensory problems
- Spasticity (muscle stiffness)
- Changes to mood and mental health
- Mobility issues
- Issues with bladder and bowel function

If you are experiencing any of these symptoms and they are causing you problems, get in touch with your GP or MS nurse or ask to be referred to the appropriate specialist. Most symptoms can be treated - so don't be afraid to ask for help.

We have a downloadable 'Symptom diary' on our website to help

you keep track of any new symptoms and how they are affecting you. This may help you to explain them in detail to your medical professionals, reflecting any patterns that may be emerging.

You will also find a useful symptom diary template towards the end of this booklet.

## More Information

Our 'MS Symptoms' Choices booklet offers more information on the common symptoms associated with MS.

[www.ms-uk.org/choices-ms-symptoms](http://www.ms-uk.org/choices-ms-symptoms)

We provide a downloadable template and guide to using a symptom diary on our website.

[www.ms-uk.org/symptoms-diary](http://www.ms-uk.org/symptoms-diary)

## Understanding relapses

Sometimes a temporary onset, or worsening of symptoms, is actually a relapse, however, it can often be difficult to determine if you are having one. Therefore, it is important to let your GP and MS nurse know if you think you are experiencing a change in symptoms so they can determine if it is a clinical relapse and if treatment is required. Relapses can often be treated, most commonly, with a course of steroids (1).

According to the **National Institute for Health and Care Excellence (NICE)** guidelines a relapse can be diagnosed if,

'The person with MS has developed new symptoms or has a worsening of existing symptoms, and these symptoms have lasted for more than 24 hours in the absence of infection or any other cause after a stable period of a least one month.'

We have created a document you can use called ‘Am I having a relapse?’ which provides a list of questions to ask yourself. These questions may help you to determine whether what you are experiencing is a clinical relapse or not. It is important to rule out other possibilities first, such as an underlying infection which can exacerbate certain symptoms greatly.

This document can be downloaded from our website and a template can also be found towards the end of this booklet.

### **More information**

MS-UK, Am I having a relapse?

[www.ms-uk.org/wp-content/uploads/2022/09/Am-I-having-a-relapse%E2%80%A5.pdf](http://www.ms-uk.org/wp-content/uploads/2022/09/Am-I-having-a-relapse%E2%80%A5.pdf)

## **My healthcare team**

Depending on the resources available in your area, your MS team may include (1)

- Neurologist
- MS nurse
- Speech and language therapist
- Counsellor or neuropsychologist
- Your GP
- A neuro physiotherapist
- Occupational therapist

As well as general neurologists there are also ‘specialist’ neurologists. These are consultants who have a specialist interest in MS and you might want to ask to be referred to one of these if available in your

**The help of my MS nurse was invaluable as I tried to come to terms with the diagnosis**

area. It is important to remember that you have a choice over where you are treated. If there are no specialist neurologists local to you, then you can ask to be referred to one wherever you are willing to travel in the UK.

You should see your healthcare team at regular intervals throughout the year, following your new diagnosis. Appointments should look similar to this <sup>(1)</sup>

6 weeks after  
diagnosis



Face-to-face follow-up appointment with a healthcare professional with expertise in MS – your neurologist or MS nurse.

New symptom/  
possible relapse



Contact your MS nurse to discuss if new symptoms could be a relapse or not and if treatment is an option. If a relapse is confirmed, treatment will be suggested as soon as possible, usually 14 days from the outset of symptoms. Contacting your MS nurse via email may be the best way of keeping in touch.

Annual  
appointment



Review at least once per year with  
your neurologist.

When you need  
information,  
support, or  
someone to talk to



Contact the MS-UK Helpline  
whenever you need to talk through  
anything related to your diagnosis.



**I feel very supported. I see the MS specialist once a year. I see the MS nurse approximately six months later and I also have a medicine nurse who calls every six months in between times**



If you are having ongoing issues with symptoms, you may also be referred to specialist services when you need them for help with symptoms like fatigue, pain and continence.


## How to get the most out of appointments

Keeping a symptom diary can be useful to help you prepare for medical appointments and can also act as a point of reference for you during them. In addition to a symptom diary, keep a note of any


particular questions you need an answer to, prior to an appointment. Some examples of the kind of questions you might need an answer to are listed below.

## Questions for your MS health professional

- What can I do to help lessen my symptoms?
- What treatments are available?
- Are there any lifestyle changes I can make, such as changing my diet, which might help?
- What should I do if I have another relapse?
- How often do I need to see my neurologist/MS nurse?
- Will I require any further tests?
- I have other health conditions (if applicable). How can I best manage these conditions together?
- Are there any brochures or other printed material that I can take away with me? What websites do you recommend?



**Log everything in a diary and take this to every appointment. Be very proactive, read before you go into each appointment. Don't be afraid to ask questions. Keep calm**



- Are there any support groups or help for people with MS in my area?
- Am I eligible for any trials/research?

If your neurologist has mentioned any medications, you may wish to ask other more specific questions about these.

## Treatment - medication

While there is currently no cure for MS, there are a range of treatments available that may help you manage your condition as well as your symptoms. It is important to know that there is a difference between the disease modifying therapies (DMTs) used to treat MS itself, and the medications that may be used to help treat an MS relapse or your MS symptoms.

### Disease modifying therapies

DMTs are medications which modify the course of MS. They target inflammation and are designed to reduce the amount and severity of relapses. Different DMTs affect the number and severity of relapses to varying degrees. Some of these drugs have also been found to delay the long-term progression of MS and reduce the number of new lesions forming.

There are currently a number of DMTs available, each have different eligibility criteria and potential side effects. All people with active RRMS should be considered for DMTs by their neurologist. The Association of British Neurologists (ABN) states that treatment should start as early as possible in eligible patients (2).

In 2019, Ocrevus (ocrelizumab) became the first disease modifying therapy licenced for early-stage inflammatory PPMS. There are



several more therapies in trial at the time of print.

In 2020 Mayzent (Siponimod) was licenced for use in the UK as a form of treatment for those with SPMS who displayed evidence of disease activity, such as relapses or in-flammation shown on an MRI (magnetic resonance imaging) scan.

## List of disease modifying therapies

### Moderately effective

- Aubagio (teriflunomide)
- Avonex (beta interferon 1a)
- Brabio (glatiramer acetate)
- Copaxone (glatiramer acetate)
- Extavia (beta interferon 1b)<sup>2</sup>
- Plegridy (beta interferon 1a)
- Rebif (beta interferon 1a)

### Highly effective

- Kesimpta (ofatumumab)
- Lemtrada (alemtuzumab)
- Ocrevus (ocrelizumab)<sup>1</sup>
- Tysabri (natalizumab)

### More effective

- Gilenya (fingolimod)
- Mavenclad (cladribine)
- Ponvory (ponesimod)
- Tecfidera (dimethyl fumarate)
- Vumerity (diroximel fumarate)
- Zeposia (ozanimod)

### SPMS only

- Mayzent (Siponimod)

<sup>1</sup> Can be used to treat PPMS

<sup>2</sup> Can be used to treat SPMS


## More Information

Our Choices booklet 'Disease modifying therapies' provides further reading about the different DMT's that are used to treat MS.


<https://ms-uk.org/choices-disease-modifying-therapies-content/>

## Making informed choices

An MS specialist neurologist should assess your eligibility and suitability for DMTs and should explain the options available to you. You may well have choices over which (if any) you wish to take.



**When it comes to information on the condition it is important that you make sure you use a reliable source and the main MS charity groups that you can find around the world are the best source of information**



There are several websites and places to go for information that will help you evaluate the risks and benefits of each DMT. For example, the MS Trust website has a tool called 'MS Decisions' with an interactive section that can help you compare the different drugs, including how each drug is administered and potential side effects (8).

Equally as important is to be aware that if you start a DMT and it does not agree with you or you are not happy, you are likely to have further options and be able to change to an alternate therapy if you wish. You are in control of this process.

Furthermore, the medical science world is ever-evolving and we would suggest keeping up to date with the latest news and research outcomes so that you can keep abreast of new developments. Make sure that you access your news from trusted

sources. A good place to start would be the MS-UK website where we share latest news and developments.

## What if I choose not to use DMTs?

You may be eligible for DMTs and your healthcare team may advise you to start taking one, however, it is your choice whether you wish to take them or not. If you choose not to have medication, it may be useful to keep a symptom diary in case you change your mind in the future.



**Keep up to date with research so that you can discuss its relevance to yourself**



## Treating relapses

When a relapse is confirmed, it can usually be treated with a short course of steroids, in the form of high-dose corticosteroids. According to NICE guidelines where appropriate, they should be offered to the patient as early as possible and within 14 days of the onset of symptoms (9).

## Symptomatic treatments

While there is a commonality in the types of symptoms that affect people with MS, the impact they have on individuals can vary. Indeed, not everyone with MS will experience all of the associated symptoms and for people with relapsing MS, many of these symptoms will improve during periods of remission.

For the most common symptoms, there are medicinal treatments available, however, the specific medications differ depending on the symptom being treated. A good place to start when looking to find out more about symptom-specific medications would be our Choices booklet titled 'MS Symptoms'. We have also produced booklets that cover common MS symptoms in more detail.

### **More information**

You can view our range of Choices booklets that focus on individual symptoms on our website.

[www.ms-uk.org/mssymptoms](http://www.ms-uk.org/mssymptoms)

## **Treatment – complementary and lifestyle**

So far, we have looked at the ways in which medication can help you to manage the impact of MS. However, there are other, non-medicinal ways which can be effective in helping you to stay healthy and enable

**There is a lot you can do to dramatically improve your outcomes - diet, vitamin D, exercise, stress reduction and medication. Medication is by no means the only option. You can take action and take control**

you to be more equipped to manage MS, including symptom-focused options. These can be used in isolation or in tandem with medication alongside complementary therapies and lifestyle changes, allowing you to formulate a more holistic approach.

Below is a summary of the different therapies and lifestyle changes that you may wish to consider implementing into your regular health regime.

## Complementary therapies

Many people with MS use complementary therapies for a number of reasons, including aiding relaxation and managing the impact of certain symptoms, such as spasticity, pain and fatigue. These can be particularly valuable when there may not be any suitable drugs available. These therapies can be used in addition to or as a complement to drug treatments, including DMTs. This is entirely a personal choice for you as an individual.



**Try different therapies to find out what one that works best for you, although give them a chance as not every therapy will feel like it's helping after only one session**



Many people who use complementary therapies report that they find them beneficial. If you are considering trying a complementary therapy, it is important to find a reputable therapist who is fully

insured and a member of a professional body. You can also contact the complementary therapy's professional body to find a therapist near you.

There are a number of therapy centres scattered around the UK which offer access to a range of therapies to people affected by MS, including complementary therapies.

### **Some of the complementary therapies offered in these centres are**

- Acupuncture
- Aromatherapy
- Indian head massage
- Massage
- Reiki
- Reflexology
- Shiatsu

Contact your local therapy centre to find out the types of therapies they offer. To source your local centre, you can use the search facility on the Neuro Therapy Network (NTN) website or by simply typing associated words such as 'MS Therapy Centre' into an internet search facility. Note that there are a few centres which do not appear on the NTN database that can be found by searching the internet.

### **More information**

Our 'Complementary and other therapies' Choices booklet provides more information on how they may be beneficial to people affected by MS, along with relevant signposting.

[www.ms-uk.org/choices-complementary-and-other-therapies-content](http://www.ms-uk.org/choices-complementary-and-other-therapies-content)

NTN website

[www.neurotherapynetwork.org.uk](http://www.neurotherapynetwork.org.uk)

## Diet

It is generally agreed that a well-balanced, healthy diet is important for everybody to maintain optimum health. This is particularly relevant for people affected by MS with many studies showing convincing evidence of the relationship between the intake of inflammatory foods (high saturated fats, red meat, processed foods) and disease progression (10).

Over the past two decades many diets have been created with managing the impact of MS in mind. There are similar themes that connect these diets, mostly involving taking supplements and restricting or eliminating various food groups such as dairy, red meat and saturated fats.



**A lot of people dismiss the power of diet. The advice I would give to others with MS is to try a diet and see if it helps them. I would also recommend that you give the diet adequate time, don't quit too early and listen to your body**



There is also increasing evidence from studies that have shown links between the health of our guts to the onset and progression of autoimmune diseases such as MS. Therefore eating foods that bolster the balance of good and bad bacteria that live in the gut

should be a consideration for people with MS (11).

## **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](http://www.ms-uk.org/choices-diet-and-supplements-content)

## **Supplements**

Many people diagnosed with MS also take various supplements with a view to managing the impact of the condition. This may be in addition to or as part of their diet. As listed in our Choices diet and supplements booklet, below are some of the main dietary supplements and vitamins that people with MS may choose to take.

- Lipoic acid
- Vitamin B12
- Omega-3
- Evening primrose oil
- Nicotinamide adenine dinucleotide (NAD+)
- Coenzyme Q10

## **Vitamin D**

Due to lack of sunshine many people may be vitamin D deficient. Research suggests that vitamin D affects the risk of developing MS and can also modify disease activity in some patients (12).

Many people with MS take a vitamin D supplement. Dr George Jelenik's Overcoming Multiple Sclerosis (OMS) programme recommends a daily dosage of vitamin D3 of 5000 - 10000IU to be taken all year round (13).




You can ask your GP or neurologist to check your vitamin D levels.

## More information


Our 'Vitamin D' Choices booklet provides more details about Vitamin D and its link to MS. [www.ms-uk.org/choices-vitamin-d-content](http://www.ms-uk.org/choices-vitamin-d-content)

## Exercise

Regular exercise is important in maintaining optimum health for everyone. Exercise can improve cardiovascular fitness, muscle strength and, particularly for people with MS, mobility, balance and coordination. It can improve mood, increase energy levels and help with weight management. It can also be a great way to meet people and socialise.



**Staying active and pushing myself helps me feel in control of my illness. Managing my day-to-day activities in accordance to how I feel that day is important. MS won't stop me being me**



If you have always been a person who exercises, just because you have been diagnosed with MS doesn't mean you have to stop. If sometimes the effort seems a bit too much, try reducing your sessions back a little and then increasing the time when you feel able to.

For people with MS, finding the right exercise is important. There is no one type of exercise recommended – it is entirely down to what you enjoy and what you are able to do as an individual.

The following are good examples of relatively accessible, low-impact forms of exercise

- Walking
- Swimming
- Yoga
- Tai chi
- Pilates

Many places, such as therapy centres, offer a range of exercise options to suit most levels of mobility.

Exercising to address certain MS symptoms is commonplace. For example, fatigue is a common symptom of MS, and while it might sound counterintuitive, moderate exercise can help you to manage its impact (14). The caveat is that you should try not to exercise through fatigue or to try to battle on when it would be better to rest, but in the longer term, adding some exercise into your daily life can be beneficial.

Another thing to be mindful of when exercising is overheating. Many people with MS are affected by heat and overheating can exacerbate symptoms.



**I got myself fitter than I've ever  
been which I know wouldn't have  
happened if I hadn't been diagnosed**

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, dance-oriented exercise 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](http://www.ms-uk.org/choices-exercise-content)

MS-UK online activities.

[www.ms-uk.org/ms-uk-online](http://www.ms-uk.org/ms-uk-online)

### **Smoking and MS**

It is common knowledge that smoking is bad for your health. For people with MS there are even more compelling reasons to quit as there is evidence that smoking contributes both to MS onset and disability progression (15).

### **More information**

Our Choices booklet titled 'Smoking and MS' provides more information about this link and how to find support to kick the habit.

[www.ms-uk.org/choices-smoking-and-ms-content](http://www.ms-uk.org/choices-smoking-and-ms-content)

## **Emotional wellbeing**

Getting support for your emotional wellbeing is something that can quite easily be overlooked, especially given the fast pace of modern life, which can leave you with little time and space to get

the help that you may need. It is important to be aware of the ways in which you can access this type of support, especially in the early post-diagnosis days. This could be in the form of connecting with others who are affected by MS, talking to family and friends, or seeking professional support, such as through counselling or emotional support offered by the MS-UK Helpline.

Furthermore, becoming more aware of the present moment can help you to enjoy the world around you and become more self-aware. When you become more aware of the present moment, you begin to experience afresh things that you may have previously been taking for granted.

It is important to remember that a healthy mind can help maintain a healthy body.



**While you'll never find someone whose disease is the exact same as yours, it's important to talk with others with similar experiences**



Below is a summary of just a few ways in which you can access the type of support that you may find beneficial for your emotional wellbeing.

## **Counselling and talking therapies**

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 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.




**The mental struggle can be harder than the physical and counselling was so important for me in accepting the diagnosis**




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

We mentioned the network of therapy centres available in the UK earlier in this booklet. Some of these centres offer a counselling service. As the therapy centres are charitable organisations their fees are likely to be discounted.

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 will have ups and downs but allow yourself time to grieve if you need it. Be kind to yourself, and instead of constantly thinking of others, take some time for yourself**



MS-UK hold a directory of fully qualified, registered counsellors who have all undertaken our '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 request from the MS-UK Helpline.

## **Mindfulness**

Mindfulness exercises are a form of meditation which help you to pay attention to the present moment, using techniques such as breathing and yoga. It can help people to become more aware of their thoughts, feelings, and body sensations so instead of being overwhelmed by them, they are better able to manage them. Practising mindfulness can give more insight into emotions, boost

attention and concentration, and improve the symptoms of pain and fatigue (1).

### **More information**

We host regular Mindfulness courses as part of our online activities. To find out more go to our website.  
[www.ms-uk.org/mindfulness-courses](http://www.ms-uk.org/mindfulness-courses)




**I decided to live life to the full and be thankful for each day, I try to concentrate on what I can do and not let myself get down about what I can't do**




### **Talking to family and friends**

Your MS diagnosis is likely to impact on you and those around you, if not immediately then possibly at some point in the future. Finding a way of discussing it with your immediate family will likely be of benefit in the long term for you all.



**I tried to keep it quiet and now I know that it is important to let people know**



Your family and friends may want to ask you questions, or may wish to conduct their own research about MS. The MS-UK website is a good place for them find out more, with our Choices booklets offering reliable information about MS. At the end of this booklet in the section titled 'Useful organisations' we signpost to other UK-based MS charities which also offer trusted information about all things MS-related.

## Connecting with the MS community

Some people find that speaking with others who are affected by MS, who are on similar emotional journeys, can be therapeutic and a great means of support. There are many ways in which you can connect with other people who are affected by MS, ranging from local and national support groups to online forums and peer groups. Your MS nurse may be aware of any local groups you can attend, and the MS-UK Helpline can find these and other methods of support that may interest you.



**I found great support in the MS-UK peer pods**

At MS-UK we offer a wide range of activities that are designed to support emotional wellbeing, including mindfulness courses and our 'Peer Support Service', which has volunteer-led peer pods exclusively created to connect people and includes a peer pod for those who have been recently diagnosed with MS.

Additionally, we have published information on our website that offers guidance to help you find support in your community and



further afield, plus a summary of the many different online forums that are dedicated to people with MS.

### **More information**

MS-UK Peer Support service. [www.ms-uk.org/peer-support-service](http://www.ms-uk.org/peer-support-service)

Finding support in your community.

[www.ms-uk.org/finding-support-in-your-community](http://www.ms-uk.org/finding-support-in-your-community)

Forums and online support. [www.ms-uk.org/online-forums-for-MS](http://www.ms-uk.org/online-forums-for-MS)

### **The MS-UK Helpline**

If you need to speak with someone, we have a trained helpline team that can offer emotional support and give more information and sign posting on anything related to MS. Contact our team by telephone on 0800 783 0518, by live web chat at [www.ms-uk.org](http://www.ms-uk.org) or by email at [info@ms-uk.org](mailto:info@ms-uk.org).

**No matter how big or small your question may seem, we're here if you need us.**

**Knowledge is power. Whatever your diagnosis it's your opportunity to move on and deal positively with your new situation/life. Accept offers of help and investigate all new experiences that could potentially help you**

## Who should I tell?

### DVLA (Driver and Vehicle Licensing Agency)

If you hold a driving licence in the UK you must tell the DVLA (DVA (Driver and Vehicle Agency) in Northern Ireland) once you have a formal diagnosis of MS. This does not mean that your licence will be taken away. The DVLA/DVA are likely to contact your doctor and ask them about your ability to drive or potentially ask you to go for a driving assessment. They may also need to review your licence every three years.

You could be fined up to £1,000 if you don't tell the DVLA/DVA about your diagnosis. You could also be prosecuted if you have an accident (16).

### Insurance

Whatever insurance you may have, it is recommended to inform the companies that insure you about your recent MS diagnosis. For example, if you drive, you should inform your motor insurance provider otherwise your cover could be void if you are involved in an accident.

It is especially worth checking your existing policies to determine if you have critical illness cover as MS will often be counted. If you are unsure about whether you should inform an insurer, it is worth contacting them to be on the safe side.



**MS-UK has been, in my experience,  
very helpful with practical assistance**



The website MoneyHelper, powered by the UK government, offers guidance regarding insurance concerns for people affected by disability, including information about your legal rights.

## **Work and employment**

Many people living with MS can and do work. Others may not feel able to. Whatever your circumstances, there is support available to you. If you are in employment, it doesn't necessarily mean that you will need to change your job or stop working just because you have a diagnosis of MS. Only you know what is right for you.

You may wish to think about talking to your employer. In some instances, you may need to inform your employer of your diagnosis, depending on the type of work you do. It is therefore wise to check your contract of employment. In many cases it is likely that you do not have to tell your employer, meaning that doing so is entirely your choice.

It is also important to be aware that Under the Equality Act 2010 and the Disability Discrimination Act 1995 (if you live in Northern Ireland) MS counts as a 'disability' even if you do not feel 'disabled'. It is a protected characteristic. This means that you are protected from harassment, discrimination and that you have some additional rights in employment (17).

Our 'MS and Work' webpages provide information about a wide range of issues that encompass this topic. These include employment law, finding employment, speaking to your employer, reasonable adjustments and much more.

### **More information**

MS-UK - MS and Work  
[www.ms-uk.org/ms-and-work](http://www.ms-uk.org/ms-and-work)

## Benefits

Living with MS can sometimes have an impact on your finances, for a variety of reasons. For example, you may wish to change your job to something more suited to your needs, or reduce your working hours, both of which may mean that you take home less pay. Some people may also need to spend more to accommodate their needs as a person with a disability.

Benefits are available to help you with living costs and can be broadly split into two categories, 'disability related' such as Personal Independence Payment (PIP) and 'earnings replacement', for example, Universal Credit (UC).

For more information on benefits please read our dedicated webpages 'Benefits and MS', where you will find information about all the different benefits that you may be eligible for, signposting to benefits calculators which will provide you with a guide to eligibility, where to access further support and information and much more.

### More information

MS-UK - Benefits and MS

[www.ms-uk.org/benefits-and-ms](http://www.ms-uk.org/benefits-and-ms)

## Further information and support from MS-UK

So far in this booklet we have signposted you to our series of Choices booklets, MS-UK website news in which we cover the


latest developments of all things MS related, our vast range of online activities and our Helpline. However, did you know about the other ways in which we can offer you support?

New Pathways is our bi-monthly magazine, which covers all of the latest MS news, real-life stories, views and special features. You can order a free copy of New Pathways today and see if you like it. Call 01206 226500 or email us at [info@ms-uk.org](mailto:info@ms-uk.org) and we'll send you the latest issue.


[www.ms-uk.org/new-pathways-magazine](http://www.ms-uk.org/new-pathways-magazine)

The MS-UK blog is also a fantastic way to stay connected, with articles that cover a huge range of topics, including the latest medical science, stories from other people affected by MS, ways to combat the impact of MS and much more.

[www.ms-uk.org/blog](http://www.ms-uk.org/blog)



**Try to think it's not the end of the world and there is so much support and amazing new, hopeful medications coming out all the time**



[illegible]

# Symptom Diary

This diary is to help you record information about how you are feeling to share with your doctor. It may be that you have been referred to a neurologist, or you have seen a neurologist and are undergoing diagnostic tests. Symptoms of MS may include fatigue, pain, muscle stiffness or spasms, balance problems, weakness, numbness and tingling or both, bladder and bowel problems, changes to vision, changes to thinking and memory, and coordination issues. These symptoms are not unique to MS. Recording symptoms can be helpful towards a diagnosis and to assist you in understanding what you are experiencing.

## Questions for your doctor

e.g. my legs are feeling very tight and stiff

## Other information

e.g. the stiffness makes it difficult for me to walk

# Symptom diary

| Date       | Describe your symptom.<br>How are you affected? | Is this a new symptom?<br>Have you experienced it<br>before? Is it worse than<br>previously experienced? |
|------------|---|--|
| eg. 01 Jul | eg. tight, stiff legs –<br>difficult to walk    | eg. I have experienced this<br>before but not this tight/stiff   |
|            |   |  |
|            |   |  |
|            |   |  |
|            |   |  |
|            |   |  |
|            |   |  |
|            |   |  |
|            |   |  |
|            |   |  |



| When did it start/stop?          | Is the symptom constant or does it fluctuate? What makes it better or worse? (eg. heat, stress, time of day) | Score how the symptom affects you. One – not at all Five – extreme |
|----------------------------------|--|--|
| eg. a week ago and is continuous | eg. continuous but worse in the morning  | eg. two/three  |
|                                  |  |  |
|                                  |  |  |
|                                  |  |  |
|                                  |  |  |
|                                  |  |  |
|                                  |  |  |
|                                  |  |  |

## Am I having a relapse?

This is to help you record information about how you are feeling to share with your doctor, to help you understand your symptoms and look for patterns. Everyone is different and it can be difficult to recognise a relapse.

Symptoms associated with a relapse may include fatigue, pain, muscle stiffness or spasms, balance problems, weakness, numbness and tingling, or both, bladder and bowel problems, changes to vision, changes to thinking and memory, coordination issues.

You may have new symptoms, or symptoms you have previously experienced may worsen during a relapse. They may appear slowly or suddenly. It is important to inform your doctor about your symptoms, so they can offer advice and treatment if necessary.

Use this form and the symptom diary on the previous page to help you assess whether you may be having a relapse.

### How are you feeling today?

Date .....

|  |  |
|--|--|
| <b>Did you sleep well last night?</b>        | Y / N<br>Hours? .....<br>Interrupted or constant?                |
| <b>Do you / could you have an infection?</b> | Y / N<br>Cough / cold / bladder infection?<br>Other?<br>Not sure |

|   |  |
|---|--|
| <b>If you feel unwell, when did this start?</b>   | Date .....   |
| <b>If you take a disease modifying treatment (DMT), did you take it yesterday?</b>  | Y / N<br>DMT Name  |
| <b>Are you taking any other medication?</b>   | Medication Name .....<br>.....   |
| <b>If applicable</b><br><br><b>Where are you in your menstrual cycle?</b><br><br><b>Have you recently given birth?</b><br><br><b>If yes, are you breastfeeding?</b> | I have my period now<br>I am due my period in a few days<br>I am mid-cycle<br>Not sure<br><br>0-3 months ago<br>3-6 months ago<br>6-12 months ago<br><br>Y / N |

To download the 'Symptom diary' document, please see the following link to our website

[www.ms-uk.org/symptoms-diary/](http://www.ms-uk.org/symptoms-diary/)

## Useful organisations

### MS Trust

The MS Trust is a UK charity who provide trusted information to help people with MS live the best life possible, train and educate MS health professionals to offer the best care and fund MS nurses in areas of greatest need.

Enquiry service 0800 032 3839

Website [www.mstrust.org.uk](http://www.mstrust.org.uk)

### MS Society

The MS Society is the largest MS charity in the UK. They have a number of local groups across the UK. They fund a range of projects to understand MS and help improve diagnosis, treatments and services. They also undertake campaigning and invest heavily in research.

Helpline 0808 800 8000

Website [www.mssociety.org.uk](http://www.mssociety.org.uk)

### Shift.ms

This is a social network for people with MS whose aim is to reduce isolation and pro-mote peer support. The charity is independent and supports thousands of people worldwide who have recently been diagnosed.

Website [www.shift.ms](http://www.shift.ms)

## Overcoming Multiple Sclerosis (OMS)

OMS is a worldwide charity founded by Dr George Jelinek in 1999. It is a whole lifestyle programme aimed at managing MS by way of diet, vitamin D supplementation, exercise and meditation. People who follow the OMS lifestyle can also get support from the OMS charity in the form of their forum, exercise videos and regular podcasts.

Website [www.overcomingms.org](http://www.overcomingms.org)

## Use me for your notes

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# 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 [www.ms-uk.org/peer-support-service](http://www.ms-uk.org/peer-support-service) or email [peersupport@ms-uk.org](mailto:peersupport@ms-uk.org).







## MS-UK's online activities

MS-UK offers a variety of online 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. Visit our website to explore and find out more.

## 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 accredited Learning courses that can help you do this. Visit <https://ms-uk.org/excellence-ms/> to find out more.

# Sources

- 1) National Institute for Health and Care Excellence (NICE). Multiple sclerosis in adults: management. [NG220] Published June 2022. Accessed February 2023.  
[www.nice.org.uk/guidance/ng220/chapter/Recommendations#diagnosing-multiple-sclerosis](http://www.nice.org.uk/guidance/ng220/chapter/Recommendations#diagnosing-multiple-sclerosis)
- 2) Practical Neurology. Volume 15, Issue 4. Association of British Neurologists: revised (2015) guidelines for prescribing disease-modifying treatments in multiple sclerosis. Scolding N, Barnes D, Cader S, et al. Published June 2015. Accessed February 2023. <https://pn.bmj.com/content/15/4/273>
- 3) National Center for Biotechnology Information (NCBI). Definition, prevalence and predictive factors of benign multiple sclerosis. T. Reynders et al. Published June 2017. Accessed February 2023.  
[www.ncbi.nlm.nih.gov/pmc/articles/PMC5721547](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC5721547)
- 4) NHS England. Treatment Algorithm for Multiple Sclerosis Disease Modifying Therapies. Definitions. Updated 8 March 2019. Accessed February 2023.  
[www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2019/03/Treatment-Algorithm-for-Multiple-Sclerosis-Disease-Modifying-Therapies-08-03-2019-1.pdf](http://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2019/03/Treatment-Algorithm-for-Multiple-Sclerosis-Disease-Modifying-Therapies-08-03-2019-1.pdf)
- 5) National MS Society. Types of Multiple Sclerosis. Accessed February 2023.  
[www.nationalmssociety.org/What-is-MS/Types-of-MS](http://www.nationalmssociety.org/What-is-MS/Types-of-MS)

- 6) Meeting the needs of people with primary progressive multiple sclerosis, their families, and the health-care community. Holland NJ, Schneider DM, Rapp R, Kalb RC. Accessed November 2022. Accessed February 2023. [www.ncbi.nlm.nih.gov/pmc/articles/PMC3882958](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3882958)
- 7) WebMD. What is Clinically Isolated Syndrome? Reviewed by C Melinosky, Lat reviewed Nov 2021. Accessed February 2023. [www.webmd.com/multiple-sclerosis/clinically-isolated-syndrome](http://www.webmd.com/multiple-sclerosis/clinically-isolated-syndrome)
- 8) MS Trust. MS Decisions aid. Accessed February 2023. [www.mstrust.org.uk/about-ms/ms-treatments/ms-decisions-aid](http://www.mstrust.org.uk/about-ms/ms-treatments/ms-decisions-aid)
- 9) National Institute for Health and Care Excellence (NICE). Managing a relapse. Last reviewed August 2022. Accessed February 2023. [www.cks.nice.org.uk/topics/multiple-sclerosis/management/managing-a-relapse](http://www.cks.nice.org.uk/topics/multiple-sclerosis/management/managing-a-relapse)
- 10) National Library of Medicine (NIH). Diet Quality Is Associated With Disability and Symptom Severity in Multiple Sclerosis. K Fitzgerald, T Tyry, A Salter et al. Published Dec 2017. Accessed February 2023. [pubmed.ncbi.nlm.nih.gov/29212827](http://pubmed.ncbi.nlm.nih.gov/29212827)
- 11) Medical Sciences, The Gut Microbiome in Multiple Sclerosis: A Potential Therapeutic Avenue, Kirby et al, Published August 2018. Accessed February 2023. [www.ncbi.nlm.nih.gov/pmc/articles/PMC6163724](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC6163724)

- 12) National Center for Biotechnology Information (NCBI). Vitamin D and Multiple Sclerosis: A Comprehensive Review. M Sintzel, M Rametta and A Reder. Published 14 Dec 2017. Accessed February 2023. [www.ncbi.nlm.nih.gov/pmc/articles/PMC5990512](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC5990512)
- 13) Overcoming Multiple Sclerosis. MS & Vitamin D Deficiency. Accessed February 2023. [www.overcomingms.org/recovery-program/sunlight-vitamin-d](http://www.overcomingms.org/recovery-program/sunlight-vitamin-d)
- 14) BMC Neurology. The impact of physical exercise on the fatigue symptoms in patients with multiple sclerosis: a systematic review and meta-analysis. Razazian, N., Kazeminia, M., Moayedi, H. et al. Published 13 March 2020. Accessed February 2023. [www.bmcneurol.biomedcentral.com/articles/10.1186/s12883-020-01654-y](http://www.bmcneurol.biomedcentral.com/articles/10.1186/s12883-020-01654-y)
- 15) National Center for Biotechnology Information (NCBI) Smoking: effects on multiple sclerosis susceptibility and disease progression. D. Wingerchuk. Published 5 January 2012. Accessed February 2023. [www.ncbi.nlm.nih.gov/pmc/articles/PMC3251901](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3251901)
- 16) Gov.uk. Check if a health condition affects your driving. Accessed February 2023. [www.gov.uk/health-conditions-and-driving](http://www.gov.uk/health-conditions-and-driving)
- 17) Citizens advice. Check if you're disabled under the Equality Act. Reviewed January 2019. Accessed February 2023. [www.citizensadvice.org.uk/housing/discrimination-in-housing/checking-if-its-discrimination/check-if-youre-disabled-under-the-equality-act](http://www.citizensadvice.org.uk/housing/discrimination-in-housing/checking-if-its-discrimination/check-if-youre-disabled-under-the-equality-act)

Last reviewed May 2023





# Call the MS-UK Helpline



You're not alone in your journey. the MS-UK Helpline can support you emotionally every step of the way. You can contact us about anything, whether it is about managing your multiple sclerosis symptoms, accessing benefits or simply just to chat.

Laura, Ryan and Shaun are here to take your call

**We're here to help**

Call free on **0800 783 0518**  
weekdays 10am to 4pm

 **MS-UK**  
Supporting your MS journey



# Check out MS-UK's online activities

Live a happier and healthier life with MS



- ✓ Accessible online exercise classes
- ✓ Chair yoga classes
- ✓ Mindfulness courses

- ✓ Interactive workshops
- ✓ Information sessions
- ✓ Peer Support Service

**Don't miss out – sign up for our new online activities today!**

**Visit [www.ms-uk.org](http://www.ms-uk.org) or contact us at [register@ms-uk.org](mailto:register@ms-uk.org)**

 **MS-UK**  
Supporting your MS journey

Registered charity number 1033731

## Stay in touch

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[www.ms-uk.org](http://www.ms-uk.org)

✕ @MSUK6

f [www.facebook.com/MultipleSclerosisUK](https://www.facebook.com/MultipleSclerosisUK)

▶ [www.youtube.com/c/ms-ukorg](https://www.youtube.com/c/ms-ukorg)

in [www.linkedin.com/company/ms-uk](https://www.linkedin.com/company/ms-uk)

📷 [www.instagram.com/multiplesclerosis\\_uk](https://www.instagram.com/multiplesclerosis_uk)

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**Registered Charity Number** 1033731

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