Newly diagnosed with multiple sclerosis

Multiple sclerosis information

www.ms-uk.org
Welcome to this Choices booklet about 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 of our Choices booklets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

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

Every time you find bold text with quotation marks like this, it is a quote directly from someone affected by multiple sclerosis.
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Visit www.ms-uk.org to find out more
You have likely been given this booklet as you have recently been diagnosed with multiple sclerosis (MS). You may well be feeling overwhelmed by your diagnosis, or even feel a sense of relief that you now have some answers. You may be experiencing a whole range of thoughts and feelings and you are wondering what to do now and where to go from here. We hope this booklet will answer some of your initial questions and also provide some first-hand experience from those who have been in your position - people who can truly understand and empathise with how you may be feeling.

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.

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, where there is no single right approach or certain path the condition may take, may be difficult to come to terms with. Managing that 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 and there can be what feels like mountains 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. 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.

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

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

**Types of MS**

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

**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 (1).

**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’ (2).

**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**

Some people are diagnosed with primary progressive MS (PPMS). 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 time. MRI scans can prove inconclusive (2).

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

**There are other sub-categories used by neurologists, these can include**

- Benign MS
- Rapidly Evolving Severe Relapsing Remitting MS (RES-RRMS)

**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. 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**

- Visual symptoms
- Problems with balance
- Cognition difficulties
- Fatigue
- Sensory problems
- Spasticity (muscle stiffness)
- Changes to mood and mental health
- Changes to mobility
- 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 these symptoms to your medical professionals and show any patterns that may be emerging.

You will also find a useful template of the symptom diary on page 32.

**Understanding relapses**

Sometimes a temporary onset, or worsening of symptoms, is actually a relapse.

It can often be difficult to determine if you are having a relapse. 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 therefore if treatment is required.

Relapses can often be treated, most commonly, with a course of steroids (2).

**According to 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?’ It has a list of questions to ask yourself. These questions may help 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 on page 34.

My healthcare team

Depending on the resources available in your area, your MS team may include (2)

• Neurologist
• MS nurse
• Speech and language therapist
• Counsellor or neuropsychologist
• Your GP
• A neurophysiotherapist
• Occupational therapist

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

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 there is one available in your area. It is important to remember that you have choice over where you are treated. If there are no specialist...
neurologists locally to you, you can 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 (2)

6 weeks after diagnosis

Face to face follow up appointment with 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 by a healthcare professional – 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 6 months later and I also have a medicine nurse who calls every 6 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**

On page 32 is the MS-UK Symptom diary. In addition to the symptom diary, keep a note of any particular questions you need an answer to. Some examples of the kind of questions you might need an answer to are listed here.

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.

Visit www.ms-uk.org to find out more.
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?
• 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

Whilst 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.

There are a number of disease modifying therapies (DMTs) used to
Disease modifying therapies

**Category 1 - Moderately effective**

- Aubagio (Teriflunomide)
- Beta Interferon 1a (Avonex, Rebif and Plegridy)
- Beta Interferon 1b (Betaferon and Extavia)
- Gilenya (Fingolimod) - more effective
- Glatiramer acetate (Copaxone and Brabio)
- Mavenclad (Cladribine) – more effective
- Tevfidera (Dimethyl Fumerate) – more effective

**Category 2 - Highly effective**

- Lemtrada (Alemtuzumab)
- Ocrevus (Ocrelizumab)
- Tysabri (Natalizumab)

treat relapsing-remitting MS (RRMS). They are designed to reduce the amount and severity of relapses. In addition, there has more recently been a drug, Ocrevus (ocrelizumab) licenced for primary progressive MS (PPMS) which is great progress. There are several more in trial.

It is important to know that there is a difference between the disease modifying therapies used to help treat MS itself, and the medications that may be used to help treat an MS relapse or your MS symptoms. It is just as important for you to know that if you start a disease modifying therapy and it does not agree with you or you are not happy, you are likely to have further options and the ability to change to an alternate therapy if you wish. You are in control of this process.
It may be an idea to keep up to date with the latest news and research outcomes so that you can be as informed about new developments as possible. MS-UK has a section on our website dedicated to sharing all the latest news. However, be mindful of potential ‘miracle cures’ or ‘break-throughs’ as whilst they often show progress and can give hope, they can also lead to raised expectations.

Disease modifying therapies

Disease modifying therapies (DMTs) are medications which modify the course of MS. DMTs target inflammation and are designed to reduce the damage caused by relapses. Different DMTs affect the number and severity of relapses in 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.

The Association of British Neurologists (ABN) states that treatment should start as early as possible in eligible patients (3).

There are currently a number of DMTs available, each has a different eligibility criteria and the potential side effects for each varies. All people with active relapsing remitting MS should be considered for DMTs by their neurologist. Most are likely to start treatment with a Category 1 drug. It is recommended that patients with more active disease use one of the Category 2 drugs (3).
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.

There are a number of websites and places to go for information that will help you weigh up the risks and benefits. The MS Trust website has a tool called ‘MS Decisions’ with an interactive section that can help compare the different drugs (4).

**Symptom management**

For those with progressive forms of MS, it is important to recognise that most symptoms can be improved. Not everyone with MS will experience all of the symptoms relating to MS and for people with relapsing remitting MS, many of these symptoms will improve during periods of remission. Some symptoms that people with MS experience may be persistent and may need consideration and ‘managing’. Most can be treated and there are ‘tips and tricks’ you may wish to try that others have found useful. It is important to remember that people are all individual and will react differently.

**What if I choose not to have medication?**

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 explore other options. 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.

Visit www.ms-uk.org to find out more.
to keep a symptom diary in case you change your mind in the future.

If you choose to take a different path for managing your MS such as making dietary or lifestyle changes, you may wish to make regular personal assessments of each change and review their benefit over time - how you are feeling in various aspects of your life and how your symptoms feel. There have been limited studies to measure the success of these approaches, as it is very difficult to measure their success, but many people choose this path. It really does depend on what is right for you and ultimately this is your personal choice.

**Complementary therapies**

Many people with MS use complementary therapies to help ease certain symptoms and to aid relaxation, especially when there may not be any drugs available to them. These can be in addition to or complementary to drug treatments including disease modifying therapies. This is a personal choice for you as an individual.

Whatever your outlook, there are complementary therapies available that may help reduce symptoms such as spasticity, pain and fatigue amongst others.

Many people receiving 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 contact the complementary therapy’s professional body to find a therapist near you.

**Some of the complementary therapies offered in MS Therapy Centres include (5)**

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

Lifestyle

Making changes to your lifestyle, including diet and exercise, may have an effect on you and your MS. Here we look at the different areas of your lifestyle that you can consider changing.

It gave me a wake up to make me really appreciate my life & what I can do. I try to take the positive from it, got myself fitter than I’ve ever been which I know wouldn’t have happened if I hadn’t been diagnosed

Diet

It is generally agreed that a well-balanced, healthy diet is important for everybody to maintain optimum health. However, many people with MS may talk about a specific diet they follow, and indeed, over the years many diets have been created with MS in mind. You may notice that similar themes run through these diets, mostly involving

Visit www.ms-uk.org to find out more
taking supplements and restricting or eliminating various food groups such as dairy or red meat (your saturated fat intake).

People diagnosed with MS may have questions about whether changes to their diet and nutrition can assist in symptom management. Many people with MS have found that by changing their diet, they find relief from some of their MS symptoms (6).

**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 (7).

Many people with MS take a vitamin D supplement. Dr George Jelenik’s Overcoming Multiple Sclerosis (OMS) program recommends a daily dosage of vitamin D3 of 5000 - 10000IU to be taken all year round (8).

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

**Supplements**

Like dietary changes, many people diagnosed with MS also take various supplements. This may be an addition or to aid their diet. As listed in our Choices diet and supplements booklet, here 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
**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 is also a great way to meet people and socialise.

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

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

- Walking
- Swimming
- Yoga
- Tai chi
- Pilates

*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*

Visit www.ms-uk.org to find out more
Many places, such as MS Therapy Centres, also offer seated exercise courses.

Fatigue is a common symptom of MS. It might sound counterintuitive, but moderate exercise can improve the symptoms of fatigue (9). It is best 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.

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

**Smoking and MS**

Everyone is aware smoking is bad for your health. For people with MS there are even more compelling reasons to quit as there is evidence smoking contributes both to MS onset and disability progression (10). If you would like to stop smoking, the NHS has numerous ways to help you. Please contact your GP or chemist in the first instance.

**Wellbeing**

Becoming more aware of the present moment can help us enjoy the world around us and understand ourselves better. When we become more aware of the present moment, we begin to experience afresh things that we have been taking for granted.

A healthy mind can help maintain a healthy body.

**Meditation**

This is the process by which a person gradually ‘lets go’ of thoughts and feelings to become more relaxed, focused and creative.
In a meditation class the teacher will encourage a gradual release of all thoughts and feelings. There are a number of different forms of meditation.

**Mindfulness**

Mindfulness exercises are ways of paying attention to the present moment, using techniques like meditation, breathing, and yoga. Training helps people to become more aware of their thoughts, feelings, and body sensations so that 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 (2).

**Talking to family and friends**

People often have preconceptions of MS and if they do know about MS it is often because they know someone else with the condition. It is important to remember that everyone is different. Your MS is likely
to impact on you and also 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.

Your family and friends may want to ask you questions, or may like to do their own research about MS. There is a list of useful organisations at the end of this booklet which you can share with your loved ones so they can search through trusted sources.

**Who should I tell?**

**DVLA**

If you hold a driving licence you must tell the DVLA once you have a formal diagnosis of MS. This does not mean that your licence will be taken away. The DVLA are likely to contact your doctor and ask them about your ability to drive or potentially ask you to go for a driving assessment. It is likely that the DVLA will review your licence every three years.

You could be fined up to £1,000 if you don’t tell the DVLA about your diagnosis. You could also be prosecuted if you have an accident (11).

**Insurance**

You may need to inform companies that insure you. If you drive, you should inform your car insurer otherwise your cover could be void if you are involved in an accident.

It is especially worth checking if you have critical illness cover as MS will often be counted. It is worth checking your policies carefully. If you are unsure about whether you should inform an insurer, it is worth contacting them to be on the safe side.
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 your job will change or stop 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 best to check your contract of employment. In most cases it is likely that you do not have to tell your employer, it is your choice.

Under the Equality Act 2010 and the Disability Discrimination Act (if you live in Northern Ireland) multiple sclerosis 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 (12).

Your employer will have to consider making ‘reasonable adjustments’ to your work or role to support you in your job. You may also be able to gain an ‘Access to Work’ grant. This grant can pay for aids, adaptations and other kinds of practical support if you have a disability. The grant and how much you will get depends on your individual circumstances (13).

If you are off work due to a relapse for example, Statutory Sick Pay (SSP) will be paid by your employer if you are unable to work. SSP can be paid for up to 28 weeks. You cannot get less than the statutory amount but if your employer has a sick pay scheme you may be paid more. It is best to check your contract of employment.

Once SSP or your sick pay scheme comes to an end you may be able to claim a benefit called Employment and Support Allowance (ESA).
The benefit system is there to help anyone who finds themselves in financial difficulty if for some reason they are unable to work either temporarily or on a long-term basis.

The main disability and sickness benefits are

- Personal Independence Payment (PIP)
- Employment Support Allowance (ESA)

**Personal Independence Payment (PIP)**

PIP was introduced in 2013 to replace Disability Living Allowance (DLA) for adults aged 16 to 64 years of age. PIP is a benefit for people who have a physical or mental disability and need help participating in everyday life or find it difficult to get around. This benefit is non-means tested, meaning it is not affected by your income or savings and you can even continue to work and claim this benefit.

**Employment Support Allowance (ESA)**

ESA, either contributory or new-style, is a benefit you can claim if you are employed or self-employed and you find that for whatever reason you cannot carry on working due to illness or disability. This is non-means tested as it is based on your national insurance contributions.

**Universal Credit**

Another benefit that is available for people of working age who are on a low income or are not working is Universal Credit. This benefit replaces the help that used to be provided through income-related ESA and other benefits including Income Support and income-based Jobseeker’s Allowance (JSA). This is a means tested benefit.

You can find out more about benefit entitlement from your local citizens...
advice team. Websites such as www.Turn2Us.org.uk or www.entitledto.co.uk have online benefit calculators that can also be helpful. You can contact the MS-UK Helpline for further information and support.

What support is there for me?

Peer support
There is a wide, active MS community that you can tap into, when you are ready. Some people may find it difficult to mix with others with MS and finding a group or community that is right for you is very important. Connecting with others can be a great way of sharing learning, asking questions, gaining support and giving support to others.

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

There are many multiple sclerosis groups across the country. There is likely to be a group near you. Your MS nurse may be aware of any local groups you can attend, or the MS-UK Helpline can find these for you. You may choose to become part of an online community. There are many MS forums out there, some are international like www.msworld.org and some are based here in the UK like www.shift.ms.

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 over any issues and it can support you to develop coping strategies for the future.

Counsellors do not offer advice or tell you what to do but help you to talk about your experiences to make is easier to find a way forward.

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

MS-UK offer a counselling service for people diagnosed with MS. Sessions are delivered via telephone or video link. You or your health professional can register your details online, or by calling MS-UK.

There may be other options available too - talk to your MS nurse as there may be forms of talking therapies available through the hospital. You may also be able to gain the support of a counsellor in the community through the NHS locally. Your GP will be able to refer you if this is available.

Most MS therapy centres in the UK offer a counselling service. As the MS therapy centres are charitable organisations their fees are

"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"
likely to be discounted in some way.

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 say which body they are registered with.

**Practical support**

You may also want to explore the following types of practical support that may be available to you

- Local support groups
- Direct payments
- Grants and funding
- Clinical trials
- Family carers support
- Personal assistants
- Blue badge
- Radar key
- Aids and adaptations

**Further information and support from MS-UK**

If you would like to talk about your diagnosis, symptoms, treatments or anything else, MS-UK can support you. MS-UK has a range of booklets called Choices where you can explore all the subjects covered in this pack at a time that is right for you. You will find these on our website at www.ms-uk.org/choicesleaflets.
We also have a dedicated news section on our website and a bi-monthly magazine, New Pathways, should you want to learn more about how you can live life to the full with MS. 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 and we’ll send you the latest issue.

If you need to speak with someone, we have a trained Helpline team that can give more information, support and emotional support on anything related to MS. Contact us by phone on 0800 783 0518, by live web chat at www.ms-uk.org/livewebchat or by email at info@ms-uk.org.

To register for the MS-UK Counselling service please visit our website at www.ms-uk.org/counselling For questions about the service, please email counselling@ms-uk.org or telephone 01206 226500.

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

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

<table>
<thead>
<tr>
<th>Date</th>
<th>Describe your symptom. How are you affected?</th>
<th>Is this a new symptom? Or one you have experienced before? Is it worse than previously experienced?</th>
</tr>
</thead>
<tbody>
<tr>
<td>eg. 01 Jul</td>
<td>eg. tight, stiff legs – difficult to walk</td>
<td>eg. I have experienced this before but not this tight/stiff</td>
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<tr>
<td>When did it start/stop?</td>
<td>Is the symptom constant or does it fluctuate? What makes it better or worse? (eg. heat, stress, time of day)</td>
<td>Score how the symptom affects you? One – not at all Five – extreme</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------</td>
</tr>
<tr>
<td>eg. a week ago and is continuous</td>
<td>eg. continuous but worse in the morning</td>
<td>eg. two/three</td>
</tr>
</tbody>
</table>

Visit www.ms-uk.org to find out more
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 .................................................................

<table>
<thead>
<tr>
<th>Did you sleep well last night?</th>
<th>Y / N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hours? ...............................</td>
<td></td>
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<tr>
<td>Interrupted or constant?</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Do you / could you have an infection?</th>
<th>Y / N</th>
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</thead>
<tbody>
<tr>
<td>Cough / cold / bladder infection?</td>
<td></td>
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<tr>
<td>Other?</td>
<td></td>
</tr>
<tr>
<td>Not sure</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Answer Options</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------------------------------------</td>
</tr>
<tr>
<td>If you feel unwell, when did this start?</td>
<td>Date</td>
</tr>
<tr>
<td>If you take a disease modifying treatment (DMT), did you take it yesterday?</td>
<td>Y / N, DMT Name</td>
</tr>
<tr>
<td>Are you taking another other medication?</td>
<td>Medication Name</td>
</tr>
<tr>
<td>If applicable</td>
<td>I have my period now</td>
</tr>
<tr>
<td>Where are you in your menstrual cycle?</td>
<td>I am due my period in a few days</td>
</tr>
<tr>
<td></td>
<td>I am mid-cycle</td>
</tr>
<tr>
<td></td>
<td>Not sure</td>
</tr>
<tr>
<td>Have you recently given birth?</td>
<td>0-3 months ago</td>
</tr>
<tr>
<td></td>
<td>3-6 months ago</td>
</tr>
<tr>
<td></td>
<td>6-12 months ago</td>
</tr>
<tr>
<td>If yes, are you breastfeeding?</td>
<td>Y / N</td>
</tr>
</tbody>
</table>

To download the ‘Symptom diary’ and the ‘Am I having a relapse?’
document, please see the following links to our website

www.ms-uk.org/sites/default/files/SymptomDiary.pdf
www.ms-uk.org/sites/default/files/Amlhavingarelapse.pdf

Visit www.ms-uk.org to find out more
Useful organisations

**MS therapy centres**
MS therapy centres are located across the UK, and offer a range of facilities to support people affected by MS, from massage therapy through to counselling services. You can find a map of centres across the British Isles on their website.

Website www.ms-uk.org/mstherapycentres

**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

**Shift.ms**
Shift.ms is a social network for people with multiple sclerosis. Hosted online and aiming to reduce isolation and create peer support. The charity supports many thousands of recently diagnosed people across the world as they make sense of MS. It’s independent and it’s free.

Website www.shift.ms

**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 they invest heavily in research.

Helpline 0808 800 8000
Website www.mssociety.org.uk

Use me for your notes

Visit www.ms-uk.org to find out more
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.

Call 0800 783 0518       www.ms-uk.org/choicesleaflets
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.

Visit www.ms-uk.org to find out more
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 Online offers a range of activities for people living with multiple sclerosis (MS). Our aim is to help people manage their wellbeing independently through exercise, information and connecting with others.

The activities offered online have been chosen by the MS community and future activities are guided by the feedback we receive.

Our current online activities include exercise classes, chair yoga, information sessions, interactive workshops and courses such as mindfulness and poetry.

To get involved, please visit the website www.ms-uk.org/ms-uk-online-exercise or email register@ms-uk.org.
Sources


Last reviewed: September 2020
Use me for your notes
Use me for your notes

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MS-UK Online!

- 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 services today!

Visit www.ms-uk.org/ms-uk-online or contact us at register@ms-uk.org

Supporting your MS journey

Charity number 1033731