Newly diagnosed with multiple sclerosis?

Read me...

www.ms-uk.org
Introduction…

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, you may even feel a sense of relief that you now have some answers. A whole range of thoughts and feelings are whizzing around your brain and you are wondering what to do now and where to go from here. We hope this information 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 your current thoughts and feelings.

Every time you see a box with an icon like this, it is a quote directly from someone affected by multiple sclerosis.

A diagnosis of MS may 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, or how the condition might progress and how it might affect your life. You may also be concerned about the effect MS will have on your family, friends, employment or hobbies.

There is no right or wrong way to react to a diagnosis. It is your MS and how it 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.

Don’t try and take everything in all at once.
Everyone differs in how long it takes to accept their diagnosis. Some people may even say that they still don’t after many years. Acceptance is important in enabling you to live your life to the full and 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 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 information 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.

We are here to support you to have choice, control and independence.
It’s not the end of the world. Life will change but you can still have a life.
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What is happening to me?

A diagnosis of multiple sclerosis 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.

Extremely shocked but determined to make the best of it.

At first I was almost relieved because it proved that the symptoms weren’t imaginary. Later I felt frightened about what the future held.

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 also important to know that MS is not hereditary. There are some genetic factors to MS but this does not mean you will definitely pass the condition on.

**Types of MS**

Although multiple sclerosis affects individuals very differently, there are four broad groups into which MS 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.

**Relapsing remitting MS**
The majority of people with MS are diagnosed as having the relapsing remitting form (RRMS). People with relapsing remitting MS experience relapses periodically – often months or years apart. When a relapse is over, the person moves into remission, hence ‘relapsing-remitting’.

To understand what a relapse is, see page 10 of this booklet.

I wish I’d been told hardly anyone dies from MS… you can live a long life with MS. Many people with MS never end up a wheelchair user. I’ve had MS 23 years, I’m 56 and can still walk.
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.

Primary progressive MS
Some people are diagnosed with primary progressive MS (PPMS). PPMS begins with a slow progression of neurological symptoms. Some people with PPMS experience a steady worsening of symptoms, and others find they become disabled more quickly. It can take many months or years 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.

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.

There are other sub-categories used by neurologists, these can include Benign MS and Rapidly Evolving Severe Relapsing Remitting MS.

Symptoms

MS-UK has found that people cope best when they look at what is happening now, 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 are 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:

<table>
<thead>
<tr>
<th>Visual symptoms</th>
<th>Spasticity (muscle stiffness)</th>
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<td>Problems with balance</td>
<td>Changes to mood and mental health</td>
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<td>Cognition difficulties</td>
<td>Changes to mobility</td>
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<td>Fatigue</td>
<td>Issues with bladder and bowel function</td>
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<td>Sensory problems</td>
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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 produced a ‘Symptom Diary’ to help you keep a 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 find this 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 be treated, most commonly, with a course of steroids. 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.

You can find this on page 34.

According to the NICE guidelines a relapse can be diagnosed by a GP or neurologist 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.’

Stress is a relapse trigger for me.
My healthcare team

Depending on the resources available in your area, your MS team may include:

- Neurologist
- MS nurse
- Speech and language therapist
- Counsellor or neuropsychologist
- Your GP
- A neurophysiotherapist
- 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 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, you can be referred to 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:

- **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 relapse is confirmed, treatment will be suggested as soon as possible, usually 14 days from 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 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.

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 kinds of questions you might need an answer to are listed here.

Ask as many questions as you need to…
Don’t be afraid to ask for help when you need it, physical or emotional.

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 not currently a cure for multiple sclerosis, there are a range of treatments available that may help you manage your condition.

Disease modifying therapies are treatments for relapsing-remitting MS (RRMS). Although there are currently no disease modifying therapy options for people with progressive forms of MS, there is currently much research going on in this area.

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.

Research into alternative drugs is good.

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. DMT’s target inflammation and are designed to reduce the damage caused by relapses. Different DMT’s effect 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.

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.

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. You can find this tool at www.mstrust.org.uk/understanding-ms/ms-symptoms-andtreatments/ms-decisions/decision-aid.

**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.

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**Disease modifying therapies**

**Category 1 - Moderately effective**
- Beta Interferon 1a (avonex, rebif and plegridy)
- Beta Interferon 1b (betaferon and extavia)
- Copaxone (glatiramer acetate)
- Gilenya (fingolimod)
- Tecfidera (dimethyl fumerate or BG-12)
- Aubagio (teriflunomide)

**Category 2 - Highly effective**
- Lemtrada (alemtuzumab, campath)
- Tysabri (natalizumab)
What if I choose not to have medication?

You may be eligible for DMT’s and it is your choice whether you wish to take them or not. Should you choose not to take any medications, this is described as being ‘drug naïve’ by health professionals. Your healthcare team may advise you to use DMTs, however the choice is still yours. If you choose to be drug naïve, it may be useful to keep a symptom diary in case you change your mind in the future.

There are many, like me, who have never gone down the drugs route and are living healthy lives after many years with MS.

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.

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

I wish more information was given about complementary therapies and exercise that could be used alongside conventional treatments.

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 organising body to find a therapist near you.

Some of the more common complementary therapies include:

- Acupuncture
- Homeopathy
- Chiropractic
- Reflexology
- HDOT (High-Dose Oxygen Therapy)
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.

The diagnosis led me to be healthier than previously, which turned out to be a gift.

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 talking 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.
Vitamin D

Due to lack of sunshine many people may be vitamin D deficient. Some research suggests there is a link between the development of MS and vitamin D deficiency.

Many people with MS take a vitamin D supplement. The Vitamin D Council website suggests doses up to 10,000IU per day are not harmful. It is suggested that 10,000IU be taken in the winter months and 5,000IU in the summer for people living with MS.

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

You can read more about the studies on the Vitamin D Council website at www.vitamindcouncil.org/health-conditions/multiple-sclerosis/#_edn26

Supplements

Like dietary changes, many people diagnosed with MS also take various supplements. This may be an addition or to aid their diet. We have listed the most common ones below:

- Calcium and Magnesium
- Omega 3 & 6
- B Vitamins
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’s 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.

In retrospect I was probably quite depressed at first. I have since found that my life is easier when I keep active and don’t dwell on my problems... It’s about what you can do not what you can’t.
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’s entirely down to what you enjoy and what you are able to do as an individual.

Walking  Tai chi

Swimming  Pilates

Yoga

Fatigue is a common symptom of MS. It might sound counterintuitive, but moderate exercise can improve the symptoms of fatigue. It’s 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.

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 ‘let’s 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.

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.

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’re 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.
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.

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 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.

**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 have, or 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.

Visit www.ms-uk.org to find out more
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. Some people may suggest that you stop working to remove all stress from your life, but 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.

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 from the Jobcentre Plus. 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.

If you are off work due to a relapse, 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.

If your employer does not pay SSP or once SSP comes to an end you may be able to claim a benefit called Employment and Support Allowance.
Benefits

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)

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 not affected by your income or savings and you can even continue to work and claim this benefit.

ESA 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.

The government plans to introduce a benefit called Universal Credit which will replace income-related ESA, but a date is yet to be set.

You can find out more about benefits from your local Citizens Advice team. There are some websites that have online benefit calculators. You can also contact the MS-UK Helpline and we will be able to give you information and support you though the process.
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 other people 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.

I think support groups are fundamental and whilst not everyone wants to join, it is far better to talk to others rather than hide it all.

There are many multiple sclerosis groups across the country. There is likely to be a group near you. If these groups are not for you then it may be that you 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.

Knowing you are not alone is invaluable.
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.

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 likely to be discounted in some way.

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 you.

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 want to talk about your diagnosis, symptoms, treatments or anything else then there are people who can support you. MS-UK has a range of information leaflets where you can explore all the subjects covered in this booklet at a time that is right for you. You will find these on our website at www.ms-uk.org

We also have a dedicated news section on our website and a bi-monthly magazine, New Pathways, if 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 an issue.

If you need to speak with someone, we have a trained Helpline team that can give more information and 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.

If you feel you would like some emotional support, we are here for you. If you feel that you need a qualified counsellor, then we will signpost you to the right place.

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

MS isn’t a death sentence but it is a life changer. I am still figuring out the ‘new me’.
## Symptom diary

**Date:** .............................................................

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<th>Describe your symptom. What part of your body is affected?</th>
<th>Is this a new symptom? Or one you have experienced before? Is it worse than previously experienced?</th>
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<td>Is the symptom constant? What makes it better or worse? (e.g. heat, stress)</td>
<td>How severe is the symptom? 5 is very severe and 1 is not severe. Describe the impact on you.</td>
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Am I having a relapse?

This diary 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.
<table>
<thead>
<tr>
<th>Question</th>
<th>Y / N</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you sleep well last night?</td>
<td>Y / N</td>
<td>Hours? ............. Interrupted or constant?</td>
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<tr>
<td>Do you / could you have an infection?</td>
<td>Y / N</td>
<td>Cough/cold/bladder infection? Other? Not sure</td>
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<td>Are you experiencing a change in symptoms?</td>
<td>Y / N</td>
<td>Describe:</td>
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<td>If you feel unwell, when did this start?</td>
<td>Date: ............................................................................................</td>
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<tr>
<td>If you take a disease-modifying therapy (DMT), did you take it yesterday?</td>
<td>Y / N</td>
<td>DMT Name: ......................................................................................</td>
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<tr>
<td>Are you taking any other medication?</td>
<td>Medication Name: ...........................................................................</td>
<td></td>
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<tr>
<td>If applicable: Have you recently given birth?</td>
<td>0-3 months ago 3-6 months ago 6-12 months ago</td>
<td></td>
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<tr>
<td>If yes, are you breastfeeding?</td>
<td>Y / N</td>
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</table>
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. Find a map of centres across the British Isles at

www.ms-uk.org/mstherapycentres

MS Trust

The MS Trust is a UK charity dedicated to making life better for people living with multiple sclerosis. They provide information to everyone affected by MS and support the health professionals who work with them.

Infoline: 0800 032 3839
Website: www.mstrust.org.uk

Shift.ms

Shift.ms is a social network hosted online aiming to reduce isolation and create peer support. They offer the speakeasy forum, which enables ‘MSers’ to talk to others living with MS.

Website: www.shift.ms

MS Society

The MS Society is the largest MS charity in the UK, supporting over 35,000 members. They undertake research, campaigning and they invest heavily in research.

Helpline: 0808 800 8000
Website: www.mssociety.org.uk
This booklet has been developed based upon the experiences of people with MS and the support of MS-UK’s Virtual Insight Panel. We would like to thank all those who were involved in creating this pack. We could not have done this without you.

Thank you to The Light Fund for its generous support to make this pack possible.

Keep in touch

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