Making Sense of MS

Multiple Sclerosis Trust MS

Treating MS symptoms

A guide to managing the individual symptoms of MS

Managing MS usually involves two different types of treatment:

- symptomatic treatments for managing the individual symptoms of MS, and
- disease modifying drugs for treating the underlying condition.

In this information sheet we focus on the different options available for treating MS symptoms.

Learning to manage your symptoms takes time and you may need to try several options to find what works for you. It can be helpful to read up about the different options so you can talk them through with your GP or MS team.

The symptoms of MS

There is a wide range of possible symptoms of MS. At diagnosis you'll probably only have experienced a few of them. Symptoms vary from person to person and can differ from day to day, and there'll be symptoms of MS that you never go on to experience at all.

The following are some of the most common early symptoms:

- fatigue – exhaustion which is out of all proportion to what you've been doing
- altered sensations – unusual feelings in the skin such as numbness, tingling or burning sensations, including a type of pain known as neuropathic or nerve pain
- problems with eyesight – changes to vision such as blurred or double vision, or pain in the eye
- cognitive problems – which might include problems with concentration, memory or planning
- walking difficulties – problems with unsteadiness, tripping, weakness or a heavy feeling in your legs.

Some other possible symptoms of MS are:

- spasticity and spasms – stiffness of the muscles
- bladder and/or bowel issues – such as difficulties with going to the toilet or needing to go more often
- emotional difficulties – feelings of anxiety or altered mood
- sexual problems – including loss of sensation or loss of desire.

Many symptoms of MS, such as fatigue and altered sensations, aren't obvious to other people so they're often referred to as invisible symptoms. However, these symptoms are very real and can usually be treated.

Don't rush. Take your time to learn about your MS. Educate yourself about the treatments that are available.

MS symptoms can sometimes get more or less intense over time. So, a change doesn't always mean your MS is getting worse, or that you might be having a relapse. If you have any concerns about fluctuating symptoms discuss them with your MS team.

What are symptomatic treatments?

Symptomatic treatments help relieve the physical or mental symptoms of a condition. They don't treat the underlying cause, or change the course of the condition. There's a wide range of treatments which are used to manage MS symptoms, they include:

- drug treatments – such as medication for pain, spasticity or bladder issues
- therapies – like physiotherapy to help with muscle stiffness, or cognitive behavioural therapy for pain, anxiety or depression, or occupational therapy to provide practical support to overcome any difficulties with day-to-day activities, so you can do as much as you can for yourself and live life as independently as possible
- management techniques – for example learning to pace yourself to minimise fatigue
- rehabilitation – which can improve day-to-day living. Depending on your needs this might include services such as physiotherapy, speech and language therapy, cognitive rehabilitation therapy or you may be given aids and equipment by an occupational therapist that can help
- complementary and alternative medicines (CAMs) – for example acupuncture, Pilates and relaxation techniques such as meditation and mindfulness. These treatments fall outside conventional medicine but are recognised as being helpful in improving physical and mental wellbeing.

What are my treatment options?

Treatments are available for the symptoms of MS regardless of whether you have relapsing remitting or progressive MS. Often people with progressive MS are under the impression that there aren't any treatments for them.

It's impossible to cover every symptom and treatment option here. Your options will depend on what symptoms you're experiencing, how much they're affecting your day-to-day life and sometimes what specialist services are available in your area.

Conventional treatments

In this section we give a brief overview of some of the typical symptoms which are seen in MS and the most common conventional approaches to their treatment. This might include drug treatments, therapies, rehabilitation strategies or management techniques.

Fatigue – learning strategies, such as focusing on the tasks which are most important to you and how to carry them out in the most efficient way, can be helpful. These can be taught by a physiotherapist and/or occupational therapist. The drug treatment amantadine (Symmetrel) helps some people with mild to moderate fatigue, but medication usually isn't a solution on its own and is usually combined with techniques such as pacing, prioritising and breaking down tasks.

Pain – treatment depends on the type of pain. Muscular or joint pain can be treated with painkillers such as paracetamol or ibuprofen. The drugs used for nerve pain include amitriptyline (Triptafen), gabapentin (Neurontin) and

I used to tear around and fill my days to the nth degree, but now I genuinely pace myself.

pregabalin (Lyrica). Physiotherapy can also help some pain. Sometimes a combination of drug treatment and physiotherapy gives the best results.

Eye problems – treatment varies depending on the issue. Steroids are occasionally used for optic neuritis (inflammation of the optic nerve which can lead to vision problems and/or eye pain). For double vision, patches or prisms on glasses are tried first, but botulinum toxin (Botox) may be used in very severe cases. Gabapentin may be prescribed if you have persistent nystagmus (involuntary movement of the eyes) to reduce the twitches.

Cognitive problems – there aren't any drug treatments that are routinely used for memory and thinking problems in MS. Rather, treatment is through cognitive rehabilitation therapy from a neuropsychologist, speech and language therapist or occupational therapist. They can teach you compensatory strategies to help work around your issues.

Bladder issues – if you have problems storing urine, such as needing to go to the toilet urgently or frequently, there are medicines that can reduce how often you need to go, such as solifenacin (Vesicare) and tolterodine (Detrusitol). If these treatments haven't worked, botulinum toxin (Botox) may be injected into the bladder wall to stop it contracting too much.

Bladder training, with the support of a continence specialist, can help you increase the length of time between toilet trips. Nerve stimulation can reduce symptoms of an overactive bladder if you don't want to try botulinum toxin and drugs haven't helped.

Making changes to your lifestyle alongside these treatments can be worthwhile too. This can include strengthening your pelvic floor muscles, avoiding food and drink that irritates your bladder, and maintaining a healthy weight.

If you have problems emptying your bladder, also known as hesitancy and retention, one option is to try using a catheter. There's also evidence holding a vibrating device over the pubic area can help to relax the valve at the base of the bladder to improve emptying. Sometimes a bladder scan after you have passed urine can help to establish if your bladder is emptying completely, or not.

Bowel issues – there are a variety of laxatives that can be tried if constipation is an issue, such as ispaghula husk (Fybogel), lactulose and docusate (DulcoEase, Dioctyl, Norgalax). Suppositories and enemas can be inserted into the back passage to stimulate your bowel. Transanal irrigation – which involves introducing warm water into your bowel – can help to flush poo out. Some people find that abdominal massage can help with constipation. This can be taught by a continence advisor.

If you have trouble controlling when your bowels open a physiotherapist or continence advisor can suggest exercises to help strengthen the muscles around your anus. There are also products available if bowel accidents are an issue. Some specialist centres offer biofeedback training where you're given help to retrain your bowel, advice on dietary changes that could help and psychological support.

Spasticity – there are several drug treatments available. Oral baclofen is typically tried first. If this doesn't work or you can't tolerate it, gabapentin is usually tried next. If these drugs don't work you should be referred to a spasticity team for more specialist treatments. Occupational therapists and physiotherapists can also offer support to help manage spasticity, this might include stretching exercises or advice on posture/positioning when you're sitting down or lying in bed, to make you more comfortable.

I lost a ton of weight, ate more healthily and started doing exercise. Made a massive difference. The power of positive thought definitely works.

Sexual difficulties – there are drug treatments available such as sildenafil citrate (Viagra) and tadalafil (Cialis) if MS causes erectile dysfunction. However, talking therapies can be a good option if MS is causing sexual difficulties such as loss of desire, changes in sensation or if you're struggling with self-esteem.

Walking problems – a physiotherapist or occupational therapist can support you with walking difficulties. The drug fampridine (Fampyra) has been shown to increase walking speed in some people with MS, regrettably it's not always available through the NHS. If you experience foot drop you may find that functional electrical stimulation (FES) can help, although unfortunately availability is patchy both on the NHS and privately.

The naming of drugs

You may have noticed that drugs often have more than one name. All drugs have a generic name, the official medical name for the active ingredient in the medication. Sometimes they also have a brand name, the trade name given by the manufacturer. The brand name always begins with a capital letter, whereas generic names don't.

Sometimes a drug is more commonly known by its generic name, for example gabapentin which is used for neuropathic pain; others are better known by their brand name like Viagra for erectile dysfunction. If a drug is produced by more than one manufacturer there can be more than one brand name for the same medication.

Paying for symptomatic treatments

In England, people with MS have to pay prescription charges, unless you qualify for free prescriptions for another reason. You can find out more about prescription charges, and prepayment certificates which can save you money if you require several medications regularly, on our website.

In Scotland, Wales and Northern Ireland there are no prescription charges.

Complementary and alternative approaches

Complementary and alternative treatments (CAMs) are often talked about as being the same thing, but there is a distinction between the two.

A treatment is said to be 'complementary' when a non-mainstream approach is used alongside conventional medicine. So, you may be taking prescription pain medication whilst also having acupuncture sessions to help with the pain.

A treatment is considered to be 'alternative' if the non-mainstream option is used instead of a conventional approach. An example of this would be if you chose to use a homoeopathic medicine rather than a conventional drug treatment.

There is a degree of overlap and many treatments can sit in both categories, for example osteopathy (the manipulation, stretching and massage of your muscles and joints) is used as a complementary treatment in some situations, whereas in others it's used on its own as an alternative therapy.

The following are just a few of the complementary and alternative approaches that are commonly used by people with MS and the symptoms they might be helpful for.

Diet – several diets have been advocated as being beneficial for MS, but none have been shown to work for everyone. Following a healthy diet benefits everyone, but it can be especially important in MS.

Maintaining a healthy weight can help with symptoms, such as fatigue and pain, by maintaining energy levels and avoiding putting excess weight on

I now make an effort to avoid processed foods and try to eat more wholefoods, fruit and veg.

joints. Ensuring you're getting enough fluid and fibre in your diet can help combat bladder and bowel issues. It's also essential to help maintain a healthy heart as high blood pressure and heart disease can also impact on MS.

If you're considering making changes to your diet there are a few things to think about such as whether it's easy to prepare, affordable and still enjoyable. If you're thinking about making major changes, it's best to get some expert advice to make sure you're not cutting out any major food groups or nutrients which might be detrimental.

Exercise – there's lots of evidence that exercise can help with MS symptoms and benefit both your physical and mental wellbeing. This might be something gentle like yoga, Pilates or Tai Chi which focus on flexibility, strength and balance; or it may be something more energetic or cardiovascular-based such as swimming, running or dancing. Exercise can help you maintain a healthy weight, improve mobility and also give your mental health a boost. The most important thing is to find something you enjoy which you can realistically manage to fit into your life, as that way you're more likely to keep it up!

Relaxation techniques – practices such as breathing exercises, meditation or mindfulness can be helpful if you're feeling under pressure or experiencing anxiety, low mood or depression. They can also be a distraction from symptoms such as pain and spasticity. Aromatherapy, reflexology and massage may also help.

If you're considering using CAM approaches, as well as considering the potential benefits it's important to think about both the costs involved and any possible risks. Some alternative medicines can interact with prescription medicines. A well-known example of this is St John's wort which some people use for depression – it can cause problems if used with some prescription depression medication and also reduces the effectiveness of contraceptive pills. Alternative medicines typically shouldn't be used if you're pregnant. It's best to have a discussion with a health professional if you're considering trying a CAM.

You can find further information on the treatment of specific symptoms, individual drug treatments, a range of therapies and management techniques, and other complementary and alternative approaches in our online A to Z of MS. For some symptoms, we also have in-depth publications that are freely available in print and online.

When should I seek treatment?

Sometimes it's difficult to know when to seek help for symptoms, especially when you're still learning about your MS. Some things can temporarily worsen your symptoms, so in some situations you might want to wait and see if they resolve themselves.

- Infections such as a cold, flu, stomach bug or bladder infection can cause a flare up. Your symptoms should improve as you recover.
- Extremes of temperature can impact on symptoms. Many people find hot weather makes their symptoms worse, whilst others see a worsening in the colder months. Using strategies to cool down, or to keep warm, should have a positive impact on symptoms if temperature sensitivity is an issue for you.
- Feeling under pressure can make symptoms harder to live with. Finding a technique that makes you feel more in control can be helpful.

The diagnosis of MS has meant that I've been able to access treatment, which has brought me hope that I will get relief from my symptoms.

If none of these apply, or your symptoms don't improve after a few days, you might want to consider getting support from your GP or MS team. The following are some examples.

- If you have new, suddenly much worse symptoms or if your walking is significantly impacted it's probably worth contacting your MS nurse right away – especially if you experience relapses.
- Sometimes symptoms creep up on you and suddenly a slow, gradual worsening over months or years might add up to a big change that you can't ignore. Your MS should be reviewed annually with your MS team, but if this isn't happening or it's not due for a while you could ask your MS nurse or GP for advice.
- If your symptoms are causing you concern, interfering with your quality of life, or impacting negatively on family or friends – don't tolerate them in silence.

Remember, new symptoms may not be due to MS, so speak to your GP or MS team if you're concerned. It's also important to keep up with any vaccinations, or health screening for conditions such as diabetes, high blood pressure or cancer, where appropriate.

Which health professionals will support me?

Although you will be in charge of managing many aspects of your MS, like taking medication as prescribed or keeping up with exercises recommended by a physiotherapist, sometimes you might need a bit of extra support to make sure you're on top of your symptoms, you've selected the best treatment option for you, or if things change.

As MS services work differently around the UK, it's worth checking with your team in advance who to contact, and how, if you have concerns. You may be reviewed by your neurologist, an MS nurse or referred to a specialist if it's more appropriate, for example a physiotherapist, speech and language therapist, continence advisor or spasticity nurse. Your GP can help with some symptoms or refer you to other services if required.

What if the treatment isn't helping?

Many treatments don't start working immediately, it may take a few weeks or months before you see any benefit. Hopefully you'll be given an idea of when you might expect to see results or be offered an appointment to review how you're doing after an appropriate time.

For some medicines, the dose might have to be increased gradually until you find the best possible relief for you. Typically you'd start on a low dose and be advised when to increase the dose and by how much, or have a review before any changes are made.

Not all treatments work for everyone, so if the treatment really isn't working, ask if there's an alternative you can try. Sometimes it can be a case of trying several options, or a combination of treatments, to find what works best for you.

Unfortunately, sometimes treatments don't get rid of symptoms completely. For instance, treatments for nerve pain may reduce the pain to a more manageable level, but you may still experience some pain in the background. The same is also true for fatigue.

The biggest benefit has come from learning to pace myself. This has been a great help with fatigue management – both physical and cognitive.

What about experimental treatments?

There is no cure for MS, so beware of anyone claiming they're offering a cure. The most important thing is to use reliable sources to inform your decisions, such as the MS Trust. Other sources may sound convincing but they may just be opinion, marketing hype or personal experience presented as facts.

If you do find a treatment that interests you, do your research. If there's been a genuine breakthrough, the main MS charities will be reporting it too. Look for different opinions on the research and consider what is being said. Often research reported in the press is at an early stage, so it might be a while before a treatment becomes widely available or it may never get to that point at all.

It can be tempting to try an experimental or controversial treatment, but you need to consider the risks of harm, potentially significant side effects and the costs involved. If in doubt, have a chat with your MS team or GP.

How do I find out about new treatments?

MS is a very active area of research and new treatments are coming through all the time. Keep asking if there are any new options during appointments with your MS team, especially if you feel your symptoms aren't being managed as well as you'd like.

Got a question about MS?

Ask our Helpline Team on 0800 032 3839
or email ask@mstrust.org.uk

Scan to support the MS Trust

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Further information

Making Sense of MS information sheets:

Making Sense of MS: first steps mstrust.org.uk/444
Making Sense of MS: newly diagnosed with MS mstrust.org.uk/448
Disease modifying drugs: an introduction mstrust.org.uk/442
Relapsing remitting MS mstrust.org.uk/450
Progressive MS: an introduction mstrust.org.uk/449

Information on our website:

What's causing my symptoms? mstrust.org.uk/symp
MS symptom treatment finder mstrust.org.uk/treatment-finder
A to Z of MS mstrust.org.uk/A-Z
Complementary and alternative medicines mstrust.org.uk/cam
Prescription charges mstrust.org.uk/prescription
Temperature sensitivity mstrust.org.uk/heat
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Printed publications can be ordered for free or downloaded from our website. Alternatively, they can be ordered by calling 01462 476700.

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Registered charity no. 1088353

Making Sense of MS

This information is part of a set of resources for people who are newly diagnosed with MS. You might like to look at our introductory resource, Making Sense of MS, which answers the questions most commonly asked around the time of diagnosis.

MS Trust Information Team
Treating MS symptoms (Order code: 455)

This edition published 2024

This publication will be reviewed in three years.

Produced by verdicottsdesign.com