

Fatigue



Welcome to this Choices leaflet about fatigue

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 leaflet we produce, MS-UK consults the wider MS community to gather feedback and uses this to inform our content. All our Choices leaflets are then reviewed by the MS-UK Virtual Insight Panel before they are published.

This Choices leaflet 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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Fatigue

Fatigue is one of the most common invisible symptoms of multiple sclerosis (MS). It is reported to affect three out of four people with MS (1) and one which can have a major impact on all aspects of life, including activity performance and unemployment (2, 3).

For some people it is the symptom that affects them the most.

Many people don't understand that people with MS have to be pre-emptive... we can't wait until we're 'too tired' but have to take measures to prevent fatigue from developing in the first place

In a MS-UK survey, when asked whether they experience fatigue, 80 per cent answered yes, 17 per cent answered sometimes and 3 per cent answered no.

Fatigue may be the first symptom of MS, or a symptom that starts much later on after diagnosis. It can vary greatly from person to person and there are many different triggers.

What is fatigue?

It is a symptom that people find difficult to explain. It isn't like the general feeling of being tired - it is an overwhelming feeling of exhaustion. It can interfere with day-to-day activities and can prevent someone from doing or completing tasks.

Fatigue can arrive without warning and can subside just as fast.



I try and treat energy levels like my bank account, and don't go overdrawn if at all possible. I like to try and keep a reserve, but if there were something I really wanted to do I would go for it, even though I might end up spending some time paying for it!



Fatigue can differ very much from person to person and can often worsen existing symptoms or bring on new ones. Some people find that fatigue can make limbs feel heavy and grip more difficult. Things like concentration, vision and speech can temporarily worsen.

There are certain things which can bring on fatigue. When you know what these things are for you, fatigue is easier to either deal with or avoid completely. Some of the most common triggers can be a hot day, humid weather, a hot bath, over-exertion, over-tiredness, a heavy meal, smoking and stress.

What causes fatigue?

Fatigue in MS is thought to be caused by many factors. There are two distinct types of fatigue – primary and secondary (4).


Primary fatigue is believed to be down to the disease process itself and is caused by the demyelination in the central nervous system. The slowing of messages from the brain and spinal cord and a buildup of muscle weakness combined can be a cause of primary fatigue.

Secondary fatigue is not directly caused by MS itself, but where the body tries to compensate for other symptoms caused by MS. For example, sleep disturbance can be common due to spasms, pain or bladder problems. This will contribute to MS-related fatigue. Side effects from medications, stress, depression and other symptoms can all cause secondary fatigue.


Treatment for fatigue

It is important to find out the best way of managing fatigue. To do this you need to understand it and find out what triggers it. It may be caused by another symptom which could be easily treatable. For example, if bladder problems at night are disturbing your sleep, then make an appointment to see your GP, MS nurse or

**Ration your energy usage over the week,
don't try to do everything in one day**



I plan each day so that I am not doing too much in any one day or on consecutive days. I have come to accept my limits (usually!) and know when I need to rest. I split tasks, such as cooking, into separate bits that I can do over a number of hours instead of trying to do it all at once. I now ask for help from family members rather than trying to do it all myself



continence advisor. This can be assessed and hopefully treated.

Or it may be about learning how to conserve energy for times of the day when more is needed, and prioritising daily activities.

Activity pacing is thought to help manage fatigue by making changes to activity patterns that are inefficient. This strategy is designed to help people experiencing fatigue to work within their body's physical and mental limits and be more efficient with energy expenditure (5).

MS nurses and MS specialist occupational therapists can help in your fatigue management. Some run their own fatigue-management courses that will teach you strategies to help reduce the fatigue and deal with day-to-day activities. Something as simple as prioritising daily tasks can make a big difference.

A range of modifiable lifestyle factors including diet, exercise, supplementation (including omega 3), alcohol intake and drug treatment were looked at in a large study. The study strongly

suggests that these factors should be considered when creating a preventative medical approach to managing MS-related fatigue (6).

It is very important to listen to your body. If you need to rest, then rest. If you know you have a really busy day coming up – a day out, a wedding or something that is going to take a lot of energy – make sure you rest well for a couple of days leading up to it.


Don't be tempted to overdo it when you have a really good day. You may well end up making yourself feel a lot worse for a few days after. It is important to pace yourself and rest when you can.

By learning how to conserve your energy for times when you need it most, you can start implementing this into your daily life. It could be useful to keep a diary taking into account the daily activities done that day. Think about what you have eaten, the time of day you might have felt more tired and anything else that could possibly be a trigger.


Exercise

The National Institute for Care Excellence (NICE) published guidelines in October 2014 for the management of MS (7). In these guidelines NICE advised aerobic, balance and stretching exercises, including yoga, in treating MS-related fatigue.

I have to give in to it and try and work with the exercises that I get at the BMSTC (therapy centre). I find that not fighting it helps me mentally and to accept it as part of my life now



All day every day I review my priorities for energy expenditure, I ask myself if I do this, I can't do that, which is the most important right now?




Studies suggest that exercise therapy can be an effective way to manage self-reported fatigue, particularly in the form of endurance training. Exercise has a positive effect on fatigue, so even undertaking short periods of exercise is better than doing no exercise at all (8).


It is advisable not to exercise to the point of exhaustion and you should stop before you reach the point of feeling tired or hot. After a session at the gym, a walk, a yoga practice or swimming you should have more energy, not less.

Mindfulness

In NICE's October 2014 guidelines, it advised that mindfulness can be used for treating MS-related fatigue (7).



I manage my fatigue by resting fully using mindfulness for around 10-20 minutes regularly during the day and then a walk on my treadmill in the evenings



Mindfulness is a meditative approach connecting the mind and the body. It is about paying attention to the moment and being aware of thoughts and feelings so they do not become overwhelming (9).

Mindfulness reduces stress and anxiety. Many studies have shown that brain wave activity is changed when a person undergoes mindfulness training – increasing positive emotions and reducing depression.


Mindfulness is usually taught in a weekly class over a period of a few months. Online courses and CDs guiding a learner through mindfulness training are also available.

Your GP may also know of courses run in your local area.


Heat and humidity

A common experience with MS is to become very sensitive to heat, particularly humid heat. Hot, humid summers can be very uncomfortable for someone with MS. It is important to keep cool. Air conditioning can be very helpful but if that isn't available then a fan in each room is a second best.

Items such as Kool-Ties and cooling vests can be helpful too.



Fresh air. I usually have a window open somewhere in the house and open the back and patio door regularly to let the air refresh. In summer I point a fan on my face as I sleep or I wake sluggish and disorientated



Kool-Ties are a tubular scarf containing polymer crystals. When soaked in water, they absorb more than 400 times their original weight and provide a continuous cooling effect for up to three days. They work by cooling the whole body and particularly the blood flowing to the brain via the carotid arteries.

Cooling vests have special cooling crystals incorporated into the material and are soaked in cold water, holding the temperature for a substantial period of time.

You may need to give a little more thought to where you choose to go on holiday. It may be better to go on holiday off-season when it is not too hot.

A hot bath can sometimes bring on MS symptoms very rapidly, as well as leaving you feeling weak. These symptoms tend to go away once the effects of the hot bath have worn off. A cool bath or shower may be a much better option.

Drug therapies

Amantadine

A GP can prescribe amantadine for fatigue. It is an antiviral medication which is also used to treat Parkinson's disease. It isn't fully known why it is effective for some people with MS. Amantadine should be offered alongside a more detailed approach to fatigue management (7).

As with many drugs, the effectiveness of amantadine in dealing with MS-related fatigue was a chance discovery. It came about when a number of people with MS were being treated with amantadine for flu symptoms and it was found that their fatigue levels improved.

It is generally well tolerated by people with MS but it can cause

insomnia, nausea, anxiety, dizziness, loss of appetite, and dryness of the mouth.

Supplements

B12

In the 2014 NICE guidelines for the management of multiple sclerosis (7), B12 injections were not recommended in the treatment of fatigue. Although there is some anecdotal evidence that suggests some people with MS may benefit from taking vitamin B12 (10).

Acetyl-L-carnitine

Acetyl-L-Carnitine is a form of L-Carnitine, an amino acid that is found in nearly all cells of the body. L-Carnitine plays a critical role in the production of energy from long-chain fatty acids. In addition, it increases the activity of certain nerve cells in the central nervous system. Some research suggests it can decrease fatigue in MS, although more study is needed (11).

Coenzyme Q10

According to research, people with MS who are affected by fatigue

I take a daily morning dose of Coenzyme Q10 capsules and supplements as recommended by my MS Nurse. They certainly work for me and raise my energy levels in the morning. They are still not fantastic but [I am] better with them than without

can benefit from taking Coenzyme Q10. A significant decrease on the fatigue severity scale (FSS) was seen during the study (12).

Coenzyme Q10 can be found naturally in foods such as oily fish and meat, or it can be taken as a supplement. There are certain risks, side effects and interactions to also be aware of (13).



I have a daily vitamin and mineral regime geared to maximising general wellbeing and energy levels



Vitamin D and omega 3

Studies have shown that taking a vitamin D and an omega 3 supplement reduces the odds of MS-related fatigue by more than half (6).

If you are considering taking supplements, please discuss this with your GP or neurologist to ensure they are right for you.

Diet

It is well known that eating a healthy, balanced diet helps to maintain good health and help you feel your best. This ideally should include plenty of fruit, vegetables and not too much fat, salt or sugar (14).

Poor diet can lead to an increase in fatigue as the body is not being fueled effectively.

Fatigue and lack of energy may also be a symptom of food sensitivity.

You may wish to consider a food intolerance test to rule out any particular foods that may contribute to your fatigue.

Other therapies

Acupuncture

Acupuncture is a therapy that has been around for many years. Acupuncture involves the use of very fine sterile needles, which pierce the skin to reach an acupuncture point. They are inserted very precisely and connect with the body's qi. A small-scale study has shown that acupuncture might be beneficial for people who experience MS-related fatigue, in addition to usual care particularly if treatment options are limited (15).

Oxygen therapy

Oxygen therapy is widely used across the country in many local therapy centres. It involves breathing 100 per cent oxygen through a mask whilst inside a pressurised metal chamber similar to that used in diving. It has been found by those who regularly attend oxygen therapy sessions that it can greatly improve fatigue levels. One study suggests that oxygen therapy is well tolerated and can decrease the severity of symptoms including fatigue (16).

Action Potential Simulation (APS) Therapy

Action Potential Simulation, or APS Therapy machines are used to treat fatigue or pain. They use a very tiny current of electricity (a micro-amp), which stimulates the body to produce more adenosine triphosphate (ATP), the energy molecule, amongst other things. For many people with MS, this has resulted in reduced fatigue (17).

APS Therapy is available at many local therapy centres in the UK.

We asked the MS community to share their 10 top tips for managing fatigue, they are...

- 1 Healthy eating and regular resting.

- 2 Meditation, relaxation and biofeedback.

- 3 Try to plan activities around the house carefully, remember there is always tomorrow, and ask others to help you

- 4 Being aware of the need to factor in rest time.

- 5 Time to myself to do exactly what I want to do with my day

- 6 Being aware of limitations, having self-awareness

- 7 Break down tasks into small units and take breaks!
Celebrate and be grateful for small successes

8 Regular daily patterns – go to bed at the same time each day and get up at the same time each morning

9 Looking after your psychological wellbeing can have a positive effect on fatigue levels

10 Trying just to do what I can that day. I will not beat it so it's pointless fighting. Learning about MS and how it affects me helps. And avoiding external stressors

Further information

Be Mindful

Be Mindful is part of the Mental Health Foundation

www.bemindful.co.uk

MS-UK Choices booklets

Exercise, Vitamin D, Diet and supplements, Complementary and other therapies

www.ms-uk.org/choicesleaflets

About MS-UK

MS-UK is a national charity formed in 1993 supporting anyone affected by multiple sclerosis. Our hope for the future is a world where people affected by MS live healthier and happier lives.

MS-UK has always been at the forefront of promoting choice, of providing people with all the information and support they need to live life as they wish to with multiple sclerosis, whether that be through drugs, complementary therapies, lifestyle changes, a mixture of these or none at all.

We will always respect people's rights to make informed decisions for themselves.

The MS-UK Helpline

We believe that nobody should face multiple sclerosis alone and our helpline staff are here to support you every step of the way.

Our service is informed by the lived experience of real people living with MS, so we can discuss any treatments and lifestyle choices that are of benefit, whether they are clinically evidenced or not.



New Pathways

Our bi-monthly magazine, New Pathways, is full of the latest MS news regarding trials, drug development and research as well as competitions, special offers and product reviews. The magazine connects you to thousands of other people living with MS across the country.

Available in print, audio version, large print and digitally.

About MS-UK

Peer support service

Our Peer Support Service enables people to connect with others in a safe space and share experiences on topics of interest. Our Peer Pods take place regularly and are all volunteer led. Please visit the website to find out more www.ms-uk.org/peer-support-service or email peersupport@ms-uk.org.





MS-UK's online activities

MS-UK offers a variety of online activities to stay active and connected for those affected by MS and manage their symptoms to live happier and healthier lives. Activities include exercise sessions, mindfulness courses, chair yoga classes, information sessions and workshops. Visit our website to explore and find out more.

MS-UK E-learning

Do you work with or support someone living with MS and want to increase your understanding and knowledge of this long-term health condition? Professionals at MS-UK have created accredited Learning courses that can help you do this. Visit <https://ms-uk.org/excellence-ms/> to find out more.

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Check out MS-UK's online activities

Live a happier and healthier life with MS



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

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

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

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

 **MS-UK**
Supporting your MS journey

Registered charity number 1033731

Stay in touch

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