MS Trust

Living with fatigue

— A guide for people with MS

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Contents

Introduction

This book is based on a fatigue management programme that an occupational therapist or MS nurse might run. It aims to provide practical ideas and suggestions to help you manage your fatigue better.

It shares comments from people with MS who know what it's like to live with fatigue and draws on experience from a range of disciplines, including occupational therapy, physiotherapy, medicine and nursing.

Fatigue is experienced by the majority of people with MS, but managing it effectively involves finding an approach that works for you. Health professionals can offer advice and support you through this process.

As fatigue can vary so much from day to day, learning how to manage your fatigue can take time and the lifestyle changes involved will take patience and perseverance.

The first step is recognising and understanding the effect fatigue has on your life. Then, when you're ready, you can begin to find ways to work around these problems.

It's not possible to make fatigue go away completely but, through an awareness of the symptom, thinking about your lifestyle and the use of particular strategies, it's possible to start to manage your fatigue and take steps to reduce the impact it has on your daily life.

> "Learning how to manage your fatigue can take time and the lifestyle changes involved will take patience and perseverance."

For more information on fatigue, scan or visit mstrust.org.uk/a-z/fatigue

1. What is fatigue?

Fatigue is one of the most common symptoms of MS and can have a major impact on your daily life. It's described as a feeling of exhaustion or sudden loss of energy that's out of all proportion to any activity you may have been doing. It can affect you both physically and mentally.

"Fatigue feels as if I am an inflatable, and someone has pulled the airstopper out! My brain goes fuzzy, I can't think clearly, my speech slurs and my eyesight goes. Swallowing becomes more difficult, my balance gets worse and my legs feel heavy and clumsy."

The level of fatigue doesn't necessarily reflect the severity of your MS. You might experience fatigue that interrupts your lifestyle or prevents you from working whilst having few other symptoms.

"As a physical sensation it reminds me of falling into quicksand – it's a viscous, heavy, pulling feeling, but if I try to fight it, it hurts like hell and robs me of breath."

Periods of fatigue may also cause your other MS symptoms to worsen temporarily. This is particularly true of problems with memory, concentration and attention span.

Often, when you're feeling fatigued, it can seem harder to think clearly or to keep your mind on the job. As the episode of fatigue passes, you should usually notice these symptoms returning to their previous level.

As with other MS symptoms, fatigue affects everyone differently.

"Fatigue leaves me feeling dulled and tired. I find it hard to concentrate and to absorb new ideas, and I'm often confused, searching for the right word, and forgetting things. My memory deteriorates dramatically when I get very tired."

"Fatigue feels like being weighed down, as if you're trying to walk up to your neck in a deep, muddy river in heavy, wet clothes carrying shopping bags full of rocks."

As an 'invisible' symptom, fatigue can be misinterpreted or misunderstood by family, friends or colleagues. The pressures of everyday life mean that most people, whether they have MS or not, experience periods of heightened tiredness or exhaustion at some point. However, this is completely different from the fatigue you might experience with MS.

"Fatigue feels like being weighed down, as if you're trying to walk up to your neck in a deep, muddy river in heavy, wet clothes carrying shopping bags full of rocks."

"I find the biggest problem about fatigue is that others don't understand it. I think it would be easier for people to understand if you were wearing a plaster cast."

If other people don't fully understand fatigue and the impact it can have on you, it can help to explain how fatigue affects you to the people you're closest to. Maybe give them some specific examples to help them understand better.

> I still feel guilty that I should do more, and sometimes slip back into my old ways of taking on too much.

"People's attitudes are an issue. If I say I'm not feeling up to going out on a particular occasion, they often assume that I'll never be well enough, so they don't ask me again. It feels as though they don't believe me, or think I'm making it up. I do want to participate, but sometimes I don't feel energetic enough to enjoy doing it on that day or I know it'll exhaust me."

You might find that you start to think negatively about yourself because of fatigue. Some people describe feeling guilty about not being able to keep up with their usual activities or having to ask family and friends for help. Other people feel like they're giving in to their MS or they're letting themselves or other people down.

When you notice these negative thoughts, try to be kinder to yourself by acknowledging that you can only do what you feel able to do and, even if you don't get everything done, that's good enough.

"I still feel guilty that I should do more, and sometimes slip back into my old ways of taking on too much, but I soon pay the price with a worsening of symptoms."

Until you've experienced it, it's hard to understand the impact of fatigue and how debilitating it can be. At first, you may even underestimate the force of fatigue yourself.

"Something I wasn't prepared for was that a simple task like cooking dinner could mean I would need to sleep for hours. When I tried to explain that level of fatigue, some people would misunderstand and say 'I've got that too' when they just mean they've had a tiring day. My fatigue feels very different from usual tiredness."

Recognising that fatigue is a symptom of MS and needs managing just like your other symptoms can take time. You might feel the urge to keep

pressing on to get the job done and be hesitant to ask for help. Often the expectations of family or colleagues, or the pressure of deadlines, can drive you to push your limits and try to work through the tiredness.

Unlike the limits of normal, everyday tiredness, which may give a little when pushed against, MS fatigue can feel like a barrier. It can be difficult to recognise what your limits are until you've overstepped them.

"My own way is to firstly admit defeat when the fatigue sets in

> Something I wasn't prepared for was that a simple task like cooking dinner could mean I would need to sleep for hours.

and not try to push myself any further. Most of the time it wouldn't be possible anyway because fatigue is not like tiredness where you can work your way through it."

Whilst recovery from everyday tiredness is relatively swift, you

may find that it takes much longer to build your energy levels back up again after an episode of fatigue.

"I drove to see my new grandchild. Although I stayed overnight to rest, trying to catch up at home on my return took its toll on me. I felt exhausted and didn't wake up for 17 hours. Even then my body felt so tired I still didn't want to move."

Coming to terms with the effects of fatigue, both for you and your family and friends, may take some time. If fatigue is having a big impact on your daily life and stops you continuing with your normal routine, you might, understandably, start to feel frustrated or low in mood.

"I feel like I'm in a jail cell as I'm so tired all the time. It makes me feel angry, bad tempered and depressed. I hate my home because I can't clean it like I used to."

"Fatigue can literally reduce me to tears, for no reason, I just find I'm crying – it's like the plug has been pulled out and my energy, almost my life, is going down the drain."

How you adapt and learn to live with fatigue will be an ongoing process. Your fatigue levels may fluctuate from hour to hour or day to day. Some days you might not notice any impact at all, whilst the next your energy levels may drop again.

"Some days I can almost keep up with my get up and go. Other days I can't even get up."

> "I feel like I'm in a jail cell as I'm so tired all the time. It makes me feel angry, bad tempered and depressed."

> "The worst aspect for me is the dread of not knowing exactly what is going to happen and when."

"The worst aspect for me is the dread of not knowing exactly what is going to happen and when. How do I explain to people that I might be feeling okay one day but the next I'm too tired to leave home?"

Over time, you can learn to recognise the sort of things that might trigger your fatigue and notice when you're showing signs of the symptom developing. With this awareness, you can develop strategies to manage your fatigue and lessen its impact. To do this it's helpful to be aware of some of the causes of fatigue.

2. What are the causes of fatigue?

The causes of fatigue in MS aren't fully understood and are still being investigated.

It's thought to result from a combination of factors, partly caused by MS itself (known as primary fatigue) and also by other factors (secondary fatigue) that affect people with MS more significantly than those without the condition.

Primary fatigue

Primary fatigue is thought to be due to nerve messages from your brain and spinal cord having to navigate the areas of damage caused by your MS. It takes more energy to send and deliver messages to other parts of the body, like the muscles in your arms and legs, causing a build-up of fatigue.

'Shortcircuiting' or neuromuscular fatigue is another type of primary fatigue. This can happen when you're performing repeated movements of a particular muscle group, which can tire the muscles out more quickly.

For example, your legs may become increasingly heavy and difficult to move when you're walking or your arms may be affected when writing for a period of time. This usually resolves after resting for a while.

Secondary fatigue

This is caused by the effect of living with MS. For instance, MS symptoms such as depression, pain or disturbed sleep due to spasms or needing to go to the toilet more often can all make fatigue worse.

Other factors that can contribute to fatigue

Fatigue may also occur as a side effect of various medications or be the result of inactivity, stress, poor diet or an infection. If you have other medical conditions, this can also cause or worsen fatigue.

Fatigue for many people is the result of a combination of several factors which can make you feel tired and lacking in energy. Once you're aware of these possible factors, you can review whether they apply to you and begin making changes.

Some of the factors that can add to fatigue include:

- lack of sleep
- low mood, depression or anxiety
- stress
- heat sensitivity
- low fitness levels and lack of exercise
- unbalanced diet
- infections or relapses
- medications for other symptoms or conditions.

> "If you have other medical conditions, this can also cause or worsen fatigue."

3. How to manage fatigue

Although fatigue can't be cured, there are techniques that can be used to reduce the impact it has on your daily life.

The basis of managing fatigue is a two-pronged approach:

- ensuring you have the best levels of energy available
- learning how to use that energy in the most efficient way.

Controlling your fatigue, as opposed to letting it control you, involves making changes to various aspects of your life. Perhaps more than with any other symptom of MS, the key person in the management of fatigue is you.

Health professionals, such as doctors, occupational therapists, physiotherapists or MS nurses, are there to advise and support you.

The following chapters encourage you to review your lifestyle and make small changes to your daily life. The suggestions may not be suitable for everyone, but they may help you think about what you can do to address the areas in your own life that may be adding to your fatigue.

Building up your energy levels

"Health professionals, such as doctors, occupational therapists, physiotherapists or MS nurses, are there to advise and support you."

Using your energy effectively

You may find this approach challenging at first. It'll probably take time for you to adjust, as well as your family and friends if you get them involved.

Getting the right balance that allows you to make the most of life will take practise and perseverance. There may be occasional setbacks too.

4. Building up your energy levels

4.1 Sleep

Sleep is a very important part of healthy living. Whilst you're asleep there are many complex processes going on in your body that allow you to wake up the next day feeling refreshed. Sleep helps to regulate your mood, memory and metabolism.

There's no set rule on how much sleep you need. Most adults need six to nine hours to function at their best, although some people operate perfectly well on four or five hours. The amount of sleep you need will change over the course of your life. It's influenced by factors like your age, gender, lifestyle, weight and pregnancy.

If you wake up feeling refreshed and you don't fall asleep during the day, this suggests you're getting enough sleep for you.

However long you need, the results of not having enough sleep are similar – lack of energy; feeling tired; low mood; decreased concentration, attention and memory; irritability and decreased motivation.

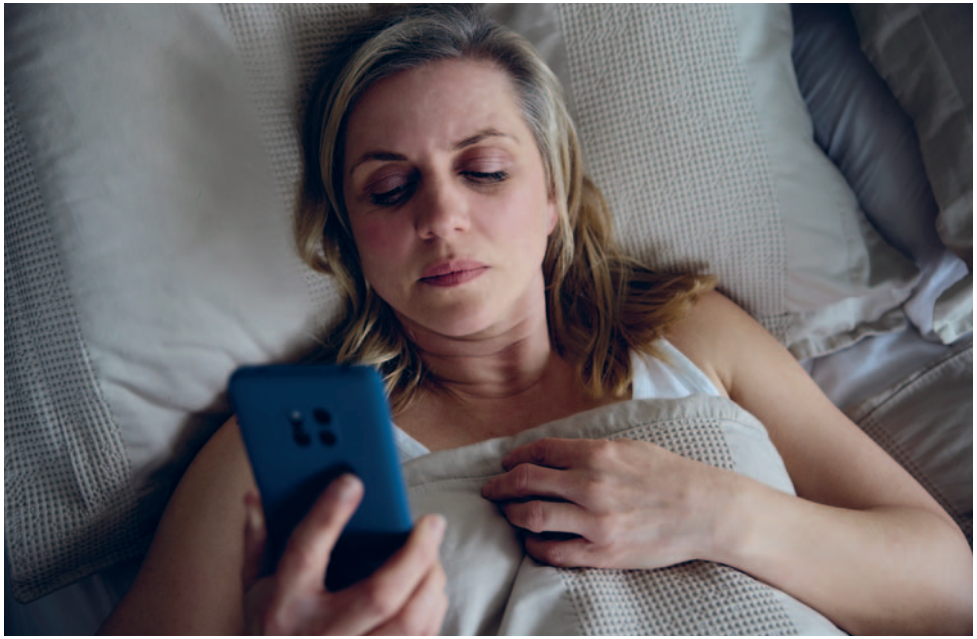
There can be many reasons why you may not be getting good quality sleep.

- MS symptoms can interrupt your sleep, such as getting up in the night to go to the toilet or painful stiffness or spasms.
- Concerns and worries can make it difficult to 'switch off' resulting in restless sleep.
- Family responsibilities may mean there's less time available for you to sleep.
- Being less active can affect your sleep patterns.

Sometimes sleeping problems can be caused by a sleep disorder rather than your MS or the stresses of everyday life. Conditions such as obstructive sleep apnoea and restless legs syndrome are more common in people with MS, so do speak to your GP if you're worried about the amount and quality of sleep you're getting.

Tips for sleeping better

If there are physical reasons for not sleeping well, such as spasms or needing to go to the toilet, you should discuss these with your doctor, or MS nurse if you have one. Reducing the impact of these other symptoms may increase your amount of uninterrupted sleep.



- Keep to regular hours for going to bed and getting up, with only slight variations for weekends and holidays. If you need to break this routine for any reason, try and resume it as soon as possible.
- Try not to get overtired by doing too much. Being too tired can make it difficult to get to sleep.
- Stay as physically active as possible. People often report that they sleep better after an active day (see section 4.6).
- Spend some time outside. Experiencing natural light during the day has a positive impact on sleep at night.
- Don't sleep too much as this can add to your fatigue.
- If you feel tired during the day, power napping (short naps generally less than 30 minutes) is better than having a longer sleep.
- Try to keep the bed as a place for sleeping, not for other activities such as watching the television – sex is an exception to this rule!

During the evening

- Consider exercising in the early evening to allow your body to wind down before bedtime.
- Cut down on caffeine-containing stimulants such as tea, coffee, hot chocolate, cocoa or cola drinks and try to drink them no later than six hours before bedtime.
- Nicotine is a strong stimulant. If you smoke, try to reduce the number of cigarettes you have in the evening.
- A glass of wine or beer early in the evening can be relaxing, though too much alcohol will worsen sleep.
- Avoid eating a heavy meal close to bedtime. However, don't go to bed hungry. Have a light snack if you need it.
- Avoid doing any mentally taxing activities in the hour before going to bed.
- Make a to-do list for the next day. This reduces the risk of thinking about these things once you're in bed.

Having a sleep routine

Here are some possible parts of a sleep routine.

- Have a warm, milky drink before bed.
- Take a warm bath or shower. The drop in temperature afterwards encourages the body to relax into sleep.
- Read.
- Listen to relaxing music.
- Do some gentle stretches.
- Try a relaxation exercise (see section 4.4).
- Use aromatherapy techniques. Many people find lavender beneficial – you can get it as a room or pillow spray, and in candles or reed diffusers.
- Keep your bedroom at a comfortable temperature; ideally this should not be more than around 60°F (15°C).
- If noise is a problem, try earplugs.
- Reduce the light in your bedroom or wear an eye mask.

Coping with not sleeping

If you can't sleep, lying in bed thinking about not being able to sleep will make dozing off even less likely. Try to focus on something else and distract your mind from trying to force sleep.

- Use relaxation techniques such as deep breathing, visualisation and muscle relaxation (see section 4.4).
- If you're not asleep within 20 minutes, get out of bed and do some activities from your sleep routine, or do something mundane until you feel sleepy.
- Move clocks out of sight to avoid the tendency of clock watching during the night.
- Keep a pad and paper next to the bed to write down any thoughts that are keeping you awake.

Further information

Sleep: *mstrust.org.uk/sleep*

4.2 Mood

When you have MS, you're more likely to experience low mood or depression than the general population.

Low mood can lead to reduced energy levels and vice versa. Often it's not clear which symptom is a result of which so it can become a vicious cycle.

Sometimes depression can be directly caused by MS because of lesions in parts of the brain that control mood. Also, living with the condition itself can be challenging and that in turn can have an effect on your emotions.

"Because fatigue affects how well I perform at work and how much I can socialise with friends, I get very low and this makes me discouraged and despondent."

Of course, not all low mood is a result of MS, and there may be other things going on in your life that are causing you to feel low.

Whatever the cause, low mood can drain your energy and motivation and have an effect on fatigue.

If your mood is affected by living with MS, seek help and support from your GP or MS nurse. They can talk through suitable treatment options such as talking therapies or medication.

Breaking the cycle of low mood

Sometimes when you're feeling down it can seem difficult to see the positives in your life. This can lead to a negative spiral that you may find hard to break.

Here are a few suggestions you may want to try if you're struggling with your mood.

- Be more active (see section 4.6).
- Make doing more enjoyable things a priority.
- Spend time with positive people.
- Take up a new activity – this could be anything from cycling to joining a local choir.

> "Sometimes when you're feeling down it can seem difficult to see the positives in your life. This can lead to a negative spiral that you may find hard to break."

> "I feel that swimming helps and makes me feel much better, it also helps my walking considerably."

- Rather than worrying about a particular concern, actively seek out information and advice to help deal with it. An MS nurse, therapist, GP, or even a friend or family member, can help.
- Talk issues through with others – this may be with a professional, a support group or just somebody you feel able to open up to. Sometimes all you need is to have someone who'll listen.

> "I try to improve my mood by going and getting my hair and nails done etc. If I look nice, I feel better."

"I remind myself frequently of all the plus points in my life, including spending time with family and friends. It's not always easy to do this, but I do try!"

"I meet up with friends and have a good moan to get things off my chest."

Positive thinking

When you're living with the problems, uncertainty and changes that MS can bring, it's easy to fall into negative thinking habits.

These negative thoughts can have a knock-on effect on your self-esteem. You may feel less confident in yourself and isolate yourself from friends and family. This can further drain your energy levels.

In contrast, positive thinking is based on looking for the good things in life and in people – and perhaps most importantly, in yourself too.

It'll take time, but by changing your thoughts to more positive ones you may feel more able to cope with the challenges your fatigue brings and be in a stronger position to start making other lifestyle changes.

One strategy you could try is turning self-critical thoughts into ones that show more self-compassion. For example, you might start to think negatively about yourself if you don't get all the housework done.

You might think: "I've not done this so I'm really lazy. I shouldn't be resting. Other people would be able to do it all and do it better than I can do it."

You can adapt your way of thinking to be more self-compassionate:

"If I push myself I'm going to end up feeling worse than I feel right now. I can do the other bits when I have more energy. I've done the amount that I feel capable to do today and that's a good achievement for me."

Small changes to your thoughts can make a big difference to how you feel.

"Research suggests mindfulness can help with easing fatigue and depression and improve quality of life."

Mindfulness

Mindfulness is a meditative technique that involves learning to focus your attention on your emotions, thoughts and sensations in an accepting and non-judgemental way.

Mindfulness encourages you to put aside regrets for the past and worries about the future, helping you concentrate more fully on the present moment. This can involve thinking about simple things that are happening around you, such as the feel of a breeze on your skin, the sound of birdsong or the taste and texture of a biscuit as you eat it.

The same observational, non-judgemental approach can also be applied to how you're thinking so you become more aware of what's happening in your body and your mind. This can help break the cycle of negative thoughts and emotions.

Research suggests mindfulness can help with easing fatigue and depression and improve quality of life.

You can learn how to practise mindfulness through one-to-one or group courses with a trained teacher. Alternatively there are books on mindfulness as well as videos, online courses and apps if you'd prefer to learn the practice at home.

Cognitive behavioural therapy (CBT)

Cognitive behavioural therapy or CBT is a psychological therapy. It's based on the idea that how you think about a situation influences how you act, and your actions in turn influence how you think and feel.

Sometimes your thoughts and behaviours can be unhelpful or unrealistic, so CBT encourages you to challenge your thought processes and adopt new behavioural techniques to help you handle your thoughts and feelings better.

Studies have found that CBT can be an effective treatment for fatigue in MS, as well as for anxiety and depression.

A CBT programme can be delivered in a number of ways and might be group-based, computer-based or by telephone. It is available on the NHS, though availability varies across the UK.

If you feel that CBT may be of benefit to you, speak to your GP who can make a referral. Alternatively, if you live in England, you can self-refer by finding your local psychological therapy service on the NHS website.

Acceptance and commitment therapy (ACT)

Acceptance and commitment therapy or ACT is another approach that uses some of the same principles as mindfulness and CBT.

Rather than trying to alter your thoughts and feelings, ACT encourages you to become more aware of the helpful and unhelpful ways you respond to them. The aim is to become more aware of, and in touch with, what matters to you and to help you find ways to do more of those things by working around any barriers you may face.

If you're interested in ACT, speak to your GP or MS nurse.

> "CBT encourages you to challenge your thought processes and adopt new behavioural techniques to help you handle your thoughts and feelings better."

Further information

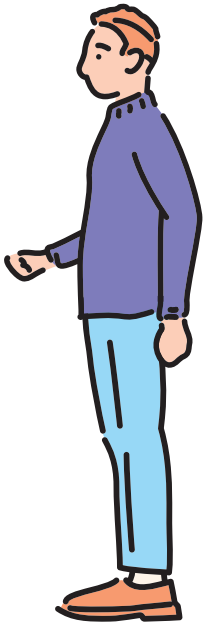
Depression:
mstrust.org.uk/depression

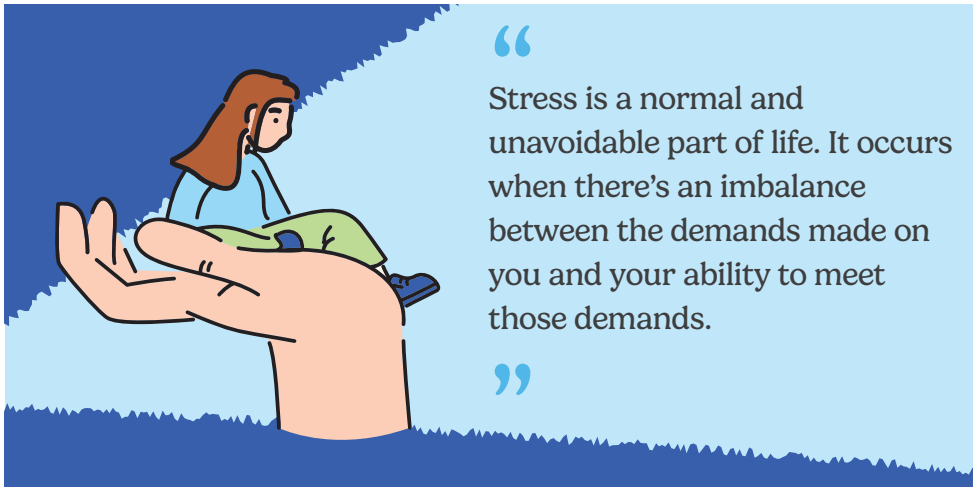
Support groups:
mstrust.org.uk/support

MS Trust Facebook groups:
mstrust.org.uk/fb-group

Psychological therapies:
mstrust.org.uk/psychology

NHS services near you
nhs.uk/service-search





4.3 Stress

Stress is a normal and unavoidable part of life. It occurs when there’s an imbalance between the demands made on you and your ability to meet those demands.

You might experience stress because of deadlines at work, family issues or if you need to adapt to new life circumstances.

Stress can cause physical changes to your blood pressure, heart rate and metabolism. In the short term, these responses can improve your physical and mental ability to cope with the stressful situation you’re facing – the ‘fight or flight’ response. However, left unchecked, excessive stress can have negative effects on both your physical and emotional health, including a direct impact on your fatigue levels.

Everybody reacts differently to stress, but there are some common symptoms you might experience:

- Physical – increased levels of sweating, muscle tightness, regular headaches, constipation or diarrhoea.
- Emotional – irritability, reduced concentration, feeling overwhelmed, problems making decisions, decreased confidence, low mood.
- Behavioural – difficulty sleeping, changes in appetite, reduced sex drive, increased drinking or smoking and reduced willingness to socialise.

Managing stress

What may be stressful for you may not be for somebody else. Lots of situations and life events have the potential to be stressful. How you deal with stress will be very individual to you.

When it comes to managing stress, there are three main stages.

1. Recognising the effect stress is having on your health.
2. Identifying what is making you feel stressed.
3. Taking action to remove or reduce the cause of stress.

Bearing these stages in mind, there are steps you can take to try and control your stress levels.

- Recognise your own signs of stress and take charge of your own emotions, thoughts and actions.
- Stay positive and keep things in perspective. Focusing on only the bad things that might happen will prevent you from enjoying the good things that are happening right now.
- Be kind to yourself.
- Take time out to do something you enjoy. Taking a step back from stressful events can change your perspective on problems and relieve some of the build up of stress.
- Discuss your worries with others rather than keeping them to yourself. Even if they can’t directly change what’s causing the stress, another person’s point of view can put things in perspective.
- Plan ahead. Prioritising activities can create more time for essential tasks and also identify potential areas of stress in advance (see sections 5.1 and 5.2).

- Stay active. Physical activity is one of the most effective stress remedies, improving mood and self-esteem. It can also act as a safe way to let off steam, or work off anger or frustration which doesn't involve taking things out on other people.
- Try some mindfulness exercises or relaxation techniques (see sections 4.2 and 4.4).

"I try not to worry too much about the things that I can't change. Not always possible, I know! There are usually ways around problems and I'm lucky, I have a supportive husband and really good friends."

"Say 'NO' occasionally! Give yourself permission to enjoy yourself – and stop feeling guilty."

"I make my feelings known to others to help alleviate stress and low mood."

Further information

Stress: *mstrust.org.uk/stress*

> "Say 'NO' occasionally! Give yourself permission to enjoy yourself – and stop feeling guilty."

4.4 Relaxation techniques

Relaxation techniques are activities that leave you with a feeling of complete peace and calm, and allow you to shut off from daily hassles and routines.

Relaxation is an active skill that requires practise. Like sleeping, you can't force a state of relaxation. It requires mental rest as well as physical and so differs from passive activities such as watching television or reading. It's also not the same as sleeping.

Regular relaxation can reduce tension in your muscles, and lower your blood pressure and heart rate. It can help with fatigue as it promotes good sleep patterns, increases the benefit of rest breaks during the day and can be used to reduce your stress levels.

Types of relaxation

Finding the right relaxation technique for you may take time. You may want to try different techniques for different purposes, eg deep breathing to help you relax before sleeping and visualisation

> "I find deep breathing encourages and increases relaxation and sleep."

techniques to boost your energy levels during the day. It's entirely up to you – different techniques suit different people.

The following list contains a few examples you could try, but there are many more.

Deep breathing

Most of the time we don't think about our breathing. However, focusing on how you breathe and creating a slow, deep and even pattern can help you to feel calmer and more relaxed. It can also distract you from any stresses or worries you may have.

"I find deep breathing encourages and increases relaxation and sleep. I breathe in for seven seconds and breathe out for eleven. I repeat this several times."

> I try to make time for a rest during the day. Visualising myself on an empty beach with cold water lapping over my feet is great.

Visualisation techniques

Visualisation involves using your imagination to go to a relaxing place. This could be somewhere you've visited, seen on the television or in a magazine, or somewhere entirely from your imagination. The knack with this technique is focusing on all the senses to experience in detail what you can see, hear, smell, taste and feel within your chosen scene.

"I try to make time for a rest during the day. Visualising myself on an empty beach with cold water lapping over my feet is great!"

You may find it helpful to use gentle background music or photos of places with happy memories. There are also apps, videos, audiobooks, podcasts and CDs available with audio that guides you through relaxing scenes. Finding the right combination of voice, speed of speaking, music and subject matter for you may take some experimentation.

Muscle relaxation techniques

These techniques help you to relax various muscle groups in your body. This helps you to feel calm and relaxed whilst helping you identify areas of your body which are particularly tense.

There are many books, videos and online resources that explain techniques and exercises in more detail, but the basics are usually the same.

- Set aside some quiet time to concentrate on the exercises.
- Lie or sit comfortably. You may want to play some relaxing music.
- Spend time concentrating on your breathing.
- Working down your body, tense one muscle at a time, hold for around 10 seconds and then relax.
- Notice how different a relaxed muscle feels – enjoy that feeling.

If you experience problems with spasticity or stiffness, discuss this with a health professional before trying a muscle relaxation technique.

Massage

Massage helps to relax your muscles and relieve tension as well as providing the soothing benefits of touch. Massage can be given by a trained professional, although courses, books and videos are available for partners or friends to learn basic techniques. Massage is sometimes combined with aromatherapy.

Aromatherapy

Aromatherapy is the use of essential oils to promote health and wellbeing. Some oils are thought to have relaxing effects, such as lavender. You can use the oils in the bath (if heat sensitivity is not an issue), as a steam inhalation, in an oil burner or during a massage.

Although aromatherapy oils are usually used with no problems, some people are allergic to certain fragrances and some oils may cause a rash if applied to the skin. It's therefore best to seek advice before starting aromatherapy.

Yoga, Tai Chi and Pilates

These exercises use combinations of breathing, movement, posture and meditation. You can do yoga, Tai Chi and Pilates yourself using commercially available books, videos and apps, or by attending a class.

"I find Pilates works best at relaxing me, and because it helps my posture it also relieves muscle tension."

If you attend a class that's not specifically for people with MS, let the teacher know so they can adapt the exercises for you.

"I find the breathing and gentle stretching of yoga very helpful for easing the tension and anxiety that stops me sleeping. It took me a long time to find a class that suited me though."

> "I find reflexology reduces my pain, helps me relax and improves my sleep.

Reflexology

Reflexology is a complementary therapy that involves having gentle pressure applied to the soles of your feet. Some people find that it helps them to feel more relaxed, eases their anxiety and reduces their fatigue.

"I find reflexology reduces my pain, helps me relax and improves my sleep."

Therapies like massage, aromatherapy, reflexology, yoga, Tai Chi and Pilates are all offered at MS Therapy Centres around the UK. These centres provide a range of non-drug therapies for people with MS. You can find your nearest centre using our online map.

Further information

Relaxation:
mstrust.org.uk/a-z/relaxation

MS services near me :
mstrust.org.uk/map

4.5 Heat sensitivity

You might find that changes in temperature contribute to your fatigue. It might be triggered by the weather, hot baths or showers, hot drinks or meals, exercising or feeling feverish because of an infection.

These effects are usually reversed when you take steps to cool down and your temperature returns to normal.

"By being too hot I can sometimes feel completely debilitated and the cooling process takes a long time. It affects me when showering and I no longer lie in the bath. Also after eating a warm meal, I need help getting up from the table. I choose salads and sip iced water while eating."

"I'm unable to function in hot weather and overheat in bed with a thin quilt on in winter! I use the lightest duvet available. It prevents overheating, as well as being lighter to handle."

There are lots of cooling techniques you could try.

- Take a cool bath or shower.
- Have regular cold drinks or suck an ice cube.
- Spray your face with cold water using a small spray bottle.
- Floor or desk fans can be useful at home and handheld fans when you're out and about.
- Use cooling garments such as neck wraps, wrists bands and cooling jackets.
- If you get hot at night, cooling pillows can help or you can try cooling gel pads which are inserted or placed on top of your current pillow.
- An air conditioning system or air cooler can reduce the room temperature during the summer. Permanent devices can be expensive, but there are cheaper, portable models available.

"I find that in extreme heat lying in a tepid bath for a while cools me down and energises me again."

"I wear cooling scarves and bandanas. Marvellous! I also use an electric fan – especially when ironing."

Although less common, some people with MS find that cold temperatures can trigger their fatigue. If this is the case for you, taking steps to warm up – such as wearing additional layers – will help to increase your body temperature and should ease your fatigue.

Further information

Temperature sensitivity: *mstrust.org.uk/heat*

4.6 Physical activity

In the past it was felt that because many people with MS experienced fatigue or found their symptoms worsened when they were hot, it was best to avoid activities that might be tiring. This view has now been completely overturned by research that shows there are specific benefits of exercise for people with MS who experience fatigue.

"I am fitter now than before diagnosis. Despite being told to 'take it easy' by people after diagnosis, I have managed to improve my stamina considerably by exercising regularly."

"I am fitter now than before diagnosis. Despite being told to 'take it easy' by people after diagnosis, I have managed to improve my stamina considerably by exercising regularly."

> “I have successfully improved my sleep, low mood and depression and maintained a positive outlook on life – all with daily exercise.”

Some form of physical activity as part of your daily routine is an essential element of a healthy lifestyle. Low activity levels cause under-used muscles to become weaker, which means that stamina levels and fitness are reduced. This means your body has to work harder when carrying out everyday activities, so they consume more energy and increase fatigue.

“I am aware that too much sleep and inactivity can have a debilitating effect and with that in mind try to keep mobile through the day as much as possible.”

Although the symptoms of MS may mean that it’s not possible to continue with the same type or level of physical activity as you enjoyed before diagnosis, it’s important to continue trying to stay as active as you possibly can.

“In the past I exercised on a daily basis. After a seven month layoff, I recognised a marked decline in my overall wellbeing. I experienced classic signs of depression and my usual sanguine outlook vanished. Having experienced the benefits of regular exercise I am confident I can turn this around but the challenge is overcoming the obstacle of fatigue.”

Physiotherapists can suggest exercises that take account of your MS symptoms. Gyms and health centres have staff who can design exercise programmes to suit your level of ability and fitness.

The benefits of exercise

Maintains fitness

Other MS symptoms can mean that it takes more energy to carry out daily activities, such as walking or climbing stairs. Keeping fit helps muscles work more efficiently and minimises the amount of energy you use when doing these activities.

“Once I worked out what was going on (less activity, leading to more fatigue, leading to less activity) I found exercising at the gym a HUGE benefit!”

Improves sleep

Regular physical activity promotes better sleep patterns.

“I have successfully improved my sleep, low mood and depression and maintained a positive outlook on life – all with daily exercise. The three are inextricably entwined; you can’t have one without the others.”

Psychological benefits

Regular physical activity helps the brain to release endorphins which give a natural high after exercise. This can improve your mood, self-esteem and confidence, reduce your stress levels and leave you feeling energised.

“I work out twice a day, and this seems to rev up my energy levels. Exercise wakes me up.”

Assists in weight management

Regular physical activity can help you to reach and maintain a healthy weight.

What counts as physical activity?

People sometimes think physical activity means high energy exercise, which can be off-putting. However any activity that increases your heart rate and your breathing is beneficial.

Everyday jobs such as ironing, dusting, climbing stairs or washing the car are all activities that can go some way towards improving health and reducing the impact of fatigue, as well as more strenuous activities like swimming and running.

"Walking my dogs is good exercise and good for my mojo."

How much should I be doing?

The Department of Health and Social Care recommends that adults should aim to be physically active every day.

It's recommended that you aim to do at least two and half hours of moderate intensity activity each week. You can do this in sessions of any length.

Moderate intensity activities include a brisk walk or slow jog, aqua aerobics or mowing the lawn. You should also try to do some activities that strengthen your muscles at least twice a week, eg using resistance bands or weights, carrying heavy shopping or digging the garden.

Use the 'talk test' to check the intensity level of the activity you're doing. During a moderate intensity activity you should able to talk but unable to sing.

One way to meet this guidance is to try and do 30 minutes of activity on at least five days a week. This doesn't have to be in one chunk – you could break it down into a few 10-minute sessions spread throughout the day.

Reducing the amount of time you spend being inactive by introducing even short bouts (eg 5-10 minutes) of light physical activity will help to improve your fitness and fatigue levels. So take it slow, fit it in where you can and build up gradually.

> "Walking my dogs is good exercise and good for my mojo."

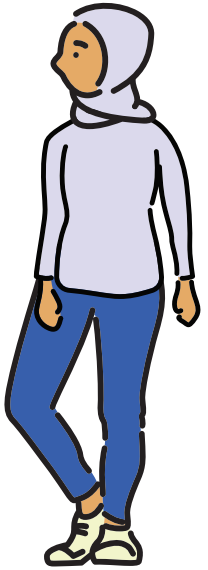
The key message here is that even a little movement is better than nothing.

"I have enrolled at the local sports centre and get there when possible. I try to walk on the treadmill at a reasonable pace and I aim for ten minutes, but if I find I'm getting too tired I sit and watch for a while."

Getting started

Which activities are appropriate for you will depend on your particular symptoms, circumstances and interests, as well as your previous activity levels. It can be trial and error to find out what's suitable and, most importantly, enjoyable for you.

"I do like getting out into the countryside. Disguising exercise as something interesting helps me."



> I do like getting out into the countryside. Disguising exercise as something interesting helps me.

"The exercises helped improve my general fatigue and the class itself improved my mental wellbeing by getting me out of the house, engaging with other people and having a laugh!"

When trying a new activity it's best to start at a level that feels comfortable. Increase the intensity gently and don't try to achieve too much too soon.

"I have found that swimming regularly has helped. I may not be a torpedo in the water but I plod along."

Take plenty of rests during physical activities, especially those done over a longer duration. Taking a couple of minutes rest every so often will mean you're not as tired at the end of the session but you'll still have achieved a lot.

It's normal to feel tired after an activity that involves effort but this shouldn't be confused with fatigue and usually dissipates within a couple of hours.

The unpredictable nature of MS means that physical activity routines should be flexible enough to respond to any problems that arise. Remember on bad days that it's OK to do less activity than planned for that day, but try to be more active again on better days.

What kind of exercise?

There's no right or wrong type of exercise – there's a huge variety that you could try. It's about finding what works best for you and this might involve a bit of trial and error.

Aerobic, balance and stretching exercises are all recommended specifically for fatigue. Any activities that increase your heart rate and make you breathe faster fall under aerobic exercise. This could include activities like walking, swimming, running and wheelchair sports, or even just doing some hoovering around the house. Balance and stretching exercises can be slower paced and include activities like yoga, Pilates and Tai Chi.

Resistance exercise is also recommended for people with fatigue. Resistance training (also known as strength or weight training) builds strength by making your muscles work against some kind of resistance, eg by using free weights (like dumbbells) or resistance bands – stretchy pieces of material that can be used in different positions to target specific muscles.

Resistance classes are available at some MS Therapy Centres around the UK.

If other MS symptoms are making exercise difficult, or you're not sure what type of exercise would work for you, speak to a physiotherapist. They'll be able to advise on exercises that will best suit you and your ability. Your GP or MS nurse can refer you to a physiotherapist in your area.

With any type of exercise, the most important thing is to make sure you start at a level that you feel comfortable with and build up from there.

Keep exercising!

It's important to keep up with your exercise routine as much as possible so you continue to see the benefits from it in the long term. Research shows that any benefits you gain from becoming more active are gradually lost if you become less active again – it really is a case of use it or lose it.

If physical activity seems like a chore, it's easy to lose motivation and stop. Here are some steps you can take to increase the likelihood of continuing with regular exercise.

- Try a variety of exercises and choose the one/s you enjoy the most.
- Enlist a friend or family member for support so you can encourage each other.
- Join a local exercise class if there's one near you.
- Set some goals for yourself, making sure they're realistic.
- Develop a routine by planning when you're going to exercise each week and sticking with this plan as far as your MS allows.

If you're struggling to build up the motivation to exercise, speak to your GP or MS nurse as they may be able to refer you to an exercise referral scheme.

Further information

Exercise: *mstrust.org.uk/exercise*

Build your own exercise routine: *mstrust.org.uk/exercises*

Neuro Pilates with physiotherapist Joanne Pritchard: *mstrust.org.uk/neuro-pilates*

4.7 Diet and nutrition

Eating a healthy, balanced diet will help to give you the best energy levels. To achieve this, it's recommended that you try to eat a variety of foods from the five main food groups.

- Eat at least five portions of fruit and veg every day – this should make up just over a third of what you eat.
- Base your meals on starchy foods that are high in fibre such as potatoes, bread, rice and pasta (choose wholegrain versions if possible like brown rice and whole wheat pasta) – this should also make up just over a third of your diet.
- Include some dairy or dairy alternatives in your diet (choose lower fat and lower sugar options if you can).
- Eat some beans, pulses, fish, eggs, meat and other proteins (including two portions of fish every week, one of which should be oily).
- Choose unsaturated oils and spreads and eat them in small amounts.

It's also important to drink plenty of fluids, particularly water, throughout the day. Being even mildly dehydrated can cause tiredness and sluggishness, adding to your fatigue. The recommendation is to drink six to eight glasses a day.

> Eating regularly and healthily definitely improves my energy levels.

"When you go out, carry water with you in the car or in a backpack – and remember to drink it!"

Trying to maintain a healthy weight is also helpful as being overweight or underweight can increase fatigue.

"I was on a weight reduction diet for about six months and found that as well as losing weight, I had a clearer head and more energy."

"Eating regularly and healthily definitely improves my energy levels. Bothering with breakfast is the most difficult for me, but makes the biggest difference!"

Sugar

Although food and drinks high in sugar can give you an initial boost, blood sugar levels quickly drop again leaving your energy levels low. They're also often low in nutrients, and the extra calories can cause unwanted weight gain.

"When I suffer fatigue, I get an overpowering craving for chocolate and sweets. They don't really work to relieve my tiredness, but I get a short lived 'comfort buzz' which has to be continuously topped up throughout the day – adding to an unhealthy lifestyle."

The rate sugars are released from foods is called the glycaemic index (GI). Foods which are rich in complex carbohydrates, such as milk, fresh fruit, yoghurt and multigrain bread, have a low glycaemic index, meaning they give a slower, more sustained energy release.

Eating a low GI food at the same time as a high GI food can slow down the rate of release, for instance a glass of milk with a sweet biscuit.

> When you go out, carry water with you in the car or in a backpack – and remember to drink it!

Preparing food

You might find it helpful to think about ways to reduce the impact of fatigue when you're preparing meals.

- Organise the kitchen to keep commonly used items close to hand.
- Keep the kitchen as cool as possible.
- Cook at times of the day when your energy levels are higher.
- Cook in bulk when you feel less fatigued and freeze for a later date.
- Sit rather than stand to prepare and cook meals.
- Get all the ingredients and utensils together before you start.
- Make use of equipment or labour saving devices where possible, such as electric mixers, can openers, soup makers and slow cookers.
- Use ready prepared foods, such as grated cheese, diced meat and pre-washed salads, to reduce the energy required in preparing these foods. Frozen fruit and vegetables are as high in vitamins as fresh.

- Use wire baskets in pans rather than lifting heavy pans.
- Microwave cooking avoids having to lift heavy pans and doesn't heat up the kitchen.
- Invest in a one-pot cookery book to save on washing up.
- A kitchen trolley is useful to avoid extra walking and carrying in the kitchen and when serving.
- Soak dishes rather than washing up straight away.
- Consider a meals delivery service – help may be available from social services.
- Have recipe boxes delivered to your home. These boxes contain recipes and all the ingredients you need, saving you energy on planning and shopping for meals.

Eating meals

It can also be useful to consider how your fatigue may be affected when you're eating meals.

- Large meals can leave people feeling bloated and sluggish. If this is the case for you then try having more frequent, lighter meals with healthy snacks in between such as fresh fruit, nuts, natural yoghurt and raw vegetables with dips.
- Try to eat main meals when your energy levels are higher.
- Don't miss out on breakfast. If the first meal of the day is lunch, then the body may have gone 16 hours or more without food.
- When fatigue is a problem it can be easy to rely on ready meals and snacks which can be high in fat, sugar and salt. Try keeping the ingredients for a few quick, healthy meals ready for use. Also have some healthy snacks on hand, like fruit and cucumber sticks.
- Convenience foods can help at times when a healthier approach is not possible. Look out for healthy eating options and add extra vegetables or salad.

"Try having more frequent, lighter meals with healthy snacks in between such as fresh fruit, nuts, natural yoghurt and raw vegetables with dips."

4.8 Infections and relapse

Other common medical conditions and infections can drain energy and cause your fatigue to worsen. This includes things like a cold, stomach bug or urine infection.

The onset of a relapse can also make existing MS symptoms like fatigue worse.

A GP can investigate whether there is an underlying medical cause that might be adding to your fatigue and can suggest appropriate treatment options or refer you on to other services. Your MS nurse can provide support if you're going through a relapse.

Once the infection has cleared or you've recovered from the relapse, your fatigue levels should go back to their previous level.

4.9 Medication

Drugs that make fatigue worse

Some medications can increase drowsiness and worsen fatigue. This applies to all types of treatments – prescription, over the counter, alternative and illegal – regardless of whether they're being used to treat MS or not. Of the drugs for MS symptoms, treatments for muscle spasms and stiffness and pain are often associated with an increase in fatigue (eg baclofen and amitriptyline).

An understanding of the potential benefits and side effects of drugs is important if fatigue is a concern for you. It may be worth asking a doctor or pharmacist to review your medication to identify potential problems and suggest solutions (eg reducing the dose or changing medication).

Drugs to treat fatigue

Medication isn't a solution to fatigue on its own and should be used in addition to the fatigue management techniques discussed in this book, not as an alternative. Medication should not be prescribed until there has been a full evaluation of the underlying causes of fatigue.

> "An understanding of the potential benefits and side effects of drugs is important if fatigue is a concern for you."

For instance, if sleep problems or lack of fitness are key contributors to fatigue, any treatment regime that doesn't also consider these issues will only be partially helpful.

There are a few drug treatments that can be considered for fatigue, although robust research supporting their use is quite limited. The medications listed below can be helpful for some people when used alongside fatigue management techniques. These drugs don't work for everyone and, unfortunately, they can't get rid of fatigue completely.

- Amantadine (Symmetrel, Lysovir)
- Modafinil (Provigil)
- Selective serotonin reuptake inhibitors (SSRIs)

These medications can only be prescribed by an MS specialist, such as a neurologist. If you're interested in trying a drug treatment for your fatigue, you should discuss this further with your MS team.

5. Using your energy effectively

As well as taking steps to build up your energy levels, the other key element in managing fatigue successfully is using the energy you have in the most effective way.

There are a range of techniques involved.

- **Planning** – looking ahead, thinking about what is achievable and not making unrealistic demands on your energy levels by trying to tackle too much.
- **Prioritising** – thinking about what you need to do or want to achieve and focusing on the most important tasks.
- **Delegating** – asking for help from others to see if there is anything they can take on for you.
- **Saving energy** – thinking through specific tasks to see if there are ways of doing them in a more energy efficient way.

> “Be realistic and know your limitations, but don’t aim too low! MS is not an excuse for ducking out of life!”

- **Pacing yourself** – doing tasks at a rate that is comfortable, with breaks and rests planned in.

These approaches overlap to some extent and effective fatigue management will probably incorporate aspects of all of them. The techniques will require some trial and error to find a routine that suits you and your daily life. It may take some time and perseverance for you and those around you to see the benefits.

Although these techniques may actually mean doing less than previously, the aim is to conserve your energy for the activities that are most important to you.

“Be realistic and know your limitations, but don’t aim too low! MS is not an excuse for ducking out of life! Concentrate on what you can do, not what you can’t.”

5.1 Planning

Planning involves taking some time to stop and think about what you need to do and what you can realistically achieve. Efficient use of limited energy supplies means that you can achieve more.

“I have found my fatigue to have lessened since diagnosis, partly because I have learnt to say no. You really have to practise assertiveness techniques. I pre-plan and only do one major task each day.”

> I plan my day using a notebook. Often, when I feel that I haven't had a good day or achieved all that I wanted to, I check the notebook and I've often done more than I thought.

"I buy a huge A4 sized diary, and write everything down I have to do, so I can see how busy the days are going to be. Then I tackle one thing at a time."

It's human nature to want to get straight on with tasks. This is fine when energy levels aren't an issue. However, when you've only got limited reserves, this can lead to jobs being left half done or important activities not being tackled as you've used all your energy on more mundane tasks.

"MS fatigue makes me feel like I'm a very old car with a dodgy battery! Most mornings I wake up full of plans and ideas for the day, by noon the battery is low and I'm feeling weary. By 3pm I'm exhausted."

"If I need to do any housework or go into town I make sure I'm done by noon. Then I have lunch and go to bed for around two hours.

That refreshes me in time to get the kids from school."

Planning is a very individual process. It requires an awareness of the effects of fatigue on you and a realistic approach to how much you can do.

You might find some activities more fatiguing than others. By monitoring the effect of different tasks, you can start to gauge what is more or less likely to add to your fatigue.

"I try not to drive into town too many times a week. I do the washing, ironing and hoovering on the days I don't have to go out."

"I have to plan life carefully. If I'm working I can do absolutely nothing else. I'm so drained I have no energy to even concentrate on reading."

Planning involves taking time to think ahead about activities. Avoid too many energy-demanding activities in a short time or when there's a higher chance you'll be fatigued.

Keeping notes in a diary or using an activity planner, for instance on the fridge door, can be helpful. There are also a wide range of apps you can download on your phone or tablet which can record to-do lists and upcoming events. Having strategies like this can help you think ahead and plan your time better.

"I plan my day using a notebook. Often, when I feel that I haven't had a good day or achieved all that I wanted to, I check the notebook and I've often done more than I thought."

5.2 Prioritising

Some jobs will be more important to you than others. If your energy levels are limited, it can be better to focus on a small number of essential tasks, rather than trying to do everything at once.

You could start by writing a list and then ordering the tasks by how important they are. Have a think about what's absolutely essential and whether there's anything that could wait until another day.

"I advocate the four Ds – dump it, delay it, delegate it, do it. If you can't dump it, delay it or delegate it, then you have to do it – but by this time there should be a lot less to do!"

It may help to break bigger activities down into smaller tasks. For instance, rather than considering doing the laundry as one activity, break it down into its various elements – sorting the dirty washing, loading the machine, emptying the machine, hanging the washing up to dry, doing the ironing. Do all of these activities have to be done as one activity? Do they all have to be done by you?

"Prioritising was such a helpful idea! My energy levels are higher in the morning so I get the 'important' tasks done then. If they're not all completed, by dealing with them on a list I'm not so overwhelmed by them and I don't get so stressed. I'm also getting better at requesting help from family and friends when necessary."

"I take each day as it comes and do only what I can. Prioritising helps and I explain to those around me how I feel. After all, they can't read your mind."

What you consider essential activities will be unique to you. They'll be influenced by your lifestyle, responsibilities, interests and beliefs. Priorities often change over time, so try not to get stuck doing things one way because you've always done them that way.

It's important to remember that essential activities should include things you enjoy. Household or work related tasks may seem more important, but if all your energy is taken up on these tasks then you may risk not having enough energy left for the more pleasurable things in your life. Try to make social activities a priority too!

5.3 Delegating

As with some other aspects of managing fatigue, it can take time to get used to delegating tasks. You may feel uncomfortable or guilty about asking others to do jobs that you'd normally do. You might feel like you're giving in to fatigue or losing control. You might be worried that someone else won't do the job exactly how you like it done.

"As 'Miss Independent' I hate asking anyone to do anything."

"I've reluctantly had to pass some tasks on to others. However, my experience of asking for help is a positive one."

Sometimes people are more willing to help than you might expect. However, when delegating, remember that people have their own lives and commitments and may not be able to help when you need it.

"Planning and prioritising is difficult as I depend on others to accomplish routine tasks. The greatest challenge is in communicating what needs doing when, so that those I depend on can plan their own time."

Properly handled, delegation frees up time and energy for important activities and means that you can achieve more.

"My kids help out a lot. We make supper a family job. I made a chore chart so they know who does what. It helps a lot."

"People like to be asked to help... I know I do! Ask for support when you need it – most people have no idea what it's like to have MS or how they can help."

"I try to put myself first and not feel guilty about leaving things half done until another time."

Delegating tasks doesn't just mean asking family, friends or work colleagues for help. It could also mean getting some help around the house by hiring a cleaner, gardener or dog walker.

> "People like to be asked to help... I know I do! Ask for support when you need it – most people have no idea what it's like to have MS or how they can help."

5.4 Saving energy

As well as saving energy by planning, prioritising and delegating activities, successful fatigue management also involves trying to do tasks using as little energy as possible. This may involve changing how you would normally do certain daily activities.

Here are a few suggestions.

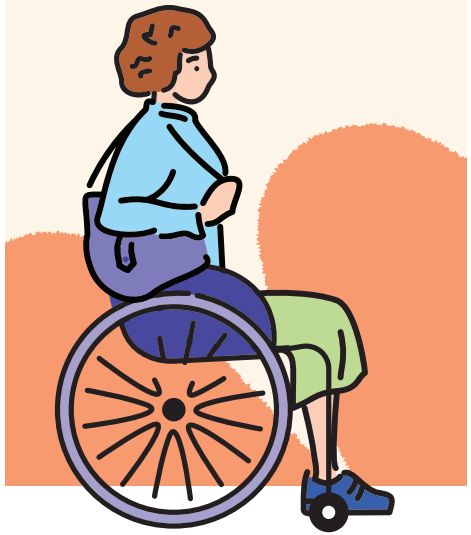
- Keep the working area as cool as possible, for instance when preparing food in the kitchen.
- Sit rather than stand for jobs where possible, such as when doing the ironing.
- Make use of labour saving equipment and products like an electric toothbrush.
- Organise the work area so everything is to hand to avoid unnecessary walking, bending and reaching.
- Store commonly used items within easy reach.
- Be aware of your posture – maintaining a poor posture or staying in one position for long periods of time takes up energy.
- Discuss changes at work that could help you conserve energy, such as being able to park closer to the building. Under the Equality Act employers have a duty to consider making reasonable adjustments to help you stay in employment.

"I shop online wherever possible – stuff gets delivered straight to my door!"

"I reduce energy spent on transporting items – for instance, to avoid carrying cleaning materials, I keep two sets of everything, one upstairs, the other downstairs."

"I've swallowed my pride and use a wheelchair when out and about! I think of it as a tool that enables me to do more by conserving the energy I'd waste lugging myself around."

> "I've swallowed my pride and use a wheelchair when out and about!"



5.5 Pacing yourself

Pacing involves taking planned breaks or rests during or between activities. Often this requires some self discipline as it can be tempting to try to get to the end of a job without stopping. However, it can be more beneficial to take things steadily rather than continuing with an activity to the point of exhaustion and then suffering the consequences.

"I used to make little attempt to pace myself throughout the day and tried to carry on like before. The only problem with this was that I'd find myself fatigued halfway through the day when all my MS symptoms would rear their head."

Recovering your energy levels if you've overdone things can take longer when you have MS. Where other people might recover after a short break, people with MS can find it takes several hours or longer. This can have an effect on your mood. It can also mean you can't do other things you had planned for that day.

"In the earlier days of my MS, a short rest would do the trick. Now I have to sit for longer between bouts of activity. If I ignore the

> In the earlier days of my MS, a short rest would do the trick. Now I have to sit for longer between bouts of activity.

signs that I need to stop, I often need several hours rest before I can carry on again, if at all."

Doing tasks more slowly or taking regular breaks can help to stop fatigue from building up. You might find you can achieve more in a series of shorter chunks broken up with periods of rest, rather than working straight through until your fatigue becomes overpowering.

A break is different from sleep, though some people do find that a nap in the afternoon for a set period can help preserve some energy for the evening. Breaks can be a short period of relaxation (see section 4.4) or minimal activity.

"I pull the phone plugs out and switch the mobile off/onto silent when resting."

"Some quiet time to myself in the afternoon makes it possible to take care of my family when they get home."

"I need to have regular breaks while I'm working, even if only to have a stretch and change position."

"I build in rest periods. When I put the potatoes on to boil, I sit down for 10 minutes and shut my eyes while they cook! Rest, rest, rest! It's boring but it works."

Conclusion

As you can see from the techniques discussed in this book, managing your fatigue will require an approach that's personal to you.

By reviewing your lifestyle and how fatigue affects you, you can start to make small changes and apply some of the practical strategies to your own life.

For more support and to explore the topics discussed in this book further, speak to your MS nurse or GP. It may also be worth asking them about taking part in a fatigue management programme.

These techniques may not make fatigue go away completely, and it won't be possible to make all the changes immediately, but they can help you start to manage your fatigue and take steps to reduce the impact it's having on your daily life.

> It's been a slow process coming to terms with the MS and fatigue, but life for me is so much better than six years ago. I feel more in control, which is important to me.

For more information on fatigue, scan or visit mstrust.org.uk/a-z/fatigue

About the authors

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Michelle has worked with people with MS for many years and was involved in the development of fatigue management interventions at The Walton Centre. These interventions helped people with MS increase their understanding of fatigue and develop strategies to manage its impact. Michelle went on to spend several years as a Lecturer in Occupational Therapy at the University of Liverpool, before returning to a full-time clinical role at The Walton Centre within a regional specialist service for people with neuromuscular conditions.

MS Trust Health Information Team

MS Trust brings together expertise from every angle to help everyone feel more in control of their MS today and every day.

Through trusted information and compassionate support, the training of new MS healthcare professionals, and research rooted in real experience – we're here for every MS. Every day.

Thank you to

MS Trust would like to thank all the people living with MS fatigue who have made this book possible through sharing their experiences. We would also like to thank the following health professionals for reviewing the text and their important contributions:

- **Jenny Thain**, MS Specialist Physiotherapist, The Walton Centre, Liverpool
- **Alison Johnson**, Occupational Therapist
- **Susan Hourihan**, Occupational Therapist, The National Hospital for Neurology and Neurosurgery, London
- **Fiona Roberts**, Senior Occupational Therapist, The Walton Centre, Liverpool

Please contact MS Trust's health information team if you would like any further information about the reference sources used in the production of this publication.

Bibliographical information

Michelle Ennis, MS Trust Information Team Living with fatigue: a guide for people with MS ISBN 1-904156-10-X

This edition published 2024. The publication will be reviewed in three years.

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