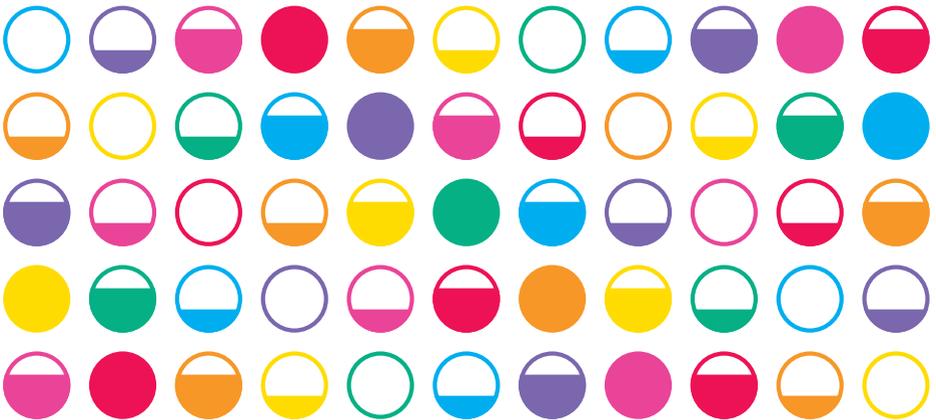


Living with fatigue

fatigue management
for people with MS



We hope you find the information in this book helpful. If you would like to speak with someone about any aspect of MS, contact the MS Trust information team and they will help find answers to your questions.

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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 people manage their own fatigue. It is illustrated with comments by people with MS who know what it is like to live with fatigue and draws on experience across a range of disciplines, including occupational therapy, physiotherapy, medicine and nursing.

Research shows that fatigue is experienced by the majority of people with MS. Managing fatigue effectively requires a very individual approach. Although several different health professionals may be able to offer help with aspects of fatigue, the key person is the one who is experiencing the symptom. Fatigue can only be effectively managed when the individual recognises and understands the effect fatigue has on their life and is prepared to find ways to work around the problems posed.

Learning how to manage fatigue is a slow process and the lifestyle changes involved take patience and perseverance. The combination of contributing factors means that fatigue levels can vary from day to day and within the day.

It is not possible to make fatigue go away completely but, through an awareness of the symptom, consideration of lifestyle and the use of particular techniques, it is possible to start to manage fatigue and take steps to reduce the impact it has on daily life.

1. What is fatigue?

What I find is that no one, but no one, who doesn't have fatigue from MS has any idea what it's like - Sue

Fatigue is one of the commonest symptoms of MS and can have a major impact on daily life. The level of fatigue does not necessarily reflect the severity of someone's MS. People can experience fatigue that interrupts their lifestyle or that prevents them from working whilst having few other symptoms.

The fatigue feels as if I had walked a mile without food and almost no water. I am not able to stand for long periods of time. Playing with my children is hard. I have no stamina - Mabra

As a physical sensation it reminds me of falling into quicksand/a swamp - it's a viscous, heavy, pulling feeling, but if I try to fight it, it hurts like hell and robs me of breath. As a sound, it's like a muted background noise of violins, scratching away, that seem to be ever increasing in speed and out of sync - while the outside world seems dampened and fading - Jackie

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

Periods of fatigue may also cause other MS symptoms to worsen temporarily. This is particularly true of cognitive symptoms such as problems with memory, concentration and attention span. Often, when people with MS are fatigued, it can seem harder to think clearly or to keep the mind on the job. As the episode of fatigue passes, these symptoms will return to their previous level.

As with other MS symptoms, fatigue affects different people in different ways.

Fatigue feels as if I am an inflatable, and someone has pulled the airstopper out! My brain goes fuzzy and I can't think clearly, my speech slurs, my eyesight goes and my eyes start to close - I think the room is full of smoke! Swallowing becomes more difficult, my balance gets worse, my legs feel heavy and clumsy - Karen

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. I end up leaving the front door unlocked, forget to switch off the fire etc. I can't remember if I've paid a bill or not, or where I put the receipt if I did pay it - Jackie

As an 'invisible' symptom, fatigue is often 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 experienced by people with MS.

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 - Jennifer

Lack of understanding of the symptom may lead others to believe that the person is just lazy or is putting it on - views that can sometimes be shared by the person with MS as they struggle to deny to themselves how fatigue affects them. Admitting to fatigue is sometimes thought to be a sign of defeat or giving in to MS, of not being up to the job and letting other people or oneself down. It is not unusual for people to feel guilty about being fatigued.

I still sometimes feel guilty that I should do more, and sometimes slip back into old ways of taking on too much, not taking a break, but I soon pay the price with a worsening of symptoms - Diane

Until it is experienced, it is hard to understand the impact of the symptom and how debilitating it can be. At first, many people with MS themselves will also underestimate the force of fatigue.

Even though I am in a wheelchair I often say that the MS without the fatigue would be comparatively nothing - Sue

I put off eating, bathing or just about anything because it's too much trouble - Bill

The realisation that fatigue is a symptom of MS and needs managing as such can take time. There is the urge to keep on plugging on to get the job done or a feeling that there is no one else who can properly do the task in hand. Often the expectations of family or colleagues or pressures of deadlines can drive people to push their 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 is a barrier. Unfortunately, most people find it difficult to recognise what their limits are until they have overstepped them and experienced the consequences. Where recovery from normal exertion and tiredness is relatively swift, for the person with MS it takes much longer to build energy levels back up again.

I drove to see my new grandchild. Although I stayed overnight to rest, trying to catch up at home on my return took a toll on me in the end. I felt exhausted and didn't wake up for 17 hours, only to use the loo. When I did wake up, my body felt so tired it didn't want to move - Tracey

Coming to terms with the effects of fatigue, both for the person with MS and the people around them, may take some time. People experiencing fatigue may find it difficult to play the role in life that they and others expect and this can put extra pressure on family members and colleagues. This in turn can lead to frustration, irritability or feelings of depression.

I feel like I am in a jail cell as I am so tired all the time. It makes me feel angry, bad tempered and depressed. I hate my home because I cannot clean it the way it once was - Liz

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, feels like it's going down the drain - Jacqueline

People's attitudes are an issue. If I say I'm not feeling up to going out on a particular occasion, they assume that I will never be well enough again so they don't ask me again. It seems as though they don't believe me, or that I'm making it up because I just didn't want to say "No sorry, I don't fancy that" or "I'm busy", when what I mean is that I do want to participate, but don't feel energetic enough to enjoy doing it, or I know that I will get exhausted from doing that activity on that day - Jackie

Learning to live with fatigue is an ongoing process. The symptom can fluctuate from hour to hour and day to day. Some days there may be no apparent effect whilst the next, energy levels will be low.

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

The worst aspect for me is the dread of not knowing exactly what is going to happen and when. Perhaps one of the worst scenarios is when I have an important meeting. How do I explain to people that I am feeling okay one day and the next I have got to get back as I'm getting very tired, or, that I couldn't even make it to meet them as I'm too tired to leave home? - Bob

Over time, it is possible to get to know the sort of things that might trigger fatigue and to recognise when the body is beginning to show signs of the symptom developing. With this awareness, strategies can be developed to manage fatigue and to try and lessen its impact. To do this it is helpful to be aware of some of the causes of fatigue.

2. The causes of fatigue

The causes of fatigue in MS are still being investigated. It is thought to result from a combination of factors, partly caused by MS itself (known as primary fatigue) and partly by other factors (secondary fatigue) that affect people with MS more significantly than those without the condition.

Types of fatigue

MS fatigue or 'lassitude' is an experience of overwhelming tiredness, lack of energy and a feeling of exhaustion. This fatigue comes on suddenly and is out of all proportion to any activity undertaken.

'Short-circuiting' or neuromuscular fatigue is another type of primary fatigue. This happens if nerve messages to muscles become confused when performing repeated movements. For example, your legs may become increasingly heavy and difficult to move when walking or your arms may be affected when writing for a period of time.

Other factors that can contribute to fatigue

There are a number of other factors that can contribute to feeling tired and lacking energy. Not all of these will be relevant to everyone and the list below doesn't cover everything. However, an awareness of the possible factors that can worsen fatigue is necessary in order to develop effective ways of managing problems.

Some factors that can add to fatigue

- Lack of sleep
- Heat sensitivity
- Low mood, depression or anxiety
- Stress
- Inadequate diet
- Poor fitness and lack of exercise
- Medications for other symptoms or conditions
- Infections or relapses

Ideas for approaching each of these factors will be covered later

3. The principles of fatigue management

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

Perhaps more than with any other symptom of MS, the key person in the management of fatigue is the person with MS.

Health professionals, such as doctors, occupational therapists, physiotherapists or nurses, are there to help you find ways to manage your own fatigue.

The basis of managing fatigue is a two-pronged approach - ensuring the best levels of energy are available and using energy in the most efficient way.

Getting the right balance that allows you to make the most of life takes practice, perseverance and occasional setbacks. Some people may find this at odds with how they have been used to living and may feel that they are losing control of some aspects of their lives, particularly when the benefits aren't immediately apparent. Family and colleagues may also take time to adjust to this approach, particularly those who are called upon to help with day to day tasks.

My own way is to firstly admit defeat when the fatigue sets in and not try to push myself any further - admit to yourself and your nearest and dearest that you can't do the washing up or whatever. Most of the time it wouldn't be possible anyway because fatigue is not like tiredness where you can work your way through it - Sue

Like all kids, mine were VERY resistant to working in the house and cross that they had to do stuff because I was fatigued - Alison

You need to be committed to the process and feel that you want to make the changes that will allow you to learn how to control your fatigue as opposed to letting it control you.

The following sections will look at ideas for how this may be achieved.

4. Managing fatigue

In October 2014, the National Institute for Health and Care Excellence (NICE) published its revised Guideline for the management of MS. The advice for managing fatigue included:

- Drug treatment with amantadine
- Mindfulness-based training, cognitive behavioural therapy or fatigue management
- Advice on aerobic, balance and stretching exercises including yoga

The follow sections contain more on these topics along with other ways to look at your lifestyle and make small changes that can help build energy levels and then use this energy most efficiently. The suggestions will not be suitable for all, but may help you think about what you can do to address the areas in your own life that may be contributing to your fatigue.

Maximising energy

- 4.1 Sleep
- 4.2 Heat sensitivity
- 4.3 Mood
- 4.4 Stress
- 4.5 Relaxation techniques
- 4.6 Diet and nutrition
- 4.7 Fitness and exercise
- 4.8 Medication

Using energy in the most effective way

4.9 Planning

4.10 Prioritising

4.11 Delegating

4.12 Energy effectiveness strategies

4.13 Pacing activity

Maximising energy

4.1 Sleep

Sleep is a very important part of healthy living. During sleep there are many complex processes going on in the body that allow you to wake up the next day feeling refreshed.

There is no set rule on how much sleep is needed. Some people operate perfectly well on four or five hours, whilst others need eight or more.

However long is needed, the results of not having enough sleep are similar - lack of energy; a feeling of lethargy; decreased concentration, attention and memory; irritability and decreased motivation.

There can be many reasons why getting good quality sleep is difficult.

- MS symptoms, such as the need to get up in the night to go to the toilet or painful stiffness or spasms that make sleep difficult or interrupted.
- Concerns and worries that make it difficult to 'switch off' and drift into sleep or that produce restless sleep.
- Family responsibilities that mean less time is available for sleep.
- Being less active, which can alter sleep patterns.

Tips for better sleeping

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

- Keep regular hours for going to bed and getting up, with only slight variations for weekends and holidays. When this routine

has to be broken 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.
- Too much sleep can add to the symptoms of fatigue. Sometimes taking ‘forty winks’ or napping for a few minutes can be better than 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!)
- Try to stay as physically active as possible. People often report that they sleep better after an active day (see section 4.7).

During the evening

- If you participate in exercise, consider doing it in the early evening to allow the body to wind down from the stimulating effects before bedtime.
- Cut down on 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 are a smoker, try to reduce the number of cigarettes you smoke 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 soon before going to bed. However, don't go to bed hungry. Have a light snack if required.
- Avoid doing any mentally taxing activities, either work or leisure, for around an hour before going to bed.
- Make lists of things that need to be done the next day as this reduces the risk of thinking about these things once in bed.
- If you have areas of concern and worry try and discuss these earlier on in the day rather than close to bedtime.

Bedtime

Possible parts of a sleep routine

- Have a warm milky drink.
- Take a bath - the drop in temperature after a warm bath encourages the body to relax into sleep.
- Read.
- Listen to quiet music.
- Do some gentle stretches.
- Do a relaxation exercise (see section 4.5).
- Use aromatherapy techniques.
- Ensure that the bedroom is 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 the bedroom. Light is a strong time cue to the body. If this is a problem, eye covers, as used on aircraft, are an easy way to reduce light stimulus and promote relaxation.

Coping with not sleeping

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

- Use relaxation or deep breathing techniques (see section 4.5).
- Get out of bed and do some activities from the sleep routine.
- Use mind games such as listing all the names, countries or animals starting with a certain letter, counting sheep or imagine doing a very mundane task in great detail.
- Keep a pad and paper next to the bed to write down ideas and thoughts that are keeping you awake.
- If you are not asleep within 20 minutes, try getting out of bed and doing a mundane activity until you feel sleepy.

4.2 Heat sensitivity

Some people with MS find that changes in temperature can cause them to become fatigued. This can be triggered by the weather, hot baths or showers, hot drinks or meals or feeling feverish as a result of infections. These effects are usually quickly reversed when steps are taken to cool down or when the temperature falls.

By just being too hot I can sometimes feel completely debilitated and the cooling process takes a long time. It affects me when showering (short showers only) and I no longer lie in the bath. Also after eating a warm meal I have to have help getting up from the table. I choose salad meals and sip iced water while eating. A cooling dessert often helps! - Val

I am 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 manhandle - Karen

Cooling techniques can be as simple as using fans, taking cool baths and showers, having regular cold drinks or sucking an ice cube. Some people find that air conditioning systems are helpful, especially during the summer. There are cooling garments available that can help with heat sensitivity. These range from relatively inexpensive collars or wrist bands through to more expensive cooling jackets. Cooling pads that can be used as pillows or cushions are also available.

I find that in extreme heat to lie in a tepid bath for a while helps cool me down and thus energise me again - Julie

I managed to get a firm in the US to post some cooling scarves and bandanas. Marvellous! I also use an electric fan - especially when ironing - Karen

Other MS Trust resources

Staying cool with MS

www.mstrust.org.uk/staying-cool

4.3 Mood

Low mood can lead to feeling lethargic and lacking in energy. Similarly, fatigue can lead to low mood. Often it is not clear which symptom is a result of which. For some people, depression can be a symptom of their MS, directly caused by the condition. For others, simply living with the condition can be difficult and may have an effect on their 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 - Freya

Even if not actually depressed, it is common for people with MS to feel low in mood. Of course, not all low mood is a result of MS, and there may be other things going on that cause these emotions.

Whatever the cause, low mood can drain energy and motivation and have an effect on fatigue. If you are feeling low or have worries and concerns, it can be difficult to remember happier times when coping was less of a problem. This can lead to a negative spiral that can be hard to break.

If mood is a matter of concern, a GP or MS nurse can help you find appropriate support and treatment. A combination of medication and talking therapies can be helpful.

Low moods and depression were more noticeable in the twelve months immediately after having to finish work. These were brought under control after a short course of anti-depression tablets - Terrence

Break the cycle of low mood

- Take regular exercise (see section 4.7).

I feel that swimming helps and makes me feel much better, it also helps my walking considerably - Chet

- Make doing more enjoyable things a priority.

I try to improve my mood by going and getting my hair and nails done etc. I think if you look nice you feel better - Tracey

- Spend time with positive people.

I spend time with friends and family, I remind myself frequently of all the plus points in my life. It is not always easy to do this, but I do try! - Meriel

- Take up a new activity.

Keeping myself busy does the trick, mentally more than physically, and not just flopping down in front of the TV and moaning 'woe is me'. Doing stuff for voluntary organisations keeps you feeling useful and needed! - Terrence

- Rather than worrying about a particular concern, actively seek out information and advice to help deal with it. An MS nurse, therapist or GP can help.

Attending a self-management course helped me - Karen

- 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 that is needed is to have someone willing to listen.

I meet up with friends and have a good moan to get things of my chest. Reading true life stories makes me realise there are others worse off - Tracey

Other MS Trust resources

Depression factsheet

Positive thinking

When living with the problems, uncertainty and changes that MS can present, it is easy to fall into negative thinking habits. Negative thinking tends to be gloomy and pessimistic leading to low self-esteem and low expectations, reducing confidence, is socially isolating and further depletes energy levels.

When the positive energy drains, fatigue sets in followed quickly by depression or stress - Alison

In contrast, positive thinking is based upon looking for the good things in life and in people - and most importantly within oneself. Positive thinking helps cope with problems through encouraging self-esteem and maintaining perspective. Developing a positive approach can be difficult and takes time and willpower, particularly when feeling fatigued and depressed, but once achieved, it can help improve the ability to cope with the changes needed to manage energy in the most effective way.

I think that I am usually optimistic. When I finished work I decided to concentrate on the 'can do's' and not the 'can not's'. I enjoy painting, drawing, reading, listening to the radio and socialising - Viv

Mindfulness

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

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

The same observational, non-judgemental approach can also be applied to how you are thinking. This helps you build an awareness of what is happening in your body and in your mind

and emotions and helps to break a downward cycle of negative thoughts and emotions.

Research suggests the approach can help with easing fatigue and depression and improving quality of life.

Cognitive behavioural therapy (CBT)

Cognitive behavioural therapy or CBT is a form of psychotherapy that is based on the belief that how you think about a situation influences how you act, and your actions subsequently influence how you think and feel. It encourages the adoption of new thinking and behavioural techniques to help you control your thoughts and feelings.

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, consult your GP. A number of studies have found that CBT can be an effective treatment for fatigue in MS as well as for anxiety and depression.

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 help you to alter your thoughts and feelings, ACT encourages you to become more aware of your thoughts, feelings and beliefs and the helpful and unhelpful ways you respond. It tries to support you to become more aware of and in touch with what matters to you and to help you find ways to do those things.

Other MS Trust resources

More on mindfulness and CBT

www.mstrust.org.uk/psychology

Examples of ACT

www.mstrust.org.uk/act

4.4 Stress

Stress is a normal and unavoidable part of life. Stress occurs when there is an imbalance between the demands made and the ability to meet those demands. This could be deadlines at work, difficulties within the family or when people are forced to adapt to new life circumstances. The greater the amount of change required, the greater the potential for stress.

Stress causes changes in blood pressure, heart rate and metabolism. In the short-term, these responses can improve physical and mental performance to cope with immediate crises - the 'fight or flight' response. However, left unchecked, excessive stress can have negative effects on physical and emotional health, including a direct effect on levels of fatigue.

Everybody reacts differently to stress, but there are common symptoms

- 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, loss of libido, increased drinking or smoking and reduced willingness to socialise.

Managing stress

Nobody can say what will be stressful for another person. Every situation or life event has the potential to be stressful and the ways in which people deal with stress are very individual.

There are three stages in stress management.

1. Recognising the effect stress is having on health.
2. Identifying what is causing stress.
3. Taking action to remove or reduce the cause of stress.

It is not possible to remove all of the sources of stress, but it may be possible to control stress by changing the situation in order to limit the stressful elements.

- Recognise your own signs of stress, take charge of own emotions, thoughts and actions.
- Keep things in perspective. Focussing on only the bad things that might happen will prevent you from enjoying the good things that are happening just now.

I try not to worry too much about the things that I cannot 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 - Viv

- Keep a positive attitude.
- Be kind to yourself.

A glass of red wine! Screaming at the phone - very cathartic. Say "NO" occasionally! Give yourself permission to enjoy yourself - and stop feeling guilty - Karen

- Communicate with others and seek support - discussing sources of worry with others rather than keeping them to yourself can help. Even if they can't directly change the source of stress, another person's point of view can put things in a different light.

Making my feelings known to others helps to alleviate stress and low mood - Ralph

- Plan ahead - prioritising activities can create more time for essential tasks and also identify potential areas of stress in advance (see section 4.10).
- Stay active and take time out for enjoyable activities - taking a step back from stressful events can change the perspective on problems and relieve the build up of stress to some degree.

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 - a route more likely to increase stress!

- Use relaxation techniques (see following section).

4.5 Relaxation techniques

Relaxation techniques are activities that generate a feeling of complete peace and calm, away from daily hassles and routines.

Relaxation is an active skill that requires development through practice. 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 is also not the same as sleeping.

Regular relaxation can lead to decreased tension in muscles, lower blood pressure and slower heart rate. Relaxation can help with fatigue as it promotes good sleep patterns, increases benefit from rest periods during the day and can be used to manage stressful situations.

Types of relaxation

Finding an effective relaxation technique may take time as different techniques will suit different people. The relaxation technique used by someone to help them get to sleep will be different from that required by someone who is looking for a way to revitalise themselves during the day.

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

Deep breathing

Most of the time we do not think about breathing. However, focusing on how you breathe and creating a slow, deep and even pattern will help you to feel calmer and more relaxed and can create a distraction from the causes of stress.

Visualisation techniques

Visualisation involves using the imagination to go to a relaxing place. This could be somewhere previously visited, something seen on the television or in a magazine or somewhere entirely from

the imagination. The knack with this technique is focusing on all the senses to experience in detail what can be seen, heard, smelt, tasted and felt within the 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! - Viv

Some people find it helpful to use gentle background music or photos of places with happy memories. There are also tapes available that guide the listener through relaxing scenes. Finding the right combination of voice, speed of speaking, music and subject matter may take some experimentation.

Muscular relaxation

There are a number of specific techniques that concentrate on relaxing muscle groups. In addition to producing a feeling of calmness and relaxation, these techniques help to identify areas of the body where tension is held. However if there are existing problems with spasticity or stiffness in limbs, discuss this with a health professional before trying a muscle relaxation technique.

There are books that detail techniques, but whilst the specifics of exercises may differ, the basics are the same.

- Set aside time to concentrate on the exercises.
- Lie or sit comfortably. Some people may prefer relaxing music to be playing.
- Spend time concentrating on breathing.

Complete the techniques to a level that is comfortable and allow time to enjoy the feelings of relaxation achieved.

Massage

Massage helps to relax muscles and relieve tension as well as providing the soothing benefits of touch. Massage can be given by trained professional masseurs, although courses and books 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 well-being and some oils are thought to have relaxing effects. Oils can be used in the bath (if heat sensitivity is not an issue), as a steam inhalation, in an oil burner or during massage. Although aromatherapy oils are usually used with no problems, some people are allergic to some fragrances and some oils may cause a rash if applied to the skin. It is therefore best to seek advice before starting aromatherapy.

Yoga, tai chi and Pilates

These exercises use combinations of breathing, movement, posture and meditation. They can be undertaken individually using commercially available manuals or videos, or in classes or group sessions.

I find Pilates works best at relaxing me, and because it helps my posture it relieves muscle tension. Learning to take an hour's catnap is also a good skill - Kathy

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

Other MS Trust resources

www.mstrust.org.uk/relaxation-session

4.6 Diet and nutrition

A healthy, well balanced diet with plenty of fruit and vegetables plus complex carbohydrates, some protein-rich foods such as meat, fish and lentils and not too much fat, salt or sugar is required to provide optimum energy levels. A poor diet or eating habits can leave the body lacking in the fuel needed to get through the day.

Although food and drinks high in sugar give an initial boost, blood sugar levels quickly drop again leaving energy levels low. High sugar foods and drinks are 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 (quick energy fixes). They don't really work as an energy boost to relieve my tiredness, but I do get a mild, short lived 'comfort buzz' from the sugar content, which has to be continuously topped up throughout the day - adding to an unhealthy lifestyle which doesn't help my long-term health prospects, with or without MS - Jackie

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

It is also very important to drink sufficient fluids, especially water. Being even mildly dehydrated can cause tiredness and sluggishness. Some people with MS restrict the amount of fluid they drink as they are concerned about bladder problems. However, too little fluid can increase the risk of urine infections, headaches and constipation, and thus worsen existing MS symptoms.

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

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 satisfactorily, I had a clearer head and more energy - Val

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

Preparing and eating meals

It can be helpful to think about ways to reduce the impact of fatigue when preparing and eating meals.

Food preparation

- Organise the kitchen to keep commonly used items close to hand.
- Keep the kitchen as cool as possible.
- Cook at times of day when energy levels are higher.
- Cook in bulk when you feel less fatigued and freeze for use at a later date.
- Sit rather than stand to prepare and cook meals.
- Get all the ingredients and utensils together before starting to cook.
- Make use of equipment or labour saving devices where possible, such as electric mixers, can openers and knives.
- Use ready prepared foods such as grated cheese, diced meat, 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 lifting heavy pans.
- Microwave cooking avoids having to lift heavy pans and does not heat up the kitchen.
- Invest in a one-pot cookery book - to save on washing up.
- A 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).

Eating meals

- Large meals can leave people feeling bloated and sluggish. If this is the case then try having more frequent, lighter meals or healthy between meal snacks such as fresh fruit, cereals or sandwiches.
- Try and eat main meals when energy levels are higher.
- Don't miss out on breakfast to provide energy and nutrients in the morning. 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 prepared and snack foods. Try keeping the ingredients for easy to prepare healthy meals ready for use.
- Convenience foods can help at times when a healthier approach is not possible. Be aware that many convenience foods are high in fat and salt. Look out for healthy eating options and add extra vegetables or salad.

Other MS Trust resources

Diet factsheet

4.7 Fitness and exercise

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 could be seen as tiring. This view has now been overturned by research that shows specific benefits of exercise for people with MS.

I am fitter now than before diagnosis as I had worn myself out trying to keep up with those without MS. Despite being told to 'take it easy' by people after diagnosis, I have managed to improve my stamina considerably by exercising regularly - Heather

Some form of exercise as part of the daily routine is an essential element of a healthy lifestyle. Low activity levels cause under-used muscles to become deconditioned, which means that stamina levels and fitness are reduced. As a result, everyday activities are more physically demanding, consume more energy and so fatigue is increased.

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 - Val

In the past I exercised on a daily basis. After a seven month layoff, MS disease progression notwithstanding, I recognise a marked decline in my overall well-being. 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 - Bill

Although the symptoms of MS may mean that it is not possible to continue with the same type or level of physical activities as were enjoyed before diagnosis, it is important to continue trying to stay as active as possible. Physiotherapists can suggest exercises that

take account of MS symptoms and gyms and health centres have staff who can design exercise programmes to meet the abilities of individuals.

Other MS Trust resources

Exercises for people with MS.

www.mstrust.org.uk/exercises

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 use of energy.

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! - Ann

Improves sleep

Regular physical activity promotes better sleep patterns.

I have successfully improved my sleep, improved 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 - Bill

Psychological benefits

Regular physical activity helps the brain to release endorphins, which give a natural high after exercise. This can create an energised feeling for a time and improves mood, self-esteem and confidence and reduces stress.

I work out twice a day, and this seems to rev up my energy level. Exercise wakes me up - Cindy

Assists in weight management

Regular physical activity can help to control weight, particularly for people with a predominantly sedentary lifestyle.

How much activity?

People sometimes think activity means high energy exercise, which can be off-putting. However any activity that involves energy expenditure above resting level 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.

I find walking my dogs good exercise and good for my mojo - Jennifer

The Department of Health recommends that adults should aim to be active daily. Over a week, activity should add up to at least two and half hours of moderate intensity activity in bouts of 10 minutes or more. One way to approach this is to do 30 minutes on at least five days a week. However, for some people with MS, even ten minutes of physical activity may be too much to begin with.

I have enrolled at the local sports centre and I try and get there if possible. I don't do too much whilst there and if I find I'm getting too tired I sit and watch for a while. I try and walk on the treadmill at a reasonable pace and I aim for ten minutes - Chris

Which activities are appropriate will depend on particular symptoms, circumstances and interests as well as previous activity levels. It is trial and error to find out what is suitable and fun. If exercise and activity seem like a chore, it is easy to lose

motivation and stop. Try to vary routines to make them more enjoyable or try and find someone else to exercise with. Joining an exercise group or class can help some people.

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

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

When trying a new activity it is 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 - Terrence

Try to 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 are not as tired at the end of the session but have still achieved a lot of physical activity. It is 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 problems that occur. Remember on bad days that it's OK to do less activity than planned for that day but try to be more active again the next day. Any benefits gained from doing activities are gradually lost if you become less active again. It is a case of use it or lose it.

I do tend to find I suffer for my lazy days - George

4.8 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 illicit - regardless of whether they are being used to treat MS or not. Of the drugs for MS symptoms, treatments for spasms, stiffness and pain are often associated with an increase in fatigue.

An understanding of the potential benefits and side effects of drugs is important if fatigue is a concern. It may be worth asking a doctor or pharmacist to review medication to identify potential problems and possible solutions.

Drugs to treat fatigue

The NICE Guideline for the management of MS included amantadine as a medication for fatigue in some people. Amantadine (Symmetrel, Lysovir) is licensed to treat flu, shingles and Parkinson's disease. Research has shown that it reduces fatigue in 20-40% of people with mild to moderate MS.

Modafinil (Provigil) is a drug that promotes wakefulness and is licensed to treat people experiencing excessive sleepiness due to narcolepsy. Modafinil was sometimes used as a treatment for some people with MS where sleepiness is a contributing factor to their fatigue. However, following the findings of a safety review, the European Medicines Agency now recommends that the use of modafinil should only be associated with narcolepsy.

Medication is not a solution to fatigue on its own and should be used in addition to fatigue management techniques, not as an alternative. Medication should not be prescribed until there has been a full evaluation of the underlying causes of fatigue. 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 be partially helpful at best.

Infections and relapse

Other common medical conditions and infections can drain energy and cause fatigue to worsen. Similarly, the onset of a relapse can make existing MS symptoms worse. A GP can investigate whether there is an underlying medical cause that is adding to fatigue and can prescribe appropriate medication or refer to other services.

Using energy in the most effective way

As well as maximising the amount of energy available, the other key element in managing fatigue successfully is to use energy in the most effective way.

Techniques involve:

- planning - thinking about what is achievable and not making unrealistic demands on energy levels by trying to tackle too much
- prioritising and delegating - separating out what needs to be done and what others might be able to take on
- energy effectiveness strategies - thinking through specific tasks to see if there are ways of tackling them in a more energy efficient way
- pacing activity - 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 experimentation to find a routine that suits the individual situation and it may take some time and perseverance for both the person with MS and those around them.

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

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 - Mary

4.9 Planning

Planning involves taking some time to stop and think about what needs to be done and what can be achieved. Efficient use of limited energy supplies means that you can achieve more.

I have found fatigue to have lessened since diagnosis, six years ago, partly because I have learnt to say no. You really have to practice assertiveness techniques. I pre-plan and only do one major task each day - Val

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. It helps to calm me down and make sure I tackle one thing at a time - Karen

There is often an inclination to get straight on with tasks. When energy levels are not an issue, this may not be a problem. However, when there are only limited reserves, this approach may lead to jobs being left half done or mean that important activities aren't tackled as energy has been exhausted on more mundane tasks.

MS fatigue makes me feel as though 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 running out fast and I'm feeling weary. By 3pm I'm exhausted - Viv

If I need to do any housework or go into town I make sure I am back for 12 noon. Then I have lunch and go to bed for around two hours. That refreshes me to get up and get the kids from school - Tracey

Planning is a very individual process. It requires an awareness of the effects of fatigue and a realistic approach to how much can be done. Some activities will be more fatiguing than others. By monitoring or recording the effect of different tasks, you can start to gauge what is more or less likely to add to your fatigue.

Try not to drive into town too many times in a week. Look ahead - pick a day you don't have to go out to do washing / ironing / hoovering - Karen

I have to plan life carefully. If I'm working I can do absolutely nothing else, come home and flop on the sofa drained, no energy to concentrate to read even - Alison

Planning involves taking time to think ahead about activities. Avoid too many energy-demanding activities in a short time or when there is a higher chance of being fatigued. Keeping notes in a diary or using an activity planner, for instance on the fridge door, can be helpful.

Planning my day is very useful. I use a notebook to do this. Often, when I feel that I haven't had a good day and haven't achieved all that I wanted to, I check the notebook and I've often done more than I had thought - Viv

4.10 Prioritising

In any plan, some jobs will be more important than others. If energy is limited, it is better to complete a smaller number of necessary activities, than to try and do everything and run the risk of completing nothing.

I advocate the 4 Ds - dump it, delay it, delegate 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 lots less to do! - Sandy

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 - collecting 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! I know that my energy levels are higher in the morning so 'important' tasks get done then. If they're not all completed, by dealing with them on a list I'm not overwhelmed by them. This was something that used to add to my stress and tiredness. I think that I'm getting better at requesting help from family and friends when necessary - Viv

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

4.11 Delegating

As with some other aspects of managing fatigue, it can take time to get used to delegating tasks. Many people will feel nervous or guilty about asking others to do jobs that they previously did. Some people will feel that this is a sign of giving in to fatigue, or of losing control. It is not always easy to trust people to do the job as you would yourself.

As 'Miss Independent' I hate asking anyone to do anything - Karen

One has no choice but to pass on some tasks to others, which I reluctantly have to. However, my experience of asking for help is a positive one - Val

Sometimes people are more willing to help than is expected. However, when delegating, remember that people have their own lives and commitments and may not be able to help out at short notice.

Planning and prioritising is difficult as I depend on others to accomplish routine tasks in and out of the home. The greatest challenge is in communicating, in advance, what my needs are so that those I depend on can plan their own time - Bill

Properly handled, delegation frees up time and energy for important activities and means that more can be achieved than if everything was done by one person.

My kids help out a lot. We make supper a family job. I made a chore chart so they know who does dishes, who puts away food, who puts away dishes. It helps a lot - Mabra

People like to be asked for help... I know I do! I should try doing it more often! Ask for help and support when you need it - most people have no idea what it is like to have MS and need to be told how they can help - Tony

Essential activities will be unique to each person, depending on lifestyle, responsibilities, interests and beliefs. Priorities will change over time, so try not to get stuck doing things one way because they have always been done that way. It is important to remember that essential activities should include pleasurable activities. Household or work related tasks may need doing, but if all available energy is expended on these and fatigue means that meeting up with friends or going out for the evening occasionally are not possible, life will be poorer and less rewarding.

Try to think of yourself first and don't feel guilty about leaving things half done / undone until another time - Karen

4.12 Energy effectiveness strategies

As well as conserving energy by planning and prioritising activities, successful fatigue management also involves looking at tasks and then trying to do them in the most energy efficient way. The following are a few suggestions.

- Keep the working area as cool as possible.
- Sit rather than stand for jobs where possible.
- Make use of labour saving equipment and products such as an electric toothbrush.
- Organise the work area so everything is to hand so as to avoid unnecessary walking, bending and reaching.
- Store commonly used items within easy reach.
- Be aware of posture - maintaining a poor posture or staying in one position for long periods takes up energy.
- If possible, use taxis instead of driving or using public transport. Some councils operate Taxicard schemes that allow some people to use taxis at a reduced price.
- Discuss adaptations to the workplace that will help conserve energy. Under the Equality Act employers are obliged to make reasonable adjustments.

Reduce energy spent on transporting items - for instance, to avoid carrying cleaning materials, keep two sets of everything, one upstairs, the other downstairs - Elaine

Use a Blue Badge - you don't have to walk so far to shops. An electric scooter that comes apart and fits in the car saves you time and energy getting around! Or even better, shop online wherever possible - stuff gets delivered to the door! - Karen

If your walking is bad, swallow your pride and use a wheelchair! Regard it as a tool that enables you to do more by conserving the energy you waste lugging yourself around. And getting a friend or partner to whizz you around the streets can be quite fun! - Kate

Other MS Trust resources

Posture

www.mstrust.org.uk/posture

4.13 Pacing activity

Pacing involves taking planned breaks or rests within or between activities. Pacing requires a degree of self discipline as the natural inclination is often to try to get to the end of a job. However, it is often more beneficial to take things steadily rather than continuing with an activity to the point of exhaustion and being forced to rest.

I used to make little attempt to pace myself throughout the day and tried to carry on as I had previously done. If I felt up to the job, I'd do it. The only problem with this approach was that I'd find myself fatigued half way through the day when all my MS symptoms would rear their head - Diane

Many people with MS find that if they overdo things their recovery time is much longer than in people who don't have MS. Where other people might recover their energy after a short break, you might find it takes you several hours or longer. This can have a damaging effect on mood, can reduce fitness levels and increases unreliability for family and friends.

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 and find this very restrictive. If I push myself and try to ignore that need to stop I will often require several hours to be able to resume, if at all - Val

Doing tasks more slowly or taking regular breaks can help to stop fatigue from building up. As a result, it may be possible to achieve more in a series of shorter chunks broken up with periods of rest than from working straight through until 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 4.5) or a short period of minimal activity.

Pull the phone plugs out and switch the mobile off / onto silent when resting. Lock the door! - Karen

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

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

Build in rest periods to jobs you are doing. Put potatoes on to boil and sit down for 10 minutes, eyes closed, while they cook! Rest, rest, rest! It's boring but it works - Jacqueline

Conclusion

Fatigue is a very common problem for people with MS but managing it effectively requires a very individual approach.

Through consideration of your lifestyle and awareness of how fatigue affects you, you can make the changes and adopt the techniques discussed in this book that are appropriate to you.

To help explore these further, it may be worth asking your GP or MS nurse about taking part in a fatigue management programme

I think that there's a lot that can be done just by looking after yourself - Gail

These techniques will not make fatigue go away, 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 has 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 - Diane

I have MS but MS doesn't have me - Chris

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