MS Society

Fatigue

We're the MS Society. Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to stop MS.

We rely on the generosity of people like you to fund our vital work. If you would like to make a donation, you can do so by:

- Calling us on: 0300 500 8084.
  Lines are open Monday to Friday, 9am – 5pm
- Visiting us at: mssociety.org.uk/donate
- Posting your donation to: MS Society, National Centre,
  372 Edgware Road, London NW2 6ND. Please make cheques payable to the 'MS Society.'

Cover image @ Amit Lennon

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Introduction

Fatigue can be difficult to describe. It's not just an ordinary tiredness that you might experience after a hard day's work or strenuous exercise. Many people with MS describe their fatigue as an overwhelming tiredness with no obvious cause. MS related fatigue might, for example, make you feel extremely tired after very little activity, or you may even wake up feeling as tired as you did when you went to sleep.

While it may not be possible to make it go away completely, there are a variety of ways to manage your fatigue and reduce its impact on your daily life. In this booklet we discuss:

- ways to describe your fatigue
- ways to analyse your fatigue
- ways to minimise the effects of fatigue on your daily life

We also refer to other organisations that offer help with different issues. You can find the organisation's contact details in the 'Useful organisations' section on page 21.

> Fatigue's a useless word that doesn't even begin to describe what we experience. I have therefore taken it upon myself to rename this neurological symptom something as more appropriate: 'Neurozombiosis'. I describe it to people as if someone had snuck up behind me and jabbed me with a hypodermic needle full of horse tranquilliser.
> **Belinda Rogers, MS Society chat rooms**

What is fatigue?

Fatigue is one of the most common, troubling symptoms experienced by people with MS. For some, it is the symptom that affects them most. 'MS fatigue' is more than the tiredness everybody feels after exertion or missing a good night's sleep. This type of tiredness can still affect you, but fatigue in MS goes beyond that.

Some people find that when they are fatigued, their limbs feel heavy and it becomes harder to grasp things or to write. Many people also find that when they are fatigued it becomes difficult to concentrate or take in new information. Similarly, when you're fatigued, other symptoms, like difficulties with balance and vision, may also get worse temporarily.

See the section 'Deal with the things that make fatigue worse' for tips on managing fatigue, including prioritising, planning and organising work spaces.

📖 For more information on balance, memory and thinking, see the MS Society publications **Balance and MS** and **Memory and thinking.**

> For me it's much more than just being overly tired … It causes me to feel weak, light headed and nauseous, it affects my eyesight and causes my speech to slur and I find it impossible to concentrate on whatever I was doing. This can happen to me many times in a day and it's a lot worse if I become warm.
> **Anonymous, MS Society chat rooms**

Describing your fatigue to others

It can be complicated to describe your fatigue to friends, family, colleagues and health and social care professionals. But helping others to understand can make daily life with fatigue less frustrating.

There will be times when your fatigue is not obvious to others – it's an 'invisible' symptom. Without understanding the issue, they may unhelpfully ask you to 'make a bit more effort' or 'stop being lazy'. Fatigue is difficult to describe, and understand, and the lack of understanding can be difficult and upsetting. People often go through many analogies before they find one their friends, family and colleagues can relate to.

Sometimes though, people close to you may notice effects of fatigue that you may have grown used to and adapted to without realising. For example, a partner might notice you are walking more slowly later in the day. If they know that this is because of fatigue, rather than a problem with your legs, they will be in a better position to offer assistance.

When I'm trying to explain my lack of energy to people, I sometimes use a 'mobile phone' analogy… I say that whilst everyone else is a mobile phone on a contract with unlimited minutes, I am a pay as you go phone, with only £1 credit each day. Whilst they can chat all day everyday, I can either send a few small text messages, or make one long phone call, but then I have to stop until I hopefully get 'topped up' the next day.
Anonymous, MS Society chat rooms

What causes fatigue?

Although it's given one name, there are two recognised types of fatigue in MS: primary fatigue, and secondary fatigue. Primary fatigue is a direct result of damage to the central nervous system, like demyelination or inflammation. Secondary fatigue is related to the symptoms of MS, such as sleep problems or the side effects of drugs.

Primary fatigue is sometimes divided into:

- **lassitude** – an overwhelming sense of tiredness not directly related to participation in activity or exercise
- **'short-circuiting' fatigue** – occurs in specific muscle groups, like the hands after typing or legs when walking and standing for a short time
- **heat sensitivity fatigue** – a rise in body temperature due to the season, infection, or a hot bath
- **cognitive fatigue** – when memory, learning, concentration and attention are affected

Secondary fatigue is a result of factors which may be related to MS, but are not MS itself. These include:

- **other MS symptoms** – such as muscle weakness, stiffness, pain, tremor and depression
- **sleep disturbance** – waking during the night because of pain, spasms, anxiety, depression or urinary urgency
- **medication** – tiredness and drowsiness are side effects of many medications
- **local environment** – lighting, noise and temperature can all affect sleep

This means that fatigue can be a different experience at different times, and for different people. People can experience any combination of the different types of fatigue outlined above.
It might change from week to week, day to day or even hour to hour. It could be one of your first MS symptoms, or something that appears years later. Some people will never experience fatigue as a symptom of MS.

What's happening in the central nervous system to cause fatigue?

The effects of MS on the central nervous system are complex and not yet fully understood. The damage MS causes to the central nervous system, as well as the way the brain adapts to this damage, have both been considered as explanations.

MS damage

Some studies have suggested that certain areas of the brain are associated with fatigue in MS. However, research has not identified any one area of the central nervous system that is affected in people with fatigue. Fatigue might not be due to damage in just one area of the brain or spinal cord.

How the brain adapts

Some researchers suggest that fatigue might be caused by the way that the brain adapts to the impact of MS.

MRI scans of people who have fatigue show that they use larger areas of the brain to carry out activities than people who don't have fatigue. Perhaps the brain is finding new routes for messages when the usual nerve paths have been affected. Finding new routes might mean it takes more energy to carry out an action, and this might cause fatigue.

However, there are other processes happening in the brain and spinal cord that may also have an effect. We don't yet know for certain if there is an exact link between nerve damage and fatigue.

Keep up to date :

🖥 Visit our web pages to find out about how research continues to improve understanding of the processes involved and how they might be managed at **www.mssociety.org.uk**

How can I manage my fatigue?

Sitting down to analyse and find strategies to manage your fatigue can, unfortunately, be a pretty tiring exercise. If you can do it though, you might find it really useful to identify things which bring on your fatigue, and find ways to work around triggers.

There is no one-size-fits-all answer to this: everyone is different, so the way you manage your fatigue probably won't be exactly the same as someone else's. However, the next three sections have tools that can be used by anybody.

- Analyse your fatigue
- Deal with the things that make fatigue worse
- Manage any fatigue that remains

You may also want to read our booklet **Living with the effects of MS**, which explores the emotional impact of MS in greater depth.

Visit our web pages to find out about how MS can affect your emotions

> My physio urged me to fill in a fatigue diary, which I did (all the while thinking it a pointless exercise). I found that if I do more than 10-15 minutes of any physical activity I'm wrecked. Just knowing that has made a tremendous difference to the way I plan my day.
> **Jane Wilson, MS Society chat rooms**

Analyse your fatigue

At some point you're likely to want to tell people you have MS. Although this can feel like a scary thing to do, it can help you to feel less alone with your MS, and to get the support you need from those around you.

You may want to tell everyone about your diagnosis – particularly if you've been unwell for some time. Or you may want to tell only the people closest to you or people who need to know.

Whoever you decide to tell and however you feel about telling people, you may find it helpful to plan what you're going to say. Many people don't know about MS, or they may have some preconceived ideas about it – for example, that everyone with MS needs to use a wheelchair – so you'll have to be prepared to answer their questions.

The information in this booklet can help. You may also want to have copies of our booklet What is MS? for people to read in their own time, or you could signpost them to our website.

Before you tell people, be aware that they might not react as you'd expect, however well you know them. They could feel more upset than you anticipate or even be surprisingly blasé about it. Although you're the one with MS, it's important not to forget that your diagnosis will affect their lives, too.

🖥 Visit our website to find out more about telling people you have MS.

> My legs get weaker the further I walk and it feels like I am wading through custard or seaweed or something. I can hold a pen for a while, but really have to concentrate to write legibly. I can't always recall words and sometimes say them in the wrong order.
>
> **Anonymous, MS Society chat rooms**

Deal with the things that make fatigue worse

By looking at your fatigue diary, your general health and any medications you take, you and your health care professional might be able to see certain things that seem to make your fatigue worse.

By completing another fatigue diary after you have made changes or had underlying symptoms treated, you can compare the two and see if the changes you have made have had the desired effect.

Sleep

Lack of sleep might be the main cause of your fatigue, or one of several causes. There are any number of things that might disturb your sleep:

- muscle spasms
- pain
- needing the toilet
- insomnia
- too much caffeine
- noise
- temperature
- anxiety
- depression
- light
- medications

Infection

Infections like colds or bladder infections lead to unexpected tiredness, particularly if they raise your body temperature.

Medication

Many drugs commonly used to manage MS and related symptoms have side effects that can add to fatigue. If you start a new medication, change doses or change the time you take the drug, your fatigue levels may also change.

Discuss any changes with the doctor that prescribed your medication – don't adjust your drugs without advice from your prescribing doctor.

Anxiety, low mood and depression

Anxiety,depression and low mood are not uncommon in MS, and they can cause feelings of fatigue. Equally, fatigue may have an effect on your mood. It can be difficult to untangle the two issues – they might be affecting each other.

There are many options for treating depression and other mental health conditions and emotional symptoms. Successful treatment might help lessen fatigue. Finding ways to minimise your fatigue can help relieve stress and anxiety.

📖 For more information on managing emotional symptoms in MS, see the MS Society booklet **Living with the effects of MS.**

Other conditions

MS can cause a wide variety of symptoms, but remember that not every health issue you experience will necessarily be related to your MS. Other possible causes, such as menopause, anaemia and thyroid issues might also be considered. Shortness of breath is one example. This could be caused by asthma or heart problems, which should be looked into further with your doctor.

> I found that doing anything physical for more than ten minutes was a disaster – my balance and coordination go to pot. But do something for ten minutes and then a nice long rest and I'm OK – even two minutes extra pushes me over the edge.
> **Jane Wilson, MS Society chat rooms**

Manage any fatigue that remains

You have now identified and tackled any secondary fatigue – in other words, fatigue caused by other MS symptoms, living with the condition, or things unrelated to MS. The fatigue that remains might be linked directly to what MS does in the central nervous system.

To manage this, it can be helpful to look again at your lifestyle – how you, and those around you, approach work, rest and leisure time. The idea is to make tasks easier and make best use of the energy you have.

Consider realistic changes

Think realistically about how fatigue affects you. Consider what adjustments you and others feel able to make. Try to find a balance of activity and relaxation, exercise and rest, work and social life. Remember that some of the changes you make could involve family, friends or work colleagues.

Professional support

At home and in the workplace, an occupational therapist may help you save energy in the everyday tasks you do by giving advice and changing how you:

- work
- rest
- plan activities
- organise living and working spaces
- sit or stand (your posture)
- exercise
- eat

Other health and social care professionals might also be helpful when you are looking at how you approach daily activities.

Our booklet **Disease modifying treatments** looks at the different drugs available, as well as things to consider when making a decision.

At work

You might need to ask your employer to make some changes – perhaps more flexible hours would help, or arranging a parking space closer to the entrance. Under the Equality Act (and Disability Discrimination (Northern Ireland) Order), most employers are legally obliged to make 'reasonable adjustments' to allow you to carry on working. A Disability Employment Adviser (DEA) from your local JobCentre Plus can explain your rights and responsibilities and help you and your employers make the adjustments you need.

📖 See the MS Society booklet **Work and MS.**

You don't have to tell your employer about your MS, but if you don't, there is no legal requirement for your employer to make reasonable adjustments. For more information, refer to **Access to Work** on the Gov website or **Citizens Advice**.

Rest

For some people, rest helps relieve fatigue and is an important part of fatigue management.

Resting can prevent you getting to a point of complete exhaustion and coming to a sudden halt, half-way through a task. Planned rest can give you more control over when you choose to be active and when you take a break.

A few small breaks are best for some people; or you might feel better after just one longer rest at a particular time. For example:

- try taking a few short rests or 'power naps', through the day
- try just one longer rest, at the same time each day
- take a break between coming home from work and getting ready for an evening out

Real rest

When you rest, try to make your rest as complete as possible. Doing smaller jobs around the house, talking to the family or watching TV might be more relaxing than work or chores, but it is not really resting. It can be tricky, but the aim should be to switch off both the mind and the body. You might want to have a short sleep, meditate or use relaxing music to help clear your mind.

If worries disturb time set aside for rest, try writing down these concerns and 'shelving' them while you are resting. You might find it easier to tackle them once your energy levels are back up again. If resting helps you manage your fatigue, it is important that other people realise how valuable this quiet, undisturbed time is.

Prioritise

Making changes to your routine can be hard, but prioritising activities can mean you save energy for the things you really want or need to do. If fatigue means you can't get everything done in a day that you would like, concentrating on the most important tasks can help. One way you might do this is to:

- list all the activities you do in a typical day or week
- mark which are important to you
- mark those jobs you would rather not do
- mark those jobs which can be done less often
- mark any that don't really need doing at all

Look at the activities you have said are important and think:

- can they be done in a more energy-efficient way?
- could they happen at a different time when it would be easier?
- can you get help for any of these tasks?

A social care services assessment (community care assessment in Scotland) might identify certain tasks that social care services (social work in Scotland) can help with. You may be entitled to benefits, for example Personal Independence Payment (PIP). This is the benefit that compensates for the extra expenses of living with a disability. You do not have to be severely disabled to receive it and it is not means tested.

See the MS Society booklets **Benefits and MS**, **Claiming Personal Independence Payment**, and the version of **Getting the best from social care services** relevant to your nation.

Plan

Knowing your priorities can help you plan your time more effectively. The idea of making a timetable for your day or week may seem a little strange or regimented at first, but planning ahead can help you be more confident of getting things done.

Planning ahead can mean, for example, building in 'down time' to recuperate if your fatigue makes you tired at a similar time each day. If you have a particularly tiring task ahead, a plan lets you make space for rest before, after or both.

Some simple tips can make planning easier:

- Set yourself targets, but keep them realistic
- Try to balance your day between easier and more difficult tasks, making time to rest
- Split a heavy task into bite-size stages, to be done a bit at a time. For example, if you are cooking a large meal, perhaps find recipes where you can pre-prepare parts of the dish, allowing for breaks in-between. Or, if you're driving somewhere, plan to take a break along the route. Consider walking the dog along a bus route where you might find a seat, or be able to get the bus back

Ask for help

People might say to you, 'If there's anything you need...' or 'If there's anything I can do...', but it is not always easy to ask for help, even when it is offered.

It can be useful to prepare a list of tasks that you'd like help with. You might have done this already in making a list of priorities (see 'Prioritise'). That way, if someone does offer to help, you can easily tell them how they could help.

When asking for help:

- remember why you are asking – asking for help is a sign of strength, organisation and a desire to get on with things. It's not a sign of weakness
- break down the task – most jobs are made up of smaller

individual tasks. Getting help with one thing might mean the task is more manageable

- timing – work out how long you think a task will take and when it needs to be done by. Don't forget to add in time for breaks!
- categorise – it may help to categorise tasks into 'personal', 'household', or 'health care'. You may not feel comfortable asking some people to do certain kinds of tasks

Organise living and work spaces

Sometimes, the simplest changes can make the workplace or home more 'energy efficient'. Useful changes to your environment, such as those mentioned here, don't always have to involve specialist equipment or major alterations:

- keep items that you use regularly within easy reach to avoid frequently getting up and down
- items that are used together can be stored together – in the kitchen, for example, you might want to keep the kettle, tea and mugs together in one place
- store lightweight items that are rarely used in higher spaces
- store heavy items that you use less often at a lower level
- keep work areas as uncluttered as possible
- make sure the lighting is good, to avoid eyestrain
- consider the items you use, like pens or cutlery. Would they be easier to use if they were lighter, had larger handles, or were adapted in any way?
- some tasks, like preparing vegetables or ironing, can be done sitting down instead of standing

An occupational therapist can help you assess the spaces you use – at work and at home – and may suggest adaptations or equipment that could help. The **Disabled Living Foundation** has more information about available equipment, and you might find useful items online.

Posture

You could save energy on a lot of everyday tasks by making sure you have a good, relaxed posture. The basic idea is to:

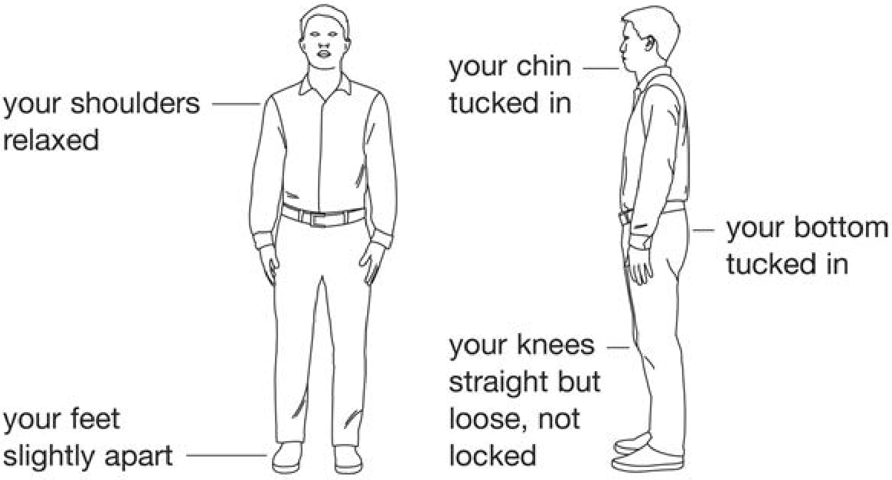
- have an upright and symmetrical posture
- avoid too much twisting and bending

Keeping a good posture takes practice, but with time it can become easier, as your body re-aligns itself.

A physiotherapist can help you identify any problems you might have with posture and suggest suitable exercises to help. If you have mobility problems you may be compensating for them by moving in ways that cause problems in other places. This can add to pain, and to fatigue. A physiotherapist can help identify these types of problems too. Ask your GP for a referral.

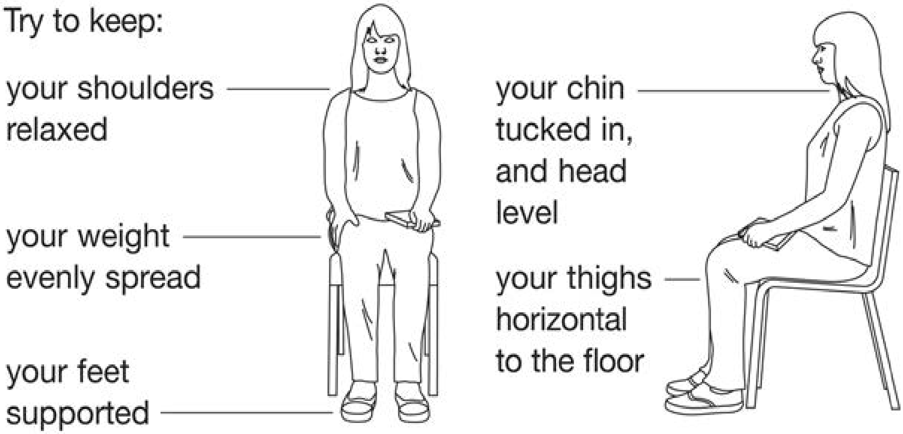
Standing

Try to keep:



Sitting

Try to keep:



Exercise

It almost goes against common sense to exert yourself if you experience fatigue, and MS symptoms can make exercise difficult. But exercise helps keep your body working at its best. Exercise can improve strength, fitness and mood and stop muscles from losing strength over time (deconditioning). Deconditioning can be painful and make mobility or weakness problems worse. Lifting mood, building strength and avoiding deconditioning can all help with managing fatigue.

See the MS Society DVD **Exercise and MS.**

It is possible to do too much exercise. Exercise needs to be balanced with rest, and a physiotherapist can help create an exercise programme for you.

If heat makes your fatigue worse you might want to plan your exercise to avoid long sessions and so overheating. Alternatively, some people find water-based exercise helps maintain a steady temperature. Cooling vests or wrist bands may also help.

See the MS Society booklet **Exercise and physiotherapy** for more information.

Healthy eating

Combining sensible exercise with a balanced diet can also help you maintain a healthy weight and get the energy you need. Weight loss and weight gain can both be issues for people with MS and can make coping with fatigue more difficult. A dietitian can work with you to plan a suitable diet to maintain a healthy weight.

What you eat can also make a difference. For example, large, hot meals can make fatigue worse and caffeine or sugary snacks might have an initial ‘pick-me-up’ effect, but leave you feeling more tired later.

Some people with bladder problems drink less to reduce their need to go to the toilet. Not drinking enough water can lead to dehydration which can cause fatigue.

See the MS Society booklet **Diet and nutrition** for more information.

Fatigue management programmes

Fatigue management programmes are often based on the kind of strategies outlined above, and can help with making changes to your habits, behaviour and routines. They are sometimes done in group settings, sometimes individually, and might involve family members, friends and carers.

One of these programmes, called FACETS, has been shown to be effective in helping people with MS manage their fatigue. The six-week programme incorporates 'energy effectiveness techniques' – like lifestyle decisions and ways of working that maximise the energy people have – alongside cognitive behavioural strategies which help participants to learn helpful ways of thinking about fatigue.

The programme was developed by researchers from Bournemouth University and Poole Hospital, and funded by the MS Society. 40% of people who took part in a clinical trial of the programme reported an improvement in their level of fatigue, compared to 19% of those who received current local practice only. These improvements were still felt a year after taking part in the programme.

FACETS is run locally by health care professionals who have taken part in a training course on delivering the programme. If you would like to go on the FACETS programme, speak to your MS nurse, physiotherapist, OT or another member of your health care team to find out if it's available in your area. If it isn't, you can ask them to contact the Education team at the MS Society on education@mssociety.org.uk or 020 8438 0967 for information about training opportunities.

If you live in England or Wales, you may also find it helpful to attend an Expert Patient self-management course. These courses help people living with a long-term health condition maintain their health and improve their quality of life. They include techniques for managing fatigue. Courses take place over six weeks (two and a half hours a week) and are led by people who themselves live with a long-term condition.

The MS Society Scotland also runs self-management courses.

Cognitive behavioural therapy (CBT) and mindfulness training have also been shown to help manage MS fatigue, by teaching techniques to help you to change your thinking and behaviour patterns.
These therapies are available on the NHS – speak to your GP if you think you would benefit from them.

Not everyone feels able to participate in programmes of this sort. But, if fatigue is a significant problem for you, you may want to consider such a course as part of the overall care you receive.

Drugs for MS fatigue

Although there are currently no drugs licensed in the UK specifically for MS fatigue, certain drugs licensed for other conditions are sometimes prescribed. There is limited evidence for their effectiveness, and what evidence there is suggests they are less effective than the fatigue management tools listed on the previous pages. However, some people find that drug treatments help them manage their fatigue.

Amantadine (Symmetrel or Lysovir)

This drug is licensed to treat Parkinson's disease, as well as some viral infections. Unfortunately, research regarding its use in treating fatigue in MS is not conclusive. However, the NICE guideline for MS states that a small benefit might be gained from taking a dose of 200mg daily. Side effects can include insomnia and vivid dreams.

Modafinil (Provigil)

This drug is used to treat narcolepsy, a sleep disorder which causes people to sleep excessively during the day. It is sometimes prescribed off-label for treating MS fatigue.
There have been several small studies looking at modafinil to treat fatigue in MS, but they have had conflicting results and have not proved the benefits of taking modafinil.

In 2010 the European Medicines Agency recommended that modafinil should only be used for treating narcolepsy. As a result, many specialists are unwilling to prescribe it for MS fatigue. However, it is sometimes still prescribed and some people who take it say it helps.
Side effects can include insomnia and headaches.

Prokarin (sometimes spelt Procarin)

Prokarin is a skin patch that contains caffeine and histamine. It is not available on prescription and can be expensive. Some consider it a complementary or alternative medicine.
In one study, people who took it reported less fatigue, but trials of this drug have not proved benefits for treating MS fatigue.

Useful organisations

Citizens Advice

Help with welfare rights, housing and disability advice. Local offices are listed in the telephone directory and on the national websites.

Online advice
🖱 **www.adviceguide.org.uk**
England and Wales
🖱 **www.citizensadvice.org.uk**
Scotland
🖱 **www.cas.org.uk**

In Scotland, telephone advice is available on
☎ **0808 800 9060**
(weekdays 9am-8pm and Saturdays 10am-2pm).

Or for email enquiries and live web chat visit
🖱 **www.citizensadvicedirect.org.uk**

Northern Ireland
🖱 **www.citizensadvice.co.uk**

Disabled Living Foundation (DLF)

Can provide information and advice on equipment that might help with preparing and eating food.

Textphone 020 7432 8009
☎ 0845 130 9177
🖱 **www.dlf.org.uk**

NHS Choices

The Live Well section has information on all aspects of healthy living, including diet and nutrition.
🖱 **www.nhs.uk/livewell**

Expert Patients Programme (England and Wales)

To find courses in your area contact:

England
🖱 **www.expertpatients.co.uk**

Wales
🖱 **www.wales.nhs.uk/expertpatient**

Gov.uk and NIdirect.gov

Government websites with information about benefits, rights, health care, social care and more.

England, Wales and Scotland
🖱 **www.direct.gov.uk**
Northern Ireland
🖱 **www.nidirect.gov.uk**

Further reading

The following books are all available to borrow from the MS Society library. Email librarian@mssociety.org.uk, call 020 8438 0900 or visit www.mssociety.org.uk/library

- *Fatigue management for people with multiple sclerosis* by Sarah Harrison. Published by the College of Occupational Therapists (Second edition 2007).
  This book includes detailed information about fatigue, some of which is aimed primarily at occupational therapists. It also contains an example of a fatigue management workbook.
- *Fighting fatigue in multiple sclerosis: practical ways to create new habits and increase your energy* by Nancy A. Lowenstein. Published by Demos Health (2010).
  An American book with tips on using occupational therapy ideas to help yourself boost your energy.
- *Coping with multiple sclerosis. A practical guide to understanding and living with MS* by Cynthia Benz and Richard Reynolds. Published by Vermilion (Revised edition 2005).
  This book includes information on coping with the symptoms and uncertainties of MS, where to find help and a summary of MS research.
- *Are you sitting comfortably..?A self-help guide to good posture* in sitting by Wendy Hendrie.
  Published by the Multiple Sclerosis Trust (2009).
  This pocket-sized publication illustrates and describes ways to improve your posture when sitting down.

Sample diary

Date	Describe last night's sleep
15 July	Worse than normal. The weather was quite hot last night whic Felt more tired than usual when I woke up.
Time	Description of your activities
7.15	Wake up and shower (standing up) and brush teeth.
7.30	Get dressed while partner gets children (aged seven and nine) up and dressed.
8.00	Make breakfast for children.
8.30	Drive children to school (four-mile round trip).
9.00	Make breakfast for myself and have a sit down for half an hour.
10.00	Sort out the post and pay the phone bill. Make phone calls.
11.00	Drive to supermarket for weekly shop (about three miles).
12.45-13.00	Have a sit down in supermarket café before driving home
13.00	Drive home
13.15	Take out frozen shopping and put in freezer. Leave rest of bags in car until later

h made it hard to get to sleep and I woke up a few times in the night.	
Fatigue Score 1-10	Comments
3	Slight balance difficulty and numbness in my left arm makes washing harder.
4	I get dressed slowly so it is not such an effort
5	I tend to rely on my right hand – my ‘better’ hand – so things take a bit longer than before
5	
3	
2	
2	
6	
6	
7	My right arm – my ‘good’ one – is starting to feel tired now, because of all the lifting and carrying

Sample diary

Time	Description of your activities
13.30	Prepare a light lunch (standing in kitchen, making sandwich)
13.40	Sit down in front of TV with lunch.
14.30 – 15.00	Hoover downstairs (living room and hallway)
15.00	Wash breakfast and lunch dishes (standing up at sink).
15.30	Bring in rest of shopping from car and put it away.
16.15	Chop vegetables and prepare fish for evening meal (sitting down while chopping, getting up to go to fridge, cupboards and cooker. Reaching for ingredients on high shelves occasionally)
17.00	Cook meal (put fish in oven and boil pans of vegetables).
17.15	Partner arrives home with children from child-minder. Partner serves food while I get children washed and ready to eat
17.30	Sit down to eat with family

Fatigue Score	Comments
7	
5	
6	The hoover helps with balancing, but it is a really heavy one to push.
7	
8	
7	Again, my right arm gets tired quickly, but both arms feel quite heavy now
8	
8	
8	Feel a bit ‘fuzzy-headed’ – difficult to concentrate fully

Sample diary

Time	Description of your activities
19.45	Sit down while partner gets kids ready for bed. Go upstairs to say goodnight to them
20.00	Chance to sit and talk with partner.
21.30	Go upstairs and get changed for bed
22.00	Turn out the lights

Fatigue Score	Comments
8	
8	Still a bit ‘fuzzy-headed’. My arms and legs feel heavy
9	
9	

Sample diary

Time	Description of your activities

Fatigue Score	Comments

Further information from the MS Society

Library

For more information, research articles and DVDs about MS, contact our librarian.

☎ 020 8438 0900

🖱 librarian@mssociety.org.uk

🖥 www.mssociety.org.uk/library

Helpline

The Freephone MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers.

Information is available in over 150 languages through an interpreter service.

☎ 0808 800 8000
(weekdays 9am-9pm)

🖱 helpline@mssociety.org.uk

Resources

Our award winning information resources cover every aspect of living with MS.

☎ 020 8438 0999

🖱 shop@mssociety.org.uk

🖥 www.mssociety.org.uk/publications

About this resource

With thanks to Sarah Thomas, Adrienne Cox and all the people affected by MS who contributed to this booklet.

If you have any comments on this information, please send them to **resources@mssociety.org.uk** or you can complete our short online survey at **www.surveymonkey.com/s/MSresources**

References

A list of references is available on request, and all cited articles are available to borrow from the MS Society library (there may be a small charge). Contact the librarian on 020 8438 0900, or visit **www.mssociety.org.uk/library**

This resource is also available in large print [and audio format]. Call 020 8438 0999 or email shop@mssociety.org.uk

Contact us

MS Helpline

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This title will be reviewed within three years of publication.