



# Living with NMO

From Fatigue To Energy



## Disclaimer

We have made every effort to ensure that information in this publication is correct. We do not accept liability for any errors or omissions, and policy and practice may change. Should you require medical advice as a result of reading the information contained within this site you should seek such advice from a registered medical practitioner.

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# IS FATIGUE PART OF YOUR LIFE?

Increased levels of tiredness (sometimes more than expected) can be experienced by some people with NMO.

The most likely time that you may experience fatigue may be both during and after your first NMO event or an NMO relapse. However, this should greatly improve with each passing week.

As with all NMO symptoms no two people are the same. Some people report that fatigue has a significant effect on their daily life, others find they notice only small or even no changes to their energy levels.

Fatigue can affect people with all sorts of medical conditions at different times. By using fatigue management strategies we can help you to have greater control over your fatigue, leading to an increased quality of life.

We hope this booklet will give you explanations, reassurance and ideas to help you make the best use of your energy levels.

Please contact either centre if you have any further concerns regarding your diagnosis or symptoms.

**NMO Service**  
John Radcliffe Hospital  
West Wing  
Headley Way  
Oxford OX3 9DU  
nmo.advice@ouh.nhs.uk  
Contact: 01865-231905

**NMO Service**  
Walton Centre Foundation Trust  
Lower Lane  
Fazakerley  
Liverpool L9 7LJ  
nmo.advice@thewaltoncentre.nhs.uk  
Contact: 0151-529-8357

This booklet can be provided in other formats including large print or as an audio file, please contact either specialist centre for details, or go to [www.nmouk.nhs.uk](http://www.nmouk.nhs.uk)

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# WHAT IS FATIGUE?

Fatigue is described as an overwhelming tiredness and feeling of exhaustion. It can have a significant impact on a person's ability to deal with everyday life.

## RECOGNISING FATIGUE

**If you are experiencing fatigue, you may have:**

- an overwhelming feeling of tiredness
- reduced energy or an increased need to rest, even after only a small amount of activity
- reduced ability to concentrate at work, home or during leisure activities
- sleep which is unrefreshing
- a general feeling of weakness
- reduced motivation or interest in engaging with your usual activities and routines.

# FATIGUE EXPERIENCES

Fatigue can be hard to explain, as it is invisible to those around you.

You may look fine and it can be difficult for others to appreciate and understand how exhausted you feel.

Employers, friends and loved ones may struggle to understand and empathise, which can cause a feeling of greater stress.

We can all relate to excessive tiredness from perhaps studying as a student, a late night out with friends, “burning the candle at both ends”, the exhaustion of a demanding job or the effects of caring for a young child and the build-up of little sleep.

When you have NMO, you may experience this overwhelming exhaustion simply from taking a bath, attempting to visit a local shop or ironing a few clothes.

Previously simple tasks can feel like a huge challenge.

This level of tiredness can be difficult to understand and can lead to a range of emotions, including feelings of frustration, inadequacy (not being good enough) and guilt.

This booklet contains examples of the personal experiences of people who have a diagnosis of NMO and wish to share their experiences.

***“As a family member, I think it is vital to know how I can help to understand the effect fatigue has on daily life. How can I make things easier for her?”***  
**Nerys, relative**

***“My memory loss seems to be as a result of fatigue, although sometimes I feel too tired to remember why! Absolute exhaustion, the only cure is sleep. Feel like a Duracell Bunny whose batteries have finally run out!”*** Althea

# RESEARCH INTO THE EFFECTS OF FATIGUE ON NMO

Research was carried out in 2013 by the NMO Service, at the Walton Centre NHS Foundation Trust, with the aim of investigating how common fatigue is in people with NMO and how it affected them. The results of the study showed:

- Fatigue is a disabling symptom of NMO, affecting 51% (51 in 100) of people living with NMO.
- Fatigue impacts on people in a physical way, resulting in difficulty carrying out everyday activities both at home and away from home.
- Fatigue tends not to affect a person's ability to think, concentrate and problem solve.

For further discussions and statistics for the publication, please visit

[www.researchgate.net/publication/256605376\\_Effects\\_of\\_Fatigue\\_on\\_Neuromyelitis\\_Optica](http://www.researchgate.net/publication/256605376_Effects_of_Fatigue_on_Neuromyelitis_Optica)

# CAUSES AND TRIGGERS OF FATIGUE

## 1. Primary fatigue

This is caused by an NMO event where there is damage to the myelin sheath (a layer of insulation around a nerve, which helps with the transfer of electrical messages), causing inflammation.

Damage to the myelin sheath means messages cannot flow as smoothly to muscle groups. This can cause either too much muscle tightening or weakness. This in turn causes fatigue. The effects depend on how much damage has occurred, as well as the resulting recovery and response to treatment.

## 2. Secondary fatigue

This affects millions of people worldwide who are living with a long term medical condition. It can be caused by a number of known symptoms or 'triggers'. Triggers most commonly related to NMO are:

- poor sleep
- increased sensitivity to heat
- low mood/depression
- stress and anxiety
- poor nutrition (diet)
- poor hydration (water intake)
- medications
- infections and relapses
- pain and spasticity (over-tight muscles)
- sex and intimacy
- continence issues (going to the toilet).

The triggers can have an effect on each other.

**Ask yourself:** *Do you know what may be causing your fatigue?*

# THE SPOON THEORY

One aspect of fatigue that others often do not understand is the impact it can have on every day activities.

In a blog called 'The Spoon Theory', Christine Miserandino, a journalist, blogger and patient advocate from New York, describes her experiences of living with fatigue. The theory is available to read in full on her blog: [www.butyoudontlooksick.com](http://www.butyoudontlooksick.com)

Christine and her friend were in a restaurant when her friend asked her what it was really like to live with a long term health condition. Christine grabbed a handful of spoons and passed them to her friend. The spoons each represented one task or one thing that uses up energy. With just one spoon left at the end of the day, Christine explained to her friend that if she cooked she wouldn't have enough energy to wash up. If she went out for dinner she may be too tired to safely drive home.

Christine has learnt the need to plan her day and always keep a spoon in reserve in case it is needed. For people who experience high levels of fatigue there is only a limited number of spoons available to use in one day. On some days there will be less than on others, for example after a bad night's sleep.

**Many people identify with Christine's story.**

***Does this sound familiar to you?***

# MANAGING FATIGUE – ENERGY CONSERVATION

The good news is that it is possible, with greater understanding of your own fatigue, to more effectively manage and control it.

Energy Conservation means:

- using your energy wisely
- finding a healthy balance between activity and rest
- making the most of your body's available energy  
getting the most tasks done (such as work) using the least amount of energy.

It can be helpful to think of your energy supply as a given amount for each day. Some people think of it in the form of **a battery, a fuel tank, a bucket of water or as a collection of spoons.**

This daily supply has to be carefully managed for you to have the energy to carry out the tasks and activities in your daily life. You may not have an endless amount.

Learning to manage fatigue takes time, acceptance that trial and error will be necessary and a willingness to take a careful look at your current coping strategies.

# MAXIMISE YOUR ENERGY SUPPLY

This approach is all about working out what factors may be depleting your energy supply and trying out some of the following solutions to help. These factors will be unique to you and may change at different times.

Causes could be one or some of the triggers discussed earlier. Many are linked to one another and can have an effect on each other. For example, if you are having continence issues this may cause disrupted sleep, which could in turn cause stress and low mood.

## POOR SLEEP

*“My biggest problem is that I get really tired by the afternoon and fall asleep, but then have trouble sleeping at night. I’ve been so tired that I can fall asleep anywhere, anytime. I have actually fallen asleep standing in the supermarket holding onto my trolley whilst shopping. When I get tired my blind eye starts to wander, as it can’t concentrate and follow the other eye like it normally does.”* Anon

*“Yawning all day long, even after just waking up. Falling asleep when sat down in a comfortable chair, especially in the evening. Can get bad tempered and snappy when I am overly tired. I wake up a number of times in the night and don’t seem to get a refreshing sleep. Is this contributing to my fatigue?”* Sandra

*“Going back to bed for a sleep doesn’t take the fatigue away. My brain is tired, too weary even to sleep.”* Bill

## Solutions which may help:

- Try to find ways of reducing the impact of continence problems, pain or spasms, if these are disturbing your sleep.
- Avoid alcohol, cigarettes and heavy meals in the evening. If you can, avoid eating a large meal less than 2-3 hours before bedtime. Try a light snack 45 minutes before bed if you are still hungry.
- Use bright lights to help manage your circadian rhythms (your body's natural sleep-wake cycle). Avoid bright light in the evening and expose yourself to sunlight in the morning; this will keep your circadian rhythms in check.
- Stick to a sleep schedule of the same bedtime and same wake up time, even on weekends. This helps to regulate your body's clock and could help you fall asleep and stay asleep for the whole night.
- Practice a relaxing ritual at bedtime. Create a “tool box” of relaxing bedtime activities. Ideas could include:
  - reading a book or magazine by a soft light
  - taking a warm bath
  - listening to relaxing music
  - carrying out easy stretches
  - winding down with a favourite hobby
  - listening to audio books
  - making simple preparations for the next day
  - dimming lights in the hours leading up to bed time.
- A relaxing activity before bedtime, carried out away from bright light, helps separate sleep time from activities that can cause excitement, stress or anxiety.
- Exercise daily.

- Evaluate your room. Check your room for noises or distractions and consider using blackout curtains, eye shades or ear plugs.
- Sleep on a comfortable mattress and pillows. A good mattress has a life expectancy of 9 to 10 years, so can be worth the price.
- Don't be a night time clock watcher. This can actually cause stress, making it harder to go to sleep. If you wake up and cannot return to sleep after 20 minutes, get up and carry out a restful activity.
- Consider learning more about "white noise" (a sound that contains every frequency within the range of human hearing in equal amounts). [www.sleepfoundation.org](http://www.sleepfoundation.org)
- Nap early or not at all. If you find falling asleep or staying asleep through the night difficult, afternoon napping may be the cause. If you cannot manage without an afternoon nap, keep it short and before 5.00pm.
- Balance your fluid intake. Drink enough fluid at night to keep you from waking up thirsty, but not enough to make you wake to need to use the bathroom.
- Think about whether you might be affected by the type of light that comes from screens of laptops and phones, which can make it hard to fall asleep.
- Talk to your GP, neurologist or NMO Service about steroid induced wakefulness, and advice about timings of medication, if you are affected.

- Stay determined! If you stick to some of the tips, your chances of achieving a more restful sleep will improve. However, not all sleep problems are so easily treated and could signify a sleep disorder requiring more expert assessment. Speak with your GP, neurologist or NMO Service if you feel further help is required.

NHS Choices has further information about insomnia and helpful suggestions.

Website: **[www.nhs.uk](http://www.nhs.uk)**

## HEAT SENSITIVITY

It is possible to feel increased fatigue when you are hot. This is due to the effects of heat on the transmission (passing on) of nerve messages within your body. The damage that NMO has caused to the myelin sheath around the nerve result in less insulation against heat for the nerve messages.

Heat can be created by the weather, hot showers, or from a virus or infection (e.g. the flu or a urine infection).

### Suggestions that may help:

- Make sure you are treated quickly for any infection, by visiting your GP.
- Try cooling techniques, such as a tepid bath, sucking on ice cubes, electric fans or pillows designed to stay cool.

## LOW MOOD/DEPRESSION

*“I could wake up and not have the strength or energy to get out of my nightdress. I would literally spend all day falling in and out of sleep. If I got up full of beans and went out shopping, etc., when I got back I’d sink into my sofa and be out like a light... later on, I didn’t let NMO stop me from going to the gym, pursuing a counselling course and going to Weight Watchers.”*

Low mood is linked to low energy levels and vice versa. It is completely understandable for your mood to be lowered by a diagnosis of a long term condition, such as NMO. This can affect you at different times and sometimes unexpectedly.

### Important advice

If you have concerns about having a low mood, or feel you may be depressed, seek help. There are many ways to help improve how you are feeling. If you feel you are in crisis and want to speak to someone straight away call NHS 111.

### Suggestions that may help:

- Speak with your GP about support and treatment options.
- Look for help online from support groups and forums:

[www.rethinkdepression.com](http://www.rethinkdepression.com)

[www.mind.org.uk](http://www.mind.org.uk)

[www.friendsinneed.co.uk](http://www.friendsinneed.co.uk)

## STRESS AND ANXIETY

*“It’s not just the actual fatigue that is challenging; it’s the emotional baggage that comes with it, feeling guilty. For example, I should be able to work full time, but feel lazy, unable to move. Should be able to wash up. It’s feeling like you have to put on a show. Not being able to think straight and sometimes not being able to string a sentence together. She’s milking it, making it up.” Lily*

### Suggestions that may help:

- If left unchecked, stress can directly affect energy levels. It is not possible to remove all sources of stress, but it is possible to more effectively manage it. Try to recognise the causes for you; do you have financial concerns, family worries or employment difficulties? Do you feel you understand your condition?
- The NMO service may be able to help answer questions that are causing you to worry.
- Relaxation techniques are activities that generate a feeling of complete calm. It is an active skill that requires practice. Techniques can help to promote sleep. They include deep breathing techniques, muscular relaxation, massage, aromatherapy, yoga, pilates and tai-chi.
- Mindfulness is the psychological process of bringing your attention to the experiences occurring in the present moment. It can effectively help you to manage daily stresses and can be learnt and practiced from books, audio books and apps.

- Details of ideas and options to help with stress are available from:

**NHS Choices**

[www.nhs.uk/Conditions/stress-anxiety-depression](http://www.nhs.uk/Conditions/stress-anxiety-depression)

**MIND**

[www.mind.org.uk](http://www.mind.org.uk)

## POOR NUTRITION

*“I want to lie down all the time, lack of energy, don’t eat properly, lack of motivation, every day chores seem like hard work.”* Anon

### Suggestions that may help:

- Eat a healthy and well balanced diet, to give you optimum energy levels.
- Eat meals and snacks that are rich in complex carbohydrates, such as milk, fresh fruits, yogurt, oat cakes and wholemeal bread. The rate at which sugars are released from foods is called the glycaemic index (GI). These foods have a low GI, which means they provide a slower and longer-lasting energy release.
- NHS Choices has up to date, expert guidance on healthy eating.

Website: [www.nhs.uk](http://www.nhs.uk)

### Tips for reducing fatigue when preparing food:

1. Prepare foods at times of the day when your energy levels are higher.
2. Make use of labour saving devices (such as electric whisks/ mixers).
3. Use healthy ready-prepared foods, e.g. grated cheese, prepared vegetables.
4. Steam food and use a microwave, instead of lifting heavy saucepans of water.
5. Try using a wire basket placed in a saucepan, to help reduce weight when draining. These are available from hardware stores or online/mail order companies.

6. Visit **[www.livingmadeeasy.org.uk](http://www.livingmadeeasy.org.uk)** for impartial information on staying independent. If you are at home during the day, sit and prepare food, batch cook (make large portions you can then divide up and freeze) and prepare food in stages.
8. Use frozen fruit and vegetables, which all provide excellent nutrition.
9. Consider a meals delivery service:

**[www.wiltshirefarmfoods.com](http://www.wiltshirefarmfoods.com)**

**Tel: 0800 077 3100**

**[www.oakhousefoods.co.uk](http://www.oakhousefoods.co.uk)**

**Tel: 0845 643 2009**

**[www.apetito.co.uk](http://www.apetito.co.uk)**

**Tel: 01225 560 726**

## POOR HYDRATION

*“Sleepiness, muscle weakness, lethargy, low levels of concentration, forgetfulness. I fall asleep whilst drinking tea and its cold when I wake up.” Parveen*

Not drinking enough can be a trigger for daytime fatigue. Drinking enough fluids is critical in maintaining good health.

### Suggestions that may help:

- The NHS Choices ‘Eatwell Guide’ suggests we should drink six to eight glasses of fluid a day. Water, lower fat milk and sugar free drinks (including tea and coffee) all count, but take care drinking drinks with caffeine, as these could affect insomnia and continence issues.

### NHS Choices

[www.nhs.uk/Livewell/Goodfood/Pages/the-eatwell-guide.aspx](http://www.nhs.uk/Livewell/Goodfood/Pages/the-eatwell-guide.aspx)

## MEDICATION

### Suggestions which may help:

- Some medications can increase drowsiness, whilst others can affect your ability to sleep. If you are experiencing difficulties, speak with your NMO Service or GP.

## IMPORTANT

NMO medication is vitally important as part of your NMO management. It must never be altered or stopped without careful discussion and planning with your neurologist or NMO service.

## INFECTIONS/RELAPSE

Infections can increase your body temperature, leading to interrupted nerve messages which make you use up more energy. Common infections include urine infections and chest infections.

Urinary tract (urine) infections can sometimes affect other NMO symptoms, including your ability to walk.

### Suggestions which may help:

- Seek treatment from your GP as soon as possible.

An NMO relapse is likely to increase your fatigue initially, as your body attempts to repair itself and you adapt to a possible change in your physical abilities.

Suggestions which may help:

**Contact your neurologist, GP or NMO service immediately if you suspect an NMO relapse.**

## PAIN AND SPASTICITY MANAGEMENT

Many people report that pain issues can significantly impact on energy levels, which then affects other triggers. Some people experience many types of pain intensity, whilst other people do not report any pain.

If you do experience pain, it is important to get as much advice and support as possible to help you effectively manage it.

### Suggestions which may help:

- Talk to your neurologist or NMO service at any stage about your pain management options; you do not have to wait for your regular review appointment. You may need alternative medications or to be shown pain management techniques to help relieve your symptoms.
- Musculoskeletal (muscle and tendon) pain can be triggered by long periods spent sitting or adopting a bad posture, such as twisting or stooping due to painful areas of the body. Posture is the way somebody holds his or her body. Make sure your bed and chairs provide adequate support and ask your NMO Occupational Therapist for advice.
- Ergonomic advice (the study of how equipment can be best used for comfort, health and safety) is available from your NMO Occupational Therapist. This can help to reduce risks and pain when carrying out everyday activities.
- Your NMO Physiotherapist can give you advice on managing any tight muscles/tendons (spasticity management). This can include exercises, or wearing special stretchy garments designed to provide additional support to muscles and increase feedback messages from your muscles to your brain.

For more information visit: [www.dmorthotics.com](http://www.dmorthotics.com)

[www.jobskin.co.uk](http://www.jobskin.co.uk)

- Eye pain can increase if you've had to work your eyes hard (e.g. a long period of reading or computer work). Build in regular breaks and look at the effects of different lights, glare or screen colours.

Contact [www.rnib.org](http://www.rnib.org) for specialist sight advice.

## SEX AND INTIMACY

You may experience sexual issues as part of your symptoms, depending on where the damage to the myelin sheath is on your spinal cord.

How much this affects you and how long it lasts for will vary, depending on how severe the damage to the myelin sheath is. Symptoms can include loss of or altered sensation, reduced ability to orgasm, or inability to gain an erection.

People with NMO and their partners often report that NMO can create both physical and emotional barriers. These can lead to stress and worries, which in turn can have an effect on your level of fatigue. Your NMO Service can help you discuss your experiences and find solutions and a way forward. There are also further sources of support from organisations for people with similar symptoms to NMO, which you may like to explore.

[www.sexualadviceassociation.co.uk](http://www.sexualadviceassociation.co.uk)

[www.myelitis.org](http://www.myelitis.org)

[www.mssociety.org.uk](http://www.mssociety.org.uk)

The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness (2nd ed.) by Miriam Kaufman, M.D., Cory Silverberg and Fran Odette, Cleis Press, 2007.

Talking to people with a similar issue can be helpful, to explore and fulfil your sexuality. There are a number of forums and sources of information that can help you recover your sensual side.

### **[www.spokz.co.uk](http://www.spokz.co.uk)**

Online retailer, providing disability sports accessories, lifestyle equipment and wellbeing services, including a range of sex aid products to help people with mobility, dexterity and sensation issues.

They have an online forum available or you can telephone 0845 25774 96. All calls are answered by professional sex therapists and counsellors.

### **[www.outsiders.org.uk](http://www.outsiders.org.uk)**

This is a social, peer support and dating club run by and for socially and physically disabled people. Members have a wide range of impairments, including visual impairments.

## CONTINENCE ISSUES

Continence issues for either bladder or bowel can be common for people who have experienced an episode of transverse myelitis due to their NMO. This can affect your sleep, either due to you being disturbed by needing to use the bathroom, or by the need to use continence products, or due to feelings of low mood and anxiety.

NMO Specialist Nurses can give you advice about successfully managing continence issues. They can also refer you to local NHS continence advisors for further support.

There is information available to give you advice about the causes of your difficulties. This may help you to learn ways to successfully manage it and reduce the effect on your daily life and sleep.

**[www.nmouk.nhs.uk](http://www.nmouk.nhs.uk)**

**[www.nmouk.nhs.uk/resources-useful-links](http://www.nmouk.nhs.uk/resources-useful-links)**

NHS booklet “Living with NMO - Bladder and Bowel”

**[www.nmouk.nhs.uk/living-with-nmo/bladder-and-bowel-issues](http://www.nmouk.nhs.uk/living-with-nmo/bladder-and-bowel-issues)**

**[www.nmouk.nhs.uk/living-with-nmo/bowel-issues-in-nmo](http://www.nmouk.nhs.uk/living-with-nmo/bowel-issues-in-nmo)**

**[www.bladderandbowelfoundation](http://www.bladderandbowelfoundation)**

Tel: **01926 357 220**

**[www.disabledliving.co.uk](http://www.disabledliving.co.uk)**

Tel: **01616078200**

**[www.bbuk.org.uk](http://www.bbuk.org.uk)**

Tel: **01616078219**



## PART THREE

# USING ENERGY EFFECTIVELY

Identifying your triggers and implementing ideas and tips can help improve your energy levels. However, it is also important to use your personal energy supply in the most effective way.

**Planning, prioritising, delegating, pacing and using energy efficient strategies** are techniques that you can use to make your energy go as far as possible. This should help you to achieve what you need to do each day.

Careful planning will lead to less uncompleted jobs. Planning allows you to carefully allocate energy to tasks.

## Planning ideas:

- Take time each day/evening to stop and think what needs to be done. Make lists to help you remember and plan.
- Use a diary, notebook, mobile or computer to note what you need to do.
- Be realistic in what can be achieved. What will be the effect on your total energy supply?
- Decide whether the task is essential or just something you would like to do. Also think about what does not need to be done.
- Try to limit tasks which require a lot of energy. Plan in less tiring tasks and breaks.
- Become aware of when you have less energy to carry out tasks. Keep an 'energy diary' to help with this.
- Choose the best time of day for the activity.
- Organise the timing of activities to avoid unnecessary trips, for example, limit the need to go up and down the stairs.

## Prioritising ideas:

- Prioritise from your lists; this will help you feel more in control and have a sense of achievement.
- Try to prioritise the most important tasks for when your energy levels will be higher.
- Do things differently; practice breaking tasks down into 'bite sized chunks'. For example, if you are at home and wish to cook the evening meal, do not attempt to cook it all in one go at the end of the day when you may be tired. Why not prepare the vegetables in the morning, sauce in the afternoon...?
- Make sure you try to prioritise energy for fun and enjoyable activities. If it is a choice between meeting a friend or vacuuming, make sure the vacuuming waits for another day!

## Delegating ideas:

Delegating tasks can feel scary and create a sense of loss of independence. With time and practice you may be surprised how willing others are to help, once they clearly know how best to help you.

By delegating the task that you find more challenging, energy can be saved for you to complete other tasks independently.

## Pacing techniques ideas:

***“I can’t do as much as I used to do in a day, I have to pace myself.”*** Anon

***“I only realise I am tired after doing such things as gardening. My brain doesn’t process it straight away, and this often causes me to overdo it.”*** Ann

- This technique can feel unfamiliar if you are used to going ‘full steam ahead’ until all tasks are completed. It simply involves taking planned breaks or rests within or between activities - simple and effective!
- Carry out tasks more slowly or take regular breaks to help prevent fatigue from building up. Use a timer to prompt you, a pop up message on your computer or a sticky note reminder on your fridge.
- Don’t cram tasks into your day; spread them out throughout the day or week.
- Stop before you become over-tired.
- Avoid rushing.

- Alternate physical tasks (such as DIY) with cognitive tasks (such as paperwork).
- By using pacing techniques you will be able to achieve more and feel less tired.

### Energy efficient strategy ideas:

Carrying out activities in the most efficient way will help to conserve energy. These ideas will take time to incorporate into your daily life, but have a go. You will be surprised how much energy you can save.

- Make use of labour saving equipment and technology.
- Put a wire basket in cooking pans, to reduce weight when lifting. Steam food. Use a microwave.
- Slide items such as saucepans and bowls along the work surface, instead of lifting.
- Spend time reorganising your kitchen/office/bedroom, so that everything you need is close at hand. De-clutter and rearrange to make your environment as easy to use as possible
- Sit rather than stand when carrying out some activities. Standard kitchen stools or perching stools can be helpful.
- Consider keeping a selection of healthy frozen meals in your freezer.
- Batch cook - cook a larger portion of food and then freeze into smaller portions.
- Think how many times you need to go up and down stairs · each day.

- If you are right handed you may need to use your left hand more if your right hand has been affected. Visit **[www.anythinglefthanded.co.uk](http://www.anythinglefthanded.co.uk)** (supplier of left handed products).
- Keep an open mind about the possible value of walking aids. Using a walking aid with a seat (e.g. using a rollator or wheelchair) for certain activities may make the difference in being able to go out on a longer distance activity.
- Find equipment that can help, such as grab rails, a perching stool, equipment to help you get in and out of the bath, a long handled sponge for washing your back or feet. Contact your NMO Occupational Therapist for advice or visit **[www.livingmadeeasy.org.uk](http://www.livingmadeeasy.org.uk)**
- **Remember - PLAN, PRIORITISE, DELEGATE, PACE - BE ENERGY EFFICIENT!**

Contact your NMO Occupational Therapist for further advice.

### The positive effects of energy conservation

- I enjoyed my day
- I feel hopeful now
- I recognise my limits
- The choice is mine
- I know I can ask for help
- I feel more tolerant
- I am more in control
- I can relax
- I'm kind to myself
- My family understand
- I am productive in my work

# WORK AND FATIGUE

*“Fatigue is part of my life and plans have to be made beforehand for every trip or appointment, to deal with it. Going from 12 hour shifts to not being able to cope with, so much fatigue is so frustrating. Feeling guilty for my wife and family.”*

The impact of fatigue can often be most challenging and stressful in the workplace. With the right working patterns and conditions for you, the effects can be managed. Continued employment can bring the financial, social and health benefits that can play such an important part in our lives.

Did you know that more than one in four workers in the UK has a long-term health condition or impairment (Labour Force Survey).

You may be recovering from your first NMO attack, or you may have experienced a relapse. To help you effectively manage your work life, it is vital that you know your rights and where to seek the most helpful advice. Knowledge is the key.

- What are my legal rights as a disabled worker?
- Who does disability legislation apply to?
- What are reasonable adjustments, and will they apply to me?
- How much time off work am I entitled to?
- Will my employer allow disability leave?
- Can I apply for a phased return to work?
- What is the Access to Work scheme?
- How can I learn more about laws prohibiting disability discrimination and the Equality Act 2010?

The organisations below can be a useful further source of information:

- [www.moneyadviceservice.org.uk](http://www.moneyadviceservice.org.uk)
- [www.worksmart.org.uk](http://www.worksmart.org.uk)
- [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)
- [www.equalityadvisoryservice.com](http://www.equalityadvisoryservice.com)
- [www.gov.uk](http://www.gov.uk)
- [www.acas.org.uk](http://www.acas.org.uk)
- [www.rnib.org](http://www.rnib.org)
- [www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)
- [www.spinal.co.uk](http://www.spinal.co.uk)

# PHYSICAL ACTIVITY AND FATIGUE

Can increasing activity levels help to manage fatigue?

The answer is yes. Regular activity is essential for everyone with health benefits in balance, endurance, strength, speed, flexibility, mood and confidence.

If fatigue is a problem for you, it is important to pace yourself and to arrange exercise and activity at the best time to suit you.

**[www.nhs.uk/activity](http://www.nhs.uk/activity)**

Speak to your NMO Physiotherapist on the best way to increase activity in your life

See NMO staying active information at **[www.nmouk.nhs.uk](http://www.nmouk.nhs.uk)**

# FATIGUE TO ENERGY ACTION PLAN

Use this section to begin to create your own fatigue management action plan. Careful detective work and trial and error will be required. Persevere and tackle one issue at a time.

Remember, many of the triggers will be interconnected. If you help to reduce the impact of one trigger, it is likely to have a positive effect on others.

Be prepared to seek help and advice from your GP, neurologist or NMO Service, to help gain greater control over your triggers. Think about making contact with the many services and charities featured in the booklet.

GOOD LUCK!

## I. WHAT ARE MY TRIGGERS?

- low mood/depression
- stress and anxiety
- poor nutrition
- poor hydration
- medications
- infections and relapses
- pain and spasticity
- sex and intimacy
- continence issues.

## 2. WHAT TIPS AND IDEAS COULD I TRY?

[illegible]

### 3. USING MY ENERGY MORE EFFECTIVELY

#### Remember!

PLAN, PRIORITISE, DELEGATE, BE ENERGY EFFICIENT.

Write down your ideas below.

- PLAN

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- PRIORITISE

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- DELEGATE

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## **FURTHER HELPFUL READING**

**[www.support.mstrust.org.uk](http://www.support.mstrust.org.uk)**

**Tel: 01462 476 700**

“Living With Fatigue - Fatigue management for people with Multiple Sclerosis”

This information includes fatigue management advice and tips similar to those for NMO.

**[www.brainandspine.org.uk](http://www.brainandspine.org.uk)**

A UK wide charity, providing information and support for people affected by any neurological condition.

**[www.nhs.uk](http://www.nhs.uk)**

Online information and guidance on all aspects of health and healthcare, to help you make choices about your health.





[www.nmouk.nhs.uk](http://www.nmouk.nhs.uk)

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