



# Multiple sclerosis information

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## for health and social care professionals

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### Fatigue

Fatigue can be described as an overwhelming sense of tiredness, lack of energy and feeling of exhaustion. More formally, it has been defined as “a subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with the usual and desired activity”<sup>1</sup>. MS fatigue is different from normal tiredness and does not correlate with age, severity of MS or mood.

Fatigue is reported to be the most common symptom experienced by people living with MS. In a survey of 2,265 people with MS<sup>2</sup>, 94% experienced fatigue, with 87% reporting an impact on their activities of daily living, which was between moderate to high. Fatigue is often described as an invisible symptom and is variable in nature. Fatigue can be the predominant reason for disability, even early on in the disease course and is reported to be one of the key factors most likely to influence people to give up their jobs. Mental fatigue can affect learning, memory, attention and concentration. Fatigue has a huge impact on participation in everyday tasks, work, leisure and social activities and can therefore impact on psychological well-being.

A good explanation of fatigue is important early on in treatment as MS fatigue exacerbates symptoms and people can fear that they are having a MS relapse. The symptoms will subside after rest which distinguishes them from a relapse.

Brain scans of people who have fatigue show that they use larger areas of the brain to carry out activities than people without fatigue. This would mean that more ‘brain power’ is required to carry out an activity, which may cause fatigue<sup>3</sup>.

Fatigue can be classified as primary or secondary fatigue depending on its cause<sup>1</sup>.

### Types of fatigue

#### Primary fatigue

Primary fatigue describes aspects of fatigue that are thought to be directly related to the disease process but much of the understanding of these features remains theoretical.

**Short-circuiting fatigue** is sometimes known as ‘nerve fibre fatigue’ or ‘conduction block’ where

performance deteriorates during continued/sustained activity but responds to a short rest break allowing activity to be resumed. For example, a person with MS may notice he or she is starting to limp when walking for a while but after a short rest walking has improved. Research suggests that a build up of sodium ions during continued activity, sometimes referred to as ‘flooding’, causes a conduction block, while stopping the activity allows time for the cell membrane to return to its resting state<sup>4</sup>.

**Lassitude** refers to ‘an overwhelming tiredness not directly related to participation in activity or exercise’. The pathogenesis of lassitude is even more poorly understood, although various immunological theories have been suggested.

**Heat sensitive fatigue** is well recognised in MS and has long been considered a unique dimension of MS fatigue differentiating it from fatigue in other conditions. A rise in body temperature of as little as half a degree can interfere with nerve conduction and cause fatigue. This is often described as Uhthoff’s syndrome where symptoms can become worse with an increase in body temperature<sup>5</sup>.

#### Secondary fatigue

Secondary fatigue is not unique to MS; it relates to factors that can be generalised across a variety of chronic and disabling conditions. The relationship between these factors is complex and their influence on the overall experience of fatigue is often difficult to discern. However, the ability to isolate these contributory factors can be invaluable in the medical management of fatigue since many secondary factors can be avoided or treated directly<sup>6</sup>.

**Medications** may cause tiredness or drowsiness as a side effect, for example baclofen, commonly used in the treatment of spasticity. Side effects of the beta interferon disease modifying therapies have also been documented as having a negative impact on fatigue<sup>7</sup>. It should be noted if there is a correlation between a change in fatigue levels and a change in medication.

**Exertion** or increased effort required by the body if mobility or coordination is affected, can cause fatigue. Reduced activity can also lead to deconditioning of the muscles and cardiovascular system, resulting in a less efficient use of energy and therefore the experience of more fatigue.

**Infection**, for example having a cold, flu or urinary tract infection, can all be associated with

increased tiredness and the need to rest, therefore worsening fatigue.

**Disturbed sleep** can exacerbate fatigue and may be due to symptoms that can be alleviated or lessened, for example spasms, pain, urinary urgency at night, depression or anxiety.

**Depression** or low mood can affect motivation and activity and increase lethargy therefore exacerbating fatigue.

**Environment** including lighting and temperature are crucial, as poor lighting increases visual effort and heat can exacerbate fatigue. The general layout of home and work environments should be ergonomic to allow energy to be used efficiently. Also, walking distance and number of stairs need to be considered.

### Fatigue management

Explanation and information may be the only tools necessary for people with MS to accept that some fatigue is inevitable, to help them minimise precipitating factors and manage their lifestyle to accommodate the problem.

For other people further help may be necessary and various fatigue management programmes have been developed and are well documented<sup>1</sup>. This approach to managing fatigue relies on a person reflecting on their own fatigue and the way that it affects their daily life. A fatigue diary can help in this process. The approach does not take fatigue away but aims to make living with fatigue easier. Fatigue management requires a coordinated approach involving family and colleagues as well as health professionals<sup>8,9</sup>.

The principles are as follows:

#### Take frequent rests

Balance activities with rests and learn to allow time to rest when planning a day's activities. Rest means doing nothing at all and it is better to take short frequent rests rather than one long one. It is crucial to rest before fatigue sets in. Some people also find relaxation techniques helpful.

#### Prioritise activities

Prioritising activities can mean that you save energy for the things you really want or need to do. Decide if jobs could be done by other people, consider outside help, and consider jobs that could be cut out of your

daily routine or done less often, such as ironing.

#### Plan ahead

A daily or weekly timetable can be useful to schedule activities and rest in a balanced way. Spread heavy and light tasks throughout the day. Set realistic targets and breakdown large complicated tasks into smaller stages that can be spread throughout the day. 'Time, not task' is a good rule to work to.

#### Organise living and work spaces

This involves looking at energy effectiveness/efficiency when carrying out daily activities at home, work and in leisure. This may involve re-organising desks or cupboards, or adjusting the temperature or lighting.

#### Adopt a good posture

Activities should be carried out in a relaxed and efficient way minimising stress on the body, which will in turn save energy. Maintain an upright and symmetrical posture during all tasks and rest on a perching stool while carrying out tasks if necessary. Avoid excessive twisting and bending.

#### Lead a healthy lifestyle

Keep generally fit. Exercise is essential but should be balanced with rests. Physiotherapists can advise on specific exercises that may be relevant. Eat a well balanced diet and remember that excess weight, alcohol and smoking can all have a negative impact on fatigue.

An occupational therapist can offer education regarding both fatigue management principles and a practical problem-solving approach. As well as clinical guidelines which support fatigue management programmes, research demonstrates that a fatigue management programme for people with MS that combines cognitive behavioural and energy saving approaches, is effective in reducing fatigue severity and increasing self-efficacy<sup>10</sup>.

Generally, medicines targeted at fatigue should not be used routinely. However, a small clinical benefit might be gained from taking amantadine (Symmetrel, Lysovir) which has been shown to reduce fatigue in 20-40% of people with mild to moderate MS. Amantadine is generally well tolerated with mild side effects including constipation, nausea, anxiety and hyperactivity. It is suggested that the dose is taken in the middle of the day to avoid problems of insomnia or vivid dreams from the drug being taken too close to the individual's normal bedtime<sup>11,12</sup>.

Modafinil is a drug that promotes wakefulness and is licensed for treating people experiencing excessive sleepiness due to narcolepsy. Research has suggested that it may be an effective treatment for the management of multiple sclerosis fatigue in some people where sleepiness is a factor in their fatigue<sup>14</sup>. However following the findings of a safety review, the European Medicines Agency recommended that the use of modafinil should now only be associated with narcolepsy.

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### MS Trust resources

Living with fatigue  
MS and me: a self-management  
guide to living with MS



Diet factsheet

### Further resources

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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.

This book has been provided free by the Multiple Sclerosis Trust, a small UK charity which works to improve the lives of people affected by MS. We rely on donations, fundraising and gifts in wills to be able to fund our services and are extremely grateful for every donation received, no matter what size.

## MS Trust information service

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The MS Trust offers a wide range of publications, including a newsletter for health and social care professionals Way Ahead and the MS Information Update, which provides an ongoing update on research and developments in MS management.

For a full list of MS Trust publications, to sign up for Way Ahead and much more visit our website at [www.mstrust.org.uk](http://www.mstrust.org.uk)



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