

Fatigue management in MS



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As occupational therapists (OTs) working in an MS service, the topic of fatigue is discussed on an almost daily basis. The statistics suggest that over 85% of people with MS experience fatigue so it is not surprising that this is one of the most talked about symptoms.

One of the challenging and frustrating aspects of MS fatigue is the invisible nature that it takes, as this can lead to misunderstanding and misinterpretation with comments like “but you look so well!”

MS fatigue can be difficult to describe. It is defined as: “A subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual or desired activities”¹

Finding a way to communicate the effects MS fatigue can have is useful, in terms of helping significant others understand and thus support the fatigue management process.

The mechanisms underlying MS fatigue are not fully understood. The literature separates the causes into primary and secondary factors.

Primary fatigue

Primary fatigue is directly related to damage or inflammation affecting the myelin in the central nervous system along with altered immune or endocrine function.

Short-circuiting fatigue

This is where the effort of doing a repetitive task becomes more difficult over time to the point of needing to stop and have an enforced rest. The good news is that it usually improves after a short rest.

Lassitude

This is an overwhelming sensation of tiredness that sweeps over the body and is often unrelated to the task that you have just been doing.

Heat sensitive fatigue

This is brought on by heat when there is a rise in the body's core temperature. People have talked about enjoying the sun, lying on a sun-bed, and then not being able to get up! Or for some it might be a hot bath that depletes energy.

Cognitive fatigue

At times of fatigue, some people describe difficulties concentrating and remembering things. This is often referred to as a form of mental or cognitive fatigue. The MS Trust has a website called StayingSmart that has some useful tips on managing cognitive problems.²



Secondary fatigue

Secondary fatigue is not unique to MS. It relates to more general factors that can affect energy levels, eg pain/spasm leading to sleep problems. Here is a brief list of areas that are important when considering fatigue and its possible causes.

Medication

What are the side effects of your prescribed medication? Is tiredness one of them and, if so, are there any alternatives?

Infection

Are there any signs of infection? These can affect fatigue levels and need to be either ruled out or treated as soon as possible.

Sleep disturbance

Do you have problems getting to sleep? Is waking in the night a problem or is there too much sleep in the day? It can be really helpful to take a close look at your sleep pattern and factors affecting this.

Exertion/de-conditioning

Is there a pattern of pushing yourself at every opportunity so as not to be ‘giving in to fatigue’ or has the fear of fatigue or difficulties with mobility led to de-conditioning? It is about getting a balance here.

Environmental factors

Are there changes that can be made in your environment, such as rearranging work surfaces or making use of labour saving devices that can make tasks easier to carry out?

Anxiety and stress

Is stress playing a part in draining energy? This needs to be considered in the whole picture.

There are many other factors in life which can affect energy levels and it is helpful to take the time out to identify all the relevant factors before looking at how to manage fatigue.

So how can fatigue be managed?

A large part of fatigue management may be regarded as common sense, however there is a difference between knowing something and actually incorporating it into everyday life. For example, we know from research that it is beneficial to have our ‘five a day’ and take regular exercise but putting it into practice doesn’t always happen! So it is important that fatigue management goes beyond the theory and gets put into practice. The MS Trust’s book *Living with fatigue* gives a good introduction to managing fatigue.³

A good starting point is to complete a fatigue diary over a few days to provide a real picture of what is happening. An OT can help with identifying a suitable way to record this information. The diary can help to identify how/if certain activities affect fatigue, how long recovery takes and what reduces fatigue. The great thing about a diary is that it can be repeated after some changes have been made to see how things are going, as it is all too easy to lose sight of where you started from and the progress you have made.

The next stage would be to consider using some energy conservation strategies. The principles of rest and pacing are key aspects of energy conservation.

Some people really struggle with the notion of rest as it doesn’t always fit into Western cultural values, which seem to promote busyness and keeping going as long as you can! Comments such as ‘if I rest I feel lazy’ and ‘I feel guilty if I rest as I am not pulling my weight’ often crop up and can get in the way of putting effective fatigue management into practice. Sometimes thinking about what you would advise a friend can help to cast a fresh light on such matters.

Getting to know how your fatigue levels relate to specific tasks can be helpful in learning to rest before you get tired, as then there is likely to be less payback time. Sometimes payback is worth it; for example, if it has been an enjoyable, much anticipated event. However, if payback happens regularly as a result of overdoing mundane everyday activities, it might be worth questioning this approach.

Prioritisation is about identifying what you want to use your energy for and finding a way to manage this. This can be achieved by using pacing techniques in conjunction with breaking tasks down into manageable chunks.

An OT can help you consider the whole picture and give ideas about equipment and adapting tasks. Other members of the MS service can offer advice and direction, and there are the various publications from the MS Trust and MS Society.

When thinking about how to keep the momentum going over time with regards to using fatigue management principles, it can be helpful to have the understanding and support of those around you, giving gentle reminders about rest and putting the principles of fatigue management into practice.

Fatigue management doesn’t lead to fatigue disappearing but it can certainly go a long way in helping you to manage the available energy more effectively and feeling more in control.

References
1. Multiple Sclerosis Council. Fatigue and multiple sclerosis: evidence-based management strategies for fatigue in multiple sclerosis. Washington; Paralyzed Veterans of America:1998.
2. StayingSmart - www.stayingsmart.org.uk
3. Ennis M. Living with fatigue. Letchworth Garden City: MS Trust; 2006.