

MS *in focus*

January 2012

Fatigue and MS



multiple sclerosis
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ISSN1478467x

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Letter from the Editor



The very first edition of *MS in focus*, published in 2003, had a special focus on dealing with fatigue. Looking back at it now, the magazine has been refined and adjusted over that time, but it still aims to provide people with MS and healthcare professionals with high-quality, independent information on MS-related topics.

We felt it was time to renew and update this very important topic. As you will see inside, fatigue is still one of the most common symptoms for people with MS, and unfortunately, still one of the most difficult to treat and manage day-to-day.

But, there have been advances. Worldwide there is increased research into fatigue and its impact, how it is measured and how it can be treated and managed. This edition of *MS in focus* considers all these aspects of fatigue, with completely new articles written by leading authorities in this area from around the world.

The issue also contains the results of the online MS fatigue survey, which more than 10,000 people from 101 countries answered. If you were one of those people, thank you – we know how important it is to acknowledge the impact of fatigue on your lives.

Nearly half of you thought that people around you generally lack an understanding of the impact of fatigue so we hope this updated edition provides a resource that can help. For those who reported to us that some healthcare professionals are not adequately prepared on the topic of fatigue, share this issue of *MS in focus* with them. We encourage every reader of *MS in focus* to disseminate information to others in the MS community by signing up family members, friends, colleagues and healthcare professionals to receive future editions at www.msif.org/subscribe.

We look forward to receiving your comments.

Michele Messmer Uccelli, Editor

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The next issue of *MS in focus* will be about "Is it MS?". Please send questions and letters to michele@aism.it or marked for the attention of Michele Messmer Uccelli at the Italian MS Society, Via Operai 40, Genoa, Italy 16149.

Editorial statement

The content of *MS in focus* is based on professional knowledge and experience. The Editor and authors endeavour to provide relevant and up-to-date information at the time of publication. The views and opinions expressed may not be the views of MSIF. Information provided through *MS in focus* is not intended as a substitute for advice, prescription or recommendation from a physician or other healthcare professional. For specific, personalised information, consult your healthcare provider. MSIF does not approve, endorse or recommend specific products or services, but provides information to assist people in making their own decisions.

Introduction to fatigue in MS – taking a comprehensive approach

Susan Forwell, PhD, OT(C), FCAOT, Associate Professor, Department of Occupational Science and Occupational Therapy, University of British Columbia, Vancouver, BC, Canada

In 2003, the first issue of *MS in focus* was dedicated to the impact of fatigue in MS. At that time, each article identified various factors that were thought to contribute to fatigue and provided ideas for treatment. There was some research to support those ideas, but this was just the beginning and research in this area has continued in the last decade.

For example, there are now studies that show that nerve fibre fatigue, also known as primary MS fatigue, is present for more than 90 percent of people with MS. In addition, approximately 70 percent of those with MS that have fatigue also have

other factors that add to daytime fatigue. It has been shown that more than 50 percent of people with MS with daytime fatigue have nighttime sleep problems and thus cannot build up the energy reserve required for the day. About 50 percent of people with MS have walking difficulties and, when not walking efficiently, a person quickly spends energy just trying to get around.

Another factor that increases the magnitude of fatigue is depression, something that occurs for about 40 percent of those with MS. Also some of the medications taken by about 20 percent of people with fatigue may have 'fatiguing' effects



during the day. So when there are several additional factors contributing to fatigue in MS, the negative impact, as described in the article on pages 7-9, is worse.

The key is to minimise and manage these factors by “spending” energy wisely and having energy in reserve each day. With this in mind, it is important to screen for the factors contributing to fatigue specifically and then to seek treatment to reduce the impact of many of these treatable factors.

There has been a proliferation of assessment tools that target fatigue generally, and also specifically fatigue in MS. Some of these are: the fatigue severity scale (FSS), the modified fatigue impact scale (MFIS), the Rochester Fatigue Diary, the visual analog scale for fatigue, the Würzburg Fatigue Inventory for MS and the PROMIS v1.0 fatigue short form. These and other measures, as well as the relationship to neuro-imaging findings, are further described on pages 10-12.

Also emerging are all-inclusive inventories, like the comprehensive fatigue assessment battery for MS (CFAB-MS), which is a self-report assessment designed to screen for contributing factors and provide a nuanced understanding of fatigue for each individual. An integral part of understanding the fatigue picture in MS is related to self-efficacy and self-management. As a result, screening assessments such as the Self-Efficacy for Performing Energy Conservation Strategies Assessment (SEPECSA) and the MS Self-management (MSSM) evaluation have also been developed. For an example of a self-management programme, please see pages 19-21.

In addition, like other aspects of MS, the problem of fatigue impacts a person’s family, friends and social network. It can be challenging to manage and maintain good relationships, but when the complexity and invisible nature of fatigue is added, the strain is evident. Research has shown that fatigue can cause a person to experience a shrinking social network and changing patterns of social interaction.

It has also been reported that fatigue has a negative effect on social function and ability and on sexual activity. This means that a person may, for example, do less socialising with their much needed supports like family and friends, limit attendance at their children’s events, reduce regular outings or trips into their local community, and engage in fewer intimate occasions.

Having better assessment tools, and understanding the full social impact of fatigue in MS, has also lead to identifying appropriate treatment strategies. There are four main groups of strategies that are used to manage fatigue in MS:

- treatment of the contributing factors;
- rehabilitation approaches;
- medications; and
- complementary and alternative methods.

Treatment of contributing factors

Treating or dealing with the additional factors (such as sleep problems, depression, mobility difficulties, deconditioned fitness level, stress, other medical problems and/or pain) that contribute to fatigue in MS is essential prior to, and concurrent with, the other three types of treatment.

It has been shown that the magnitude of the fatigue experienced increases as the number of factors that contribute to fatigue increases. Depending on the factor, the treatment will vary, though the important principle is to make sure these factors are identified and treated, as they add to the primary fatigue experienced in MS.

Rehabilitation approaches

Several studies have been conducted demonstrating the positive results of rehabilitation programmes dedicated to managing fatigue. Some MS societies offer face-to-face group programmes, or teleconference programmes, that are effective for managing fatigue in MS. The US National MS Society has a 5-session video series about managing MS fatigue.

Examples of specific energy saving ideas include using a bath bench or shower chair to reduce energy demands while bathing and to prioritise the

things you need and want to do, rather than the things you should do. For example, calling a friend or going out for a visit rather than doing a domestic chore. As one person with MS puts it, “I don’t bother about guilt or worry or ‘should-itis’... it is a waste of time and makes me feel bad.”

It should be pointed out that a number of rehabilitation programmes that were not specifically targeting fatigue have also been shown to have a positive impact on reducing the fatigue experience in MS. These include mobility and exercise programmes that contain balance training, treadmill workouts and elliptical exercises, as well as self-management programmes. In the article on pages 13-15, there is a detailed description of appropriate rehabilitation programmes and non-invasive strategies to consider when managing fatigue in MS.

Medications

While there have been a number of studies to determine the effect of medications on fatigue in MS, the two most commonly prescribed are amantadine and modafinil. An article about these and other medications that may be used for fatigue in MS is presented on pages 16-17.

Complementary and alternative methods

There is also some research showing that selected complementary and alternative methods, such as yoga, tai chi and hydrotherapy, as well as vitamins B and B12, wearing cooling garments and mindfulness training could be useful as part of the fatigue management arsenal. It should be noted that these strategies are rarely used in isolation; rather they are part of a well-considered combination of methods that are suited to each individual’s situation, preferences and resources.

Advice from people with MS fatigue

Using the ideas and combinations described, advice can also be provided by people who are managing their MS fatigue and are able to do what is important to them. Examples of their strategies and ideas include:

- “Give yourself permission to do something

enjoyable and don’t feel guilty... that’s a waste of energy.”

- “I do my most energy-consuming activities at the beginning of the day.”
- “Acceptance enabled me to ask for help.”
- “I now prioritise socialising with friends rather than cleaning the house.”

Read more about people with MS-related fatigue in the interviews on pages 24-25 and also in the results of the online survey on pages 22-23.

Conclusion

As shown by the articles in this issue of *MS in focus*, there are benefits to using a comprehensive approach that is specific to each person when dealing with fatigue in MS.

This approach includes identifying and treating the factors contributing to fatigue, then using a combination of rehabilitation strategies and appropriate medications to support the optimal management of fatigue in MS.



Defining and identifying fatigue in MS

Roger Mills, Consultant Neurologist, Lancashire Teaching Hospitals Trust, Sharoe Green Lane, Fulwood, Preston, UK

Fatigue in MS

Fatigue is the most common symptom in MS. In some studies it has been reported that as many as 95 percent of people with MS have fatigue, and it can actually be the presenting symptom of the illness in up to one third of people. Up to two thirds experience it on a daily basis. It is considered by 55 percent of people with MS to be among their most disabling symptoms and their worst symptom by 40 percent.

The impact of MS fatigue on a person's quality of life is, therefore, considerable. It is among the top reasons cited for unemployment. Unfortunately, the cause of this devastating and chronic symptom remains elusive, despite more than two decades of research. It is not even clear whether MS fatigue is an extreme exaggeration of normal fatigue experienced in health, or whether it is unique to MS.

What is MS fatigue?

Previous definitions of fatigue, as a clinical symptom in MS, included: overwhelming sense of tiredness, lack of energy or feelings of exhaustion; difficulty initiating or sustaining voluntary effort; feelings of physical tiredness and lack of energy distinct from sadness or weakness; a subjective lack of physical and/or mental energy that is perceived by the individual or the caregiver to interfere with usual or desired activities.

For a symptom which is very complex, those definitions do not always really describe the phenomenon. Recently, a more comprehensive approach looking at the features of fatigue has been proposed. Fatigue is a dynamic symptom meaning that it can come and go at different

times or in different circumstances. In some, the symptoms are mild and not bothersome, in others it is all consuming. People with MS describe the following features of fatigue:

Motor fatigue (power to muscles)

Weakness develops the more muscles are used, speech can become slurred, it can become difficult to do things which are usually simple or routine, for example 'having to think of putting one foot in front of the other'.



Cognitive fatigue

The ability to think and coordinate becomes more difficult as brain power is used, mistakes are made easily, concentrating on individual tasks becomes difficult, and memory, recall and word finding is impaired.

Motivation is reduced, with a strong desire to rest, if not sleep. The fatigue leads to changes in behaviour such that certain fatiguing activities are avoided. Rest or sleep is best done in quiet or calm surroundings. Interestingly, people with MS also learn to rest in anticipation of some fatiguing event, even if not feeling fatigued at the time. Some notice they yawn excessively or sweat easily during fatigue.

Fatigue can come on quickly with a specific task but can also build up in the day to reach a peak in the afternoon, or come on without clear reason.

Sometimes fatigue can occur on the day after the event which caused it. Generally, MS fatigue is experienced for months or even years at a time.

There are clearly recognised triggers or exacerbating factors – physical and mental work as mentioned, humid and hot conditions, eating a heavy meal, being unwell for another reason, for example an infection, broken or unrefreshing sleep at night, pain, long periods of inactivity, and mental stress or anxiety. Fatigue is almost universally present during an MS relapse.

Fatigue can be relieved, perhaps temporarily, by rest or sleep in the day, or anticipatory or scheduled rest or sleep. In some, a good night's sleep will also be beneficial. Pacing activity by doing things slowly and avoiding certain activities can also help. Finding ways to cool down or avoiding hot and humid environments may also provide relief.



How does fatigue relate to the other features of MS?

Fatigue and age, gender and disease duration

Levels of fatigue do not relate to being either male or female and are not related to age (contrary to common belief). Similarly the duration of MS does not affect fatigue.

Fatigue and disability

Fatigue increases with increasing disability, particularly once walking ability is affected. People with progressive MS have greater levels of fatigue.

Fatigue and sleep

There is a very complex relationship between fatigue and sleep. About 50 percent of people with MS sleep during the day and most find this helps to reduce fatigue, even if it is just a short nap. If people sleep in the day because of fatigue, it doesn't affect their ability to sleep at night.

However, a longer sleep at night does not necessarily reduce fatigue, in fact levels of fatigue are the same in those who sleep for either 11 hours or 4 hours at night. Lowest levels of fatigue occur in those who sleep for 7.5 hours. Unfortunately, it is not known whether changing the duration of sleep at night would improve fatigue.

Fatigue and depression

Tiredness is an integral part of depression and some people think that MS fatigue is just the result of depression, but when measured, MS fatigue is only weakly related to depression. People with MS do not tend to mention depressive symptoms when describing fatigue, and antidepressant medication does not improve fatigue.

Another interesting difference is that people who sleep in the day because of depression usually feel worse, not better for it, in direct contrast to day sleep for fatigue. For these reasons, MS fatigue should be considered to be distinct from depression.

Fatigue and medication

Many treatments for pain, spasticity or bladder overactivity can have sedating side effects and so



can compound the effect of fatigue. Whether such medications can actually cause MS fatigue is not clear.

What causes MS fatigue?

The cause of fatigue in MS remains unknown. The principal mechanisms are thought to be:

- a) due to structural abnormality in the brain caused by demyelination and axonal loss,
- b) a product of the immune activity in the brain itself and also problems of hormone production from the pituitary gland in the brain, and
- c) due to problems with control of the heart or chemical changes in the muscles.

The scientific evidence that any of these mechanisms are responsible for fatigue is not strong however. Investigations so far have perhaps been hindered by not being able to easily define fatigue and not being sure how it should be measured.

Conclusion

Fatigue can be one of the worst symptoms of MS. It is a surprisingly complex symptom which is difficult to study or even define. It is related to disability and sleep but is different from depression. The real cause of MS fatigue remains unknown.

Measurement of MS fatigue

Lauren B Krupp, Stony Brook University Medical Center, Department of Neurology, Stony Brook, New York, USA

Introduction

Fatigue's pathogenesis and primary causes remain unclear and there are no consistently reliable therapies. A major obstacle towards understanding fatigue is the absence of a universally accepted measure that adequately quantifies the often incapacitating and elusive experience of fatigue. Without such a measurement tool, progress in fatigue therapy will remain restricted.

Another obstacle towards understanding fatigue is the commonly confused concepts of fatigue and fatigability. This article discusses this distinction and reviews the current state of knowledge regarding self-reported fatigue measurement in MS, including the types of requirements put forth by the regulatory authorities regarding clinical trials and preliminary neuroimaging markers of fatigue in MS identified with brain magnetic resonance imaging (MRI).

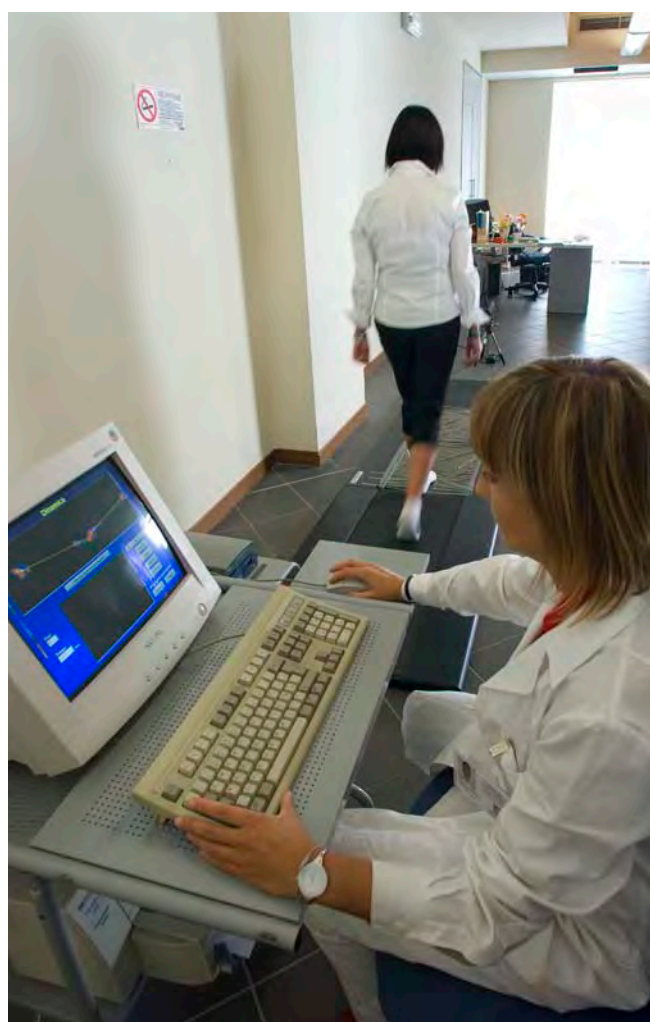
Fatigue versus fatigability

Perceived fatigue is what is generally meant by the term "fatigue" as it is defined by a person's subjective experience. "Tiredness and exhaustion" are related terms. Perceived fatigue is typically assessed with structured questionnaires or scales that target the individual's subjective experience. Measures can be subscales of more comprehensive quality of life assessments or can be specific to fatigue. In contrast, fatigability is defined by a performance decline on a task, usually due to a loss of endurance.

For instance, fatigability occurs when an individual with MS and a subtle motor impairment is asked to walk over a specific time interval, quickly and without stopping or slowing down. Initially, the subject begins to walk at a brisk pace

but eventually tires and slows down or eventually stops during the specified time interval. The reasons could vary and the loss of endurance might be due to weakness, exhaustion or lack of energy.

In comparison, an individual without motor fatigability would be able to walk the same distance maintaining their initial rate, neither slowing down nor stopping. While this



A physiatrist assesses a person's walking to identify the impact of fatigue.

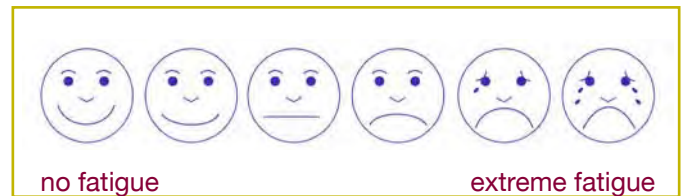
example refers to “motor fatigability”, similar experiments could be devised to test mental fatigability. This is the type of fatigue measure that researchers or regulatory bodies much prefer because it appears “objective”. However, unfortunately, the vast majority of performance-type measures of fatigue fail to correspond with the subjective “feeling” of fatigue.

Therefore, most clinicians (researchers interested in clinical trials designed to address the subjective sense of fatigue experienced by individuals with MS) are looking for a clinically meaningful measure which captures the sense of tiredness or exhaustion that someone with MS might feel independently from activity level. This fatigue can be compared to the sense of exhaustion that someone experiences when they have the “flu”. The remainder of this article will focus on the measurement of the subjective experience of fatigue.

Fatigue scales

Fatigue measures can be compared across several features. These include whether they can be used to assess fatigue in all situations or just in MS, whether they have been shown to correspond to non-subjective measures (such as MRI findings) and their psychometric properties (which include reliability, validity and responsiveness).

Self-report measures specific to fatigue vary in item numbers. A single item scale frequently used for researchers of other symptoms (for example, pain) is a visual analog scale. A 10cm (3.9in) line or diagram is provided to a subject in which least-to-most fatigue is represented by the left and right hand ends of the line (see right, above). The subject then indicates on the line the amount of fatigue they are experiencing. While intuitive and uncomplicated, such measures are often found to have poor reliability (for example, under stable conditions the scores are not reproducible) and such an approach is vulnerable to generating impulsive responses. Therefore, including multiple items can add to reliability and more broadly capture the experience of fatigue.



An example of a visual analog scale

Some examples of MS fatigue specific scales include the Fatigue Scale for Motor and Cognitive Functions, the Würzburg Fatigue Inventory for MS (which contains sub-scores for cognitive and physical fatigue), the MS-specific Fatigue Severity Scale (MFSS), and the Fatigue Descriptive Scale (which identifies three modalities of fatigue by distinguishing asthenia, or fatigue at rest, from fatigability, or worsening symptoms with exercise).

Among the more commonly used self-report scales in MS are the Fatigue Severity Scale (FSS) and the Modified Fatigue Impact Scale (MFIS). Both are relatively short, and have good validity and reliability. For example, both scales have been tested in large patient and healthy control samples, show a close fit to other fatigue measures, remain stable if nothing has happened to modify the fatigue, and appear responsive to changes in fatigue due to disease progression or treatment.

The FSS was designed as a one-dimensional scale. A special statistical test (a Rasch analysis) performed on the FSS indicated that the removal of some items improved the scale’s psychometric properties. The Rasch analysis involves performing mathematical procedures on the individual scale items including ranking the items by difficulty so that the scale can fit into a linear model.

The Modified Fatigue Impact Scale (MFIS) uses a multi-dimensional approach with cognitive, physical and psychosocial components. It too has been subjected to a Rasch analysis. The physical dimension is most associated with measures of motor impairment such as the Expanded Disability Status Scale (EDSS). In contrast, neuropsychological measures do not correlate well with the cognitive dimension.

Another scale is the Fatigue Scale, of interest because it was shown to reflect improved fatigue levels among MS participants in a trial of cognitive behavioural therapy to reduce their fatigue.

A variety of newer measurement techniques have developed using a combination of qualitative interviews and quantitative psychometric procedures. One tool incorporating these methods is the Neurological Fatigue Index (NFI-MS), which was created through interviews with people with MS, item generation, and factor analysis and more recent statistical approaches such as the Rasch analysis.

The measure was tested in two sets of individuals with MS. The first group tested was called the evaluative sample. The second group was the validation sample. The summary ten item scale includes items from physical and cognitive subscales.

Another measurement approach comes from a National Institutes of Health funded effort to improve the quality of “patient” reported outcomes. Development of a fatigue measure from this initiative involved interviews, the review of more than 1,000 fatigue items from published scales, and input from an independent fatigue expert.

Ultimately, a bank of 95 items was developed which can be used to select specific fatigue measures of varying lengths for different purposes. The items are listed on the internet at: <http://www.nihpromis.org/default.aspx>.

Despite these methodological improvements in fatigue scale development, challenges remain. All self-report measures suffer from recall bias and respondents can be influenced by the context within which fatigue is evaluated.

Nonetheless, fatigue scales are readily available, can be quickly administered, and can easily be incorporated into clinical trials.

Fatigue and neuroimaging markers in MS

Neuroimaging has helped our understanding of the mechanisms which might underlie fatigue. MRI studies most frequently include either the FSS or MFIS. Fatigue is not easily localisable to a single area of the central nervous system and early studies of fatigue using MRI and self-report measures found little association between FSS scores with lesion burden, atrophy or enhancing lesions.

However, more contemporary methods of MRI analysis have revealed that when either the FSS or MFIS is used to classify people with MS who are with or without fatigue, those with fatigue have more atrophy of the grey and white matter, including atrophy in specific cortical and subcortical grey matter regions.

Other measures of fatigue derived from larger quality of life questionnaires, which include fatigue among the symptoms that they assess, have also been used in the evaluation of MRI findings.

In a longitudinal study, brain atrophy was noted to have a positive association between global measures of fatigue, using a measure of tiredness derived from a larger multi-item quality of life questionnaire. Measures of grey and white matter atrophy, as well as overall T2 lesion burden and T1 volume, correlated with a measure of fatigue and thinking. However, many other studies do not demonstrate a difference between people with or without fatigue relative to total lesion volume.

Summary

In the past twenty five years there has been tremendous growth in our knowledge of MS and of MS-associated fatigue. MRI markers of brain injury show associations clarifying that fatigue is a complication of the central, and not the peripheral, nervous system. Statistical methods used in scales development have become more sophisticated and have led to the generation of more psychometrically sound measures.

Rehabilitation, exercise and MS fatigue

Francois Bethoux MD, Mellen Center for MS Treatment and Research, Cleveland, Ohio, USA

Despite a growing body of evidence demonstrating their efficacy, rehabilitation and exercise are still under-utilised in the management of MS fatigue.

Exercise and fatigue

In the past, rest was recommended to people with MS to avoid triggering a worsening of MS symptoms. In fact, more recent studies have shown that exercise is safe in MS, and may improve fatigue.

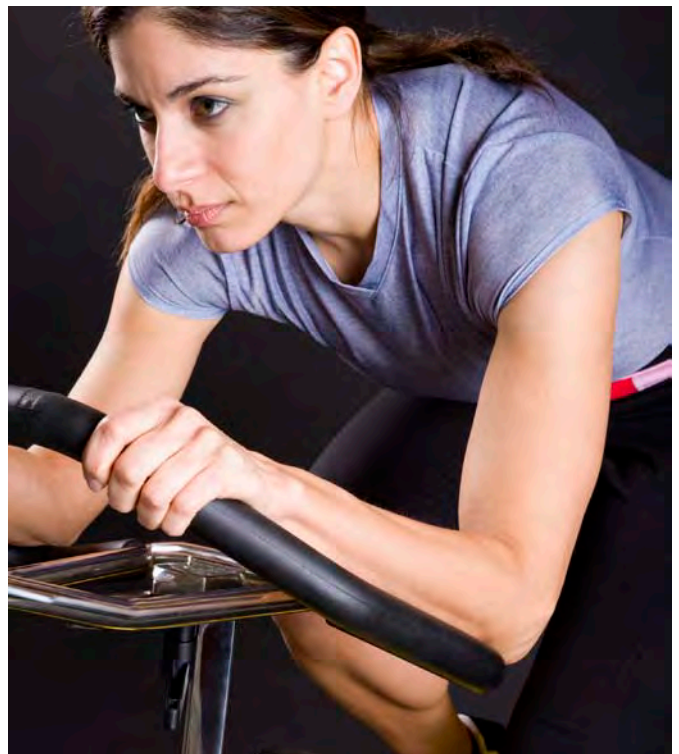
Different types of exercise have been tested (for example, aerobic exercise, resistance training and yoga), with generally positive results on the sensation of fatigue and on quality of life.

However, in daily life, it is often difficult for people with MS to initiate and maintain an exercise routine. They may find that access to exercise facilities, as well as the ability to use various types of equipment, is limited. The intensity and duration of exercises recommended for the general population are usually not adequate for people with MS. In many cases, an individualised exercise regimen is needed to best address the person's needs.

When a person first starts an exercise programme, a transient worsening of MS symptoms may occur, and the benefits on fatigue are not felt immediately. This sometimes leads to abandoning exercise altogether, when an adjustment in the intensity and/or duration of the exercise may have led to better tolerance. Fluctuations of MS symptoms from day to day, or from one time of the day to the other, may interfere with the ability to carry out a daily exercise routine.

General recommendations for exercise in MS include:

- Start low, increase slowly. Exercise sessions should be short and low intensity at first, and the duration and intensity should be increased very gradually (for example, increased by a few minutes every week).
- Exercise on a regular basis, at least three times per week or every day if possible. Some people choose to perform different exercises on different days, to avoid loss of motivation or doing too much in each session.
- Choose exercises and machines that are safe and well tolerated. For example, people who have difficulty with walking and balance may want to



perform aerobic exercise on a stationary bicycle instead of a treadmill. A recumbent stationary bicycle can be helpful to those with back pain or trunk weakness.

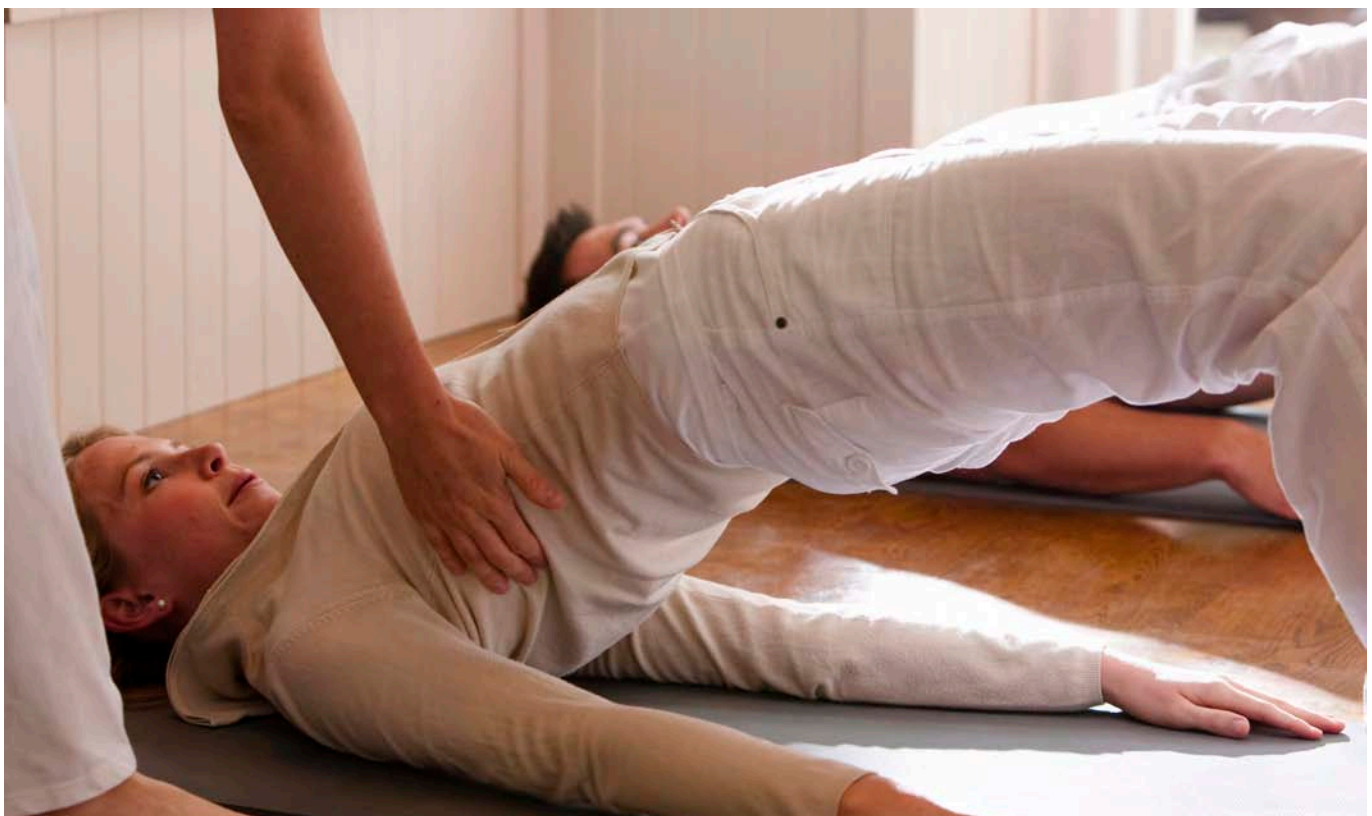
- Choose a time that fits into your daily schedule and your level of energy. Many people like to exercise in the morning, before they get involved in other activities, and at a time when their energy and motivation levels are optimal.
- Avoid overheating by exercising in a climate-controlled room, using a fan or wearing cooling garments.
- Consider exercising in water because it facilitates movement and improves comfort. The water temperature should not be too high, for example 27-29 degrees C (80-84 degrees F).
- Finding an “exercise buddy” or exercising in a group can help increase motivation and gives an opportunity to socialise. A helper may also be needed, for example to get into an exercise facility, to get on and off machines safely or to perform some exercises.

Rehabilitation

Rehabilitation involves a variety of interventions, all aiming to help a person achieve and maintain an optimal level of function and quality of life, in the context of an illness or injury. Rehabilitation can be carried out in an inpatient setting when a person needs daily intensive interventions, for example after a severe exacerbation of MS or after surgery. In MS, rehabilitation services are most often provided in an outpatient setting (clinic or office) or at home.

Various professionals may be involved in the rehabilitation process, including physiatrists (rehabilitation physicians), rehabilitation nurses, physical therapists (PT), occupational therapists (OT), speech therapists, orthotists, social workers and many others. Rehabilitation professionals work as a team, and communicate with other healthcare providers (for example, neurologists, primary care physicians) to ensure a good continuity of care.

Rehabilitation treatments are often delivered for a limited period of time, and the maintenance of gains from rehabilitation requires that the person perform a home exercise programme on a regular basis, alone or with a helper.



What can rehabilitation do for fatigue?

The management of fatigue involves lifestyle recommendations and non-pharmacologic interventions, which often involve rehabilitation professionals (mostly physical and occupational therapists), who may, for example:

Help design and initiate an exercise programme adapted to the person's needs and abilities.

After the therapy sessions have ended, the person can continue exercising at home or at the gym. Periodic re-assessments are recommended to check if the exercise routine has been properly maintained and if any adjustments are needed.

Teach energy conservation techniques. Since people with MS often have a reduced “energy pool” for the day, the goal is to optimise the use of energy over the course of the day, so that activities that are important or desirable are completed before running out of energy. Some of these measures can also increase the pool of energy.

Assess the need for assistive devices to reduce the energetic cost of daily activities.

For example, a leg brace, a cane, or a walker may reduce the energy needed to walk. Many assistive devices can help compensate for a loss of hand strength or dexterity.

Recommend modifications. These can be to the home, car or workplace, and are designed to help facilitate routine activities.

The rehabilitation process

Usually, a person is referred to rehabilitation services by a physician or nurse practitioner, based on the person's needs. In some instances, a physiatrist will be involved. The rehabilitation process involves:

- assessing the severity and the consequences of fatigue on the ability to function;
- identifying and addressing causes of non-MS fatigue;

Examples of strategies used to minimise fatigue

- Prioritise tasks and activities for the day
- Take rest periods at strategic times
- Organise tasks to minimise the effort needed, or so that they can be broken down into small periods
- Use adaptive equipment to reduce the energy cost of tasks
- Use fans or cooling garments to avoid overheating
- Use relaxation techniques
- Optimise sleep at night
- Organise/modify the home, car and workplace to minimise energetic cost

- defining realistic goals, taking into account the person's priorities and needs, sometimes with input from significant others. This step may be facilitated by the use of a diary to describe daily activities and when fatigue occurs.

- designing a rehabilitation plan, using all professionals and interventions that are deemed necessary to achieve the goals;

- carrying out the interventions;

- re-assessing fatigue and function periodically to verify if the goals are met;

- transitioning to a home exercise programme at the end of rehabilitation.

In conclusion

Fatigue is one of the most frequently reported symptoms in MS, and can cause disability by itself. Even though the mechanisms which cause MS fatigue have not been fully elucidated, evidence shows that exercise and lifestyle changes can be beneficial. Rehabilitation can be helpful in implementing these interventions, and in helping people with MS participate in and enjoy daily activities.

Pharmacological management of MS fatigue

Elizabeth McDonald, MBBS, FAFRM, RACP, Medical Director, MS Australia

The past decade has seen much progress and activity into the basic mechanisms underlying MS and the development of clinical treatments, yet the symptoms of MS remain a daily challenge to those with the disease. Fatigue is nominated in many international studies as the most common and disabling symptom, yet it remains poorly understood and poorly appreciated by the wider community.

MS fatigue, also known as lassitude, is a “hidden disability” and has been defined as “a subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities.” In real life this translates to the person with MS feeling so exhausted that performing the personal daily activities of life, work and socialisation, becomes difficult or impossible and, if not understood, the person can be perceived as lazy or poorly motivated. Nothing could be further from the truth.

Recognition of the issue of fatigue, the type of fatigue and its impact is paramount if it is to be addressed and managed in a positive and beneficial way.

This article aims to address the currently available pharmacological treatments of primary MS fatigue. Consideration of such treatments should only be given when other non-pharmacological approaches have been addressed as outlined in the accompanying articles.

Importantly, a review of medications already being used should be undertaken, as there are numerous types of medications that can cause sedation. This includes medications taken for MS itself and symptom management as well as for any other conditions, either prescribed or bought over-the-

counter. If possible, reducing the dose of such medications or even ceasing them is warranted before trialling medications specifically for fatigue. This should be part of the overall assessment of fatigue in MS which frequently requires a multidisciplinary approach.

See the table below for a list of types of medication which can cause fatigue.

Amantadine

Amantadine is an antiviral medication, also used in Parkinson's disease. It has been used in the treatment of MS fatigue since the 1980's but a review of clinical trials has shown it to provide small and inconsistent improvements, from 20-40 percent in the short term.

The exact mechanism of amantadine in the treatment of MS fatigue is not fully understood but it helps in the release of a chemical called dopamine, which is a neurotransmitter, and this may increase neural activity. Amantadine is relatively safe, well tolerated and inexpensive. It is recommended as a first-line treatment for mild fatigue. Dosage is usually 100-200mg daily, taken in the early part of the day to avoid sleep

Medications that can cause fatigue

Analgesics	Antipsychotics
Anticonvulsants	Immunomodulators
Antidepressants	Muscle relaxants
Antihistamines	Sedatives/hypnotics

Source: Multiple Sclerosis Council for Clinical Practice Guidelines, 1998



disturbance. Side effects are usually mild and may include strange dreams, hallucinations, hyperactivity and nausea.

Modafinil

Modafinil is a central nervous system stimulant used as a wake-promoting agent in the treatment of excessive daytime sleepiness. The mechanism of action is believed to be related to increasing activity in the part of the brain that regulates normal wakefulness.

Trials using modafinil in MS fatigue have involved small numbers and have been over a short treatment period (a maximum of 12 weeks), but have mostly shown a positive effect. Further studies are recommended to ascertain the effect of modafinil in the longer term and the appropriate dose.

A usual treatment regime is starting at 100mg in the morning for a week and increasing to 200mg in the morning as a maintenance dose. Side effects include insomnia, headache, nausea and weakness at higher doses (400mg a day). Modafinil has a long half-life which means that it stays active in the body for a long time; therefore taking doses later than noon may increase the incidence of insomnia, and compound the daytime fatigue the person with MS is trying to combat.

Other medications

Methylphenidate, a stimulant used for narcolepsy and attention-deficit hyperactivity disorder, and selective serotonin-uptake inhibitors (SSRIs) types of antidepressants are sometimes used for MS fatigue but they have not been studied in clinical trials. The side effects of methylphenidate include agitation, anxiety, insomnia and high blood pressure. There is also the risk of addiction. The side effects of SSRIs include nausea, sleep disturbance, weight gain and sexual dysfunction. The use of these medications in MS fatigue needs to be considered on a case-by-case basis.

Aminopyridines are drugs which improve nerve conduction where there has been damage to the myelin sheath, the covering of the nerve fibre that facilitates conduction. Clinical trials of sustained release 4-aminopyridine (also known as dalfampridine or fampridine) have shown improvement in the speed of walking in MS but significant positive changes have not been seen in self-report scales used to measure fatigue.

There is no evidence to support the use of vitamins or supplements to improve MS fatigue yet they are frequently advertised as being beneficial. The safety, cost and potential interactions with other medications needs to be considered and discussed with the person's doctor before commencing any medication for MS fatigue.

Summary

Fatigue is a common and complex symptom of MS. With increasing understanding of the underlying mechanisms, there will be the opportunity to develop more effective pharmacological treatments than we have to date.

Until this time, the management of fatigue involves the individual assessment and management of all factors which can contribute to the problem, the use of energy conservation techniques and strategies to minimise the fatigue such as exercise. Only then should the pharmacological treatments currently available be considered.

Complementary and alternative approaches for managing fatigue in MS

There have been a limited number of studies on non-medical approaches to managing fatigue in MS using a clinical trial design. Below is a brief summary of some of these.

- A randomised, control-group study compared the use of teleconferencing to face-to-face, group-based self-management for better managing fatigue, including 190 people with MS. The teleconference training focused on the strategic use of rest, communication, activity analysis and modification, and setting priorities about energy use. The teleconferencing programme was more effective and efficacious for reducing fatigue impact but not fatigue severity. The positive response to teleconferencing was maintained three and six months after completing the programme.

- Sixty-nine people with MS participated in a randomised controlled trial of yoga compared to a weekly exercise class using a stationary bicycle and to a control group. Both yoga and weekly exercise produced improvement in fatigue and quality of life compared to the control group.

- Exercise focused on endurance training to improve fatigue has been studied in people with MS. The problem with many of these studies is that the people studied were not necessarily experiencing fatigue and there was inconsistency in whether primary or secondary fatigue was measured, thus, the results are heterogeneous. Of nine clinical trials of endurance training, only three demonstrated a positive effect on fatigue.

- There are three reports in the literature of exercise focused on resistance training but only one that used a randomised design. This found a significant

effect on fatigue using machine exercises for lower extremities. In studies of combined exercise, of five reports, three used a clinical trial design, one of which found that the combination of endurance training, strengthening and balance activities produced a positive effect on fatigue.

- Aquatic exercise has also been shown to be of benefit for improving fatigue in people with MS. One randomised study of 71 subjects compared exercises performed in a swimming pool led by a physiotherapist, to exercises performed in a therapy room. Aquatic exercises which focused on balance, strength, relaxation, flexibility and breathing, produced an improvement in fatigue as compared to the control group.



Self-management of fatigue

Nicki Ward-Abel, Lecturer Practitioner in MS based at Birmingham City University, outlines the fatigue self-management programme she runs for people with MS at Queen Elizabeth Hospital, Birmingham, UK

Fatigue in people with MS is a complex symptom that is notoriously difficult to treat, not least because it is extremely subjective and is experienced differently by each person. Owing to the prevalence of this symptom, most people with MS who are seen in outpatient settings complain of fatigue and experience the disabling effect it can have on day-to-day living. Fatigue particularly affects people in their employment, whether this is in paid work or as they care for their family at home. Managing and treating this symptom is a challenge, although there is some evidence that applying fatigue management principles can potentially reduce the debilitating effect fatigue has on people with MS.

Outline of the programme

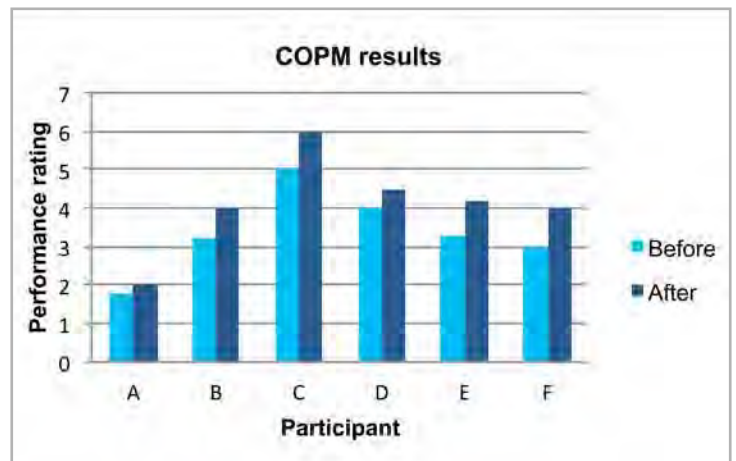
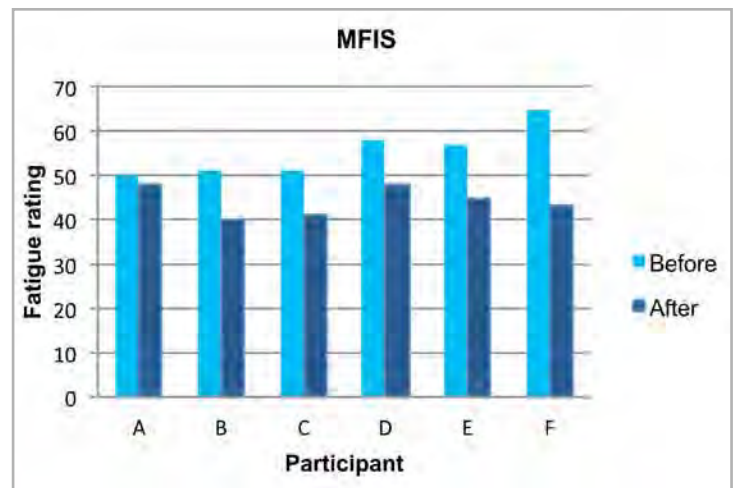
The fatigue management programme consisted of seven once-weekly sessions (see pages 20-21 for details) each facilitated by an OT and a specialist MS nurse. OT are recognised as the healthcare professionals who play a major role in assisting people to manage their fatigue. Specialist MS nurses play a key role in education, providing a greater understanding of symptoms such as fatigue, and assist in empowering people, whenever possible, to self-manage their disease. Fatigue management requires a multidisciplinary approach, and consequently, other members of the team were also asked to contribute to this programme.

Evaluating the programme

Participants were assessed before and after the programme using the Modified Fatigue Impact Scale (MFIS, see page 11) and the Canadian Occupational Performance Measure (COPM – a tool used by OT to detect change in a person's self-perception of occupational performance over time). We also used the MS Impact Scale-29 (MSIS-

29) to assess the person. This tool is disease specific and combines the person's perspective with rigorous psychometric methods. It uses 20 physical items and nine psychological items to measure the impact of MS.

The results of a pilot study of two of the assessments are shown in the graphs below. The higher the score on the MFIS scale, the greater the impact of fatigue on the person's life. The scores were undoubtedly lower three months after, indicating that the people taking part were experiencing a reduction in their fatigue levels. The second graph examines the results from the



Week 1

- Programme aims were discussed and participants were asked to add any they considered appropriate. These aims reflected a patient-centred approach to their care and encouraged a self-management philosophy.
- An overview of recent fatigue studies was discussed. This was important as many people benefit directly if they perceive their symptoms to be recognised as being genuine. The principles of fatigue management were highlighted and their significance explained.
- Completed MFIS, COPM and MSIS-29: these enabled participants to rate the impact of fatigue and rate their performance in activities of living. This highlighted any specific areas of difficulty for them, enabling them to set clear goals.
- Fatigue management diary homework: each person was asked to keep a diary for seven days, scoring the level of fatigue they were experiencing. This identified specific activities for each person, as well as their perception of whether these activities were fatiguing.

Week 2

- Discussion of the diary: helped participants to highlight specific difficulties and to identify key problem areas in their daily lives.
- Fatigue management principles: the literature suggests that fatigue management principles are effective in managing fatigue (Table 1). These were discussed and written information was provided. The principles were adopted throughout the course.
- Completion of a sleep questionnaire: although primary fatigue is not fully associated with disturbed sleeping patterns, there is a need to establish whether a participant is experiencing any disruption of sleep, as it can have a significant effect on daily functioning.
- Introduction of prioritisation of tasks: participants were asked to list their daily activities and then prioritise them according to whether they were essential, desirable, transferable or unnecessary. This was a personal choice based on what was most important to them. For example, one woman said that reading to her children was essential,



whereas shopping was a task that someone else could do. It was important that participants determined what they considered essential (and often enjoyable) tasks. There was also homework set on this.

- Relaxation session

Table 1: Fatigue management principles

Balancing exercise and rest
 Planning and organising daily activities
 Prioritising jobs
 Energy conservation
 Work simplification
 Keeping fit
 Healthy eating
 Labour-saving equipment
 Relaxation
 Postural support
 Avoiding heat
 Receiving counselling

Source: Schapiro (1991); Welham (1995); Bowcher and May (1998)

Week 3

- Discussion of homework
- Prioritisation management
- Advice and leaflets on energy conservation
- Relaxation, including a relaxation exercise to practice at home.

Week 4

- Exercise discussion by a physiotherapist. Exercise can be a powerful way of combating deconditioning, and in the short term, it has been shown that an exercise programme to improve fitness can also improve wellbeing, reduce fatigue and improve strength.
- Discussion on sleep
- Relaxation

Week 5

- The principles of healthy eating were presented by a dietitian. While the evidence on the influence of diet in the management of fatigue is lacking, Shaw (2001) lists poor eating and overeating as one of the most common triggers of fatigue in some people. Discussion on foods that could be energising and those that could cause a person to feel sluggish.
- Alternative therapies
- Cooling therapies: the relationship between heat and fatigue is now recognised. Most people with MS report that heat dramatically worsens their fatigue, and this is discussed regularly in fatigue literature. Cooling therapies may be beneficial and provide relief to those affected.
- Living a healthy lifestyle
- Discussion of the impact of fatigue on employment

Week 6

- Drug management: there has been limited success with drugs such as amantadine and modafinil for fatigue. The potential benefits of these drugs was discussed.
- Partners invited to a session on fatigue management while the person with MS is setting an action plan to address their own individual goals with an occupational therapist.
- Complete MFIS, COPM and MSIS-29
- Course evaluation form

Week 7 (6 weeks after the end of the programme)

- People gave feedback on their action plans, progress and achievements.
- Indian head massage or reflexology
- Completed MFIS, COPM and MSIS-29

COPM. It identifies the COPM before starting the programme and matches it to the results three months after completing the programme. A low result indicates a lower level of performance and satisfaction as perceived by participants regarding their daily activities. These results indicate an overall increase in both performance and satisfaction in this particular area.

Both outcome measures highlight an improvement in people's perception of their fatigue and their performance and satisfaction. Although the results are not dramatic, they do show a positive trend. Greater improvements are probably unrealistic because of the very nature of MS and the inability to remove fatigue completely.

Conclusion

Anecdotal reports show that people with MS-related fatigue find self-help courses helpful, supportive and beneficial. A key to their success is people with MS identifying the goals that are important to them, and to be motivated to make and maintain the lifestyle changes needed to achieve these. This can be difficult to do, so support from healthcare professionals, as well as family and friends, is crucial.

There are indications that our fatigue management programme produced positive benefits to each participant; it is therefore felt that programmes such as these are of benefit to people with MS.

Nicki is now undertaking a randomised controlled trial on fatigue management programmes.

Results of the online fatigue survey

10,090 people from 101 countries took part in our online fatigue survey, which was available in 11 languages. A summary is provided here, but for the full results please go to www.msif.org/fatiguesurvey or contact MSIF.

86% of respondents said that fatigue was one of their three main symptoms, confirming what a common symptom this is for people with MS. When asked about when fatigue affected them the most, more than a third of people said it comes and goes throughout the day and night, while 16% said all the time.

Would you say fatigue is one of your three main symptoms?



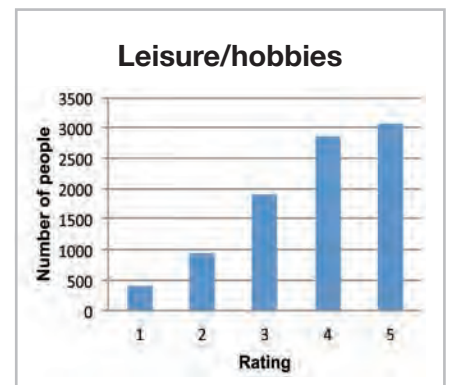
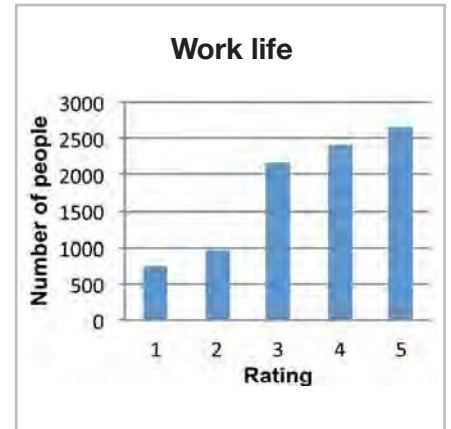
These results highlight the fluctuating nature of fatigue in MS and suggest that this symptom can have a significant impact on day-to-day life, in particular the ability to maintain regular work hours or family responsibilities. Other respondents said they were most affected in the afternoon (26%), evening (13%), morning (7%) or at night (2%).

“Arms, legs, my entire body feels weighed down with lead.”

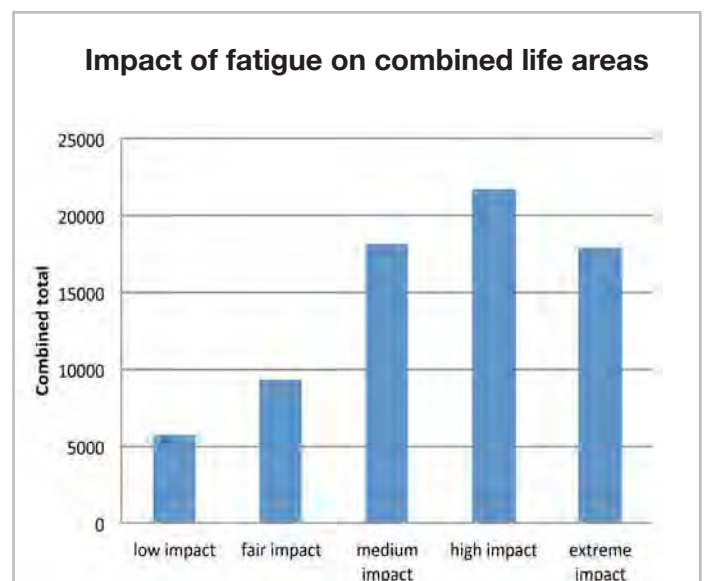
“It affects everything, but I prioritise my limited energy to work and family.”

Respondents were asked to rate how much fatigue affected eight different “life areas” from 1=no impact to 5=extreme impact. For work and

leisure/hobbies, the majority ranked the impact of fatigue as 5. Other life areas (home life, social life, sexual life, mental health and physical health) had a majority ranking of 4, while family life had a 3.



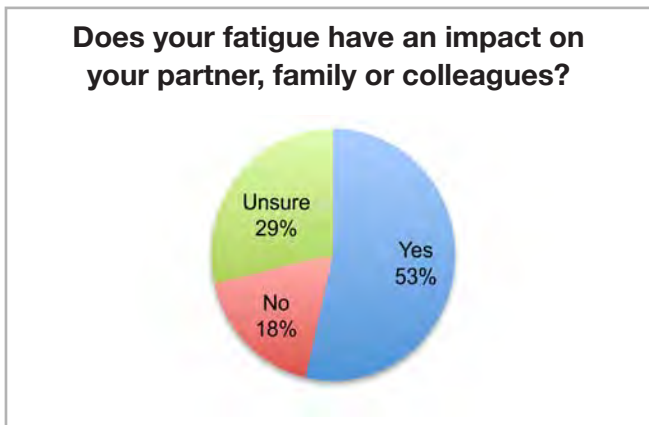
These results show that for the majority of people with fatigue, this symptom has a medium-extreme impact on all areas of life.



This was confirmed by respondents rating the overall impact of fatigue on their life as high (45%) or medium (43%).

“It is incredibly frustrating. I feel that I am missing out on my life mostly due to the fatigue.”

Many also recognised the impact of fatigue on those around them, with more than half saying that their family, friends or colleagues were impacted by their fatigue.



84% said that their fatigue worsened with heat (or when they overheated), highlighting the importance of using strategies that help in managing fatigue caused or worsened by increased body temperature (see page 26).

“It goes only with rest. A couple of short naps help.”

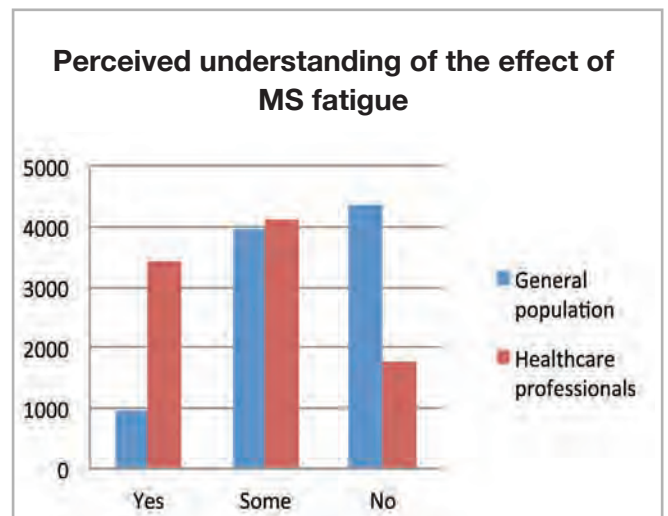
The majority of respondents (62%) had not used medication, complementary therapies, rehabilitation or exercise for managing fatigue. Of those who did, complementary therapies and rehabilitation were reported to be unhelpful in improving fatigue while exercise and medication were reported to be reasonably helpful. (Editor’s note: Rehabilitation may have been found to be unhelpful due to a lack of specialist rehabilitation healthcare professionals in many countries.)

Other methods or coping strategies, such as rest, sleep, keeping cool and scheduling day-to-day activities, were used by 45% of respondents.

“It’s taken a long time to discover how to manage it, and I’m still learning.”

Nearly half of respondents did not feel that the effect of MS fatigue was understood by the people around them. However, when asked specifically about their healthcare professionals, 37% reported that fatigue was well understood and 44% reported that at least some of the professionals involved in their care had some understanding of the impact of fatigue.

“People do not understand how a person can be fine one minute and exhausted the next.”



“At work, my boss got me a pull-out bed, a pillow and a blanket to take naps throughout the day. Up to that point, I didn’t think that she was aware of my extreme fatigue and how it affected me.”

“Anytime there is mental pressure, I feel a restriction of effort I can make with MS, especially mentally.”

Living with MS fatigue – personal views from Portugal and Thailand

Portugal

My name is António Casimiro. I am 54 years old, divorced, a father of two sons, and a military nurse since 1982. I am now on sick leave, waiting for retirement. Besides having MS, I also have diabetes.

I was diagnosed with MS in August 2002. In that moment, I felt frustration for being diagnosed with a disease without a cure, but at the same time, I felt relief. I also realised that my professional life would be interrupted against my will. MS has also interfered severely in my personal life and family plans.

My main symptoms are a loss of strength in my arms and legs, general fatigue, sensory changes, sexual dysfunction and a loss of balance/coordination.



Fatigue has had a major impact on me. The biggest impact is the dependency I feel when I want to carry out the little things of everyday life, like personal hygiene and nutrition. I get frustrated by not being able to do things that even a child would do! My meal preparation often has to be done by someone else now. I cannot go out by own, and have to rely on other people.

And because I have not found a way to address or eradicate the fatigue, I spend a lot of time lying down to avoid exhaustion. I also avoid hot clothes and environments, to prevent raising my body temperature. At the moment, I am waiting to start treatment with Fampridine®, to try to manage my fatigue.

I have the support of my son to help me get around in the city and I have hired someone to help me to do the daily tasks at home.

My friends get frustrated that they are not available to help me more and this causes a strain on our friendships.

I find understanding in the healthcare professionals that work with me regularly and who are naturally more aware of the needs of people with MS. I feel less understanding from those professionals that are not connected with MS. They do not give me as much information as I need regarding the symptoms, specially the invisible ones, like fatigue and depression.

I find it a challenge to live this alternative life with MS; constantly having to adapt to symptoms that change daily. The challenges for people with MS in Portugal are ceaseless: we must try to avoid forced unemployment, try to keep up our personal and family quality of life, live with an absence of accessible buildings and streets, face high drug costs to manage MS symptoms, as well as the lack

Thailand

My name is Malee*. I live near Bangkok with my older sister and my mum. I am 30 years old and I can only move my arms.

I was diagnosed with MS when I was 20 years old and in my second year in university. Until my diagnosis, I had no idea about MS, so I thought that the symptoms would go away again. I had weakness on my right side, which got worse over the next two years. I also started to have patches of fatigue. The fatigue got so bad I couldn't go to university anymore. There was no support offered at all by the university. I couldn't do anything but sleep. It was very depressing.

I have fatigue most of the time and it stops me being able to do normal activities or enjoy my life. I feel I don't have a future, and it makes me very sad. Since I stopped being able to walk, I don't see my friends because I feel embarrassed.

I have support at home from my mother and sister – we are a very close family. They help me to do many things day to day, such as taking a bath and changing my clothes.

My sister is the only person in my family who can work now. At the moment she doesn't have time for dating or getting married.



*Malee (not her real name) did not wish to be identified in this interview.

Here in Thailand it is hard for people with MS. There are only a few physicians who specialise in MS, and they are in Bangkok. There is no local support where I live.

The development of an MS society would help people make contact with each other and to help them locate a specialist physician. I hope we can connect and exchange the experience of MS and fatigue in the future.

Contact the Thai MS Patient Support Group by emailing msthai@yahoo.com

of psychological support to manage emotional ups and downs and depression.

I am a member of the Sociedade Portuguesa de Esclerose Múltipla (the Portuguese MS Society) and I receive the benefits of the services provided by the organisation, such as psychological clinical appointments, law counselling and neurorehabilitation. I also attend regular information sessions about MS.

My advice for other people with MS fatigue around the world would be to try to avoid raising your body temperature, so that fatigue does not manifest itself. I have found moderate exercise,

physiotherapy and water training, guided by a physiotherapist, to be helpful. Try to avoid depression by seeking psychological support and, if necessary, take drugs prescribed by your doctor to manage it.

But most of all, keep having hope for the future regarding treatments and research that will help fatigue. In the meantime, join your national MS society if you have one. Spread the word and share the needs of people with MS and their carers within your community.

Contact the Sociedade Portuguesa de Esclerose Múltipla at www.spem.org

Your fatigue questions answered

Dr Francois Bethoux, from the Mellen Center for MS Treatment and Research, Cleveland, Ohio, USA

Q. My family and friends don't seem to understand what fatigue is – they think I am just tired and lazy. How can I explain fatigue to them?

A. Fatigue is one of the “hidden symptoms” of MS, since it is experienced by the person with MS but not readily observable by others, unlike a problem with balance or walking. People with MS can be frustrated when they are told, “But you look so good!”.

One good place to start is to explain how fatigue is different from “normal tiredness”. It is often helpful to give concrete examples of when and how profoundly fatigue affects you, and which strategies you have implemented to fight it.

Educating family and friends can also be carried out by reviewing educational materials in print or online with them, by bringing them along to medical appointments, or inviting them to educational sessions or support group meetings, so they realise how much fatigue is part of MS, and what they can do to help. You could also involve those who are close to you in the implementation of energy conservation strategies, such as planning and prioritising activities.

Q. Why does fatigue get worse with heat? How can I keep cool?

A. Heat sensitivity is very common in MS. Worsening of neurologic symptoms (including fatigue) with heat was even used to support the diagnosis of MS in the past. Even though the exact mechanism is not fully understood, it is likely that heat further impedes the conduction of signals along demyelinated axons. Heat sensitivity may interfere with the ability to exercise and to enjoy activities outdoors.

Limiting exposure to heat is the first line of defense, for example avoiding hot baths. Fans and air conditioners help control the indoor ambient temperature. Cooling garments can be used to lower body temperature.

The most common are passive garments, such as cooling vests with ice packs or ice strips, and cooling collars. Active cooling suits, with chilled fluid circulating within the suit, are more effective, but more cumbersome (the suit is connected to an external cooling unit), require a source of power and are more expensive.



Q. Why is fatigue one of the main symptoms of MS?

A. Many surveys and studies confirm what we hear from people with MS every day: fatigue is the most commonly reported symptom of MS. This suggests that what we call “primary MS fatigue” is related to the disease itself. Even though the exact cause of MS fatigue remains elusive, there are several hypotheses: demyelination and the loss of axons may increase the “effort” needed for the brain to perform its usual functions; MS may damage areas of the brain or pathways that control energy; immune, hormonal, or metabolic changes may also play a role.

Other consequences of MS also constitute contributing factors to fatigue (“secondary fatigue”). Difficulty sleeping (for example due to bladder problems), difficulty moving around, depression or pain, are examples of such factors. Other factors may be indirectly or not at all related to MS, such as decreased fitness (deconditioning), medications and other medical problems.

The good news is that, increasingly, various interventions are shown to partially improve fatigue. Therefore, after recognising the importance of the problem, it is important to address it to the best extent possible, based on an individualised management plan.

Resource reviews

Fighting Fatigue in Multiple Sclerosis by Nancy Lowenstein 2009, Demos Publishing

Reviewed by Wessal Muhawes, Saudi Arabia

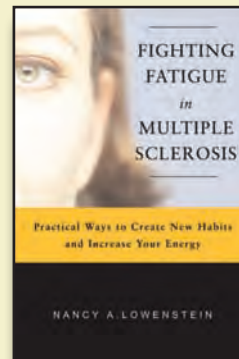
I was diagnosed with MS 15 years ago, and this book is the first of its kind that I have found. This would be so helpful to all people with MS, caregivers and loved ones. It speaks in lay terms, and doesn't read like an instruction manual.

Instead, it is more like a workbook. It is very easy to personalise, and is suitable for almost all the stages

of disease progression. It sets out the need to delegate and prioritise tasks and chores.

My only criticism is that this would be hard to follow for a parent of younger children as they dictate most of the daily activities, as well as the ease and speed in which they occur!

Overall, however, in one word, the book is "essential".



Living with Fatigue by Michelle Ennis 2006, The UK MS Trust

Free to download or read online from
www.mstrust.org.uk

Reviewed by Pavel Zlobin, All-Russian MS Society

Perhaps all people with MS have found it difficult to describe what is happening to them. Fatigue in MS is likely to be the vaguest thing to explain.

Yet, the author manages to do it in a normal way for the MS community. Family members and people around a person with MS need to know and understand what fatigue means, and the book readily helps with this.

The insights and experiences of people with MS fatigue form an outline of the book that captures readers and can help find the right words to explain what he or she feels. The book breaks the different

aspects of fatigue down into smaller elements, which makes finding strategies to fight fatigue seem less difficult. The author does attempt to deal with the challenge of increased fatigue in MS as the disease develops, but some people may find this information insufficient.

Another drawback is the type size of the book; people with MS with impaired sight may have some difficulty reading the text in the book version. [Editor's note: this publication can also be read online, zoomed in.] And, I cannot say I always agreed with the highlighted phrases in balloons – in my opinion, there were other more important pieces in the text to focus on.

The definite advantage of the book is that there are clear-cut tips which are easy to follow. The layout of the book also meant it was easy to read in one go or in smaller sections.

One cannot expect any book to give all answers to one aspect of MS. I would rate this book about effective fatigue management as very good. The main objective of the book was achieved. It reveals fatigue holistically as a symptom and presents realistic ways of how to live with it.

MSIF member society contact details

Argentina: Esclerosis Múltiple Argentina
info@ema.org.ar; www.ema.org.ar

Australia: Multiple Sclerosis Australia
info@mssociety.com.au www.msaustralia.org.au

Austria: Multiple Sklerose Gesellschaft Österreich
msgoe@gmx.net www.msgoe.at

Belgium: Ligue Nationale Belge de la Sclérose en Plaques/Nationale Belgische Multiple Sclerose Liga
ms.sep@ms-sep.be www.ms-sep.be

Brazil: Associação Brasileira de Esclerose Múltipla
abem@abem.org.br www.abem.org.br

Canada: MS Society of Canada /Société canadienne de la sclérose en plaques
info@mssociety.ca www.mssociety.ca
www.scleroseenplaques.ca

Cyprus: Cyprus Multiple Sclerosis Association
multipsy@cytanet.com.cy www.ms-cyprus.org

Czech Republic: Unie Roska česká MS společnost
roska@roska.eu www.roska.eu

Denmark: Scleroseforeningen
info@scleroseforeningen.dk www.scleroseforeningen.dk

Estonia: Eesti Sclerosis Multiplex'i Ühing
info@smk.ee www.smk.ee

Finland: Suomen MS-liitto ry
tiedotus@ms-liitto.fi www.ms-liitto.fi

France: Ligue Française contre la Sclérose En Plaques
info@lfsep.asso.fr www.lfsep.com

Germany: Deutsche Multiple Sklerose Gesellschaft Bundesverband e.V.
dmsg@dmsg.de www.dmsg.de

Greece: Greek Multiple Sclerosis Society
info@gmss.gr www.gmss.gr

Hungary: Magyar SM Társaság
smkozpont@albatct.hu www.smtarsasag.hu

Iceland: MS-félag Íslands
msfelag@msfelag.is www.msfelag.is

India: Multiple Sclerosis Society of India
mss.allindia@yahoo.co.in www.mssocietyindia.org

Iran: Iranian MS Society
info@iranms.org www.iranms.ir

Ireland: MS Ireland
info@ms-society.ie www.ms-society.ie

Israel: Israel MS Society
agudaims@netvision.net.il www.mssociety.org.il

Italy: Associazione Italiana Sclerosi Multipla
aism@aism.it www.aism.it

Japan: Japan Multiple Sclerosis Society
jmss@sanyecorp.co.jp www.jmss-s.jp

MSIF member society contact details (continued)

Latvia: Latvijas Multiplas Sklerozes Asociacija
lmsa@lmsa.lv www.lmsa.lv

Luxembourg: Ligue Luxembourgeoise de la Sclérose en Plaques
info@msweb.lu www.msweb.lu

Malta: Multiple Sclerosis Society of Malta
MaltaMS@gmail.com www.msmlta.org.mt

Mexico: Esclerosis Múltiple México
emmex-org@hotmail.com http://emmex-ac.blogspot.com

Netherlands: Stichting MS Research
info@msresearch.nl www.msresearch.nl

New Zealand: MS Society of New Zealand Inc
info@msnz.org.nz www.msnz.org.nz

Norway: Multipel Sklerose Forbundet I Norge
epost@ms.no www.ms.no

Poland: Polskie Towarzystwo Stwardnienia Rozsianego
biuro@ptsr.org.pl www.ptsr.org.pl

Portugal: Sociedade Portuguesa de Esclerose Múltipla
spem@spem.org www.spem.org

Romania: Societatea de Scleroza Multipla din România
office@smromania.ro www.smromania.ro

Russia: The All-Russian MS Society
pzlobin@yahoo.com www.ms2002.ru

Slovakia: Slovenský Zväz Sclerosis Multiplex
szsm@szm.sk www.szm.szm.sk

Slovenia: Združenje Multiple Skleroze Slovenije
info@zdruzenje-ms.si www.zdruzenje-ms.si

Spain
Asociación Española de Esclerosis Múltiple
aedem@aedem.org www.aedem.org
and
Federación Española para la Lucha contra la Esclerosis Múltiple
info@esclerosismultiple.com www.esclerosismultiple.com

South Korea: Korean Multiple Sclerosis Society
sweethany@paran.com www.kmss.or.kr

Sweden: Neurologiskt Handikappades Riksförbund
nhr@nhr.se www.nhr.se

Switzerland: Schweizerische Multiple Sklerose Gesellschaft
info@multiplesklerose.ch www.multiplesklerose.ch

Turkey: Türkiye Multipl Skleroz Derneği
bilgi@turkiyemsderneği.org www.turkiyemsderneği.org

UK: MS Society of Great Britain and Northern Ireland
info@mssociety.org.uk www.mssociety.org.uk

Uruguay: Esclerosis Múltiple Uruguay
emur@adinet.com.uy www.emur.org.uy

USA: National MS Society
www.nmss.org

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multiple sclerosis
international federation

Skyline House
200 Union Street
London
SE1 0LX
UK

Tel: +44 (0) 20 7620 1911
Fax: +44 (0) 20 7620 1922
www.msif.org
info@msif.org

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With many thanks

MSIF would like to thank Merck Serono for their generous unrestricted grant, which makes the production of **MS in focus** possible.

