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**MULTIPLE
SCLEROSIS
AND
FATIGUE**

ms.

Multiple Sclerosis Society of New Zealand

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INTRODUCTION

Fatigue is one of the most common and frustrating symptoms of MS and its effects can be felt in many areas of daily life.

Fatigue can be an invisible aspect of MS. This means some people have trouble understanding the problems it can cause.

Unlike other types of tiredness due to excessive activity or lack of sleep, MS-related fatigue can be persistent and is not solved by rest and relaxation. However, it is possible to take a proactive approach to the condition and improve your quality of life.

This booklet describes strategies for reducing and overcoming fatigue that can make a significant difference in facing the day-to-day challenges of MS. It also explains the impact fatigue can have and helps people with MS (and others) to understand the condition better.

MS & FATIGUE

Fatigue affects people differently and to varying degrees. It can be very hard to describe fatigue, but most people define it as a feeling of ongoing weariness that strongly affects their ability to do things and cannot be easily overcome by rest.

Some common challenges for people with fatigue include problems concentrating or making decisions, absence of energy or strength, loss of sex drive, difficulty sleeping and being upset easily.

People with MS who experience fatigue may do so because of its direct effect on the nervous system ('primary fatigue'), or because of other factors ('secondary fatigue'). The various factors can co-exist, requiring multiple management strategies.

The following pages list the main types of fatigue experienced in MS and describe strategies for managing the various issues that arise.

Note: People with MS may also experience fatigue because of something entirely unrelated to their condition, such as an unknown infection. Thus, it is important to discuss any substantial increase in fatigue with your doctor.

PRIMARY FATIGUE

FATIGUE DUE TO AN OVERACTIVE IMMUNE SYSTEM

When the immune system detects infection, such as influenza, it increases white blood cells (“lymphocytes”) and special proteins (“cytokines”) to fight the virus. It is presumed the production of these substances is what causes the tiredness one usually associates with “having the “flu”. Similarly, it maybe that when the immune system attacks the nervous system (as it does in MS) it secretes the same substances, bringing on fatigue and tiredness the same way as when fighting an infection.

Whatever the actual mechanism, this type of fatigue usually occurs in the early to mid-afternoon, but can improve by the evening. It mirrors the daily temperature variation of the body, which peaks in mid-afternoon – although it is not known if there is a direct link.

Usual treatment

Steroids suppress the immune system response (i.e. the secretion of attacking substances) and this may be effective in reducing fatigue as well as speeding up recovery from a relapse. However, steroids can be prescribed only sparingly for this type of treatment.

Some non-MS medications may also be useful in treating this type of fatigue (e.g. amantadine and modafinil) and your neurologist or GP will be able to discuss whether they are likely to be of benefit to you.

FATIGUE DUE TO INCREASING BODY TEMPERATURE

When the body's temperature is raised through exercise, heat, change in climate or infection, the signs and symptoms of MS can become more obvious and weakness can be increased. Even an increase of one quarter of a degree in body temperature can affect a demyelinated nerve's ability to conduct the electrical impulses that make up nervous system messages.

So, when the change in body temperature prevents the nerve fibres from sending messages through the body, this causes fatigue in the fibres themselves and contributes to limitations in activities.

Usual treatment

Minimising the amount of heat to which the body is exposed will reduce the likelihood of fatigue, so air-conditioning, cooling vests and cool showers can all help. Because exercise can increase body temperature, it may be best to consider exercising in cool environments, such as swimming and aqua jogging.

The increase in body heat does not cause any further damage to myelin or to the nerves and any problems are generally temporary. Lowering the body temperature will usually alleviate the symptoms.

SECONDARY FATIGUE

FATIGUE DUE TO INFECTIONS

Infections and other health problems can contribute to fatigue. This is especially true if the infection is accompanied by fever.

Usual treatment

This type of fatigue is best dealt with by treating the underlying problem.

FATIGUE DUE TO MEDICATION

Many of the medications commonly used to treat MS symptoms can cause or worsen fatigue as a side-effect. Particular medications to note include interferons, steroids (especially on withdrawal from a high dose), antidepressants and medications for spasticity or pain.

Usual treatment

Because the range of medications that may aggravate fatigue is wide, it is important to talk to your GP or neurologist if you have concerns about any medication you are on.

Note: Drugs that assist with sleep may cause sedation and drowsiness during waking hours, which can be confused with fatigue. If you have any concerns, talk to your GP or neurologist.

FATIGUE CAUSED BY DISABILITY

MS can cause problems with mobility and muscle control.

Compensating for these disabilities requires greater energy and effort than would otherwise be necessary to perform daily tasks.

When some muscles cannot perform certain tasks other muscles are used instead and the extra work can tire those muscles, leading to additional fatigue.

Usual treatment

Neurophysiotherapists and physiotherapists can demonstrate exercises to strengthen and maintain body functioning and there is a range of equipment available to help conserve energy and reduce stress on muscles and joints.

Occupational therapists can suggest modifications to your home or workplace to improve your efficiency and reduce the effort involved in daily tasks.

MS Society Field Workers, friends, family members and other people with MS can be useful sources of practical advice on ways to reduce energy needs.

FATIGUE DUE TO DISRUPTED SLEEP

MS causes a variety of symptoms that disrupt sleep. Muscle spasms, pain, bladder problems and breathing difficulties can all affect sleeping patterns.

Usual treatment

The solution to this type of fatigue lies with identifying why the sleep is being disrupted and treating the underlying problem. Your GP or neurologist can help with this.

FATIGUE AND DEPRESSION AND STRESS

While depression and stress don't technically cause fatigue, they can affect energy levels in a similar way, in part by disrupting sleep.

Usual treatment

Stress and depression are brought about when we have difficulty coping with the various challenges we face. Try to reduce the problematic aspects of life wherever possible and seek help from others. Support and information is available from GPs, counsellors and help lines. An MS Society Field Worker is also available for one-on-one discussion and can provide a referral to services in your community.

FATIGUE DUE TO POOR NUTRITION

Poor diet and dehydration can contribute to fatigue, as the body does not have the necessary nutrients to provide energy.

Usual treatment

Foods that combat fatigue include complex carbohydrates and foods rich in potassium, iron and vitamins B and C. You should also maintain an adequate intake of liquids.

A dietician can provide specialist advice on nutritional needs. This is particularly important if you also have bowel problems.

FATIGUE & WELL-BEING

Coping with fatigue can be draining. Thus, feelings of tiredness and exhaustion can lead to more feelings of tiredness and exhaustion. However, maintaining a healthy lifestyle can help you cope better with fatigue.

Keeping physically fit is very helpful and it is possible to develop a balanced programme of activity that takes account of any limitations. A physiotherapist can help with specific exercises, but they must be aware of the potential limitations MS imposes.

(Remember to monitor your body temperature in case this increases fatigue.)

Managing time and energy and minimising stress is also important. Whether at work, home or elsewhere, conserving energy and taking periodic breaks will make a big difference to how much can be done each day. It may be useful to plan each week's work, social and late-night activities in advance so that the most important activities take priority.

Maintaining a healthy and balanced diet is important for everyone, but especially for people with MS. Be aware that excessive alcohol can increase fatigue and toxins like nicotine should be avoided.

Each day's activities should include opportunities for relaxation (such as gentle exercise, yoga or meditation) and moments of high energy should be balanced with adequate rest periods.

EXPLAINING FATIGUE

It is difficult to explain fatigue to others. Because it is invisible, people can misunderstand what you are experiencing and may think you are really just depressed or lazy. It can be hard to gain support and understanding when this happens, but reassure yourself that you are doing the best you can to cope with fatigue and describe its effects to others. Ultimately, you are not responsible for what others think.

In these circumstances, some people with fatigue find it too hard or too tiring to explain how it feels and instead make other excuses for their difficulties - such as being short of sleep or feeling sore. However, it can be better in the long run to take the time to explain fatigue, so that the nature of your difficulty is understood and supported.

A good way of explaining what fatigue feels like is to use an example to which others can relate, such as:

- “I feel like I have a bad case of the ‘flu that won’t go away”;
- “I feel like a person who went for a 5km run at 3am and then couldn’t get back to sleep afterwards because they were just too tired. But, then I had to come to work anyway.”

It is really good when you can make people understand what fatigue feels like. They may still offer unhelpful (but well-meaning) advice, such as ‘have more rest’, or ‘take a vitamin supplement’, but you can feel supported.

FINAL THOUGHTS

While coping with ongoing fatigue can be very draining, there are good approaches available for lessening its impact on your life. These strategies apply to anyone, whether their fatigue is MS-related or not.

It is important to be aware of the causes of fatigue and to avoid as many of those triggers as possible. This means staying healthy, minimising stress, maximising rest and avoiding other illnesses.

Without minimising the difficulties that fatigue can bring, it can provide positive outcomes as well. Firstly, fatigue requires people to take stock of their lives and identify the real priorities. This can make life more purposeful and, thus, potentially more satisfying.

Secondly, the need to slow down and rest more can provide an opportunity for contemplation and relaxation that not everyone has.

Some people with MS will not be able to avoid fatigue and it can be a frustrating problem. However, a proactive and positive approach to coping with fatigue can provide you with more control and confidence.

SOURCES OF SUPPORT AND INFORMATION

THE MS SOCIETY OF NEW ZEALAND

Each Regional Society has skilled and experienced Field Workers who, if required, can assist you in finding the services you need, including:

- ➔ working with those newly diagnosed with MS on a one-to-one basis;
- ➔ offering up-to-date knowledge of MS and its management;
- ➔ providing advocacy and support;
- ➔ offering counselling or referrals to appropriate agencies;
- ➔ supporting partners, carers, families, friends, health professionals, employers and workmates;
- ➔ facilitating groups for people newly diagnosed and their partners, carers, children, workmates;
- ➔ offering assessment facilitation;
- ➔ providing social contact, for those who want it, with other people with MS, on either a group or individual basis
- ➔ liaising with home-based care providers, community health services, counsellors, health professionals and Work and Income to coordinate client needs;
- ➔ carrying out assessments for total mobility.

Some MS Societies also offer physiotherapy, yoga classes, hydrotherapy at local pools and access to Riding for the Disabled, as well as assistive devices for daily living.

Our contact details are over the page.

CONTACT DETAILS

THE MS SOCIETY OF NEW ZEALAND

MSNZ

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Website www.msnz.org.nz

REGIONAL MS SOCIETIES

Northland	09 438 3945	Manawatu	06 357 3188
Auckland & North Shore	09 845 5921	Wellington	04 388 8127
Waikato	07 834 4740	Marlborough	03 578 4058
Bay of Plenty	07 571 6898	Nelson	03 544 6386
Rotorua	07 346 1830	West Coast	03 768 7007
Gisborne	06 868 8842	Canterbury	03 366 2857
Hawkes Bay	06 835 8542	South Canterbury	03 684 7834
Taranaki	06 751 2330	Otago	03 455 5894
Wanganui	06 345 2336	Southland	03 218 3975

OTHER SOURCES OF SUPPORT

weka: *What Everyone keeps Asking* - about disability
website www.weka.net.nz phone 0800 17 1981

Enable NZ

website www.enable.co.nz phone 0800 362 253

Carer's New Zealand - NZ's national organisation for carers

website www.carers.net.nz email info@carers.net.nz

phone 09 406 0412



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