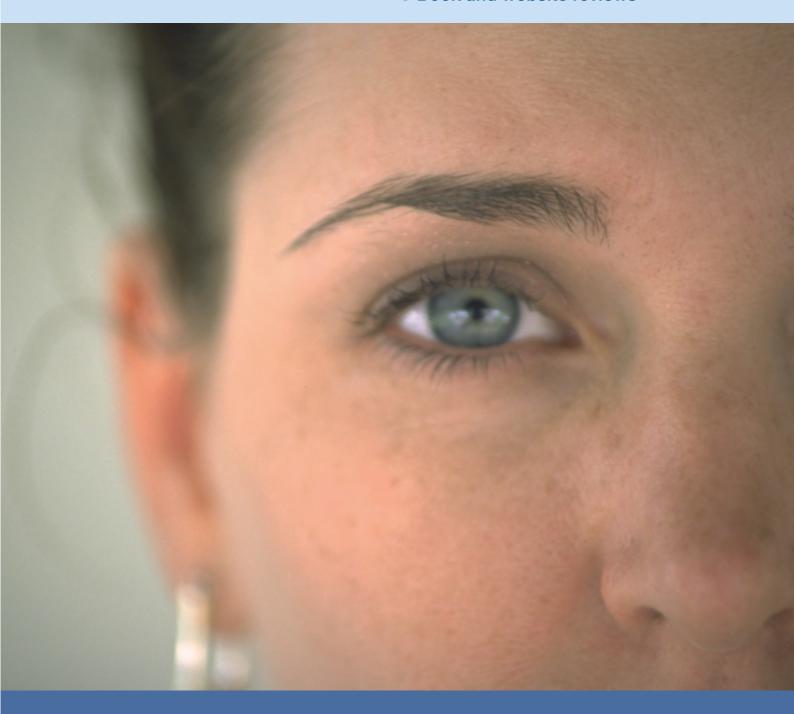
MS in focus Issue 1 • 2003

- Special focus on dealing with fatigue
- Organising theme seminars
- Your questions answered
- Book and website reviews





Multiple Sclerosis International Federation

Established in 1967, the Multiple Sclerosis International Federation links the work of national MS societies worldwide.

We are committed to working together and with the international research community to eliminate MS and its devastating effects. We also speak out on a global level for those affected by MS.

Our priorities are:

- Stimulating global research
- Stimulating the active exchange of information
- Providing support for the development of new and existing MS societies

All of our work is carried out with the complete involvement of people living with MS.

Designed and produced by

Cambridge Publishers Ltd 53/54 Sidney Street Cambridge CB2 3HX

01223 477411 info@campublishers.com www.campublishers.com

ISSN1478467X

Editorial Board

Executive Editor Nancy Holland, EdD, RN, MSCN, Vice President, Clinical Programs and Professional Resource Centre, National Multiple Sclerosis Society USA.

Editor and Project Leader Michele Messmer Uccelli, BA, Department of Social and Health Research, Italian Multiple Sclerosis Society, Genoa, Italy.

Managing Editor Chloe Neild, BSc, MSc, Information and Communications Manager, Multiple Sclerosis International Federation.

Production Assistant Leila Terry, BA, Research Administrator, Multiple Sclerosis International Federation.

MSIF Responsible Board Member Prof Dr Jürg Kesselring, Chair of MSIF International Medical and Scientific Board, Head of the Department of Neurology, Rehabilitation Centre, Valens, Switzerland.

Editorial Board Members

Guy Ganty, Head of the Speech and Language Pathology Department, National Multiple Sclerosis Centre, Melsbroek, Belgium.

Katrin Gross-Paju, PhD, Estonian Multiple Sclerosis Centre, West Tallinn Central Hospital, Tallinn, Estonia.

Marco Heerings, RN, MA, MSCN, Nurse Practitioner, Groningen University Hospital, Groningen, The Netherlands.

Kaye Hooper, BA, RN, RM, MPH, MSCN, Board of Directors, International Organization of Multiple Sclerosis Nurses.

Martha King, Director of Publications, National Multiple Sclerosis Society, USA.

Elizabeth McDonald, MBBS, FAFRM, RACP, Medical Director, MS Society of Victoria, Australia.

Monica Nortvedt, RN, PhD, Department of Public Health and Primary Health Care, University of Bergen, Norway.

Elsa Teilimo, RN, UN Linguist, Finnish Representative, Persons with MS International Committee.

Copy Editor Emma Mason, BA, Essex, UK.

Letter from the Editor

One of the goals of the Multiple Sclerosis International Federation is the dissemination of high quality information, on all aspects of the disease, to people affected by MS worldwide.

With this in mind, it is with great pleasure that I present this first issue of MS in Focus, the official magazine of MSIF. MS in Focus will be published on a bi-annual basis, each issue focusing on a particular theme, with the content developed by an international mix of MS society and healthcare professionals and people with MS.

Our aim is to bring the best of available information from MS societies into a single magazine, along with articles written by some of the most knowledgeable people in the field. Each issue will feature an MS society programme relevant to the current theme, in the hope of encouraging the adaptation of successful programmes in other countries. We encourage both professionals and people with MS to write in with comments, which may then appear in the 'Letters to the Editor' section. In addition, each issue will include questions received from our readership, as well as replies from experts.

We hope you will agree that the themes we have chosen for MS in Focus are important to people living with MS and that each has been comprehensively addressed. We also hope MS in Focus becomes an information resource for MS society and healthcare professionals, but especially for people with MS. I look forward to receiving your comments and questions.

Michele Messmer Uccelli Editor

Contents

From the Editor	3
Theme seminars	4
Fatigue: An introduction	6
Managing day-to-day life	9
Physiotherapy	12
Nursing	14
Pharmacological treatment	17
Questions and answers	18
Interview: Ian Gray	19
Reviews	20
MSIF: An overview	22
Calendar dates	24
Member Societies	24
The World of MS website	26



The next issue of MS in Focus will be on Bladder Management. Send questions and letters to michele@aism.it or marked for the attention of Michele Messmer Uccelli at the Italian MS Society, Vico chiuso Paggi 3, Genoa, Italy 16128.

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. Information provided through MS in Focus is not intended to 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.

Theme seminars for people with MS and their family carers

By Michele Messmer Uccelli, BA, Department of Social and Health Research, Italian Multiple Sclerosis Society, Genoa, Italy.

Rationale

The Italian MS Society wanted to provide special topic seminars for people with MS and their family carers in a way that could combine a respite stay with education and information.

Objectives

- The objectives of the Theme Seminars are to offer education and information on topics that are important for people with MS and their families, and which impact on their daily life and their quality of life.
- A second objective is to encourage couples and families to take advantage of the location where the seminars are held as a respite from daily life.
- Finally, the MS Society wanted to be able to guarantee a relatively worry-free stay in a completely accessible facility.

Background

The Autonomy Project began in 2000. Focus groups of people with MS decided the topics that were most relevant to their lives and these topics became the Theme Seminars that are now offered throughout the year. The seminar facilitators are experts on various topics relating to MS and focus on providing information that is practical for the person with MS and his or her family carer, as well as on stimulating interaction and discussion among participants.

The site is named "I Girasoli" (The Sunflowers) and is located in Tuscany. The MS Society opened the facility for its first guests in July 2000.

I Girasoli is completely accessible and includes many services and amenities including a swimming pool and health club where physiotherapy sessions and demonstrations are provided.

Marketing the Programme

A brochure is inserted in the MS Society's magazine that describes the Theme Seminars and how a person can select the topic or topics in which he or she is interested and reserve a place. The objectives of each course and a full description can also be found on the MS Society's website.



I Girasoli, Tuscany, Italy

Programme structure

Depending on the topic, a seminar can last between two and five days. Expert speakers are matched to each topic. In some cases, especially for lengthier seminars, the facilitators can be two or three experts from different disciplines. Methods of instruction range from formal presentation, to role-play, to small group work. Each seminar also provides an opportunity for participants to share their personal experiences with one another.

Each seminar accepts a limited number of participants, varying between 10 and 20. Participants pay their travel expenses, and the rest of the expenses are covered by the MS Society, including room, board and the cost of the seminar itself.

'I think everyone should bring their partner or spouse to the course because then they'll learn just how disabling fatigue can be for a person with MS.' Luca 'I learned a few new strategies for managing my fatigue that I hadn't thought of on my own.' Monica

Outcomes/results

The Italian MS Society held 35 seminars in 2001-2002. All were quite successful, with the favourites being Fatigue and Daily Living, Rehabilitation and Managing Stress.

Expenses

Expenses to be considered should include the following:

- Brochures, flyers or other types of advertising and postage
- Speaker expenses
- Participant travel, room, board (or any combination of these)
- Meeting room
- Coffee breaks
- Audio/visual equipment

Limitations

- A relatively limited number of MS societies have a holiday home or similar facility at their disposal.
- If you consider using a hotel for this type of activity it can be quite costly.
- Even using your own facility has its costs (such as room, board, coffee breaks, speakers' expenses).
- Not all experts in the field can take the time to participate in a seminar of this type, especially when the topic requires more than one or two days.
- The seminars require a great deal of preparation on the part of the experts.

 Seminars that last for more than a day require a lot of participant interaction. This makes it necessary to limit the number of participants for any one seminar.

Suggestions

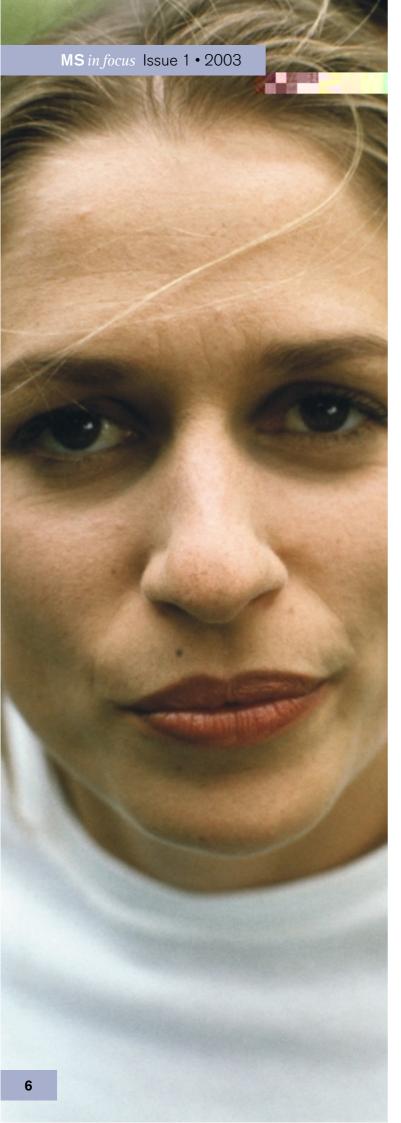
- If possible, include any advertising materials (such as brochure or flyer) with the society magazine to save on postage costs.
- If you decide to charge participants a fee and have never offered this type of programme before, begin with a relatively low fee in the first round of seminars and be flexible enough to reduce or waive it for anyone who cannot afford to pay.
- If the MS Society has no holiday facility and no resources for using a hotel, cut costs by organising the seminars at the local level (branches) so people won't require a hotel stay.
- Whenever possible, utilise experts who work for the MS Society or who are affiliated with the Society. (Don't invite experts who require a stipend!).
- Develop the daily schedule of the seminar with several short breaks to help fight fatigue.
- Make beverages available throughout the seminar.
- Ask participants to complete an evaluation form at the end of each seminar, giving their impressions of the seminar itself as well as of the facility and the organisation.
- Use the evaluations for determining the most appreciated topics, in order to decide to repeat those later the same year and which ones to repeat next year.

If your MS society or organisation is interested in reproducing this programme in your country, further information is available from Dr Roberta Litta, email: psicologo@aism.it

Theme Seminars:

- Fatigue and everyday life
- Living with MS
- Disease modifying therapies
- Communication problems
- Rehabilitation
- Occupational Therapy

- Architectural barriers
- Employment and legislation
- Employment: new opportunities
- Social assistance: legislation and rights
- Using the Internet
- Aids and adaptive appliances for independence
- Adapting your car
- Managing stress
- Role of good nutrition
- Complementary therapies
- Wellness
- Urinary problems
- Sexuality and intimacy
- Cognitive aspects



An introdu

MS in Focus Issue 1 is devoted to the subject of fatigue. This introduction is based on a fact sheet written by the Multiple Sclerosis Society of Great Britain and Northern Ireland

FATIGUE and multiple sclerosis

Fatigue limits the lives of 85 per cent of people with multiple sclerosis. It is important that fatigue is taken seriously and its management is considered carefully.

What is fatigue?

MS fatigue is different for everyone; for some it causes overwhelming tiredness, whilst in others it worsens symptoms such as visual disturbance, difficulties with concentration, memory, mobility and muscle spasms. Fatigue may make it more difficult to deal with everyday activities.

Primary fatigue

Primary fatigue is experienced as a direct result of damage to the central nervous system. The body responds to this damage by slowing down reactions and thus causing fatigue.

People with MS experience different types of fatigue including:

- Lassitude: an overwhelming tiredness not directly related to participation in activity or exercise.
- 'Short-circuiting' fatigue: occurs in specific muscle groups; for example, the hand after writing for a short time.
- Heat sensitivity fatigue: a rise in body temperature can cause fatigue. This kind of

Fatigue is one of the invisible symptoms of MS

ction to fatigue

fatigue can occur due to the seasonal changes in the weather but may also be triggered by other things; for example, taking a hot bath or eating hot meals.

Secondary fatigue

Fatigue can be experienced as a result of other factors that are not necessarily directly related to your MS. These can include:

- Sleep disturbance: this is often due to symptoms that can be alleviated or lessened; for example, spasms, pain, urinary urgency at night, depression or anxiety.
- Infection: may cause a number of symptoms that could bring on specific MS fatigue; for example, having a cold or flu may raise your body temperature.
- Exertion: the increased effort required by the body, if mobility or coordination is affected, can cause fatigue.
- Medication: there are many medications that may cause tiredness or drowsiness as a side effect. It is important to be aware of this. If you notice that there is a correlation between a change in fatigue levels and a change in medication, tell your general physician.
- Depression: may be due to nerve damage or because of the emotional impact of adjusting to MS.
- Local environment: the lighting and temperature within a work area is crucial, as poor lighting increases visual effort and heat frequently exacerbates fatigue.

Fatigue management

Fatigue requires a coordinated approach that involves active participation and involvement from family and colleagues, as well as health professionals. You may feel that your personal relationships are affected because people do not understand how fatigue affects you. If you would like to talk about the difficulties you are experiencing coping with fatigue, it may be worth talking to a trained counsellor. Your national MS

society will be able to advise you on where to find counselling, or may even offer such a service itself.

Drug Treatments

Primary fatigue management will probably involve the use of drugs. It may take several attempts to find the most suitable drug and dose for you. Because MS fatigue is caused by damage to the nerves, standard fatigue medications are not effective.

It is common for someone with MS fatigue to be treated with drugs that are also used in the treatment of Parkinson's disease, flu or narcolepsy (excessive daytime sleepiness). This is because they have been shown to have an effect on MS fatigue, not because your doctor thinks you have any of these conditions. Drugs for fatigue include:

- Amantadine: Side effects experienced may include dizziness, headache and difficulty sleeping.
- Modafinil: This is a new treatment still undergoing clinical trials. Small-scale studies have supported its use for MS fatigue. Side effects can include headaches, weakness and nausea.

There is further information in the article on page 17.

Non-drug treatments

Changes to your daily routine can help manage your fatigue. These changes are best achieved with the support of occupational therapists, physiotherapists, your general physician, neurologist and MS nurse.

Occupational therapy and physiotherapy

The occupational therapist's role is to adapt tasks and incorporate strategies that allow daily activities to be carried out in an efficient, energy-effective way. There is further information in the article on page 9.

MS in focus Issue 1 • 2003

Physiotherapists help strengthen, stretch and relax muscles. This increases joint movements and improves circulation. They can structure an aerobic exercise programme for you.

There is more information about physiotherapy in the article on page 12.

Areas to consider when examining your daily routine should include:

Rest and relaxation

If there is regular pattern to your fatigue, it is ideal to take the rest before it is at its worst, as this enables the body to recuperate more quickly.

Relaxation techniques are available on compact discs or audiotape, and are an effective method of complete relaxation. The relaxation method used must not require active contracting and relaxing of muscles, as this can increase muscle spasm.

Prioritisation of daily activities

If you make a list of your regular habits and routines, some activities will be an obvious priority. Others can be shared, altered or even eliminated.

Some changes will require the cooperation of others; it is important that everyone understands why the changes need to be made and the benefits they will have to you.

Planning and adapting daily activities

Daily activities demand varying levels of physical and mental effort. It is important to balance these tasks, rather than rushing to complete everything in one go. Activities are ideally planned around regular rest periods. It is best to complete essential tasks when fatigue is at its minimum, and also break tasks down into manageable stages.

Organisation

You can ensure energy efficiency and effectiveness during a task, for example by keeping frequently used items within easy reach.



Many factors that cause secondary fatigue can be controlled

Gadgets such as food processors, remote controls and headset telephones also limit the effort required in completing activities. Key areas where this can help are the kitchen and work place.

Your national MS society may be able to recommend sources of equipment and adaptations in order to conserve energy.

Good posture and positioning

Sitting rather than standing is desirable in maintaining a good posture and saves energy during lengthy tasks. It is important to consider your technique when handling or lifting objects. This helps prevent injury and uses energy effectively.

Healthy balanced diet

A low fat diet, avoiding heavy, hot meals, is effective in limiting fatigue. Excessive alcohol and smoking can also have a negative impact on the level of fatigue you experience.

Appropriate exercise

Gentle aerobic exercise is a positive approach to managing fatigue. It promotes muscle efficiency and strength, as well as increasing stamina. It is important to consult a health professional before starting any exercise regime.

Managing the ordinary things of everyday life

By Susan Forwell, Senior Instructor, Division of Occupational Therapy, and Research Associate, MS Clinic, Division of Neurology, University of British Columbia, Vancouver, Canada.

FATIGUE and multiple sclerosis

Although fatigue is recognized to be the most common problem for those with MS and researchers are increasing their efforts to understand this invisible symptom, there remains the challenge of reducing the impact of fatigue for each person in their everyday life.

Fatigue can affect all kinds of everyday activities, such as seeking and maintaining employment, going grocery shopping, watching your child's soccer game, going out for dinner, taking a shower or bath, vacuuming your home, going for a walk, planning and making dinner, working at a computer, and doing the laundry.

Research has shown that fatigue can affect adversely activities that are important and meaningful not only to the person with MS, but also to their friends, family and social network.

People with MS report that when they are fatigued they 'can't do fun things – only the necessities' and that 'it [fatigue] destroys



spontaneous choice. They also say 'my memory gives up', 'I'm feeling guilty about it [fatigue] because I look lazy', and 'people don't believe that I can't do something. These testimonials demonstrate that fatigue affects psychological, cognitive, social, and physical aspects of life for persons with MS.

Managing non-MS related fatigue

To manage effectively and make a difference in everyday life, the potential causes of fatigue must be assessed rigorously and identified.

There is the type of fatigue that is directly related to MS and is thought to occur because of the damage the disease causes to the protective sheath around the nerve fibres (the myelin sheath). However, people with MS can suffer from fatigue that stems from other factors that are not related directly to this damage.

Table 1 provides a list of causes of non MS-related fatigue that may be present in those with MS. Experiencing fatigue as a result of one or more of these causes is very common among people with MS.

Managing MS related fatigue

Fatigue directly related to MS is categorized into primary MS fatigue, which is thought to be nerve fibre fatigue, and secondary MS fatigue, which can occur with the onset of disability.

Currently pharmaceutical agents and non-invasive strategies are used to treat MS-related fatigue. Occupational therapists recommend the following eight non-invasive techniques for managing fatigue and enabling people with MS to do the things they want: education about the characteristics of MS-related fatigue, self-monitoring techniques, energy efficiency and work simplification strategies, use of equipment, monitoring core body temperature, relaxation

routine, sleep routine, and attending to the physical environment.

The goal of these strategies is not to correct the underlying mechanism of fatigue. Rather, the focus is to provide tangible strategies for proactive decision-making, tailored to individual needs and energy patterns to enable participation in activities. In Table 2 there are some examples and principles of each of these strategies.

Research has shown that if people with chronic illnesses such as MS take part in a community-based, occupational therapy energy conservation programme, there is a positive effect on their ability to manage fatigue and improve their quality of life.

Table 1: Potential causes of non-MS related fatigue

Potential causes*	Some examples*	What to do
Infection	• Colds, flu	See your doctor to manage
	Bladder infections	the infection.
Medications/substances	Side effects of some drugs	See your doctor or
	Interaction between drugs	pharmacist to review your
	Non-prescriptive drugs	complete list of drugs and
	Non-traditional substances	substances.
Sleep problems	Difficulty falling asleep	See your doctor about
	Disturbed sleep due to frequent	sleep problems. If severe,
	urination, spasms, pain, sound or	seek help from a sleep
	movements of others	specialist.
	Waking tired or with a headache	
Depression	Feeling down, irritable	See your doctor.
	Lacking interest in usually stimulating	
	people or topics	
	Feeling inadequate or a failure	
Deconditioning	 Reduced physical condition of muscles, 	See your physio-therapist
	heart, and lungs due to inactivity	who understands MS.
Pain	Back pain	See your doctor or other
	Pain due to arthritis	specialists to manage the
	Headaches	pain.
Stress	Difficulties in your workplace	Seek assistance from a
	Family tension	counsellor or social worker.
	Financial worries	
	Issues related to MS	
Breathing problem	Asthma, shortness of breath	See your doctor.

^{*} This is not an exhaustive list and there are other causes and examples of non MS-related fatigue. These examples have been provided to assist description and demonstrate the diversity of fatigue.

Based on the principles and examples outlined in Table 2, let's return to three everyday life activities (maintaining employment, watching your child's soccer game, planning and making dinner) noted at the beginning of this article. How might these strategies be implemented to reduce the fatigue and still enable you to participate in these important activities?

Notwithstanding the need to include individual assessment for specific needs, examples of strategies for maintaining employment in the face of MS-related fatigue might be to consider a work assessment by an occupational therapist to ensure your work environment is ergonomically-friendly, the temperature is moderate (air-conditioning or other cooling strategy), and rest breaks can be incorporated into the workday.

To ease attendance at a child's soccer game, use prescribed walking aids to help cope with walking distances and uneven terrain, avoid sitting in the sun, use a cooling garment, and sit to watch the game. The final example, planning and preparing dinner, is a task that could be segmented to conserve energy as an initial fatigue management strategy. Prepare dishes in advance that can be used for a couple of meals. Rest before preparing the meal and get the family involved so as to turn it into a social time and reduce the burden on you. Whatever the approach, it must be understood that daily lives are increasingly more demanding. Coupled with the complexity of fatigue in MS, one must expect that a comprehensive, multi-strategy approach will be required in order to make an impact on managing your fatigue in your everyday life in the 21st century.

Table 2: Non-invasive strategies for MS related fatigue

Strategy	Examples and principles
Education	 Ignoring, pretending, or 'fighting it' does not promote performance or ability to do chosen activities One needs to take control of fatigue, rather than the fatigue doing the controlling
Self-monitoring	Implementation of rest:activity ratio
techniques	principles as determined for each situation and individual
Energy	Use conveniences such as elevators,
efficiency	disabled parking
strategies	Organise tasks to be done in parts, so it is easy to stop and restart
Equipment	Use a chair in the shower to sit rather than stand
	Walking aids to reduce energy needed to walk
	Use environmental control units and remote controls
Body	Sensitivity to elevated body temperature
temperature	increases fatigue experience, for
	instance, after exercise or in hot
	environments
	Use cooling garments and reduce sun exposure
Relaxation	Use to rejuvenate the system, do not need sleep in all situations; technique used depends on individual
	There are contraindications to some
	relaxation methods for some people with MS
Sleep routine	Sleep at night in different locations to
'	where you rest during the day
	Pay attention to pre-sleep routine
Environment	Keep commonly used items on the
	easiest to reach shelves
	Set up convenient places to rest where
	you spend a lot of time, for instance at
	work, home and school

Your occupational therapist will be able to discuss each of these strategies with you in detail and help you to select the best combination of strategies to meet your particular needs.

Physiotherapy: a partnership

By Jenny Freeman, Senior Lecturer, Institute of Health, Plymouth University and Honorary Lecturer, Institute of Neurology, London, UK.

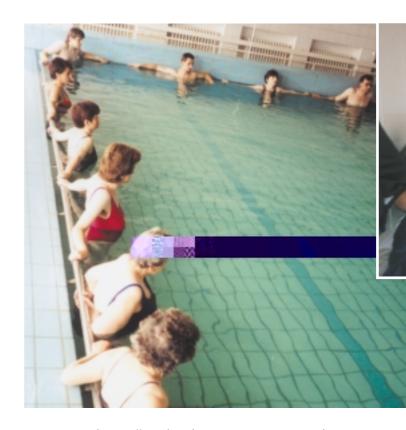
FATIGUE and multiple sclerosis

Physiotherapy can benefit people with multiple sclerosis, according to a gradually accumulating body of scientific evidence. Physiotherapy has also been suggested as an important component of a comprehensive approach to helping people with MS manage symptoms such as fatigue.

However, it encompasses an enormous range of techniques and approaches and we are only just beginning to scratch the surface in terms of finding out what works best.

Evidence suggests that some aspects of physiotherapy, such as aerobic and strengthening exercises, promote proper posture and walking, which can help to reduce fatigue. But there can be considerable variation between people with MS at different stages of the disease, and this means that they may not always respond to a particular intervention in the way that studies suggest they should.

Therefore it is important that there is an active partnership between the physiotherapist, other healthcare professionals, the person with MS and their family to discover what works best for that particular individual and to help them sustain the resulting improvements over time. This requires a frank exchange of information, negotiation and co-operation, with everyone working together to establish the goals of



treatment that will make the most impact on the person's everyday life.

Specific treatment approaches vary among therapists depending on the resources available, experience of the therapist, and personal preference of both the therapist and the person with MS. Treatment can be offered in a variety of settings: as an inpatient or outpatient or within the community. This flexible approach is essential since every person is unique, and their needs ever-changing.

Short bursts of physiotherapy input alone will not enable an MS person to achieve and maintain optimal physical fitness and function.

Continuous, effective self-management is a vital part of the physiotherapy approach in order to minimise the impact of symptoms such as increased tone (spasticity), fatigue, weakness and pain. This requires an understanding of the nature of the symptoms and the rationale behind the management approach, as well as the ability

approach



to apply appropriate strategies and techniques. Such knowledge not only enables the person to have better control of their symptoms but also a clearer idea of when to seek help. Education is a key role of the physiotherapist.

In line with this approach it is important that physiotherapy exercises should not dominate one's lifestyle but should be integrated into everyday life. This can be achieved by:

- Adopting postures which are comfortable and maintain good alignment of muscles and joints, for example when lying in bed or sitting in a chair
- Using movement patterns which do not promote asymmetry or increase tone and spasms
- Participation in aerobic forms of exercise
- Correct use of equipment.

'Carryover' is a word that physiotherapists often use to describe whether improvements gained are sustained over time. They measure whether

The primary aims of physiotherapy are to:

- Provide a comprehensive assessment of physical needs, focusing on posture and movement
- Facilitate functional independence
- Encourage self-management
- Provide education on a range of issues including aerobic exercise, moving and handling, and how to avoid falls
- Prevent secondary complications, such as pressure sores and the permanent shortening of muscle and tendon tissue
- Optimise general physical fitness

changes have been maintained, or have continued to improve, in areas such as the speed and efficiency of walking, level of fitness, range of movement, and level of functional independence. Where things have deteriorated they determine whether this is because of ongoing neurological deterioration or for other reasons.

Such assessment is important because restrictions in health care resources mean that long-term ongoing input is difficult to justify if positive changes are not occurring, or if the improvements made are not maintained.

Therefore, ongoing self-management in partnership with the physiotherapist is the cornerstone of any successful treatment strategy.

By Marco Heerings, Nurse Practitioner, Department of Neurology, Groningen University Hospital, Netherlands.

FATIGUE and multiple sclerosis

Over the past few decades people with MS have tried various methods of alleviating fatigue, even before it was known that MS fatigue stemmed from a different cause than 'normal' fatigue.

As early as the 1960s it was common to advise people with MS to bathe in cold water when they felt fatigued, and for many this treatment did seem to relieve the symptom and provide renewed energy. Today we have cooling garments to achieve the same goal without requiring the person to get wet, dry off and dress again every time he or she feels fatigued (a process which itself requires a great deal of energy). As the fields of medicine, physiotherapy and occupational therapy have advanced, people with MS now have many options available for better identifying and managing fatigue.

MS nurses have an important role in the assessment and management of fatigue. They may begin by asking key questions in order to understand the details relating to the person's symptom. In some cases nurses may use fatigue impact scales or questionnaires to measure the effect that physical, emotional and psychosocial factors may have on fatigue. Finding out which factors are involved can help in determining the best intervention and can help nurses in referring the individual to the most appropriate type of healthcare professional for further assessment and intervention. If the underlying cause of the fatigue is related to physical factors then physiotherapy and exercise may help to improve the person's fitness. However, if the fatigue may be related to depression then a referral for counselling might be the most appropriate intervention. If an infection with increased body



The role of

temperature may be the cause of fatigue, the nurse's primary goal would be to identify and treat the infection.

As part of the assessment, it is important the MS nurse asks about the person's sleep patterns. Typically this can be accomplished with a few relevant questions posed by the nurse during regular visits. The nurse should ask whether the person with MS wakes during the night needing to urinate. If yes, how many times? The medical term for frequent urination during the night is 'nocturia'; it is a problem experienced by many people with MS and is a cause of secondary fatigue. It is also helpful to ask whether the person's breathing is interrupted during sleep and if loud snoring occurs, perhaps pointing to sleep apnoea (interruption of breathing during sleep due to temporary obstruction of the airway), which causes restless sleep resulting in tiredness the following day.



the MS nurse

Medications that can cause fatigue (otherwise known as lassitude, weariness, lethargy and tiredness) *

Analgesics

Anticonvulsants

Antidepressants

Antihistamines

Antihypertensives

Anti-inflammatory

Antipsychotics

Asthma drugs

Carbonic anhydrase inhibitors

Cardiac drugs

Diabetic agents

Gastrointestinal agents

Genitourinary agents

Hormone replacement

Immune modulators

Muscle relaxants

Nicotine agents

Sedative hypnotics

Adapted from Physician's Desk Reference, 1998, Medical Economics, Inc.

Another useful tool in assessing fatigue is a diary kept by the person with MS to record the times and situations in which they experience the greatest fatigue, and also, perhaps even more importantly, times and circumstances in which fatigue is at its minimum. The MS nurse can help the person in getting started with a fatigue diary.

What can be done to alleviate fatigue?

An important strategy for learning how to deal with fatigue is talking with other people who experience the same symptom. Comparing self-management strategies is often of more help than suggestions from a healthcare professional.

It is also important for the person with MS to communicate openly about his or her fatigue with family and friends so that they understand the problem and can be more helpful when necessary. Knowing that fatigue is a real symptom of the disease helps people talk with others more openly. The MS nurse can have an important role in educating the individual and family members to understand and deal with fatigue better.

It is common for people with MS to take various medications at the same time. For this reason, the nurse has a role in encouraging the person to keep a list of all medications, including complementary therapies, and to continually update the information. There are many medications taken for other MS symptoms that can cause or worsen fatigue and it is important for the person to assess his or her medication list at every meeting with the nurse and neurologist.

Just because a person has been diagnosed with MS does not exclude him or her from having other illnesses, so the medication list must include all medications, not only those being taken for MS-related problems.

Being realistic is important

Successful fatigue management is never easy. There are many different strategies for dealing with fatigue although not all of them are appropriate for every person with MS. It is important to be patient and flexible in trying out

different strategies until the individual discovers what works best for him or her. The MS nurse can help in assessing fatigue, suggesting strategies, educating, making referrals to other healthcare professionals and in setting goals toward optimal fatigue management.

Fatigue Diary: Instructions

- **1.** Assign a number from 1 to 10 (1 being very low and 10 being very high) for:
- Your level of fatigue
- The value or importance of the activity you are doing (by comparing it to other activities you would like to do during the course of the day)
- Satisfaction you feel with your performance of the activity
- **2.** Describe the physical work done in the Activity column (eg stood to shower for 10 minutes,

- carried two bags of groceries up 15 stairs, walked 300 metres to the neighbour's house).
- **3**. List MS symptoms as they appear or worsen during the day in the Comment column, including problems concentrating, visual problems, weakness, dragging foot, pain, numbness, etc. Include temperature of the environment when relevant.
- **4.** Record information every hour that you are awake and write the times you were asleep.

For example:

Name: Date: Describe last night's sleep:

12:00	Fatigue 7	Value 3	Satisfaction 2	Preparing lunch	Blurred vision, very
				standing 15 minutes	warm in kitchen

Sample form:

Time	Fatigue	Value	Satisfaction	Activity	Comment
06:00					
07:00					
08:00					
09:00					
10:00					
11:00					
12:00					
13:00					
14:00					
15:00					
16:00					
17:00					
18:00					
19:00					
20:00					
21:00					
22:00					
23:00					

Adapted from Activity Diary, Fatigue and Multiple Sclerosis, Multiple Sclerosis Council for Clinical Practice Guidelines, Paralysed Veterans of America, 1998.

Pharmacological treatment of fatigue

By Elizabeth McDonald, Medical Director, MS Society of Victoria, Australia.

FATIGUE and multiple sclerosis

People with MS nominate fatigue as one of the most common and disabling symptoms of their disease. Studies indicate that as many as 95 per cent of individuals with MS experience fatigue. Fatigue in MS, also known as lassitude, is 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'. This fatigue does not appear to be related to the type of MS, disease severity or duration; and, to date, the underlying mechanism is poorly understood.

In this article, the treatment of primary MS fatigue is considered. Other articles in this magazine discuss alternative causes of fatigue that can confuse and even compound the problem, such as existing medical conditions, the side effects of medications or sleep problems.

Recent studies have reinforced that there is a definite role for the use of medications in the treatment of primary fatigue in MS, by way of altering the brain chemistry. The newer agents focus on promoting normal wakefulness rather than stimulating the central nervous system.

Amantadine

Amantadine is an antiviral medication and it has been used in the treatment of MS fatigue since the 1980s. Its method of action in reducing fatigue is not known. It is considered a first-line treatment and is recommended for mild fatigue.



Amantadine has been shown in studies to benefit about one third of patients with MS. A positive benefit is usually seen within one week.

Amantadine is relatively safe, well tolerated and inexpensive. Its side effects are usually mild and may include dreams, hallucinations, hyperactivity and nausea.

Modafinal

Modafinal is a wake-promoting agent used in the treatment of excessive daytime sleepiness. Recent studies using modafinal for MS fatigue have shown positive benefits in about two-thirds of subjects after about two weeks of therapy. Its use is recommended for those with moderate to severe fatigue or mild fatigue that has not responded to amantadine. Modafinal is relatively safe and well tolerated. Its side effects include headache, nausea and weakness at higher doses.

Pemoline

Pemoline is a central nervous system stimulant and has been used to treat MS fatigue, but studies have failed to show significant benefit using fatigue assessment scales. Pemoline is poorly tolerated in about 25 per cent of patients and, as higher doses can cause liver damage, careful monitoring by regular blood tests is required. It is not recommended as a first-line treatment for MS fatigue.

Other Medications

Aminopyridines (4-aminopyridine and 3,4-aminopyridine) are drugs that improve

Continued from page 17

nerve conduction in nerves with damage to their protective myelin sheath (demyelination) and have shown some benefits in MS fatigue related mainly to heat sensitivity.

Their use is not advocated as side effects include the risk of seizures, trigeminal neuralgia* and heart problems.

Central Nervous System stimulants have a very limited role in the treatment of MS fatigue. Side effects include agitation, anxiety and high blood pressure and the added risk of addiction.

Antidepressants

There is little evidence to support the use of antidepressants in MS fatigue but they may be of benefit in some individuals.

Summary

Fatigue is a complex and common symptom of MS and recent advances in the treatment of fatigue are proving beneficial. As our understanding of the underlying mechanisms increases, so will the potential to develop more tailored and effective treatments.

Questions and

FATIGUE and multiple sclerosis

Q. At work I have difficulty in following through with my office tasks because I'm easily distracted and have trouble concentrating and remembering details, especially in the afternoon. My colleagues have commented that I seem like a different person in the first part of the day. I'm sure this must somehow be related to my MS, but how can I manage these problems before I risk losing my job?

A. A first step in managing problems with concentration and memory is to understand whether they occur during a particular part of the day, or are present more or less all of the time. If it is clear that concentration is more difficult in the afternoon, this is a sign that the cause could be related to MS fatigue. Energy conservation techniques and fatigue management strategies can help in managing these problems.

Q. I'm so exhausted all of the time that I feel very unmotivated to have sex with my partner. He feels threatened that I'm no longer interested in him and I wonder if I'm just being lazy. Is this related to my MS and is there anything I can do about it?

A. Sexual problems can often be related to other MS symptoms, such as fatigue. Energy conservation and fatigue management are important in promoting sexual activity and enjoyment. For some people, implementing strategies such as having sex when one's energy level is at its highest, napping before sex, and minimising positions that may increase fatigue, are sufficient for lessening the impact fatigue has on a sexual relationship. Others may require pharmacological intervention or a combination of medication and self-management strategies.

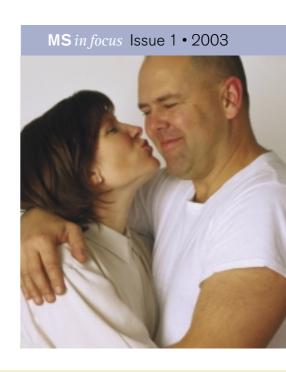
Q. When our MS society plans seminars and conferences people with MS are not always satisfied with the organisation because of how fatiguing an all-day meeting can be for them. What are some practical tips for helping our conference attendees enjoy a meeting while minimising fatigue?

A. When organising conferences, seminars and courses in which people with MS participate, it is important to choose a location that is accessible, has an easy entry and exit, has toilet facilities

^{*} Trigeminal neuralgia is a disorder of the sensory nerve of the face, in which sudden episodes of excruciating stabbing pain occur in the cheek, lips, gums, chin or tongue.

answers

not far from the meeting room, a restaurant, elevators and so on. It is very important that the meeting space has temperature control, such as air conditioning. When air conditioning is not available, electric fans can be helpful. The programme should include several breaks throughout the meeting, with enough time for going to the toilet and having a drink. Places to sit and to rest glasses or plates should be available during breaks. Avoid buffetstyle meals! Arrange for volunteers to be available to help during breaks and meals. Leave cold water and glasses in the back of the room throughout the meeting.





Mr Ian Gray, President of Persons with MS in Victoria, Australia, talks with Dr Elizabeth McDonald about the fatigue he experiences with his MS.

How long have you had MS?

My diagnosis was confirmed in 1990, but looking back I know I had been fighting the disease for some considerable time prior to this.

How has MS affected you?

Initially my walking was affected. I noticed that I began to stumble. Over the years the distance I could walk became less. I became extremely fatigued after relatively minor exertion and noticed that my memory was not as reliable as before. I retired from work in April 1998.

The fatigue you experience – can you describe it?

The fatigue is like an overwhelming feeling of unnatural tiredness that exacerbates all my MS symptoms to the extent that I can no longer function. Rest returns me to normality. The time this takes depends on the ambient temperature.

Has your fatigue changed since diagnosis?

My fatigue has increased. Initially I hardly noticed it; then with secondary progressive MS I became

fatigued more easily with less exercise. It now appears to have stabilised.

How does fatigue impact on your lifestyle?

I have to use a wheelchair to preserve energy. I can wake up feeling energetic and after a short period of activity become fatigued. It takes me much longer to complete tasks. I have to pace myself to do anything.

Has your fatigue had an impact on your family and friends?

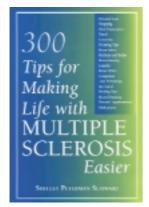
Yes, it restricts activity for everyone, but now we adapt and my family and friends are all supportive.

Do you rest when tired or push on?

Sometimes I push on, particularly if I am doing something I enjoy. For instance, when gardening on my hands and knees, if I overdo things I can get so fatigued that I cannot get up without help. Then it takes a little longer to recover.

lan, thank you for sharing your story with us.

Book Reviews



Demos Medical Publishing Inc, USA. 1999. Price \$16.95. ISBN:1-888799-23-4

300 Tips for Making Life with Multiple Sclerosis Easier

by Shelley Peterman Schwartz

Review by Elsa Teilimo, Finnish Representative Persons with MS International Committee.

This book has tips, advice and techniques to help people who are seriously disabled with multiple sclerosis (MS) find ways to manage an ordinary but challenging day.

Written by Shelley Peterman Schwartz, who has MS herself, the book deals with the different situations that arise in everyday life, such as housekeeping, dressing, shopping and meal preparation. She has put an enormous amount of work and imagination into writing this easy-to-read guide.

There are some ingenious tips, such as putting your medication bottle into your slippers at bed-time so that you don't forget to take your pill in the morning, or using rubber bands around your drinking glass to give you a better grip.

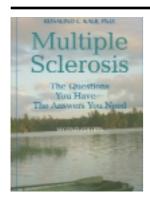
However, there are also many other tips that can only be put into practice in the USA, where the author lives in her own home.

She is apparently well to do and many suggestions reflect her way and standard of living.

What is not taken into consideration is the situation of people who do not own their own homes and who are subject to restrictions regarding structural changes to their accommodations, which is common in many parts of the world.

In addition, many of the useful addresses in the last chapter list toll-free telephone numbers that are only accessible if calling within the USA. To be more accessible for non-Americans, it would have been helpful to have website addresses as well as postal addresses.

In summary, the book is easy to read and provides helpful information, although non-American readers may find that many tips are not applicable in their own countries.



Demos Medical Publishing Inc, USA. 2000. Price \$39.95. ISBN: 1-888799-43-9

Multiple Sclerosis: The Questions You Have - The Answers You Need (2nd Edition)

Edited by Rosalind C. Kalb.

Review by Tom Houle, US Representative, Persons with MS International Committee.

This is a solid reference book that should be made available to anyone with MS, carers, and others working in the field of MS. Its comprehensive coverage of topics and manner of presenting information make it a valuable resource.

Each of the 17 chapters, written by an expert in MS, addresses a specific topic through a question/answer format.

In addition, each chapter provides a list of follow-up readings, and six appendices at the end of the book add to the wealth of information. Two areas lacking coverage are on issues for carers and on complementary and alternative medicines. While information is present on each topic, separate chapters would have added to their importance.

Of necessity, authors occasionally use scientific terms and more explanation of these terms would be helpful for those with less technical knowledge.

In some chapters it would help if the author had given additional emphasis to ways people with MS could use the information. While the information is sound, readers would profit from

more advice and encouragement on how to translate those words into practical action.

Lastly, it should be noted that this book was written by North American specialists, and while the medical and technical information may apply universally, some topics of a social nature, such as insurance, psycho-social issues, employment and long term care, tend to be culturally specific and may have less value to non-Western cultures.

Notwithstanding these comments, there is much to recommend this guide for those seeking substantial knowledge about MS in one book.

Web site review

Jooly's Joint: www.mswebpals.orgBy Sandy Burnfield, Consultant in Child and Family Psychiatry, Hampshire, UK.

When I went on-line in 1997, Jooly's Joint (JJ) was the only site for people with MS I could find. Five years later it is still there and has matured into one of the most useful international sites there is on the Net for people with MS, as well as family and friends.

So what makes this such a cool site? I think it is because it is managed and cared for by just one person – a young British woman, Julie Howell, who has MS herself.

Julie provides many and varied ways for people to use the site, without becoming dominant or intrusive – on the contrary she keeps in the background and encourages others to explore JJ in their own way and to share experiences of MS together.

The JJ site is responsibly run, providing accurate information and links to genuine evidence-based websites where issues can be explored in more depth.

The site is well laid out and easy to use with



separate pages on key subjects. There are pages with links designed for people with MS, for people who live or care for us, as well as a newsdesk, bookstore, and a fun page where people can enter competitions, download a screen saver or buy JJ T-shirts.

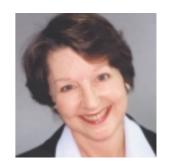
There are several other ways that JJ offers help and support to people who have MS, including a chat room, and a place for people to make webpals or show each other their pictures.

I spent some time in the chat room – this was busy, international and supportive – messages were easy and quick to send to the group.

This is not a site for wish-fulfilling fantasists or those with a chip on their shoulder – thank goodness – there are too many of these sites already!

Jooly's Joint is a friendly, informative, and positive site for people involved with MS. Take a look for yourself at **www.mswebpals.org**

MSIF: An overview By Christine Purdy, CEO, MSIF



Sylvia Lawry, an extremely dynamic woman entirely committed to eradicating multiple sclerosis, established the US MS Society in 1946 after her younger brother was diagnosed with the disease. Then in 1948, with \$25,000 seed money she helped set up the Canadian MS Society. MS societies started forming throughout Europe soon afterwards.

Two decades later, in 1967, delegates from 17 national MS societies met in the House of Lords in the UK to hammer out the final details of a constitution and by-laws for a federation of national societies to fight MS at an international level.

Shirley Temple Black was one of those original motivators and signatories to the new

constitution. Now MSIF comprises 42 Member Societies, and its Secretariat is in regular contact with societies in over 30 other countries.

The dual fundamental purposes behind establishing an international movement were to share information and research and to stimulate the development of struggling national societies. It is altogether fitting, therefore, that MSIF's major international research project is called The Sylvia Lawry Centre for Multiple Sclerosis Research.

MSIF is the Member Societies' unified attack on MS reaching beyond national and regional boundaries. MS in Focus contributes to the international sharing of information in this global struggle.

Sylvia Lawry Centre for Multiple Sclerosis Research

By Leila Terry, Research Administrator, MSIF

The SLCMSR is MSIF's key research project. The project was set up, after stiff international competition, at the Institute of Statistics and Medical Epidemiology, Technical University of Munich, in February 2001.

The Centre relies on the effective combination of computer science, mathematics and medicine. Its ambitious aim is to speed up the development of future MS therapies and in turn make them less costly.

Using mathematical models based on a collection of placebo data from clinical trials and natural history data, the SLCMSR's first objective is to identify clinical and magnetic resonance imaging

markers for the disease. Compared to current methods, these markers will predict more reliably how a person's MS will develop.

The SLCMSR has already collected and started to pool 41 data sets (over 14,000 patients and nearly 55,000 patient years). All the major MS-related pharmaceutical companies have contributed.

The project, currently unparalleled in medical research, is an excellent example of what can be achieved when industry and academics work together.

To find out more, visit www.slcmsr.org

Persons with MS International Committee

An Introduction by the Chair Susan Tilley

People with MS can become actively involved in the global MS movement and join MSIF's various projects and programmes by being elected to the Persons with MS International Committee (PwMSIC). The Committee ensures MSIF can speak out with a global voice on behalf of people with MS worldwide.

In Spring 2002, I was elected to be the Committee's new Chair. I am delighted to fill this role and am really looking forward to meeting the challenges ahead. The Committee has the opportunity to be involved with many exciting projects, and to direct the future growth of MSIF to ensure that it truly meets the needs and aspirations of people affected by MS worldwide.

Amongst the key projects that the Committee supports are the MSIF conferences. In October



Introducing the International Medical and Scientific Board

By Leila Terry, Research Administrator, MSIF.

MSIF's International Medical and Scientific Board (IMSB) is an extraordinary group that brings together the expertise of almost 100 MS professionals. Their aim is to promote, support and guide MSIF's research, professional education and information services. Indeed it was IMSB that led the way to establishing the SLCMSR.

Each Member Society nominates up to two members, ensuring international scientific contacts and credibility for MSIF. IMSB also links



Sue Tilley, Chair, Persons with MS International Committee

2001, the Committee contributed to the success of the Persons with MS day at the Melbourne Conference in Australia. One of the most moving talks was given by the Committee's former chair, John Golding, and his wife, Elizabeth, who spoke intimately about changes they have made in their lives to deal with John's MS.

Following the success of the Persons with MS Day in Australia, another is planned for the MSIF 2003 International Conference 'Gateway to Progress' that is taking place in Berlin, Germany, 21-25 September 2003.

To find out more about the PwMSIC and their activities visit the MSIF website: www.msif.org

MSIF to key professional organisations such as the World Health Organisation and the World Federation of Neurology.

Recently, four key IMSB members published Multiple Sclerosis: The Guide to Treatment and Management, which may now be viewed online at www.msif.org.

"...this little book provides a rigorous, comprehensive and very readable summary of treatments currently available for MS. I think every library should have a copy, and I am delighted that it is being made available on the Internet." The International MS Journal, issue 9:3, 2002.

MSIF 2003 International Conference

21-25 September 2003, Estrel Conference Centre, Berlin, Germany. Organised by Deutsche Multiple Sklerose Gesellschaft (DMSG) and MSIF.

Contact: DMSG, Bundesverband e.V., Küsterstrasse 8, D-30519 Hannover, Germany.

Tel: +49 (0)511 968 340. Fax: +49 (0)511 968 3450. Email: dmsg@dmsg.de.

Website: www.dmsg.de

MS Awareness Days/Weeks around the world

Australia	MS Week: first week in June	www.msaustralia.com.au
Belgium	MS Week: second/third week in September	www.ms-sep.be
Brazil	MS Week: 26-30 August	www.abem.org.br
Canada	MS Month in May	www.mssociety.ca
Czech Rep.	MS Day: during June	www.roska-czmss.cz
Denmark	MS Day: 24 May 2003	www.scleroseforeningen.dk
Finland	MS Week: 12-18 November	www.ms-liitto.fi
Hungary	MS Day: during September	www.sm.alba.hu
Ireland	MS Week: first week in May	www.ms-society.ie
Italy	MS Week: 17-25 May 2003	www.aism.it
Malta	MS Week: first week of May	No website
Netherlands	MS Day: in second week of November	www.msweb.nl
New Zealand	MS Week: 18-24 September	www.mssocietynz.co.nz
Norway	MS Day: last Saturday in August	www.ms.no
Poland	MS Day: 6 December	http://ptsr.idn.org.pl
Portugal	MS Day: 8 December	www.spem.org
Romania	Second weekend in May	http://msromania.bizland.com
South Africa	MS Day: 6 July	www.kznms.org.za
Spain	MS Day: during December	www.aedem.org
Turkey	MS Week: third week of May	No website
UK	MS Week: 6-13 April 2003	www.mssociety.org.uk

MSIF Member Societies Worldwide

Argentina

Esclerosis Múltiple Argentina Tel: +54 1 4 831 6617 www.ema.org.ar

Australia

Multiple Sclerosis Australia Tel: +61 2 9955 0700 www.msaustralia.org.au

Austria

Österreichische Multiple Sklerose Gesellschaft Tel: +43 1 40 400 3121 www.ms-ges.or.at

Belgium

Ligue Nationale Belge de la Sclerose en Plagues/ Nationale Belgische Multiple Sclerose Liga Tel: +32 2 736 1638 www.ms-sep.be

Brazil

Associação Brasileira de Esclerose Múltipla Tel: +55 11 5533 0582 www.abem.org.br

Canada

MS Society of Canada/Société canadienne de la sclérose en plaques Tel: +1 416 922 6065 www.mssociety.ca or www.scleroseenplaques.ca

Chile*

Corporación Chilena contra la Esclerosis Múltiple Tel: +56 2 2765556

Cyprus

Cyprus Multiple Sclerosis Association Tel: +357 22 423644

Czech Republic

Unie Roska ceská MS spolecnots Tel: +420 2 41728619 www.roska-czmss.cz

Denmark

Scleroseforeningen Tel: +45 36 46 36 46 www.scleroseforeningen.dk

Finland

Suomen MS-liitto Tel: +358 2 439 2111 www.ms-liitto.fi

France

Ligue Française contre la Sclérose en Plagues Tel: +33 1 53 98 98 80 www.lfsep.com

Germany

Deutsche Multiple Sklerose Gesellschaft Tel: +49 511 9 68 34 0 www.dmsg.de

Greece

Greek MS Society Tel: +30 1963 3383 www.visit.to/mssociety

Hungary

Hungarian MS Society Tel: +36 22 314 198 www.sm.alba.hu

Iceland

MS Felag Islands Tel: +354 568 8620

India

Multiple Sclerosis Society of India

Tel: +91 22 444 2067

Iran*

Iranian MS Society Tel: +98 216490945 or +98 216951187-8

Ireland

MS Society of Ireland Ltd Tel: +353 1 269 4599 www.ms-society.ie

Israel

Israel MS Society Tel: +972 3 560 9222 www.mssociety.org.il

Italy

Associazione Italiana Sclerosi Multipla Tel: +39 010 27 131 www.aism.it

Japan

Japan Multiple Sclerosis Society Tel: +81 3 3847 3561

Latvia*

Latvijas Multiplas Sklerozes Asociacija

Tel: +371 7 351 792

Luxembourg

Lique Luxembourgeoise de la Sclérose en Plagues Tel: +352 40 08 44 www.webplaza.pt.lu/public/mslux

Malta*

Multiple Sclerosis Society of Malta

Tel: +356 418 066

Mexico*

Esclerosis Múltiple México Tel: +52 55 56 59 24 19

Netherlands

Multiple Sclerose Vereniging Nederland Tel: +31 70 374 7777 www.msweb.nl

New Zealand

MS Society of New Zealand Inc.

Tel: +64 4 499 4677 www.mssocietynz.co.nz

Norway

Multippel Sklerose Forbundet I Norge Tel: +47 2296 3580 www.ms.no

Poland

Polskie Towarzystwo Stwardnienia Rozsianego Tel: +48 22 630 72 20 http://ptsr.idn.org.pl

Portugal

Sociedade Portuguisa de Esclerose Multipla Tel: +351 21 837 6610 www.spem.org

Romania*

Uniunea Nationala a Organizatiilor de Multipla Scleroza din România Tel: +40 59 41 71 36

Slovakia*

Slovensky Zväz Sclerosis Multiplex

Tel: +421 033 534 4581 www.stonline.sk/szsm

Slovenia

Zdruzenje Multiple Skleroze Slovenije Tel: +386 1 568 72 99 www.zdruzenje-ms.si

South Africa

South African National Multiple Sclerosis Society Tel: +27 11 673-9643 www.kznms.org.za

Spain

Asociación Española de Esclerosis Múltiple Tel: +34 91 4481261 www.aedem.org

Sweden

Neurologiskt Handikappades Riksforbund Tel: +46 8 6777010 www.nhr.se

Switzerland

Schweizerische Multiple Sklerose Gesellschaft Tel: +41 1 466 69 99 www.multiplesklerose.ch

Turkey

Turkiye Multipl Skleroz Derneg Tel: +90 212 275 2296

UK

The Multiple Sclerosis Society of Great Britain and Northern Ireland

Tel: +44 20 8438 0700 www.mssociety.org.uk

USA

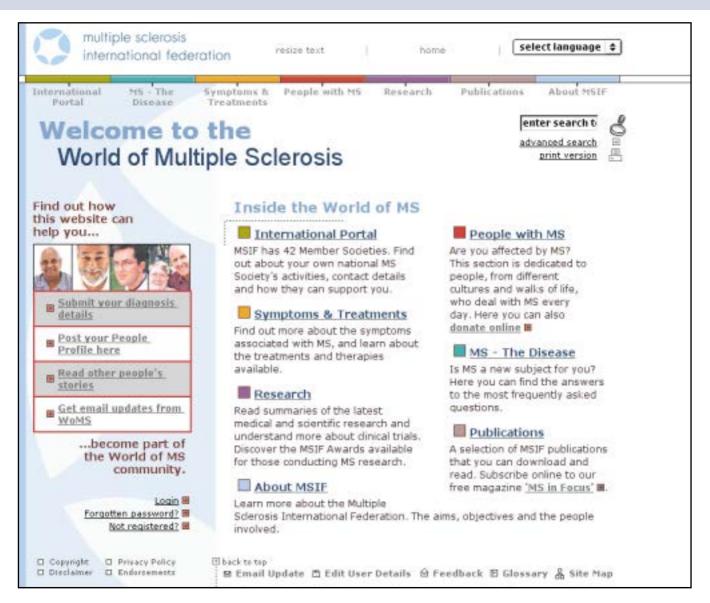
National Multiple Sclerosis Society Tel: +1 212 986 3240 www.nationalmssociety.org

Zimbabwe

Multiple Sclerosis Society of Zimbabwe

Tel: +263 4 740 472

*Associate Member



The World of MS website

Visit the 'World of MS' website. Here you will find a great deal more than a broad compilation of general knowledge on MS:

- Researchers will find up-to-date listings and a database of latest medical and scientific papers
- Healthcare professionals will benefit from MS: The Guide to Treatment and Management, a comprehensive evaluation of frequently used treatments in the management of MS and its symptoms
- People interested in what is happening world-

- wide in the MS movement can subscribe to the MSIF magazine, MS in Focus
- People with MS can share information with others in similar situations through the 'People with MS' pages that include life stories under 'People Profiles'.

The website is multilingual, with many sections in English, German, Spanish and French. Further languages are also planned.

www.msif.org

MS in focus



Skyline House 200 Union Street London SE1 0LX UK Tel: +44 (0)207 620 1911 Fax: +44(0)207 620 1922 Email: info@msif.org

MSIF is a non-profit charitable organization 501(c)(3) IRC chartered in the State of Delaware, USA, in 1967

Subscriptions

The Multiple Sclerosis International Federation produces **MS** *in focus* twice a year. With an international cross-cultural board, easily accessible language and free subscription, **MS** *in focus* is available to all those affected by MS worldwide. To subscribe, log on to www.msif.org



With many thanks

MSIF would like to thank Serono for their unrestricted grant which made the production of **MS** *in focus* possible



As a global leader in biotechnology, Serono understands well its responsibility towards both present and future generations and is committed to bringing innovative and effective treatment options to people suffering from multiple sclerosis.

To identify the optimal treatment strategy for MS, Serono has conducted several clinical trials using interferon beta in different dosing schedules in relapsing-remitting MS, early MS and secondary progressive MS.

The role of interferon beta in the body is to help coordinate the immune system in its fight against infection and regulate inflammation. Inflammation in the brain and spinal cord is a major cause of MS manifestations.

Serono's extensive clinical study programme in multiple sclerosis also helped the medical community understand more about the disease itself.

These insights are being applied to our research and discovery efforts as we look for even better therapies and perhaps, one day, find a cure.