

MS *in focus*

Issue 2 • 2003

- **Special Focus on
Dealing with
Bladder Problems**



multiple sclerosis
international federation

Editorial Board

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

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, Australia/USA.

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

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

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

Copy Editor Emma Mason, BA, Essex, UK.

Letter from the Editor



I am pleased to report that the first issue of *MS in Focus* has been a great success. We received many messages of congratulations from people with MS, healthcare providers and MS societies around the world. Aspects of the issue that our readers told us they appreciated the most included the multi-disciplinary approach to covering the topic of fatigue, the clarity and straightforwardness of the content and the variety of realistic strategies proposed for managing fatigue. On behalf of the Editorial Board, I would like to thank everyone who sent in comments.

In this issue, which focuses on bladder problems in MS, we present another aspect of the disease that is both widespread in people with MS and potentially devastating for anyone who experiences one or a combination of these problems.

Just as for fatigue, we have decided to dedicate an issue to a comprehensive discussion of bladder problems since they can have such a negative impact on so many aspects of a person's life, including work, family life and self-esteem. Given this impact on daily life, it is vitally important that people with MS have healthcare professionals at their healthcare facilities whom they can contact easily and with whom they feel comfortable discussing their concerns regarding bladder function and other aspects of the disease. Accurate information and support are key to the effective management of bladder problems.

I hope you will find this current issue comprehensive as we have gathered a number of experts from the field in order to provide a multi-disciplinary discussion of the topic. I look forward to receiving your comments.

Michele Messmer Uccelli, Editor

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.

Contents

From the Editor	3
MS Learn Online	4
Teamwork is key	6
The neurologist's view	7
A nurse's advice	10
Urology and surgery	15
Rehabilitation techniques	17
Your questions answered	20
Interview: Diana de Avila	21
Book reviews	22
Keep S'myelin website review	23
MSIF worldwide	24
2003 Charcot Award winner	24
Australia's champion carer	25
Virtual placebo group	26
Calendar dates	26

The next issue of *MS in Focus* will be on Family Issues. 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.

MS Learn Online: Interactive learning on the internet

By Nancy Law, Vice President Client Programs, National MS Society, USA.

Imagine a live interactive programme that reaches people with MS and their families anywhere they live, without anyone – including the speaker – having to leave his or her own home. Through the wonders of modern technology it is possible to reach audiences that are not always served well through traditional ‘in-person’ group programmes.

MS Learn Online is a series of programmes from the National MS Society of the United States that has served more than half a million people in at least 50 different countries since its inception in 1999, utilising an Internet technology called ‘webcasting’. Anyone with online access can participate. These programmes have focused on a variety of subjects of interest to people with MS and their families. There are programmes for the newly diagnosed, programmes on specific issues like managing pain or cognitive problems, research oriented programmes and programmes on wellness and coping topics. In total, 31 programmes are archived on the US National MS Society’s website www.nationalmssociety.org.

MS Learn Online has been particularly effective in addressing sensitive topics such as bladder and bowel symptoms or sexuality, as the programme format offers complete privacy and anonymity for participants. Topics on progressive MS have also been popular, appealing to those whose symptoms make it difficult to leave their homes to attend group programmes. Newly diagnosed participants, who may not have disclosed their MS publicly, appreciate being able to attend a programme from the privacy of their own homes.

Some *MS Learn Online* webcasts have used video streaming technology, but for most

programmes, participants listen to an audio-lecture from an MS expert while following along with a series of slides. Each live broadcast offers an ‘ask the expert’ segment, during which participants can email questions to the lecturer. A Society staff member screens the questions, the most interesting of which are put to the experts by a professional moderator.

MS Learn Online is a truly international programme. Not only do people with MS from all over the world use the programme, but also speakers can give their lecture from anywhere there is a telephone line. Programmes were only in English initially, but in 2003 the first programme in Spanish will be broadcast.

MS Learn Online programmes average about 600-1,000 participants on the day of the live broadcast. However, two to three weeks after each broadcast, the programmes are archived, and many more people benefit by either listening to the audio programme or by reading the transcripts.

Sample *MS Learn Online* programme: Understanding and Controlling Bladder Dysfunction

- MS and urologic effects
- Bladder behaviour: storage and emptying
- Neurological evaluation
- Functional issues (diet, clothing, environment etc)
- Non-pharmacological management
- Pharmacological therapies
- Surgical management

HOME • FIND YOUR CHAPTER • GET INVOLVED • ADVOCACY • PRESS ROOM • ABOUT THE SOCIETY • SITE MAP

ABOUT MS | LIVING WITH MS | TREATMENTS | RESEARCH | HEADLINES | SPECIAL EVENTS | FOR PROFESSIONALS

MS NATIONAL MULTIPLE SCLEROSIS SOCIETY

donate | pledge | search | contact us | become a member

keyboard shortcuts

LIVING WITH MS

[Family and Social Life](#)

[Healthy Living with MS](#)

[Library and Literature](#)

[Mind and Emotions](#)

[Newly Diagnosed](#)

[Personal Connections](#)

[Planning and Independence](#)

[Progressive MS](#)

[Treatments](#)

[Webcasts and Conferences](#)

Webcasts and Conferences > MS Learn Online

Providing quality information and convenient access

Since its first broadcast in 1999, MS Learn Online, the National MS Society's Internet program, has been a successful way to educate people about multiple sclerosis. Hundreds of people, at times thousands, tune into each live or [archived](#) program to learn more about MS from the convenience of their own computers. Programs cover a wide variety of topics such as information for people newly diagnosed, employment, intimacy, care-partners, alternative therapies, and progressive MS.

Information on MS is ever-changing, so it's crucial that the National MS Society provide information in the fastest way possible, while at the same time ensuring that people can

Next program

May 15
Current Research Trends in MS featuring [Stephen Reingold, PhD](#)

2003 Schedule*

June 19
El Cuidado Clinico de la Esclerosis Multiple MS Clinical Care (Spanish broadcast) featuring Elida Greinel, RN and Victor Rivera, MD

September 18
Vision and MS: What I Need to Know featuring Elliot Frohman, MD Ph.D

*subject to change

Do you have topic ideas for upcoming programs? We'd love to hear from you

Online programming is feasible in any country in which a reasonable percentage of people with MS have Internet access. The problem of limited access to computers and the Internet, which is a relevant obstacle in many countries, could be addressed by an MS society bringing audiences together at various local sites, such as MS society branches or centres, to view the programme. Although this seems like a costly programme,

the potential number of people who can be reached may justify an investment of this type. The National MS Society has been successful in obtaining pharmaceutical company funding to support all programme expenses (direct costs of about US \$13,000 or €13,000 per broadcast). Societies interested in webcasting as an educational programme can contact Dr Beverly Noyes at beverly.noyes@nmss.org.

MS Learn Online Programmes 2003

- 19 June 2003: El Cuidado Clinico de la Esclerosis Multiple. By Elida Greinel, RN, and Dr Victor Rivera (in Spanish)
- 18 September 2003: Vision and MS – What I Need to Know. By Dr Elliot Frohman (in English)

Team work is the key to success



Team work by the person with MS and healthcare professionals is important.

By Nancy Holland, Vice President Clinical Programs, National MS Society, USA.

BLADDER PROBLEMS *and multiple sclerosis*

Up to 90 per cent of people with MS are affected by impaired bladder function at some time during the course of their illness. These symptoms may come and go, but should not be ignored as they can become worse.

Bladder symptoms, which may occur at the onset of MS or at any time throughout the course of the disease, interfere with vital life activities such as a person's ability to socialise, be employed outside the home and engage in satisfying sexual activities. Serious illness and hospitalisation may occur from neglected management of the bladder problems underlying bladder symptoms.

However, there is good news. There has been a dramatic decrease in bladder-related illnesses, thanks to improved diagnostic and management measures. Distressing and disruptive bladder symptoms can be successfully managed, and bladder complications and associated serious illness can be prevented.

Two main types of bladder dysfunction happen in MS: storage dysfunction and emptying dysfunction. Symptoms of urgency, frequency, night-time awakening and bladder accidents may be present in both types. Research has shown that symptoms are not useful in determining the type of problem. Testing must be done in order to select the appropriate therapy.

A neurologist, urologist, nurse or any combination of these can diagnose bladder problems in MS.

Which healthcare professional is involved in the process may depend on how a clinic, department or centre is organised in that particular country, and on opportunities for specialised professional training.

Most people experiencing MS-related bladder problems can benefit from management techniques. Healthcare professionals can tailor strategies to suit the needs of individuals and to deal with the particular type of bladder dysfunction – storage or emptying. Strategies often include a careful balance of medication and catheterisation, worked out in consultation with the person with MS. Occasionally non-invasive strategies such as these are ineffective in managing more serious problems and bladder specialists may suggest a surgical intervention, but this is rare in MS (see page 15).

Bladder problems are usually quite disturbing for an individual. Bladder symptoms in MS can create other health-related problems, but they can also result in social isolation, early retirement from employment and decreased self-esteem. Diagnosis, treatment and regular follow-up are essential in helping the person with MS take control of his or her situation. The relationship between the individual and the healthcare team is vital in achieving successful bladder management.

The key factors are recognition of the seriousness of the problem, knowledge of appropriate tests and treatments, realistic belief in the potential for satisfactory relief of symptoms and team-work by the person with MS and the healthcare professional in all phases of management.

The MS bladder and medications

In consultation with Clare Fowler, Department of Uro-Neurology, National Hospital for Neurology and Neurosurgery, UCLH NHS Hospitals and Institute of Neurology, London, UK

BLADDER PROBLEMS and multiple sclerosis

The spinal cord plays a central role in bladder dysfunction in MS. When MS damages the myelin, messages between the brain and the section of the spinal cord that controls the bladder can be interrupted, resulting in bladder problems.

The areas of the central nervous system that control the urinary system are situated in the lower part of the brain and the lower part of the spinal cord. Messages are transmitted between the brain and the urinary system along the nerves that make up the spinal cord (Figure 1). In a normally functioning urinary system, the brain receives a message that the bladder is full. The brain then replies to this sensation, when the social circumstances are suitable, by sending a message down the spinal cord, to the area that controls bladder functioning. The message tells the muscle in the bladder wall, called the detrusor, to contract at the same time as the muscle at the outlet of the bladder, called the sphincter, relaxes. This co-ordination between the muscles allows urine to be expelled from the bladder. As the figures show, the spinal cord is critical for making the connections between the brain and urinary system.

There are two major types of urinary malfunction that commonly occur in MS – failure of storage and failure of emptying. It is

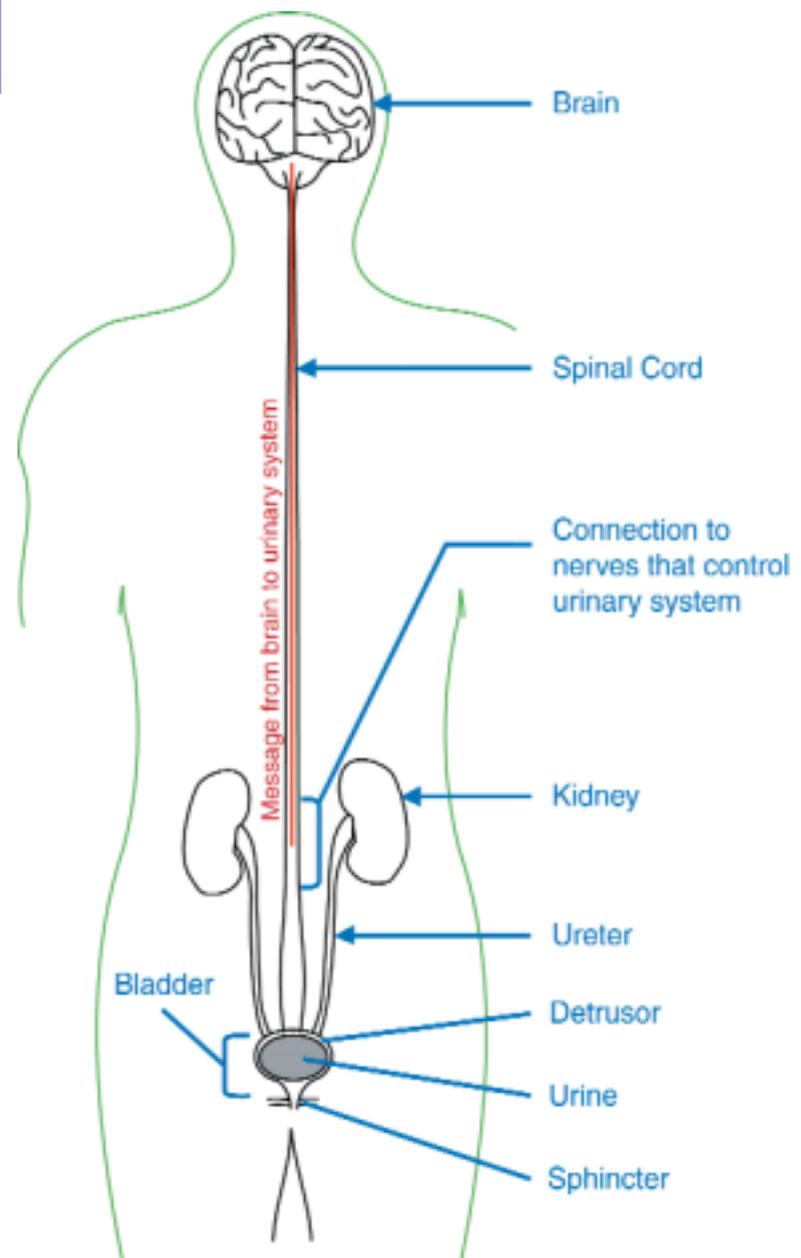


Figure 1. How the urinary system works

Table 1: Common symptoms of bladder dysfunction and their prevalence in people with MS*

Urgency (80%)	The feeling of having to empty the bladder immediately
Frequency (80%)	An increase in the number of times urination occurs
Nocturia (80%)	Frequent urination during the night
Incontinence (50%)	Inability to hold urine in the bladder
Hesitancy (20%)	Difficulty in beginning to urinate

* Percentages taken from *Multiple Sclerosis*, DW Paty, GC Ebers eds. FA Davis Company, Philadelphia. 1998.

not known why some people experience one disorder and not the other, or why some individuals experience a combination of both.

Failure of storage occurs when an interruption of the spinal connecting pathway transmits messages that cause involuntary bladder contractions. This is known as an 'over-active' bladder and results in the person feeling the need to urinate frequently, but only in small amounts. Also people with an over-active bladder may experience urgency. If this is severe, the individual may also experience urge incontinence – a leakage of urine by involuntary detrusor muscle contraction together with a strong urge to urinate.

'I have bladder problems which drive me crazy. There were days when I never 'went', but I am now on a medication which has really helped.' **Sandra**

The other type of malfunction in the urinary system relates to inadequate emptying of the bladder. Instead of a co-ordinated activity between the important muscles, the sphincter (bladder outlet) does not relax when the detrusor (bladder wall) contracts so that urine flow is poor and interrupted, making bladder emptying incomplete. The urine left in the bladder, known as the residual volume, can then stimulate further bladder contractions. People with MS who have this type of bladder problem

may complain of feeling as if the bladder is not empty and of a continued need to urinate. Others may not experience this sensation but urine still remains in the bladder. This residual volume can be confirmed by performing simple tests. It is important to assess the amount of residual urine in the bladder because it can be the source of infection and other complications, as well as making frequency and urgency worse.

A comprehensive evaluation of bladder problems by experienced healthcare professionals and motivation on the part of the person with MS results in successful management of these problems.

The pharmacological management of bladder problems

The management of bladder problems in MS includes two key components:

- The use of clean intermittent self-catheterization to manage incomplete emptying
- Medications to treat an over-active bladder that results in inadequate storage of urine and urgency or frequency problems.

Anticholinergic medication is a common treatment, but because it may decrease bladder emptying efficiency and therefore increase residual urine left in the bladder, it is important to check the residual before beginning treatment.

Table 2: Medications for treating an over-active bladder

Oxybutynin

Oxybutynin helps decrease bladder muscle spasms and the frequent urge to urinate. Oxybutynin is likely to cause a variable degree of dry mouth because the same chemical messengers control the bladder and the salivary glands. As this medication can worsen other MS symptoms while treating the bladder problem, some people may switch to another treatment.

Oxybutynin – extended release

This extended-release form of oxybutynin is relatively new and not available in all countries. It needs to be taken only once a day, as the tablets are designed to release the drug at a controlled rate, maintaining a steady level of medication in the body. A skin patch with fewer side effects, is also available in some countries.

Tolterodine

Tolterodine is used to treat bladder spasms causing urinary frequency, urgency, or urge incontinence. It works by reducing bladder muscle contractions. Tolterodine has fewer side effects, but is more expensive than oxybutynin. Patients should take the exact amount prescribed by their doctor as too much can cause adverse effects. An extended release form is also available.

Tropium chloride

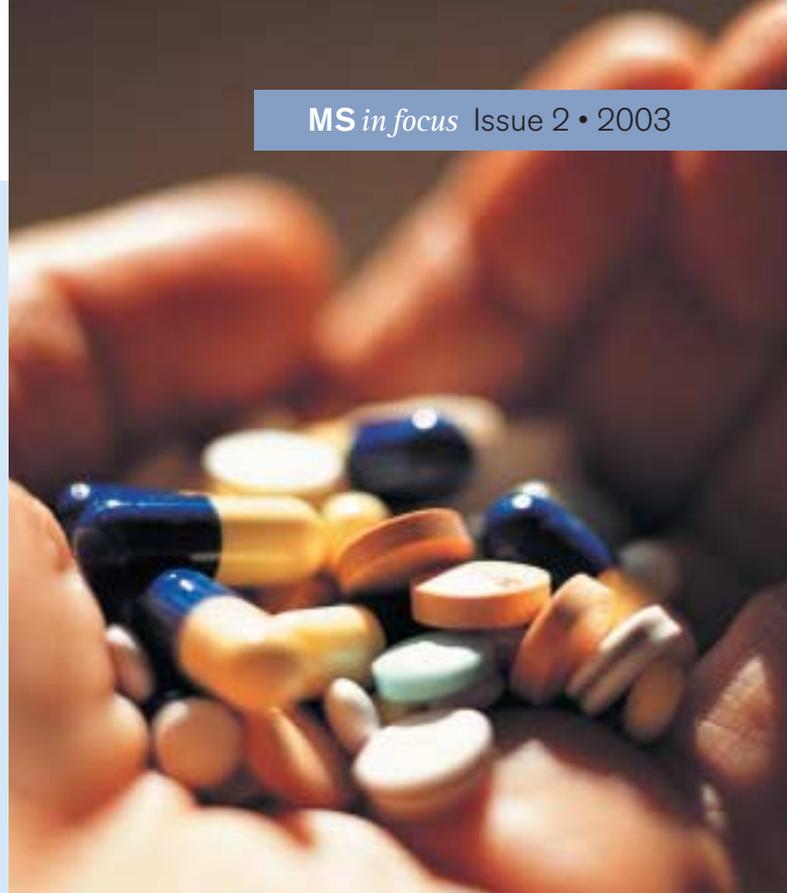
Tropium chloride is an alternative for those who find the side effects of oxybutynin unacceptable.

Propiverine

Propiverine is another alternative to oxybutynin.

Imipramine

Imipramine is usually used for the treatment of depression. However its main use in MS



is to treat bladder symptoms, including frequency and urge incontinence, though it is used occasionally for MS-related neurologic pain. Sometimes this treatment is combined with oxybutynin. If taken at bedtime imipramine can also help to reduce insomnia.

Desmopressin

Desmopressin is a hormone used as a nasal spray. The hormone works by reducing the amount of urine the kidneys produce thereby reducing frequent urination. This medication needs to be kept in the refrigerator and must not be allowed to freeze. Desmopressin can cause an increase in blood pressure and must not be taken by those with heart disease or high blood pressure.

- *Always ensure healthcare professionals are aware of any other medications being taken, as interactions may occur. Since it may be difficult to distinguish between some side effects and certain common symptoms of MS, healthcare professionals should always be consulted if an abrupt change occurs after starting a course of any medication.*

How to find strategies to manage the unpredictable

By Roberta Motta, Nurse Specialist and Continence Advisor,
Italian MS Society Rehabilitation Centre, Genoa, Italy.

BLADDER PROBLEMS and multiple sclerosis

Bladder problems associated with MS can be just as unpredictable as the course of the disease itself. Studies show that bladder symptoms may be related to the duration of MS, may be more prevalent amongst those whose MS began at a younger age and may correlate with a person's level of disability. Statistics can help in a better understanding of a trend or tendency, however as is true for any MS symptom, each person lives his or her own individual experience of bladder problems.

Bladder symptoms occur due to interrupted transmission of messages between the brain, spinal cord and urinary system (see page 7). However, bladder problems can also be related to, or worsened by, difficulty in mobility, architectural barriers, complicated clothing, fluid intake, medications etc.

In turn, bladder problems themselves can make other aspects of life worse. Incontinence can cause embarrassment and anxiety, which may lead to social isolation and early retirement from employment. This can lead to unwanted changes in family dynamics and decreased self-esteem for the individual. This example underlines the complexity of bladder problems and their overall impact on a person's life; it shows how important it is to make a comprehensive assessment of the individual and the approach to caring for and managing their MS, rather than addressing one symptom at a time.

Timely evaluation and management are important, not only because bladder problems negatively



Bladder symptoms occur due to interrupted transmission of messages between the brain, spinal cord and urinary system.

impact on a person's daily activities, but because they can also have long-term consequences on one's life-style, self-image and well-being and can even result in serious health consequences including kidney failure, dialysis and permanent damage.

Diagnosing bladder problems

The key to correct diagnosis of bladder problems is a thorough history of bladder habits and symptoms together with appropriate investigations. The MS nurse (or other healthcare professional, depending on the country and healthcare provision available) plays an important role in the diagnosis phase, as well as in management.

Initially the MS nurse will talk to the person with MS and gather relevant information on:

- the person's concerns regarding bladder function
- what type of problems exist
- whether the person uses any self-management strategies and whether these strategies are effective

In addition to a thorough discussion, the MS nurse can ask the person to complete a urinary diary (Figure 1, see page 12). This is used to record the number, quantity and circumstances of urination (for example, if incontinence, urgency, hesitancy were experienced and the type and quantity of liquid consumed) over a period of 24 to 48 hours.

This information will help the MS nurse to have a better idea of the nature of the person's bladder problems. It is also important to determine whether the individual has urine remaining in the bladder following urination (this is called 'post-void residual'). This is generally done by a procedure, called catheterisation, and it is usually performed by the nurse, who catheterises the person after he or she has voluntarily urinated, in order to measure the amount of urine that is still in the bladder. However, other testing methods including ultrasound may also be used (see page 16).

Based on information from the clinical history, urinary diary and post-void residual, the nurse can determine whether there is a failure to store urine or a failure to sufficiently empty urine from the bladder, and in turn which course of action to follow.

As a standard rule, when bladder problems are present, it is important to perform a urinalysis and urine culture. This helps determine if the symptoms are caused by a urinary tract infection or are directly related to MS. The treatment for each type of symptom is different. When bladder problems cannot be attributed to MS or to a urinary tract infection, the individual is referred for further evaluation.

Managing bladder problems

Together with the nurse, the person with MS can

explore various self-management strategies that can be useful in maintaining quality of life. The most commonly utilised strategies include bladder training, also called timed voiding, intermittent catheterisation and regulating fluid intake. These strategies, depending on the specific problem (failure to store urine or failure to empty the bladder completely), can be utilised in combination with medications that have been found to be effective for the treatment of bladder symptoms in MS (see page 9).

Bladder training is a behavioural technique that can be useful in improving bladder functioning. The individual has to follow a daytime schedule for urinating, for example, every two hours. Between the scheduled times the person must resist the urge to urinate. The MS nurse can determine whether this technique is appropriate for the individual, give instructions on the requirements for successful bladder training, and follow-up regularly to monitor progress.

'When the neurologist told me I would have to start self-catheterisation, I was really opposed to it. I now know that all you have to do is accept it and get on with it. I am doing just fine, it's easy.'

Mark

Intermittent catheterisation is a technique for managing bladder problems related to insufficient emptying of the bladder. It is used as a rehabilitation technique for retraining the bladder and may even be discontinued if there is sufficient improvement in bladder emptying. Otherwise, intermittent catheterisation is an ongoing strategy for bladder management.

The aims of intermittent catheterisation are to prevent infections by reducing residual urine in the bladder and promote continence. Intermittent self-catheterisation encourages autonomy and helps maintain self-esteem. Once the individual masters the technique, he or she is able to feel more in control of bladder problems, more confident and less anxious.

Figure 2. Steps for performing intermittent self-catheterisation

Gather the necessary equipment:

- cleansing wipe or soapy washcloth and a wet washcloth for rinsing
- towel for drying (if cleansing wipe is not used)
- container to collect the urine (if not on a toilet)
- appropriate sized catheter

Wash your hands. Sit in a comfortable position on the bed or toilet. If you are in bed, place a towel under your hips to protect the bedding.

Instructions for females

1. Wash the urinary meatus (opening from which the urine drains) with the cleansing wipe or soapy washcloth. Then rinse with the wet washcloth and dry the area.
2. Use your non-dominant hand to separate the labia.
3. Hold the catheter in your dominant hand and insert it into the urinary meatus, directing it upward and toward the umbilicus until urine flows freely.
4. Hold the catheter in place until the bladder has been drained. When the urine flow begins to slow down, slowly withdraw the catheter.

Note: a small portable mirror can be helpful when first learning the technique.

Instructions for males

1. Wash the penis with a cleansing wipe or soapy washcloth. Then rinse with a wet washcloth and dry the area.
2. Use your non-dominant hand to hold the shaft of the penis straight and upward. This position makes insertion easier.
3. Hold the catheter in your dominant hand and insert it into the urinary opening, about 8-10 inches until the urine flows freely. When the urine begins to flow, let the penis return to its natural position.
4. Hold the catheter in place until the bladder has been drained. When the urine flow begins to slow down, slowly withdraw the catheter.

If you notice any of the following changes, contact your MS nurse:

- change in the colour of the urine or if it appears cloudy
- odour to the urine
- blood in the urine or bleeding
- sediment in the urine
- back or abdominal discomfort accompanied by fever
- trouble passing the catheter
- increased discomfort when passing the catheter
- leaking while performing the technique



Optimal management requires that the nurse is able to make the person with MS feel comfortable talking about bladder problems.

Self-intermittent catheterisation is not appropriate for everyone. It does require a sufficient level of manual dexterity. It may be difficult or impossible for people with tremor, upper limb weakness or poor co-ordination. In these cases the MS nurse can teach the technique to a personal assistant or carer. For carers already responsible for many other personal assistance duties, intermittent catheterisation can add to the burden of care and alternative management techniques may be considered.

The idea of performing intermittent catheterisation can be daunting for many people. However, it is easy to learn and does not create a risk of infection when performed correctly. It is necessary to learn the technique from the MS or continence nurse and is usually mastered in a short time. It is helpful to think of intermittent catheterisation as a way of gaining control of bladder problems, of being autonomous in managing a difficult MS symptom. Figure 2 lists the steps to follow for performing intermittent catheterisation. For

information on other types of catheters see pages 16 and 20.

Other strategies

Regulating fluid intake by decreasing the amount consumed is often the first self-management technique used by many people with MS, in the hope that it will decrease urinary frequency and prevent incontinence. However it can be unhealthy and can create other problems, such as constipation.

It is important to drink one and a half to two litres of fluids every day, preferably water, even for people with bladder problems. A strategy for maintaining this level of fluid intake without worsening urinary frequency is to divide up the required amount of water and drink it at three or four times in the day, rather than sipping small amounts throughout the day which can result in frequent trips to the bathroom.

Some fluids, such as alcohol and drinks containing caffeine, are bladder irritants and can make bladder problems worse by increasing symptoms of urgency and frequency. It is better to avoid these types of drinks.

Cranberry supplements (tablets) are often used by people with MS as a self-help strategy for the prevention of urinary tract infections since cranberry makes urine more acidic, helping to inhibit bacterial growth. On the other hand, it is best to limit intake of citrus juices since they make urine more alkaline than acidic, which favours the growth of bacteria.

Importance of communication

The MS nurse or similar healthcare professional plays an important role in assessing and managing bladder problems. Optimal management requires that the person with MS feels comfortable talking about bladder problems with his or her nurse, and requires that the nurse has an understanding of his or her patient's clinical history, concerns, goals and lifestyle. Working together, through open communication, the person with MS and the nurse can identify problems and decide the strategies for best managing bladder symptoms.



It is important that the urologist evaluates the individual and carefully explains the options

Bladder tests can lead to surgical answers

By Professor Dirk De Ridder, MS Urologist, Department of Urology, Universitaire Ziekenhuizen, Leuven, Belgium

BLADDER PROBLEMS *and multiple sclerosis*

Once diagnosed accurately, bladder problems in MS are often effectively managed using medication and intermittent catheterisation. Occasionally these strategies are only partially successful and the overall health and well-being of the person is put at risk. For example, intermittent catheterisation may not be possible if the person with MS has significant spasticity of the legs, making it impossible to separate the legs enough to perform the technique. In these cases the urologist must evaluate, together with the individual, other more invasive, permanent ways of managing these problems.

In addition to the various evaluations and tests mentioned in previous articles, there are a number of additional tests that can help the urologist identify

the exact cause of the bladder symptoms (see table on page 16). These tests are not always performed on every individual with bladder problems but their necessity is indicated by the person's history, post-void residual urine measurement and the judgement of the urologist.

Urodynamics

Although the term urodynamics has a wide meaning, including any measure of the function of the urinary tract, it is often used as a synonym for cystometry. The purpose is to determine whether or not there is bladder over-activity. Urodynamic testing involves filling the bladder with saline through a transurethral catheter, which allows a number of different measurements to be obtained, including the capacity of the bladder (maximum volume tolerated by the patient), bladder sensation, involuntary detrusor contractions, the amount of pressure on the inner abdomen and detrusor, and the amount of pressure within the bladder. Also,



bladder-emptying ability is evaluated by measuring urine flow ('uroflow') and detrusor pressure during emptying.

Surgical options

All of the procedures described are considered permanent and, obviously, not appropriate for everyone with MS experiencing bladder problems. It is important that the urologist evaluates the individual and explains carefully the options available to someone who may need to consider a surgical intervention for effectively managing bladder symptoms.

A supra pubic catheter may be appropriate for a person who has a urethra that is too narrow for a regular catheter or some other problem that creates an obstacle at the level of the urethra. A catheter is inserted directly into the bladder through a small abdominal incision above the pubic area to allow for continual emptying of the bladder. A tube connects the catheter within the bladder to an external bag that collects the urine.

The urologist may recommend a catheterisable stoma as an alternative to a supra pubic catheter because of the complications associated with a

supra pubic catheter, especially infection. With this procedure a small hole is made surgically in the abdomen which is then connected to the bladder with a tube that is constructed from the patient's own tissue. Urine can then be drained by passing intermittently urinary catheters, through the stoma.

Another surgical option is bladder augmentation to enlarge a very small bladder. It involves the addition of a piece of the patient's tissue (frequently the intestine) to the bladder to increase the bladder size.

When there is excess tissue where the bladder and urethra meet or the bladder outlet is obstructed, a urinary diversion procedure may be necessary. This procedure is rare and more often an option for men with MS than women.

Conclusion

Successful management of bladder problems is not always possible with non-invasive techniques. Surgical interventions must be carefully considered following an extensive evaluation. When determined appropriate, a surgical intervention can help in managing difficult bladder problems and may help in avoiding serious health complications associated with a poorly managed MS bladder.

'One aspect of MS which is extremely frustrating is the lack of urinary control, as it sets one's agenda and timetables. I cannot, or dare not go on a long distance journey unless I have been to the bathroom or know that I will have fairly immediate access to such a facility'

Boris

Test	Purpose
Ultrasound (also called sonogram) of bladder and kidneys	Helps to rule out structural abnormalities that cause bladder symptoms, such as blockages
Intravenous urogram (also called intravenous pyelogram)	Outlines urinary passages and tests kidney functioning
Urodynamic studies	Evaluates how well the bladder is functioning

Rehabilitation techniques to complement treatment

By Caroline Vermeulen, Physiotherapist,
National MS Centre, Melsbroek, Belgium

BLADDER PROBLEMS and multiple sclerosis

The pelvic floor: An introduction

The floor of the pelvis is made up of layers of muscle. These muscles stretch like a hammock from the tail bone at the back to the pubic bone in front and are referred to as the pelvic floor. Figure 1 demonstrates where the pelvic floor muscles are situated in men and women. Strong pelvic floor muscles are important for maintaining continence since the bladder is supported by these muscles, helping it to stay closed, and the urethra passes through them.

Pelvic floor rehabilitation has evolved into a widely accepted form of therapy for helping people with different types of bladder problems. The few studies conducted on the effectiveness of pelvic floor rehabilitation for people with MS and clinical experience show that it can improve bladder symptoms in some patients. Pelvic floor rehabilitation can also play a preventative role in strengthening the pelvic floor area before symptoms occur.

People can have a weakened pelvic floor for all kinds of reasons whether or not they have MS. For example, it can be caused by continual straining to empty bowels (usually due to constipation), chronic cough (such as smoker's cough), persistent heavy lifting, pregnancy and being overweight. For people with MS, poor pelvic muscle functioning (either weakened or overactive muscles) is due to neurological damage and can be even worse if compounded by these other causes.



A physiotherapist can help you identify your pelvic floor muscles.

Box 1: Identifying the pelvic floor muscles

- Sit or lie down comfortably with the thigh, buttocks and abdomen muscles relaxed. Tighten the muscles around the anus without squeezing your buttocks. Relax and repeat until you are exercising the correct muscle.
- While urinating, try to stop the flow mid-stream, then restart it. (This is only a test and not an exercise to do regularly since it can worsen bladder symptoms).

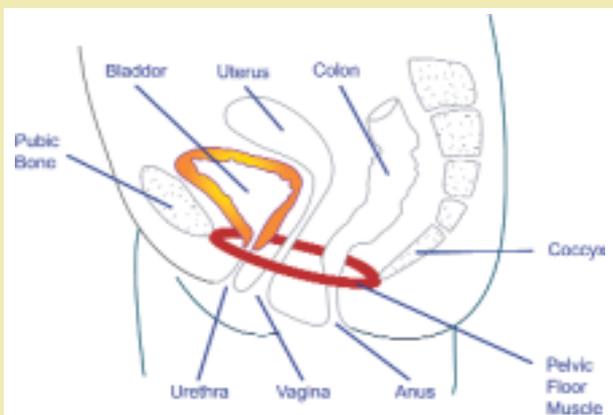
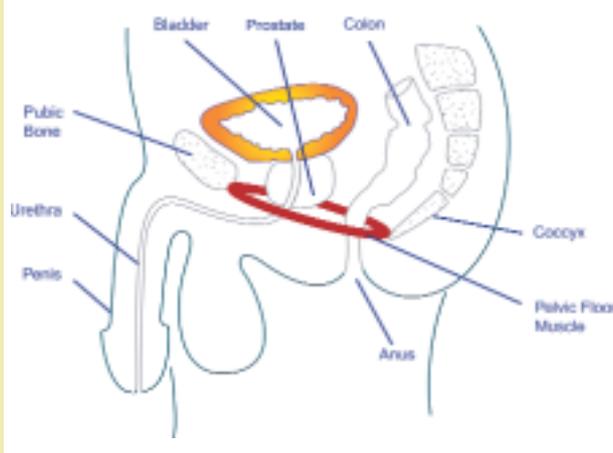


Figure 1. Positioning of pelvic floor muscles in women and men



'It really upsets me when I have accidents at the office. I think this is going to drive me out of working, as you can't go to meetings etc when you're incontinent.'

Eva

Increasing awareness of and strengthening the pelvic floor muscles can help to improve bladder symptoms common in MS such as frequency, urgency, incontinence, hesitancy and an intermittent stream or flow of urine. These exercises can also be helpful for people with MS who have sexual and bowel problems due to weak muscles, and bowel problems related to weak or spastic pelvic floor muscles. Pelvic floor rehabilitation combines work with a physiotherapist and a home programme. Rehabilitation is based on the initial strength of the person and also takes into consideration the presence of fatigue, spasticity and mobility problems.

Does pelvic floor rehabilitation help everyone with bladder problems and MS?

A neurologist or urologist can determine who is appropriate for pelvic floor rehabilitation. This therapy is most effective when the individual:

- is able to contract and release the pelvic floor muscles on command and can relax after contraction, immediately or with only a slight delay;
- is able to walk, preferably without using assistance, although people needing a stick or walker may also benefit from these exercises;
- is motivated, since exercises must be performed at home regularly.

Pelvic floor rehabilitation

Pelvic floor rehabilitation is planned by a physiotherapist who first instructs the person on how to identify the pelvic floor muscles that need to be exercised and strengthened. Increasing awareness of contracting and relaxing pelvic floor muscles are key to this type of rehabilitation. Learning to relax them, even without strengthening exercises, can help promote smoother urine flow. Table 1 describes two ways of identifying these muscles. Patients are also provided with an individualised exercise schedule to follow at home.

Doing pelvic floor exercises

Once the person has identified the pelvic floor muscles he or she can begin strengthening exercises. Table 2 describes how to perform

pelvic floor exercises to help to increase endurance.

To increase strength, a strong contraction is held for one second, followed by a two to three second relaxation period then repeated. The number of repetitions depends on the initial endurance and strength of the patient.

A key to successful muscle training is to achieve total relaxation of the muscles between every contraction. It is also important that relaxation time is at least double that of contraction time in order to achieve full recuperation of pelvic floor muscles.

Biofeedback

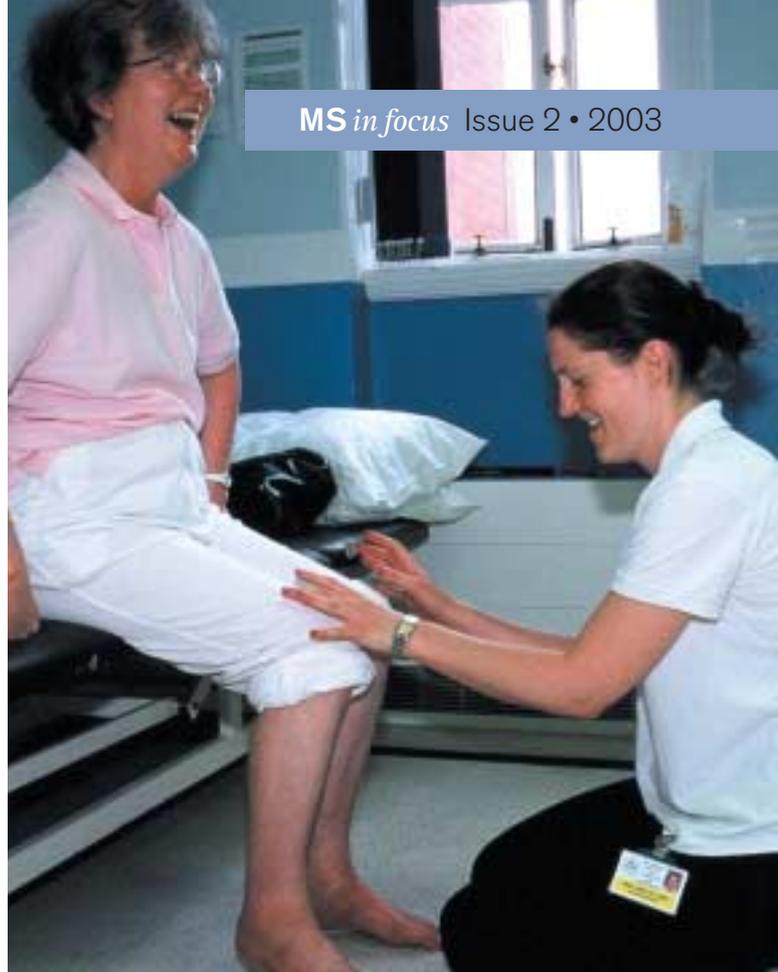
Biofeedback uses an electronic device to provide the individual with visual feedback about how pelvic floor muscles are working (and improving). For people with MS who experience bladder problems, pelvic floor muscle training together with biofeedback can help teach the person how to relax over-active muscles. This technique is performed by a healthcare professional (usually a physiotherapist) and though not directly beneficial, biofeedback helps ensure patients gain maximum benefit from their pelvic floor muscle exercises

Electrical stimulation

Electrical stimulation applies an electric current to strengthen the muscles around the bladder.

Box 2: An example of how to do pelvic floor exercises

1. Tighten (contract) and strongly draw in the muscles around the anus and the urethra all at once, lifting them up inside
2. Hold for 5 to 10 seconds
3. Release slowly and relax for 10-20 seconds
4. Repeat steps 1 to 3 up to 10 times



Strengthening the pelvic floor muscles can help improve bladder symptoms common in MS

This current is passed via a small anal (or vaginal) probe in close contact with the pelvic floor muscles. It is not painful and can also be self-administered using a portable stimulator at home. For people with MS it is a therapy that should be monitored by the physiotherapist.

This treatment may be used for between 20 minutes and an hour per day for a period of up to 20 days. Some people have found this treatment very effective, and there is evidence it can be as useful as pelvic floor exercises. For long-term treatment these techniques are typically used in combination.

What to expect from pelvic floor rehabilitation

It is important that people with MS have realistic expectations of the possibilities of pelvic floor rehabilitation. It cannot completely solve bladder problems, but helps the person to regain some control of bladder functioning. In turn, this helps to improve a person's self-image and self-confidence. Good results require a commitment from the person with MS to do the exercises carefully and regularly.

Your questions answered

Readers of *MS in Focus* put questions to the Editor, Michele Messmer Uccelli

**With many thanks to our bladder dysfunction experts for their advice.*

Q. I have been using an intermittent catheter for some time. Does this mean that in the future I will have to use a permanent one? If so, could you fill me in on what this would involve?

Best regards, Sandy

A. There is no indication that people with MS who do intermittent self-catheterisation will eventually require a permanent catheter. Since there are different types of catheters and terminology can be confusing it might be helpful to clarify the difference between them.

You mention a permanent catheter, which is technically referred to as supra pubic catheterisation. It is a technique in which a catheter is inserted directly into the bladder through a small abdominal incision above the pubic area to allow for continual emptying of the bladder. A tube connects the catheter within the bladder to an external bag. The supra pubic catheter is usually used in people who have a urethra that is too narrow for a regular catheter or some other problem that creates an obstacle at the level of the urethra.

Another type of catheter is an in-dwelling or Foley catheter. This is used for either short-term treatment or long-term use. It also allows for continual bladder drainage, but with a tube that enters the bladder by way of the urethra, similarly to a catheter for intermittent use. A Foley catheter has a balloon attachment at one end, which is inserted and filled with sterile water to prevent the catheter from leaving the bladder. The tube empties urine into an external bag. An in-dwelling catheter is used in individuals whose

bladder problems cannot be managed effectively with medications and intermittent catheterisation. In your case, if intermittent self-catheterisation is working well for you, there is no need to believe that you would need an in-dwelling catheter. However, if it is not effective in managing your bladder problems you should discuss other options with your neurologist or urologist. I hope this is helpful.

Q. Because of bladder problems related to my MS I stay at home now. I do not like to go out because of the embarrassment an accident causes. When it is absolutely necessary to leave the house, for instance for a doctor's appointment, I wear an absorbent pad. It's humiliating and I worry about the risk of being embarrassed. I'm 40 years old and this kind of life is becoming unbearable.

Josè

A. You've made a positive step towards changing your life by affirming that staying in your house and using absorbent pads is no way of life for you. As you'll read in this issue of *MS in Focus*, there are strategies that can help you gain some control of your bladder problems. It is important that you talk with your neurologist so that you can be evaluated for medications and the possibility of learning intermittent self-catheterisation. Many people with MS self-catheterise just before leaving home. In this way, they have increased confidence that accidents are much less likely to occur, since the bladder has been completely emptied. This is one strategy, but your neurologist and MS nurse can tell you more.



How I found freedom

Diana de Avila, web architect, talks to Chloe Neild about how she has dealt with her incontinence symptoms

How long have you had MS?

I was diagnosed definitively in June 2002.

When did you first suffer MS-related bladder symptoms?

They started in February 2002 and were one of the initial manifestations of my MS.

Can you describe the bladder symptoms you experience?

Initially I had an urgency and frequency problem. I felt as if I had to 'go' a lot and very urgently. Now it is more an inability to empty completely because I don't sense my bladder being full. This became apparent through continual urinary tract infections that would not resolve easily. A post-void residual test showed I was retaining quite a lot.

Have your bladder symptoms changed since diagnosis?

Yes, initially I just needed to urinate frequently. This turned into more urgency and an inability to actually perform the natural emptying function. Summer heat makes my body less co-operative.

How do your bladder symptoms impact on your lifestyle?

Initially, the need for a rest room governed my activities, but now self-intermittent catheterisation (SIC) keeps things stable. SIC has given me much greater freedom and released me from always needing a rest room.

How did you first hear about self-catheterisation?

I read about it on various websites. It became a reality for me after I went through urodynamic studies and a cystoscopy, which determined the need to combine medicine with SIC. My doctor then taught me SIC.

What were your doubts and concerns about self-catheterisation?

Quite honestly, during week one I worried about my ability to learn my own anatomy and be able to perform self-catheterisation with one hand leveraging a mirror, and the other manoeuvring a catheter. By week two it became much easier and was not awkward any more. I no longer needed the mirror and trusted my experience using the 'touch method'.

Did you receive support from healthcare professionals during the learning process?

I have an email relationship with my urologist and his assistant. This electronic medium helped me to get answers to any initial questions.

What impact has self-catheterisation had?

A very practical benefit is the ability to sleep through the night without having to get up several times. I also play ice hockey and bladder issues no longer interfere with this as I can manage them. I think of SIC as a 'tool' to stay healthy and I refer to catheters as my 'hoses'. Humour and perspective is important to me and I do not let pride get in my way.

Any advice for others who may be sceptical about learning self-catheterisation?

SIC is so simple and no big deal. Don't be nervous. You will gain your freedom and the psychological investment will quickly pay off. Find your own style, your own way to accomplish this. It becomes very natural, very quickly. I carry a small pouch containing a 6" catheter, a mirror, cleansing wipes, and anti-bacterial hand gel. I have several pouches and stash them in backpacks or wherever. With MS it is much easier to do SIC than try to let nature do its own thing. Go for it, don't look back, just move forward.

Diana, thank you for sharing your story.

Book Reviews

Alternative Medicine and Multiple Sclerosis

by Allen C. Bowling MD, PhD

Review by Helmut Butzkueven, MS neurologist, Melbourne, Australia.

In this book Allen Bowling sets out to inform patients with MS about the various alternative or complementary health strategies available. In the process he helps to bridge the gap that can arise between conventional and complementary medicine, and which can, in some cases, cause patients to conceal from their doctor any complementary treatments they might be taking.

Unfortunately such concealment can result in a complete absence of dialogue and exchange of ideas between those trying to look after people with MS.

In my experience, virtually every person with MS will seek information about complementary therapies offered for their disease. The amount of information on this subject in MS is astounding, and has become universally accessible via the worldwide web. However, the quality of the information varies wildly, and the challenge of evaluating it is usually overwhelming.

The book achieves its primary aim of providing concise and accessible information to people with MS very well, and it also creates a handy and lucid reference for health professionals.

Each topic is organised into several sections including treatment methods, studies in MS, practical information, and side effects. In general, this works fairly well but is a little stretched when trying to describe the side effects of pets, music or spirituality. I found the repeated statements that no large, published clinical studies exist for a particular treatment a little obvious.

Perhaps the book should have given a more direct voice to some of the complementary therapists to explain their philosophies.

This book will be a valuable addition to any MS library. I have already found it very useful and I am sure it will become one of my most frequently used references in patient care.

*Publishers: Demos Medical Publishing Inc, USA, 2001.
Price US \$39.95. ISBN: 1-888799-52-8
<http://www.demosmedpub.com>*

One particular harbour

by Janet Lee James

Review by Rolande Cutner, Board Member of Ligue Française contre La Sclérose en Plaques and French Representative PwMS International Committee.

This autobiography shows how a profoundly disabled person with MS can live the life she chooses. Highlighting that freedom, with all its joy and heartbreak, is what really matters in the end.

Janet was 23 and beginning a career as a rock 'n' roll disc-jockey when she was diagnosed with MS. Hoping she would be one of the vast majority able to lead full and productive lives relatively undisturbed by MS, she took off alone for the wilds of Alaska to fulfil her dream of a life of excitement and adventure. Her penchant for black humour, cold beer and handsome men results in some great tales, leaving you feeling as if Janet is an old friend.

Generally, I avoid books written by other people with MS, as they can be depressing. However, I devoured this book as fast as I could; the pleasure just continued as I read.

Janet's story is fascinating and honest. I immediately understood Janet's hopes, fears and regrets; they are also mine. It was as though I became the heroine. As I read anecdote after anecdote, in her vigorous and entertaining style, it became difficult to figure out where Janet ends and I begin. We are both women in love, in fear, in despair, trying to lead full, productive lives. We both left home, work and family to live our dreams.

This is a wonderful read and I recommend it to mature adults experiencing a midlife crisis, young adults bored with life, recriminating teenagers unhappy with what they have, and spoiled retirees complaining about their daily chores. All will benefit greatly from Janet's story.

*Publisher: Excel Press. US \$14.95.
ISBN: 0-595-00115-7 <http://www.iuniverse.com>*

Online fun keeps kids S'myelin

By Christopher, James, Tara, Jessica, Alexandra and Michael

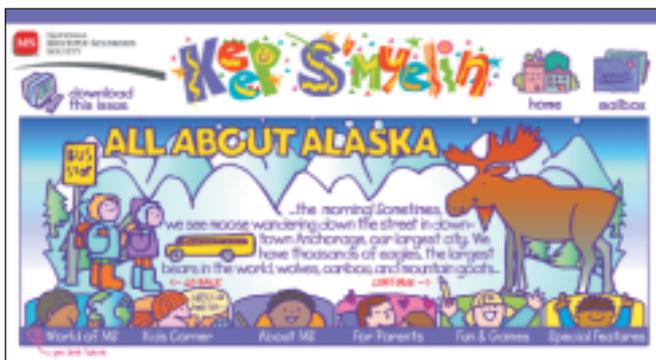
Six children, aged from 8-10 years, each of whom has a parent with MS, reviewed a special children's website during two workshops set up by social workers from the MS Society of Victoria, Australia. Keep S'myelin (www.nationalmssociety.org/keepsmyelin/resources) is an award-winning publication of the National Multiple Sclerosis Society (USA) for children with parents or relatives with MS. It is published quarterly online, making it accessible to children all over the world. It provides age appropriate information about MS in a friendly, practical and fun way.

'The website is fun, and it tells you about MS. It is easy to use. It would be easy for other kids to use if they don't know anything about MS. It is colourful and the games are fun, not too hard. I enjoyed the word searches and other games.'

Christopher (10)

'I thought the Keep S'myelin website was really good. My favourite part was the Fun and Games programme, especially the word search and the 'can' game. I found the stories to be very informative. A good place for people to find out about MS.'

James (8)



Keep S'myelin teaches kids about families living with MS around the world



Tara enjoys exploring Keep S'myelin

'I liked the website Keep S'myelin. It was easy, not like all the other sites I've been to. The games were challenging and not too simple. It was easy to find my way around and it kept an archive of previous issues so I could play the past games. I liked the way the pictures were done and the way the kids on the links popped up when you put your mouse on them. I also liked the bits about other places, like Alaska, and how the moose was at the bus stop! But I got through everything very quickly and I think they should add more.'

Tara (11)

'It's really good. The games are OK.'

Michael (8)

'The website Keep S'myelin tells us a lot about MS and can help us understand. The colours are nice and bright. I like how they have the stories and how it is set up. I like all the pictures. I can understand the stuff.'

Jessica (9)

'It is really good, lots of variety, interactive rather than just reading a book. It's colourful and helps kids understand about MS. Parents could support kids and help them learn more by reading the part for parents.'

Alexandra (10)

- Keep S'myelin is edited by Jennifer Ricklefs, Debra Frankel and Rosalind Kalb. The children at the workshops loved their introduction to the website, ignored the afternoon tea provided and kept on with the games. They thought that their teachers should know about it and spread the word further.

MSIF: Supporting National MS societies worldwide

By Christine Purdy

One of MSIF's stated aims is the development of national MS societies, and *MS in Focus* contributes to that aim by providing a platform for Member Societies to share experiences. Additionally, MSIF has other publications that help in this same cause.

These publications, and all the additional information on the MSIF website, are designed to help in the growth of national societies and can be used, for example, as the basis for a local workshop or skill-share.

In addition to the MSIF publications, ideas for the development of national societies will be plentiful at the MSIF Conference in Berlin this September, where a whole day has been set aside for sharing innovative projects and programmes.

See you in Berlin...

MSIF publications include:

Exhibition and booklets for awareness raising:

- The History of MS (exhibition and report)
- MSIF Annual Review
- How to Develop a National MS Society (due for publication August 2003)
- How to Work with the Media (under development)

'How To' series, supporting the MS movement locally, regionally, nationally and internationally

- How to Influence Public Policy
- How to Develop a Mutual Support Group

Directories and Guides:

- Multiple Sclerosis: The Guide to Treatment and Management*
- MSIF International Directory

For further information see www.msif.org



Charcot Award Winner, Dr Henry McFarland, is currently chief of the Neuroimmunology Branch of National Institute of Neurological Disorders and Stroke (NINDS), USA.

Life of achievement

By Prof Jürg Kesselring

MSIF's International Medical and Scientific Board is proud to announce that Dr Henry McFarland has won the 2003 Charcot Award for a lifetime achievement in MS research. The Award will be presented at the Berlin Conference in September 2003 where Dr McFarland will give the Charcot Lecture.

As one of the world's leading neuroimmunologists, Dr McFarland has made outstanding contributions to the understanding of MS and has conducted research in the areas of neurovirology, immunology, genetics, clinical trials and imaging.

Beyond his own personal research efforts, Dr McFarland has also trained many

young researchers from all over the world and he has contributed greatly to the work of the US National MS Society and MSIF.

Speaking of Dr McFarland's contribution to MS research, Dr Stephen Reingold, Vice President, Research Programs, National MS Society, USA, stated: 'Few have devoted as much of their career to ending the devastating effects of MS; few have made as significant scientific contributions to the field; few have combined these professional achievements with a dedication to the concerns and issues of the voluntary health agencies that represent the needs of people with MS and their families worldwide.'

Award for Australia's champion carer

By Trevor Farrell, Executive Director, MS Society of Queensland, Australia

Australian schoolteacher, Jon Ferguson, is the winner of the MSIF Nicholson Award 2002 for the International Caregiver of the Year. The award, judged by the Persons with MS International Committee of MSIF, recognises carers who have demonstrated an outstanding commitment and devotion in the support of a loved one with MS.

Jon and his family live in the 'Garden City' of Toowoomba, a provincial city 90 minutes west of Brisbane, the capital of Queensland.

This devoted father of two and teacher of 36 years has provided intensive care for his wife Carolyn since her MS worsened in 1990. Jon reduced his school hours in 1994 to devote more time to his caring role, and recently took Carers Leave so he could concentrate on supporting Carolyn full time.

A former Cub Scout leader, junior hockey coach and Sunday school teacher, Jon has been involved with the local People With MS Support Group since its inception and is a member of the Queensland Council of Carers.

At the official presentation of his award in December, Jon commented: 'There are only two things I regret in accepting this award: first, that Carolyn has MS and second, that they [researchers] have not yet found a cure.'



Jon and Carolyn at the official presentation dinner held in Brisbane. The event was attended by members of the executive of MS Queensland and Board members of MS Australia

Jon's words of wisdom for other carers:

1. Talk to lots of people
2. Don't be afraid
3. Don't hold grudges
4. Make caring an enjoyable experience for you both
5. Laugh and learn from your mistakes
6. There is no perfect way to do anything
7. Use services that are available, which allows the carer to have their own space
8. Have lots of breaks

In search of the virtual placebo group

By Leila Terry, Research Administrator, MSIF

Have you ever wondered how MSIF's multi-million Euro research project, the Sylvia Lawry Centre for MS Research (SLCMSR), relates to people with MS? Here is a brief explanation of this unique and complex project.

Recent research and the approval of partially effective MS drugs have generated great optimism about the development of further treatments. However, in order to have a new MS treatment approved for use, a large placebo-based clinical trial is required, which can be lengthy and expensive. Meanwhile, to deny a potentially effective treatment to a person with MS and expect them to take only a placebo during a clinical trial has become ethically unacceptable.

The SLCMSR aims to address this problem by analysing a large collection of placebo data from past clinical trials. This will be used to find out whether it is possible to:

- model the expected course of MS and therefore develop a 'virtual placebo' group that can indicate whether or not an experimental treatment is effective, with the result that in future clinical trials no one will have to take a placebo; and
- identify 'markers' that will allow the prediction of the course of MS, so neurologists can make a more accurate prognosis for the person with MS.

The team working at the SLCMSR is making excellent progress and the database is now large enough to produce preliminary results.

MSIF continues to seek funds for this exciting new project. For more information contact MSIF or visit www.msif.org or www.slcmsr.org

CALENDAR DATES

6th IBRO World Congress of Neuroscience

10-15 July 2003, Prague, Czech Republic

The Czech Neuroscience Society is looking forward to preparing an intellectually and socially rewarding Congress in Prague in collaboration with the world community of neuroscientists.

www.ibro2003.cz/index.html

7th Congress of the European Federation of Neurological Societies

30 August-2 September 2003, Helsinki, Finland

The EFNS unites and supports members from 39 national neurological societies across Europe, thereby representing more than 12,000 neurologists. The Congress's scientific programme will be composed of teaching courses and plenary sessions covering progress in the main fields of neurology. In addition, a large number of exciting focused workshops and special sessions are included. www.efns.org

MS Nurse Workshop

16 September 2003, Milan, Italy

These workshops, sponsored by Sirono Symposia International, are designed to provide nurses who treat MS patients with up-to-date information on the latest care options available. This particular event will focus on the International MS Nurse Care Plan which has been adapted by a number of countries. The national versions of the plan are evidence based documents that

address nursing issues across the disease from diagnosis to complex symptom management. The plan provides an excellent practical clinical resource that may also help nurses preparing for the International MS credentialing exam.

http://www.seronosymposia.org/ms/events_upcoming.ihtml

19th Congress of the European Committee for Treatment and Research in MS (ECTRIMS)

17-20 September 2003, Milan, Italy

ECTRIMS is one of the largest meetings of healthcare professionals and researchers working on MS. The programme of this annual ECTRIMS meeting is designed to cover a wide range of recent advances in both basic science and disease management.

www.akm.ch/ectrims2003/

8th Annual Meeting of the American Committee for Treatment and Research in MS (ACTRIMS)

19 October 2003, San Francisco, USA

ACTRIMS brings together leading basic

scientists, clinical researchers, and clinicians active in the research and treatment of multiple sclerosis and related demyelinating diseases.

www.actrims.org

128th Annual Meeting of the American Neurological Association

19-22 October 2003, San Francisco, USA

The American Neurological Association is a professional society of academic neurologists and neuroscientists. The Annual Meeting provides a platform for world-renowned speakers to address topics of basic and applied neuroscience.

www.aneuroa.org/

European Charcot Foundation Symposium 2003

10-13 December 2003, Lisbon, Portugal

The European Charcot Foundation is a non-profit, independent organisation for the advancement of MS research in Europe, sponsored by private organisations, MS societies and industry. This meeting is called 'Preserve the neuron: on brain atrophy, axonal loss, remyelination and stem cells in MS'. www.charcot-ms.org/

GATEWAY TO PROGRESS: THE MSIF AND DMSG INTERNATIONAL MS CONFERENCE, BERLIN 2003

This year's MSIF Conference 'Gateway to Progress' will be hosted by the German MS Society (DMSG) in Berlin, on 22-24 September 2003. Since the fall of the Berlin Wall, Germany's capital has become a symbol of unified Europe and confidence in the future.

The 'Gateway to Progress' is also intended to be a vehicle for worldwide research and co-operation in the field of MS. The exciting programme will cover many forward-thinking topics such as childhood MS, possibilities

opened up by neuroprotection and international standards of therapy.

Workshops and lectures associated with these themes will provide opportunities to share knowledge and develop new ideas amongst those working in the MS field, whilst presentations on innovative and successful projects being conducted by MS societies will provide a stimulus for work in the international MS movement. The final day will be dedicated to the emerging topic of the 'Young MS Patient'. www.gateway-to-progress.com/

MS *in focus*



multiple sclerosis
international federation

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

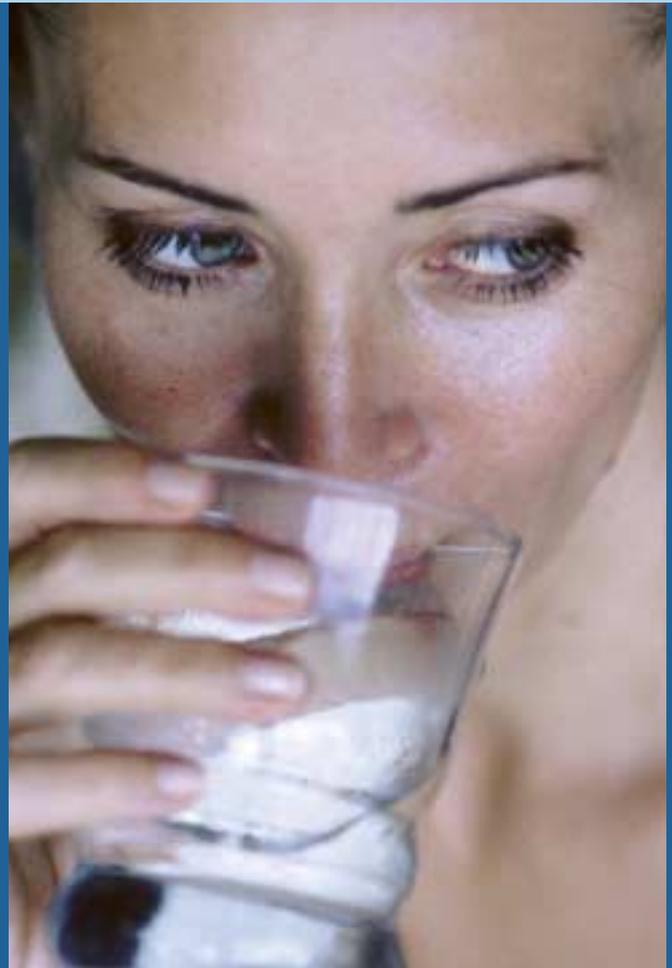
MSIF is a non-profit charitable
organization 501(c)(3) IRC chartered in
the State of Delaware, USA, in 1967

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.