MS *in focus*

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Tremor and ataxia in MS

multiple sclerosis
international federation

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- Support the development of effective national MS societies
- Communicate knowledge, experience and information about MS
- Advocate globally for the international MS community
- Stimulate research into the understanding, treatment and cure of MS

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Letter from the Editor

Tremor and ataxia are both symptoms of MS that impact movement. Tremor is described as an unintentional, rhythmic, muscle movement involving to-and-fro movements of one or more parts of the body. Ataxia is described as incoordination and unsteadiness which can affect posture, walking, eye movements and speech.

These symptoms are considered by health professionals to be one of the most significant challenges to successful MS management and can be very disabling.

Today there is no consistently effective medication for MS-related tremor and ataxia, although some drugs have been shown to be partially successful for some people. Unfortunately there is limited research being done in this area considering that tremor and ataxia are estimated to affect at least a third of people with MS.

While many symptoms of MS – such as fatigue – are "invisible", tremor and ataxia are unfortunately distinctly visible. Tremor and ataxia can have a negative impact on a person's self-esteem. Many people with even mild tremor or ataxia can be at risk of losing contact with their social networks, tending to avoid public situations due to the embarrassment these symptoms can cause. For those dealing with severe tremor or ataxia, independence in caring for one's self and in performing day-to-day activities can be in jeopardy. Tremor and ataxia can have a negative impact on other areas of a person's life such as their work or their sex life.

For many people with tremor or ataxia, pharmacological therapy is ineffective or only partially effective. In these cases healthcare professionals can be helpful in identifying different strategies for managing tremor in non-pharmacological ways, such as through the use of assistive aids, exercise, weighting and other means that are described in this issue of *MS in focus*.

This issue provides a complete discussion of tremor and ataxia from different points of view by healthcare professionals and researchers who have years of experience in these topics. The complexity of evaluating and managing tremor and ataxia, as well as the lack of effective medications, underline the need for a comprehensive approach.

I look forward to receiving your comments.

Michele Messmer Uccelli, Editor

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

Editorial statement

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Ataxia and tremor in MS: historical reflections

Jock Murray, Professor Emeritus, Dalhousie University, Dalhousie MS Research Center, Halifax, Nova Scotia, Canada

In his defining lectures in 1868 on *sclérose en plaque disseminée*, now known as multiple sclerosis, Jean-Martin Charcot indicated that tremor was one of the common symptoms of this disorder. He added that no one should be caught in the snare of confusing it with the tremor of Parkinson's disease. In fact, the Frenchman's presentation was to show the differences between these types of tremor. In his description of the symptoms in MS he began with tremor.

No one should be caught in the snare of confusing it with the tremor of Parkinson's disease.

In his presentation of the case of Mademoselle V, a young woman aged 31, he noted she had a tremor that was absent at rest, unlike Parkinson's tremor, but became more marked as she raised a glass towards her mouth, causing her to spill the water. The tremor, Charcot said, was an intentional tremor that worsens when an action is attempted but absent when the limb is at rest. It was not only seen in MS, as he had seen it with other conditions as well. Although he concentrated on a description of tremor in the arms and hands, he indicated that tremor could also be seen in the trunk, head and legs, and even in the muscles used in speech, resulting in a characteristic "scanning speech".

Charcot explained that the tremor of MS was usually a late symptom, if it appeared at all, although he had seen it in earlier cases on rare occasions. He also noted that people with tremor in MS often also had a staggering gait, known as ataxia. His student, Georges Gilles de la Tourette (remembered today for his description of Tourette Syndrome) used to map the gait of ataxic patients by having them walk on long strips of paper with the soles of their feet inked.

Charcot felt that MS was resistant to most available forms of therapy but perhaps would be treatable when more was understood about the underlying mechanisms of the disease. At the Salpêtrière, the huge French hospital in Paris where Charcot worked, therapy was still attempted for cases of MS and the approach for ataxia was a suspension apparatus that held the person elevated by straps around the chest and under the arms (see page 6).

Later, investigators clarified that the commonest tremor and ataxia in MS were due to lesions affecting the cerebellum and related structures, an area of the brain that is particularly involved in coordinating muscle movements. The intention tremor mentioned by Charcot is usually due to involvement in the fibres leaving the cerebellum. An English neurologist of the early 20th century, Sir Gordon Holmes, noted that the intention

tremor of cerebellar involvement had errors of rate, range, direction and force of movement, and neurologists developed specific tests to observe the tremor, the best known being the finger-to-nose test (see page 11), and the heel-shin test.

Although cerebellar tremor is the most common tremor in people with MS, there are other forms of tremor that could be seen. Everyone has a physiological tremor, which is barely visible in most people in their outstretched hand, and more evident if they become anxious (or if they put a page of paper on their hand to make it more visible). In some this is more obvious and is called an essential tremor, often familial, and can affect the hands, head or voice (as it did in the actress Katherine Hepburn). If there is a lot of sensory loss, a person with MS could have more unsteadiness in their hands if they are not watching them closely, and have ataxia due to the fact that they are not fully aware of where their numb feet are being placed (sensory ataxia). To compensate for sensory tremor and sensory ataxia a person may watch his or her hands when they are carrying out tasks or look down when walking. He or she may touch furniture or the wall to get a better sense of their position in space.

The assessment used to document the status of a person with MS is the Extended Disability Status Scale (EDSS), developed by Dr John Kurtzke, which includes a section to rate the cerebellar involvement in the scale. The scores are from zero with no involvement, through to six for severe and incapacitating tremor and ataxia. If the person also has weakness, spasticity, or sensory loss they can have even worse balance and gait and these are reflected in other sections of the scale.

During the 20th century, neurologists following the description by Charcot recognised that tremor and ataxia were very difficult to treat and were very disabling to the patient. The basis of the tremor and ataxia was an incoordination of muscle movements and resulted in the unsteady action of the limbs and other muscles.

Jean-Martin Charcot

Over the years, many physiotherapy and rehabilitation techniques have been tried without much success, although training in mild cases can be of assistance. Further, in the last 50 years attempts to provide benefit with drugs such as tranquillisers, anticonvulsants, a diuretic called acetazolamide, high doses of an anti-tuberculosis drug isoniazid and various anti-Parkinson drugs were tried but these did not provide much help. Using a beta-blocking agent such as those used for high blood pressure (propranolol) can reduce tremor when it is mild, but is most helpful in physiological and essential tremor (which explains its use by some public speakers and musicians who have tremor when they are on stage. It has been prohibited in Olympic sports such as shooting, because athletes were using it to steady their physiological tremor).

Suspension apparatus used at the Salpêtrière for ataxia

Physical methods such as training and education to compensate for the incoordination can be helpful. Steadying a limb by bracing a joint can help, such as resting an elbow when using the hand. Adding a third or fourth point when walking by using a cane or walker, can help with an unsteady gait. Adding weights to the wrists can provide assistance in some cases. A head rest helps if there is head tremor. In rare cases neurosurgery has been used for marked tremor. This has been more successful in Parkinson's disease and other movement disorders, especially if one side is more affected, but not usually indicated in MS as it creates one more lesion and can have many potentially serious complications.

In this issue, current understanding and therapy of ataxia and tremor will be reviewed. Dr Marcus Koch will outline the pathophysiology that underlies tremor and ataxia, and Dr Sundus Alusi will explain how it is evaluated and measured. Dr Roger Mills will discuss the pharmacological approaches to managing ataxia and tremor, and the surgical approaches that can sometimes be helpful. Dr Guy Nagels will explain attempts at rehabilitation approaches to manage and compensate for these symptoms.

Although ataxia and tremor do not affect everyone with MS, when it does occur it can be one of the most frustrating and difficult problems. It is hoped that some practical and useful information in this issue will bring assistance to those who are dealing with these symptoms.

What's going wrong in ataxia and tremor in MS?

Marcus Koch, MD PhD, Universitair Medisch Centrum Groningen,

Groningen, the Netherlands

Introduction

Almost all people with MS develop some degree of problems with coordinated movement during the course of their disease. While weakness and spasticity directly impact the ability to move a limb, ataxia and tremor impact movement even if the strength is normal.

People with ataxia lose control over their movements, so that the movements become less smooth. It can also become difficult to start and to stop a movement. While ataxia affects all movements of a limb, it is especially obvious in skilled movements, such as writing, typing, using cutlery, working with a computer mouse or reaching for small objects.

Tremor is a rhythmic shaking movement that most often affects the arms and hands in people with MS. Tremor in MS is often associated with ataxia and can affect all tasks that require a steady hand.

While weakness and spasticity directly impact the ability to move a limb, ataxia and tremor impact movement even if the strength is normal.

How frequent are ataxia and tremor in MS?

Ataxia and tremor are both common in MS. One study found that four out of five people with MS experience ataxia at some point of their disease course, and another study showed that one third of a large group of persons with MS had ataxia and tremor that was severe enough to influence their ability to function.

The most common forms of tremor in MS are tremor that occurs when a limb is held up against gravity (postural tremor) and tremor that occurs when grasping for an object (intention tremor). Intention tremor of the hands can be especially disabling because the shaking movement becomes worse the nearer the hand gets to the object, for instance when taking off one's glasses or when reaching for a cup. Tremor can be detected in one quarter to one half of all people with MS, but is severe in only a minority (about one in ten).

What causes ataxia and tremor?

MS is a disease that causes damage in many different places in the brain and spinal cord. This makes it difficult to link a symptom to a specific area of damage, and consequently to find the specific cause of any symptom. However, ataxia,

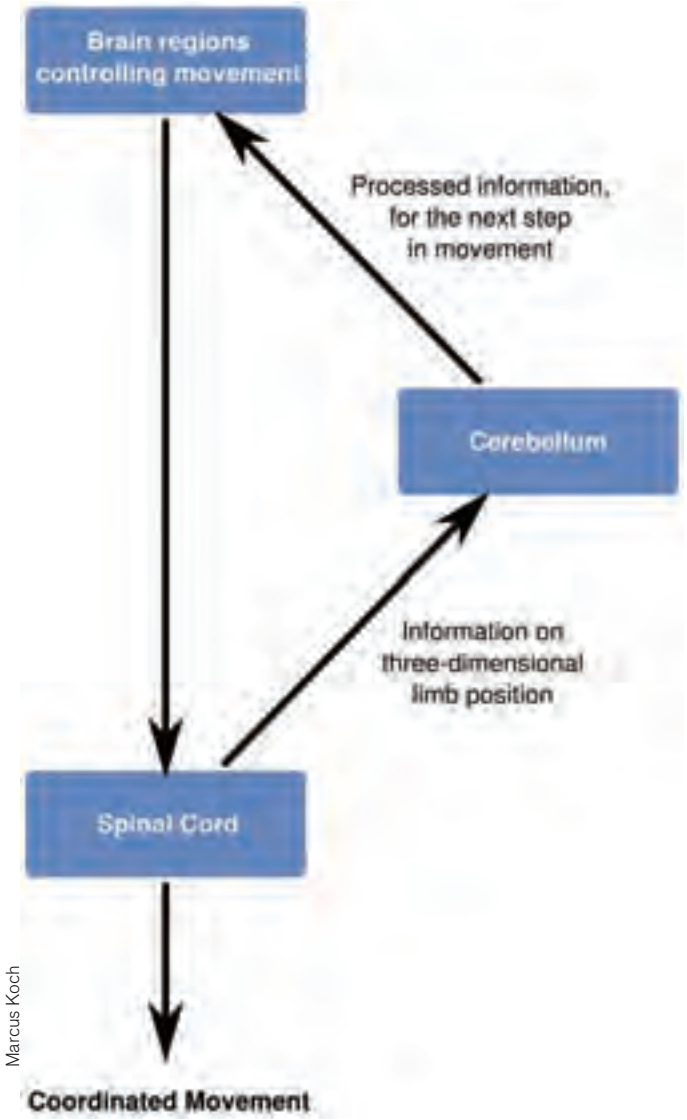
intention tremor and postural tremor are all believed to be due to damage to the cerebellum (see opposite) and its connections, mainly because these symptoms in MS are very similar to those seen in other diseases of the cerebellum. Some evidence for this assumption comes from research studies which showed that the disability from ataxia in MS is related to the amount of damage to the cerebellum.

Normal coordinated movement

To make a coordinated limb movement, such as picking up a pen or reaching for a cup, the actions of the many muscles in the arm are required to be precisely coordinated. The activation of muscles with opposing actions needs to be precisely timed so they do not interfere with each other. This precise control is achieved by a network of nerve cells in the cerebellum and other regions of the nervous system that uses information on the position of the limbs and activation levels of the muscles to generate a plan for smooth movement.
The cerebellum is central in this network and does much of the actual processing work. We can get an idea about the difficulty and complexity of this task from the fact that the cerebellum contains about half of all nerve cells in the brain.

The cerebellum:

- receives detailed information on the three-dimensional position of the limbs and joints and about the activation of the muscles via the spinal cord;
- processes this information;



Marcus Koch

Figure 1: nervous system network

- develops a plan for the next step in the movement, and;
- communicates this plan to the regions of the brain that control the movement.

A simplified scheme of this network is shown in figure 1 (above). Every small step of an ongoing movement is processed via this feedback loop, which makes a smooth movement possible overall.

The cerebellum contains about half of all nerve cells in the brain.

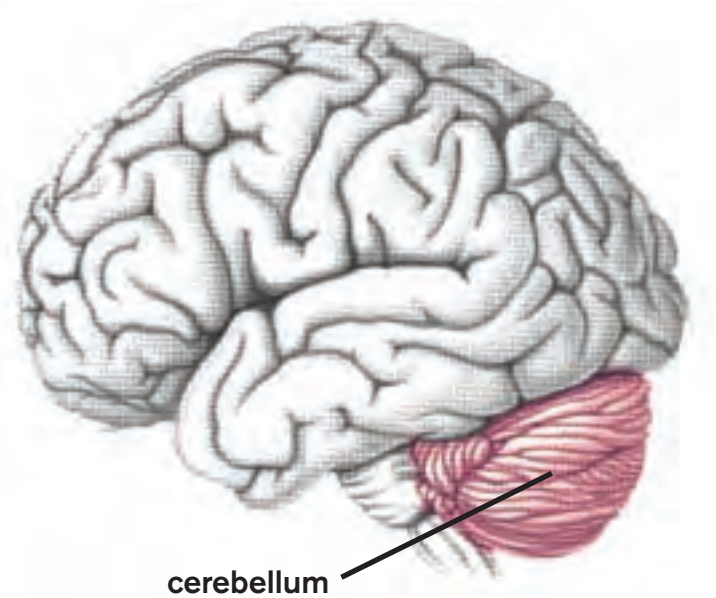
What goes wrong in MS?

The network of the cerebellum and its connections is relatively widespread and encompasses the spinal cord, the cerebellum and several further regions in the brain. Damage to any of the components of this network can occur relatively easily, for example when a demyelinating plaque develops in the cerebellum or in a pathway that connects the cerebellum to the other components of the network. Any such damage can impair the working of the whole network and lead to a lack of coordination: ataxia.

Intention tremor is closely associated with ataxia and is also caused by damage to the same system. The cause of postural tremor in MS is less well understood, but some believe that damage to the cerebellum and its connections plays an important role in the development of this form of tremor as well.

Conclusion

Ataxia and some forms of tremor are very common problems in MS. Ataxia, and probably tremor in MS, are the result of damage to the cerebellum and its connections, which form a highly complex network of nerve cells in the brain and spinal cord. These symptoms can cause much disability and remain a major challenge for MS treatment.



Evaluation and measurement of tremor and ataxia in MS

Sundus Alusi, The Walton Centre for Neurology and Neurosurgery, Liverpool, UK

Introduction

Tremor is an involuntary shaking movement of a body part. In MS tremor can be mild, but if severe it can cause significant disability. Ataxia is a Greek term which means lack of order. In medicine, it is used to describe incoordination of purposeful movements. In MS, ataxia can affect eye movements, speech, limb movement, standing and walking.

Why assess tremor?

Evaluating the impact of tremor on a person's life is crucial for its management. Certain types of tremor respond better to medical or to surgical treatments. Therefore, knowing the type of tremor and its severity can prevent inappropriate therapies and unnecessary side effects.

Assessing tremor features

Evaluating tremor affecting the arms

When tremor is assessed, the examiner wants to know the following:

- Is tremor present at rest with the limb muscles in a relaxed position (rest tremor)?
- Is it activated while maintaining a posture against gravity (postural tremor)?
- Is it worse on moving the affected limb towards a target (intentional or goal directed tremor)?
- Is one or both arms affected?
- Is it distal (affecting the hands and wrists mainly) or proximal (affecting the shoulder)?
- How significant is the associated ataxia?

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The finger-to-nose test.

In most individuals with MS-related tremor, the involuntary movement is present when attempting to maintain posture or/and with movement. Rest tremor is highly unusual in MS, unlike Parkinson's disease.

Examination of MS arm tremor

The postural part of the tremor is best assessed with the arms outstretched in front of the individual first, then with the elbows bent. The intentional component of the tremor is assessed by asking the individual to move the hand between two targets (for example, the finger-to-nose test). If the shaking worsens as the finger approaches the target, the tremor is considered intentional.

Evaluating tremor affecting the head, trunk and leg

Head tremor in MS is mostly of the "yes-yes" type. It is usually not associated with abnormal head and neck position (dystonia), although a mild head tilt can sometimes be seen. The tremor disappears when the head is rested, for example when lying down.

Trunk tremor can accompany head tremor and is assessed with the patient standing or taking steps. Leg tremor is best assessed with the individual lying down and the leg lifted rather than on walking, because it is a postural tremor.

Voice tremor is a feature of essential tremor rather

than MS but it has been reported to occur rarely in MS (this is different to dysarthria, which is described below). It is usually assessed by asking the person to sing a note. Face tremor is rarely present in MS and jaw, chin and tongue tremors are not seen.

In most individuals with MS-related tremor, the involuntary movement is present when attempting to maintain posture or/and with movement.

Assessment of tremor severity in MS
Tremor severity can be scored from the examination described above on simple scales such as 0-10, where zero means no tremor and a score of 10 is the most severe.

The tremor can also be rated by assessing its effect on a person's hand function such as handwriting, drawing a spiral (see below) or holding a cup of water. These functions can also be scored on a scale.

Drawing spirals is a useful aid in determining arm tremor severity, especially if it is mild to moderate in severity, but it is less useful in severe tremor.

The effect of tremor on everyday life can be evaluated by activities of daily living (ADL) scores (see page 18).

Sundus Alusi

Spiral drawings by an individual with MS tremor using right and left hands.

Ataxia

Eye movements
In order to assess whether ataxia involves the eye movements, the individual is asked to look straight ahead, then in various directions. The presence of nystagmus (involuntary rhythmical movements of the eye balls) indicates the presence of ataxia.

Speech
If speech is affected by ataxia, it can sound slurred and is called dysarthria. The severity of dysarthria can be scored on a simple scale 0-4, (zero being normal speech, four being unintelligible).

Arm movements
Incoordination of arm movements can be assessed by asking the individual to perform alternate hand movements. Slowing or impairment of these movements is an indication of the presence of ataxia and is called dysdiadochokinesia. The severity can be scored on a simple scale as mentioned above. Scales designed to look at arm function can also provide helpful indications to the degree of the incoordination.

Stance and gait
Assessing an individual's ability to stand with or without aid is useful in determining the degree of ataxia affecting the trunk.

Similarly, measuring the distance and the speed of walking with or without aids is helpful, but not specific to ataxia as it can also be affected by leg weakness or numbness. Nevertheless, tests like the "100-metre timed walk" are useful tools in evaluating the effect of ataxia on a person's mobility and day-to-day functional ability.

Summary

Assessment of ataxia and tremor and its severity, as well as evaluating the impact these symptoms have on a person's life, are crucial for their management and should be a priority.

Treating tremor and ataxia

Roger Mills, Department of Neurology, Queens Medical Centre, Nottingham, UK

Introduction

Ataxia and tremor are among the most difficult MS symptoms to treat. Commonly tried treatments involve drug therapy along with rehabilitation. Another approach, which is much less commonly used, involves brain surgery.

Drug treatments

Many different medicines have been suggested to be useful for tremor and ataxia over the past 25 years. Surprisingly however, only a few have been tested by randomised controlled clinical trials, which is usually considered to be the best method of assessing the effectiveness of any particular treatment. This makes recommendation of many of the treatments difficult.

Ataxia and tremor are among the most difficult MS symptoms to treat.

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Several clinical trials of cannabis… agreed that it had no beneficial effect on tremor.

Only one drug, called isoniazid (sometimes known as INH), has been shown to have a modest effect on tremor in randomised controlled clinical trials. However, the trials involved only a small number of subjects. Isoniazid was actually developed in the 1950's to treat tuberculosis. It can have side effects on the liver and potentially causes damage to the peripheral nerves (the nerve endings in the arms and legs) and so must be taken with vitamin B6 (pyridoxine) to prevent this. A typical dose of isoniazid, when used for tremor, would be 1,200 mg per day.

There are two drugs which have been shown to be unhelpful for either ataxia or tremor in MS. The first is cannabis and the cannabis-based medicines. There have been several clinical trials of cannabis for a wide variety of MS symptoms but all the trials agreed that it had no beneficial effect on tremor. The second drug is baclofen, which is commonly used to treat spasticity, spasms and cramps in MS. Unfortunately, improving spasticity does not appear to help unsteadiness or ataxia.

This leaves the other drug treatments in the undecided category; we are simply not sure of their effectiveness because they have been inadequately tested. Such drugs include anti-epileptic drugs such

as levetiracetam, gabapentin and carbamazepine. A group of medicines known as the 5HT3 antagonists, which include ondansetron and dolasetron, have shown some early promise, but larger controlled trials are needed to prove their effectiveness. These drugs are usually used to treat nausea in cancer patients and work by reducing the action of serotonin (a chemical transmitter in the brain). There are some treatments which are known to be effective in tremor caused by other conditions (notably essential tremor) such as beta-blockers or even alcohol, but their effectiveness in MS tremor remains unclear.

Surgical treatment

Two types of brain surgery can be used to treat MS tremor. Both involve altering the activity of the nerve cells in a part of the brain called the thalamus. In the first type of procedure, a thalamotomy, a wire is inserted into the thalamus and the tip of the wire is heated (or made very cold) in order to permanently disrupt the nerve cells there. The second type of procedure is called deep brain stimulation and similarly involves insertion of a wire into the thalamus connected to a pacemaker device under the skin near the collarbone. A small electric current is passed which temporarily blocks the nerve cells. The amount of stimulation can subsequently be adjusted or turned off.

In the short term, the results of such procedures can be very effective in reducing tremor. However, there are several drawbacks. First, there are potentially serious risks with the surgery including brain haemorrhage, stroke or even death. Secondly, it is only effective in certain types of tremor and the person with MS has to be otherwise well enough to undergo the operation. This means that the surgery is by no means an option for every case of MS tremor. Thirdly, the effects of thalamotomy or deep brain stimulation can wear off in around six months, and there may not be any improvement in overall disability for the person with MS. For these reasons, very careful consideration has to be given by the person with MS, their neurologist and the neurosurgeon about whether surgery would be a suitable treatment option for that individual.

Conclusion

Tremor and ataxia are probably among the most treatment-resistant and yet disabling symptoms in MS. There is little evidence that any current treatment has good long-term effectiveness. That is not to say there is no hope that such a treatment will be found, particularly as both new drugs and surgical techniques are developed and tested, and as the understanding of the cause of ataxia and tremor increases.

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The role of rehabilitation in tremor and ataxia in MS

Dr Guy Nagels, Department of Neurology, National MS Centre, Melsbroek, Belgium

The evaluation of tremor and ataxia in rehabilitation should include a description of the clinical signs, an assessment of the severity of the problem as well as the impact of these symptoms on the daily functioning of the person with MS with regard to personal care, domestic activities and participation in the community.

While quantitative measures are important in the evaluation of therapies for tremor and ataxia in MS, a statistically significant change on a measure is not necessarily clinically significant, nor meaningful for the individual. For example, on a scale of improvement for tremor there may be a statistical improvement but this may not be compatible with the person's subjective experience. For this reason, it is important to assess the impact of tremor and ataxia on daily functioning.

Studies on the efficacy of neurorehabilitation (or physiotherapy) in ataxia and tremor are limited. Most studies have included relatively small numbers of subjects with various methodological designs. The Cochrane Collaboration (see right) conducted a review of therapies for ataxia and tremor in MS that included pharmacological and non-pharmacological treatments. The review included three comparative studies on neurorehabilitation. No standardised outcome measures were used across the studies. Although some did show promising results, the authors reported that there is not enough evidence to suggest that rehabilitation provides sustained improvement in ataxia or tremor.

The Cochrane Library is a collection of databases that contain high-quality, independent evidence to inform healthcare decision-making. Cochrane reviews represent the highest level of evidence on which to base clinical treatment decisions. In addition to Cochrane reviews, The Cochrane Library provides other sources of reliable information, from other systematic review abstracts, technology assessments, economic evaluations and individual clinical trials – all the current evidence in one single environment.

www.cochrane.org

While physiotherapy for tremor and ataxia can be associated with short-term gains that are difficult to maintain over time, there are components of rehabilitation that can help. The techniques described here can be useful for some people, but

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Activities of daily living

Goal setting in rehabilitation of more severe tremor and ataxia symptoms may focus on the basic activities of daily living (ADLs) consisting of these self-care tasks:

- Bathing
- Dressing and undressing
- Eating
- Transferring from bed to chair, and back
- Continence
- Using the toilet
- Walking (not confined to a bed)

Instrumental activities of daily living are not necessary for fundamental functioning, but enable the individual to live independently within a community:

- Light housework
- Preparing meals
- Taking medications
- Shopping for groceries or clothes
- Using the telephone
- Managing money

Occupational therapists also evaluate other areas of ADLs when completing patient assessments. These include 10 areas of ADLs that are generally optional in nature, and can be evaluated by various other rehabilitation or healthcare professionals:

- Care of others (including selecting and supervising caregivers)
- Care of pets
- Child rearing
- Communication device use (for example a computer)
- Community mobility
- Financial management
- Health management and maintenance
- Meal preparation and cleanup
- Safety procedures and emergency responses
- Shopping

do not resolve tremor or ataxia completely. The aim is that the symptoms are more under control, thus, improving functioning to varying degrees.

Immobilisation uses splints and braces across a joint to stabilise it in one position. This reduces the random movement caused by tremor. Positioning of the brace depends on the action that needs to be performed. A brace can be used at the ankle or foot to provide stability in standing, or applied to the wrist, hand or arm for eating, writing and other similar tasks. Immobilisation can also be achieved by using the arm to brace the affected limb during the tremor or to hold an affected arm close to the body which can sometimes be useful to gain motion control.

Orthoses made using a Lycra™-based stretch fabric to achieve a close fit have also been suggested as helpful in some cases. Although there is no specific evidence from MS clinical trials, it is believed that the close fit gives increased pressure on certain muscle groups and improves proprioception leading to better awareness of the affected part of the body. However, a controlled trial is required.

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Weighting is based on the theory that more muscles will be used to stabilise a distant point in the body, such as the hands, when a heavier object is involved. The limb itself, or the object being used, can be weighted (some people find either weighting the limb or the object works better for them). Items such as weighted eating utensils, cups and writing instruments are available commercially. Hands-free or voice-activated devices are also available.

Adaptive equipment or assistive devices can be used in the home or workplace to make performing many activities easier and safer. Examples include large handles on doors and cooking utensils, zippers rather than buttons on clothing and non-slip pads under plates. The purpose of these aids and modifications is to help the person to continue performing activities that he or she likes or needs to perform as independently as possible.

Goal setting

Goals in rehabilitation should be person-specific and focused on the activities of daily life (ADLs – see left). The rehabilitation team must assess, together with the individual and their family, the sorts of activities the individual performs or would like to perform throughout the day.

Most often, these activities involve personal hygiene, eating, communicating, for example using a keyboard, taking care of the household, moving about and carrying objects, and participation in some leisure pursuit. The rehabilitation team must understand from the person what the priorities are and ensure that goals are realistic and attainable. Goals should be clearly defined, measurable, realistic in the therapist's view and meaningful for the person.

Multiple sclerosis resources in the world – the *Atlas of MS*

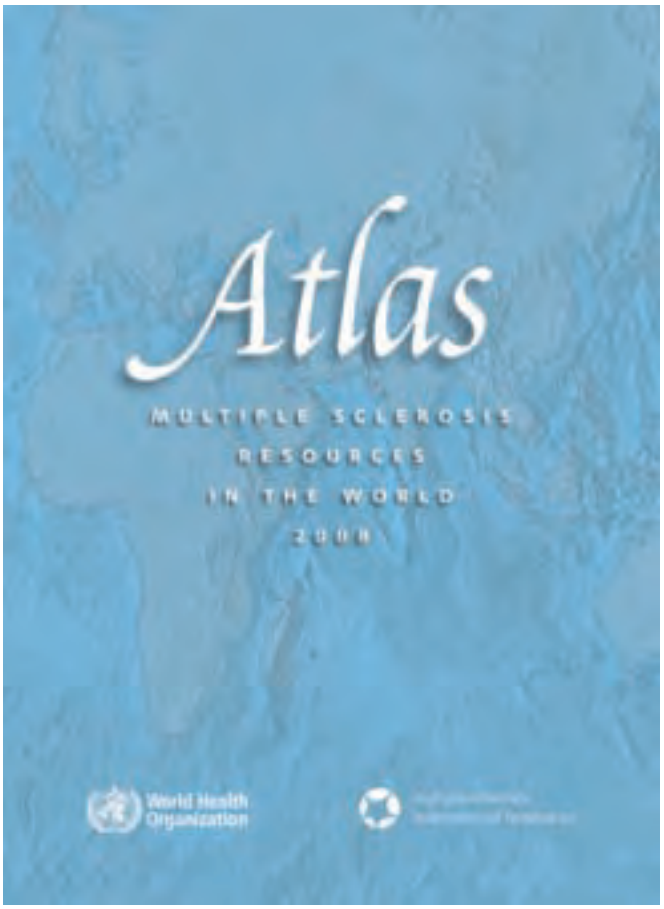
Paul Rompani, Deputy Chief Executive, MSIF

In 2005 MSIF and the World Health Organization (WHO) noted that, despite the considerable medical, social and economic impact of MS, little was known about its occurrence, frequency and distribution (epidemiology) in all countries with a significant prevalence of MS, and even less about the resources available in those countries to diagnose, inform, treat, rehabilitate and support people with MS.

Consequently, between 2005 and 2008, MSIF and WHO embarked on the most comprehensive study of its kind ever undertaken. Data and information about the occurrence of MS around the world and the availability of resources to provide services and support to people with MS was gathered from more than 100 countries representing 88 percent of the world's population.

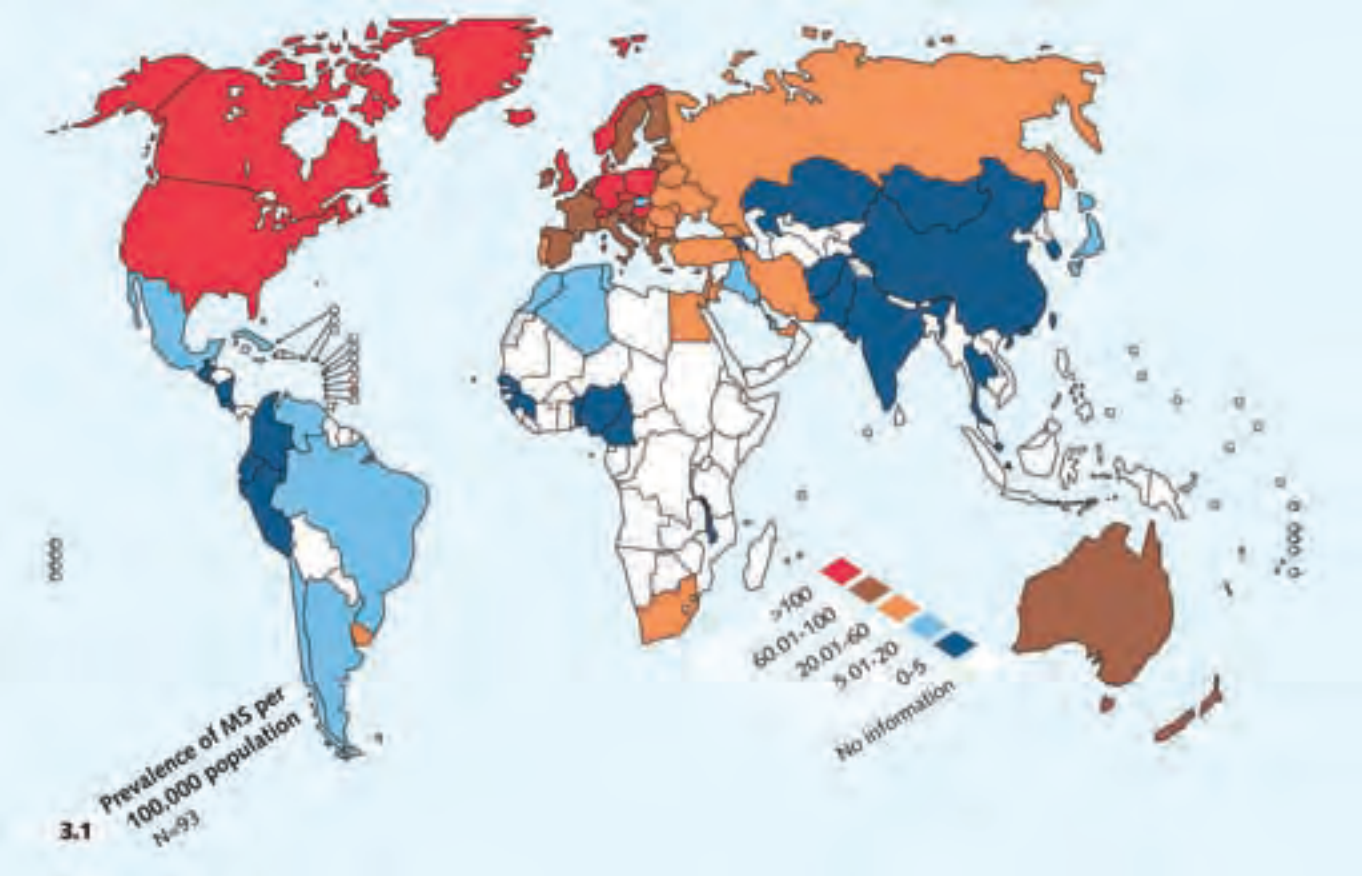
Key topics include:

- Epidemiology – prevalence, incidence, total numbers, average age of onset and male/female ratio
- MS organisations
- Diagnosis
- Information
- Support and services
- Drugs and treatment
- Human resources
- Disability entitlements, legislation and social insurance
- Major issues for people with MS and health professionals



On 17 September 2008, during the World Congress on Treatment and Research in Multiple Sclerosis in Montréal, MSIF and WHO launched the report on their findings, the *Atlas of MS*.

The report highlights considerable discrepancies between countries in the availability of information and support to people affected by MS and the accessibility of educated and informed health professionals, diagnostic equipment, such as MRI scanners, and treatment and therapy to alleviate symptoms and modify the course of the disease.



The report clearly indicates that, despite limitations to the data collection:

- no one country provides adequate resources;
- in many countries the resources that are available are grossly inadequate; and
- the availability of resources varies widely between countries, both within all regions and across the world.

Among the many recommendations contained in the *Atlas of MS* is a call to governments to:

- Enact policies to alleviate the "information deficit" about MS amongst the general public, employers and health care professionals;
- Invest more in diagnostic equipment, rehabilitation services and global research; and
- Strengthen support structures and access to employment for people with MS.

The *Atlas of MS* raises awareness of the global MS situation, encourages further research and data collection and is a key tool supporting initiatives to develop public policy, service provision and support.

The value of the *Atlas of MS* is that it replaces impressions and opinions with facts and figures. The findings have specific implications for the work of health professionals, patient groups, the health industry, policy makers and governments – and will inform national and regional advocacy and development policies.

You can download a PDF of the *Atlas of MS* at www.msif.org/atlasofms or, if you'd like to be sent a printed copy, you can contact info@msif.org.

In addition, you can see all the data gathered for the *Atlas of MS* study presented in maps, charts and graphs by accessing the Atlas of MS online database www.atlasofms.org.

In 2009 MSIF will update all the data gathered for the *Atlas of MS* and make it available on the Atlas of MS online database. For further information subscribe to our weekly email newsletter Making Connections at www.msif.org/subscribe.

Your questions answered

Italian MS Society

The Editor, Michele Messmer Uccelli, answers your questions about ataxia and tremor

Q. I use sharp instruments in my work and after a non-MS fall, my boss put a lot of pressure on me to quit for safety reasons as I sometimes have a tremor. Could an occupational therapist help with this? What are my rights to stay at work?

A. An occupational therapy or OT evaluation could be very helpful. An OT can also offer suggestions as to assistive devices or modified aids that can make some activities related to occupation (at work and at home) easier, less fatiguing and safer. A person's rights in the workplace are often country specific. Your national MS society might have resources that can help you.

Q. Are there any dietary changes I could make to help with my tremor?

A. Unfortunately there is no evidence that any change in diet can help tremor.

Q. To anyone else, it looks like I have the symptoms of Parkinson's disease – I sometimes have difficulty eating, or carrying a cup of coffee without shaking. Are there any suggestions to help with these tasks?

A. An occupational therapist can recommend adapted plates, eating utensils and cups whose aim is to promote independence in eating and drinking. Sometimes these supports can be expensive and unfortunately they may not be covered by the healthcare system in some countries. In that case, they can be purchased through commercial vendors. It is best to ask the advice of an OT before purchasing these types of aids.

Q. My ataxia and tremor have really affected me socially. I find myself feeling anxious and hiding away at home more and more because I get embarrassed by my twitching and others seem to as well. Do I need to see a counsellor?

A. Some symptoms of MS have been associated with increased social isolation. It is not uncommon for a person with a noticeable MS symptom such as tremor to feel like staying at home rather than participating in social activities. For many people with MS, anxiety seems to worsen their tremor and ataxia. Social situations in which the person feels self-conscious can also worsen the symptoms.

A counsellor might be helpful in dealing with feelings of anxiety and embarrassment – your own and those of others. A visit to a neurologist or nurse prescriber might result in you trying a treatment that has at least some positive effect on your symptom. And, an occupational therapy evaluation can provide you with insight on how to deal with tremor and ataxia in social settings. In other words, the symptoms you experience and their negative impact on your social life can benefit from a comprehensive approach involving input from different healthcare professionals.

Interview: Eduardo García, Peru

Ana Chereque, President of the Asociación Esclerosis Múltiple Perú (ESMUP), interviews Eduardo García, who has ataxia and tremor as part of his MS.

Q. Please could you give us a brief biography?

A. My name is Eduardo García, and my nickname is Lalo. I am Peruvian and 57 years old. All my life I have been a very active person; my job as a policeman has taken me around my country, serving society. I am married and my three grown-up children are finishing their university studies. I have many happy memories of my youth growing up in a farming community and, for a time, making my living as a fisherman.

Q. Could you tell us how long you have had MS and what your main symptoms are?

A. I was diagnosed with multiple sclerosis in 2007, but I began to have symptoms of the disease at least six years earlier. But I didn't pay attention to them because I thought that they were fleeting things. The problem of a loss of strength began in my legs and I was not able to walk. After that I lost control of my bladder and bowel and even had problems speaking with fluidity. Now my main symptoms and obstacles are the problems of strength and coordination in my legs; the tremor in my head and even in my eyes that takes away the pleasure of reading; and the problems of balance that force me to use a support to move around.

Q. How would you describe your ataxia and tremor? Have they changed in any way over the time?

A. It is a strange sensation not being able to control my movements. The ataxia limits many things and I feel that I cannot do anything to control it – it is controlling my life. The tremor means I cannot read or watch TV. In spite of it being only a short time since my diagnosis, these symptoms have become serious and have gotten worse within the last few months.

Q. Are you taking medication for ataxia and tremor?

A. Yes, but it did not work so I stopped using the medicine. I now use a surgical collar to stop the head tremor, but for my walking and other movements I do not have any treatment.

Q. Do you do physiotherapy for ataxia and tremor?

A. Yes, I have therapy twice per week. I do exercises to help improve my coordination and to gain strength in my legs and therefore to walk better. In fact, in spite of the difficulties, I am currently able to walk with the aid of a walking frame. I do not have any specific therapy for the tremor.

"By attending workshops that offer psychological support at ESMUP I have learned to accept the change and adapt my day-to-day life to MS."

Q. Does your ataxia and tremor stop you from doing what you want or need to do, day-to-day?

A. Yes, of course. Before having these problems, I was an independent person, a worker, sportsman, someone who had normal life, dedicated to his favourite hobbies. My sexual life was active like every man of my age. Now, everything is different. I need the support of somebody to do day-to-day activities, even to put on my shoes. My symptoms are hard obstacles to overcome and because of them my life has changed very much. I feel very frustrated by simple things that I am not able to do.

Q. What helps you to manage the challenges of ataxia and tremor?

A. The encouragement and positive energy that I receive from other people keeps me going. My feelings of frustration have reduced since I have become involved in the Asociación Esclerosis Múltiple Perú (ESMUP). Here I have found the support that my life needs. I share feelings and experiences with others who also live with the disease. By attending workshops that offer psychological support at ESMUP I have learned to accept the change and adapt my day-to-day life to MS. My twice weekly visits to ESMUP give me a change of scene and a chance to get out of the house where I am almost always alone.

Q. Do you have good support from your health services?

A. I receive help from the Peruvian social security department. They have many administrative problems, but provide me with medication to alleviate my symptoms and, when necessary, to go to hospital to receive cortisone treatment.

Tremor and ataxia online survey: the results

The English-language ataxia and tremor survey was completed by 688 people, and a further 88 undertook the Russian-language survey. This large response shows the importance of looking at these subjects, despite the fact that they are generally considered hard to treat.

Many survey respondents found that tremor and ataxia interfere with household activities.

More than 71% of respondents had a tremor and almost 80% had ataxia, meaning that most experienced both symptoms, and have experienced them for varying lengths of time – from one month through to 25 years.

Tremor

For those with tremor, the legs (64.9%) and hands (60%) were most often affected, although a significant portion had affected arms (36.9%), head (14%) or trunk (10%). Other affected parts of the body noted were eyes, feet and toes. One respondent reported an "internal tremor".

Almost two thirds said they had a tremor at rest and 57.9% experience tremor when trying to grasp or reach for an object, indicating that many survey respondents had both types. More than 70% felt their tremor worsened with stress, while 85% said that fatigue or tiredness made it worse.

"Everything gets worse under stress. When they are present, the tremors seem to want my undivided attention."

"I think I am probably stressing over little things when it happens."

"Stress makes it worse, as well as not eating right or getting enough sleep."

62% found that tremor interfers with activities they need or want to do, particularly carrying out household activities, performing self-care or

pursuing hobbies. A number of respondents specifically noted that getting out of bed was difficult due to tremor, as was walking, writing, sleep and sex.

"My hand tremor is constant making normal activities such as food preparation, tea pouring, nail cutting or applying makeup quite difficult."

"Almost everything is affected at some level, but I just do activities in a different moderation."

"I refrain from joining group activities because people have commented on my tremors. It makes me feel uncomfortable."

Ataxia

For those with ataxia, a high number of respondents said their balance was affected (91%), followed by walking (85%) and standing (69%). Problems controlling a range of movement was noted by 43%, while sense of perception affected 41.8%. One third said their speech was affected, and 30% had difficulties with eye movement. Other specific problems cited were sitting and eating.

Again, a high proportion said stress (77.1%) and tiredness/fatigue (92.5%) worsened the symptom. Quite a few noted that heat also made their ataxia worse. A number of respondents said they didn't know if either situation was a trigger.

"I am not sure if the stress induces the ataxia or if the ataxia induces stress."

"Early on it was hard to recognise that stress made it worse."

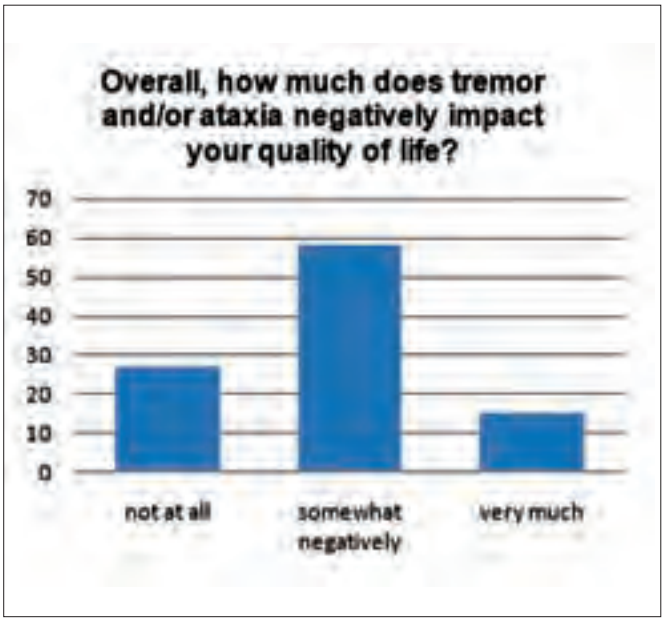
"When I am tired I sense my legs are heavier and do not respond to my commands."

"Because I struggle not to let the ataxia show too much, I fatigue easily."

A high number (86%) felt that ataxia interferes with activities they like or need to do, particularly exercising (76%) and carrying out household tasks (71.6%).

The majority of those who replied to the survey (70.9%) did not take any medication for either symptom, but of those that did, almost half used gabapentin. Most had not used alternative or complementary therapies for ataxia or tremor, but those that were found to be helpful for some included cooling therapy, dietary or herbal supplements, guided imagery and relaxation, massage and yoga. Only 1.2% had any form of surgery for either symptom.

When asked about physiotherapy, the majority (64.6%) did not have any; of those that did, 25.4% found it helpful. More than half of those surveyed found that exercise helps (many particularly said swimming), but one third said it had no effect. Overall, 58% said that tremor and ataxia "somewhat negatively" impacts their life, with 27% saying "not at all", and 15% saying "very much". The survey shows the effect these symptoms have on people living with MS and the importance of assessing each person's situation and tailoring treatment and rehabilitation plans accordingly.



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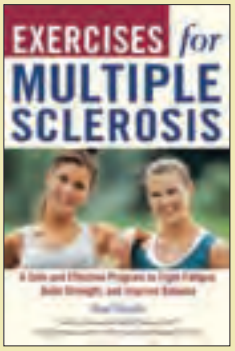
Reviews



Exercises for Multiple Sclerosis
By Brad Hamler. Published by Hatherleigh Press, USA, 2007, US$15.95, ISBN-10: 1578262275, 160 pages.

In *Exercises for Multiple Sclerosis*, the author aims to present a safe and effective programme to fight fatigue, build strength and improve balance.

The first four chapters give generalities about MS, drug treatment possibilities and the treatment of symptoms are described. Here, in these early chapters, I think there is a clear lack of the multidisciplinary approach to rehabilitation.

The following practical part of the book is about gait analysis, core/abdominal training and resistance training. The approach is a total body training starting with what the author calls the "largest muscles" and working down to the "smaller" ones. The exercises are well illustrated and explained and different exercises are given for the same muscle or muscle groups to avoid repetition in the training programme.

Another chapter describes a positive mental approach, in which the author proposes doing a mental workout. He suggests trying to visualise yourself doing the workout, and trying to feel the physical changes and efforts you would make while performing the exercises.

The exercise workload (for example the frequency, intensity, number of repetitions, how to define the starting weight) is not always clearly stated. However, the author proposes exercising three times a week and undertaking 20 to 30 repetitions for each muscle or muscle group with rest periods of 45 to 90 seconds between each exercise.

One positive aspect of the book is that the author writes about good and bad days in MS and the need to adapt the training programme and workload to those days by doing less or more. However, one of the aims of the book is to manage fatigue, and while we all believe that people with MS can benefit from exercise, fatigue management needs to involve much more than just exercise.

It is clear that the professional background of the author is the field of fitness and that general fitness principles are applied to people with MS from the author's own experiences. The book does point out correctly, however, that people with MS should get advice from an MS-specialised physiotherapist or rehabilitation specialist before undertaking an exercise programme.

Reviewed by Paul Van Asch, physiotherapist in sports and neurology, Manager of Fit Up Fitness Centre, Belgium.

MS *in focus*

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Issue 5 Healthy living
Issue 6 Intimacy and sexuality
Issue 7 Rehabilitation
Issue 8 Genetics and hereditary aspects of MS
Issue 9 Caregiving and MS
Issue 10 Pain and MS
Issue 11 Stem cells and regeneration in MS
Issue 12 Spasticity in MS

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