

# MS *in focus*

Issue 12 • 2008

## ● Spasticity in MS



multiple sclerosis  
international federation

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MSIF leads the global MS movement by stimulating research into the understanding and treatment of MS and by improving the quality of life of people affected by MS. In undertaking this mission, MSIF utilises its unique collaboration with national MS societies, health professionals and the international scientific community.

Our objectives are to:

- 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



Spasticity is an inadequately acknowledged but extremely common symptom related to MS. It is estimated that as many as 85 percent of people with MS experience spasticity to some degree. Spasticity can be a debilitating symptom with a negative impact on a person's participation in family life, work, social interactions and intimate relations. It may also affect a person's autonomy and self-image. Ineffectively treated spasticity can have serious, long-term complications and may also make other symptoms more difficult to manage.

Given the far-reaching consequences, timely evaluation and treatment by clinical professionals with specific knowledge of spasticity is crucial. A comprehensive assessment of spasticity includes not only an evaluation of the physical changes associated with the symptom, but also requires an understanding of a person's lifestyle, coping strategies, expectations and personal goals.

Pharmacological and other treatment options for spasticity can be effective for many people. On the other hand, some medications cause adverse effects that preclude their use in others. When oral medications do not achieve successful spasticity management, other possible strategies, such as surgery, may need to be considered. Fortunately there are different options available which can be evaluated by the person with MS, their family and the healthcare team together.

An important theme in this issue of *MS in focus* is the interdisciplinary approach to the evaluation, goal-setting and treatment of spasticity. The contributors are from a variety of professional backgrounds including nursing, medicine, rehabilitation and research. This combination of expertise provides a comprehensive view of spasticity in a language that is accessible to healthcare professionals and people with MS alike.

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 ataxia and tremor. Please send questions and letters to [michele@aism.it](mailto: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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# Introduction to MS and spasticity

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

Spasticity, which refers mainly to feelings of muscle stiffness and involuntary muscle spasms, is a well-defined consequence of MS. It can be identified and assessed, for the most part, based on reported symptoms and findings on clinical examination and without sophisticated tests, and effective treatment options are available. However, although clinical practice guidelines for the management of spasticity in MS were published in 2003 by the Consortium of MS Centers, spasticity remains under-recognised and is often not optimally addressed for people with MS.

There are published data demonstrating that spasticity occurs frequently in people with MS. In a large survey of more than 30,000 people, by the North American Consortium of Multiple Sclerosis (NARCOMS) Registry, 84 percent of the people surveyed reported that they had spasticity. Male gender, older age, and longer duration of the disease were associated with an increased severity of spasticity. The level of spasticity also correlated with the level of disability related to MS.

Quality of life can be affected through troublesome symptoms and functional limitations, and severe spasticity may even lead to medical complications such as skin breakdown or contractures, where a limb can become fixed in one position. All of these elements underscore the need to recognise and address spasticity and its consequences.

However, it is sometimes difficult to identify

spasticity among other symptoms. For example, a sensation of stiffness in the legs may result from spasticity, but also from abnormal sensations or from the weakness associated with MS. In addition, the presentation and severity of spasticity varies widely across people with MS and even in the same person over time. As a consequence of spasticity constantly fluctuating and evolving, any treatment or rehabilitation plan must adapt to the different stages that are unique to every individual, as with other MS-related phenomena.

*The same principles applied to the management of MS in general can and should be applied to the management of spasticity.*

In many cases, initial interventions such as stretching, exercise and rehabilitation are helpful. They also enhance the potential efficacy of other interventions such as medication, particularly when functional improvement is sought. Medications can also be useful and are usually safe, although the dosing and timing must be optimised to minimise potential side effects.

People with MS and healthcare providers are sometimes hesitant to consider more invasive treatments such as local injections and intrathecal baclofen therapy (ITB, a subcutaneously placed infusion pump, see page 15), although they can be very effective and well tolerated. Where available, a referral to a spasticity clinic with experience in the use of these therapies increases the chance of a successful outcome.



Italian MS Society

*Exercises in a swimming pool can be part of a rehabilitation programme.*

In summary, the same principles applied to the management of MS in general can and should be applied to the management of spasticity: information and education, early detection, thorough evaluation, careful treatment planning and goal setting and monitoring over time. And we should never forget that, in some cases, at least some spasticity should be preserved to avoid a loss of function – for some individuals a degree of spasticity serves as a functional crutch and helps them to walk or carry out other physical activities.

One key to enhancing the overall management of spasticity is to inform people with MS, caregivers and healthcare professionals about the symptom and its treatment. This is the purpose of this issue of *MS in focus*. After a review of what spasticity is and how it occurs, this issue of *MS in focus* will examine the methods used to evaluate the consequences of spasticity, and will present various management options and their results. We hope that readers will be enticed to seek further information or advice on this problem.

# What is spasticity and what causes it?

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## Introduction

Spasticity is commonly experienced by individuals who have damage to their central nervous system such as spinal cord injury, stroke, closed head injury, cerebral palsy and MS. In a 2001 survey of the North American Research Consortium on MS (NARCOMS) registry, approximately 85 percent of people with MS reported experiencing some spasticity. Spasticity is generally defined as being “velocity dependent”, which means that when a quick stretch is applied to a muscle, the resistance is increased. What it generally means for people with MS-related spasticity is that they have an increased stiffness or tightness in their muscles, which often adversely affects movement. They may or may not experience other components of abnormal muscle tone, such as spasms.

The biggest challenge with spasticity management is determining what the optimal level of muscle tone is for an individual. In some cases an increased muscle tone may assist with movement, but more commonly it negatively affects an individual's normal movement.

## A look at the inner mechanics

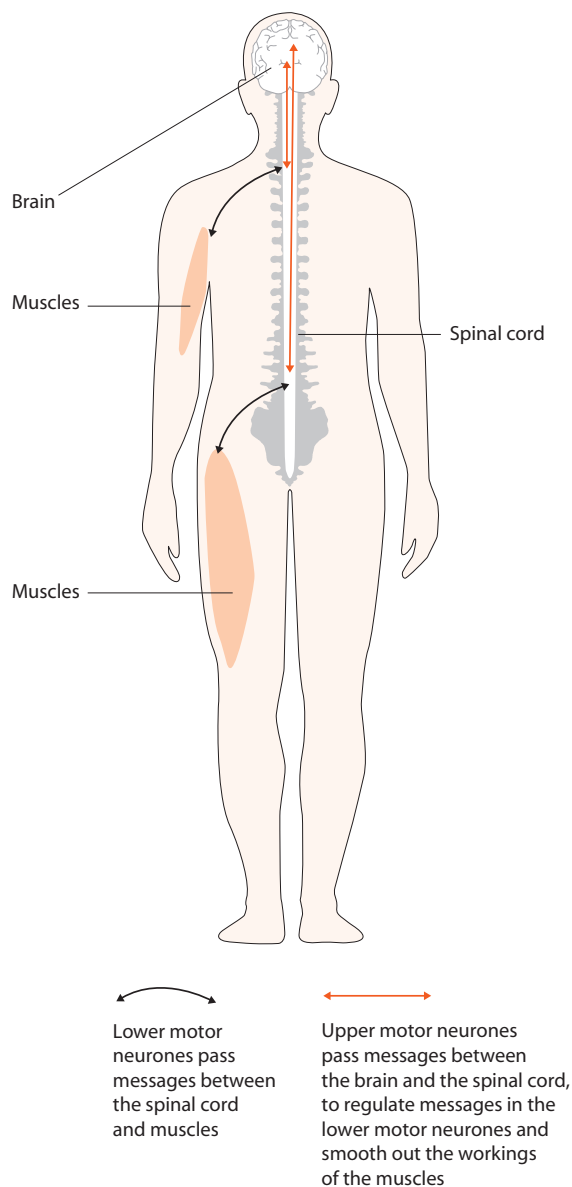
In MS, spasticity is due to nerve conduction being interrupted by a lesion located in the brain or spinal cord. It can be present at any point of the disease (early or late onset) and the symptoms can vary from mild to severe.

Spasticity occurs as a result of an imbalance between the excitatory and inhibitory signals from the brain and/or spinal cord. Excitatory signals send messages to other neurons, firing them into action, whereas inhibitory signals stop neurons firing and suppress a response, such as stopping a full bladder from spontaneously emptying itself. The primary theory is that there is an interruption of the inhibitory signals along the spinal cord and in the brain which results in an increased excitation and therefore an imbalance.

*An interdisciplinary team can better identify goals and make the adjustments necessary to attain optimal spasticity management.*

The nerve pathway connecting the brain and spinal cord is made of upper motor neurones. The pathway between the spinal cord and muscles is made of lower motor neurones. Spasticity is a consequence of an “upper motor neuron (UMN) syndrome”. The interruption of signals caused by MS lesions means that the upper motor neurones can no longer regulate messages to the lower motor neurones. The lower motor neurones can then become overactive and hypersensitive, causing stiffness or spasms in the muscles.

Other common symptoms seen with UMN syndromes include increased deep tendon reflexes or hyperreflexia, such as overactive or over-responsive reflexes, decreased strength, coordination and motor control, and even the appearance of primitive reflexes, which are reflex actions commonly seen in infants (such as the sucking reflex, where babies suck anything that



### *The messages that control our muscles.*

touches their mouth) but which do not usually continue into adulthood.

In addition to spasticity, it is important to consider other aspects of abnormal muscle tone. This may include movement disorders such as dystonia, which creates involuntary muscle contractions causing twisting or repetitive movements, or forces the body into unusual postures. It may also include “non-neural” components such as changes in muscle or connective tissue. An example would be a contracture, such as muscle or connective tissue shortening, which then alters the muscle’s ability to stretch. It is important to determine all aspects of abnormal muscle tone when developing a

treatment plan, since the cause will help guide the treatment.

### **What spasticity does**

Spasticity affects body functions as identified by the International Classification of Function. It can cause activity limitations and participation restrictions, primarily due to its effect on functional movement.

*The biggest challenge with spasticity management is determining what the optimal level of muscle tone is for an individual.*

Some of the detrimental consequences associated with spasticity include:

- interference with mobility, ability to exercise and the range of motion in joints
- negative impact on endurance and energy expenditure
- interference with the activities of daily living
- discomfort or pain
- sleep disturbance
- increased difficulty for caregivers (for example with transfers or hygiene).

These factors can contribute to a decreased independence, a decreased quality of life and may impact on a person’s role within the family, such as being a parent.

Spasticity can fluctuate due to outside influences. For example, hot temperatures may cause a decrease in spasticity for people with MS while infections and exacerbations may cause a significant increase in spasticity. It is important that a person receives treatment if there are drastic changes in spasticity, but the cause of the change must first be determined. If it is due to an infection, it is crucial that the infection be treated first. The same is true of skin breakdown or an MS exacerbation. Any residual increases after treating the “cause” should then be addressed through



*Spasticity can interfere with gardening, exercising and performing activities of daily living.*

additional assessment and management of the spasticity.

### **Managing spasticity**

It is particularly important to approach spasticity management from an interdisciplinary team approach (neurologist, nurse, rehabilitation physician and other rehabilitation specialists), including the person with spasticity and their caregiver. An interdisciplinary team can better identify goals and make the adjustments necessary to attain optimal spasticity management.

Goals of spasticity management should be orientated towards the improvement of function and improved comfort, and an individual's response to interventions such as medications, rehabilitation or surgery should be closely monitored. With close monitoring and the involvement of an interdisciplinary team, adjustments can be made according to changes in spasticity and function. Medications can be

increased or decreased, appropriate adaptive equipment can be recommended and training provided, and other interventions can be explored.

When treating spasticity it is important to focus goals on management and not necessarily on the elimination of the spasticity since some individuals use their spasticity to assist with functional movements. In addition, for individuals who have restricted movement, spasticity may help promote circulation by maintaining muscle contractions which can promote the return of blood to the heart.

### **Conclusion**

People with MS may experience many different symptoms during the course of the disease, and spasticity is one of the most common. However, spasticity is often a treatable symptom and can be managed to decrease its adverse effects on overall function. Utilising a team approach can be very effective for proper identification, goal-setting and appropriate interventions.

# Evaluating and measuring spasticity

Louise Jarrett, MND Network Coordinator,  
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Spasticity, described as involuntary muscle stiffness, is one of several symptoms grouped together under the title of upper motor neuron syndrome. Often people with spasticity also have spasms and muscle weakness. They describe their affected limbs or trunk as stiff or difficult to move and associated with a “pulling” or “tugging” sensation that can be painful.

The intensity of the symptoms varies from person-to-person, day-to-day, hour-to-hour and can impact on many daily activities. For instance it can affect physical activities such as walking, transferring (moving from a seated to standing position for example), sexual activity, washing, dressing and picking up objects. A person's safety while sitting and lying can also be compromised due to spasms or persistent poor positioning. The ongoing presence of spasticity and spasms can be described as painful, annoying, exhausting or embarrassing and can have an emotional impact, for example on mood, self-image or motivation.

*“My muscles feel stiff all of the time; any movement feels like I am pushing through syrup.”*  
(Marion who has MS and spasticity)

However it is important to remember that spasticity is not always detrimental; some people are able to stand, transfer or walk on their lower limbs due to spasticity or extensor spasms. In addition, some individuals like to see and feel the movement that a pain-free spasm affords them.

Poorly managed spasticity can unfortunately result in muscle shortening and the development of tendon and soft tissue contractures, such as when a limb becomes fixed in one position. Once present, contractures are often difficult to treat and can have major functional implications, particularly in maintaining a person's skin integrity, personal hygiene and positioning. Contractures and spasms can lead to the development of pressure sores, which in turn may increase the severity of spasms and spasticity.

***Spasticity can occur in MS at any time and its management should reflect a person's changing needs over time.***

Spasticity and its associated symptoms can occur in MS at any time and its management should reflect a person's changing needs over time. Such variability in presentation and individual expectations makes managing spasticity a challenge. Management should aim to sustain the balance between maintaining function, while minimising the effect of weakness, pain and other symptoms.

## **What is the purpose of evaluating and measuring spasticity?**

Everyone's experience of spasticity and spasms is unique. To appreciate the impact on each person's lifestyle, healthcare professionals need to engage in a process of detailed evaluation or assessment. The information gained in the process also guides the appropriate and timely selection of different treatments.

### What does evaluation involve?

The evaluation process involves two integrated phases: firstly, an appreciation of the person's history, current coping strategies, expectations and future lifestyle plans; and secondly, a physical assessment of both active and passive movements, including the recording of outcome measures. These phases will continually evolve as the healthcare professional and person with spasticity work together.

### Paying attention to terminology

Terminology between health professionals and individuals with spasticity should always be clarified to avoid confusion and

*There is no one tool that adequately measures spasticity.*

misinterpretation of symptoms. For instance, a person may say their limbs feel "heavy", but this statement could relate to either a weakness or stiffness and so will require further explanation.

### Specific spasticity measures

There is an abundance of literature on measurement scales relating to spasticity. These have recently been vigorously reviewed and fall into three domains: clinical, biomechanical and neurophysiological.

These reviews established that there is no one tool that adequately measures spasticity. In practice, a series of measures (Figure 1) is often required to reflect different aspects of spasticity.

### The purpose of measurement

The aim of measuring spasticity is to compare a person's degree of spasticity, spasms and pain over time or pre- and post-treatments such as stretching programmes or particular medications. In the case of intrathecal drug trials, measurements can guide the person with MS, their family and the healthcare team to

*Emphasis must be placed on the fact that it is not a test and there is no right or wrong.*

appreciate the potential impact of proceeding with an intrathecal treatment.

### How does it feel to be measured?

When measuring, the healthcare professional concentrates on the degree they can move a person's limbs and how it feels when they do so.

They ask the person to focus on their main problem and what would be the one thing that could improve their current lifestyle. Between the "measurers", numerical scores are shared, using for example, the Ashworth Score (Figure 1); however, all too often this has little or no meaning to the person with spasticity.

People can respond to the measurement process both positively and negatively. Positive statements may include: "It feels really good to be stretched like this as it hasn't happened for years". Conversely, individuals may ask, "Is it good or bad?" or "Have I passed the test – will I be able to get a baclofen pump now?"

For some people, being measured can make them feel as if they are enduring a test or being judged. The process encourages them to focus on their level of disability, which can be emotional, challenging and, at times, distressing.

Healthcare professionals need to be alert as to how a person may be feeling and provide support through education, engagement and involvement to enhance the measuring process.

### Evaluating and measuring spasticity in partnership?

Education involves explaining why measurement is required, how it will help the team assessment and what the person's role is in it. Emphasis must be placed on the fact that it is not a test and there is no right or wrong.

How a person is actively engaged in the measurement process is important. For people with high levels of cognitive impairment this may require creativity and flexibility to engage with them when they are most able; for example, breaking the process down into small sections to ensure they do not become too fatigued. The close involvement of a family member, friend or caregiver may be helpful to provide a perspective on how the outcome may affect the person's lifestyle and care routine at home. Their involvement requires sensitivity, as the measuring process can also impact on their perception of their family member's disability.

Measurement tools that involve self-reporting, especially those using visual and verbal analogue scales, can help the person with MS or carer to engage and feel part of the process. It also helps the person to focus and be more specific about changes they feel in their bodies or in the impact of spasticity on their lifestyle.

In summary, effective ongoing management of spasticity requires careful evaluation and consideration. Using measurement tools that foster partnerships with the person, their family member or caregiver and the healthcare team can be particularly beneficial.

*Figure 1: An example of a series of measures used in clinical practice (Stevenson and Jarrett 2006)*

| SCALE AND PURPOSE                                                                                                                            | DESCRIPTION                                                                                                                                                                                                                   |
|----------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Goniometry:</b> to measure passive and active range of movement ( <i>Norkin and White 1985</i> )                                          | A long armed hinged protractor is used to measure joint angles.                                                                                                                                                               |
| <b>Range of passive hip abduction:</b> to assess ease of maintaining lower half washing and dressing ( <i>Hyman et al 2000</i> )             | In a lying position the person's hips are passively abducted and using a tape measure, the maximum distance between the knees is measured.                                                                                    |
| <b>Ashworth scale:</b> to assess stiffness in limbs. This will be influenced by both neural and non-neural changes. ( <i>Ashworth 1964</i> ) | An ordinal scale of tone intensity with five grades from 0-4. The scorer passively moves the limb through available range and assesses the level of stiffness.                                                                |
| <b>Penn spasm frequency scale:</b> measures frequency and type of spasms ( <i>Penn et al 1989</i> )                                          | An ordinal rank scale (0-4) based on the person self-reporting how many and the type of spasms experienced in an average hour.                                                                                                |
| <b>Numeric rating pain intensity scale:</b> measures frequency and type of spasms ( <i>Kremer et al 1981</i> )                               | A verbal analogue scale that asks the person to rate their pain on a scale of 0-10.                                                                                                                                           |
| Numeric rating scale for leg stiffness:                                                                                                      | A verbal analogue scale that asks the person to rate their level of stiffness on a scale of 0-10.                                                                                                                             |
| Goal setting                                                                                                                                 | An individualised goal agreed on between the team and person with MS that focuses on what will actually make a difference to the person's lifestyle, not just changes visible during a treatment session or stay in hospital. |

# Treating spasticity

Thomas McNalley, MD, MA, Acting Assistant Professor and Jodie Haslekorn, MD, MPH, Director MS Center of Excellence West, Veterans Health Administration and Professor, Rehabilitation Medicine at the University of Washington, Seattle, Washington, USA

The most important principle of treating spasticity is to develop reasonable and flexible goals that target specific manifestations of spasticity – pain, fatigue, stiffness or weakness – and, together with the person with MS, frequently reassess the effectiveness of treatments.

Spasticity can affect just a few parts of the body (focal spasticity), or it can manifest in multiple places (generalised spasticity). It can range from insignificant to incapacitating, with many levels in between. Spasticity can also increase and decrease. Many people with MS recognise increased spasticity as a sign of a bladder or other infection, or of the increase in core body temperature that is associated with a fever or excessive exercise, or of a full bladder or colon.

Other causes of increased spasticity include:

- noxious stimuli such as a skin lesion
- a bladder or kidney stone
- fractures
- tight clothing
- menstruation
- psychological stress
- extreme environmental temperature
- hunger
- an MS exacerbation
- treatment with some disease modifying or antidepressant pharmaceutical agents.

It is important that people with MS and their healthcare team examine reasons why spasticity may suddenly increase and address them appropriately.

If there are no recent changes in health that could



*Applying an ice pack may reduce mild spasticity.*

explain an increase in spasticity, then it is reasonable to think about different approaches to managing spasticity and this does not necessarily mean medication. Often the simplest way for many to reduce muscle tightness and soreness is with range-of-motion exercises and stretching. Maintaining range of motion can be done with a regular home exercise programme, home physical therapy programme or through a community-based exercise class. Ice has also been shown to reduce spasticity in some studies, and the application of local heat can aid in stretching, although there is a lack of consensus about how often and long to stretch.

## Oral medications

A number of medications have been used to treat

generalised spasticity. Although there is variability in response to and tolerability of different medications, most practitioners will suggest baclofen as a first-line agent. It works at the level of the spinal cord to help the body inhibit muscle movement. A number of studies have shown that baclofen is effective in reducing pain, improving gait and overall function, as well as decreasing spasm frequency.

However, baclofen can cause fatigue, dry mouth, dizziness and nausea and many people start on baclofen and say it doesn't work for them. However, if assessed carefully and consideration is given to dose and timing, the results may be more positive. A written regime, with slowly increasing doses that help a person with MS assess how baclofen affects them over a period of time, and regular review can make the use of baclofen much more successful. Even so, some people with MS still find they cannot tolerate the dose of baclofen required for efficacy because of the side effects.

Another medication clinicians frequently prescribe is tizanidine. Again starting at a low dose, tizanidine appears to be particularly effective for painful spasms at night. Like baclofen, it can cause sleepiness, dry mouth, dizziness and fatigue.

Diazepam is also effective in treating spasticity in some people. It appears to have a greater risk of causing sleepiness and muscle weakness, and it has the potential for dependence and addiction which can affect adherence.

Dantrolene can be used for spasticity and it works at the level of the muscles to limit contractions. Besides sharing most of the side-effects of diazepam, baclofen and tizanidine, dantrolene also requires frequent laboratory monitoring to ensure the medication does not damage the liver. As a result, dantrolene is not prescribed as frequently as the other medications.

Other medications that may be prescribed include clonazepam and gabapentin, although again, side effects can be problematic.

*Often the simplest way for many to reduce muscle tightness and soreness is with range-of-motion exercises and stretching.*

A combination of therapies may also be helpful for some people, and this approach has become increasingly utilised by clinicians.

### Local treatments for spasticity

For those with spasticity affecting a small area (focal spasticity), or who do not get relief from oral medications, local injections of botulinum toxin or phenol into the muscles can improve quality of life.

A typical example of spasticity treatable with botulinum toxin would be the overactivity of muscles that flex the wrist, reducing the ability to reach and grasp objects. Making those muscles weaker can improve both function and pain. There are two types of botulinum toxin, type A, known as Botox® in the United States and Dysport® in Europe; and type B, Myoblock®. A local injection of botulinum toxin can last 3–6 months and make functional activities easier to undertake.

Phenol or alcohol blocks are done less frequently, and involve identifying a point where nerve and muscle meet. Phenol is injected to destroy the nerve endings in that area only.

With both phenol and botulinum toxin, the effects are temporary and may require frequent injections. Also, individuals can build up antibodies to the botulinum toxin over time, making it ineffective. Some people are able to switch from the type A toxin to type B to prolong the therapeutic effect. The most appropriate treatment plan usually includes work with a physical and/or occupational therapist after the injection to improve functional movement of the affected area.

### Surgery for spasticity

Orthopaedic surgeons and neurosurgeons might get involved in the management of spasticity in two ways. If a person experiences spasticity that has caused permanent deformity, a surgeon can

lengthen tendons or fuse joints or otherwise address malformations. Surgical correction of deformity coupled with proper rehabilitation interventions can prolong sitting times in a chair, prevent skin breakdown or its recurrence, and reduce pain.

Surgeons can also contribute to the care of a person with MS who is a candidate for intrathecal baclofen therapy (ITB). Generally reserved for those who have lower extremity spasticity and do not have an adequate response to medication or who are unable to tolerate them, ITB involves the placement of a catheter into the thecal sac, a space around the spinal cord. The catheter connects to a reservoir and pump that has been placed under the abdominal skin. The pump delivers medicine directly to the spinal cord, which for most people provides relief from spasticity without the side effects caused by the oral form of baclofen, such as fatigue and drowsiness.

Although ITB was originally used primarily in people with severe spasticity who could no longer walk, it is now also used to help improve walking in some people with MS. Evaluation for this kind of intervention should, ideally, take place at an MS centre or a clinic where experienced providers and therapists can make initial assessments, trial test doses and adjust for the best functional outcomes. If a person with MS and the healthcare team decide to investigate the value of an ITB, the person will first

### *Optimising management of spasticity can have a dramatic impact on the quality of life of people with MS.*

be given a test dose of the medication via a lumbar puncture to gauge response. With an appropriate response, the person will be scheduled for surgery to permanently implant the pump and the catheter. The medication will be titrated for best effect. Refills are done by subcutaneous injection into the pumps port. The frequency of refills ranges from monthly to twice a year, depending on the dose necessary to achieve an optimal effect and the size of the pump reservoir. Pumps can remain in place for 5–7 years, at which



*ITB involves the placement of a pump under the abdominal skin and a catheter into the thecal sac.*

time the batteries wear out and need replacement.

It's important to note that any abrupt withdrawal of baclofen therapy, oral or intrathecal, can lead to seizures. Those who are considering ITB should know the warning signs of a low or leaking reservoir. Oral baclofen doses similarly need to decrease under expert medical supervision.

Optimising management of spasticity can have a dramatic impact on the quality of life of people with MS, through a reduction of pain, weakness and muscle inefficiency. If a person with MS has troubling spasticity, working with the healthcare team to identify clear goals for treatment, adjusting treatments as needed, and understanding that spasticity will probably change over time will set the stage for the most effective interventions and the most satisfactory outcomes.

# Rehabilitation in spasticity

Peter Feys, PhD, Hasselt University/PHL and National Multiple Sclerosis Centre, Melsbroek, Belgium and Paul van Asch, Director of Physiotherapy, National MS Centre, Melsbroek, Belgium, both Chairmen of SIG Mobility Group, RIMS

The severity of spasticity (mild, moderate and severe), its interference with body structure and functional activities, and the distribution of affected muscles (leg, back, arms) varies in every person with MS. Rehabilitation interventions should provide tailored information and treatment options based on goal-setting with the person with MS, with the aim of promoting self-management.

## **Mild spasticity and rehabilitation**

In the early stage of MS, people with MS do not often report signs of spasticity although a therapist may detect them. At this early stage, a general level of fitness is advised while optimally preserving muscle flexibility.

### ***Self-stretching and strengthening exercises***

A physiotherapist will give guidelines on how to stretch the muscles which are prone to spasticity, such as quadriceps, hamstrings and calf muscles. Self-stretching should be performed twice a week, with 3-5 repetitions of 30 seconds' stretching for each muscle, with emphasis on breathing out during the stretch. Stretching can also be achieved during more global positions such as a lotus sitting position. Additionally, weak muscles

such as hamstrings and foot dorsiflexors can be strengthened during functional activities, for example by using elastic bands and/or weights or fitness equipment.

Information about spasticity and other MS symptoms can help a person with MS judge whether movement abnormalities are MS-related or not. For example, experiencing a stiff knee after hours of physical labour in the garden compared to spontaneously experiencing stiffness in a knee.

## **Appropriate management of moderate spasticity**

After a number of years, spasticity may manifest as increased muscle tone and muscle stiffness which may interfere with activities such as walking. An individual may show an inwardly rotated foot position, a stiff knee or excessive trunk extension during walking.

### ***The positive and negative effects of spasticity***

To decide whether interventions are needed at this stage, one must determine whether spasticity has occurred as a compensation for decreased muscle force or whether it is impeding muscles (such as knee flexors or foot lifters) from contracting easily. For example, a stiff knee may be needed to be able to walk when the quadriceps muscle is too weak for weight-bearing. In this case, reducing spasticity may lead to decreased walking capacity and perhaps to increased wheelchair dependency. Similarly, some may need the increased muscle tone of leg extensor muscles and trunk to enable independent transfers from wheelchair to bed.



*A physiotherapist works with a person with MS to stretch affected muscles.*

***Treatment approach for moderate spasticity***

As well as self-stretching or stretching with assistance, spasticity can be reduced by tone-inhibiting movements (such as weight transfer between legs, active forward lean, active unloaded, passive cycling or horseback riding) and postures. When maintaining tone-inhibiting postures, muscles should be stretched for a period of time (30 seconds). Tone-inhibiting postures may be used to stretch calf and hamstring muscles, or by lying in a prone position, for a prolonged stretch of the hip flexor muscles. Weights can be used to reinforce the effect.

Weak muscles have to be strengthened when possible. During walking, a simple orthosis, which is a device that can be used to prevent or assist movement or a more advanced technique, such as functional electrical stimulation, can help facilitate a proper gait.

**Severe spasticity**

In a later stage, people with MS may need the aid of a wheelchair due to pronounced muscle



Italian MS Society

*A physiotherapist can advise on different stretches to relieve spasticity.*

***Rehabilitation interventions should provide tailored information and treatment options based on goal-setting with the person with MS.***

weakness and stiffness and the increased risk of muscle contractures. Painful spasms may also sometimes manifest in the lower limbs.

***Aggravating factors and treatment approaches***

Spasticity and spasms can occur spontaneously or be aggravated because of sensory contact, manual manipulation, pain, urinary tract infections, decubitus ulcer or pressure sores.

It is important to identify the aggravating triggers of these symptoms and to ensure clear communication about them between the person with MS and the multidisciplinary team. For example, a urinary tract infection must be detected and treated in order to avoid the worsening of spasticity, or a family member or caregiver should be instructed how to handle the leg or other parts of the body sensitive to manual contact.

At this stage, physiotherapy may also include mobilisation to prevent muscle contractures and stiff joints and to help facilitate comfortable sitting and lying positions, as well as to facilitate a person's personal care (for example, dressing and bathing). The mobilisation of legs, arms and the trunk is passive or may be incorporated into active movements. Also taken into account is the mobilisation of connective tissue such as peripheral nerves, for example, with neurogliding techniques, which mobilise rather than stretch neural tissues. Passive mobilisation must be executed slowly and should be carefully sustained when approaching the natural limit of the muscle or joint, especially when sensory loss is a factor.

Cooling therapy has been suggested as a means for improving spasticity, although rigorous scientific studies with large groups of subjects



*A stretching or exercise class may help provide social support.*

are lacking. There is variability as to the most efficacious cooling techniques, which range from ice and cold water baths to cold packs and cooling garments that use circulating coolants and run on a battery.

When sitting for long periods in a wheelchair, there is a greater risk of tone increase and muscle shortening (for example of hip adductors and hip flexors). Rehabilitation should then include instruction on sitting correctly in a tone-inhibiting posture (for example, with knees separated). Tone-inhibiting postures enable long-term stretching of the spastic muscles and are effective in preventing muscle shortening. Another option is to use a tilting table to stretch hip flexors and calf muscles using body weight. For the arms, one can consider individually adapted splints, for example to maintain an

open hand position, which is important for hand hygiene.

Muscle contractures (for example, hamstrings or hand flexors) may be present at this stage. When these hamper functional activities, serial casting (a temporary cast) can be used to recover a full range of motion.

## Conclusions

Rehabilitation can offer guidance and therapy to reduce spasticity and prevent muscle contractures and joint stiffness. However, a multi-dimensional evaluation must be performed to investigate the interplay between spasticity and functional mobility before selecting the best rehabilitation approach. Rehabilitation interventions can then be used alongside pharmacological and neurosurgical treatments.

# Cannabinoids and spasticity

Paul Smith, PhD, Professor of Neuropharmacology, Department of Pharmacology and Toxicology, School of Medical Sciences, University of Otago Medical School, Dunedin, New Zealand

Many survey studies and anecdotal reports suggest that some people with MS self-medicate with marijuana (or cannabis, Latin name: *Cannabis sativa*) in order to relieve their spasticity. Experimental pharmacological studies support the hypothesis that cannabinoid chemicals within cannabis, such as delta-9-tetrahydrocannabinol (delta-9-THC) and cannabidiol (CBD), exert muscle relaxant effects. While delta-9-THC does this via a specific cannabinoid receptor (the CB1 receptor) which was discovered in the central nervous system in the late 1980's, CBD appears to have more complicated actions and may affect cytokines (proteins that are released by cells of the immune system and play a role in the generation of an immune response).

Initial clinical trial data did not support the efficacy of delta-9-THC in reducing spasticity. The first report from the "Cannabinoids in Multiple Sclerosis" (CAMS) trial, a blind and placebo-controlled trial in the UK, suggested that delta-9-THC had no statistically significant effect on spasticity when evaluated by the objective Ashworth scale. However, in a 12-month follow-up study involving 630 patients, delta-9-THC was shown to have a small but significant effect. Nonetheless, in

both studies the patients reported a subjective improvement in spasticity. It is a matter of some controversy whether the initial lack of effect using the Ashworth scale reflects the lack of sensitivity of that scale for quantifying spasticity.

The natural cannabis extract in the pharmaceutical product marketed as Sativex® has been reported to alleviate spasticity in a number of clinical trials. Sativex is a 1:1 ratio of delta-9-THC and CBD and can be administered as a sublingual (under the tongue) or oromucosal (nasal) spray. Not all trials testing the efficacy of Sativex® have been blind or placebo-controlled, raising questions about the quality of the data collected. Most trials that have been well controlled have still found a significant

*Long-term studies suggest that cannabinoids are reasonably well tolerated by patients but there is still concern about potential long-term adverse effects.*

improvement in spasticity, at least according to subjective rating scales, however there is also some contradictory evidence regarding this. The most common adverse side effects reported have been oral pain, dizziness, diarrhoea and nausea. Of the other cannabinoids that have been investigated, the synthetic cannabinoid, nabilone, has been reported to reduce pain related to spasticity in one recent study.

There have now been more than 12 clinical trials published on the effects of cannabinoids on



spasticity and pain in MS. Although not all of these studies demonstrate a significant improvement in symptoms with delta-9-THC or CBD, evidence is accumulating that cannabinoid drugs may be useful in at least a subset of patients, and at least as an adjuvant therapy. Even where cannabinoids have failed to reduce spasticity according to the Ashworth scale, it has been pointed out that many commonly used anti-spasticity drugs have also failed to generate statistically significant results according to this scale.

Long-term studies suggest that cannabinoids are reasonably well tolerated by patients but there is still concern about potential long-term adverse effects, such as cognitive impairment, impaired foetal development and psychiatric side effects. However, it must be recognised that many conventional anti-spasticity drugs such as baclofen also have significant side effects. It should also be noted that in some countries cannabis is an illegal drug, which affects its accessibility.

# Your questions answered

**Q. My spasticity comes and goes and is often triggered by heat – I've tried ice but is there anything else I can do to help prevent it coming on?**

**A.** The first thing to do in order to prevent heat from worsening an MS symptom is to avoid it whenever possible. Moderately warm showers rather than hot ones are recommended. Many people with MS also avoid sunbathing and performing some activities in the heat (such as exercising under the hot midday sun). Other ways to help curb the heat's influence on worsening symptoms is to use air conditioning, drink cold beverages and wear light, loose-fitting clothing. Some people with MS use a body cooling system to avoid becoming overheated. While these systems are available in different countries, they can be very expensive and have not been tested in rigorous studies with large numbers of subjects.

**Q. My legs are often sore and stiff at night and stop me from sleeping. Why are the symptoms worse at night and are there any exercises I can do before bed to help?**

**A.** You may be describing restless leg syndrome (RLS), a condition in which your legs feel extremely uncomfortable while at rest. RLS has been found to be a very common problem for people with MS, although the cause is unclear.



An evaluation at a centre that specialises in sleep disorders would help to better understand your symptoms. The feeling is usually relieved by moving around and this is why it seems like the symptoms worsen at night. Some strategies for managing RLS include reducing caffeine and alcohol intake and regular, moderate exercise. A healthcare provider can recommend appropriate exercises and/or medications.

**Q. I have a pressure sore on my tailbone. My MS nurse mentioned that this can worsen my spasticity. What are other types of stimuli can aggravate spasticity?**

**A.** Cutaneous stimuli (those that relate to the skin) that can aggravate spasticity include ingrown toenails, broken or infected skin and tight-fitting clothing. Visceral stimuli (those that relate to internal organs) that can worsen spasticity include bowel dysfunction, bladder infection and urinary retention.

Silvia Traversa, from the Italian MS Society, spoke with Giulio Adamo about how he deals with spasticity. Giulio is 61 years old and retired and lives with his wife in Genoa.



Italian MS Society

# Interview: Giulio Adamo, Genoa, Italy

Charming, outgoing and always ready with a one-liner – his speciality? – telling jokes in Genoese dialect! Giulio worked for years as a truck driver. His first MS symptoms were attributed to tiredness associated with long road trips and then he was misdiagnosed with a back problem. In 1991 he was finally diagnosed as having MS. Giulio experienced spasticity after only a few years with MS, in 1996, and since its onset it has been a constant presence.

## **How would you describe your spasticity?**

Spasticity is a very annoying problem and it affects my left hand, arm and both legs. It feels like my arm retracts with cramps and my hand tends to close up into a fist and I can't reopen it. My legs are very rigid.

## **You've been dealing with spasticity for 10 years now. Has it changed in any way over time?**

Unfortunately it has only worsened with time. Personally, I've never experienced periods of improvement, even if I've tried different therapies and devices. For example, at night I use a device that keeps my hand open. It gives the slightest bit of relief but actually doesn't help too much.

## **Are you taking medication for spasticity?**

I'm taking baclofen. In the past I even tried the baclofen pump. The point of it was to benefit from the slow release of medication but I still couldn't tolerate it. I was always tired and weak and most of the time felt like jelly. So I had the pump removed.

## **Have you ever tried an alternative therapy?**

Sure. I'm currently trying acupuncture. My rehabilitation physician suggested that I try it. I began three weeks ago... let's see what happens! For now it seems to be working. At night my hand is less painful than it usually is. Maybe the needles relax some parts of the body. I'll try everything! I'm not planning on giving up.

## **Do you do physiotherapy for spasticity?**

Yes I have had physiotherapy. I was prescribed physio three times a week for three months. I also did occupational therapy at the specialised MS rehabilitation centre I attend. I think it definitely is important to try different treatments, even if, for me, I still haven't found the solution for my spasticity. Unfortunately spasticity is here and it looks like it's going to stay.



Italian MS Society

*This mobility aid helps Giulio keep his hand open.*

**In your opinion would you say that spasticity is one of the most difficult symptoms of MS?**

Definitely. I would say spasticity is the most disabling symptom too. It puts a lot of limits on a person. But mostly it can put you in a position where you have to ask others for help.

**So your experience is that spasticity impedes you from doing what you want or need to do?**

It stops me from being autonomous in many things I'd like to do on my own, without help. For example, I need help with eating, cutting food on my plate and opening a bottle. I try to be as autonomous as possible even if it's not always easy.

**What helps you cope with the challenges of spasticity?**

For me the most basic thing is not to let spasticity and MS get the best of me. I'm a naturally positive,

happy person and these qualities really help in dealing with MS. I certainly don't pass my days thinking about everything that's not right. I believe that complaining and worrying serves no purpose, and neither does always talking about MS! My

*"I believe that complaining and worrying serves no purpose, and neither does always talking about MS!"*

advice to others dealing with spasticity or any problem related to MS is this: focus on the fun things in life and not on the negative aspects.

**What is something fun that you focus on?**

For example, with the local branch of the Italian MS Society, we've created a theatre group and soon we have a performance scheduled for a very famous theatre in Genoa. I play the part of a director of a lunatic asylum. It's great fun!

# Spasticity online survey results

The spasticity online survey was completed by 487 respondents in English and 205 in Spanish. The discussion below uses the results of both surveys combined.

The part of the body most affected by spasticity was reported to be both legs (72.8%), followed by the one leg (26.5%), the trunk (21.6%), one arm (18.7%), and two arms (17.8%). Other areas of the body noted were the neck, hands, fingers, bladder, bowel, buttocks, throat, face and jaw, while some said that they had spasticity in their whole body.

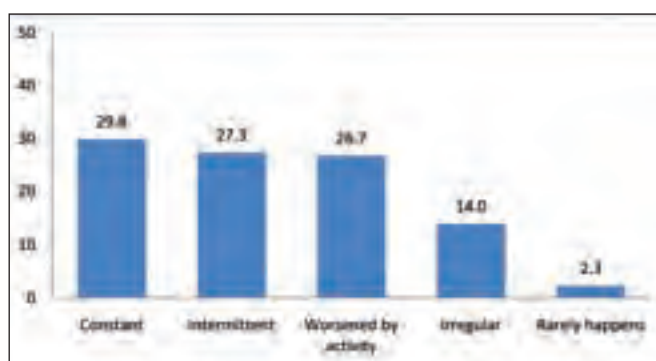
*“Typically it is just my right leg that is affected, but at times it can be both depending on how tired I am.”*

A high number of respondents recorded experiencing stiffness and/or tightness (88.7%), while cramping, pain, involuntary movements and/or difficulty performing voluntary movements was experienced by more than half of respondents. A third said their spasticity was constant, while 27.5% described it as intermittent and 27.1% found it was worsened by specific activities or situations. Many noted that their spasticity was often worse in heat and when they were tired or stressed. Others found it worse when they relaxed or at night when they were lying down.

*“The pain and discomfort caused by spasticity affects my ability to sleep as it tends to be worse at the end of the day.”*

Of particular note is the high number that found that spasticity interferes with activities they like or need

## Please describe your spasticity

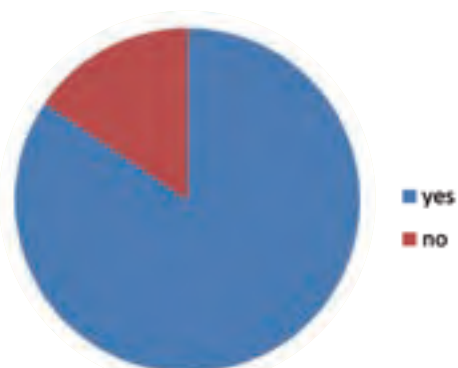


*“Just suddenly it’s there. One minute I am fine and then the next I am really stiff and sore.”*

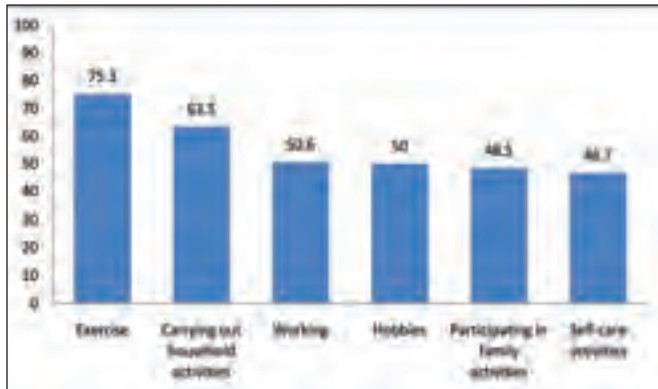
to do, highlighting the impact this symptom can have on daily living. The activities most affected were exercise and carrying out household activities, while approximately half of respondents felt that the other categories (self-care, hobbies, family activities and working) were also affected. Under “other”, many respondents mentioned sleep interference.

*“I find my legs stretching all by themselves, as if I were doing a stretching warm up before exercise, although I am lying in bed.”*

## Does spasticity interfere with any activities you like or need to do?



### Which activities does spasticity interfere with?



*"I have learnt to improvise and continue to do everything myself. The worst part is not being able to run when it starts pouring!"*

An interesting result from the survey was that of those who answered the English language survey, almost two thirds were taking medication for spasticity, while the majority (54.9%) of those who answered the Spanish survey were not taking medication. This may indicate a difference of availability, approach or preference between these two groups of respondents. The most commonly used medication in both surveys was oral baclofen.

A third of the people who replied had used alternative therapies. Specifically mentioned were

the use of heat and cold (such as ice), acupuncture, yoga, pilates, massage, smoking marijuana, meditation, prayer, magnet therapy, reflexology, vitamins and osteopathy.

*"It kills me that I can't play a game of tennis with my wife (which we did on our first date)"*

Only 14.4% had used local treatment techniques (mainly botulinum toxin) and 2.3% had had a surgical intervention. Only a small number of respondents (27) had had a neurosurgical procedure and of those, most had ITB. These results show a general preference (or limited options) amongst respondents for "conventional" treatment.

The majority found that exercise or physiotherapy helped their spasticity "definitely" (27%), "often" (16.2%) or "sometimes" (32.6%) showing the high value of this therapy for people with spasticity. A quarter found it rarely or never helped.

*"Physiotherapy is fantastic. I feel like a new person. The physio is showing me exercises to strengthen muscles and that is improving everything in general."*

*"We have adapted our family outings to allow us all to fully participate."*

## Reviews



### **Spasticity Management: A practical multidisciplinary guide**

*Edited by Valerie Stevenson and Louise Jarrett, foreword by Alan J Thompson.*

*Published by Informa Healthcare, UK, 2006,*

*200 pages, price: £169.95, ISBN: 978-1-84184-560-9 (hardback) 978-0-203-09054-1 (electronic).*

This book offers an exhaustive and practical review of the most important aspects of spasticity treatment and management.

The first chapters describe the anatomical and pathophysiological bases and the clinical aspects of spasticity. There is also a chapter dedicated to the importance of education and the promotion of self-management. The physical management of spasticity is discussed using a number of diagrams and figures which are extremely helpful to show the practical activities that can be used in different rehabilitation settings.

There are three chapters devoted to the pharmacological treatment of focal and generalised spasticity, which describe the use of botulinum toxin, intrathecal baclofen and phenol injection, among other pharmacological management approaches.

I particularly enjoyed chapter eight on setting up a spasticity clinic, in which the authors provide practical suggestions based on their extensive experience in this field.

The last section of the book provides 14 appendices that summarise a number of specific issues such as outcome measures and managing an intrathecal baclofen pump. The inclusion of these appendices is particularly useful, and is often, unfortunately, not included in texts on symptom management.

The authors should be complimented on their layout and style. The text is structured into concise sections. Instructive summary tables and lists are often used. The major achievement of this book is that it provides an extensive amount of clinical and pharmacological information presented in a reader-friendly style. The references at the end of each chapter provide opportunities for further reading.

The only caveat is the lack of a description of the principal diseases related to spasticity in order to have a better understanding of the underlying bases of the symptom.

The book can be an important resource for specialists in neurology and rehabilitation medicine, but also for non-physician professionals. It can be a great reference for the multidisciplinary team caring for people with spasticity as well as for busy professionals who need quick answers.

*Reviewed by Claudio Solaro, MD (Neurologist & Psychiatrist), Department of Neurology, ASL 3 Hospitals, Genoa, Italy.*



## ***Multiple Sclerosis for Dummies***

*By Rosalind Kalb, Ph.D., Nancy Holland, RN, EdD, MSCN, Barbara Giesser, MD and David L. Lander. Published by Wiley Publishers, 2007, 362*

*pages, price: £21.99, ISBN: 978-0-470-05592-2.*

I have read many books about how to deal with MS but I have never found a book like *Multiple Sclerosis for Dummies* before.

The book is divided into six parts (excluding the appendix), which give an A-to-Z about MS and its management.

The first two parts, "When MS Becomes Parts of your Life" and "Taking Charge of Your MS", give a brief explanation about what MS is, how MS can affect our bodies, and what we should do if we've just been diagnosed with MS.

The next parts were "Staying Healthy and Feeling Well" and "Managing Lifestyle Issues". I found these parts to be very useful, not only for a person with MS but also for their family and friends because they suggest solutions to some of the problems which could arise in the life of someone with MS and his/her social circle.

The last two parts, "Creating Your Safety Nets" and "The Parts of Tens" will make people with MS aware of how they can prepare for everything for living with MS in the future.

After reading every word in the book – which has a very clear and easy-to-understand explanation of MS – I think this book can really open the dummies' eyes. It's really worth reading!

*Reviewed by Kanya Puspokusumo, writer and editor of a health magazine and President of the Indonesia Multiple Sclerosis Group.*

## Evaluation and Management of Spasticity in Multiple Sclerosis

A presentation featured on the Consortium of MS Centers' website, [www.msccare.org](http://www.msccare.org)

The ease of access to high quality, evidenced based on-line teaching resources has had a significant impact for all those wanting to further their knowledge and expertise in specific areas, but are unable to attend a classroom-based educational setting. A major advantage to presentations, such as this one means that the 'student' can learn at a time and place that is most convenient for them, even if this means learning through the night. As clearly stated in the introduction to this session, spasticity is a complex area of MS management and to be able to go through the course at your own pace has obvious advantages.

This video presentation is contained on the website of The Consortium of Multiple Sclerosis Centers who have worked tirelessly to provide education (and to conduct research) to enable those affected by MS to receive "state-of-the-art healthcare and related services." It has a well-known reputation across the globe for doing just this. This presentation, and indeed all the resources on this site are free to access and do not require a password making them an extremely attractive prospect for many. The resources are updated and added to on an ongoing basis.

This resource has been produced for healthcare professionals who provide care for people with MS and spasticity, but all those affected by MS could find it interesting and informative, although the medical terminology could be off-putting for some.

The information within it is current and presented by eminent people in the MS community such as Francois Bethoux. The presentation has six sections, which are navigated with ease by a drop-down menu on the opening page. Each section can be looked at in isolation or in its entirety. The visual effects are



very attractive and add quality and 'watchability' to this presentation. The varied media maintains interest and enjoyment and helps the student demystify some of the complexities of spasticity management.

The six sections include an overview of the pathophysiology of spasticity, how to assess the person with spasticity, treatment options and how spasticity is managed in day-to-day practice. The reader can click the pause button to stop and re-start the presentation at any time. Each section can be looked at in isolation or in its entirety. Section three provides a comprehensive and realistic approach to patient assessment and is very informative, providing practical tips and advice. Section four details current treatment options and provides a helpful overview of each treatment strategy, clarifying the benefits and limitations of each.

The presentation is very professionally produced and is of a high quality. The speakers articulate well. It is sponsored by Medtronic and as such has a bias towards informing the student about intrathecal baclofen therapy, which section five is almost exclusively dedicated to it. That aside, this presentation will be of interest to all practicing healthcare professionals who want to provide realistic and effective management strategies for those who experience MS and associated spasticity.

*Reviewed by Nicki Ward, Lecturer Practitioner in MS, Birmingham City University, UK*

# MS *in focus*



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Merck Serono, a division of Merck KGaA, are specialists in innovative prescription pharmaceuticals with products available in over 150 countries worldwide. We have been active in the fight against MS for over a decade. Through pharmacogenomics, we

are active in research towards understanding the genetic basis of MS. Merck Serono has a long-term commitment to people with MS through constant research and discovery efforts as we look for new therapies and hopefully, one day, a cure.