

MS *in focus*

Issue 10 • 2007

● Pain and MS



multiple sclerosis
international federation

Multiple Sclerosis International Federation (MSIF)

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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Cambridge
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+44 (0)1223 477411
info@cpl.biz
www.cpl.biz

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Letter from the Editor



Pain is a common symptom in MS. Those who experience pain feel its effects on their daily life activities, such as work and recreation, and in their mood and enjoyment of life.

The fact that a record number of people responded to our online survey (results on page 24-25) for this edition of the magazine shows how important this problem is for the many people who experience pain. Alarming, 90 percent of people with MS said they were not completely relieved of pain with treatment. This discrepancy highlights an area that demands attention from health care professionals and researchers.

Many clinical features of pain are often unrecognised by clinicians and it may be difficult for many people with MS to find the right words to describe the pain they experience. At the same time, scales for evaluating pain rely on subjective reports and may be biased by any combination of circumstances, making the evaluation of pain severity and its impact on daily living difficult.

Pain is often present with other symptoms, such as depression, spasticity and mobility difficulties, underlining the importance of addressing MS comprehensively. The situation is complicated further by the fact that a person with MS may also have other illnesses, making the diagnosis and treatment of pain very complex. Another concern is that in some cases the side effects of pain medication can be as distressing as the pain itself and therefore cannot be used at an optimal level.

Considering it has a significant influence on a person's quality of life, unmanaged or ineffectively managed pain can have consequences that go beyond issues of symptom management. Therefore, involvement of the MS team, including the person with MS and his or her family, is fundamental for the identification, assessment and optimal treatment of pain.

We hope that this edition of *MS in focus* will clarify some issues related to the diagnosis and management of pain and be a useful resource, particularly for health professionals who may not realise the impact pain has.

Michele Messmer Uccelli, Editor

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The next issue of *MS in focus* will look at stem cells and regeneration in 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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Introduction to pain and MS

Heidi Wynn Maloni, PhD, RN, Veterans Affairs Medical Center, MS Center of Excellence East, Washington, DC, USA

Pain in multiple sclerosis? Pain is not a symptom that is commonly associated with MS. But, when findings of worldwide MS research studies suggest that pain is a key factor in MS, it is important that people with MS and their families, friends, carers, MS society staff and health professionals, take a second look at the symptom of pain and its impact on the lives of people with MS. Such studies have revealed that approximately two thirds of people with MS experience pain at some time during the course of the disease; pain can be an early and presenting symptom; pain can be the most debilitating symptom, impacting function; pain is under-treated; and that pain is associated with depression, anxiety and fatigue.

Pain in MS – is this something new?

Indeed, knowledge of the experience of pain associated with the diagnosis of MS existed in the 1800's as Jean Martin Charcot associated pain observed in patients with a neurological condition he termed insular sclerosis. In 1853, French neurologist Trousseau noted that pain had epilepsy-type characteristics, guiding scientists' use of anticonvulsants, also known as antiepileptic drugs, to treat pain. Phenytoin was used to manage painful tonic spasms in the 1940s, and in the 1960s, several case studies and isolated

reports of pain in MS emerged. Anticonvulsants were still first-line treatments at the time. It was not until the 1980s that the incidence, prevalence and characteristics of MS pain were described through findings from population-based studies conducted in North America and Europe. Associations of pain with other symptoms and the psychosocial implications were further explored in more recent studies. These studies supported pain as a common feature in MS and suggested ways of managing the symptom.

Why does pain occur in MS?

Pain is a sensory symptom directly related to two occurrences – the disruption of central nervous system myelin and the effects of disability. Myelin speeds nerve conduction, aiding smooth motor activity, integration and interpretation of sensory stimuli and effortless cognition. When pain is the result of a disruption or alteration of nerve conduction, it is termed neurogenic, or having its genesis or roots in the central nervous system. Some literature also uses the term “neuropathic”. There is currently no agreement on which term is more correct.

Nociceptive pain occurs when bone, muscle or body nociceptors warn of tissue damage which

“Research studies from populations of people with MS worldwide report that approximately two-thirds of people with MS experience pain at some time.”

may result from disability. This can be secondary to musculoskeletal changes in MS due to weakness or incorrect posture for example. If a person walks in a different way than normal then joints may be stressed and become painful as well. One of the side effects of steroids is bone loss but this is usually not an issue in MS as they are generally used for short periods. Immobility can result in a loss of bone density but this is not usually painful unless it results in a fracture. Nociceptive pain can also occur when skin breaks down or is expected to bear weight over an extended time without movement.

How does MS neurogenic pain present?

Neurogenic pain is described as continuous and steady or spontaneous and intermittent, and is reported in varying degrees of severity. One large North American study found that half of those reporting pain said their pain was continuous and severe. Intermittent, spontaneous pain is characterised as shooting, stabbing, electric shock-like, or searing and is often evoked by stimulus that normally do not cause pain, for example touch, the weight of bed covers, chewing or a cold breeze can all bring about spontaneous neurogenic pain.

Neurogenic pain described as steady is typified by burning, tingling, tight or band-like sensations, aching and throbbing. Steady neurogenic pain is often worse at night, worse during temperature change and worsened by exercise.

How can MS pain be treated?

Pain is an individualistic symptom that can only be described by the person experiencing it. Some altered daily functions, such as sleep, mood, and the ability to work, play and enjoy life, give clues as to the impact of pain on the lives of those who experience it.

Assessing the type and the cause of pain is important to appropriate pain treatment. Pain management is approached medically, behaviourally, physically and in some cases, surgically. Pain is complex and often requires a

multidisciplinary approach and the skills of pain management experts.

Medication

If the cause is neurogenic, medications that modulate excitatory neurotransmitters and enhance inhibitory transmitters are prescribed. Medications used in MS pain management include antidepressants and opioids because an increase in neurotransmitters minimises pain. MS pain is modulated with anticonvulsants (see page 7) and antiarrhythmics because they calm excited nerve firing.



The most common pain syndromes experienced by people with MS include:

- headache (seen more in MS than the general population)
- continuous burning pain in the extremities
- back pain
- painful tonic spasms (a cramping, pulling pain)

Painful tonic spasms, or spasticity, are considered a secondary cause of pain in MS – pain due to a symptom rather than neurogenic. If the cause of pain is related to disability, meaning muscular or skeletal pain, pain from infection or skin ulcers, it is addressed using common analgesics, antispasmodic treatment or antibiotics, depending on the cause. The use of medications to manage pain in MS is always a balance of risk versus benefit. In other words, medication side effects are considered and continually evaluated in terms of their impact on a person's quality of life.

Behavioural

Behavioural mechanisms for pain management include relaxation, meditation, imagery, hypnosis, distraction and biofeedback. Getting involved in work or social activities, joining a support group or even having a good laugh are proven mechanisms to minimise pain. Higher pain severity is reported by people with MS who are unemployed or homebound.

Physical

Physical agents that minimise pain include the application of heat, cold or pressure, physical

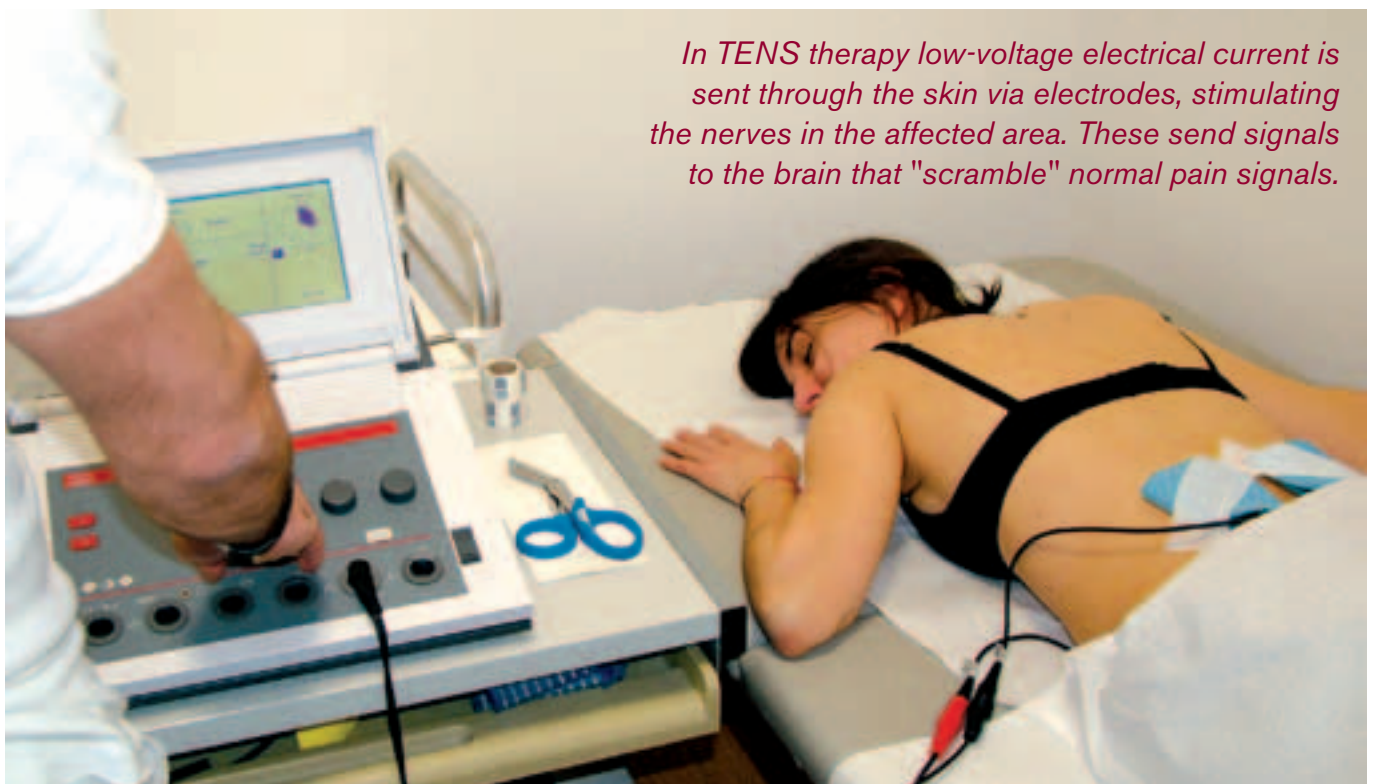
therapy, exercise, massage, acupuncture, yoga, tai chi, and Transcutaneous Nerve Stimulation (TENS, see photo below) These techniques and therapies are often overlooked but should be considered from the onset of pain symptoms.

Surgical

Surgical pain management interventions are sought when medical, physical and behavioural options fail. Procedures such as regional nerve blocks are reversible and safe. Neurosurgical options, rhizotomy, cordotomy, and Gamma Knife radiosurgery, are known to offer relief, but carry risks.

Summary

Today pain is recognised as a common symptom of MS directly related to the disease and its consequences. Symptom management is based on the mechanisms of the pain experienced. The direction and focus of continued research includes a better understanding of the mechanisms of pain in MS and its effective treatments. The following articles will provide further insight into the experience and management of pain in MS.



In TENS therapy low-voltage electrical current is sent through the skin via electrodes, stimulating the nerves in the affected area. These send signals to the brain that "scramble" normal pain signals.

Medications used for the treatment of pain common in MS

Drug	Use	Side effects
<i>Anticonvulsant drugs</i>		
Carbamazepine	Trigeminal neuralgia	Drowsiness Dizziness Coordination difficulties
Gabapentin	Dysesthetic pain	Dizziness Coordination difficulties Fatigue
Clonazepam	Dysesthetic pain	Sedation Dizziness
Lamotrigine	Painful tonic spasms Trigeminal neuralgia	Dizziness Double vision Coordination difficulties Insomnia
Phenytoin	Dysesthetic pain Painful tonic spasms Trigeminal neuralgia	Dizziness Nausea Insomnia Uncontrollable eye movements Coordination difficulties Slurred speech Confusion
Pregabalin	Neuropathic pain	Dizziness Drowsiness
<i>Anti-depressant drugs</i>		
Amitriptyline	Dysesthetic pain	Dry mouth Blurred vision Sedation Urinary retention
<i>Steroids</i>		
Methylprednisolone & prednisolone	Optic neuritis	Metallic taste in the mouth Increased heart rate Hot flashes Mood changes Difficulty sleeping
<i>Anti-spasmodic (muscle relaxant) drugs</i>		
Baclofen	Painful tonic spasms	Weakness Drowsiness Dizziness
Tizanidine	Painful tonic spasms	Drowsiness Dry mouth

Note: Use in MS is not necessarily an approved indication for the medications that appear in this table. Refer to approved production information for indications on use. Adapted from the Australian MS Nursing Manual, 2004.

Prevalence, classification and measurement of pain

Brenda Stoelb, PhD, and Dawn M Ehde, PhD, Multiple Sclerosis Rehabilitation Research and Training Center, Department of Rehabilitation Medicine, University of Washington School of Medicine, Seattle, Washington, USA

In the past, many scientists and health care providers considered MS to be a “painless” disease. Many people living with MS, however, might disagree with this assumption. Research conducted in the last decade has shown that pain is, unfortunately, common in MS. Recent recognition of the problem of pain in MS has increased attention to and research about pain in MS.

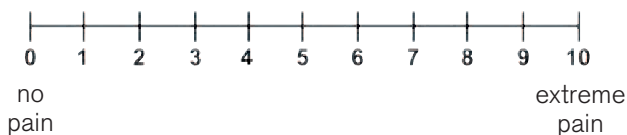
Prevalence of pain

While reported rates of pain have been as low as 28 percent and as high as 90 percent, the vast majority of studies that have been conducted indicate that anywhere from 43-80 percent of people with MS report MS-related pain. This variability, while confusing, may be explained by the fact that research studies use different sources for obtaining

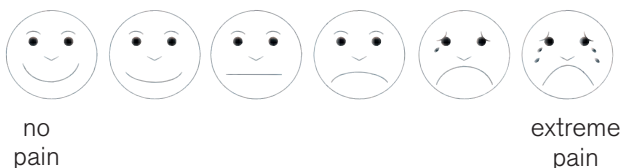
Tools to measure pain

In order to determine the optimal treatment strategy for pain experienced by people with MS, a comprehensive assessment of all aspects of the symptoms needs to be undertaken.

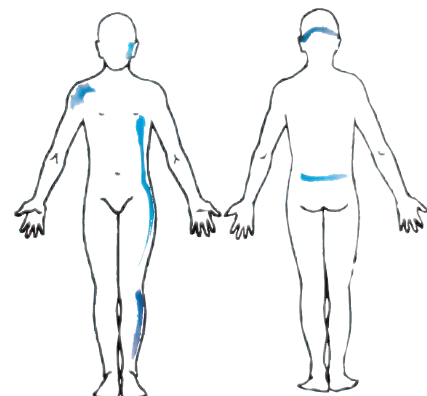
Numerical rating scale



Visual analogue scale



Pain body map



A pain map can be used to locate MS-related pain.

participants (for example, hospital versus outpatient clinic) and different methods for selecting which participants will be surveyed (referred to as “sampling”). According to several European studies and at least one US study, pain problems may occur more frequently and with greater severity in people living with MS relative to the general population.

Classifying MS-related pain

The World Health Organization classifies pain syndromes as nociceptive and neurogenic (or neuropathic). Nociceptive pain occurs as an appropriate physiological response transmitted to a conscious level when nociceptors in bone, muscle or any body tissue are activated, warning a person of tissue damage, and in turn, eliciting coordinated reflexes and behavioural responses, such as the quick removal of a hand from something hot. Neurogenic pain in MS is typically initiated by a primary lesion or dysfunction in the peripheral or central nervous system, which has no biological advantage (such as warning) but causes suffering and distress. Clinical hallmarks are a burning, piercing pain, allodynia (a painful response to non-painful stimuli), and/or hyperalgesia (an increased

response to painful stimuli). In MS, some types of pain can be experienced over a long period of time or can be intense but brief. Many people living with MS experience both.

Measuring MS-related pain

Researchers and clinicians measure a number of features of MS-related pain. *Pain intensity* refers to how much a person hurts. This is usually assessed by asking a person to rate how intense or severe their pain has been during a specified time period on a 0-10 scale, where 0 = “no pain” and 10 = “pain as bad as it could be.” This type of scale is referred to as a numerical rating scale (see page 8). Visual analogue scales and verbal rating scales can also be used to measure pain intensity. Visual analogue scales typically have images that represent levels of pain or a straight, horizontal line with one end

“Pain problems may occur more frequently and with greater severity in people living with MS relative to the general population.”

Here are some questions that can help health care professionals better understand the pain experience:

- Where is the pain located? Which part of the body?
- How long does the pain last?
- How frequently does the pain occur?
- How would you describe the pain you experience? (Since describing pain can be difficult for some people, it is helpful to provide examples of descriptive words, such as burning, stabbing, throbbing, etc.)
- How intense is the pain? (In assessing intensity, it is helpful to use a visual or other type of analogue scale – for examples see left.)
- Does the pain prevent you from performing any usual activities such as working, socialising, leisure activities or household chores?
- Have you noticed anything that you do that worsens or improves the pain?
- How much would you say pain affects your daily life? (In assessing the impact of pain, it is helpful to use a visual or other type of analogue scale – for examples see left.)
- How would you rate the effect of your current treatment on pain relief? (In assessing the efficacy of treatment, it is helpful to use a visual or other type of analogue scale – for examples see left.)

indicating “no pain” and the other end indicating “worst pain” (see page 8). Individuals are then asked to mark where on the line their pain falls. With verbal rating scales, people with MS are presented with a list of words that describe various levels of pain intensity. They are then asked to circle which word best describes the intensity of their pain.

It is important to find out not only where a person feels pain (the *pain location*) but also what the pain physically feels like (referred to as *pain quality*). These are most often assessed by simply asking an individual to describe where they hurt and what it feels like. For example, a person with MS might describe pain in their legs that is dull and aching, while another person may describe pain in their face that is sharp and stabbing.

Pain affect refers to how unpleasant or how bothersome the pain is. Pain affect taps into the emotional component of pain; in other words, how much distress or disruption the pain causes. For example, an athlete in the midst of running a marathon may rate her pain intensity as a 7 on a 1-10-point scale, but be so mentally focused on

finishing the race that she rates her pain affect as a 2. Or, an air traffic controller with a mild headache may rate his pain intensity as a 3, but find it so bothersome due to the demands of his job, that he rates his pain affect as an 8. Pain affect can also be assessed using numerical rating, visual rating, and visual analogue scales.

Pain interference refers to how much pain interferes with or gets in the way of participating in daily activities. Pain interference is typically assessed by providing people with a list of common activities (such as work, sleep, leisure) and then asking them to rate how much their pain interferes with these activities on a 0-10 scale, where 0 = “no interference” and 10 = “unable to carry on activities”.

Conclusion

In summary the understanding and measurement of MS-related pain has grown and improved tremendously in the last decade. Continued research will help to provide the tools needed for physicians and therapists to help people with MS to manage their MS-related pain in new, effective ways.



Neurogenic pain in MS

Claudio Solaro, MD, Department of Neurology, ASL 3 Hospitals, Genoa, Italy

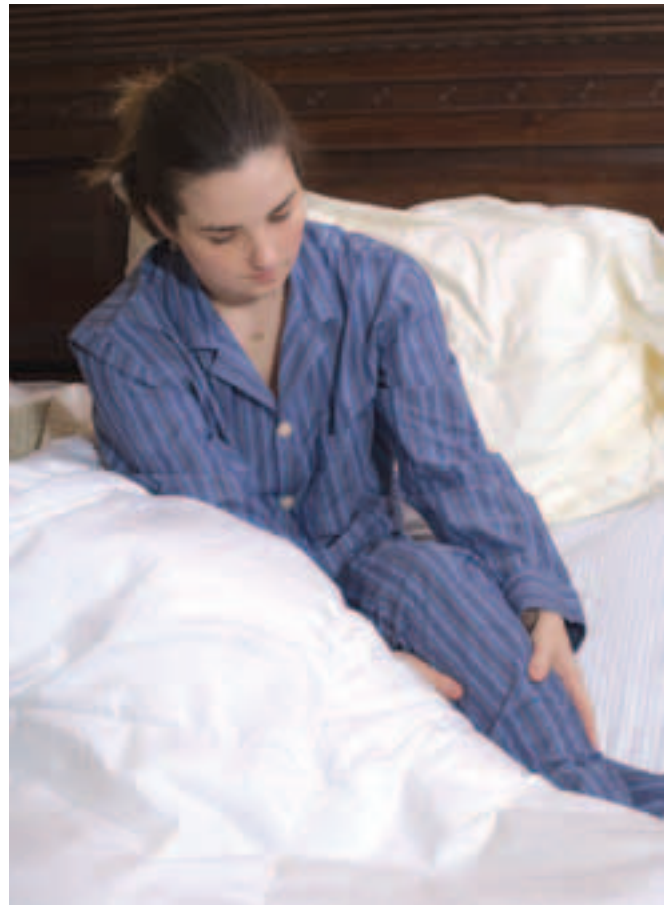
Introduction

Pain is defined as an “unpleasant sensory experience associated with actual or potential tissue damage or described in terms of such damage”. Although symptom management in MS represents a primary focus for health care professionals, data available in the literature on pain management is lacking. Neurogenic pain common in MS includes dysesthetic pain, trigeminal neuralgia, painful tonic spasms and Lhermitte’s sign. Ethical issues regarding studies on pain make it difficult to identify the best treatment strategies based on comparisons of medication versus a placebo. Thus, for many of these symptoms treatment is based on anecdotal information and small, unblinded trials.

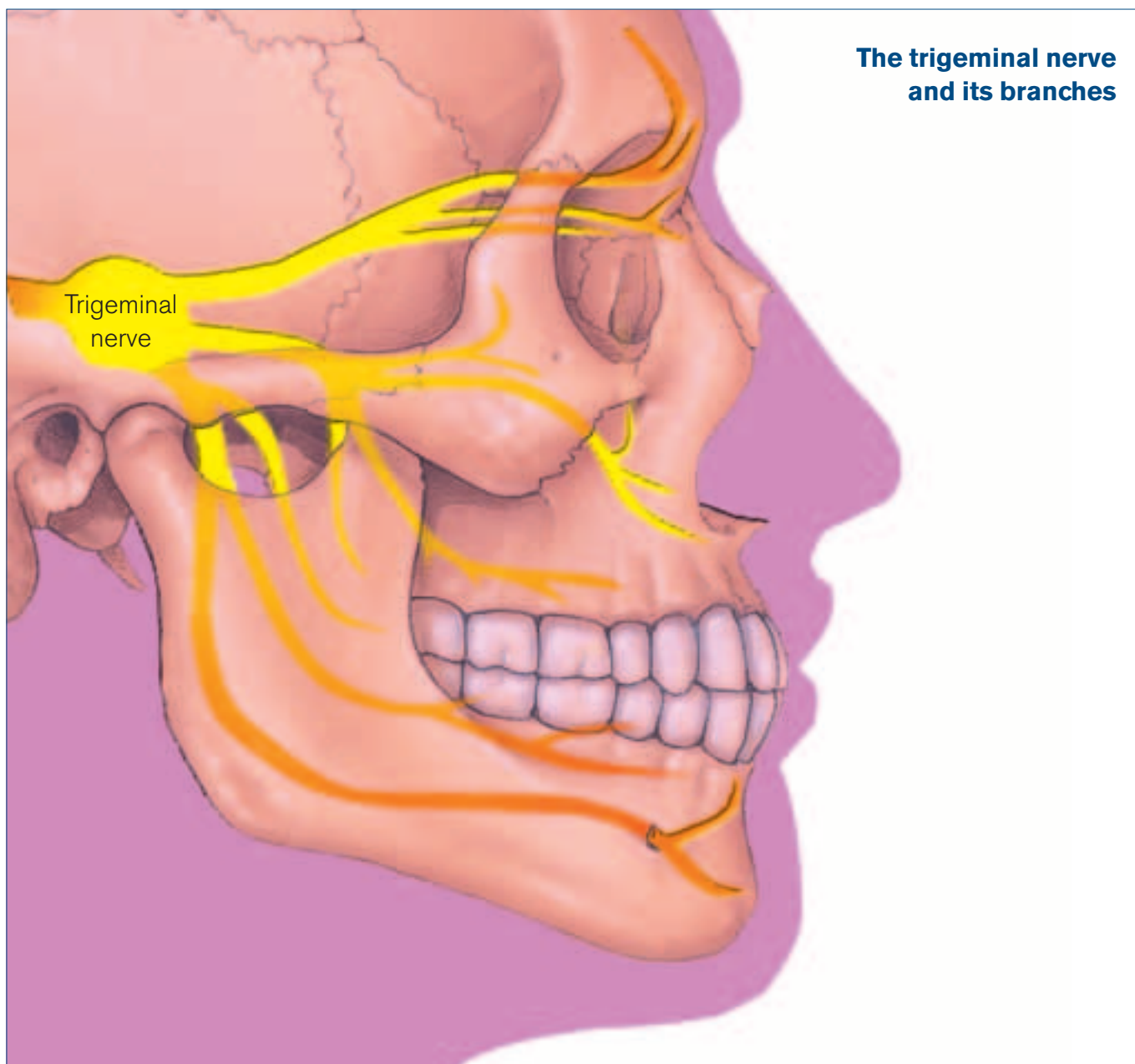
Dysesthetic pain

A number of studies have reported dysesthetic pain to be among the most common pain syndromes associated with MS. Dysesthetic pain is described as a constant symmetric or asymmetric burning sensation, usually affecting a person’s lower limbs, more frequently distally (meaning farther away from the body, such as in the feet and lower legs) than proximally (meaning closer to the body, such as in the upper part of the legs). A degree of sensory loss associated with dysesthetic pain can be detected during a neurological examination.

First-line medications for the treatment of dysesthetic pain in MS are tricyclic antidepressants, including amitriptyline, nortriptyline and clomipramine. Anticonvulsant medications such as



carbamazepine, lamotrigine and gabapentin are also used in treating dysesthetic pain associated with MS. Carbamazepine appears to have a higher incidence of side effects, when compared to gabapentin and lamotrigine. Some people have difficulty tolerating this medication due to its side effects, and are not able to even reach the dose necessary for the medication to be effective. It is not uncommon for a person to try different medications before finding one that is effective and tolerable.



Open communication with the neurologist is very important throughout this process.

In general, anticonvulsant medications, as well as tricyclic antidepressants, may be useful in some MS patients, although unfortunately there is not enough data available from studies with large numbers of participants, which is necessary for drawing conclusions as to the best choice of medication.

Trigeminal neuralgia

Trigeminal neuralgia (TN) is probably the most widely recognised neurogenic pain syndrome in MS. It affects the trigeminal nerve, one of the

largest nerves in the head (see above). The trigeminal nerve sends impulses of touch, pain, pressure and temperature to the brain from the face, jaw, gums, forehead and around the eyes. TN in people with MS has been widely studied, with prevalence ranging from 1.9 percent to 4.4 percent. TN is characterised by paroxysmal (sudden), episodic facial pain which occurs in the area of the fifth cranial or trigeminal nerve, often triggered by touch, chewing, shaving or even a light breeze.

TN in MS and essential TN (TN not related to MS) differ in that TN in MS is more often bilateral

(occurs on both sides of the face) and tends to occur at a younger age. Essential TN is most frequently caused by a blood vessel pressing on the nerve near the brain stem. Over time, changes in the blood vessels of the brain can result in a blood vessel rubbing against the trigeminal nerve root. The constant rubbing with each heartbeat wears away the insulating membrane of the nerve, resulting in nerve irritation. TN in MS is likely to be caused by a plaque at the TN nerve entry zone in the nerve fibres on the lower front surface of the brain. However, magnetic resonance imaging (MRI) studies have demonstrated conflicting results, pointing to multiple causes of TN, even in the same person with MS. Treatment of TN primarily consists of anticonvulsant medications. Some antidepressant drugs can also be helpful in relieving this type of pain.

Non-pharmacological interventions for trigeminal neuralgia

When medications are ineffective or if they produce undesirable side effects, neurosurgical procedures are available to relieve pressure on the nerve, to reduce nerve sensitivity or to interrupt the nerve pathway. These procedures have been reported as treatment for TN associated with MS, although with small numbers of people and limited follow-up. These techniques can cause nerve damage which may lead to increased sensitivity or numbness in the affected area, decreased corneal reflex, temporary difficulty chewing and hearing loss.

Painful tonic spasms

Painful tonic spasms (PTS) are described as a cramping, pulling pain and can affect both the upper and lower limbs, although they are more common in the lower extremities. The spasms are triggered by movements or sensory stimuli, often occurring during the night. PTS are estimated to occur in approximately 11 percent of people with MS.

PTS indirectly result from a lesion triggering the painful spasms in the central nervous system. Antispasticity medications, such as baclofen and

Optic neuritis

Painful optic neuritis is not neurogenic in nature and is probably a unique kind of pain. It is characterised by inflammation of the optic nerve, with pain occurring behind the eyes which is intensified with eye movement. In addition to pain, optic neuritis can be accompanied by blurred vision, visual acuity loss, impaired colour vision and complete or partial loss of vision. Corticosteroids (oral prednisone and intravenous methylprednisolone) can significantly increase the rate of recovery from optic neuritis.

benzodiazepines, gabapentin and tiagabine, are largely used for the treatment of PTS.

Lhermitte's sign

Lhermitte's sign, a short-lasting paroxysmal (sudden) pain radiating down the spine to the lower extremities triggered by flexing or extending the neck forward, is strongly linked to MS. It is experienced by approximately 40 percent of people with MS at some point throughout the disease course. If the phenomenon becomes persistent, small doses of carbamazepine have been recommended for reducing the frequency and severity. Often people with MS who experience this symptom do not require medication.

Conclusion

Neurogenic pain in MS is variable with different treatment strategies. Often these painful symptoms can have a negative impact on a person's quality of life, and therefore require involvement of the neurologist and health care team in order to identify and treat them as effectively as possible. Achieving relief for neurogenic pain in MS may require trying different medications and dosages before identifying the most effective solution. Since many types of pain common in MS are difficult to treat effectively with standard medications, clinicians should also be open to discussing non-standard strategies for improving pain relief.

MS pain and

Carolyn Young, The Walton Centre for Neurology and Neurosurgery, Liverpool, UK

Pain is common in MS, affecting most people during their disease course, sometimes severely and often persistently. There are interesting results from research which compares pain in all people with MS in a defined geographical area, and age and sex matched controls or national data. The prevalence of pain is similar between MS and non-MS populations, but in MS, pain may be more severe and produces more impact on daily life.

A large sample of people with MS drawn from the North American Research Committee On Multiple Sclerosis (NARCOMS) Patient Registry showed that severe pain was more common in women, in those with MS-related disability and in individuals without higher education. Severe pain was perceived to interfere with many aspects of daily life, notably recreation, work and mobility.

Whether analysing an individual or a population, it can be difficult to understand the relative significance of different types of pain, to quantify pain, and to understand its impact on a person. One way to understand the impact of pain is to study health-related quality of life in people with pain.

Health-related quality of life

Quality of life is a complex concept, often difficult to define. For health-related studies, general concepts such as life satisfaction or living standards are not primarily considered. Instead researchers examine aspects of personal experience that might be related to health and health care. Domains that people consider important include pain, mobility, activities of daily living (ADL), relationships, work, dependence, body image and the future. Most published quality of life scales measure some of these but none all. However, pain is frequently included.

Measurement of health-related quality of life

Health-related quality of life measures can be generic or disease-specific. Generic measures include areas like pain or mobility which are widely



quality of life

acknowledged to influence health-related quality of life. Generic measures are often familiar to a wide audience and results can be used to compare health-related quality of life between different conditions. Examples of commonly used generic health-related quality of life measures are the SF36, EuroQol and the Nottingham Health Profile. However, studying aspects of quality of life which are associated with a specific condition require a disease-specific health-related quality of life scale. For MS these include the Functional Assessment of MS (FAMS), or two scales based on the generic SF36; the MS Quality of Life health survey (MSQoL 54) which adds 18 additional items relevant to MS, or the MS Quality of Life Index (MSQoLI) which adds nine additional items.

The influence of pain on quality of life

The relationship between pain and health-related quality of life is complex and not fully understood. Health-related quality of life examined in population-based studies, which compare all people with MS in a specified area to national statistics, report that the physical function, vitality and general health domains of people with MS are worse than the general population. Other research has shown that in MS, mental health correlated with pain, and that anxiety and depression in women were significantly related to chronic pain. Unpublished British data suggests that people with MS with pain have less energy than those without pain. In summary, the available data suggests that in MS, health-related quality of life may be worse in terms of physical function and energy and, if chronic pain is experienced, mental health may be adversely affected.

Nevertheless these studies also show that health-related quality of life in MS may be relatively well

preserved, with the majority of people satisfied with their quality of life. Researchers in quality of life have long realised that the measured quality of life of groups may be higher than healthy observers would anticipate. For example, 50 percent of a sample with moderate to severe disability experiencing ADL problems, social isolation and limited income reported at least a good quality of life, and people with peritoneal dialysis or haemodialysis showed higher quality of life than the general population. This disability paradox is explained in part by a response shift – that is, the frame of reference by which a person judges quality of life may change over time.

It is important to acknowledge the complexities of analysing the causes of pain, its relation to MS, measuring pain and relating pain to quality of life. Apart from understanding the difficulties of measuring quality of life over time, research suggests that if quality of life is used as an outcome measure for an intervention, anxiety and depression must also be assessed as they influence the relationship between disability and quality of life.

We need to consider how pain impacts on disability and quality of life. Pain, like fatigue and mood, is not well measured in most disability scales. Therefore, assessing disability using these scales will underestimate issues like pain or fatigue that are important to people with MS. Pain may also directly influence an individual's participation in life. This may be because physical discomfort causes social withdrawal, or because pain worsens mental health (or poor mental health worsens pain and participation). It is clear that careful studies are needed to unravel these relationships.

Promising psychosocial treatments for pain in MS

Dawn M Ehde, PhD, and Brenda Stoelb, PhD, Department of Rehabilitation Medicine, University of Washington School of Medicine, Seattle, Washington, USA

For some people with MS, medications provide complete relief from pain. However, many pain sufferers do not achieve adequate pain relief by pharmacological means. Fortunately, medications are not the only treatment option available for MS pain. A number of non-pharmacological approaches can be used that have been proven to be effective in other groups of people with chronic pain.

The biopsychosocial model of pain

The experience of pain is very complex, involving not only the body but also the mind. Current thinking is that chronic pain is best understood from a biopsychosocial perspective, which recognises the importance of the underlying biological basis of pain (for example, nerve damage due to MS). However, it also acknowledges that psychosocial factors may have a significant impact on the experience of pain and its effects on life. Some of these factors include one's emotional reactions to pain and how one thinks about or deals with pain. The biopsychosocial model has led to treatments that are effective for decreasing pain severity and the negative impact of pain.

People with pain sometimes worry that others think that their pain is "not real", exaggerated, or a sign of mental illness. On the contrary, chronic

pain is a serious condition that is "in one's head" only because pain signals are processed in the brain. Advances in brain science have confirmed that psychological factors such as one's emotions or stress can affect physical health, including pain. Living with MS and pain can also cause chronic stress. The brain (mind) and body influence one another in ways that science is just beginning to understand.

Relaxation training

Pain and other stressors often result in a natural response of repeated and prolonged tensing of muscles, which tends to worsen pain. Research has shown that one of the best ways to counteract the tensing effects of pain and stress is to practice various forms of relaxation. There are many methods to achieve relaxation – deep breathing, baths, music, meditation or prayer for example. Some relaxation strategies can be tried without instruction, whereas others may need to be learned under the guidance of a professional.

People vary in their ability to relax, so trying a variety of relaxation techniques may be necessary to find what works best. Relaxation exercises may also work best when paired with other coping strategies.

"One of the best ways to counteract the tensing effects of pain and stress is to practice various forms of relaxation."

Deep breathing is the basis for many relaxation techniques, so it is often a good skill to learn first. It is generally done lying down or sitting in a comfortable chair. The basic method involves



taking a deep breath through the nose, trying to cause a rise in the abdomen, followed by a brief pause, and then exhaling through the mouth. To heighten the sense of relaxation, some people say calming words to themselves, such as “relax” or “peace” on each exhalation. To achieve maximum benefit, deep breathing should be practiced for at least five minutes, several times per day.

Self-hypnosis training

Research published over the past decade supports the benefits of self-hypnosis training for helping individuals better manage both acute and chronic pain. Like relaxation training, self-hypnosis is a way to use the power of the mind to manage pain by altering the experience of pain. This may include distracting from pain, focusing

on more pleasant sensations, or even experiencing pain as decreasing or going away. Contrary to how hypnosis is portrayed in the media, people using self-hypnosis always remain in control of themselves. Training in self-hypnosis should be done with a professional experienced in its use for pain. It can often be learned in only a few sessions and should be practiced regularly to maintain benefits.

Like medications, self-hypnosis training rarely, if ever, eliminates pain completely; nor does it benefit everyone who tries it. However, there appears to be a subgroup of individuals, including those with MS, who report substantial decreases in pain severity following self-hypnosis treatment and who are able to maintain this improvement over time. In addition, unlike some medications,



Exercise can be beneficial in relieving pain.

the “side-effects” of self-hypnosis training are positive. For example, in a study that included people with MS, 40 different benefits of self-hypnosis were identified in addition to pain relief and no negative effects were reported.

Cognitive behavioural therapy

Numerous studies indicate that the way people think can have a big impact on how much pain

they experience, how they deal with pain, and how much pain interferes with their lives and functioning. Things people do to cope with their pain can also be helpful (for example, using relaxation techniques) or unhelpful (for example, using alcohol excessively to relieve pain). Cognitive behavioural therapy (CBT) involves teaching people how to change their pain-related thoughts and behaviours in order to reduce pain and its associated suffering. In CBT, individuals are taught to examine the thoughts they have about pain, determine whether these thoughts are helpful or unhelpful, and replace any unhelpful thoughts with helpful, reassuring ones. CBT often also includes teaching other pain management techniques such as relaxation training, distraction techniques, or activity scheduling. It typically involves either group or individual treatment by a professional with expertise in CBT, and optimally, pain.

Other psychological interventions

Other psychological treatments may be useful in addressing pain and its impact, including support groups, pain education, and psychotherapy. Treating depression, when present, is recommended, given that depression and pain often impact one another. Physical exercise (for example, walking, swimming, or yoga) often has beneficial effects not only on a person’s physical condition but also on pain and stress.

How to find help

Unfortunately, many people with MS pain are offered these treatments only after all medical treatments have been tried and found to be inadequate or ruled out. Psychological interventions should be considered early, soon after the development of pain, along with other appropriate and effective treatments such as medications or rehabilitation. The sooner these treatments are used, the more likely they are to be of benefit. For those who do not have access to specialists in the psychological treatment of pain, text and web-based resources may be available from your national MS society, or via your nurse or doctor.

Cannabis as a painkiller in MS: real or imaginary?

Claude Vaney, MD, Medical Director of the Neurological Rehabilitation and MS Centre, Montana, Switzerland

Marijuana, a forbidden but popular “medicine”

It is estimated that 15 percent of people with MS use the drug hemp (cannabis or marijuana) on a regular basis. Although cannabis does not modify the disease process of MS, many people believe that the drug relieves their symptoms such as stress, sleep disorders, muscle spasms and pain more effectively than any conventional medicine and they are willing to break the law for their belief. Does this relatively high prevalence of cannabis use among people with MS mean that they have found “the most valuable medicine we possess” as the famous 19th century physician, Dr J Russell Reynolds, said? Or are they vulnerable people who are victims of a hoax?

An ancient painkiller banned

Cannabis has been known as an analgesic agent for more than 4,000 years and belongs to the plant-drug group that, along with coca and opium, remains in use today. The plant was introduced into European medicine from India in 1842 to relieve pain, muscle spasms, convulsions of tetanus, rheumatism and epilepsy and was used medicinally as *tinctura cannabis* well into the 20th century. But because of quality control issues and political pressure in a world of growing drug abuse, cannabis was eliminated from the modern Western pharmacopoeia in 1961 when the United Nations Single Convention on Narcotic Drugs decided that cannabis had no medical or scientific benefit. No wonder – nobody knew at that time that the human body possesses its own endocannabinoid system with analgesic properties!

How does this endocannabinoid system work?

Tetrahydrocannabinol (THC) is largely responsible for the psychopharmacological properties and physical effects of cannabis. Interest in therapeutic uses for cannabinoids increased after the discovery of a human cannabinoid receptor (CB1), anandamide. Anandamide, naturally present particularly in the brain, is a neurotransmitter that targets the same brain structures as THC, the active ingredient in cannabis. Neurotransmitters are the chemical messengers of the brain. They work by transporting electrical signals between nerve cells. These signals cause changes in the sensations and emotions that we experience. Additionally, CB1 receptors are found on pain pathways in the brain and spinal cord and also outside the central nervous system, and are



thought to be involved in cannabinoid-induced analgesia (perceived pain reduction). However, the precise way in which cannabinoids produce analgesic effects at these sites remains unclear.

Cannabis studies

Following a recent trial, Sativex®, a cannabis extract which is sprayed in the mouth (see photo below) and contains equal amounts of THC and cannabidiol (another cannabinoid of the hemp plant) received approval in 2005 in Canada for the symptomatic relief of neurogenic pain in MS. In the trial, 66 people with MS experiencing painful spasms or dysesthetic pain (uncomfortable sensations such as pins and needles, burning pain, numbness or tightness) received either a cannabis-based medicine or placebo in the form of a mouth spray. Pain and sleep disturbances were recorded on a visual analogue scale. The treatment group reported a reduction of 2.4 on an 11-point pain scale (0-10), while the placebo group report a reduction of 1.4 points. The participants also reported a similar improvement in sleep (Rog DJ et al., *Neurology* 2005).

The analgesic properties of THC were also examined in a 2004 Danish study where 24

participants with MS who had received THC reported an improved quality of life and felt a reduction of their pain (Svendsen KB, *BMJ* 2004). The participants of the large CAMS study in the UK who took cannabis capsules reported an improvement in spasticity and sleep, and also in pain. Finally a recently published Canadian meta-analysis of cannabis-based treatments for neurogenic and MS-related pain involving 298 patients concluded that cannabinoids were effective in treating neurogenic pain in MS. This review however, was based on a small number of trials and subjects (Iskediyan M, *Curr Med Res Opin* 2007).

In the future – overcoming the barrier of psychoactive side effects

Alongside the positive effects on pain symptoms reported in these different studies, it was also noted that the use of cannabis caused side effects, especially at higher doses, such as weakness, dry mouth, dizziness, mental clouding, short-term memory impairment and space-time distortions. These side effects may explain the high drop-out rates in some studies. Recent research studies have also suggested that excessive use of recreational cannabis in young people may lead to mental health problems. Finally, the double blind character of these studies has also been questioned because cannabis is psychoactive and tends to make people feel “high.” This means that people taking the active drug during a clinical trial usually become aware of it, thus, “unblinding” the study and possibly biasing results. This particular aspect has led some to think that the effects are only imaginary. Some practitioners believe that for people who can tolerate the drug, cannabinoids represent a valuable alternative when pain has not responded to other drugs.

In the future, the goal of new therapy development that focuses on the CB1 receptor should weigh the risk-benefit ratio of the treatment, because the current relationship between symptom relief and the psychoactivity of cannabis is unbalanced. Cannabis continues to be a controversial treatment in MS and remains illegal in many countries.



Your questions answered

The Editor, Michele Messmer Uccelli, answers your questions on pain and MS.

Q. I have tried using medication to relieve back pain but it is not working, despite my doctor's best efforts. I find exercise – especially swimming – helps sometimes but not always. Are there any other complementary approaches that might be able to help?

A. Since medications for pain are not always effective when used alone, adding a complementary therapy seems to be helpful for some people with MS in optimising pain relief. In addition to these, a few studies have been conducted on chiropractic therapy for pain for people with MS. Spinal manipulation was commonly used and people with MS often reported pain relief. Further, chiropractic management of chronic pain specifically in MS using manipulation has been reported to be effective for low back pain, although this is based on anecdotal accounts from pain sufferers and not based on well-designed trials. A physical therapist or rehabilitation physician should be able to help you assess whether this complementary approach to treating your back pain is right for you.

Q. For about a month I've been experiencing occasional sharp pain in my left breast. People in my MS support group told me that pain is common in MS and that it's probably related to my disease. Should I be worried that it's something else, or is it probably just MS?

A. Breast pain has not been associated with MS in the literature as a type of pain related to the disease. Remember that having MS unfortunately does not safeguard people from other illnesses. It is important that you speak

with your general practitioner about the pain you are experiencing so he or she can advise you on what you should do.

Q. My doctor doesn't seem to take my pain concerns seriously and hasn't really acknowledged that it is part of my MS. What should I do?

A. Pain has not always been acknowledged as a symptom related to MS and some people with MS may find it hard to explain the pain they are feeling. The result of this may be that many physicians, particularly general practitioners, are not familiar with the fact that people with MS can experience pain of different types and origins, or that MS pain is often neurogenic in origin. Whether we're talking about a general practitioner or other health care professional, you can have an important role in educating him or her about your disease. Many MS societies have literature available on MS symptoms, of which pain is included. Helping your health care practitioner access this material may be one way in which you can actively arrive at a solution for having your experience with pain acknowledged and addressed.



Interview: living with pain and MS



Trevor Farrell, Executive Officer, Queensland MS Society, Australia and Australian representative on MSIF's Person's with MS International Committee, interviews **Stephen Papadopoulos** who experiences pain as part of his MS.

TF: Would you tell us a bit about yourself?

SP: I am 28 and I live in Sydney, Australia with my Mum and Dad. My family is from a Greek background and my two sisters and I had a happy and active upbringing. After I was diagnosed with MS in 2001 I took a year off from my magazine job just to deal with it all and then, after working for a while for a television company, I started getting involved at the MS Society. I became an MS Readathon presenter in 2003 and I work at the head office doing administrative work. I've also recently become an MS ambassador and an MS peer support worker, so I'm heavily involved and do as much as I can.

TF: Can you tell us about your diagnosis of MS?

SP: I got my first symptoms when I was 16 but I wasn't diagnosed with MS until I was 22. There were all these little things going on at different times. I got blurry eyes, stuttered my speech, had bad balance, a loss of sensation in my skin, and was very fatigued. At one point I had pins and needles across my whole body for eight weeks, 24/7. I didn't understand what was going on. Each time I went to

my doctor I had blood tests or was given tablets or it was suggested that I live a healthier lifestyle. But then in 2001, the symptoms all hit me at once. I went to a different GP who referred me to a neurologist. After an MRI, I was diagnosed with MS. I take my MS medication injections regularly. My symptoms are usually OK, but I've had some issues with pain, which I get as an exacerbation.

TF: What types of pain do you experience and how often?

SP: It started in 2004 as a sharp stabbing pain in my right kneecap. I thought I'd sprained it because I know that you can't blame everything on MS. My GP arranged an ultrasound and I was told it was inflammation caused by MS. Within a month it had spread up and down my leg and then started in my left leg in the same way. So since then I've had sharp stabbing pains constantly in both my legs. In January 2006 I started getting a similar pain in the back of my neck – this feels like I'm being stabbed with a knife and someone has left it in there and every couple of minutes they give it a bit of a turn, just so I know it's there. It has been very hard to adjust to that. And then in about June 2006 I started getting sharp stabbing pains in the sides of my neck, in my arms,

and in my lower back. The lower back one has also been particularly hard to deal with.

TF: When you say it was difficult to deal with, could you describe to us how the pain impacts on your day-to-day life?

SP: I try not to let it affect me and to do everything as normal. But the biggest thing is that I can't drive for more than 15-20 minutes without my legs really hurting. This is annoying because if I get stressed, I like to jump in my car, turn the music on and go for a long drive, which I can't do now. I have to use public transport and at off-peak times so I have plenty of leg room and can move around. When I go to the cinema my legs hurt and I sometimes need to stand up or stretch them out. But I still play sport and go out clubbing and to work. I'm lucky because I have friends and family who offer to drive me.

TF: Does the pain affect the way you feel?

SP: It does, because all the pain medications I try are strong and all affect me very differently, including my mood. It takes a couple of days for my body to adjust and I get really moody – my friends say that MS stands for “Moody Steve”. Also I don't get a lot of sleep because the pain is worse at night when I am lying still. During the day I can move my legs around and it's not as bad, but when I'm lying in bed, I notice it so much more. I am lucky if I get three hours sleep a night, which of course makes me moody and tired.

TF: Have you tried using other approaches to pain relief such as complementary therapies?

SP: I meditate and do breathing exercises and listen to music which doesn't do a lot for the pain but it relaxes me and calms me down, especially when I'm trying to sleep.

TF: Do you find it easy to discuss pain with your neurologist or other health care professionals?

SP: With my neurologist yes; she is brilliant and is really concerned. She'll check up on me once a

month and see how any new medication is going and if there is any change and how I'm feeling. It is harder for my GP to see that I'm in pain. I can tell him what I'm feeling but I don't think he understands it because I say it with a smile on my face. To look at me you wouldn't guess that I'm in pain because I don't show it. So I think he finds it hard although he tries to help me as much as he can. But my neurologist has a different approach – she knows that the pain is there and that I just cover it up because if I'm not smiling and laughing then I'm crying. I definitely try to take the positive approach to life and my MS.

“This feels like I'm being stabbed with a knife and someone has left it in there and every couple of minutes they give it a bit of a turn, just so I know it's there.”

TF: Do you have any tips for other people who have similar experiences as you?

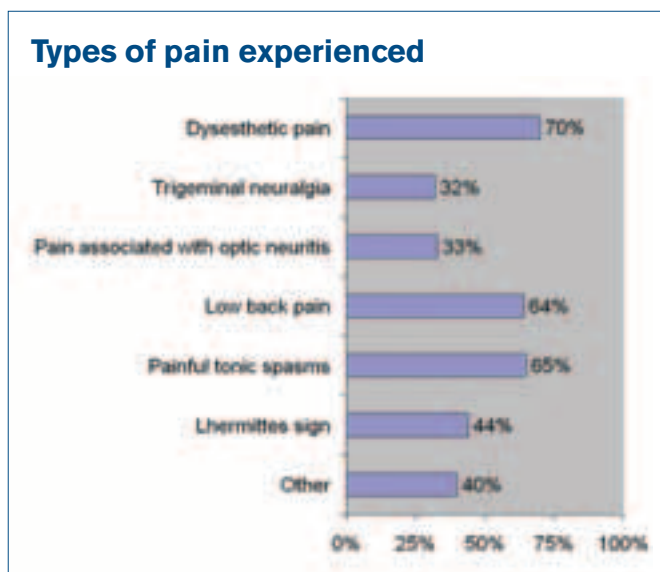
SP: I honestly don't know – often I am just grinning and bearing it myself. I did the whole sad, depression, feel-sorry-for-myself thing but it didn't suit me so I made myself be happy and enjoy life. Sure I can't drive long distances, but there are a number of people who are willing to drive me and do things for me. I'm very lucky in that way and I count my blessings. I'm so thankful for my friends and family. Little good things happen all the time, like if I win a CD or have fun hanging out with friends, and I think things aren't so bad. They could be much worse.

At the end of the day, I'm a happy person. I can walk, I can see, I can talk, I can work. I live a pretty normal life and that is something that I'm extremely grateful for. For me, the key has been doing things like meditation and relaxation. It is not something I would have done five years ago – I would have laughed and scoffed – but it works for me. Not for the pain, but it works to relax me and make me a happy person. I think that is what you have to do – find the trigger to get the balance. Even though you live with the pain 24/7, there are other things in life that can take priority.

Pain online survey results

A record high number of people – 763 – responded to the MSIF online survey about pain and MS, reflecting the importance of this subject for people with MS. The results show that people experience a wide variety of painful symptoms as part of their MS and that it has a big impact on their quality of life.

Three quarters of people surveyed felt that the pain they experience is related to MS, or in other words, was not a separate disease or problem, but part of their MS. The most common type of pain experienced was dysesthetic pain (burning pain), followed by low back pain and painful tonic spasms (see graph below).



More than 300 respondents also had types of pain that were not listed, including pain in specific parts of the body, such as toothache, genital pain or pain in the legs. Others reported tingling or pins and needles pain, sharp or shooting pains that radiate around the body or down the legs or back, painful skin such as the scalp when hair is brushed, headaches, muscular pain, a feeling of being pressed from the inside out, a feeling that parts of the body are frozen, or even whole body pain.

When asked to rate the effect of pain on quality of life, almost half of respondents (47 percent) rated the effect as 7 or higher (where 0 is no effect and 10 is an extreme effect), indicating the high negative impact pain in MS can have on day-to-day life.

Promisingly, 74 percent of respondents regularly discussed the pain they experience with their neurologist, nurse or other health professional, and the majority treated pain with medication (77

“The kind thing about my MS pain is that it travels and does not stay in the same place for too long!”

“I often wake up at night because of pain.”

“My muscles are very tight and painful all over my body. I'd say this pain is the single most hampering thing of my MS. It prevents me from walking more,

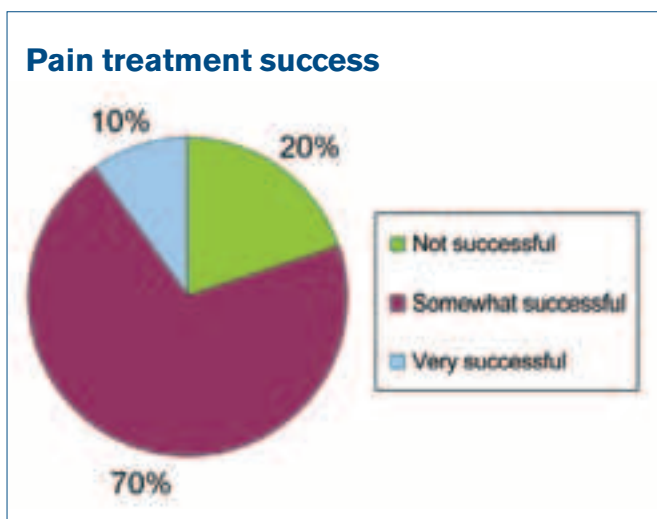
sleeping better, and generally living a better life.”

“My treatment is hit and miss as my doctor and nurses don't view pain as part of MS.”

“When I was first diagnosed with MS in 1981, pain was denied. Now much more information is available.”

percent). Other treatments were lifestyle changes such as exercise (39 percent), physical therapies (28 percent), and complementary therapies (24 percent) such as hydrotherapy, acupuncture, massage, reiki and meditation.

Amongst other responses were no treatment and just “living with it”, rest, heat or cold packs, using marijuana and using a TENS unit (see page 6). When asked how successful the treatment had been, only one tenth said it had been very successful, 70 percent said it was “somewhat successful”, while 20 percent said it had not been successful.



Almost half of respondents (47 percent) said that they had found it difficult to find information about pain and MS, compared with those who had found it easy (39 percent). 14 percent had not looked for information.

“I don’t think I have found a good information source because I have trouble describing some of the things that happen. I lack the knowledge of the disease and the correct vocabulary to describe it to my doctor.”

“Other friends with MS are often the best source of information. They get it.”



The main source of information about pain was found to be the Internet (80 percent), followed by MS society information booklets and materials (66 percent) and a doctor or nurse (60 percent). 14 percent of people answered “other”, with main sources including other people with MS (both at support groups and at online chat rooms or by email), books, journals and physiotherapists.

Conclusion

Pain is seen by many as a major part of their MS and a symptom that can adversely affect quality of life. The wide variety of pain-related symptoms and treatments listed by people gives an indication of the individual nature of pain in MS and the difficulty respondents and their health care team have in effectively treating pain.

“The information is there, but the treatments are not!”

“It is very frustrating at times when most of the information out there glosses over pain as a symptom. Not enough people report pain with MS to make it matter. It is my biggest symptom along with fatigue.”

Reviews

Neurological Rehabilitation of Multiple Sclerosis

*Edited by Prof Alan Thompson.
Queen Square Neurological
Rehabilitation Series.*

*Published by Informa Healthcare,
2006, 176 pages, price: £60.00,
ISBN: 9781841845593, ISBN-10:
1841845590.*

The book is written by professionals from a variety of backgrounds who are experts in the management of multiple sclerosis. The book aims to provide an evidence base for rehabilitation for people with MS.

There are six chapters, each with a list of references that are useful for MS professionals. The first chapter focuses on the mechanisms underlying disability and recovery in MS that are critical for effective rehabilitation. The chapter "The impact of living with MS: the need for a collaborative approach to care" reviews some literature and provides an insight into the reality of living with MS provided by testimonies from people with MS.

In the chapter "multidisciplinary rehabilitation" the author describes the roles of different rehabilitation professionals, the elements of the rehabilitation process and a concise literature review about rehabilitation treatment for each stage of MS (minimal, moderate and severe disability).

The fifth chapter is "measuring multiple sclerosis rehabilitation outcomes", and provides effective information on the main issues surrounding the use of rating scales in MS rehabilitation. The last chapter discusses clinical and organisational aspects of rehabilitation service delivery in MS.

There is a part dedicated to symptom management – mainly with pharmacological treatments. There are only a few rehabilitation indications because it is not a technical book for rehabilitation professionals.

This short book delivers the approaches and process required to ensure the comprehensive management of patients with MS in a concise and user-friendly fashion with the aim to be a resource for all people involved in the rehabilitation of MS.

*Reviewed by M Laura Lopes de Carvalho, MD
Physiatrist, Medical Director of Italian MS Society
(AISM) Rehabilitation Centre, Genoa, Italy.*



The MS Workbook: living fully with multiple sclerosis

*By Robert T Fraser,
George H Kraft,
Dawn M Ehde,
Kurt I Johnson.*

*Published in 2006, New Harbinger Publications,
Oakland, 243 pages, price: US\$19.95, ISBN 1-
57224-390-2.*

There are numerous MS self-help books, but this one is different. In most instances the book gives consideration to its claim to show that there can be a full life after being diagnosed with MS. And it offers a lot of ways of how to get there. It glances at the whole human being: emotionally, spiritually and physically.

There are 15 chapters including an introduction to the disease and its medication, alternative therapies, health promoting behaviours, time management, important aspects of psychotherapy

and job-handling, sexuality, partnership and financial planning. These combine to provide a basic knowledge for people recently diagnosed with MS who need guidance through the first irritations and confusions.

The layout is reader-friendly and well designed and the book is written in an easy-to-read style. Illustrations and quizzes help ease the reader through concentrated information. Checklists and worksheets help readers to evaluate specific situations and how to meet their individual needs. Some chapters are, however, too specific to the US for an international audience, particularly the chapter about Social Security.

Though there is a lot of information in the book, in some chapters there is not enough detail, for example in “perspective on psychotherapy” you would expect more precise information.

All in all, it is a valuable book that offers a wide range of ideas, advice, and proposals to find your own way to deal with MS.

Reviewed by Nicole Murlasits, Austrian MS Society magazine editor.



Living with Multiple Sclerosis

By Christine Craggs-Hilton.

*Published by Sheldon Press,
price: £7.99, paperback,
ISBN 0-85969-982-X.*

Living with MS is one of the Sheldon Press's Overcoming Common Problems series, which runs to more than one hundred titles. The author does not have MS, nor give any indication that she has any background in MS, but has written on health issues after developing a chronic pain condition.

The book, which is 130 pages long, claims to provide “a straightforward, accessible guide” to

MS “and how best to live with it”. It aims to cover all the bases, with chapters including symptoms, diagnosis, treatment options, diet, causes and complementary therapies.

There are a number of problems with the book. Most controversially, it puts too much emphasis on diet as being the main cause of MS, being so bold as to claim “the main trigger is believed to be dietary in nature” whilst allowing for “other possible triggers”. In the chapter on diet, we are told, “for a number of people with MS, eating the type of foods that early man ate can halt the progression of the condition” before going on to recommend the “Palaeolithic Diet”.

In fact, the book is a giant plug for the so-called ‘Best Bet Diet’ that has been promoted in the UK by Dr Ashton Embry and the MS Resource Centre. After theorising (without presenting any substantial evidence) about the role of diet in MS, the book then goes on to give a list of culinary dos and don'ts: no to dairy products, wheat, gluten, beans, eggs and sugar; yes to white meat, fish, fruits and vegetables.

The book is not without some strengths. The section on symptoms is relatively comprehensive as are the sections on complementary therapies and emotional responses. However, in general the negatives outweigh the positives. Given the lack of substantial evidence, the book is too focused on diet as a cause and remedy.

It is also poorly indexed, would benefit from some graphics, and gives a very limited list of scientific references, indicative of the fact that there is generally little evidence referenced throughout.

In summary, the book is a compact survey of cause, symptoms and remedies but is too confident in its assertions without presenting sufficient evidence that diet is at the heart of the solution for people with MS.

*Reviewed by Ian Douglas, MSIF volunteer,
London, UK.*

MS *in focus*



multiple sclerosis
international federation

Skyline House
200 Union Street
London
SE1 0LX
UK

Tel: +44 (0) 20 7620 1911
Fax: +44 (0) 20 7620 1922
www.msif.org
info@msif.org

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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.