

● Complementary and alternative therapies in MS



Editorial Board

Multiple Sclerosis International Federation (MSIF)

MSIF's mission is to lead the global MS movement to improve the quality of life of people affected by MS and to support better understanding and treatment of MS by facilitating international cooperation between MS societies, the international research community and other stakeholders.

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 and facilitate international cooperation and collaboration in research into the understanding, treatment and cure of MS

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Letter from the Editor



Complementary and alternative medicine (CAM) use in MS is a topic of truly international relevance. Around the world, CAM is widely used by those with MS. However, despite this widespread use, there are significant challenges for people with MS who are interested in CAM.

Specifically, in many countries, conventional medical practitioners, including MS specialists, may not be able to provide CAM information to people with MS because they lack knowledge and experience in this area. Furthermore, other common sources of health information, such as books and the internet, may provide CAM information that is inaccurate or potentially dangerous for those with MS.

This issue of *MS in focus* is devoted to providing objective, practical, MS-relevant CAM information.

The article by our Guest Editor, Dr Allen Bowling, provides a broad overview of CAM and highlights MS-relevant CAM therapies that are especially promising as well as those that may be dangerous or ineffective. Subsequent articles, written by CAM experts from different countries, focus on specific CAM therapies or practical strategies for using CAM.

I would like to thank Dr Bowling for his assistance with this issue and for his help in ensuring that it covers the most relevant topics around CAM and MS. I hope that the articles will help facilitate wise decision-making about CAM for people with MS.

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 Employment and 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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Complementary and alternative medicine: A globally important topic in MS

Allen Bowling, Medical Director, Multiple Sclerosis Service and Director, Complementary and Alternative Medicine Service, Colorado Neurological Institute; Clinical Associate Professor of Neurology, University of Colorado-Denver and Health Sciences Center, US

Many different terms are used in the area of complementary and alternative medicine (CAM). A broad term is *unconventional medicine*, which refers to therapies that are not typically taught in medical school or generally available in hospitals. The terms *complementary* and *alternative* indicate the way in which these unconventional therapies are used – *complementary* therapies are used *in conjunction with* conventional medicine, while *alternative* therapies are used *instead of* conventional medicine.

Since CAM is defined in relation to conventional medicine, the definition is relative and highly dependent on when and where one lives. This concept is made clear in a definition of CAM used by the US National Institutes of Health: "... healing resources...other than those intrinsic to the politically dominant health system of a particular society...in a given historical period". This definition highlights the international



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Medical traditions and cultural attitudes may shape the way in which diseases are diagnosed and treated.

relevance of this subject and raises important issues about how medical traditions and cultural attitudes may, sometimes in a manner that may not be readily apparent to health professionals or

people with MS, shape the way in which diseases are diagnosed and treated within conventional medicine.

CAM use in MS

Studies in many different countries have documented that CAM use is common in MS. In the United States, about one half to three quarters of people with MS use some form of CAM. One quarter to three quarters of people with MS have been reported to use CAM in studies conducted in Europe, Canada, and Australia. A consistent finding in these studies is that most people with MS use unconventional medicine in combination with conventional medicine. In other words, most people with MS appear to be using unconventional medicine in a complementary manner.

Sources of information on CAM

There is significant concern about the quality of some CAM information. Specifically, people who provide CAM information may have biases, financial incentives, or limitations in their knowledge base that lead them to provide inaccurate, and sometimes dangerous, information. For example, people who are only knowledgeable about a few CAM therapies may, without evidence, make those therapies relevant to an excessively wide range of diseases, including MS. Also, people with financial interests in specific CAM products or services may provide information that is excessively supportive of those therapies. Finally, people with little or no specific knowledge of MS and MS medications may apply CAM therapies to this complex disease in a way that is incorrect or overly simplistic. The article on page 20 provides practical guidelines for evaluating CAM therapies.

Potentially beneficial therapies

In MS, there are two major types of therapeutic effects that may be produced by conventional as well as unconventional therapies. One type of effect, known as “disease-modifying”, acts to slow down the disease course, while the other type, known as “symptomatic”, decreases the severity of

MS symptoms, such as fatigue or muscle stiffness.

Several CAM therapies that may provide symptomatic effects in MS are reviewed in this publication. Yoga may relieve MS fatigue, while various mind/body approaches may be beneficial for several symptoms, including anxiety, depression and pain. Acupuncture and traditional Chinese medicine may also provide symptomatic effects, as may music therapy.

There are some CAM therapies that may have both symptomatic and disease-modifying effects. Vitamin D, which is an effective treatment for an MS-associated condition, osteoporosis, may also slow down the disease course of MS. Cannabis may have a disease-modifying effect and may alleviate multiple MS symptoms, including muscle stiffness and pain. Low dose naltrexone has been suggested as potentially useful in MS.

All these therapies are discussed in this issue of *MS in focus*.

Ineffective or potentially harmful therapies

There are some dietary supplements that raise safety concerns for people with MS. Several supplements are sometimes recommended for MS despite the fact that they have no known benefit in MS and may actually produce serious side effects. Supplements in this category include skullcap, germanium, chaparral and comfrey, all of which may produce serious kidney or liver toxicity. Serious liver toxicity is also associated with kava kava, a herb that may alleviate anxiety.

Specific MS concerns are raised by dietary supplements that stimulate the immune system. MS is characterised by excessive immune system activity, and MS disease-modifying medications typically produce their therapeutic effects by inhibiting the immune system. Thus, dietary supplements that stimulate the immune system could worsen MS or interfere with the therapeutic effects of MS medications. Echinacea is one of the most widely known “immune-stimulating” supplements. Another is an Ayurvedic herb,



Italian MS Society

If you decide to try a CAM, discuss it with your neurologist or MS nurse.

ashwagandha, which, for unclear reasons and with no supporting evidence, is sometimes recommended for MS. Other common immunostimulating supplements include alfalfa, astragalus, cat's claw, garlic and Asian and Siberian ginseng.

There are some CAM therapies that have undergone clinical testing in MS and have been found to be ineffective. Nevertheless, these therapies are still sometimes claimed to be helpful for MS and marketed to people with MS. CAM therapies that have been found to be ineffective in MS are hyperbaric oxygen (HBO) and bee venom therapy.

A new medicine?

Exploring conventional and unconventional

therapies highlights how diagnosing and treating disease is often shaped by the medical and cultural attitudes of a particular country. This shaping process may lead to medical practices that are accepted within a country because they are suited to the prevailing attitudes and traditions. However, those practices may not be ideally suited for all individuals living within that country. These practices may be restricted in scope, thus limiting the range of therapies that are offered and potentially impacting the quality of care that is provided. It is possible that treatment for many people with chronic diseases, including MS, could be improved by taking a more holistic or "global" approach that broadens the range of therapies beyond those that, within a particular country, are traditionally viewed as conventional and appropriate.

Acupuncture and Traditional Chinese Medicine in MS

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Traditional Chinese Medicine (TCM) as practised today developed from a body of knowledge of an ancient healing system that first appeared in China in written form around 100 B.C.

This system describes human physiology and psychology in a similar manner to modern medicine. However, it also depicts the body and its function in terms of life energy called qi (pronounced 'chee') and the pathways along which the qi moves within the body, called meridians. TCM holds that the fundamental causes of illness are the blockage of meridians and imbalance of qi.

The TCM practitioner will first identify the meridians involved in the illness process and the nature of qi imbalance, based on the symptoms, then develop and implement a treatment plan, which often includes acupuncture and Chinese herbal medicine.

Qi

Qi is an essential concept in Chinese medicine. When used with the name of an organ or system, qi means the life energy that supports all the functions of that organ. For example, the heart qi keeps blood circulating throughout the body, and the blood qi is the nourishment the circulatory system provides to the body. Qi is also used to describe emotions, such as anger qi, or joyful qi. "Symptoms" of qi imbalances

include deficiency, stagnation, rebellion, and collapse. According to TCM, MS symptoms such as visual disturbance, dizziness, muscle twitches, and migrating pain are often due to liver blood deficiency. Memory loss, insomnia, lower back pain, incontinence and erectile dysfunction are believed to be caused by kidney qi and essence deficiency. Muscle weakness and atrophy, fatigue, indigestion, lack of mental clarity and bruising easily are thought to indicate spleen qi deficiency.

The nature of qi is also categorised as *Yin or Yang*. Yin qualities include cold, stillness, and physiologic processes involved in nutritional support, while Yang qualities include heat, moving and physiologic processes involved in function. In the normal state of health, Yin and Yang are in balance with each other.

A TCM practitioner would interpret MS symptoms such as restlessness and involuntary movement of muscles and extremities as signs of Yang qi, which may be the result of too much Yang qi or too little Yin qi in the system. For the TCM practitioner, it is critical to differentiate these two conditions to tailor the most appropriate treatment.

We can see parallels to Yin and Yang in modern medicine, such as excitatory and inhibitory neurotransmitters in the neurologic system and

suppressing and stimulating cytokines in the immune system. Restoring the balance is the goal of acupuncture and Chinese medicine.

Diagnosis and treatment

Each person must be thoroughly evaluated by a well-trained and experienced TCM practitioner, who applies the comprehensive theoretical foundations and techniques of ancient Chinese medicine in the diagnostic and therapeutic process. According to Chinese medicine, people who have the same MS subtype may have a different qi imbalance and therefore require individualised treatment.

Acupuncture

Acupuncture is a tool to balance Yin and Yang,

open meridian channels that are blocked, remove qi stagnation, redirect rebellious qi and facilitate qi circulations to produce an effective therapy.

In treatment, the acupuncturist inserts sterile, disposable, fine needles on the surface of the skin at the point (often called acupoint) that is connected with particular meridians. Some people may feel a minimal sensation when the needle is inserted, while others experience a brief but sharp pain. After inserting the needle, the acupuncturist needs to touch and manipulate the qi, which will generate sensations such as dull aching, pressure, tingling and numbness that may also radiate along the meridians and may sometimes linger hours after the treatment. Side effects associated with acupuncture are



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extremely low. Minor adverse reactions include bruising at acupuncture sites, fatigue, needle pain, and bleeding. Serious complications are rarely seen and are often caused by negligent or poorly trained acupuncturists. Using a clean needle technique, avoiding vessels when inserting the needle and performing the treatment with the person in a relaxed position can reduce side effects.

Chinese herbal medicine

Chinese herbal remedies are an essential component of the healing process in TCM. Unlike many synthetic medications or vitamins, these remedies do not have specific biochemical targets from an isolated compound. While a herb may have many chemical agents, they are chosen based on the energy output of the whole. The treatments are selected based on the practitioner's evaluation of qi energy, yin and yang balance and other components of the diagnostic portion of the visit.

Chinese herbs should be used by an experienced practitioner and not indiscriminately because, according to TCM, the body's life system changes over time. Prolonged use should be evaluated at regular intervals to ensure that the treatment is continuing to promote harmony and balance. The qualities of herbal remedies vary with manufacturers and people should always consult a practitioner with experience in using these products.

Research and clinical studies

A review of the available studies on acupuncture commissioned by the National Institutes of Health in 1997 concluded there was "clear evidence" that acupuncture was beneficial for relieving pain and certain other symptoms, and stated that the evidence was as strong as it is "for many accepted Western medical therapies". The panel found that acupuncture was "remarkably safe with fewer side effects than many well-established therapies". It is important to keep in mind that these were not studies on MS.

There are few studies on acupuncture and MS specifically. These have shown mild, short-term benefits. One suggested there might be improvement in MS-related bladder difficulties and others have



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Taking pulses is an important part of diagnosis in traditional Chinese medicine.

shown conflicting results on spasticity. A large-scale survey reported that around two-thirds of MS patients benefited from acupuncture, with improvements in pain, bowel and bladder problems, spasticity, weakness, coordination, tingling, and sleep disorders. However, subjects also reported increased fatigue, spasticity and dizziness.

There are limited well-designed studies on acupuncture or herbal medicine in treatment of MS. Due to the deficiency of modern research methodology and inconsistent and inadequate treatment intervention, the conclusion from clinical studies needs to be interpreted with caution.

Editor's note: There have been no well conducted studies to evaluate the safety or effectiveness of Chinese herbs in MS. Some Chinese herbs do contain compounds with immune-stimulating activity. Thus, on a theoretical basis, these herbs could worsen MS or antagonise the effects of disease-modifying medications.

Vitamin D and MS

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For decades, a consistent geographical pattern of MS has been recognised, with prevalence and risk greater in countries further away from the equator in either direction. Sunlight and ultraviolet (UV) radiation exposure are inversely correlated with MS risk and prevalence, and this may explain

the relationship between latitude and MS. Serum 25-hydroxyvitamin D (25(OH)D), the marker of vitamin D in blood, is a direct product of sun/UV exposure on skin (the primary source of this vitamin) and is also inversely correlated with MS risk and prevalence.



Increased sun exposure in childhood is associated with decreased likelihood of future MS development.

MS patients have relatively low serum 25(OH) D. Although sun avoidance, steroid use and other behaviours could be factors, the relationship between UV exposure and decreased MS risk is quite strong, stronger than the link between UV exposure and increased risk of melanoma. Researchers have also found that increased sun exposure in childhood is associated with decreased likelihood of future MS development.

Studies of vitamin D and calcium in the animal model of MS have shown that if one pre-treats the animals with vitamin D and calcium before the process to induce an MS-like disease, there is no evidence of the disease. If this treatment occurs after disease induction, the animal still benefits. In laboratory studies, vitamin D has been shown to reduce blood markers of inflammation implicated in MS.

Early studies suggest a true relationship between Vitamin D, MS risk and MS activity.

It is clear that many people living in countries far from the equator, have relatively low 25(OH) D. Considerable research has been performed to determine what dose of vitamin D is optimal, and what blood level of vitamin D promotes good health and even protection from some diseases such as MS.

Current recommendations of vitamin D intake range from 200-400 international units per day (IU/d) in the general population, although this was based on the prevention of rickets (a childhood disease caused by vitamin D or calcium deficiency). Such doses would not lead to measurable changes in 25(OH)D levels in the blood. Recent studies suggest people may need up to 4,000 IU/d to achieve a blood 25(OH)D level of approximately 100 nanomoles per litre (nmol/L), a value associated with decreased risk of MS in a large study of more than 7,000,000 in the United States.

With respect to MS, small observational studies have shown that relapses occur more frequently in the winter months, as do more newly enhancing lesions on MRI, suggesting a lack of UV exposure (presumably vitamin D), may be responsible for these findings.

More recently, a large controlled study of children presenting with a first demyelinating event demonstrated that those with lower vitamin D levels were more likely to convert to definite MS than those with higher levels of vitamin D.

But the question remains, what dose of vitamin D, and what blood level of 25(OH)D, will either prevent the development of MS, or provide benefit to those already with the disease. Despite the evidence linking vitamin D to MS risk and immune activity, what constitutes an appropriate dose remains uncertain. Furthermore, the dose studied and ultimately recommended may differ based on the intended goal (MS prevention or treatment versus simply promoting bone health).

Despite understandable concern for the potential of higher-than-recommended doses of vitamin D leading to side effects, serum 25(OH)D acquired through sun exposure ranges up to 220 nmol/L with no recognised issue of tolerability. Case reports and trials in which subjects took between 10,000 and 40,000 IU/d for several months have not yielded evidence of side effects. If side effects were to occur with extremely high-dose vitamin D, they would be related to the possibility of elevated blood calcium, which could cause symptoms ranging from fatigue to cardiac arrhythmia, paralysis and coma.

In summary, the possible role of sun/UV radiation, and presumably vitamin D, has been studied for the better part of half a century, with early studies and trials suggesting a true relationship between vitamin D, MS risk and MS activity. If we can ultimately determine an ideal dose and blood level that improves and even prevents MS, it could offer an inexpensive oral option for people with MS and those at risk.

Low dose Naltrexone and MS

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Naltrexone, which is an antagonist to opiates, causes an artificial blockade of the endorphin/opioid receptors in the brain. At a 'normal' dose of 50-100 milligrams (mg) per day it is used to treat drug addiction, and works by maintaining this blockade continuously, preventing any derived pleasure from taking drugs such as heroin or alcohol.

"Low dose naltrexone" (LDN) refers to the use of naltrexone at a fraction of its usual dose. It is hypothesised that LDN (~3mg to 5mg) blocks the endorphin receptors for only a few hours. The theory is that during that time, endorphins are unable to attach to the receptors and the body compensates by creating more. Once the LDN has been metabolised, the amount of endorphins in the body returns to a level comparable to that of a healthy person. The link between endorphins and immune system regulation is not completely clear.

In terms of symptomatic relief, it has been proposed that endorphins reduce inflammation and can reduce unpleasant sensations of fatigue, pain and depression. Given this, LDN may potentially have an effect on some disease symptoms.

LDN and MS

There is a lot of talk in the MS community about LDN treatment. Much of it is confusing and controversial. On one hand, there are widespread

anecdotal reports claiming that LDN is effective for treating MS symptoms and slowing down the disease course. Moreover, there are reports that LDN is an effective treatment for immune diseases such as Crohn's disease, lupus, arthritis and fibromyalgia.

Studies of LDN in MS

A study on mice with EAE, the animal model of MS, found that LDN decreased inflammation in the nervous system, decreased disease severity and decreased activation of immune cells. Another study included 80 people with relapsing-remitting and progressive MS. While LDN did not appear to improve physical functioning in this study, it did show important improvements (statistically significant) on some aspects of quality of life such as mental health, pain and self-reported cognitive functioning.

During a third study 40 people with primary progressive MS were treated with LDN for six months in a phase II study. Phase II studies assess the safety and tolerability of a drug. Subjects were administered 4mg of LDN per day. Although the study was not designed to specifically assess efficacy, a significant effect on spasticity was found. Approximately one third of subjects reported worsened pain. Neurological disability progressed in only one person. The study demonstrated an increase in Beta-endorphins, the most important endogenous opioid found in the neurons of the



Bradley Stenke/flickr

central nervous system as well as in the peripheral cells of the immune system. The increase in beta-endorphins was present three months after beginning the therapy and still evident one month after subjects stopped therapy.

There is a lot of talk in the MS community about LDN treatment. Much of it is confusing and controversial.

Currently LDN is prescribed “off label” because it has not been approved specifically for MS. Rigorous safety data on LDN use in MS is not currently available. We do know that, considering the low doses used, few side effects have been reported. Vivid dreaming has been reported by some subjects at the beginning of treatment. LDN may be associated with mild abnormalities in cholesterol, blood counts and liver function.

It may cause irritability in some individuals. LDN should not be combined with any opiate-based medications such as narcotics or pain medications, including oxycodone, hydrocodone or codeine.

Before beginning treatment with LDN a complete evaluation should be performed, including a neurological examination and the assessment of spasticity, pain, fatigue and depression, as well as complete biochemical and urinary analyses. These evaluations should also be performed periodically during treatment.

Currently there is no evidence that LDN is superior to any conventional therapy for MS. LDN could be effective as a symptomatic and a neuroprotective agent although randomised, placebo-controlled, double-blind trials are needed to further investigate the efficacy of LDN in people with MS.

Cannabis and MS



Adam Ross/flickr

Richard Hosking and John Zajicek, Clinical Neurology Research Group, Peninsula Medical School, Plymouth, UK

The plant *Cannabis sativa* has attracted medicinal interest throughout history. Modern cannabis research stems from the 1960s, when Israeli scientist Raphael Mechoulam discovered the plant's active molecules, which he called *cannabinoids*. This led to the discovery of the body's own cannabinoid system, which is important in many organs including the brain.

People with MS report improved symptoms following cannabis use, and here we describe the scientific background, clinical trials, potential risks and legal issues involved.

Scientific background

Cannabis is known by a variety of names: for example *marijuana* describes dried leaves, while *hashish* refers to blocks of resin. The plant contains over 60 cannabinoids (CB) with different biological activity. Tetra-hydro-cannabinol (THC) is the main

psychoactive cannabinoid, and synthetic CB have also been developed. So far, two specific CB receptors (CBR) have been discovered. Surprisingly, the first (CB1R) is the most common among all receptors within the nervous system. The highest number of CB1R occur in brain regions involved with thinking, memory, movement and coordination. This explains why cannabis users experience difficulty in these areas. The second receptor (CB2R) is found on cells of the immune system. Animal experiments highlight the importance of CB in many disease processes relevant to MS. Significantly, studies of MS *post-mortem* brain tissue show that many cell-types involved express CBR. Work is ongoing in trying to determine what their purpose may be.

Clinical trials

The hope that cannabis may help MS has led to numerous clinical trials. However, treatment

response in MS is difficult to evaluate, and reliable studies require large numbers of subjects and careful planning. The psychoactivity of THC causes further complications. Nevertheless, results have been encouraging – particularly in relation to pain, muscle stiffness and bladder disturbance.

Pain is a significant feature of MS. Animal studies show that CBR are important in pain control. Several trials have confirmed that cannabis-based treatments alleviate MS-related neuropathic pain. Surveys of people with MS who smoke cannabis often report improved muscle stiffness (spasticity). Animal studies show that CB1R activation is central to this. The *Cannabinoids in Multiple Sclerosis* study recruited more than 600 subjects for 15 weeks and confirmed improvements in self-reported spasticity and pain. A significant reduction in clinical spasticity occurred after 12 months of treatment.

Animal data also imply that immune-cell CB2R-activation produces anti-inflammatory effects which may slow disease progression. The follow-up study showed a relative preservation of walking ability, which will be further assessed. Finally, some results suggest that cannabis extract reduces bladder dysfunction via CB1R activation.

Cannabis preparations

It is not known which cannabinoids (plant-based or synthetic, alone or in combination) are most effective in MS. Importantly, plant-CB activity is altered by methods of drug preparation. For example, heating (that is, smoking) may destroy anti-inflammatory properties. Liver metabolism also reduces drug activity, but is bypassed with oral sprays which allow direct bloodstream absorption. A cannabis-based medicinal-extract (CBME) spray called Sativex®, which contains THC and cannabidiol, is licensed in Canada for MS-related neuropathic pain, and can be prescribed in the UK on a named-patient basis. Sativex® is currently undergoing further tests before receiving a full UK MS-licence. Another CBME, named Cannador®, has recently been shown to help symptoms in a UK trial.

Risks and side effects

Psychoactivity is proportional to how much THC each cannabis preparation contains. People with MS prescribed CB often report mild side-effects, while those with impaired cognition or depression may suffer more serious effects. Smoking cannabis rapidly increases blood THC concentrations, which then quickly fall due to metabolism and body fat distribution. This limits drug activity and any corresponding psychoactive effect. Smoking cannabis probably carries the same risk of lung injury as tobacco. Eating cannabis, however, causes THC levels to rise slowly and remain elevated, prolonging any psychological effects. THC can be detected in urine drug tests for long periods after use.

No deaths have been attributed to cannabis overdose. However, cognitive impairment means that its use should be avoided during potentially dangerous activities (such as driving). Risk of long-term psychiatric disturbance is controversial, but teenagers and chronic users may be the most vulnerable. Withdrawal symptoms can also occur.

Much debate surrounds the classification of cannabis as an illicit drug. It is currently illegal in many places around the world. It is important to know the law in your jurisdiction.

Conclusion

Further research will clarify the role of cannabis in MS, and drug development may reduce psychological side-effects. Current evidence supports CB treatment of MS-related pain, spasticity and bladder disturbance. Perhaps one of the most exciting areas of research is in establishing whether CB can slow the actual disease course of progressive MS. Overall, the future is bright for these naturally-occurring molecules, which have been used in medicine since antiquity.

Editor's note: Cannabis is illegal in some countries. Possession and use of cannabis can carry severe penalties.

Yoga and other mind-body therapies and MS

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Mind-body therapies are practices that focus on the relationship between awareness, behaviour and the physical body. They constitute a physical practice form of CAM. Relaxation is usually an important component of mind-body therapies. As psychological stress often plays a role in disease processes, mind-body therapies may be helpful in treating disease. Mind-body therapies include such practices as yoga, hypnosis, meditation, biofeedback, tai chi, visual imagery, and qigong.

Yoga is a mind-body practice that incorporates components of both meditation, including awareness and breathing techniques, and physical activity or body postures. There are many varieties of yoga.

Research has shown that psychological stress may impact the immune system and susceptibility to disease. Additionally, mind-body therapies have been associated with alterations in brain and immune function in diseases including MS. Thus it is logical to suspect that stress-reducing practices such as yoga and other mind-body interventions may be beneficial in a disease of immune

dysregulation such as MS. However, Bikram yoga, a type of yoga practiced in hot temperatures, may exacerbate MS. From this framework of suggestions stems the need to study directly the impact of yoga and other mind-body therapies on MS.

Despite this rationale, there have been only a limited number of studies directly examining the effect of mind-body therapy on people with MS. A nonrandomised, noncontrolled study of 19 people with MS found that following an eight-week t'ai chi programme, subjects experienced improvement in walking speed, flexibility, energy and mental health. Another nonrandomised controlled study examined the effect of a course of "mindfulness of movement" on MS. This study found that people who participated in the mindfulness of movement course experienced improvement in many of their symptoms as well as their balance as compared to controls. A single randomised controlled trial of 69 people with MS found that six months of either yoga practice or exercise with a stationary bicycle was associated with an improvement in energy level and fatigue as compared to a wait-list control.

Many patients with MS suffer from chronic pain and headaches. Although not specifically studied in patients with MS, a ten-week programme in mindfulness meditation was associated with improved pain scores in people with MS with chronic pain. There is also evidence suggesting that

relaxation techniques, hypnosis and biofeedback may be effective in treating chronic pain. Trials for chronic headache have demonstrated that relaxation training, biofeedback, and t'ai chi are associated with improvements. Relaxation therapy and thermal biofeedback are considered to have the highest level of evidence for the prevention of migraine by the American Academy of Neurology.

In general, mind-body therapies are associated with low physical and emotional risk and relatively low cost. Thus these treatments are popular, not prohibitively expensive, and supported by some promising if preliminary evidence.

Mindfulness is the development of the ability to pay deliberate attention to one's experience from moment to moment, to what is going on in one's mind, body and life, and to do this without judgment.

Biofeedback is a process that involves measuring bodily functions such as blood pressure, heart rate, skin temperature, sweat gland activity and muscle tension, conveying the information to the person in real-time. This raises the person's awareness and therefore the possibility of conscious control of those functions.



Music therapy with MS

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For many, music is so much a part of our lives that we often forget its potential as therapy. Music affects us in many ways. It can help us relax, reminisce and generally feel better. Because music affects the brain on many levels, it can be used to alleviate or help improve certain physical, psychological and cognitive conditions. Music is not processed in one specific region of the brain but rather is processed in many areas, suggesting its potential for multiple therapeutic applications.

What is music therapy?

Music therapy is the systematic use of music within a developing relationship between a professional music therapist and a person to restore, maintain, and/or improve physical, emotional, psychosocial and neurological function. Not only songs, but the various components of music, such as a specific tone or frequency of sound, certain patterns of beat or rhythm, harmony, and melody can be used independently to provide a clinical effect. The music therapist will work with the person to explore various types of music and/or actively engage them in musical improvisations to assess how music can maximise therapeutic outcomes.

How can music therapy help people with MS?

From aiding in stress management to reducing pain and spasticity, research in music therapy indicates that it can have a positive impact on many issues faced by people with MS, particularly psychological. For example, the rhythm of music can be used to help with balance and coordination. Rhythm can stimulate the impulse to move and help maintain motivation to increase physical activity. People who listen to music while they walk or exercise find that their movements are more even.



Jamie Wilson/Stockport

The music therapist explores various rhythmic patterns or musical styles with the patient to establish which patterns will help with walking, balance and movement in general. People with MS report that by focusing on rhythm and trying to feel its pulse they can walk or perform consecutive tasks better. Increased physical activity and attention can also be encouraged in those with even limited function through therapeutic drumming and rhythm-based activities that allow for spontaneous responses.

Music therapy can also help with short term memory issues and cognitive impairment. Just as TV or radio commercials use musical jingles to help listeners remember phone numbers and addresses, a music therapist can create a musical tool to help a client remember names, phone numbers and addresses. For long-term memory problems, music of personal importance can stimulate feelings and associations of past events. In music therapy the use of familiar music can also help improve attention and recognition memory, increase verbalisations, reduce anxiety and offer other improvements in quality of life.

Some people with MS have hypophonia (soft voice) or dysarthria (a motor speech problem), making verbal communication difficult. Singing the words of a song can improve the breath support needed for audible speech, as well as the articulation and timing issues needed for intelligibility. The music therapist will work with the individual to encourage lyric singing or provide vocal exercises that may aid improvement in speech.

Music therapy may also improve psychological problems, including depression and anxiety. The music therapist will encourage expression through improvised or composed music that focuses on a specific issue. The person may express verbally or non-verbally, in music, an emotional response, which may allow them to cope with feelings related to the past, or to present issues such as current injury, disease, loss of function or independence. Music therapy has also been

applied to help individuals express and deal with fears, anxieties, mental blocks and resistances so that they can gain more control over their personal health and quality of life. Participating in music therapy groups, including therapeutic drumming groups, dance and movement groups, can provide an outlet for self expression and a closer connection to others. Thus active music therapy may promote both physical and emotional health and well-being.

Because some symptoms of MS appear to worsen with stress, it may be useful to find tools to help with stress management and relaxation. Research has shown that listening to pleasing music may elevate levels of certain neurotransmitters, resulting in enhanced mood and reduced discomfort or pain. Music aids in promoting relaxation through the associations one has to the music as well as its calming physical effects. The music therapist can work psychotherapeutically to create a musical environment or engage the individual in a musical experience, which may help the individual better understand their stress and the emotional issues affecting their mood. Techniques similar to the relaxation exercises used in meditation and yoga can be facilitated with music by cuing slow breathing.

In addition to music therapy there are other sound-based treatments that may be beneficial. For example, physioacoustics is the use of specific sound frequencies to induce sympathetic vibrations in particular areas of the body, such as the back or legs. It uses a chair or bed equipped with a frequency generator that is programmed to cycle through certain sound frequencies depending on the target area of the body.

Music therapy is a low cost, low risk treatment option that may help ease some MS-associated symptoms. Although large-scale, rigorous clinical studies have not been conducted, a review of music therapy research related to MS found that music therapy had a positive impact on improvement in self-acceptance, anxiety and depression, among other possible benefits.

Evaluating CAM

Roberta Motta, Clinical Nurse Coordinator, Italian MS Society Rehabilitation Centre, Genoa, Italy

For many people with MS, the nurse may be the first point of contact for talking about CAM. This is particularly true in settings where the MS nurse has the opportunity to establish a relationship based on mutual respect and openness. In this type of setting, the person with MS will feel free to discuss CAM without the fear of being judged. Fear of being judged prevents many people with MS from being open with healthcare professionals, particularly if the CAM is controversial.

It is important that questions about CAM use are part of every visit. The nurse can set the example of the importance of discussing CAM in the healthcare setting by making it part of the routine consultation, along with current medications and symptoms.

If the individual expresses interest in a particular CAM, but has not yet tried it, the nurse has an important role in helping evaluate the CAM. There are several aspects that should be discussed, including the following:

- Who is proposing the treatment? If it is an individual, does this person have specific knowledge and verifiable credentials in the field related to the CAM being proposed? Does the person know anything about MS? Does this person gain financially from promoting the treatment? If it is a company, does the company have experience in MS?
- What is the rationale behind the treatment? Is it based on sound scientific concepts?

- Has it been tested in MS? Is there any proof that it is effective? People should be warned about treatments that are promoted based solely on anecdotal stories.

- What does the treatment entail and how long should it be maintained?

- What are the risks and side effects of the treatment?

- What are the contraindications of the treatment in relation to other “conventional” therapy the person is currently following?

- How much does the treatment cost?

If the person discloses that he or she is currently using a CAM, the nurse should try to understand what effect it could have on MS. In order to do this, it is important to search for information on reliable websites or publications and to talk to other members of the healthcare team who may be knowledgeable about CAM. It may not be possible to discuss and evaluate the CAM immediately, particularly if the nurse is not familiar with a particular treatment – in this case it can be helpful to schedule another appointment, to allow the nurse time to gather information.

If the person with MS discloses that they have replaced a conventional therapy or treatment prescribed by the neurologist or other healthcare professional with a CAM, it is important that the nurse clearly explains the possible consequences. For example, discontinuing an immunomodulatory



Italian MS Society

therapy may result in an increased risk of relapse. The time necessary to re-establish the full therapeutic effect, once the medication is resumed, can be weeks, months or even longer. Further, some CAM, as explained in this issue of *MS in focus*, have a stimulating effect on the immune system. While for some diseases or problems immune system stimulation might seem appropriate, for MS the consequences could be potentially damaging. Some other characteristic features of MS, such as heat sensitivity or spasticity, make some CAM unsafe.

Often people with MS who have tried a CAM claim that their MS improved due to the treatment. The nurse should reiterate that MS is an unpredictable disease characterised by relapses and remissions. For some CAM success stories, there is no way to prove that was indeed the improvement due to CAM and not due to the spontaneous changes that characterise MS.

Some CAM have been reported to show benefit in people with MS, even though most have not been tested using the same type of rigorous studies that are required of conventional therapies. Anecdotal reports and media publicity create expectations and often raise false hope. A complete evaluation of a

CAM, which involves the healthcare team supporting the person in understanding possible risks and benefits, will help in making an informed decision.

Above all, the nurse will want to maintain a supportive relationship with the individual even if mutual agreement is not possible.

Some general recommendations for people with MS considering a CAM:

- Discuss the CAM with your MS nurse or neurologist *before* trying anything new; share with them any information you find on the CAM you are interested in.
- Do not discontinue/substitute any medication without consulting your MS nurse or neurologist.
- Be suspicious of “secret formulas” often publicised in the media.
- If you have any concerns about the CAM, you could request that the promoter of the CAM be contacted by your MS nurse or neurologist for more information.
- If you decide to try a CAM, keep your neurologist and MS nurse updated.

Your questions answered

Readers pose questions to our guest editor, Dr Allen Bowling.

Q. In my MS support group it seems like everyone is taking *Ginkgo biloba*, saying that it helps with concentration and memory. Is this true? Can it help MS attacks too?

A. Small preliminary clinical studies of *Ginkgo biloba* in people with MS indicate that it may be beneficial for cognitive difficulties and fatigue. However, these findings are not definitive – larger and more rigorous studies are needed. There have not been any studies that have evaluated *Ginkgo biloba* for MS attack prevention. Importantly, *Ginkgo biloba* may produce side effects, including bleeding and seizures.

Q. I have heard of hyperbaric oxygen being used for severe burns but can it be helpful in MS as well?

A. In 1983, a study reported that hyperbaric oxygen (HBO) produced beneficial effects in people with MS. However, multiple subsequent studies of HBO have not found a therapeutic effect in MS. Two independent reviews of all of the HBO and MS studies have concluded that this therapy does not produce consistent therapeutic effects in MS.

Q. I always seem to have an MS attack when I'm fighting a bad cold. A friend recommended Echinacea to keep the colds from lasting too long. But I've also read that people with MS should not use Echinacea, especially if they are taking interferon. As I'm taking Copaxone, can I try Echinacea next time I get a cold?

A. The concern with Echinacea and MS is that, like many other supplements that may decrease the severity or duration of the common cold, it may activate the immune system. Thus it carries a theoretical risk of worsening MS or inhibiting the therapeutic effects of MS medications such as glatiramer acetate (Copaxone®) and interferons (Avonex®, Betaseron®, Rebif®).

Q. We're always told not to try a CAM that doesn't have proof that it works, but it seems like so few actually do have any proof. Why aren't there more studies to prove or disprove alternative treatments for MS?

A. The funding for many of the clinical trial studies in MS (and other diseases) is from drug companies who hope to ultimately develop a patentable, profit-making product. However, most alternative treatments are not patentable and there is thus less interest in funding these types of studies. However, over the past five to ten years, more funding has become available for funding alternative therapy studies through the National Institutes of Health and the National MS Society in the United States and multiple other MS and medical research organisations around the world.

Q. I get frequent urinary tract infections. Should I drink cranberry juice once I have the UTI to cure it or all the time?

A. Cranberry may be effective for *preventing* urinary tract infections (UTIs) but has not been shown to be effective, and should not be used, for *treating* UTIs. The only therapies that are known to be effective for UTI treatment are conventional antibiotics. Cranberry is usually well tolerated.

Q. Shouldn't people with a chronic disease like MS take a lot of different vitamins or a multi-vitamin to be healthier and feel better?

A. For some people with MS, a limited number of dietary supplements may be reasonable. However, it is important to keep in mind that supplements are specific molecules that alter multiple biochemical processes in the body. Through these processes, supplements – like drugs – have the potential to produce beneficial as well as harmful effects. People with MS using supplements should discuss this with a health professional and they should be taken in a thoughtful and individualised manner.

Editor's note: The use of any CAM should be discussed with a healthcare professional.

Interview: Claude Vaney

Claude Vaney is Head Physician at the Centre for Medical and Neurological Rehabilitation, Berner Klinik Montana, Crans-Montana, Switzerland

Q: What is your general opinion of the use of CAM by people with MS?

It is a well known fact that more than 50 per cent of the people suffering from a chronic condition such as MS will look for alternatives when most of the conventional care options have been exhausted. So I assume that many of my patients will be taking CAM too. As their physician I like to be informed about their use of CAM and I encourage them to talk about it.

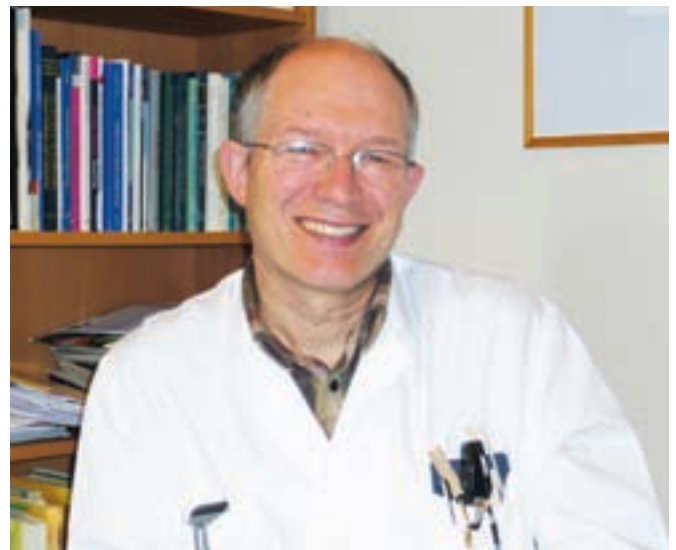
The use of CAM can be seen as the patient's valuable way of being in charge of his or her disease and the doctor's job is merely to advise, so that people don't harm themselves.

Q: Do people with MS commonly come to you with questions about CAM? And do they ask questions before starting a CAM, or after?

If there is mutual respect and trust, the resulting good communication will mean that questions about CAM are openly discussed. There is however no rule. Sometimes it is only when I propose a CAM, such as acupuncture or herbs, that the patient reveals he or she has already tried it. Or sometimes when a CAM a patient has chosen fails, they then come to me for advice on another one.

Q: What is your usual approach in talking to patients about CAM?

When taking the history, the use of CAM should be addressed in a systematic way, just like questions about drugs, allergies and new



symptoms. I routinely ask about CAM during clinic visits and record CAM use in my patients' medical charts.

Q: Do people try to hide the fact that they are using CAM from you, or from other healthcare professionals?

Interestingly many of my patients say they have not talked about CAM with their GP, fearing his or her disapproval.

Q: Do you find that people with MS are well-informed about CAM?

The internet has greatly broadened people's knowledge on CAM. Some patients have very detailed information – usually they know more than we do. We health professionals should keep ourselves informed on this topic so that we can advise our patients well.

Wellness Days in Australia

Craig Hassed, Monash University Department of General Practice, Melbourne, Australia

Over the years, MS Australia has received consistent feedback from people living with MS who want to self manage their MS. In particular, people wanted to learn what they could do to improve their quality of life.

MS Australia responded by developing programmes to inspire people to become more involved in their own healthcare.

The MS Society in Victoria ran its first *Launching Hope* days in 2001. These were an immediate success. Today, similar programmes, called *Wellness Days*, are run in Victoria, Tasmania, New South Wales and Canberra.

The *Wellness Days* start with an interactive presentation on the 'essence' of managing MS. ESSENCE stands for:

- **Education** not only about the medical condition but also about ourselves, our motivation, how to set goals, and achieve lifestyle change
- **Stress** management including the mind-body relationship and psychoneuroimmunology
- **Spirituality** which relates to where a person finds meaning and purpose in their life
- **Exercise** the importance of physical activity for physical, mental and social health
- **Nutrition** healthy nutrition generally and specific information relevant to people living with MS
- **Connectedness** the importance of relationships and social support, including the role that support groups and organisations such as the MS Society can play
- **Environment** including the specific role that regular moderate doses of sunlight can have.

The days also include a workshop on mindfulness-based stress management and detailed presentations on healthy nutrition for people with MS, such as the potential benefits of increasing

omega-3 fatty acids, fruit and vegetable intake, and vitamin D and of reducing saturated fats.

A key feature are the 'Come and try' sessions – short experiential workshops on topics such as massage, exercise and strength training, yoga, tai chi and qi gong, usually run by local health practitioners.

Feedback from all programmes is very high.

Practicalities

Wellness Day programmes are marketed through the MS Australia website and brochures and promoted by Community Support Workers and Nurses.

Expenses include costs for venue hire, equipment, external health professionals, food, staff to cook and clean at the facility, travel, accommodation, and marketing.

It is not possible to cover all remote locations and sessions can only be run if the numbers are high. Video conferencing facilities and the production of DVDs to screen some presenters offsite could increase the number of sessions.



MS Australia – ACTNSW/VIC Wellness Day, 2009

Complementary and alternative medicines: survey results

622 people took the online survey on CAM. They ranged from people newly diagnosed with MS to those who have been living with MS for many years – over 50 years in two cases.

CAM use

Whilst 19.6% of respondents had never tried a CAM, 80.4% had tried at least one, and almost half (46.7%) had tried between two and five CAM. A significant minority – 16.4% – had tried six or more different therapies.

Two thirds of respondents currently use one or more CAM. A huge range of CAM are used, the most popular being vitamins, supplements and other dietary approaches (particularly the 'Best Bet' diet), LDN, acupuncture, massage and yoga.

"I think there is a place for ALL treatments and professionals should recognise them."

Health professionals and CAM

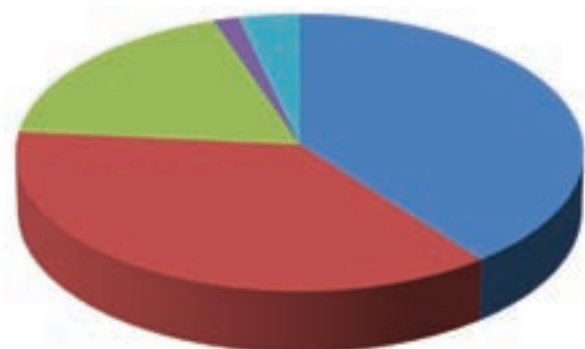
More than half of respondents (58.3%) had not consulted an MS health professional before starting a CAM. When asked the reasons for not consulting a health professional, 20.3% were concerned that their healthcare professional might have a negative opinion about the therapy and 15.3% did not want to be discouraged, while 71.6% simply thought it was unnecessary or irrelevant.

Effective or not?

76.5% of respondents felt that CAMs had had a positive effect on their health whilst 5.2% had felt they'd had a negative effect. 18.3% noticed no difference.

"Some CAM for MS are promoted unethically using pseudo scientific 'facts'."

More half have no concerns about using CAM, but of those that do, the most common concern was about costs (37.6%), with many feeling aggrieved that national health services or insurance schemes will pay for costly drug treatments but not for CAM, which many feel to be more beneficial to their overall health and well-being. 11% were concerned about possible interactions of CAM with their MS medication, and 10% were concerned about reactions of their MS health professional.



Very positive effect	39.6%
Some positive effect	36.9%
No difference	18.3%
Some negative effect	1.5%
Big negative effect	3.7%

How do you feel CAM have affected your health?

Reviews

www.neurologycare.net

It is difficult to find detailed and accurate information about complementary and alternative therapies. On the website www.neurologycare.net a wide range of complementary and alternative therapies and their specific use in people with MS are explained with great rigour by Dr Allen C. Bowling.

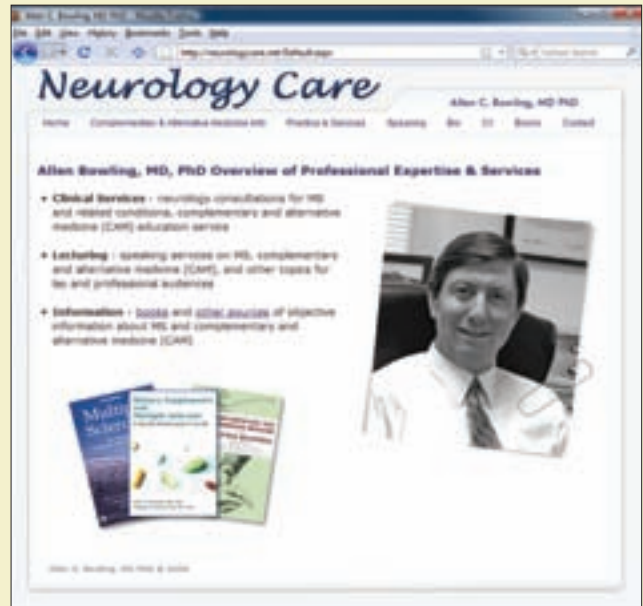
Dr Bowling is a neurology practitioner with extensive training and experience in MS, and an expert in complementary and alternative medicine. He has written many books and articles, given lectures and acted as Consultant in Neurology for Multiple Sclerosis organisations.

The authorship, the quality of information, the accuracy in the presentations and the wide number of references make this site a reliable source of information. It is especially useful for people with MS who are considering using an alternative or complementary therapy and wishing to obtain unbiased information on the different options. Besides, health professionals and people interested in the subject can use this resource to find information.

More than 60 alternative and complementary therapies are discussed, listed in alphabetical order. Each is detailed in a specific section that explains different aspects:

- Explanation of therapy
- Treatment approach
- Assessment in MS and other conditions
- Adverse effects
- Summary
- References and additional reading

The website clarifies that MS is a complex disease and the purpose of the website is only informational; it should not be considered a



substitute for visiting a healthcare provider or using conventional medicines.

The website is well structured, it is very easy to use and is accessible to people with visual disabilities.

In conclusion, www.neurologycare.net is a trustworthy resource for people with MS.

Reviewed by Sandra Fernández Villota, Head of Communication and Coordination, FELEM MS Society, Spain

Dr Allen Bowling's book *Complementary and Alternative Medicine and Multiple Sclerosis* is also available to buy in bookshops or online.

● ISBN-10: 1932603549

● ISBN-13: 978-1932603545

The Dutch organisation MS Anders has published a Dutch edition.

This is available for the cost of postage only from MS Anders. Contact: info@ms-anders.nl

www.stayingsmart.org.uk

Staying Smart is an online project from The MS Trust and Royal Holloway, University of London. Staying Smart is indisputably a much needed and longed-for site, both for people with MS and specialists working with them. As it says on the site, *Staying Smart* is designed for people who want to know (or know more) about how MS can affect thinking.

The site is divided into sections of problems with memory, attention, wayfinding, finding things, language or executive skills, and the goals of the website are to support learning, build confidence in managing and facilitate sharing of knowledge and experience about cognition in MS.

Each section is covered both for professionals and non-experts, with sub-sections like "Research" or "Tips and tricks". The sections are well structured and clear; the advice given is practical and useful. It is also possible to add one's own techniques for managing cognition problems, which makes it continuously "up to date".

The page is very modern – you can go straight to Twitter or share it otherwise from here! The website is innovative and it is only starting to grow and gather experiences, but the future does seem to be rather promising.

Reviewed by Liina Vahter, PhD, Clinical Neuropsychologist, Estonian MS Centre, West-Tallinn Central Hospital, Estonia



Taking flight: World MS Day 2009 in Argentina.

World MS Day is the day when the MS community globally joins together to raise awareness of MS and to unite, broaden and mobilise our movement

Last year, thousands of people joined World MS Day activities in 67 countries. This year, let's make it even bigger and better.

Contact your national MS society to find out what's planned in your country.

www.worldmsday.org



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- Issue 13 Tremor and ataxia in MS
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With many thanks

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