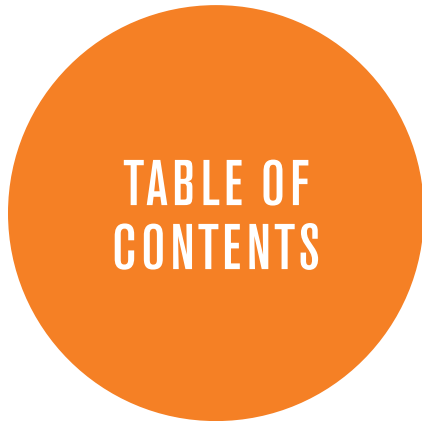


MANAGING PAIN & SLEEP ISSUES IN MULTIPLE SCLEROSIS



NORTH AMERICAN EDUCATION PROGRAM 2012

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- University of Pittsburgh and the University of Pittsburgh Medical Center
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- McGill University and the McGill University Health Centre
- Montreal Neurological Institute and Hospital
- Veterans Affairs Medical Center — MS Center of Excellence East, Washington, DC
- Neuroscience and Regeneration Research Center — Yale University School of Medicine and VA Connecticut

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PREFACE



NORTH
AMERICAN
EDUCATION
PROGRAM

Welcome to the 2012 North American Education Program — *Managing Pain and Sleep Issues in MS*, produced by the National MS Society of the USA in collaboration with the MS Society of Canada.

Our program this year focuses on the management of pain and sleep disorders in multiple sclerosis — two issues that often cause confusion and frustration for people with MS, their loved ones, and their healthcare providers. Both pain and sleep disorders are treatable, but it is often hard to understand the root causes and determine the best strategies for management.

In the video portion of the program, you will hear from scientists and clinicians who treat these symptoms or are working to find better strategies for managing them.

This program booklet provides information from studies that are completed or in process that add to our body of knowledge about MS management.

We want to thank Biogen Idec, EMD Serono, Genentech, Genzyme, Novartis, and Teva Neuroscience for providing generous educational grants to make this program possible.


We hope you will find the program informative. For further information, go to nationalMSSociety.org or mssociety.ca, or call 1-800-344-4867 (USA) or 1-800-268-7582 (Canada).

BEST REGARDS,

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PROGRAM OVERVIEW & GOALS



MANAGING PAIN & SLEEP ISSUES IN MS

**WE ARE A DRIVING FORCE
OF MS RESEARCH AND
TREATMENT TO STOP
DISEASE PROGRESSION,
RESTORE FUNCTION,
AND END MS FOREVER.**

National MS Society Strategic
Response to MS, 2011–2015

**OUR VISION IS A BOLD ONE.
BY 2015, ANSWERS TO THE
FUNDAMENTAL QUESTIONS OF
THE CAUSE AND PREVENTION
OF MULTIPLE SCLEROSIS
WILL BE FOUND.**

MS Society of Canada,
Momentum 2015

These statements are what drive us at the National Multiple Sclerosis Society and the MS Society of Canada, to connect people living with MS to information, resources in their communities, the best doctors, and the best treatment options. The North American Education Program (NAEP) is a part of that effort. For over 20 years the National MS Society has offered a nationwide education program for people with MS and their families. Over the last decade, the National MS Society has welcomed partnership opportunities with the MS Society of Canada, making this resource widely available across North America.

Recent programs have focused on progressive MS, the cause of MS, clinical trials, cognition, and nervous system repair.

This year, the NAEP's focus is on two issues that can have a profound impact on quality of life: pain and sleep disorders. You'll learn more about managing these problems, available treatment options, and research to identify the cause of pain and sleep disorders in MS. Lastly, we'll connect you with Christina and Elysa, two women living with MS who share information about how they manage their pain and sleep problems to maintain a good quality of life.

PRESENTERS



MODEL OF DEDICATION

DAWN EHDE, PhD

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University of Washington School of Medicine

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STEPHEN WAXMAN, MD, PhD

Bridget Marie Flaherty Professor of Neurology, Neurobiology, & Pharmacology, Director, Center for Neuroscience & Regeneration/
Neurorehabilitation Research
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WHAT'S IMPORTANT IS THAT WHETHER OR NOT PAIN IS CAUSED BY MS, IT CAN GET IN THE WAY OF YOUR LIFE AND IT'S WORTH TREATING.

DAWN EHDE, PhD


Dr. Ehde is a professor in the Division of Clinical and Neuropsychology, Department of Rehabilitation Medicine at the University of Washington School of Medicine, Seattle, WA. She received her PhD in clinical psychology from the University of North Dakota in 1992 after completing her predoctoral residency at the University of Washington School of Medicine. She completed a clinical fellowship in rehabilitation psychology as well as a National Institutes of Health funded fellowship in rehabilitation research.

She is also an attending psychologist in the outpatient Rehabilitation Medicine Service at UW Medicine (Harborview Medical Center), providing neuropsychological and psychotherapy services to persons with multiple sclerosis and other acquired disabilities. She has participated in controlled trials that evaluated the efficacy of various cognitive-behavioral, pharmacological, and/or exercise interventions for pain or depression in persons with MS and other disabilities, and is the principal investigator and training director of a postdoctoral fellowship program in MS rehabilitation research, funded by the National MS Society.

Dr. Ehde is a Fellow of the Division of Rehabilitation Psychology of the American Psychological Association, and has served in elected positions on its board. She is on the editorial boards for the journals *Archives of Physical Medicine and Rehabilitation* and *Rehabilitation Psychology*.




I AM VERY EXCITED ABOUT OUR
WORK WITH FUNCTIONAL MRI.
WE'VE TAKEN AN ENORMOUS
STEP IN TRYING TO UNDERSTAND
HOW OUR BODY WORKS, HOW OUR
BODY PROCESSES PAIN, AND HOW
WE'RE GOING TO BE ABLE TO
BEST TREAT THAT PAIN.




GILBERT FANCIULLO, MD, MS

Dr. Fanciullo is the Director of Pain Medicine at the Dartmouth-Hitchcock Medical Center and Professor of Anesthesiology at Dartmouth Medical School in New Hampshire. He received his medical degree from Albany Medical College in 1987 and a degree in hospital administration from Russell-Sage College. In 1990, Dr. Fanciullo completed his residency in anesthesiology at Brigham and Women's Hospital, followed by a fellowship in pain management and vascular, thoracic, and obstetric anesthesia. His past research focused on pharmacological and systems management of patients with chronic pain.



I FIND THE MOST SUCCESSFUL PATIENTS OFTEN DO A COMBINATION OF THINGS. IF NEEDED THEY TAKE A MEDICATION, BUT THEY START OFF WITH SOMETHING AS SIMPLE AS STRETCHING OR PRACTICING CERTAIN TYPES OF MIND/BODY EXERCISES.



ROCK HEYMAN, MD

Dr. Heyman directs the MS Center and the Infusion Center at the University of Pittsburgh. He received his undergraduate and medical education at Ohio State University. He completed his transitional year internship and neurology residency at University of Pittsburgh Medical Center Montefiore. He also completed a fellowship in electroencephalography (EEG) and received additional training in evoked potentials and sleep disorders.

Dr. Heyman has a large clinical practice in multiple sclerosis and related disorders. He is active with the National MS Society, serving on the regional board of trustees, and chairing the Western Pennsylvania Chapter Clinical Advisory Committee. Additionally, he is a member of the National Clinical Advisory Board and Council of Clinical Advisory Committee Chairs. Dr. Heyman also chairs the Education Committee of the Consortium of Multiple Sclerosis Centers (CMSC). Additional education efforts involve numerous Continuing Medical Education (CME) programs regionally and nationally, as well as producing CME materials for physicians and educational brochures and videos for patients nationally.



WE NEVER JUST TREAT
A SLEEP STUDY. WE
TREAT PATIENTS.

JOHN KIMOFF, PhD

Dr. Kimoff is Associate Professor of Medicine and Director of the Sleep Disorders Centre in the Health Centre Respiratory Division of McGill University in Montreal, Quebec. His clinical activities focus on internal and respiratory medicine and sleep disorders. He is active in teaching and research in the field of sleep-disordered breathing and is an established member of the international sleep medicine community. He recently served as Chair of the Assembly on Sleep and Respiratory Neurobiology of the American Thoracic Society. His current research activities include studies on the impact of sleep disorders on fatigue in MS. He received his medical degree from McGill University in 1983 and was Chief Medical Resident at Royal Victoria Hospital in 1986. He completed his research fellowship at Royal Victoria Hospital Respiratory Division, followed by a research fellowship at the Department of Medicine, Clinical Science Division of the University of Toronto.

“START WITH THE NURSE. SHE CAN HELP YOU FRAME IN A SUCCINCT WAY WHAT TO TELL THE NEUROLOGIST ABOUT YOUR PAIN.”

HEIDI MALONI, PhD, ANP-BC, CNRN, MSCN

Dr. Maloni received an MSN and PhD from Catholic University of America. She is a Certified Neuroscience Registered Nurse, a Certified Adult Nurse Practitioner, a Certified Multiple Sclerosis Nurse, and a MS pain management specialist. She coordinates research and programs at the Veterans Affairs Medical Center, MS Center of Excellence East in Washington, DC.


Dr. Maloni has served as a clinical instructor at the Catholic University of America School of Nursing. Through role delineation, item writing and review, and test development, she led the campaign for certification of MS nurses internationally. With 18 years of experience working in the Neuroimmunology Branch of the National Institute of Neurological Diseases and Stroke (NINDS) at the National Institutes of Health, Dr. Maloni's responsibilities involved several levels of patient care and coordination of protocols in MS research. She has also served as an expert faculty member of the National Capital Chapter of the National Multiple Sclerosis Society and does field work with multiple sclerosis patients and families.




**THE MOST COMMON SLEEP
DISORDER WE FOUND IN MS
PATIENTS WAS OBSTRUCTIVE
SLEEP APNEA.**

DARIA TROJAN, MD, MSc

Dr. Trojan is a physiatrist (specialist in physical medicine and rehabilitation) and associate professor in the Department of Neurology and Neurosurgery at McGill University. She works as a physiatrist at the Montreal Neurological Institute and Hospital, McGill University, in Montreal, and at the Jewish Rehabilitation Hospital in Laval, Quebec. Dr. Trojan obtained her MD degree from the University of Connecticut School of Medicine, and an MSc degree in epidemiology and biostatistics from McGill University. Her residency training was at the Columbia-Presbyterian Medical Center, Columbia University, at the University Hospital, Boston University, and at the Montreal General Hospital, McGill University. She also completed a three-year clinical research fellowship at the Montreal Neurological Institute and Hospital. Dr. Trojan has directed the Post-Polio Clinic of the Montreal Neurological Hospital since 1998. Her research has focused on fatigue in post-polio-myelitis syndrome and more recently on MS. She has published a number of studies on the late effects of poliomyelitis, and in the last few years on fatigue and sleep disorders in MS.



WE ARE JUST BEGINNING THE PAIN IMAGING RESEARCH, BUT MY HOPE IS THAT WE'LL ALSO LEARN A LOT ABOUT THE BASIS OF PAIN, HOW TO DETECT IT EARLIER AND TREAT IT EARLIER.



HEATHER WISHART, PhD

Dr. Wishart is associate professor of psychiatry and neurology at Dartmouth Medical School and a member of the Neuropsychology Program and Brain Imaging Laboratory. She completed her doctoral training at the University of Victoria in British Columbia and postdoctoral training at the University of Rochester School of Medicine in New York. She has a longstanding scientific interest in MS and other progressive neurologic disorders. Her current work concerns imaging genetics of individual differences in disease progression and the neural basis of pain in MS, using MRI and other quantitative measures. Dr. Wishart currently serves as a volunteer expert on the National MS Society's Advisory Committee for Research on Patient Care, Management and Rehabilitation.

“PAIN RESEARCH IS IN THE
MIDST OF A RENAISSANCE. IT’S
AN INCREDIBLY EXCITING TIME.”

STEPHEN G. WAXMAN, MD, PhD

Dr. Waxman is the Bridget Flaherty Professor of Neurology, Neurobiology, and Pharmacology at Yale University and was Chairman of Neurology from 1986 until 2009. He founded and is director of the Neuroscience and Regeneration Research Center, a collaboration of Yale University, the Department of Veterans Affairs, and the Paralyzed Veterans of America. His work bridges basic research and clinical medicine.

Prior to moving to Yale, Dr. Waxman was at Harvard, MIT, and Stanford. He is also a visiting professor at University College London and the Institute of Neurology, London. He has received international recognition for his research, which uses tools from the “genomic revolution” to identify new therapies that will promote recovery of function after injury to the brain, spinal cord, and peripheral nerves. Dr. Waxman serves as a volunteer expert on the National MS Society’s Research Programs Advisory Committee.

PART 1: PAIN IN MULTIPLE SCLEROSIS

INTRODUCTION TO PAIN IN MS



MS CAN
INDEED
CAUSE PAIN

Thousands of people with multiple sclerosis (MS) are told by their doctors that the disease doesn't cause pain. That's largely because, until relatively recently, pain was an unrecognized symptom associated with the disease. However, it is now clear MS can indeed cause pain. Regardless of the type of pain you experience, pain has a negative impact on your quality of life. Pain is exacerbated by sleep disorders and spasticity. It can lead to increased depression, anxiety and fatigue. For these reasons, pain management in MS requires a comprehensive, interdisciplinary team approach that includes neurology, nursing, rehabilitation, and mental health.

It is especially important to recognize and treat psychological factors involved in pain such as depression. Physical and occupational therapists can assist by introducing self-management techniques that have been shown to be effective in minimizing pain. Social support and a strong relationship with your medical team are critical components of successfully managing pain.

PAIN MANAGEMENT IN MULTIPLE SCLEROSIS

The goal of pain management in MS is ultimately to enhance quality of life by relieving suffering and improving a person's ability to function. Before pain can be managed effectively, its cause must be determined.

About two-thirds of people with MS report that they experience pain, with one in five reporting pain at the time of diagnosis. Compared to the general population of people with MS, those who are at increased risk for developing pain are most often older and have lived with MS longer. They often have low activity levels and are deconditioned, and tend to have a more progressive disease course and greater disability.

HOW IS PAIN PRODUCED & WHAT CAUSES IT?

Pain is the body's response to a physical threat. It protects us from harm and warns us that something is wrong in our bodies. Pain starts when nerve cells register a sensation and transmit that sensation to the spinal cord. For example, when your finger touches a hot stove, the heat stimulates temperature and danger receptors in the skin. These receptors trigger a sensory impulse that travels to the central nervous system (CNS). The sensory neurons connect with interneurons that, in turn, connect to motor neurons. The motor neurons send impulses that cause the hand to quickly withdraw from the heat. And this entire process happens reflexively — without conscious thought.

The information is then transmitted from the spinal cord to the brain, which results in the conscious awareness of the pain — the “ouch” that quickly follows the automatic withdrawal of the hand.

The pain signaling system can be affected by MS in a variety of ways. Damage to the myelin sheath that encases and protects nerve fibers in the CNS is the hallmark of MS. As a result of this demyelination process, myelin is damaged or destroyed and nerve fibers are exposed, affecting the messages carried from the spinal cord to the brain. The damaged nervous system

can signal pain that isn't there or exaggerate what would normally be a mild sensation of discomfort into full-blown pain. Abnormal pain impulses are created and pain signals become amplified. Pain can be exhibited in many ways, such as hot, prickling pain around the waist or spasms that tighten leg muscles.

TYPES OF PAIN IN MS


Everyone experiences pain of various types, whether they have MS or not. Although people with MS experience all the same types of pain that everyone else does, some types of pain are a result of MS — either directly, as a result of the demyelinating lesions in the CNS, or indirectly, as a result of the effects that MS has on the musculoskeletal system.

Pain resulting from MS is classified into two categories: neurogenic (nerve pain) and non-neurogenic (musculoskeletal pain). Neurogenic pain is directly correlated to demyelinating lesions in the CNS, while musculoskeletal pain is a consequence of MS-related imbalances in the bones, muscles, tendons, and ligaments that make up the musculoskeletal system.


NEUROGENIC PAIN

Neurogenic pain that results from demyelinating lesions in the CNS may be either a steady, continuous pain, or it may be intermittent. It can be evoked by touch or a specific movement or action, or it may occur spontaneously. Neurogenic pain in people with MS may be classified into several types:

Trigeminal neuralgia (TN), sometimes called “tic douloureux,” is an intense, severe, sharp, electric shock-like pain that affects the eye, cheek and jaw. Typically, it is *unilateral* — occurring only on one side — but in some cases it affects both sides of the face. TN may occur



I WENT THROUGH A LOT, SEVERAL YEARS OF NOT BEING BELIEVED ABOUT THE MS SYMPTOMS. THERE IS AN ELEMENT OF THAT WITH MS. IT'S NOT LIKE YOU HAVE SOMETHING VISIBLE THAT SHOWS PAIN. 'IT'S ALL IN YOUR HEAD.' YEAH, I WAS TOLD THAT. WELL IT REALLY IS ALL IN MY HEAD. IT'S IN MY NERVES.



Elysa, diagnosed in 1989

spontaneously, or it may be triggered by touch, talking, chewing, or other facial movements. People with TN often note a specific point of pain, such as one tooth. Attacks can last from several seconds up to several minutes. The frequency of attacks varies, and there may be periods of remission. TN is 20 times more common in people with MS than the general population.

Lhermitte's sign is a brief, stabbing pain that occurs when the neck is bent forward. It moves from the head down to the spine, and usually lasts for less than a second. Lhermitte's sign may come and go throughout the course of MS, and can signal an exacerbation. Forty percent of people with MS report experiencing Lhermitte's sign during the course of MS.

Optic Neuritis (ON) is the most common visual symptom of MS. It results from inflammation of the optic nerve, or as the result of MS-caused lesions along the nerve pathways that control eye movements and visual coordination. ON may result in blurred vision, dimming of colors, pain when the eye is moved, blind spots, and loss of contrast sensitivity.

Dysesthesias are the most common types of pain in MS. They are abnormal sensations, often painful, and most commonly involve burning, prickling, band-like, or tingling sensations. They may also be associated with feelings of warmth or cold in the extremities that are unrelated to the actual temperature, worse at night and aggravated by physical touch. They typically affect the legs and feet, but may also affect the arms and trunk. The most common forms of dysesthesia

AS THE MS PROGRESSED I HAD MORE NEUROGENIC PAIN SUCH AS STABBING PAIN IN MY EAR AND BEHIND MY EYE. I GET BURNING, LIKE ICE BURNING IN MY HANDS, ARMS, FEET AND UP MY LEGS.

Elysa, diagnosed in 1989

seen in MS are the “MS hug” and allodynia. *MS Hug* is a term for a feeling of constriction, usually around the trunk area, which results from constriction of the tiny intercostal muscles between the ribs. *Allodynia* is pain that results from a stimulus that does not normally provoke pain, such as changes in temperature or physical stimuli such as clothing or bed sheets touching the skin.

Paresthesias also involve burning, aching, numbing, prickling, or “pins and needles” sensations. They may worsen after surgery or a broken bone. In contrast to dysesthesias, which occur in response to a stimulus, paresthesias occur spontaneously.

Paroxysmal symptoms of MS are characterized by their brevity (they last no more than 2 minutes), their frequency (from 1-2 times/day up to a few hundred times/day), and by their lack of association with any residual neurologic damage.

One of the most common types of paroxysmal symptoms of MS is *painful tonic spasms* (PTS), which involve the sudden tightening of a limb,

clawing of a hand or arm, or kicking out of the leg. Spasms last less than two minutes and are often a result of touch, movement, hyperventilation, or emotional stress. They occur in about 11% of people with MS, most commonly in individuals who have had the disease for many years and who have more advanced disability.

MUSCULOSKELETAL PAIN

Back and other musculoskeletal pain in MS can have many causes. It can result from a variety of MS symptoms including weakness, immobility, spasticity, and the deconditioning that result from fatigue and lack of exercise. All of these conditions place stress on bones, muscles, and joints. Pressure on various parts of the body caused by immobility, the incorrect use of mobility aids, or struggling to compensate for gait and balance problems may all contribute to musculoskeletal pain. This type of pain tends to be associated with greater disability, particularly if joint pain is a factor.

“MY DAUGHTER AVALON WAS TWO YEARS OLD. I WAS HAVING A BAD ATTACK. ALL OF A SUDDEN SHE THROWS SOMETHING OUT THE WINDOW. SHE'D THROWN OUT TWO PUZZLE PIECES, MAD AND SAD, OF A LITTLE BEAR PUZZLE WITH FACES AND DIFFERENT EXPRESSIONS. I THOUGHT, THAT'S MY CHOICE. I CAN THROW THEM OUT THE WINDOW.”

Elysa, diagnosed in 1989

Spasticity is a common symptom that results from MS lesions in the nerves that control movement. It may result in a mix of neurogenic and musculoskeletal pain that feels like severe cramping, tightening, aching, or pulling. Spasticity is often accompanied by muscle weakness and leads to an increase in fatigue.

PAIN RESULTING FROM MEDICATIONS USED TO TREAT MS

Pain can also be caused by MS treatments such as steroid-induced osteoporosis, side effects of interferon-beta medications, and injection site reactions. This type of pain is commonly referred to as “iatrogenic,” meaning that it was caused by a medical treatment. You should discuss

your treatment and possible side effects with your healthcare provider, including whether a change in treatment is necessary.

PAIN & YOUR EMOTIONS

We already know that people with MS are at increased risk for depression because of neurologic and immune changes, as well as the challenges of life with a chronic illness. Pain can bring an added dimension of depression and anxiety. The randomness of pain is in itself challenging, and increased fatigue as the result of pain can further limit daily activities and affect quality of life. Does pain mean that I'm getting worse?

THERE'S A LOT MORE YOU NEED TO COMMUNICATE TO YOUR PROVIDERS. IT'S IMPORTANT TO NOT ONLY TELL THEM HOW MUCH YOU HURT BUT — EVEN MORE IMPORTANT — IS TO COMMUNICATE HOW YOUR PAIN IS AFFECTING YOU. WHAT IS IT GETTING IN THE WAY OF?

Dawn Ehde, PhD

Dr. Heidi Maloni comments that “The emotional part of pain can become a catastrophe. People can look at pain and say such things as ‘I will never get rid of this pain,’ ‘I will never be better,’ ‘My life will never be better.’ That type of thinking is destructive, and tends to make pain worse.” For this reason, it is important to recognize and treat the psychological factors associated with pain in MS as early as possible. In addition to medication and counseling, increased support from loved ones and trusted medical providers can have a positive effect on both depression and pain.

According to Dr. Dawn Ehde, “It’s really important to treat both pain and depression. We know from the general primary care literature that, if you’re treating pain in a person who is also depressed, it’s harder to treat the pain if you don’t also address the depression. Pain and depression need to be treated together to achieve the most benefit.”

DISCUSSING PAIN WITH YOUR HEALTHCARE TEAM

Pain can be tricky to discuss with your doctor. It can be difficult to describe your feelings and to assign a quantitative value to the degree of pain you are experiencing. It will help if, before your next doctor’s appointment, you prepare a detailed history of your pain so that you can discuss it accurately. Note what circumstances trigger your pain, if any — for example, do you experience flare ups after certain activities? Bring a list describing all your pain symptoms. Rate your pain on a scale of zero to ten and note what activities, time of day, and any other possible contributing factors that affect your pain. Know what medications you are taking and any possible side effects they may have.

This information can help your doctor determine whether your pain may be related to MS and to rule out other possible causes. Make discussing pain a priority during your appointment; don't leave it for an afterthought. Communicate clearly and keep your emotions in check. Your doctor is most able to help if you come to your appointment prepared and are able to communicate effectively.

RULING OUT OTHER CAUSES – IS IT MS-RELATED PAIN OR NOT?

Dr. Maloni indicated that, when a patient talks to his or her physician about pain issues, a good assessment tool is the most important way to rule out certain causes of pain and to identify those that may be involved. A good assessment will address the following:

- When does the pain occur?
- How often does it occur?
- What part of the body does it affect?
- What does it feel like?

“Describe exactly what the pain feels like. Sometimes that's hard to do, especially if you are experiencing cognitive issues. If it's a new type of pain or pain that is relatively recent, you may want to see your neurologist to discuss it. “Because people with MS experience all the same types of pain that other people do, it's particularly important when pain first presents itself to know where the pain is coming from.” According to Dr. Ehde, “that might lead to different kinds of treatments. What's important is that whether or not pain is caused by MS, it can get in the way of your life and it's worth treating.”

TREATMENT OPTIONS

Pain management in MS should be based in an interdisciplinary team approach. Every treatment option should be explored until the right combination is found. A comprehensive approach to managing pain may include medication, self-management tools, and complementary and alternative therapies — all working towards the achievable goal of pain management.

OPIOIDS

Opioids act predominantly in the CNS to modulate the pain response. In MS-related CNS pain, opioids are only minimally useful and are often effective only at very high doses. Neurogenic pain generally responds poorly to opioids and the side effects often outweigh whatever little relief can be achieved. For these reasons, *the use of opioids in MS central pain is not recommended*. Most neurologists are concerned about relying on opioids to treat MS and hesitate to refer patients to pain centers, where there tends to be a heavy reliance on opioids; they also may not be properly equipped to handle MS patients or knowledgeable about the best ways to treat MS pain.

MEDICATIONS

A wide variety of medications may be used to treat pain, depending on its origin and type. Treatment often includes drugs used “off-label,” meaning that they have been approved for conditions other than MS, but that physicians have found them effective for MS-related pain. This includes medications such as anticonvulsants, which are effective in trigeminal neuralgia, L’Hermitte’s sign, and tonic spasms; antidepressants; analgesics such as acetaminophen; and nonsteroidal anti-inflammatory drugs (NSAIDs) such as Advil®, Motrin®, and others. If spasticity is a major cause of pain, antispasticity agents and botulinum toxin may be helpful.

Sometimes, topical agents may be useful. Opioids are rarely helpful in MS. The following chart summarizes the medications commonly used to manage MS-related pain.

INTERVENTIONAL PROCEDURES

Interventional procedures offer additional treatment options to manage pain. They are generally considered only minimally invasive (they don’t involve major surgery), although some are more aggressive than others, and they offer a targeted approach to pain relief. Interventional procedures are indicated when other treatment options have failed to provide sufficient pain relief.

INTERVENTIONAL PROCEDURES

Type of Intervention	Treatment	Indications
<i>Minimally invasive interventions</i>	Intrathecal baclofen or morphine; Botox® injections; trigger point injections; epidural steroids; regional blocks; spinal cord stimulators	Indicated when other treatments fail or side effects are intolerable.
<i>Neurosurgical procedures — nerve block procedures typically used to treat trigeminal neuralgia (TN)</i>	Includes cordotomy, rhizotomy, percutaneous balloon compression, percutaneous glycerol injection, radio frequency rhizotomy, and gamma knife radiosurgery	These are used when pain relief has not been achieved through drug intervention, or when minimally invasive procedures are not expected to be useful or have been used and failed to control pain. Can result in significant increase of quality of life, but effects may be short-lived and can result in facial numbness and worsening of TN pain.

MEDICATIONS COMMONLY USED TO MANAGE MS-RELATED PAIN

Type of Pain	Characteristics	Treatment
<i>Trigeminal Neuralgia (TN)</i>	Excruciating, sharp, shock-like pain in cheek and/or forehead, lasting seconds to minutes; may be triggered by speaking or a touch	Carbamazepine, gabapentin, lamotrigine, misoprostol, phenytoin, baclofen (medications may be combined) Botulinum toxin Surgery to destroy nerves either temporarily or permanently; used when medications fail
<i>Tonic Spasms</i>	Brief muscle twitching or sudden, sharp muscle spasm; may also burn or tingle	Same medications as for TN
<i>Paroxysmal Limb Pain</i>	Painful burning, aching, or itching of any part of the body but more common in the legs	Same medications as for TN; also amitriptyline, clonazepam, and diazepam Application of heat and cold (some MS specialists avoid using heat) Capsaicin ointment Pressure stockings (some MS specialists recommend using pressure stockings; others do not)
<i>Headache</i>	Migraine, tension, or cluster headache types	Treatment determined by type of headache
<i>Optic Neuritis</i>	Sharp, stabbing eye pain	Intravenous methylprednisolone, nonsteroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen

<i>Spasms</i>	Muscle cramping, pulling and pain	<p>Stretching exercises</p> <p>Medications such as baclofen, tizanidine, dantrolene, or intrathecal baclofen</p> <p>Botulinum toxin</p>
<i>Dysesthetic Extremity Pain</i>	Chronic burning, tingling, tightness, or pins-and-needles feelings; a dull warm aching; worse at night and after exercise; aggravated by temperature and weather	<p>Same as for TN and paroxysmal limb pain</p> <p>Dull aching pain responds best to tricyclic antidepressants such as amitriptyline; may require maximum dosing</p>
<i>Musculoskeletal Pain</i>	Caused by the physical stress of living with MS; Physician should first rule out spinal disc disease or other non-MS-related issues	<p>Stretching exercises</p> <p>Posture and gait evaluation</p> <p>Exercise (especially swimming) to increase strength and flexibility</p> <p>NSAIDs such as ibuprofen</p> <p>Proper seating, position changes, support and cushioning</p> <p>Application of heat and cold</p>
<i>Pain resulting from other MS treatments (iatrogenic pain)</i>	Pain caused by a medication or treatment, such as steroid-induced osteoporosis, interferon side-effects, injection site reactions	Discuss treatment with your healthcare provider; treatment may involve changing medication
<i>Secondary pain of MS symptoms</i>	Pain associated with pressure sores, stiff joints, muscle contractures, urinary retention; urinary tract infection, or other infections	<p>Treating the cause usually alleviates the pain</p> <p>Physician should assess for depression</p>

NON-MEDICAL INTERVENTIONS

Many people with MS are unaware of the benefits that non-medical interventions can have on pain. Physical therapy, appropriate exercise, stretching, and nutritional support are all part of managing MS in general, but they can also have a positive effect on pain. In the past, people with MS were counseled to avoid exercise. Exercise was thought to make pain worse. However, research has shown that people who exercise, engage in a stretching regimen, and stay active, tend to have less pain, and the pain they experience tends to be less disruptive. Staying active is important, and people with MS should consider consulting a physical therapist to identify an exercise and stretching routine that is suitable for them. Physical therapy can help people with MS get active in a safe way.

We know that stress makes pain worse. Actively looking at the causes of stress and finding ways to manage stress often result in better

pain management. The mind plays a role in managing pain as well. Negative thoughts can be harmful. People tend to do worse with pain management if they engage in negative thinking. Deep breathing, guided imagery or relaxation can dampen pain signals in the brain and provide something else to focus on. Relaxing muscles can help manage stress and decrease pain.

Learning ways to harness positive thinking, engaging in self-talk, and seeking professional counseling can help manage pain and give you a sense of control over your pain.

COMPLEMENTARY & ALTERNATIVE THERAPIES

Medication in combination with complementary and alternative therapies (CAM) can improve pain relief for many people. In the past, complementary therapies were considered a last resort, but they are now part of an integrated treatment plan from the start. Not only can complementary therapies help people cope with pain more effectively, but

CANNIBIS DISCLAIMER

Based on the studies to date — and the fact that long-term use of marijuana may be associated with significant, serious side effects — it is the opinion of the **National MS Society's National Clinical Advisory Board** that there are currently insufficient data to recommend marijuana or its derivatives as a treatment for MS symptoms. Research is continuing to determine if there is a possible role for marijuana or its derivatives in the treatment of MS.

MS Society of Canada Position Statement on Cannabis as a Treatment for MS-related Symptoms:

The MS Society of Canada endorses the use of cannabis for medical reasons providing Health Canada's Marijuana Medical Access Regulations are followed appropriately. Activities including possession, production and trafficking of marijuana other than as authorized under the regulations remain illegal. The cannabis-derived drug Sativex® (GW Pharmaceuticals) received approval from Health Canada in 2005 for use in adult patients with MS neuropathic pain and cancer pain.

they can also reduce reliance on medications with the added benefit of minimizing side effects associated with those medications.

CAM therapies include a variety of interventions that come from many different disciplines and traditions. They are generally considered to be outside the realm of conventional medicine. When used in combination with conventional medicine, they are referred to as “complementary;” when used instead of conventional medicine, they are referred to as “alternative.” You should always consult your healthcare provider and keep him or her informed of any CAM therapies you are using.

Some common complementary therapies used by people with MS to manage pain include:

- acupuncture
- chiropractic treatment
- biofeedback
- meditation
- dorsal column stimulators
- massage
- music therapy
- aromatherapy
- hypnosis

WHY SOME DOCTORS ARE HESITANT TO TREAT PAIN

Statistically, only about half the patients with MS who experience pain use medication. Dr. Maloni believes that pain is often undertreated for a variety of reasons. “I was with a patient yesterday and he said to me, ‘you know providers just don’t get it!’ I’m not too sure that’s exactly true. I think providers are trying really hard to get it. It’s a team approach between you and your provider.”

What are some of the barriers to getting treatment for pain? Dr. Maloni says, “Some of the barriers might rest with you, the patient. You may not feel that your pain is very important. Other things may seem more important when you have that 15-minute talk with your provider. Perhaps you want to know more about walking, or bladder control, so pain takes back seat and doesn’t get expressed during the appointment.”

Often, people with MS don’t want to be on medication for pain. The side effects are of concern and they tend to take the approach that less is better. However, that doesn’t always help when it comes to managing pain. In addition, not all doctors know how to treat pain.

According to Dr. Gil Fanciullo, “There’s a lack of training and lack of knowledge about how to treat pain effectively. Treating pain tends to be a very labor-intensive process. It’s not like telling your doctor that you have a sore throat, where the doctor makes a quick determination that you have strep throat, gives you penicillin, and you get better. It involves a process, a lot of time up front, and treatment with a lot of different interventions. There can be side effects to deal with and barriers to implementing those interventions. It’s a labor intensive process for doctors and an area where their skill sets might not be up-to-date.”

RESEARCH

One of the challenges for understanding pain in MS is that a good animal model doesn’t exist. There isn’t a cellular model of the disease. Researchers know that nerve wires (axons) damaged during the course of MS are more sensitive and can become hyper excitable. If those wires are in a pain pathway, they may generate abnormal impulses and be interpreted by the brain as pain.

It is still unclear what the molecular drivers of neuropathic pain in MS and related disorders are. This information would help in the development of new and more effective treatments.

To understand how MS causes pain, we must first look at how pain is produced. Dr. Stephen Waxman is studying the role of ion channels in producing pain. Ion channels act a bit like pores, and they regulate the flow of charged particles into nerve fibers. Nerve cells contain hundreds of thousands of one type of ion channel, called sodium channels, that help generate nerve impulses. Dr. Waxman's research demonstrates that the loss of myelin exposes parts of nerve fibers that don't contain enough sodium channels, and they are unable to produce nerve impulses.

Research on underlying mechanisms of pain is advancing significantly. Translational efforts are underway around the world trying to turn new understanding into new therapies. According to Dr. Waxman, "sometime in the foreseeable future — three years, five years, ten years — we're going to have new, much more effective, non-sedating classes of drugs for peripheral neurogenic pain that don't put pain signaling to sleep. The challenge is to translate that approach and similarly be able to dissect the black box of molecules that causes inappropriate firing along pain pathways in diseases like MS. We have a lot of work to do."

Adding MRI findings to the diagnostic criteria for MS has enabled tremendous progress. According to Dr. Heather Wishart, this has greatly reduced the window of time between symptom onset and diagnosis, "which is very important because an earlier diagnosis may potentially mean earlier treatment." MRI has also been used to expand understanding of MS

and has helped determine the impact of therapies during clinical trials.

Traditional MRI offers a way to look at brain structure, lesions, and changes in brain tissue. Functional MRI (fMRI) is an imaging method that allows researchers to look at brain activity, not just structure. It measures activity in specific parts of the brain based on blood flow and oxygenation levels. fMRI allows researchers to indirectly observe which areas of the brain are activated while a person is doing a specific task. Drs. Wishart and Fanciullo are using fMRI to measure pain. By establishing a person's mild pain threshold using simple pressure simulation, that mild pain threshold can be duplicated while the person is undergoing an MRI. The research team looks at blood flow and oxygenation levels during periods of mild pain and rest in order to see which areas of the brain are active during pain processing. They hope to gain insights into central pain processing in MS using these techniques. According to Dr. Wishart, "We are just beginning the pain imaging research, but my hope is that we'll also learn a lot about the basis of pain, how to detect it earlier and treat earlier."

Developing better tools for measuring pain is important for both the early detection of pain problems and for selecting appropriate treatment options for each individual. Currently, a person may need to try several different treatment options before finding something that works for his or her pain. Dr. Fanciullo says, "I am very excited about our work with functional MRI. We've taken an enormous step in trying to understand how our body works, how our body processes pain, and how we're going to be able to best treat that pain."

PART 2: SLEEP ISSUES IN MULTIPLE SCLEROSIS

OVERVIEW OF SLEEP ISSUES IN MS



EVERYONE
NEEDS QUALITY
SLEEP

As discussed earlier, people with MS are not immune to all the types of pain experienced by everyone else. The same holds true for sleep problems: as many as 50 million Americans and approximately 3.5 million Canadians suffer from some type of sleep disorder.

Everyone needs quality sleep to maintain good health and feel productive. Sleep disorders can be an added barrier to quality of life for people with MS, in addition to fatigue, pain, and many other symptoms. Studies suggest that people with MS may be up to three times more likely to experience sleep disturbances than the general population.

In addition, they are about twice as likely to experience a reduced *quality* of sleep. Poor sleep has serious consequences for cognition, fatigue, mood swings, and physical symptoms such as balance, spasticity and pain.

CONSEQUENCES OF POOR SLEEP

Everyone has experienced lack of sleep at some point in their lives and is well aware of the effects of a reduced quantity and quality of sleep. Problems falling asleep, staying asleep, or getting the right kind of sleep prevent people from waking up feeling refreshed. If you're not getting the proper amount of restful sleep — eight hours a night — your thinking may not be as sharp, you'll feel tired throughout the day, and you may not be as productive.

“WHEN I DON'T GET THE SLEEP I NEED, MY COGNITION IS AFFECTED. I CAN'T FOCUS. MY DAUGHTER WOULD PROBABLY SAY THAT I GET VERY ORNERY. I GET MAD WHEN I CAN'T DO SOMETHING BECAUSE I'M TIRED. I HAVE A STRONGER RELATIONSHIP WITH MY DAUGHTER WHEN I GET THE SLEEP I NEED.”

Christina, diagnosed in 1998

With MS, that's just the beginning because many symptoms can be connected and affect overall quality of life.

Cognitive impairment can be magnified by lack of sleep. Balance and gait can be affected by reduced sleep quality, making you more prone to falls.

Waking up not feeling refreshed may be a sign that your level of emotional well-being is affected. In turn, not getting the proper amount of sleep can also affect your mood and emotional health.

THE ROLE OF FATIGUE IN SLEEP ISSUES

Even though fatigue is common in MS, the disease itself may not be the only reason you're tired. Many factors can contribute to fatigue including other medical conditions, heat, medications, stress, depression, and sleep problems. There is a particularly strong correlation between fatigue and sleep disorders. Depression and anxiety, both common in MS, can also affect fatigue and the quality of sleep you get. Because so many MS symptoms are related and can interact, it's important for you and your doctor to look at your symptoms and determine a management strategy to help you achieve a good quality and amount of sleep.

According to Dr. Rock Heyman, “MS is a complex disease and many factors can be related to MS fatigue. One of the biggest things I look for that will make me think a person’s fatigue is related to a sleep disorder rather than normal MS fatigue is whether the person wakes up refreshed. If the person does wake up refreshed, perhaps he/she might not feel wonderful, but the energy level is the best it’s going to be for the day because MS fatigue will set in as the day goes on. If someone wakes up and is still exhausted, that tells me his/her sleep quality or quantity is not good enough, and a sleep study is probably going to be needed to better determine why. The biggest red flag to indicate ‘this isn’t just MS fatigue’ is waking up tired.”

WARNING SIGNS OF A SLEEP DISORDER

Dr. Heyman recommends that you should seek help for your trouble with sleep or fatigue if it interferes with your quality of life. Look for these warnings signs that you’re not getting the appropriate amount of sleep or quality of sleep:

- You’re tired right after getting up and don’t feel refreshed
- You need an alarm clock to wake up
- You fall asleep during the day when you don’t want to
- You either can’t fall asleep, or wake up after a few hours and can’t fall back asleep
- You kick off the bed covers
- You get up frequently at night
- You snore

Addressing these warnings signs with your healthcare team can be the first step towards determining if you have a sleep disorder and managing the effects of a reduced quality of sleep.

CAUSES OF SLEEP DISORDERS

Sleep problems may result from a variety of MS symptoms, such as spasms, urinary frequency, depression or anxiety, as well as medications used to manage a variety of symptoms associated with the disease.

Many people with MS experience bladder problems. Nighttime visits to the bathroom (nocturia) interrupt sleep cycles. Restless leg syndrome (RLS) and periodic limb movements (PLMS) are common in MS. Pain, spasticity, and cramping can all wake you, cause insomnia, and reduce the quality of sleep you get. Some of the medications you may take for your MS symptoms can affect sleep quality. For example, depression and anxiety can prevent you from falling asleep and staying asleep, but some treatments for these symptoms also can interfere with sleep.

One study showed that sleep apnea was the most common sleep disorder in people with MS. It is characterized by repeated episodes of disrupted breathing during sleep, which results in intermittent falls in the level of oxygen in the blood. Each time this happens, a person either wakes up or moves from deep to lighter sleep. Research has shown that the disruption of sleep due to sleep apnea is a contributing factor to fatigue in multiple sclerosis.

As discussed above, some medications used to manage MS and its symptoms can interfere with sleep. For example, interferon-beta medications produce a feeling similar to that of viral infection, and medications used to help treat fatigue during the day can impair nighttime sleep. This can lead to the proverbial “vicious cycle,” in which symptoms disturb sleep, and the lack of needed sleep in turn worsens a variety of symptoms, especially fatigue.

SLEEP HYGIENE

Developing good sleep habits is critical to managing a sleep disorder and the fatigue that it produces. Communicate with your spouse why good sleep habits are critical. Your partner can play a role in helping you maintain sleep hygiene.

Fairly simple changes can help enormously to ensure a good night's sleep. They include:

- Set a regular sleep schedule, matching that of your partner's if possible. Go to bed and get up at the same time every day, including weekends. This will help your body adjust to a normal sleep pattern.
- To minimize nighttime trips to the bathroom, don't drink a lot of fluids in the evening.
- Don't use your bedroom for watching TV or reading.
- Don't exercise in the evening; whatever your exercise program, do it earlier in the day.
- If you can't fall asleep after 10 minutes, get up. Do something quiet that keeps your mind mildly active.
- Avoid caffeine, alcohol, or tobacco near bedtime.
- Make sure your bedroom environment is conducive for good sleep — dark, cool, and quiet.
- Be sure you have a comfortable bed, pillow, and covers.
- Listen to relaxing music.

DISCUSS SLEEPLESSNESS WITH YOUR HEALTHCARE TEAM

It can be difficult to communicate with your doctor or healthcare team about your fatigue or challenges with sleeping. It is helpful to maintain open communication and a good relationship with your medical team, including the physician's assistant, nurse practitioner, and doctor. Give concrete examples of how the fatigue and sleeplessness are interfering with your quality of life. For example, tell your provider if you have had to stop attending your children's events in the evening, or are napping at work. Be prepared for your medical appointments.

Keep a sleep diary. Track your habits, including exercise, caffeine intake, and bedtimes. Ask your family members for their observations. Note if you snore or gasp for breath and whether you experience restless legs. Bring a list of all your medications, including dosing information. The more information you provide to your medical team, the better equipped they'll be to determine if you have a sleep disorder.

TREATMENT OPTIONS

TREAT SYMPTOMS THAT MAY CAUSE SLEEPLESSNESS

The first step in treating sleep disorders or reduced sleep quality is to address any symptoms that are affecting your ability to sleep. Depending on your specific symptoms, a variety of treatment options are available:

Bladder issues (nocturia). Nocturia is the excessive need to urinate at night. You need to address bladder issues even if your symptoms are manageable during the daytime. Treatment options include medications and/or behavioral strategies to reduce the urgency and frequency of urination and allow for more complete emptying of the bladder before bedtime. If necessary, hormonal medications are available to reduce urine production from the kidneys for 4-6 hours at night.

Spasticity. Treatment options include higher doses of spasticity medicines. Their main side effect is sedation, so it's easier to take a higher dose at night. The medication may not last through the night, so your doctor may want to combine several medicines. If you're always up in the middle of the night because of your bladder, put the next dose out to take before you go back to sleep. This second dosage during the night may help control spasms into the morning. Your doctor might also want to discuss the idea of a timed-release pump.

Restless Legs Syndrome or Periodic Limb Disorder. Several medications are available to help decrease these movements.

Pain. Treatment options include medication and various complementary therapies. Some pain medications may cause sedation, which isn't a problem at night, particularly if you have sleep difficulties.

Sleep Apnea. Treatment options include the use of a continuous positive airway pressure (CPAP) mask and oral appliances that open up the airway for better breathing.

Depression. Anxiety or depression can cause sleep disturbances. It's difficult to fall asleep if your mind is racing or you're under a lot of stress. According to Dr. Heyman, "waking before you're completely rested can be a hallmark symptom for depression, even if you're not feeling particularly sad." Treatment options for depression include anti-depressants and psychotherapy.

CONSIDER THE SIDE EFFECTS OF MEDICATIONS

When treating MS symptoms, it's always important to consider the potential side effects of medications. For example some medications, including those to treat depression, pain and spasticity, may cause drowsiness, which can help nighttime sleep. Other medications can interfere with sleep. Medications prescribed to treat fatigue help with energy during the day, but may impair nighttime sleep. The interferons prescribed to slow disease progression can give people a feeling similar to that of a viral infection, with chills and body aches that prevent deep sleep.


It's important to maintain ongoing discussions with your doctor about your symptoms, treatment options, and the effects of both on your sleep quality.

SLEEPING PILLS

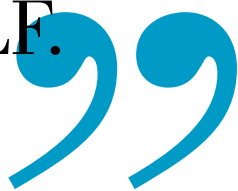
Sleeping pills may be of some benefit, at least for a short time. However, many experts recommend taking them as only a last resort because they lose their effectiveness quickly and are potentially addictive. Over-the-counter Benadryl® and Benadryl-containing products may be helpful, but should not be used on a regular basis.

SLEEP STUDIES

A sleep study is usually done overnight in a laboratory. It involves placing electrodes, wires, and sensors on various parts of your body. They measure brain waves, eye movements, breathing, oxygen levels, and movements during sleep, while a camera records your body positions and movements.



SLEEP MANAGEMENT TECHNIQUES FOR ME ARE MASSAGE THERAPY, STRETCHING AND STRENGTHENING, REDUCING MY STRESS BY SETTING BOUNDARIES AND HANGING OUT WITH PEOPLE WHO ARE POSITIVE. IN THE PAST I WOULD FEEL SELFISH IF I TOOK TIME FOR MYSELF, BECAUSE I FELT LIKE I HAD TO DO FOR EVERYONE ELSE. I NEED TO TAKE CARE OF MYSELF.



Christina, diagnosed in 1998

Dr. Heyman acknowledges that, “A sleep study sounds like a lousy way to sleep, but we still despite all of that can get very useful information and understanding.” Sleep studies aim to answer a series of questions related to sleep:

- Do you actually sleep?
- Do you experience normal types of sleep?
- Do you breathe normally?
- Do legs spasms wake you up, even though you don't remember waking up?

This information can point to a diagnosis of a sleep disorder and the appropriate treatment regimen.

SELF-MANAGEMENT & COMPLEMENTARY STRATEGIES

Dr. Heyman noted that, “People with MS and healthcare professionals need to keep in mind that very good things can be done and are proven to help, such as having an effective stretching regime to control spasticity. I find the most successful patients often do a combination of things. If needed they take a medication, but they start off with something as simple as stretching or practicing certain types of mind/body exercises.”

RESEARCH

Drs. Daria Trojan and John Kimoff of McGill University in Montreal, Quebec recently completed a study looking at the correlation between fatigue and sleep disorders. Their findings indicate a strong association between sleep apnea and fatigue. Furthermore, treatment of sleep apnea and other sleep disorders seems to help fatigue.

According to Dr. Kimoff, evaluations of sleep disorders need to take into consideration many factors, such as sleep quantity and continuity, and also existing medical conditions.

These factors can often be explained by the presence of a medical sleep disorder such as sleep apnea or frequent limb movements during sleep. In a recently published study, Drs. Kimoff and Trojan compared 62 people with MS to 32 normal controls. All subjects completed overnight sleep studies to evaluate sleep disorders and blood tests (to exclude other conditions, such as reduced

levels of vitamin B-12, that can contribute to certain sleep disorders). The most common sleep disorder, found in 58 % of those with MS, was obstructive sleep apnea — sleep apnea caused by a physical obstruction in the breathing pathway. Restless leg syndrome was the second most common sleep disorder. Overall sleep was more disrupted in the people with MS than those in the control group.

They then looked at the association between sleep disorders and various clinical symptoms. In the group with MS, there was a strong correlation between severe fatigue and severe sleep apnea. According to Dr. Kimoff, “the disruption of sleep due to sleep apnea or due to many other causes certainly is one of the factors that we believe contributes to fatigue in MS.”

Dr. Trojan noted that there are several ways in which sleep apnea can contribute to fatigue in MS. “First, the MS disease process is associated with neuronal injury, or loss, both of which have

GOOD SLEEP IS IMPORTANT. HERE ARE SOME THINGS YOU CAN DO TO IMPROVE YOUR CHANCES OF GETTING ADEQUATE SLEEP

- Repetitive mental exercises, such as counting sheep or repeating a mantra, a commonly repeated word or phrase.
- Visualization — seeing yourself being lulled to sleep in a tranquil environment.
- Progressive relaxation, which involves mentally “putting to sleep” each part of the body by first tensing and then relaxing muscles. People with spasticity should exercise caution when doing this.
- Take only short rest periods during day. Long naps may interfere with sleep later.
- Herbal supplements such as melatonin should be used with caution. They may interact with other medications and stimulate the immune system, which is not advisable for people with MS.

been associated with fatigue. Some studies in the general population have also suggested that sleep apnea itself can be associated with neuronal loss in the brain. So the additional neuronal loss caused by sleep apnea in MS, if this truly does happen, can produce additional fatigue. A second way that sleep apnea can produce fatigue in MS is by causing cortical reorganization and increased activity in the brain. The MS disease process itself is also associated with “cortical reorganization” — changes in brain structure and increased brain activity to compensate for neuronal injury and loss. This increase in brain activity — caused by both sleep apnea and the disease itself — may potentiate the fatigue in MS. The third way that sleep apnea can contribute to fatigue in MS is through inflammation. MS is known to be inflammatory disease and sleep apnea is also known to produce systemic inflammation. So the added inflammatory effect of sleep apnea can increase inflammation, and in some studies inflammation and fatigue have been linked in MS.”

A more recent study by Drs. Trojan and Kimoff looked at the association of various parameters that are assessed by sleep studies with quality of life. Quality of life was assessed with a measure called the SF-36, which calculates two summary scores, one for mental quality of life, the other physical quality of life.

They found that measures of disturbed sleep are associated with poor mental quality of life. A greater number of awakenings, longer time in light sleep, greater sleep apnea, and a greater total arousal all were associated with poor mental quality of life. However, they did not find a similar association with physical quality of life.

Another study awaiting publication focuses on possible treatment options for sleep disorders. Preliminary data show that treating specific sleep disorders can result in improvements in fatigue, as well as a reduction in daytime sleepiness and a significant improvement in sleep quality.

Dr. Kimoff believes that fatigue should be a major area of focus when treating individuals with MS. “It’s very clear that many factors can contribute to fatigue, and both patients and their treating neurologists have a major challenge in trying to maintain a global perspective on the many things that can contribute to sleep disorders. Our evidence suggests that sleep disorder breathing, or obstructive sleep apnea can be a major factor in MS fatigue. The nice thing about this is that we’re looking at something that’s treatable.”

GLOSSARY



DEFINITIONS

ACUPUNCTURE

Acupuncture involves stimulating specific locations on the skin, usually by inserting thin, disposable metallic needles into points along the meridians in the body in order to alter the flow of energy.

AROMATHERAPY

A form of alternative medicine that uses volatile plant materials, known as essential oils, and other aromatic compounds for the purpose of altering a person's mind, mood, cognitive function, or health.

BIOFEEDBACK

The process of becoming aware of various physiologic functions using instruments that provide information on the activity of those same systems, with a goal of being able to manipulate them at will. Biofeedback may be used to improve health or performance, and the physiologic changes often occur in conjunction with changes to thoughts, emotions, and behavior. Eventually, these changes can be maintained without the use of extra equipment.

CANNABIS

Also known as marijuana, refers to preparations of the Cannabis plant intended for use as a psychoactive drug and as medicine.

CHIROPRACTIC TREATMENT

Restores normal function to joints and their supporting structure. Following a simple examination, and often radiological evaluation, the chiropractic practitioner applies precise adjustments to the vertebral column to bring structures back into alignment. This realignment is supposed to eliminate irritation to the nerves and restore normal function.

COMPLEMENTARY & ALTERNATIVE THERAPIES (CAM)

Include a variety of interventions from many different disciplines and traditions. They are generally considered to be outside the realm of conventional medicine. When used in combination with conventional medicine, they are referred to as “complementary;” when used instead of conventional medicine, they are referred to as “alternative.”

COGNITIVE BEHAVIORAL THERAPY

Talk therapy that uses the mind's ability to change emotions and how symptoms are perceived by challenging habitual thought patterns and behaviors. A psychotherapeutic approach that addresses dysfunctional emotions, behaviors, and cog-

nitions through a goal-oriented, systematic process. The name refers to behavior therapy, cognitive therapy, and therapy based upon a combination of basic behavioral and cognitive research.

DORSAL COLUMN STIMULATORS

A device used to exert pulsed electrical signals to the spinal cord to control chronic pain.

DYSESTHESIAS

Abnormal sensations, often painful, that most commonly involve burning, prickling, band-like, or tingling sensations. They typically affect the legs and feet, but may also affect the arms, trunk, and spinal cord. The most common forms of dysesthesia seen in MS are the *MS hug* and *Allodynia*. *MS Hug* is a term for a feeling of constriction, usually around the trunk area.

Allodynia is pain that results from a stimulus that does not normally provoke pain, such as changes in temperature or physical stimuli such as clothing or bed sheets touching the skin. It may also be associated with feelings of warmth or cold in the extremities that are unrelated to the actual temperature.

FUNCTIONAL MRI (fMRI)

Measures small metabolic changes in the brain related to the flow of blood and oxygen to specific parts of the brain. Regular MRI imaging evaluates various aspects of the structure of the nervous system, while fMRI evaluates *functional activity* of various parts of the nervous system.

GUIDED IMAGERY

A technique used by many natural or alternative medicine practitioners as well as some medical doctors and psychologists to aid patients in using mental imagery to help with healing their bodies, solving problems, and reducing stress.

HYPNOSIS

A trance-like state that resembles sleep but that is induced by a person whose suggestions are readily accepted by the subject.

INSOMNIA

The most common sleep disorder. Defined as having trouble falling asleep, staying asleep, or having poor quality sleep.

LHERMITTE'S SIGN

A brief, stabbing, electric-shock-like sensation that runs from the back of the head down the spine, brought on by bending the neck forward.

MASSAGE

The most common bodywork therapy. Used to relax muscles, reduce stress and relieve conditions exacerbated by muscle tension.

MEDITATION

Any form of a family of practices in which practitioners train their minds or self-induce a mode of consciousness to realize some benefit.

MUSIC THERAPY

One of the expressive therapies, consisting of an interpersonal process in which a trained music therapist uses music and all of its facets — physical, emotional, mental, social, aesthetic, and spiritual — to help clients improve or maintain their health.

MUSCULOSKELETAL PAIN

Includes weakness, immobility, spasticity, and deconditioning that results from movement dysfunction.

NEUROGENIC PAIN (NERVE PAIN)

A direct consequence of a demyelinating lesion in the central nervous system. Neurogenic pain may be either a steady, continuous pain, or it may be intermittent. It can be evoked by touch or a specific movement or action, or it may occur spontaneously.

NOCTURIA

Frequent nighttime urination.

OPIOIDS

A class of drugs that act predominantly in the central nervous system to modulate pain response. Often used to manage moderate to severe pain.

OPTIC NEURITIS (ON)

Results from inflammation of the optic nerve, or as the result of MS-caused lesions along the nerve pathways that control eye movements and visual coordination. May result in blurred vision, dimming of colors, pain when the eye is moved, blind spots, and loss of contrast sensitivity.

PARESTHESIAS

Like dysesthesias, these also involve burning, aching, numbing, prickling, or “pins and needles” sensations. They may worsen after surgery or a broken bone. They differ in that dysesthesias occur in response to a stimulus, while paresthesias occur spontaneously.

PAROXYSMAL SYMPTOMS

Characterized by their brevity and frequency. One of the most common types of paroxysmal symptoms of MS is *painful tonic spasms* (PTS), which involve the sudden tightening of a limb, clawing of a hand or arm, or kicking out of the leg. Spasms last less than two minutes and are often a result of touch, movement, hyperventilation, or emotional stress.

PERIODIC LIMB MOVEMENTS (PLMS)

A sleep disorder in which the patient moves limbs involuntarily during sleep. PLMD should not be confused with restless leg syndrome (RLS). RLS occurs while awake as well as when asleep, and when awake, there is a voluntary response to an uncomfortable feeling in the legs. In contrast, PLMD is involuntary, and the patient is often unaware of these movements altogether.

RESTLESS LEGS SYNDROME (RLS)

A neurologic disorder characterized by an irresistible urge to move one's body to stop uncomfortable or odd sensations. It most commonly affects the legs, but can affect the arms, torso, and even phantom limbs. Moving the affected body part modulates the sensations, providing temporary relief.

SF-36 QUALITY OF LIFE MEASURE

A commonly used quality of life measure in sleep studies. Calculates two summary scores: one summary score for mental quality of life, and another for physical quality of life.

SLEEP APNEA

A sleep disorder characterized by repeated episodes of disrupted breathing during sleep, resulting in intermittent falls in the level of oxygen in the blood. Each time this happens, a person either wakes up or moves from deep to lighter sleep.

SLEEP HYGIENE

The practice of following behavioral guidelines in an attempt to ensure more restful, effective sleep.

SLEEP STUDY

A test that includes measurement of different variables including brain waves, eye movements, breathing, oxygen, and movements.

SODIUM CHANNEL

One of several types of ion channels. Tiny pores that allow charged particles, such as sodium, potassium and calcium ions, to pass in and out of a cell. Sodium channels open for a fraction of a second to allow just enough sodium in to trigger a nerve impulse.

TRIGEMINAL NEURALGIA (TN)

Sometimes called "tic douloureux," a stabbing pain in the face. It can occur as an initial symptom of MS. While it can be confused with dental pain, this pain is neurogenic (caused by damage to the trigeminal nerve) in origin.

SUGGESTED READINGS & RESOURCES



BROCHURES

The National MS Society has an extensive library of resources about MS, including publications about treatment options, symptom management, and the day to day challenges of living with the disease.

For more information on managing pain and sleep disorders in MS, the publications listed below are available at nationalMSsociety.org/brochures or by contacting an MS Navigator® at 1-800-344-4867 (1-800 FIGHT MS).

BROCHURES

STAYING WELL

Clear Thinking about Alternative Therapies

Facts and common misconceptions, plus practical ways to evaluate benefits and risks of unconventional therapies.

Exercise as Part of Everyday Life

Describes ways to make physical activity a regular part of staying healthy. Includes tips on handling MS symptoms.

Food for Thought: MS & Nutrition

A guide to healthy eating, which includes managing symptoms, changing eating habits, and the effects of diet on MS.

Managing MS through Rehabilitation

An overview of what rehabilitation can do for mobility, fatigue, driving, speech, memory, bowel or bladder problems, sexuality, and more.

Stretching for People with MS

An illustrated manual showing range of motion, stretching, and balance exercises for a basic at-home program.

Stretching with a Helper for People with MS

An illustrated manual showing most of the same exercises, but designed for individuals who need a helper.

MANAGING SPECIFIC ISSUES

Controlling Spasticity in MS

Managing this common, sometimes disabling, MS symptom — roles of self-help, medications, physical therapists, nurses, and physicians.

Depression & Multiple Sclerosis

Discusses the symptoms of depression, the relationship between MS and depression, available therapies, and where to find help.

Fatigue: What You Should Know

MS fatigue can be reduced with treatments and self-help.

Pain: The Basic Facts

Overview of treatments and strategies for managing MS-related pain.

Review of Regular Medications & Supplements

A form to help people keep track of their prescription drugs, over-the-counter remedies, herbals, vitamins, or other dietary supplements.

Sleep Disorders & MS: The Basic Facts

Reviews common sleep problems and what can be done about them.

Urinary Dysfunction & MS

A sophisticated explanation of treatments for MS-related urinary problems. Detailed descriptions of diagnostic testing, management strategies, and commonly prescribed medications.

ONLINE

MS LEARN ONLINE SERIES

MS Learn Online offers online video programs on a wide range of issues, including disease modifying medications, symptom management, health and wellness, and many other topics of interest. Each educational program features MS experts. Transcripts and podcasts are available for most programs. Visit MS Learn Online at nationalMSsociety.org/mslearnonline for a complete listing of all MS Learn Online programs available, including programs specific to pain and sleep management:

- Types of Pain in MS
- Pain is a Real Symptom for People with MS
- The MS Hug — Q&A Session
- Narcotics for MS Pain — Q&A Session
- Getting a Good Night's Sleep with MS
- Invisible Symptoms of MS: Parts 1 & 2
- Managing Symptoms in MS: Pain
- Spasticity and MS
- Spasticity and MS: Management Strategies

MS SOCIETY OF CANADA



BROCHURES

The MS Society of Canada offers a variety of publications and materials that deal with the many aspects of life with MS, including the following resources on managing pain and sleep disorders. These and other publications are available online at mssociety.ca or by calling 1-800-268-7582.

STAYING WELL

Everybody Stretch: A Physical Activity Booklet for People with MS

This illustrated workbook outlines a flexible, individualized exercise program that can be adapted to changing physical abilities.

Healthy Eating: A Guide for People with MS

Based on Canada's Food Guide, this booklet discusses the importance of a well-balanced diet and offers practical tips on meal selection and preparation.

MANAGING SPECIFIC ISSUES

Spasticity, Mobility Problems & Multiple Sclerosis

Provides a comprehensive overview of spasticity and mobility issues including rehabilitation techniques and treatment strategies.

MS and Your Emotions

This booklet explains the effects that MS may have emotionally and psychologically on individuals.

Living Well with MS: Managing Fatigue

Provides information on the impact of MS fatigue, its causes and diagnosis, and strategies for managing this common symptom.

Living for Today: Managing MS Pain

Discusses the different types of pain experienced in MS and the steps that can be taken to prevent, eliminate, or lessen this pain.

Urinary Dysfunction & MS

A comprehensive guide to MS-related urinary problems, including management strategies and commonly prescribed medications.

ADDITIONAL RESOURCES



ORGANIZATIONS

CANADIAN SLEEP SOCIETY

Website:

canadiansleepsociety.com

THE CANADIAN PAIN SOCIETY

1143 Wentworth Street West,
Suite 202
Oshawa, ON L1J 8P7

Tel: 905-404-9545

Website:

canadianpainsociety.ca

MAYDAY FUND (FOR PAIN RESEARCH)

c/o SPG, Christina Spellman,
Executive Director
127 West 26th Street, Ste 800
New York, NY 10011

E-mail:

inquiry@maydayfund.org

Website: maydayfund.org

NATIONAL SLEEP FOUNDATION

1010 N. Glebe Rd, Ste 310
Arlington, VA 22201

Tel: 703-243-1697

Website: sleepfoundation.org

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**National
Multiple Sclerosis
Society**

The National Multiple Sclerosis Society is a collective of passionate individuals, moving together to create a world free of MS.

nationalMSsociety.org
1-800-344-4867

PUBLISHED IN PARTNERSHIP WITH:



Our mission is to be a leader in finding a cure for multiple sclerosis and enabling people affected by MS to enhance their quality of life.

mssociety.ca
1-800-268-7582