National Multiple Sclerosis Society

Recognizing and Managing the Symptoms of Multiple Sclerosis (MS)

For People With MS

The Difference between Symptoms and Relapses

- A relapse is a worsening of old symptoms or the appearance of a new one that may or may not disable you in some way
  - Relapses can be hard to identify
- You may think something you are experiencing is a symptom - but it could be a mild relapse
- Could be triggered by something clinical, like a lesion on your brain or spinal cord
- It is important to keep track of any symptoms or relapses you have and discuss them with your doctor
- Frequent relapses may be a sign your MS is worsening – and your doctor may want to consider changing your treatment

Sources: National Multiple Sclerosis Society. Available at www.nmss.org

Some common signs and symptoms of MS

- Fatigue
- Mind/mood dysfunction
- Spasticity (muscle stiffness and spasms)
- Pain
- Tingling/numbness
- Emotional problems

Source: National Multiple Sclerosis Society. Available at www.nmss.org

Understanding Fatigue

- One of the most common symptoms for people with MS
- Experienced by 75% to 95%
- 50% to 60% say it is the worst problem
- 2 general types of fatigue
  - Chronic persistent: activity-limiting sluggishness for more than 6 weeks, more than 50% of the days and during some part of the day
  - Acute: activity-limiting sluggishness that has just appeared or become noticeably worse within the last 6 weeks
    - Can be a warning sign that other MS symptoms may flare up
- Can be directly or indirectly related to MS
  - May not be the only reason you are tired

Source: National Multiple Sclerosis Society. Available at www.nmss.org

Causes and Management of General Fatigue

Causes	Treatment Options
Other medical problems (an infection)	Medication, as prescribed by your doctor, depending on problem
Weather, specifically heat	Dress lightly and coolly. Use air conditioning
Medication	Adjustments, substitutions, or changes made by your doctor to current treatments
Stress	Reduce stress. Talk to a mental health specialist who works with people with chronic illnesses
Depression	Treated by a doctor with antidepressants or psychotherapy

Speak to your doctor to determine what type of fatigue you have. He or she can help you manage it.

Source: National Multiple Sclerosis Society. Available at www.nmss.org

Causes and Management of General Fatigue

Causes	Treatment Options
Sleep Problems	Medication as prescribed by your doctor or special sleep testing, as prescribed by your doctor to locate the source of the problem
Overdoing physical activity	Keeping active in moderation

Speak to your doctor to determine what type of fatigue you have. He or she can help you manage it.

Source: National Multiple Sclerosis Society. Available at www.nmss.org

Causes and Management of MS-Related Fatigue

Problem	Cause of Problem	Treatment Options
Overwhelming/ severe sleepiness that can come on quickly and acutely	Most likely a biochemical reaction to disease related activity	Rest and recharge! A 20-minute “catnap” can dramatically boost your energy level Planning ahead – spreading your heavy physical activity out over the week Pace your activities and activity level. Take breaks and rest in the middle of activities when needed Prioritize: focus your energies on activities that must be done first Learn to let go of the guilt – it’s OK if you can’t do it all Prescription medication per your doctor’s orders Caffeine (if you don’t have any bladder problems)

Sources: National Multiple Sclerosis Society. Available at www.nmss.org; Schapiro RT, *Managing the Symptoms of Multiple Sclerosis, fourth edition,* 2003; Bowling CA, *Alternative Medicine in Multiple Sclerosis,* 2001.

Causes and Management of MS-Related Fatigue

Problem	Cause of Problem	Treatment Options
Weakness in the limbs	Nerve damage in areas of the CNS that control movement and limbs	Mobility devices (eg, canes, walkers) Working with a physical therapist to find an exercise program that is appropriate for you
Muscle stiffness or spasticity	Nerve damage in areas of the CNS that control movement and limbs	Stretching exercises Prescription muscle relaxants per your doctor's orders (Be careful: they can help relax the muscles, but some may actually increase the feeling of fatigue)
Breathing problems	Nerve damage in areas of the CNS that affect the muscles that allow you to breathe	Working with a therapist on breathing exercises Working on proper seating, support, and posture with a physical therapist

Sources: National Multiple Sclerosis Society. Available at www.nmss.org; Schapiro RT, *Managing the Symptoms of Multiple Sclerosis, fourth edition,* 2003

Understanding MS-Related Mind and Mood Dysfunction

- 50% to 55% will have some problem with mind/mood dysfunction
- Thought to be caused by lesions in the heavily myelinated cerebral hemispheres (left brain/right brain)
- Depression, anxiety, memory and comprehension problems can be caused by MS
- They can be managed with some easy techniques (see next few pages)

Sources: National Multiple Sclerosis Society. Available at www.nmss.org; Schapiro RT, *Managing the Symptoms of Multiple Sclerosis, fourth edition,* 2003

Managing MS-Related Mind and Mood Dysfunction: Treatments

Mind/Mood Dysfunction	Treatment Options
Memory/Recall problems	Use a calendar/planner/palm pilot or journal to keep track of events and appointments Reprioritize your daily activities; focus on only the most important things Establish a memory notebook to keep track of daily events, reminders, and messages Don't write things on random scraps of paper. Keep notes, messages, and lists in one central notebook Store commonly misplaced materials (keys, eyeglasses, cell phones) in an assigned place Do things now to avoid forgetting them
Abstract reasoning and problem-solving problems	Include friends and family in problem-solving and when making big decisions

Sources: National Multiple Sclerosis Society. Available at www.nmss.org; Schapiro RT, *Managing the Symptoms of Multiple Sclerosis, fourth edition,* 2003

Managing MS-Related Mind and Mood Dysfunction: Treatments

Mind/Mood Dysfunction	Treatment Options
Visual-spatial relation problems	Use mental pictures Ask people to keep directions simple
Verbal fluency/"tip of your tongue" syndrome	Don't keep trying to find that word! It will come to you later.
Speed of information processing	Repeat information and write it down Always write down the name of new people you meet and the context in which you met them
Depression	Treated by a doctor with antidepressant medication and/or psychotherapy

- Consider professional evaluation and rehabilitation for serious cases
- Except for depression, no medication is approved to treat these problems—but research is ongoing

Sources: National Multiple Sclerosis Society. Available at www.nmss.org; Schapiro RT, *Managing the Symptoms of Multiple Sclerosis, fourth edition,* 2003

Understanding Spasticity

- One of the most common symptoms of MS
- Occurs when there is demyelination in the nerves that regulate muscle tone
- Spasticity literally means stiffness
  - Increased muscle stiffness means more energy is exerted to perform daily activities
  - Reducing spasticity can mean greater freedom of mobility, less fatigue, and increased coordination

Sources: National Multiple Sclerosis Society. Available at www.nmss.org; Schapiro RT, *Managing the Symptoms of Multiple Sclerosis, fourth edition,* 2003

Managing Spasticity

- Several key ways to treat spasticity
  - Treat the problems that increase spasticity – infections (especially bladder), pain, and skin breakdown
  - A thorough stretching program including various types of stretches
  - Mechanical aids, like orthoses, as needed
  - Prescription medication
  - Surgical procedures when medication or other treatments fail

Source: Schapiro RT, *Managing the Symptoms of Multiple Sclerosis, fourth edition,* 2003

Understanding MS-Related Pain

- More than 50% consider pain to be a problem
- For about 20% it is a significant problem
- Results from “short circuits” in the tracts that carry sensory impulses between the brain and the spinal cord
- Various types of pain require different treatments
- Talk to your doctor before starting any treatment for pain

Source: Schapiro RT, *Managing the Symptoms of Multiple Sclerosis, fourth edition,* 2003

Causes and Management of MS-Related Pain

Type of Pain	Symptom/Cause	Treatment Options
Chronic pain	Burning, aching, “pins and needles”	Prescription medications may work only sometimes Wearing a pressure stocking or glove Meditation, acupuncture, biofeedback
Spasticity pain	Muscle spasms, cramps, tightness, aching in the joints	Prescription medication for spasms and muscle relaxants Stretching exercises
Chronic back and musculoskeletal pain	May be due to a pinched nerve or abnormal posture from an unusual MS-related walking pattern	Exercise routines Chiropractic care Heat Massage Physical therapy Spasticity medications Ultrasound waves

Sources: National Multiple Sclerosis Society. Available at www.nmss.org; Schapiro RT, *Managing the Symptoms of Multiple Sclerosis, fourth edition,* 2003

Causes and Management of MS-Related Pain

Type of Pain	Symptom/Cause	Treatment Options
Dysesthesias	Burning, aching, or "girdling" pain in the extremities or trunk	Prescription medications may work only sometimes Wearing a pressure stocking or glove Meditation, acupuncture, biofeedback
Lhermitte's sign	Stabbing, electric-shock-like sensation running from the back of the head down the spine, brought on by flexing the neck	Because pain comes so quickly, medication is not helpful Soft neck collar to limit neck movement
Trigeminal neuralgia	Severe, stabbing facial pain	Prescription medicines for pain For severe cases, rhizotomy, a surgical procedure that severs the roots that carry sensation

Sources: National Multiple Sclerosis Society. Available at www.nmss.org; Schapiro RT, *Managing the Symptoms of Multiple Sclerosis, fourth edition,* 2003

Understanding and Managing Tingling and Numbness

- Numbness and tingling are very common symptoms
- For most, they are not disabling symptoms
- Occurs when the nerves that transmit sensation do not conduct information properly
- In serious cases that affect hand, finger, or sexual function, doctors can recommend or prescribe treatments
  - Prescription medications, including steroids
  - Acupuncture
  - Talk to your doctor about other treatments that may help

Sources: Schapiro RT, *Managing the Symptoms of Multiple Sclerosis, fourth edition,* 2003; Bowling CA, *Alternative Medicine in Multiple Sclerosis,* 2001.

Managing Your Lifestyle, Emotions and Working With Your Family and Friends

- Take an active part in managing your physical and emotional health
  - Learn what you can
  - Eat well
  - Exercise
  - Talk about your feelings
- The feelings you are having about your MS are natural and normal, and more common than you think
  - Expressing them is an important part of managing your MS
  - Don't ignore or hide your feelings
- Schedule regular "talk time" to share how both you and your family and friends are managing
  - Don't forget that your MS affects them, too
- Collect your thoughts before talking with your family and friends
- Make long-term plans with your family and friends

Sources: National Multiple Sclerosis Society. Available at www.nmss.org; Schapiro RT, *Managing the Symptoms of Multiple Sclerosis, fourth edition,* 2003

References

1. National Multiple Sclerosis Society. Available at: http://www.nmss.org.
2. Schapiro RT. *Managing the Symptoms of Multiple Sclerosis, fourth edition*. Demos. New York, NY. 2003.
3. Bowling CA, *Alternative Medicine and Multiple Sclerosis*. Demos. New York, NY. 2001
4. Rebif® [Patient Medication Guide]. Rockland, Mass; Serono, Inc.; 2003.
5. The PRISMS Study Group, and the University of British Columbia MS/MRI Analysis Group. PRISMS-4; long term efficacy of interferon –ß-1a in relapsing MS. *Neurology*. 2001; 56: 1628-1636.
6. PRISMS Study Group. Randomised double-blind placebo-controlled study of interferon β-1a in relapsing/remitting multiple sclerosis. *Lancet.* 1998;352:1498-1504.
7. Li DKB, Paty DW, and the UBC MS/MRI Analysis Research Group and the PRISMS Study Group. Magnetic resonance imaging results of the PRISMS Trial: a randomized, double-blind, placebo-controlled study of interferon-β1a in relapsing-remitting multiple sclerosis. *Ann Neurol.* 1999;46:197-206.
8. Panitch H, Goodin DS, Francis G, et al, for the EVIDENCE Study Group and the University of British Columbia MS/MRI Research Group. Randomized, comparative study of interferon ß-1a treatment regimens in MS: the EVIDENCE Trial. *Neurology.* 2002;59:1496-1506.
9. Data on file. Rockland, Mass; Serono, Inc.; 2003.