

# Taking Fatigue Seriously: New Focus on This MS Symptom

*First in a three-part article series*

**M**S fatigue, as described by one MS support group participant, is the feeling that even sitting up in bed reading is just too strenuous. “You want to do something across the room but you can’t get your body to move,” he explained. “You negotiate with yourself: how many steps will I have to take to get there?”

For those who have never had the experience, the unique brand of fatigue that often accompanies MS may be hard to fathom. Those affected commonly describe it as an overwhelming sense of exhaustion, not relieved by resting or by getting more sleep at night.

More than 90% of individuals with MS experience fatigue that significantly impairs their quality of life. Yet, many with MS also have felt that their fatigue has been downplayed in the overall management of their condition.

This attitude is changing as the importance of fatigue in MS is recognized and as new treatment options become available. For example, the MS Council for Clinical Practice Guidelines—the governing body that establishes MS treatment protocols—developed a report to guide clinicians in managing MS-

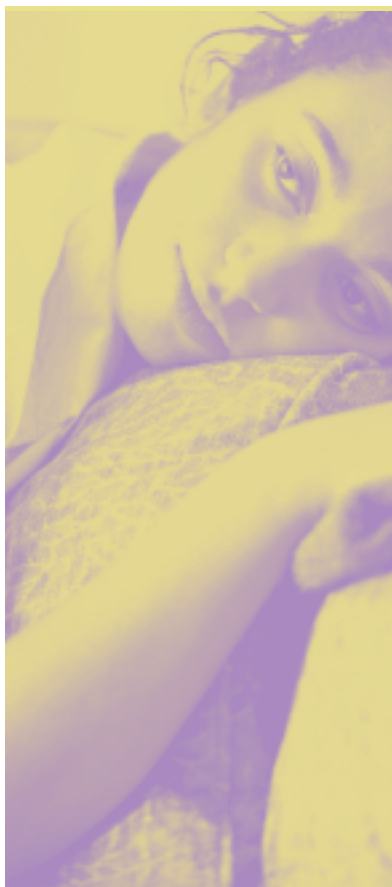
related fatigue. More educational programs are being developed for health professionals involved in MS care to help them properly diagnose and manage MS-related fatigue.

How far-reaching is the impact of MS-related fatigue? More than 50% of those with MS who experience it report fatigue as their most disabling symptom. In addition to severely limiting physical functioning and the

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ability to perform activities of daily living—such as going to work or doing household chores—MS-related fatigue also may affect cognitive functioning and the ability to emotionally cope with the disease.

“Fatigue really changes your view of the world,” explains Henry Shapiro, MD, a developmental pediatrician whose condition



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was recently diagnosed as MS. “Even small things like a slight incline in the sidewalk or a longer walk to the car become extra efforts that sap your energy. You have to constantly weigh whether an activity is going to be worth the exertion or whether you should save your energy for something else.”

Fortunately, fatigue is no longer a fact of life with which people with MS simply must cope. Effective methods of treatment are available, including drug therapy and self-management strategies. By working in partnership with their health care providers, many people with MS-related fatigue are able to achieve significant symptom relief.

The initial step toward fighting fatigue is to assess its impact on daily life. A widely used method is the Fatigue Severity Scale (FSS), shown on page 7. Using the scale, individuals rate how well each statement describes them on a scale of 1 to 7, with 1 representing “disagree” and 7 representing “agree.” If the total score is 36 or more, it is recommended that the person seek advice from a health care provider about managing fatigue.

It is important that the FSS not be used to self-diagnose MS-related fatigue. Its purpose is to give the clinician a perspective on how someone is affected by fatigue. Other possible causes of fatigue, such as disrupted sleep, stress, or depression, may need to be considered or ruled out.

Although the underlying causes of MS-related fatigue are poorly understood, it has become clear that this symptom responds to some medications. In 2001, the Working Group for Pharmacologic Therapy in MS-Related Fatigue established drug treatment guidelines based on those developed by the MS Council for Clinical Practice Guidelines.

The Working Group recommended amantadine (Symmetrel®), an antiviral drug, as first-line therapy for those with MS who experience mild fatigue (an FSS score of less than 40).

The Working Group also recommended the use of modafinil (Provigil®) as first-line therapy in the treatment of moderate-to-severe MS-related fatigue (FSS score greater than or equal to 40). Modafinil is the only drug therapy used for MS fatigue that has been shown to produce a significant change in FSS score when compared with placebo.

Acknowledging MS-related fatigue as a serious symptom that requires medical attention is the first step in obtaining relief. Increased recognition of this debilitating symptom should help reduce its undermanagement.



# MS-Related Fatigue: It's More Than Just Feeling Worn Out

*Second in a three-part article series*

**BY BONNIE DARVES**

**M**ost people think they know what fatigue is but for those with MS, the concept goes well beyond the “normal” definition of tired or listless.

MS-related fatigue is now being recognized as a serious aspect of the disease that is distinct from fatigue from other causes. However, this distinction is rarely cut-and-dried. People with MS may have fatigue that is caused primarily by the disease but their symptoms might also be caused by certain medications, by depression, or by lack of sleep.

“It’s very important to identify as many treatable causes as possible before devising a specific plan for managing MS-related fatigue,” explains Richard Ransohoff, MD, a neurologist at the Mellen Center for Multiple Sclerosis Research and Treatment at the Cleveland Clinic in Ohio.

For example, conditions such as anemia, thyroid disorders, or chronic sinus infections may cause or worsen fatigue. Sleep apnea (intermittent breathing interruptions resulting in nonrestorative sleep) can also exacerbate fatigue. Medications such as antihistamines,

anti-inflammatory drugs, antihypertensive and heart medications, muscle relaxants, and diabetes therapies may cause or aggravate fatigue.

According to Dr. Ransohoff, some fatigue in MS can be explained by the following causes:

**Neuromuscular fatigue** occurs when the leg muscles begin to tire or weaken after walking a short distance, which may cause

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the person to limp. At longer distances, neuromuscular fatigue may make a person feel like he or she might collapse.

**Substitution fatigue** results when stronger muscles work harder to compensate for weaker muscles. This imbalance in muscle usage often leads to strain in the overused muscles, eventually causing fatigue.



**Primary MS-related fatigue is the form that is most likely to respond to medications such as amantadine and modafinil.**

**Cardiovascular fatigue**, caused by inefficient heart and lung function, is often due to lack of exercise. Some people with MS avoid exercise because they fear it will tire them but poor physical fitness may actually worsen fatigue in the long run.

About 30% of those with MS who experience fatigue have primary MS-related fatigue, which cannot be linked to any explainable cause, says Dr. Ransohoff. “Theories about primary MS-related fatigue are many but facts are harder to come by,” he says. “The underlying cause might be related to the inflammatory process in the central nervous system.” Primary MS-related fatigue is the form that is most likely to respond to medications such as amantadine or modafinil, he adds.

MS-related fatigue generally occurs daily, rather than intermittently, and it tends to worsen as the day goes on. This type of fatigue is also likely to be more severe than normal fatigue and often is aggravated by heat and humidity. In many people with MS, symptoms of fatigue also come on easily or quite suddenly.

Since poor sleep is a leading cause of fatigue, assessment often begins with an analysis of sleep patterns. Some people with MS sleep poorly because spasms or bladder problems wake them

during the night. Others sleep through the night but wake up feeling as though they haven’t rested. In such cases, the clinician might look for other underlying medical conditions.

Depression, another potential cause of fatigue, is understandably prevalent in those with MS. Defined as a marked loss of energy and interest in life, depression usually interferes with sleep and makes working or exercising more difficult. Many people with MS who experience depression can be successfully treated with antidepressant medications.

In addition, mobility limitations in MS—struggling to get around and simply expending more energy than one would normally—are underrecognized causes of fatigue, Dr. Ransohoff believes. Identifying mobility problems and making lifestyle modifications to optimize energy usage can help many with MS to achieve major improvements in fatigue symptoms.

Those who believe they must simply “deal with” their fatigue are urged to discuss their symptoms with their clinicians, suggests Dr. Ransohoff. The Fatigue Severity Scale on page 7 is one way to help define the impact of fatigue and to raise this discussion with a health care professional.





# MS-Related Fatigue and Quality of Life

*Third in a three-part article series*

**BY BONNIE DARVES**

**F**or reasons that are not yet understood, MS-related fatigue afflicts some people far more severely than others, regardless of the extent of disease progression.

Some people who experience this type of fatigue are able to continue working and pursuing many regular activities, while others find it too strenuous to walk across a room.

For David Mowen, owner of a small giftware manufacturing firm in Hood River, Oregon, fatigue is the most debilitating symptom of his MS—the factor that, in the seven years since his diagnosis, has most affected his ability to work.

Like many people with MS, Mr. Mowen does his best to manage the disabling effects of fatigue. He naps several times a day and tries to maintain a modest fitness regimen, two strategies that provide some relief. “I’m a can-do person who looks at the glass as half full, not half empty. So I still try to do things I enjoy—it just takes me longer,” he says.

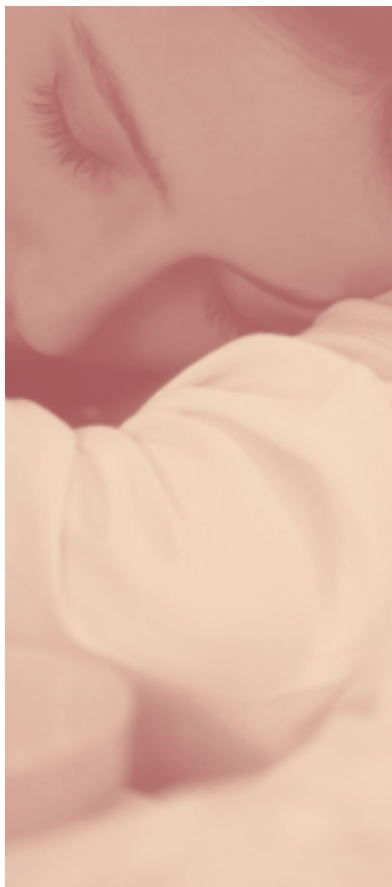
For Lynda Emerson, who was diagnosed with MS at the age of 22, “fatigue was the feeling of wanting no stimuli whatsoever—whether it was having the TV on or listening to people talking loudly in a room. It was

really all I could do to just get up, go to work, and then come home and go to sleep,” says Ms. Emerson, who is currently a program coordinator for the Greater Washington Chapter of the Multiple Sclerosis Society (MSS).

Fortunately, Ms. Emerson’s neurologist, Craig Smith, MD, at the Swedish Regional Multiple Sclerosis Center in Seattle, helped her obtain relief through a two-faceted ap-

Some people with this type of fatigue are able to continue working and pursuing regular activities; others find it too strenuous to walk across a room.

proach. He prescribed a medication to address a preexisting thyroid imbalance, as well as modafinil (Provigil®), which is a stimulant that has proved beneficial for treating fatigue in MS, Parkinson’s disease, and other neurological conditions. “For me, it was a day-and-night kind of turnaround,” Ms. Emerson says.



Frequency of exercise is more important than intensity. Fifteen or 20 minutes five days a week should help make fatigue better.

Other approaches that have helped Ms. Emerson manage her fatigue include exercising. After training for several months, she recently participated in a walking marathon in Seattle. She also balances her choice of activities carefully, so an evening spent at a dance club with friends might be followed by a weekend resting at home.

Tom Holtackers, PT, has fine-tuned his fatigue-management balancing act. The 60-year-old physical therapist, who was diagnosed with MS in 1980, works in rehabilitation and patient education at the Mayo Clinic in Rochester, Minnesota. “The main thing I do is try to ‘read’ my body. If I become too fatigued, I rest—whether it’s in the middle of the day or in between working with patients,” he says. Like Ms. Emerson, Mr. Holtackers believes that inactivity worsens his fatigue, so he sticks to his fitness schedule whenever possible. He sometimes uses adaptive equipment, such as a wheelchair or a walker, to optimize his energy expenditure.

Francois Bethoux, MD, Director of Rehabilitation Services at the Mellen Center for MS Research and Treatment, a part of the Cleveland Clinic, stresses the importance of proper fatigue management. The center has developed a multifaceted fatigue-management program for its clients, using medications such as modafinil and the antiviral drug amantadine along with a rehabilitation program.

“Our approach combines education with behavior and lifestyle changes, such as the use of relaxation techniques,” Dr. Bethoux explains. “We create personalized home exercise programs and provide clients with guidelines on how they can save energy throughout the day.” He notes that many people with MS tend to schedule activities for early afternoon—precisely the time when most of us have naturally decreased energy levels—and advocates rearranging the day’s schedule to avoid activities that “collide with” that time of day.

Dr. Bethoux also points to growing evidence that physical fitness and exercise are crucial to effective fatigue management. “Frequency of exercise is more important than duration or intensity,” he adds. “If a person with MS does 15 or 20 minutes of specially tailored exercise at least five days a week, it should be enough to help make his or her fatigue better.”

Those with MS who do not have access to multidisciplinary treatment teams can obtain the fatigue management guidelines published by the MSS. The Fatigue Severity Scale (page 7) can be used as an entrée to discussing MS fatigue with a clinician.





## Fatigue Severity Scale

The Fatigue Severity Scale is a method of evaluating the impact of fatigue on you. The questionnaire contains nine statements that rate the severity of your fatigue symptoms. Read each statement and circle a number from 1 to 7, based on how accurately it reflects your condition during the past week and the extent to which you agree or disagree that the statement applies to you.

A low value (eg, 1) indicates strong disagreement with the statement, whereas a high value (eg, 7) indicates strong agreement.

It is important that you circle a number (1 to 7) for every question.

**During the past week, I have found that:**

Disagree  $\longleftrightarrow$  Agree

1. My motivation is lower when I am fatigued ..... 1 2 3 4 5 6 7
2. Exercise brings on my fatigue ..... 1 2 3 4 5 6 7
3. I am easily fatigued ..... 1 2 3 4 5 6 7
4. Fatigue interferes with my physical functioning ..... 1 2 3 4 5 6 7
5. Fatigue causes frequent problems for me ... 1 2 3 4 5 6 7
6. My fatigue prevents sustained physical functioning ..... 1 2 3 4 5 6 7
7. Fatigue interferes with my carrying out certain duties and responsibilities ..... 1 2 3 4 5 6 7
8. Fatigue is among my three most disabling symptoms ..... 1 2 3 4 5 6 7
9. Fatigue interferes with my work, family, or social life ..... 1 2 3 4 5 6 7

Total Score \_\_\_\_\_

### Scoring your results:

Now that you have completed the questionnaire, simply add all the numbers you circled to get your total score.

### The Fatigue Severity Scale key:

A total score of less than 36 suggests that you may not be suffering from fatigue.

A total score of 36 or more suggests that you may need further evaluation by a physician.

### Your next steps:

This scale should not be used to make your own diagnosis.

If your score is 36 or more, please share this information with your clinician.

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