

MS EMPOWERMENT SERIES

SHARED DECISION MAKING IN MULTIPLE SCLEROSIS



FATIGUE IN MULTIPLE SCLEROSIS

*What Causes It?
How Do I Manage It?*



An educational series for people with multiple sclerosis (MS) developed in conjunction with the International Organization of MS Nurses (IOMSN).

Provided through educational grants from Biogen, Celgene, and Sanofi Genzyme.

Hello, and welcome!

Fatigue is considered the most common symptom of multiple sclerosis (MS). We think that some of the fatigue in MS has a neurologic cause related to the disease process. But fatigue can be part of a cycle of interacting issues—for example, fatigue may lead to daytime sleepiness, which leads to sleep problems, which contributes to mood disorders.



If you suffer from fatigue, it's important not to give up. We have many interventions that are effective for treating fatigue, and many people have experienced improvement and learned to make adaptations that enable them to enjoy life and participate in their activities.

The MS Empowerment Series was developed for the International Organization of MS Nurses (IOMSN) to provide information for people with MS on topics that affect their lives. As a neurology nurse working in MS care and research for over 30 years, it's my privilege to be part of this program.

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Developed by Delaware Media Group in conjunction with the International Organization of MS Nurses (IOMSN)

Publishers: Joseph J. D'Onofrio, Frank M. Marino
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FATIGUE IN MS

"Fatigue" comes from a French word meaning "weariness." But with multiple sclerosis (MS), the concept of fatigue takes on a whole new meaning. For some people with MS, fatigue is not the same as just "being tired," in the sense that a brief rest, or even a long night's sleep, will help resolve it.

Fatigue can mean different things to different people. For some people with MS, fatigue might be brought on by walking a long distance or being "out of shape" physically. For others, it might be mental fatigue from a long day's work or trying to focus on a challenging task. Many people with MS find that fatigue can arise on its own, without any obvious trigger.

"For people with MS, fatigue can have both primary and secondary causes," explains Marcia Finlayson, PhD, an occupational therapist



and an expert on MS-related fatigue. “Primary fatigue is due to the MS disease process itself, while secondary causes of fatigue are things that could affect anyone. These might include deconditioning (being out of shape), depression, diet, medication side effects, infections, or sleep disorders.” Dr. Finlayson, Vice Dean of Health Sciences and Director of the School of Rehabilitation Therapy at Queen’s University in Ontario, Canada, says that much progress has been made in learning how to manage MS fatigue over the past 20 years (see Q&A, page 8).

Got Fatigue? You’re Not Alone

Fatigue is considered the most common MS symptom, affecting anywhere from 75% to 95% of persons with this disease. Fatigue is also one of the main MS symptoms that contributes to poor quality of life. Some of the ways that fatigue can affect one’s life include:

- Interfering with work, family, and social activities
- Reducing physical stamina, making it hard to exercise or keep up with activities
- Worsening other symptoms, including pain and mood disorders like depression

Because fatigue is an “invisible” symptom of MS, it may lead to conflicts in personal and work relationships. Others may not recognize how severe the fatigue can be, or how it affects the person with MS.



Fatigue in MS: Causes & Contributing Factors

MS-Related Fatigue

Mobility Problems

- Effort from physical exertion leads to fatigue
- Can occur in people who have weakness in arms or legs.

Motor Fatigue

- Occurs in muscles (usually legs/arms that are not receiving adequate nerve impulses.
- Muscles may tire quickly, causing feelings of extreme weakness and recovering after a period of rest.

Respiratory Problems

- MS can affect breathing, making simple activities tiring
- May occur in people with more severe MS symptoms

Primary MS Fatigue

- A diagnosis of elimination, after other causes have been ruled out or treated

Additional (Non-MS) Causes

- Other medical conditions (diabetes, thyroid disorders)
- Hot, humid weather
- Medication side effects
- Sleep problems (insomnia, sleep apnea)
- Stress
- Depression or anxiety
- Physical inactivity/deconditioning
- Doing too much, too fast (superhero syndrome)

How Do I Find Out What's Causing My Fatigue?

Even though we often try to separate medical problems into neat little boxes, fatigue is one of those things that rarely has just one cause.

To treat fatigue, your MS nurse or other care provider will try to identify your particular issues, including any possible secondary causes of fatigue. He or she may have you complete a questionnaire to rate how fatigue affects your daily life. Some of the questionnaires that might be used are shown in **Table 1**.

The evaluation may involve a physical examination and blood work. In addition, you may be asked questions about how possible secondary causes of fatigue affect your life. Secondary issues that might cause or worsen fatigue include:

- Other medical conditions you may have, for example a thyroid disorder
- Medications you are taking. Many medications have side effects that may cause or worsen fatigue
- Sleep problems, including insomnia (difficulty falling or staying asleep) and sleep apnea (a breathing disorder that occurs during sleep)
- Stress levels. High stress can cause hormonal disruptions that cause or make other health problems worse
- Mood disorders, including depression and anxiety

Table 1. Screening Tools for Fatigue

| Name of Screening Tool | How long does it take to complete? | What's involved in the test? |
|--------------------------------------|-------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------|
| Visual Analog Scale | A few minutes | 3 items. On a scale of 1 to 10, rate effect of fatigue on your daily life, daily activities, and household or occupational activities. |
| Modified Fatigue Impact Scale (MFIS) | About 10 minutes | 21 items. Rank from 0 (never affects you) to 4 (almost always affects you). |
| Fatigue Severity Scale (FSS) | About 8 to 10 minutes | 9 items. Rank on a scale from 1 (strongly disagree) to 7 (strongly agree). |

- Exercise habits and physical activity levels. Are you exercising regularly, or rarely? Maybe overdoing activity on the weekends when you have more time?

What Is Primary MS Fatigue?

MS is a disease of the central nervous system (CNS), which consists of the brain and spinal

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Q&A

With a Rehabilitation Expert on MS Fatigue



Marcia Finlayson, PhD
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Q: Can simple do-it-yourself steps to improve fatigue make a real difference? Or, do most people with MS require a comprehensive intervention?

A: “To manage fatigue on your own, you need good self-awareness and the ability to monitor your fatigue. You also need to be able to analyze your patterns of activity, set priorities, and consider alternative approaches to doing things. An alternative approach might mean making changes to the timing, duration, order, or environment for an activity. It might also mean using an adaptive device or equipment, or engaging others for help.”

“Many people find it hard to make these lifestyle changes on their own. Some people are able to be successful with these changes by using education and available resources. However, evidence suggests that most people

need guidance and support to make behavioral changes that they can maintain over the long term.”

Q: Have we made any headway into treating fatigue? Or, is it just something that people with MS have to live with?

A: “Yes, we have made progress in treating fatigue. In particular, there is now quite strong evidence from well-designed studies that a good self-management program, particularly one with a cognitive behavioral component, can reduce the impact of fatigue on daily life for many people with MS. We also know that some exercise programs reduce the impact of fatigue in MS. Self-management programs and exercise programs can work as well or even better than the medications available for treating fatigue.”

Q: Have you observed cases where treating fatigue can improve functioning and quality of life for people with MS?

A: “Definitely! The research that we have done over the past 20 years has clearly shown that when people with MS are able to make changes to better manage their fatigue, they are able to reduce the impact of fatigue on their daily activities, engage in activities that are important and meaningful to them, and improve their quality of life.”

cord. Increased inflammation in the CNS may affect the nerves in ways that cause or produce fatigue. Primary fatigue may also be related to altered metabolism of some brain chemicals, atrophy (shrinkage) of the brain, or damage to myelin, the coating or “sheath” that surrounds nerve fibers in the brain and spinal cord.

Primary MS fatigue is a diagnosis of exclusion, Dr. Finlayson says, meaning that other causes of fatigue have been ruled out or treated successfully and some fatigue still remains.

Primary fatigue is not as readily treated as some of the secondary causes, Dr. Finlayson notes, so many of the treatment approaches are “compensatory.” This means that the primary fatigue often cannot be eliminated, but many strategies can be used to partly relieve fatigue, or to help the person better adapt to fatigue.

What About Medications for Fatigue?

Medications are prescribed commonly in an effort to relieve MS fatigue. These include modafinil (Provigil) or armodafinil (Nuvigil), which are medications that promote wakefulness. Antidepressants and stimulants are other categories that have been used. These medications are not approved by the FDA specifically for the treatment of MS fatigue, so they are prescribed off-label. However, research shows that behavioral and exercise interventions are actually more effective for many people, Dr. Finlayson explains. There may be concerns



about side effects associated with these medications, so it’s important to discuss these with a physician or MS nurse.

Exercise: Proven Benefits in MS Fatigue

It may seem counterintuitive that exercise can help fatigue. If one feels truly fatigued, it might seem that working out would be the last thing you’d want. However, there is a substantial amount of research showing that exercise can help and produce long-term benefits. The most effective exercises are well-tested programs taught by a rehab therapist or kinesiologist trained to guide you in these methods. The best part is that when done correctly, exercise is safe and relatively free of side effects. Some types of exercises shown to help fatigue are listed in **Table 2**.

Table 2. Fitness Guidelines for People with MS with Mild to Moderate Disability

| Aerobic Exercise | | Strength Training | |
|-------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| How often? | 2 x per week | How often? | 2 x per week |
| How much? | Gradually increase your activity so that you are doing at least 30 minutes of aerobic activity during each workout session. | How much? | Repetitions are the number of times you lift and lower a weight. <ul style="list-style-type: none"> • Try to do 10–15 repetitions of each exercise. This counts as 1 set. • Gradually work up to doing 2 sets of 10–15 repetitions of each exercise. |
| How hard? | These activities should be performed at moderate intensity (about 5 or 6 on a scale of 10; causes your heart rate to go up). Generally, while doing moderate intensity activity, you can talk but cannot sing a song. | How hard? | Pick a resistance (free weights, cable pulleys, bands, etc.) heavy enough so you can barely (but safely) finish 10–15 repetitions of the last set. Be sure to rest for 1–2 minutes between each set and exercise. |
| How to? | Aerobic activities may include: <ul style="list-style-type: none"> • Upper body exercises: arm cycling • Lower body exercises: walking, leg cycling • Combined upper and lower body exercises: elliptical trainer | How to? | Strength training activities for the upper and lower body: <ul style="list-style-type: none"> • Weight machines • Free weights • Cable pulleys |

 Aerobic and strength training activities can be done on the same day

 Rest your muscles at least one day between strength training sessions

 Other beneficial types of exercise

- Elastic resistance bands
- Aquatic exercise
- Calisthenics

Source: MS Society of Canada. Recreation and Social Programs/Physical Activity/The Guidelines. 2013. Reprinted with permission.



Take-Home Points

“The most important message I would like to convey to people with MS,” Dr. Finlayson stresses, “is that it is possible to manage fatigue and continue to participate in activities that are important and meaningful. Managing fatigue does not mean being fatigue-free. It does mean developing skills and strategies to allow people with MS to be engaged in daily life,” she says. Managing fatigue requires practice and persistence. “There are proven interventions to manage fatigue in people with MS,” Dr. Finlayson concluded.

Coping With MS Fatigue: Insights from a Person With MS

Joan H. is a middle-aged woman from the Philadelphia area who has had MS for 20 years.

“At first I would think that I was just getting tired. But then I would find myself falling asleep sitting up and taking a 2-hour nap. Of course, this was disrupting my lifestyle. I decided to approach it by trying to listen to my body more. I improved my diet, avoided things like caffeine and triggers that I found would sap my energy.



These days I tend to sleep longer overnight. I also rest routinely through the day, often just to look at something (reading is more difficult) or play sudoku. But, I have also found ways to pursue my interests while adapting them to my MS. One special activity is a kayaking group, which is something I love and have always wanted to do!

“I think the most important thing I have learned is how to pick and choose my commitments, and to say no when I think an activity will be too much. I think that’s something many of us need to learn in order to slow down and take control of our lives. We also need to recognize that MS fatigue is not just ‘doing too much.’ So we need to approach it from a few different angles.”



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