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The information in this Guide is not intended to substitute for professional medical care. If you develop unusual fatigue, contact a physician or other appropriate health-care professional.

This Guide has been prepared based on scientific and professional information known about fatigue and multiple sclerosis in 2000. It is recommended that you periodically review this Guide with health-care professionals from whom you regularly receive care.

Multiple Sclerosis Council for Clinical Practice Guidelines  
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National Multiple Sclerosis Society  
Paralyzed Veterans of America  
Rehabilitation in Multiple Sclerosis  
U.S. Department of Veterans Affairs



# FATIGUE: WHAT YOU SHOULD KNOW A Guide for People with Multiple Sclerosis

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# ALICIA



**ELEVEN YEARS AGO** I was diagnosed with MS when my first child was only 18 months old. After my first couple of horrible episodes of MS way back then, I have been pretty lucky and have had few problems.

Now I'm 34 years old and maintaining a very busy household with 4 children (the youngest is 3 years old), a husband, and a dog. Life has gone on—except for one thing. I am exhausted. I get tired so quickly and don't seem to bounce back the way I used to. Getting to my children's ball games is impossible because the summer heat zaps me of all my energy. I don't have the energy to keep my house as clean as it used to be. The usual routines around the house are falling apart and I'm sure the kids think I am less interested in all their activities. My husband has been very understanding, though because of my fatigue we don't have the same intimate relations we used to.

I was desperate so I called my doctor who did tests and helped me with some medication. My doctor also referred me to an occupational therapist. The therapist taught me about fatigue in MS and gave me lots of great ideas like changing the household routines to let me rest while the kids are at school or napping, rotating the dishwashing schedule among everyone in the family, and helpful laundry energy-saving tips like putting my laundry basket on a wheeled cart. There were many more wonderful tips, but the biggest thing I learned was not to struggle so long before contacting my neurologist and working with an occupational therapist to learn how to manage my fatigue.

I'm still working things out on how best to save and restore my energy, but I am feeling better and know I'm on the right track.

## Who Should Read This Guide?

- People with multiple sclerosis (MS).
- Family, friends, personal care attendants, and other caregivers.
- Health-care professionals, including doctors, nurses, physical therapists, occupational therapists, speech-language pathologists, and psychologists. Many medical specialists can be helpful in treating conditions associated with MS.

Members of your professional health-care team can order a free copy of **Fatigue and Multiple Sclerosis**, a clinical practice guideline, by calling (888) 860-7244. They can also download a copy from the web site at [www.pva.org](http://www.pva.org).

### One Size Doesn't Fit All

Everyone's circumstances are different: family situation, finances, support network, community resources, work flexibility, personal preferences, physical function. Some options may not be practical for you. The more your health-care team knows about these details, the better they'll be able to help.

## Why Is This Guide Important?

Fatigue is the most common symptom of MS. As many as 75% to 95% of all people with MS have fatigue; 50% to 60% say that it's one of their worst problems. In fact, fatigue is one of the major reasons for unemployment among people with MS.

No one knows what really causes MS-related fatigue, but we do know some things that can help. This Guide explains some options.

**IMPORTANT:** If lack of energy is interfering with your regular activities or quality of life, tell your doctor. You could have a non-MS problem that can be treated. Even if it's related to MS, there are things you can do to improve the way you feel. Together, you and your doctor can decide the best options for you.

## What Is MS-Related Fatigue?

Fatigue is a lack of physical energy, mental energy, or both. Everyone has low-energy days. And everyone knows what it's like to be down in the dumps and not feel like doing much of anything.

MS-related fatigue is different, and it's not always easy to spot. With MS fatigue, people have more "off" days than "on" days. Before it can be identified, other possible causes need to be crossed off the list of suspects. (See **What Causes Fatigue?**, page 2)

So if you have MS and are feeling flat, ask yourself this question: Is fatigue interfering with my everyday activities or quality of life? If the answer is yes, your doctor needs to know.

\*Words in italics are explained in the Glossary on page 11.



## Are There Different Types of Fatigue?

Yes. The next step is to find out what type you have. This Guide refers to two general types of fatigue. Either type may, or may not, have a direct association with MS:

**Chronic Persistent Fatigue**—Activity-limiting sluggishness that goes on for more than six weeks, more than 50% of the days, during some part of the day.

**Acute Fatigue**—Activity-limiting sluggishness that has either appeared (new) or become noticeably worse during the previous six weeks. Acute fatigue can be an early warning that other MS symptoms are about to flare up or become worse.

Think about your energy levels over the past several weeks. You may want to track how you feel for a couple of weeks, simply by making notes on a calendar. Now review the two descriptions of fatigue above. Which one best fits you? Tell your doctor which type of fatigue you think you have, and why.

Each type of fatigue has different potential causes and treatments. Other possible causes need to be explored before MS-related fatigue is considered. (See **What Are the Types of MS-Related Fatigue?**, page 4.)

**IMPORTANT:** Pay special attention to your MS after an episode of unusual fatigue. If your other MS symptoms seem to be getting worse, let your doctor know.

## What Causes Fatigue?

Even though fatigue is common in MS, MS may not be the reason—or the only reason—you're tired. Many factors can cause or contribute to fatigue. They include:

**Other medical conditions.** Even something as simple as a minor infection can sap energy.

**Weather.** Heat makes many people feel like overcooked pasta, and humidity can make the effects of heat worse. Both facts are especially true for people with MS. Heat and humidity are measured together to produce the “heat index” often mentioned during weather reports.

**Medications.** Some medications can cause fatigue as a side effect. Make sure your doctor has a list of all medications you take (see Appendix 1).

**Sleep problems.** Problems falling asleep, staying asleep, or getting the right kind of sleep (insomnia) prevent people from feeling refreshed when they wake up. A sleep questionnaire can help your doctor pinpoint the cause of your fatigue (see Appendix 2).

**Stress.** Stress can make anyone tired, and MS can make life more stressful. Many things can cause stress: more demands than a person can meet; conflicts with other people; disruptions in routine; death of a person close to you, divorce, and other major losses.

**Depression and anxiety.** Difficult issues at home or at work can be emotionally and physically draining. Depression and anxiety are common in MS. If you or others close to you notice changes in your mood or loss of interest in once-favorite activities, be sure to tell your doctor.

**Superhero syndrome.** It's easy to overdo physical activity if you don't work up to it gradually. Weekend sports, gardening, housecleaning, errands, and shopping can all be draining.

Be prepared to discuss these subjects with your doctor or nurse. You may also be asked to answer a questionnaire that covers these areas in detail. After examining you, the doctor may order laboratory tests or refer you to a specialist for more evaluation.

## How Is Non-MS Fatigue Treated?

The results of your examinations and tests will guide the next steps. For example:

- Other medical conditions can be treated by your doctor or a specialist.
- Hot weather and muggy climate can be handled with cooling techniques.
- Medications sometimes can be adjusted, changed, or stopped—but always talk with your doctor first. It can be dangerous to make medication changes on your own.
- Sleep problems can have a physical or psychological cause. Special sleep testing can locate the source and direct treatment.
- Stress results from problems people encounter and how they cope with those problems. Reduce stress-causing aspects of your life as much as you can. For help in learning ways to cope with stress, see a mental health professional who specializes in working with people who have chronic illnesses.
- Depression is one of the most treatable symptoms of MS. It can be treated with antidepressant medications, problem-focused psychotherapy, or both. (Together they can be more effective than either approach alone.) According to recent research, when people with MS who are diagnosed with depression are treated effectively for depression, their fatigue may be reduced.

## Keep Track of Your Medications

For many reasons, it's helpful to keep a list of all medications you take (Appendix 1). That includes:

- Prescription drugs.
- Nonprescription drugs, such as aspirin, ibuprofen, and products for colds, flu, and allergies.
- Herbal therapies, alternative or “natural” medicines.
- Vitamins, minerals, and other dietary supplements.

When you go to a doctor's office, bring the list with you. If your medications change, update the list.

Your doctor can find a detailed list of medications that may cause fatigue in **Fatigue and Multiple Sclerosis**. This clinical practice guideline is available free from Paralyzed Veterans of America at (888) 860-7244 or [www.pva.org](http://www.pva.org).



Ask your doctor about a follow-up visit to find out if treatment is improving your fatigue problems. A short questionnaire, such as the Modified Fatigue Impact Scale (MFIS), may be part of this assessment. (The MFIS is available in **Fatigue and Multiple Sclerosis**) Over a period of time, you may take the same test several times. This tool helps your doctor assess the effects of treatment. If treatment isn't working, your doctor will discuss other options with you.

When all non-MS causes of fatigue are under control, you may find that fatigue isn't really a problem anymore. If it is, the culprit is likely to be related to MS.

## What Will My Insurance Cover?

Medical insurance plans vary greatly. Read your policy. If you have questions about what medical services, equipment, and medications are covered, talk with someone in the human resources department at work or call your insurance company.

For all medical matters, including mental health issues like depression and anxiety, some companies cover only visits to professionals in their official "network." (You can get a list of providers in the network from your insurance company.) Some limit the number of visits they will cover. Even Medicaid policies differ by state. That's why it's a good idea to find out about your insurance company's policies before you begin seeing a mental health professional. Remember: You always have the option of seeing any health-care professional and paying the full costs yourself.

## What Are the Types of MS-Related Fatigue?

Here again, there are broad categories:

**Fatigue related to mobility problems.** With MS, sometimes ordinary activities take so much physical effort that they're exhausting. This is especially true for people who have leg weakness.

**Fatigue related to respiratory problems.** MS can sometimes affect breathing, and when it does, even simple activities can be tiring. This is especially true for people who have the most serious physical symptoms of MS.

**Primary MS fatigue.** This is a diagnosis of elimination. After all other causes of fatigue have been ruled out or treated successfully, primary MS fatigue is what's left.

## How Is MS-Related Fatigue Treated?

### Movement and Breathing Problems

Your doctor will do an examination of the way you move and breathe. That may include checking:

- Your strength.
- Your muscle coordination (any problems, including ataxia).
- How stiff or flexible you are (spasticity).



- How you walk (your gait).
- How you move from one position to another (transfer), especially to or from a seat, like a wheelchair, toilet, or commode.
- If you use a wheelchair, how you get around in it.

Depending on the results, you may be referred to an occupational therapist, physical therapist, or both for more evaluation.

Table 1 lists treatment options for breathing and movement problems related to MS. With any of the options in Table 1, your doctor may want to see you to monitor your response.

**TABLE 1.**  
**Treating Breathing and Movement Problems**

Problem	Treatment Options
Weakness or problems with muscle coordination (ataxia)	<p><b>Equipment</b> to help you move around more easily (<i>gait assistive devices and mobility devices</i>): canes, crutches, walkers, <i>transfer devices</i>, wheelchairs, and scooters.</p> <p>Evaluation to find out whether an <b>exercise program</b> is right for you and if so, what type of program. A little improvement in strength and flexibility may help with the challenge of everyday activities.</p>
Stiffness (spasticity)	<p><b>Stretching exercises.</b> You'll feel better and move better when you keep your body as flexible as it can be. A therapist can show you the proper form for appropriate stretches.</p> <p><b>Medications.</b> Muscle relaxants may help you loosen up. However, muscle relaxants can also increase fatigue.</p> <p><b>IMPORTANT:</b> If you take muscle-relaxing drugs, do not take sedatives or alcohol, including nonprescription sleep aids. Together, these products can have an exaggerated effect. If you have any questions about which medications are OK, ask your doctor.</p>
Breathing problems	<p><b>Breathing techniques.</b> A therapist can teach you breathing exercises to improve the efficiency of your lung power. Your doctor may refer you to a specialist for an evaluation of your lungs and breathing.</p> <p><b>Proper seating and support.</b> A physical or occupational therapist can recommend changes and aids to make breathing less tiring. For example, changing from a manual wheelchair to a powered wheelchair can do a lot to ease breathing-related fatigue. Switching from a chair with a soft back to one with lumbar support can also help. Sitting upright instead of slumped often makes breathing easier.</p>

### Primary MS Fatigue

If low energy is still a problem after all other causes have been addressed, you probably have primary MS fatigue. Treatment options include strategies that specialists can teach you and prescription drugs. They can be used alone or together.



TABLE 2.

## Self-Help Energy Boosters

Strategy	Why It Helps and Tips
Stop smoking.	Smoking puts a strain on your lungs, making fatigue worse and compounding the effects of MS. Quit the habit, and breathing and simple activities may not tire you out so much.
Eat a healthy diet.	Eating a well-balanced, low-fat diet energizes your body. Try eating breakfast soon after you get up. Consult with a professional about an appropriate diet.
Plan your day around your natural body rhythms, and establish a regular sleep schedule.	Schedule your must-do activities for your most energetic times. To help you sleep, drink warm milk 30 minutes before bedtime. Keep exercise equipment and TVs out of the bedroom. If you've been trying to fall asleep for more than 30 minutes, get out of the bed and do a quiet activity until you feel tired.
Adjust your activity levels.	Save energy for what matters most to you. Set priorities, then focus on them. Cut out low-priority tasks.
Take naps.	Naps give tired muscles a break and pump energy back into your system. A nap for 10–30 minutes can help. (See “How To Make the Most of a Nap” on page 8.)
Drink cool liquids.	Chilled drinks, ices, and popsicles help keep your body's temperature in the comfort zone. Make sure you get plenty of water during the day, no matter what else you drink.  Note: Caffeine can prevent you from falling asleep. Alcohol may help you doze off, but it can keep you from getting a good night's sleep.
Stay cool.	Lowering your body temperature helps you feel refreshed. Cool showers, air conditioning, swimming/pool therapy, and lightweight clothes or cooling equipment can help you beat the heat.
Consider an exercise program.	Exercise has been shown to improve problems with MS fatigue for some people, but it doesn't help everyone. A proper exercise program should increase your energy level, not deplete it. <b>Check with your physical therapist, and get an OK from your doctor.</b>
Save your exercise for a planned exercise session.	Don't confuse exercise with function. Take the elevator, not the stairs. Use parking spots set aside for people with disabilities—save the steps and your energy.
Do relaxation exercises.	Deep breathing, <i>visualization</i> , yoga, and tai chi are relaxation exercises you can learn to do at home.
Get help if you need it.	If you're feeling down or people tell you they think you're depressed, see a mental health professional.

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Table 2 lists lifestyle changes that have helped people with MS feel and function better. Various professionals can assist with these strategies. For example, a nutritionist or dietitian can help with meal and snack plans; occupational and physical therapists can help with activity planning and exercise programs; and a therapist or nurse can help with relaxation techniques.

To find out what resources are available in your community, see “**Resources Available for People with MS**” on page 13. Your doctor and health plan also can provide information.

For primary MS fatigue, your doctor may suggest medication. Prescription drugs for fatigue are of some help to some people, but they’re not a cure-all, and they don’t benefit everyone.

One prescription drug used to treat MS fatigue is amantadine (ah-man-tuh-DEEN). Some doctors also recommend pemoline (PEM-uh-leen). (Other drugs may become available after publication of this document. Ask your doctor for more information.) Both products come in pill form. **NOTE: Recent research suggests that pemoline may damage the liver.**

Most prescription drugs have possible side effects, and some drugs shouldn’t be mixed with others. Before you start any prescription drug, make sure your doctor has a current list of all other medications you’re taking. That includes vitamins, minerals, and other herbal or dietary products (Appendix 1). Also be sure to ask your doctor about possible side effects and what to do if they occur. It’s a good idea to get this information in writing and share it with family members and caregivers.

**IMPORTANT:** If you’re having problems with any medication, tell your doctor right away. Do not just stop taking it! Some medications need to be cut back gradually before you can safely stop taking them.

## What Else Helps?

You’ve tried basic lifestyle changes (Table 2) and maybe medication. They helped, but not much. You still feel like a tire with a slow leak. What next?

It’s time to call on professionals with special expertise in adaptive equipment, energy-saving tips, and general exercise and aerobic fitness. Occupational and physical therapists are trained in these areas. They’ll start with some of the same issues addressed by your doctor, such as your history of fatigue, how hot weather affects you, how you move, and what you’ve already tried to improve your energy. Occupational and physical therapists will evaluate:

- **Your general physical condition**—strengths, weaknesses, and areas that can be improved.
- **Your environment**—where you live, work, and spend time regularly, including any devices you use to help you function.
- **Your aerobic fitness**—how well your heart and lungs work during physically demanding activities.



## How To Make the Most of a Nap

A nap is any quiet rest period—not necessarily sleep—during daylight hours when you'd normally be awake. An occupational therapist can help you determine whether your nap schedule is helpful for your situation. Naps are helpful only if they don't interfere with your nighttime sleep.

**Where:** a sofa, recliner, a bed (on top of, not under, the bed covers). You can even nap with your head down on a desk.

**How often:** one to three times per day (daylight hours), when you'd normally be active.

**How long:** 10–30 minutes, as often as one to three times per day; 1–2 hours, not more than once per day.

### HELPFUL HINTS:

- Turn TV and music off or go to a quiet environment.
- Loosen tight clothes (don't put on sleepwear).
- Dim the lights; if you can't do that, face a corner or use an eye mask.
- Close curtains or blinds.
- Use light covers or sweater or jacket to avoid getting chilled or overheated.

- **Any mobility devices** you use to help you move around: canes, crutches, walker, wheelchair (manual or powered), scooter, ankle/foot orthotic.

They can also help you fill out something called an Activity Diary. By showing which activities take the most out of you, it helps in monitoring MS fatigue problems and finding solutions.

The results of all these assessments will be used to tailor fatigue-fighting strategies for you. Suggestions will be in one or more of the following areas:

**Energy effectiveness strategies (EES).** Together, you and the expert (usually an occupational therapist) will come up with a plan to help you meet your goals. You'll meet several times to develop and refine strategies. With training, you'll be able to use these strategies effectively by yourself.

**Aerobic exercise.** You'll get an exercise program that may include at-home exercise, group exercise, or both, depending on what works best for you. Along with your exercise program, you'll learn more about ways to keep cool and adjust other activities. As you progress, the expert (usually a physical therapist) will guide you in adjusting your exercise level to reach your peak fitness.

**IMPORTANT:** Over-exercising can cancel out the benefits and worsen fatigue. Follow the exercise program you and your therapist developed. If it stops working, it's time to call your therapist for a review of the program.

**Equipment changes.** Changes in equipment can make a big difference in the energy you expend doing basic tasks at home or at work. The expert (an occupational or physical therapist) may suggest that you modify devices you already use or try new ones. Trial periods with different equipment will show which changes help. Occupational and physical therapists know how to use equipment properly. They can also help you with reimbursement issues for the equipment.

**Environmental changes.** The expert (occupational or physical therapist) may visit your home and workplace and explore your usual mode of travel. Whether you



drive or take public transportation is relevant. The therapist will discuss possible changes with you, to find out what's practical. You'll need to try each change to see what works. In fact, you may test several changes before you find one that makes a difference.

## How Does the Americans with Disabilities Act Relate to Work?

The Americans with Disabilities Act (ADA) became a U.S. law in 1990. Thanks to the ADA, it's illegal to discriminate against people with disabilities including MS. The ADA covers several areas, including jobs, for all places of business that have at least 15 employees.

A key aspect of the ADA is the idea of reasonable accommodations. These are changes to a job or worksite that make it possible for a qualified person with a disability to apply for a job, do a job, and have equal employment benefits. Examples of reasonable accommodations include:

- Making the workplace easily accessible.
- Providing or modifying equipment and devices.
- Restructuring jobs.
- Changing work schedules.
- Reassigning staff to a vacant position.
- Providing readers or interpreters.
- Adjusting exams, training materials, and policies.

This law has many details and exceptions. If you have questions about how the ADA applies to your job or other areas such as access and public services, call PVA at (800) 424-8200, EPVA at (800) 404-2898, or the National Multiple Sclerosis Society at (800) FIGHT-MS (344-4867).

## What If Treatment Stops Working?

Human bodies change as they age. MS, too, changes over time. Changes may come suddenly or with warning. Know your body. Pay attention to changes in your body. If you notice increasing problems with fatigue (or anything else), check in with your doctor. Options you haven't tried yet may make a difference. And remember that medical progress is being made every day. By the time you need it, a new treatment may be available.

# TOM



**IT'S BEEN ABOUT A YEAR** since I had a bad exacerbation, which left me weaker in my legs and more fatigued. When I have had exacerbations in the past, the problems have always gone away in a few months and I have been able to continue my normal activities. But this time, I was still tripping a lot and getting very tired every afternoon.

I tried to maintain my normal physical routine and ignore the symptoms, still walking to the restaurant down the street for lunch every day, taking the stairs rather than the elevator, etc., but things were getting worse, not better. When my boss brought up my reduced performance in the afternoons, I knew I better try something new.

I called the National MS Society, got the names of local MS physical and occupational therapists, and went to see them. At the OT and PT treatments, I found that there were a lot of things I was doing that contributed to my afternoon fatigue and many things I could try to decrease it. For instance, I got a brace to help me lift my foot and this actually resulted in my being less fatigued. An aerobic exercise program I started in PT has really helped me feel fit again. By reducing how much I was standing and walking during the day, I found that I could perform again at work. My boss has commented on the improvement.

Now, even though these symptoms look like they are going to be permanent, I am really doing pretty well and feel good about my ability to manage my MS problems.

*Tom*

## Glossary

**adaptive equipment**—Any device or tool that helps a person accommodate physical limitations present since birth or caused by injury or illness. It can be an aid for mobility, personal care, or work or leisure activities.

**aerobic exercise**—Activity using large muscle groups that raises the heart and breathing rates and increases endurance.

**ankle/foot orthotic (AFO)**—A device that helps stabilize the lower part of the leg and foot for standing and walking; a “short leg brace.”

**ataxia**—Problems with muscle coordination. Ataxia can be small coordination problems, some irregular muscle movements, or total inability to coordinate body movements.

**energy effectiveness strategies (EES)**—Techniques to modify activities to reduce fatigue. EES involves careful analysis of a person’s regular work, home, and leisure activities.

**gait**—The way a person walks.

**gait assistive devices**—Equipment to help people move around more easily. They include canes, crutches, ankle foot orthotics, and other types of leg braces for walking.

**health-care team**—A group of professionals who work together to coordinate a person’s medical care. For people with MS, the team may include a primary care doctor, physician specialists, nurse, physical therapist, occupational therapist, speech-language pathologists, social worker, psychologist, or psychiatrist.

**insomnia**—Problems falling asleep, staying asleep, or both.

**mobility devices**—Equipment to help people move around more easily. They include gait assistive devices, wheelchairs, scooters, and transfer devices or aids.

**Modified Fatigue Impact Scale (MFIS)**—A short questionnaire that helps doctors evaluate a person’s energy levels and the success of different approaches to improving problems with fatigue.

**occupational therapist (OT)**—A person trained to use daily activities, adaptive equipment, and environmental changes to help people increase their physical, mental, and emotional function and prevent disability in their work, play, and personal care.

**personal care attendant**—A person, such as a family member, friend, or hired helper, who assists with personal care or household tasks on a routine basis.

**physical therapist (PT)**—A person trained to use techniques such as exercise to prevent or reduce physical disability caused by pain, disease, or injury. PTs also are trained to evaluate when adaptive equipment may be helpful.

**psychiatrist**—A person trained to do assessment and counseling and prescribe medications for mental, emotional, and behavioral issues.

**psychologist**—A person trained to do assessment and counseling, for cognitive, emotional, and behavioral issues.

**reasonable accommodations**—Under the Americans with Disabilities Act, these are changes to a job or worksite that make it possible for a qualified person with a disability to apply for a job, do a job, and have equal employment benefits.

**sedative**—Medications that calm or soothe.

**spasticity**—Muscle stiffness or lack of flexibility caused by illness of the nervous system or injury.

**transfer**—The action of moving from one seat to another.

**transfer devices**—Equipment to help people move from one position (often sitting) and place to another. Include sliding boards and mechanical lifts.

**visualization**—A relaxation technique that includes a mental journey to a peaceful place or favorite activity.



## Resources for People with MS

### **National Multiple Sclerosis Society**

733 Third Avenue  
New York, NY 10017-3288  
(800) Fight-MS (344-4867)  
[www.nmss.org](http://www.nmss.org)

The National MS Society's mission is to end the devastating effects of multiple sclerosis. Achieving that mission includes funding research, improving quality of life and health care, securing civil rights, and providing hope.

### **Paralyzed Veterans of America (PVA)**

801 18th Street, N.W.  
Washington, DC 20006  
(800) 424-8200  
[www.pva.org](http://www.pva.org)

PVA, a congressionally chartered veterans service organization, works to address the special needs of its members—veterans of the armed forces who have experienced spinal cord dysfunction. PVA is a leading advocate for high-quality health care for its members; research and education addressing spinal cord dysfunction; benefits available to members as a result of their military service; and civil rights and opportunities that maximize the independence of PVA members and all people with disabilities. It maintains offices throughout the country.

### **Eastern Paralyzed Veterans Association (EPVA)**

75-20 Astoria Boulevard  
Jackson Heights, NY 11370  
(718) 803-3782  
[www.epva.org](http://www.epva.org)

EPVA is dedicated to enhancing the lives of veterans with a spinal cord injury or disease by ensuring quality health care, promoting research, and advocating for civil rights and independence. EPVA, a nonprofit organization, is a chapter of the congressionally chartered Paralyzed Veterans of America. It maintains offices in Jackson Heights, Buffalo, and New York, NY; Newark, NJ; and Philadelphia, PA.

### **Your State's Department of Vocational Rehabilitation**

See the blue pages in your local telephone directory or the website below for contact information on the Department of Vocational Rehabilitation in your state.  
[trfn.clpgh.org/srac/state-vr.html](http://trfn.clpgh.org/srac/state-vr.html)

State vocational and rehabilitation agencies coordinate and provide a number of services for people with disabilities, including impaired sight and hearing. These services can include counseling, evaluation, training, and job placement. For more information, call or write the office nearest you.

### **Consortium of Multiple Sclerosis Centers (CMSC)**

718 Teaneck Road  
Teaneck, NJ 07666  
(973) 837-0727  
[www.ms-care.org](http://www.ms-care.org)

CMSC pursues projects and tasks in multiple sclerosis care, research, and education for the benefit of multiple sclerosis patients, professionals, and caregivers.

### **CMSC-NARCOMS (North American Research Consortium on MS) MS Patient Registry**

Timothy L. Vollmer, M.D.  
NARCOMS Program Director  
Yale Neuroimmunology Program  
P.O. Box 208018  
New Haven, CT 06520-8018  
(203) 764-4289  
[www.ms-care.org/narcoms/about.html](http://www.ms-care.org/narcoms/about.html)

The purpose of the Registry is to speed the development of new therapies and health-care services by facilitating research and reducing the time and cost of research studies. The CMSC-NARCOMS Registry is a database in which patients enroll voluntarily, to be used for research purposes only. Those enrolled may be asked to complete a questionnaire, have a phone interview, donate a blood sample, have a medical exam, or participate in a clinical trial of a new treatment.



# DIANA



## AFTER I WAS FIRST DIAGNOSED

with fatigue, almost two years ago, I couldn't stand to even think about it. My husband, John, and I had just been married. He was wonderfully supportive, but I didn't want to talk to him about it.

Even before I was diagnosed, I seemed to get tired frequently, but afterward it started getting worse.

Of course sometimes it didn't bother me at all, but for the bad days or weeks, I could barely make it out of bed to get to work on time. I started to feel like there wasn't any point anyway. Eventually, on the weekends I'd just stay in bed all day and not take a shower or get dressed. Finally, John said that he was really worried about me. I told him that I was just tired, but he pointed out that I never wanted to go out with our friends anymore and had stopped playing the piano, which I used to love. He convinced me to go back to the doctor who had first diagnosed my MS.

It was the best thing I've ever done. The doctor referred me to a psychologist, who I went to see the next week. I've been seeing Sheila for about six months now. She treats a lot of people with MS. She's really gotten me to see things in a new way, and now it doesn't feel like the disease is smothering me anymore. I feel very hopeful about my future. Fatigue rarely bothers me anymore, I've gone back to playing the piano, and John and I have even started mountain biking. Now when I do get especially tired, I realize that it's just a bad day and that tomorrow will be better.



**APPENDIX 2.**

**My Sleep Habits**

Share your answers with a doctor, nurse, or therapist who can help you use the information to suggest energy-improving strategies.

Your name \_\_\_\_\_ Date \_\_\_\_/\_\_\_\_/\_\_\_\_

**Section A**

- 1. I usually sleep \_\_\_\_\_ hours every night.
- 2. I usually go to bed at \_\_\_\_\_ o'clock (please note a.m. or p.m.).
- 3. I usually wake up at \_\_\_\_\_ o'clock (please note a.m. or p.m.).
- 4. I usually fall asleep in about \_\_\_\_\_ minutes or \_\_\_\_\_ hours.
- 5. I usually  do or  don't wake up at night. If you usually don't wake up at night, go to Section C.

**Section B**

- 6. I usually wake up about \_\_\_\_\_ times at night.
- 7. Reasons I wake up (check all that apply):
  - a. I don't know.
  - b. I'm worried about something.
  - c. Children or other family members wake me.
  - d. I have to go to the bathroom.
  - e. I have muscle spasms.
  - f. I have pain (other than muscle spasms).
  - g. Other reasons: \_\_\_\_\_

**Section C**

- 8. I've had insomnia.  yes  no  
If yes, describe your sleep problems and when you had them. \_\_\_\_\_
- 9. I feel extremely sleepy during the day.  yes  no  
If yes, how long have you felt this way? \_\_\_\_\_

*continued*



## APPENDIX 2. continued

10. I fall asleep even though I'm not trying to.  yes  no  
 If yes, at what times? \_\_\_\_\_  
 How often? \_\_\_\_\_  
 How long do you sleep? \_\_\_\_\_
11. I usually feel refreshed when I wake up in the morning.  yes  no
12. I have headaches when I wake up in the morning.  yes  no  
 If yes, how often? \_\_\_\_\_  
 How long do they last? \_\_\_\_\_  
 Where is the pain? (e.g., forehead, behind eyes)? \_\_\_\_\_
13. I snore when I sleep.  yes  no  
 If yes, when?  only when I'm congested  most of the time
14. I thrash around while I'm sleeping.  yes  no  
 If yes, how often?  sometimes  most of the time
15. I often drink alcohol at night.  yes  no  
 If yes, about how much, and what type(s) of alcohol? \_\_\_\_\_  
 \_\_\_\_\_
16. I drink beverages with caffeine in the morning (coffee, tea and many soft drinks).  yes  no  
 If yes, how much, and what type(s)? \_\_\_\_\_  
 \_\_\_\_\_
17. I take naps during the day.  yes  no  
 If yes, how often?  some days  most days  
 How many naps? \_\_\_\_\_  
 When? \_\_\_\_\_  
 For how long? \_\_\_\_\_
18. I usually feel rested after a daytime nap.  yes  no



## Acknowledgments

The Multiple Sclerosis Council for Clinical Practice Guidelines is composed of 23 organizations interested in the care and treatment of people with multiple sclerosis. In October 1998, the Council published the clinical practice guideline, *Fatigue and Multiple Sclerosis: Evidence-Based Management Strategies for Fatigue in Multiple Sclerosis*. This consumer guide for people with MS, based on that guideline, addresses the problems of living with fatigue.

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