

Fatigue: What You Should Know

A GUIDE FOR PEOPLE WITH MS

CONSUMER GUIDE TO CLINICAL PRACTICE GUIDELINES



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A GUIDE FOR PEOPLE WITH MS

NATIONAL MULTIPLE SCLEROSIS SOCIETY EDITION BASED ON
GUIDELINES PUBLISHED BY MULTIPLE SCLEROSIS COUNCIL FOR
CLINICAL PRACTICE GUIDELINES

This guide was originally based on **Fatigue and Multiple Sclerosis: A Clinical Practice Guideline for Professionals** developed by the Multiple Sclerosis Council for Clinical Practice Guidelines.

We are deeply indebted to the staff of the Paralyzed Veterans of America who provided organizational, administrative and financial support for the development of the original guide. Paralyzed Veterans of America oversaw the preparation, production, and printing of the original book.

Copies of the PVA's Guidelines are available at pva.org or through the PVA Distribution Center (toll-free: 888-860-7244).

This guide has been updated based on current research and clinical findings about MS-related fatigue. We recommend that you periodically review this guide with healthcare professionals from whom you regularly receive care.

Additional information about current medications, research directions, and dealing with fatigue can be found at nationalMSsociety.org. Search the site using the keyword "fatigue".

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 healthcare professional.

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Copies of this edition are available at nationalMSsociety.org or 1-800-344-4867.

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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 two 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 for my fatigue. 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 every one in the family, and helpful 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
- Healthcare professionals, including doctors, nurses, **physical therapists, occupational therapists, speech-language pathologists and psychologists**

Members of your professional **healthcare team** can order a free copy of, **Fatigue and Multiple Sclerosis: Evidence-Based Management Strategies for Fatigue in Multiple Sclerosis**, by calling 888-860-7244.

They can also download a copy from the website at **pva.org**.

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.

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 select the best options for you.

* Words in bold are explained in the Glossary on page 15.

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 healthcare team knows about these details, the better they'll be able to help.

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?** on page 3.)

If you have MS, 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.

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 or lassitude 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 for the first time 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 level 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. Then 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. All other possible causes need to be explored before MS related fatigue is considered. (See **What are the types of MS-related fatigue?** on page 5.)

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:** Many other medical conditions can cause fatigue, including anemia, heart disease, diabetes, hyperthyroidism (overactive thyroid), hypothyroidism (underactive thyroid), among others. 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 in 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. Sleep apnea is also a very common cause of fatigue. A sleep questionnaire can help your doctor pinpoint the cause(s) 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, or other major losses. Even happy times such as a wedding or holiday activities can cause stress.
- **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.
- **Physical inactivity:** Reduced activity because of fatigue or limited mobility causes the body to become deconditioned, which in turn leads to greater fatigue. And when a person is deconditioned, it requires more effort and energy to do things, which further adds to the person's fatigue.
- **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 fill in a questionnaire called the Fatigue Severity Scale 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 physical or psychological causes. Special sleep testing can locate the source and direct the choice of 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.

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**. See box.) 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 are the types of MS-related fatigue?

Here again, there are broad categories:

- **Fatigue related to mobility problems:** With MS, mobility problems can make ordinary activities require so much physical exertion that a person is exhausted by the effort. This is especially true for people who have weakness in their arms or legs.
- **Motor fatigue:** A type of fatigue that occurs in muscles (most often in the legs or arms) that are not receiving adequate nerve

KEEP TRACK OF YOUR MEDICATIONS

For many reasons, it's helpful to keep a list of all medications you take (see Appendix 1). This 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 pva.org.

impulses due to demyelination. These muscles may tire quickly with repeated use causing feelings of extreme weakness and recover following a period of rest.

- **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 or toilet
- If you use a wheelchair, is it appropriate for your current needs and abilities
- If you use an assistive device, is it the proper one for your current needs and are you using it correctly
- If you are not using an assistive device, would a device help to increase your safety and mobility and reduce your fatigue

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

Table 1 (page 10) lists treatment options for breathing and movement problems related to MS. If you use any of the options in Table 1, your doctor may want to see you to monitor your response.

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 (page 11) 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 for People with MS** on page 16. Your doctor and health plan can also 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.

Prescription drugs used to treat MS fatigue include amantadine (ah-man-tuh-DEEN), which is available in generic form, modafinil (moe-DAF-i-nil), and armodafinil (ar-moe-DAF-i-nil). The brand name for modafinil is Provigil®. The brand name for armodafinil is Nuvigil®. These products come in pill form. A recent small study suggests that aspirin may be of benefit for MS fatigue, but further research will be needed to confirm these findings. Antidepressant medications and

psychostimulants may also be used to relieve fatigue in some people.

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 herbal or dietary products. (See Appendix 1) Always 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. What next?

It's time to call on professionals with expertise in **adaptive equipment**, **energy-saving adaptations**, 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 level** — how well your heart and lungs work during physically demanding activities.
- **Your strength, balance and coordination** — how smoothly and safely are you able to move around.
- **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 an Activity Diary. By showing which activities take the most out of you, this document will help identify specific fatigue problems.

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 develop. If it stops working, it's time to call your therapist for a review of the program.

Equipment changes

Changes in equipment or the use of assistive technology 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 you which changes help. Occupational and physical therapists know how to use equipment properly. They can also help you with reimbursement issues.

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. The therapist will discuss possible modifications or changes with you, to find out what's practical. You'll need to try each change to see what works. In fact, people often test several changes before finding one that makes a difference.

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.

Some policies only cover visits to professionals in their official "network" for all medical matters, including mental health issues like depression and anxiety. (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 benefits before you begin seeing any healthcare professional. Remember: You always have the option of seeing any healthcare professional you choose and paying the full costs yourself.



Diana

After I was first diagnosed with multiple sclerosis, 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.

Table 1: Treating Breathing and Movement Problems

Problem	Treatment options
Weakness or problems with muscle coordination (ataxia)	<p>Equipment to help you move around more easily (gait assistive devices and mobility devices): canes, crutches, walkers, transfer devices, wheelchairs, scooters.</p> <p>Evaluation to find out whether an exercise program 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>Stretching exercises. You'll feel better and move better if you keep your body as flexible as it can be. A therapist can show you the proper form for appropriate stretches.</p> <p>Medications. Spasticity medication may help you loosen up; however, they can also increase fatigue.</p> <p>IMPORTANT: If you take spasticity medications, 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>Breathing techniques. A therapist can teach you breathing exercises to improve the efficiency of your lungs. Your doctor may refer you to a specialist for an evaluation of your lungs and breathing.</p> <p>Proper seating and support. 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>

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, with plenty protein and adequate fluids, 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 sleep schedule	<p>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.</p> <p>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.</p>
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 12.)
Drink cool liquids	<p>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.</p> <p>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.</p>
Stay cool	Lowering your body temperature helps you feel refreshed. Cool showers, air conditioning, swimming or pool therapy in cool water, lightweight clothes, and cooling equipment can help you beat the heat.

Table 2: Self-Help Energy Boosters (cont.)

Strategy	Why it helps and tips
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. Check with your physical therapist, and get an OK from your doctor.
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, visualization, 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.

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 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.



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 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'd 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 sessions, 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.

How does the ADA relate to fatigue at 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 most 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 the National MS Society, PVA, or the United Spinal Association (see page 16), or contact the U.S. Department of Justice ADA at ada.gov (1-800-514-0301).

What if treatment stops working?

Human bodies change as they age. MS, too, changes over time. Changes may come suddenly or with warning. Pay attention to changes in your body. If you notice increasing problems with fatigue (or anything else), check 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.

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.

Healthcare 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.

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 help people improve their ability to perform everyday tasks at home and at work using adaptive equipment and environmental changes to conserve energy, increase physical, mental, and emotional functioning and prevent disability.

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 help patients reduce pain and improve or restore function and mobility. PTs teach patients how to manage illness or injury by using treatment techniques and equipment to promote ability to move, decrease pain and prevent or minimize disability.

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 problems in the nervous system or injury.

Speech-language pathologist: A person trained to diagnose and treat speech and swallowing disorders.

Transfer devices: Equipment to help people move from one position (often sitting) or place to another. They 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 MS Society

800-344-4867

nationalMSsociety.org

Our mission: people affected by MS can live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever.

Paralyzed Veterans of America (PVA)

800-424-8200

pva.org

PVA, a congressionally chartered veterans service organization, works on behalf of veterans of the armed forces who have experienced spinal cord dysfunction including multiple sclerosis. 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 independence. It maintains offices throughout the country.

United Spinal Association (formerly EPVA)

718-803-3782

unitedspinal.org

United Spinal Association is dedicated to enhancing the lives of all people living with a spinal cord injury or disease by ensuring quality health care, promoting research, and advocating for civil rights and independence.

Your State's Department of Vocational Rehabilitation

See the blue pages in your local telephone directory or the Web site below for contact information on the department of vocational rehabilitation in your state:

parac.org/svrp.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)

201-487-1050

mscare.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 Committee on MS)

MS Patient Registry; Timothy Vollmer,
MD, FAAN-Clinical Director

800-253-7884

narcoms.org

Email: **msregistry@narcoms.org**

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 people with MS enroll voluntarily, for research purposes only. Those enrolled may be asked to complete a questionnaire, have a phone interview, or participate in a clinical trial of a new treatment if interested.

Appendix 1: My Medications List

Keep this list current and bring it with you when you visit your regular doctor and see any new doctor.

Your name _____ Date ____ / ____ / ____

Prescription Drugs

Drug name	How much?	How often?

Nonprescription Drugs

Drug name	How much?	How often?

Herbal and Alternative Products, Vitamins, Dietary Supplements

Drug name	How much?	How often?

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 _____ : _____ a.m. p.m.
3. I usually wake up at _____ : _____ a.m. 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 a night
7. Reasons I wake up (check all that apply):
 - I don't know
 - I'm worried about something
 - Children or other family members wake me
 - I have to go to the bathroom
 - I have muscle spasms
 - I have pain (other than muscle spasms)
 - 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? _____

Appendix 2: My Sleep Habits (cont.)

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 (eg, 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/or soft drinks). Yes No

If yes, about 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

Multiple Sclerosis Council for Clinical Practice Guidelines Panel (2000)

Fatigue Consumer Guide Development

R. Philip Kinkel, MD (Chair)

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The National Multiple Sclerosis Society (“Society”) is proud to be a source of information on multiple sclerosis related topics. The information provided is based on professional advice, published experience, and expert opinion, but does not constitute medical or legal advice. For specific medical advice, consult a qualified physician. For specific legal advice, consult a qualified attorney.

The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered helpful information. The Society assumes no liability for the recipient’s use of any product or service mentioned. The Society does not independently verify whether the information provided by each service provider is accurate. The Society undertakes no responsibility to verify whether the service provider is appropriately licensed and certified and has applicable insurance coverage.

Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your healthcare professional and contacting the National MS Society at **[nationalMSSociety.org](https://www.nationalmssociety.org)** or 1-800-344-4867.

The Society publishes many other resources about various aspects of MS. Call 1-800-344-4867 or visit **[nationalMSSociety.org/brochures](https://www.nationalmssociety.org/brochures)**.

Other popular resources include:

- Taming Stress in Multiple Sclerosis
- Food for Thought: MS and Nutrition
- MS and Intimacy
- Managing MS Through Rehabilitation

The National MS Society's mission is for people affected by MS to live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To fulfill this mission, the Society funds cutting-edge research, drives change through advocacy, facilitates professional education, collaborates with MS organizations around the world, and provides services designed to help people with MS and their families move their lives forward.



National
Multiple Sclerosis
Society

nationalMSsociety.org

1-800-344-4867