

Tackling fatigue

by Heather Boerner and
Bridget Murray Law

MS fatigue comes on suddenly and can foil a person's most doable to-do list. Just unpacking the dishwasher can seem overwhelming. Holding down a job can feel downright impossible.

Upwards of 80% of people with MS experience unusual fatigue, with over half ranking it one of their most troubling symptoms, according to the Society's MS Information Sourcebook. It's complex, with many possible contributing factors, and it's invisible, which makes for huge human problems.

The good news? Fatigue can be tackled. See your doctor for a full work-up to pinpoint what contributes to **your** fatigue. Possible triggers: depression, stress, medication side-effects, and sleep disruption from symptoms such as frequent urination or muscle spasms. Beneath those "secondary" causes is "primary" MS fatigue, sometimes called lassitude—which is a direct result of myelin loss.

When factors such as bladder problems or spasticity are under control, your doctor may prescribe

It's invisible and it can affect everything. But it can be tackled. Check out the management tools in these six pages. Learn more from Society resources in print and online.



an anti-fatigue medication to fight lassitude.

If depression or stress is slowing you down, consult a mental health professional, but be aware that some antidepressants increase sleepiness.

"There are exceptions to this. Prozac (fluoxetine) helps some people feel more energized," said Dr.

Rosalind Kalb, a clinical psychologist who heads the Society's Professional Resource Center. "People's experiences with antidepressants vary greatly. You should expect to work with your physician to find the medication strategy that works for you." And no matter what fatigue factors are involved, it's essential to conserve energy by changing your approach to daily tasks.

Heather Boerner, a medical writer based in San Francisco, and Bridget Murray Law, managing editor with The Magazine Group, collaborated.

Drug name	Dose in MS	Drug profile
Amantadine	100 mg morning and early afternoon	Antiviral agent typically used in influenza or Parkinson's disease treatment—has also shown fatigue relief for some with MS
Modafinil (Provigil)	200 mg a day	Wakefulness-promoting agent for treating narcolepsy that a study has shown reduces self-reported fatigue for some people with MS
Methylphenidate (Ritalin)	10–20 mg early morning and at noon	A central nervous system stimulant indicated for treatment of attention deficit disorders but also helpful for MS fatigue in some people

Source: National MS Society Medical Advisory Board

Spending energy



JOSH NEUFELD

Bank your energy

What do your energy level and your savings account have in common? Both benefit from the same rule of thumb: The less you use now, the more you'll have later. Burn through all your energy or dollars at once, and you're tapped out.

The "save now-spend later" mantra of energy rationing is especially important for people with MS, who tend to start the day with lower energy stores than the average person.

"Think of it like a bank," said Kathleen Matuska, an associate professor of occupational therapy at the College of St. Catherine in Minnesota. "When you rest, you're depositing energy, and when you're active, you're spending it. So you need to budget."

You can build energy assets by approaching daily tasks in cost-efficient ways.

Chill out. First the obvious: Heat drains energy, so it's rejuvenating to cool down with spray bottles and fans. Keep the bedclothes light at night. In summer, try ice-packed clothing and stick to air-conditioned buildings, when possible.

Rest often. Take short breaks throughout the day. "Probably the biggest mistake people with MS

make is exhausting themselves early in the day by trying to get everything done while they still have energy," said Matuska. Instead, "Rest **before** you get tired," she advised.

Conserve. Use that handicapped permit and park close to the building. Store often-used supplies where they're easily reached.

Sit to work. Scooters, wheelchairs, and stair lifts save energy otherwise lost to walking, standing, or stair climbing. (See page 54.) They don't spell "giving in" to MS; they spell smart management.

Work out! This seems counterintuitive but exercising boosts energy by strengthening easily tired muscles. Set aside energy for 30-minute aerobic workouts three to four times a week, experts recommend. Talk to a physical therapist if your symptoms include spasticity, balance problems, poor coordination, or overwhelming weakness. There's a good exercise program for **everyone**.

Check your chair. Ensure that your office chair and computer set-up fit your body, so you're not stooping, stretching, or straining. Whether at home or at work, it's worth getting an ergonomic consultation on your workstation. An OT or occupational therapist is the expert.

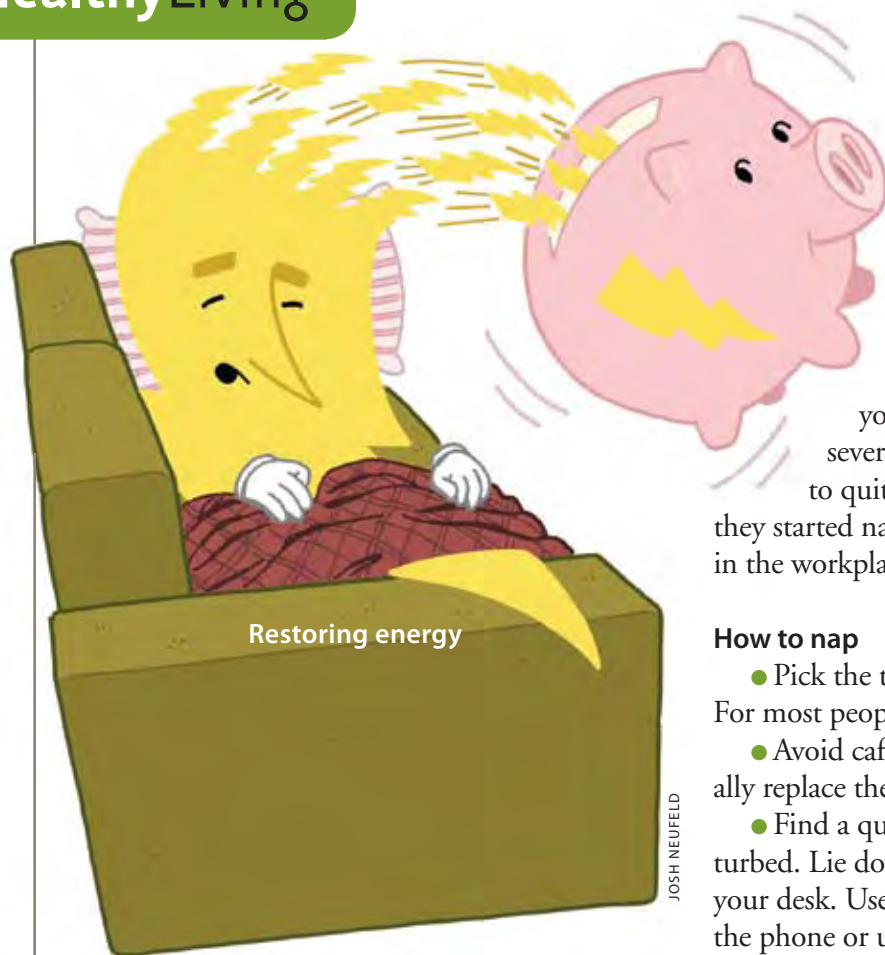
Plan ahead. Gather cooking ingredients before meal prep to avoid repeated trips to the fridge and cabinets. Make to-do lists and decide what can wait for tomorrow—or next week.

Cut the clutter. Mess makes things difficult to find, and you burn energy searching and stressing out. Set aside some time to toss the junk and organize the rest. When you do ...

Tap your friends. Delegate, delegate, delegate. Ask for help. Be specific about what and when. Hire help when you can.

Lower the bar. Perfectionism is exhausting and unnecessary—you can go with what you've got. "Don't feel bad about changing your standards, particularly for activities that are not very meaningful to you," Matuska advised. "Preserving your energy is key to a better quality of life."

—Bridget Murray Law



Restoring energy

JOSH NEUFELD

Nap to snap back

by Allison Shadday, LCSW

If you could do something in 20–30 minutes that would reduce stress, irritability, and fatigue, while improving relationships, memory, and mood, would you do it? If the answer is yes, then it's time to start napping.

No one needs to nap more than we do

People report that exhaustion is the most disabling of all their MS symptoms. This makes sense. Since MS impairs the central nervous system, our bodies must work much harder to send and receive information. The extra work is tiring. Insomnia, another common MS symptom, can also cause profound weariness.

For the person who doesn't struggle with chronic illness, fatigue is something that can be pushed

through or ignored when duty calls. Not so with MS. Napping honors our need for rest.

I prescribe restorative napping to my clients, just as a neurologist would prescribe medication. If viewed as an integral part of your MS treatment plan, it's easier to give yourself permission to nap. I've had several clients who feared they would have to quit work because of fatigue, but once they started napping, they found the energy to stay in the workplace.

How to nap

- Pick the time of day when your energy wanes. For most people that time is around 3 p.m.
- Avoid caffeine beforehand. A nap may eventually replace the need for an afternoon caffeine hit.
- Find a quiet place where you can't be disturbed. Lie down or lay your head on a pillow on your desk. Use a light blanket or sweater. Turn off the phone or use earplugs.
- Then focus on your breathing—take long, slow, deep breaths. Don't pressure yourself to fall asleep. Even if you simply reduce the stimulation of sights and sounds for a few minutes, you will feel restored.
- Set an alarm for 20 to 30 minutes so you don't stress about oversleeping.

Find time to nap

It's estimated that between 40 and 60% of the world's adult population makes time to nap on a daily basis. Unfortunately, Americans tend to leave napping behind after kindergarten. Here are some smart ways to squeeze in your time out:

- If you work, keep a pillow and blanket in your car. At lunch hour, go out and take a quick cat nap.
- Arrive a half hour early to pick up the kids or for other appointments and use that time to snooze.
- When the kids get home from school, let them watch a video so you can take 30 minutes to lie down.
- Shut your office door or create a quiet space in

the employee lounge. Ask your employer to provide a cot or reclining chair.

See how you feel after napping each day for a week. The results should keep you motivated.

Sweet dreams!

Napping resources

The Art of Napping, William A. Anthony, Larson Publishing, 1997.

Sleep to Save Your Life, Gerard T. Lombardo, HarperCollins, 2006.

Power Sleep: The Revolutionary Program That Prepares Your Mind for Peak Performance,

James B. Maas, HarperCollins, 1998.

The Power Nap Kit, www.powernapkit.com (guided relaxation CDs).

Take a Nap! Change Your Life, Sara Mednick, Workman Publishing, 2007.

National Sleep Foundation, www.sleepfoundation.org.



Allison Shadday, LCSW, psychotherapist, person with MS, and MS advocate is the author of **MS and Your Feelings: Handling the Ups and Downs of Multiple Sclerosis**—available from Hunter House (800-266-5592) or Amazon.com.

Percussionist with MS keeps the beat

by Patrick Hayes

Of all her MS symptoms, “fatigue gets me the worst,” said Jennie Brooks, 33. But she doesn’t let it get in the way of performing percussion with the Salisbury, N.C.-based rock quintet Fisher Street.

When touring with her band, Jennie plans ahead to keep herself energized during performances every other night. She puts diet and hydration at the top of her list of pre-show fatigue fighters. Jennie eats a fortifying high protein meal—a basic chicken and rice dish, for instance—with plenty of vegetables and water. But she times that meal for at least an hour before the show.

“If I eat too close to the start, all the blood rushes to my stomach and I feel like jelly,” said Jennie, who was officially diagnosed with MS in 2006 after experiencing exhaustion and a slight drag in her right leg.

Another key strategy is staying cool. She favors air-conditioned venues for concerts, and she keeps a fan trained on her while drumming.

Finally, like the good musician she is, Jennie paces herself. She takes one day a week to recharge her batteries with lots of sleep and



Jennie in motion

nutritious meals. And when she’s traveling and sight-seeing between shows, she keeps her bandmates informed of her energy level, and they match their step to hers.

“They’re always looking out for me,” she said.

Patrick Hayes is a writer with The Magazine Group.

Alternatives also fight fatigue

When MS fatigue strikes, exercise, sleep, and prescription medication aren't the only rejuvenators. Some people with MS look to alternative therapies for boosts.

Can any of these therapies really help MS fatigue? A few probably offer some benefit, according to Dr. Allen Bowling, director of the Complementary and Alternative Medicine Program at the Rocky Mountain MS Center. But some alternatives can worsen fatigue or cause other adverse effects.

Promising fatigue fighters on his list include:

- **Tai chi and yoga.** These and more mainstream forms of exercise can help boost energy levels by strengthening the muscles.

- **Caffeine.** Its stimulant benefits are obvious, but limit intake. Too much irritates the bladder.

- **Acetyl-L-carnitine.** This dietary supplement appeared to reduce MS patients' fatigue severity, and no such effect was seen with the more standard MS fatigue medication amantadine in a small study. This study—published in the **Journal of the Neurological Sciences** in 2004 (V. 218, pp 103–108)—looked at a sample of just 36 people with MS, so the evidence is not considered very strong.

Some red flags. Some herbs people use for fatigue cause problematic side-effects in MS, Dr. Bowling warned. These include androstenedione, chamomile, DHEA, goldenseal, kava-kava, nettle, passionflower, sage, St. John's wort, Siberian and Asian ginseng, spirulina and valerian. For more information, visit www.ms-cam.org.

—Bridget Murray Law



Tai chi

Step forward for the stairs challenge

Scooters and wheelchairs are trusted tools for staying mobile and saving energy. Trouble is, they don't go up stairs. That poses problems. But so do stairs in general for people with MS who find climbing them tiring and dangerous.

One solution for chair users or walkers is a “stair lift”—a button- or joystick-operated chair that runs on a railing along the staircase. Not to be confused with platforms that raise and lower wheelchairs, these devices retail in the range of \$1,500 to \$5,000.

“That's pretty expensive, but the device may pay for itself if it means you don't have to move to another house,” said Dr. Virgil Mathiowetz, associate professor of occupational therapy at the University of Minnesota. A sampling of companies that sell stair lifts includes:

Savaria

www.savaria.com/step-saver-straight-stair-lift.htm

Acorn

www.acornstairlifts.com/us/index.php

AmeriGlide

www.ameriglide.com/item/electric-powered-stairlift.html

ThyssenKrupp

www.tkaccess.com/citiastairlift.asp

Brooks

www.brooksstairlifts.com/straight.php

Summit

www.summitstairlift.com/Stairlifts.htm

—Bridget Murray Law



Fight fatigue with a sleep study?

If you wake up tired most mornings, it doesn't take Sherlock Holmes to deduce you may have a sleep problem. Seems like a no-brainer, right? Not if you have MS. MS doctors typically link sleep problems to medications, depression, spasticity, bladder problems, and so on. Until now.

A new study suggests that the normal sleep cycle may be disturbed by MS. This may explain a good deal about MS fatigue. In research on 60 of his patients with MS, neurologist Dr. Mark Gudesblatt, and his South Shore Neurologic Associates Comprehensive MS Center Care Team found all patients studied had sleep abnormalities.

"It appears these patients are getting fragmented sleep, which might result in more daytime fatigue and moodiness, as well as a shortened attention span," said Dr. Gudesblatt, whose collaborators include Dr. Myassar Zarif and nurse practitioner Barbara Bumstead. Sleep studies with these people revealed the following:

- **Trouble falling asleep.** Participants took, on average, 45 minutes to fall asleep—some as long as two hours. The average person starts sleeping in under 15 minutes.

- **Delayed REM (dream sleep) onset.** Partici-

pants took an average of two and half hours to reach REM (Rapid Eye Movement) sleep. These are periods of lighter, dream-filled sleep that follow deep sleep. The average person slips into REM in under two hours; 10% of the participants never reached REM.

- **Night wakefulness.**

Participants had average sleep efficiency of 75%, meaning they were awake a quarter of the time spent in bed. Normal sleep efficiency is at least 85–90%.

- **Breathing problems.** Many participants experienced an average of 30 episodes of stopped or reduced breathing (sleep apnea and hypopnea) per hour. These interrupt sleep, sometimes waking people completely. More than 10 episodes an hour is cause for concern; more than 30 is considered severe.

- **Twitching muscles.** Seven of those studied were disturbed by Periodic Limb Movement Disorder (PLMD)—rounds of muscle jerking in legs or arms. Five participants had one episode an hour; two had 11 an hour.

Dr. Gudesblatt is not sure what causes these problems but he recommends sleep studies for anyone who has MS-related fatigue that doesn't respond to standard management.

"If we identify what's abnormal, we might be able to intervene more effectively," he explained. For example, sleeping pills might benefit those who don't fall asleep easily. And medications like ropinirole hydrochloride (Requip) can tame PLMD.

Sleep studies are expensive and they may not be covered by insurance, so discuss this option with a knowledgeable health-care provider.

—Bridget Murray Law

Society resources for managing fatigue

The Society recognizes the impact fatigue can have and offers many resources to help.

Explore nationalmssociety.org/Fatigue where there are links to our webcast “Fatigue” and many articles including:

- **Fatigue: An Overview**, nationalmssociety.org/FatigueOverview
- **Exercise as a Part of Everyday Life**, nationalmssociety.org/Exercise
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The Society’s Professional Resource Center offers “Management of MS-Related Fatigue” for professionals and those looking for more in-depth infor-

mation. It can be downloaded at nationalmssociety.org/FatiguePaper. People without Web access can call **1-800-344-4867** for this or any of the Society’s publications.

“FATIGUE: TAKE CONTROL”

Kathleen Matuska’s energy-saving advice comes from the course “Fatigue: Take Control,” when she taught it for the Society’s Minnesota Chapter.

This six-week workshop offered in chapters includes two videos plus manuals for the chapter workshop leaders and take-home materials for the people who attend.

Call **1-800-344-4867** to see if this program is offered in your area.