

MS fatigue

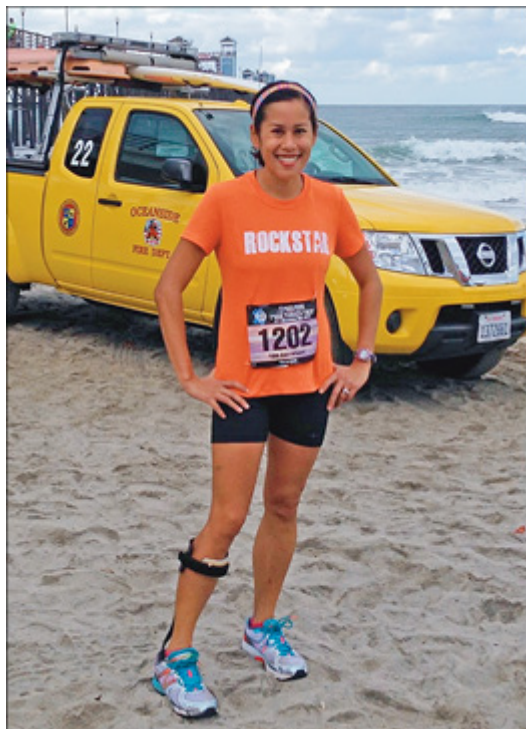


It's the most common symptom of the disease, but there are ways to manage it.

by Vicky Uhland

Every day, Donna Rice wakes up in her Issaquah, Washington, home around 9 a.m. For the next hour, she lies in a fetal position, mustering the strength to get out of bed. “The best way I can describe it to others is that my body aches all over, like when you have the flu,” says Rice, who was diagnosed with multiple sclerosis in 2004 at age 43.

Once she's finally on her feet, Rice eats breakfast. She rests for an hour and then showers. From about 11 a.m. to 3 p.m.—what she calls her prime time—she visits her doctors, runs errands, socializes with friends and tries to get in a daily walk. By 5 p.m., she's exhausted and ready to settle in for the evening.



Cheryl Hile says that exercise helps improve her mood and fights muscle atrophy. She runs three miles most mornings because fatigue sets in during the afternoons. Photo courtesy of Cheryl Hile

Farther south along the Pacific Coast, Cheryl Hile begins most of her days by strapping on the ankle-foot orthotic that helps prevent foot drop and then heads out for a 3-mile run through her San Diego neighborhood. Hile, who was diagnosed with MS in 2006 when she was 32, believes this exercise regimen improves her mood and fights muscle atrophy, but she must do it first thing in the morning because of afternoon fatigue. Her fatigue also heightens the cognitive deficiencies that forced her to leave her job as an accountant in 2017.

“As the day progresses, it’s harder for me to find words, pay attention and focus on people,” Hile says. Even math-related tasks she’s an expert in, like balancing her checkbook or doing the family taxes, are more difficult in the afternoon, when fatigue makes the mistakes creep in. “It’s like when you have an allergy and you’re on Benadryl—that kind of brain fog,” she says. “Sometimes I tell people it’s like being jet-lagged.”

Although Rice and Hile’s fatigue and their solutions for dealing with it take different forms, their symptoms are familiar to nearly everyone who has been diagnosed with MS. A variety of studies show that a majority of people with MS experience fatigue, which a 2017 research review defined as “extreme and persistent mental and/or physical tiredness, weakness or exhaustion.”

MS fatigue cuts across age, gender and ethnicity, and can occur at any stage of the disease. Fatigue levels frequently vary, making it difficult to predict how you'll feel on any given day—and when you'll hit a wall. And unlike typical feelings of tiredness, MS-related fatigue can have an enormous impact on how you function in every aspect of your life, playing havoc with relationships, jobs, hobbies and even simple, everyday tasks like getting dressed or cooking dinner.

While living with MS fatigue can be a challenge, a variety of therapies, strategies and tools can help you identify the types of fatigue you have and how to manage more effectively. Here's how to ensure you have enough energy for the things that matter most in your life.

The two types of fatigue

Like MS itself, the cause of fatigue in MS is unknown. But researchers do know there are two types of MS-related fatigue: primary and secondary.

Primary fatigue is related directly to the disease of MS. John Schafer, MD, founder and director of Mercy MS Center in Sacramento, California, says research shows this type of fatigue may be due to several causes.

One potential culprit is immune-system hormones called cytokines, which are released as part of the inflammatory process in MS. Cytokines are what make you feel weak and exhausted when you have the flu or an infection, and Dr. Schafer says there is some evidence they may contribute to MS fatigue. Demyelination and the subsequent decline in nerve conduction may also lead to a gradual erosion of muscle strength and endurance.



Donna Rice's daughter, Kaela Graham (right), organized a team of her sorority sisters to participate in Walk MS in Clarkston, Washington. Photo courtesy of Donna Rice

Another suspected cause of fatigue has to do with how MS interrupts nerve pathways in the

brain. As a result, the brain may have to enlist more regions to do a task that one region could normally do on its own. Some research shows this may cause wear and tear on brain circuits, contributing to cognitive fatigue.

“Think of your brain like a computer. If you try to work on various programs simultaneously the computer’s processing speed is going to be slower,” says Augusto Miravalle, MD, chief of the Multiple Sclerosis Division at the University of Florida College of Medicine. “There are neural structures by which MS patients use networks not normally used by individuals with intact brains in order to compensate for brain damage. MS can require your brain to recruit other areas to do a simple task, which slows down your mental processing speed.”

Secondary fatigue is usually due to MS symptoms. For instance, Dr. Miravalle notes that depression is a common symptom of MS, and fatigue is a frequent symptom of depression. Bladder issues that force you to wake up throughout the night and interrupt sleep can worsen fatigue. So can muscle spasms and pain. MS-related heat sensitivity can worsen the typical fatigue many people feel when temperatures soar. And some medications may contribute to fatigue (see sidebar on page 25).

Chronic stress can also be a cause of fatigue, although once again, researchers aren’t sure how.

There could be a biological correlation in people with MS, Dr. Miravalle says.

“We do know that the younger the patient is, the more likely that external factors like medications, depression and stress are factors in fatigue,” he says. “These are people whose muscles may not be tired, but who still crash at 2 p.m.”

The complicated causes and treatment of MS fatigue led Dr. Miravalle to open the University of Florida College of Medicine’s Multidisciplinary Comprehensive Fatigue Clinic in early 2017. This one-stop shop includes an occupational therapist who can help with energy-conservation solutions at work and home, and a physical therapist who designs personalized exercises to improve muscle strength and mood. A neuropsychologist addresses the mental and emotional aspects of fatigue. And a doctor and nurse practitioner evaluate patients for secondary causes of fatigue, making referrals to specialists like urologists or psychiatrists who can address those root issues.

A pharmaceutical approach to fatigue

Some medications can directly influence fatigue levels, so it’s important to discuss your options with your healthcare providers and tell them about all the medications you are taking, including any over-the-counter medications.

Many treatments for pain, spasticity or bladder overactivity can have sedating side effects

and so can compound the effect of fatigue. Whether such medications can actually cause MS fatigue is not clear.

Some MS disease-modifying therapies (DMTs) can make primary fatigue worse and may also contribute to depression-related fatigue, says Augusto Miravalle, MD, chief of the Multiple Sclerosis Division at the University of Florida College of Medicine. On the other hand, research shows that other DMTs can reduce symptoms of fatigue and depression.

One study of 164 people with MS, published in 2015 in *Frontiers in Neurology*, found that after a year of taking natalizumab (Tysabri), 92 percent of the participants had either stable or improved fatigue symptoms.

John Schafer, MD, founder and director of Mercy MS Center in Sacramento, California, says some pain medications and antidepressants can cause or aggravate fatigue, so ask your doctor about side effects if you take these types of drugs.

There are medications specifically for fatigue, but Dr. Schafer says their effects vary. Amantadine has been helpful for some people with MS, he says. He has had more success with Provigil and Nuvigil, which are stimulants originally designed to treat narcolepsy. "Many patients report that they feel more energized and have more mental focus with these medications," he says.

On the minus side, Provigil and Nuvigil are expensive and may make people feel "wired," Dr. Schafer says, but reducing the dosage may help with both of these factors. Stimulants like Dexedrine, Ritalin and Adderall are cheaper, but they can create the same jittery feelings, are more likely to be abused, and have been linked to cardiac and thyroid issues, he says.

If you don't have a similar resource nearby, you can still consult with each of these types of practitioners. There are also quite a few steps you can take on your own to help manage your fatigue.

Defining your fatigue

It's difficult to deal with your particular type of fatigue if you don't know how it manifests, says Abbey Hughes, PhD, assistant professor in the Division of Rehabilitation Psychology and Neuropsychology at Johns Hopkins University School of Medicine. Hughes recommends her patients start by keeping a diary of their fatigue, tracking what points in the day they feel tired and what they were doing, or what was happening around them at the time. While fatigue levels can vary from day to day, this can help you determine a pattern of when you tend to feel most exhausted and what may exacerbate it.

Many people find that fatigue is associated with constants in their life, including work, family, friends and other relationships, and responsibilities at home. While it may be impossible to jettison some or any of these factors, there are ways to modify how you deal with the people and things in your life to help reduce fatigue.

Hughes recommends the spoon theory to help determine what's truly important to you—and what you can let go. Start by imagining you have 10 spoons to use throughout the day. When you're confronted with an activity or obligation, ask yourself, "Is this something I want to spend my spoon on?" Hughes says.



John Quarles, a computer science professor, manages his fatigue by being selective about how he spends his time and energy. Photo courtesy of John Quarles

People who don't understand your fatigue may feel like you're lazy or inconsiderate if you don't want to devote a spoon to their needs or desires. Depending on how important they are to you, Hughes says there are different ways to address this.

For close family or friends, Hughes recommends describing your fatigue to them so they don't confuse it with the tiredness that everyone feels at one point or another. "You could talk to them about how it's like pain—ask them to imagine they have a chronic knee problem and then say, 'That's my fatigue. It can overtake my attention and physical function for a period of time, go away and then come back,'" she says.

John Quarles, a San Antonio, Texas, computer science professor who was diagnosed with MS in 2005 at age 24 and began using a wheelchair in 2009 mainly due to his fatigue, prefers an exercise analogy. "I tell people: 'You know how when you go to the gym and work out too much, and your legs feel like jelly? That's how I feel all the time.'"

Quarles has developed his own version of the spoon theory. “I find I’m constantly doing a cost-benefit ratio in my head. I’ll think, ‘How much energy am I going to expend to go out to lunch with my friends? Will it seem more like work than fun?’” he says. “I’ve always been reclusive, but I’m probably even more now because of my fatigue.”

For casual acquaintances, work colleagues or others with whom you don’t want to discuss your disease, Hughes suggests telling them that you have a health condition that causes a lot of fatigue, and here’s what you need to do—work at your son’s school fair in the morning rather than the afternoon, skip the company softball team, go out to lunch rather than dinner or take some other specific solution.

The psychology of fatigue

One key point to consider when defining your fatigue is that it may not just be physical or cognitive. There are also emotional aspects that can influence how your fatigue manifests.

For instance, Hughes says someone might feel so overwhelmed by his disease that he can’t get out of bed. Another person might have difficulty paying attention for long periods of time, which makes her upset and exhausted. And mental or emotional fatigue might make people with MS feel less motivated to do anything that requires physical effort.

Jagriti “Jackie” Bhattarai, PhD, an MS rehabilitation postdoctoral fellow at the Johns Hopkins University School of Medicine, is working on a new study that shows, among other things, that people with fatigue are more likely to rate their cognitive or physical function as worse than it actually is.

“When you feel fatigue, you may not have the resources to make yourself feel as capable as you really are,” Bhattarai says. “Because people limit their activities based on their fatigue, they may feel like they’re not functioning well even though they actually are.”

Bhattarai and Hughes both note that cognitive behavioral therapy (CBT) can be effective in combatting these perceptions of fatigue. For example, maybe you feel like you’re a bad mother or not a team player because you can’t do a four-hour shift at your daughter’s school bake sale. But this guilt is actually zapping energy that you could be spending on the things that really matter to you.

The key to CBT for fatigue is to create goals that are reasonable and achievable based on your values, and then examine how your thoughts and feelings work with those goals. A therapist or psychologist can help you with this.

Above all, CBT involves giving yourself a break. “None of us can do everything we want all of the day, all of the time,” Hughes says. “And for individuals with MS, that is even more apparent.”

Hughes says a CBT skill called behavioral activation (BA) can be particularly helpful for people struggling with fatigue associated with depression. Basically, BA is “pleasant activity

scheduling,” or purposely making time for activities you like or that help reduce depression. This could include yoga, progressive muscle relaxation or something as simple as a five-minute meditative break every hour to pace yourself and help conserve energy.

Working through fatigue

Along with dealing with the psychological aspects of fatigue, there are specific steps you can take to physically reduce your fatigue—or work around it.

“Rehabilitation professionals often talk about the four P’s of fatigue or energy management: planning, positioning, prioritizing and pacing,” says Amanda Rohrig, a physical therapist with Horizon Rehabilitation Centers in Omaha, Nebraska.



Mario Martinez decided to cut back on his work hours to better manage his fatigue. Photo courtesy of Mario Martinez

Planning refers to organizing your day in ways that optimize your energy. Say, for instance, your fatigue diary shows your workload or activity peaks in mid-morning and then about half an hour later, you feel fatigued. You can counter that by spreading your high-stress tasks throughout the day. Or, like Mario Martinez, who was diagnosed with MS in 1996 at age 26, you might need to cut back your work schedule to deal with your fatigue.

Martinez feels so drained by factors like the afternoon heat and humidity in his Mexican border town of Weslaco, Texas, that he can no longer work full time in his job at an independent living center. “I only work 8 to 12, then sometimes go straight home and take a nap. I get so fatigued I probably couldn’t drive myself home if I worked in the afternoon,” says Martinez, who uses a wheelchair and drives with hand controls.

The second “P” of energy management, positioning, refers to how you physically move around. “For example, standing uses more energy than sitting, so activities such as meal preparation and grooming, if completed in a seated position, will cumulatively conserve energy for later in the day,” Rohrig says.

Tracy Carrasco, an occupational therapist with the MS Comprehensive Care Center at Orlando Health in Orlando, Florida, points out that sitting in an ergonomic chair that encourages proper posture can reduce your daily energy expenditure by as much as 25 percent. “Good posture encourages good respiration and helps ensure you’re not working one set of muscles more than another,” she says.

Calm colors and cool temperatures in your home or office can also reduce the external factors that help create fatigue, as can appropriate lighting. “Overhead lights can be fatiguing,” Carrasco says. “Use close, soft light like lamps.” And in areas like the office or kitchen, organize your space so you don’t have to make multiple trips around the room to do simple tasks. Another option is to prepare meals during the weekend, freeze them and then reheat on evenings when you feel too fatigued to cook.

The final “Ps” of fatigue management, prioritizing and pacing, can also be thought of as proactive resting.

“Often in the clinic, I hear of people ‘feeling good’ on a given day, so they do everything on their to-do list,” Rohrig says. “By the end of the day, the client is exhausted and it may take two to three days to recover.” She suggests pacing yourself by scheduling rest breaks throughout the day—even if you feel like you don’t need them.

Occupational therapists who understand MS can help you figure out how to order and prioritize your day, week or month to help you successfully manage your fatigue as well as help others understand your abilities. This can include making a family calendar so everyone knows when important events are coming up and that you need to rest in advance, or explaining to children that mommy is tired when she gets home from work so she needs to lie down before helping with homework.

Exercise and fatigue

It seems counterintuitive to exercise when you’re tired. But people with MS who work out regularly say it can substantially reduce their fatigue.

“A common thing I hear from people who have fatigue is they don’t exercise,” says Ronith Dunn, who has lived with MS for 23 years. Dunn does weight training, spinning, yoga or another form of exercise at least an hour each morning. “It helps me focus, get my day started and strengthen my legs,” she says.

John Quarles, who was diagnosed with MS in 2005, says “warming up his legs” through walking on a treadmill, doing squats or other exercises helps him sleep better and improves his mood, which in turn reduces fatigue.

Because fatigue is individualized and can change in a matter of minutes, it’s a good idea to learn a few different workouts from a physical therapist. “Have exercises that can be completed when fatigue is minimal or moderate, as well as exercise options when fatigue is terrible and overwhelming,” says Amanda Rohrig, a physical therapist with Horizon Rehabilitation Centers in Omaha, Nebraska.

For example, if you feel so tired you can’t get out of bed, something as simple as deep, diaphragmatic breathing exercises or a few simple stretches may help energize you.

“I do not want people wasting valuable energy on exercises that are not encouraging function or helping them work towards a goal they wish to achieve,” Rohrig says.

Forging a relationship with fatigue

Baltimore resident Ronith Dunn was diagnosed with MS at age 23, a few years before her first child was born. For the last decade, she’s been a single mother to two girls, now ages 19 and 14, along with a pair of family dogs. MS fatigue definitely affects the family dynamic, but Dunn has learned how to not only manage it, but also explain to her daughters how it affects her—and them.



Ronith Dunn, a mother of two girls, has learned to balance her energy levels with her family life. Photo

by Riku Foto

“I’m able to work a full day, but when I’m done, I’m done. When the fatigue hits, I feel like I’ve been run over by a train, and then I start to have elevated MS symptoms—pain in my hips, numbness in my arms,” Dunn says. “At nighttime when I’m tired, I tell my daughters my MS is bothering me, and they understand. I’m usually in bed by 8:30 or 9.”

Carrasco says reframing the situation can help when you feel like you’re failing the people around you because of your fatigue. For instance, rather than being burdened, children who do extra chores can learn independence and feel proud to help. And delegating duties can encourage teamwork and help your colleagues or friends develop new skills.

Dunn learned that lesson seven years ago, when an MS exacerbation had a major impact on the attention she could devote to her daughters. “I started to feel terrible I couldn’t do stuff,” she says. “And then I thought, ‘There are a lot of moms who don’t do a quarter of what I do, and they don’t have MS.’ I’ve learned to keep my mental health by never thinking there’s anything wrong with me—including my fatigue.”

Vicky Uhland is a writer and editor in Lafayette, Colorado.

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Read about some of the research being done on MS fatigue at [Focus on fatigue](#).