

WHY AM I ALWAYS TIRED?

If you ask yourself that question, you might have Chronic Fatigue Syndrome, a devastating illness whose very existence remains a mystery.

BY HEATHER MILLAR ■ ILLUSTRATION BY JOE SORREN

Chronic Fatigue Syndrome is a terrible name. It doesn't accurately describe the serious symptoms of the affliction. A few case studies prove the point:

- Stephen, a 41-year-old molecular biologist living in Los Angeles, contracted the flu 19 years ago and never really got better. As the years passed, he discovered that most of the food he ate made him sick. He stopped eating dairy products, wheat, chicken, vegetables, nuts, and beans (though he now tries to eat some of these in rotation to have a more manageable diet and takes allergy treatments). If he goes for a short hike, he feels spent for days. To get through the workday at his scientific research job, he sometimes sleeps in his car at lunchtime. He feels lucky to be able to work.
- Jeeney Captain, 50, of Staten Island, New York, sleeps 12 hours a day, but when she wakes up she

feels like she's been up all night. Her muscles ache and burn, though she hasn't been able to exercise in almost a decade. She has irritable bowels and bladder. She gets migraine headaches. Often, her vision blurs. Her illness so debilitates her that she's lost her business, her home, her independent life in Fort Lauderdale. She now lives with her parents.

- Mary, a retired schoolteacher in Virginia, was diagnosed with the illness in the mid-1980s. She had to give up pursuing a master's degree in computer science because she was unable to retain the information. Now 60, she feels washed out and ill most of the time. She and her husband gave up their season tickets to the theater and stopped entertaining. She dropped out of the neighborhood garden club. Even the local sewing club has gotten to be too much for her. "It's been a series of losses," she says.

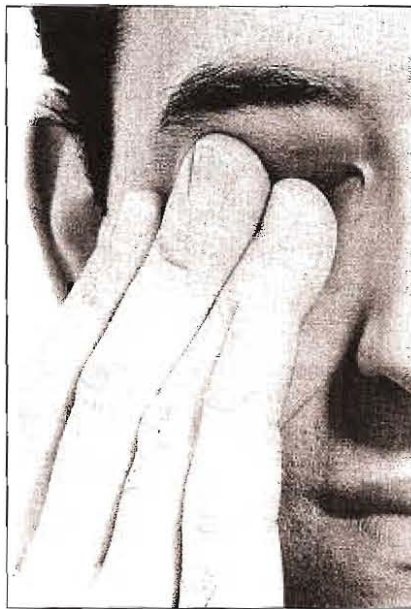


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■ Amy McLaughlin, a 19-year-old in Andover, Massachusetts, earned her high school diploma last year. That was no mean feat. Amy has been ailing since fifth grade. She's so fatigued most of the time that she spends 22 hours a day in bed. Her eyes can't focus on books, so tutors read to her. Sometimes, even sitting up in bed is almost impossible, so Amy did her schoolwork at home, in five-minute increments. Though college is not an option right now, Amy hopes someday to become a forensic psychologist.

The circumstances of these patients, the way they got sick, the severity and exact combination of their symptoms vary widely. Yet all four have been diagnosed with CFS. And despite almost two



exertion, and not made better by rest.

In addition, patients must suffer from at least four of eight other symptoms such as sore throat, muscle aches, joint pain without swelling or redness, and headaches. If tests show that these symptoms cannot be explained by substance abuse, severe obesity, the side effects of medication, depression or psychotic disorder, or another diagnosis to explain the chronic fatigue, then a diagnosis of CFS often follows. Almost everyone – doctors, patients, researchers – agree on one thing: The emphasis on fatigue leads some to assume that those with CFS are malingerers. Hence, CFS already has been changed to “Chronic Fatigue and Immune

RESEARCHERS RECENTLY SUGGESTED THAT “GRADED EXERCISE THERAPY” MIGHT HELP. HOWEVER, SOME PATIENT GROUPS HAVE CRITICIZED THIS APPROACH. “IT’S RIDICULOUS,” SAYS JILL MCLAUGHLIN, OF THE CFIDS FOUNDATION. “ASKING SOMEONE WHO CAN BARELY WALK TO EXERCISE IS LIKE TORTURING THEM.”

decades of research, scientists have yet to pinpoint a cause for it. While the Centers for Disease Control in Atlanta has launched an ambitious study seeking to define a genetic profile for CFS, there is still no laboratory test to diagnose the illness.

“Is chronic fatigue one thing? Nobody has a really good answer to that,” says Stephen, the L.A. biologist. “I have a hard time myself really defining it, grabbing on to some boundaries. Are we in the same boat or not? It’s hard to say.”

Those who suffer from CFS have long struggled to be taken seriously. When it was first described, many dismissed the illness as the “yuppie flu.” Early CDC surveys seemed to show that the syndrome was relatively rare and that the majority of sufferers were white women in upper-income brackets. But the CDC

now estimates that as many as 500,000 Americans have a CFS-like condition. A recent DePaul University survey puts that number as high as 800,000 and concludes that the majority of those are low-income minorities.

“It’s not the yuppie flu; it’s just the opposite,” says Dr. Leonard A. Jason, the professor of psychology who directed the DePaul study. “It’s much more common than we thought. It affects many more minorities, and the majority, as many as 90 percent, have not been diagnosed.” Jason estimates that 420 people in every 100,000 have CFS.

WHAT IS CFS?

For now, CFS is mostly identified by what it isn’t. CDC guidelines describe it as unexplained or relapsing fatigue that is not lifelong, not the result of

Dysfunction Syndrome” or CFIDS by the two largest patient advocacy organizations: The CFIDS Association of America and The National CFIDS Foundation.

“To the uninitiated, chronic fatigue [syndrome] is that you’re tired and you’re trying to make a big deal about it,” explains Jill McLaughlin, executive director of The National CFIDS Foundation. “The name undermines any understanding or description of the disease. You can’t raise money. People don’t want to give money to tired people.”

McLaughlin’s group has collected 6,000 signatures on a petition to change the name to “Myalgic Encephalomyelitis” a disorder recognized internationally. With ME, first described in 1934, patients experience muscle weakness and prolonged recovery time.

“I don’t think the public understands

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the severity," says Kim Kenney, president and CEO of The CFIDS Association of America. "Some people with CFIDS are homebound, bed-bound, completely disabled, completely unable to have any sort of normal function."

A lot of people struggle with the syndrome, and that number seems to be increasing. It has hobbled celebrities such as Lauren Hillenbrand, who took four years to write her best-selling book, *Seabiscuit*, about the 1930s champion racehorse, and Keith Jarrett, a world-renowned jazz pianist. Michelle Akers, the star of the U.S. Women's Soccer Team, finally had to quit the sport because of CFS. Speed skater Amy Peterson, a five-time Olympian, struggles with CFS. And despite growing public and scientific attention, tracing the syndrome back to its source has proved difficult.

More than 1,000 academic papers on the syndrome have been published, and there's now a journal dedicated to its research: *The Journal of Chronic Fatigue Syndrome*. Yet few answers have emerged. Studies have linked CFS to all sorts of causes: viruses, brain abnormalities, low blood pressure, heart abnormalities, and an imbalance of hormones produced by the pituitary, hypothalamus, and adrenal glands. Yet each time one study suggests a cause, another survey refutes it or sheds doubt on the new theory.

"It's an umbrella definition," explains Dr. Nancy Klimas, a professor of medicine at the University of Miami who directs a center devoted to researching CFS. "So whatever study you do, you'll find that not everybody has this. You have these overlapping circles that have absolutely been the source of all our confusion as far as conflicting studies."

While all the scientific details have yet to be pinned down, the working theory now is that multiple triggers

DO YOU HAVE CFS?

The CDC estimates that as many as 85 percent of those who have CFS haven't been diagnosed. Researchers led by Dr. Leonard Jason at DePaul University in Chicago put the number at 90 percent. CFS symptoms have some overlapping symptoms with those of other diseases, such as fibromyalgia, Gulf War illnesses, and multiple chemical sensitivity. Lupus, hypothyroidism, and Lyme disease can also cause problems similar to CFS symptoms. Still, if you answer "yes" to most of the following questions, it might make sense to be evaluated for CFS:

- Do you experience severe fatigue that doesn't seem to be related to a busy schedule, lack of sleep, physical exertion, or illness?
- Have you had this fatigue, or recurring episodes of fatigue, for more than six months?
- Does the fatigue severely affect what you can accomplish?

If you've been ill for more than six months, have you also suffered from at least four of the following symptoms?

- Loss of short-term memory or concentration
- Sore throat
- Tender lymph nodes
- Muscle pain
- Multi-joint pain, without redness or swelling
- Headaches of a new type, pattern, or severity
- Insomnia, or sleep that doesn't refresh you
- Feel exhausted for more than a day after exertion



may cause the immune system to go on "hyper activation," which causes it to overreact to problems. Some think this hyperactive state may even be connected to infections that went into dormancy but have reactivated. This constant immune response in genetically or environmentally susceptible individuals may help cause the fatigue. It may also create a cascade of reactions in other body systems, leading to the horrible grab bag of symptoms linked to CFS: dizziness, chemical sensitivities, memory problems, nausea, insomnia, rashes, headaches, muscle aches,

joint sensitivity, sore throat, irritable bowels, weakness, and constant pain, or "fibromyalgia."

"The thinking is that something comes along and whacks us, and for some reason our immune system doesn't get back on the right track," says Mary, the retired schoolteacher who is also on the steering committee for the Chronic Fatigue Syndrome Association of Arizona.

That immune response, the theory goes, creates all sorts of other problems. For instance, "You can't keep the immune system pressed 'on' without

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A RESOURCE GUIDE



The CFIDS Association of America, P.O. Box 220398, Charlotte, North Carolina 28222-0398; (704) 365-2343, <http://www.cfids.org>

The National CFIDS Foundation, 103 Aletha Road, Needham, Massachusetts 02492; (781) 449-3535, <http://www.ncf-net.org>

U.S. Centers for Disease Control, National Center for Infectious Diseases: Chronic Fatigue Syndrome, <http://www.cdc.gov/ncidod/diseases/cfs/>

affecting the nervous system and the endocrine system," explains Dr. Klimas.

Scientists also have begun to divide CFS sufferers into subgroups such as those with primarily neurological symptoms, those having mostly immune symptoms, or those plagued chiefly by muscle problems. The hope is that doing studies of people with similar clusters of afflictions will be more effective than the research performed so far, which mostly lumps all CFS patients together.

THE TREATMENT DILEMMA

There may not be a chemical marker for all kinds of CFS, but there could be one that chiefly affects the immune system and another that affects the central nervous system or the endocrine system, scientists believe. "It's a mixed population of people," says McLaughlin, of the

CFIDS Foundation. "You're not going to find a single cause because it's not a single entity."

The few clinical trials of drugs like the anti-inflammatory prednisone or the antiviral gamma globulin, have so far failed to show much use in treating CFS. Several more are now in progress, such as an open-label trial of thalidomide for fibromyalgia. Other trials aim at modulating the immune system, including Isoprinosine, which is used to treat herpes viruses in Europe.

Until this new round of research yields new treatments or sheds more light on the cause, or causes, of CFS, doctors will continue to treat the disease mostly by trying to ease its symptoms. These treatments usually involve several medical specialties and are geared to the needs of each individual. For instance, a patient with a lot of

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gastrointestinal problems and rashes might see a diet specialist and a dermatologist, while a patient with dizziness might seek out a neurologist.

"You have to use lots of techniques, [such as sleep therapy and pain relief] not just one," explains Dr. Veeraindar

Goli, assistant clinical professor of psychiatry and anesthesiology at Duke University School of Medicine, who specializes in treating CFS. "And the treatment has to be tailored to each patient."

Someone whose main problems are pain and sleeplessness, say, might get

prescriptions for pain relievers and sleep aids such as Ambien or Remeron. A depressed patient might take low doses of antidepressants such as Paxil or Zoloft, and so on.

Though it's unclear why, many CFS patients are hypersensitive to almost all medications, so the dosages may be smaller than usual. Physicians often recommend supplemental or "alternative" therapies to help people deal with their illness. Meditation and biofeedback may help some patients cope with the stress and anxiety of living with CFS. Others may benefit from "cognitive behavioral therapy" that aims to help patients control and cope with their reaction to their symptoms.

Researchers recently suggested that "graded exercise therapy" might help some sufferers. Under supervision, people with CFS are encouraged to increase their activity level. The idea is to increase stamina. However, some patient groups have criticized this approach. "It's ridiculous," says McLaughlin, of the CFIDS Foundation. "Asking someone who can barely walk to exercise is like torturing them."

There are still more questions than answers. But CFS researchers say their understanding of the disease is better now than it used to be. Though the trigger remains elusive, doctors now understand much better how the immune system responds in those with CFS. Doctors hold out hope for gene research like the diagnostic study now being done by the CDC. The hope is that analyzing tens of thousands of genes will yield a distinctive pattern shared by CFS patients. "With genomics," explains Dr. Goli of Duke University, "we may be able to find not only the markers for this disease, but the genes that cause it." ©

NEW YORK CITY-BASED WRITER **HEATHER MILLAR** HAS CONTRIBUTED TO ATLANTIC MONTHLY, SMITHSONIAN, AND WIRED.