Unrelenting exhaustion

No longer called 'yuppie flu,' chronic fatigue syndrome is striking all levels of society

By Susan Frick Carlman
STAFF WRITER

It's called brain fog.

Sometimes it hits when you're recovering from a bug. Other times it's a consequence of sleep deprivation. Anyone who has suffered through a substantial hangover knows what it feels like.

Now imagine experiencing brain fog off and on, but mostly on, for many years. For an estimated 800,000 Americans, brain fog is an element of daily living.

But that's not the least of it. A generalized sense of aching and overwhelming exhaustion, headaches, sore throat and lymph node tenderness also hound people who suffer from chronic fatigue syndrome, once known as "yuppie flu."

Contrary to initial perceptions of the disease, it is not limited to high-achieving professional women in their 30s and 40s. Recent research has found that the condition actually discriminates in a more traditional way, striking minority and less-educated, low-income populations far more frequently than upwardly mobile executives.

Bill Mathis believes that the early misnomer set back much-needed research, frustrating efforts to find causes and cures for the mysterious and debilitating condition.

"It has been trivialized," said the Lockport resident, whose life has changed completely since he developed CFS 3½ years ago.

The matter is anything but trivial for Mathis. Resigning from his job as executive director of S.O.S. Children's

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Who gets it?

DePaul University researcher and psychologist Leonard Jason found the following prevalence rates for chronic fatigue syndrome in a 1999 community-based study. The figures represent incidences per 100,000 people in the United States.

TOTAL: 422

By occupation:

Professional	325
Skilled workers	701
Unskilled/ semi-skilled workers	486

By age:

18-29	30-39	40-49	50-59	60+
318	412	805	413	354

By gender:

Men	Women
291	522

By race:

White	Black	Latino	Other
318	337	726	491

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Village, the long-term foster care facility in Lockport, last June was only one of the myriad changes he has had to make in his efforts to cope with the malaise.

"In my past I was used to burning the candle at both ends," he said. "(CFS) is the type of situation where you have to manage your energy, and I've never known anything but full speed ahead."

It wasn't all that difficult initially to suppress the need to confront the disease, because for a long while he really didn't know what was ailing him. It took more than two years to put a name on the symptoms. At first he believed that the aches, joint pain and sore throat were the aftermath from a bout of viral pneumonia he had developed in August 1997. But when consultations with numerous doctors could find no cause for his misery, the process of elimination and some Internet research led him to chronic fatigue, which is also known as chronic fatigue and immune dysfunction syndrome (CSFIDS), postviral fatigue syndrome or myalgic encephalomyelitis. The problem is that there are no specific lab tests that can identify the condition.

"Chronic fatigue syndrome is a diagnosis of exclusion," Mathis said. "I can't tell you how many tests I've had. I've had CAT scans, I've had MRIs . . . I was tested for depression."

Because the symptoms of the syndrome often mimic those of depression as well as other long-term diseases, including fibromyalgia, multiple sclerosis, Epstein-Barr Syndrome and systemic lupus erythematosus, physicians typically have to screen for everything else before declaring a case of CFS.

Usually a diagnosis is made when other possibilities are eliminated and the patient exhibits at least four of the most frequent symptoms at the same time. Common complaints include sore throat; tenderness in the lymph nodes; muscle pain; pain in multiple joints without any evidence of redness or swelling; headaches of a new type, severity or pattern; sleep that doesn't lead to a rested feeling; tiredness following exertion that doesn't go away after taking it easy for a day or two; and ongoing problems with concentration and short-term memory that call for an adjustment in activity level.

People with CFS do not sleep soundly, and many never reach the deeper levels of sleep that bring true rest. Mathis said that a year ago he underwent a sleep study that found him going in and out of rapid eye movement (REM) sleep about 30 times an hour.

"You wake up in the morning feeling more tired than when you went to sleep, almost as if you're encased in cement," he said.

Many patients report that they can pinpoint precisely the day that they began feeling ill, often after episodes of flu, pneumonia or a bad cold. In that way the condition appears to prey on weakened immune systems, but others with CFS develop its symptoms gradually.

"I tend to think of this as a condition that, there is some physiologic data to indicate, involves overactivity of the immunologic system," said Leonard Jason, a clinical and community psychologist and professor at DePaul University in Chicago and a leading CFS researcher.

Ripple effects

The disease remains nearly as undiagnosed as it is mysterious.

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According to the Chronic Fatigue and Immune Dysfunction Syndrome Association of America, an estimated 90 percent of those who have CFS do not know it.

Understandably, a mysterious illness that drags on for months or years before being diagnosed can be taxing on loved ones in addition to the sick person.

Mathis said his wife Carol has been very supportive, but he noted that the appearance of the illness in their lives has resulted in a sense of loss for both of them. The couple has been married for 4½ years, and Mathis said he regrets that he was only himself, in health terms, for the first 18 months of the marriage. The illness has meant that he has much less energy when leisure time becomes available to him and his wife, and it also has resulted in a postponement of earlier plans for Carol to reduce her work schedule to part-time. Even tasks as simple as running a quick errand at the store are often more than Mathis is able to manage anymore.

"It definitely affects the whole family," he said. "The hard part for my wife has been in several areas . . . She's not sure what to expect when she gets home from work. It's my job to make dinner, but when she comes home and sees me moving like a 100-year-old man, she knows she's going to have to help."

The condition also can have an alienating effect. Jason said called the stigma of CFS "terrible."

"People hate having to say they have it, because 25 percent of the population at any given time is fatigued, so if you say you have chronic fatigue syndrome they'll say, 'So what? I'm tired too,'" he said.

Finding a new name for the condition would help. Authorities and patients agree that the current CFS label ignores many of the other factors involved.

"Chronic fatigue doesn't describe it, but CFIDS really doesn't fit it either," Mathis said. "It's kind of like saying if you have Parkinson's disease you have shaky-arm disease."

Jason, who is part of a name-change work group aiming to select a new tag, said that one current frontrunner is Neuroendochrine Immune Disorder, or NEID. Another possibility might be myalgic encephalopoly.

A redesigned life

Like its causes, remedies for CFS remain elusive. Trials of Ampligen, a prescription medication, are awaiting FDA approval for federal funding, and several other drugs are used to treat the disease, but few have been effective so far.

According to Jason, the progress of the disease shouldn't be considered recovery, because most people don't seem to reach a state of being cured. Getting better is more a matter of managing the circumstances that have become daily reality.

"I would say your 'recovery' is seeing whether you're able to resume some of the activities you've had to give up," he said.

Jason, who has noted that improvement generally comes after patients recognize the problem and cut back on their daily activity, counsels patients to attend to their symptoms as they cope with coming to terms with the protracted illness.

"If you're having headaches, you treat them with medication. If you have an irritable bowel, you deal with that," he said.

He uses a model that involves batteries and envelopes.

"Normally you have 100 of your energy in your battery," Jason said. "Think about having just 10 percent of your total energy available to you."

He advises his clients to pay attention to their "energy envelopes," and to remain within them.

Mathis heard that suggestion from Jason, and he has heeded it. Although it's been difficult, he has had to come to grips with the idea that things take him longer now than they used to. He has dealt with his bruised pride and now feels thankful that he's able to get out of bed most days, unlike many others who suffer from CFS. He said he has found strength in his faith in God as he works on adjusting to a far lower level of productivity.

"That's the hardest thing for me, realizing that even on good days you have to set limits, because if you don't, your body will set them for you," he said.

"You have to live within your envelope, but you want to push it gradually so that you don't fall out of it, but you don't sink to the bottom of it and just sit there."

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Jake Herrle / Staff photographer

Exercising in a pool helps Bill Mathis to build strength and stamina with limited danger of overexerting himself. Mathis, a Lockport resident, had to resign from his job after he was diagnosed with chronic fatigue syndrome and is undergoing treatment to combat effects of the disease.