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Spotlight on Chronic Fatigue

What to do to feel better—one small step at a time.

BY SALLY LEHRMAN

Carol Sieverling had finally found a calling that seemed a perfect match for her interests and skills. After seven years of teaching teenagers math and English, she'd returned to school herself—this time to get a degree in divinity and Christian education. Afterward, she worked 18 months at a Presbyterian church in North Carolina, and the congregation invited her to lead them long term. She was ready to be ordained.

But as the day for her appointment neared, she caught what felt like the flu. Unlike the bug that was going around, this one plagued her with muscle aches and exhaustion that didn't go away in a week. As she lay in bed, church members brought a meal to her door every day. They bought her mother a plane ticket to come visit. They even kept her on the payroll for six months, but it was no use. Sieverling could feel the illness dig deeper. Most of the time she just lay in bed, unable to get restful sleep. Finally she had to resign from the church. "It was devastating," she says.

Since that day in 1996, Sieverling, 45, has been coping with chronic fatigue immune deficiency syndrome, also known as CFIDS or CFS, a lingering malady characterized by disabling fatigue, pain, cognitive difficulties, and sleeplessness. No one knows

what triggers it, although some experts point to an infection that seems to stay dormant until some physical or emotional stressor—another infection, say, or trouble at work—stimulates long-term symptoms. Some believe the condition results from a hypothalamus gone haywire; others attribute it to the cumulative effect of multiple chemical sensitivities. Whatever the cause, Sieverling says, for the people affected, "it's like a complete shutdown of the energy-producing mechanisms of your

body. We feel like we're living in a shadow world." To make matters worse, CFS often travels hand-in-hand with fibromyalgia, a complex disorder that hammers patients with chronic pain throughout their bodies.

Western medicine has little to offer people with CFS, other than antidepressants, anti-inflammatories, and sleeping pills, which don't always help. Alternative medicine has no cures, either. But in the past few years, a handful of doctors *have* developed successful

Sufferers often feel isolated, but support groups can help.



strategies for bringing CFS sufferers closer to leading normal lives. Most of these practitioners use a blend of complementary and alternative therapies to address the immune, neurological, and metabolic systems that are presumed to have gone awry.

There's not much research on such



One patient found that after giving up soda and sweets, her "brain fog" began lifting and she felt more energetic.

combination treatments, but what little there is looks promising. One of the most rigorous studies was carried out by physician Jacob Teitelbaum of Annapolis, Maryland. His plan focuses on improving sleep, normalizing hormone levels, battling yeast and parasitic infections, and providing nutritional support. (Teitelbaum himself knows the syndrome intimately: It forced him to drop out of medical school for a year.) In his study, 91 percent of 33 patients with chronic fatigue and/or fibromyalgia felt better after three months of his mix of therapies.

Granted, the prospect of attacking symptoms on so many different fronts may seem overwhelming, especially when you're already using all your energy simply trying to meet life's basic needs. The key, say experts, is to tackle one aspect of the syndrome at a time, starting with the worst. "Say to yourself, 'What can I do to make *some* improvement?'" suggests Leonard Jason, a professor of psychology at De Paul University in Chicago and lead editor of the *Handbook of Chronic Fatigue Syndrome*. Making gains in one area can encourage you to take on the next.

Here are the highlights of this step-by-step approach.

Dietary strategies

A couple of years after she resigned

from the church, Carol Sieverling found her way to Paul Cheney, a North Carolina physician who's a founding director of the American Association for Chronic Fatigue Syndrome.

Cheney's first advice to Sieverling was to cut several things out of her diet, including sugar, NutraSweet, "bad" fat

(like the saturated kind), red meat, caffeine, and, as much as possible, gluten and dairy products. The worst offender is sugar, some practitioners believe; it fuels the overgrowth of abnormal microorganisms in the digestive tract (including yeast) and promotes cell-damaging free radicals. Getting rid of the whole group is thought to aid

digestion and ease pain.

At first, the assignment seemed impossible. For one thing, Sieverling was downsizing about two liters of Dr. Pepper a day. (Many CFS sufferers rely on sugar and caffeine for stamina.) But soon after she gave up soda and sweets, her "brain fog" began lifting, and she felt more energetic.

Sieverling began taking enzymes and probiotics such as acidophilus to help her digestive system function better, too. When digestion isn't working properly, some alternative practitioners believe, minute food particles can cross into the bloodstream and trigger an allergic response. Cheney also tested her for food sensitivities, a common problem for CFS patients. And he regularly rotated certain foods out of her meals. For weeks at a time, Sieverling found herself eating only fish, vegetables, and muffins made with spelt and kamut—grains she'd never heard of. "But I felt so much better," she says.

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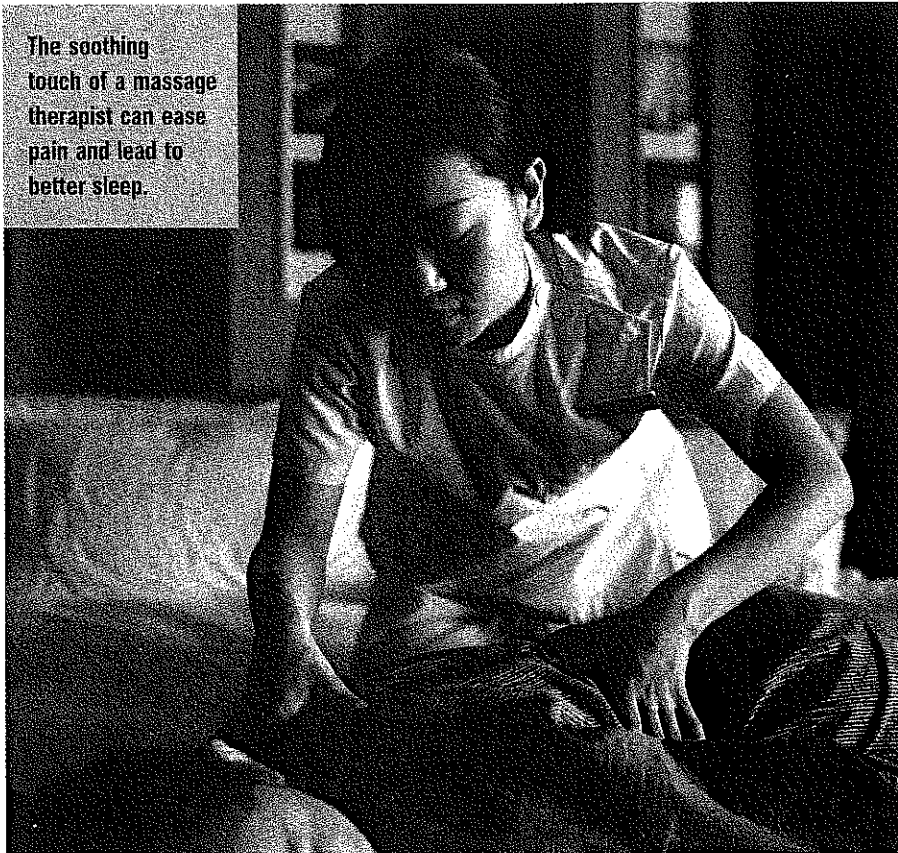
Could It Be Chronic Fatigue?

Lots of things in life can make a person tired. If you find it a bit of a chore to get up in the morning and sometimes like an afternoon nap, you probably don't have CFS. The illness is marked by extreme fatigue that lasts six months or longer and has no known medical cause. Other symptoms can include impaired short-term memory, muscle pain, and tender lymph nodes. If you suspect you might have chronic fatigue, try filling out the assessment questionnaire provided by the CFIDS Association of America on its website at www.cfids.org.

To find a doctor well-versed in alternative strategies, contact a local CFS support group for recommendations. (For a list of support groups in your state, email the CFIDS association at cfids@cfids.org or call 704.365.2343.) University-affiliated medical schools, even outside of your area, are also good places to look. Many clinicians belong to the Seattle-based American Association for Chronic Fatigue Syndrome (206.781.3544). You can compare your doctor's strategy to Jacob Teitelbaum's integrative protocol by reviewing the information on his website at www.endfatigue.com. Finally, if you'd like to check out the website that Carol Sieverling maintains for fellow chronic fatigue patients in her Texas-based support group, go to www.virtualhometown.com/dfwcfids.

—S.L.

The soothing touch of a massage therapist can ease pain and lead to better sleep.



Supplements and herbs

Rows of pills now pack Sieverling's cupboard; according to some alternative practitioners, fortifying the diet with certain supplements helps guard against free radicals, which CFS patients seem to produce more of. Sieverling regularly takes multivitamins, antioxidants, lipoic acid, quercetin, glutathione, essential fatty acids, and coenzyme Q10.

She also takes magnesium. While she hasn't experienced the severe aching and burning that many with CFS do, she has battled terrible migraines, which have been linked to a deficiency in this mineral. Magnesium may also be helpful for many with fibromyalgia; two studies suggest it eases pain and sensitivity.

Valerian and melatonin are also on Sieverling's list because she's found they help with one of her biggest problems: an inability to sleep that can leave her feeling wired and tired at the same time. Both supplements are proven sleep aids.

Relaxation strategies

For many with CFS, getting consistent and restful sleep is a crucial but elusive goal. Helpful practices include picking the same time each day to go to bed and to rise, developing a consistent routine for winding down at night, and



Even minimal physical activity can help. One CFS sufferer began by contracting her muscles for just ten seconds at a time.

eliminating television from the bedroom. Meditation, progressive relaxation, and listening to soft music can also help, as can noise- and light-blockers such as foam earplugs or eyeshades.

Movement

After Sieverling resigned her position at the church, she left North Carolina and moved back to her mother's home

in Euless, Texas. At first, she could barely get out of bed. But CFS specialists emphasize that even when pain and fatigue make it seem impossible, doing whatever physical activity a patient can manage will help stave off muscle atrophy. Sieverling began with isometric muscle contractions she could do in bed for just ten seconds at a time. She eventually worked up to walks around the block twice a day. She hasn't tried yoga, but many people in a support group she's joined find it helpful. Experts suggest, though, that CFS sufferers may feel more comfortable in classes designed for people with chronic diseases.

Vitamin B-12 injections

Research has linked B-12 deficiency, documented in many CFS patients, with cognitive problems. Sieverling has found that a nightly dose helps her sleep and keeps mental fuzziness at bay. (She injects it because she requires a high dose.) Some CFS and fibromyalgia patients have found that B-12 eases pain, too, though studies haven't confirmed this.

Bodywork and acupuncture

Sieverling has gotten a lot of comfort from the craniosacral and myofascial forms of massage. Standard massage,

which can increase serotonin and dopamine in the brain and contribute to improved sleep, may help reduce pain, too. In one five-week study of 24 fibromyalgia patients in Miami, for instance, those who received massages twice a week slept better and had lower levels of the chemical messenger that transmits pain. The bodywork that Sieverling got, in fact, allowed her to

stop taking pain medications.

She hasn't tried acupuncture, though many fibromyalgia patients find it helpful. And one small but well-designed study showed promising results, which are probably due to the release of endorphins, the body's natural painkillers. Experts typically recommend weekly acupuncture treatments, long term.

Energy management

"You've got to listen to your body, know what your limits are, and stay within them," Sieverling says. For instance, distractions such as loud music or energy-sappers like anger or distress can eat away at a patient's reservoir of stamina. Sieverling worked for a year with a therapist on coping strategies, meditation, and stress management. The therapy also helped her come up with a workable schedule for herself.

For the time being, she has up to four good hours a day, but she parcels out her active time in small stints of about 15 minutes apiece, resting in between.

These days, Sieverling channels much of her limited energy into the support group she dropped in on after she returned to Texas. Before she knew it, they'd asked if she would take over its leadership. Now the group puts out a ten-page newsletter for 800 people, maintains a website and email list, and brings in a national speaker for an audience of 200 or so every year. Sieverling gives referrals, listens a lot, and helps families and spouses come up with coping strategies.

In some ways, her life now is not so different from the one she'd planned for herself before she got sick. While she was never ordained, she has acquired a new congregation.

"In the surprising way that God or the universe or the higher power works," she says, "this has turned into a ministry that I never expected." **A**

Sally Lehrman is a writer in Montara, Calif. She wrote "Home Free," about healthy living spaces, in the September issue.

SOURCES

For more information on some of the studies mentioned in the story, check these references.

- ◆ Teitelbaum, J, et al. Effective treatment of chronic fatigue syndrome (CFIDS) & fibromyalgia (FMS)—a randomized, double-blind, placebo-controlled, intent to treat study. *Journal of Chronic Fatigue Syndrome* 2001;8(2). Available at www.endfatigue.com/home.nsf.
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