

IS IT ALL IN YOUR HEAD?

MILLIONS OF CANADIANS SUFFER FROM CHRONIC CONDITIONS THAT DOCTORS AND SCIENTISTS CANNOT ADEQUATELY EXPLAIN. HERE ARE FIVE. BY LIA GRAINGER

1 CHRONIC FATIGUE SYNDROME

For months, Teresa Serice had been exhausted. Sleep came rarely, and when it did, it offered little relief from the fatigue that made every movement excruciating. Yet Serice, a resident of Keizer, Ore., was determined to keep her job as a budget administrator. “Work was my drug. It was what I lived for,” says the once-active 50-year-old.

On January 8, 2009, Serice parked her car and attempted to walk the two blocks to her office door. “By the time I got there, I could barely move,” she says. “I couldn’t lift my arms and it felt like there were weights on my chest.” She quit her job soon after and was bedridden for three months. “Walking from my bedroom to the kitchen felt like crossing the Sahara,” says Serice.

Her family doctor was quick to give her a diagnosis of chronic fatigue syndrome (CFS), but was flummoxed by how to treat it. Treatment was made more difficult by the fact that Serice has another severe chronic condition. Eventually, her physician ran out of options. “My doctor basically said, ‘I can’t help you.’”

Serice has also faced obstacles with her insurance company. “They told me I wasn’t sick enough to claim long-term disability,” she says. And the cost to see a CFS specialist is prohibitive, so she visits a local homeopathic doctor. The treatments have been successful, but she still hopes for a cure. “I know my life isn’t over,” says Serice, “but sometimes it sure feels like it.”

Serice is not alone. It’s estimated that

there are at least 800,000 Americans and more than 300,000 Canadians living with the condition, characterized by relentless fatigue that does not improve with rest. Sufferers are primarily female. The causes of CFS are unknown, but theories range from viral infection to immune-system dysfunction. Its mysterious origins make treatment difficult, and doctors are forced to focus on alleviating symptoms. And while today CFS is less likely to be dismissed as psychological, patients still face physicians who are not always well-informed about the debilitating nature of their illness. “It’s time-consuming and difficult to treat and diagnose. A number of conditions, such as Lyme disease, present very similar symptoms,” says Christopher Snell, who chairs the Chronic Fatigue Syndrome Advisory Committee in the U.S.

In the October 2009 issue of *Science* journal, a team of American researchers announced they had found XMRV (xenotropic murine leukemia virus-related virus) in the blood of 67 percent of the CFS patients they tested. The retrovirus is similar to HIV, a connection that made many CFS patients cautiously hopeful about future treatment with antiretroviral drugs. But so far, no other researchers have been able to duplicate the results.

“Even if XMRV doesn’t pan out to be a single bug-and-a-drug model, there is still much better recognition than even five years ago,” says Kimberly McCleary, president of the CFIDS (chronic fatigue and immune dysfunction syndrome) Association of America.

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2 FIBROMYALGIA

By the time she was 18, Debbie Keats knew there was something very wrong with her. An active teenager, Keats began experiencing bowel problems, insomnia, chronic pain in her legs and crippling fatigue. For a decade, she bounced from doctor to doctor in her hometown of Ottawa. Each time, she underwent a battery of tests and the results always came back normal.

Finally, at 28, she saw a doctor who administered a “tender points” test, gently pressing on 18 spots on her body to see if she felt tenderness in at least 11. She did, and was finally given a label for her condition: fibromyalgia.

The term was coined in 1982 by Dr. Muhammad Yunus to describe a condition of chronic and unexplained pain. Fibromyalgia sufferers—who are overwhelmingly female—feel exquisitely tender in certain spots. Many complain of a host of other symptoms, including headaches, insomnia, irritable bowel syndrome and chronic fatigue.

The mainstream medical community is at odds over whether fibromyalgia is an actual condition. Sufferers usually appear perfectly healthy when examined, and because there is no laboratory test to support or discredit symptom testimony, doctors must base their diagnoses solely on their patients’ word. “The problem for many physicians is that it becomes a self-defined disorder,” says Dr. Frederick Wolfe, the lead author of

fibromyalgia diagnostic guidelines from 1990. He says many doctors believe the label causes more harm than good because it places a condition that some sufferers simply tolerate into the category of a chronic disease.

Many believe these symptoms are psychosomatic and will refer patients to a psychiatrist. Dr. Ellen Thompson, a pain specialist and medical advisor for FM-CFS (fibromyalgia and chronic fatigue syndrome) Canada, disagrees: “When doctors don’t understand a condition, they always make this leap to the head,” she says. Like other doctors advocating for treatment of fibromyalgia, she entertains a number of physiological explanations for the disease, including genetic predisposition, autoimmune dysfunction and biochemical abnormalities, possibly triggered by viral infections.

Further deepening the chasm in an already-divided medical community was the release over the past five years of the first Health Canada-approved drugs labelled specifically for fibromyalgia: pregabalin and duloxetine HCl. “These new and improved drugs have made life considerably better for people with fibromyalgia,” says Thompson, who maintains the condition should be treated “as an illness like any other.” Rheumatologist Dr. Nordin Hadler, of the University of North Carolina, disagrees. “The fibromyalgia-labelled population has no biochemical abnormality,” says Hadler, who has written extensively



on the condition. He believes the drugs—whose side effects can include dizziness, weight gain and edema—actually make patients sicker: “Their benefits are trivial, if there are any.” Wolfe adds that the drug companies “engage in the most egregious type of marketing and disease-mongering—they want you to have this.”

In May 2010 Wolfe and several colleagues revised the fibromyalgia diagnostic guidelines, removing the tender-points test and adding several new symptoms, such as insomnia and cognitive difficulty, to the list of complaints that may indicate the condition.

In the absence of a medical consen-

sus, patients such as Keats must come to their own conclusions about the best possible treatment. Though she’s decided against the new fibromyalgia drugs because “everyone I know says they just make it worse,” she does take a low dose of an anti-anxiety medication to help her sleep.

Keats’s doctor does not believe she has fibromyalgia. “I think it’s sad that after all these years, we have to jump through hoops to prove ourselves,” says Keats. “Just to have a doctor believe me would make me feel so much better.”



3 MULTIPLE CHEMICAL SENSITIVITY

It started in 2005 as a series of common ailments that Kathleen Shea-Starks, now 53, just couldn't seem to shake—a cold, a niggling flu bug, a mild fever. The tipping point came when Shea-Starks, an artist and teacher in Ann Arbor, Mich., signed up for a course in digital filmmaking at the local community college. Twice a week, she spent the evening in a poorly ventilated room filled with the warm hum of about 40 computers. "I would come home sick," she says. "I'd have trouble breathing and get a fever and sore throat, and it would take me the whole weekend to feel better." Halfway through the semester, she dropped the class. It helped, but didn't cure her condition.

After several months of fruitless medical consultation, she listened to

a friend who suggested she see an environmental doctor, who diagnosed her with multiple chemical sensitivity. The trigger? The outgassing of chemicals from those 40 computers.

Multiple chemical sensitivity (MCS) is characterized by a chronic inability to tolerate exposure to low levels of a variety of chemicals. In some cases, MCS is brought on by a single high-dose chemical exposure, while in others—like that of Shea-Starks—symptoms set in gradually.

"My life looks 100-percent different now," says Shea-Starks. She avoids most indoor spaces, as the chemicals in stores, her church and even her parents' carpeted house make her ill. Mostly she stays home, where she is guaranteed a sterile environment. On the rare occasion she does venture out, Shea-Starks wears a personal air ionizer around her neck. But even with this, something as innocuous as

the smell of dryer sheets from a neighbour's home can cause a full-blown reaction. "I can't breathe, my eyelids swell up, I get nausea and feel congested," says Shea-Starks.

Unfortunately, the development of diagnostic tests for MCS and strategies for treating sufferers hasn't quieted the medical establishment's doubts. Nearly everything about the condition continues to be contested—including its name. While the doctors who treat sufferers prefer "multiple chemical sensitivity," skeptics in the scientific and medical community prefer "idiopathic environmental intolerance" (IEI), which implies its causes are purely psychological.

As a response to those who believe the condition is psychological, Riina Bray, medical director at the Environmental Health Clinic at Toronto's Women's College Hospital, points to studies indicating that certain genetic defects commonly found in MCS patients may lower their ability to cope with environmental chemicals. Other sufferers, she says, may simply have been exposed to more than their bodies can handle. "We see these patients as 'canaries' who, due to a lifetime of exposure, have exhausted their capacities to tolerate chemicals and other environmental hazards," says Bray.

But the doubters, such as psychologist Herman Staudenmayer, author of *Environmental Illness: Myth and Reality*, see things differently. "These patients do not have a physiological disease," says Staudenmayer. Numer-

ous studies, he argues, have found MCS patients cannot differentiate between offending toxicants and placebos. "This is a belief system," he says. "They do have symptoms, but the symptoms can be explained by stress responses and stress physiology, or anxiety and depression disorders."

Patients face even more frustration when they turn to health and governmental organizations for help and recognition. The World Health Organization's International Classification of Diseases describes MCS as "a range of nonspecific symptoms" without "toxicological or physiological basis." In the United States, the Centers for Disease Control and Prevention says MCS is a "rather poorly understood disease," and the U.S. Social Security Administration recognizes it as disabling only on a case-by-case basis. In 2007 the Canadian Human Rights Commission officially recognized environmental sensitivities as a disability, promising patients the protection of the Canadian Human Rights Act.

Despite disagreement, advocates are happy the condition is at least being discussed. "In the last ten years there has been tremendous progress in general public recognition," says Lourdes Salvador, founder of the advocacy group MCS America. For patients, though, there's still a long way to go.

"It's hard enough to have the condition, but each patient also has to be an educator and advocate as well," says Shea-Starks.

4 MORGELLONS

Stan Skoumal was working in a hospital in Chilliwack, B.C., when he first felt it. “It was like something was crawling under my skin,” says the 59-year-old social worker. The doctors at his work suspected he had contracted lice or scabies, and prescribed an ointment. That night in the shower, as Skoumal was applying the cream, he felt a sharp pain in his ankle. Looking down, he saw a grey ring forming around his leg. As he watched in horror, the grey colour crept upward, and his leg hair curled up along with it, starting at his ankle.

The onslaught of strange symptoms continued. Skoumal’s back erupted in small “wounds,” which he describes as “lesions that would open, with small black fibres in them.” Over the next few weeks, the skin eruptions became “holes a quarter-inch wide and half an inch deep.” Next, his face swelled until his features, he says, were puffed beyond recognition.

Nearly every doctor he visited was convinced his condition was either self-inflicted or psychological. Skoumal’s family doctor told him he was scratching in his sleep, while a dermatologist lectured him on “the wonders of the mind.” Frustrated, Skoumal turned to the Internet and discovered a phenomenon that described his symptoms perfectly: Morgellons.

The symptoms are alarming: itchy rashes, sores, crawling sensations and strange fibres emerging from the skin.

Sufferers of Morgellons also mention “brain fog” and depression.

The term first appeared on the Internet in 2002, when a South Carolina woman assigned the name to the skin condition she claimed was plaguing her young son. Google “Morgellons” today and you’ll find scores of entries theorizing on possible causes—bacterial infection, toxic “chem trails” sprayed by the government via jets, even sophisticated nanotechnology. There are also discussions on the merits of alternative treatments such as extreme diet changes, long-term antibiotics and ingestible liquid silver. For some physicians the diagnosis is simple: delusional parasitosis, or DP. (Those suffering from DP believe they are infested with mites, fleas, lice or other organisms.) Cuts and wounds are self-inflicted, and those mysterious fibres? Household debris embedded in their scabs.

“There’s nothing you can do to treat what they *believe* is the problem,” says dermatologist Dr. Jeffrey Benabio, who has treated numerous cases. “What you can do is treat them for their underlying psychosis, which we do often and usually with success. Not surprisingly, Morgellons patients reject the “all in your head” diagnosis. They have banded together in Canada and the United States to prove the condition is real. The Morgellons Society of Canada, which is several-thousand strong, focuses on providing information and support. The Morgellons Re-

search Foundation in the United States has 15,623 registered families, and funds ongoing research it hopes will lead to understanding and a cure.

Randy Wymore, assistant professor of pharmacology at Oklahoma State University, is one of the few scientists to delve into the mystery. In his research, he submitted fibre samples, collected from several patients by doctors and other health-care providers, to be analyzed by the Tulsa Police Department’s forensic lab. The samples did not match any of the 900 or so commercially available textiles in the lab’s database—a finding regularly cited by Morgellons advocates. In response to increasing pressure from these advocates, the Centers for Disease Control and Prevention (CDC) announced in September 2009 the formation of an external review panel to investigate what they label “unexplained dermatopathy.” The Public Health Agency of Canada has stated they are keeping abreast of new Morgellons research, such as the CDC investigations, in order to give sound information to health professionals.

Skoumal, for one, isn’t holding his breath. “I realized a long time ago that mainstream medicine isn’t going to help me. I’m on my own.”



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5 LIBERATION THERAPY

Multiple sclerosis isn't a controversial disease, but a new treatment for it, called "liberation therapy," is provoking fierce debate

A multiple sclerosis (MS) sufferer since 1992, Michael Duffy has been wary of "crackpot theories" about potential cures. But after learning about a procedure that claimed to be getting miraculous results, the 44-year-old lawyer from St. John's, N.L., became cautiously hopeful. Eighteen years with MS had left him with blurred vision, poor balance, burning and numbness in his extremities and con-

stant fatigue. If a simple surgery could slow or even halt his symptoms, why not try it?

Known as liberation therapy, the procedure announced to the world two years ago was conceived by Italian researcher Dr. Paolo Zamboni as a treatment for chronic cerebrospinal venous insufficiency (CCSVI), a condition Zamboni argues has connections with MS. With CCSVI, parts of the venous system in the head and neck are blocked or narrowed, causing nerve-tissue damage. This triggers an immune response also seen in MS patients. Zamboni's surgery uses balloon angioplasty to open jugular

veins and, according to his report, patients with relapsing MS experience a significant decrease in symptoms following this therapy.

However, the surgery has not been approved in Canada, so in June 2010 Duffy travelled to Sophia, Bulgaria, to undergo the procedure. The travel and surgery cost \$18,000, which was covered by his insurance company. For Duffy, positive results were almost immediate. He was able to descend a flight of stairs unaided mere hours after being released, a feat he'd been unable to perform for years. And almost a year on, the improvements continue. He sleeps better, has fewer muscle spasms and sees and hears better than he did before the treatment. He is also off the drugs for MS that cost him \$4,000 a month.

"I went to a lumberjack event and participated in the chainsaw competition and the axe throw," Duffy says with a laugh. "There's no way that would have happened without this surgery."

Canada has one of the highest rates of MS in the world. More than 50,000 Canadians suffer from the neurological disease, whose symptoms include dizziness, impaired speech, fatigue, double vision and paralysis. Its causes are unknown and there is no cure. So why is liberation therapy not available to Canadian MS sufferers? Why must they travel to countries such as India, Poland or Mexico to have the procedure performed?

Dr. Paul O'Connor is a neurologist

at St. Michael's Hospital in Toronto and was on the federal panel that, in August 2010, decided clinical trials would be premature. O'Connor argues the connection between insufficient vein dilation and MS is unproven. He warns that Zamboni's trial had no comparison groups and that patients and physicians were aware of the treatment, leaving them susceptible to the placebo effect. O'Connor says he personally examined more than 20 patients who had undergone the procedure and saw no major changes in their neurological exams.

And indeed, of the hundreds of Canadians who have had liberation therapy, not all have reported improvements. Watson McGregor of Rosetown, Sask., travelled to Bulgaria multiple times at his own expense to have the surgery. His symptoms improved immediately after the surgery, but his health has deteriorated since. "It was a letdown," says the 53-year-old.

Over the past year, Canada's MS patients have gained the support of multiple provincial governments. Manitoba has announced \$500,000 for possible future trials; Alberta and Newfoundland and Labrador will fund observational studies of patients who have had the procedure done outside Canada; and New Brunswick has committed \$500,000 to help MS patients access treatment. Saskatchewan—a province with one of the highest rates of MS—has set aside \$5 million to fund future clinical trials of CCSVI therapy. ■

