healthzone.ca

Vivan Song photo

Joanne Saraiva, 50, wears a tri-coloured ribbon representing three chronic illnesses which often strike together: fibromyalgia, chronic fatigue syndrome and multiple chemical sensitivities. It took years for her to get an official diagnosis.

Clinical depression often blamed before diagnosis of fibromyalgia

May 18, 2010

Vivian Song

Special to the Star

When Joanne Saraiva went to her doctor for her chronic pain and fatigue and debilitating mental fog, the physician chalked it up to depression and sent her to a psychiatrist.

She was just depressed, her doctor said, and had taken on too much. After all, Saraiva, now 50, had changed jobs, was raising two boys and had suffered a loss in the family.

Desperate to get better and resume her normal life as a busy, active mom and career woman, Saraiva complied and was popping anti-depressants to treat her degenerating health. She was constantly exhausted and was always in pain.

“It was like someone took a bat and beat me up all over,” Saraiva says in her Brampton home. “Like I was walking on nerve endings.”

While she could endure the pain, it was the cognitive decline that most alarmed her.

“It felt like someone was pulling down the blinds on the window,” she says. “My energy, concentration, ability to process information, word retrieval and perception were all going.”

But after a year of visits, the psychiatrist looked at her and confirmed what, deep down, Saraiva always knew.

She wasn’t depressed. There was something else more insidious at play.

“I know my own body. I wasn’t sad over anything. And in fact, I work better under stress, that’s who I am,” she says.

Misdiagnosing illnesses like fibromyalgia, myalgic encephalomyelitis or chronic fatigue syndrome, and multiple chemical sensitivities as psychiatric problems and figments of the imagination is common practice among today’s doctors who lack a general understanding, says Dr. Riina Bray.

“We have to educate physicians so that they don’t blow patients off as looney,” says the medical director of the **Environmental Health Clinic at Women’s College Hospital**. “That’s probably the easiest way out, to blow them off as psychiatric issues.”

But there’s a huge difference between people who suffer from depression, and those who suffer from legitimate medical conditions, adds **Alison Bested**, a hematological pathologist and specialist at the same clinic.

People who are depressed, for instance, are so low emotionally they can find little inertia to get going and have lost all enjoyment of life, Bested says. Meanwhile, those who suffer from one or a combination of the three illnesses live for their good days, she says.

“On a good day, these people are off to the races.”

It would take years for Saraiva to get an official diagnosis and understand what was wrong with her. She suffers from chronic fatigue syndrome, characterized by pathological exhaustion that cannot be reversed by rest — she's incapable of deep, restorative sleep. She also suffers from fibromyalgia, chronic pain throughout her body. Both can be traced back to a series of viral infections that left her bed-ridden, a common trigger. With these illnesses, brain fog is also common.

Saraiva was misjudging the stairs and would draw complete blanks at work where she multi-tasked as a senior clerical worker. Suddenly, simple tasks eluded her: She couldn't remember how to put people on hold, and was reduced to writing cheat sheets on how to log on to the computer she'd been using for years.

For the 440,000 Ontarians who suffer from either one or a combination of these illnesses, getting an official diagnosis is often half the battle, said Jeanne Samonas, president of the **Myalgic Encephalomyelitis Association of Ontario**.

"It blows your mind that that number of people — the size of a city — are not getting diagnoses or treatments," Samosas says.

That's because there are few specialists in Canada with the training to diagnose and treat the three illnesses, which often strike as a package deal. The **Environmental Health Clinic** at Women's College Hospital in Toronto is one of two clinics in Canada — the other being in Nova Scotia — where patients can seek help.

"It's a huge problem," Bested says. "There are only a handful of doctors trained on the pathology of these illnesses and there's virtually no ongoing research which is deeply needed."

Twenty years ago not a word was written about these illnesses in textbooks, she says. Fibromyalgia, for example, was added in the World Health Organization's International Classification of Diseases in 1992.

"Physicians my age and older haven't had the education or training to diagnose these illnesses," Bested, 56, says. "I learned about this because people were coming to me with the illness."

Saraiva only got her official diagnosis after doing her own online research, which led her to the Toronto environmental clinic. She was put on a 10-month waiting list.

"Doctors didn't know what to do with me," Saraiva says. "I had to become my own advocate."

During the waiting period, Saraiva battled her employer's insurance company for long-term disability payments: Company doctors ordered her to go back on anti-depressants and join a gym. She was given a pedometre and had to clock 800 steps a week. They also treated her illnesses as a psychiatric, lifestyle choice, despite appeals from her own psychiatrist and doctor who wrote on her behalf.

Similarly, she was denied three times for Canadian Pension Plan disability benefits and had to take the case to a tribunal which ruled in her favour.

“We’re dealing with powerful, wealthy insurance companies who have a bottom line,” Samosas says. “A lot of people have had horrendous cases in court with CPP and fight for years.

A lot of that stems from the fact that fibromyalgia, chronic fatigue syndrome and Multiple Chemical Sensitivities aren’t recognized as chronic illnesses, Bested notes, and consequently receive no funding for research. Nor do they figure well in resident training.

“At the government level, they’re invisible.”

Yet last month, Canada became the first country in the world to ban blood donations from people diagnosed with chronic fatigue syndrome in the wake of groundbreaking study published in the prestigious journal **Science**, advocates point out. U.S. researchers discovered a human retrovirus, XMRV, that could be linked to CFS. The move was a precautionary measure as it’s feared the virus, which closely resembles the AIDS virus, could be transmitted through blood transfusions. Australia followed suite a few weeks later.

“We can’t get funding because we’re not considered a chronic illness, and yet they won’t take our blood,” Saraiva says.

In a rare public display, sufferers organized a rally at Queen’s Park May 12 to mark **International ME/CFS & FM Awareness Day** and appeal for a treatment centre.

According to the results of a 2005 Canadian Community Health Survey prepared by Statistics Canada, of 23 chronic health conditions, chronic fatigue, chemical sensitivities and fibromyalgia topped the list for unmet health care needs.

“After diagnosis that’s where it all ends for a lot of people,” Samonas says.

Saraiva is still looking for someone to treat her. She misses the woman she used to be: The woman who others called “supermom,” who jogged three times a week and was the go-to person at work whenever there was a problem.

“It’s time,” she says. “It’s time that we’re recognized and we get treatment and funding.