

Chronic-illness group voices call for national diagnostic clinic

Linda Nguyen, Canwest News Service: Wednesday, May 12, 2010



A national diagnostic and treatment centre is desperately needed to help the more than one million Canadians suffering from chronic fatigue syndrome, fibromyalgia and multiple chemical sensitivities, according to a support group for those with the conditions.

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TORONTO — A national diagnostic and treatment centre is desperately needed to help the more than one million Canadians suffering from chronic fatigue syndrome, fibromyalgia and multiple chemical sensitivities, according to a support group for those with the conditions.

"It's very important that people hear us," said Jeanne Samonas, president of the Myalgic Encephalomyelitis Association of Ontario during a news conference Wednesday. "We're real people with real illnesses and we need help."

Samonas led a group of 100 people to rally at the Ontario legislature to call on politicians and the medical community for drastic changes in how these complex conditions are diagnosed and treated.

According to the 2005 Canadian Community Health Survey, 1.3 million Canadians suffer from at least one of these chronic ailments, making it difficult for people to go about their daily lives.

Currently, there is only one diagnostic centre in Ontario and it is only capable of seeing 400 people a year, leaving thousands untreated and undiagnosed, said the group.

According to the survey, multiple chemical sensitivities is the third most common ailment following diabetes and heart disease in Canada. If triggered, a sufferer can have increased muscle pain, migraines, chronic fatigue and an inability to concentrate.

Last week, a Toronto woman who suffered from multiple chemical sensitivities was evicted from her home following a four-year battle with her landlord. She is now reportedly living on her elderly father's condo balcony because any other location, other than her home, is too chemically toxic for her to be present in.

Samonas was diagnosed with all three conditions 10 years ago and said some days she doesn't even have the energy to get out of bed. Most days, she's too sick to watch her three sons play sports.

"I'm there trying to do the best I can with my limitations. I'm still their mother but I'm not out there," she said. "Everyone pays. My family, the children, my friends. Most people (like me) are at home, just trying to do the best that they can do."

Dr. Alison Bested, who has treated patients with these conditions, said these conditions are controversial in the medical community because of a lack of training and awareness about them, forcing some sufferers to wait 10 years for a proper diagnosis.

"These people are too sick to get out of bed, too ill to do the grocery shopping and to do the other things we take for granted in our lives," said Bested. "Patients get sicker than they need to be and stay sicker, longer."

limguyen@canwest.com

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