Waiting list already 7 months long at Toronto's new Environmental Health Clinic

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In brief

FOLLOWING THE LEAD SET BY NOVA SCOTIA, Ontario now has a clinic devoted to the treatment of patients with "environmental illness." It opened in Toronto last year, and patients must be referred by their family physician and complete a 16-page previsit questionnaire. They receive a 3-hour assessment in which their medical history is explored, plus a full physical examination and blood and urine tests. Dr. Frank Foley, who heads the Toronto clinic, says his patients have seen from 8 to 10 health care professionals in the 2 years before their visit and most have been told the problem is "in your head." He says they need to "have their symptoms validated and their distress acknowledged."

En bref

SUIVANT L'EXEMPLE DE LA NOUVELLE-ÉCOSSE, l'Ontario a maintenant une clinique consacrée au traitement des patients atteints de «maladies environnementales». La clinique a ouvert ses portes à Toronto l'année dernière et les patients doivent y être envoyés par leur médecin de famille et remplir avant la visite un questionnaire de 16 pages. Au cours d'un examen de trois heures, on étudie leurs antécédents médicaux et les soumet à un examen physique complet et à des analyses de sang et d'urine. Le Dr Frank Foley, qui dirige la clinique de Toronto, affirme que ses patients ont consulté de huit à 10 professionnels de la santé au cours des deux années qui précèdent leur visite et que la plupart se font fait dire que le problème se situait «dans la tête». Il affirme qu'il faut «valider leurs symptômes et reconnaître leur détresse».

Marg Benner, 56, was one of the first patients seen at Toronto's Environmental Health Clinic, which opened in March 1996 in Women's College Hospital. "I had to wait 6 months for my appointment," she says, "but it was worth it. It was my first contact with somebody who understood, who didn't try to make me believe it was all in my head, or due to an emotional imbalance. It gave me hope, because I know now that they're working on it, and that there are other people like me."

Dr. Frank Foley, a family physician who serves as clinic director, has heard many stories like Benner's. In its first 9 months, he assessed 112 patients with the presumed diagnosis of "multiple chemical sensitivity" (MCS). Most had already seen several health professionals before they reached him. "After I had a croupy cough for too long," recalls Benner, "I went to see my GP. From there I went to an allergy clinic . . . [then] an internist, a voice therapist. I tried cortisone. I was really frustrated." By the time she made the journey to the clinic from her home in London, Ont., she was an angry woman.

Foley sees a lot of anger. "We give our clients advice on working with their health professionals to reduce antagonisms. On average, they have seen 8 to 10 professionals in the past 2 years. Many have been told that 'It's in your head' or 'There's nothing more I can do.' They need to have their symptoms validated and their distress acknowledged."

Yet multiple chemical hypersensitivity syndrome is a chronic condition of un-

Dr. Frank Foley

certain prevalence, variable case definition and unknown etiology. This makes for controversy within a medical community used to dealing with hard data such as laboratory results. Many physicians distrust a diagnosis that is so vague, and most are unaware of the existence of Foley's clinic. (Benner heard about it through the lawyer who tried unsuccessfully to help her with a long-term-disability claim.)

An American survey of physicians with a particular interest in MCS found that although 70% of them agreed that the physical environment may cause the syndrome, a high proportion thought that the patient's personality was also a factor. Foley found his own colleagues "fearful and suspicious" when he first started discussing MCS, which is also known as environmental illness, ecologic illness, environmental hypersensitivity and total allergy syndrome. He suggests that the illness is similar to chronic fatigue syndrome, which did not gain general acceptance until rigorous case criteria were published. He hopes that, if he can establish rigorous criteria, he may help to establish MCS as a recognized syndrome.

The Toronto clinic is not the first in Canada — that honour belongs to Halifax, which has had one for several years. It was set up by the provincial government, partially in response to an outbreak of environmental illness at a Halifax hospital complex. In 1994, Dr. John Ruedy, dean of medicine at Dalhousie University and a professor of both pharmacology and medicine, persuaded the government to put some money into research as well. In April, a new clinic will open in Fall River, on the outskirts of Halifax, with a mandate for both research and treatment. (When the clinic was being built, stringent rules meant construction workers couldn't smoke at the site.) "Research and treatment are so closely intertwined," explains Ruedy. "We need to validate a diagnosis of this condition or these conditions. And we need to investigate which diagnostic and therapeutic interventions are appropriate."

The Halifax clinic is in close touch with what is happening in Toronto, where the new clinic has been 10 years in the making. The Ontario Ministry of Health created a task force to investigate what was happening when cases involving people who were unduly sensitive to environmental pollutants started to make headlines in the 1980s. Its findings, and those of a second study group in 1986, led to the formation of a joint research and clinical program to investigate the condition. The funding was finally approved in 1991, and in 1993 Dr. Gail McKeown-Eyssen, a professor in the Department of Preventive Medicine and Biostatistics at the University of Toronto, began a survey of 4000 patients in the Toronto area who had health problems related to chemicals or the environment. (She is currently analysing 2500 responses, and plans to publish her findings in 1998.)

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In 1996 the Toronto clinic was established with a mandate to provide medical assessments and consultations for MCS patients, to collaborate with the research team and to help provide education and support for health professionals. Foley, former medical director of the Casey House AIDS Hospice in Toronto, became its first director. He also has experience with chronic illness and geriatric patients, and works closely with McKeown-Eyssen.

The clinic had hardly opened its doors when the phone started ringing off the hook. Foley took calls from outside Ontario, just as the Halifax clinic has been doing for years; by mid-January 1997 there was a 7-month waiting list for appointments in Toronto. (Patients must be referred by their family physician and complete a 16-page previsit questionnaire. Upon arrival they receive a 3-hour assessment in which their medical history is explored, plus a full physical examination and blood and urine tests.) "On average," says Foley, "each patient has 35 to 40 symptoms. This is often the first time anyone has been able to hear the whole history."

A pattern soon emerged from the first 38 patients. Eighty percent were women, with a mean age of 49 years. One-third had no idea what precipitated their health problems; among the rest, personal stress, surgery or reaction to a new building or workplace appeared to have been the most common triggers. They complained of sensitivity to odours (21%), neurologic symptoms (18%), allergies to food or medication (18%) and breathing problems (8%), plus a smorgasbord of other symptoms such as headaches, fatigue, malaise and swollen glands.

More than half were unemployed, although all had steady jobs before the onset of their illness. Many lived in older homes, and 20% had a history of sexual or emotional abuse. Excessive sensitivity to smells is by far the most common symptom, says Foley, and "traditional medicine cannot explain that reaction."

Marg Benner's choking cough was first triggered by her husband's cigarettes and by the perfume some women

wore when they came to see her in the days when she was a clerk in a seniors' residence. As time went on, other substances joined the list of triggers — books, newspapers, magazines, exhaust fumes, barbecue fumes. She had to give up her job and her husband had to quit smoking near her. Today she is usually safe in her own home, which she has scrubbed clean of contaminants. But she rarely ventures out to shop, attend church or visit friends.

When Foley presented preliminary data to the Ontario College of Family Physicians, he suggested that "persons with this condition suffer from a heavy burden of physical, social and neuropsychiatric symptoms, which will require significant physician and societal support." He is careful to remain as objective as possible when looking at the evidence. "I've chosen to use the educational rather than the crusading mode with my colleagues, because I think I will get more response that way. But I recognize that, for my clients, the subjective experience of chronic illness is overwhelming."

The new Toronto clinic felt like a bunker for the beleaguered — for those for whom the world is both a health-threatening and unsympathetic place.

Ruedy agrees that many doctors remain sceptical about a disease for which there is no clear diagnostic test. "But in Halifax, far more physicians today accept the idea that there is a biological basis for the diagnosis compared with 5 years ago." However, controversy continues to surround treatments, particularly since many patients, dissatisfied with conventional medicine, have turned to alternative methods. "We only have experiential evidence of what works and what doesn't," he says.

The Toronto clinic is on the fifth floor of the Women's College Hospital, an older facility in downtown Toronto that is itself threatened by the provincial government's hospital-restructuring program. To reach the clinic, clients must brave the fumes of downtown streets, the accumulated odours of floor coverings, furniture and cleaning fluids in the hospital corridors, and the dust that older buildings always generate. Once through the clinic's double doors, however, they enter a more sterile environment.

In fact, it is deliberately shabby. The desks and chairs are more than 10 years old, to ensure that they are no longer discharging any gases, and there are no carpets or curtains. When I arrived for a 9 am interview there were no newspapers to read because, explained the secretary, "they're not clean yet." However, there was lots of reading material from CAN DO: The movement for Clean Air Now. It included leaflets on environmental tobacco smoke, gases emitted by carpets, biological agents and combustion pollutants. There was also a list of foodstuffs that may contain sulfites, and a list of 10 ways to make the air in homes safer. Another leaflet gave the addresses of organizations concerned about environmental pollution and hypersensitivity. The clinic felt like a bunker for the beleaguered — those for whom the world is both a health-threatening and unsympathetic place.

Once patients have received an appointment and braved the environmental hazards, what can Foley do for them? "Up front, I make it clear that this is not a treatment centre," he says. Patients make a maximum of 2 visits, although they are encouraged to phone if they have further questions. Most leave the clinic "somewhat better," suggests Foley, because they have been given helpful lifestyle advice and the reassurance that the condition is not "all in the mind." This encourages them to comply with any precautions that have been suggested.

For Marg Benner, the visit gave her the confidence to insist that her own children could not visit her unless they were "clean" and didn't smoke. "I never felt I could do that before. I didn't want to be labelled as a witch, or an antismoking bigot."

Dr. Foley is a long way from reaching any definitive conclusions about what causes MCS. "Allergy rates tripled from the late 1970s to the 1980s," he remarks. "Maybe indoor air quality has something to do with it — that was the period of the oil crisis, when Canadians started insulating their homes better to reduce heating costs. As a result, many of those homes are now poorly ventilated."

Marg Benner certainly feels that her visit to the clinic was worth while. Her anger toward health professionals has diminished a little, and the assurance that research into MCS is under way has lifted her depression.

"For 4 years, the energy just steadily drained out of me," she says. "Now I'm now finally getting a little back." ❓