

Canadian Government and Medical Science Finally Recognize Crippling Effects of MCS

by **Helke Ferrie**

2004 *Vitality Magazine*, Toronto's Monthly Wellness Journal

It is said that when you come to the end of your rope, tie a knot and hang on.

For those whose lives have been devastated by Multiple Chemical Sensitivity (MCS) and who have been hanging on to that knot for quite some time now, this determination is finally paying off. It appears that with regard to MCS, Canada is beginning to live up to its reputation of striving for a just society. I am reporting on developments that I have been part of since April.

In Spring of 2002, Canada's most senior Senator, Herb Sparrow, had personally observed a CPP appeal hearing of one of his MCS-afflicted constituents from Battleford, Saskatchewan. This person had become disabled from a massive exposure to pesticides.

Events at that appeal convinced Sparrow that the federal pension and disability program is indeed influenced by serious bias against people diagnosed with chemical injuries. He reported the procedural abuse he had witnessed to the Minister of Human Resources, the Hon. Jane Stewart, requesting her help.

On April 10, the Minister hosted a meeting in her office with Senator Sparrow, representatives of the Research Advocacy and Information Network (RAINET – the advocacy organization working for this CPP applicant), and me at RAINET's request. The files of this and several other MCS cases similarly tainted with procedural bias, often for many years and with heartbreaking effects, were formally given to the Minister. A lively discussion about health and environment ensued.

Believing that nobody can ever have too much education, I presented the Minister with a copy of the book my publishing company had recently released: Dr. Jozef Krop's *Healing The Planet One Patient At A Time*. She not only leafed through it with interest and asked many pertinent questions, but began to tell us about people in her own Brantford constituency who had become ill from environmental toxins. She requested detailed reports from RAINET and from me for the senior administrative staff of her department to assist with the process of drawing up new guidelines for MCS-afflicted applicants.

RAINET was founded by Hilary Balmer, a nurse who became disabled due to chemical injury. Her organization wants to identify "chemically/ environmentally induced injury and/or illness as an officially recognized disability."

In partnership with workers' advocacy groups and medical organizations, Balmer has helped many people. With the unexpected help from the Senator, Balmer's efforts have matured into truly meaningful discussion with the federal government.

In her report to the Minister, Balmer observed (supported by ample documentation) that "pervasive prejudice against persons with disabilities such as MCS permeates the agencies charged with the responsibility of adjudicating applications for disability benefits. The incapacitated person is perceived as a psychological misfit and thus undeserving of disability benefits."

The subsequent meeting with senior Human Resources administrative staff was friendly and collegial. New guidelines are being created and some messed-up cases have already been resolved.

Existing legislation is excellent because it focuses on how disabled a person is, regardless of the diagnosis that can change or be difficult to make. Between 1998 and 2003 three Supreme Court decisions and one federal appeals court have spelled out how the government must interpret the law governing disability benefits and what characteristics a reliable expert opinion has.

In 1998 the court stated that the law must be understood “in broad and generous terms so that any doubt arising from the language of such legislation ought to be resolved in favour of the claimant” (Rizzo).

In 2000 it ruled that applicants must be “accommodated” according to their level of disability (Granowsky), and in 2001 clear “tests for disability” were defined (Villani) to protect the “benevolent purposes of the legislation.” In May (C.U.P.E. 2003) the Supreme Court defined experts as having the qualities of “neutrality, independence and proven expertise.”

Nevertheless, the reality is that when a person carries an MCS diagnosis, the competing interests of insurance companies, employers, and government programs often erect seemingly insurmountable barriers for the applicant.

Furthermore, not only is MCS a new disease, but it is caused by substances upon which industrialized economies depend.

This situation began some 200 years ago when coal-fired industries caused asthma, allergies, and cancer to appear in unprecedented numbers. Since then, tens of thousands of even more toxic substances have become part of everybody’s environment – with a predictable increase in corporate and public attempts to avoid responsibility.

Lawyer Matthew Wilton of Toronto has defended many doctors who diagnose environmental illness, such as the internationally renowned environmental medicine expert Dr. Jozef Krop and the asthma expert Dr. Sukhdev Kooner who works in Canada’s asthma capital, Windsor. These physicians often run into trouble with regulatory agencies and industry because they stand up for their patients against insurance companies and government agencies denying the reality of MCS and even traditional environmentally mediated illnesses, such as mold toxicity.

A large part of Wilton’s practice is devoted to clients with insurance claims. The typical case is that of a disabled person whose private insurance is running out and whose employer wants to fire him or her. Insurance companies turn to their own doctors who are trained by their organization, the Canadian Association of Independent Assessors, in the fine art of discrediting a patient’s application.

A few years ago, a formal complaint was lodged by Ontario doctors with their licensing authority, the College of Physicians and Surgeons, objecting to this obvious lack of medical ethics when a doctor actively works against a trusting patient’s interests. The College replied that this wasn’t unethical because the patient was merely referred and not actually the doctor’s own patient – a twisted logic arising from the fact that representatives of the insurance industry sit on the College’s council and sometimes are even members of the disciplinary committees prosecuting doctors who stand up to the industry.

Insurance doctors routinely assert that MCS is just another form of panic attacks.

“Experts” are produced who insist that nothing at all is the matter with this person. The “proof” is in each case the same: outdated medical literature is cited, current medical research results are ignored, meaningless tests are demanded, and the physician who treated this disabled patient on a regular basis, and is thus qualified to defend her case, is dismissed as being ignorant. Often this medical garbage becomes part of an applicant’s file with Canada Pension and Disability and so both the private and public insurance processes become fatally flawed.

Wilton insists, however, that this systemic injustice can be overcome successfully.

“Don’t ever think it’s useless to fight!” Generally, judges fully understand the difference between an “expert” from the insurance industry and the informed opinion of the treating physician.

“Judges understand that the GP has nothing to gain by stating the truth about a person’s disability, while the insurance doctor certainly does stand to gain by denying that disability.”

As long as your own doctor stands by you, the applicable legislation, especially the Ontario Human Rights Code and current employment laws, will generally support your claim.

Most people in this situation are close to destitute as well as browbeaten, so Wilton often handles them on a contingency basis, an approach that is almost always successful for all concerned.

What is it about Multiple Chemical Sensitivity that brings out the best and the worst in people? Simply put, MCS challenges the way we run our world. It challenges the chemical industry the way cancer did the tobacco industry. Both brought their products to market before their safety was established and both have to face the fact that these products are not, and never will be, safe.

Symptoms of Multiple Chemical Sensitivity

In the early 1950s, allergist Dr. Theron Randolph had a patient who had severe allergic symptoms unrelated to the usual suspect triggers.

Careful observation showed that her symptoms were present only when certain wind patterns brought high concentrations of petrochemical particles into the Chicago area. This was the first recorded case of environmental hypersensitivity, as Dr. Randolph called her untypical allergy. In 1965 he founded the American Academy for Environmental Medicine, which to this day teaches doctors from all over the world how to diagnose and treat illness caused by many environmental toxins, fossil fuel products, pesticides, organic industrial solvents, and carbon monoxide poisoning being chief among them.

Today, the illness is called Multiple Chemical Sensitivity; it consists of a whole family of diseases of which the best-known ones are Fibromyalgia, Chronic Fatigue Syndrome, Gulf War Syndrome, and Cacosmia (the MCS variant in which people lose all tolerance for scents – toxic or otherwise).

The international consensus statement on MCS syndromes was published in June 1999 [*Archives of Environmental Health* 54(3)]. The definition states that symptoms are reproducible with repeated exposure, the condition can be chronic, low levels of exposure cause symptoms that improve when offending chemical is removed, many substances can cause reactions, and many organ systems are involved.

Common complaints include acute intolerance to light and noise, chemical smells of all kinds, extreme fatigue, muscle pain, swollen joints, muscle weakness, shortness of breath evolving frequently into asthma, anemia, chronic urinary tract infections, nausea, diarrhea, migraines lasting days, tingling in hands and feet, irregular heart beat, watery and itchy eyes, generalized itching and more.

Harvard University's environmental medicine publication, *Environmental Health Perspectives*, published a survey in September of 2003 showing that about one third of MCS patients became ill from pesticides, another third from solvent exposure. Similar results were obtained in a study done by the University of Toronto and submitted to the Hon. Jane Stewart by Dr. Lynn Marshall, the director of the Environmental Health Clinic at Sunnybrook & Women's College Hospital.

Rachel Carson's research in the 1960s into the health effects of the pesticide DDT, a declassified biological warfare chemical from World War II, showed that small, frequent exposures to a toxic chemical can cause permanently disabling illness or cancer. This finding turned upside down the traditional notion that the amount of a poison determined how sick one became.

In 1960, 10 billion pounds of toxic chemicals were released into soil, air and water. Currently, about 35 billion pounds of pesticides, organic solvents and other products containing heavy metals are released annually. Most have never been tested for their health effects. However, as more and more people are affected, scientific investigation has increased rapidly: in the 1950s the world medical literature had five articles on the subject; in 1997 only 120 research studies existed; today more than 10,000 are listed. In 2001, the Ottawa based Environmental Illness Society of Canada commissioned the first socio-economic study of MCS. It showed that about four million Canadians are chemically sensitive, about 500,000 severely so. Some 5,000 are relatively disabled as a result and roughly 50 to 60 people are forced to seek assistance such as federal pension benefits. Among the most severe cases, about 60% attempt suicide. The illness costs \$10 billion in lost productivity, about \$1 billion in lost taxes, and another \$1 billion in avoidable health costs. The subject of medical research worldwide, MCS now has many clearly defined biomarkers, and sophisticated as well as simple and inexpensive tests are available to establish a clear diagnosis for each of the different MCS syndromes.

In 2000, the Canadian government published a report urging reform of the pesticide legislation (which has been done), and recommending that MCS be officially recognized and its treatment covered by Medicare (not yet done). But now that the Canadian Medical Association Journal published a whole series of research papers (April through June 2002) on the health effects of the environment, and the Ontario College of Family Physicians is hosting its first conference on the subject this October, maybe MCS will become fully recognized at last.

The Ontario Human Rights Commission already instructed the Ministry of Health on April 9, that people sensitive to pesticides must be protected from any spraying for West Nile virus.

While justice for the severely disabled MCS patient is now within their reach and the recognition of this condition fully recognized by medical science, the battle is not over. Consider the fact that the same month when the international consensus on MCS was published (June 1999), the College of Physicians and Surgeons of Ontario found environmental medicine expert Dr. Jozef Krop 'guilty' of diagnosing MCS and reprimanded him for it in September of this year – when simultaneously the federal government began to remove the systemic bias against MCS disability pension applicants.

So who else is still opposing the diagnosis of Multiple Chemical Sensitivity? One powerful group is the Environmental Sensitivities Research Institute established in 1995; it accepts only corporate members (I tried to join and was refused!) and its board of directors consists of the major pesticide producers of North America such as DowElanco, Monsanto, Proctor & Gamble, and the Cosmetics, Toiletry and Fragrance Association. The chairman is the CEO of the pesticide industry association called RISE.

Indeed, the chemical industry's worried about its future are justified. But we can take comfort in the fact that humanity has been through such crises before and society always emerged much improved by the experience. Facing the truth of MCS has started the process making the world cleaner and healthier.

Our Toxic Times

A publication of the Chemical Injury Information Network, febr. 2004