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# Getting the disease right

By Richard Starr

**A** cardinal rule of journalism is to get the name right. By that criterion alone, we've been doing a pretty lousy job reporting on people with environmental sensitivities.

Over the past 10 years, Canadian reporters — myself included — have covered the illness, sporadically. We've described people with a wide range of chronic, often debilitating symptoms — including severe headaches, fatigue, abdominal pains, respiratory problems and nervous system disorders. We've said those symptoms are caused by exposure to low levels of chemicals and other substances in the environment. We've reported estimates — there are no official figures — that as many as 15,000 Canadians may suffer from the illness.

We've given the condition more names than Fred Demara, the great imposter, has. We've dubbed it the 20th Century Disease, Bio-Ecological Illness, Environmental Illness, Total Allergy Syndrome, Environmental Hypersensitivity, and Multiple Chemical Sensitivity.

Sometimes we hedge our bets. One recent *Globe and Mail* story called it 20th Century Disease in the headline and Multiple Chemical Sensitivity in the body of the story. An earlier piece in the *Globe* had Environmental Illness in the headline and Environmental Hypersensitivity in the story.

This lack of precision can't be blamed on journalists alone. It mirrors the confusion among the experts, who are divided over the cause, diagnosis, treatment and even the existence of the illness.

Even a proposed new name is not much help. Health and Welfare Canada conducted a workshop on environmental sensitivities last year. It recommended that the condition henceforth be called Idiopathic, Poly-system, Symptom Complex which means a condition of un-

known cause whose symptoms span many organs of the body.

But according to Chris Brown, getting the name wrong is the least of the media's sins when it comes to reporting on environmental sensitivities.

Brown is the president of the Ottawa branch of the Allergy and Environmental Health Association. He was diagnosed as environmentally sensitive in 1980. A journalist until 1984, he is now a tenacious advocate for people with environmental sensitivities.

There has been much to advocate. Be-

**Media have stigmatized people  
with environmental sensitivities**

cause standard physical examinations and lab tests can't find a cause, many patients have had trouble getting adequate medical care or disability benefits. For the same reasons, they've carried a stigma. Unable to apply a familiar label to their illness, they've had to deal with doctors, family members or employers who say, "It's all in your head."

Brown takes issue with some of the tags journalists have hung on the illness. For example, he says evidence of environmental sensitivities pre-dates the 20th century. But his main criticism is that journalists have helped in stigmatizing people with environmental sensitivities.

I first heard from Brown in late 1989 when I was working for the now defunct CBC radio program, *Media File*. He called to say that his organization was going to give Mock Human Rights Awards to a couple of CBC journalists. The awards, which were never presented, were for covering the story of an environmentally sensitive woman who had been evicted from her home in Smith

Falls, Ontario. She couldn't find another place to live that didn't make her sick.

The story made the news in 1983 when Brown was working as a writer/broadcaster at CBOT in Ottawa. Journalists quoted doctors who disagreed with the diagnosis of environmental sensitivities and suggested that the cause was psychological. At the same time, they ignored information that legitimated the woman's claim — including the fact that she was on a disability pension and that the Ontario Medical Insurance Plan had been paying some of the costs of treatment for environmental sensitivities for years. Brown says the coverage left the impression that the woman's claim was fraudulent.

The Ottawa media were not alone in reporting stories that questioned the mental state of people with environmental sensitivities. During the mid '80s, a *Globe and Mail* headline announced, "Twentieth Century Disease psychosomatic, MD says," and the *Toronto Star* declared, "Twentieth Century Disease may mask mental illness - MD."

Chris Brown says that just because doctors can't find a physical cause for someone's illness doesn't give them licence to jump to the conclusion that the cause is psychological. As he puts it: "People should not be trashed on the basis of an absence of information." Journalists, he says, should demand hard evidence before passing along such "trashing," even if it's coming from professionals.

In making such an assertion, Brown could be accused of that chronic sin of media bashers, shooting the messenger. But it seems to me that reporters can't dodge criticism that easily.

In 1985, the Thomson Report on Environmental Hypersensitivities criticized the way the media have framed the story. The report expressed "unease" at the polarization of attitudes on environmen-

tal sensitivities "often fuelled by media reports that highlight ... extreme positions."

A quick survey turns up several examples of such polarized reporting.

On one pole are doctors who adamantly insist that there is no such thing as environmental sensitivity and that the symptoms have other causes, usually psychological.

On the other side, journalists present a smaller embattled group of doctors, called clinical ecologists, who hold that the environment is making their patients sick. They treat those patients with a technique known as provocation-neutralization and hospitalize them in specially designed ecological units at a cost of up to \$50,000 a month. Their stories are told under headlines like "An allergic reaction to modern life," which topped a *Maclean's* story in 1981.

Sometimes the two positions get presented in the same story. An eight-page spread in *Harrowsmith* in 1982, sympathetic to the claims of the clinical ecologists, bore the headline "The Pariah ... Syndrome: The world they knew rejects them and the world they know can kill them. They are the victims of a poisoned environment, and they may just be the first." The story told the tale of a woman from Port Carling, Ontario who had to wear a gas mask whenever she left her home.

The article also carried the comments of the naysayers. One immunologist said clinical ecologists "rip people off ... they take people whom no one can help because of psychological problems and say it's an allergic thing."

The coverage hasn't evolved much in the 10 years since that *Harrowsmith* piece appeared. A front-page article in the *Globe and Mail* last summer, called "Living in isolation," told the sad story of a woman from Barrie, Ontario. She faced the prospect of paying out of her own pocket part of the cost of treatment at a \$1,000-a-day clinic in Texas.

The obligatory naysayer, an immunologist at St. Michael's Hospital, was quoted as describing environmental

sensitivity as "hocus-pocus medicine" and declaring, "They're making a non-disease into a disease."

Reporting like that upsets Brown, and not just because he takes issue with the views of the medical establishment. He acknowledges that many of the claims of the clinical ecologists are unproven. He says that he and others who are environmentally sensitive don't even subscribe to them. Yet, whenever the plight of people like him is discussed, journalists trot out the dispute over clinical ecology.

He says journalists "continue to focus on a puddle of controversy, ignoring an ocean of acceptance and legitimacy in officialdom."

The acceptance and legitimacy is coming from a group of doctors, health bureaucrats, human rights commissioners, and even some politicians. They don't know what causes the disability or how to treat it. But they do believe that people with the disability are ill and deserve the same rights as anyone else who is sick.

There are a number of examples that have received scant attention:

- In 1986, the Thomson committee told the Ontario government that whatever the cause, people with

environmental sensitivities definitely were sick and "should not be caught in the medical debate about this problem."

- In 1988, Federal Human Rights Commissioner Max Yalden wrote to Health Minister Jake Epp: "We owe it to people to be more public and more vocal in acknowledging that sensitivities are a true medical problem."
- In early 1991, Health and Welfare Canada sent the report from its workshop on environmental sensitivities to doctors across the country urging "respect and support" for people with environmental sensitivities.

If we as journalists want to keep writing about environmental sensitivities, maybe we should be looking for some new angles. Perhaps we should be examining how Health and Welfare is slowly changing attitudes within the medical profession. That may not be as exciting as a story pitting clinical ecologists against mainstream medicine, but at least we would be advancing the story — and not trashing people. □

*Richard Starr is a CBC producer in Halifax and former host of Media File.*

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# Media insensitive to a real problem

By Chris Brown

**W**e have a grandmother in our Ottawa branch who can't understand all the fuss about environmental sensitivities. She's had sensitivities all her life. So did her grandmother.

Environmental sensitivities, as experienced doctors know, have been around for generations.

Nonetheless, as the press has reported, some doctors and health officials have stated the problems are all in the mind.

People with emotional problems who can't cope with a psychiatric diagnosis somatize disabling reactions and latch on to a more socially acceptable diagnosis. Reporters pass this on as expert opinion, and deal with objections as if our feelings have been hurt by what may be the truth.

There's a lot more than hurt feelings at stake. Families have broken up when one spouse decides, on the basis of "expert opinion," that the other is just not trying. Professional reputations and careers have been ruined. Doctors have caused increased disability by ignoring these concerns.

Then there's the fact of the reactions themselves. A 1985 Ontario government study lists symptoms affecting various systems of the body, with effects ranging from mild discomfort to serious disability. One woman I know loses the use of her legs when exposed to Ottawa's relatively mild pollution. Others experience central nervous system reactions including anxiety, depression, hallucina-

tions, learning and behavioral disabilities, emotional changes and so on. Reactions are very individual or idiosyncratic. Sometimes, when I'm having a bad reaction, I can't write more than two words. My brain slows down. Some have called this an *idiotic* reaction!

Fortunately, reactions are relatively easy to avoid with co-operation. However, because of attitudinal pollution, some have had a hard time getting the small amount of co-operation needed to

If you're going to tell your readers that there are bigots out there, tell them the consequences. And give them an idea of the quality of work such comments are based on.

For instance, most of the "critical" studies that have been done have criticized — often legitimately — clinical ecology as a theory explaining our experience, and have not questioned the experience itself. But over and over again, reporters get the two separate sub-

jects confused. It's as if we exist only by virtue of some doctor's theory. Read Sartre. Or Socrates.

Some outrageously illogical studies have proudly surmised that because not all the problems are caused by immune dysfunction, the rest are psychosomatic. One study correctly observed that of two dozen patients, slightly more than half had central nervous system symptoms. Ignoring the fact that sen-

sitivities can affect the central nervous system, the author confidently decided that the tens of thousands of diagnosed cases of environmental sensitivities around the world were all in the mind. Ignoring the obvious problem with her sample size, that's as logical, ethical and scientific as saying there's no such thing as brain tumors because people with brain tumors develop psychiatric symptoms. At least one suicide has been directly linked to abuses based on this one study.

Meanwhile, reporters generally leave out the fact that there were scores of



prevent disabling reactions. There have been several suicides of people overwhelmed by the consequences of unnecessary attitudinal pollution.

I'm not suggesting that it's wrong to report doctors shouting hocus-pocus. It should be exposed. But with these consequences at stake, surely such statements must be backed by evidentiary reason and due process. Surely, wholesale disparaging remarks about diverse members of a disabled group are out of line, unless you're into crip-bashing.

All I ask is that they be put in context.

supportive scientific studies over the past two centuries. Former Judge George Thomson and a panel of doctors appointed by the Ontario Ministry of Health declared in 1985 that it was "clearly untenable" to state that "all the identified patients are emotionally ill." Their work was based on clinical evidence, patient submissions and literature dating back decades. Even if all the scientific and medical evidence that is available were ignored, it would still be unethical to bring people's experiences and reputations into question on the basis of an absence of information. Human rights people call this "arbitrary interference".

The great sin is that the environmentally sensitive have been abused by the very authorities now in a position to help. If medical associations, provincial ministries of health and, to a lesser extent, major media outlets — which passed on unsubstantiated damaging opinion as credible — were to come clean on the issues, it would involve an implicit — in some cases explicit — acknowledgement that serious damages have been caused through a chain of unethical acts.

Our fight has been similar to climbing Mount Cashel. It has taken longer because authorities have allowed abuse to continue, unwilling to implicitly acknowledge that compliance with previous abuse was simply unethical.

But let's end on a high note. The woman in Smiths Falls who was trashed by pack journalism in 1983 (see Richard Starr's article in this edition of *Content*) has a new house, renovated to lessen indoor pollution with disabled program grants from the Canada Mortgage and Housing Corporation.

Health and Welfare recently started to address attitudes in the health community, thanks to Dr. Bruce Halliday, M.P., chair of the Standing Committee on Human Rights, and to Perrin Beatty, former minister of health. Margaret Cately-Carlson, the new deputy minister, has been an important player.

It will be interesting to see which provincial ministries of health lend a hand. A new deputy minister of health in

Ontario recently pledged support for action on attitudinal concerns.

The chief commissioners of both the Canadian and Ontario human rights commissions have denounced the abuse. Members of three federal parties have spoken out in the House of Commons. Government and non-government organizations are helping with accessibility issues and special needs. Many of our more seriously affected members are receiving disability pensions from both government and private plans. We even get tax deductions for medical expenses from Revenue Canada.

If you're writing a story, do us a favor. Ask yourself if it's right to suggest a person is out-to-lunch on the basis of an absence of scientific understanding of their medical problem, and if it's helpful to pass on this suggestion to your audience. If your outlet has the guts, there's a story in the fact that such suggestions have been made.

Ask a medical ethicist if it's ethical for doctors to use their patient's credibility as cannon fodder when defending their theories, whatever those theories may be. Ask a human rights commissioner if it's legal to put forward damaging suggestions about a person or group on the basis of their having a disability. Understand harassment.

Think of the emperor's clothes when you hear doctors dismiss that which they do not understand as hocus-pocus, and look for evidentiary reason. When it comes to this topic, education, a white coat and a prestigious position do not an expert make, for the issue is not one of science, it is how we act while not omniscient.

There are some very serious issues held up by the hocus-pocus debate. For instance, Marion Boyd, when she was minister of education in Ontario, stated that sensitivities should be considered a possible contributing factor to learning and behavioral disabilities in kids in schools. Waterloo-Wellington and Halton school boards are leaders in this field, with many others beginning to follow.

Is the school board in your area abus-

ing kids with this disability? Does it put kids in environments that can cause susceptible kids to develop it? Do some kids face accessibility barriers in "accessible" schools?

Does your municipality co-operate with people who have sensitivities, the way Chemlawn does in Ottawa, by keeping a registry and giving advance notice of paving operations? Has your transit system dealt with access issues? Is your local health unit informed or stalling?

There are recommendations from several authorities, including one from the former federal health minister, that sensitivities should be ruled out before potentially detrimental psychiatric interventions are embarked on. So far, that's not being widely acted on, with the consequence that some patients are being caused increased disability because psychiatrists prescribe neuroleptic drugs, or place patients in hospitals with building sickness. How many of Canada's 10 daily suicides result from psychiatric abuse of persons whose central nervous system dysfunction is caused by undiagnosed sensitivities?

There are untold horror stories in the North, particularly because of diet changes, smoking and extremely unhealthy buildings. The consequences of acknowledging these problems are as great as those arising from denial, but one hell of a lot less costly, not only to victims but to their associates and to society as a whole.

Fortunately, by setting aside issues of compensation and retribution, we're winning the fight. But it's hard to know if this is bringing justice to those who are being abused. Jacob Timmerman writes of this dilemma in Chile. If you press for justice for the abused, the abusers, like doctors, have totalitarian powers, and you will not achieve social change. If the abusers are powerful, you must first achieve change. Justice comes later. Or maybe charity on the part of the survivors.

We'll think about it. □

*Chris Brown is president of the Ottawa Branch of the Allergy and Environmental Health Association.*