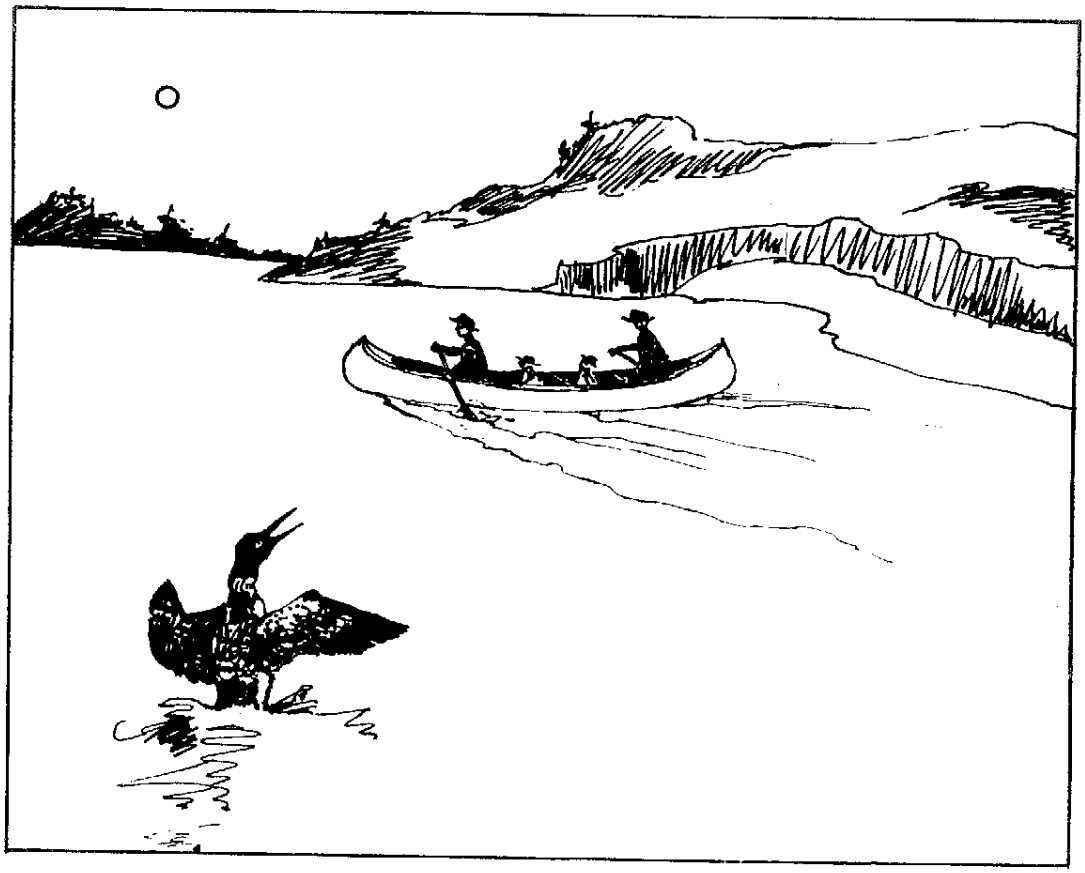
Eco-Sense

The Allergy and Environmental Health Association of Canada
Association allergies, santé et environnement du Canada
Ottawa Branch



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Summer/Fall 1998

Brief Presented to Health Minister's Office

Briefing notes for a meeting on April 14, 1998 with:
David Rodier, Environmental Health Policy Advisor, Office of the Minister of Health

and

Chris Brown, Leslirae Rotor, and Debra Sine Allergy and Environmental Health Association

Environmental Sensitivities

"Environmental sensitivities" is an umbrella term used to cover all kinds of sensitivity to environmental agents, including foods, natural and synthetic substances, or other physical phenomena such as temperature, or electromagnetic radiation. Reactions involve varied internal mechanisms, differing from individual to individual, with consequences ranging from mild discomfort to serious disability and death.

Environmental sensitivities are not "a disease". They can be caused by a wide variety of different diseases and naturally occurring anomalies. Some, such as problems with intestinal wall penetration or toxin buildup due to liver dysfunction, are fairly well understood. In 1986, Health and Welfare described these problems as involving a "compendium of disorders". If you read the literature for the past two centuries, or pay attention to clinical or consumer experience, you will no doubt agree with the department.

Many of our problems stem from very hostile reactions to the overly simplistic approaches put forward by some doctors with a special interest in "environmental medicine". Although some of these physicians have a more comprehensive understanding, in general, they were heard to be saying that sensitivities are caused by one, immune-mediated disease, and only they could cure people with this disease.

As the rest of medicine was quick to point out, people with sensitivities do not have one disease, but many. Unfortunately, this fact was lost in the ensuing controversy as journalists, government officials, politicians, and physicians began a very unhelpful debate–an extremely bipolarized debate about a non-existent homogeneous group–about whether this homogeneous group had the overly-simplified illness described by some doctors of environmental medicine or whether, because that didn't make sense, they were therefore mentally ill for thinking they reacted to things. Other long-recognized options and approaches were not discussed very much, except within consumer groups, where people wanted to know what was actually going on amongst themselves so they could do something about it–and among physicians, including some prominent medical leaders, who are trying to come to terms with what to do, including what to do about attitudes.

Aside from ignoring our history, generations of experience and a couple of centuries of literature, some parties in the debate made another fatal mistake. To use the words of Catherine Frazee, former Chief Commissioner of the Ontario Human Rights Commission, some people and agencies have "placed the presumption on the wrong side". Damages arose from the fact that

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parties with social and legal responsibilities declared repeatedly, in a variety of ways, in a variety of fora, for at least two or three decades, that people who claimed to have sensitivities should be presumed to be mentally ill until proven otherwise.

Journalists generously passed on this unsubstantiated damaging statement, ignoring our history, ignoring the strong support we have in medical leadership, and refusing, in several instances, to examine their own ignorance and misconceptions and how they were helping to cause damages in the community. (Journalists also refuse to cover the issue in anything but a "David and Goliath" form, where perfect doctors of environmental medicine are up against a monolithically hostile medical establishment, consumers exist only to illustrate David's theories. Issues concerning journalism in Toronto are especially important because of the national implications.)

For most people with sensitivities, pejorative labelling caused more damage than their illness. Families break up when one spouse is advised not to indulge the other's delusions. Children with special needs are subjected to abuse, based on the same premise, in schools. Professional reputations and careers have been ruined when people have been subjected to harassment and failure to accommodate in the workplace. Some have been caused increased disability in the health care system, some have been killed, some have committed suicide because of the impossibility of getting accommodation for their disability, considering the problematic attitudes various parties have fostered in the public. Several public servants were told, with evidence such as a Health and Welfare handwriting analysis, that their problem was psychological.

After testimony at the Parliamentary Standing Committee on Health and at the Parliamentary Standing Committee on Human Rights and the Disabled, after letters from the Chief Commissioner of the Canadian Human Rights Commission, the Ontario Chief Coroner, after statements from (then) all three parties in the house, in the late 1980's, Health Canada began to address attitude problems. After the Chairman of the Standing Committee on Human Rights, Dr. Bruce Halliday, approached the Minister of Health, Perrin Beatty, helpful forces within Health Canada were empowered. A conference was organized, with experts about sensitivities from all over North America. The proceedings recommended against dismissing patients as "neurotic", but for giving "respect and support". The recommendation, distributed across the country, was not implemented in Health Canada facilities serving native people or public servants. There are consequences.

The proceedings of this workshop were distributed to 20,000 physicians, using CMA lists of related professionals and to relevant provincial government ministries. The report, as others have done, emphasised that we are dealing with a wide variety of diseases, and that no one medical approach is either subscribed to by patients, nor appropriate in the opinion of professionals.

In 1991, after the federal health department took the huge step of reversing its practice of saying that persons with sensitivities should be presumed to be mentally ill until proven otherwise, the community of politicians, public servants, and consumers who were dealing with the problem moved

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on to the next step. We knew that, because of the consequences of hostile attitudes in medicine, there are many people in high risk groups who have sensitivities as a significant part of their problem who have not been properly diagnosed, some of whom are being caused disability or death in the health care system, some of whom are being made ill, some driven to suicide by symptoms they do not understand. A few obvious high risk groups can be determined by the lists of symptoms reported by patients in the Appendices to the Thomson Report (Ontario, 1985). (Suicides in the group of people already diagnosed continue, as people face the attitudinal remnants of previous statements by authorities that members of the group should be presumed to be mentally ill.)

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With this in mind, again with Dr. Halliday's encouragement in conjunction with Perrin Beatty's office, Health Canada sponsored a workshop on just one of several high risk groups–those persons with central nervous system problems resulting from sensitivity. Results of this workshop, including expert information in the area of CNS sensitivity and psychiatric sequelae, were distributed to related provincial ministries, to the Federal-Provincial Advisory Task Force on Mental Health, and to professional and consumer NGOs.

After the 1992 conference on psychiatric implications and responsibilities, when Health Canada decided to "wait for [even] more science" before acting to prevent the ongoing abuse of psych patients whose problems are caused by sensitivity, the file manager on the subject, Dr. John Davies, took an early retirement, saying the decision was "irresponsible and dangerous".

Since 1993, the department has slipped back into considering "both sides" in a misleading portrayal of sensitivities as resulting from a single illness, for which there could be a single disease description, with a physiologically-based diagnostic test. The current file manager tells people at international conferences that the problem is not significant. Four years into his responsibilities, during which time there were many suicides, Dr. Li said that literature on the subject is only recent, then later acknowledged that he has only looked back to 1980. During the same conversation, two years ago, Dr. Li said he was unfamiliar, after four years, with the report Health Canada itself published in 1987, called "Healthy Environments for Canadians", which has references on CNS sensitivities back to 1908, or with references in Ashford and Miller going back to 1880.

One political difficulty facing the group is that Health Canada has abused people with sensitivities, in its own facilities, for more than a decade since the Thomson report in Ontario prescribed specific means of protecting people from abuse, including addressing problematic attitudes in the health care system. (There is a parallel here with the recommendations concerning HIV in blood.) It has been nearly a decade since Health Minister Perrin Beatty supported a recommendation that people with

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EpiPens Recalled

If any of you have an EpiPen, EpiPenEZ or PeiPenJr, check with your pharmacist or online at http://www.fda.gov/medwatch/safety/1998/epipen.htm to see if yours is affected by the recall. 47 lots from the three products have been recalled by the manufacturer in a voluntary Class 1 recall due to a manufacturing problem which could result in users not receiving a full dose of the drug. The URL http://www.fda.gov/medwatch/safety/1998/epipen.htm contains the FDA press release about the recall, dated May 08 1998, and lists the lot numbers affected. Consumers will get a free replacement of the unit and should return it to the place they purchased it from.

It affects pens distributed in Canada, US, Germany, Israel, Denmark, Turkey, Australia, Greece and South Africa.

Susan Beck

Editor's Note: I had to replace two pens that I bought one week before the recall in May, so the pens are in our area. Replacements are readily available. <<>>

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ambiguous symptoms be protected from potential harm. There have been many suicides and deaths since. Several public servants' careers have been ruined, not to mention their health, due to denial in the public service of such problems as sick buildings, one cause and/or trigger of sensitivity.

Now the situation continues to require:

1) Addressing attitude problems in Health Canada.

2) Addressing attitude problems in the broader community.

3) Rescuing people in high risk groups who are being knowingly mistreated

4) Addressing, in a healing way, issues of integrity in Health Protection Branch and, more importantly, in Health Canada management.

We enclose a copy of letters from a few of the Liberals who have supported this issue, from the Canadian Medical Association (Carole Guzman, Associate Secretary General, CMA, former President, OMA - 613 731 9331), Association of Canadian Medical Colleges (David Hawkins, Executive Director 613 730-0687), the Ontario Medical Association representative to the Ontario Ministry of Education and Training's Special Education Advisory Committee (Dr William Mahoney, Chedoke-MacMaster Pediatrician 905 521-2100, extension 7605), and a letter from a past national president of AEHA (Dr. Greg Booth, of Halifax (902 477-5803).

For a third-party reference to the story of what is really happening at the community level, we invite people to contact Al Raven, Environmental Health Inspection, Health Department, Regional Municipality of Ottawa Carleton (613) 722-2200, or Terry Gihlen, Executive Director of the Social Planning Council of Ottawa-Carleton (613) 789-3658.

For comments about research, and the portrayal of research, please contact Dr. Michel Joffres, of Dalhousie University, at 902 494 1932, or at the Fall River Clinic, at 902 860 3069.

Chris Brown <<>>