

# Rachel's Environment & Health News

## #585 - A New Mechanism Of Disease

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Multiple chemical sensitivity (MCS) is an ailment, or a family of ailments, that has very real consequences for tens of millions of Americans.

In various large surveys 15% to 30% of Americans (37 to 75 million people) report that they are unusually sensitive or allergic to certain common chemicals such as detergents, perfumes, solvents, pesticides, pharmaceuticals, foods, or even the smell of dry-cleaned clothes. An estimated 5% (13 million people) have been diagnosed by a physician as being especially sensitive. Many of these people react so strongly that they can become disabled from very low exposures to common substances. [1,pgs.232-233] Typical symptoms include prolonged fatigue, memory difficulties, dizziness, lightheadedness, difficulty concentrating, depression, feeling spacey or groggy, loss of motivation, feeling tense or nervous, shortness of breath, irritability, muscle aches, joint pain, headaches, head fullness or pressure, chest pains, difficulty focusing eyes, nausea, and more. This group of symptoms is known as environmental illness or, more commonly, multiple chemical sensitivity (MCS), meaning "sensitivity to many chemicals."

MCS has been recognized by its symptoms for 50 years because MCS sufferers in many geographical areas, researchers studying them, and doctors treating them, have reported a remarkably consistent picture of disease. However, because MCS sufferers react to chemicals at levels that are hundreds or thousands of times lower than allowable occupational exposures, traditional toxicology dictates that their symptoms cannot be caused by chemical exposures. Nor is MCS a true allergy because there are no IgE-mediated reactions involved, so allergists don't know what to make of it.

In sum, because MCS does not fit any of the three currently-accepted mechanisms of disease --infectious, immune system, or cancer -- traditional medicine has not known how to explain MCS, and so has often labeled it "psychogenic" --originating in the patient's mind. This has left MCS sufferers in limbo. Told they are crazy, or imagining their disease, or making it up, they find themselves passed from physician to physician without any satisfactory answers and often without relief from their very real distress. (Some MCS sufferers DO have psychological symptoms, but that doesn't necessarily mean their disease ORIGINATES in their mind.) Forty percent of MCS sufferers report having seen more than 10 medical practitioners.

MCS came to the attention of mainstream science and medicine forcibly in 1987 when U.S. EPA (Environmental Protection Agency) installed 27,000 square yards of new carpeting and painted and remodeled office space at its Waterside Mall headquarters in Washington, D.C. Some 200 agency employees developed symptoms associated with "sick building syndrome"[1,pgs.174,76-77] --and several dozen EPA employees later reported developing MCS. The National Research Council has now accepted that "sick building syndrome" is a real phenomenon, producing MCS-like symptoms.

Most recently, MCS has been in the news because there are two new, large populations of people who exhibit some or all of the symptoms of MCS: Gulf War veterans, and women with silicone breast implants.

Since 1990, progress has been made defining and understanding MCS, though there is still a long way to go. Nevertheless, real progress has been made. A new book --a second, updated edition of **CHEMICAL EXPOSURES; LOW LEVELS AND HIGH STAKES**, by Nicholas A. Ashford and Claudia S. Miller[1] --offers a lucid, thoughtful description of the current science and medicine of MCS, suggests a hypothesis (which could be tested) about the origins of the disease(es), and offers real hope to sufferers that one day their ailments will be understood and treated, possibly even prevented.

The stakes are enormous, and the chemical industry knows it. If a clearly-defined disease emerges from research on MCS, with chemical causes that are understood, then it can't be too many decades before chemical corporations will have to face liability and compensation claims from millions of victims harmed by their products. Who knows where this might lead in the relationship between corporations and an angry public?

Like the tobacco companies before them, the chemical corporations are bent on casting doubt on the serious medical research now being conducted to discover the causes and physiologic mechanisms of MCS. The chemical corporations have labeled such research "junk science," and they have funded a new research arm of their own (modeled on the Tobacco Research Institute?) called the Environmental Sensitivities Research Institute (ESRI). DowElanco, Monsanto, Procter and Gamble, the Cosmetic Toiletries and Fragrances Association, and other companies and trade associations involved in the manufacture of pharmaceuticals, pesticides, and other chemicals, each pay \$10,000 per year to keep ESRI going. The head of ESRI is Dr. Ronald Gots, who also runs something called the National Medical Advisory Group, which provides expert witnesses to defend the chemical corporations in tort lawsuits. Dr. Gots has published no original peer-reviewed research on MCS, yet he and ESRI specialize in claiming that MCS is a mental disorder. Dr. Gots says, "[E]verything that is known about MCS to date strongly suggests behavioral and psychogenic explanations for symptoms." [1,pg.280] In other words, if you exhibit some or all of the symptoms of MCS, you are probably crazy and if your doctor thinks otherwise, he or she is probably a charlatan. Such a claim has special staying power because it cannot be tested scientifically. As long as anyone is around to assert its validity, such a claim surrounds MCS research with an aura of controversy --and controversial topics have trouble attracting mainstream funding.

Here is a typical "advertorial" by ESRI from the February, 1996 issue of THE MERCHANDISER (Spring Grove, Pennsylvania):

"Multiple Chemical Sensitivities: Fear of Risk or Fact of Life?"

"Scientists are increasingly concerned that a doubtful new diagnosis-- supposedly caused by everything 'man-made' in the environment--is unnecessarily making thousands of Americans miserable each year. One of these so-called 'modern diseases' is called MCS, for Multiple Chemical Sensitivities. Many established scientists and physicians doubt MCS actually does exist; it exists only because a patient believes it does and because a doctor validates that belief. For information on MCS, write the Environmental Sensitivities Research Institute, 6001 Montrose Road, Suite 400, North Bethesda, MD 20852."

The authors of the new book on MCS are highly qualified. Nicholas Ashford is professor of technology and policy at Massachusetts Institute of Technology (MIT) with advanced degrees in chemistry and law. Claudia Miller is a medical doctor with a masters degree in environmental health; she teaches at the University of Texas Health Science Center in San Antonio. Their 1989 report on MCS, funded by the New Jersey Department of Health, won the prestigious Macedo award of the American Association for World Health. Their new book is a pleasure to read. It is clear, thoughtful, intelligent, and carefully written. It makes an important contribution to our understanding of chemical sensitivity.

In reviewing several hundred studies --not all of them of good quality --Ashford and Miller describe the common themes that emerge from the good ones: MCS seems to be a disease (or family of diseases) that occurs in two stages. MCS is "initiated" by a high exposure (for example, a chemical fire, or spill) or by repeated moderate exposure to pesticides or solvents or some other strong chemical(s) such as those found in chemical dumps or used in remodeling homes or offices, including new carpeting. After the "initiating" exposure, symptoms are then "triggered" by extremely low exposure to many different chemicals, such as those found in

fragrances, or tobacco smoke, pharmaceuticals, or foods. Not everyone exposed to chemicals gets MCS, just as not everyone stung by a bee goes into anaphylactic shock. A certain portion of the population seems predisposed to react strongly to chemicals after an initiating event.

The mechanisms of MCS are not understood, but recent evidence suggests that the nervous system (or perhaps the nervous and immune systems together) somehow become sensitized by an initiating exposure. Thereafter, low exposures to common chemicals bring on major symptoms way out of proportion to the size of the stimulus.

Ashford and Miller suggest that MCS is not really the best name for this ailment or family of ailments because it fails to reflect the importance of the initiating chemical exposure. They suggest that the name Toxicant-Induced Loss of Tolerance (TILT) better describes the true nature of the illness(es) --initiated by a toxic exposure which leads to the loss of tolerance for common chemicals. They suggest that different initiating events may give rise to somewhat different ailments, all of which cause sensitivity to chemicals --just as different infectious diseases can all cause a fever.

The scientific community has held several symposia on MCS (or TILT) since 1990 and a scientific consensus has been reached on the double-blinded, placebo-controlled research that needs to be conducted to define this disease (or disease family).

Despite this consensus, the research is not being conducted because the needed facilities do not exist. A special "environmental medical unit" needs to be built, preferably in a hospital, to test MCS patients by exposing them to chemicals under controlled conditions and observing their responses. Despite numerous recommendations that such a unit should be built --including a recommendation from the National Research Council --the funding is not there.

Without naming him, authors Ashford and Miller blame Ronald Gots and others like him for the logjam: "...those who continue to promote untested and untestable psychogenic theories for MCS are part of the problem. Their lobbying of policymakers and others in this regard has contributed to widespread governmental inertia on this issue, making it near impossible to obtain funding for essential studies specifically directed toward MCS. Many of those who advocate psychological explanations in government-sponsored meetings and in the scientific literature are paid corporate spokespersons or consultants with financial conflicts of interest. Yet these conflicts generally are not revealed when these individuals appear in scientific meetings, author scientific articles, serve on official panels or boards, or serve as reviewers of grant proposals. Policymakers and publishers of scholarly journals need to recognize and remedy this appalling injustice." [1,pg.256]

These are not academic questions. Seventy thousand Gulf War veterans, alone, have sought help. They are told they must prove their disease exists --but without research they have no proof. The same is true of tens of thousands of women whose breast implants have left them with many of the symptoms of MCS. (David Kessler, when he was head of the Food and Drug Administration (FDA) said, "We know more about the life of a tire than a breast implant.") These and millions of other people are genuinely suffering, yet they are told --with no research basis -- that there is nothing medically wrong with them--it's all in their minds. Only research can find the truth.

Quite possibly, MCS or TILT is a new, fourth disease mechanism parallel to infections, immune disorders, and cancer. Those suffering its symptoms cannot gain relief from their torment until the needed research is done. Those who are being paid by chemical corporations to stand in the way of that research deserve the labels

inhuman and inhumane. Would criminal be too strong a word?

--Peter Montague (National Writers Union, UAW Local 1981/AFL-CIO)

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[1] Nicholas A. Ashford and Claudia S. Miller, CHEMICAL EXPOSURES; LOW LEVELS AND HIGH STAKES. Second Edition. (New York: Van Nostrand Reinhold, 1998). ISBN 0-442-02524-6.

Descriptor terms: mcs; multiple chemical sensitivity; environmental illness; allergies; nicholas ashford; claudia miller; low levels and high stakes; tobacco strategy; junk science; monsanto; dowelanco; procter and gamble; cosmetics, toiletries and fragrances association; ronald gots; esri; national medical advisory group; pharmaceuticals; pesticides; fires; environmental sensitivities research institute; solvents; nervous system; immune system; toxicant-induced loss of tolerance; tilt; environmental medical unit; research agendas; emu; gulf war syndrome; silicone breast implants; breast implants; disease mechanisms;