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## Exposed!

**It may not be a 'real' illness, but symptoms are very real to people with a sensitivity to common chemicals**

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When **Marny Turvill** of Evanston gets a whiff of certain cleaning products, fabric softener or gasoline fumes, she feels depressed, irritable, tired and foggy-headed.

But at least one doctor ridiculed her self-diagnosed hypersensitivity to chemicals. Friends wondered about her mental health. And once, while on an airplane, a perfumed flight attendant gazed at the respiratory mask and snarkily asked, "Where are you going, Mt. Everest?"

Such is life with a disorder known as multiple chemical sensitivity (MCS), a confounding illness that is not officially recognized by the U.S. medical establishment but has very real symptoms for an estimated 12 percent of the population.

Though a controversial new branch of medicine called clinical ecology (or environmental medicine) has sprung up to help treat people who are hypersensitive to chemicals, the disagreement over whether the condition actually exists has provoked a major schism among physicians and made it difficult to find care and research funding.

The theory behind the disorder is that vague symptoms such as fatigue, depression, memory loss, headaches, confusion and difficulty concentrating are triggered by either one large chemical exposure such as a pesticide application or low-level exposure to everyday chemicals in the environment. But so far, science hasn't been able to link the causes and the symptoms that patients describe.

"People who don't have it think [we're] crazy, making it up, or hypochondriacs because [the triggers] are products that people are around all the time but have no problem with," said Turvill, a pediatrician who recently retired from practice to open **Healthy Green Goods** in Evanston, a store that caters to those with environmental sensitivities.

MCS, which has been described since the 1940s, has been discounted as an organic disease by several groups, including the American Medical Association and the American Academy of Allergy, Asthma and Immunology. It's often confused with an allergy because many of the reactions, including headaches, fatigue, general malaise, swelling and breathing difficulties, can be the same as those in delayed-type allergic reactions to foods.

"We have no real evidence to believe those things, at least in mainstream medicine," said dermatologist Andrew Scheman, director of the North Shore Center for Medical Aesthetics, who specializes in contact allergies. "A fragrance can give you a rash, but if you [think the fragrance] is behind fatigue, weakness or vague symptoms, then you go see Jerry Leikin," the state's only

medical toxicologist.

But Leikin, of Evanston Northwestern Healthcare, hasn't found evidence of MCS and says it's not a toxicological illness because it doesn't follow the usual pattern: the higher the dose, the greater the effect. And patients often say they're suffering from overt chemical sensitivity rather than toxin accumulation.

Still, MCS is recognized by the National Institute of Environmental Health Sciences as a "chronic, recurring disease caused by a person's inability to tolerate an environmental chemical or class of foreign chemicals." The Americans With Disabilities Act includes MCS as a disability. And researchers such as Claudia Miller, a professor of environmental and occupational health at the University of Texas Health Science Center at San Antonio, suggest that toxicants are the cause not just of MCS but of a host of other illnesses and disabilities as well.

"The mainstream likes to say this doesn't exist because they have refused to acquire the knowledge base that it takes to diagnose this and treat it," said internist Martha Howard, medical director of Wellness Associates of Chicago, who treated Turvill. "It is much easier to write off these patients as 'hypochondriac' or 'crazy.'"

#### No clear definition

One problem is that MCS is not clearly named or defined. Since 1996, it has been officially called "idiopathic environmental intolerance" but it has also been labeled environmental illness, toxic injury, chemical AIDS, 20th Century disease, total allergy syndrome, chemophobia, sick building syndrome and toxicant-induced loss of tolerance.

The symptoms, which can affect the central nervous system or cause respiratory or gastrointestinal problems, vary depending on the person and the trigger. One study of 20 patients in the journal *Clinical Toxicology* showed that mold, indoor volatile organic chemicals and ink printers were thought to cause symptoms. In that study, a 30-year-old woman said she had migraines and dizziness from household cleaners, a 47-year-old man complained of back pain from model rocket glue and a 59-year-old woman experienced weakness and tremors from toilet tissue. But after evaluations, the researchers could not find a toxic cause in any of the cases.

"The symptoms they have are anything they want them to be," said Mark Aronica, a physician in the department of pulmonary, allergy and critical care medicine at Cleveland Clinic. "There are hundreds of known exposures that can lead to medical conditions such as occupational asthma, contact dermatitis and a variety of other well-defined organic conditions related to known chemical or toxin exposures." But, he says, these types of exposures "don't fall into the category of MCS the way it is being defined by 'environmental specialists.'" (See accompanying story.)

Chemical sensitivity also overlaps with other "real" diseases, including chronic fatigue syndrome and fibromyalgia, making it impossible for someone to know which one is causing the problem. Some people believe it's a "sick building" phenomenon; other theories on the mechanism include allergy, a conditioned response, impaired biochemical and neurochemical pathways, psychological or psychiatric illness, a psychosomatic condition, or altered sensitivity of the nervous system.

#### The avoidance cure

The only "cure" is to avoid exposure, which means limited access to public places, including libraries, doctor's offices, grocery stores and churches. Some people also make drastic dietary

changes such as removing wheat gluten, yeast and dairy from their diet or avoiding all processed foods, which contain trace amounts of processing chemicals.

"[For me] fragrances are by far the worst offender," said Lynn Tondat Ruggeri, a physiological psychologist and co-author of "Safer for Your Baby: A Guide to Living with Fewer Chemicals" (SaferWorks, \$9.95) after becoming chemically sensitive in her 30s. "Going anywhere near the soap and laundry aisle in the store is torture."

If she does, she might experience "a headache, nausea, and even mental confusion within minutes to an hour if I stay in the area of the chemical."

Turvill, a mother of two, figured out she had MCS about five years ago, primarily because her mother also suffers from it. "In typical mainstream fashion I thought she was nuts," Turvill said. "Then I started having clear symptoms."

Driving in the car, for example, made her feel depressed and tired. "But as soon as I put on the recirculation button and didn't breathe in fumes, I was fine," she said. She also found she had trouble around plastic products and anything that emits gases or has the "new" smell.

The realization forced her to overhaul her life. With Howard's help, she cleaned out her house, began eating a plain diet of meat, vegetables and fruit, and stopped going out in public. Finally, she even left her job as a pediatrician because if she spent 30 minutes in an exam room breathing in chemicals from fabric softener from a patient's clothing, she'd be knocked out for the day.

"People will discredit things that threaten their well-being," said Turvill, who suspects the increase in chronic childhood illnesses is due to chemical exposure. "To be told products you use every day are full of dangerous chemicals is a very threatening thing."

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Could it be MCS? Here's how to tell

These six criteria must be present for a person to be diagnosed with multiple chemical sensitivity, according to the Chronic Fatigue and Immune Dysfunction Syndrome Association of America:

1. The same symptoms occur with repeated exposure to the same chemical.
2. The condition is chronic.
3. Low levels of exposure (lower than previously tolerated) bring on the syndrome.
4. The symptoms improve or go away when the triggers are removed.
5. Responses occur to multiple chemically unrelated substances.
6. Symptoms involve multiple organ systems (most commonly the neurological, immune, respiratory, skin, gastrointestinal and musculoskeletal).

-- Julie Deardorff

Common chemicals, uncommon reactions

Here are the chemicals that generally cause the most problems for MCS sufferers, according to

psychologist Pamela Reed Gibson of James Madison University, author of "Multiple Chemical Sensitivity: A Survival Guide" (New Harbinger Publications, \$16.95):

\* Pesticides.

\* Formaldehyde.

\* Fresh paint.

\* New carpets.

\* Diesel exhaust.

\* Perfumes and air fresheners.

Other triggers include tobacco smoke, fresh asphalt, moth balls, nail polish and remover, fabric softener, dry cleaning chemicals, hair spray, auto exhaust, shampoos and conditioners, and newsprint.

-- J.D.

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