

Excerpt from
Casualties of Progress

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My daughters and I are among the lucky people who developed MCS and have recovered sufficiently to be able to live our lives without excessive restrictions. There was no obvious exposure that made us all sick, and the reasons why each of us developed MCS years apart are not at all clear. My surveys and extensive personal contacts with people with MCS, however, have indicated that it is highly likely that there is a genetic predisposition to develop MCS.¹ Nevertheless, it appears to me that almost anyone can acquire MCS, given a sufficiently large exposure to a toxic substance.

One of my first major exposures to chemicals occurred when I was about 11. For a year or two, I moved out of the bedroom I was sharing with an older sister and set up a bedroom of sorts in the corner of our unfinished basement, I slept right next to our coal furnace. It was my job to remove the clinkers from the furnace, so every night before I went to bed, I would lift them out into the bucket sitting by the furnace door, where they cooled all night, giving off acrid fumes as I slept only a few feet away. Thinking back, I remember that this was a period when I had constant colds and bronchitis.

Years later when I got married and moved to Maine, I once again had some extensive exposures to chemicals. I fell in love with New England antiques and would go to antique shops and auctions to buy bargains that could be refinished. Over the next half-dozen years, I refinished at least 18

¹ Robert Haley, M.D., Department of Internal Medicine, University of Texas Southwestern Medical Center, Dallas, Texas, has published results of a study showing that Gulf War vets who developed Gulf War Syndrome have lower levels of an enzyme that hydrolyzes several organophosphates. (Many leading pesticides are organophosphates and act as neurotoxins.)

pieces of furniture. We have many nice pieces of antique furniture in our house now, but they probably were not the bargain I thought they were if one considers health costs. At any rate, I removed coat after coat of paint with paint stripper, which is a fairly potent solvent. The labels on the cans said to use with adequate ventilation, so I would open a window a few inches when I had to strip a piece of furniture inside because it was too cold outside for the paint stripper to work.

My husband and I also did all the redecorating work that we were capable of doing ourselves when we bought an older house. We stripped ugly varnished woodwork all through the house, we painted walls, kitchen cabinets, and woodwork, and we varnished floors. For months we were breathing toxic fumes.

Another thing that fascinated me in New England was the beautiful hand-braided rugs I saw in older houses. I decided to braid one, so for a couple of years, I often had pots of dye and wool simmering on the kitchen stove. I can still remember how strong the hot dye smelled. But at that time in my life, I did not notice any effect from all these exposures.

One other exposure that I've sometimes wondered about occurred when my husband had a sabbatical and we spent a semester in Paris. There was a gas hot water heater in the kitchen of our apartment, and I have a clear memory of walking into the kitchen every morning and flinging open those tall French windows to let in as much fresh air as possible because I could smell gas fumes.

The next winter I happened to have a fairly heavy exposure to cigarette smoke because I was on a committee that met in my kitchen a couple of nights a week. One member was a heavy smoker and would smoke six or seven cigarettes in the course of the evening. That, of course, was back in the days when you didn't dare ask anyone not to smoke in your house.

That March I had pneumonia, and about three weeks after I recovered from that, I began having migraine headaches for the first time in my life (I was 33). After I had had several of these migraines, I made the connection that they always started early the next morning after I had been exposed to heavy cigarette smoke the previous evening. I can still remember lying in bed feeling sick as a dog with a throbbing headache and frequent vomiting or

dry-heaving, while my second daughter, who was just two and a half, wandered around the bedroom trying to get me to read her a story or play with her. One interesting aspect of these migraines was the ten-hour delay between exposure and reaction.

After a few months, I also began to see that exposure to heavy diesel fumes could trigger a migraine, sometimes with only a few hours delay. Then the following October I began to have so much joint pain when I got out of bed in the morning that it was difficult for me to pull my nightgown off over my head. When I walked downstairs, my left knee hurt, and it was painful to turn my left hand into position to play the violin. These symptoms were totally new to me; I had never experienced any joint problems previously. I had tests for rheumatoid arthritis, but they were negative. Finally, it crossed my mind to wonder if my joint pains could be related to our oil furnace going on at the beginning of October.

The connection between my bout with pneumonia and the development of chemical sensitivity three weeks later seems quite apparent, and I always used to say that pneumonia was the precipitating factor for me. As I've thought over the chronology in preparation for writing this story, however, I now see that it is quite likely that the heavy exposure to cigarette smoke precipitated the pneumonia and the double assault on my system from the smoke and the pneumonia produced the chemical sensitivity. And of course my earlier exposures to coal smoke, solvents, and dyes could certainly have "primed" me to develop MCS. As in so many MCS cases that I have heard about, it is often difficult to decide which factors were paramount in the development of chemical sensitivity.

Back in 1972, when I first experienced clear symptoms of chemical sensitivity, there was virtually no information available about the subject. At last I did find out about the work of Theron Randolph, M.D., the "father" of the field of environmental medicine who lost his position on the faculty of Northwestern University Medical School after he began talking about chemical sensitivity. I found Dr. Randolph's book *Human Ecology* to be very helpful, and it was a great relief to find someone at last who understood the unusual condition I had developed.

In the early 1970s, only a handful of doctors in the entire country were familiar with chemical sensitivity and were attempting to treat MCS patients. There was not the present variety of therapies to choose among. My only option was avoidance of chemical exposures and problem foods, which still seems to be the most effective way of recovering some degree of tolerance. I started preparing almost all of my food, including bread, from scratch, and I have always used as many organic ingredients as were available. In addition, I drank spring water to avoid chlorine. I decided to go on a rotary diet, which I followed for about a year. On this diet one eats a given food like wheat or carrots only once in four days.² The diet did help me see, for example, that coffee or chocolate, anything with caffeine in it, could cause a migraine and onions could make me feel unwell. When I eliminated those foods and drinks from my diet and avoided cigarette smoke for a year, my migraines disappeared. I only had migraines for two years and suspect that in many people migraines can be traced to sensitivity to various chemicals or foods.

My husband and I also decided to make major changes in our home to reduce my exposures to chemicals. The main thing we did was to replace our oil furnace by an electric boiler to heat the water that went through our hot-water radiators. Heating with electricity in Maine is expensive, but good health is worth it. Not only did my joint pains disappear, but from that point forward, my husband and I almost never had a cold. We also went through the usual MCS routine of changing over to less-toxic cleaning products, laundry detergent, and personal care products.

I was fortunate because I worked at home as a violin and piano teacher at this time. Younger students didn't wear perfume or shampoo their hair every day, and I could ask older ones not to wear perfume or use a particular shampoo that might be bothering me. Eventually, I decided to switch from giving music lessons to doing freelance editing, which gave me more

² For an excellent description of the rotary diet, see Doris Rapp, M.D., *Is This Your Child: Discovering and Treating Unrecognized Allergies in Children and Adults* (New York: William Morrow, 1991), pp. 457-480.

flexibility to choose my own working hours. Had I been working outside my home, it would have been far harder to recover.

Within the six-month period after I started the rotary diet, removed the oil furnace, and generally eliminated other sources of toxins from our house, my health went back to normal. No more arthritis, no more migraines, and I was no longer hypersensitive to perfume. We were even able to conceive another child, which we had been trying to do unsuccessfully for four years.³

I am grateful to my husband, who never questioned the reality of my chemical sensitivity. Like me, he was ready to look for cause and effect. When I had a reaction, the question was what had I eaten or been exposed to, not whether I had had a stressful day. For a year he did all of the grocery shopping so that I could avoid the cigarette smoke that used to fill so many stores.

I'm in good physical shape now. Last summer when I had just turned 60, I hiked 19 miles round trip with a 5000-foot altitude gain. Before we made the switch to an electric boiler for our heating system, I was having knee pain going down a flight of stairs—descending steep mountainsides would have been out of the question with that level of joint pain. My health in general is excellent; I never have the flu and rarely have a cold. Apart from the occasional physical, I only see my doctor once every couple of years.

There is virtually no physical symptom I experience that I can't trace to an exposure to a chemical or food. Once my left heel suddenly became so sore I could hardly walk on it. I realized at once that I was probably reacting to the heavy pine terpenes from a couple dozen freshly cut pine boards I had picked up at a local mill and put in the basement so I could make some shelves. Out went the boards, and the heel returned to normal.

On another occasion I photocopied a lot of pages that ended up with large areas of black ink on them. When I was sorting them out at home a half hour later, my heart began to feel as if it were flopping around in my chest and my heartbeat became very irregular. Anytime I spend too long using a

³ My survey research suggests that chemical sensitivity may reduce fertility. See the article titled "Reproduction" in my March 20, 1997, booklet (Appendix 2).

photocopier, I notice slight irregularities in my heartbeat, but again, there is always a substantial delay between exposure and effect. Exposures to moth balls will produce this same irregular heart beat.

I have recovered from MCS to a large extent, but I still have to be aware of my underlying chemical sensitivity. It places no great restrictions on my life at this point, however. I go where I want and do what I want in general. It's rare for me to think that I can't do something I want to do because I have MCS.

When our daughters began, one at a time, to develop MCS a few years later, we understood the condition. When one daughter started getting dizzy at her summer job at a drive-in restaurant, we asked the right questions and found out she was frequently waiting for orders near a large gas range. When she went to Stanford and after a few months suddenly started having vomiting episodes, we asked about exposures and learned that a new carpet had just been installed in the common room on the first floor of her dorm. By walking quickly through the first floor area to get to her room on an upper floor, she was able to eliminate the vomiting. It came back three months later, however, when they carpeted the hall outside her room. By keeping her door shut and holding her breath as she walked down the hall, she was able to avoid any further problems.

Another daughter would get extremely weak just from sitting in a bathtub of our regular municipal water, which contained a high level of chlorine. We eventually had a whole-house filter put on our water system. The car heater gave one daughter a headache from the time she was five years old, so we never used the heater, even in the frigid Maine winters.

When one daughter had a migraine when she was about 12, I immediately asked what she had eaten that morning and the culprit turned out to be a chocolate-covered cherry. She didn't have another migraine until a few months later, when she happened to eat a cherry tart that was dyed with the same bright red dye.

We had some very difficult periods when we were raising our daughters. One, for example, had a period when she was in the eighth grade when she would wake up totally exhausted and unable to get out of bed until the middle of the morning. There was a period of six weeks when she couldn't attend

school at all. In her case, we learned by taking her to Colorado for a few months that mold was a huge component of her problems. (Mold gives off toxic chemicals.) By the beginning of high school, she was well again. It wasn't easy raising daughters with MCS, but we kept them healthy enough to be starters on their basketball teams, and they eventually got degrees from Harvard and Yale law schools. One reason they have been able to stay healthy is that they always look for apartments with hardwood floors, electric stoves, and hot-water radiators. Although my daughters have been leading "normal" lives for some time, they can only maintain this status by rigorously avoiding exposures that they know have caused problems in the past. For example, my oldest daughter has been working as a lawyer for a large New York law firm for six years. Her job involves long hours and a fair amount of international travel. She has been very fortunate that the air quality at her law firm is excellent. Nevertheless, exposure to perfumes on colleagues or clients, or air fresheners in taxis or public restrooms will instantly set off headaches and cognitive symptoms that greatly diminish her capability to work for hours at a time. Any exposures to new carpeting, paints, solvents, or offgassing construction products produce a similar effect.

Avoidance of exposures has been the one thing that has worked to return all of us to health. We each still have some chemical sensitivities, but we can work around them well enough to live full and productive lives.