

Amputated Lives: Coping with Chemical Sensitivity

by Alison Johnson

Introduction

Four cataclysmic events have rocked the United States in the last two decades: the 1989 *Exxon Valdez* oil spill, the 1991 Gulf War, the destruction of the World Trade Center in 2001, and Hurricane Katrina in 2005. At first glance, these events might seem to have little in common, but all left in their wake significant numbers of people who are now chronically ill after exposure to large amounts of toxic chemicals. Some were volunteers or held jobs that left them little choice; some were just in the wrong place at a very wrong time. Hundreds of thousands of Americans became the “designated fall-guys,” finding themselves on the front lines of wars or natural disasters. During the cleanup operations in Alaska, at Ground Zero, and in the New Orleans area, thousands of people stepped forward to remove toxic substances in an effort to enable the pristine waters of Prince William Sound, the world’s financial hub in Lower Manhattan, and the jazz capital of America to return to at least some semblance of normalcy.

Regrettably, the national attention span is short. The sick workers who helped clean up the oil from the Alaskan beaches are not on any-one’s radar screen. Two whom I interviewed were coughing so hard because of the asthma they had developed after cleaning the beaches that we could hardly continue the conversation. In November 2000, the *American Journal of Epidemiology* published a study showing that 34 percent of those who served in the Gulf War—over 200,000 veterans—are now chronically ill.¹ The young men and women who answered their country’s call to serve on what has been termed the most toxic battlefield in history have felt abandoned for over seventeen years.

Then there are the heroes who responded to the World Trade Center disaster. Slogans on bumper stickers and in store windows throughout New

¹ Lea Steele, “Prevalence and Patterns of Gulf War Illness in Kansas Veterans: Association of Symptoms with Characteristics of Person, Place, and Time of Military Service,” *American Journal of Epidemiology* 152, no. 10 (2000): 993.

York proclaimed that the 9/11 heroes would never be forgotten. Now most feel they have indeed been forgotten as their health deteriorates and they lose their jobs and the medical insurance that went with those jobs. In the case of Katrina, neglect has been even more evident, and little has been done to acknowledge the widespread exposure to toxic chemicals and mold encountered by residents and cleanup workers.

Large numbers of people who became chronically ill after these major exposure events have developed a new sensitivity to the chemicals they encounter in everyday life in substances like perfume, paint, gasoline, cigarette smoke, diesel exhaust, new carpet, cleaning products, and air fresheners.

But before these four cataclysmic events, there was a minor prelude in 1987 that barely caused a ripple in the national attention. It was an event that, had its importance been realized, would have laid the groundwork for saving tens of thousands of people from developing chemical sensitivity as a result of the *Exxon Valdez* cleanup, the Gulf War, the terrorist attack on the World Trade Center, and Katrina.

What was this preliminary event? In 1987 the EPA installed thousands of square yards of what turned out to be particularly dubious new carpet in its Washington, D.C., headquarters, a building that had very poor ventilation. This new carpet sickened a large number of the lawyers, scientists, and others working in the building. Within a few months, the agency found itself faced with a dilemma that might not have seemed significant at the time but would have immense and far-reaching consequences for the health of not only affected EPA employees but other Americans from all walks of life—beauticians, teachers, custodians, nurses, mechanics, artists, Gulf War veterans, 9/11 First Responders—the list goes on and on. In the latter decades of the twentieth century, more and more people began to develop a newfound sensitivity to everyday chemicals, a condition that is now most commonly called “multiple chemical sensitivity,” or MCS. This condition was first described in the 1950s by a visionary professor of allergy at Northwestern School of Medicine named Theron Randolph. Dr. Randolph soon lost his position for promoting the heretical idea that some people develop serious symptoms in response to low levels of chemical exposure.

The EPA’s dilemma was this: should it carry out serious health evaluations to discover if its recent carpet installation had led to the development of chemical sensitivity among many of its employees or should it stonewall the situation, acting as if nothing was really wrong, and thereby avoid incurring the wrath of the carpet industry?

Unfortunately, the EPA chose to placate the carpet manufacturers and ignore its sick employees. Thus in 1987 the agency established to protect Americans from toxic substances in their environment failed to protect even the employees in its own national headquarters and thereby missed an opportunity to alert the nation to the insidious and potentially devastating condition of multiple chemical sensitivity (MCS). With classic cases developing within its own huge Washington office building, the agency was in an ideal position to study the phenomenon of MCS and encourage other high government agencies like the National Institutes of Health to devote substantial funds to research the condition. If the EPA had alerted the nation to chemical sensitivity when it developed in its own headquarters in 1987, Exxon executives and the government officials who advised them would have been far less cavalier about letting hapless workers clean the oil-soaked beaches in Alaska while wearing minimal protective gear. And if the EPA had understood the tremendous effects that multiple chemical sensitivity can have on people's health, the agency might have thought twice about encouraging Exxon to spread on the oily beaches a coating of Inipol or Corexit, strong chemicals that were supposed to help break down the oil. Unfortunately, these products added to the workers' exposure to toxic substances, thereby increasing the possibility that large numbers of them would become sensitized to many other chemicals.

Had the EPA recognized the development of multiple chemical sensitivity in its own employees in 1987, the leaders of the medical profession and physicians across the country might have begun to take MCS seriously. They would then have been in a better position to recognize why so many veterans of the 1991 Gulf War were seeking medical help for a wide variety of chronic symptoms like headaches, asthma, joint and muscle pains, gastrointestinal problems, and severe memory loss. These veterans suffered for years in an increasing state of frustration while their health and financial situations were declining as the Department of Defense and the VA attributed their symptoms to stress.

Change comes very slowly in huge government bureaucracies, but Dr. Ronald Blanck, who was the U.S. Army Surgeon General and the Commander of Walter Reed Army Medical Center during much of the 1990s, was one leader who began to question the stress theory that assumed that the illnesses suffered by so many returning veterans were psychologically based. In my documentary *Gulf War Syndrome: Aftermath of a Toxic Battlefield*, 2004 version, Dr. Blanck states:

In the mid-1990s, I commanded Walter Reed Army Medical Center. I continued to work on looking for causes for the illnesses suffered by many Gulf War veterans, illnesses that were clearly more than stress related. I looked at vaccines, I looked at exposure to smokes, to other toxic chemicals, petrochemicals, and so forth, all that were part of that battlefield experience, and I came to the conclusion that at least one of the explanations was multiple chemical sensitivity, something where a variety of toxic elements, even at low levels by themselves, in combination may in susceptible individuals be causing these illnesses. And I believe so much more work needs to be done on that, but it is clearly one of the explanations.

Although there's been increased recognition that there are causes other than stress for these illnesses, really the sea change happened in the last year or so and is highlighted by an article in the *New York Times* of October 15, 2004, that states many of the ill veterans "suffer from neurologic damage caused by exposure to toxic chemicals."

A decade separated the Gulf War from 9/11, but the EPA learned nothing during this period. Instead, the political appointees heading the EPA circled the wagons in response to a lawsuit initiated in 1992 by a group of its sick employees, who claimed that exposure to new carpet fumes and other renovation substances had caused them to develop multiple chemical sensitivity. As a result, when the planes struck the World Trade Center towers, MCS was not high on the list of potential health risks at Ground Zero for Christine Todd Whitman, the head of the national EPA, or for the official who headed the EPA office in New York City. These EPA officials did nothing to warn the tens of thousands of people who toiled in the toxic clouds at Ground Zero to help clean up the World Trade Center debris or those who lived and worked in the area blanketed by smoke for weeks that among other risks to their health, the development of MCS would be a very troubling possibility. None of these people were warned that MCS would have the potential to change their lives forever, eventually making it difficult for them to find a workplace or apartment or house they could tolerate, as is sadly illustrated by Chapters One and Two.

In a 1999 article in *Archives of Environmental Health* that was titled "Multiple Chemical Sensitivity: A 1999 Consensus," a group of thirty-four

researchers and clinicians proposed the following criteria for the clinical diagnosis of MCS:

1. The symptoms are reproducible with repeated exposure.
2. The condition is chronic.
3. Low levels of exposure result in manifestations of the syndrome.
4. The symptoms improve or resolve when the incitants are removed.
5. Responses occur to multiple chemically unrelated substances.
6. Symptoms involve multiple organ systems.

One of the most distinctive features of MCS is that people who develop the condition begin to react to low-level chemical exposures that never bothered them previously. Some MCS patients have only mild cases; for others the condition can be life threatening. In most cases, as the illness progresses, the patient reports that more and more substances cause symptoms. People with MCS can have a wide variety of symptoms as the result of chemical exposures, with different patients having different symptoms. A given patient, however, will usually have the same symptom in response to a given exposure, perhaps getting a headache after exposure to paint or getting arthritic pains after exposure to natural gas.

Even though researchers do not yet agree on a precise definition for the condition, the stories in Part II illustrate how chemical sensitivity can destroy a productive life all too quickly. Many people with MCS are so sensitive to fragrances that they virtually become prisoners in their own home, unable to go to church, work, classes, or social gatherings because they will react to the perfume, aftershave, shampoos, detergents, or fabric softeners used by others. To make matters worse, some of those who insist that MCS is a psychologically based illness state that these people are suffering from agoraphobia, or fear of crowds. That's as cruel as saying to a paraplegic in a wheelchair, "Too bad you don't like to walk."

Newspaper reporters often refer to multiple chemical sensitivity as a rare condition, but this is hardly the case. In 2004, *Archives of Environmental Health* published a national prevalence study by Stanley Caress and Anne

Steinemann.² These researchers reported that in their national random phone survey, 2.5 percent of the respondents said that they had been diagnosed with MCS. This result suggests that over seven million Americans may be suffering from multiple chemical sensitivity, a number that exceeds the population of Massachusetts. This is hardly a “rare condition,” as it is frequently termed in the media.

The potential for MCS to gradually increase a person’s sensitivity to the point that he or she can’t find a workplace that can be tolerated leads to a situation in which large numbers of chemically sensitive people eventually end up with no choice but to turn to public assistance like SSSI (Social Security Supplemental Income). This is yet another reason why the medical profession and government bodies should turn their attention to a condition that has the potential to be a huge drain on public finances.

The loss to society of the contributions of teachers, mechanics, nurses, and others is significant. A case in point is a highly intelligent young woman who appears in my documentary *The Toxic Clouds of 9/11: A Looming Health Disaster*; her story appears in Part II of this book. Jenn Duncan received her B.S. degree from MIT and her M.S. degree from New York University. One of the jobs she loved most was working for the Children’s Television Workshop, which produced “Sesame Street.” Ironically enough, when Jenn developed severe MCS and lost the ability to think clearly enough to read and write, she taught herself to read again by watching *Sesame Street*. One of the great regrets of her life is that she is no longer in a position to contribute to society by doing the creative work she loved so much.

By contrast, Victoria Savini, who has a less severe case of MCS than Jenn, has been able to keep working. She developed multiple chemical sensitivity while working in the accounts payable office of the Disbursement Division of the Hart Senate Office Building. Because two letters containing anthrax spores were sent to senators in the Hart Building during the 2001 anthrax scare, the building was fumigated. In addition, in order to protect against contaminated mail, the government started irradiating all mail coming into congressional offices. This irradiation process had an extreme effect upon the paper, causing some of it to turn yellow and disintegrate on its edges, as I saw in person when I visited a congressional office during this period. I was also told that the young staffer who opened

² Stanley Caress and Anne Steinemann, “Prevalence of Hypersensitivity to Common Chemicals: A National Population Study,” *Archives of Environmental Health*, 59, no. 6 (2004): 300-305.

the bag of office mail every day felt nauseated by the fumes she inhaled. Victoria describes in her story in Part II how she had to leave her Senate job after she became chemically sensitive. Fortunately, she was able to find work with a major foundation in the Washington area that was willing to accommodate her MCS. As a result of this enlightened policy, Victoria has been able to work productively for the past seven years.

With MCS affecting millions of Americans, why is there so little recognition of the condition and why has so little money been spent to research it? In their book *Chemical Exposures: Low Levels and High Stakes*, Nicholas Ashford, Ph.D., J.D., and Claudia Miller, M.D., M.S., two of the leading authorities in the field, explore this issue. The *Journal of the American Medical Association* described their book as “a stimulating review of the controversy surrounding multiple chemical sensitivities” and also said, “Clinicians and policymakers would do well to read and heed the advice of this book.” Ashford and Miller decry the lack of research funds for MCS:

Scientific investigation related to chemical sensitivity is being stymied by scientists and physicians with financial conflicts of interest (e.g., those working for the chemical industry and those acting as defense expert witnesses in legal cases on MCS) who serve on government panels, editorial review boards, and grant review committees. These conflicts generally remain undisclosed.

Ashford & Miller, p. 271

One of the most respected researchers in the field of chemical sensitivity is William Meggs, M.D., Ph.D., a toxicologist and professor at East Carolina University Brody School of Medicine. Dr. Meggs has published many articles in peer-reviewed journals detailing, among other topics, his research using biopsies to investigate damage to the nasal lining of chemically sensitive patients. When I interviewed Dr. Meggs for my documentary on MCS, he stated:

I've spent a lot of time applying for research grants to try to study these illnesses and the role of chemicals in these illnesses, and my grant applications come back with scathing comments [like] “Don't spend any money on this research because everybody knows this is all psychological.”

It's hardly surprising that industry doesn't want anyone to believe that chemical exposures could produce a debilitating condition like MCS. The consequences for corporations would be enormous if members of the public increasingly began to wonder if installing new carpet, using pesticides in their house or yard, or buying particleboard cabinets or furniture might affect their health. And imagine the potential liability problems if people could prove that exposures in factories, hospitals, schools, or offices had destroyed their health.

To understand the power that industry wields regarding MCS, one need only remember that the tobacco industry managed for decades to keep the public from recognizing the hazards of smoking. They were able to succeed in this agenda not only by funding research that would encourage people to think that smoking was safe, but also by discouraging any research that might show the dangers of smoking. If the tobacco industry, which represents a very small fraction of American business, could exercise so much power, it is indeed staggering to consider the influence against validating MCS that is wielded by corporations when almost every business in the United States is significantly involved in chemical use in one way or another. What advertiser would want to run ads on a TV show that raised the possibility that chemical exposures could be creating serious illness? Certainly not advertisers from the cosmetic, pesticide, construction, or carpet industries.

In their book, Ashford and Miller also discuss at length psycho-logical issues related to MCS. They make the important point that while some MCS patients have psychiatric symptoms from time to time, that does not mean that the illness is psychological in origin. An illustrative example is Mad Hatter's disease from the nineteenth century; the Mad Hatters were indeed crazy, but their insanity was caused by the mercury in the felt with which they worked. One study has shown that panic disorder can be precipitated by exposure to solvents in the workplace.³ A particularly telling argument against the theory that MCS is simply a psychological condition related to a fear of chemicals comes from animal research. Several recent experiments replicate features of MCS in a rodent animal model, showing that rodents can react with debilitating symptoms to extremely low levels of chemicals. These rodents are obviously not influenced by media accounts of the

³ Stephen Dager et al., "Panic Disorder Precipitated by Exposure to Organic Solvents in the Work Place," *American Journal of Psychiatry* 144, no. 8 (1987): 1056-58.

dangers of chemical exposure. This area of research clearly cries out for funding.

Another unfortunate aspect of the psychological approach to the issue of chemical sensitivity is that critics of MCS frequently suggest that “secondary gain” is a strong component of the condition. According to secondary gain theorists, those with MCS are engaging in certain behavior patterns in order to get special attention or because they want others to take care of them. One does not have to read many of the stories in Part II before it becomes apparent that this suggestion at best is made in ignorance and at worst represents an exceedingly cruel attitude toward people whose illness has in all too many cases cost them their job, their home, their friends, or their spouse. MCS is in all too many cases an illness of devastating and overwhelming loss, not secondary gain. John, a former Shakespeare professor living with chemical sensitivity, described his situation in these poignant words:

I have been told that early retirement is the American dream. Early retirement because of disability and a chronic, progressive illness is nothing but a bad dream, involving the loss of family, home, career, friends, mobility, income, and one's health— almost everything one holds precious.

Casualties of Progress, p. 162

Nor is “secondary gain” a phrase that would come to mind when one reads the words of Randa, a woman who had worked in a land-use planning office in California and enjoyed activities like hiking in the Himalayas before she developed MCS:

Living with chemical sensitivity is being chronically ill and feeling crummy most of the time. After nine years of that, it really wears on you. It's really tiring, and I don't know how to explain this condition to people. It's drudgery and monotonous and lonely and isolating, and your old friends and your family don't want to hear about it, and I don't want to hear about it, but it's my life.

Casualties of Progress, p. 138

The concept of secondary gain would also hardly apply to two chemically sensitive people who recently told me how MCS has affected them:

MCS has had a profound impact on my life. I went from a life of plans and dreams—like getting married and having a family—to a life of constant struggle. During my sixteen years of illness, there have been literally hundreds of days of frustration, isolation, and extreme discomfort. Every day becomes a challenge to minimize the exposures that will make me sick. But the exposures are everywhere and never-ending: scented fabric softener fumes from a neighbor's dryer vent, nearby pesticide spraying, a co-worker using perfume or cologne, toxic cleaners used on a store floor, and office buildings with out-gassing synthetic materials, etc. Surviving this burden for so many years has undoubtedly been the greatest accomplishment of my life—an amazing accomplishment that will go completely unnoticed by most of the people I know.

Eric

Getting MCS has meant that within a year I lost my job of \$40,000 a year as a social worker, I lost my boyfriend of four years, and basically lost my home, as I could not sleep in it. Having MCS has meant enormous difficulties in finding work even if I have five degrees, including a Ph.D., as there are so many indoor environments I can't tolerate.

Nathalie

Reading *Amputated Lives* should quickly dispel any thought that people who suffer from chemical sensitivity are simply malingering. Far too many chemically sensitive people are living desperate lives, not lives spent in comfort while others care for them.