

Multiple Chemical Sensitivity:
Reflections by
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Multiple Chemical Sensitivity

Multiple chemical sensitivity, or MCS, is a multisystem disease that is characterized by symptoms associated with the exposure to low levels of chemical vapors. These levels of exposure are commonly found in the ambient environment. Systems that are affected by MCS include the respiratory system, the neurologic system, the gastro-intestinal system, and the skin in some cases.

For those with less severe illness and disease, symptoms may include cough, shortness of breath, and headache in association with the exposure to chemicals on an elevator, or when they open a magazine and have a scented insert in the magazine. For those who are more severely affected, however, symptoms can be truly disabling. They interfere with a person's ability to engage in gainful employment. They interfere with a person's ability to use public transportation. They interfere with a person's ability to live in a multifamily housing unit. They interfere with family life. They are isolating in short, so that individuals with MCS who are severely affected often feel very isolated. I see this in patients that I see at the MGH. One of the reasons for their isolation is that physicians do not get this disease; they don't understand this disease. Medical students are not taught about multiple chemical sensitivity. Physicians in training know very little about multiple chemical sensitivity, or MCS.

In my practice at the MGH I'm fortunate enough to have fellows—pulmonary fellows and also fellows in allergy and immunology—who shadow me, who spend time with me in my clinic. So these fellows, who are physicians in training, now know about MCS. They are aware that it exists. They are able to talk to patients who have MCS. They are able to consider the diagnosis.

As physicians, we apply the methodology of differential diagnosis to every patient that we see. If a patient comes in with MCS and the diagnosis of MCS does not occur to that physician

because he or she doesn't know about MCS, then the diagnosis will never be made, and when that happens the patient leaves feeling more isolated than ever. Not only are family and friends having trouble understanding the disease, but they don't even have a physician to whom they can go to discuss their medical symptoms. So one of the things that is very much needed in the area of multiple chemical sensitivity is adequate training of young physicians, adequate training of medical students, adequate training of fellows who are in specialties that are more likely to see patients with MCS, and this would include, very importantly pulmonary, very importantly neurology; the principal area of need is neurology, gastroenterology, and allergy and immunology.

The basic mechanism or mechanisms of MCS are not well understood. Consequently there are no good diagnostic tests for MCS, which is one of the reasons that it's difficult to diagnose. Without research into this area of medicine, we will not be able to understand the basic pathophysiologic mechanisms and we will continue to have great difficulty treating MCS. There are very few modalities available for treating people who have MCS. The only consistently reliable, and that doesn't mean consistently effective, but consistently reliable method of treatment in my opinion is avoidance of exposure.

The cornerstone of treatment for individuals with MCS in my opinion is avoidance of exposure to the extent that that is possible. It's very difficult often, in fact, it's impossible to achieve complete avoidance of exposure, but with careful planning individuals are able to reorganize their activities of daily living so that they can decrease direct contact with chemicals. For example, if they go to the grocery store, they can avoid certain aisles where there are likely to be scented products. If they have a dentist appointment, for example, they can schedule theirs

as the first appointment in the morning. For example, another thing that individuals with MCS can do is replace a gas stove with an electric stove.

There are those who believe that MCS is psychogenic, that is, that it's all in the mind. Based on my experience over the past more than twenty years taking care of patients with MCS at the Massachusetts General Hospital, I have no doubt that MCS is a physical and physiologic disease. It is not a psychogenic disease. There are often visible manifestations of disease in patients who come into my office. These include, for example, flushing of the face, swollen mucous membranes of the nose that are directly associated with the exposures, in some cases increased heart rate, in some cases increased blood pressure. When these individuals are not exposed to chemicals, their skin is normal, their blood pressure is normal, and their heart rate is normal. Unfortunately, there is no laboratory test that has an MCS sign on it. You can't take a chest x-ray and diagnose MCS. You can't draw a complete blood count and diagnose MCS, and that's one of the difficulties. Hopefully, with research and improved understanding one day we will be able to do that, but presently it is not possible.

The onset of MCS is often in association with a relatively high-level chemical exposure. It can occur, however, with lower-level chemical exposures. I've seen a number of patients whose disease began during the course of their work in a building or an office with inadequate ventilation, with poor indoor air quality.

In June of 2009, the CDC put on its internal website an Indoor Air Environmental Quality Policy intended to maintain good indoor air quality in buildings in which its employees work. Among other things, the CDC policy states:

“Scented or fragranced products are prohibited at all times in all interior space owned, rented, or leased by the CDC. This includes the use of the following products:

- Incense, candles, or reed diffusers
- Fragrance-emitting devices of any kind
- Wall-mounted devices, similar to fragrance-emitting devices, that operate automatically or by pushing a button to dispense deodorizers or disinfectants
- Potpourri
- Plug-in or spray air fresheners
- Urinal or toilet blocks
- Other fragranced deodorizer-re-odorizer products

“Personal care products (including colognes, perfumes, essential oils) should not be applied at or near actual workstations, restrooms, or anywhere in CDC owned or leased buildings.

“In addition, the CDC encourages employees to be as fragrance-free as possible when they arrive in the workplace. Fragrance is not appropriate for a professional work environment, and the use of some products with fragrance may be detrimental to the health of workers with chemical sensitivities, allergies, asthma, and chronic headaches and migraines.”

The CDC Indoor Air Quality Policy is a very important policy and provides an example of what we should be doing in every workplace in this country. I think all workplaces should be fragrance-free. The number of people who are chemically sensitive and/or with diagnosed MCS is increasing on a daily basis. This problem is very similar to the problems faced by workers when smoking was allowed in the workplace. The implementation of a smoke-free workplace policy by the Occupational Safety and Health Administration and other regulatory agencies has been very important in preserving the health of workers in those workplaces. Since the smoke-free policy has been implemented in workplaces, we have found out much more about the toxic effects of secondhand smoke. I think the same thing is true with regard to the toxic effects of chemical vapors. There are a number of vulnerable individuals in the workplace, not only those with MCS, and I think that as a matter of public health policy, we have a responsibility to protect all of those workers.

A fragrance-free policy allows these individuals who are chemically sensitive to continue their employment. As a result, they do not have to turn to Social Security Disability for income. Those who are not the beneficiaries of a fragrance-free policy are often unable to work and do find themselves on Social Security Disability.

In addition, the CDC policy encourages or requires advance notice if new chemical products are going to be introduced into the workplace or if renovation work or installation of new carpeting is to be carried out in the work environment. This practice would enable people with MCS and with other chronic diseases such as asthma, allergies, chronic obstructive lung disease to make other arrangements while the renovation work is going on, for example, or the new carpeting is being installed. It also would allow them to discuss with their supervisors new chemicals that are being introduced into the work environment because often people who are

chemically sensitive have knowledge of alternatives that are less toxic, not only for them but also for other people who may be affected.

Because many practicing physicians, most practicing physicians, do not understand MCS, patients who have MCS feel as if they are not heard by their physicians, and in fact they are not heard by their physicians. As a result they seek alternative methods of care. They seek alternative types of health care practice, alternative types of practitioners. In many cases, these alternative therapies actually do more harm than good, so that great care needs to be taken in advising MCS patients with regard to treatment. As I have said, in my opinion the only treatment that has been shown to be effective at the present time is avoidance of exposure to the extent that that is possible.

Patients with MCS and physicians who may be treating them need to remember that if it's too good to be true, it probably is too good to be true. There are no miraculous cures out there, at least none that I know about. Patients with MCS travel great distances sometimes to receive what is touted as a miracle cure. They spend lots of money to receive this so-called miracle cure, and in the end it is not a miracle cure. It often makes symptoms worse rather than better, and at the end of the day it does not cure the disease. Until we better understand the pathophysiologic mechanisms, we are not going to be able to do much better than avoidance of exposures in my opinion. And to better understand the pathophysiologic mechanisms, we need funded research in this area.

A principal concern, a principal problem for many of the patients that I see at the Massachusetts General Hospital, is housing. Individuals who are moderately or severely affected

by MCS ideally need a single family home, ideally need a two-bedroom home if they are living alone, so that they have a safe place to go if fragranced products are inadvertently brought into their home. Multi-family dwellings are problematic because of common areas where scented products are often used, because of neighbors who use scented products, who burn scented candles, scented products are used to clean the common areas, so multifamily dwellings are really very difficult, and this limits the housing availability for people with MCS. They have to be able to afford a single-family dwelling, for example, and many people because they are not able to work as the result of their disease don't have the financial resources to buy or rent a single-family dwelling, so it's a major problem for my patients.

I have had patients who have lived in HUD-subsidized housing, have made their housing acceptable for them only to have the subsidies withdrawn, so that they then have to go out and find another place to live. So it's something that those of us without MCS don't think about very much, but for people with MCS it's a major life problem.

Hello. I'm Alison Johnson and I would like to read for you passages from my book *Amputated Lives: Coping with Chemical Sensitivity*. I would like to begin with the Preface.

All my books and documentaries have had a central goal in mind—to convince readers and viewers that chemical sensitivity is real and is devastating far too many lives. In the ten years that have passed since I produced and directed my first documentary, *Multiple Chemical Sensitivity: How Chemical Exposures May Be Affecting Your Health*, more and more people have been succumbing to this condition. Hardly a day goes by that I do not hear from someone who is

close to despair because they see their former life slipping away from them as they struggle with a condition that the medical profession has largely ignored.

Last month a taxicab driver from Las Vegas e-mailed to say: “I was making good money driving a taxi and had to resign because the other driver would spray it with air freshener. Eventually the cab made me so sick I had to quit.” A man in a state prison wrote to say that he was getting terrible headaches from the scented products that his cell mate uses. Another e-mail came from a New York City police detective who toiled for months on the World Trade Center cleanup and is now too sick to work. He has become extremely sensitive to cleaning products, fragrances, and diesel exhaust and summed up his condition by saying, “I am beyond miserable.”

An artist who has found it enormously difficult to find a place to live that she can tolerate expressed her frustration by writing: “In the search for a new home, I came to know full well an overwhelming feeling of desperation, and along with that desperation came the growing conviction that the chemically sensitive are viewed as ‘throw away’ people.”

In Part II, people who are chemically sensitive describe in their own words how this has changed their lives forever. I have also used extensive quotes from these individuals in Part I instead of filtering their experience through my own words. It is my hope that this book will persuade readers that those unfortunate enough to have developed multiple chemical sensitivity are not “throw away” people, but the proverbial canaries in the mine alerting us that the rapid proliferation in chemical products in our environment may be endangering all of us.

My Introduction begins in this way. 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 large numbers of people who are now chronically ill after exposure to large amounts of toxic chemicals.

Chemicals and the products in which they are found constitute an important part of our economy, and they make our lives easier in so many ways. Many of these chemicals, however, are toxic, and the government has tested and regulated only a small percentage of them.

Some people who are exposed to large amounts of toxic chemicals or even smaller amounts on an ongoing basis develop the condition known as MCS. People who develop chemical sensitivity begin to react to chemicals they encounter in everyday life in substances like perfume, paint, gasoline, diesel exhaust, cigarette smoke, cleaning products, new carpets, pesticides, and air fresheners.

Continuing with passages that I wrote in my Introduction, 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. 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.

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."

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

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.

The next passages that I would like to read from Chapter Three, “The Consequences of Disbelief,” concern suicide or suicide attempts. Now I realize that suicide is a topic people really shy away from discussing. It’s almost a taboo topic in our subject, but there are times we must address it in order to save lives in the future. Continuing reading from my chapter on the consequences of disbelief:

Sue, who suffers from extreme chemical sensitivity, did give up on life on two occasions, both directly related to the great difficulty she had experienced trying to find a safe place to live and to work. In her story in Part II, she describes in poignant terms the despair that drove her to try to take her own life, even though she had a very supportive husband who loved her very much. In her story, she relates the enormous sense of frustration she felt when physicians, friends, and family viewed her symptoms with skepticism.

One particularly tragic example of the fact that disbelief can indeed sometimes kill appears in an e-mail that I recently received from Ann McCampbell, M.D., a board member of the Chemical Sensitivity Foundation, who has written a very useful educational booklet on multiple chemical sensitivity. Dr. McCampbell wrote:

A woman, Rachel, had called me a couple weeks ago and wanted to order 50 of my booklets. When I called back to say they were ready to ship, a woman answered the phone and said that Rachel was "deceased," had hung herself about a week ago! How awful. She lived in Ohio.

I am wracking my brain to remember what she might have told me about her situation. I know she wanted booklets to try to increase awareness of and sympathy towards chemical sensitivities, but I don't remember the details.

It's clear that Rachel was so concerned about the disbelief she was encountering that she was willing to spend a considerable amount of money on booklets to try to counter this disbelief. Rachel's tragic death and Sue's two suicide attempts show that there are many ways to "assist" in suicide. Dr. Jack Kevorkian was strongly condemned for assisting in suicide. Unfortunately, many physicians, employers, family, and friends are in effect assisting in suicide through their disbelief.

In 1996, I happened to hear, somewhat by chance, that in the same three-week period that year two chemically sensitive people took their own lives and another woman with MCS ended up in the hospital with a failed suicide attempt. A number like this must unfortunately be only the tip of a dismaying iceberg. When I asked in my 1996 survey of 351 people with MCS if the respondents had heard of MCS suicides, I received reports of dozens of such suicides.

One sometimes hears reporters or people in the medical profession say somewhat glibly that no one ever dies of multiple chemical sensitivity. Would these same people say that no one ever dies from bipolar disease, which has a significant mortality rate from suicide?

Twelve years as an advocate for the chemically sensitive has led me to the sad realization that a large number of chemically sensitive people have taken their own lives and many others are inching ever closer to that decision because they find it such a daunting task to locate a safe place to live or work and are rapidly running out of money. And at the same time that they are engaged in this herculean struggle, far too many of them are facing a discouraging skepticism from those about them.

Alison Johnson has followed the field of Multiple Chemical Sensitivity for forty years, first as a patient and then as an advocate. See her website www.alisonjohnsonmcs.com for more information or to purchase her books and DVDs:

Books

Casualties of Progress:
Personal Histories from the
Chemically Sensitive

Gulf War Syndrome:
Legacy of a Perfect War

Amputated Lives:
Coping with Chemical Sensitivity

Documentaries

Multiple Chemical Sensitivity:
How Chemical Exposures May
Be Affecting Your Health

Gulf War Syndrome:
Aftermath of a Toxic Battlefield

The Toxic Clouds of 9/11:
A Looming Health Disaster

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