

Excerpt from
Amputated Lives:
Coping with Chemical Sensitivity
by Alison Johnson

Chapter Three

The Consequences of Disbelief

One of the most difficult challenges faced by those with MCS is the widespread disbelief in the condition that they encounter from people who think it is simply a psychological disorder. Dr. Robert Haley of the University of Texas Southwestern Medical Center in Dallas, who is heading a \$15 million-a-year research program on Gulf War syndrome, used to hold that opinion. When I was interviewing him for my book, *Gulf War Syndrome: Legacy of a Perfect War*, Dr. Haley told me: “Before I got involved in the Gulf War syndrome research, I assumed that MCS was a psychological problem. I’ve seen it now reported by so many veterans who clearly are not psychologically impaired that I now consider MCS and related problems a very serious medical issue in need of serious research” (p. 145).

The idea that chemical sensitivity is simply a psychological condition is illustrated by an article titled “Functional Somatic Syndromes” that appeared in *Annals of Internal Medicine* on June 1, 1999. In this article, Drs. Arthur J. Barsky and Jonathan F. Borus, psychiatrists at Brigham and Women’s Hospital in Boston, stated: “The term functional somatic syndrome refers to several related syndromes that are characterized more by symptoms, suffering, and disability than by disease-specific, demonstrable abnormalities of structure or function.” The authors note that physicians are “increasingly confronted by patients who have disabling, medically unexplained, somatic symptoms. . . . These patients often have a strong sense of assertiveness and embattled advocacy . . . And they may devalue and dismiss medical authority and epidemiologic evidence that conflicts with their beliefs.”

Barsky and Borus's statement offers an excellent example of how people with chronic illnesses such as Gulf War syndrome, multiple chemical sensitivity, chronic fatigue syndrome, fibromyalgia, and sick building syndrome are viewed by physicians who do not like to have their authority questioned. These conditions, which many observers believe to be variants of the same underlying condition, are all listed in the Barsky and Borus article as examples of functional somatic syndromes. It is worth noting that Brigham and Women's Hospital, where Barsky and Borus work, was featured in a NOVA special on sick building syndrome that described how many nurses and other staff members of the hospital had developed chronic debilitating conditions like multiple chemical sensitivity. The hospital will have a substantial liability problem if multiple chemical sensitivity is recognized as a valid medical condition that can be precipitated by exposure to toxic chemicals.

Barsky and Borus's viewpoint is unfortunately held by many physicians and has contributed to an attitude of disbelief about chemical sensitivity among people such as landlords, employers, insurance companies, relatives, and friends, who affect in important ways the daily lives of those with MCS.

When I showed my *Toxic Clouds of 9/11* documentary in Ottawa in November 2006, a young woman in her twenties told me afterwards that she couldn't even spend Christmas with her family the next month. The reason? Her mother said they wouldn't be able to have a fire in the fireplace if she came. It seems likely that the mother thought her daughter's problems were imaginary and therefore did not deserve to be accommodated.

Disbelief was also a huge problem for Linda, who worked as a nurse in the VA state nursing home in Vermont. She developed MCS, as did four of her coworkers; they attributed their chemical sensitivity to the strong cleaning products used in the nursing home. When these women started asking their coworkers to refrain from wearing perfume, they were ostracized, as Linda describes in her story that appears in my book *Casualties of Progress*:

Coworkers stopped speaking to us, and jokes were made at our expense. Then a new assistant administrator came on board who asked us if we were aware of internal e-mail messages that some of the women in the facility had been sending to one another about us on the company computers. . . .

I find it hard to describe my emotions when I read the e-mail messages. I felt like I had been kicked in the stomach. . . . Reading how my coworkers conspired to wear heavy amounts of perfume, all the same kind on the same day, was horrifying. They even named the day according to the perfume they chose to wear that day; for example, one day was named Peach Petals day.¹ They bragged about spraying the bathroom that we used with perfume and about spraying the top of the stairway that we used. They joked how all of us should dress up as "bubble people" for Halloween and they should dress up as cleaning products. One of the worst perfume offenders wrote on the e-mail, "like I said before, shoot the bitches. I know where we can get some bullets." And this woman is a registered nurse.

We did not obtain the e-mail messages until September 1996. It happened that my mother had died on July 15, 1996. I remember working on July 14, 1996, so ill I didn't think I could survive because the perfume was so heavy that day. The nursing home that my mother resided in called me on July 14 to tell me that she might not survive the night. My husband begged me to go to the emergency room for myself because I was having such a hard time breathing. My lungs were so congested that he could hear my respirations across the room. When I went home before going to be with my mom, my little girl said, "Mommy, you stink like perfume." My coworkers had worn so much perfume that day that I had absorbed it in my hair and clothing. But I couldn't take time to go to the emergency room because I wanted to be with my mother as she was dying. As it turned out, the nurses at her nursing home worried more about me that night than about their patients. I cannot forget how I suffered that night, both from losing my mom and from the physical suffering that I later learned was the result of a malicious prank by my coworkers. When I read the e-mail and recognized the date of Peach Petals day as being the day I was called to the nursing home to be with my dying mother, I felt violated. My grief felt fresh all over again.

Casualties of Progress, pp. 44-45

Because of the e-mail evidence, Linda was able to take her case to the Human Rights Commission of Vermont. In December 1996, its members

¹ Editor's note: To avoid possible liability, the real name of the perfume has not been used.

voted in favor of her claim, stating that she had been discriminated against on the basis of a disability—MCS. I have heard of many similar cases, but I suspect that most people who hear about such abusive practices discount the reports, thinking that no one could be that mean. Sadly, the Vermont case indicates that even nurses can be cruel in some instances.

Unfortunately, the widespread disbelief about MCS in the medical community, which affects the attitudes of the general public, emboldens people like the nursing home employees who were in effect assaulting Linda and her sensitive coworkers with perfume. They may well have justified their bad behavior by a belief that Linda and the other women were just delusional people who were trying to control others in an unreasonable way.

Sp4c. Tara Batista, whose story appears in Part II, served as a medic and ambulance driver in the Gulf War and returned with a serious case of multiple chemical sensitivity. She encountered major problems with disbelief at the prison hospital in Massachusetts where she worked as a nurse.

A former marine who served in the Gulf War, S.Sgt. Terry Dillhyon, received a discharge summary from the VA hospital in Washington, D.C., that listed among his conditions “possible multiple chemical sensitivity.” Terry reports in his story in Part II: “The doctor who told me I had multiple chemical sensitivity said he wasn't allowed to write that in the diagnosis—he could only say “possible multiple chemical sensitivity.” The disbelief of a different physician had a huge financial impact on Terry, who is too sick to work and must use a wheelchair much of the time.

When I went to a civilian doctor in connection with my application to obtain Medicare coverage from the Social Security Administration, I happened to mention that I had MCS. He went ballistic and said, “So you're one of those people. Let me tell you what, you just lost all your credibility with me.” He turned in a negative report to the Social Security board, which then denied me Medicare coverage.

Not long after Terry was turned down for Medicare coverage, he ended up in the hospital because of an asthma attack precipitated by exposure to a perfume insert in a magazine he was reading. His ambulance, emergency room, and hospital bills totaled over \$5,500, which Terry had to pay himself because he had been turned down for Medicare.

One of the sadder e-mails I recently received offers yet another example of the problems engendered by disbelief:

I'm homeless in Washington DC. I reside in a homeless shelter that has no empathy for my chemical sensitivity. . . . The Staff at the shelter do not understand and do not take serious how ill I become when I have prolonged exposure to full strength bleach, pine sol, ammonia, aerosols.

At times, the residents mix the chemicals together and also these chemicals are placed in pump-spray bottles and the residents spray these chemicals around the shelter just as you would air-freshener. Now that the residents know of this problem I have, just out of spite the residents just spray aerosols anytime most of the time when it is late at night and I can not leave the shelter for air. . . . I have spoken to staff about this and the issue, and of being assigned chores using these chemicals. The shelter director finds this issue a joke.

Joy, whose housing problem was described in Chapter 2, feels very isolated because of her children's attitudes toward multiple chemical sensitivity:

After seven years of sharing information about my sickness with my children by sending videos, books, and articles, I found out they do not believe there is any such thing. My children and their spouses are in the medical profession. My son said that he is trying to understand, but everything I have sent is anecdotal with no medical proof. My daughter believes I am being "fed" symptoms, so that I believe I am ill. She is angry because I cannot travel 3,000 miles to visit. . . .

Their disbelief has devastated me more than the disease itself. My children led me to believe they understood, but now I know they don't. I could take most of society believing it is "all in my head" but my own children!

I thank the good Lord for a kind and understanding husband who respects me and knows how ill I get near chemicals and helps me so very much.

Casualties of Progress, p. 209

One of Robert McCloskey's famous children's books, *One Morning in Maine*, describes a morning spent taking his two little girls, Sal and Jane, from the family island over to the mainland to buy supplies. The setting seemed idyllic and pristine, but decades later, Jane, who was still living in

the same area of coastal Maine, developed multiple chemical sensitivity. She too has had to struggle with disbelief:

Over the years I have often experienced anger about how skeptics treated my MCS with contempt, skepticism, and a lack of compassion. Would the skepticism be overcome with time and truth, or would it remain forever? The answer, ten years later, is that many people are still skeptical and righteous in their disbelief. . . . Now I am resigned that without a research breakthrough, which doesn't seem likely, conventional doctors and those who trust them will continue to treat us with disbelief.

Casualties of Progress, p. 198

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.² 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.

² See www.chemicalsensitivityfoundation.org, "Recommended Books and Videos" section, for further information on Dr. McCampbell's booklet.

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 man replied:

Yes. It is fundamentally disturbing to me to relate that a very good friend of mine, a dear friend, committed suicide some few years ago. She was young, maybe 30. She was exquisitely sensitive and finding a reliably safe place for her to live was almost impossible. Her biggest problem though: No money except the minimum Social Security Income. Thoughts of her suicide still make my mind go numb. I myself will commit suicide sometime in the next few years. Why? Too maladaptive with no money as offset.

Casualties of Progress, pp. 145-46

About five years after this man wrote this passage, I met him when I was traveling on the West Coast. He is a very intelligent, reasonable, and likable person who is doing his best to stay alive, and I hope he does.

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.

What can people who are lucky enough not to have developed MCS do to ameliorate this tragic situation? Keeping an open mind and a compassionate attitude would be a good first step. An overview of the subject of MCS is available on the website of the Chemical Sensitivity Foundation, www.chemicalsensitivityfoundation.org. That website also contains a long bibliography of research studies on chemical sensitivity that have been published in peer-reviewed journals. Even just skimming that bibliography should dispel the notion that there is no scientific evidence that MCS is a physiologically based medical condition. (This twelve-page research bibliography, which includes studies from not only the United States, but also Japan, Denmark, Germany, Greece, Spain, Italy, and Sweden, also appears on pp. 289-300 of this book.)

Physicians and nurses need to educate themselves more about the condition of chemical sensitivity, so that MCS patients can get more help from the mainstream medical community. At present, disbelief among many physicians has the outcome that many chemically sensitive people seek out alternative medicine practitioners. The latter are helpful in many cases, but there are also many people in this group who are taking advantage of the desperate plight of people with multiple chemical sensitivity.

It is particularly important that psychiatrists, psychologists, and social workers begin to understand that MCS is indeed a medically valid diagnosis and not just a quaint and annoying delusion of patients who are paranoid about chemicals in the modern world. When professionals in these fields view MCS patients as being delusional and paranoid because they report that chemical exposures are causing them to develop various symptoms, the consequences can be extreme. There have been many cases in which family members or neighbors of MCS patients have attempted, sometimes successfully, to have them admitted to mental hospitals for no reason but their belief that they are suffering from multiple chemical sensitivity.

Some professionals in this field as well as members of the general public have gone so far as to suggest that parents who have children with MCS are “creating” this illness in their children in order to obtain attention from the medical community. These skeptics are suggesting that what is involved in these chemical sensitivity cases is a rare syndrome that has been termed “Munchausen by Proxy” in which a parent actually inflicts minor injuries on a child because they enjoy the resultant medical attention. The mother of an eight-year-old boy named Zack, who developed severe chemical sensi-

vity following a furnace explosion when he was a baby, faced this kind of accusation:

People tend to be skeptical about Zack's illness and look for other explanations for whatever is wrong with him. After an article about Zack appeared in the local newspaper, some woman went to the school and handed one of the administrators an article on Munchausen by Proxy.

Casualties of Progress, p. 77

Christi Howarth is a single mother with a twelve-year-old son who almost lost her son in a court battle with California's Child Protective Services. She had been a teacher in the California system for over twenty-five years, with a specialty in teaching gifted children. Unfortunately, Christi and her son both developed MCS in their adjacent school buildings located a block from the ocean. She reports that there were mold problems in both schools, her building had ongoing gas leaks, and contaminated soil was removed from the site of the schools. Blood tests showed benzene in her blood and xylene in her son's blood. Christi went to some highly respected physicians in the field of chemical injury and mold exposures and has extensive documentation for her and her son's health conditions. Their chemical sensitivity is severe enough that she can no longer teach and he cannot attend school. He would develop migraine headaches, breathing difficulty, extreme fatigue, and nose bleeds in his school building. He has been diagnosed with asthma, and his symptoms now include facial tics and rashes upon exposure to various chemicals. Christi finally decided to home school him, and his symptoms have diminished with the reduced exposures.

An ophthalmologist who saw Christi was concerned because she had inflamed eyelids and recommended that she consult an infectious disease specialist. Christi decided to include her son in the appointment because his eyelids were similarly inflamed. To her dismay, the specialist whom she consulted was totally dismissive of the records Christi brought along that documented chemical sensitivity and mold reactions in her and her son. In fact, she immediately reported Christi to the Child Protective Services, saying that she was delusional about her son's health problems. That started a nightmare for Christi, who was forced to spend almost all her savings to fight a difficult legal battle. And Christi was alone in this fight; she was raised by her grandparents, now deceased, and her son's father is not in the picture. Christi not only had no one to help her financially, she also was

devastated to think that her son, who is the only family she has, could be taken away from her and put into foster care.

Her son was also traumatized by the whole affair. What could be more terrifying to a twelve-year-old boy than to think that he is about to be taken away from his mother, who is the only family he has? Life with a foster family, who would have almost certainly been instructed by Child Protective Services to ignore his delusion about chemical sensitivity, would have been an impossible nightmare for this child.

Fortunately, Christi finally prevailed in the court system, and the court procedures to allow Child Protective Services to assume custody of her son were terminated, but not without a crushing financial cost to Christi. In an appalling aftermath of the whole nightmare, Christi's name was listed on an index of child abusers after the initial visit she received from a social worker from Child Protective Services, who thought Christi's medical beliefs were delusional. This means that if she recovers her health sufficiently to be able to teach school again, no school system will hire her. Her legal counsel has advised her that it is a very difficult and costly procedure to have one's name removed from the index of child abusers once it has been placed there.

A little time spent by individuals who are not chemically sensitive to educate themselves about the field will have an important effect on the lives of many desperate people like Christi. And such increased awareness of chemical sensitivity may even produce unexpected health benefits for those who have never pondered the issue.