

Amputated Lives: Coping with Chemical Sensitivity

by Alison Johnson

Chapter 1

The Struggle to Find a Safe Workplace

Work is key to our existence. It pays the bills for us and our families. It helps define us as a person. But what happens when the ability to work becomes almost beyond reach because one reacts to chemical exposures in the workplace?

It's not easy to find a job where chemical exposures are not a problem. Fragrances are ubiquitous in almost all workplaces. Most factory jobs involve substantial exposures to toxic chemicals; health care facilities use heavy amounts of cleaning products and disinfectants, which are in effect dilute pesticides; and office air is polluted by the fumes from printers, copiers, and computers. And forget any kind of job that involves mechanical skills since exposure to diesel, gasoline, oil, and lubricants are out of the question for the chemically sensitive.

Jay Wilcoxon was very sensitive to chemicals after he came home from the 1991 Gulf War. When he retired from the military and took a job driving a truck, he would vomit every time he put diesel in his vehicle. During the Gulf War, Patricia Browning drove a tractor-trailer truck. Like so many other soldiers, she came home with Gulf War syndrome, with its accompanying chemical sensitivity, and this severely impacted her ability to drive a truck. In her story in my book *Casualties of Progress*, Pat writes, "I was a reservist for a number of years after the Gulf War, but even when I didn't need a cane anymore, I couldn't drive a truck because every time they would crank up the trucks, I would get deathly ill."

Randa had to give up her good job in a land-use planning office in California when she developed chemical sensitivity after a new carpet was glued down. When I filmed her in 1998 for my video on multiple chemical sensitivity, she said, "I haven't worked for over ten years now, and that

really does a job on your self-esteem.” Make that twenty years now that Randa has been unable to work.

Richard was a very successful painting contractor before his work-place exposures sensitized him to a wide variety of chemicals. Like Randa, he found that being unable to work had a huge effect on his sense of his personal worth:

I think especially as a man, not being able to work was very difficult. For all of my adult life, I guess I had identified with what I was doing for a job and had identified with my role as a business owner, someone who was providing employment for other people, someone who was performing a service for people, someone who got a big fat paycheck when the job was done.

Casualties of Progress, p. 115

Michael owned a large tree and pesticide business in which he sprayed over 100,000 gallons of pesticide every year. When he eventually developed MCS, he found it especially difficult when he was unable to work:

People—my wife, my family, other people, my brother especially—used to complain about what a workaholic I was, how I was just unbelievably driven, I would never stop. I would work weekends, I would work till dark. I just couldn't get enough. Going from being a workaholic to wondering how you're going to provide for your wife and your two children is pretty tough to take, especially as a male in this society. Society expects you to provide for your family, and people look at you strangely when you don't seem to be working your normal forty hours or more.

Casualties of Progress, p. 11

National Guard Captain Richard Caron developed Gulf War syndrome and chemical sensitivity after his service in Desert Storm. In his case the severe memory loss this condition often causes made it almost impossible for him to work, as he recounts:

Before I went to the Gulf War, I had a full-time job as a carpenter. I was also the pastor of a Baptist church and the chaplain of my Army National Guard unit. . . .

I have had to make many adjustments in my life because of the chemical sensitivity I had brought back from the Gulf War. I had to give up my job as pastor at my church because I was having a hard time remembering scripture passages that I used to know by heart.

Because the construction trade was slow at the time I returned from the war, I got a job in law enforcement because I had previous experience in the field. I worked for the sheriff's department for a while and also for a city police department. I wasn't able to continue that line of work, however, because I had become very forgetful since my return from the war and would get confused about where I was. There would be times when I'd be out driving on roads that I'd traveled many times before, and sometimes I couldn't remember where I was. I would just have to keep going, and finally I would realize where I was. When I was trying to work in law enforcement, I would get a call to go to a certain location where something was happening, and I couldn't remember where that street was located. So I just had to give up that work.

Casualties of Progress, pp. 62-63

Sgt. James Green is a young man who developed multiple chemical sensitivity while he was in the Air Force:

My memory is so bad now that I can't even drive on back roads here where I've driven since I was sixteen because I forget which way to go. I also became very sensitive to various chemicals; I can't stand being around cleaning chemicals, and diesel fumes or exhaust always gave me horrible headaches. Finally I just couldn't keep working around all the diesel exposures on the flight line, so I left the Air Force. For a couple of months, I drove a truck for a man who was laying cable for TV's, and the only way that worked was that he told me where to go and when to turn. The worst thing was that my diarrhea was so bad that we would have to stop every half hour for me to use a bathroom. Of course, after a while I had to quit that job.

Casualties of Progress, p. 99

One particularly poignant description of a long struggle to find a job he could tolerate comes from Abner Fisch, who worked productively as a chemical engineer for a dozen years before he developed MCS. At a 1996 hearing held by the Governor's Committee on the Needs of the Handicapped

in Santa Fe, New Mexico, Abner testified about the problems he had encountered in his search for a job:

I've had MCS since 1984. Since 1984, I've had twenty different employments. I've been looking very hard for steady employment, and it seems to be elusive. Two things are very difficult for people with MCS. One is that there are many jobs we just cannot do because of new carpet or carbonless carbon paper or new equipment or employees wearing perfume. Another problem for people with MCS is that when we have a job, sometimes we have to resign our job because of changes in the environment that take place.

I graduated as a chemical engineer in 1971. I worked for five years for two different state governments in pollution control, and then I started to work for 3M. . . . When I acquired MCS in 1984, 3M tried to accommodate me. They transferred me from a chemical pilot plant to an office job, but at that particular time, I was too sensitive to function well and I received a very bad performance evaluation. . . .

I had several jobs, and I went back to school and got a teaching certificate in Minnesota, and I have done substitute teaching there.

I've applied for many jobs. I applied for a job with the city of St. Paul which would require me to work with carbonless carbon paper. After the interview, I told them I couldn't do the job. Shortly after I left 3M, I applied for a job as a consulting engineer, but I couldn't wear the clothes, nor could I work in the building with new carpet.

Just last week I applied for a job in the Questa elementary schools, and the superintendent, Señor Gonzales, . . . took me into the building. Within a couple of minutes, I knew that I would get dizzy and disorganized and I would be irritable with the children. I couldn't justify being a teacher and being irritable with the children because of the physical structure of the building. It's just not fair to kids. So I told Señor Gonzales I couldn't do it.

In other cases, there have been jobs I had to quit because new carpet was installed. I had a job as a counselor in a halfway house and had to quit the job when carpeting was put in. I was a personal care attendant, and when the family remodeled the house and put in new carpet, I had to quit. I was flipping burgers and running a cash register, and I got a very good performance evaluation after two months

and after four months, but when they hired new employees who wore perfume and kept scheduling me with them, I had to resign.

I do substitute teaching, and when I substitute teach, every day when I come home I have to wash my clothing to get the perfume off.

Casualties of Progress, pp. 144-45

Six months after he gave this testimony, Abner took his own life. Lynn Lawson, the former editor of the *Canary News*, the newsletter of the Chicago MCS group, told me that two or three weeks before he ended his life, Abner called her to ask if she knew of any housing anywhere in the country that would be safe for MCS people. His suicide was almost certainly related to the two major problems facing those with MCS: finding a safe place to work and finding a safe place to live.

As chair of the Chemical Sensitivity Foundation, I frequently receive e-mails from desperate people, and it's not easy to know what to reply. The following message came in February 2005:

I have been plagued with multiple chemical sensitivities for about fourteen years, ever since the carpets in my home were cleaned and treated with a stain-repellent chemical.

My biggest concern is finding an occupation and/or work-place for someone with my problems. I don't know if this is something that your organization can help me with, but I'm at my wit's end and don't know where to turn. I need and want to work; I have started and had to quit so many wonderful jobs in the past four years due to becoming sick in the workplace.

If you have any information on how a MCS person can obtain gainful employment, I would be deeply grateful.

What can society offer this woman? She wants a job, not a handout. Some way must be found to accommodate such people in at least some workplaces so that they can remain productive members of society. Given the rather alarming increase in MCS during the last decade, there is some potential for the number of people needing public assistance to overwhelm the Social Security Disability Income and Supplemental Income programs if this growing problem is not addressed.