

Amputated Lives: Coping with Chemical Sensitivity

by Alison Johnson

Chapter 2

The Elusive Search for a Place to Live

Chemically sensitive people face a difficult struggle to find a place to live that will not exacerbate their health problems, a struggle that sometimes can seem almost overwhelming. Some people who are chemically sensitive are so reactive to the carpet or paint or gas heat in their living quarters or to their neighbors' use of pesticides or dryer sheets that they end up feeling lousy on bad days and half-sick most of the rest of the time. An exposure that might seem slight to the ordinary person can cause the intense pain and nausea of a migraine that can last for a couple of days or it can bring on an asthma attack. In other cases, an exposure can produce a dull headache or joint or muscle pains that make it hard for people to accomplish what they would like to do. Some exposures leave susceptible people feeling exhausted for days.

The chemically sensitive are often driven to lengths that seem astonishing to others, if not downright unbelievable, as various excerpts from the personal histories in my book *Casualties of Progress* illustrate. A former college English professor named John reports that his chemical sensitivity originated when he was exposed to pesticide fogging while attending graduate school in Gainesville, Florida. Despite various resulting health problems, he was able to teach in the State University of New York system for ten years. Then in 1978 when his college remodeled the building in which he taught, putting in new carpet, painting the walls with an oil-based paint, and introducing a new floor wax, twenty-six teachers became so sick that they signed a petition protesting their working conditions. The floor wax, which contained a formaldehyde preservative, was withdrawn from the market the following year. Unfortunately, these new exposures to toxic chemicals caused John such health problems that he had to give up his career as a college professor. Like many others with chemical sensitivity, he

eventually moved to the desert Southwest, where his extreme sensitivity to building materials caused him to adopt a highly unusual life-style:

I once read a study that said the average American spends 98% of the day inside. I've reversed that proportion and spend 98% of my time outdoors, sleeping on my patio and cooking there on a hot plate. I use my house as an oversized closet, storage area, and bathroom. I've been basically living outdoors for twenty years now.

Casualties of Progress, p. 161

Michael owned a very successful pesticide company in Connecticut and supervised the spraying of 100,000 gallons of pesticide every year. Not surprisingly, he developed chemical sensitivity after a few years of this exposure and When Michael's chemical sensitivity forced him to sell his large pesticide business, he moved to a farm in northern New England. His wife Judy describes in *Casualties of Progress* the problems they experienced while trying to make the farmhouse they had bought livable:

After we renovated our farmhouse with all nontoxic substances, we moved in in a flurry pace. Within 48 hours, however, Michael was sleeping outside on the porch under five wool blankets and three sleeping bags because he was unable to live in the house. It was November, and it was beginning to snow, so he was really freezing out there. We had been renovating the house for four months, and Michael had been in the house every single day with no problem until the last two or three weeks when we were working on the kitchen floor. We were having it laid with linoleum flooring, and Michael noticed he was losing his voice and not feeling very good. We are convinced that the glue that was holding the linoleum to the floor was what pushed Michael out the door. He was unable to enter the house for another month after that except for very short periods of time. When he did, you could see a red rash develop on his face and he would get beady eyes, glassy, watery eyes.

Casualties of Progress, p. 15

After Randa developed extreme chemical sensitivity because of new carpeting glued down in her office, she started reacting to her gas heat and gas stove. She had to turn off the gas and buy electric heaters, an electric toaster oven, and a hot plate. Mold had never bothered her in the past, but

now she started to react to it, so she had to rip out her carpeting, which was slightly moldy. She followed her doctor's suggestion and moved to Santa Fe because of her new and troublesome mold sensitivity, but that did not solve the problem:

My particular problem in finding housing here in Santa Fe is that the majority of houses are pueblo-style architecture and have flat roofs that typically leak when the houses are over ten years old. The leaks cause irreparable mold in the roofs. If I walk into a house that is over ten years old, it's almost always too moldy for me and my lungs tighten up immediately.

Casualties of Progress, p. 139

After looking at about two hundred places in Santa Fe, Randa found a condo that worked fairly well for a while until new carpet in an adjacent apartment caused her serious problems:

Unfortunately, my upstairs neighbor installed new carpet at the beginning of summer, and that made me homeless for over three months until the carpet had outgassed enough that it was tolerable for me. As soon as the carpet was installed, my apartment filled with toxic chemicals and made me very ill and I had to leave right away. I had to sleep on friends' porches for many weeks.

Casualties of Progress, p. 140

Randa did not consider building her own house to be a good option:

I really haven't thought seriously about building my own house because many people with MCS who have built their own houses have had disasters and have not been able to move into their places for a long time (sometimes years). I am so exquisitely sensitive to building materials that it would be very hard for me to build a house that I could move into immediately. At least with an existing house, I can walk in and get an idea whether it will work. . . . The financial risk is just too great if it doesn't work.

Casualties of Progress, p. 139

A graphic artist named Ariel had very mixed success with various attempts to find safe housing. Her odyssey started after she developed

chemical sensitivity that she attributes to an improperly vented computer printer at work. As her health grew worse, she and her husband decided to take early retirement and move out of the city to a rural area on the western slope of the Colorado Rockies. Unfortunately, it didn't occur to them that living right next to an orchard was not a good idea. Ariel later described this experience:

Each time the farmer sprayed his trees, I reacted with symptoms that were frighteningly severe—face and hand numbness, a total inability to focus my eyes, an extreme pressure in my head . . . chills that seemed to turn the marrow of my bones to ice and produced uncontrollable shivering. . . . These initial symptoms would gradually give way to a chronic flu-like state that involved bone-racking aches, extreme fatigue, and difficulty breathing.

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Because the severity of the reactions I suffered with each spray event indicated that future exposures could result in anaphylactic shock, my doctor recommended that we move to an area free of pesticides. So in 1991 we moved to a beautiful valley where we felt safe behind the twenty miles we knew separated us from the nearest agricultural areas, where there might be herbicide or pesticide spraying.

We bought a house and made the necessary changes to create a nontoxic home, adding a large artist studio for my work. We planted extensive gardens of vegetables, fruits, and berries to assure a pesticide-free food source.

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In 1997 my illusion of safety fell apart when an extensive noxious weed containment program was instituted in our area. . . . 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.

Casualties of Progress, pp. 121-22

Ariel and her husband finally located a house they thought she could tolerate, only to find that the previous owners' assurances that they had used no pesticides in the house were incorrect. In the crawl space, they discovered several insecticide bombs whose lot numbers indicated they had

been used by the previous owners. Faced with an extremely difficult choice, Ariel and her husband decided to build a new house on the property. They slept all winter in their trailer and camper, using the bathroom and laundry facilities in the other house while they built their new one. It was not an easy decision, as Ariel recounted:

The necessity to build a new house has required us to cash in the last of our IRA's and other savings accounts. . . . It's taken a large amount of mental fortitude and energy to pick up and start all over, to trust that we'll get it right this time and will not have to move again. We have once again cleared the brush, put up a deer fence, tilled and planted a large garden, planted fruit trees and berries. . . . Once again we are facing the dilemma that so many MCS people and their families face: spending down their income and savings to accommodate their illness, with no guarantees, no protective laws, no safety nets, and little basis for hope.

Casualties of Progress, p. 123

A woman named Marian had developed such serious health problems related to her chemical sensitivity that she decided to move to the middle of the desert in southwestern New Mexico. For the first year or two she was there, her husband had to continue working elsewhere, although he eventually retired and joined her in the middle of the desert. In her story that she sent me in 1998, she described in poignant and haunting terms how difficult it was to leave her old life and house behind and the challenges she faced in moving to an isolated desert home.

I was very ill. We took the recommendation to avoid toxic chemicals to heart. We sold our comfortable bed, the couch I had selected with so much care, the chairs that complemented it. . . . The recliners we had relaxed in for years were given away. Sewing, knitting, crochet projects were thrown out half finished. Much of our clothing went with them. The carpets were torn up, the gas pipes disconnected. Books, housewares, personal belongings, little things of no value and little things of great value, important parts of our lives were discarded with abandon in our zeal to clean up our house and improve our health.

An attractive and comfortable house in a pleasant setting is very important to me. I cannot easily shut out my surroundings. I get

nourishment and comfort from what is around me. My body is gradually recovering as the toxic level that surrounds it has decreased, but the emotional cost of making the changes was enormous. The psychological effect of seeing the house I had so carefully furnished and decorated and made into a comfortable house turned into a bare and ugly barn was devastating, especially at a time when I was physically very, very debilitated and much in need of a comfortable and supportive environment.

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I get lonely living by myself in the middle of the desert, so one day on a whim I tucked some snapshots around the light switch over my desk: My husband having breakfast outdoors wearing the slouchy hat I made for him, a bunch of wildflowers on the table in front of him. My older son, smiling at the camera as he squats beside a huge agave plant. My younger son, a tiny figure perched on top of an enormous rock, spreading his arms wide to soak up the warmth and beauty of the world. My daughter in a moment of attentive repose, looking up to watch her children at play.

Some days I talk to myself. I could talk to my husband, but he is presently living and working more than 200 miles away. I could visit our neighbors, but their home is full of chemicals. I could call a friend on the phone, but the phone is plastic. I could go hiking with some of the Mountain Club members, but they all use scented products. I could get together with a friend who also has chemical sensitivities, but the closest one is sixty miles away and that is a long drive in a smelly car on a smelly highway. I could talk to my dog and two cats (and sometimes do), but they don't answer, at least, not in words. But there are times when it gets too lonely if I don't hear the sound of a live human voice, so some days I talk to myself.

I try not to dwell on how seldom I see my family, how seldom I get to hug them, to share a meal with them, to enjoy the feel of their company. I try not to notice how my grandchildren are growing up without my getting to know them very well, or their getting to know me and my husband very well. I try not to realize the great physical distance and separation my chemical sensitivities have put between me and my family. I try very hard not to think of these things, for there is a great empty, aching void inside me when I do.

One of the strongest motivating forces in helping me endure my present life of isolating avoidance is the hope, the dream, the

expectation that some day my children and grandchildren and my husband and I can move more freely between our two worlds.

Unfortunately, Marian never saw that dream realized; she died in 2003.

Carina was an executive secretary for a large railroad who started to become chemically sensitive after she moved into a brand new apartment that contained particleboard cupboards, new carpets, and a gas furnace in a closet. She eventually bought a condo and made the mistake of pesticing it because she thought previous owners might have had pets.

[I started] reacting to many different chemicals and had to flee my pesticide-contaminated condo and leave all my clothing and furniture behind me. I moved into a stripped-down apartment with no furniture and slept on a pallet on the floor. During this period, I was living on savings and waiting and worrying every day whether my application for disability would be approved. Thank God, it was. I was able to find someone to rent my condo, furnished, until I sold it. The loss of my belongings wasn't hard to take in the beginning, as I learned you could live without "things" in your life. But now, I seem to feel the loss more because I identified with all my things.

I found housing with an MCS couple [in Nevada] and stayed there almost three years. But when the couple got a divorce, I lost my safe housing and could find no other place to live. I went back to Arizona, where I spent almost a year moving from one temporary place to another. Many times I slept in my car. I couldn't handle this nomadic life physically, emotionally, or financially, however, so I returned to polluted southeastern Michigan, where my aunt took me in. I've been in her not-very-safe house for eight years now.

Casualties of Progress, pp. 150-51

Joy, whose chemical sensitivity would appear to be the result of her former work as a beautician and exposure to pesticides when their Arizona house was treated for termites, was forced to seek a new house. She hasn't succeeded in finding a safe place to live, as she explains:

We were in such a hurry to move so that I would feel better that we bought a home we knew we should never have moved into. We called the builder, and he told us their homes had very little particleboard; it was just used in the floor. The former owners swore they had never

sprayed and never used scented products. They were such "nice" people that I believed them. But it turned out that I couldn't go in the house after the first time I tried because I got so dizzy. Thinking it was the thick new carpet making me sick, we had a subfloor put in and \$9,000 worth of tile before we moved in. . . .

We stayed a month in a motel trying to heat and air out the house. Finally as funds were about to give out, we moved in and found that the cabinets that looked like hardwood were hardwood only on the doors. Every drawer, closet, and cabinet was made of particleboard, even the material under the counters.

The closets had been sprayed with pesticide, so I have to keep my clothes on racks in the bathroom because I cannot even open the door to the huge walk-in closet. The washer and dryer that came with the house took months to air out because the previous owners had used scented detergents and fabric softeners. I cannot open the doors to the cabinets where the detergents were kept.

We thought that because the area was desert and no lawns, there would be no pesticide spraying. Wrong! The neighbors spray every weed that grows so it will be nice sandy landscaping. I cannot open my windows in the summer. The neighbors also burn wood, and the smoke comes right into our house when the wind is in our direction.

We immediately put the house up for sale because of the formaldehyde gassing out of the particleboard . . . but after trying to find a safer place for me to live, we finally took the house off the market. We did this in fear that another place might be worse than this one. We came to this decision after looking for a safe place and finding none. At our age we are just too tired to try again. I am 70 and my husband is 73.

So each day I live in fear of my neighbors using their herbicides and pesticides, as I am bedridden for two to three weeks each time they do.

Casualties of Progress, pp. 208-9

Neighbors' use of pesticide led indirectly to the death of Nancy Noren, a computer systems analyst who was extremely sensitive to pesticides. According to an October 3, 1998, article in the *Albuquerque Tribune*:

A life-threatening disease often forced Nancy Noren to flee her Rio Rancho home in the middle of the night to find refuge and a few

hours' sleep on a remote mesa. But it was on that mesa that the 51-year-old Rio Rancho woman may have met her death. Authorities confirmed Friday that a partly concealed body found earlier this week west of Albuquerque was Noren, who had been reported missing since July 17.

The police eventually arrested a twenty-two year old man who was stopped for speeding while he was driving Nancy's truck. Notes he had written indicated that he had been stalking Nancy on the mesa for some time. He was tried and convicted for her murder.

Friends of Nancy relate how her extreme sensitivity to the pesticides that her neighbors sprayed on their lawns affected her. One friend reported:

Nancy was totally incapacitated by pesticides and told me that it affected her whole body. The worst thing was that some of her neighbors were just not willing to talk about it at all and were quite rude about it. She wanted to ask them if they would at least warn her before applying pesticides so she could have the windows and doors closed, but they weren't even willing to do that.

When she would detect that pesticide had been sprayed, she would fly around the house closing windows as fast as possible, but it would still get in and cause her lots of pain. That's why on bad days she would have to just abandon the house and go walk on the mesa for most of the day. When the pesticide fumes were really bad, she would take her truck and camp in the camper shell on the back for a few days. Most of the time she camped out on the mesa because in a campground the charcoal lighter fluid and the cleaning products in the restrooms were a major problem for her.

Casualties of Progress, pp. 156-57

One of Nancy's other friends wrote:

Nancy realized her home was no longer good for her to be in, but she really couldn't conceive of moving for both financial and physical reasons, and we all know how difficult it is for people with MCS to find safe, affordable housing. She admitted to being overwhelmed by the idea of having to move.

Casualties of Progress, p. 157

Many people with MCS have committed suicide because they were unable to find housing that did not make them terribly sick. As the personal histories in my book *Casualties of Progress* illustrate all too well, many others across the country are living desperate lives. Some may be about to give up. Nancy Noren would be alive today had she been able to find suitable housing where she wasn't exposed to pesticides.

Finding safe housing is crucial for an individual attempting to climb out of the mire of MCS because living with constant exposure to toxic chemicals usually exacerbates or perpetuates the condition. Three national studies have shown that avoidance of chemical exposures is about the only therapy that seems to help virtually everyone with MCS feel better and regain some degree of health.¹ In some cases, a period of avoidance allows people with MCS the opportunity to reduce their level of sensitivity to chemicals sufficiently to enable them to work once again and to move about more freely in society.

The issue of constructing housing developments that could be viable for the chemically sensitive is not an easy one to handle because of the wide variety in building materials that are tolerated by various people with chemical sensitivity. A useful first step, however, would be for some public-spirited developers to create developments that reduced toxic exposures in the outside air. Such developments would benefit not only those with multiple chemical sensitivity but also those with asthma and other respiratory diseases. In such communities, it would be important to have bans on wood stoves or fireplaces, pesticides, smoking, barbecues, and the use of fabric softeners or dryer sheets, which spread fumes through a wide area surrounding the dryer vent. If the outdoor environment were protected in this way, then individuals could build their own houses using materials that they think they can tolerate and be free to open their windows to get some fresh air.

The need for such housing developments is immense. They would be a lifeline for people like the woman who sent me this e-mail in December 2005:

¹Gibson, Pam, et al. "Perceived Treatment Efficacy for Conventional and Alternative Therapies Reported by Persons with Multiple Chemical Sensitivity." *Environmental Health Perspectives* 111, 1498-1504; LeRoy, James, Davis, Trina, & Jason, Leonard (1996, Winter). "Treatment Efficacy: A Survey of 305 MCS patients." *The CFIDS Chronicle*, pp. 52-53; Johnson, Alison, "Table of Survey Results from 351 Respondents." MCS Information Exchange Newsletter, September 19, 1997.

I have Multiple Chemical Sensitivities so severe that I have had to resort to living in my vehicle in a National Forest in _____ for the past 14 months. I suffer severe neurological disturbances with exposures. Over the years my brain function has greatly diminished & I have become less able to fight the seemingly fruitless battle for housing & proper medical documentation. I cannot go on living in a vehicle any longer & wonder if you know where I can turn to for help.

Someday I hope there will be an answer for desperate people like this. Now there is little, if any. Mark, whose story appears in Part II, has lived in his car for over ten years. And he is perfectly sane; I've met him on several occasions. You would not pick him out as a guy who has any problems, but his severe chemical sensitivity prevents him from working, and the disability check he receives would not enable him to pay for a housing situation that wouldn't involve sharing a house or apartment with roommates using scented products or pesticides. He lives in a car because he's not ready to give up on life.