

Community Spotlight:

Jon Neiss

“Our furnace malfunctioned and I was exposed to carbon monoxide, carbon dioxide, polyurethane and paint fumes.”

How long have you been ill with chemical sensitivity?

I believe I have been ill with chemical sensitivity since the early 1980's. I only realized there was a problem after a chemical accident in 2003. Our furnace malfunctioned and I was exposed to carbon monoxide, carbon dioxide, polyurethane and paint fumes.

I have tried to trace back the sources of my bad health. I had allergies as a kid and went to an allergist and even had an air filter in my room. My brother also had allergies as a kid and he developed asthma. It has been a very severe form of asthma and he has almost died a couple of times from it. Interestingly, he is also very "allergic" to polyurethane, the particular substance that, I think, put me completely over the edge. So, perhaps there is a genetic predisposition in regards my immune system. Of course, we both grew up in Northern New Jersey, not far from NYC and were undoubtedly exposed to many toxins. Neither my father nor my mother had allergies. So, who knows?

I also had direct exposure to various things. When I was three years old, they found me sucking on and eating batteries! They had to pump



my stomach. My dad was a jeweler and he made metal toys for me that he cast out of lead! So, you never know.

I was a victim of violent crime in late 1982. I was kidnapped and held for a week. Within a year or so after that, I developed incredibly severe insomnia and, no doubt, Post Traumatic Stress Disorder. The insomnia was so bad that I slept perhaps 45 minutes to one hour per night for about ten straight years. I can't imagine that there was much left of my immune system after that.

I lived a life with a great deal of stress. During that time, I also lived without heat for three straight winters. I lived in poverty, often in very dangerous neighborhoods. For example, in one place that I lived for 7 years there was gunfire about 100 yards from my house, my upstairs neighbor had 32 arrests as a juvenile, and my neighbors across the hall were two young women whose boy-friends were gun-toting drug dealers.

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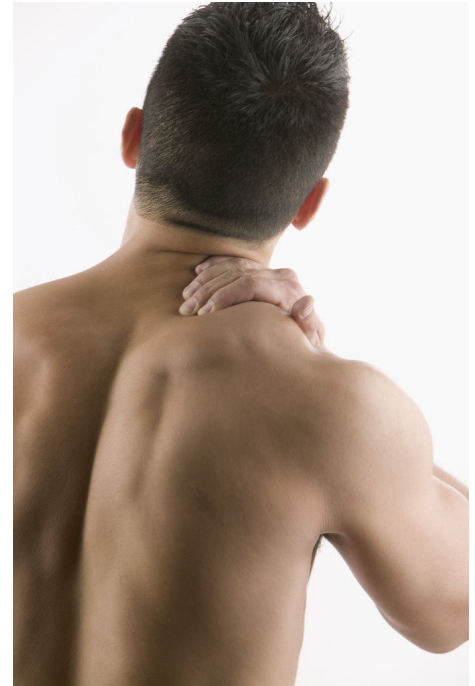
I was abused by the Social Security system. They were constantly harassing me and lying to me. I was abused by landlords. They would never fix anything and they treated me horribly in any number of ways. My family disowned me and my friends left me. I remember once going through my day and realizing that I had not talked to another human being in three straight weeks. I did not take a vacation in 13 straight years.

So, I think all those things combined to destroy my immune system.

My back first collapsed in 1999. I saw a chiropractor to try and heal it. It helped and I thought I was fine. In 2002, I was thrown off of an ATV. That precipitated another collapse of my back.

They put me on hydrocodone and flexeril. I think those two things were the final straw that destroyed what was left of my liver. I just would not heal. I spent most of 2002-2003 lying down and constantly having powerful muscular cramps. I knew something was profoundly wrong. I tried more chiropractic, Alexander Technique, Feldenkrais, Hatha Yoga, and more. Nothing helped.

Then, in November of 2003, I got the carbon monoxide poisoning. The story is a little more detailed. After the carbon monoxide poisoning, my girlfriend and I left the house. We went down to my mother's house. I started getting profound panic attacks, maybe 5 to



15 per day. After a few days they started to calm down to one or two per day. My mother was having work done in the house. A contractor was working on the kitchen. I asked her not to do the work because I was worried about my breathing. She refused. I had no other place to go. There was a tremendous amount of dust in the air. Then, my mother made me some tea in an old tea pot. Some of the lining of the pot chipped off into the tea and I drank it before I realized what was going on. The very last straw was when the contractor bombed the kitchen with polyurethane. The stuff went through the house and that was it for me. I was in the emergency room. In a last added bit of horror, my 83 year old dad was in the house at the same time. He was in poor health to begin with. He died a few months later. I am sure that the exposures in the house were the final straw for his life.

In what ways has MCS changed your life? What have you lost in terms of work, hobbies, foods, lifestyle?

MCS has changed my life in every way. I had a 4.0 in high school, got into an Ivy League School and was on track to be a doctor. Before the illness, my life had changed and I was already on a different course. I might mention that before being kidnapped I was probably an exceptionally healthy person. Even as a young kid, my mother was taking me to health food stores (ironic, since her later refusal to care for my health nearly killed me). By the time I was 13, I would not drink soda or eat food with preservatives. In high school, I became a vegetarian. And by the time I was 19, I was already becoming involved with herbal medicine. Prior to the kidnapping, I had been practicing Hatha Yoga and meditation for a year. So, I had a lot of preparation for the health problems that were to ensue.

So, once I became ill, I never developed any means to support myself. I lived with my abusive parents for several years, before I took them to court. After that, I lived on disability and supplemented that by working about half-time at very low wage jobs. I was always under-employed.

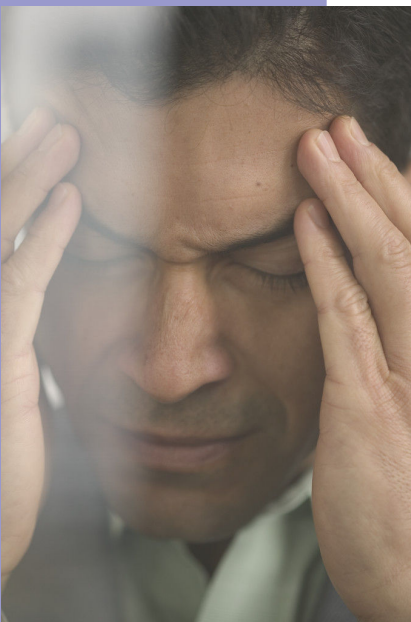
I worked at jobs with characters that were less than reputable. I have seen knives and guns pulled out. I have been around people involved in a lot

of criminal activity. That has also been a great, great stress. I did manage to maintain my dignity and choose poverty rather than join in their criminal activities.

So, I was always under employed, suffering the abuses of working at low wage jobs, often under the table, in NJ, where those jobs were in bad environments. On top of that, I had the stigma of being an adult working for low wages. People always assumed bad things about me. They assumed that I was a drug addict or mentally ill or whatever else.

Has it affected your relationships with your family & friends?

My illness caused profound problems with relationships, but the problems started before the illness hit. My interest in Eastern Religion caused a huge rift in my family. My family basically disowned me and actually became very hostile toward me. When I became ill, they ascribed everything to mental illness. So, in addition to everything else, I had that stigma attached to me. I had to take my family to court. I got smart and went to a psychiatrist and got a legal diagnosis in order to prevent my family from trying to commit me (which they did try once!). One big mess! My parents were trying to claim all sorts of lies and craziness. The diagnosis I got was an anxiety disorder with no mania, delusion, schizophrenia or the other lunacy my parents were trying to claim. It was that diagnosis that allowed me to get on disability. I never got on disability through a medical claim.



“How else can you survive severe problems and sufferings, unless you become a warrior in your life?”

Since my parents were claiming all these things about my mental health, it destroyed my reputation and all sorts of relationships with friends. Really, I lost all my friends, every single one of them. Within a year of being sick, they lost interest in me. Within two years, they altogether ceased having any contact with me. It took me about ten years to develop a new circle of friends, but it was never the same.

Have you learned or gained anything by having this illness?

I think I have learned a great deal from this illness. I was certainly forced to learn a great deal about health problems. Even before I recognized that I had MCS, I was constantly trying to protect and improve my health. The various sufferings also forced me to learn many, many things in order to survive. My primary coping mechanisms were through prayer and meditation. I also learned some techniques from martial arts in order to enhance my willpower. That allowed me to “burn” through great pains and

problems. I think we learn from every experience that we encounter. I certainly learned plenty about the darker nature of humanity. In that sense, it has been one big lesson in human behavior and psychology. I guess it brought forward that “warrior” that exists inside us. How else can you survive severe problems and sufferings, unless you become a warrior in your life?

I had severe brain fog all through this time. I had problems with concentration. To overcome them, I used a bunch of techniques from meditation, including meditation based concentration techniques. Since my regular thinking was clouded, I think my intuition and creative abilities became heightened. In the early 90's I began to paint and also perform on stage. I performed stand-up comedy, poetry, was an MC, and did some performance art.

One of the things I found from being underemployed was that many organizations need volunteers. So, I began doing a lot of volunteer work. Some of that was in activism. I was involved in activism in the environmental movement, the peace movement, and in human rights. I had done volunteer work and activism prior to being ill, but far more afterward, especially in the frequent periods when I had no work. That certainly was an education in politics and in political issues. I eventually became a part-time staff person at a peace group, ran a local Amnesty International group, and I even gave a few talks, set-up a talks, and did various other things.



“That place had a polyurethane floor that was installed improperly. The fumes put me in the hospital.”

I think what I primarily learned were spiritual lessons. I believe in suffering as part of a spiritual life. I think that in our modern era that believes so much in the individual, suffering is seen as anathema. However, in Christian mysticism (and other world religions), suffering is often seen as part of the path to God. So, I see my suffering almost as a gift that I have been given. I see it as a profound opportunity to become closer to God. I think that our human desires for personal pleasure are an obstruction to that relationship becoming closer. So, I think suffering strips away some of the walls that actually separate us from God.

Has making your home safe or finding safe housing been a challenge for you?

Absolutely! Here is the chronology of my housing saga: After the furnace accident, I went to my mother's house. She was having construction done and that put me over the edge and into the hospital. I refused to go back to the apartment where the furnace failed. The landlord became vicious. She refused to let us out of the lease. I was too sick to go to court to fight her. We wound up paying six months rent on two different places! We went down to stay at a friend's at the Jersey

shore. I was recovering a bit. Then, they got annoyed with us being there and forced us to leave!

We got an apartment. The garage of the place was under the building. There was an entrance from the garage right into the foyer. The car fumes used to fill the building!

Even the non-MCS tenants complained. The landlord also sprayed for bugs. I asked him to stop; he refused. It was a nightmare.

We finally moved out of there into a new place. That place had a polyurethane floor that was installed improperly. The fumes put me in the hospital. I refused to go back there. My relationship with my girlfriend almost broke up over this.

I went to live in a hotel. That was another nightmare. There were all sorts of characters at the hotel, not least of which was the sleazy manager. The fire alarm kept malfunctioning. It was a real siren. It went off maybe 7 times in a month. Each time that went off, there was a full evacuation with the police and fire department showing up. There were tons of problems there. Being in the hotel was a continuation of the situation with two rents. We were going very deep into debt and my girlfriend began to have panic attacks.

We tried to move into my mother's house. She had moth balls in every closet of the house, in almost every drawer in the house and who knows what else. That made me even sicker than I was in the hotel.





**“Do
you
have
insurance?”**

Finally, we moved into a two family house. It has no direct contact with the first floor. It is the best air I have found so far. I am still living in Northern New Jersey, however. We are now about \$50,000 in debt and falling deeper.

Then there is the issue of making the air in the house safe. I have done tons of things to make it safer. I have also had to make many compromises in order to appease the landlord and other people. Trying to balance all my needs and concerns with the desires of other people is a real stressful ordeal.

Has any treatment been helpful to you? Have any been harmful? Is it a challenge for you to find appropriate medical help?

I just finally started with an EI doctor a few months ago. I am still in the testing stage.

Of course, I have been doing tons of things on my own, and for years. Everything I have done has helped a bit. Certainly all the spiritual practices have helped. Since I have back and neck injuries, I have done chiropractic, Hatha Yoga, Alexander Technique, acupuncture, cranio-sacral therapy and Feldenkrais. All these things have helped my back and joints. Additionally, I think that they have helped my general health. I think they have boosted my immune system by giving me some relaxation too.

I have been taking vitamins and other supplements for years. I think they have helped me tremendously. This has been going on for years and years. The first supplement which made a difference for me was just calcium. I think it aided brain and nervous function.

I have also taken things which were apparently harmful to me. I am probably still taking some. Without money to get appropriate medical care, I have had to figure things out on my own.

My history with getting medical care has been horrible. I have tons of nightmare stories.

A few months before my back collapsed in 1999, I suspected something was wrong. I set up an appointment to get a physical. I brought in a photocopy of my insurance card. They said that I had to have the actual card and proceeded to bill me for the missed appointment!

After my back collapsed in 2002, I went to an orthopedist. As I walked into his waiting room, I collapsed on his floor. The very first words out of his mouth were (this is a direct quote), “Do you have insurance?” What a heartless thing he was to me! Those are just two stories among tens of horrible interactions, maybe even more than a full hundred!

Is there anything else you would like to add?

Just that I wish everyone in the MCS community well.

-Jon Neiss