

Stories about doctor's behavior when meeting people with environmental illnesses (MCS or EHS)



The healthcare system frequently treats people suffering from environmental illnesses with cluelessness, disrespect, and occasional cruelty. This is a collection of such stories.

Keywords: healthcare, doctors, disrespect, refuse accommodation, multiple chemical sensitivity, MCS, electrical hypersensitivity, environmental illness, environmental sensitivity

The healthcare system is the one part of society where people who are sick should be able to go and be taken seriously, and not be further harmed. As these stories show, that is often not the case for people with severe environmental illnesses, such as multiple chemical sensitivities or electrical hypersensitivity.

Physicians, and other health providers, don't like patients they cannot help, and diseases they do not understand. Perhaps it challenges their egos too much. Then it

is much more comforting to blame the victim, brush people off, or mislabel them as imagining their illness.

The severely ill have to be evaluated by insurance-hired physicians when applying for disability. Some of these physicians are far too well aware of the power they hold over the person in front of them, as a denied application can have serious consequences of poverty and homelessness.

The following stories are all told on condition of anonymity. Some are copied from published journals and books, as listed.

I was summoned for a re-evaluation of my disability to a physician I've never met before. His office was upstairs in a two-story building with parking in the back.

When I walked into the waiting room it was packed with people and it felt very "electric" in there. I asked the receptionist if I could wait out in the parking lot. All she needed to do was walk out the door of the office and fifty feet along the elevated walkway to the corner of the building where she could wave at me. They've done that at other clinics, but here it was refused.

I didn't dare complain. That doctor had tremendous power over me, so I had to sit there and burn for an hour. Luckily it took only 24 hours to recover, it could have been much worse. And the doctor signed the papers that I was still disabled.

Some years ago, a friend with both MCS and epilepsy was in a coma for three days. We took turns watching over her in the intensive care unit.

When she started to wake up, she rolled on her side and tangled up the tubes. The ICU hospitalist physician came in and ordered the nurse to administer the drug Haldol. It paralyzes people and is dangerous, especially for people with epilepsy.

The reason he wanted to use this drug was solely for the convenience of the staff.

We tried to talk the doctor out of it, but he got upset we questioned his order. The nurse took our side, which didn't help. Upset, he left the room and in the door he turned around and shouted "the order still stands!"

One of us carried a Power of Attorney for Healthcare, but didn't tell the physician, to avoid further confrontation. It wasn't needed, as the nurse agreed with us and refused to follow the order.

Our friend woke up about an hour later and made a full recovery. The ICU nurse was great and even put up a sign instructing anyone wearing fragrances to check with the nurse before entering the room. I shudder to think what they would have done had we not been there to defend our friend.

The first time I tried to talk to a doctor about my MCS, I didn't know what was going on. I got these headaches and blurry vision, which wasn't bad, but then I had an episode where I had to be helped home. When I told the doctor, she said I had not drunk enough water. I knew that was not true, but she was not interested. Next patient.

A friend told me that when she had cataract surgery, the surgeon told her to sit in the waiting room for a couple of hours afterwards. That was to make sure she was fit to drive herself, I think.

The waiting room had a new carpet so she said she would sit on the sidewalk outside their door. They did not allow her to do that. When she insisted, they said they would force her to stay inside, if she tried to walk through the door.

They did not explain this absurd refusal, but they might have thought she would just leave and that could possibly be a liability problem. They could have solved the issue by holding on to her driver's license or purse, but nobody thought of that. She was forced to endure the toxic air.

When I applied for disability, I was sent to a physician hired by the insurance company. Since I got sick I've met several pompous physicians, but this guy took the prize. He clearly relished having a captive audience. He lectured me for an hour and a half about all sorts of irrelevant things, and had no interest in what I had to say.

A few times he would stop and ask me a question, but each time he cut me off after just a few words. One question he asked was whether I had sex with a lot of girls when I was in college.

At the end he suggested that I become his patient, with the unspoken understanding that it would make his evaluation more favorable. By this time I was so dizzy it didn't occur to me what he was offering, so I declined. His report did not support my case.

I told the story to other MCS people in town, and one told me she had been there too and he asked her for sex. Neither of us complained, nobody would believe us, and nothing would come of it.

I had to drive hundreds of miles to finally see a doctor who understood MCS. After the visit we did phone consultations.

Some months later we needed to do another blood test. Her staff mailed me a kit which I took to my local clinic, but they refused to draw the blood. That was all they had to do, the kit was complete with an overnight express mailer, but they refused.

I found another clinic where they were willing to do it, but it had to be completely off the books. I paid the lab technician cash in hand. How ridiculous!

This may sound trivial, but the little signs of disrespect add up. Like this allergist my insurance sent me to. I had to wear a respirator in there, I took it off so he could inspect my nose. Then he said "You can put it back on – if you must." I doubt he'd say that to people on crutches.

Later on he referred to the MCS-housing I lived in as a "group home." A group home is a supervised place for developmentally disabled people.

Years later I saw an old article in a local magazine. There he stated that he had never seen anyone disabled by MCS, instead people were disabled because their doctor told them they were!

When I was still working I was moved into a newly remodeled office with a new carpet. The carpet was making me sick so I asked my supervisor to move me to another office. He said he needed a doctor's note to allow me to move offices, so I went to my primary care physician.

The doctor got upset and yelled at me: "I'm not doing that, I'm not getting involved in this, you are probably crazy, don't ask me again."

One of the first doctors I went to was an allergist. He had a strong air freshener in the bathroom – in a clinic for people with asthma! I told the doctor, he said “you do not have MCS, that doesn’t exist.”

He wanted me to do a maximum air flow test and then if taking Albuterol helped, that “proved” it was asthma and not MCS, he said. Taking the Albuterol did help my asthma a little bit. He said that demonstrated I did not have MCS.

I was sick for three days after being in his clinic.

I had been going to this primary care physician for some fifteen years, long before I knew I had EI. We were always pretty friendly, she treated me like a regular person.

When I learned I had EI, I took a meter to her office so I knew where it was best to sit. That upset her and she put a note in my chart that I was some sort of looney.

Then she started recording her notes with this lapel pen. I told her the Bluetooth bothered me. She was visibly offput. She threw the thing on the table next to me, which wasn’t any better.

Her nurse was always very kind to me, so I tried to schedule seeing her. She didn’t use any recording device. But that really upset the doctor who sent me a letter banning me from ever coming there again. She wrote I was a “non-compliant” patient, which made no sense. When I called for an explanation nobody would talk to me and they wouldn’t let me talk to the nurse.

My wife had one appointment with a GP in a nearby major city who several people had told us was compassionate and a very good doctor. I spared myself the exposure by initially waiting outside while she went in for a consultation. After more than an hour, someone came out from the office, confirmed my identity, and told me that there was no cause for alarm, but the doctor was asking to see me.

Apparently, the doctor had become so frustrated, trying to convince my wife that MCS isn’t “real,” that he had brought me in assuming that “the man in the family” would take his side and assist him in talking some sense into her. To his surprise, I not only supported her belief in MCS, not only confirmed everything she had told

him about herself, but also told him that I suffer from MCS, too. He had obviously never anticipated that; he became huffy and increasingly dismissive.

By the end of a fairly long conversation, he had obviously washed his hands of us. He told us that he had, at home, a four-foot tall stack of medical journal article reprints, videotapes, and other materials about EI, given to him by previous patients. He bragged that he had never read a single one of the articles, never even watched a single video. My wife noticed that he had included the term “schizo” in his written assessment of her, apparently his highly unprofessional opinion of brain fog.

My wife, “T,” is unable to use the phone, so it fell to me to make her appointments, call in prescription refills, etc. On one occasion, I called in a refill for her thyroid prescription and was told by the doctor’s assistant that T couldn’t have a refill because she hadn’t had any bloodwork done in the past three months. I replied that, at the end of T’s last appointment, the doctor had told her, “See you in six months,” and that her next appointment was scheduled accordingly. The assistant said that bloodwork had to be done every three months, no exceptions. (Apparently, the patient was expected to be able [to] read the medical assistant’s mind.) As we argued, I became increasingly angry and finally said, “You realize this is life and death for her, right?” and she said, “Yes.” I said something like, “So, you’re just going to let her die, because of a miscommunication?” but apparently the answer to that was also “Yes.” Not long afterwards, T received a letter stating that the doctor was terminating her professional relationship with T, with no reason for it given. I have always believed that the assistant with whom I argued had printed the termination letter herself and then forged the doctor’s signature. In any case, T switched to a non-prescription desiccated bovine thyroid product and her health improved considerably.

I had some routine bloodwork done by a new doctor, and the results were frightening: high blood pressure, dangerously high LDL, runaway triglycerides, and low thyroid. She wanted to put me [on] prescription drugs for the high blood pressure and cholesterol, plus a synthetic thyroid hormone. She also told me to take an aspirin every day, to prevent heart attack. I told her that, as an EI, I was concerned with side effects and adverse reactions and was not about to start taking any of those things. Instead, I made some dietary changes and started a daily exercise routine. A few months later, I was retested and all of my numbers were back to normal. The doctor didn’t ask me how I’d lowered my numbers without using meds. She became furious, refused to speak with me on the phone, and had

her Medical Assistant call me to say that, despite the test results, I still needed to be taking all those prescription meds.

For example, once I asked my doctor's receptionist to allow me to wait out on the porch for my appointment. She said no, their office policy would not permit that. I asked whether the fragrance emitters in the waiting room could be unplugged while I waited, and was told no, and to reschedule. I was sick and needed help, and that doctor was the only one I could go to who accepted my Medicaid/Medicare benefits within several hours' drive.

In a few days I received a letter from the doctor's office saying he could not meet my medical needs and that I should find another provider. I was essentially 'fired' and couldn't find another doctor, even another inaccessible one, for over two years.

Source: Susan Molloy letter to U.S. Health and Human Services, Docket HHS-OS-2022-12-1, October 3, 2022.

One close friend in Oakland, Barbara, had repeatedly been made so sick by the fragrances on the hospital staff, the cleaning chemicals, and air "fresheners" that her doctor consented to gynecological exams in a car in the hospital parking lot. Friends held up bed sheets around the car. Barbara was going to need treatment for the cancers that had spread throughout her abdomen.

Source: Susan Molloy letter to U.S. Health and Human Services, Docket HHS-OS-2022-12-1, October 3, 2022.

Another friend of mine, Noel, had gotten sick so severely from chemicals and fragrances in medical offices that she lived for 2-3 years with an aggressive untreated breast cancer, until she died from it.

Source: Susan Molly letter to U.S. Health and Human Services, Docket HHS-OS-2022-12-1, October 3, 2022.

The following is from someone with MCS who worked in a medical clinic. They refused to accommodate her, so she tried to get help from a local MCS clinic:

I invited the [MCS] clinic educational person to my workplace to “educate” the medical staff about MCS. The main doctor came in late to the presentation and he said, “look, I don’t want to listen to this. Everyone who has this illness is crazy.”

Source: Environmental issues and work: women with multiple chemical sensitivities, Juliene Lipson and Nathalie Doiron, *Health Care for Women International*, 27, 2006.

They’re very dismissive and you hear them talk about you in the hallway, you see them rolling their eyes, oh yeah the woman in there with all the chemical things.

Source: Unmet medical care needs in persons with multiple chemical sensitivity: a grounded theory of contested illness, Pamela Gibson et al., *Journal of Nursing and Practice*, 6, 2016.

The author Jerry Evans relates how his first disability evaluation took place in a high-EMF office that was extremely uncomfortable.

When he was summoned for his second evaluation, and the note said he must be prepared for a three-hour stay, he asked the physician to meet him at his environmental doctor’s clinic. It was only a couple of miles down a major road, and his own doctor sent along a note supporting this request.

The evaluation physician had only contempt for the request and simply cancelled the appointment. He didn’t even have the decency to tell Evans.

Source: *Chemical and electrical hypersensitivity: a sufferer’s memoir*, by Jerry Evans, 2010.

Upon two occasions I found myself using the emergency room of our local hospital. Upon mentioning my problems with chemicals, I was either ignored or – as one suggested – it was all bunk and proceeded to make fun of my situation and thought I was nuts. Another time I had to have minor surgery in the emergency room and tried to explain to the nurse that the disinfectant she opened up bothered me. Again, I was ignored.

Source: *Bodies in protest*, Kroll-Smith and Floyd, 1997.

It got to be a ritual. Every time I sat on his examining table, I would tell him that I thought this or that was making me sick. He would look puzzled, shake his head, and tell me I looked fine. I would tell him I might look fine but I feel terrible. He would tell me the tests were negative. I respond with, “Well, we need to make up

some new tests.” Both of us thought my symptoms were strange. The difference is I believed what I had was real and he wasn’t sure he believed me.

Source: *Bodies in protest*, Kroll-Smith and Floyd, 1997.

After thousands of dollars’ worth of tests and lots of time and energy with this rheumatologist, his diagnosis was that I must have a bowling injury – and I was not a bowler!

Source: *Living with multiple chemical sensitivity: narratives of coping*, Gail McCormick, 2001.

I got a call from the [disability] evaluating doctor and he made a couple of sarcastic comments and told me to go back to work, said I was just afraid to go back there because of the smells.

Source: Environmental issues and work: women with multiple chemical sensitivities, Pam Gibson, *Health Care for Women International*, 2006.

I have friends who work in healthcare – I won’t mention in which capacities – and when we meet in town we don’t greet one another. People at the workplace, the general hospital, are unaware that they are electrohypersensitive – and they don’t dare mention it.

Source: *Black on white – voices and witnesses about electrohypersensitivity*, Rigmor Granlund-Lind and John Lind, Sweden: Mimers Brunn, 2004.

Editor’s note: This story is from a nurse, talking about her emergency room visits.

Why can’t anybody tell I’m sick? Why aren’t those blood tests showing? ... I’m, I’m, you know, I’m dying! And dealing with a doctor who would often be cruel – stand there and say “There’s nothing wrong with you.” In the ER, [they’re] saying, “Do you work?” I said, “Well you know, I’m ill, I’m not working right now.” And just write it down “Psychiatric.” This is very sad ... having been a medical professional, you think, “Please support me.” “You are my colleague, please understand,” and they didn’t, because they didn’t have the information ... Even for me as a medical practitioner – I’d look in all my books, I’d look on the internet ... where am I in these textbooks? How come I’m not there?

Source: Multiple chemical sensitivities: stigma and social experiences, Juliene Lipson, *Medical Anthropology Quarterly*, Vol 18, 2, 200-213, 2004.

I told a doc I couldn't tolerate the antibiotic he prescribed (cipro), he said "Then I can't be your doctor." He wouldn't prescribe an alternative I tolerated.

I can't even tell them how serious my MCS is for fear of them not wanting to treat me at all.

Source: Women growing older with environmental sensitivities: a grounded theory model of meeting one's needs, Pamela Gibson et al., *Health Care for Women International*, 2016,

When she arrives for her initial consult, the gastroenterologist subjects the patient to a diatribe in which he pours scorn on the MCS diagnosis, ridicules the diagnosis of yeast-related illness, and strongly advises the patient to seek care from a mental health professional. Nearly speechless, the patient resolved not to receive treatment from this physician.

... a medical student was present. He witnessed the physician's attack on the patient's diagnosis, and the "off the cuff" recommendation that the patient seek mental health care.

Caring for people with multiple chemical sensitivities: creating access to health care, *Townsend Letter for Doctors and Patients*, January 2001.

I can't wear my mask with this doctor because he's really egotistical. He was covered with after-shave and I've been sick all day. Doctors say "There's nothing wrong with you – go see another doctor and you'll be fine." If somebody says "I'm allergic to fragrances" or "Don't put Betadine on me" – just believe them. The Hippocratic Oath says, "Do no harm." It doesn't say, "You're crazy. If you just believed differently, it wouldn't be real." You know, that's been the hardest thing, watching doctors "put us down" like we were "crap."

Source: Multiple chemical sensitivities: stigma and social experiences, Juliene Lipson, *Medical Anthropology Quarterly*. Vol 18, 2, 200-213, 2004.

I had reading problems, memory problems really bad. I described it like a record running on the wrong speed. I had foot drop. I was shuffling like a person with Parkinson's. And the neurological stuff was very obvious, even to my husband who's just a construction person. However, one worker's comp neurologist who

checked me over really fabricated his report and said that it was all in my head. It's been horrible. He said, well I was just faking it.

Source: Multiple chemical sensitivities: stigma and social experiences, Juliene Lipson, *Medical Anthropology Quarterly*, Vol 18, 2, 200-213, 2004.

The fumes from my neighbor's carpet cleaner continued to come into our apartment and I got so sick from it – shaking and dizziness and trembling. I told my allergist about it. He said, "I'm going to tell you a secret, but you must never mention it around here because I'll get into trouble. I think you're chemically sensitive. It means you have to be really, really careful around chemicals." But that's all he told me. He didn't dare go on to tell me what could possibly happen.

Editor's note: The allergist was referring to his colleagues, as medical politics can be fierce.

Source: Multiple chemical sensitivities: stigma and social experiences, Juliene Lipson, *Medical Anthropology Quarterly*, vol 18, 2, 200-213, 2004.

In my experience, dealing with the healthcare system has by far been the worst part in all of this. The suspicion they cast on you. How can you possibly treat people like that?

Source: Impact of self-reported multiple chemical sensitivity on everyday life: a qualitative study, Sine Skovbjerg et al., *Scandinavian Journal of Public Health*, 2009.

Editor's comments

They are not all as described in these stories. We have also heard stories where doctors were willing to accommodate the sick people. Examples include:

- An insurance-hired doctor who was willing to meet outside in the yard for the evaluation.
- A podiatrist in Arizona who came to the patient's home and wore the patient's non-toxic clothes.
- A dentist serves several people with MCS and maintains a less-toxic clinic.
- Most clinics do allow people to wait outside.

The majority of physicians and staff are decent enough, as long as you don't ask for anything that inconveniences them. Most try to just ignore anything that they do not understand or believe in.

Here in the United States, doctors are highly regarded. They are often put on a high pedestal and thought of as somehow "better" than the rest of us. If that was true, then why is our healthcare system so focused on greed, and when there are attempts at reigning them in they vigorously fight any healthcare reform?

The truth is that they are no more ethical than other people. Some are better, some are worse. Their lavish pay attracts some people to whom money is paramount. By the time they finish their training, they tend to have a super-sized ego, which they are smart enough to keep under wraps most of the time.

How people treat defenseless animals says a lot about their character. Similarly, how a doctor treats a vulnerable patient is equally revealing.

More doctor stories

Marty Makary, a surgeon at Johns Hopkins University, wrote the book *Unaccountable* with lots of horror stories from the surgical suite.

Author Marcus Sedgwick wrote *All In Your Head* about how the British health care system treated him when he got sick with CFS/ME. The title says it all.

Sources

The stories shown without attribution were either experienced by the author, or told directly to the author by those who experienced it themselves.

More information

For more stories on living with environmental illnesses, go to www.eiwellspring.org/facesandstories.html.

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