One woman’s story dealing with extreme formaldehyde sensitivity and MCS, including when building a healthy house.

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There is a plethora of information on scents and their pervasiveness in the world, the difficulties in avoiding them and the subsequent ills they can cause people, especially those with MCS and asthma.
However, there are other categories of chemicals capable of causing equal harm. One of those, which I will address is formaldehyde. This is the chemical that I react most severely to.

I recall Dr. Michael Gray saying at a presentation he gave to our HEAL group long ago (probably around 1998 timeframe) at the Quaker Meeting House, that formaldehyde is one of the lowest molecular weight chemicals. Petrochemicals and auto exhaust, for instance, are much heavier and can therefore more readily be filtered out using a carbon mask or filter than the lower weight molecules. He talked about how much further, faster and more easily these lower weight molecules could travel and how damaging they could be due to the fact that there is no smell in very low concentrations. It was very good for me to hear this, as it helped me to understand why it might be that I would react to very low levels of formaldehyde from quite a distance. I asked him if this would be why and he stated most likely it was.

My formaldehyde sensitivity became profound soon after we moved into a newer home in 1990 that had an unfinished garage, attic and bedroom (read, fresh raw exposed particleboard also known as OSB for oriented strand board). Also all the kitchen and bathroom cabinets had interiors and bottoms of unpainted, unsealed particleboard. To make matters even worse, after we'd been there a few months, a new neighborhood of about a dozen homes began to be constructed in the block next to ours, then later, several more were built just behind us on our 1/4 acre lots.

My health was affected first with severe migraines, burning pain in my joints and muscles, increasing inability to absorb and digest foods (I lost 30 lbs./15 kg in that house), and maybe the worst of all was the blind rage attacks. No, really the worst was having a 4 yr old and a 6 month old to care for, who had no understanding (but totally able to sense their security was being threatened) of what was happening around them. Before I fully understood what was happening, we tried to continue living a normal life, but most outings would end with me bedridden for days, not a "luxury" a young mom can easily afford. I literally thought I would not make it out of that house alive at times, but I did after 2 yrs and while I have recovered the ability to tolerate many chemicals to a greater degree, I have never recovered the ability to tolerate the tiniest amounts of formaldehyde exposure.

My sensitivity is still severe enough to this day that I react with a 2-5 day migraine, nausea, vomiting, terrible brain fog and feeling quite sick overall for 3-5 days after even a secondhand exposure to formaldehyde. The migraines have at times been bad enough that I can feel my brain swelling and subsequent pressure
Effects of Formaldehyde

on the roof of my mouth and brainstem, which is a very dangerous place for swelling and pressure to occur. This is because when there is enough pressure on the brainstem the resulting consequence can be seizures, loss of consciousness, and loss of life since it is the brainstem's function to control cardiac, respiratory and central nervous system function. Once, I did lose consciousness and was injured when I came to, flailing and kicking. I still don't know if I had a seizure, oxygen deprivation or what exactly occurred. In milder reactions, I have central sleep apnea from some exposures, which is no fun either, it makes it very difficult to fall asleep as I jerk myself awake repeatedly, gasping for air. I sometimes catch myself in the early stages of falling asleep, not breathing.

Our daughters, Aine and Annalise are still mildly affected by formaldehyde exposure. Fortunately, at this point, it is not enough to severely limit their lives and they are well aware of how important avoidance of this and other chemicals are for them. Aine will get mild headaches, forgetful and quite spacy from exposure to engineered wood. Annalise is more likely to have bloody noses, become a bit irritable, have rashes and sleep disturbances. Even Chase has a mild feeling of un-wellbeing after a large formaldehyde exposure and I have learned that he has a typical appearance from it, a very characteristic darkness under his eyes.

I also suffer from secondhand exposure, which happens from being around someone who has either been to a home improvement or hardware store (of the type that sells particleboard or plywood at their location, stored inside or out) or just been in a car that they have taken to a hardware store recently. I am also affected by stores which sell doors as so often these are made of engineered woods. I can also be affected when in the presence of a person who has been near a large area of construction, usually homes or a commercial site under construction with large amounts of these types of wood. I have recently heard that there is a new, non-formaldehyde glue containing type of particleboard and that these can be detected by the green paint on the ends. I have yet to see this being used in the Tucson area, however, perhaps some of you may have seen this.

The simplest solution by far is for me and anyone who lives with me, such as Chase, to NEVER for any reason whatsoever go to a store that sells these woods. We live our lives as if those stores don't exist (and would prefer greatly that they didn't, or at least stopped selling the awful formaldehyde laden glued woods). If by chance, we inadvertently have an exposure to someone who has been to one of these stores (and this also includes Michaels craft stores for exact reasons unknown to me at this point) our car gets a spritzing of 1/2 white vinegar + 1/2 water solution and then scrubbed with a scrub brush on the upholstery to work the
vinegar solution into all the fibers, which effectively neutralizes the formaldehyde residue enough for me to tolerate the car again without getting migraine while in the car. We also use a sponge soaked in the solution on the dashboard and hard parts. If this is not enough, i.e. the exposure has been a particularly potent or toxic one, we resort to 100% white vinegar. Chase says he most often uses the 100% solution, probably in an effort to save time. Once, when I asked him if he'd remembered to clean his contaminated car with vinegar before getting into it to go to work, he replied, "I felt like a pickle by the time I got to work." Our clothes are always washed using 1/2-1 cup of vinegar per load in the wash cycle, I've found I feel better and am less formaldehyde reactive overall when my clothes are consistently neutralized from this chemical.

An example showing the degree to which I have been sensitized (or poisoned would be a more accurate term) is this: if my husband happens to have a meeting at work with several people in a smaller conference room and one of those people has either been to a hardware or craft store carrying offending items, I react strongly to him after he comes home, even after he's showered and changed into freshly vinegar laundered clothing. Apparently he breathes enough in to be offgassing through his lungs and skin pores to affect the air which I then breathe in his presence. Sometimes if his exposure has been one that has lasted long enough, such as, he's been on a business trip that lasted more than 1 day......it takes 3 days for him to outgas enough for me to tolerate being near him. When we finally figured that out, I realized the only way for me to not be very ill was to have him stay in our sealed off bedroom to outgas. I am very grateful that we had the foresight to make this room he stays in on occasion a separate air space from the rest of the house. Thankfully, the banishment to the detox room doesn't happen very often.

One of the best ways I can describe the pain of formaldehyde exposure for me, is it feels as though I've had an IV of pure acid run in. Everything burns. Not only that, but I am just entirely too sick to function for several days after. This, combined with the horrible brain swelling migraine cause me to do whatever I can to avoid this exposure. It is primary in why I have been so meticulous in discovering exactly what the cause is. In the beginning, I could not have imagined how profound my sensitivity was, as I'm sure many of you may feel about a particular chemical or set of chemicals that affect you.

Once, I had a neighbor who discovered she had urea foam formaldehyde insulation in her home, which is now banned, and she was in the process of ripping it out of her walls. I didn't even know myself how severe my reactivity was at the time and
made the mistake of talking to her for 5 minutes outside. I was doubled over in exquisite pain for several days after that small exposure to her. Within a year of that, she was diagnosed with cancer. The man who'd lived there before she did, died from cancer. She was more fortunate and has since recovered.

Interestingly enough, there seems to be more information on the toxicity of the sweetener aspartame (as opposed to straight formaldehyde) and how it metabolizes into an aldehyde in the body. Many things do that, including alcohol, sugar, molds, and candida. I also learned that lyme spirochetes also produce the toxic by-product of ammonia in vast quantities which exacerbates the whole issue. Because I also have lyme disease, this may help explain my reactivity to formaldehyde. It may be that I got just the right exposures at just the right times, the perfect storm. I did consume more than my fair share of aspartame in the mid 80's.

Someone asked me recently, how do I know that I am reacting to formaldehyde in particleboard/plywood from the hardware store and not all the other chemicals they sell and have there. This is what I told them: I do not like the smell of all the other chemicals in hardware stores and there are quite a few Ace Hardware stores that sell none of these woods. I can go into them myself, do not like the smell at all on any level, but I am fine and do not react at all, that I can tell. However, the ones that carry the offending woods cause me the greatest misery. Also, I react identically to zones under construction with large amounts of particleboard or plywood or in anyone's home which contains those woods, especially in raw unfinished form.

The main reason we chose to live 40 miles out of town is because of the consistency of something being built or a neighbor putting an addition onto their home or the danger of it happening. When this happened, we couldn't spend time outside around our house, the house had to be closed up tight, and I became profoundly more reactive to everything else. When we found the property we now live on, it was with delight that we realized most of our neighbors had mobile homes. This meant that if anyone else were to move in, the likelihood was greater that it would be a new mobile home placed on the lot (goes up in about 3 days) as opposed to construction which may take up to 6 months, devastating my life in the process. We looked at places near Vail and Sahuarita but realized the potential for having homes built around us was great. Also there were 40 acre lots in Sonoita which would've been nice, but all around were 40 acre parcels just waiting for someone to come along and build on. Yes, even 40 acres would not be enough buffer for the resulting formaldehyde of one home being built for me. I could tell in town if a small house was being built 3 blocks away from my home. Closer than
that, or more homes than that and I had to move almost immediately. One very nice benefit of moving into such a rural area has been that I can now be closer to areas under construction temporarily without the same ill effects I once had.

For instance, there is a home currently being built using particleboard about 1/3 of a mile (3 blocks) away from our home and I cannot decipher any reaction at all from it. This is a huge improvement for me and I am very grateful.

We did many things not according to the book when we built our house to keep formaldehyde levels to absolutely zero.

If we had chosen to use a synthetic type of countertop for our kitchen, I would've had them use 100% silicone caulk in place of glue to seal the joints. But, as it was, we ended up going with two different countertops, stainless steel and tile. We were told we needed to have a plywood underlayment to support the counters. We used poplar 2x4's instead.

For the floors, we used portland cement and sand to lay/set the tile in and also for the grout. True, it does crack more easily, but commercial thinset and other adhesives were just not tolerable for me. We put in stainless steel cabinets as solid wood was more expensive and all other cabinets are formaldehyde laden composites. We used redwood behind our shower surrounds as opposed to the standard greenboard as I react to that like it's been soaked in formaldehyde. We found a cheap source for all of our interior doors which are solid poplar, the doors that lead to outside are glass or metal. Our den storage cabinets are also solid poplar we had custom made. And for the walls we used a mix of adobe clay, sand, and Keene's cement. Wallboard was quite difficult for me to tolerate due to glues and newsprint, however there are new types now that may be tolerable to the severely formaldehyde sensitive. For the roof, we used metal trusses with the metal roof placed directly on top to avoid using decking, the plywood underlayment that is usually used these days. Even still, while the roofers were here, I had to stay completely sequestered from them. I found them quite toxic, as they normally do their job installing, laying on. and standing on top of particleboard and plywood all day. One day, I ventured out of my 8x35' trailer and about 4 of them were approximately 50-60 feet away, and yep, I got the quintessential migraine from that few minutes.

I have found some things which help me to deal with the formaldehyde follies and those are primarily anything that helps to rid my body of the toxic effects of ammonia and aldehydes in general. Dr. David Jernigan's Neuro Antitox formulas
have been very helpful. He designed these to eliminate the toxic by-products of lyme spirochetes, ammonia in particular. Also, I am having some success with following some of the recommendations of Amy Yasko, author of the book, *Genetic Bypass*. In general, what I've found to help me with formaldehyde exposure are supplements which get rid of ammonia buildup and help the kidneys to detox. Some of these are magnesium, ornithine, carnitine and a supplement called ora kidney (kidney glandular). It also helps me to eat a low protein diet in addition to eliminating candida, parasites, mold, and sugar.

As you might imagine, this is somewhat difficult (avoiding protein AND carbs) and as a result I do best eating mostly raw vegetables, seeds, nuts and fruits. I also eat plenty of oils such as coconut oil, hemp and flax oils.

**And, from the "normie" in the house:**

My introduction to the degree of Dana's sensitivity came in 1991 when we were living in the house that brought her to full blown MCS. When the construction around us was in full force, I would come home, remove my clothes in the garage, and run upstairs to shower. One week, when Dana was out of town (seeing Dr. Lieberman in South Carolina), the phone rang just as I entered the house. I stopped to answer it, and then continued upstairs to shower. The following week, Dana asked if I had used that phone before showering while she was gone, because when she used it, she got a rash on that side of her face.

In case you haven't noticed, formaldehyde is a life changer for Dana. It is difficult to watch her suffer from an unexpected exposure. Watching your wife with dry heaves, hoping that maybe they will help alleviate some of the suffering is not fun. Not like Disneyland. As you would expect, this has taught me to be hyper-vigilant to prevent inadvertent (or purposeful) exposures.

Most with MCS have their own story of suffering. I am thankful that we were able to find a way to create a safe living space to minimize the frequency of severe reactions, while allowing Dana to increase her ability to tolerate the occasional outing into the 'real' world.

Some websites/articles which may be of interest are:
www.dorway.com/badnews.html
www.dorway.com/detox.txt
www.nccn.net/~wwithin/aspart.htm
www.health-diets.net/healthsearch/detox.htm
www.aehf.com/articles/A44.htm

(Some of these websites no longer exist, but may be retrieved using archive.org, ed.)

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This document is a compilation of some people's experiences. Actual rules vary with location and over time. This document is not a complete list of what you need to know, and not a substitute for your own thorough investigation of any program you may consider.

More MCS stories

Go to www.eiwellspring.org/facesandstories.html for more MCS stories. Our Healthy housing section is at: www.eiwellspring.org/saferhousing.html.