THE AVOIDING MOLD ARCHIVES

QUESTIONS & ANSWERS ABOUT MOLD AVOIDANCE 2013-2014
“The Avoiding Mold Archives”

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For more information about the role of mold toxins in chronic multisystem disease, please visit the Paradigm Change website.

www.paradigmchange.me
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Chapter 1

Overview
Q. 1:1 - Mold is Everywhere

How on earth does one avoid mold if it is everywhere? That does not seem possible.

Lisa Petrisin

It's hard to get away from mold entirely, and most mold does seem to make toxins that are slightly problematic to people who have become sensitized. However, some mold toxins are much worse than others -- meaning that if you can just avoid those toxins, you have the potential of getting a whole lot better.

When I moved out of the house where I lived for the 14+ years of my acute CFS, leaving behind my stuff, I got a lot better within just a couple of months. I was still in Chicago and the apartment I moved to was not pristine, but the exposure that I was getting didn't prevent me from improving. Even a little exposure to my cross-contaminated belongings from the bad house were enough to throw me back into full-fledged illness though.

Later, when I went camping in a good location and got really clear, I got even better (to the point that pretty much all my symptoms went away). That was great, but wouldn't necessarily be realistic for everybody. Getting away from just the worst mold toxins and getting considerably (but not fully) better is something that I think many people realistically can do, if they pursue it in the right way, though.

A.M. Runyan

Sure, mold is everywhere, but what you really want to avoid is certain mold toxins/ biotoxins. Those are typically present around water-damaged buildings or trailers etc., as well as in certain geographic locations. There is plenty of "mold" that is not really a problem.

In terms of how to avoid it: Live in a city that is not known to be extremely toxic (see Locations Effect board), find a well-maintained dwelling with no history of water damage that is not around moldy buildings (preferably not old housing), and practice good mold hygiene: clean up spills, keep the humidity low, use mold-killing natural cleaning products, circulate fresh air, beware of moldy vents/ducts/central heating and cooling, etc.
Julie Rehmeyer:

What other folks have said pretty much covers what I'd say too, except for one other thing that occurs to me: When I was very reactive, it was critical that I take a shower whenever I got home after being out. I live outside Santa Fe, and while the air on my land is very good, the air in town isn't so great, because there are a lot of moldy buildings in Santa Fe (I think because of the flat roofs). So anytime I went into town, I ended up with some amount of mold on my skin, hair and clothes, and if I didn't rinse it off before going to bed, I felt terrible.

Karen Dean

Mold spores are everywhere. So if you want mold, just add water and wait. That said, the seeds, or spores are everywhere, but mostly in a quiet, dormant state.

Mold growth, when it becomes a colony, a visible toxin forming colony, is what is for the average person, or average avoider, to be avoided. Those sensitive must also avoid areas that a colony has released fresh spores. Mold plumes can form, wafting off of moldy houses, air conditioners, or travel trailers. So things to be avoided are water damaged buildings, trailers, or areas near them. For the most part.

For me, when the wind was right, I could be sickened by my neighbors moldy trailer, which was a half mile away, so someone living in an area with a lot of moldy housing, might be in big trouble

Joseph Salowitz

Here is what I do to avoid mold. I remember the humorous admonition that “There is no problem so big that it can’t be run away from!”

One of the joys of my life was being able to attend religious services in the Shul that my father had attended, when he was alive. The continuity of a family tradition was very comforting, at my age [70]. Then, last November, Hurricane Sandy flooded my neighborhood, filling the basement of my shul with 5 feet of water. In the weeks following the flooding, a massive crop of toxic mold was produced in the basement. So I ran! I miss the shul, but I am alive to tell you of my experience. See what a beautiful place it appears to be.

http://www.cspjc.org/
**Erik Johnson**

The only molds that bother me appear to have a sticky quality to them.

The bad stuff feels to me like it wants to glom onto things more than it wants to waft and travel.

On one hand this is bad because it readily contaminates objects, but is good because having stuck itself down, it doesn't generally go far.

I avoid or limit my time in Hot Zones and prevent contaminated objects from entering my safe area, and i can live in fairly close proximity to a bad colony, thanks to this peculiar stickiness it has.

**Terri:**

You're right in that mold is everywhere. However not all molds are toxic. There are approximately 11 or 12 molds that are considered toxic in that they release mycotoxins. There are other things to consider also. When mold interacts with various chemicals or VOC's the interaction can produce toxins. It's a misnomer to think that this is 100% about mold. It's about mold AND how mold interacts with the environment.

A certain percentage of the population has a genetic susceptibility to molds and/or Lyme. These people are much more susceptible to the harmful effects of mold and cannot effectively detox.
Q. 1:2 - Mold Allergy vs. Toxicity

I am not allergic to mold. Does that mean that I am less likely to be sensitive to toxic mold too?

Julie Rehmeyer

Before I started avoidance, I had no clues that mold was an issue for me. I'd lived in four different states and many many different houses during the time I'd been sick, and moving had never seemed to make any significant difference. I'd never lived in a noticeably moldy building. I had never gone into a building and suddenly felt much worse. I had been tested for allergies and mold never came up.

The only reason I got interested in the idea that maybe mold was contributing to my health problems was that I was out of other ideas, and that the theory seemed more coherent than any other that I'd heard. I went to Death Valley for two weeks with none of my own belongings, and when I got home, thirty seconds in my own home was enough to leave me crippled. I stayed with friends and stayed away from my own stuff, and a week later, I was able to go for a steep hike for the first time in more than a year. Avoidance and detox has now gotten me nearly well.

Andrea

We are able to now after many years of rebuilding our immune function finally able to live in a certain amount of mold for a certain amount of time without falling ill. It has not been easy.

A.M. Runyan

Don't bet on it.... the toxicity sensitivity and allergy seems to be related to different genes. Also, at a certain concentration, almost everyone is going to be affected in some way by toxic mold; it can be that bad.

Joseph Salowitz

Nobody knows the answer to your question. I am unlucky enough to have had mold "allergies" for 60 years, and "toxic mold" reactivity for 15 years. As the
"Allergy vs Toxic Exposure" comment in this chain explains, the symptoms are entirely different. The problem with doctors is, that they will always diagnose you as having a mold "allergy," simply because they are uneducated about the existence of "toxic mold" reactivity. Anything outside their area of expertise will always be diagnosed as a "mental problem" that the patient has.

Lisa Petrison

If you go to an allergist, there are two kinds of mold allergy tests that they can do: IgE and IgG.

IgE is for standard allergies, like the kind people have to pollen or dust mites, with runny nose, red eyes, maybe breathing issues. I've not seen anything to indicate that mold toxic people have more of these symptoms than anyone else. I didn’t have any of these symptoms.

IgG suggests that you have had recent exposure to a particular kind of mold spore. This could be mold in your external environment, mold growing in your body or mold in food. (Note that Stachybotrys does not appear to colonize and is not a big food contaminant, and so a high IgG to that suggests environmental exposure.) If people are living in a bad building, they may have high IgG regardless of whether they are being affected by the toxins.

Some/most/all (we need research to find out for sure which of these choices!) CFS patients have hyperreactivity to the toxins made by mold. This means that they may be very affected by mold toxins in the environment even when there is not much of the mold that makes them present. (Or, if cross-contamination of the toxins alone is driving response, then there may not be any of the mold spores that originally made the toxins present.)

Some people do come back from allergy testing with very high IgG levels and find that informative (particularly with regard to their environment being bad). But IgE type allergies (observed or tested) seem to be totally unrelated to toxic problems, as far as I have seen and heard.

Beatrice Latherings

As far as I can tell, I am not allergic to mold. But I have a significant inflammatory response when exposed to mycotoxins.
Moulduk Mould

Interestingly one of our family members reacted as allergic negative. Common sense would say that means not allergic. However, a negative result can be false. In other words a positive is positive but a negative can be wrong. Very frustrating.

Avoiding Mold

An article related to this topic:

Q. 1:3 - What Am I Reacting To?

I know that am reactive to my apartment environment (and am on some lists for low-income housing), but am not sure what I'm reacting to. Possibilities are outgassing rugs, animal dander through the bathroom vent, and of course mold toxins. There was basement flooding here about five years ago with professional remediation. I am on the first floor.

So a few questions:

1) If I were suffering from mold toxicity would I likely have seen or smelled mold in my residence?

2) Could this reaction here be related to mold exposure at an earlier point, then exposure to toxins here?"

Jeff Charlton

Disproportionate numbers of clients of mine who have severe mould allergies also have pets (animal dander). The previous flood may have resulted in moisture and or spores (biological contamination) rising through the building to cause effect in your apartment (Stack effect). Any toxins or allergens produced would remain but it is my belief only active mould produces the VOCS (Volatile Organic Compounds) that result in odors. This means the contamination could be present but no odors present.

Lisa Petrison

There are several articles in the Stachybotrys literature that suggest that the mold destroys olfactory parts of the brain, decreasing the ability to smell things in general.

This seems to me very clever, since if people can't smell the mold, they will be less likely to clean it up.

But even buildings that do not smell moldy to anyone often have severe toxic mold problems.

Mold frequently hides inside drywall (or as in my house behind paneling) and cannot be seen. When it is visible, it often looks more like smears of dirt on the wall than mold.
Certainly there are many stories of people who became poisoned/sensitized by a bad environment and then were unable to tolerate even mildly moldy buildings that are okay for most people. Many other sensitized people remain sick as a result of proximity to contaminated possessions or the outside air, even if the building itself would come up perfect on an ERMI. So any of these could be happening to you.

A.M. Runyan

I don't have much experience with reacting to animals or VOCs, but in terms of mold, think it is possible to react to it without smelling it. There are plenty of buildings that give me strong biotoxin symptoms but don't smell at all. When people really get into avoidance, that seems to be the norm - they learn to observe reactions that happen with no smell involved, and those reactions are a much better guide than the presence or absence of a mold smell. In fact, these days, sometimes I'll smell mold outdoors but it doesn't bother me. It's much more about particular bad toxins, which often do not smell.

I went in a library a few days ago that didn't smell like mold but nonetheless was really toxic and I got sick and had to leave and those toxins cross-contaminated my car. No smell doesn't mean no biotoxins.

A history of water damage can be a little iffy, since professional remediation sometimes does not clean buildings to the point that ill people with bad HLA genes would require. In some sense it doesn't matter what you are reacting to, if you are going to leave? or some measures that would fix one thing would tend to fix many types of problems (ventilation, burn soy candles - good for burning VOCs as well as burning mold toxins - I find it works better than expensive air purifiers).

In terms of prioritizing what to avoid in a new living situation, mold/biotoxins/water damage is absolutely something to prioritize, because the toxins that come from those can be toxic on an entirely different level than simple straight/known toxins, and biotoxins also seem to be able to cause sensitivities to other toxins.

I wish there were PSAs and a huge ad campaign telling people with CFS and Lyme to prioritize living in mold-free housing, even if they don't find themselves to be particularly mold-sensitive yet, simply because having these conditions and related genes puts people at risk for developing environmental illness and mold hypersensitivity if they are exposed to a decent amount of the toxins. Probably goes for things like fertilizer and other MCS triggers too. We need to have a list of things we know to avoid in order to try to prevent more cases of environmental
illness.

Julie Rehmeyer

Definitely not. Smell is not a reliable guide. 2) It is certainly possible that your stuff got contaminated at some point earlier, and that you're reacting to it rather than to the apartment itself.

Erik Johnson

I inspected an apartment and got slammed in the exact center of the room. Bent over and it was in the carpet. No leaks, no water damage, no smell, and no sign that anything was ever there.

Turns out this office space was used by a renter who just passed away after long illness, along with his very sick dog at about the same time.

His desk was in the center of the room. The place I pointed at was where the dog always curled up at his feet.

I immediately thought, "I'll bet I know why he and his dog were so sick, they brought something in from their sick house."

This was the advantage provided me by military biowarfare training, as bioweapons would contaminate in this same manner. I was mentally prepared to accept it.
**Q. 1:4 - Humid Climate**

If you can’t change the climate you live in, is it possible to make a mold prone house into a safe place to live? Or will there always be problems every time you step outside and bring molds in with you?

**Julie Rehmeyer**

If it’s a currently moldy house, and you’re already sick, then my sense is that it will be very difficult to recover there, even if you remediate. But I don’t think every house in a damp climate is going to be a big problem. It depends on the particular location and the particular house. And in some locations, even ones that aren’t outstandingly damp (like Berkeley), it’s likely to be hard to recover even in a very well-built house.

**Jeff Charlton**

Mold prone means it has a moisture problem. I would recommend reducing humidity to below 65% which is approaching mould growth requirements. Repair any water damage such as leaks. Remove any visible mould with soapy water. Ensure dew point condensation isn’t a problem by improving insulation and or ventilation. Then install positive air pressure to keep stuff out. The air which is supplied to create positive pressure should be filtered and or conditioned (to remove excess humidity).

The objective is to prevent mould and associated toxins from entering the living space and keep them inside cavities and voids. The air changes will dilute airborne contamination to some extent and this just leaves the wiping off of contaminated surfaces.

Mycotoxins are not water soluble so removal may require solvents which may have other health issues and finally perhaps consider using a PVA water (IPA) based glue to spray on all surfaces to leave a protective film. All subject to risk and hazard assessments.

**Lisa Petrison**

"Climate" (in terms of humidity) does not seem to be particularly correlated with the amount of particularly bad biotoxins in the outside air. Some dry locations (such as Phoenix) can be very problematic, and some humid locations can be
great. So I wouldn't bother thinking about that factor too much.

Even for Moldies who don't react abnormally to chemicals themselves, pristine locations almost invariably feel better than ones where chemicals have been applied. This is part of why Erik started thinking that it was mold in the context of chemicals that was the problem, rather than mold by itself.

If you are living in a place with really problematic outside air, you will not need to go outside in order to be influenced by the mold toxins in the outside air. They will get inside your dwelling even if you seal it up tight and never go out.

"Modern" houses seem to me prone to mold even out in the desert. On the other hand, almost every house I've been in without wall insulation, HVAC systems or drywall has felt quite good. This has included old Victorians, log cabins, timber frames, adobe and metal sheds. (The one straw bale house I've been in also was very good, but Erik is concerned that if the straw is moldy before the house gets built with it, that could be an ongoing problem.)

So if possible, that's the sort of house I would suggest trying to get, regardless of the climate.

Erik Johnson

It was almost impossible for mold to grow anywhere at Tahoe when I was growing up. Now it is everywhere.

This change has happened so quickly that it appears what might have been a normal house yesterday will be a mold prone spore factory tomorrow.
Q. 1:5 - House Doesn’t Have Mold

I have been sick with CFS for seven years. My house doesn't have mold but there are some old, musty smelling items and I'm wondering if they should be removed? If a building doesn't have mold, are there other things people should look out for?"

Julie Rehmeyer

How do you know that your house doesn't have mold? The thing is that there are levels of mold that are perfectly safe for a healthy person that will keep a person with ME sick. I don't know all that much about testing, but my understanding is that there's really no test at this point that is sensitive and specific enough to tell you if a house is good enough for someone to recover in.

Also, contaminated belongings can be enough to keep you sick as well. And they don't have to smell moldy. Unfortunately, smell is really not a reliable indicator. I've had some musty smelling things not be an issue for me, and other things that don't smell at all are a big issue. Pretty much all smells are volatile organic compounds, but we can't smell all volatile organic compounds.

The best way to figure out if your house is making you sick is to get away from it for a while, and from all of your belongings, and go to a safe place. Two years ago, I went to Death Valley with none of my own stuff for two weeks. Before that, I had no indications that mold was an issue for me -- I'd never lived in an obviously moldy building, I'd never gone into a building and suddenly felt much worse, I'd lived in many different houses in four different states and it had never seemed to matter one way or another. But after my trip, 30 seconds in my own living space was enough to cripple me. When you're in mold all the time, your body gets kind of overwhelmed, and you're sick all the time but you may not get much better or worse quickly enough to tell when you're exposed. But once you're clear, you react much more strongly and obviously.

After that, I got rid of all my stuff, moved into a clean house (I got very lucky here -- it can be very difficult to find housing that's good enough), and got dramatically better. Within a week of returning from Death Valley, I was able to hike again, which was stunning. I've spent the last two years carefully avoiding mold and detoxing, and I'm mostly recovered now.
Karen Dean

As with the previous poster, the mold between the walls of my house went undetected by normal means for over 10 years, making my husband and I very sick. Testing can be a tricky thing.

Beatrice Latherings

What testing have you done to prove your house doesn't have mold? My house had no visible mold nor any odor of mold but the mold inside the wall from a leaky pipe almost killed me. Once you prove through adequate testing (HERTSMI-2) that your house doesn't have mold, then you can move on to what else may be causing the problem.
Q. 1:6 - How Much Improvement?

For those practicing mould avoidance, how much of an improvement has it made to your health? How many of your ME symptoms do you still have? Do you still suffer from crashes, and if so what are they caused by?

Julie Rehmeyer

It has made an astonishing difference in my health. At this point, I get detox symptoms, which for me consist of brain fog, muscle aches, and general unwellness, but further detox usually helps with that.

When I'm exposed, I get some symptoms from that, which are sometimes tricky to distinguish from detox, but also include things like chattering teeth (that's a pretty sure sign of exposure), painful skin (it seems like I can literally feel the mold on my skin), fatigue, a general sense of oppression.

Earlier in avoidance, I'd get far worse reactions to exposure, particularly an inability to walk or even near paralysis of my whole body. I'd also sometimes have difficulty breathing, or my face would contort into these bizarre grimaces, or I'd have great difficulty talking. It could be quite frightening. But as I've progressed with detox, those dramatic reactions have gone away.

The difficulty walking was a symptom I had before beginning avoidance, and it came and went with little discernible pattern, though too much exercise was certainly a trigger. Moldy buildings, interestingly, didn't seem to be a problem, because I was so steeped in mold all the time that it didn't make much difference.

I haven't had difficulty walking now since February. Fatigue is nothing on the same level that it once was. At this point, if you weren't living with me, you probably wouldn't realize that I have any health issues at all.

Really extreme, extended exertion can still trigger several days of exhaustion, but I've only allowed myself to go that far once, for my wedding. And I really pushed myself for that, in a way I haven't allowed myself to do in a very long time.

I can exercise now, though sometimes that diminishes with detox. I'm working pretty much full-time, and my work demands a lot of mental effort. I'm not 100% well yet -- my health still demands time and energy, and I can't count on myself being functional all the time -- but I'm pretty damn good.

And in 2011, I was bedbound half the time, sometimes too weak to turn over in
A.M. Runyan

It has felt like a cornerstone that has made all the other treatments I'm doing feasible and made me able to detox (with CSM, etc.) without the debilitating symptoms I used to get when detoxing without doing extreme avoidance. Um, in terms of improvements: I can now exercise quite a bit, for an hour at a time or so, and I can drive, which I was not able to do for 10 years while I had CFS and then Lyme on top of it, since I didn't have the mental focus or concentration to drive.

The biggest difference is that I feel like I have my real, adult personality back, and I no longer have the easily triggered irritability and sort of child-like, not fully there feeling I had when around mold. I am much more able to spend time alone and don't need other people to balance me emotionally as much, and when I get triggered emotionally it's nowhere near as difficult as it was when I was more toxic/around mold.

The way I see it, what we are being exposed to with mold is like living among biotoxin warfare, and it would make sense it would be hard to heal in such a situation. Certainly, if you are trying to get healthy, getting out of the war zone is a good first step. It would make sense that it's hard to do much else health-wise when these particular inflammatory, gene-modifying, protein synthesis-inhibiting toxins are involved at high levels. Mold avoidance is definitely something to prioritize in healing from CFS and Lyme.

Do I still have crashes? Well, I still get symptoms if exposed to really bad stuff, and it's mainly the odorless really toxic stuff that seems to get me these days; mold I can smell doesn't bother me as much as it used to. But not really random crashes, and also exertion does not cause crashes - I can handle a lot of stress, work, and activity and not crash. And the more I detox, and the more I use things like Alka Seltzer Gold during exposures, the briefer and less overwhelming exposures are.

It can be a big problem if my home environment gets contaminated, since I end up getting exposed to that for a long time, sleeping here, but in general, exposures feel less threatening with time and with detox.

Karen Dean

Without practicing the most extreme avoidance, and more is required each year,
I am totally unable to participate in anything remotely like a life
Q 1:7 - How Fundamental?

How fundamental was mold avoidance and treatment for your health problems? Was it the first and biggest step to getting better? The step on which other treatments depended?

A.M. Runyan

My personal belief, after what I've seen from years of health issues, and then the treatments I've done, is that these particular really terrible biotoxins (from water-damaged buildings and certain contaminated cities) are possibly one of the major causative factors not just in CFS and Lyme but in a lot of illnesses, as in accounting for maybe 25% of why people are sick. From what I hear, EMFs might be involved in making some of the building toxins worse/more prevalent.

In general it seems that these second-order toxins, created through interactions between microbes and various pollution types, could be major, major factors in disease, and we don't even know exactly what they are, since they might not be studied much in labs yet, although studies are coming out that start to show some of the microbe/pollution interactions, such as with toxic mold making more toxins if exposed to certain chemicals.

They say you don't know what you have until you cure it and you can look back and see what it took to fix it. The farther I go on the journey, the more all of this seems like it was a toxicity illness. Also, I realize that I had it most of my life, even from when my family moved to a bad city when I was a few years old.

Far from CFS or Lyme being an isolated thing, where a few treatments off the shelf would fix it, I'm finding that it was more of my lot in life, as someone with biotoxin-sensitive genes and a few bad detox genes, to have this generalized "biotoxin illness" until I was lucky enough to get it bad enough, and to be in contact with Erik and Lisa and a few other people, to learn how to start healing it.

I can't emphasize enough how potent and important biotoxins seem to be for health. It's hard to tell if people have always been around them, since then there's no comparison, but for the people who have been around them (and been sensitive to them) and then gotten away from them and detoxified, the difference is _profound_.

So to answer the specific question, yes, biotoxin avoidance has been a cornerstone for other treatment, and something I really had to figure out to get beyond a certain threshold of how much better I could get, before adding that on.
Before avoiding mold, I could make a certain amount of progress, but some things never went away before mold avoidance:

- fatigue
- exercise problems if I exercised more than about 30 minutes
- needing to rest a lot
- getting sick easily
- feeling like my brain was congested (I called it "running into a lot of red lights" in my brain - things were slower)

Those things have all turned around with mold avoidance.

Also, and this is a change that I love - I can do as many detox treatments as I like while doing mold avoidance, and while I can get some symptoms as toxins come out, I never get that kind of runaway inflammation I used to get when I'd detox in a moldier environment (CSM used to give me really intense inflammation symptoms).

Not only has biotoxin avoidance been a cornerstone for my doing better from my recent health issues; it's shown me that I was sick with biotoxin symptoms far earlier in life than I realized. I can see now that I had these symptoms even as a young child, when I thought I was normal and healthy. I'm getting back certain brain functions I don't seem to have had since I was 2 or 3 years old, like the ability to look around a room and take in the environment fully with my brain (I've been living in sort of a cloud/fog in my own small space around me since that age, due to toxicity).

Lisa Petrison

I started to get sick in 1994 and stayed in the same house until I found out about the mold and moved out (leaving behind my possessions) in 2007. I spent a good bit of time early in my illness learning about different treatments, and I encountered Dr. Dale Guyer (of Indianapolis) when he was first starting his practice. I tried hundreds of different things. And I found a number of treatments that made a difference (including controlling candida, avoiding certain foods, natural hormone replacement and Klonopin). They made me feel a bit better, and I definitely felt worse when I skipped them.

However, during those 13 years, the course of my illness was steadily down, until I got to the point of being in bed almost all of the time and literally comatose the vast majority of the time. It only was after I started doing avoidance that the
course reversed. Since then, though there have been periodic brief downturns (some related to exposures, a few "random"), it has been a steady course back up.

Treatment for CFS while doing mold avoidance is totally different than doing it without avoidance. With avoidance, none of the treatments I used when in the moldy house have been necessary. I don't seem to have a candida problem even if I eat sugar; I only seem to have problems with food if they are contaminated with mycotoxins; I don't take any hormones because it seems like too much trouble and expense for the benefits I observe from taking them; and I sleep like the dead and thus don't need Klonopin. My focus since avoidance has been on detox and on killing pathogens (mostly intestinal parasites, plus I also took herpes antivirals for a while). Those things are not easy with avoidance, but they were impossible without avoidance.

Julie Rehmeyer

Oh my goodness yes. Until I began avoidance, really nothing I tried made any difference, much. Electrolytes were somewhat helpful for POTS and NMH, but other than that, it was pretty much just a matter of constantly trying to figure out how much my body would allow me to do and adjusting my life accordingly. When I started avoidance, I immediately started getting much better."

Shari

Yes, nothing else is even possible without getting out of mold first.

Vicki

Since mold was the first exposure thing that caused my CFS in 1976 (I didn't know the cause at that time), and then again in 1995 (also didn't know the cause), I avoid it like the plague!

When I was diagnosed in 2011 using Dr. Shoemaker's HLA DR and found out I was multi-susceptible, my medical history from 1976 forward made perfect sense. There are buildings I will now never be able to visit, even the only Quest lab in our town. They have to come to me, and I am grateful that they will. There are friends that I will have to visit in a "neutral" place, so they don't contaminate my home because their home is contaminated.
I am fortunate that my home is safe, so many people do not have that blessing. Without the CSM treatment to detox I would still be very sick; I feel it is one of the most very important parts of this treatment. With avoidance, CSM and Lyme treatment, my labs have normalized, even the viruses have been beaten back, VIP has risen.
Q. 1:8 - What Percentage Benefited?

Of the mold-injured or CFS patients you have observed or heard about, what percentage of them have benefited from avoidance alone?

Lisa Petrison

If you're talking about people who have just done casual avoidance, the percentage is perhaps not that high.

Of the people who have followed Erik's extreme avoidance instructions (based on protocols that he learned in the army), all of them have reported benefits.

A problem here can be that for those people who have problems with drainage, fibro-type issues can become worse when doing avoidance. So those may need to be fixed first. (I agree with Paul Cheney that those are not that hard to address effectively though.)

Symptoms may improve only a little at first. The body needs time to do repair work and address infections, in some cases.

Not all symptoms may reverse themselves totally even with effective avoidance. Brain symptoms may improve but not get totally better with just avoidance, for instance.

In my opinion, the main reason to do avoidance is not to feel better in the short term. It's to facilitate detox, so that people will actually make real health improvements and decrease the need for as much avoidance.

From my experience and the reports that I've heard, the body does not like to release toxins if it is not clear, which means that avoidance is key for successful detox. Trying to detoxify without pursuing effective avoidance tends to be unpleasant and ineffective, from what I have heard and experienced.

Julie Rehmeyer

I really don't know if any of the people I know have *done* only avoidance. I see detox as part of the package. Certainly the combo of detox and avoidance, without drugs, has been highly effective for me.
Q. 1:9 - Sudden Onset

My illness began suddenly, 15 months ago, and came on hard and fast as a fever, chills, and brain fog. A few months later, a brain MRI showed several 'punctate' lesions. Are either of these features consistent with a mold-related illness? Lisa's story (and others) sounds more like a gradual onset.

Lisa Petrison

Those "Unidentified Bright Objects" are discussed in Osler's Web. They were associated with the AIDS patients and the CFS patients that emerged in the early 1980's, that book reported.

Of course, it seems that AIDS is a mycotoxin-related illness in at least some cases. Not that the government is interested in that. The researcher who did these studies seems about as angry about their lack of interest in mold as I am:

The UBO's come and go, apparently. I had some of them on an MRI that I had done early in my illness. Of course, the official analysis of the MRI was that there was nothing wrong.

I've known a number of people who have had sudden onset of the drop-dead flu whose experience with mold avoidance has been the same as mine and others'. (Though if you query almost all ME/CFS patients carefully, you will find that they did have mild but noticeable symptoms before they totally fell apart.)

I think the reason that my onset was more gradual was because I was not getting a terribly large amount of exposure to that outdoor toxin, most of the time. It also may have been that the mold problem in my house got worse over time.

Nat

I have moderate CFS/ME with a classic infectious onset (flu-like illness) that lasted about a week and I never recovered. It was definitely sudden. It wasn't until a year later that I stumbled upon mold. We had a roof leak off and on for 3 years. I failed the VCS test and all my labs point to mold. I think sometimes your body fights the toxins as best it can until you get hit by that "trigger" and then it's game over.
Vicki

My exposure to blue green algae produced those exact symptoms within 8 hours of exposure, so I suppose a big mold exposure could do the same thing as they both produce biotoxins. I believe Dr. Shoemaker says that with MRI the brain often will show lesions after a mold exposure. Maybe you could take the online VCS test to see if biotoxin illness could be causing the symptoms.
Q. 1:10 - Fibromyalgia

Have you heard of any people with fibromyalgia trying mould avoidance? If so, how did they do with it?

Lisa Petison

Yes, I've seen quite a few. What seems to be happening here is that the fascia gets all gummed up, preventing the easy flow of lymph out of the body. Candida seems to play a role. I once had an M.D. researcher posit that gliotoxin (made by candida and other fungi) may be substituting for glutathione in the fascia, and that sounds plausible to me.

I've seen a few fibro patients get clear and actually get worse with some of their symptoms (such as the pain). Avoidance seems to trigger the release of toxins from the cells, but if they cannot flow through the lymph and out, it's not going to be a pleasant experience. At one point in my own recovery, lymph flow seemed my biggest problem.

However, as Paul Cheney says, fibro is not that hard to fix. I have seen the following be helpful: reduce sugar/carbs in diet, probiotics, neural therapy, yoga, massage/bodywork, exercise, enzymes, hyperbaric oxygen.

Once the lymph flow is fixed, fibro people seem to do great with avoidance. I've seen some who have gone from being desperately disabled back to full-time work living in a regular house in a city, for instance.
Q. 1:11 - Developmental Delays

I have a three year old with some mild developmental delays. Since moving into our new house his already-present health issues seem to have worsened somewhat. He is now testing positive for one Lyme band and his immune system is in rough shape.

How can I determine if mold is an issue in our home and what should I do if it is?

We did Petri dish testing. Our environmental MD who reviewed photos of the dishes said that nothing grew in or near his bedroom and nothing "troubling" grew at all.

My son has old carpet in his room and I would love to replace, but worry he may react to chemicals from new flooring as well.

His TGF beta 1 levels were high - 6,640 (when 2,300 was top of "normal" range). His IgG levels to common molds and fungi were very low, indicating little immune response to those particular species. He has low stamina, heavy metals issues, and leaky gut from antibiotic usage as well. I would love some advice on how to proceed.

By the way, our home is in Georgia, and is on a slab. Built in 1997. No knowledge of prior water damage, although everything had just been painted so I am not sure how we would know.

The leaky gut, heavy metal, and low stamina issues were present before we moved into this home.

A.M. Runyan

The high TGF-beta tends to be associated with current or prior mold/water damaged building/biotoxin exposure, so perhaps look into getting a doctor to help with CSM or PK protocol or biotoxin detox.

Lisa Petrison

I've seen enough cases now that I am reasonably convinced that classic ME/CFS is always associated with hyperreactivity to various mycotoxins/biotoxins. Whether other health problems are also associated with that, I'm not sure.
In ME/CFS, the way that this typically works is that people first get exposed to a moldy house and get somewhat sick. After that, they become reactive to even small amounts of various toxins. This includes toxins in the outside air, which can end up being even more problematic for them than the toxins from the original moldy house.

If the problem is toxin in the outside air, then testing the house in any way is going to be misleading since "science" has not taken upon itself to study/measure outdoor biotoxins yet.

The exercise that has worked for people with ME/CFS is to go on a vacation to a known good place, with all new possessions, staying either in a tent or a known good building. They may or may not feel a lot better during vacation, but regardless are then more able to figure out what in their home environment is bad (e.g. home, possessions, outside air, other buildings) and make appropriate changes to get away from the toxins.

Obviously this is expensive and a lot of trouble. I also am not sure if a three year old can communicate to you effectively what things are making him feel bad, even if the trip successfully unmasks him enough to be able to tell. And as I say, although I've yet to see anyone with Chronic Lyme, Fibro or CFS who is not reactive to these toxins, I would hesitate at this point to suggest that every "mystery disease" in the world has a connection to it.

In general though, my instinct here based on the info that you have shared is that this could be an outdoor problem rather than an indoor problem. (If you have noted that his illness is much worse in winter or during times of approaching storms, that would be another piece of evidence to suggest outdoor toxins.)

Of course, you can have the ERMI done if you like. But I wouldn't put too much faith that you've eliminated the idea that environmental toxicity is the issue if it comes out okay. The ERMI doesn't measure outdoor toxins, and it also doesn't measure the effects of cross-contaminated possessions from previous residences. And sometimes, from what I've heard, it doesn't even come up as problematic for truly bad buildings.

Rhonda

A lot of times houses built on slabs can be trouble because the slabs don't get sealed. I would do the ERMI test. The other thing is that if he still has Lyme it will present the same illness picture as mold. They are both neurotoxins.
Beatrice Latherings

If there are mold mycotoxins being produced anywhere in your house, they will circulate in the air, and his proximity to the source won't matter much. I don't personally think petri dish tests are anything more than a very broad look.

Something more specific like ERMI or HERTSMI-2 might give you a better picture. If you know of a moldy spot in the house, one person I know got results from air testing that she didn't get from either of the other two tests I mentioned. You need mold species and spore counts to have an accurate test, not just quantity.

As for the carpet....is it possible to carefully remove it and then not put anything else down? Have an unattractive but non-toxic floor for him?
Q. 1:12 - Books

Can some good books be recommended to learn more about mold and mycotoxins?

Lisa Petrison

Here are a few different books, which I think of as serving different purposes.

1. "Surviving Toxic Black Mold Syndrome" by Mary Beth Short-Ray, D.O.

This is a short, easy-to-read book that is appropriate for cognitively challenged patients and friends/relatives who want to read something fast about the basics of mold illness.

Unfortunately it is getting a little dated (2007) and is not available in Kindle form.

Also, I can't speak to the remediation instructions for ordinary people, but it is very dangerous for people with neuroimmune illness to attempt such remediation themselves even with a mask. I have seen people get much more sick for very extended periods of time as a result.

The book is available through Amazon only from independent sellers. It also can be purchased through the author's website (here).


2. Ritchie Shoemaker's Q&A's (membership from Surviving Mold).

For people who want to just learn about Shoemaker's take on this illness, his Q&A's (which he's just been doing for a couple of months) are terrifically informative. Many of the questions are from physicians and the answers are short and straightforward.

The ones from the recent newsletter were: Can mold cause Chiari syndrome? A patient with exposure to a water-damaged building and a low MSH has an MRCoNS that is resistant (as shown by the antibiograms) to gentamicin -- may I still use BEG spray? What do you think about using a combination of hydrogen peroxide and vinegar for cleaning?

3. "Mold Warriors" by Ritchie Shoemaker
I read this book in 2007 when I was extremely sick, and it convinced me that mold was something that I needed to look into. So I give Ritchie Shoemaker (along with Erik) credit for having saved my life. So I have to recommend it.

It is mostly stories about people who suffered mold illness, along with some basic information about what was known at the time it was published (2005) about mold illness and treatment. The stories are still worthwhile reading.

http://www.amazon.com/Mold-Warriors-Fighting-Americas-ebook/dp/B004PLMBYS/


The authors wrote this book while recovering in Montana from a mold exposure from Hurricane Katrina. They interviewed some people knowledgeable about mold at the time and share the things that they believe helped them recover.

Here is a Mercola article that mentions the book:


The book is here:

http://www.amazon.com/Mold-The-War-Within-ebook/dp/B007EVXUVE/

5. "Surviving Mold" by Ritchie Shoemaker

This is a more advanced book on mold illness that needs to be approached as if it were a textbook (e.g. take lots of notes!). Unfortunately, there is no index (the Kindle search function is helpful as a replacement) and no references, and it sometimes is unclear whether something has been published in the literature or is Dr. Shoemaker's opinion.

There's a lot of information in here that you won't find elsewhere and that undoubtedly will be seen in the future as way ahead of its time though.

6. "Back from the Edge" by Lisa Petrison.

This is my own bio of Erik Johnson, meant to provide a brief, fast overview of a variety of tough concepts (mold, CFS, mold avoidance, mold theory) in a readable, enjoyable format. A good starting point.

http://www.amazon.com/dp/B00EDGEHT2

Note that I definitely would not advise buying any mold books used, because of likely cross-contamination issues. Even new books are suspect (since people may contaminate books and then return them). In general, ebooks are preferred.

Beatrice Latherings

The one I got the most out of was “Mold Warriors,” but there is an immense amount of material about fighting court cases, which of course was a big part of it for Shoemaker.
Chapter 2

Hyperreactivity
Q. 2:1 - Becoming Sensitive

Can anyone describe what becoming mould sensitive felt like? Did you become just mold sensitive or chemical sensitive in general?

Vicki

For me, it felt like a fast sinking into overwhelming fatigue, (over a period of days and weeks the first time, faster each subsequent exposure) followed by fluish feelings (aches, inflammation, fevers off and on), followed by a feeling of doom. Mental confusion of varying degrees, changing from day to day.
Q. 2:2 - Increased Sensitivity

What can cause an increase in mould sensitivity? When you get better, will your sensitivity ever decrease, so that you can go into buildings you used not to be able to?

A.M. Runyan

What can cause an increase in sensitivity: getting poisoned more.

With both myself and the person I used to live with, our sensitivity went up dramatically in the space of 48 hours while the apartment was very waterlogged, and suddenly all these buildings that had seemed fine started to smell moldy and give us symptoms.

Does sensitivity go down with detox? Yes!

In my own experience, there have been several buildings that used to be hard for me that are now alright, and I've only been doing extreme avoidance and detox for about five months.

In general, with more detox, I find that while my body still notices mold, it is less interested in it.

Julie Rehmeyer

For me, the course of things was that after I got clear, I got more and more reactive over time, for a year. Then it dramatically dropped. At this point, yes, I can go into buildings I used not to be able to. I'm currently at a conference in Germany, and most of the buildings (but happily not my hotel) are somewhat moldy. It takes a bit of a toll on me, but I'm able to tolerate it. My sensitivity -- i.e., my ability to tell if a building is moldy -- is still high.

Lisa Petrison

Mold reactivity generally goes up with being poisoned more, and goes down with detox or (to some degree) killing off pathogens (e.g. with antivirals or antibiotics).

Mold sensitivity is generally defined as the ability to feel the toxins (rather than the extent that one is harmed by them, which is the reactivity). Getting clear will
increase sensitivity, allowing you to avoid toxins more even as reactivity goes down.

Gwyn

Once I got away from the toxic environments I got better but I had to stay away from all bad places for at least 6 months. After that I can still tell a building is bad but I can be in it for about 30 min to an hour, example being my church. At first my sensitivity was immediate. I could feel my internal organs react. (Yes everyone thought I was crazy and laughed at me.) After a lot of detoxing with CSM I can go in some buildings but I know it's not a place to linger. I also took powdered Glycine every morning. I was told it helps turn off your mold gene.
Q. 2:3 - Sensitization

I think I have a theory about why my sensitivity is so high, almost everywhere I go. Analyzing the ERMI done in my mouldy apartment, I realize that the apartment had high levels of Ochratoxin, Penitrem A, and some Tricothecene (based on the species of mould present). So I guess I'm sensitized to all of the big ones.

Is this the usual story for most of us? Do some of us react mostly to one or the other, or do most of us tend to be sensitized to all of these toxins?

Erik Johnson

All the CFSers I've taken on "The Mold Tour" have had an adverse reaction to the places where clusters of "mystery illness" occurred.

Lisa Petrison

As would be expected, mold illness victims often seem to exhibit specific symptoms that are in accordance with the particular mold toxins that they have had a lot of exposure to. As an obvious example, ochratoxin exposures tend to lead to kidney issues.

I'm not convinced based on the cases that I have seen that heavy exposure to a particular kind of mold increases sensitivity to it in particular, compared to other molds. It's seeming to me more like once your storage areas get filled up with any kind of mold toxin (or possibly other biotoxins such as Lyme toxin), the protective mechanisms go away and subsequent exposures to any kind of mold cause harm. And at that point, it seems to me that it's the inherent toxicity of the toxin that matters, rather than whether or not you've previously been exposed to a lot of it.

Of course, it does seem that after the body has been around a particular toxin a lot and realizes that it is being damaged by it, the allergenic component of the illness (e.g. that some people hypothesize to be related to mast cells) flips on faster upon exposure. That's something different than the actual harm that is caused to the body by the exposures to the toxins though.

The remarkable thing that I have observed is how similar the responses to various places, buildings and objects are across Moldies. If the driver here were the extent to which people had been exposed to a particular toxin, there would be
a lot more diversity. Sometimes, of course, some people will be reactive to more things than others -- for instance, less toxic molds or chemicals may bother some people but not others. But in general, I've yet to hear stories that suggest that a particularly bad toxin was a knockout for some people and not a problem for others. Bad is bad.
Chapter 3

Getting Started
Q. 3:1 - Will Avoidance Work?

Even trying mold avoidance sounds like a big commitment. Is there any way to know in advance if it would work for me? How long do I need to do mold avoidance to see if mold is an issue for me?

Moulduk Mould:

For us it was heart wrenching at the time, so terribly sad, unbelievable and distressing. Now, it's become our way of life. We would never exchange our improved health for our old belongings.

Oh and I should say it took about 3 months for the brain fog to lift. That was when we realized just what a state we had been in!

Damien Blenkinsopp:

I think this question is very personal, but I'd like to point out something that may help in the decision.

Mold avoidance is an unlikely option to try for most because:

1. High cost: It is extreme and difficult, and can be expensive depending on how done. You may also have to give up even more of the things in life you like (where you live, infrastructure, social circle where you are etc.).

2. Very uncertain reward: The reason I say this is because it's hard to believe in, it seems a bit crazy on first hearing that mold can affect us and there is no social support for this belief (in fact there is a lot of social pressure to not believe in this currently - everyone in the normal world you talk to will think it's extreme and that mold can't do this). There's no concrete proof that it will work and not even social proof.

Result: Costly and uncertain reward. In business only the most arrogant entrepreneur would pursue this course - 1 in a million.

So for me, even with having read a lot on the subject and found a lot of correlations and patterns between mold/ mycotoxins and my symptoms and situation - it was a hard decision.

I think the people who make the decision have one of a few things that get them
to make it:

1. They have hit bottom: They are desperate. They have lost a lot of functionality and nothing is working for them. Their quality of life is so low that they have nothing left to lose. This eliminates the cost side of the equation and makes it much easier to make the decision.

2. They have high standards for their life: This is a bit intangible, and I hope it doesn't come across as offensive. It's something I know from business and I think it applies directly here. The higher your standard for the quality of life you can support - the more aggressively you will fight and the more extreme you will be willing to go to get improvements in your standard of life. For me this was important, some of the doctors I saw early on basically told me I'd have to live with this - that was completely unacceptable for me, I wanted 100% of my life back - nothing less, and can't accept less. I think a lot of people get encouraged to accept the situation and lower their standards for the quality of life they will live with. If you do not accept that mindset - if you aren't willing to sacrifice quality of your life, you will find it easier to take more extreme decisions to get back.

3. They have greater clarity about mold: If you have a clearer belief in mold/mycotoxins this can tip the balance for you too. How can you get this if you don't have it? Read the Shoemaker books, read Dave Asprey's work, go out and find other books and information and research papers about it. Also importantly try to connect with people who have experience in mold avoidance, if you get to know them and understand them - ideally meeting them in person, you will get a feel for if you can trust them - and their experience. Collect data related to possible sources of mycotoxins/mold and how it affects you. Are there patterns that fit? If you can get shoemaker blood labs, VCS and other relevant labs to provide proof - that helps too of course. The correlation that led me to mycotoxins and mold was a strange reaction to chocolate and coffee (both of which are very susceptible to mold/mycotoxin contamination). So all these things will help you get more clarity.

Julie Rehmeyer

Mold avoidance *is* a big commitment, particularly the extreme variety. If you're sick and/or desperate enough to try it, the thing to do is to go somewhere very mold-free for about two weeks, with none of your own belongings. But be prepared, because you may not be able to go home afterward.
When I tried it, honestly, the whole thing seemed pretty crazy and unlikely to me -
- but I didn't have any better ideas, and I was too sick to be at all functional, or
even to reliably be able to take care of myself. So I figured, what the heck?

Lisa, who advised me in this (and to whom I am enormously, enormously
grateful), warned me that I needed a plan for what to do if I couldn't go home,
and I figured, well, if it really does turn out that mold is making me sick and that I
can get better if I totally avoid it, it'll be worth it, and if it doesn't, well, it'll be an
interesting experience and at least I won't have the problem of dealing with my
moldy stuff and home to deal with!

The desert is the best way to go, though if you know someone with a house that's
clear of mold in a very good area, that could work too. Not easy to find such a
thing.

Shoemaker has some blood tests you could take to get some sense of whether
mold is an issue for you. They're covered by insurance, if you can find a doctor
who will prescribe them. I don't know how well-vetted his interpretations of the
tests are, though I do know that every moldie I've talked to about them who's
taken them has shown both a genetic vulnerability and high inflammatory
markers. Another option is the Real Time Labs urine mycotoxin test, though it's
expensive, and I'm not confident that a negative result means that you don't have
a problem; it could mean that you have a really big problem, because your
kidneys aren't able to get rid of the stuff. But those tests could be a way of getting
some sense of whether this is worth pursuing for you.

If you're not that sick and/or desperate, but you have reason to think that mold is
an issue, you could try lesser steps: moving into a house with a low EMRI score;
storing objects like books and and soft furniture that that definitely can't be
effectively cleaned, washing clothes many times and hanging them in the sun;
doing detox like CSM, coffee enemas, and saunas, etc. I honestly don't know
how effective that would be, but it might be worth trying.

Beatrice Latherings

Well, have you found anything else that is working? Are you fully functional
physically and mentally? If your answers are yes, then you don't need to try mold
avoidance. If your answers are no, the commitment is to your life and what you
want it to be in the future. You don't have to abandon everything you own, just
set it aside for a couple of months. When you know the results of doing
avoidance, you'll find it easy to make the decision of whether it is the right thing
for you or not. But it's like alcoholism.....you have to avoid completely, not just
mostly, or it will be wasted effort.

Janis Bell

I got benefits within a few weeks if tent camping. However I already knew that my house and my town made me sick and that I felt better out West. I already had all the Shoemaker biotoxin markers and the RTL mycotoxin results. I already knew about my numerous viruses, metals, Lyme toxins, chemical toxins and had tried many worthwhile therapies with modest results for the immodest cost.

So I was willing to take the plunge into radical avoidance. Plus I was crazy enough to think I'd find a good rental in a few months, ha ha, so I didn't have to deal with the fear of this becoming a lifestyle.

Despite cost, stress, and annoying weather, it's been a great journey. I've met extraordinary people and grew to admire my own resourcefulness and physical strength which, after two decades of CFS, I thought were gone. Now they are back and 20 of my symptoms are gone. Know you can always go back to being sick if you want comforts too much to slog through the muck of the avoidance journey and its perils.
Q. 3:2 - Starting Blind

I am unable to sense whether or not mold affects me. I do live in San Francisco, in a very old house, and it is possible that I am living in mold. I am able to tell what chemicals I am sensitive to - mainly fragrances and such because I have removed those from my life since I was a teen, as I was always sensitive to them. And so when I encounter them, I know immediately.

But I cannot for the life of me tell if I'm sensitive to mold, and I understand that if one is living in a moldy environment and exposed to it 24/7, one cannot tell. I am home-bound, and I get much worse when I leave my home...so it's not like staying out of my home for a day works.

I understand that moving to a better location won't do much if you move into a moldy house. I am much too ill to camp and cannot go to the desert or low humidity areas for other health reasons. It seems like I will have to stick with the coast.

If I were to try another location, I would have to live in an apartment or home and I cannot go house hunting. I would have my healthy partner do this and we would just end up moving blindly, hoping that the new house is ok. And moving is so strenuous, I won't be able to move again for at least a couple years due to a crash. (Unless I luck out of course!)

I also cannot move far away from my partner's work as I rely on him as I cannot shop, cook, clean, and need help with basic hygiene. We are thinking of possibly Santa Cruz area? We cannot move further down the coast than that.

Lisa Petrison

San Francisco itself is a mixed bag, apparently due to the fact that it is all-residential (without historic toxic manufacturing such as the solvents used for washing silicon chips) and the general breezes off the ocean (that blow toxins east). Sometimes (maybe most of the time), it feels about as good as almost anywhere. But sometimes, depending on things like barometric pressure and wind, the really bad toxins from other parts of the Bay Area will make their way to SF and cause problems.

So it really depends on how reactive people are. For people who are very reactive, the cross-contamination from the bad days may be enough to keep
them really sick all the time, even if they never drive through any of the surrounding bad areas. For someone whose system is stronger, possibly living in SF would be doable (though still perhaps not optimal).

I visited Santa Cruz a bunch of times last winter and never had any problems with it. So I would think that would be safer.

An experiment that could be worth considering is moving to Santa Cruz, to a house with a good ERMI/HERTSMI score, and not bringing any of your current possessions. I do realize that that would be a huge amount of investment if you're not convinced that mold is a problem for you though.

If you hadn't mentioned the dry air, I would have suggested a three-day trial in one of the cabins or the rental house at Mercey Hot Springs, just so that you could see what "clear" felt like.

Unfortunately I don't know that much about Santa Cruz hotels and so am not sure which one to tell you to pick. I stayed once at the Hampton Inn near downtown Santa Cruz and it was not terrible, but not pristine either. So maybe you could consider a short vacation there, with all different possessions, and then spend as much time as possible outside, to see if you felt any difference at all?

Damien Bienkinsopp

You can take a VCS (Visual Contrast Sensitivity) test that will screen you for biotoxin/ mold illness. It costs just $15 and can be done on your computer at home. It's a no brainer to do this if you suspect any form of mold illness.

Julie Rehmeyer

I think the investment of moving and getting rid of your possessions is so huge that it's almost impossible to do without being convinced it's going to make a big difference. So I'd focus on coming up with some way that you can test the hypothesis first. Of course, that's not so easy either. If you could find a good-enough hotel in Santa Cruz, that'd be a decent way of running the experiment. Shoemaker's blood tests are another way of getting a sense of how much of a role mold is playing. And ERMI on the house you're living in now would be interesting, though not definitive -- the problem could be stuff that you brought in from a previous moldy house.
Q. 3:3 - Seems Impossible

The standard advice to throw out (or put in storage, but buy new ones to use while detoxing) all your possessions and either camp long term (weeks? months?) or live in a clean house makes no sense to me. If so many buildings are moldy, that would mean that most of the people we encounter and most of the buildings we enter are full of mycotoxins. So what can be gained by buying new things from potentially moldy stores? And getting re-contaminated every time we come into contact with someone, who chances are, is living in moldy housing? It seems impossible to completely avoid mycotoxins.

So my questions are:

1. What is the point of replacing my car, clothes, everything, if the stores I buy the new stuff from are probably moldy?

2. What is the point of looking for 'clean' housing when I am sick and don't know what I react to? I have no idea if I am in clean or moldy housing. I always pretty much feel the same, even when I was camping for 4 nights earlier this month.

3. Is there no other way to heal your body? Perhaps address the snp's that cause us to be sensitive to mold?

How on earth do people afford this? I see no way I can afford in the near future to replace my car, my wardrobe, spend even more money on diet to eliminate all contaminated foods, and rent a house that potentially is more expensive.

A.M. Runyan

As a quick answer, the stuff people need to avoid to heal is not all mold, or not all toxins, but rather very specific toxins.

These are not on everything you buy, and I'm able to buy a lot of items that don't contain these toxins. Most of what I get on Amazon is totally fine and in fact I think there's been only one item, a supplement, that seemed to have problematic toxins, and it was an herb manufactured in Texas and just tasted moldy, not even that toxic.

As for it being daunting: 10 or 20 years ago, avoiding gluten was really daunting.
Yet now, more people are doing it and more people have realized that as hard as it is, it's worth it, and a good idea for most people with serious health issues. Mold is headed in the same direction.

The body doesn't care if it's hard to avoid something. It just knows what it likes and what it doesn't like. And over time, as more people realize mold is bad I think we'll see better building practices, and frankly more and more business/resources/supplies for low-mold living, particularly for affordable tiny houses, etc.

As for expense, for now,

-In general getting sick people healthy is expensive, whether you use drugs, doctors, supplements, IVs, etc. As a treatment, the basics of mold avoidance probably constitutes one of the most cost-effective CFS/Lyme treatments, in terms of the results per cost (this is if you think in terms of just sleeping anywhere cheap.)

-It depends on how sick people are, how extreme they need to be with avoidance. I am typically assuming on this page that readers have CFS or Lyme or mold illness, and are not mostly healthy, and thus that they need to be as extreme as possible with avoidance.

-Some people keep their cars, clean them as much as they can with ozone, and then use decontamination every time they use their cars (shower and change clothes and wash the clothes when they get home).

-Low mycotoxin diet does not need to be expensive. Grass-fed butter is fairly cheap per calorie. I honestly end up eating less food since I don't have sugar cravings now. There are articles on "hacking the cost of the bulletproof diet." Cooking your own food saves money over eating out.

-As a really low budget way to do this, some people just sleep in Walmart parking lots, camp in people's back yards, etc. You learn to just think in terms of "Where is a clean place where I can sleep tonight."

-For clothing, I buy most of my clothing online from Amazon and found cheap items that are not moldy, and I just send them back if they get contaminated beyond the point of rescue. There are packs where you can get a lot of socks, white shirts, etc. at once, or decent shirts for $7 or whatever. You learn to see clothes as functional rather than decorative. During the first few months of avoidance when it was hard to maintain a set of clothes that felt clean enough, I would tell people I mainly wear clothes so I don't get arrested for nudity (Now I
Lisa Petrison

There are many kinds of mold in the world. Some is more or less non-toxic. Some is moderately toxic. Some is extremely toxic (e.g. for a sensitized person, beyond anyone’s wildest imaginings).

The goal of avoidance (in my opinion) is to scrupulously avoid the really bad toxins; avoid the moderately toxic stuff as much as reasonably possible; and not worry too much about the non-toxic stuff.

The reason to do a test away from possessions is to see which category they fall into, insofar as they are contaminated with mold at all. If they are not contaminated or contaminated only with the non-toxic kind of mold, then all is good. If they are contaminated with the moderately toxic kind, then you may be able to wash them and keep them. But if they are contaminated with the horrifically toxic kind, then you may not be able to salvage them.

From what I have seen, people who have CFS or related illnesses invariably are carrying around the worst kinds of toxins, unless they have been away from the place where they got sick for a very long time. So it’s not just a crapshoot, to think that maybe you can keep your stuff because most places aren’t contaminated.

With regard to specific questions.

1. Most things from stores are not going to be contaminated with the worst toxins. You may end up washing everything that you buy before using it. You may have to bring some items back because it turned out that you couldn’t tolerate them. (Note: REI and LL Bean have terrific return policies.) The key is for you to be clear enough that you can judge which items are safe for you.

2. If you are reactive to your possessions that you took camping and/or went camping in a bad place, then I would not expect you to feel different when camping. To get clear, you need to control for all factors of exposure, including a) building/vehicle/tent (tents can be cross-contaminated, of course), b) possessions, c) outside air.

3. Lots of people have asked that question about healing the body in other ways, looking at snps, etc. From what I have seen so far (based on interviews that I’ve done with mostly recovered people), almost all of those who do get well
after extended illness all end up acknowledging that, yes, they know they are
reactive to mold and yes, they avoid it, and yes, they get sick around it.

4. Yes, this is expensive. In my experience, being disabled and deathly sick is
more expensive. So for me, this has been worth it.
Q. 3:4 - Evaluating Options

I have been temporarily staying in the guest house of my employers (with all my stuff, some of which I had with me in the very moldy house that may have contributed to my sickness). I need to find my own place. I am not severely ill, but I am far from well and would like to try mold avoidance.

Here are my options:

1. Put all my stuff in storage and rent the safest house I can find: an old adobe house that has no drywall in it. Would this be enough to 'get clear' and start to heal? I need to keep my nanny job, and would therefore continue working a few days a week in my employers' house, where I have of course been entering with all my contaminated things since I moved here. Would working in a house where I had previously entered be enough to prevent me from getting clear?

2. Wait to do mold avoidance until next year, when I can quit my job after saving up money and camp for a couple weeks or more?

I want to only replace my belongings once, so I would hate to take option 1 and buy new stuff if the experiment would fail, i.e., I'd get recontaminated by continuing to keep my job. But I'd also not like to postpone healing.

A.M. Runyan

I like the idea of a short trip... even a weekend trip can be informative. Also, lots of us are used to being on the verge of having to replace belongings for long periods of time... You can get less expensive stuff and simplify so that if you do have to replace it, it's less expensive... For example, I don't have a bed now... I sleep on a blanket on the floor. During the period of healing it really helps to have fewer possessions and cheaper possessions, and it's kind of fun to live more simply for a while. Mold illness will really teach you to value people and your own health/feeling like yourself over things.

Lisa Petrison

I think you should do an experiment attempting to get clear now, even if it's not for two full weeks. Then you will be better able to judge what's happening in your environment based on your reactions to them, rather than guesswork.
I've yet to visit a KOA Kabin that has been problematic with regard to mold, and at least on previous occasions when I've visited it (a few months ago and a couple of years ago in November), Las Vegas, NM, felt good to me. So I would consider going on a sabbatical there for a few days. This may or may not get you dramatically clear, but if you don't bring along suspicious possessions, at least it would be a start. There's also a decent health food store in Las Vegas, which makes this kind of thing easier.

**Michele**

Interesting that Lisa mentioned the cabin's at KOA. I did a 4 day cabin/ camping retreat this summer, and felt great. I had a re-exposure upon returning home; within the same week. I agree, taking a short sabbatical should help you understand how you are feeling in a "clean" place. I will have to say, in my opinion. If you're sick but, "not so bad right now", I would not take the risk and wait another year. If you can take the right steps now, it could save and retrieve your health. The faster the better; when getting out of a mold exposure.
Q. 3:5 - Symptom Alleviation

Is there an order or guiding symptoms alleviation indications that people notice things happening once you reach the pristine environment, like first you may just notice a bit more energy, then you notice digestion normalizing, then temperature intolerance, etc.? Or is it different for everyone?

Lisa Petrison:

If people are really clear, then symptoms that are the direct result of the inflammatory processes generally improve pretty quickly. Specifically, sleep issues, brain fog, exercise intolerance, emotional lability, overall feeling like crap may diminish. Especially if people have symptoms that wax and wane, that you have good days and bad days with, they may see a fast change. Because an avoidance trial is like systematically creating a good day.

I think the temperature intolerance that some people experience may be due to a bug. It seems to take a lot of avoidance to resolve.

I wouldn't necessarily count on digestive issues getting better right away. Some people actually find that they get worse, apparently due to mycotoxins having a disruptive effect on the gut as they leave the body.

Getting clear helps make the brain feel clearer, but I did not find that it returned my brain to pre-illness functioning even after a lot of it. Valcyte helped a little with brain function, but what seemed to help most was detox.

Energy seems to return gradually for most people. Faster for some than others.

Beatrice Latherings:

I just slowly felt better overall, and it didn’t go away like the temporary improvements do.

Daliya Robson:

It takes years to get well.
Q. 3:6 - Not Feeling Better

I've been living in a water damaged house for about six months and just moved out. I believe mold was giving me chronic fatigue and chronic headaches. How soon can I expect to feel better being out of the water damaged environment? If, having left the house, I still have headaches, is this suggestive that it will take a while to detox or of some deeper neurological issue?"

Lisa Petrison

If your headaches are like migraines but not one-sided, then my initial suspicion is that you may be reacting to a particularly bad toxin in the outdoor air, which causes that kind of symptom as well as a bunch of others, which I will list below. What seems to happen is that living in a bad home will make people less able to tolerate ALL problematic mold toxins, including some that are in the outside air. And this one in the outside air (I have found it to be particularly bad in certain places -- parts of the Tahoe area, parts of SF, Dallas, Ann Arbor) bestows particularly bad symptoms, much worse than the ones that I had when I was living in my house with the Stachy in it.

It's extremely difficult to get much better with even a small amount of exposure to this particular toxin, from what I've observed. And it cross-contaminates easily, meaning that even if people are in a good building, their possessions may be contaminated by exposure to the air. And avoidance is tricky, because symptoms may be delayed. Unfortunately, no one says this is easy! If avoidance just meant moving to a good house, a lot more people would have gotten better from this disease.

* Heart pain (in particular, a feeling of a needle through the heart).
* Heart palpitations.
* Chest pressure (a feeling of a dagger through the chest or a marble - sometimes actually swollen - at the sternum).
* Excruciating headaches (migraine-like but not one-sided).
* Extreme photophobia (light sensitivity).
* Extreme noise sensitivity.
* Cognitive problems that go beyond brain fog (e.g. inability to add numbers or recognize words)
* Weird memory losses (like the inability to remember the name of one's hometown or to find the way home)
* Seizures or "white-outs" (where the brain goes 100% blank for extended periods of time, sometimes even when a concerted effort is being made to bring
up thoughts)
* Severe trembling.
* Organ pain (particularly kidney pain).
* Strong suicidal feelings.
* Feelings of paranoia, like people who are usually your friends have become enemies.
* Strong feelings of anger and lack of inhibition in expressing it.
* Other emotions that are bizarrely inappropriate to the situation.
* Convulsions.
* Extreme MCS.
* Marked gait problems.
* Inability to sit or stand up.
* Severe POTS (e.g. needing to use a wheelchair)
* Extremely deep skin "dents."
* Feeling of skin being burned.
* Sore throats that make eating difficult or impossible.
* Veins pop out of skin (look "ropy")
* Stuck thinking (e.g. spend all day clicking on the same three websites or playing game like "Farmville")

A.M. Runyan

Sounds to me like it could take you a while to detox to get those symptoms to go away. Took me about three months to get the obvious symptoms to go away (confusion, delirious feeling, memory loss), and then another year to try to get mold levels low enough to stop being hypersensitive to mold.
Q. 3:7 - Hosting a Newbie

I am doing well with avoidance and am living in a very good house. A friend of mine visited me a couple of weeks ago, and I ended up reacting to her clothes. That was a pretty strong indication to me that her house is pretty bad, because that doesn't happen much anymore. She also contaminated my house slightly, though fortunately not in a terrible way.

She's had autoimmune and other health problems, so naturally, it seemed quite plausible that the mold is linked. We're going to Europe for a month, so I offered to let her stay in my house while we were gone as a way to get clear, provided that she brought nothing with her.

To my surprise, she's game. I've warned her that she may not be able to go home afterward, and she's had the experience of avoiding wheat and then becoming hypersensitive, so she has a sense of what I'm talking about. She has no plan for what she'll do if that happens, but she feel alike she'll figure it out, and that it'll be worth it to have a path to improve her health -- which is pretty much where I was when I got clear too.

She also has had a chronic sinus infection which she thinks may well be fungal. Antibiotics help, but only as long as she's on them.

She doesn't have a doctor who's clued in to this. I'm a little worried that if she does have an active fungal infection, it will compromise the experiment. So I'd like to ask our assorted experts about this, to see if anyone has any relevant experience."

Lisa Petrison

When I moved out of the house where I got sick, I had a fungal sinus infection as well as some kind of lung infection (which I think may have been aspergillosis).

After about four days of living in an ordinarily (rather than horribly) moldy building and putting my contaminated possessions aside, I started hyperreacting to my possessions intensely. Within about two weeks, the lung infection went away permanently. The sinus infection got better too. And a number of the other symptoms I had receded as well (although it would take quite a few more months before I got to feeling even semi-recovered).

So if your friend is living in a particularly bad building, I tend to think that whatever internal fungal infections she has will not prevent her from making
A.M. Runyan

I don't know about sinus infections specifically, but from what I've gathered, most of us with mold illness have some degree of fungal sinus infections. In fact, paying attention to my sinuses now, I might still have some degree of it. And I'm pretty sure I had some fungal issues there before moving and doing extreme avoidance. So to me at least it doesn't seem like that would knock out the possibility of improvement. The lungs/ breathing are a major way to inhale toxins constantly, so if your friend gets a break from inhaling them that way she might notice changes.

I'd be a little concerned about the house, since if she's there and not around her clothes or belongings this time, she might spew toxins out of her clothes.

Perhaps if she uses cholestyramine or alpha lipoic acid while visiting she will detox less onto your house/ things in your house. You might also want to have her shower frequently to wash the toxins off her skin, since they probably will be coming out. People who have soaked up toxins can be like sponges for them, and when they start to do avoidance it's like starting to wring out the sponge.... lots of stuff can come out. These measures would be good for her too and would probably help the experiment to be more effective.

When I was first doing avoidance, my sweat was so toxic I ended up throwing away or returning most of my clothes after wearing them. I'd wear a shirt until it became too toxic, and that was the end of that shirt. Just an example of how people can put out a lot of toxins when they first get away from exposures.

Karen Dean

Even if she brings nothing with her, her skin will dump toxins all over your house, especially the bed. I have experienced this from my own body after an especially bad exposure. When I started to recover, everywhere I had been, sat or touched was contaminated from my having sat there before. It was really hard for me and strange for my friends to watch me walking around a table playing “eenie meenie miney moe” to pick a chair I had not sat in before.
Q. 3:8 - Stepping Down Gradually

Is it better to get clear of mold by stepping down my exposure gradually rather than getting clear in a pristine place from the beginning? Is it possible to recover from mold illness without going through a period of extreme hyper-reactivity? I'm looking for a balance between being able to lead a normal life, being able to work in a building, but still recovering my health.

Lisa Petrison

I have seen numerous people (including me) move from a bad environment to a better but not pristine one, without cross-contaminated possessions, and see substantial health gains. That especially is the case if they routinely decontaminate when returning home from suspicious environments.

The main challenge here is making sure that the environment that you are living in is okay rather than problematic. Possibly an ERMI test would help with the building, and possibly the Locations Effect site would help in choosing a location. Possessions tend to be the biggest wildcard, because it's hard to know if they are a problem without getting away from them. Some possessions are fine; others are fine with a wash; and some are going to be a deal-killer no matter what you do with them. And it's hard to know which category yours fall into, until you've gotten away from them (or possibly had another Moldie test them).

If people can manage to get to an okay building in an okay location, without particularly problematic possessions, and especially if they decontaminate routinely, then I would predict that most would generally see some gradual improvements over time. In particular, various treatments of whatever sort may work better, and various symptoms may improve.

The main problem with "moderate avoidance" (other than getting there), in my opinion, is that the body seems to detox effectively mostly only when it is really clear (at whatever level of avoidance is required for that particular person). And based on my understanding of this illness, I don't think it's possible to really recover without getting rid of the toxins. So if the goal is to eventually live a normal life, then focusing on the front end on extreme avoidance plus a lot of detox may make sense.

A question is whether it would be possible to detox effectively without being super-clear. I think Ampligen has potential for that, but it can cost up to $50k per year, and most of the Ampligen doctors are located in really bad places. I think
that Gerson may have potential (in a decent environment), but it truly is a full-time job even for a well person to do all the food prep, and I don't know if this diet would be appropriate for a severely ill ME person even if they had help. I've seen a few people detox effectively through Yasko's approach, as patients of Amy Yasko, but that is expensive too.

The other thing that I wonder about are therapies that "reset" the system, such as the stem cell treatments that Cheney patients got or the bone marrow transplants just reported as being helpful (maybe curative) for some M.S. patients. Maybe there is something screwy in our immune systems, e.g. with Th17 cells, that if fixed would permit us to detoxify without having to be in as good of a place. But of course, those treatments are expensive and likely at present impossible to actually get.

One rule of thumb is that the sicker people are, the more scrupulous they are going to likely have to be in terms of avoidance. So if someone is working at present rather than totally bedridden, I would suggest that there is a good chance that the reactivity to most molds is only going to be moderate, and thus that effective avoidance will be much easier than it was at the beginning for me.

Corinne

I agree that it depends on how sick you are. for me I needed that in-between step. I rented a cob house that was made out of natural materials and was more or less fragrance free and only brought one outfit with me and my meds. from there I was able to improve and also figure out what toxins I was sensitive to. it helped me to gain enough energy to be able to make the next step to a cleaner environment and figure out what I could bring and not bring. I have improved more in the second, cleaner location. ideally there would be a third step for me going forward as I continue to become more sensitive I cannot get my current environment prefect.

Beatrice Latherings

I did not make spectacular improvement until I got in a really clean place for six months. Then I came back to my not-quite-as-good-air place and have maintained progress. I vote for outside living for at least a year and maybe two. The less you are taking in, the more you can get out.
Q. 3:9 - Skipping the Sabbatical

Has anyone recovered by finding an okay house and workplace, as opposed to doing a wilderness sabbatical?

A.M. Runyan

It seems important to get to where you are able to notice mold. I had a different path than some people, in that I had already developed acute mold sensitivity before even trying to do avoidance, from having a lot of mold exposure at once, and that sensitivity taught me to do avoidance already, so I didn't have to go to the extreme wilderness to learn where mold was, and it was pretty clear to me, and in fact I was simply forced out of my state by not being able to find any tolerable housing there/bad outdoor air. I stayed in hotels for three months in dry areas in the west while detoxing and then found a decent apartment. Some people need to go to much clearer areas in order to be able to detect and avoid mold though.

Lisa Petrison

In my observation, to get even somewhat better from a severe level of this illness, people need to be a) in a pretty good home (whether it be house, apartment, tent or RV), b) in an area with pretty good outdoor air, c) not having possessions contaminated with particularly bad toxins, and d) decontaminating after exposures to problem places.

I have seen many people do this living in an apartment or house. But it's not going to be living in, say, Ann Arbor. And contaminated possessions (even if washed, in many cases) can be another total deal breaker.

The reason to do a wilderness sabbatical is not with the intent of living in the wilderness, but to get sensitivity up enough so that it's possible to efficiently gauge the outdoor air in different places, choose a good house and workplace, and decide whether just washing possessions is enough. Without the ability to make those judgments, you're shooting blind.

It's not necessarily the case that the "getting clear sabbatical' needs to be done with a tent in the Godforsaken desert. I know one person who got clear initially by visiting the very good home in a very good town of someone who had gotten to "mostly recovered" status from this disease.
But it's a rare recovered Moldie who is going to open their home to someone sick with this disease, and it's hard to know if anywhere else is going to be good enough. So the tent camping sabbatical in a known good place is usually more easily available.

Of course, this does depend on how far along the level of illness is. For some very reactive people, like I was at the beginning, a good home in a decent town may be enough to prompt improvements but not a move toward real wellness. In that case, exposure to somewhere really clear for longer than a week or two might be really helpful. But not necessary to achieve improvements, in most cases.

**Julie Rehmeyer**

Getting clear changed everything for me. Before that, I was stewing in the mold from my possessions, and that was so bad that I couldn't tell at all when I went into a good or bad place. Afterward, it was unmissable. I couldn't possibly have taken the extreme steps I had to take without the certainty of their necessity that getting clear provided, nor could I have known where I could recover. Had I somehow stumbled into a really good place and gotten rid of all my stuff and been able to avoid recontaminating my home even though I couldn't detect contamination, yes, I think I would have gotten clear without a wilderness trip and would have recovered. But the chances of that were exceedingly slim.

**Beatrice Latherings**

It depends on the severity of the exposure and your response to it. Over my life I've lived in awful places and some fine places. The problem was that I didn't know what was causing the problem until it went over the top in an awful place, and after that it was too late.

**Gwyn**

Oh sure. There are several people I know. We either had to quit our jobs or move to another house or both but we still got better. Your life will be totally different but the price is worth your health improving.
Chapter 4

Mold Sabbatical
Q. 4:1 - Where to Go

I currently live in Ann Arbor, Michigan, and have what I would consider 'moderate' CFS. I have the 'low MSH' HLA type. I have seen several suggestions that camping in Death Valley is a good way to test out the location effect. I may have talked a friend into accompanying me on such a trip, so I want to ask your suggestions about where to go, how to go about it, etc? Also, what other locations do you know of that are currently considered 'good'?

Lisa Petrison

Of the places that I've been, here are some spots that I think would be reliably good for a mold avoidance sabbatical in addition to Death Valley.

* Mercey Hot Springs

This is about two hours from the Bay Area, totally off the grid in the California desert. They have tent camping, RV spots and cabins (including a house). The buildings seem fine to me (except the one with indoor tubs). The only downside is that they don't offer food and so you have to bring your own. However, if you brought your own refrigerator and used their electricity for it, I think that would work out okay.

* Ghost Ranch (Abiqui), NM

This has been one of my favorite places for decades, and it still felt exceptionally good to me recently. It is a retreat center run by the Presbyterian Church, with seminars, camping and nightly room rentals. I'm not sure about all the buildings, but the air is great. They serve food and there are restaurants in town. I'm going to go back and spend time there myself. A large public campground near Abiqui Lake is also nearby, and that feels good too.

* Black Hills, SD.

I've not been here for a couple of years and so am not absolutely sure that fire retardants haven't ruined it. But it felt very good in the past, and has a lot of available camping, restaurants and attractions. (Not much organic food though -- there is one small healthy food store in Rapid City.) A possibly good place for the summer months.

* Palm Springs/Joshua Tree.
There is one park in Desert Hot Springs that allows tent camping. The Joshua Tree area is not as warm, but also is a possibility. I wrote a while back, called "Things to Do in Palm Springs (and Environs)."

* Death Valley

I wrote a summary about "Camping in Death Valley."

* St. George, Utah

This is the warmest part of Utah. The state park, Snow Canyon, always has felt good to me. It is just a short drive to town, which has some health food stores and a variety of restaurants. ("Snow" is someone's name, not a weather descriptor. Winter camping is possible, though a bit chilly at night.) Forebearance also identified some resorts that felt good to her near St. George, and I think commented on them on the Locations Effect board at one point. For warmer months, much of Utah feels terrific.

* Las Vegas, Nevada

There is a park just outside Las Vegas called Red Rocks, with campground. No electricity or showers. The upside here is that it is a short drive from the Yuppie part of Las Vegas, with a variety of restaurants and stores.

As always, I suggest that people looking for good locations check out the Locations Effect board in advance, and then share their experiences on it later on.

Julie Rehmeyer

There are quite a few different places that are good to camp to get clear, though in the wintertime, Death Valley has the advantage of being warmer than most anywhere else. The key to implementing this idea is to go with none of your own belongings, because your own stuff is likely to be contaminated. That includes not taking your own car.
Q. 4:2 - Minimum Length

How long is minimum to test avoidance during an initial sabbatical and notice a difference? I know people will say 'it depends on how toxic you are' but by now there should be enough people having tried it that you can say 'sometime between 1-x weeks you should notice a difference, if it is going to work at all.' To that point, how many people have tried this but noticed NO difference? My sense from reading is that everyone notices a difference. So is it just a matter of degree? If not everyone notices a difference, then I would like to know exactly what the odds are that it is going to work.

Lisa Petrison

Of the people with ME/CFS that I've seen go from a suspected bad environment to a clear environment (whether building, camper or tent), in a good location, without contaminated stuff, this is the range of responses that I've seen.

* A couple of people have immediately felt much better, within a day or two, and immediately been able to go hiking, feel almost well, drink beer, and other unusual activities. These people generally have no problem when they get home concluding that their home environment is a problem. (The fact that it was so problematic is undoubtedly why the shift made such a big difference for them.)

* Some people feel better when camping, but not necessarily better than they occasionally do anyway. They generally can start after a few weeks of being clearer to tie new exposures to downturns in health. With continued avoidance (e.g. in a more civilized environment), they tend to experience more health gains over time. I've seen a lot of people fall into this category.

* Some people notice a shift in some of their symptoms when they get to a good location in terms of mold (especially a decrease in brain inflammation). But they do not necessarily feel better because their other sensitivities (noise/light/chemicals/cold/hot/campfires) cause them to feel generally sick or weak or not to be able to get any sleep. From what I have seen, people who are motivated enough to get to this stage and who do see a benefit in some symptoms eventually figure out how to control the conditions to be able to feel better in general. But this can take some doing.

* I've seen a couple of people with fibro issues say that they actually feel worse in a really clear place with regard to some of their symptoms, especially the physical pain ones. I think that this is because the body naturally starts throwing
off toxins in a good place and then they get backed up in the lymph, if it is not flowing properly. So fibro sufferers may need to figure out how to address this issue, if they are going to be able to benefit from avoidance. Options for this could include bodywork, probiotics, diet changes or herbs, for instance.

* I occasionally have heard of people who say that they tried this experiment and that it didn't make a difference for them. Usually though, they tell me that they camped in, say, England or on the East Coast, which is a very good explanation right there. There is one person who went camping in Joshua Tree (a good place) that I hear didn't feel like it was a useful experience, but I don't have enough details (about either the trial or the specific health condition) to make a definite conclusion about it. Of maybe 20 people that I've conversed extensively with prior to their trying this, all have fit into the categories above. (I don't do that kind of counseling any more though.)

In terms of length of time, probably the amounts recommended for gluten avoidance trials would be appropriate. Two weeks probably would be optimal. One week would be enough to probably notice at least something, I would generally think, though.

Julie Rehmeyer

I fell into Lisa's second category. When I got home, I was suddenly very reactive to my own living space, which had never before been a problem. I stayed out of it and stayed with friends. A week later, I was suddenly able to exercise again, which was almost unbelievable. That was the first indication I had that avoidance was actually going to make me feel better.

Beatrice Latherings

There is a learning curve with avoidance, in which you find out what avoidance really is. It took me several months to feel better, but I was not out in the pristine desert, just outside in a desert city. Back before I was so incredibly toxined up, I'd notice a distinct difference in just three days, but that was when I only had moderate exposure going on.

Daliya Robson

Without a strict food plan and lots of probiotics and avoidance of all chemicals and mold it takes longer to heal. I have spent 23 years working on this. I'm kind
of ok now but still avoid and watch food and take 1000 billion of probiotics about 4 times a week. I don’t go anywhere without yards of carbon to protect myself from odors on and from mattresses closets carpets sofas and anything that might come thru windows.
Q. 4:3 - Low Functionality

I am thinking about going on an initial mold avoidance sabbatical and have some questions.

First, what is the minimum functionality status that you need to try this without someone else’s help? How about with someone else's help?

If I cannot drive myself, then how can I do a sabbatical? If I bring someone with me to help, what considerations should I be thinking about related to this?

Lisa Petrison

I have not seen anyone do a tent camping trip in the wilderness from that level of debilitation. I'm not saying that it cannot be done, but I've yet to see it. And even people who have been able to drive moderate distances if they are very careful seem to have had a difficult time on camping trips.

I have seen people at a more moderate level of illness do well going straight to a camping trip. For instance, "mostly housebound," with some bad days spent immobile in bed, but still able to drive -- that I have seen succeed for a couple of weeks tent camping a number of times.

I've seen some really sick people go on a sabbatical to a good home in an area with good air (of course without suspicious possessions) and do well. They can be crazy reactive when they get back, but at that level of illness, an indoor environment seems more appropriate.

I've seen a number of people (including me) spend 6-12 months in an improved indoor environment and regain some health, and then successfully participate in a camping trip. I think if the new location were okay, and suspicious belongings were discarded, an ERMI probably would be sufficient most of the time to provide some reassurance about the building. (Though the ERMI can be wrong too.)

If someone has done camping earlier in life and has a really helpful partner, then maybe camping at a severe illness state would work. But I've not seen it so far.
Beatrice Latherings

If you cannot drive yourself you're in somewhat of a pickle. If you bring someone with you, they must also be practicing extreme avoidance as severely as you are, because otherwise the toxins they bring in will negate your efforts.
Q. 4:4 - Too Sick to Camp

What do you do if you urgently need to camp in the wilderness, but are too sick and weak to do so? What if you have no car or ability to drive in order to reach a remote area, and are not strong enough to provide for your own needs in a remote area without help? What are the remaining options?

Lisa Petrison

I've heard of almost no extremely sick people who have gone camping in a good environment as their first step of mold avoidance. And I'm not sure it would be a good idea even if they could find someone to take them out there and then babysit them while they were there. Once someone that sick gets really clear, it can be hard for them to get any exposure at all.

So starting out at more moderate avoidance may be a better idea, as a first step. If you know or strongly suspect that your town is problematic for you, or if others insist that it is particularly problematic for them, then I would strongly advise going to a different place where other people have done well. I definitely wouldn't bring any contaminated possessions. And I would try to find a place that was at least decent mold-wise, by using the ERMI or (if I had a sense already of how mold affected me) my own reactions.

I've actually known people who have moved from very bad environments into a "random" home in a new city (without checking it out) and done okay, as a starting point. Of course, it's possible that it will be just as bad as the place that's been evacuated, but if it's in a generally good city, chances are it might be okay.

Hopefully these measures and some time will help to stabilize and provide energy, allowing more extreme avoidance to be considered. (Of course, if people are only moderately sick and are able to go camping, that is going to provide faster and probably more dramatic results.)

Erik Johnson

When I was crawling on the floor and barely getting enough energy to stand up for a few minutes at a time, I realized that if I were to completely collapse, most likely I would be found and taken to a hospital where they would pump me full of drugs, not believing or understanding when I ask to be taken to the desert.

At the time it seemed that if I did not make it out there while I still could, my only
option was suicide.

This is why I spent all these years showing my Mobile Environmental Control Unit to researchers, explaining that making something like this available would be a Godsend that could pull people back from a very low place.
Q 4:5 - Easing In

I have some questions about the process of going to a good place and unmasking. I don't have a solid plan yet, just some potential places to go try.

I want to ease into avoidance safely. I am concerned that going to 'the country' for three nights to try out a location could unmask me enough that I will be in deep trouble if I come back to my bad city next week and can't handle it. I will need to be at least passing through this city again if I want to take any trains or airplanes out of this area to get to other locations, if this first attempt ends up not being a good enough place. I also have will have nowhere else to go until I figure out another plan.

It seems strange to worry about getting too clear too quickly, but part of Lisa's response to Question #15 seems to suggest some caution for people with severe illness: 'Once someone that sick gets really clear, it can be hard for them to get any exposure at all.'

I honestly don't know how sick I am because I'm too high on biotoxins to be able to tell. But I think I really need to be cautious, because I have few resources and little energy, and absolutely cannot afford to get into dangerous trouble.

I am thinking that I probably need to have a very safe and stable place to stay, and some sort of plan, before I unmask too much.

A few questions:

How long does it take a sick person to unmask?

Would taking my mouldy possessions with me on a short trip be enough to ensure I don't unmask to the point of getting myself into trouble when I return?

It is better to assume I will _not_ be able to return at all and that this is not in fact just a three-day experimental trip?

How have other people dealt with this situation?
A.M. Runyan

It's really unclear how to do any of this because not enough people have experimented yet. So whatever you do will be adding to the pool of knowledge, but there just isn't enough experience out there to say definitively how long it takes to unmask or what would happen.

I find personally that if I am detoxing/dumping, and then I expose myself to some of the mold/toxins that I've been exposed to a lot, the detox stops almost instantly. Sometimes exposures actually make me feel better for this reason (if they stop my detoxing).

So it would be my vote that bringing some moldy stuff in bags could be a way to modulate your mold exposure, where you don't get to too low of an exposure level too quickly. Maybe you could keep it sealed at first to see how the new environment impacted you, and then if you seemed to be detoxing too much or dumping or your body was changing too much, you could slow it down or halt it by immersing yourself in the moldy stuff. Or maybe you'd want to stay there, if it proved to be a good location.

Since you would not be changing climates the change shouldn't be too drastic. I came straight from a wet climate to Denver and that was a big change for my body and started some pretty intense dumping. Maybe better for now to get to 2/3 of the mold you're at now, then 1/2, then 1/3, etc. - if you can step down gradually?

Really extreme avoidance doesn't have to be the protocol for everyone. That's often something people do if they don't know mold is a problem and need to learn how to detect it. For people who are already mold toxic it might be more about stepping down the exposure levels gradually so as not to shock the body, and doing as much detox, in all ways, as you can handle without side effects in the process. I'm learning more about the PK protocol which involves a particular form of phosphatidylcholine, butyrate, and some other stuff, and there are always coffee enemas (glutathione gets rid of a lot of toxins), etc. The real goal is simply getting the stuff out of the body, not living in Death Valley or being in the lowest mold area in the world. I see the avoidance, or the stepping down in exposures, as a means to the end of getting the body to agree about letting toxins out (and to have the body not freak out with inflammation if you try to use mold detox treatments, as it tends to do if you are still having too high an exposure).
Lisa Petrison

I've seen a couple dozen people go through this process by now, and it's seeming pretty predictable to me. I think it's the same timetable as getting clear from gluten -- you might start to feel somewhat better within a few days or maybe not, but after two weeks you should at least get to the point where you're feeling a little better and where the intensification reaction will occur when re-exposed.

Of course, this assumes that you actually get clear enough of the problem substances, which is not always an easy feat. And some people never make it the two week in a good place because of things like chemical sensitivities, noise/light/heat/cold intolerance, etc.

If you are currently quite sick and living in a suspicious place, I would not bring possessions with you on a mold avoidance sabbatical. Just a little bit of exposure might nullify any positive effects (since even a tiny amount of some toxins is devastating). Unless you are very skilled at extreme avoidance, it is too difficult to keep them from cross-contaminating, especially if they are really problematic.

FYI, the most common response to going on an avoidance sabbatical and then back to a bad place is to totally flip out emotionally and feel suicidal. On at least one occasion, someone actually did commit suicide. So that is something to be prepared for.

I think it's better when starting avoidance to assume you will not be able to go back to your current dwelling. Questions about not being able to go back to your current town make things more challenging.

I don't do avoidance counseling any more, and I certainly don't provide emotional support to new mold avoiders. But the one thing that I think I'm willing to do is what I did for Julie and Giles (and others): to have people write down their histories (with a detailed description of buildings lived/worked, town characteristics, illness symptoms, everything dated). I then may be able to give you some thoughts on how to best proceed. So if you want to do this, let me know.

Beatrice Latherings

I'm not sure what you mean by "un-masking." That is a term that MCS people usually use that means that they have somehow become accustomed to an exposure to something, and then when they remove themselves, all of a sudden they are aware of a reaction.
In my own personal experience, I do not have any "masking" to mold. I have an inflammatory reaction that builds up over time. I have been so totally overwhelmed that I lost the ability to take care of myself or make decisions, and was literally on the edge of suicide, having taken actions to put my affairs in order.

When I started to get clear, these things all improved. When exposed again, these same symptoms show up. There isn't any masking that I know of.
Q. 4:6 - Back Yard

I probably have a moldy house due to living in the UK. But I also have a fair sized garden and don't live in a very built up area. Is it a silly idea to try living in a tent at the bottom of the garden for two weeks? If I came indoors to shower would that ruin it? I'm thinking of buying new tent and new clothes. Thoughts from the experts please?

Lisa Petrisin:

There is an awfully lot of mould in the UK. However, some moulds are much worse than others and can have an effect even in ridiculously tiny amounts. Based on the reports that I've gotten, the most potent moulds may be more common in the UK than in the US (though they are here too).

If you suspect you could have that kind of mould in your house, then your goal for this experiment will be to get as much away from it as possible. Definitely going inside the house to shower would be enough to totally negate the experiment, because the cross-contamination of clothing/hair (plus whatever you breathed in while inside) could be enough to keep you just as sick as if you were actually in the house all the time. This is a very weird paradigm!

After I started doing extreme avoidance, sometimes I would shower in a place that didn't feel that good to me and then afterwards go elsewhere to change clothes and rinse my hair with water. This was only when places had just moderately problematic mold though, and only after I got to know what I was doing.

I'd have to know more about your history to give specific thoughts on the outdoor environment that you're in.

Julie Rehmeyer

I think it depends substantially on where you are in the UK. Yes, going inside to shower would be a problem. You'd have to stay out of your moldy house entirely.

A.M. Runyan

It's hard to say whether a tent would be better without having someone who is able to detect mold compare the house and the outdoor air, but you could always
try it and see what you observe.

It depends on how bad the house is. If it's not that bad you might be able to run in quickly for things. I used to stay in a very slightly moldy hotel and sleep outside but use the hotel for obvious things like showering. If the house were really bad, however, you would not want to go in there at all while detoxing.

A lot of this really depends on how your body responds. You might notice nothing while living in a tent for two weeks, which could suggest you might want to try a brief trip to somewhere likely to be less moldy for comparison, or you might start to feel a lot better, and the house might bother you more, etc. A lot of this is guided by how your individual body is responding.

It seems to me that the main test is whether, after going to places that are less likely to be moldy without bringing stuff, you react to or notice mold when returning to a given place. And then you stay away from those places while doing detox.

**Moulduk Mould:**

Avoidance means avoidance. I fear running a shower would aerosolise the little baddies that you want to avoid.
Q. 4:7 - Sick Leave

I am keen to go on a sabbatical to do mould avoidance. Ideally one wants a doctor's note and sick-leave, or leave, instead of having to resign. Perhaps Dr. Shoemaker could give me a note. But I am afraid it won't count unless it is for a recognized medical condition. Anyone been in a similar position?

A.M. Runyan

I think that at least in some ways, environmental illness is a recognized medical condition and might qualify for medical leave. It qualifies me for a disability accommodation of working remotely (although my employer is pretty flexible and understanding and other employers might give me more trouble). See MCS and EI listed here in the Job Accommodation Network literature:

http://askjan.org/media/mcs.html

But yes typically some sort of note is needed; a lot of doctors probably would be able to write such a note though, most integrative doctors, EI doctors, etc.

Also keep in mind that after starting avoidance it might be really difficult to return to where you got sick for at least a year and it might take a lot of detox (can be hard to find a location that's good for both avoidance and intense detox, since many detox protocols are easier in a house/building).

On the good side, you might get smarter and able to work more hours, though, if mold/toxins are causing you fatigue. I frequently find from detox that I get vastly better at my job and my boss noticed it a few times that I was sharper - and I said, yes, it's from mold detox, thanks for letting me work remotely.

Janis Bell:

In the US we can get medical leave and even disability for CFS and MCS. We only need doctors' notes for things like cancelled vacations to collect insurance. To get support from a doctor, try asking your local to read shoemaker's book and run the tests. Or work with another mold doc like Janette Hope in CA or M. Gray in AZ, or one of the certified Shoemaker practitioners.
Q. 4:8 - Food

If I go on a sabbatical to the wilderness, how should I handle resupply and keeping of foodstuffs? Do you just use coolers? Don’t people spend most of their time going back and forth to town getting fresh food? Also, does Erik have a favorite brand of mycotoxin-free peanut butter (or does anyone)?

Julie Rehmeyer

I made much of my food in advance and froze it. I brought a powered cooler, which I supplemented with ice. So I didn't have to restock food the whole two weeks.

Lisa Petrison

The more picky that you are about food (in terms of things like wanting organic especially), the more challenging this is going to be, because most of the places with really good air do not have organic food stores nearby.

I don't especially like spending a lot of money on stuff and therefore have only stored food in a regular cooler or in the RV refrigerator. Some people who want to keep things really frozen have gotten refrigerator/freezers that work on the cigarette lighter of the car, and then also added ice.

Even when I was tent camping with just a regular cooler and no refrigerator, I was able to manage to spend up to a week in the wilderness without having to go back to town for supplies.

If I were tent camping now, I probably would use a smaller cooler for items that I definitely wanted to keep cold and didn't want floating in water (such as meats and dairy) and then keep an eye on it. Then I would put the produce in a large cooler with a spout on the bottom, and just add ice to that periodically.

This does assume that you are going somewhere that you can buy ice. Which is a pretty low bar.

I've eaten peanut butter (expensive brands or fresh ground) on occasion since doing avoidance and don't feel like it's made me really sick. There are aflatoxin limits on foods in the U.S. My feeling is that trichothecene or ochratoxin
contamination is probably going to be more of a problem in foods that contain them, since there are not limits on them in the U.S.

But still, I'm not a big fan of peanut butter and only eat it rarely. I am much more inclined to eat sunflower seed butter or certain other nut butters (such as Artisana’s raw ones), if I have a craving for that kind of food.

Beatrice Latherings

For the mycotoxin-free food list, see stuff that Dave Asprey has written. I don't think there is aflatoxin-free peanut butter. Sorry.

Daliya Robson

Go for organic almond butter or any tree nuts and don't ever do peanuts- they are ground nuts.
Q. 4:9 – Laundry

Another question about going on a sabbatical. If you have to leave all your possessions behind (aside from phone, I assume), where do you launder all the new stuff you have before you wear it? Similar questions about new-to-you tents/sleeping bags, etc. off-gassing before you use them. So if I hit REI on the way out of town and get all my new stuff, I assume I don’t just go to a laundromat--what if its laundry machines are moldy? Game over before you even get to Death Valley. But what is the alternative?

Julie Rehmeyer

I laundered my stuff in a laundromat, and I got lucky and that was fine. It was a relatively new laundromat, so I’m sure that helped. I wouldn’t advise that, though, because it’s kind of a Russian roulette. I’d wash stuff by hand and hang it to dry.

Beatrice Latherings

I bought a wheeled garbage can and just this week soaked my tent in it with borax for a couple of days. Then I rinsed it and hung it on the line to dry. Same thing with my sleeping bag. Here drying outside is not difficult, even for down bags. If you want to agitate like a washing machine, buy a toilet plunger and use that.

Lisa Petrison

When I first started doing avoidance, I was able to use a pretty high percentage of laundromats as long as I just used the washers and then hung clothes to dry. Sometimes public washers were cross-contaminated with the problematic toxin (the one that I associate with Tahoe), but usually not.

Now I am hearing about a new toxin that goes crazy in washing machines (I think growing in them) though. So I am not using washing machines at all any more. I am washing everything in the sink and then putting it through a spin dryer. And not really using items that are too big for that.

What I did in the wilderness when washing things like sleeping bags or tents was to use one of the plastic bins that I used to store stuff in the car. That was big
enough for a medium sized tent or a sleeping bag, because I really was just rinsing things anyway. I never found that soap was that helpful for mold toxins anyway, so for that, I didn't use it.

To wash clothes and actually get them clean in the wilderness (or at home), a Wonder Wash is a good tool.

I also have a spin dryer. I never found that it was necessary camping in dry places, but it could be an option for places where clothes don't dry fast enough.

The wheeled garbage can idea is a good one too.

Daliya Robson:

Use carbon fabric in the laundry machines two times and then do your laundry. Fumes of mold and other people's odors are removed.
Q. 4:10 - Bus Travel

Next week I will begin a two-week sabbatical in Death Valley to get clear of mold. After this camping trip, I might need to take a bus into Mexico to camp long-term or find a rental there, as I doubt I can afford to buy a new car to get around the U.S. So, any advice for traveling in a potentially moldy bus? Would I need a respirator? And how to prevent my belongings from getting contaminated in the bus?

Lisa Petrisson

I would keep my possessions in a bag and wear washable clothing. If the bus is such a problem that this would be insufficient, then I think it is a very bad idea to be traveling on that bus to begin with, with or without a mask.

I have personally avoided wearing masks of any sort, but I do know people who have been helped by them.

Beatrice Latherings

At the least I would own an I Can Breathe mask, which is cheaper than respirator and won't scare people when you wear it.
Q. 4:11(1) - Planning a Trip

I live in NM and am planning to go camp to try to get clear for at least two weeks next month. Is Death Valley the best place to go? One mold avoider I talked to says to stay away from campgrounds as they are full of moldy campers. But this person also says to wash clothes and self with water after food shopping and campgrounds have running water. So where is best? I will need to food shop because I need lots of food especially meat.

Lisa Petrison

Death Valley (at least last I heard!) has very good air, but food is definitely a problem. There is one very small grocery store, with almost no fresh produce and a very few frozen meat items. There is one overpriced mainstream restaurant (where the otherwise healthy companion of a mold avoider got food poisoning) and a few rather expensive restaurants.

Beyond that, you will need to drive maybe 90 minutes to Pahrump to get conventional food, or more than 2 hours to Las Vegas to get organic. Which (especially if you are not sure about the car you brought) sort of defeats the point.

In some cases (including in mine), people tent camping there have brought coolers and kept them replenished with ice. In other cases, people have just eaten at the restaurant. But regardless, food is a challenge.

Here is some information from the Locations Effect website about "Camping in Death Valley."

http://locationseffect.proboards.com/thread/243

I think that if I were in your position, I would consider Snow Canyon State Park, which is just outside of St. George, Utah. It is one of my favorite campgrounds; the air quality is great; it is really beautiful; it is less than half an hour from a fairly large town (with some organic food stores); the temperature should be okay at this time of year (70s during the day, maybe 40 or so at night); it has free showers that always have felt good to me; it has an outside terrace where you can sit and recharge your computer while you use it; and it's not extremely expensive. I see on Mapquest that it would be about 11 hours' drive, which is considerably closer than Death Valley.

Zion National Park probably would be nice during the fall months too. I doubt they have showers there though.

It's possible that there are places in southern NM that are still good, but I am not sure where. I used to like City of Rocks, but I think that it has become problematic, for instance. Maybe Karen has some suggestions.

The Four Corners area is excellent in terms of air, and Canyon de Chelly is beautiful and has free camping nearby. But food is a problem in that area. And no showers.

Cottonwood, Arizona, has a very nice state park with tolerable showers, a few years ago. But Arizona has changed so much in recent years that I don't know for sure that is a good place any more.

In terms of contamination from other campers: I would mostly be concerned about this from RV's, not from tent campers (though I guess it could happen). Snow Canyon has one section for RV's and tents widely spaced out in the rest of the campground, so I don't think that would be something you would have to be too concerned about there.

**Julie Rehmeyer**

I never experienced such symptoms, fwiw.

**Janis Bell**

Death Valley did not have showers when I went there in April.

**Andrea**

Four weeks, you mean. Because you'll need two weeks to recover from the poisoning because of the pneumonia-like symptoms that are guaranteed to follow in the third week of cleansing from mold.

**Christine**

Campgrounds are hard for me due to all the smoke from the campfires.
Q. 4:11(2) - Planning a Trip

1. I am planning to ozonate my car. Is that enough to make it safe?

2. In Lisa’s response to my question about driving to get food, she says, "Which (especially if you are not sure about the car you brought) sort of defeats the point." Even if I bring all my own food, I would still have to drive to get ice. So is getting in the car at all to be avoided while camping to get clear, even if I ozonate it?

3. I will be driving 12+ hours to camp. Should I ozonate the car before leaving, then change into clean (new clothes) before getting in the car? I'm not sure how to manage the logistics of avoiding contaminating my car and new clothes while leaving my house.

4. Should I avoid supplements while I'm camping? I do take Armour thyroid and would need to continue that.

Lisa Petrison

1. If the car is badly contaminated, the ozone will do virtually nothing. If the car is not badly contaminated, probably you will not need the ozone. I wouldn't bother ozonating anything until you are clear. Then it may help a smidge in some circumstances. Or maybe not.

2. I would need to know more about the history of the car to guess about how contaminated it is. Cars that have lived in places with really bad outdoor air can be extremely badly contaminated, for people with this illness. Occasionally if people have exceptionally bad mold in their home, they can cross-contaminate the car. Sometimes cars have mold growing in them. (I know one person who insisted that his car made him sick, rather than his house being that bad. That does not seem implausible to me.)

3. Without knowing more about your situation, I would suggest that you would want to treat your car as a contaminated zone. The idea would be to shower and change out of your clothes into clean ones each time you drive in the car. At Snow Canyon, the showers are near the campsites. In Death Valley, they are a short walk away, and I would check to see if they limit visitor usage in terms of times of day. (Note: By clean, I mean not exposed to mold. That does not mean that you have to wash clothes if they are feeling grungy, e.g. what other people would define as "dirty.")
4. I would suggest ordering some inexpensive clothes by mail order and then not unpacking them until you get to the campsite. Ditto for camping equipment, though an alternative might be to borrow a healthy friend's equipment (well wrapped in plastic before you put it in your car). Switching cars with a healthy person prior to the trip is another thought.

5. I wouldn't especially suggest not taking supplements that are helpful to you on the trip. You could do it like the clothes -- buy new containers and then keep them well-wrapped to protect against cross-contamination until you get to your destination. If you bring current bottles, I would leave them in the car and then just access them when you are going to take them. However, while it may be that ingestion of cross-contaminated items may be better than breathing in the cross-contamination, of course it would be better not to eat things that you are suspicious might be cross-contaminated either.

Beatrice Latherings

My car was definitely contaminated with the same mold as my house. I consider my car contaminated, but....I had the AC foamed (stank for a year) and the cabin filter changed. I still had problems with the car. Then I bought an ozone machine and ozoned it with the AC running for four hours. Since then I can drive in it with the windows up if I have to, but still consider it contaminated, meaning that if I have been in the car I do the whole shower/wash hair/change clothes routine. It's possible that a rental car would be considerably cleaner than your car is, but that is something you can't tell ahead of time.

Don't stop taking the supplements that help you. Do find a way to start with new containers.

I like the idea of buying clothing mail order but remember it will also have to be washed in borax or whatever before you wear it, because you still do not know where it has been. Some of that may be easier to do before you leave....washed and bagged.

By the way, if your campsite has electricity, a Presto Heat Dish, assuming you are ok with electricity, can be a wonderful thing. As can be an electric blanket or heating pad. Just sayin'. Double sleeping bag is better than one huge over-warm one. These will need to be cleaned before use too, because everything is made in China and lots of China is moldy. Sometimes you have to wash a bag five times to have it not smell.
Janis Bell

Why not plastic Op lock bags for all pills? Cheaper and less or a space hog

Andrea

When I was in your position, I found a newer clean hotel and did that. We used white vinegar in my windshield wipers to eliminate VOC’s in the vents. If you’re desperate over your food situation, dig a hole to put fresh vegetables in and eat raw. Eat to live instead of live to eat.
Q. 4:11(3) - Planning a Trip

Can I bring anything that I didn't buy new? I'm thinking I will need my laptop, cell phone, bank card and ID at the minimum. Is there a way to clean these?

Is it okay to bring books and art supplies if I mail-order them and keep them wrapped in plastic in the car until I get to the campsite?

Should I buy a small camping washing machine to avoid laundromats?

Julie Rehmeyer

I put credit cards in a ziplock bag, which I used as a wallet. I also put my cellphone in a ziplock and used it through the plastic.

Lisa Petrison

A little washer probably would be a good idea. I have a Wonder Wash.

Beatrice Latherings:

I would get a Wonderwash and a metal clothes drying rack, which can even be set up inside a tent if need be. I am finding that new books, kept in ziploc bags, are ok for me to have. Old ones, no. Sometimes the new ones sort of stink of ink and stuff, but that wears off and so far the new ones have not been moldy. Bank card and ID I would soak in a strong solution of borax and water for at least 24 hours, then keep in ziploc. The computer.....can you leave it outside for a while? It may or may not be a problem. But I would keep it wrapped in a garbage bag and only use it outside. It does depend on what kind of mold everything was exposed to, whether it has "sticky spores" or not. Unfortunately some of that is going to come from experience. Karen's rule is bring in one thing at a time, no more often than every three days, and if you start to feel not so hot remove the last thing you brought in. Sometimes it's an accumulation of contaminated things and not just one. Experience is the unfortunate teacher. The more fresh air you have flowing through, the less mycotoxin concentration you will have. But if you react violently to spores (some do, some don't) then you may find that you have to be "extreme extreme." Best of luck.
Chapter 5

Intensification Response
Q. 5:1 - Getting Clearer

We have been out of our moldy home for about six weeks. Even though we are still working to toss and clean our old items (so we are in contact with those things a bit) we are more and more sensitive to contaminated objects and places. When we first left it was difficult/impossible to tell. Does this mean that we are 'getting clear'?

A.M. Runyan

Yes. Any chance you can you get someone else to handle the old objects for you? When I was first going through this I exposed myself so much to my old items, but I probably could have started to heal faster if I'd taken it more seriously that I needed to avoid the old stuff.

Lisa Petrison

Or at least, getting clearer.

Janis Bell

Yes.

David Ou, M.D.

It’s not uncommon to develop a greater sensitivity to mold and other substances when you are exposed to clean air.
Q. 5:2 - Chemical Sensitivities

Since moving to a better geographic location last week to begin doing more extreme mould avoidance, I find I am much more sensitive to car exhaust and other chemicals. I almost cannot tolerate any car exhaust at all, and will probably need to begin wearing masks to walk down the street. I am told this increased sensitivity is a good sign, yay! Just wondering if others can share their experiences with this phenomenon.

Lisa Petrison

After I got away from the moldy house and my contaminated possessions, and was just moderately clear otherwise, my MCS went way up. It was like that for maybe six months and then went down a good bit. However, after I got exposed to the outdoor toxin in Dallas (about a year after moving away from the moldy place), it went way up to unprecedented levels.

When I went to Tahoe to visit Erik, we went to Truckee High School (which is an unusual building because it has a good bit of that outdoor toxin in it). Then we went to a grocery store where he usually does fine, except on this occasion he got quite sick from the cleaning chemicals there. He said it was because of the exposure he’d just gotten.

So from what I’ve seen, MCS often will increase during early avoidance (sometimes for up to a year or more after starting), but after that mostly re-emerges after exposures to that particularly bad toxin.

A.M. Runyan

I had this happen to me. I am told it has to do with a sudden increase in oxygen levels in the body when you get away from mold, and having more oxygen around can make some chemicals more harmful.

As I detoxed more while doing avoidance this symptom went away back to the levels it had been at before I started doing avoidance. Or maybe I’m still a little more sensitive to exhaust than I was before, only if a car is idling near me for a while.
Michele

When I got out of my mold environments, this was a Major new symptom that hit me like a ton of bricks. I developed major MCS. It seemed to have been settling down, and I was not as sensitive for a few weeks to a month. However, after a re-exposure in the summer, the MCS has come back again, as strong as before. Exhaust, perfume, detergent, hairspray, mouth wash. you name it, I smell it (and it makes me physically sick). I was also told that MCS was a sign of detoxing, and getting out of Mold. I am just not sure after my recent experience; because the MCS came back full force after a re exposure to mold; unless I was detoxing from the exposure quicker.
Q. 5:3 - Intensity

I am wondering if experienced mould avoiders can share some of their experiences with the intensity of unmasking. I knew about this phenomenon before, but never imagined how horrible it would be. I want to avoid further occurrences of bystanders calling ambulances for me if the reaction happens somewhere in public and I can't get home before it overtakes me. How long should I expect the intensity of unmasking to stick around?

Also, how common is it for mould reactions to be triggered by chemicals (absurdly foul smokey exhaust from a truck spewed directly in my face, in this case)? Is it a phenomenon of one more toxic thing tipping a person over the edge? Chemicals have never caused me mould-type reactions in the past, and never, ever this extreme.

This chemical exposure felt to my body like the worst biotoxin I have ever encountered. But maybe that is just the unmasking speaking? How do I know if it was objectively horrible enough, say, to merit throwing out the clothing I was wearing?

I'm not talking about an MCS reaction (for me) like the ones I have had since moving. This felt like something very, very terrible.

Janis Bell

Awful predicament. I too became sensitive to diesel, solvents, and things I didn't smell. It's been over 2 years. First off, get a mask with charcoal filter and use it. Get a charcoal blanket from Daliya Robson that you can keep in car for times like this. Try nasal-crom before you get exposures to see if it helps. Methylation supplements and support for other detox pathways can both reduce your toxic load and also increase your tolerance.
Q. 5:4 - Housing Intolerable

Is it common for people who do a mold avoidance camping trip to become so hypersensitized that they can no longer live in housing? I don’t really want to confine myself to living outdoors long-term.

A.M. Runyan

I was concerned about this when I first started doing mold avoidance - would I end up homeless and in exile?

I took that anxiety and put it into heavy detox from all the methods that seem to work for other mold detoxers, and it seems to have worked. I'm in an apartment and my body is far less concerned about mold than it used to be. There are many types of mold that don't bother me anymore.

I think if one is able to continue doing really good detox during avoidance, then it's possible to get over the hypersensitivity hump. The problem is when one is so sensitive/exiled that it's hard to do detox treatments (coffee enemas and infrared light being among the primary ones, and other stuff like glutathione, whey, methylation support, juicing, bodybio pc and bodybio chlorella possibly helping too). So I think prioritizing having some money and space/logistics for doing detox while doing avoidance is critical.

Some people don't do anything beyond avoidance and just detox over time, but I wasn't that patient... didn't want to have to camp/be exiled that long.

Note: I slept outside for much of the summer so I was getting pretty low exposures then, even though I wasn't camping.
Q. 5:5 - Contaminations

I have not successfully been able to keep bad toxins out of my apartment. I am not able to keep it under control. The bad toxins are everywhere, it seems, both locally and on items received in the mail. It is difficult to trust my intuition about items arriving from unknown locations in isolation and out of the context of their environments.

I sniff something and even if I feel a bit dizzy, I say to myself, "No way, that can't be toxic, that would be ridiculous, it's probably fine." I sometimes wonder if I'm just imagining symptoms, but they turn out to be very real, and the toxins very toxic. There are a few different sites of contamination in my apartment now, and a few different bad toxins. I am sleeping in smaller and more cramped and awkward corners of the room as I lose space in which I am able to step.

First it was contaminated supplements from Nevada, then a replacement slow cooker, Original Crock Pot brand, in the mail from Missouri, a bad toxin that came from a cheap item made in China, and random other sources of bad toxin that seemed to come from tincture bottles from a local naturopathic college. Some of these contaminated items were present in my space for several hours before I figured it out, and some just for several minutes. There are so many sources of bad toxin and lingering contamination in here now that I'm tiptoeing around my room and not touching most things or sitting anywhere. It is kind of bad.

Also I live with other people who occupy a different floor of the house, so I cannot control what items they bring into the house. It had been mostly fine until now, but I suspect they want to keep the Crock Pot, for example, on a lower floor. I probably could negotiate that it leave the house completely (I think I reacted for days to it being at the base of the stairs outside my room), but as a general rule, they are not practicing avoidance as I am.

Just in case it was not clear, the other people in the house never enter my space, my apartment/suite is completely brand new and was 'clean' when I moved in, and no one has ever lived up here other than myself. It is the same building, but the heating vents are sealed off so I do not share airflow.

Can I rescue the situation in my living space? Would this be as bad if I were living in a metal MECU (would I be able to decontaminate the inside of that type of space more easily from these bad toxins)? Or is it over for a given
space once bad toxins get introduced? I can't move just yet to a better geographic location, or to a different dwelling, so how can I make this work?

Lisa Petrison

You seem to be going through intensification response, in a really extreme way, that all these different sources of contamination are having this much of an effect on you. The good thing is that you must be in a fairly clear environment in general, for you to be reacting so strongly to these objects. On the other hand, the reactions do make it challenging.

I haven't known a lot of people who have gotten to the point of being that reactive to a wide variety of random cross-contaminations, while living in an apartment in a city. One example that comes to mind though is someone who ended up finding that a blowtorch worked on a wide variety of items. He even used it on his sofa. I am not suggesting that anyone do that, and I have not done it myself! I'm more speaking to the level of desperation that is involved, to use a blowtorch indoors for that purpose.

Personally, if I were in your position, I would stop purchasing anything unless it's really necessary, and would test anything new that I brought into the apartment thoroughly before introducing it into the living space (and especially into my sleeping quarters). And I definitely would wash everything before introducing it, even if I thought it was okay.

I'd also focus on detox as much as possible, with the goal of getting the reactivity down. Coffee enemas, especially.

Anonymous:

As someone new to this as well, the description of how you respond to what your body is saying is so familiar. Learning to trust own sensations is a journey.

Also I find I'm trying to recreate my home before I understood the mold connection. And trying to use the "travel light" principle. Fewer things I have, fewer things that may become contaminated.
Q. 5:6 - Extremely Reactive

1) I am extremely, extremely reactive, and trying to start coffee enemas. I am wondering if others who are extremely reactive can tell me whether the coffee from S A Wilson's comes uncontaminated. I am referring specifically to outdoor biotoxins, which I have had a huge problem with when receiving things in the mail, from a variety of places. S A Wilson's products seem to come from Ontario, so I am worried. I would prefer to buy coffee locally, where I can sniff it out before purchase and avoid dragging something potentially contaminated, unseen (unsniffed), over from another province, but I don't have a coffee grinder and cannot buy one because of reactivity (I cannot buy anything that is not food and/or sealed that I can transfer to a new container). If I use a coffee grinder present in the grocery store, I am certain I will have reactivity to the coffee, given that I cannot even walk by the coffee section in the store without having reactivity. Also, it seems to me that purchasing things at this time of year is risky, because winter has just ended / is still ending, and the outdoor biotoxins seem worse now than, say, when purchasing things in autumn. I was fine with purchases from certain places in October, but not fine with purchasing things from the same places in December or February. So, reports on coffees I will be able to get pre-ground at this time of year, non-toxic?

2) I am so confused about the outdoor biotoxin situation. I had been waiting eagerly for March, when I thought the outdoor biotoxin situation would improve, since the season for some of the worst toxins, I had understood, is usually November to February. I was sure I would feel better come spring. Spring is here, and if anything, I feel worse. I felt worse all of March, and still now, I feel worse. There is more wind lately, so I thought at first there might just be more plumes getting blown into my area. It seemed plausible, since on some particularly windy days I felt more toxins around the city. But I don't know. Another theory is that I am just hyperreactive following a winter of too many exposures to the bad toxins. The winter has ended, and maybe my toxin load is higher now, having gone through a bunch of bad months-? For whatever reason, I am much more reactive now than I was previously, after having moved to my new location. I didn't think unmasking would go on and intensification would increase for a duration of seven months, but maybe I am mistaken -- am I just unmasking further and further, having more and more intensification, even though I have not decreased my toxic exposures any further since moving here? How long should one expect unmasking to continue, while remaining in the same location?
I thought that by definition it would not be intensification if I were getting more rather than fewer exposures, but maybe it still is just because it’s less exposure than I had a year ago.

I had read the reports that the bad outdoor toxin season began early last fall, I believe, so I guess I am wondering if there are reports that it has continued late this spring, too.

Lisa Petrison

So sorry to hear all this! You are a person who seemed really reactive to all manner of things before starting avoidance though, and so it’s not surprising to see your body reacting strongly to the toxins subsequent to getting more clear.

When hyperreactivity is unbearably high, the first thing that I think about is Vitamin C IV’s, to take the edge off the oxidative stress. Those have made a big difference for me at various points during my own recovery process, especially with regard to living in a city (Chicago) that otherwise would have been over tolerance for me. So if you have access to someone who could give those to you, and are able to tolerate the place where they would be given, that would be something you could consider.

I've never been quite as hyperreactive to coffee toxins as you seem to be. I haven't heard anything about Wilson's coffee and have not personally bought "especially for enema" coffee myself. (I think the main difference is that it is light roasted.) Maybe if I were you, I would try this Mount Hagen organic instant coffee from Germany, until I got the coffee grinder situation figured out. I used to drink it on occasion and don't recall getting any negative symptoms from it. Which doesn't mean that it's clean enough for you, but still. And though instant coffee may not be ideal for enemas, I've used it before and it does work.

Especially if you can't get the IV's, but even if you can, I am still thinking about Vitamin C as a possible thing to consider for you. Like I have used this Lipo Vitamin C in enemas (with or without the coffee) and thought that it was helpful. A lot of things seem to get absorbed a lot better when administered rectally than orally, for me. And Vitamin C seems to have a really cleansing effect, which I found helpful too.

Erik said one day recently in Tahoe was quite good but that another was pretty problematic. I haven't heard any other reports.

Once people get unmasked, the hyperreactivity can go on for a long time. How
fast it comes down seems to depend mostly on how much detox is done (which in turn depends largely on how clear people can get). If you are feeling better than before you started avoidance in general but the reactivity is remaining high (or even increasing), that would be very consistent with stories that I have heard and with my own experiences. Sorry this is so hard.

Betsy

I'm still waiting on the usual springtime improvement in air quality in Colorado. There have been just a few days where I love the air. Many more where I think it's actually worse than the winter air was. It's my third year here, and it was nice to find that I didn't feel quite so bad during the winter as in my first two winters post-escape. I've been wondering if the lack of improvement is local, due to flame retardants used to put out wildfires and toxins from heavy flooding, or if it's a broader change.
Chapter 6

Your Own Testing
Q. 6:1 - Safe Enough to Heal

Some of the comments here have suggested that the ERMI is not sufficient to judge whether a dwelling is good. So then how does one determine a place that is safe to heal if you are saying that even a good ERMI score is not enough?

Karen Dean

I would only take a place if I had slept there for at least 3 nights. Ask for a 4 day lease. Shoemaker labs elevate after 3 days. You should be able to tell by then

Jeff Charlton

Unfortunately capability of economically testing or identifying mycotoxins on surfaces isn’t available. The Institute of Medicine (2004) stated that even after thorough cleaning some people may not be able to return to a home or use contents. They also state that sometimes the only choice is to see if a home affects the occupants health

Julie Rehmeyer

Your reactions are the most reliable guide -- but if you're living in mold all the time, they're not reliable either. The way I figured things out was by getting clear of mold by spending two weeks in a particularly pristine desert with none of my belongings. Then I could really tell when I went into a building that bothered me. But as Karen said, sometimes (particularly early on in avoidance, when you're still learning about your reactions) it takes a little while to figure out that a place is bad.

Lisa Petrison

My sense is that it really depends on what your goals are. If your goal is to remove yourself from environments that are going to actively poison you and slowly move toward healing, then I think you can do that in a place that has a decent ERMI/ HERTSMI score (by Shoemaker’s standards), as long as you're not living in a bad location and haven't brought along contaminated belongings. Probably this strategy will not bring you to the top of Mt. Whitney in six months (or maybe ever). But I think it would be enough for most people to reclaim some
sort of livable life.

I'm not sure whether, for that level of avoidance, cross-contamination from particularly contaminated belongings would be enough to totally ruin a building permanently (e.g. if someone moved in their contaminated possessions, then later got rid of everything and cleaned thoroughly). I would tend to think that for most people in that circumstance, slow healing would still occur (and probably other random exposures such as going into bad buildings and not decontaminating would be more of a factor).

If people want to get totally clear so they can get more dramatic results, then getting to the point of using one's own reactions to find exposures is likely the only way to do it. And in that case, the ERMI becomes not only unhelpful but misleading.

Erik Johnson

If mold is doing what I think it might be (making nanoparticles to serve as a delivery device for the mycotoxins), ERMI cannot possibly apply to this situation.

David Ou, M.D.

Shoemaker has reported that there are people who still are reactive in buildings that have good ERMI/HERTSMI scores. He says that ultimately, you need to look at symptoms and lab tests.

There are several variables with ERMI testing. The only lab that Shoemaker uses is Mycometrics. Their methodology is different than any other lab that runs ERMI s. Their sensitivity appears so much high. An ERMI run by any other lab can not be interpreted by Shoemaker's criteria.

Collection methods for the ERMI are important too. The original carpet collection kit can be skewed if shoes or pets bring in mold from outside the building onto the carpet. If you use the Swiffer cloth, you'll get different numbers than the carpet kit for a number of reasons.
Q. 6:2 - Rapid Deterioration

I started avoidance several months ago and am currently living in a town on the Pacific coast of Mexico.

I moved into a new house a couple of days ago and have watched the following:

1. Aches in my joints have crept up steadily - last night I was in too much pain to sleep. My arms were weak and heavy, difficult to type.

2. I noticed slightly blurred eyes the first day.

This is a rapid deterioration from where I was, with a clear VCS just the day before coming here. I did find some evidence of previous water damage that the owner says he will fix in a ceiling upstairs.

My question is if you would have an opinion on whether it is

A) the house that has a big mold issue that is causing this - and I'm unlucky to have chosen one like this again.

B ) Or if I'm becoming more sensitive and thus small amounts of mold are affecting me more?

C) Or If somehow the mold is following me and infecting houses quicker as I move?

I'm contemplating leaving Mexico because the rain here has been pretty bad the last months (worst in 13 years) and a lot of apartments have had leaks as a result.

The owner here is very 'hands on' and positive and happy to tear up the ceiling and get it redone. In your experience would this fix it? Or would I be wasting his time, because potentially I'd still eventually need to move out?

Choosing where to live is becoming the hardest decision I make. I put more effort into it than anything else now - incredible when you think about it.

Julie Rehmeyer

Sounds like a bad building, at least bad for you. Remediation is unlikely to make
it good enough for you. Finding housing during the period of extreme reactivity really is tough.

**Lisa Petrison**

It sounds like your current environment, even if not objectively bad by ordinary standards, is worse than your previous one.

I've yet to hear any success stories where Moldies have turned problematic buildings into good ones for them through any sort of remediation. I also would be afraid that having the owner try to remediate the mold without hazmat protocols could make the problem worse for you.

The past few weeks have been particularly problematic throughout all of North and South America, based on the reports that Erik and I are getting. Lots and lots of people doing really badly no matter where they are. Apparently associated with all the rain, and apparently a lot of the problems have been outdoors. My first suspicion was that the Fukushima people evaporated a bunch of that radioactive water into the air like they were suggesting they were going to do, and that this was making atmospheric molds more toxic, but I've not heard of any confirmation that they've done anything but dump the water in the ocean. Hopefully it is just a little dip in the weather and things will recover. I'm not sure that moving somewhere else is going to be an answer, though.

**A.M. Runyan**

I agree. The types of symptoms associated with being in a clear space and detoxing tend to be different and less inflammatory, less chance of a VCS test being worse.

The water damage sounds bad. Maybe keep looking, and try to wash your clothes frequently and dry them in sunlight if possible, and if you can, keep clean belongings in ziplocs while traveling so that your things are not contaminated if you happen to stay in a bad place temporarily.

**Christine**

Some of those symptoms you describe I can also get from chemical exposures in indoor furniture, flooring, leftover cleaning products, pesticide spraying etc. Personally after being so sick from exposures I do not want to hang around
anywhere near an indoor or outdoor renovation. Too much risk for further health compromises in my opinion.
Chapter 7
Perceptifying
Q. 7:1 - Mold Symptoms

What symptoms, besides obvious increased fatigue, do you get when in a worse place? I think I get fibro pain, all over my body. I also get this strange sticky film on my skin. These are the first signs, and I think it depends on mold type. Another is a prickly heat sensation, neurological buzzing, and increased hair loss. Besides the symptoms I mention, are nightmares something people experience when reacting to mold toxins? I've had the most horrifying dreams for the last few days.

A.M. Runyan:

Never heard of the sticky skin. I've had nightmares when exposed to mold about themes that seemed like mold (a wizard coming to take away my life force). There can be a whole variety of symptoms.

Originally, I just knew I did not want to return to my apartment after being out, and that I tended to be more irritable there.

Later, I was able to smell mold strongly in many places.

Now, I have just learned to recognize subtle changes in my breathing, my brain (like neurofeedback), insomnia, agitation, heart rate, irritability, etc.

Lisa Petrison

This is a difficult question for me, because I had so many symptoms associated with exposure.

When I finally got really clear out in the wilderness (about eight months after moving out of the bad house), I found that just about all of these went away. But even a little exposure could prompt any or many of these (or others!) to come back very quickly.

Also, when I started detoxing intensely, I found that detox could prompt some of these symptoms to come back even when I was really clear. I think detox is really important, but sometimes I was confused about whether the symptoms were from a new exposure or just detox.

One thing that I found is that if I was really clear, I would not get insomnia even when detoxing intensely. I more slept like the dead for very long stretches of time.
(and was zombie-like much of the rest). I also found that static shocks seemed associated just with new exposures rather than detox. So those are two symptoms that I attended to closely.

The outdoor toxin that I think is the worst (at least for me) has some distinctive warning symptoms for me. These include a stabbing sensation in my sternum or heart; a ghastly sort of depression (kind of how the "Dementor's Kiss" is described in the Harry Potter books), trembling as if I'm cold (regardless of the temperature) and migraine-like headaches. If I go somewhere and get those symptoms, I know it's time to flee immediately and to take all my stuff with me -- because I always have regretted it when I've not done that.

With other symptoms, even if I am attributing them to a new mold exposure, sometimes I just deal with for a while. It's too hard to avoid all mold/biotoxins scrupulously all the time, and so I've learned to pick and choose my battles.

**Julie Rehmeyer**

As Lisa commented, it is sometimes tricky distinguishing tox from detox, but some symptoms of exposure are really distinctive for me. These days, the thing that's most notable and comes on the quickest for me is a feeling of brain compression, of general oppression, almost a sense of being crushed. Chattering teeth is another sure sign for me. Sleepiness can be a symptom, and that one can be hard to distinguish from just, well, being tired.

I'm pretty far along with detox now -- and doing really, really well! -- and there used to be a lot more symptoms, particularly as I was first learning to detect mold, not always doing so quickly, and hence getting bigger exposures. The fairly minor ones I'm remembering at the moment are irritability, sudden, unreasonable hunger, and just a general sense of unwellness. The dramatic ones were, well, pretty dramatic: a kind of dimming of consciousness and an inability to walk that could progress to near-complete paralysis together with difficulty breathing or talking. The very worst thing that an exposure ever caused for me was a seizure, which was extremely frightening. I also once walked into a moldy building that was so bad that I took two steps and then collapsed onto the ground.

I suspect there are lots of symptoms I'm not thinking of right now as well.

**Cha Cha**

Sensation of oxygen deprivation similar to higher altitude. This causes confusion;
difficulty following one train of thought (let alone multiple); sensitive to light, sound, visual movements (especially if there is more than one of these). I also get a funny sensation in my teeth, like raw nerves. It's as if my teeth feel metal-y.
Q. 7:2 - Outside Air

How can you tell if there is toxic mold in the outside air? Can you smell it? Feel it? Or do you have to learn?

**Julie Rehmeyer**

Toxic mold in the outside air causes similar reactions to toxins in inside air.

Until I got clear of mold (by going to Death Valley for two weeks with none of my own stuff), I couldn't tell. Not a thing. After that, initially, I could only tell when it was really bad, and my reactions were sometimes delayed. So there is indeed a learning process.

I don't react very strongly to mold in the outdoor air in Santa Fe. It tends to be more cumulative for me; if I go into town and don't shower afterward, eventually I don't feel so good (or at least that's the way it used to be; now it's not such a problem).

I do react very strongly to ambient molds in Berkeley (where I used to live), at least insofar as I react to stuff that's been in Berkeley, even if it's only been there for a few days. I haven't gone back to Berkeley since starting avoidance, so I don't know for sure, but I'd certainly expect that just walking down the street is likely to be bad there.

The stories that I've heard from others suggest that they sometimes feel outdoor molds much more strongly than I do. For example, Erik describes plumes of mold in the outside air. If I'm susceptible to that kind of thing, and if I've experienced it, then apparently I haven't learned to recognize it yet.

In buildings, the mold is sometimes bad enough to smell it, but it has to be *really* bad for that. Ordinarily, I can't smell it at all, even when it's pretty bad. In general, I don't find smell to be a reliable guide, because sometimes something will smell a bit moldy but not bother me. It's all a question of what kind of mold it is.

**A.M. Runyan**

In my experience the effects are usually felt as bodily sensations. Some of the worst toxins don't smell at all. You learn what your particular reactions feel like. Things like irritability, lack of appetite, suicidal feelings, wanting to give up, racing
heart, insomnia, muscle paralysis, muscle contractions, bulging veins, etc. can be involved. Much of the reaction seems to come from mast cells although there are probably direct effects from the toxins too.

I think being able to detect it comes from having had some degree of toxic injury from mold, such that your body prioritizes making you able to detect it (and does not want you to get any more of it), and then also being clear enough from mold most of the time that you can tell the difference when you are around it. So in order to start to detect it, you need to first spend some time in locations that are very likely not to be toxic. Could mean anything from camping in the desert to just getting out of the house and spending hours out or at a coffee shop etc and returning, etc.

The good thing is that some people who have already gone through the conditions above (having mold poisoning and then avoiding mold) can report on some locations that are particularly bad so that we can be pretty sure about it without having to test for ourselves. I'd heard that Dallas-Fort Worth area was bad, but I ended up going there myself after having mold poisoning, and in my experience it is toxic beyond belief, with the outdoor air feeling just as bad as some of the worst buildings I've been in. Many people also agree that the Berkeley area and Ann Arbor are toxic for some reason.

Also, for obvious reasons, the outdoor air around bad buildings, trailers, etc. will be bad. I looked at a newly constructed apartment complex in my city that was built next to a trailer park. The apartments were not moldy but the outdoor air was very bad, from probably a few really toxic trailers in the trailer park.

Lisa Petrison

I've encountered several toxins outdoors that I believe to be mold toxins. One seems to be associated with agricultural areas that have been treated with Roundup (I believe this to be trichothecenes from Fusarium). Another seems to be associated with areas that have been treated with fire retardants. Bad buildings or bad RV's not infrequently emanate toxins that I can feel outside. The outdoor toxin that I attend to the most seems to particularly problematic in certain locations (though a lot of cities have small amounts of it) and associated with sewers. There may be a connection with PBDE fire retardants or chemical spills (maybe of solvents such as TCE). It is toxic in especially small amounts and cross-contaminate easily. It tends to be worse in winter and when the barometric pressure is low.

At first, I thought the symptoms sounded more like a cyanobacteria toxin than a
mold toxin, but that did not make sense since cyanobacteria do not grow very much in sewers. Now I think it may be a mold toxin called Penitrem A.

After a lot of discussion with other mold avoiders, I came up with the following list of associated symptoms. However, a lot of these symptoms do not kick in for 4-24 hours after exposure. Warning symptoms tend to be more vague -- heart palpitations, feeling of needle through heart/sternum, weird ghastly depression.

Sometimes this toxin can be found inside (especially if there have been sewage backups), but more often it seems to be outside. If people experience a lot of these symptoms, then they may consider an avoidance trial to somewhere other than their immediate geographic area.

From what I have seen, living in a place with this toxin in the outside air is substantially more damaging than living in the vast majority of homes that have some mold in them.

Common symptoms:

* Heart pain (in particular, a feeling of a needle through the heart).
* Heart palpitations.
* Chest pressure (a feeling of a dagger through the chest or a marble - sometimes actually swollen - at the sternum).
* Excruciating headaches (migraine-like but not one-sided).
* Extreme photophobia (light sensitivity).
* Extreme noise sensitivity.
* Cognitive problems that go beyond brain fog (e.g. inability to add numbers or recognize words)
* Weird memory losses (like the inability to remember the name of one's hometown or to find the way home)
* Loss of sense of direction (e.g. driving around randomly)
* Seizures or "white-outs" (where the brain goes 100% blank for extended periods of time, sometimes even when a concerted effort is being made to bring up thoughts)
* Severe trembling.
* Paralysis (literal paralysis or feelings of paralysis)
* Organ pain (particularly kidney pain).
* Strong suicidal feelings.
* Feelings of paranoia, like people who are usually your friends have become enemies.
* Strong feelings of anger and lack of inhibition in expressing it.
* Other emotions that are bizarrely inappropriate to the situation.
* Convulsions.
* Extreme MCS.
* Marked gait problems.
* Inability to sit or stand up.
* Severe POTS (e.g. needing to use a wheelchair)
* Extremely deep skin "dents."
* Feeling of skin being burned.
* Sore throats that make eating difficult or impossible.
* Veins pop out of skin (look "ropy")
* Stuck thinking (e.g. spend all day clicking on the same three websites or playing games like "Farmville")

**Beatrice Latherings**

Someone gave me great advice near the beginning, and that was to notice where I felt better, as opposed to where I felt worse, and gravitate to those places. That's how I chose the land I bought, because I feel good there.

**Erik Johnson**

Surprisingly, as one can see by all the people I have taught, this is something they have to learn.

Not because they can't feel it, but because they cannot accept it until their perceptions are "enabled" by confirmation from someone else.

The very first people I showed this to, were of course, the sick teachers during the 1985 outbreak.

But because doctors didn't believe, they "disabled" their ability to act in accordance with what they could feel, because to do so would have made them "as crazy as Erik."

**Christine**

When I am outside and walk next to a moldy building my body acknowledges this right away or if I walk next to a person living in a moldy building the clothes have the same scent as the building.
Jackie

What I originally thought was a curse, turned out to be a blessing. As I was getting mega doses of IV vitamin C and glutathione (to treat EBV), I became more and more sensitive to mold. The smell started by driving me out of my bedroom and ended with me finally having to flee my own home, and stay in hotels until I could find a mold-free place.

I have become so sensitive to mold, that I can smell it on the tiniest of objects, even from a different room. I'm now happy that I can smell it, because I'm able to avoid it before it makes me sick.
Q. 7:3 - Mold or Chemicals?

People here have listed some symptoms of toxic mold, indoors and out. How can you determine if this is from mold or a chemical exposure? Does it matter?

A.M. Runyan

With these biotoxin-sensitive genes, and sensitive health, we are supposed to be avoiding all of this stuff to the best of our ability. I try to avoid mold as well as fabric softener, car exhaust, pesticides, etc.

As for what is causing symptoms, it's often much clearer if, say, fabric softener is a cause, if you are reacting to someone's clothes, whereas mold toxins can be extremely tricky, persistent, confusing, etc.

In any event, if you're reacting then you try to clean, air out, vacate, etc. You don't need to know exactly what it is in order to try to avoid it.

In fact, a lot of what we refer to as "mold" is most likely bacterial endotoxins in wet situations, anyway. Not mold.

Lisa Petrison

In his books, Dr. William Rea talks about the concept of "primary reactivities" (basically the chemical that first made you sick) and "secondaries" (other reactivities that pop up through the "spreading" mechanism).

He suggests that if people avoid their primary irritant especially scrupulously, then their other reactivities will fall away. He seems to think you can eventually make the primary one go away too, with enough detox, but that takes much longer.

So I generally think of this as particular mold toxins being my "primary" reactivities and other things (including more minor mold toxins) being my secondaries. And though I don't know this for sure, the info that I have at present suggests to me that most people with classic ME also have primary mold reactivity (while people who have others sorts of MCS may have other kinds of primary reactivities, due to exposures to -- say -- industrial chemicals).
When I started doing avoidance, I made a conscious decision just to follow Erik's advice about everything and be done with it. He had specialized training and success, and it seemed pointless to reinvent the wheel. So after he said that he avoided mold really scrupulously but chemicals only insofar as they were really bothering him acutely, that's what I did too. So I frequently would say to myself, "Yes, this is bothersome, but it's just chemicals, so I'm not going to worry about it too much."

Another thing about mold is that it seems to cross-contaminate much more than chemicals. Mold toxins seem much stickier and much harder to get rid of (even for people who are very MCS also). So avoidance strategies are different because of that.

The outdoor toxin associated with Tahoe is more problematic before storms and during winter (when mold counts in cities are high anyway); it cross-contaminates really strongly; and my reactivity to it has not gone down very much even though my chemical sensitivities and most of my mold sensitivities have faded. So I think it's a mold or other biotoxin. But I'm not sure.

The important thing is to avoid toxins that cause problems, and the real issue with this toxin is that there is a delay before the big effects kick in. So what I would most suggest is that when people go to new places, they do it in a controlled way, keeping track of both how they feel acutely as well as how they feel over the next few days. Once you figure out what your warning signs are for toxins that cause the most harm (whether they are biotoxins or something else), avoidance becomes a lot easier.

Julie Rehmeyer

I haven't had problems with chemical sensitivities myself so far as I can tell, with the possible exception of flame retardants in mattresses. What I've gathered from hearing others' experiences is that the key is to identify what's most problematic for you and put most of your energy toward avoiding that. If you can avoid the worst stuff, and detox, eventually all sensitivities should go down.

As far as figuring out what's worst, well, that can be tricky, particularly if you're living in a moldy environment and hence are steeped in it all the time. Then you won't necessarily be able to tell that mold is what's bothering you just judging by your body's reactions. The best way to tell is by running the experiment of going to the wilderness with none of your own stuff for a couple of weeks, and seeing if you react more strongly when you get back.
One key aspect of that experiment: You may or may not feel better while you're in the wilderness. The determinative thing is whether you react more strongly to mold once you get back. If mold is part of the problem, getting clear of it will actually ramp up your reactions. That's highly inconvenient from the perspective of just living your life, but highly convenient from the perspective of figuring out what the hell the problem is and learning to avoid the damn stuff.

Beatrice Latherings

You can determine if it's from mold by testing your environment. You can test if it's chemicals by getting away from them for a period of time.
Chapter 8

Depression Response
Q. 8:1 - Moods and Judgment

I have noted two things about what happens when I am exposed since starting mold avoidance: my judgment is impaired and at best unreliable, and I am having mood shifts from feeling really down to feeling much happier than it makes sense to. Has anyone else reported these experiences?

Lisa Petrison

Yes, those are very typical.

Julie Rehmeyer

Yes, that's common.

Karen Dean

Yes, I actually am very depressed right now from an exposure. Happens all the time. Resist the urge to end it all, it will pass.

Audrey

Yes.

Beatrice Latherings

I find that my mood tanks so badly that my view of everything is negative, which can affect my judgement. Knowing that the mood is chemical doesn't help me figure out how to have better judgment. I also get fairly immediate disorientation, for example not remembering where I parked my car if I went in a store that was moldy, or getting disoriented driving around if I went through bad air.

Janis Bell

Sounds a lot like a methylation issue that was blocked when in mold environment. Take methylation support with niacin on hand in case you take too
much and see if you can smooth those extremes. Should improve if body clears and starts working but not everyone can do without extra help from supplements.
Q. 8:2 - Depression and Anxiety

I am living in a house in New York State. I moved here in February because it was free of mold, and it has served its purpose. But, now I am just not sure if something is going on in the house, with my detox, or with re-exposure from people (including my son who attends school) on a daily basis.

I had a re-exposure in the summer, and it took me weeks to recover. Over the last 2 weeks, I have started a strict 'detox' protocol again.

I am starting to really get unnerved about my depression and anxiety. I suffered with it so bad for years, while living in my mold homes -- suicide was a repeated thought in my mind. I had finally regained my happiness and some stability over this past winter. However, it has come back -- the depression and anxiety and bad mood swings -- and it will not let up. It has been over about a month now. I would think that it would stop, and I am losing patience.

Is it possible for someone who is in detox mode to go into a severe depression with anxiety for almost a month? I would think it would have passed by now. Or should I be concerned that something more is at play here, such as possible contamination of my environment or being exposed to my son after he gets home from school everyday?

I am just looking for some insight as to why this may be happening. I may also add that on top of the mind disturbances, I am also itching all over, sore throats that come and go, as well as swollen glands. Should these symptoms be lasting this long with a detox protocol well?"

A.M. Runyan

While I can get those feelings from exposures, I never get those particular feelings from detox, and I'm going through really intense detox right now. Detox symptoms for me are much more about being sluggish, emotional, feeling drunk, and maybe having muscle issues, but in general they are very calm and the emotions are neutral, not bad.

To me it sounds like you might be getting exposed to something. Could you go somewhere else you are pretty sure is clear for an afternoon (not the house), and then use that clarity to test other locations (the house, the school, friends' houses, etc.)? Maybe something happened and your son's school started to be
worse or he's in a worse classroom. I feel sorry for kids who get affected by this, but I'm realizing I was probably being affected by biotoxins since I was a kid, and for people with the mold genes, it builds up in the body, so it probably would have helped me if my parents HAD been aware of this and trying to reduce my exposure, at least at home.

From a standpoint of relief of mental symptoms, TriSalts or alka seltzer gold go a long way for me. Also liposomal C can help. A lot of the negative emotional symptoms seem to be mast-cell related... I try to mention that a lot because it helps to take them a little less literally, if it's clear they are coming from one's own immune cells. There have been a number of articles about immune activity and depression. Good for you for abstracting the feelings and seeing them as a symptom and not the way life really is; life feels much better when these sorts of exposures are not going on

Lisa Petrison

Here are several different thoughts and possible approaches, based on stories I've heard.

Erik and I have been getting a whole bunch of reports from all over since the end of August that the outdoor air has deteriorated everywhere. Some people, if only mildly reactive or in a good spot to begin with, have been only moderately affected. Some people seem to be more being pushed down into the devastation level. This includes both North and South America. So far, I just have heard about people in the western half of the U.S., so I don't know about east of the Mississippi (which on average is worse than the western half to begin with). I was surprised to hear an unusual complaint corresponding to this time frame from someone in England, but that was just one person. But anyway, this general downturn would seem to correspond to your time frame and is a potential issue to consider.

Typically, November - February is what Erik has termed "Suicide Season," due to the outdoor toxin associated with the Tahoe epidemic. In some places (like Ann Arbor), this toxin is a year-round phenomenon. In others (like Chicago), there is basically none at all present in summer but quite a lot in winter. This is a strong enough phenomenon that if you read the CFS boards in late October or early November, you can usually find a thread where everyone has collapsed at once. Meaning, all around the northern hemisphere. So this is always something to consider.

Your description does not sound like detox to me, based on any of my own
experiences or any of the stories I've heard.

What it most sounds to me like is a very rare toxin (more rare in the U.S. than in England though) that causes skin problems (itching, hives, burns) and suicidal thoughts, and cross-contaminates in unbelievably small amounts (even compared to other problem toxins). I don't have personal experiences with it, but I've heard enough very consistent reports from extremely reliable witnesses that I feel like it's a distinct -- if quite unusual -- phenomenon. The name that's been used most frequently for it amongst the mold avoiders I know is the "Itch Toxin."

My best understanding of this toxin based on my current knowledge is that it grows very rarely in buildings (e.g. maybe 1/10,000 homes), possibly due to a certain rare strain of mold that has evolved to utilize an ingredient in a certain kind of glue. Then people living in those rare homes cross-contaminate other places. And this stuff spreads so easily, in such small quantities, that for a sensitized person that cross-contamination can be enough to keep them totally sick all the time. I know one person who found all of England intolerable because she kept running into this stuff and so moved to the U.S. where she has been basically fine and almost never encountered it.

So yes, of course, check your kid's school. But based on the stories I've heard, I think you should consider the idea that cross-contamination from even one item contaminated with this "Itch Toxin" could be the issue.

The way that I would suggest testing for that is to spend a few days in a hotel. It doesn't have to be the most pristine hotel in the world -- even if you're not 100% well there, you're looking for changes in symptoms (e.g. the itching and suicidal feelings to go away). Decontaminate really aggressively and of course don't bring along current possessions or clothes. It would be best to change rooms and then decontaminate again at some point, in event that the decontamination measures were not extreme enough upon arrival. Wait to see if the symptoms go away.

If they do go away, then you can carefully go back to your house. You might be able to be sensitive enough then that you can figure out what's causing the problem by symptoms returning. Maybe you then can get rid of whatever specific items are contaminated, if indeed that is the issue, and then clean things well enough to make your home okay again. Though I do know a several people who have felt it necessary to throw out all their stuff and start over again, just because of casual cross-contamination with a toxin that caused this "feeling."
Beatrice Latherings

I'd go and see how you feel in your son's school. If he's bringing toxins home every day, you will either need to educate him in doing total decon when he comes home, or find a better school. Total decon: bag clothing, shower and wash hair, *immediately* upon coming in the house, without touching anything, sitting down, etc. How about the car? I have my car in the contaminated category because I get in my car after having been in a wide variety of places, and I don't see how it could remain pristine.

Michele

I am wondering, especially after reading about outdoor exposures, if it is something in the outdoor environment. Could that be possible? I know myself, I have not considered outdoor exposures a concern until fairly recently. Perhaps the person has a garden, or a stagnant type of pond in their backyard; in close proximity to their home. With fall now here in NY State, gardens decomposing, grass being mowed for hay, etc., could this be the source of the possible exposure?

Joseph Salowitz

The "decontamination" of a child on a daily basis had driven me, and my child, insane, 35 years ago, when all I had to decontaminate was "cat hair", which I could see with my eyes, on the weekly visitations of the divorce merry-go-round. The cat hair gave me asthma problems.

I agree that the parent should visit the school, and allow herself to get deathly ill, as the definitive way of finding the source of the mycotoxin contamination. She should take her child with her, after school hours, so that she can visit every room that the child visits during the school day.

If you are lucky enough to discover that the school is the source, then it is mandatory that the child be transferred to another school.

If the child continues going to the same school, and sleeps in the hotel, they will never be certain if they are "detoxing in a clean environment", because, if the school is the source of the "bad stuff," they will be cross-contaminating from the school.
Q. 8:3 - Lifelong Depression

Has anyone been cured of lifelong depression by mold avoidance?

A.M. Runyan

Something else did that for me - getting MTHFR diagnosed and getting on methylfolate. Avoiding mold has definitely helped me emotionally though, although the biggest changes are in the encephalopathy/brain inflammation/cytokine symptoms, such as how I was formerly pretty irritable when toxic/dealing with mold.

Lisa Petrison

I first experienced depression at age 9, when my family moved into a house that I know was extremely moldy many years later (and that I suspect was already moldy at the time). It was a problem in varying degrees thereafter -- sometimes very severe, sometimes gone entirely.

After starting avoidance, the depression was totally gone as long as I was really clear but would come back severely in a flash if I was hit. I remember one day being at the Grand Canyon (apparently after running through a plume on the way) and wondering seriously if throwing myself into it would successfully kill me or just annoyingly injure myself. After rinsing my hair and changing my shirt, and taking a short nap, I felt perfectly great again.

Despite being pessimistic about the future of this planet, I never get the sorts of depression that I used to, even when I get exposed. Though if I got a big or long enough exposure, I'm sure it would set in.

I think that what changed this was detoxing a huge amount of what I believe to be mold poison from my brain, after the use of Natrum Sulphuricum (1M, Hahneman brand). Lithium orotate did give me a happy feeling at one point, and I've taken a lot of methylation promoting supplements at one time or another myself. I definitely was low in activated folate or a long time, and took Deplin for quite while. But that was not the turning point for the mood volatility, for me.

Beatrice Latherings

Yes. And lithium orotate helped immensely too, put the icing on the cake. (1.25
mg; not the same stuff as is used for bipolar.)

Vicki

Yeah, that brain inflammation/cytokine flare up is nasty for me with lots of depression and irritability. Anxiety too. Much much better now that I've gotten cytokines down and VIP up.
Chapter 9

Cross Contamination
Q. 9:1 - Protecting a Clean Space

How do you avoid cross contaminating a clean space?

Julie Rehmeyer

When you're hypersensitive, it takes a lot of care. I shower and change clothes immediately upon getting home (a bit less strictly now that my reactivity isn't sky-high). And I brought in objects slowly, so that I could tell if anything bothered me. Even so, cross-contaminations occasionally happen, and they then require a lot of detective work to figure out where the contamination came from and where it spread to.

Lisa Petrison

Routinely shower and bag clothing when coming back from any suspicious place. Be careful about bringing in objects purchased in stores or otherwise acquired. Open mail order packages outdoors to make sure that the contents are okay before bringing them indoors.

Admittedly, I am pretty lax in doing this now, a lot of the time. I used to be much more stringent.

Forebearance

If anyone has the answer to this, they deserve a gold medal! All I can think of is to be very careful about what you bring in to it. I use an intermediate space, like a porch or a back yard or a garage to set things in at first.

Andrea

Start from scratch.
Q. 9:2 - Less than Optimal Setting

What is the best way to avoid contaminating belongings when living/staying in a less than optimal setting? An older home for example?

A.M. Runyan

I used to keep all my belongings in Ziploc bags. Single-bagged for everyday, double-bagged if the location was bad. Might just re-wear what you're wearing and wash it each night (have 2-3 sets of clothes) and keep the other clothes sealed. Possible to get $2 solid plastic boxes at Walmart to keep things even more sealed (storage containers).

Lisa Petrisin

Everything that I owned was in plastic bins or nylon stuff sacks except for the moments that I was using it, for quite a while.

Kathy

Ziploc bags and plastic bins!

Beatrice Latherings

I don't trust any location to not contaminate my stuff.
Q. 9:3 - Dishes and DVD’s

When we left our moldy house, we brought our things with us to our new apartment because we didn’t know not to. We left that apartment for another one and didn’t bring our clothes and furniture, but did bring things that had been in our moldy house like dishes, DVDs and things like that. They have all been washed several times. I keep reading on this site to not bring possessions with you when you leave a moldy environment. Would the dishes, DVD’s etc. be a problem?

A.M. Runyan

It would depend on how sensitive you are.

Here's the formula.

You take the cost of the item, multiply by the chances that you can clean it to an acceptable level, and the difficulty of replacing it, and then compare that with the cost of the other items it might contaminate and ruin if you were to keep it, or the likelihood of it contaminating the new living space.

For a few things, like a laptop, I thought it was worth keeping it since it would have been a major hassle to replace it, but for cheap things... Walmart has $3 dishes, you might just want to replace them to be safe, or put the old ones in storage until you are less sensitive.

A good rule of thumb when moving to a new location is to limit what you bring from any old place at first to the essentials, and then if you want to try bringing it in later, you can bring items in one by one to see if they cause reactions. That’s better than simply contaminating the new place from the start and then not having a clear baseline for comparison.

Erik Johnson

If one is bringing in remediated items until they have a reaction, it might not just be the last one that was brought in.

It could be the sum total of all of them finally hitting the limit.
Lisa Petrison

For people who are very sick, leaving a very bad place, it seems much simpler and safer just to not bring anything. It tends to be really difficult to wash things in a manner that no cross-contamination gets carried to the new place, and it's difficult for someone just starting out to determine whether washed things are going to be problematic to them.

From the point of where you're at right now (everything has already been washed, you've moved a couple of times), I think it may be going too far to just wholesale get rid of things from the moldy place unless you have a sense that they actually are problematic.

A few thoughts:

Plastic seems to hold onto toxins much more than glass or metal. And items like dishes that are washed frequently likely will have had more of the toxin removed.

An item like a CD, that can be stored in a non-contaminated container, is going to be less problematic than something that sits right next to your bed.

Personal items used frequently or up close (bedding, clothes, eyeglasses, computer) are going to be more problematic than ones rarely encountered.

Items that cannot be thoroughly washed (like electronics) are likely going to be more problematic.

Large items left in the open (like a table) may be more problematic than smaller ones kept put away most of the time.

I definitely reacted very strongly to my own washed clothing when I was not even totally clear, so I would be careful about that.

If I were in your position, probably I would remove all the suspicious items from the bedroom so that I had a good sleeping space and then evaluate everything else on a case-by-case basis based on my intuition about it.

In general, if people are in recovery in a different place with some washed items from their previous place, and are following basic decontamination procedures after going to suspicious places (showering and changing clothes), and still aren't doing as well as they would like, my suspicions about exposures probably would not be primarily on the washed items. I more would suspect the home itself (the
ERMI seems better than alternative tests but not totally reliable) or -- especially -- the outside air.

**Julie Rehmeyer**

I get worried about electronics, because you can't clean the inside, and there are generally plastic components that can collect mold. Also fans can then blow the mold all over the place. DVDs themselves are again plastic, so potentially problematic. I brought items that were strictly glass or metal into my house, slowly and carefully, washing everything first and putting it all in the sun for a while. I didn't run into problems with that kind of thing. In general, I would recommend initially bringing nothing, and then if there are things you'd really rather not replace that seem likely to be safe, bring them in slowly and carefully so that you can detect problems if they arise.

I couldn't keep my laptop, btw -- had to replace it. Even a used one from elsewhere bothered me.

**Beatrice Latherings**

Part of it seems to depend on what kind(s) of mold you had. My house did not have Stachy (or at least, did not test as having Stachy) and my washed (in the washing machine in the moldy house) and aired clothing did not bother a severe reactor I visited who has extreme reactions to spores. So my stuff, I consider washable because it appears that it doesn't have "sticky" spores/mycotoxins on it. I'm still occasionally taking a piece of clothing out of the house, which now smells really badly of mold, and soaking it in a bucket of borax and water for a week, and doing ok.

But if I had had Stachy, I don't know if I'd get away with that.
Q. 9:4 - Books

I am moving from a slightly moldy apartment to a cleaner one this weekend. What can I do with my boyfriend's books, besides keeping them in a plastic bin? The clothes are getting cleaned pretty well by washing them with half a container of kefir and about 4 Kyodophilus probiotics (billions of probiotics), in a location with good outdoor air.

Lisa Petrison

I can't think of any better ideas than keeping them in plastic bins. But if the place that you are in now is only slightly moldy, then maybe the books will not be a problem at all. I've known people who have found even fairly contaminated books to be fine after a few weeks in the sun, so you could try that when the weather gets better.

Forebearance

If he doesn't need to use them, I'd put his books into storage. Or else keep them in a plastic bin in a closet or a place away from the bedroom.
Q. 9:5 - Taking Your Things

What if you must take your things?

I know this is a huge no no, when I did my first relocation I took nothing but the clothes on my back and changed into brand new clothes when I walked in the house. This enabled me to go from near point of death (I was dying) to being somewhat functional, far from death, but not well. I was unfortunately forced out of the place I was healing in and along with one of the people I was living with, took his things to a new place he thought would be good.

Within a week I began to have mold symptoms, some severe. I've been bedridden for three weeks straight. We have gotten out of the lease thanks to the graces of our landlord and a note from my doctor. Knowing more about how to inspect a place and having developed some sense of what mold smells and feels like, we have found a new place that seems pretty pristine.

He is nervous about taking it but it is literally my only option, I am too ill to go anywhere else as I am on the severe end of the spectrum and have no place to go to. The issue is even though the things we brought came from a low mold environment they have now been here, he will not get rid of them.

So what do I do? Can things be washed? We have only been here 1 month which is different than the 1st place I came from. What can be detoxed and what can't? I have no power over this."

A.M. Runyan

In my experience:

1) It tends to be easier to cope with fewer objects rather than more. A collection of many objects seems to have a stronger mold effect than a few isolated objects. So if you are going to have to bring objects, the fewer the better.

2) Obviously, porous items are much harder to clean, thick clothes being the worst, then clothes in general. Metals seem to be easiest to save. I saved my laptop and it's alright now.

3) To decontaminate stuff, soap and water is almost always safe, but other chemicals like hydrogen peroxide, bleach, etc. can sometimes cause
unexpected changes in the toxins. I found that when I was first doing avoidance, things that had worked for me before to apparently clean mold no longer worked well enough (like ammonia, H202) and I was left still reacting to objects I had brought with me (I got into this accidentally and brought a lot at first).

4) There can be odd ways to decontaminate objects, besides the obvious ones that are passed around. I've become a fan of using foods and supplements to clean objects, if regular cleaning fails. Some of my favorites include kefir, chlorophyllin drops, chaga powder (source of superoxide dismutase), reishi, grapefruit seed extract, etc. If it works in the body, I figure it could work on objects, too. I soak it in stuff and then rinse and wash with soap and water afterward. I've saved a lot of very toxic stuff this way, but it doesn't work every time.

5) For non-porous objects, I found that rubbing them with butter and then washing the butter off with soap and water worked pretty well for removing toxins, since lots of the toxins that bother us seem to be fat-soluble and seem to be absorbed into fat. So it might be possible to use butter as a sort of sponge for toxins.

Lisa Petrison

My increasing belief is that there are a very few buildings (e.g. less than 5%) that contain particularly problematic mold toxins that actually cause (in combination with other factors such as genetics) some people to become sick. There also are lots and lots of buildings (maybe up to 90% of buildings in some places) that contain more minor mold toxins that are not problematic enough to make people sick but that are problematic to keep people who already are sick from getting better, I believe.

In addition, I believe that the really problematic mold toxins that are present in only a small percentage of buildings are very difficult to remediate and cross-contaminate in very small amounts.

Thus, if people are leaving a place where they first got sick or suffered a significant permanent decline, or if they still have their belongings from a place like this (and less than 10 years have elapsed since they left), it seems prudent (at least as an experiment) to start totally fresh.

With regard to the question: certainly, it's possible that you are in a building with the particularly problematic toxin. But it may be a less problematic toxin, that is
easier to remediate.

Especially when significant others are involved, it does get tedious to keep throwing things away. And it's possible it might not even be necessary.

I would suggest the following: 1) put everything that cannot be washed in storage (or at least sealed in boxes for an initial trial); 2) wash everything that can be washed; 3) designate a sleeping space in your new house/apartment that will not have any of your current possessions; 4) put your own washed clothes/bedding aside and purchase some new ones.

Hopefully, the toxin that you are currently being exposed to will not cross-contaminate enough to be a problem that will keep you sick.

But if you conclude that the possessions that you brought with you are indeed still problematic, then you can make further adjustments then.

Julie Rehmeyer

I don't have a lot of relevant experience here, but I can offer a few ideas.

I know one person successfully decontaminated clothes by washing them many, many times and letting them hang in the sun for a long time. Washing and sun have definitely been helpful to me in decontaminating things that have picked up transient contaminations.

And although I've heard from one person that ozonation made things worse for her, I've found it helpful for detoxifying things.

Finally, it does seem that what's near you when you sleep is most critical. Perhaps you could make a point of hand-washing your sheets in the bathtub and keeping all old items out of your bedroom. Being careful to shower before getting back into bed would also be helpful.

Karen Dean

I have tossed many times. If you have a yard, you can store things outside in boxes, or get a storage spot for things you really need, try and de-con them with washing, ozoning (outside only in a box,) or an overnight soak in Vulpex soap.

Bringing objects inside you know are contaminated is asking to move again. How
do you know the place is good or bad if you are confusing the experience with objects you know are bad?

Living with cardboard boxes that are new and clean is a better option in the beginning.
Chapter 10

Decontamination
Q. 10:1 - Decontaminating Routinely

What do people mean when they say that they 'decontaminate routinely'?

Lisa Petrison

I take this to mean that as soon as I come home from going out, I take off my clothes and bag them to be washed, then head straight to the shower to wash my body and hair. I just use gentle organic regular soap/shampoo. I usually let the water from the shower rinse out my nose too, and then blow it. That's all.

Karen Dean

If I feel I have been in anyplace that might have been contaminated, I take my clothes off outside the bathroom, wrap my hair in a towel, and go directly into the shower. I always carry a change of clothes and towel in the truck, If I am in town, where there are public baths, I reach inside, get my clean gear, and head for a spa. That way I do not contaminate the truck cab.

Beatrice Latherings

Same as Lisa. Even if I have been "only" in the car, I do this. It becomes a way of life for avoiders.
Q. 10:2 - Best Practices

What are the best practices for showering to decontaminate after coming into contact with mould? For example, is it necessary to use soap over the entire body or just to rinse with water? Do you have to wash your hair each time you get exposed? And are these judgment calls made based upon the severity of your reaction, or upon the duration of the exposure? If you walk into a mouldy building and walk right out again within a few minutes do you still have to shower and change clothing?

Julie Rehmeyer

I wore a baseball cap and kept my hair in a bun, so that as little hair as possible was exposed. Then if a building felt bad to me, I immediately changed my shirt and hat. I tried rinsing my head on the spot, but I didn't find that very effective, maybe because I have too much hair, and as long as I always wore a hat, that solved the problem. I also rinsed my face and neck and hands and arms. When I got home, I'd immediately take my clothes off and shower, whether I knew that I had ben exposed or not. Like Lisa, I didn't find that soap was really necessary, though I typically did use it. A shower would immediately end even extreme reactions -- it was quite remarkable. At times, I was literally unable to walk, sometimes hardly able to use any of my muscles, and then the water would run over me, I'd stand up and be fine.

The amount of time of exposure didn't matter. If I walked into a moldy building, I suffered if I didn't immediately change my shirt and hat and rinse off.

Lisa Petrison

My habit was to shower after returning home from going out, unless I felt confident that I hadn't been hit.

If I went into a building and felt bothered by it, I would rinse my hair, wipe off my face with a wet towel, and change my shirt. And the sooner the better. That tended to be enough to stop the reaction until I got home. Usually I just did this in the car (I kept bottled water in the car for this purpose), but sometimes I would go to a Starbucks or fast food restaurant (those tended to rarely be moldy, I found).

My hair was quite short for the whole time I was really reactive.

Often 30 seconds in a particularly bad building would be more than enough.
exposure to force me to choose between either getting extremely sick or immediately decontaminating, yes.

After I got to the point that I could recognize that particularly bad outdoor toxin, I was much more proactive in showering immediately after being exposed. But mostly, I just tried to stay away from places where I thought any of it might be.

Using soap or shampoo never seemed necessary to get rid of the toxins. Just water always seemed enough.

This may not be specific to mold avoidance, but in terms of soap that feels pure and good to me, Andrea Fabry's "Just So" brand of soap is by far my favorite. It's one of those rare products that makes me feel unreasonably happy to use it, just like some particularly good locations make me feel unreasonably happy.

http://momsaware.org/online-store.html

Beatrice Latherings

Since my reactions are delayed, I have a rule that when I get home I completely soap shower and wash my hair, and bag my clothes.
Q. 10:3 - Hair

Has anyone had problems with mold in hair or reacting to their own hair? Besides vinegar rinses or shaving it, what are other options?

A.M. Runyan

Yes of course - hair seems to pick up mold very well, perhaps from static electricity?

Usually washing once or twice makes me stop reacting to the hair. One time my hair was especially contaminated, I coated it in butter for 30 minutes and washed it out with shampoo, but I think that dried my hair some.

There is a "pre-poo" (pre-shampoo) movement where people put oils in their hair before washing; that might help to trap the fat-soluble toxins to get them out.

I sometimes use the Giovanni Tea Tree shampoo (triple treat or something like that) to kill spores.

If I'm ever reacting to a room, like a humid bathroom, I'll put a towel over my hair before going in there, to keep it from sticking to my hair.

Erik Johnson

I wrote the following to Dr. Joseph P. Klein in 2002:

> It's absolutely awesome to hear someone else describe the ability of hair to maintain and transport the mold. I found that wool garments are no different.

> I noticed that some contaminated places give me a huge "hit" but that I could walk away and recover without decontamination. Other places might hit me less, but I would carry the "reaction" with me. This led me to believe that the neurotoxic reaction was to aerosolized mycotoxins and not necessarily inhalation of spores.

> I tested this by placing a contaminated article in HEPA filters and taking it to my "clean" place. I put it under six layers of blankets and slept on it. I got the usual reaction and removed the article but went back to sleep on the same blankets. The reaction was gone.
This convinced me that spores had not penetrated the filter or blankets and that the toxic gas was truly my primary irritant. This was confirmed by Dr Marinkovich who told me that a housing project in Sweden had recently been identified with sick inhabitants but no spores could be found. Only when the walls were opened up were the colonies found, but they were so tightly sealed in the walls that only the toxic gas could escape.

Many places that give me mold hits are strictly VOC hits and not spores. When I leave these areas I do not have to bother with decontamination.

I told Dr Klein that I wear a hat into bad places, just so I can take it off.

http://stachy.5u.com/

Lisa Petrison

I've heard of a number of people reacting to their hair even after washing it, after moving out of a bad place. One person said that it stopped bothering her after spending a few hours swimming in a chlorinated pool, if I'm remembering correctly. But hair grows pretty quickly -- I would think that just cutting it short would eliminate all the problem within a few weeks.

In terms of transitory contaminations, I found that rinsing my hair immediately after a bad exposure almost always resolved that problem entirely. No shampoo necessary. If places are bad enough that a transitory exposure would cause the hair (or anything else) to be permanently problematic, it's better to avoid those places entirely. Though of course, it's easy to make mistakes.
Q. 10:4 - Driving Home From Exposures

What do you do if you have to go somewhere slightly moldy and drive home in your car? Change clothes? Sit on trash bags in the car?

I went to get a library card the other day, and the library was a little moldy and a little got in my car. Essential oils didn't seem to be enough, so I'm ozonating my car with a heavy-duty room ozonator. Any other suggestions?

Lisa Petrison:

When I first started doing extreme avoidance and went into even moderately moldy buildings, it was like being whacked on the head with a frying pan. This happened pretty frequently. And I would need to decontaminate immediately if not to be pushed into a real downward spiral.

So I always carried an extra shirt, some bottled water and a towel (or at least some paper towels), so that I could rinse my hair (very short at the time!) and change my shirt. Just dumping water on my hair seemed sufficient to stop the reaction to it. I didn't find I needed to change my pants or skirt, usually. And then I would bag my shirt to be washed.

Sometimes I sat on garbage bags or towels in the car, to protect the car. But mostly if I could tolerate an exposure enough not to be forced to decontaminate right away, I found that whatever cross-contamination there was (of non unusual building toxins) died down fairly quickly.

The trick with cars that I've had the most success with is driving them temporarily to a higher altitude. This works even on outdoor toxin that I find the worst. Things feel worse at the high altitude, but a lot better when back at the lower altitude. However, in some cases I've felt like there was invisible poison dust all over everything that needed to be washed away after that process. (The difference was that it felt like it _could_ be washed away, rather than being totally stuck to things.)

The most dramatic time that I tried this, I started at 500 feet and drove up to 8000 feet for a few hours. That worked really well at decontaminating my whole RV. But Erik seems to think that it is not necessary for the altitude difference to be that dramatic, and that less than 1000 feet would be enough. So that could be worth trying, if a cross-contamination seems really bothersome.
Julie Rehmeyer

I've sat on trash bags. And yes, ozonating a car can definitely make a difference in getting rid of that kind of transient contamination. But if a car is really bad -- it's had a leak, or it's lived in a place that's especially bad for toxic mold like Berkeley or Dallas -- it's hopeless. Sell it and get a car that's OK for you. That's what I had to do with mine, which had lived in Berkeley.

Kelly

Shampoo & clothes change, 95% effective, the sooner the better. If I breathed it in, that's another story (burning sinuses and throat for weeks, other symptoms). Also, Rescue Remedy seems to help a little.

Beatrice Latherings

I consider my car to be contaminated because of the impossibility of keeping it pristine.

Since I don't sleep in my car, and I drive with the windows down, I don't feel I have to be extra careful unless an object has an obvious problem.

Every time I go anywhere in the car, even if it is just to somewhere outside, I do the entire self-decontamination procedure when I get home. Shower, wash hair, clothes in the hamper, before I touch anything in the trailer.

All libraries are moldy, by the way. Maybe not the building but always the books.

Karen Dean

I always keep a change of clothes and towel, soap, shampoo in the truck. I reach in and grab them, go to a public rest room and change and clean up as much as possible. If I am in Truth or Consequences, it is easy. Being a spa town, I can shower and soak in many places. The thermal waters here are especially good at de-activating toxins.
Avoiding Mold

Not specifically related to transitory cross-contaminations, but nonetheless relevant to the discussion of cars, is this post from Andrea Fabry:

Q. 10:5 - Negative Effects from Showers

My skin cannot handle all these showers! It held up for about a week and a half of daily or twice-daily showers, but now it has had it. I have extremely dry, painful skin, raw patches, painful to lie down. During cold, cold winters, I usually shower only a couple times a week because I cannot handle any more than that, and even that is torturous sometimes. As it is, it's still warm out, I've even skipped a day or two of showering when I didn't leave the house/get exposed to mould, and my skin is still painful. It is not tolerable. Sometimes I shower and decontaminate after being out, and then go outside to take the garbage out, and feel I need to shower again. But I can't do that! Too painful.

The only solution I can think of is to stop getting exposed, ha. Then I won't have to decontaminate. But now that I have set these high standards for feeling clean and uncontaminated (and erring on the side of caution if unsure), I feel 'icky' from doing anything -- stepping in the wrong place, touching the wrong thing. I wonder if this is some degree of obsessiveness, and it's difficult to tell. Partly that is because I already feel terrible in my skin, as a norm, in sensory terms, and have a low tolerance for anything that feels not right on my skin.

I realize there's a possibility that if I feel I'm getting contaminated this often, maybe I'm just not in a good enough place. Maybe I am sometimes mistaking chemical 'ick' for mould 'ick', and feeling the need to shower to deal with that?"

Julie Rehmeyer

FWIW, I still take many showers, and when I was more reactive, I took many more.

Lisa Petrison

I am wondering about the quality of your water, with regard to at least two issues.

First, it could just be that your skin is reacting to all the chlorine. A filter would likely take care of that problem.

Second, depending on where your water is coming from, it could be contaminated with cyanobacteria toxin. Erik talks in the "Edge" book about how
he boils all his water before using it for anything (including showering). He talks mostly about how it drives him farther down on the power curve systemically, but inflammatory toxin could be disturbing your skin too.

To my understanding, communities have to supply info on the quality of the water (and do usually mention cyanobacteria), so you could start with that.

In terms of things you could put on your skin, I am wondering about this cream kefir that Andrea Faby talks about in the second article on this page. Coconut oil sounds like a good thought too, if you haven't used that.

http://momsaware.org/natural-alternatives.html
Question 10:6 – Decreasing Reactivity

I am wondering what decon procedures to use when getting better. I am past peak reactivity and now with CSM I am better overall (energy, PEM all that), and I am less sensitive and less reactive. Should I continue to shower/change clothes, not bring items inside based on my reactions to people and places before CSM?

Julie Rehmeyer

I have indeed started being somewhat less cautious. Occasionally, yes, I get myself in trouble, but my reactivity is down enough that it's not the end of the world when that happens.

Beatrice Latherings

Yes.

Lisa Petrison

Glad to hear that you are feeling less reactive! Even though I am much less reactive too, I do tend to change clothes and shower routinely when I return from going out. Some toxins cause much bigger effects over long exposures than they do immediately, so keeping them out of my immediate environment (such as bedding) seems a good idea. For objects, I am cautious about evaluating them (including physical changes and intuition) before bringing them into my environment, just using immediate reactions. If I don't notice any physical changes and feel good about it, then I go ahead. Hopefully this strategy will keep working though - you never know.
Chapter 11

Clothing and Bedding
Q. 11:1 - Type of Bed

What kind of bed or mattress do you sleep on and why?

A.M. Runyan

After losing hundreds of dollars of beds to mold in the past, I now sleep on the floor on things that cost as little as possible so I can wash or throw them away if they get contaminated. I used a closed-cell camping mat for a while that was pretty comfortable and held air well. Lately I sleep on top of a towel, opened-up sleeping bag, or if I don't have either of those, a trash bag. :) It's actually really nice sleeping near the floor and on a firmer surface, and when I sleep on beds now I don't particularly like them. I think it does something good for the back to get stretched a little from being on a firm surface, and it feels grounding. That's how we slept for a long time anyway in evolution.

I used to be an extremely sensitive sleeper and I needed a really soft, comfortable bed, but since doing mold avoidance more assiduously I can sleep in a wider range of situations.

Julie Rehmeyer:

I had an extremely hard time finding a bed I could sleep on after starting avoidance. I slept on an REI camping pad for many months, and that worked well. I was in no hurry for anything else until, well, a fellow entered my life, and then sleeping on a camping pad didn't seem like the nicest thing anymore.

So I tried multiple mattresses, multiple futons (including a nearly new, fancy, organic one), and multiple air beds, and for reasons I don't fully understand, none of them worked. Even the air beds!

I ended up getting a pricey latex mattress that -- hooray! -- worked out well, and I haven't had any problems with it. I've certainly gotten bedding contaminated, but I've never felt like the bed itself has gotten contaminated.

During the period when I couldn't find a mattress I could tolerate to buy, I did sleep on one mattress at someone's house that was just fine, and it was nothing fancy at all, in fact it seemed like a real cheapo mattress. I considered asking them if I could buy it from them, and then hauling it a few hundred miles home!
All very mysterious. I thought it might be fire retardants that I was having such trouble with, but I really don't know. Seems unlikely to me that the fancy organic futon had flame retardants. Thank god for the REI camping pads!

**Beatrice Latherings:**

I have a two inch foam pad, a small air mattress, and another two inch foam pad. I sleep on a five foot long metal bench in my trailer, and I took out all the cushions that came with the trailer because they cannot be adequately cleaned. With the foam and the air mattress, they are disposable should they develop a problem. I would use just foam but it is not soft enough.

**Corinne**

100% wool mattress has been one of the most worthwhile things I bought when I started avoiding chemicals. My sleep improved immediately.

**Erik Johnson:**

Piled up cotton blankets. That way the "mattress" is entirely washable.

**Jeff Charlton**

Mattresses and pillows are humid and full of dead skin. The bed is also humid and Dust mites can thrive. Mould will form on dead skin which is in a humid environment. The mites eat the skin and excrete the mould as a tiny sub micron fragment which is easily absorbed. Keep the bed dry by reducing bedroom temperatures and avoid sweating by reducing bed clothes/cover. Try a mattress cover which stops dust coming through and wash regularly. I read some time ago that a pillow can double in weight over a few years increased by dead mites, excreta and skin.

**Lisa Petrison:**

I've encountered a number of mold avoiders who have said they were especially reactive to a wide variety of sleep surfaces. Often they have suspected fire retardants. One person from England sleeps on a leather sofa, for instance. (Apparently leather is naturally fire resistant and thus often not treated, he said.)
Personally, I've reacted on occasion to mattresses or futons, but not any more often than to other random items. My suspicion was always cross-contamination rather than something inherent, so maybe I am not as acutely sensitive to fire retardants/whatever as some people. (Though they would be a good idea to avoid anyway.)

When I started camping and doing extreme avoidance, I was most interested in washability in case of cross contamination. I used a 2" Therm-A-Rest self-inflating mattress for a long time and was happy with that (and still have it).

When I bought my RV, the first thing I did was get rid of the foam-filled cushions. They would have been impossible to clean properly, I didn't like having all that foam, and I didn't find them comfortable anyway.

Eventually I added this mattress to my RV. It does have a bit of foam in it, which I would prefer not to have, but it felt more comfortable than the plain camping pad. I'm not necessarily recommending it for anyone else though.

http://www.llbean.com/llb/shop/63623
Q. 11:2 - Washing Clothing

Can contaminated clothing be washed clean? Hot water? Boiling water? What about kitchen things - ceramics etc.?

I'm moving into a brand new custom made chemical-free house and don't want to bring any hanger-on-ers with me!

A.M. Runyan

If the previous place was moldy, the rule of thumb is not to bring any clothes or porous items, at least not at first.

Once you have gotten used to the new place you can try bringing in remediated stuff from the previous place one by one to see if you react.

If the previous place wasn't moldy, there are ways people wash clothes. I don't have any clothes from my original moldy house, but I regularly have to wash stuff that gets mildly contaminated.

For routine clothing care, I tend to use a lot of supplements on my clothes.

Supplements I have had good results using in clothes (washing them individually in a stainless steel sink):

- Grapefruit seed extract to kill any spores
- Chaga powder - helped me with really bad toxins from Dallas/Fort Worth
- Kefir - might help to deactivate toxins but wash it out thoroughly or clothes smell weird
- Chlorophyllin drops - but dilute in water first so they don't turn clothes green, and use only on dark clothes

If something is safe enough to be a supplement, it's probably safe enough to have on skin/clothes, and lots of the things we use to kill or treat mold internally seem to have an effect on clothes, at least for me.
Beatrice Latherings

I soak stuff for a week in a bucket of water with borax. So far so good but my house did not have Stachy.
Q. 11:3 - Materials

Are there certain clothing materials that hold contamination less than others? I’m wondering if polyester or other synthetic materials are easier to clean than cotton, after a brief encounter with a mouldy building.

A.M. Runyan

Thinner clothing seems easier to clean. I used to wear these very thin Dickie's women's shirts. Thick stuff like jeans or sweatshirts are very hard to clean.

Lisa Petrison

I've not noticed a difference between synthetics and cotton, with regard to their tendency to be permanently cross-contaminated.

However, especially in a humid climate, synthetics tend to air dry faster than cotton. Since moldies rarely can find dryers that they can use successfully (dryers get cross-contaminated easily and also tend to consolidate all the toxins in the air on the clothes), that can be important.

Julie Rehmeyer

I haven't noticed a difference either, but I don't have much confidence that I would have.
Q. 11:4 - Reacting While Washing Clothing

Do others react when they try to decontaminate their clothing? I delayed washing mine for 24 hours post-exposure reaction (because I was scared of going near it) and now I feel unwell washing it. I was worried this would happen, because my reaction yesterday was so extreme. I am keeping the bathroom door closed while I wash the clothes in the sink, to avoid contamination spreading. I guess all toxins behave differently, so I cannot know how this one will act, right?

A.M. Runyan

Yes, I've had that happen. Sometimes I'll throw random things in the water to see if they take down the reaction I'd have around the sink when soaking them. Vitamin C crystals and chaga mushroom powder have helped, and those are both antioxidants. If they are that bad, sometimes I'll just leave them in the sun or outdoors for initial treatment or get rid of them.
Q. 11:5 - Cross-Contaminating Washer

I recently had a pretty big cross contamination when my daughter apparently brought mold home with her one day, polluting the car, her bedding, the towels and now the washing machine.

I'll be getting rid of all her clothes and starting over, as well as the clothes of mine that became cross contaminated, but it's the washer I'm most in need to get back. I had taken a chance and used it when I didn't know what the contamination was from (I'm now pretty sure it's mold as I went into a house yesterday that I was sure had mold and my reactions were similar).

A friend who is mold sensitive told me that he had had very good luck removing mycotoxins with the washers that are high efficiency with a steam clean cycle. That is what I have. He felt that the combo of the steam and soap made stuff tolerable for him (he was staying at a friend's and couldn't use their bedding) that hadn't been before.

So I used the machine on the sanitize/steam cycle with lots of rinses. I now fear I've contaminated the machine for good.

What is your experience with washing machines? I am struggling to keep my daughter with me as she is only nine and really needs me. I am highly sensitive but not highly sick at this point. I am MCS as well, a universal reactor.

My current plan is to use some cheap clothes I bought as an experiment. Soak them in milk, then borax and baking soda. Wash some by hand a few times and one in the machine on this process, then compare my reactions to the two. I plan on running the machine empty first with borax and the sanitize steam cycle as well.

It took me a year to get this machine off-gassed to where I could use it and I really don’t want to start over.

Have folks had experience with washing machines? Can they be deconned or should I throw it out and start over?

If I need to get a new machine, suggestions on one that off-gasses quickly and will serve a Moldie's purposes best?
Lisa Petrison

My impression from the stories that I've heard is that there are some toxins that are bad enough to contaminate a washer permanently. What I wonder is if they actually start growing in the washer, just from a small amount of spores.

In general, for people who are really reactive, the safest way to do laundry is by hand. You may be surprised at how much better the clothes and bedding feel to you.

This is what several people have recommended and what I have used. You may want to have a clothes wringer as well.

http://www.laundry-alternative.com/.../the-wonderwash.html

Erik Johnson

I use a wonder wash. So far, so good.
Q. 11:6 - Another Cross-Contaminating Washer

I have been doing avoidance for several years and am living in a house with my husband and children in Boulder, Colorado. Recently my washing machine became contaminated with a particularly bad toxin and no matter what I have done to try to repair the situation, any clothes that I wash in it become very contaminated. Does anyone have suggestions on how to fix the washer? How do others doing avoidance handle their laundry?

A.M. Runyan

Kefir works well for me with laundry, and also chaga powder. But if nothing is working, it might be the outdoor air. I've been to Boulder a few times since the floods and feel like the outdoor air in general is a struggle for me. I've had to throw away two items of clothing I wore there since I couldn't fix them.

Lisa Petrison

Oddly, I have heard two people in Boulder getting their washing machines permanently contaminated with a mystery toxin that causes skin issues and other symptoms and is impossible to remediate. I think that the microorganism making the toxin may actually grow in the washer after cross-contamination.

The only thing that I think possibly I would bother to try is to make several jars of milk kefir and then put them in the washer. And then add warm water and/or milk and let it sit for several days. Probiotics neutralize mycotoxins (this is from the literature) as well as attacking spores, and I personally had success with it.

But I really think that family or no, it may be a better idea for people who are mold reactors to do all laundry by hand. It seems too dangerous otherwise. I just bought this little spin dryer and am exceptionally happy with it. There is more information about it on my own FB page.

I've used a Wonder Washer (from "The Laundry Alternative") before, but at present am just doing everything by hand in a large sink.
Q. 11:7 - Still Another Cross-Contaminating Washer

I recently became the caregiver for a friend with MCS and ME.
I cut off all my hair, brought new clothing and tried to not bring anything potentially bad in. There's only one washer and dryer and I have been sharing it with her.
It became apparent that there was something on me or my new clothing making her react.
Her MCS now seems to have gone through the roof; she reacts to everything. She can smell fragrances on brand new fabrics that I cannot smell.
If I try touching her with brand new clothing on, the fragrances are overpowering and her skin starts to burn and she has to wash. I also have to wash to touch her if I’ve worn them and remain nude.
In hindsight, using the same washer and dryer was a mistake; her clothes seem to have been affected by whatever is already on these fabrics when they're bought. (Bedding is particularly bad). Thankfully she can still wear one pair of pajamas,
My questions are: How do we get this stuff off of the clothes?
How do we get whatever is in the clothes out of the washer and dryer?
I'm especially confused about how to deal w/ the dryer, since it's, well, dry. Is there a method to clean it?
Is there a way to lessen her inflammation while we try this? We are trying to prevent her from becoming more sensitive.
Also is there a more effective way to get these fragrances off my new things than simply using fragrance free detergent?
At the moment, there is no replacing these appliances; they are new and were not problematic before.

Lisa Petrison

Prior to about two years ago, I only occasionally heard of laundry (washers and dryers) becoming cross-contaminated in this way. My feeling was that it was from people living in a particularly problematic place (such as, say, Mountain View) bringing a load of their laundry and washing it in an otherwise good place.
The public laundry room at Death Valley/Furnace Creek became contaminated in this way, for instance. At one point, it felt great to me. I was able to wash clothes and dry them. Then one day, it became incredibly problematic (for me and for others). Washing clothes or drying them would cross-contaminate them. Over a period of maybe six months, it gradually became better until I could use it again. Considering how hot and dry Death Valley is, and how no mold was actually growing in that laundry room, that seemed a long time.

Within the past two years though, something seems to have shifted. I have heard repeated stories of people who have encountered a particularly problematic toxin (with a particular symptom of burning) that seems to have a particular affinity for washing machines. Perhaps it actually grows inside the washing machine? In any case, I've not heard of anyone being able to repair their washing machine as a result of being exposed to this toxin, and many mold avoiders have abandoned the idea of using automatic washing machines at all because they are afraid of it.

I've not heard that dryers exactly "activate" this toxin in the same way that washers do, but I wouldn't imagine it would be possible to remove their effects from the dryer either.

Based on the horror stories that I have heard from a whole bunch of experienced mold avoiders (at least half a dozen at this point), I would advise all people doing mold avoidance to stop using automatic machines for any possibly contaminated items. If you have a washing machine that feels good to you, then I would use it only for items that you know are not contaminated but that need to be washed to remove dirt (e.g. bedding).

In the place of an automatic washer and dryer, I would suggest the following:

1) Large Sink or Wonder Washer

http://www.amazon.com/The.../dp/B002C8HR9A/ref=sr_1_2...

2) If needed, clothes wringer or this spin dryer.

http://www.amazon.com/.../dp/B00CDWTQKI/ref=pd_sim_la_2...
Chapter 12

Practicing Avoidance
Q. 12:1 - Principles

I've realized that a single contamination can cost me 50+ hours and possibly several hundred dollars. So just being extremely conservative about contaminations seems like a good principle. Are there any other principles you've learned during mold avoidance that make it easier? Things like detoxing your way out of sensitivity, or having back-ups available, or cleaning supplies, etc.

Lisa Petrison

If I could break the response by getting to a really good place for even a few hours, everything became more tolerable. On the other hand, if I sat around exposing to contaminated things trying to clean them, then I never got the response damped down enough to move higher up on the power curve.

Christine

A tank of oxygen for surprise exposures. After the last one in CA my doctor agreed I should have it at home. Said the ER would have no clue what to do for you.

Vicki

For any accidental exposures, I plan on taking CSM for several days following it. I want to try to head off CIRS starting up again. Also, if exposed, I plan on leaving my clothes in the garage, washing them separately, and heading straight to the shower!
Q. 12:2 - Old Friend

I have an old friend from high school. Haven’t seen her in 20 years. She is living in mold, getting very sick. She knows she has to get out. But, is still in denial phase about how to do it, money, etc.

Well, she wants to get together. I know for certain I cannot go there. So now this old friend is coming here.

I feel terrible. But, I feel like asking her to shower when she gets here and put a pair of my clothes on. That is how sensitive I have become, and how much I want to and try to avoid exposure.

Maybe we’ll stay outside for the night. Do you have any other thoughts or suggestions?

Lisa Petrison

Since starting avoidance, I've met a couple of dozen people with various levels of CFS-like illness, in various stages of illness or recovery. With only a few exceptions, I've had problematic experiences with all of them. They either are carrying around toxins especially problematic to me (even if they claim to be pursuing mold avoidance), or in one case appeared to be detoxing toxins problematic to me, or in one other case I appear to have caught from the person some kind of pathogen that took me months to get over (since I acquired a symptom problematic for this person that I had never had before).

This is striking because I almost never have problems interacting with people who don't have this sort of illness. They almost never are carrying around the worst toxins, whereas the CFS patients are usually carrying them around even when they've made efforts to get rid of them. Of all the evidence in my possession, this is the most convincing to me that these really bad toxins are the core cause of this illness paradigm.

(As a side note: from the reports I've gotten, a very high percentage of people with MCS -- including those living in tents in the wilderness -- are carrying around large amounts of particularly bad mold toxins and have no idea of it. And this seems like the bad breath phenomenon: only your best friends will tell you, while the mold avoiders you might know more casually are so used to having people be mad at them for bringing the topic of mold up that they usually say nothing.)

If people have been doing avoidance for a long time and are "mostly recovered,"
then getting together is something that I might consider. Otherwise, I've become really hesitant.

A.M. Runyan

It could be risky to have her visit at all. People who are getting sick from mold tend to exude it from their skin, even if they shower and change clothes.

If she does visit, you're probably justified in assuming you'll have to be as extreme as possible in terms of avoidance, like staying outside in fresh air, or in separate tents, or whatever, since it's better to be surprised that the reaction/toxicity is not as bad as you imagined, than to be surprised when your efforts to avoid contamination are not good enough.

I had two really uncomfortable, unfortunate visits with people who were having biotoxin symptoms and then visited, even though I took what I thought was enough precautions (having them shower, wear totally new clothes, stay in a separate hotel room, etc.). I got sick and it was unpleasant for them too, and it is never fun to have to choose in the moment between being a good host/hostess and getting exposed to toxins.

Also even being exposed at a low level can make people irritable, which can make for unpleasant interpersonal interactions (I was crying and freaking out and very upset/desperate when one guest arrived, because of the biotoxin reaction, and she thought I was being possessed by demons (she is very religious)).

If the person is actually getting sick from mold, not just living in it asymptomatically, chances are they have bad biotoxin genes and store the toxins in their body and they are more likely to exude a lot of toxins, particularly if they go to a lower-mold area (remember how many of us sweat out toxins when we first started avoidance).

I've come to recognize that I just can't be around biotoxin-sensitive people who are living around mold and who are having symptoms unless they have moved somewhere clean and detoxed for at least a month or two. Skype is a great way to keep in touch with these people, since it's almost like having coffee in person, and you can see body language and all.

I Skype with my mom several times a week. I was realizing though that if I were to get married while still dealing with this disease, I don't even think I'd let her come to the wedding; I am just that sensitive to the toxins from where she lives. Biotoxin-sensitive people seem to become "biotoxin diffusers" almost like an
essential oil diffuser, when they are somewhere cleaner.

Oh, and even after I was doing avoidance for months, people have reacted to me! Biotoxin-sensitive people can really concentrate and release toxins like crazy.

**Julie Rehmeyer**

Oh yeah, be super careful here. Staying outside sounds like a good idea -- and even there, you may well take a hit just from being around her. Definitely don't let her come into your house without showering and changing, but even that could be risky. It's awful to have to be so careful about these things, but it really is necessary.

**Karen Dean**

Let her come only if she will dump all her clothes and shoes outside, wrap her hair in a clean towel, and go directly into the shower, then put on clothes you leave for her. My space has been contaminated totally just by people walking into it for 5 seconds. My past boyfriends have always accommodated me in this fashion.

**Moulduk Mould**

What about a Skype date?

**Beatrice Latherings**

The only time anyone has been allowed inside my travel trailer was wearing a hazmat suit. I had to have help installing a toilet (four hands necessary). Fortunately he was not badly contaminated.
Q. 12:3(1) - Caregivers

A year ago, I decided to try mold avoidance and moved out of the place where I was staying, which had Stachy in it. I didn't bring any of my things and I got somewhat better. However, the situation fell apart and I have been kind of forced back into the care of the people I was staying with at the place with the Stachy in it.

I had thought that they would fly here to see me and follow the same protocol that I did, just getting all new possessions so that the toxin would not follow them. Unfortunately that did not happen. They came by car and brought along mostly new clothes and luggage. The car is obviously from the place where I got sick and I have no way of knowing if it's ruined their new clothes.

I'm living in a hotel, and while I don't know how clear it is, I don't think it's causing the problems I'm having. Every time one of them comes in here, my whole body is wracked with the most crippling pain. Each time, it seems the pain gets worse. I don't know what it is, it's them, if it's their clothes from being in the car, or what. I knew this would be bad, but I didn't expect to need to be completely quarantined from them.

What do I do? I have to make this work somehow. The place I was living in where I was feeling better, I can't go back to. If they're making me sick, I don't know what I'll do. Can you give me ideas on why this is happening and how to fix it? I know something can be done, right?

I've lost all my strength at present and so am not able to help myself. It would be easy to replace the luggage and clothes, but if the problem is coming from them or from the car, then I don't know what to do. Could their bodies be holding onto the toxins? If that is the case, how long will that go on? Even if it's just the car, that is not helpful since they have to use the car daily and will get recontaminated again.

Please help, this is a nightmare.

Lisa Petrison

If this is their car, then I would imagine it would have to be cross-contaminated, just from their using it in the past after being in the house. And that being the case, I would guess that the new clothes may be too cross-contaminated for you to tolerate too. But even if they had followed the strict decontamination protocols,
you could still react to toxin stored in their body.

This does not sound to me like your body is reacting unnecessarily to the toxin. It sounds to me more like it is a particularly harmful toxin that your body has already had too much of and has no defenses left against it. Especially since you were extremely sick before starting avoidance, I think it would likely be in your best interest to do your best not to have any more exposure to it, even in this tiny amount.

Of course, how to explain to these people that you can't be in physical proximity to them for the time being, and how to get the help you need without being in physical proximity may well be a challenge, I'm sorry to say.

A.M. Runyan

Sorry it's happening.

Your reactions are not unreasonable and are in fact similar to what other mold avoiders experience in similar situations.

First comment: car is likely contaminated, perhaps they could get it professionally ozonated, rent a professional quality ozone machine? I have never done that but I've been reading about it and ordered a max blaster ozone machine for myself since my car got moldy this past week from getting rain in it.

With regard to the people:

There are many reasons why you could be reacting to them. Mold sensitivity can be like peanut sensitivity - even small amounts of cross-contamination can cause dangerous or severe reactions.

Even if they had come in a clean car and done all the protocols correctly, you still could react to toxins coming out of their bodies. People in the initial stages of detox can react to toxins from others' bodies, and even farther into detox, people seem especially sensitive to stuff from the places where they got sick/got the largest toxin doses.

Since you are ill/sensitive, you might have to keep some physical distance from them - like not have them in your room or stay several feet away from them.

I had someone visit me from a toxic place I used to live, and even following the strictest protocols I could come up with, I still could not be within 20 feet of this
person. When we spent time together we had to go on walks and walk on separate sides of the street. I could not have them in my room or be in a car with them.

I don't know how much ability you have to stay away from these people physically but you might need to explain it the best you can - meet them outdoors and keep a distance, for example.

In terms of coping with reactions if you can't help getting exposed, Alka Seltzer Gold, trisalts, etc can help quite a bit with the mast cell reactions, it seems. And Claritin and mast cell stabilizers might help some.

Taking Vitamin C to bowel tolerance can help to actually shuttle the toxins away as you get exposed. Liposomal C is another great way to detox. High-dose Vitamin C seems like a last-ditch way to cut down on toxic effects by more or less putting the detox system on life support. Not ideal to depend on for long term support since too much can cause kidney stones (not sure if this is just Vitamin C, or particularly sodium ascorbate), and lipo C can be expensive at the high doses it can take (3-6g a day), but if I ever have to go somewhere moldy, I take it.

Also, the people's mold levels might go down over time. Maybe they can try cleaning their belongings the best they can, and perhaps ozonating the car, but it's never certain exactly how ozone will react with toxins. I've had it make things worse at times, but I was using a cheap ozonator. I'm getting a max blaster and hope that that will be more consistent.

Sorry you're in a bad situation. This is one of the craziest diseases that exists on earth these days. It's weird to be dealing with this living organism (mold) that can grow, attach to things, create psychoactive substances, etc. - something out of a science fiction movie. Good job hanging on.

Anonymous

The people who are caring for her could be colonized with mold, or could be emitting mycotoxins in their sweat. She could be reacting to either. They may need treatment. One thing that helps me is to have my husband shower with detox soap before we're in close contact, but even that isn't always enough.
Beatrice Latherings

My extreme avoidance includes my car. If I have been in it, all clothing comes off into the laundry, and I shower and wash my hair, before *touching* anything inside my trailer. Visitors who want to come inside must do the same. I have had no visitors.

Some people react to other people's "detox emanations," but I would expect the people they are reacting to to also be Moldies.
Q. 12:4 - Event

What do you do if there is an event you like to go to that's in a slightly moldy/toxic place? How have you worked it out when you want to be involved in something but it can involve some transient mold exposure? Anything to do in terms of supplements beforehand or clean-up before driving home?

There's a biweekly meeting I used to love to attend, but I was able to walk there, and then I'd wash my hair and clothes upon returning home. Now I'd have to park far away (since the entire neighborhood is moldy), change clothes before driving home, and might contaminate my car even still, etc.

I checked it out yesterday for a few minutes, just drove by and got out of the car for a minute or two, and could feel that it's toxic there. Sometimes I feel more sensitive when starting new detox treatments like BodyBio phosphatidylcholine.

I haven't figured out when or whether I can go back to this meeting, and they miss me there.

Julie Rehmeyer

When I was at your stage of things, I pretty much didn't go anywhere I knew to be somewhat moldy. When I went into a building and discovered it was moldy, I'd change my shirt and wash my face and neck and arms, and I'd sit on plastic bags. I also wore a hat whenever I was going into an unknown building, and I'd put my hair in a bun so that as little of it was exposed as possible. Then I could take off my hat afterward if the building was bad. Whenever I went out, I went armed with multiple hats and multiple shirts!

Lisa Petrison

Back when I was reacting in an extreme way, I divided toxins into two different kinds: ones that were "regular bad" and ones that were "super bad." (I believe that I am talking just about mold toxins here, though I can't be absolutely sure of that.)

There were only a couple of super bad toxins, which would cross-contaminate in really small amounts and make me really sick. I avoided those at all costs and scrupulously decontaminated after any unexpected exposures. With the
moderately bad toxins, I wasn't worried about them cross-contaminating the car, because they died down pretty fast. I was more careful about my sleeping area with those toxins.

I will say honestly that there were a couple of years there that I stayed out of most buildings entirely. It was a lot easier to withdraw from life for a while than to keep being hit.

Undoubtedly there are some buildings (e.g. ones that are making healthy people sick) that I would react to. But that is a very small percentage (e.g. under 5%). Most of the time, I don't react to buildings much at all now, and so I have stopped worrying much about them.

David Ou, M.D.

Dr. Shoemaker usually recommends taking a binder such as CSM or Welchol during the event and then a few days afterwards. It will help lower, but not eliminate the symptoms and help you recover quicker.

Karen Dean

Lots of Vitamin C, in Sodium Ascorbate form, the night before, enables me to partake in things I would not otherwise be able to. Change clothes, wrap your head in a towel, and sponge off as much as possible using wet wipes or baby wipes from Walmart before you contaminate your car.
Q. 12:5 - Indoor Swimming Pools

Does anyone dare go to indoor swimming pools, even rather new ones that appear to have 'clean' facilities?

A.M. Runyan

I don't like being around that much chlorine, since it suppresses thyroid function by competing with iodine.

Lisa Petrison

I've been in a few buildings that have indoor swimming pools and not gotten reactions, but very frequently buildings (especially hotels) that have indoor pools are particularly problematic with regard to mold. I don't seem to react to chlorine a lot, but I don't like it and so generally don't swim in pools that have it. Which is too bad, because swimming seems to be a good exercise for me, and (according to Cheney and other doctors) CFS patients in general.
Q. 12:6 - Gym

I used to work out in my apartment gym, and it was not moldy at all. But after that long rain about a month ago, it's been moldy. Do you think the complex might let me ozonate it with the MaxBlaster? Or should I just give up on going there if I'm early in avoidance (first six months). I could just get weights for my house. I also find I can't exercise very heavily while detoxing since the toxins coming out cause oxidative stress.

Lisa Petrison

Personally, I probably would give up on going to that gym.
Q. 12:7 - Composting

I am interested in composting but am of course worried about mold as well as other problems. Has anyone had success with a composting system? Are there things that I should know before proceeding?

Janis Bell

Add a good mask. Inhaled spores are the big problem

Christine

My doctor initially told me to keep my hands out of the soil/garden. I would think the same about composting. If you do it make sure you have really good non-reactive protective gloves.
Q. 12:8 - Air Conditioning

I know central A/C and heating can be problematic from a mold perspective. However, A/C is also an effective dehumidifier. Are there better options for those who live in hot and fairly humid climates?

Beatrice Latherings

I have chosen to use PTAC units in the house I am building. These are what you see in the wall of the motel room you rent. I chose them because they fit in a sleeve and can be removed easily, and because they can be used with a filter of your choice, and because you can buy a unit to bring in a certain percentage of outside air. I did not want duct work or shared air, and this was the best solution I found.
Q. 12:9 - Water Spill

Monday morning at about 1 a.m., I spilled about 8+ ounces of water onto the brand new carpet of a newly built apartment. It is a very loose shag, I can spread the fibers and easily see the plastic it’s coming up through.

So I tried towels on the wet area, and it was not pulling up all the fluid. I know it was only 8-10 ounces but I'm nervous. It’s now 10 hours later and I'm trying to figure what to ask my maintenance guy to do. Would a blow dryer be enough? Should I have it sucked up by his cleaning guy?

It feels a lot dryer now but even w such a small spill I don't want to take chances or wait much longer. I've contacted him (he's aware of my condition/situation). I'm worried I've ruined this apartment or at least the carpet.

Am I overreacting? What should be done? Should he call in an extractor for an 8 ounce spill?

A.M. Runyan

I've done this a few times, dropped a small amount of water.

I put towels over it and stand on them, to really press the water out of the carpet. Then I follow it up with paper towels so i can keep doing it until I'm not getting any water out.

That's not that much water. I don't think it will be a problem.

Lisa Petrison

I wouldn't worry about it.

Erik Johnson

I wouldn't worry about it.
Q. 12:10 - U-Haul

I notice that certain U-Hauls are extremely toxic. My boyfriend is going to be moving and was planning to use a U-Haul, but I realize that might contaminate his stuff (which is currently more or less fine for me).

Should I be there to vet the U-Haul? Or is there some other way to move a double bed that doesn't involve renting moving equipment?

It seems that moving equipment gets lots of people's stuff going through it, some of which is very toxic, and even one person putting bad items in a van could contaminate it for months, I imagine.

Lisa Petrison

If he could wrap everything in plastic before putting it in the U-Haul, that might serve as protection. Otherwise, if it were me, I guess I'd want to go check it out.

Julie Rehmeyer

Beds can be tied to the roof of a car. It's easier with a roof rack, but it isn't essential.

Solarventi Au

May I suggest hiring the van the night before you load. Place a chlorine dioxide odour/mould removal kit in the vehicle area overnight (Follow the instructions.) Next morning open up and aureate.

You will now have a sterile environment with which to transport your goods. If have two kits you could also place one in the new area that you wish to reside in. Again you will be entering a clean environment.

This is a biocide which is very cost effective (I don't know the brand name in the US) In Aus, it is Exstinkt. It will not damage the vehicle. Problem solved both cost effectively and health effectively.
Q. 12:11 - A Doctor’s Visit

I have been tentatively planning a two-day trip to Woodinville WA (just NE of Seattle) to see a doctor later this month. I thought I was making a calculated decision, considering that I run into Hell Toxin sometimes every day where I am now, so how much worse could it be? And anyway, I will be going in a car I know to be safe, in which I can sleep if I can't find a hotel floor to sleep on.

But yesterday I used a supplement that I had purchased in Woodinville the last time I was there over a year ago, and got Hell Toxined badly (though not any worse than I have encountered on other items from other places, including locally). It's easy to forget how bad it can be. Thinking about it today, I'm sure it could be worse than I care to imagine. Now I'm scared, thinking this is a huge risk that could be destructive beyond the extent of usual toxic encounters that I have in my city (which can be horrible). I'm worried I shouldn't go to the appointments.

I had been hoping to seize this opportunity because I was being offered a direct ride in a safe vehicle, and it is not a far trip. The route being taken would mean avoiding downtown Seattle altogether, approaching instead from the North, which seems safer (maybe?), in terms of biotoxins. If I move to a different location in the next couple of months, in search of better air, it will be much farther and maybe never again possible for me to ever return to this clinic. There are no similarly-trained practitioners in my province who I could go to instead.

I had thought this trip might be a good opportunity to get some more Shoemaker tests done (the free VCS test is not effective or accurate for me, I guess I'm in that 10% for whom it's not a reliable indicator of exposure), and have a doctor check me out. I'm floundering, and could use doctor help, but maybe this is too big a risk. I'd really welcome some thoughts on this, particularly from anyone who has been in that area recently.

Lisa Petrison

I think probably going to see any specialist in this sort of disease is going to have some risks due to cross contamination from other patients. Maybe bring your own chair? Put a towel over the seat in the car to protect it? Shower at a Pilot or TA truck stop soon afterwards, with handfuls of Epsom salts as scrub and changing afterwards?
Q. 12:12 - Dishwasher

Does anyone have thoughts on dishwashers? Is it dumb to have one if you are mold sensitive? Is one kind better than another, and are there ways to diminish the chances that a dishwasher will become a mold problem?

Lisa Petrison

I've not encountered any dishwashers that I've found to be problematic, and I haven't gotten any sense from others that mold (or at least problematic mold) tends to grow in dishwashers. Of course, I have heard of people with a leak behind the dishwasher that has become problematic, but that falls into the category of plumbing/drywall problems in general, not dishwashers themselves.

The only appliance that I've heard reports of problems with mold are front loading washing machines. These reports are from extreme mold avoiders, and also have been publicized in the news media. So I would suggest avoiding front loaders and sticking with top loaders (or using a non-electric washer such as a Wonder Washer).

A.M. Runyan

I've been fine with dishwashers. I try not to leave them closed with any dampness in them - I crack them open after they run and remove the dishes promptly. I also put about 20 drops of grapefruit seed extract in when I run the wash, from time to time, as a mold precaution.

Julie Rehmeyer

I haven't had problems with using one, FWIW.

Janis Bell

If you run an appliance regularly and keep the seals clean and free of moisture, filter the household air to limit mold spores that settle on objects in the house (there are always some mold spores in the outdoor air that come in), and don't leave food on the dishes to rot and mold before you wash it, I can't see that a dishwasher would be problematic.
Susan

There are dishwashers with filters that you can remove and clean, also make sure to get one that has a dry cycle that does the job, keep the seals clean and dry and do not close the washer when not in use. We also run the washer and do not leave dirty dishes for any length of time.
Q. 12:13 - Preparing to Move Out

I just found out that I live in a sick building and have some questions as I prepare to move out.

1. What is skin perfusion / hypo-perfusion in the context of mold illness?

2. I'm looking for a decent area to live for a bit, as my first step away from a sick building. I'm hoping to find something within a 60 to 90 minute drive of the Bay Area (Sebastopol? Santa Cruz?), until I can sort out my old life in the Bay and move to a much better area. I don't need "perfect" for this intermediate step, just better than Berkeley/Oakland. Any tips?

3. What do I do for my cat, who is living with me in a sick building? I'm moving us to a safer location asap; will it benefit him if I try to wash (or at least rinse) him before moving? I want to help him, but absolutely don't want to cause him any unnecessary stress. (He's never had or needed a bath before.)

4. Should it be assumed that all indoor plants exposed to a sick building are covered in mold/mycotoxins and unsalvageable, even if they seem healthy? (Should I not give them away to neighbors when I move to a better location?)

A.M. Runyan

I would do at least something to the cat.

Having done this whole moving thing, I ended up not keeping much that was not extremely expensive and portable but able to be wiped down (laptop) or small but hard to replace (IDs). Plants were not on that list.

Good luck. It's worth it to feel better.

Lisa Petrisan

1. Hyperperfusion is the decrease in oxygen to the capillaries. It is discussed in the context of mold illness by Ritchie Shoemaker and by a number of ME/CFS doctors as well.

It is the observation of some mold avoiders (perhaps especially Erik) that this tendency increases when acute exposures to mold toxins (and perhaps
especially some mold toxins such as the one that is particularly problematic in Lake Tahoe).

For instance, Erik pointed out to me at one point that he sometimes will look at the indentations on his calves from his socks as an indicator of how badly he is being exposed. The more dramatically the patterns remain for an extended period of time, the more problematic the exposure.

I do remember one really salient example of this myself, from right after we went together into Truckee High School. I was carrying a hat with a cord, and I briefly rested my hand lightly on the cord while we were sitting in the car. There was a deep indentation on my palm in which I could see not just the cord but the indentations from the stitching on the cord, and it remained dramatic for at least 15 minutes afterward. That was unusual for me, and an indication that something weird had happened.

2. My vote would still be Hollister, which is about 90 minutes from downtown SF, because I know that the air there is consistently fine. Or toward Paicines would be even better. Santa Cruz would likely be okay too, but my feeling is that there may be more moldy buildings there than in Hollister since there is more rain there.

3. Erik owned a cat throughout his acute illness and recovery. (And yes, the cat did become a mold reactor.) My recollection is that he has said that he did not bath the cat and just kept it on towels to keep it from cross-contaminating for a number of days. That is surprising to me. I think I would be inclined to at least give the cat a quick wash in the bathtub upon arrival at a better location, to keep cross-contamination at a minimum. Having once had a Himalayan that did benefit from an occasional bath, I would say that cats do not especially like being washed, but that it still sounds like a wise idea both for the humans involved and possible for the health of the cat as well.

4. I know one person who once got her stuff contaminated with something that seemed to act like what is now being called the "hell toxin" or the "itch toxin." She repotted a few of her plants (using gloves and I think a mask) and then gave the repotted plants to a friend. Later, after getting settled, the plants seemed okay to her and so she reclaimed them and put them on her patio table. The wind knocked the plants over and she was able to sense the bad toxin. Then little grey specks, apparently mold, started growing in the little puddles of water on the table, creating an even worse sensation of the bad toxin. As a result of this, the whole apartment was contaminated permanently for her. She abandoned both it and all her possessions inside, and started over again.
This is the sort of story that makes people believe that mold avoiders are making stuff up. But since this person is quite reliable when it comes to other observations, I think it was a true story.

Based on what I can tell about this "Hell Toxin," it seems to grow like crazy. Just a few spores and it grows like crazy inside washing machines, in plant dirt, inside refrigerators or on RV drainpipes. That makes me nervous.

If what we're talking about is just the regular outdoor toxin or just regular building mold (including Stachy), I don't have a strong sense that it's such a problem in plants that they couldn't be given away to non-Moldies. But at some point down the line, a lot of people feel like just throwing everything into a dumpster and being done with it, like (for instance) the Fabry family did. Maybe, despite its surface feeling of wastefulness, that's not a bad instinct.

Andrea

2. Any brand new environment for at least 2/3 years will be sufficient to get well enough to bare a minimal spore exposure(s).

3. I would bathe him. I've had cats all my life there are ways to bath cats with minimal stress. Cats go where we cannot so it must be assumed he carries spores on his fur too.

4. Yes!
Question 12:14 – Settling Into New Apartment

I've just moved into a condo that is one year old and have cleaned and stored most of my things. I brought my kitchen stuff which was very well cleaned and toiletries, but bought new clothes and am buying new bed, etc. So I'm doing my best with what I've got. I'd like to try to reintroduce some clothing after a month or so.

I have a few questions so hoping those much more experienced can help. Did lots of research before, but now have no computer.

1. So computer is my first question. I've not charged or turned it on since I moved and it's in a plastic bin. I understand that the fan shoots out mould spores. So, can I use it at a friend's house or on my balcony? Is charging it in the apt an issue? At some point doesn't the heat from the computer and the constant fan activity rid the computer of any spores? I can't buy a new one and am really struggling without it.

2. What about other appliance type things like hair dryer, blender, phone, beaters/mixer? I've stored hair dryer for now, but would like to use the other stuff.

3. What about people coming over to visit or sleep over? or me visiting at someone else's place? Is this compromising my test period?

4. I saw the question re: air filters. My Aller Air is metal, so in theory if I clean it with Benefect and change the filters, shouldn't it be ok?? The fan can only suck air in and push it through the hepa which captures all mould. Also reading about Miele vacuum and disappointed to see how it can be a problem.

Thanks for the help.

Beatrice Latherings

No one is allowed inside my dwelling because if it goes bad I have nowhere to go and I got very tired of being homeless. Think very carefully before you take the wild chance of even letting someone inside.
Lisa Petrison

It's hard to answer these questions because I don't have a sense of how your health is doing since moving. If you haven't experienced any changes in your health and you are not overtly reacting to buildings (including your old place) or objects, then I would suggest that you haven't gotten clear enough to be able to approach this in a systematic way. You could still be getting exposures that are way over tolerance for you from your new apartment, from the outside air, from the possessions that you did bring, or from cross-contamination from going into other buildings.

This becomes much easier when people can start to identify when they are being exposed to mold based on their own reactions. Otherwise, it's all just shooting blind. So my main suggestion for you is to try to figure out how to identify the toxins that are most problematic for you so that you can start to avoid them. Although unfortunately, without a sabbatical in a known clear place, that is more easily said than done.

That being said, here are some answers to your questions.

1. My current understanding is that a computer that is contaminated with what is being called "Hell Toxin" has the potential of cross-contaminating other items very easily, especially when it is turned on. Other toxins have the potential of contaminating computers to the extent that they computers cannot be used, but are not so potent at cross-contaminating things. So a possibly relevant question here was whether you experienced substantial burning or itching at the old place. If not (or if the burning was only mild), then I would suggest cautiously trying the computer outside to start out with, to see how you react to it.

2. Again, it depends on what kind of mold toxin was present. You could cautiously try washing those items and then seeing if they have an effect on you, preferably starting outside.

3. People who are carrying bad toxins on their person should not come into your home, whereas people who are not carrying bad toxins on their person can come visit. In general, if people are sick with some kind of mystery/autoimmune illness, I would be hesitant to let them come visit. Otherwise, it's a crapshoot.

4. Air purifiers and vacuum cleaners that have been used in a bad place tend not to be remediable in terms of a hyper reactive person being able to use them, from what I've seen.
Karen Dean

Anyone who wants to come in my clean space must give me their clothes in advance for de-con, strip outside, shower and shampoo, then put on the fresh clothes reserved for them. One person walked into my Scamp 4 years ago, I still have not been able to make it safe.

Julie Rehmeyer

I did not replace my phone, though I was cautious with it, keeping it inside a Ziploc bag for a long time and not using it near by the bed. It worked out OK. I have heard of someone who managed to keep her computer, though I replaced mine -- and I had to return a used one that I tried. But the amount of trouble that goes with keeping possibly contaminated belongings is enormous.
Chapter 13

Remediating Objects
Q. 13:1 - Conventional Wisdom

We bought our home in the UK in June 2011. We are a family of four that have been involved in a claim with NHBC since September 2011.

Once we started to suspect the mould for our ill health we started research online, making contacts with a range of specialists by email. We were advised by various people that we contacted on line that we should move out, mould can make you ill, and provided with a wealth of information, mostly American.

It took us nearly 6 months to convince NHBC, a massive organisation responsible for new build homes, to provide us with alternative accommodation. If we knew then, what we know now, we would have left the house and lived in a tent but we kept doubting our instinct as our own local professional agencies didn’t seem to agree with the research we provided.

Within our household we have an asthmatic child and an adult with an autoimmune disease. Still nobody listened.

It has been 9 months since we moved out of our home and 9 months since we had personal possessions, 9 months since the children have had toys, books and access to familiar things.

As far as our physical heath is concerned it is the best decision we have made. Once the horrendous 'brain fog’ cleared, nearly 3months after leaving, we were able to start seeing our reality.

Eventually we instructed an expert to air test our home. Outside total spore count 230, inside 5200!!

Eventually we found a few private consultants that were willing to see us without GP referrals. However, although helpful, they are not specialists in the field and do not seem to fully understand the ramifications of exposure.

We have managed to get one diagnosis of Type 3 Hypersensitivity Pneumonitis to Mould with reduced lung capacity. (We could not afford to test everyone.) IgE count of 59 Aspergillus.

We have contacted various people at the NHS that are supposed to be specialists but we haven’t had a response. We have asked the new GP for
referrals but she only appears to have limited information available, or limited willingness.

The consultant that gave the diagnosis said that any further exposure would exacerbate symptoms and continued exposure could result in a long term condition.

There are many other health issues too but we are concentrating on this one as we have, at least some, evidence to support it.

So, our question is this, can mould toxins etc be removed from all household contents?

Everything we have read and been told says it cannot. Yet NHBC are adamant that it can and are refusing to consider our contents as contaminated. A summary of what they believe is as follows - wipe with bleach, fog the house or a wash in a machine, all of that will do the trick.

We are not prepared to risk further exposure, having had a hospital admission for breathing difficulties this winter and seeing the reality it isn't an option. Therefore we have to decide if we believe items can be cleaned and we will need to see evidence of that."

**Julie Rehmeyer**

My experience is that it can't be removed from most belongings, not thoroughly enough that you'll be able to tolerate it while hypersensitive. But I also think that's likely to be impossible to prove to an insurance company's satisfaction, sadly.

**Jeff Charlton**

The UK now possibly leads the world in helpful legislation. The health hazards of mould and bacteria fragments have now been accepted and sampling and measurement criteria established which generally flies in the face of academics who rely culture based sampling. The documents are both British Standards and require evidence to state a property is clean and sanitized.

**Lisa Petrison**

I think that maybe if you were an extremely skilled and successful lawyer
yourself, with intimidating credentials, and seemed willing to put in infinite amounts of time to winning the case, the insurance company might buckle and give in (especially if there was a non-disclosure agreement) just to not have to invest any more time into the project themselves. That's the only kind of circumstance that I've seen people win this kind of case against insurance companies. They definitely don't want to set precedent that can be used against them, if nothing else.

If you and your family are still sensitized from the exposure, then I would think that your possessions from the bad place could have a big negative effect on you. At the very least, I would do an experiment by exposing myself to them for an extended period of time to see how I felt afterward before moving them all into my new living space.

Erik Johnson

Up until the early 1980's, mold could be removed with such ease and was such a non-issue that it was feasible to simply dry it out and paint over, and no harmful consequences were ever seen where this was done.

Then something changed.

In those places, this is a completely new paradigm, which closely approximates my training in biological warfare agents.

The medical profession has yet to come to grips with this situation. If someone's circumstances give the indication that they are in the grip of this new substance, it would be imprudent to practice too much prudence.

They must act in accordance with their perceptions of the severity of their illness.
Q. 13:2 - Second Moldy Home

We just left our second moldy home, and fled the humid subtropical area where we were living. Mold was rampant and impossible to avoid.

The first time we left we lost everything except a few kitchen items. This time it is simply not possible to start from scratch again.

We have thrown away all clothes and bedding. We have had little success cleaning nonporous items with hydrogen peroxide, some success with thyme oil and white vinegar, and best success with Clorox (yuck! And terrible for MCS!). What else can we use?

A.M. Runyan

Depending on how bad it is, it might not be possible. Mold seems to have weird electrical effects on some items. Sometimes nonporous things like glass cups were extremely contaminated for me and no amount of washing fixed them.

If you want to try, though some ideas:

Butter seems to be good at grabbing fat-soluble toxins off things. Rubbing the in grass-fed butter and then washing it off with soap.

Leaving in the sun for a long time.

Soaking in a mixture of kefir and water (kefir might deactivate some mold toxins). Soaking in water mixed with various supplements: chlorophyll drops, Vitamin C, antioxidants.

Orange oil typically helps me and I don't think it's ever made things worse.

What exactly are you trying to save though? Some of it you might be able to replace cheaply from Walmart or online or something. I try not to own anything expensive since I know I might have to replace it at any time.

I feel bad about this, but for more expensive items, if they get contaminated beyond repair I buy a new one and then "return" it and send the old item back to amazon. That way I can return things and get a new one, even if the original return period of 30 days has passed.

I really pay attention to return policies on anything I buy, because, well, it is
difficult to have a medical condition requiring that you replace a lot of your items on an unpredictable basis. Whenever I'm dealing with any contaminations, I wear returnable clothes that I could send/take back if they get too contaminated to fix.

**Julie Rehmeyer**

I've had success with ozone for transient contaminations, but I'm not at all confident it would be effective on things that were thoroughly steeped in mold. I do know that one person had success with simply washing clothes many, many times and leaving them in the sun for a long time. Actually, there's one piece of fabric that had been in Berkeley that I left in the sun for several weeks and then seemed okay, though I have it in a place where I don't get all that close to it.

**Lisa Petrison**

Usually, I don't try to clean things with anything except water and maybe a little Dr. Bronner's Soap. However, one time I contaminated the black water tank in my RV and was thinking I was going to have it replaced. But I tried pouring some homemade milk kefir in it, filled it with water and let it sit overnight. After that, it felt fine to me. However, I do realize that soaking things in kefir is not practical for most items.

**Beatrice Latherings**

I've had pretty good success with things that will go in the washing machine. Borax. ammonia, washing a few times, let sit out in the air and sun, wash again. I did not have Stachy though, but other toxic molds.

**Damien Blenkinsopp**

Dave Asprey recommends cheap vodka with grapefruit seed extract (GSE) to kill + prevent regrowth.
Q. 13:3 - Dry Desert Environment

If mold exposed items such as supplement bottles or books air out for some time in a dry desert environment, will they eventually become safe? Or will they trigger reactions for quite a long time?

I'm heading to the southwest and I've escaped my moldy living arrangement, but I've noticed I'm still reacting to my few belongings. I understand some of you are about absolute avoidance but for those who've not taken it that far, how well has it worked for you?

Lisa Petrison

If things have been stored for an extended period of time in a place with particularly problematic toxins, it may be many years before they become okay again.

But it's hard to know upfront how long it will take before they calm down, because I don't know what kind of toxins you are dealing with or how severe your reactivity is.

There are some "supertoxins" that, quite frankly, I don't think anyone should be around. So if that is what you are dealing with, then I don't think that losing possessions is much of a loss.

But there are many other mold toxins that are not that bad -- that will die down quickly or are only slightly problematic.

I guess that what I would say is that if you react much more to your own possessions than to just about anywhere else you go or anything that you encounter, probably that should be taken to mean that you are dealing with a really bad toxin and that perhaps you would be better getting rid of the stuff.

A.M. Runyan

I don't have many things from my old place to answer this question with regard to, but here's my experience:

1) I still have my laptop, some bank cards, glasses, etc., and I no longer react to them, about six months after moving. I stopped reacting after a month to the laptop (had to ozonate and wipe down a lot).
2) Had some very strange things happen related to stuff I brought with me when first moving, where even when I bagged it all up and put it in a hotel fridge, I'd still react to it through the fridge, or I could sense it when coming back to the hotel room. Had surprisingly strong reactions to it. I think in addition to general biotoxin sensitivity, people tend to have particularly strong reactions to things they've been exposed to a lot, as exemplified by how I get more sensitive to any particular toxins I get large doses of since moving and can detect small amounts of them for days or weeks afterward. It was a huge nuisance having stuff from my old place, while trying to move, and it made it harder for me to scope out new places since it was sometimes unclear if it was my stuff or the place giving me the problem. Wish I hadn't brought anything but the items above, and I ended up throwing away everything but those items.

3) People's perceptions about their stuff can change when they become clear. Supplements that seemed really crucial can seem unnecessary, books can seem like a complete liability (I try to go for mostly kindle books or online books), and just being clear - as great as it feels - can take much higher priority than having any particular item from one's old place.

4) It's kind of nice to get a fresh start and not be reminded of one's prior, moldy place - I like that I don't have any objects that directly remind me of where I used to live; thinking of that place makes me shudder. Getting clear of mold means a new life.

5) I have heard of items getting safe to use but after years. I've reacted to stuff months after it was contaminated, meaning it had been sitting here in a low-mold environment for a few months and I still had problems with it... It's not that the reactions are that bad; it's that *small amounts of these toxins can shut down or severely reduce the rate of detox* - and getting through the hump with this seems to be about being as clear/unexposed as possible and detoxing as fast as possible - to get through the uncomfortable period of being very reactive, to land in a more comfortable place where one is more detoxed and reactions are not as intense.

The risk in bringing stuff is that it could contaminate new environments, make it harder to find a good new place, and if you have to be around it to move it/deal with it, - slow down the detox process.

It might be a good idea to use no supplements or few supplements for the first few months of trying to be low-mold, because then it's easier to read body reactions. I felt a definite aversion to supplements when I first moved, and only added certain things back later since I saw they could turbo-charge my detox.
Coffee enemas are fairly cheap though and probably could be used the whole time, ideally with a fairly clean coffee grown at high elevation, but even extreme mold avoiders seem to do ok with any organic coffee too.

It's a real switch to realize that avoiding mold seems more important for recovery than any supplement ever could be.

Really, I have yet to see a supplement that comes close to mold avoidance in terms of impact. Supplements are like fake vanilla, compared with real vanilla of just being away from the stuff.
Q. 13:4 - Couch

Would it be in my best interest to get rid of furniture (couch) that was in my moldy home? The couch is over 10 years old and even though there is no visible mold on the couch I am pretty certain it is saturated with spores.

Lisa Petrison

There are two issues to consider here: the toxins and the spores.

Based on the stories that I've heard, mold toxins do eventually die down to the point that contaminated objects eventually can be tolerated by even extreme reactors, even without washing. However, how long that will take may vary considerably by type of mold toxin (and of course from person to person). In many cases it seems to take at least five years, and in some cases a lot longer. Since your couch is more than 10 years old, the chances seem fairly strong that it has died down to the point where extreme reactors would not be bothered by it, but I am not guaranteeing anything. (This also presumes that it has not been exposed to problematic toxins since then.)

The other issue with upholstered furniture is the spores. These may die down to the point of not being toxic, but insofar as they are intact rather than particulates, they have the potential of immediately springing back into live mold (of the same species that was in the moldy home). So that would be another reason to dispose of upholstered furniture from a bad place, even if a successful extreme avoider knows that it is not causing a reaction.

It's my understanding that items such as clothing will be relatively free of spores if they are washed in water. Toxins that adhere to the items may remain a problem, however.

Julie Rehmeyer

It would be critical to do so. If you're sick, don't keep anything from your moldy home, except for metal and glass. Otherwise, you'll carry the contamination with you, and that can be enough to keep you sick for years.

Beatrice Latherings

Depends on how long it has been out. Lisa seemed to assume that you meant it
had been away from the toxic home for ten years, but what I understood is that it's ten years old and was / is in a moldy home, in which case I'd just toss it. Not worth the risk of its contaminating a new space.

Karen

Toss it.

Forebearance

Personally, I would get rid of the couch. If it were sentimental I'd put in into storage.
Q. 13:5 - Flaming

In response to Question 208, Erik suggested 'flaming' the computer. Just checking - does he mean... blowtorch? Just a small flame? I was a bit confused by that.

Lisa Petrison

There are certain mold avoiders -- including Karen, Branislav and Erik -- who have talked about how they have used a flamethrower to decontaminate their possessions. Apparently this works pretty well. I've heard of people even using it on upholstered furniture. The idea is to move it quickly so that things don't catch on fire. This sounds really dangerous to me, so I have not tried it. I would be hesitant to try it on the computer, but maybe it is all in the technique.
Q. 13:6 - Air Sterilizer

Has anyone had luck with this device or others like it? It seems to be more helpful than the HEPA filter I have. So far, having the air sterilizers in every room has enabled me to be inside without a mask.


Karen Dean

I clear spores by using a torch, very effective if you don't burn down the house. Finding the source and getting rid of the mold, or moving, are the only real solutions

Jessica Grow

My dad bought me one and how it works is the spores are circulated close to the heated ceramic which kills the spores. My doctor told me that does not get rid of the toxins though. You would need a HEPA filter along with it to collect the toxins. So I sold mine and bought a HEPA filter.

I should add that I do not have a moldy source in my house, it is more for any mold that comes in the windows from all the hay bales around my house.
Q. 13:7 - Laptop and Cell Phone

What's the best way to clean mycotoxins off a laptop and cell phone?

Julie Rehmeyer

I don't know of any way. They get contaminated inside, and I don't think there's any way of completely getting rid of that. I did manage to use a contaminated cellphone for some months by keeping it in a ziplock bag and being careful where I used it. Laptops are especially dangerous because they can blow contamination all over the place.

A.M. Runyan

I used to wipe mine a lot with damp paper towels and then bake them in direct sunlight for 15 minutes at a time. I still have the same laptop and no longer react to it. Anytime it gets contaminated I bake it in the sun, allowing the keyboard in particular to get hit from all angles by UV light.

Lisa Petrison

Shoemaker suggests wiping computers off and then using a vacuum cleaner to try to remove some of the stuff from the inside. Possibly this would be sufficient for milder toxins or for people who are only very mildly sick, but the likelihood that it is going to work well enough for someone who is sick and evacuating a truly bad place seems really slim to me.

I would be especially cautious about bringing a possibly badly contaminated computer into a theoretically clean living environment. I've heard a lot of stories about people who have cross-contaminated their whole environments with computers as soon as the fan came on.

If I needed to use a computer that I suspected might be contaminated, I probably would use it outside and then decontaminate as soon as I came inside.
Q. 13:8 - Technician

Has anyone tried to salvage a contaminated laptop by having a technician clean the fan and remove all the dust?

Lisa Petrison

I've not heard of anyone trying that.
Chapter 14

Tent Camping
Q. 14:1 - Tent Brands

Has anyone found a particular brand or type of tent that's less reactive/less off-gassing?

Lisa Petrison

I only buy things like that from LL Bean and REI, because they have good return policies.

At my most reactive, I did react to the cross-contamination of tents (apparent mold toxins). After they baked in the desert sun for a month or more, they started to become more tolerable.

Tents can also be cross-contaminated with really bad toxins. I never was sure if that was because someone purchased it and then took it back, or if it was made in a bad factory in Asia.

A.M. Runyan

I got a tent at Walmart and it didn't smell like anything to me. I put it in the sun for half a day and aired it out before using it just in case and had no problems with it. I don't have very intense MCS though; I don't like fabric softener but I don't have other bad reactions.

Karen Dean

REI tents have been ok for me. Get one without integral poles, then you can wash it in the washing machine

Janis Bell

Some brands advertise no VOC’s. I went with big Agnes for that reason. But their zippers keep breaking.
Chapter 15

Mobile Environmental Containment Unit (MECU)
Q. 15:1 - Commercial Trailers

Might a caravan be a good way to avoid mould? Or will it get mouldy in winter if you have any form of heating?

Lisa Petrisin

From what I can tell, a "caravan" is the British (and maybe Canadian?) term for a travel trailer or maybe any kind of an RV.

The problem is that most commercial trailers have wood buried in the construction, and therefore tend to get moldy. And perhaps because RV's tend to use a lot of particularly bad chemicals, the mold frequently is really bad mold.

The RV's that I've heard people have success with are Airstreams, Camplites and Casita/Scamp.

The safest thing to do here is to buy a utility trailer and convert it into a trailer, as Erik describes doing in the "Back from the Edge" book.

The good things about having an RV is that it allows people to easily get out to the wilderness to get clear; to compare different environments to see which ones are better; and to have a way to easily shower if getting hit.
Q. 15:2 - Free Trailer

I’m getting a free trailer soon that I will be gutting and rebuilding with non-toxic materials since I cannot tolerate any buildings anymore. Problem is, that when I went in the trailer I got classic mold symptoms and had to leave.

Now my question is, if I am completely gutting and renovating it and therefore removing any mold present, is this going to be an issue?

I will also be ozoning it with an industrial strength ozone machine and cleaning everything down afterwards with 50/50 ammonia water.

Does this sound like a bad idea on the basis that it felt moldy in there to me? If it’s properly remediated, it not be an issue right? Or wrong?

It's possible that there is no mold and it was just all her belongings as well.

This is my only option right now. Soon enough it will be too cold to live outside and I couldn’t afford both the costs of a trailer plus to fix it up so this is my best bet.

Would appreciate any thoughts from those knowledgeable about remediation and whether this is a good idea or not, thank you!"

Lisa Petrison

Almost all RV's have buried plywood in the structure (e.g. plywood roof caps, wood stuffed in the metal for “strength”). And almost all RV's eventually leak. So this is a recipe for mold growth in places where it is very difficult to remediate. In addition, RV's tend to use a variety of chemicals of various sorts, and I am suspicious that those will contribute to particularly mold toxins being manufactured when mold does grow.

Remediating that kind of structural hidden mold is very difficult, and if the RV already feels problematic to you then it likely will take a long time (e.g. years) to die down. So I don't think this would be my choice. I think I would take the money I was planning to use rehabbing the trailer and put it to some other use.

The most inexpensive and most reliable RV just for sleeping purposes is a plan utility trailer. Most do have wood floors, but since they are exposed are not as much of a problem as buried wood (and can be removed). If you had one of
those for sleeping, and were able to find a place to stay that had a bathroom that you could tolerate, then you would at least have a stable place to stay. Then perhaps eventually you could make changes to make it more livable (e.g. adding windows, a sink, a vented stove, maybe even a bathroom).

In terms of conventional RV's, there are a few that are less problematic than others. Camplite is all metal with no wood, but it may take a while to die down in terms of the chemicals. Airstreams have often felt good to me -- they may have wood subfloors, but those seem less problematic.

Fiberglass trailers (Casita, Scamp) also have wood subfloors and (since they are fiberglass with carpets on the walls) may take a very long time to die down in terms of the chemicals. In addition, Casita is manufactured near Dallas, which is a bad city in terms of outdoor toxins that may cross-contaminate (from reports from three of the mold avoiders that I trust the most and from my own observations). And the fiberglass sucks up bad toxins like a sponge.

So if I were going to purchase one of those, I'd be looking for an older one (several years old at least) that had spent its life since purchase outside of Texas or other bad areas.

**Julie Rehmeyer**

Unless built very carefully, trailers are almost always moldy. They are tin cans with wood inside, and very little insulation. The result is that there's condensation on the inside of the metal that causes mold on the wood. You generally can't see it at all. So you're _really_ going to have to gut it to get rid of it all.

I first started getting sick when leaving in a travel trailer while I was building my house. I wasn't in a bad area, and the trailer wasn't horribly moldy, so I only got mildly ill. It wasn't until I moved to a bad area that I really fell apart. So it also depends on where you'll be in this trailer.

**Karen Dean**

As far as the trailer is concerned, if it is the typical metal trailer with wood structure, the wood may have absorbed much toxin that may not come out. Also if moved, they flex and need re-caulking often to stop them leaking.

Remember to wash well with a non-killing product like Simple Green before you ozone, it will remove a lot of spores. Also, my favorite way to remove spores is
with a propane torch, walk it around the inside for 10 in. Don't burn it down.

As far as your ability to live outside if you are unable to remediate the trailer, I have lived outside off and on for years, and in the cab of my truck, and the backseat of rental cars. Once the temp went to almost 20 degrees below freezing.

If you have electricity you can sleep very well with an electric blanket inside a sleeping bag. You can also buy down booties that are heated buy lithium ion batteries.

**Beatrice Latherings**

I would suggest that you not gut the trailer yourself. Protecting yourself from the toxins may be impossible. I'd hire someone to do it at a remote location, have them thoroughly clean it, and then walk in it again and see how you react. Pay other people to do the work until you feel okay inside.
Q. 15:3 - Renting a Trailer

It looks like I finally have someone that’s interested in helping with avoidance. Unfortunately, I have never been well enough to pursue it completely alone.

I was just wondering what you recommended for trailers? Is renting possible because I’d rather not buy unless I see it work and see significant improvement.

Julie Rehmeyer

The place to start is with a two-week trial. It’s too big an investment until you have strong evidence that mold is a major issue.

What are you looking for in a trailer? Do you just need a protected place to sleep? Do you need climate control, a kitchen, a bathroom?

If you need all of those things, it’s going to be pretty tricky, to rent or to buy. If you can handle it, I’d recommend just camping. If you feel like you need a protected place to sleep, you could rent a U-Haul trailer or truck and have your partner wash the inside very carefully.

Lisa Petrison

A couple more pieces of information that I happen to know: this person is currently living in Dallas (which based on my own experience there and the reports of three of the mold avoiders I trust the most is particularly problematic), got sick while living in Tahoe, has felt better on a trip to the Caribbean, has identified certain other places (including Portland) as feeling bad, and feels worse in overtly moldy buildings. So my feeling is that the question is less whether this person is a mold reactor and more whether pursuing avoidance in an extreme way will result in enough health improvements to make it worth the inconvenience and expense.

From what I have seen, the key factor for people leaving places with the particularly problematic outdoor toxin (such as Berkeley/Oakland, Tahoe, Dallas) is to not bring along any of their contaminated possessions. If they can do that, then even moving to an "okay" building in an "okay" city can provide really substantial health gains. This is a hard concept for those who think that mold illness is an indoor problem to fathom, but (based on the case studies that I have
seen) it is very consistent. So for people who are very debilitated or want to pursue this more gradually, this could be a good first step.

To answer the specific question: with very few exceptions, all RV's have buried wood in the construction and thus usually become moldy (even in dry locations) in ways that are impossible to remediate. In addition, when RV's do grow mold, it seems to be on average quite toxic mold (perhaps due to the fact that RV's have a lot of chemicals in them?).

Camplite is all metal and so likely will not grow much mold (but can be irritating to people with MCS until it dies down). Airstreams seem pretty mold resistant (but are quite expensive).

Casita/Scamp have wood only in the subfloor (heavily surrounded by fiberglass), but Casita is manufactured near Dallas and those RV's are certainly toxic when new (and sell like hotcakes used).

The safest choice seems to be Erik's suggestion of taking a plain utility cargo trailer and converting it into an RV. The one very reactive person who followed Erik's instructions on this has been very successful in regaining health through avoidance. Erik keeps talking about producing these to sell to people -- if folks are interested, perhaps letting him or me know would make him more likely to actually give it a try.

So anyway, if you want to "go extreme" right off the bat, I can see three possible choices that I think would be a fair test. 1) Tent camp in a pristine place. 2) Buy a utility trailer to sleep in (possibly hiring someone to do some sort of conversion) and use it in a pristine location. 3) Try sleeping in a KOA Kampin' Kabin in an excellent location or in one of the cabins at Mercey Hot Springs.

I think by doing those things, you would get some improvement within a couple of weeks at most. But if the goal is to see how well you could be, you may want to plan for longer, like at least a couple of months.

A.M. Runyan

I never tried having a trailer, but early on in avoidance, when I was the most sensitive and detoxing the most, I liked not committing to anything - housing, clothes, sleeping bags, etc. I liked that I was using cheap stuff and could just throw it away or return it (Walmart accept returns without receipts) if anything happened to it that made me react to it. I wasn't ready to commit to any expensive objects for about four months.
The main thing is getting as clear as possible in the early period of avoidance, and then your body can be the guide as to what you can tolerate, where you should be living, etc. When I'm really clear I found I could handle sleeping situations I never would have been able to sleep in before doing avoidance, just because my nervous system was calmer from being less toxic, and I was able to handle far more stress than I could handle before avoidance.

If someone had told me the places I'd be sleeping (and where I'm sleeping now, for example - on a towel on a carpeted floor) before I started avoidance, I never would have believed them, because I used to need a huge amount of creature comforts when i was moldy just in order to sleep.

Karen Dean

The fall is coming, and now may be the best time to do tent camping. Tents from REI or LL Bean seem to be clean to me, and they are returnable. REI will take them back for any reason.

I have done emergency minimalist camping just sleeping in the back seat of a rental car. It's amazing how much you can do without when you need to
Q. 15:4 - Fumes and Dust

I've never understood how pulling a trailer behind a truck doesn't fill the trailer with toxic fumes and dust. Are they really that airtight? Similarly how do you deal with other people's fumes/campfires etc. when camping? Do you need to go so far out that other people are not a concern?

Julie Rehmeyer

Personally, I camped in the backcountry in Death Valley, far from anyone. I only camped for a couple of weeks to get clear, not as an ongoing lifestyle.

Lisa Petrison

Usually the bathroom is toward the front of the RV, near the hitch. So you are not getting a lot of fumes from your own car.

I was mostly concerned about driving through outdoor areas with a lot of really bad toxin in the outdoor air and then cross-contaminating the trailer with it. And it is true that when I drove through Ann Arbor (not even stopping), I was unable to sleep in the trailer for weeks afterward without feeling bad.

But especially when the walls have carpet on them (as the Casita does), they eventually get kind of grimy. I had to buy a steam cleaner.

It people are really sensitive to campfire smoke, then that does restrict choices. From what I have seen, that is a sensitivity that fades for a lot of people after some successful avoidance, though no guarantees.

Other people's moldy RV's definitely can be a problem. Crowded RV spots where you can't pick your own spot may be best to avoid.

Beatrice Latherings

That is why I don't do RV parks; you can't get away from other people's moldy RVs. When mine is towed, I close it up. So far have not had a problem with stuff getting into it. If you can ride in a car on the highway, that's the same air that is hitting the trailer. If you're really worried, then use metal tape to seal up all the windows and vents etc. But you might have to carry a ladder to get anything on
the top.

Daliya Robson

Use carbon fabric over windows and doors.
Q. 15:5 - Traveling Around

I have heard that some people have travelled all of the US in an RV to escape mold in order to try to heal from this illness. Does this kind of approach work? Do you have any suggestions for someone who would like to try that? My husband and I are desperate. Everywhere we go, there is mold; apartments, new construction, hotels, etc. It truly seems as if we cannot escape it.

A.M. Runyan

If you're that sensitive, that you're sensing mold everywhere you go, then some people in that state do find they need to become mobile for a bit, go to drier/less toxic areas, camp, sleep outdoors in some fashion, stay in temporary situations like extended hotels until they detox enough to get a new stable home, etc. It's hard to detox if the exposure level is still high enough that you are noticeably reacting. (Not everyone has to camp in Death Valley! There are many different ways that people find solutions where their exposure is low enough they can turn the situation around and start taking toxins out rather than putting more in.)

But it's good to combine that approach with heavy detox, so you don't get stuck exiled out in these dry, nontoxic areas or sleeping outdoors, etc. and have trouble returning to society, so the focus is not just on finding a clear location but also on doing whatever promising detox treatments you can manage to apply to yourself in the meantime (which can help you to tolerate more locations - even a few weeks of coffee enemas and infrared light has often brought down my mold sensitivity).

I think the general rule of thumb is that you want to get to somewhere that is low enough in mold and toxins that you are not reacting at all, you have signs of low inflammation and being "clear," and then you detox as much as possible there (and the detox is easier in such a location, where it's not going to stir up the runaway inflammation that often happens when people do detox treatments when still dealing with inflammation from being exposed- I did that and it was horrendous, trying to use CSM and detox in the same part of the country where I originally got sick, apparently still around quite a bit of mold and toxins).

Some people camp. I ended up negotiating a good rate at a hotel in New Mexico and stayed there for three months, sleeping on the porch most nights for maximum detox, and then I added in increasingly strong detox treatments, and a few months later was able to find an apartment I've (luckily) tolerated quite well since then, which is a home base for detox treatment. (It's easier to do with a
stove, large fridge, electrical sockets, space to spread out, etc.) It's been a big life change but I can't imagine my life without getting this _huge_ amount of toxins out of me (I never would have imagined how much was in there), and it's brought back much of the "me" that I slowly lost over the years as I became more toxic.

Lisa Petrison

I did travel over most of the western half of the U.S., first tent camping and then in an RV. But in looking back, I think that I was more on a mission than anything else, to try to learn more about this phenomenon. So it's not something that I would necessarily recommend that other people do, unless they think it would be fun.

It's not any easier to find a good RV than a good stationary home. The key, in my opinion, is to get away from modern construction in both (e.g. buried plywood, cellulose wall insulation, drywall). There are some homes that are decent in some places, and some RV's are better than others.

One good thing is that a decent RV will allow trying out more locations, and if a location goes bad, it's easier to move somewhere else. But it's not necessarily a magic solution. Good homes in good locations can be just as good.

I suggest looking at the Locations Effect board to see what good locations appeal to you and starting with that.
Q. 15:6 – Connectedness on the Road

I need to start camping, but I have a web development business that I love and am desperately trying to hold on to. For those of you who have camped long term, how did you handle an internet connection and keeping your computer charged? I feel like I can't afford to stay at places that provide electricity and water, I was thinking more boondocking.

I am in Tucson, in case that is relevant.

Lisa Petrison

I tended to move around a lot. Part of the time, I stayed in places with electricity and Wi-Fi. Part of the time, I stayed in off-the-grid places.

For electricity, I tried to keep my computer charging while driving the car as much as possible (with an inverter that would plug into the cigarette lighter). My computer at the time had a removable battery, and so I had an extra one of those and tried to keep both fully charged when possible.

In civilization, I would try to find places that had Wi-Fi and electricity (such as cafes) and plug in there to charge both batteries. (Though I would be hesitant to do this now, since cafes seems to be more problematic to me these days than they used to be, possibly from the super toxins that have been reported to be contaminating some laptop computer products?)

I had solar on my RV, and it charged a battery. So that provided some electricity as well. Even if tent camping, you still could get an electricity setup that way.

Another possibility is a generator that converts fuel into electricity.

For Internet, I had a device from Verizon that used cell phone to connect to the Internet. Admittedly, many of the places that felt the best to me were out of cell phone coverage, but usually it was not that far away from cell phone reach.

The device I had just hooked onto my computer and did not require electricity of its own. Later, Verizon introduced a device that did require electricity. I would suggest possibly getting an older device that did not require its own electricity, even if was slower.

It's possible to use the cell phone as a "hot spot" as well, but that burns up data charges very fast. A separate device may end up being more economical.
Another alternative is, if near civilization and the goal is to just to spend a little while on the Internet per day, to go to town and find a Wi-Fi to hook onto.
Q. 16:1 - Spoiled Food

What about mold on food? Is it bad for our health? Should we bin things before they have a chance to get moldy? For example - I found a moldy apple in the fruit bowl today - have I made myself worse because I didn't spot it sooner?

Karen Dean

Besides being sickened by mycotoxins and spores in the environment, I have been made sick by mold growing on food. As I am now living in the small efficiency style room that includes the kitchen, I have a lot of experience with this. Onions grow As. Niger, and after being made sick by bags of onions, I only buy individual ones. The black powdery As. Niger causes me burning eyes, throat, and other mold toxin symptoms. Recently, a pomegranate that was in a box of dry goods grew it. Even packed away, it affected me, and caused a game of "find the mold" that lasted a few hours. A cake wrapped in plastic grew multicolored mold and was making me sick even sealed up, so it was definitely the toxins soaking through causing another morning of "find the mold." Keeping a clean pantry and fridge is essential. Apples can grow a very bad mycotoxin called patulin I believe, which scientists spend their whole lives trying to get out of apple juice. But I think it is mostly something that if eaten is bad. Never eat the bad spots on apples.

Lisa Petrison

There are a bunch of articles in the literature about dogs who got extremely sick after eating spoiled food contaminated with the mycotoxin Penitrem A, and I would have to think that that could cause symptoms if inhaled as well. So concern is justified.

Living in locations that felt pristine to me, I never felt like mold growing on food was problematic to me. More recently, living in an area that is sporadically more problematic (because my tolerance has gone up), I do feel like food mold can be problematic (though not to the point that it would contaminate a home permanently).

So I'm a little skeptical about the idea of home composting. I lived for a while in a pristine desert with a compost pile of all-organic foods, and it felt fine to me. But I shudder to think about the mandatory curbside composting in Portland, Oregon, a damp city that apparently has a lot of mold toxins in the air and where all rotting
food is thrown unbagged into bins until collection day.

If I had to pick one food mold that does seem to have an effect on me consistently, it would be the white/green mold growing on oranges (which looks like the mold that can create Penitrem A). Apples never have seemed as much of a problem for me.

Julie Rehmeyer

I've never had problems with food mold myself.
Q. 16:2 - Peanut Butter

I have heard that peanut butter contains mold. Is this true? I ask because my child has high mold sensitivity. That said, she gets hiccup tics and the only way she has ever been able to stop them is with a spoonful of peanut butter. I have never noticed any problems with it. But, I want to make sure that I'm not hurting her.

A.M. Runyan

After getting acute mold poisoning from a leaky building, I hated being around peanuts... could not have anything with peanuts around me, even if someone else ate it out of the house.

Maybe honey would do the same thing, without the risks of peanuts- raw local honey?

Karen Dean

Ground nuts are very subject to mold. In Africa, the export the good nuts, eat the moldy ones, this has caused so much cancer that In S Africa they opened years ago a mycotoxin research center. Stay away from peanut butter. As a child I hated it, guess I had natal good sense.

Lisa Petrison

Peanuts are one of the foods that are prone to aflatoxin-producing mold growth. Aflatoxin is recognized as a major risk factor for liver cancer and recently has been recognized as an apparent progression factor in AIDS. It also causes other serious diseases.

Food manufacturers in the U.S. are required to test foods for aflatoxins, to keep them within specific levels. In Africa, where there are no such requirements, much of the foods consumed by most people (especially grains and peanuts) are highly aflatoxin contaminated.

On the other hand, in the U.S. (at least insofar as I can find with a lot of search), there are no limits on ochratoxin or trichothecenes in foods. (Those are regulated in Europe or certain other countries.)
I've never personally eaten a lot of peanut butter, but I've never felt really sick when I have eaten it. Foods that tend to be contaminated with other mycotoxins that are not regulated in the U.S. (such as grains or coffee) seem to be more a problem for me.

In general, in both my experience and based on what I've read, food contamination with mycotoxins seems to be somewhat correlated with quality/price of the food. The one time that I did note being strongly made ill by nuts (actually cashews) was when a long time ago, I purchased a cheap brand from a convenience store. Recently an inexpensive organic bread made me feel pretty ill too. The money has to come from somewhere if items are going to be sold cheaply, and since not too many people understand that mycotoxins can cause problems, that can be a good way to cut corners.
Q. 16:3 - Shellfish

Does anyone know if shellfish are safe for us? I am thinking here in terms of ciguatera with reef fish, is there a problem with a bioaccumulating toxin with shellfish?

Lisa Petrison

I wouldn't be surprised if seafood contains enough marine biotoxins to cause reactions to biotoxin-sensitive people, but to my knowledge I've not experienced it.

Janis Bell

Metals and hepatitis are biggest risks, but since people get ciguatera from reef fish, question worth pursuing.

Family of the Way

No shellfish is safe for anyone to eat because they are the scavengers of the ocean and they eat all kinds of bad things.
Chapter 17

Super Toxins
Q. 17:1 - Delayed Response

I had been feeling better since moving away from the Bay Area. Then a few days ago, I went back there to go to see my doctor. I was basically okay during the trip, but now I am feeling horrible physically and cognitively. Can one have a 24-hour delayed response to an exposure? If it is related to an exposure, is there anything I can do to reduce the effects?

A.M. Runyan

In general, when I bring a small amount of toxins into my space (not spores, but just toxic stuff), it will hang around for a week or so but eventually get oxidized by the air, I suppose, and it dies down. So all is not lost.

When things get contaminated in my space, I wash them individually in the stainless steel sink, which doesn't seem to store toxins the way a washing machine can. I try to air it out, if the outdoor air is clean. I'll burn soy candles, since those seem to oxidize any toxins in the air.

For physical symptoms - yeah, coffee enemas, liposomal Vitamin C, getting enough minerals (particularly zinc, selenium, manganese, molybdenum - I use the BodyBio taste mineral kit that I found for $23 or so to test mineral status), having CSM or psyllium before meals, etc.

For really bad reactions, I use mast cell stabilizers (CLaritin, D-hist) and alkalization - TriSalts, or alka seltzer gold.

Can you see your doctor by phone in the future? It's often not worth getting contaminated for the sake of health, if that makes sense. I won't see doctors in bad areas.

Julie Rehmeyer

Yes, a delay is entirely possible. The key thing is to make sure you haven't contaminated anything in your living space. The clothes you wore may or may not be savable. Don't wash them in your washing machine! They could easily contaminate it, and then the contamination could spread to everything else you wash in it. I've had some nightmares with that, having to wash everything in the house over and over. Either give up on them or wash them by hand in the bathtub and then hang them outside for several days. Test them carefully before bringing them in the house.
Ideally, you would have taken your clothes off immediately upon getting home and showered; if you didn't, you'll have to wash anything you came into contact with. I also found ozonation helpful in this kind of situation. Coffee enemas made a big difference in recovering from such exposures for me, though I sometimes needed as many as four in a row to make a difference.

Lisa Petrison

Whatever the particularly bad outdoor toxin is that is present in some locations, it doesn't fully manifest its effects for 24-48 hours. I found that out very clearly when I got hit with it camping outside of Truckee, and other encounters with it have confirmed that. Erik has talked about this as well.

(This is not that unusual for biotoxins, according to the scientific literature, btw. People who have big exposures to cyanotoxins usually do not experience symptoms for a while, and some mold toxins also have a lag time.)

Learning what your immediate warning signals are to that toxin thus are important to practice effective avoidance. For instance, mine are a particular sort of depression, a feeling of having a needle in my sternum, and sometimes skin dents (related to hypoperfusion).

Bagging all the items you took on the trip and putting them somewhere not in your immediate proximity (like a closet) is a good first step. Then think about changing bedding if it might have gotten contaminated and washing (or at least brushing with a wet sponge) anywhere else you think might have been cross-contaminated. It's hard to force yourself to go out when you are feeling really bad, but if you suspect your apartment could be cross-contaminated, breaking the response in a really good place could be helpful.

Eventually that kind of secondary cross-contamination will die down, especially if you attend to it. Maybe within a week or two, I would guess, for you.

Beatrice Latherings

Absolutely. My reactions are always delayed; usually it is the next morning when I stretch and my calves cramp up, that I know I inhaled too many mold toxins. That is why, whenever I have been out, even just in the car, I bag my clothes and shower and wash hair before I touch anything in the trailer. I have had no problems with contaminating the washing machine.
Q. 17:2 - Worst Toxin

What does it mean if you come across some of the 'worst' outdoor toxin in a given city or area? Does it mean there's more nearby? It may have just been carried in on a vehicle from somewhere else, right? But I'm afraid to go outside now. The place I'm staying is slightly mouldy, but it's _nothing_ compared to that outdoor toxin I came across.

A.M. Runyan

It's true that these "worst" toxins put regular mold toxins to shame, and that's why people who have been around the block typically prioritize avoiding those things. I don't know if it means it would be all over that part of town. I've encountered really bad toxins from vehicles/trailers.

Lots of U-Haul vans seem bad, actually. If I ever use one I'd insist on checking it first before renting the particular van, since if one person puts really terrible stuff in the van it could be contaminated for months. I guess vans like that are unusual because they get a lot of use by lots of different people, so it's like encountering 60 vehicles at once (rather than a single vehicle with a single user).

Probably try to carry a change of clothes in a plastic bag, and some trisalts or Alka Seltzer gold, for use sort of like an epi pen if you get exposed. Maybe even have a card with instructions about what is happening and what to do if you can't communicate well so you could just show people the card?

Also the more you can detox the less bad those kinds of reactions should feel... you still notice them but the scariness and degree of symptoms goes down.

Lisa Petrison

It's pretty rare for cities not to have any of that really bad outdoor toxin at all, though in some cities it is not as big of a problem as others (e.g. only in certain places, only in winter or relatively mild).

If you can sense it on your clothes, then my guess is that it likely would be "homegrown." Otherwise, it's possible that it could have been carried from somewhere else -- though with the level of response you are reporting, I tend to doubt that.
Q. 17:3 - Contaminated Package

I received a contaminated package two weeks ago. The items were drenched in a very bad toxin that didn't go away even with repeated washing. I brought the items inside and tried to clean them before I realized it was not working. My hands were contaminated even after many washings, and I accidentally contaminated my computer by touching and sitting near it. I think I successfully dealt with most of the contamination in my living space, but after two weeks, my computer is still badly contaminated. I get strong head pains, ear pain, and heart pain from sitting near it, even if not touching it. I have had constant tinnitus for at least a week (and I have not had that symptom since evacuating my mouldy dwelling). I am sleeping in a different room than the computer, showering before bed and putting on clean clothes. I still have tinnitus after a night of sleeping. I don't understand.

The package came from Minden, Nevada, which is close to Lake Tahoe. But it is close to the southeast shore, not the north one. I have received packages from the same place before, as recently as two months ago, and they were fine, not contaminated as far as I could tell. So maybe this is a winter toxin phenomenon. Who knows. Is it possible, given the location, that this is the '?' toxin from the Tahoe area?

What should I do about the contamination? I would put the computer in the sun except that there is no sun. The next sunny day may be a week from now, and even then it might not be strong sun. I feel concerned that all might be lost for my living space, but that cannot possibly be the case...I hope. I am mostly just reacting when I am near my computer.

Lisa Petrison

This does not sound like the Tahoe toxin to me. That stuff is present in small amounts in many places and does not cross-contaminate to the extent that you are describing, from what I have heard and experienced.

This sounds like a particularly bad toxin, that you might not have experienced before. Based on your description, my guess is that it is what has sometimes been called the "Itch Toxin," which seems to be more prevalent in England and that a few people have reported is now associated with Apple laptops (and possibly also iPads) and as a result Apple stores. And also that has been reported by a few people as permanently contaminating washing machines so that they never can be used again, just from briefly cross-contaminated clothing
having been washed in them.

My guess would be that one of the items that you purchased had been shipped out to a customer living in a particularly bad building and then returned to the company. This especially would be my suspicion if the product was one that people with "mystery disease" often purchase, such as particular supplements or books.

I have known people who have had their computers transiently exposed to cross-contamination of this stuff and then never have been able to use the computers again. (In at least one case, a cross-contaminated computer managed to contaminate a whole roomful of clean stuff when the fan came on.) People with a lower degree of reactivity might have a shot at saving the computer after it is exposed to this stuff, but people whose reactivity is higher may have a more difficult time of it.

Increasingly, I am thinking that mail order companies specializing in products for people with "mystery disease" (such as the companies that Patricia Kane and Dietrich Klinghardt are associated with) should not accept returns. This is just a guaranteed way to spread around toxins to people susceptible to them, in a very efficient way. It reminds me of the gay bathhouses in NY and SF, during the AIDS epidemic. Eventually those did get shut down, but it took a very long time and a lot of people getting sick in ways that could have been avoided before it happened.

A.M. Runyan

I actually would not recommend ozone for this kind of toxin, as I've found that it can spread these types of really sticky, non-spore toxins that can come with mail and that seem to spread like wildfire.

Airing out, air ventilation, and even UV light from a cloudy day. UV light and air seem to fix everything eventually.

I agree that doctors who treat people with these mystery toxin diseases should not accept returns.

Also increasingly I think they might need to see patients remotely or get patients to shower and change clothes at the office or not come to the office, or patients might have to find ways to self-treat if it becomes too dangerous to go to offices where they might pick up things that cross-contaminate their space.
It all reminds me of Cat's Cradle with that weird crystallizing toxin (ice-9) that turned water into ice and sort of spreads with bad consequences.

I also want to comment that I've also had it happen that my hands got contaminated from things in the mail (most notably some chloralla from BodyBio), and then even after multiple washings I was still contaminating objects with my hands. Laptops seem particularly prone to this kind of hand-contamination, so if I feel it's a risk I prohibit myself from using my laptop for 15 minutes to an hour.

I also had an incident with mail contaminating stuff, from Israel. but I left the item outside in the sun for a month and it's ok now.

**Julie Rehmeyer**

My sympathies! Ozonation might help. It's not good for an ongoing mold problem, but I have found it helpful for cross-contamination issues. And yes, sun can be quite helpful as well, particularly the combination of sun and fresh air.

**Erik Johnson**

I was driven out of Minden/Gardnerville.

All I could do was get out of town and wait for it to die down.

(I didn't know about this technique at the time, but I would try "flaming" it.)

**Beatrice Latherings**

Put the computer outside away from any air flow that might be from it towards your living space. Wait a long time. See if it is better. Otherwise, throw it out. You won't be the first to have to do this.

**Forebearance**

Personally, I would put the computer in storage for a few years, or get rid of it and start over with a new one. It takes poisoned computers so long to die down.
Q. 17:4 - Protecting a Clean Item

I have to bring a sort of valuable, clean item into my apartment which is moderately contaminated, likely with the 'Itch' toxin. I am wondering what would be the best way to keep it safe from contamination. Is plastic really best? What about paper or cardboard? I have found that glass is useless as a barrier against toxins. It seems to become permanently contaminated by these very bad toxins. Sometimes paper seems to work better than plastic, but I don't have it figured out.

Corinne

Aluminum foil and aluminum tape. If it's an awkward size then in a box covered in aluminum foil.

Lisa Petrison

Plastic appears to be solid, but (at the molecular level at the size of these toxins) it really is not. It may provide a barrier with regard to spores and spore fragments, but the toxins appear to sail through, from what I have experienced and heard.

A cardboard box may be a bit better, from what I have heard. I am a bit surprised to hear you say this about glass, though I've not experimented that much with practicing contaminating things.

I agree about the aluminum foil likely being the best barrier, from what I have heard.

Karen Dean

Yes, toxins soak right through plastics. I have found a thick layer of newsprint to keep toxins out.

Beatrice Latherings

Re-consider whether you "have" to bring it in.
Q. 17:5 - Laptops

(Note: This question is from October 2013.)

I want to warn you about something.

I recently purchased a MacBook Air laptop from the online Apple store. After using it for a few hours, I realized that it was horribly poisoned. And the kind of toxin radiating out of it was really bad. It burned my face, arms, and hands. I haven't run into a toxin this bad since I grew the 'ick' on my patio table. It acts exactly like that toxin, so to me it seems like "ick" toxin.

Before I figured out what was happening, I wore the same clothes I had been wearing to work on the computer into my hotel room, and they cross-contaminated every object that was sitting out. Including the room itself. And then the cross-contaminated objects cross-contaminated other objects.

After a lot of work to recover from that situation, I thought that the computer might just be some kind of fluke, so I returned the computer. Next I tried going to an official Apple Store in person, to see if I might have better luck there. Normally Apple Stores do bother me. They make my kidneys hurt in the same way as the Bay Area toxic soup does. But this time, a store I have been to many times before was unusually toxic. Just being in the store made my hands develop Reynaud’s phenomenon (blotchy pink and white patches on the skin). Touching a couple of the packaged items on display made the skin on my fingertips shrivel. Both are signs of the presence of mold toxins, for me. I sat on a stool at the Genius Bar for a few minutes. I was in the store for 10-15 minutes total.

Driving home I realized that my bottom was burned, through my clothes, just from sitting on the stool in the store. By the time I was in a place where I could take a shower, my face and arms and hands were burning. I had purchased another laptop, but I returned it unopened the next day. I'm sure it would be poisoned, too.

I think something bad is happening at the Apple factory or one of its suppliers. Some component of the newest laptop computers appears to have been exposed to a very bad toxic mold at some point in its life. This was not the case in the past! Apple computers used to be fine.

So I want to warn people who are sensitive to mold toxins to be very, very
careful around new Apple computers and Apple Stores. In a different store, where the atmosphere was less toxic, it did appear that the iPads were not as badly poisoned, and a new iPad may still be okay. I didn’t check out the iPhones or desktops.

This is really depressing. If every new Apple laptop is going to be radiating the very worst kind of mold toxins, that is going to make our lives a lot harder. What is going to happen to places like Panera and Starbucks where many people use computers???

As far as I can figure out, this shift to poisoned laptops seems to have happened some time this summer. Maybe it came on gradually over the summer. Or maybe Apple started to use some new component from a new supplier that has a serious mold problem.

The only hope for someone who wants a new Apple laptop right now seems to be to try a small, independent Apple retailer where the stock rotates a lot more slowly, and to look for a model that has been in stock for a long time, like since last spring or earlier. Or to buy a used laptop. Or maybe to use an iPad instead.

Julie Rehmeyer

I bought a MacBook Air online in June without difficulty.

A.M. Runyan

I noticed that something like this, with a good product going bad, happened with the Jarrow Methyl-B12 this past summer.

Beatrice Latherings

If they are made in China, many of us have noticed that almost everything from China is badly mold contaminated. I even saw a news item a while back that there was a law passed that made it illegal to force Chinese workers to work in a moldy building. They must have an incredible problem there.
Betsy

I really didn't want to think this could be, but I found our local Apple Store horrifically toxic today. I have been there many times over the last two years, and several times just a month or so ago, and it was fine for me. And bought a laptop about six weeks ago, returned it and tried another, and both were fine. But today after about three minutes in the store I had to leave. Started to retch very soon after, lost my voice, hurried home to shower. Really bad stuff. I'm considering throwing out the clothes I wore. And such a change, so fast.

Anonymous

I'm not sure if this is the same thing, since it happened to me three years ago, and before I was aware of my mould sensitivity.

When I bought my new Apple laptop in 2010, during the first month or so my hands burned terribly from touching it. At the time I thought it was related to the metal alloy used. I found that the burning persisted after hand-washing. It was actually worse after hand-washing. I found that the more natural skin oils I had on my skin the less the burning would be.

The reaction spread so that whenever I touched any other metals, such as keys, doorknobs, taps, my hands would burn, too. It was pretty painful. I tried to return the computer, but it was too late and they wouldn't accept it.

So I kept using it, and the reaction went away for the most part. Occasionally, and recently, I will still get the burning on my hands or arms where they have touched the metal of the computer. Maybe this is some other thing than mould toxins, though, I don't know. Maybe it is an incidence of electronics concentrating toxicity.
Q. 17:6 – Hell Toxin Prevalence

I am running into Hell Toxin absolutely everywhere. I don’t feel better after showering -- the burning, inflammation, and oxidative destruction feeling persist, as does the irrational emotional mess-ups and brain takeover. At this point, given the disastrous spread of this toxin on laptop computers, it seems that anywhere within civil devastation is dangerous. Even if I move to another city, a smaller one in the pristine mountains, there will be people with their laptops. Even if I get rid of all my clothing and start over in a new place, this toxin is assured to be present where there are people and their laptops, so, short of living alone in the wilderness without human contact, I don’t know how it will be possible to avoid it. I can’t even walk outside of Starbucks and other coffee shops without harm: I have to walk far away from the outdoor tables of those places, and the far edge of the sidewalk isn’t far enough away, and if the employees are outside, I have to avoid them by a several metre radius. Once it’s on me, I suffer for days or longer. I am still recovering from the Hell Toxin plume that swept through town and into my window, onto my belongings. I wonder what we as a community can do about this plague. Does anyone have any ideas? Are others noticing the same increase and what do we all think?

Lisa Petrison

One person said that using a facial exfoliator was helpful with regard to removing the Hell Toxin in the shower. Maybe a bath brush would be helpful as well.

I generally feel ill at ease in cafes these days, which I am guessing is due to low levels of this toxin there.

It does seem to be that increasingly the winning strategy in playing this game is establishing a safe refuge and protecting it fiercely (including not going into public places any more than necessary).

The only solution that I can think of is the development of tools that would allow people to detox safely without being totally clear. Probably "science" could develop those, if "science" put its mind to it. But so far, "science" does not show any inclination to do that.

So I'm not sure what else to suggest.
Anonymous

I have been running into hell stuff constantly since spring. Found could get it off body with washing hair 4 times, using exfoliator and most important step using Epsom salts, bath with several cups soaking all body parts or even using handfuls in shower like exfoliator including scalp. Need great care not to cross contaminate until clean. Ozone works.

Julie Rehmeyer

I haven't encountered this, and I'm not sure what to make of it. I spend time in Boulder, which is one of the places it's been reported, and never seem to have encountered it. I also just had problems with my iPhone and had to replace it, and the new one seems to be just fine. (It's an older model, though, a 4s, so maybe that makes a difference.) My computer is a year old, and it's been fine for me. I don't know if I've just gotten lucky or if I'm not susceptible to it at this point.

Erik Johnson

It is becoming quite the challenge, isn't it?

Karen Dean

I have heard the Hell Toxin is all over Boulder, so if you are there, that's a problem. I do not encourage using killing products on spores, as it causes a toxin release, but for the hell toxin spores, EM1 sprayed in the environment, will at least keep the hell spores from taking root and spreading. Just don't spray anywhere you want to live. I have heard that Epsom salts rubbed on the body helps get rid of the toxin. But the key with the hell toxin is to not irritate the spores or you WILL have a hell of a toxin.

Lots of Vitamin C helps me deal with mold toxin of all types. Liposomal C has given me a real tool. If I have to do a show and be exposed all day to all types of mold toxin, I take in as much C as possible the day before, and Liposomal glutathione also. My doctor sells Reddy Sorb glut and I think it is the best. The only other gambit is stripping and de-toxing as much as possible before you come into your clean space. Swimming in a chlorinated pool has helped me a lot in the past.
Q. 17:7 – Hell Toxin & Grocery Stores

I'm wondering if any other severe reactors are noticing an increase in tiny amounts of Hell Toxin and/or Tahoe Toxin in grocery stores and on groceries. Granted, I am in the midst of extreme intensification, but I don't think this is 'just me' -- I think it is objectively happening to the groceries. I almost cannot bring any food into my apartment at this point. Example: I was suspicious of the butter I was trying to buy today, from the moment I picked it out at the store and sniffed it. I bought it anyway, bagging it separately from the other food, and removed it from the wrapper before bringing it inside on a clean plate, but I still felt an immediate increase in tinnitus, weakness and dizziness once it was inside. I had to remove it right away and give it to the neighbours! I keep losing grocery stores in which I can shop. After a few weeks shopping at a given store, I start reacting more and more severely to the groceries I buy there until I cannot bring any food into my apartment from the given store. My fridge is pretty much unusable from having had a few contaminated groceries in it for just about one hour, a month ago. I still get heart pain in my kitchen from having had transient cross-contamination in there. The reaction feels very much like a biotoxin reaction, and not at all like the more mild type of reaction I get from fragrances or other manmade chemicals, that I am aware of.

I am also wondering if anyone has used Isagenix products other than their whey powder, for detox (they have detox formulas). I am encountering many hurdles in doing detox protocols like coffee enemas and CSM, but realize I absolutely need to be doing _something_ to try and detox, even before getting to a clearer place. I have switched to spring water and am no longer consuming tap water after realizing I was reacting to it, and that has helped me to be able to continue to drink (was previously getting badly dehydrated from being unable to tolerate water).

Lisa Petrison

I have talked to someone who has been contaminated with the Hell Toxin and has found it difficult to get free of it. The conclusion finally has been that trying to clean things that are even slightly contaminated seems to be an enormous mistake, and that the only way to deal with it (for someone who is extremely reactive to it) is to get rid of all possessions and start over.

This person has said that stores that s/he has visited in the past (especially during times that were less clear) have become impossible to return to in the future. It is like the whole store becomes contaminated.
Probably this person has become especially sensitized to this toxin due to fighting with it for months (e.g. trying to clean things that were cross-contaminated with it), and thus is picking up on really tiny amounts. But insofar as s/he is describing actual reactions to these formerly visited places (which I think is true), this is a very disturbing phenomenon.

That is why I do not think that mold avoidance is in any way an answer. We cannot get anywhere by helping one another, because this phenomenon is too terrible for that. We need societal help.

Personally, I used to go out (e.g. to cafes) a lot more than I do now. Recently when I have been to cafes, I have felt uneasy. Not sick, and as far as I know without any lasting repercussions, but uneasy. And I have gotten to the point that when I feel uneasy somewhere, I flee. So I am in agreement that this could be an increasing problem. (As would be expected, if what I am hearing about how this stuff travels and its contaminating certain laptops has validity to it.)

The way that Erik and some other people managed to climb back up the power curve so that they could tolerate larger amounts of the super toxins was by attending to the cyanobacteria contaminated tap water. This meant boiling water used for all purposes, including clothes washing, bathing, dish washing and toilet flushing (in the RV). They have stated that without boiling the water, it cross-contaminates enough to keep them much lower on the power curve, and thus makes survival (especially in a place where getting exposures) much more difficult. Erik has stated that he believes that breathing the residue of the water on things that have been washed in it is worse than actually drinking the water.

Obviously, boiling all water used for everything would be difficult. For someone who wants to climb back up on the power curve though, I would consider at minimum using boiled water to wash pillowcases and shirts, and to rinse hair after a regular shower. I did that when I was living in Chicago at the time of year when the tap water was contaminated, and it helped a lot.

The other thing to consider doing is to try to find a local place that feels especially good, and then to spend as much time there as possible. When I was living in Chicago for a few months, I went to the Chicago Botanic Garden every single day, for at least several hours. By breaking the response in this way (with hair and shirt rinsed with safe water), I was able to tolerate more exposures the rest of the time.
Karen Dean

I would ozone the room for 4 or 5 days to remove Hell Toxin

I used Isagenics for detox and got little too no result

Beatrice Latherings

I avoid certain grocery stores but it's because of the air quality. I have not yet had problems with food I bring inside, but I do buy the vast majority of my food at two small local businesses that use extreme care to buy local organic food; they are very picky. So far so good.

Vicki

One thing that has helped me tolerate detoxing and intensification is to take Alka Seltzer Gold a couple times a day. I guess keeping me more alkaline is helping in some way. Also I increased my liver support (milk thistle/dandelion root) and that has also helped keep my liver enzymes in range. I know this doesn't specifically address your question, but maybe these things would help you tolerate your intensification like it did me. Best wishes.

Jill

Can you shop at an all organic grocery store or an organic outdoor farmers market?

I'm very aware of my reactions in certain stores too.
Q. 17:8 – Computer with Hell Toxin

My computer has been contaminated with Hell Toxin since December. It was doing better in the past little while. I had continued the routine of washing my hands each time I touched it, and tried not to get too close, but I was able to use it without much or any problem. Nothing has changed, it has stayed in my apartment since then, but....today I picked it up with both hands (first time picking it up in a while) and it got too close to me. I was burning and feeling bad, washed my arms and face but was still suffering. So I brought it outside into the direct sunshine for a bit. I stood around near it to sort of supervise, so no one would steal it. Of course, like the Sunny Day Slam, it got initially worse. I hadn’t thought it through. I didn’t have all day to stand outside with it, so I brought it back inside but left it outside of my apartment proper. It is now downstairs. I showered and I’m using it now, downstairs, but not feeling great. How many hours outside would it need in order to stop getting worse and start getting better? I don’t feel safe bringing it into my apartment (I did for just a moment and then took it immediately out again, because it felt very dangerous, like it was spewing toxins), but the downstairs of this house isn’t an avoidance space, so I don’t know if it is great to leave it down there. On the other hand it is probably the most contaminated item down there, so I don’t suppose it would get worse from the environment; if anything, it would be doing the contaminating, not getting any more contaminated... I think. Anyway, I will have to bring it upstairs into my space on Saturday. What’s the best way to do this safely? More time in sun, or less time in sun? Honestly this toxin is so bad it feels truly truly dangerous to me and I fear for my safety when the toxin flares up like that.

Beatrice Latherings

Since it is probably a total loss anyway, I would put it in a garbage bag on some kind of rack that will let air flow all around, cut a small outlet hole at the end, and put an ozone machine above it with its inlet taped into the bag. Just turn it on and leave it there for 48 hours and see how it turns out.

Lisa Petrison

I haven't heard of many people successfully remediating objects from Hell Toxin, except through a very long period of time (years) or with a flamethrower torch. One person said that long periods of ozone work, but that the object does get worse before it gets better. So this is a difficult question.
Chapter 18

Outdoor Toxins
Q. 18:1 - Growing Outdoors

Do toxic molds grow outside? Or is it that mold toxins encountered outside always emanate from buildings?

A.M. Runyan

As time goes on my body becomes much more concerned with these mysterious, non-smelling outdoor toxin(s) and less with mold.

I sometimes wonder if it's these worse toxins that are making it harder for us to cope with lesser types of mold - some sort of hierarchy of toxins. The more I get the really bad stuff out (and sometimes it is painful, makes my heart and muscles hurt on the way out) the less I'm impacted by regular building mold (not Stachy, but just the usual low-level mold in a lot of buildings).

I feel like what we are really doing is "supertoxin avoidance" - avoiding supertoxins that might not have existed in noticeable quantities before a few decades ago.

I live in a complex where people move in and out and bring trailers, and trailers from Illinois, Iowa, and Florida have bothered me before. I found it impossible to stay in Fort Worth/Dallas for more than a few hours last spring.

Lisa Petrisan

The worst slam that I've ever gotten was at Sierra Hot Springs, which is about half an hour from Truckee. It is WAY out in the middle of nowhere, and the couple of buildings on the premises felt fine. I was okay there tent camping for two nights; on the third, the barometer dropped and the really bad toxin came out. It cross-contaminated my stuff so that I had to donate a lot of it to a Goodwill type place (they were very happy to get such nice sleeping bags and camping gear). The stuff I didn't get rid of took a year to die down.

In 2010, I drove back to the Midwest. I was perplexed that Kansas and Nebraska felt great to me, while Indiana, Ohio, Illinois and Missouri felt awful. Agricultural areas felt much worse than cities in those latter states, including places where almost no buildings were present. Finally I concluded that maybe the difference was type of crop (wheat/alfalfa vs. corn/soybeans), and ran into a few studies that suggested that the glyphosate (Roundup) used on corn/soy made the toxin-producing mold Fusarium grow like crazy. (The ability of Roundup to cause
dysbiosis in both the soil and gut is pretty widely discussed now, but was totally under the radar then.) So my feeling is that the reason that those corn/bean states feel basically like a moderately moldy building to me is because of the trichotheccenes from the Fusarium.

Periodically, in the West, I have run into an outdoor toxin that blankets wide swaths of land. Sometimes it is in cities (like Flagstaff recently), but others it has been in total wilderness areas (e.g. Custer State Park in SD, Big Sur in California). It seems to be associated with places that have been treated with fire retardants, but since it always is months or years after the fire retardants have been applied (rather than worse right after application), I don't think it's the fire retardants themselves, but rather microorganisms growing in the wake of fire retardants.

Erik discusses in the "Back from the Edge" book about his primary interest being the substance that is present to a particularly large degree in Tahoe (and that seems to be what I got hit with in Sierraville). He actually encountered it growing on a moldy log (that triggered his collapse into severe illness) and has felt it coming from sewers. Only occasionally does it seem to be present in buildings based on the symptoms (I agree with that).

Of course, since "Science" does not seem to be interested in looking for outdoor molds, since "Science" does not believe that outdoor molds can cause harm, it is not a surprise that "Science" is not aware of this particular one. So far, we have been unable to change "Science's" mind though.

FWIW, the mycotoxin that seems to me to be the strongest match for the mystery toxin that is still present to a disproportionate extent in the Tahoe area is Penitrem A. It has the glutamate type effects that typify the Tahoe toxin; grows in sewers; is extremely toxic even in tiny amounts (and is recognized as such by conventional researchers); and is a match in appearance for the mold that Erik found on that log. However, since it is not a building toxin and "Science" does not believe that outdoor toxins can cause harm, no one seems interested in studying it very much.

A bonus story: After Erik got hit by that moldy log and was about to pass out, Erik's brother picked up the log, said "It doesn't bother me" and threw it in with the rest of the firewood. And then burned it in their wood stove. Erik said he suspected that this was why the house was so intolerable to him after that, but since his general reactivity was higher after that, he wasn't absolutely sure if that was the reason and so wouldn't let me mention that in the book.
All molds create toxins as part of their natural protective system. In nature, this is usually balanced out by other microorganisms, some of which break down the fungus and its toxins. But we've messed with the outdoor environment so much with all our bacteria sides I'm fungicides that I think it's possible to finally toxic molds anywhere. However, most people can handle some mold outdoors because the Effects are disbursed with the air circulation. Indoors, you have a higher concentration, and you have fungicides on the wood and drywall kill off the less harmful molds and allow the ones that have mutated to multiply without competition. So you're going to have a higher concentration of toxic molds in indoor spaces and out in nature. Outside, you will have plumes of toxic mold spores and mycotoxins wafting from buildings that are moldy.

Science studies mold toxins and their effects on humans. They are just in the dark ages/denial phase of connecting this with human illness because most of them get their salaries and research grants paid by companies that make environmental toxins (including pharmaceuticals). They choose their careers and livelihood over a small group of sick people for the same reason that few of us are altruistic. Survival usually comes first. But look at the history of lung cancer in relationship to tobacco. Look at how many years - decades in fact - it took for the evidence become overwhelming. Look at how many scientists continue to deny the connection despite the evidence. Eventually they lost. We too will prevail but our numbers will have to grow, and our voices will have to swell and we will have to find a few altruistic scientists willing to produce studies to support the evidence behind our claims of mold illness.
Q. 18:2 - White Fungus

I went to a break-water at the ocean to breathe some fresh air. It is long, and I walked along it all the way to the end, waiting for the air to get better as I got further out from the shore. Near the end of it, as it curved, one side of the break water had large white spots of fungus growing on it. I didn't like the way it felt at all. It seems to be on the parts of the structure that had gotten wet with ocean water, near the edges, and more on one side than the other. What is that stuff? Is it toxic, or is benign, and I am just super sensitive right now? I can’t believe that even out on the ocean I’m having reactivity!

A.M. Runyan

It's common in the beginning of avoidance to react to a wide variety of things seemingly everywhere. In my first few weeks, I was reacting to almost any lawn with a sprinkler, frozen berries, a huge number of buildings, the outer/outside parts of buildings, etc.

Lately, I'm getting more experiences where I see an item that used to bother me a month ago, smell it and think, oh, I barely notice anything.

Detoxing well greatly reduces this everything-reactivity.

Lisa Petrison

I've not spent a lot of time on beaches since doing avoidance, so I'm not sure. My suspicion based on what I know of your situation is that it's mostly just that you are really sensitive right now. It's good that you have gotten clear enough that you are able to pick out things that are bothering you!

Anonymous

I have come across this mold frequently near the jersey shore. Not just on the shore, but my first (old) house I ever owned, the walls had this thin, whitish, almost transparent film. I would wash it off and it would come back a few weeks later. Even after I painted over it. I had a lot of anxiety and insomnia and infertility in that house, but I wasn't very sick yet.

I came across it again recently while looking for a new car. We found a 2012
"new" car that was leftover. Would have been perfect. Only a few miles, no one else owned it, off gassed already. Yet I felt sick after driving it. Sore joints, sensitive skin. My husband had noticed as we were getting out from the test drive that the rear leather seats had that same fine whitish film on them. It wouldn't rub off- it was sticky.

And then I heard about a local woman who bought a house in this area that had "toxic white mold" and she had to gut her house as it made her really sick.

I think this stuff must be a mold that exists near the shore. The whitish film may indicate a layer of salt? Maybe it thrives in an alkaline, salty environment? Not sure what it is, but it's not a safe mold. That's for sure.

I have to add that I haven't come across it on the beach though. If I did, it hasn't bothered me. I usually feel very good on the beach. Just when it settles on surfaces and propagates does it cause me a problem.
Q. 18:3 - Fog

Why does fog feel so toxic? Every time the fog rolls in I have to barricade myself inside, close the windows, and wait until it passes, which can be a few days. This fog has a smell, something like rancid oil, or gas, or stale basement air. I used to smell a similar toxic fog occasionally in the previous location I was living in, and thought it had to do with industry or chemicals. But apparently it's just as bad here on Vancouver Island, coming off the ocean. This means it is not likely from industry. And the rain does not have the same effect.

Lisa Petrison

One thing that I know is that fog along the coastline can have methylmercury in it.

Beatrice Latherings

If you're near Nanaimo, I think that area is not so good. On the west side of the Island the air on the coast seems quite a bit better. But to get good air you have to get away from civilization, which makes it hard to make a living. Those who find a way to work from home often have the best luck.
Chapter 19

Locations Effect
Q. 19:1 - Caribbean

Why is it that many CFS patients do so well in the Caribbean (what has been called the 'locations effect')? Do you think that is related to toxic mold avoidance, or is it something different?

Lisa Petrison

This is a really excellent question. Good research is needed.

I've not been to the Caribbean or anywhere similar since doing avoidance, but experienced mold avoiders I know have said that they believed that mold toxins that are problematic for them were less present there than in many other places (but that there also are many other places where they feel equally good).

Here are some possibilities with regard to why mold toxins might be less prevalent or problematic in the Caribbean:

* All things being equal, being next to the ocean or surrounded by water seems to be a good thing with regard to mold toxins. Mold toxins do not grow on the ocean (though cyanobacteria toxins sometimes do), and mold toxins from shore tend to be blown out to sea. (This is true even for congested islands like Manhattan, according to many reports.)

* Certain features present in the Caribbean (including bright sunshine, heat, negative ions, sand and salt in the air) may neutralize whatever toxins are present.

* Some Caribbean islands have building styles (such as concrete buildings without drywall) that are especially mold-resistant. (Cuba, which reportedly does have this sort of building style, appears to produce the most consistent "locations effect," from the reports that I've heard.)

* The Caribbean tends to have more of a tourist rather than agricultural emphasis. Agricultural chemicals can have negative effects on people's health, but some of them (such as Roundup) also have been shown to create dysbiosis in the soil, making certain toxic molds (such as Fusarium) more likely to proliferate. (Rumor has it that Cuba has traditionally grown mostly organic food, too.)

* People traveling to the Caribbean often buy new clothes for the trip and spend a lot of their time swimming or in bathing suits on the beach. This means that
whatever cross-contamination they might have brought with them from home could be less of a factor. (This is one possible explanation for why more people with active CFS report spontaneous remissions in the Caribbean than in places like, say, Death Valley that experienced mold avoiders think are inherently just as good.)

But this is all just speculation, based on previous discussions I've had on this topic. I'd like to see more people who have experienced the Locations Effect in the Caribbean contribute their thoughts!

Jeff

This is just a thought but genetics may play an influence. Significantly they generally live in well ventilated homes, don’t use weed killer products to the extent we do, don’t have strict fire regulations which most countries have, and don’t require flame retardants applied to clothing and furniture.

Damien Blenkinsopp

As with Lisa, I think some good research is needed. But I have a few thoughts to add based on my own experience (living in Yucatan/ Quintana Roo - Mexico).

1) The molds and mycotoxins may be of different varieties here so may pose less of a problem. There are definitely issues with mold here though - I've found it growing in a few buildings and in some I've reacted badly to it. Also in air conditioning. So it isn't an absence of mold, that is for sure.

2) The 'outdoor' effect: Due to temperature and conditions you tend to spend a lot more time outside in fresh air and when you are indoors you tend to leave the doors open anyway - at least we do, even at night. So it's never an enclosed building air situation.

3) Favorable wind conditions on the coast: The wind here, at least East Mexico coast in Yucatan is onshore - meaning it should be relatively air toxin free, and possibly also limits to a much larger extent the spores that are getting blown into buildings along the coastal towns.

4) Lower EMF waves: This is very speculative. I saw one experiment where they had tested the output of mycotoxins from molds exposed to different levels of EMF vs. none (control). The results reported were that the molds were somehow reacting to EMFs by putting 100s of times more mycotoxins out -
perhaps perceiving being attacked. There is certainly less EMF activity here although it is growing quickly depending on where you are. So potentially mold is here, but mycotoxins levels dispersed are lower due to less EMF activity.
Q. 19:2 - Altitude

Can you comment more on the effects of altitude? I was thinking of moving to the mountains (higher altitude) to help with CFS/MCS issues, but I've heard from some people that higher altitudes can be harder.

Lisa Petrison

All things being equal, the air at higher altitudes tends to be a lot cleaner. That may especially be the case with mold toxins, since many of the worst toxic molds (such as Stachybotrys) tend to be heavy and thus to fall/blow to lower altitudes. Even a small altitude change (such as 200 feet) can make a difference. When I was in Chicago, I was amazed at how much better the higher areas of the metropolitan area felt than the lower ones -- even though Chicagoland is generally not a place that is usually thought of as hilly.

Unfortunately, mold does seem to grow just fine at high altitudes. Tahoe-Truckee (7000+ feet) has lots of moldy buildings (bad enough to get the police to put yellow tape around them); very toxic mold growing outside on logs (as described in the "Back from the Edge" book); and a particularly problematic toxin that we believe to be a mycotoxin emanating from the sewers. Telluride (9500 feet) has moldy buildings bad enough to get ongoing newspaper coverage. Fire retardants tend to be used more heavily at higher altitudes (because there are more trees), and observationally places where they have been used tend to be ones where many Moldies react.

So just moving to the mountains does not guarantee good air, much less a good building. Plus some people have allergies to non-toxic molds that can grow in mountains or other vegetation, or they simply don't do well at high altitudes. (Some people find they can tolerate altitude much better once they're really clear though.)

Another altitude-related topic is the "epo effect," which Erik and Jonathan Wright discuss in "Mold Warriors." The idea here is that if you go to a higher altitude than the one that you're accustomed to (and especially if you exercise there a bit), you can damp down inflammation and feel better for a while (e.g. maybe a few days).

Beatrice Latherings:

Moving to 8000 feet has made a definite difference for me. The air is very much
cleaner and even though we've had 15+ inches of rain since July 1st, I'm feeling just plain fantastic up here. I have always liked altitude, though, and if you are someone who does not do well at altitude in general, it might not be the best move for you. My issue is mold illness and I don't have MCS to any great extent. I'd try a camping trip first in the mountains and see how you do. I just love camping on the north rim of Grand Canyon, which is also about 8000 feet. There are many high altitude campgrounds in the Rockies. Colorado, Utah....and you will see some gorgeous country, too.

Cha Cha:

Altitude causes a slowing down of bodily functions due to a lack of oxygen to cells. Extremities can feel almost numb, your cognitive abilities can slow down, blood pressure drops causing dizziness, and I personally suffer from extreme nausea.
Q. 19:3 - Mold Escape

I live in London and am looking into going away for about one month and trying to avoid the moulds I have in my home. What sort of place is best to go to? Warm and dry? Warm and in the mountains? My options right now would be somewhere in Europe.

Jeff

Dry is the key but avoidance of decaying organic material is also important. I would head for high mountains areas (winter ski resorts) now walking routes.

Shari

I have found dry is the absolute best. This also tends to be hot.

Julie Rehmeyer

I don't know Europe well enough to make specific recommendations about where to go, though Myhill's advice is sounds in a general way. I'd add a few things, though.

I live in Santa Fe, NM, which is quite a dry climate --- however, there are a lot of buildings with flat roofs, and the result is that there are a lot of moldy buildings and a certain amount of toxic mold in the outside air from the buildings as well. I live outside of town in a good house and do fine. But that makes it clear that not every dry place is terrific mold-wise.

Also, and this is critical, if you take a two week holiday in a mold-free environment you need to take none of your own stuff. If you're living in a moldy environment, all of your stuff will be contaminated with it, and you'll end up bringing the mold with you to the new place.

One more thing that might be helpful is to check out the Locations Effect board.

Lisa Petrison

I think the most important part of this experiment is not bringing along any belongings at all. It would be best to purchase new clothing and other necessities
by mail and have them waiting at your destination when you arrive, so that they don't get cross-contaminated.

The reason for this is that not all mold toxins are equal. Some are much worse than others. And CFS patients almost always (in my experience) are living amongst really bad ones. If this is the case for you, and you can get totally away from those toxins, then you have the potential of improving a lot even if you're not in a perfect place. On the other hand, if you take really bad toxins with you on your stuff to even a pristine place, you may not improve at all for many years (until your stuff dies down). So the experiment free of the existing stuff is critical, in my opinion.

A location that is at least reasonable in terms of outside air is also preferable. Smaller towns or the country tend to be better than big cities (but agricultural areas can be problematic). A lot of people like the beach (which has an added benefit of not requiring many clothing purchases). In addition to the Locations Effect website, we also have a Facebook page that may serve as inspiration:

The tough part about going on vacation for this experiment is the possibility that you might be staying in a problematic building. I would in general advise against modern hotels (climate controlled, centralized duct systems, etc.). Eventually you will learn what a bad building feels like, but it's tough at first.

One possibility here is a heart rate monitor. If your heart rate is lower sitting outside than sitting inside, that's a good indication that the building is bad. The difference becomes more dramatic as you have become clear for longer -- at one point my own heart rate would jump from 70 bpm to 155 bpm (consistently) upon entering a bad building. But even for a beginner, the difference might be enough to give a good indication if a building is bad enough to totally ruin the experiment.

Beatrice Latherings

Not only should you not take anything with you, but I would advise camping or living outdoors, because you have no guarantee that another building won't also have mold. If you feel significantly better after living in the wilderness for a month, that is pretty good evidence that something in civilization is making you sick.

Avoiding Mold

UK physician Sarah Myhill (who specializes in ME/CFS) on this topic
The key to diagnosing mould allergy is the history and if patients are improved in a mould free or low mould environment then this is highly suggestive that moulds are a problem. In order to survive moulds have to get their water from air, therefore they do not exist either in very dry climates (which may be hot dry or cold dry), above three thousand feet where the air is too thin to hold sufficient moisture, or on sea fronts where the prevailing winds are onshore. Since moulds do not live in oceans, their spores are constantly blown in land.

Therefore, to diagnose mould allergy I currently recommend that people have a two week holiday in such a mould free environment. They may have already done this and not realised that their improvement was actually due to the control of their mould allergy and ascribe improvement to other factors such as freedom from stress, or sunshine, or whatever.

Being free from moulds in our temperate climate is extremely difficult.

http://www.drmyhill.co.uk/wiki/Mould_Sensitivity
Q. 19:4 - Ski Resort

Would getting a job at a ski resort be a good way to be in a low-mould environment? Or might the accommodation be problematic? Would a hot country be better?

Lisa Petrison:

My own travels as well as others' reports suggest to me that Tahoe is not a fluke in terms of ski resorts being particularly problematic. Definitely buildings in places that get a lot of snow can be quite moldy, but the real problem seems to be outdoors (i.e. mold creating toxins in the presence of chemicals). The biggest suspect here is the use of fire retardants (since ski resorts tend to have lots of trees and lots of expensive homes that "need" to be protected). Another possibility is silver iodide used to create snow.

Rather than looking for "hot" or "dry," I tend to do best when I look for areas that are pristine. However, unfortunately, some areas that appear to be pristine really are not. Usually, again, the biggest culprit of the non-pristineness is fire retardants.

Christine

I do really well at about 1200 meters. Lived in a Swiss ski resort for three years. Had to get to the village by train. Only a few electrical vehicles allowed so the pollution issues were very low.

Like anywhere chalets can have mold when water damage is not remediated correctly. However, I have found in areas in Europe in the mountains, windows are built to keep cold (and other exposures) out so for me with MCS it was more secure.

I would never make a decision about housing anywhere without physically being there and stepping into the potential rentals.
Q. 19:5 - Desert Heat

I notice a number of people feel better camping in the desert. Are we talking in summer when it’s really hot? How hot? Or is this in the winter? I ask because I would not be able to cope in the heat - I know that too hot makes me feel really ill.

Lisa Petrison

It really is misleading to talk about "the desert" being the answer to this illness. There are a lot of deserts with really problematic air, and there are a lot of non-deserts that feel great. I have felt just as good in much of the Plains states (such as Kansas and Nebraska), in some wooded areas, in some mountains and near some beaches as in "the desert," for instance.

I would advise more trying to seek out places that are clean in terms of manmade toxins rather than to necessarily look for deserts. In general, it seems to be the intersection of molds and chemicals/metals that creates problems for most people -- not all molds.

Some people who say that all molds are problematic for them do seem to do better in deserts. They seem to be a pretty small minority though.

I suppose my first suggestion for people who have traveled a lot is to think about the places where they have felt best and then work from there. Reading casually on the Locations Effect website should give some possible ideas.

Beatrice Latherings

I go up to 8000 feet. I love altitude. Everybody has to find what works for them.

Janis Bell

I'm one of those. Summer is hell. Most go to the northernmost desert where it is bearable in the shade. Others can handle dry mountainous areas but I could not.
Q. 19:6 - Dry Climates

The best results I have gotten are from living outside and in drier climates so far. I am looking at some of the driest places on earth for my next stop in a week or so to accelerate recovery - Atacama Desert in Chile/Peru. I saw that some people have felt that towns in dry areas, like Las Vegas, had more mold issues (because of air conditioning?). I'd appreciate any perspectives or data points on this before I take the jump next week.

Lisa Petrison

I've been to quite a few homes in hot desert places that have felt good to me, even when the central air conditioning was running all summer and even when I was really reactive. Las Vegas has a bad reputation, but I think that may be that much of the housing there went up very fast and very inexpensively. I'm not crazy about HVAC systems in general, but they're not necessarily a deal killer. Though admittedly, for people who are super-reactive, they very often are a problem.

What I have periodically found is that in really dry places (such as Death Valley) people often don't pay much attention to roof problems because they are not concerned about rain. Then when it finally does rain hard for a few days in a row, every couple of years, the water drips inside. Even that would not be a deal killer, if the interior ceilings weren't made of drywall or ceiling tiles. But I have found a number of buildings that used to be okay become no-go for me, in the desert, as a result of just a few days of rain. Like the general store in Shoshone (on the way to Death Valley), for instance.

Karen Dean

Consider well leaving an existing support system for the great unknown

Beatrice Latherings

The mold issues are due to lousy construction and swamp coolers. Leaky homes and too-high humidity. Outside in the desert away from cities, people do very well. Altitude helps. Chile/Peru seems a long way to go, but would be quite the adventure.

The fact that you are able to travel to a place like Chile, which means being in airports and probably staying in hotels, makes me wonder why you consider that
you need an area like that in the first place, compared to those of us who cannot go in hotels or airports. If you like the idea of traveling to new place, sure I can see that, but it seems a mismatch to me of your ability to travel internationally and having mold illness sufficient for you to seek out a desert in a foreign country.
Q. 19:7 – Dry vs. Damp Climate

Hello! I was hoping to pose a question to the experts. I'm a bit confused at how mold grows in damp places so logic tells us to live in a dry climate... yet I hear of so many ‘avoiders’ doing well on islands and on some coasts. Do you have any thoughts on this you'd be willing to share? I'm 'new location hunting' and am trying to get my head around all the variables. Thanks!

Dave Ou

A water damaged building creates a unique ecosystem indoors of molds, mycobacteria, actinomycetes, and amoeba. Together they produce numerous toxic substances. This ecosystem does not usually occur in the outdoors. While there are some people who are sensitive to outdoor molds, the majority of people with mold illnesses are sensitive to water damaged buildings. For the majority, all that matters is history of water damage in a building, which is unrelated to the outdoor weather.

Lisa Petrison

Probably there is a good bit of mold on many islands and coasts where mold avoiders tend to feel good, but it may not be toxic mold.

Based on my experiences, places that are really pristine (away from chemicals, cell phone radiation, etc.) always feel good to me no matter how much humidity there is.

Also, certain factors about islands may degrade or nullify mold toxins. Those could include bright sun, sand and negative ions. The low-mold air blowing from the sea may be an even more important factor.

Betty Keen

I think Lisa nailed it. I also think the salt water is healing. All the minerals in the sand and water, constant sun, and vitamin D; plus I feel as though there is more bioavailable oxygen on the coast. Possibly the salt in the air aids it in getting into cells in the lungs. All of these things create an overall feeling of well-being and promote detox. Even in the presence of mold.
I think molds in dry climates become uber toxic when exposed to water. That's been my experience anyway. I tend to feel better along a coastline.

I just want to add that I don't tolerate humidity if I'm a certain distance from the shore. So that is what makes the difference. My guess is it's the salty air that helps. You don't find that far from the shore.
Chapter 20

Specific Locations
Q. 20:1 - Optimal Places

I am in great need of knowing of the most optimal places to live in the US while trying to detox. What suggestions do you have?

Lisa Petrisin

I would suggest spending time on the Locations Effect website.

Janis Bell

You and a thousand others. Alas there is no perfect place year round. Each of us react to different species and to other chemicals. Look for a place where you feel good, before or after detox episodes. And live there. No shortcut until you explore various locations and climates.
Q. 20:2 - Permanent Residence

I have spent a bunch of time on the Locations Effect website. I'm having trouble really finding a 'good' place to live year round.

My husband is in school, so we haven't been able to think about moving to a different location until now. However, once he's done, we're outta here!

We're looking for:

- location within 1 hour of decent size airport/city amenities
- drier climate (not damp)
- no extreme heat (100+ temps)
- clean air
- affordability (single family home $250,000-400,000)
- small town/city living (not suburb)
- access to mountains (a bonus)

What I mean is that I could do a small town (realistically, probably a small tourist town... I need city folk/resources) OR a city where I could live in city limits or just outside. Preferably not a suburb though (imagine neighborhoods of matching houses with aluminum siding). I like a city/town with a gathering space/center. And universities are good.

Also, we are hoping to have kids, so schools are a consideration. We were raised with Catholic schools, and would like to provide that to our kids if possible... so we probably need a town of either a certain size (most mid-sized towns have them) or the right demographic.

I am reactive to mold and to the environment, but not as super-reactive as some people. Any suggestions that people might have would be great!

Lisa Petrison

The way that your question is phrased now, there are lots of places that meet the criteria. However, if you add in a couple of things that many people who write to me want -- organic food and a relatively sophisticated population of people -- then the choices get somewhat narrower.

Here are some thoughts, by state. Note that I have not been to a lot of these places for a few years, so it's possible that they may have been affected by fire retardants since then.
* Colorado.

Grand Junction. The weather map says the average summer heat is 93 degrees in July, which is hot but not (in my opinion) unbearably hot since it gets a lot cooler at night. And I think it meets all your other criteria. (My recollection from a long time ago is that the airport was pretty moldy, but I was quite reactive at the time.)

I also like Durango a lot, for a small town. It does have an airport, but it may be too small for you.

* New Mexico.

Albuquerque would be doable for someone at a moderate level of hyperreactivity. For even better air, I liked Socorro, which is a college town about an hour from Albuquerque.

I wouldn't advise Santa Fe since the air is problematic in much of it, and it's pretty expensive there. Taos is about 2 1/2 hours from Albuquerque, so too far.

Las Cruces (near El Paso) might be a possibility. I lived there one winter when I was really reactive and thought it mostly felt okay, but there are certain days that I could feel that "?" toxin there, maybe blowing from somewhere else.

* Utah

You actually could consider living in Moab. It's only about 1 1/2 hours from Grand Junction. They are building a campus of University of Utah there, I was told. It might be a little pricey though, more than some of the other places I am mentioning.

I like St. George fairly well, but it has a Las Vegas type climate that might be too hot for you. Cedar City is a higher altitude and a college town, but it feels more typically Mormon to me than St. George or Moab.

* Montana

I really liked Helena a lot, and i see that there is an organic grocery store there now. But of course, Montana does get cold in winter.

Bozeman is one of those odd tourist towns that do not belong in the state, like Jackson Hole or Telluride or Sundance. And the air did not feel as good to me as
Helena, and it is rapidly shooting up in price. But I have known people (especially moderate reactors) who have liked it there.

I visited Missoula very briefly and it felt good too. There's a university there.

* South Dakota

I liked Rapid City and that whole Black Hills area, and the winter weather is supposed to be relatively temperate compared to the rest of South Dakota. The concern would be organic food -- there was one small organic store there when I visited a few years ago. Possibly that has changed by now though and there is more.

* Kansas

Wichita is the best big city that I have been to (explaining why the "CFS" patients in the CDC study did not look very sick). And it fits all the other criteria except for maybe the sophistication of the people. It's a generic Midwestern city, but still, it's an actual city. And I personally think Kansans are great people, on the whole.

* Arkansas.

I know one mold avoider I trust (currently at a moderate level of hyperreactivity) who just visited the town where Wal-Mart's headquarters is (Bentonville), and who seemed to like it in general and thought it felt pretty good. I have not personally been there.

* California

Most of California is either super-expensive or super-hot or super-toxic. I liked Hollister though, if you had a great desire to be close to SF.

* Arizona.

This state is really too settled in the urban areas to feel good, and they use a lot of fire retardants there. I used to feel good in Flagstaff, but the last time I drove through there, the whole town was a no-go area for me. The Sedona area possibly may still be okay, but I am not sure. Unless you just are drawn to Arizona, I would skip it.
Q. 20:3 - New Mexico

I want to live in NM and some people here have advised against Santa Fe. Would Albuquerque be better? How about El Dorado? Does altitude make a difference here?

Lisa Petrison

In general, when considering places to live, it might be useful to start off by checking out the Locations Effect website. (And it also would be helpful to others if people who have experiences in various places would post them on the site.)

The general consensus seems to be that Albuquerque is more doable than Santa Fe.

Albuquerque is a typical city in that it has a fair amount of recognized city toxins (e.g. car exhaust) and small amounts of the toxin that is so problematic in Tahoe, typically worse in winter. Santa Fe has a larger amount of a newer toxin that seems to be associated with the fairly recent use of fire retardants and that, while tolerable to even severely reactive Moldies for limited periods of time, eventually seems to knock reactive people down in terms of their health.

I had never heard of El Dorado, but in looking at Google, it seems like it's just the area of Santa Fe near the outlet mall. I don't think that's going to be any different than the rest of Santa Fe. You have to get to the other side of the mountain, going toward Las Vegas (NM) before the air gets better, in my experience.
Q. 20:4 - Arizona or New Mexico

I have been starting to plan a trip to the southwest. I am thinking about the Arizona red rocks region (Sedona/Zion) or New Mexico (high desert/mountains). Is there any info that can be provided on some good spots to visit for health, possible relocation, etc.?

Lisa Petrison

Things are changing so much due to the use of fire retardants that it is hard to know for sure.

Flagstaff used to be wonderful and now it is horrible. But there aren't as many trees in Sedona, so it may still be okay. Though there are enough trees that I still am concerned.

NM is not a pristine state, and people who are very ill may have a difficult time. More moderately affected people may find it to be a good place. I've had the most difficulty in Santa Fe (both in terms of buildings and outside air) and in the area north of Santa Fe (e.g. Espanola/Ojo Caliente). Again, the association with fire retardants is key. Most of the rest of the state seems better to me.

A.M. Runyan

I was a fan of New Mexico anywhere south of that RailRunner bridge that goes over I-25 just south of Santa Fe. Also anywhere north of and including Wagon Mound (where I'd always stop for gas).

Didn't really like the Santa Fe area.

Albuquerque is just as high in elevation as Denver, and the city varies quite a bit in elevation - it's possible to live part of the way up the mountains.

New Mexico is a cheap state, so if finances are an issue that can be helpful. Low cost of living and even things like renter's insurance and car insurance are less there.
Beatrice Latherings

I've had feedback from someone else that the area around Portal AZ has very good air and inexpensive land. I haven't been there myself.

Susan

I second Lisa's evaluation of NM, especially regarding Santa Fe and further north.

I learned from some truckers that the major trucking routes, especially where there are route intersections, like Flagstaff. These roads are drenched with chemical de-icers in the winter.

I've also read that an MCS person is leaving the Phoenix area because they became sick from a new chemical put in the water trucks used to keep the dust down. Arizona approved the usage to help meet attainment levels of PM 10 for federal monies for roads.
Q. 20:5 - New Mexico

Any recommendations for camping to get clear of mold in New Mexico during early spring? Preferably somewhere that doesn't go below freezing.

Lisa Petrison

It's been a couple of years since I've done camping in NM, and so I'm not absolutely sure about how good places are these days. However, here are some thoughts. Check out the Locations Effect website for details on some of these.

* Tucumcari, NM: This is in the NE of the state, near Texas. Surprisingly good. Lower altitude. I was at a KOA there, but there may be public camping as well.

* City of Rocks. Remote, but the campground may have nice amenities. I wonder if the hot springs next to it have reopened. I think someone reported that the air quality there had gone down though.

* Abiqui. A favorite place in NM. There is a campground at the lake there, and camping is also allowed for visitors of Ghost Ranch.

* Aguirre Spring (Las Cruces). This is a nice campground about 10 miles from town. Occasionally it does get drunken guests from town, but generally (in 2009) it was okay in terms of both air quality and safety.

* Pie Town. There is a free campground here, and two pretty good non-organic restaurants. There also used to be a business catering to people hiking the Continental Divide (with laundry, groceries, etc.). The air here used to be superb (I don't know about now). But it is at 7000 feet and so is still a little chilly at night.

Beatrice Latherings

All of S AZ and S NM, other than the mountains, will be above freezing at night now. In very short order though it is going to be "warm" during the day, which might be the same as "hot" if you lived elsewhere. 100 in dry heat is no big deal as long as you stay out of the sun.
Beachy Keen

I have camped at City of Rocks a few times in the past. Once in June 2012 and once in mid April 2013. I remember in April it got pretty cool at night, maybe 40-50, but the daytime temperatures and weather were perfect. The air is pretty good there, it's sunny, but it does get windy and sometimes dusty. Although most of NM is like that, I believe. The bathrooms there are ok. I think most campground bathrooms are bad, but this one wasn't as bad as most.

Cave Creek campground in Arizona has good bathrooms and temps are probably good at night there right now. Probably 50-60 at night. But it may be getting up to 90 during the day now. Good luck.
Q. 20:6 - Oahu or Anaheim?

Unfortunately my recovery was taken from me just recently and I'm falling apart fast. I am of the severe degenerative spectrum of the "ME" expression where my whole body just falls apart and I spiral toward death fast.

My question: I have two friends who have offered me asylum. I don't know if I'm even strong enough to fly to them or what their homes are like.

So my choices here are Oahu or Anaheim, California. The person in Anaheim would be better equipped to care for me until I am (hopefully) stronger, but I'm unaware of either's living conditions.

The one in So Cal seems very eager to help and learn, but again it's a crap shoot and once I land, I'm there. Any advice?

Corinne

I've always felt better on tropical islands. Check the locations effect page and board?

In Hawaii it would be warm enough to camp outside if the house doesn't work. Clean ocean air all around. I came back from feeling that I was going to die last summer.....I would push to get somewhere better. Reach in deep for that last bit of energy and get on a plane to somewhere with clean air and more help.

A.M. Runyan

So Cal seems closer to the rest of the country/not as hard to get there or go elsewhere if it doesn't work. Also I hear there is radiation in Hawaii. Just my thoughts.

Lisa Petrison

On average, the air in Hawaii is probably better than Anaheim. But a lot of Hawaii is not pristine either. Remote areas on the side of the island that gets the ocean wind are better, apparently.

The good thing about Anaheim is that it would be close to the "Godforsaken
"desert," if you can eventually recover enough health to try it out.

Knowing about the relative moldiness of the homes before going there could be helpful.

If you are going to be highly dependent on someone for care, than the interpersonal aspects would seem to be really important too.

Janis Bell

Hawaii is tough. Hard to get around, expensive (like gas at $4.99 a gallon, same for water!), and the mold from the wet side of the islands blows across the mountains to the dry side of the islands, so even without rain, life on the dry side means breathing mold spores. I could not feel good camping there and tried two islands and five locations.

Beatrice Latherings

Hawaii is very moldy. Given that CFS/ME may have a strong mold exposure component, I'd ask both parties to do a HERTSMI-2 test and report the results. Nothing like data to help answer your question.

Vicki

Go with your intuition or instinct. It's often right. Good luck!
Q. 20:7 - Southeastern U.S.

Who has had success healing from toxic mold in the southeastern or south-central US? I know these are not ideal locations. The Gulf Coast is definitely out of the question but several hours north are areas that are much drier (especially in winter). Though it can rain for days in a row in fall/spring/winter, there are dry spells too. I am looking for ideas about how to survive and heal here. Green buildings, dehumidifiers and air purifiers? What else could make it work?"

Julie Rehmeyer:

I was in the Boxley Valley near the Buffalo River in Arkansas and it felt fine to me there.

Lisa Petrison

I do know people who have spent time in both Georgia and Florida, and done reasonably okay there. Take a look at the Locations Effect site.

David Ou, M.D.

My practice is in Atlanta and I've had a few patients find clean homes to recover in.

Beatrice Latherings

I would avoid "green" buildings like the plague. They do not breathe and are very prone to developing mold. Remember that toxic mold grows in enclosed spaces; the molds that grow outdoors are not toxic. However, the outdoor air may have a lot of mycotoxins in it if there are many moldy buildings nearby.

Andrea

I'm near the Mississippi River. The humidity and moisture (mold) is disgustingly unbearable at times. We don't go outside in the fog!

If you can create an extreme "bubble-like" environment and give your body time
to recover before any more blows, you can survive anywhere.

A good book is “What's Toxic, What's Not.”
Q. 20:8 - Denver Area

Suppose I wanted to move within 2 hours of Denver eventually - as far south as Pueblo or as far north as Cheyenne, ideally somewhere with a low cost of living and organic food. Any reviews of air quality or biotoxin issues in any of those areas?

Also, have any of you been to Boulder recently? Just wondering if I'm going to have problems going there after the flooding."

Lisa Petrison

Colorado has the potential of changing fast, because of the use of fire retardants there. But I think you should be able to find something okay.

There's an engineer in Colorado Springs named Rock Cogar who has put more thought into how to make homes mold-free than anyone I've ever encountered. So it's possible he might prove to be helpful.
Q. 20:9 - Cortez, CO

I've been checking the Locations Effect board, and I noticed some good comments about Cortez, Colorado, from a few years back. Has anyone been there lately? Do you know much about it? Is there fracking there? Farming? Is it in a flood zone? My uncle owns land there, and we may have an opportunity to buy it cheaply and build. But I've never been there, and have no idea what it's like.

Lisa Petrison

I was just in Cortez last week, and also was there last year. It is true desert (though at a somewhat high altitude), in the vicinity of the Four Corners reservation area, and always has felt good to me.

This is desert and so I don't think there's much flooding or farming. I don't know about fracking. I was told there is a lot of wind in winter.

Mesa Verde National Park, nearby, has been treated with fire retardants and felt somewhat problematic last year.

You would have to drive to Durango (about 45 minutes) to do much shopping though.
Q. 20:10 - Big Bend, TX

Is Big Bend a clean enough place to get clear of mold while tent camping? Anywhere else in Texas that might be safe?

Beatrice Latherings:

Beware of drug and people traffickers.....anywhere wild near the Mexican border can be extremely dangerous. Stay in official campgrounds and you should be okay.
Q. 20:11 - Canada

I am living in Toronto and wondering what Canadian safe places there are in my area that I can go to even in winter.

I am pretty sick right now and need a place to heal ASAP.

I’ve lived at sea, in African villages and been way healthier there than anywhere else, mainly around Toronto where I grew up. In fact the first time I returned to Toronto, after living at sea and in Africa for 3 years, I was very ill for at least a year. Even then my MD thought it was related to the environment.

I just learned my health problems are probably mold related. Even though my apartment is very dry, there are squirrels living between the floors and creating what I believe to be mold forming conditions.

I am really freaked out as I don't really know what I can do until spring summer, when I can sleep outside again. Thnx for any suggestions you can offer.

Lisa Petrisen:

The only civilized places in Canada that I've heard good things about are on the western coast, Victoria or Vancouver.
Q. 20:12 - Seattle

I am considering moving to Seattle. How bad is the mold there? Is there a useful mold test that can be done in prospective houses before buying one? Are there any proactive measures (buying a certain kind of house, using glossy paint, running a dehumidifier, putting food away promptly, etc.) that reliably reduce mold hazards in an environment that humid? Can doing the right things make it safe for someone with mild mold allergies, or is it a lost cause?

I do not have extreme mold sensitivity. I have had mild reactions to seasonal fall leaf mold in VA and under-the-sink mold in one apartment in Bay Area CA. Still, I am prone to occasional bronchitis as well as asthma triggered by too much engine exhaust, so I don't want to increase my exposure to lung irritants. I also need to maintain a healthy immune system to keep my mostly-cured tick-borne infections in remission. I know that mold can be a compounding factor in these kinds of situations.

Lisa Petrison

I've known a few mold avoiders who have lived moderately successfully in Seattle. I do think there are a lot of moldy buildings there, and that it is important to be very careful to choose a good one. The outside air seems somewhat problematic.

Joseph

I recently left the Seattle area, and am exploring drier climates. I had experienced mold problems in many homes of friends, as well as public buildings. I did not have problems outdoors except in a rainforest. My mold exposure and sensitivity, however, was considerably greater than what you describe.

I would avoid staying in any basement room or apartment. They are most problematic. I would avoid lingering in any building where you suspect mold. I'd avoid certain friends' homes where I knew mold was a problem.
Sarah

I have mold sensitivity from living in a house with toxic mold. I was very sick. We remediated the house, sold it and moved to the Seattle area from St. Louis.

Before buying a home in Seattle, we had it professionally evaluated by a mold inspector for any mold contamination. I have not had any illness since we moved here. In St. Louis I could smell the mold everywhere in stores.

I personally think I was sensitized to certain molds. Maybe they're more prevalent in St. Louis.

If you had toxic mold in your house and remediated the house, don't bring your furniture from that house! Even if they say it's been remediated, it has not.

We brought a lot of our furniture and have had to get rid of it all! It smelled like mold, and started making us sick. Now the furniture is gone and we are fine and our new house is fine. We thought we were starting the nightmare all over again.

Good luck and get a mold inspection for peace of mind. It's worth the cost when you're dealing with your health.

Beatrice Latherings

There is a lot of mold in Seattle. My brother lives there, keeps his house very clean, and his wife's shoes in a closet have had mold growing on them. I don't know if it was mold that produces toxins or not. The test that many people use to screen a dwelling is the HERTSMI-2 which costs $125. Most people who are not extreme cases can live in a situation where the score is less than 10.
Q. 20:13 - Washington, D.C.

I'm wondering if anyone has reports of reacting to people, items, or visits to/from the DC area.

Susan

Yes.

Lisa Petrison

I have a few reports from mold avoiders that D.C. is problematic with regard to outdoor issues, and there are also lots of problematic buildings there. I had a hard time there in about 2002, in a way that I now feel confident was due to particular outdoor toxins.

Lisa

It is awful there. I think it's definitely some kind of toxin.
Question 20:14 – Little Rock, AR

Any reports of Little Rock, AR? I am thinking of going there for a conference.

Betty Keen

It was awful for me, personally. Muggy and stuffy stale air. Whatever you do, avoid the Whole Foods.

Lisa Petrison

I drove through there this year and the city didn’t feel great. It wasn’t so bad that I wouldn’t give it a try if I had a particular reason that I needed to go there though.
Question 20:15 – Mold Avoidance in Australia

I'm from Melbourne Australia and I'd like to trial mold avoidance, does anyone know where I could trial this nearby? Or has anyone from Melbourne or Australia have any tips for me?

Mara Pacers

Hi, I'm also from Victoria in Australia. I used to live in Melb but moved about 15 years ago to a 'cleaner' location. I haven't specifically avoided mould but rather focused on chemicals, but mould has always been a problem and I have made adjustments to lessen that as well. I'd say I have been pretty successful given the severity of my condition. There is an organisation Australia wide, but based in Melb that deals with multiple chemical sensitivity (MCS) called AESSRA. They have a lot of experience and a lot of information. However, they don't focus on mould alone, but the whole burden of toxins and immune disfunction. Look them up on the WEB. With regards to the locations effect, in consultation with my allergist) I identifies the south west coast of victoria as a good clean area. Think on the coast in the Warrnambool area. Here the prevalent winds are from the South West, and are scoured 'clean' by their long passage over the southern ocean. They make landfall on this coast. That in itself is not enough, the house must be built of appropriate materials and be positioned in a dry airy position that discourages mould. Hence raised, building in a open and windy place is the best. In my experience there are no simple solutions, but by putting a range of things in place the condition is manageable. All the best to you.

Daliya Robson

Dear friend from Melbourne go inland where there are no sea breezes or winter and summer and spring and autumn rains all year round from every direction. Not much mold where there is not rain or damp or monsoons in the summer - Sydney is not good because of that but they do have 300 days of sunshine .
Question 20:16 – Holland, MI

I am wondering if you have any mold reports for Holland, MI.

Lisa Petrison

I went on a driving trip to western Michigan, including staying in Holland, in the early 1990's. Looking back, I think I felt a good bit worse on that trip than I did at home (Chicago). But whether it was specific to Holland, I don't know.

In general, Michigan may be a bit worse than the rest of the Midwest, from the reports that I've heard. I tend to think that this could be related to the fact that the large amount of industry there has resulted in a lot of chemical spills.
Chapter 21

Weather
Q. 21:1 - Rain

I notice when it rains my symptoms will pick up a little bit, and then there will be an instant where it is gone. I don't know if it's because I'm sensitive to the pressure changes or if it's mold or toxin related.

Erik Johnson

I wrote the following in 2001:

> The immunological upregulation involved in the “disease of a thousand names,” CFS being the most recognized, is characterised by overpowering depression. Anybody who has experienced this knows that this depression is a physiological response and not one of attitude.

> Doctors and psychiatrists are trying desperately to convince people that their depression is the result of physical discomfort and emotional stress. They have completely failed and will continue to fail because the depression response so clearly does not correspond to times of pain and stress, but rather occurs seemingly at random.

> The exception to random onset of depression is at times of weather change. Many people recognize a connection but no sensible immunological trigger comes to mind that has the potential for such a profound response. Neurotoxic volatilized compounds from mold spores are that immunological trigger.

> Mold spores are primed to release their toxins at times of weather change when conditions of wind and potential water give spores their best chance for dispersion and survival. The first signs of immunological response to mold are depression and anxiety.

> Whenever you have sudden onset of anxiety, ask yourself if you might not have been exposed to mold because of a change in weather, wind direction, physical movement to a contaminated location or even someone who might have contaminated clothing moving into your space.

> I have talked to hundreds of people with CFS and almost all of them have mentioned the same symptoms and clues that led me to my conclusions about this response to mold. The amount of mold required to trigger this response is so
slight that it seems inconceivable to anyone who does not have this reactivity.

>Once you recognize a relationship between mold as a trigger and anxiety/depression, no doctor will be able to convince you otherwise because the correlation can be felt so strongly.

> All I have to do is draw this to your attention. The mere consideration of this as a possibility will be enough to let you draw your own firm conclusions.

Lisa Petrison

I spent a long stretch of time staying at a place called Mercey Hot Springs, which in my opinion is by far the best feel-good location anywhere near the SF Bay Area (it's about two hours away).

One day, I was in the swimming pool talking to an apparently perfectly healthy 10-year-old girl and her mom, and out of the blue she said, "It rained here last night, and the rain doesn't feel sad here!"

Which is Erik's point. There's a certain toxin in some places that comes out when it rains, that causes depression but also (in already-damaged people) other acute health symptoms. But this stuff isn't everywhere. So one way to figure out if it's something about the barometric pressure itself or about what the barometric pressure does in certain locations (e.g. to the toxins there) is to try a different location and see if it happens.

The other thing that I know is that if I am in a particularly bad place when the barometric pressure is dropping, my possessions will get contaminated from the outside air. This happened to me camping outside Truckee in Sierraville, for instance. I was fine in the Tahoe area for three days, but on the third night the barometric pressure dropped fast and the bad toxin came out. I got very sick and ended up having to throw everything that was exposed to the air away.

To my understanding, different molds release spores into the air at slightly different times of the year or of barometric pressure cycles. But usually for me, the worst time is when the pressure is dropping rapidly right before a big storm.

Here's a link to Mercey's website. It's a great place, but unfortunately there is no food there and it is a long way away from everything. So it does take some planning.

https://merceyhotsprings.com/
A.M. Runyan

I feel like although humidity will make mold worse, there is a way in which rain tends to clean the air. Rain also causes soil bacteria to make ozone, which cleans the air. So yes, I find it can go both ways; sometimes rain does make things better.

Beatrice Latherings

Despite mold illness, I have always felt better in the Pacific Northwest. I attribute this to not being allergic to mold; it's the detox pathway for mycotoxins that is messed up.

Kathy

I notice this effect for sure. I thought it was a new sensitivity to barometric pressure but can see where the reason could be as Erik explains.
Chapter 22

Detoxification
Q. 22:1 - Does Detox Matter?

Do you think that detoxification has been helpful to you, or has it just been avoidance that has made a difference?

A.M. Runyan

Oh gosh, detoxification has been the only thing that has made avoidance feasible for me, because it's gotten me over the hump of the extreme sensitivity that can develop when you first get away from mold and get "unmasked."

I had read stories of people moving to the desert or living outdoors and then having trouble going back in buildings, and I didn't want that to happen to me, so I made it a point to detox very heavily.

When I'm not being exposed, I "stack" a lot of detox treatments on top of one another, since they seem to work better in combination. Some of the most powerful have been infrared light (whether from an infrared sauna or an infrared heat lamp), coffee enemas, binders (CSM), methylation support for my particular genes, juicing, transdermal alpha lipoic acid, and liposomal Vitamin C.

I can tell that 1) detox gets toxins out of me, because I feel a dramatic difference as they come out, and symptoms I didn't even know I had resolve, and 2) detox decreases my sensitivity to mold, since when I do it, I notice that known exposures (particular buildings or rooms) do not bother me as much as they used to bother me.

The way I see it, avoidance is only a means to an end, and that end goal is detox, because it is actually getting the toxins out of the cells that helps you to go back to normal more. It really is possible to reduce sensitivity to mold (and other toxins at the same time, like cigarettes or exhaust) through detox and to reverse the symptoms by getting the stuff out. So long as it's in the cells, it influences the body a lot, with elevated NFkB, renegade fats, inflammation, etc., but you need a clean environment in order to get it out, because the body simply will not let go of it if you are already handling more toxins from the environment than it wants to be around. The cleaner the location the easier it is to dredge up toxins from your cells with other methods and be done with them.
**Julie Rehmeyer**

What A.M. Runyan says overlaps with what I'd say. I'd just add that avoidance sets the stage for detox; from what I understand, the body is unable to detox if it continues to get mold exposures.

**Lisa Petrison**

Detox has been extremely important for me, I believe. Even with the most extreme avoidance, I did not recover my cognitive function until the toxins drained out of my head. And it's been critical in lowering my reactivity, I believe. The body seems to need to have gotten "clear" of the toxins (e.g. the inflammation dies down) in order to detox effectively. For some people, that can mean a whole lot of avoidance. And there can be lots of reasons why people don't detox well even if in a clear place (e.g. nutritional deficiencies, liver problems, lymph backups, previous injuries, genetics). So it can take some tweaking.

I was astounded at how much toxin came out of my body, once I got the pieces in place. It just went on forever too.

**Shari**

Detox is a necessary part of healing but only possible with avoidance

**Beatrice Latherings**

Detoxification cannot, in my experience, keep up with exposure. It didn't make any difference for me while I was still exposed, except that it cost me a lot of money. Getting out of exposure was key. I still do things to detox because I have to live in the world and go into buildings that are not pristine, just to buy groceries and other things.

**Kimberly**

We had to get out of the moldy house! You can't keep exposing yourself and expect to get rid of the toxins at the same time! First and foremost-you have to get away and then avoid it while you detox.
Q. 22:2 - Going Through Detox

Can someone explain how to go through detox during/after mold avoidance?

Julie Rehmeyer

I take a bunch of supplements to support liver function; I do coffee enemas; I've drunk veggie juice at times and I generally eat lots of veggies, mostly organic; I do far-infrared saunas; and I exercise when my body is so inclined. There are also other things that I've tried briefly that may or may not have had an effect, but in any case aren't an ongoing part of my detox regime.

Honestly, the only thing I'm really confident has made a difference are the coffee enemas. They have a profound, immediate impact on how I feel, reducing or eliminating the symptoms that I've come to associate with being toxic. The other things I do either because I've heard so much about how they can be helpful that, well, that many people probably are onto something, or because they make a certain kind of sense (like the supplements to support liver function), or because I just want to do them anyway (eating veggies and exercising).

I really long for more solid science about detox, and I feel more cautious about many in this community about ascribing particular effects to the detoxifying powers of a particular thing. Not that I think others are wrong -- I'm not being at all critical. I just feel cautious about it personally. One of the things I really want to do at some point is dig into what's known in the science about detox more.

For me, personally, CSM didn't seem all that helpful, and I stopped it. But I know that others have found it very helpful, and who knows, maybe it made more of a difference for me than I realized.

Heavy metals seem to be part of the illness for many people. The things above have some effect on heavy metals, but at some point, further steps may be necessary on that.

I did a liver cleanse that an acupuncturist recommended at one point that seemed like it would be pretty mild but had such a strong detox effect that I had to stop it at the time. I'll probably try it again soon. It was just a super clean diet; replacing one meal with a shake including a detox powder; taking milk thistle and psyllium; and maybe a couple of other similarly seemingly benign things.

And I've found that emotional work can prompt a powerful detox. I did a couple of
EMDR sessions and had very strong symptoms that I associate with toxicity afterward, symptoms that were alleviated by coffee enemas.

Karen Dean

I think the most important thing is to start 4-6 doses of CSM as soon as possible. I could actually feel it working when I have had mold exposures, and nothing else works as well. I also believe it is much easier to remove toxins while they are circulating. After they have been stored in fat and organs, much more difficult, but I have met people who were very overweight who miraculously recovered after dropping most of the extra weight. While loosing weight CSM should be taken also.

Joseph Salowitz

Start watching this video at 56 minutes into the video.

Excellent, excellent video on mycotoxins! How they make you sick, with all kinds of illnesses, and how the speaker was able to cure himself!

The segment of the video dealing with Mycotoxins begins at 13 minutes and 45 seconds into the video. Just slide the progress bar at the bottom of the video, forward to 13 minutes and 45 seconds into the video. His discussion of the regimen that he used to cure himself begins at 56 minutes into the video.

This video is really great! Watch it.

http://www.bulletproofexec.com/bulletproof-video-get-stable-energy-perform-better-by-avoiding-these/

Michele

Since I have been in a "free" environment, my weight gain stopped. I was terribly underweight, then went to the opposite extreme, all in a year and a half. Outside of mold avoidance, I have tweaked my protocol, in hopes of detoxing more. I was told that as the body releases and rids itself of more mycotoxins (and metals) that the weight that was gained would shed. I have not seen that. I have been content with staying at the same weight, and not gaining. But, I am under the impression, that when you practice avoidance, and detox and rid. The body will loose the weight, and this is a sign of recovery. So, I have saved this info and have to
tweak some more. As I have apparently come to a standstill, and after an exposure a couple weeks ago, have to in a way, also start all over.

Perhaps I will try the CSM again, as it was very hard on me and intolerable, when I was first diagnosed. Perhaps now is the time to re-add that. I am also getting the sense, with the detox protocol, that clearing the nasal passages is very important, and will add to improved health.

Lisa Petrison

Here are some comments that I made on my own page about different aspects of detoxing about a month ago.

1. Good environment

I think that people need to be quite clear before the toxins can come out to any significant extent. Just how strict they need to be depends on how toxic/ill they are though. In general, if people can exercise fairly vigorously, that's a good clue they're in a good enough place. The goal is to get the inflammation damped down, since the system does not seem to like releasing biotoxins if it's not free of external inflammatory toxins. (I've succeeded in detoxifying things that did not seem like biotoxins to me, such as metals/chemicals, in less good places such as cities though.)

2. Heat

Many people talk just about infrared light, but I think there's something to be said for the use of heat of whatever sort. Part of why I've spent so much time in the desert is not just lack of mold but also because it's hot there. There have been times when I've been in places where the temperature goes up to 105 during the day, and where I didn't have air conditioning, and that was quite detoxifying. (I was taking a bunch of showers per day.) Dry saunas and hot springs baths have also done this. I think it mobilizes the toxins from the fat cells. I'm currently in a place where the weather is perfect for summer (near Taos) and I really miss the heat.

3. Methylation

I do think that lack of methylation is a problem in CFS. I think that there's a certain amount of detox that people can do without supplementing, but the mold avoiders that I've seen that have not supplemented have tended to plateau while still being pretty reactive. I had a number of conversations with Rich van K about
this -- our conclusion was that the toxins get stuck in the cells and don't move out. Figuring out what to supplement is quite an art (and the basis of Amy Yasko's entire practice).

4. Lymph Flow

I have come to believe that fibromyalgia is a sign of backed-up lymph, due the fascia becoming all gummy and right and thus constricting the vessels. (A researcher once posited to me that gliotoxin might be substituting for glutathione in the fascia and doing that, and that does not sound wrong.) If fibro is problematic enough, detox won't occur at all (and in fact people will feel worse in bad areas because the toxins will get backed up in the brain or body and hurt). Some suggestions: neural therapy, bodywork (massage, cranial sacral), candida control (probiotics, good diet), lymph herbs, exercise. I think the reason that the Nat Sulph (which I discussed in a recent post on homeopathy) was so important is because it cleared the backup in my brain (maybe from a head injury), allowing the toxin to flow out. There's no way to get brain function back if the brain is still full of toxin, no matter how little you are reacting to toxins, I think.

5. Removal from Gut

If toxins don't move quickly through the gut, people may feel worse instead of better, plus they may be reabsorbed. Coffee enemas, water enemas/colonics, binders (csm, clay, charcoal) may be helpful here. Also good bacteria has the ability to break down toxins, so I focused a lot on that when I was detoxing mold heavily (e.g. drinking a quart or more of homemade kefir per day plus other ferments).

6. Chelation

Hate to bring this up, but it was the final puzzle piece for me. If I'd died and had an autopsy, the coroner would have been amazed at what s/he saw in my small intestine! Klinghardt talks about worms of various sorts, and now he is reportedly saying exactly what I have found (and what has been reported in the literature): That they are capable of sequestering unbelievable amounts of heavy metals. Klinghardt states that they use it as a protective coat so that the WBC's cannot kill them, and that makes sense to me (since my body has not attacked the tapeworm even though I'm pretty well in general). So I recently I have been killing the tapeworm, and using chelation suppositories (Medicardium) to sop up the heavy metals as they are released. Supposedly other things will chelate metals too (e.g. chlorella, ALA), but I didn't have nearly as good of an experience with those as I have with the suppositories. So far, I've done the equivalent of 30 chelation IV's, and the end is not here yet. So I now think that metals have
definitely been a factor in my illness.

Avoiding Mold

Here's a comment that A.M. Runyan made on her own page about a month ago, that I just happen to have found. Maybe she will have further thoughts.

>Well, the way I see the sensitivity is - I have opted to avoid mold and biotoxins pretty radically for maybe a year with the goal being to get my body into such a low-exposure state that I can dump sequestered toxins. That seems to be what is happening. When I stay away from anything that I notice to be an exposure, and do detox on top of that, I detox massively and quickly, and my sensitivity does go down on a weekly basis. For example, I can tolerate a lot of buildings I couldn't tolerate two months ago. So I guess I am getting at the sensitivity through detox. and that requires staying away from any exposures that are bad enough to stop my detox, like this stuff was, unfortunately. Regular mold is bothering me less and less.

>it's a big debate in the community about whether to attack the sensitivity or go for extreme avoidance. but from my experience, if a lot of things are in line, like methylation and low exposure status and coffee enemas and infrared light, I just pour out toxins.

>But if any of those are not in line almost nothing happens. It seems like the body requires extremely specific, sensitive conditions in order to dump these toxins. and getting rid of them seems to be a big part of actually recovering (I am recovering a lot of brain functions through this method that I doubt would have come back if I had treated the sensitivity without detoxing). Having the toxins in the body seems to impact gene regulation. I imagine there is some component of the disease that goes beyond just the toxins, to the body's reaction/memory etc., and I guess I will increasingly get at that with other methods. but for now I get a lot out of just pushing detox as hard as I can tolerate, which is pretty hard now, because I have already detoxed a good amount of stuff and it's hard to squeeze much more out now. Feels like wringing out a shirt, but instead wringing out my cells.

A.M. Runyan:

Some things seemed to be more effective than others for me.

1) CSM is invaluable, particularly in the beginning, when it can skim off huge
chunks of toxins. I built up to taking 4-6 packets per day. Taken too long it seems to deplete fat-soluble vitamins and thyroid hormones. I no longer get that amazing decrease in toxins from taking it that I

2) Infrared light seems to mobilize the toxins from tissues, so that detox can go deeper and you can get more out. I had great improvement in symptoms like balance when using IR light to dredge up toxins. I just made a small $30 infrared heat lamp (like used for chickens) since I could not afford to buy a whole IR sauna, and even that is very powerful.

3) Patricia Kane protocol seems important

4) Coffee enemas

5) Low stress, trauma processing, keeping body in low-stress state where it can dump toxins, which for me means avoiding caffeine except for from coffee enemas.

Janis Bell

Some of us have chronic fungal sinusitis which keeps dumping fresh mycotoxins into the mucosa and brain. If you have sinus issues like stuffy nose get this checked out. You can use Neti pot QID and nasal sprays (prescription and OTC) to clean them up.

Diane

Avoidance first. Cholestyramine is the strongest toxin binder. Welchol is also effective, but csm is four times faster at binding the toxins.
Q. 22:3 - After an Exposure

How long does it take you to clear out most of the mold from your system after an exposure and what’s your go-to strategy for doing so?

Erik Johnson

As told in Surviving Mold, I never thought the problem was any kind of normal product of mold, but rather, some kind of intermittent emission of a super toxin of which the medical profession knows nothing.

I think the variables of this yet-to-be-researched phenomenon are so unknown that there is no way to predict outcomes from avoidance reliably.

Lisa Petrison

Back when I was really reactive, a big exposure (e.g. several days in a problematic place, a short exposure to a super-problematic place) seemed to take up to a week to totally clear out of my system. That is why I became so diligent about avoidance at the time (e.g. immediately moving my RV etc. to another location) -- because the negative consequences of not doing so were so severe even with decontamination).

Now I seem to recover pretty easily from most exposures (though undoubtedly some really bad ones would still do me in), within a day at most. And the symptoms tend to be pretty mild.

For loose toxins floating around the system from recent exposures, coffee enemas are my go-to strategy, hands down. CSM also seemed somewhat helpful for that, though I've not used it for a long time.

A.M. Runyan

I think the operable question is not just how to clear it out after a single exposure, but how to clear the accumulated amount of the body back to a level where the body can operate (and defend against mold again).

Mold toxins impair Nrf2 and protein synthesis and also tend to make the body low in oxygen, bloodflow, and ATP, so it's hard to bounce back when the body is full of them.
There are things like extreme mold avoidance, glutathione IVs or enemas, R-ALA IVs enemas or oral supplements, cholestyramine, infrared saunas, exercise, hyperthermia/sweating, etc. that tend to promote faster excretion/recovery. I think I could have taken years to get as much toxins out as I've done in six months, had I not been pushing it so hard and experimenting. Once I started doing extreme mold avoidance, detox became very easy, probably because I was not dealing with so much inflammation or the acute effects of inhaled mold toxins. Before that, even taking a packet of CSM a day was a struggle.

**Julie Rehmeyer**

For me, it's typically gone in a day or two. Coffee enemas are extremely helpful.

**Chrissy Mann**

Due to the nature of mold, a person may never recover completely from mold exposure/contamination. There are thousands of variables including one's environment, diet, lifestyle and any number of other factors. Remaining free from added exposure is another consideration as well as being with people who are carrying mold spores on their person.

**Beatrice Latherings**

It took me an entire month to get rid of the calf cramps from spending two hours in a moldy house, and that is while living in open air. I do not / did not take anything like CSM though, which would have sped up that process.

**Forebearance**

I'd say it takes me 1-4 days to recover from a brief exposure. To help in recovering I take showers, soak in a hot tub, take soluble fiber, drink some apple cider vinegar diluted n a glass of water, and if necessary take Flor Essence detox tea. I don't follow the directions on the bottle. The suggested course of treatment would be too much. I take one dose of the Flor Essence and then allow it to work. The effects last for several days in me. And of course, I spend as much time as possible outdoors in a place with good quality outdoor air.
Chapter 23

Coffee Enemas
Q. 23:1 - General Thoughts

What do you think of the idea of coffee enemas? I do them, but it's always hard to know if I'm doing the right thing or not.

Julie Rehmeyer

Coffee enemas have been absolutely essential for me. I've done several each morning for a year and a half, and I've often done them later in the day too.

I haven't used special low-mycotoxin coffee; I don't know whether it would make a difference for me, but the way I've done it has seemed very effective.

I use 1-2 cups of weak coffee (I brew it strong, and then I mix it 50-50 with water, either cool or hot to make the combo approximately body temperature) and then I hold it for about 15 minutes. I sit on a pad so that I don't have to worry about leakage.

I do them in succession in the morning, until I feel better (I typically feel my worst when I first wake up). Later in the day, if I'm sagging, usually one will do the job.

I haven't had any difficulties with the impact of the caffeine --- it doesn't affect me like drunk coffee at all. I can do one right before bed without difficulty.

The need for them is starting to fade for me, though it hasn't disappeared yet. It has a really remarkable impact. My husband can look at me and tell when I need one -- my eyes and the rest of my face are puffy, and my brain is slow, and sometimes my muscles hurt and don't work very well. A couple of enemas and all that is gone.

Lisa Petrison

They've been very helpful to me. I've done between 2-5 per day for the past three years or so. Ditto basically everything that Julie said.

A.M. Runyan

Coffee enemas have been incredible for me. Great way to raise glutathione-s-transferase and open up bile ducts/clean liver.
I use these enema bulbs because they are a lot easier to clean than the large enema bags, and the neck is wide enough you can clean them, and they're cheap enough to replace and all:

http://www.amazon.com/Cleanst.../dp/B004LYEKQG/ref=sr_1_5...

I use coffee brands from Joey's list of low mycotoxin coffees, because I have had a little bit of reaction to coffee i'd get at the grocery store, etc.

http://blog.healclick.com/mycotoxin-free-coffee-brands/

Um, you basically grind the coffee in a grinder (I grind some fresh every day, a few tablespoons), simmer it on the stove (I use a stainless steel butter warmer so I didn't have to buy a whole pot) with distilled water, then I add distilled water to dilute it and get the right volume and do between 1-3 coffee enemas a day.

I have add-ons where I try to take some glutathione precursors before doing the enemas, like a grass fed whey smoothie or methyl-b12 or NAC and plenty of minerals, and then while lying on the floor to do the enema I use my infrared light bulb set-up on my body to stimulate even more release of toxins.

Then afterward, it usually feels like I've dumped a lot of toxins, so I might use binders, psyllium, CSM, if it feels like I've dumped stuff into my bloodstream (from bile ducts opening, or increased glutathione), or lately I've been taking BodyBio chlorella, which has been very powerful.

Coffee enemas seem to be a cheaper stand-in for glutathione IVs. I remember being really opposed to the idea for two years after getting Lyme, but once I started doing them I was amazed. It's also kind of relaxing to get an excuse to lie on the floor, and I think lying down sometimes during the day is good for adrenal recovery and emotional balance.

With regard to mold detox, I know I'm doing coffee enemas right when, after them, my eyes feel healthier, my vision is better, I suddenly feel like a veil has been lifted from my brain, my heart feels healthier, etc. That's what you're going for - lots of toxin dumping and increased clarity.
Q. 23:2 - Contaminants

I have heard of people doing coffee enemas before, but am concerned about the possibility of toxins, pesticides or other chemicals being present in them. Has anyone had any negative reactions to them?

Lisa Petrison

A long time ago, while still living in the moldy house, I did a coffee enema with regular non-organic supermarket coffee (Folgers or something similar). And I did feel a lot worse. So I definitely would not recommend non-organic coffee or cheap coffee for enemas.

I've never used non-organic coffee since, and I usually choose brands that are relatively high priced. I don't think I've ever had a substantial reaction to any of them, though some feel a little better to me than others.

Coffee can have a toxin in it called ochratoxin, and this is not measured in the U.S. So if people are really reactive to ochratoxin, toxin in coffee could be a problem.

I just tried some of the Bulletproof Executive "Upgraded" coffee, which is supposed to be low in mycotoxins. I don't really feel like it was substantially different than the organic good coffee that I usually buy. But (if you buy it in five-pound bags) it's not any more expensive than regular organic coffee, so I may keep purchasing it anyway.

I may not be that reactive to ochratoxin. The mold problem in my house seems to have been mostly Stachy, and insofar as I'm reactive to molds in foods, it more seems to be things like corn, which can be contaminated with trichotheccenes.

A.M. Runyan

These brands have been fine for me:

http://blog.healclick.com/mycotoxin-free-coffee-brands/

Also, I use distilled water for them.

And I don't use them at high temperatures; I have them basically room temperature so they don't impact the plastic or whatever is in the enema.
bag/bulb.

Also there is a stainless steel/silicone enema set-up sold by Seeking Health, and they have a somewhat expensive coffee they sell for this.

In my experience they seem to take toxin levels way down; that seems to be the cumulative effect.

Peg

From a fellow Moldie:

http://www.upgradedself.com/upgraded-coffees.html

Sherri

You can buy organic coffee online that is made for this.
Q. 24:1 - Overview

What is CSM and why is it so beneficial?

Julie Rehmeyer

CSM is cholestyramine. It's a binder that's more typically used to help bring down cholesterol levels. Dr. Ritchie Shoemaker strongly recommends it for absorbing mycotoxins in the gut, which then gradually helps them release from the rest of the body.

As I mentioned elsewhere, I never felt like it was all that helpful, but Shoemaker is extremely enthusiastic about it, and I do know that quite a few Moldies have found it helpful at some stage of their recovery.

One issue with it is that most formulations have artificial colors and sweeteners in them, so you have to order it somewhere special to get it without those things. I'm sure someone around here knows where, but I don't.

Beatrice Latherings

I took CSM for two years; it definitely helped after I was out of high levels of exposure, but it cannot be used as a crutch to allow you to continue to live in high levels of exposure, because it just can't keep up with a high level of incoming mycotoxins.

I stopped taking it when my gut started complaining about it, which was simultaneous with my moving to very clean air at 8000 feet. I hadn't realized that just the air in my neighborhood was so contaminated with mold. And by the way, over the two years my cholesterol did not budge; but my fat-soluble vitamin levels went down.

Damien Bienkinsopp

I'm currently on CSM, and my own feeling is that patients can get very different results depending on how they execute and how compliant they are with the protocol.

Unfortunately, as was in my case, physicians don't always give precise information on how to take it.
A two biggest hurdles are:

1. Taking enough of it (4 X 4g per day)

2. Taking it away from fats in particular so it binds to your bile and not just the fats you have eaten.

CSM binds specifically to fats, including bile, and mycotoxins circulate within the bile. In someone with the right genetics the immune system would eliminate them from the bile, but in the unlucky 24% they circulate without getting eliminated.

I struggle with getting in the 4 X per day because I'm also trying to make sure it is away from food with fats and even more importantly fat-soluble supplements that I take that do good things for me. I also want to take it away from other detox supplements I take - basically it's difficult to say if CSM and the other detox supps will interfere with each other - so I'm trying to do too much at the same time. This is my approach, not the most scientifically controlled, but more potential to get me 'better quicker' if I've got my protocols right.

The easiest way I've been able to take enough of it away from fats is by having two main meals per day and taking the CSM in between. It gives me more time.

As for the different versions, you can get:

1. Questran: Sugar, aluminium are the negative additives. I'm using this one as easily available and not too bad.

2. Questran light: Aspartame, aluminium. Strongly recommend you don't use this one because of aspartame.

3. Pharmacy compounded: I understand that in the U.S. via physician prescription you can get cholestyramine compounded for you in many pharmacies without the sugar or the aluminum. So ask about it - it's the best option if you can get it.

As for effectiveness, I believe it is effective. My VCS test results have been improving since on it in line with changes in LDL cholesterol (CSM escorts cholesterol out of the body too).

If you are getting exposed to mold/ mycotoxins while on it, it will definitely take longer. That's another variable which is hard to separate out from patient's experience.
In terms of priority I would say you need to:

#1 Avoid any mold / mycotoxin exposure.

#2 Get the existing mold/ mycotoxin out of you (e.g. CSM)

Without #1, you're just treading water. This is what Shoemaker says.

Lisa Petrison

I used csm a lot in the early stages of my recovery and feel that it was helpful. But there are a few things to know about it.

1) Some of Shoemaker's earlier writings implied that a few weeks of the medicine was sufficient. This is clearly not true. I expelled large amounts of toxins for about two years using it, for instance.

2) Many very ill patients are unable to use csm without getting very sick with an increased inflammatory response. However, those doing successful extreme avoidance have been consistently able to take it without those negative effects. (Along with being able to exercise without PEM, this seems like it may be a reliable indicator that people actually are clear.)

3) CSM just removes toxins that are moving through the intestines. The theory is that as that happens, the body will automatically release more toxins from stored locations, in the hope of expelling those too. However, it seems that there are many factors (such as methylation difficulties) that may prevent this from happening. So if may be that people will need to work on clearing detox channels in a variety of different ways, rather than just relying on CSM, if they want to get really well.

4) To my understanding, CSM is similar to tiny pieces of plastic that (through an electrostatic charge) grabs hold of oppositely charged mycotoxin molecules as it moves through the gut. Thus, even if you get the compounded version without artificial color/flavor/sweetener and without possibly GMO sugar, it still does not qualify as organic. Some people have expressed concern that especially with leaky gut, the product might end up being absorbed systemically. Whether that happens, I don't know.
Q. 24:2 - Increasing Effectiveness

I have been taking cholestyramine under direction from my doctor who is new to it. What I find is that my brain clears after a bowel movement but the effect doesn't last long. Do you have any tips for increasing its effectiveness?

A.M. Runyan

It used to be that even 4 packets of CSM a day was barely enough to mop up all the toxins I was dumping. As time went on I didn't need as much CSM.

Other ideas for simply clearing up things:

Liposomal Vitamin C - can neutralize toxins by increasing glutathione

Coffee enemas- allow bile to dump and increase glutathione-s-transferase

Gynostemma or Jiaogulan - tends to just clear up toxic feelings, great adaptogen (I like Paradise Herbs brand)

Electrolytes - I like Ultima replenisher - tend to keep detox going properly

Lots of water

Flber, psyllium, agar agar, acacia fiber

Lying on the floor, following whatever the body recommends that you do, following body intuition - can help body to stay in a relaxed, detoxifying state

Suma - fairly cheap herb (I like Nature's Way) that helps with oxygenation and overall feeling good, even if you are detoxing

Lisa Petrison

Letting mold toxin sit in the gut, regardless of whether csm is involved, is not a great thing. I used Vitamin C to bowel tolerance when taking CSM. I wouldn't hesitate to use colonics, enemas or colon cleaning herbs to keep things moving.
David Ou, M.D.

According to my mentors, coffee enemas and colonics work by causing the gallbladder to dump bile. This is important because the liver pulls toxins, such as mycotoxins, out of the blood and into the bile. Over 95% of the bile is reabsorbed in the colon. Binders such as CSM prevent the bile from being reabsorbed. Therefore, combining CSM with colonics/coffee enemas is often a good combination. Some people feel sick afterwards but using a binder such as charcoal can help.
Q. 24:3 - Still in Exposure

Is it worthwhile to take cholestyramine while you are still being exposed? Also do you have to follow a low amylose diet while on it?

Lisa Petrison

Shoemaker acknowledges that there are lots of people who cannot take csm at all. Usually these are folks that are in an advanced stage of the illness, I think. I don't think there is enough evidence to suggest whether this is specific to Lyme or just toxicity in general.

I believe strongly that not being able to tolerate csm is a symptom of not being clear, just as not being able to exercise without PEM is a sign of not being clear. However, for a very sick person, the amount of lack of exposure needed to tolerate the medicine (or exercise) may be unobtainable in some situations.

From what I've heard, csm may be help people tolerate short-term, occasional, mild exposures a little better. I've not heard any stories where people said that it helped them to live in a bad place, though perhaps there are some out there (especially amongst mildly affected sufferers, perhaps).

Shoemaker insisted on the low amylose diet for the use of Actos, which he no longer recommends (because of current warnings about dangerous side effects). I never heard it being required for the use of csm.

The unusual thing about that diet is the insistence on no root vegetables (potatoes, yams, carrots). My impression always has been that most chronic illness patients tolerate those vegetables pretty well. And I've yet to hear people raving about how much better they felt by eliminating them on this diet. So I'm not sure that I would stop eating them just for the sake of a theory, as personal preference.

Vicki

I continued to take cholestyramine while my Lyme was being treated, which would be considered an exposure, I believe. I have not followed a low amylose diet while being on the CSM.

In one of Dr. Shoemaker's books he took CSM before, during, and after planned exposures to blue green algae in lakes that he was taking water for testing.
Avoidance is the most important thing, but of course, binding toxins, even while being exposed, may still be in your best interest."

**Beatrice Latherings**

During my second severe exposure I was already taking CSM. I was house sitting and once again, there was no odor or visible sign of mold. However, after about a week, I started losing weight, and I was at the time still leaving a lot of hours between food and CSM, like four hours both sides. So I thought I was losing weight because of having to space my meals so far apart. I decided to stop the CSM for a week to see if I could put some weight back on. Ooops. Then I really got sick, totally crashed, and had to abandon the place and go live in my yard. So the CSM was definitely doing something.

**Jessie**

I couldn't tolerate CSM, but I could tolerate Welchol which I believe is Shoemaker's runner up after CSM. And I'm a Lymie too, still exposed to mold.

**Chispa**

An LLMD trained in Shoemaker's protocols says that a person still infected with Lyme can take CSM. (My opinion is that most of us with chronic Lyme will always have some.) My understanding of the non-use of Actos is that hi dosing with EFA/DHA (fish oils) helps greatly. This is to reduce the inflammation that taking CSM and the biochemical processes that triggers. People who can't handle CSM can take Welchol but still need the fish oil. And a friend who is having astounding benefits from Shoemaker's protocols (and has all the lab biomarkers, which are mostly the same as for mold) says the low amylose diet helps a lot but she still has >>>improvement when noncompliant. I think mold has a different aspect in that living with constant exposure to mold gives one a greater increase in toxins. Still, the above info is pertinent. But you need to get out of that environment or you won't benefit enough from all the treatment effort.
Q. 24:4 - Treatment Schedule

How do you schedule your doses of CSM?

Lisa Petrison

I did not find the typical suggestions of spacing the CSM throughout the day to be optimal for me. Considering that the body seems to do most of its detoxification at night, it seems to be appropriate to time the use of CSM accordingly -- and then to have most of the food consumption on its own, during the day.

When I was focusing on CSM, I would tend to take one dose before bed, one first thing in the morning, and one later in the morning. And if I woke up in the middle of the night, sometimes I took one then too. And then unless I felt like I was toxic, rarely any during the course of the day.
Q. 24:5 - Adding to Enemas?

Given Dr. Ou's remark on this page about bile getting reabsorbed and hence CSM being helpful in combination with coffee enemas, it occurred to me that adding CSM to a coffee enema might be helpful. Then the CSM would be in the right location at the right time, and you also wouldn't have to be so careful about timing the CSM away from supplements. Has anyone ever tried it? Can anyone think of any reason it would be a bad idea?

Lisa Petrison

My initial fear here would be that it would clog up the enema tube and be very difficult to wash out.

A.M. Runyan

Yes, there are some reasons it would not be a good idea!

CSM works by absorbing bile, which is in the middle of the digestive tract, relating to the gall bladder and liver. I don't think you are going to absorb bile through the colon walls, which is how enemas work (transfer across/around colon walls). It needs to be in the stomach as prescribed, typically before fat-containing meals, so you can dump bile onto it as it goes into the first part of the intestines.

Also the non-pure CSM has lots of things in it you would not want to be absorbing into the bloodstream through the colon walls, like artificial flavorings and colorings.

I don't think the coffee enema would work properly with CSM mixed into it.

If something is a prescription I take it in the manner in which it's prescribed. Taking things in a route other than the one they are prescribed can cause problems since absorption can differ greatly depending on the route of administration.

Julie Rehmeyer

The bile ducts empty into the duodenum, which is in the upper part of the small intestine. The CSM in an enema would be way too low to help.

David Ou, M.D.

I agree that you want to bind the bile with CSM, chlorella or other binder before it reaches the large intestine. Therefore, using an enema will not deliver the CSM to the right place.
Chapter 25

Exercise
Q. 25:1 - Exercise Tolerance

The 'Back from the Edge' book makes it look like Erik is able to exercise without problems when he is avoiding mold, even though he had (has?) exercise intolerance when exposed to mold. Have others found that they are able to exercise more when pursuing avoidance too?

A.M. Runyan

Yes, I can exercise vastly more since pursuing (more) extreme avoidance. Back in Massachusetts before I moved, even when I thought I was fairly mold-free, I could only walk about 3/4 mile or exercise 15-20 minutes. Upon moving to the desert (and finding some of the few buildings here that aren't moldy- many have swamp coolers), I was able to start walking 9 miles in a day, hiking (which I hadn't done in years), jogging sometimes, working out for 45 minutes on the elliptical, etc.

Furthermore I find that my work ability goes up, too. I used to have to take a lot of breaks during the week, but now I'm able to do productive stuff almost all the time, if I want to. I remarked early on that because of doing avoidance, each week feels like it's equivalent to three weeks in the past - I just get that much more done in a week. I take this all for granted now and I'm surprised if I'm ever tired or have almost any symptoms, besides mold sensitivity, detox symptoms if I really drive detox hard, and some lingering food sensitivities and hyperacusis, these days... mold avoidance can definitely spoil you, where you get used to it and take being fairly "normal" for granted!

Lisa Petrison

Briefly: yes, I went from severe exercise intolerance in the moldy house to being able to hike for many hours on fairly steep trails (including at 10,000+ feet altitude) after about eight months of extreme avoidance. And my ability to exercise would go down dramatically with any mold exposure at all, especially when my reactivity was high.

A couple of other notes about exercise.

1. During the last few months of living in the moldy house, I could barely go down the half-flight of stairs to the kitchen without feeling worse. But I started having
the impulse to drive to the Chicago Botanic Garden, about 20 minutes from my house. Once there, I would collapse on an outdoor bench and just lie there with my eyes shut for a couple of hours. Then, oddly, I would feel compelled to walk around slowly for a while, for maybe 30-60 minutes. When I got home, I would feel like resting, but I definitely didn't feel worse than before I left.

I was literally delirious at the time and couldn't make sense of it. After I started doing avoidance, I realized that the Botanic Garden is likely the best spot in all of the Chicago area, and that breaking the response there when I was close to the end of the road was literally helping to save my life. Obviously I wasn't clear since my clothing was contaminated, but even the decreased exposure seems to have made the exercise intolerance a lot better.

2. There have been times in my recovery process when a lot of metals have been loosened up in my system -- when killing a tapeworm (parasites sequester metals) and after a cilantro juice enema (cilantro sucks metals out of tissues/bones but doesn't bind it tightly enough to remove it). My exercise intolerance as well as my OI went way up then, even when I was totally clear (and even though I had been doing avoidance for years). So I am going to posit that a problem with metals (or likely more specifically methylation problems) are in part responsible for the exercise intolerance issues.

Julie Rehmeyer

Absolutely. One of the biggest things that got me into avoidance was reading City Changer’s blog post detailing how he could exercise again. It seemed almost unbelievable. At that point, I was really, really sick, unable to get out of bed many days, and the idea of being able to do real exercise again was intoxicating. I spent two weeks in Death Valley with none of my own belongings, and while I was there, I didn't feel especially better -- somewhat, but well within the range of normal variability. But when I came back home, I reacted enormously to my own living space, which was how I knew that mold (or some environmental contaminant) was contributing to my issues. I stayed out of my house, with friends. A week later, I ended up walking to the top of the hill behind my house, which I hadn't been able to do in well over a year. It's a good climb, several hundred feet.

My ability to exercise has varied through the detox process. At one point, I was running 12 miles again. That somewhat mysteriously fell off, but I'm back running again, shorter distances. I've also been doing a high intensity interval workout. Unimaginable before avoidance.
Avoiding Mold

Here's one of City Changer's blog entries, where he talks about his ability to exercise again. More details about his progress can be seen in other blog posts.

http://ampligen4me.wordpress.com/2012/05/13/still-climbing/

Michele

Since being in a mold-free environment, I do find I am able to tolerate walks; even uphill at times, short hikes and have started some minor leg exercises, without the usual fallout, or the actual inability to do it. In the past, it was not just the fallout afterwards; it was an actual inability to do the slightest tasks that required any endurance, or use of muscles without breathing problems, dizziness and then major fallout afterwards. I have recently had an exposure, but it is getting out of my system now, and I plan on charging forward; and starting where I left off, in hopes that I can continue to build up my threshold again. So yes, there is definitely a difference for me.
Chapter 26

Other Treatments
Q. 26:1 - Still Suffering Greatly

I'm suffering greatly at this point. I've left our moldy home and done what I can to get healthy. Leaving was not enough for me and am trying to perfect my diet, as well as avoid mold. This part is not easy. So far it seems mold is everywhere and if it isn't mold bothering me it is another chemical, building problem, etc.

I am so sensitive to everything - so many foods, chemicals and building produce symptoms for me. I truly feel I cannot detox with diet alone. I really feel a mold knowledgeable doctor may be able to help me but I cannot find one in my area.

I know all the recommendations for detoxing but have a hard time with supplements as I am extremely sensitive. I haven't even been able to take a probiotic. Maybe I haven't found the right one yet or the dose was too high to start with. It also seems the food I've eliminated from my diet, now produces reactions 10 times worse if accidentally ingested.

I'm the first to admit I've made diet/chemical/exposure mistakes. I'm learning, and it hasn't been very long since I realized I had to change my diet to help me recover. I'm working on perfecting it and finding a place to buy all organic, grass-fed reliable foods.

I also see conflicting advice about diet. Some people rely on the candida diet, others Bulletproof. I know everyone is different but any suggestions/experiences about either that would be helpful as well.

I apologize for the length of this email. But I really need help. I feel like I'm dying and losing my mind.

A.M. Runyan

In general, doctors seem to underestimate the importance of location, or the need for extremely mold-free locations for people with significant mold toxicity, perhaps because they don't want to be counseling all their patients to move away from them.

They typically recommend at least some treatments that require doctors, like IVs or prescriptions, but it's rare for them to say, that house is probably not clear enough, try taking a trip, etc. But they might start saying this in the future.
In my experience, I am doing much better living in the desert in what I found to be a fairly mold-free apartment (while doing extreme avoidance and able to detect mold really well), than I was when living in Massachusetts and seeing an ostensible mold doctor.

Location + self-directed treatment (following doctors' protocols I can find online and in books) is working better for me than living in a moldy, humid state and paying out-of-pocket for a holistic doctor.

As for doctors, I used to go to Northampton Wellness in western Mass, and while they were not very helpful for treatment, at least they would prescribe me CSM and low-dose naltrexone. They also recommended Alka Seltzer Gold for when I had exposures, and that helped, although TriSalts are perhaps even a little better.

It seems that the main things doctors offer for this condition are pretty simple: CSM (which many primary care doctors can be convinced to prescribe; it's pretty inert and doesn't get absorbed into the bloodstream), Vitamin C IVs (liposomal Vitamin C in the right doses can give a very similar effect, and it's cheaper than paying out of pocket for IVs), alpha lipoic acid IVs (I've been experimenting with transdermal R-ALA, mixing it in cream, and it seems to boost my glutathione production dramatically and detox me - although too much can deplete thyroid hormone levels), low-dose naltrexone, and the basic recommendations that most of us know about avoidance, diet, supplements, etc.

You probably need at least a primary care doctor who would work with you on scrips and lab tests, but it seems hard to find really great mold docs and they might be expensive, far away, etc. If you can get one, great, but I end up spending the money I would spend on doctors on treatments. Not sure if this is the right choice, because it makes me seem less credible in the eyes of family and friends that I don't have a designated mold doctor, but a lot of the protocols can simply be found online. And there are sometimes primary care or other agreeable doctors who will oversee, do lab and basic scrips, etc.

Right now I am doing the Patricia Kane protocol as outlined in her Detoxx book for doctors, and it's pretty astounding, but as with most treatments, it seems like something that is most effective when you are not around mold, and that could be hard to handle around mold.

The first step is focusing on getting a clear/mold-free location where you are not reacting. Taking a break from where you are to go somewhere lower in mold is usually a great way to get the "mold vision" necessary to find a clear place, as observed by having some degree of spontaneous detoxing happen there, low
inflammation, absence of many mold symptoms.

Then once you have the clear place, people move into intense detox and healing protocols, which are so much easier to handle when away from mold... that's the way I am doing it. It is really unpleasant for the body to try to detox and heal around mold and the body seems to fight it, since if you're around more than a certain degree of mold the body emphatically wants you to hold onto it and sequester it rather than letting any out.

**Lisa Petrison**

Based on all the case studies that I've seen, I do not believe that people should be experiencing these types of symptoms regardless of their core level of health unless they are still being exposed to substantial quantities of particularly bad biotoxins.

The problem is that even if a person moves from a bad home to an exceptionally good one, that only eliminates one source of exposure. Other sources may be continuing to keep people feeling as sick as if they had never left the bad home. (Though it still may be worth leaving since the increased accumulation of new toxins in the system may decline in quantity away from a particularly bad place.)

You don't state if you still have any of your possessions from the problematic place with you. Depending on the type of toxin, that might be enough to keep you totally sick even if they have been washed.

I don't know where you are living, but another strong possibility in my mind is that you are experiencing exposures to particularly bad biotoxins in the outdoor air. (The tip-off in my mind here is the severe MCS and the feelings of dying and losing your mind.)

It's also possible that casual exposures (such as occasionally going into a bad building) may be driving you down, but that alone tends to result in a moderate level of recovery with relapses rather than desperate levels of illness, in my observation.

It sounds to me like what you are experiencing is very similar to where Erik was at during his relapse in the 1990's (Chapter 12 of the "Back from the Edge" book), so I would suggest that you take a look at that.

http://www.amazon.com/dp/B00EDGEHT2
Ideally, what you would do is to get totally clear for a couple of weeks, then return to your current environment to gauge what is having an effect on you. The classic example of getting clear is tent camping in Death Valley with all new possessions, but that is not the only possibility.

Once you have gotten clear and then return home, you may find that your possessions from your previous place are really problematic or that your new residence (even despite a good ERMI score) is itself intolerable to you. Or you may find that certain areas of town feel particularly bad. Or you may find (to your horror) that the whole town feels awful to you. Whatever you learn, it will allow you to make changes that will allow you to move toward increased wellness.

Of course, I'm not guaranteeing that this will work or be worth it. I've yet to see anyone with classic ME that this exercise has not worked for and who (barring fibro-related drainage problems) hasn't benefited substantially, but there are no guarantees.

It's also obviously very difficult for a really sick person to pull this kind of exercise off. The monetary expense is another stumbling block.

Insofar as people are in really bad exposures, including cross-contamination of possessions or outdoor mold exposures, I've not seen anything that mold doctors (or CFS doctors or any other kind of doctors) do help them more than just a little. It's very easy to spend a lot of money and a lot of years and end up getting nowhere, if avoidance is not effectively attended to first.

Karen Dean

You do not mention 2 things.

Are you taking Cholestyramine (CSM)? And, how long have you been out of the moldy house? CSM is the best binder of mycotoxins, IMHO, and the only one clinically proven. Any doctor can script it, download info on it and give it to your GP.

Second, how long are you out? it took me a year and three months to recover from the original moldy house. But you should see improvement within a couple of weeks, as long as you did not bring all your contaminated things with you. If you have not recovered at all, and you brought all your stuff with you, you may have to move again, this time with nothing.
Julie Rehmeyer

Just echoing that it sounds like you're dealing with continuing contamination.

Joseph Salowitz

I agree with Lisa. Feeling like you are dying and losing your mind, after having left your moldy home more than 2 months ago, is in my opinion, an indication that your new home has mold, and/or you have brought all of your possessions with you, from your old home, to your new home, and have "cross-contaminated your new home."
Q. 26:2 – Treatments Helped Most

Other than avoidance, what treatments have helped you most?

Lisa Petrison

In random order:

1. Vitamin C IV's or buffered Vitamin C to bowel tolerance (up to 30 g per day). Reduced oxidative stress and inflammation from mold exposures. Prevented constipation with CSM.

2. Coffee enemas and cleansing enemas. Up to five per day. Essential.


4. Bodywork to reduce fibromyalgia and allow toxins to flow freely through the lymph rather than getting stuck: neural therapy, massage, craniosacral, yoga.

5. Heat to encourage sweating and toxin release: living in dry desert (up to 105 degrees), hot springs, sauna, infrared light.

6. Killing parasite in my small intestine. Used herbs, diaomaceous earth, ozone water (oral and as enema), a drug for this. I think all of these work; the problem is the metals release (discussed in #7).

7. Chelation suppositories (Medicardium EDTA, DMSA). Parasites can sequester enormous amounts of metals and release them when they die, so the chelation was essential when getting rid of the worm. ALA was also helpful (oral, capsules used as suppository, and IV's).

8. Natrum Sulphuricum 1M. A traditional mold remedy; caused a massive rush of mold toxin to flow out of my brain. I never would have recovered brain function without that.

9. Herbs for liver support.

10. 100% organic diet, massive amounts of fresh produce. Included juicing, green smoothies, cooked and raw veggies. I really do mean _organic_ meat and eggs, not pastured where they feed the animals Round-up contaminated crap.
And not factory farmed organic. Top quality of everything, after huge amount of search to find the best. I don't think gluten has been a big problem for me, but mycotoxins in food (present especially in cheaper products) do seem to matter. High-quality oils: coconut, Kerrygold or other good butter, real olive oil from small California producers. Good wildflower honey.

11. Supplemented probiotics. Homemade kefir with extremely high-quality raw milk (Claravale) or other premium organic milk (e.g. Straus), up to two quarts per day. Homemade yogurt (made with Dale Guyer's probiotic mix), water kefir, kombucha. Three Lac. Fresh fermented sauerkraut. Especially when detoxing mold through gut, essential.

12. Live cell therapy shots. Thymus (seemed to reduce reactivity a bit). Liver (helped when liver was stressed).

13. CSM. The only other binder I've found very helpful has been arabinogalactan.

14. Antivirals (Famvir, Valcyte). These reduced reactivity a touch, but if I could do it over again, I may have just focused on detox and skipped them. Not sure.

15. Exercise. I've focused less on exercise than a lot of people, but when clear enough to tolerate it, it can be helpful (encouraging sweating, release toxins, lymph movement). Mostly hiking, swimming, yoga. Intensive metals detox seems to preclude exercise even when totally clear, btw.

16. Frequent showers. This is part of doing avoidance, but also was important to cleanse away toxic sweat during detox process.

17. Mag07, which acts to scrub out the intestines. Colon cleaning herbs, when necessary.

A.M. Runyan

Let's see.

1. A year of ozone saunas for Lyme disease.

2. Coffee enemas with one of Joey's presumed low-mycotoxin coffees (see heal click, low-mycotoxin coffee)

3. Infrared light from this cheap setup I made since I could not afford a big infrared sauna (http://www.youtube.com/watch?v=utqkCp_tK8Y)
4. Electrolytes. I use Ultima replenisher but I'm going to try the BodyBio version too.

5. BodyBio phosphatidylcholine, which is really something else compared with regular phosphatidylcholine. It's part of the Patricia Kane protocol.

6. Liposomal Vitamin C, which works pretty much like Vitamin C IVs.

7. High fat, grain-free Bulletproof diet - look up online. Ketogenesis, intermittent fasting - not always eating breakfast. Autophagy (letting the body recycle its own proteins while you are not eating much). Having fat while fasting, so that you still get calories but stay in a fat-burning state.

8. Random supplements I've come to really like: Gynostemma (detoxifying adaptogen), suma (for oxygenation), reishi, chaga, Moducare, Swanson essential sugars complex (has the glyconutrients in aloe vera, but cheaper than taking that much aloe vera)

9. Liposomal turmeric (Meriva) seems to do something profound to my gene expression, but I'm not sure if it slows down detox. It majorly changes my body and it inhibits NFkB.

10. Alka seltzer Gold. Can really turn down mold reactions and chemical reactions, and seems to put my body into a different, less reactive state. Seems to do something similar to amygdala retraining, or to contribute to my amygdala being less anxious.

Beatrice Latherings

I haven't found a treatment that makes any difference other than avoidance.

Karen Dean

Six months of two ALA IV's a week made me feel like a teenager again, and cleared up every symptom. Now Vitamin C and quercitin really help
Q. 26:3 - Shoemaker Protocol

Is the Shoemaker protocol (expensive tests; various drugs) worth doing? Or is it better to focus on avoidance and detoxification including cholestyramine?

A.M. Runyan

CSM is not that bad of a drug/doesn't get absorbed, so many doctors, even primary care doctors, are comfortable prescribing it. Also I haven't heard that the expensive drugs provide benefits for everyone. Also Shoemaker is expensive. I don't even see a mold doctor right now, since what I need to do is obvious and my money seems to go farther if I just use it on housing and key supplements/tools rather than on doctor's visits or IVs, although if I had more money I'd like to try ALA and Vit C IVs in addition to avoidance.

I like to think of the situation as a hidden biowarfare war going on in the country in many locations - some entire areas, and many buildings - and if you see it like that, then of course the thing to do is to find a safe place away from the biowarfare, stay away from things that were formerly in bad contaminated areas, and just try to create a healing space for the body, with sweating, exercise, infrared light, CSM, or whatever seems to support healing and detox.

Julie Rehmeyer

I took Shoemaker's test early on, because they were covered by insurance and were helpful in connecting my experience to his research. I haven't done any of his treatments other than CSM, and I only did that pretty briefly. And I'm sufficiently recovered that I'm able to stay in a somewhat moldy flat with an extremely moldy lobby in Paris right now without difficulty so far.

Lisa Petrison

From what I have seen, the extent to which people recover from this disease is very highly correlated to the extent that they are able to successfully get away from the toxins (and especially from the "supertoxins"). If people are still being hit by really problematic toxins (whether they be from a home, their stuff, the outside air or casual encounters that they don't decontaminate after), they're not going to improve very much even with the best treatments in the world, based on all the case studies I've seen.
So I don't consider it an either/or choice. I'm not saying that the only way to make significant improvements is to do extreme avoidance as Erik does it or that I have done it. That is not practical for everyone, and not everyone needs to climb to the top of Mt. Whitney in order to live a rewarding life. But based on what I have seen, insofar as people who are at a later stage of this illness are exposed to really bad toxins, no doctor's treatment is going to be of much help.

Once people are in at least a "fair" environment, it seems to me that many different types of treatments have the potential of helping. Everything goes better without mold! I've seen people who think that Shoemaker's approach was helpful to them at that point, and I've seen people who have pursued other approaches that they say were helpful. A lot of people are so happy to have anything work that they try all kinds of things. I personally am glad that there are options out there.

I think the tests are mostly helpful if people are suspicious about the idea that mold might be a problem for them and want some kind of evidence. From a research standpoint, I am interested in seeing people's test results, because it gives me more information about the disease. But from an individual standpoint, once you know that you have mold illness, the test results aren't going to give you any information about whether some treatments will be better for you than others. Maybe someday that will be the case, but we're not there yet anyway.

**Damien Blenkinsopp**

If you have the resources I would do both. The shoemaker labs give you invaluable insights into your particular case and its severity. If you see you are a more extreme case - you will be more willing to take extreme actions. So information is power the way I see it. So for anyone who has the resources I would recommend at the least doing the baseline inflammation labs and genetics (tgf beta, c4a, c3a, mmp9, hla dr, msh, VIP and coneg staph - marcons). the marcons is also important because it can block recovery if you have it even if you remove the mold toxins (CSM + avoidance). So especially if you are not getting results from avoidance / csm testing for marcons is important (only $85).

**Vicki**

I think the tests are initially very worthwhile because it verifies the diagnosis and gives you labs to follow as you recover. His protocol also gives you a roadmap to regain your health. Avoidance is one of his highest priorities. I have been on
protocols from other doctor/researchers concurrent to Shoemaker’s protocol and these other protocols have been extremely helpful as well. (Just to clarify, I have not seen Dr. Shoemaker, but my doctor uses his protocol to treat patients.)

CSM is very valuable for detoxification as well as to treat exposures. Now, certain individuals may need more than just CSM for detox (I have). You may not need to do all the Shoemaker labs after each step in his roadmap; I have not done them repeatedly like that and I am still doing well in recovering and my doctor still knows the direction we should head. I think that doing those labs repeatedly has helped Dr. Shoemaker in his research and verification, but maybe not every patient needs that and it is certainly a huge expense.
Q. 26:4 - Mold Illness Doctors

I am thinking about seeing a doctor who knows something about mold illness. Is this worth doing? If so, who should I consider?

Lisa Petrison

There is a list of doctors on the Paradigm Change website. I have good reports from patients about all of them, except for a couple who are included just because they are Shoemaker certified or suggested by other practitioners I trust.

A question here is what you want the doctor to do for you. For people who are self-directed, the issue here is whether doctors can do things that you can't do without them. Of treatments that I've heard that have been helpful in this disease, in rough order of helpfulness, I would suggest that they are:

1) Mold avoidance, and the more the better.

2) Dietary changes (avoidance of trigger food, improved nutrition such as juicing, probiotics such as kefir)

3) Coffee enemas

4) Sweating (exercise, sauna, hot springs)

5) IV's (Vitamin C, ALA, Glutathione, Myers' Cocktail, EDTA)

6) Addressing Lyme, parasites and other pathogens (e.g. drugs, ozone, herbs)

7) CSM

8) Bodywork (e.g. massage, neural therapy) if fibro/drainage issues are present

9) VIP

10) Low Dose Naltrexone

11) Chelation (e.g. EDTA suppository or oral)

12) Homeopathy

13) Nebulized glutathione
So a lot of this can be done effectively with no doctor at all.

If you have a good bit of money that you can afford to sink into IV treatments, those do seem to be helpful for many people. In that case, you would want to find a doctor who does IV’s and who is near a place where you live currently or would like to live. (Bozeman could be a good choice at least in summer, for instance.)

I've encountered a lot of people who have found non-mold doctors to prescribe CSM. If you want the kind without the additives or sugar, then you should get the info on where to get it (I think it is still Hopkinton?) in advance.

LDN seems more used by CFS than mold doctors. I know that Berndtson, Berkson, Guyer and (I think) Hope have prescribed it.

Any of the Shoemaker physicians probably will prescribe VIP, when patients are at the designated point (supposedly not a first step).

The homeopath that I saw in Las Vegas, Terry Pfau, was spot-on in terms of finding a helpful remedy for me (Hahneman Nat Sulph, 1M). Other than that, I'm not sure what to say about that.

A few people find nebulized glutathione helpful. Some of the broader doctors (Guyer, Hope) often prescribe that.

I have a very hard time suggesting to people that they go to really bad place to get treatment for mold illness. So I would have a hard time encouraging people to go to Dallas to see Rea, even though he seems quite good otherwise. I also would be prepared to thoroughly decontaminate after going to see any mold specialist, due to the cross-contamination that sick patients will unavoidably be bringing into the office.

This is not necessarily a comprehensive list -- I may have forgotten some therapies.
Q. 26:5 - Colloidal Silver

I was wondering if anyone has experience with using colloidal silver in the battle against mold, either internally or around the house?

Beatrice Latherings

Have also used it in sinuses, with a tad of DMSO for penetrating biofilms. Burns like crazy if you have an infection, stops burning when the infection is taken care of.

Karen Dean

I have used it 2 ways very successfully. One is as a sinus flush if I feel I am getting a sinus infection. You must do a real flush, hanging your head off the side of the bed, and filing the sinuses from all directions. It can be painful, but sure feels better afterwards. The other way is removing all itching from the scalp, after years in the moldy house and trying everything else. Just rub it in all the itchy spots and leave it on till the next day.

A.M. Runyan

I haven't really used it for mold. I have used grapefruit seed extract internally and on laundry. It seems to work really well on clothes that might have gotten some mold spores lodged in them. I just put a few drops into the laundry or use 3-5 drops when washing clothes in the sink. I also use kefir and a small amount of chaga powder on clothes that encountered bad toxins, and sometimes it works.

Lisa Petrison

I took MesoSilver orally for a while (mostly while in the moldy house and shortly after leaving) and feel like it did kill yeast and maybe other infections. I also nebulized it toward the end of my time in the moldy house, when I acquired a pneumonia like cough that I think may have been caused by a fungal infection, and it worked somewhat for that. (The cough went away permanently after I moved out of the house.) And I have used a nasal spray for sinus infections. However, nanoparticles seem to be of increasing concern, and so I wouldn't do it again unless there is more definitive science saying that they're not dangerous.
Here's an article I just found on this topic.


Christine

I used it in the nose initially for the chronic sinus infections. Felt good but no long term change until I left my workplace and started using nizoral (antifungal) compounded nasal spray. No sinus infections since 2005

Michele

I have used silver, and had no real benefit from it. I have had a friend tell me that silver will undoubtedly "wipe away" the mold in my system. This has not been the case. But, I do use it externally, which helps. And it has helped when my sinuses become a problem, but only in the beginning, not when it involves facial bone pain, etc.

Lena

Makes a great rinse for berries. They keep much longer in the fridge with none of the usual mold issues.
Q. 26:6 - Increasing Glutathione

There are many ways to try to increase glutathione to help with getting well from mold exposures. What have been your experiences with glutathione: s-acetyl glutathione, sublingual, IV, transdermal, liposomal, etc.?

A.M. Runyan

Things I have used:

-S-acetyl-glutathione, from NatureDoc. Does something for me. According to the PK protocol you're supposed to take Bodybio phosphatidylcholine first, then have glutathione 15-30 mins after, so I do that. I've never had glutathione IVs but this is supposed to work kind of similarly to that.

-BodyBio taste minerals kit, to assess if you are deficient in minerals. Helps to keep mineral status adequate (you take any individual minerals you are low in) so you have building blocks for detox enzymes - not just glutathione, but also catalase and superoxide dismutase

-ozone - increases glutathione through hormesis (causing oxidative stress and the body bounces back with an increased antioxidant response). I used this before I had major toxic injury, and use it at a lower level now.

-Liposomal Vitamin C - One of my favorite detox things, see Dr. Levy's talk on it, helps to increase glutathione

-Coffee enemas. discussed thoroughly and amazing.

-Grass-fed whey protein. amazing.

-Occasionally small amounts of NAC, but it has a little-known side effect - it can cause shortness of breath in high doses or with prolonged use, which can feel like mold symptoms.

-Nrf2 activator herbs, like turmeric, green tea extract, ashwagandha, .... tell the body to make more of its own antioxidants

-R-ALA. I put it on myself with cream, transdermally, and it does a lot. I just can't use it continuously because it makes my hair thinner and displaces thyroid hormones.
Lisa Petrison

I've had IV glutathione, nebulized glutathione and liposomal glutathione. All of them while living in the moldy house and then again while doing extreme avoidance. I've never found any of them to do anything noticeable at all. (B12 and activated folate were helpful though.)

Undenatured whey protein is supposed to provide a dose of glutathione to the liver, and I do think that has periodically been a bit helpful. At one point I had some leftover glutathione that wasn't helping anything when I nebulized it, and I tried using it rectally. That felt slightly more helpful, though certainly not enough for me to buy a supply to continue using it.

I have known some people who say they have benefited tremendously from various use of glutathione though, so I definitely think it could be worth people giving it a try to see if it is helpful to them.

Beatrice Latherings

Before you go diving into glutathione you should do some genetic testing to see if it is contraindicated. I found out I am CBS +/+ and a lot of things that are supposed to be good for moldies are not good for me because of problems in the sulfuration pathway. Glutathione, ALA, some other stuff. I tried ALA once a few years ago and could not discern any benefit, while a friend of mine says it was extremely beneficial. I'm betting she has different genetics.

Christine

Had a doctor once who said it was better to do the precursors to Glutathione so prescribed glycine and cysteine instead

Madeline

I get it with IV. Seems to help the brain fog.
Q. 26:7 - Fish Oil

I read somewhere to limit fish oils during mold exposure, or maybe it was in general. What is the reason for this? Can they increase reactivity? I notice I don’t tolerate salmon with skin on since my mold exposure. It triggers the mold inflammation.

A.M. Runyan

What kind of salmon are you reacting to? Atlantic or farmed (which might have mycotoxins), or Alaskan, which would probably be better? (I can eat alaskan salmon.)

As I understand it from Patricia Kane’s writings, people with biotoxin illness often have inadequate arachidonic acid, and taking too much Omega-3 can imbalance the little they have. She recommends her Balanced oil with a 4:1 ratio of Omega-6 to Omega-3. I take that and I love it. Good brands of sunflower and flax oil would probably help too (in some sort of ratio I guess). She also recommends fairly high dose evening primrose oil.

I've been taking her oils, and I still feel like I want some fish oil now and then. But it does feel great to be getting these Omega-6 oils. I was having major oil cravings before getting those oils above.

Eating grass-fed butter seems to help too, and there could be many ways it helps (fat-soluble vitamins, CLA, and simply stimulating bile release from having lots of fat).

Lisa Petrison

Some published studies suggest that fish oil can be helpful in reducing the inflammatory effects of mycotoxins, which is why Ritchie Shoemaker started suggesting it to his patients.

I don't know that I ever had an overt inflammatory reaction to it, but I have to admit that even good brands (such as Pure Encapsulations) seem pretty yucky to me. While some fish are less toxic than others, in general the oceans are so toxic that it’s hard to imagine any fish being pristine. And the fatty part of fish (e.g. the oils and the skin) probably are especially toxic, compared to the flesh.

Historically, I've felt okay with fairly modest amounts of wild Alaskan salmon as
well as certain sardines (Wild Planet from northern California and Bela or Cole's from Portugal). Whether any fish from the Pacific is safe now, with Fukushima, I don't know.

The only fats I currently consume are really good butter (Kerrygold or similar); coconut oil (Nutiva seems the cleanest); organic olive oil (from small California growers, Berkeley is my favorite); and very high quality milk/animal fats. Since sticking to just those, I've not found any particular desire to seek out other fats.
Q. 26:8 - EMF’s

Now that we hear from Dr. Klinghardt that toxic mold makes more toxins when around EMFs, are there any cheap ways to reduce EMFs in the home? I don’t use Wi-Fi and I turned off the Wi-Fi searching part of my laptop, and I use an earthing band, but are there any other things to do that don’t cost too much?

Lisa Petrison

I’m a little concerned about the extent to which (at least in this most recent interview) Dr. Klinghardt is talking about the idea of reducing EMF’s in the home and the lack of focus on the issue of considering existing toxic mold. I don’t think that he is suggesting that if you fix the EMF’s in your home, mold problems will improve -- even if it were true that mold only makes toxins when stressed by EMF’s, and even if it were true that you could completely shield your house from those EMF’s, this would do nothing about the toxins that the molds had made in the past. But without his specifically talking about considering environmental mold, I fear that his followers will feel it’s okay to not focus on it themselves, to their detriment.

Erik has lived in a Faraday cage (metal trailer) for years, but that has not stopped incredibly toxic mold from growing in the trailer at any opportunity (e.g. on the cardboard hidden inside the insulation of his refrigerator, on the glue that he used to seal his drainpipes). So I am very suspicious of this idea that EMF’s are the main problem here. I more think it’s related to manmade chemicals and nuclear radiation interacting with microbes. Though the EMF’s undoubtedly don't help.

Heather Plude

www.lessemf.com

Avoiding Mold

From mold illness survivor Suzanne Somers.

**David Ou, M.D.**

Dr. Klinghardt recommends to his patients that they turn off the fuses to their home at night. I personally note an improved quality of sleep when I do that.

**Beatrice Latherings**

He did say he used carbon fiber paint in his office and fine wire mesh (silver!) in his curtains. He also said he has mesh in his clothing.

If you have a burglar alarm it may be wireless.

**Vicki**

Dr. Joseph Mercola has some articles on reducing EMF's in your home.
Q. 26:9 - Enzyme Potentiated Desensitization

My doctor mentioned enzyme potentiated desensitization (which I don't understand). Might it help biotoxin illness?

A.M. Runyan

That kind of treatment (desensitization) works under the assumption that the body is malfunctioning by being sensitive.

What I've found suggests that is not the case, and that actually the body is being very smart by encouraging us to avoid further exposures since those would be dangerous.

If we give the body a clean place where it can detox (and if you're impatient, speed up the detox with coffee enemas and infrared saunas), then the sensitivity goes down through detox.

If I had simply reduced my sensitivity through desensitization back when this all started, I would not have had the massive gains in consciousness, depth perception, brain processing, brain speed, and seeing myself as my own person that I've had through detoxifying this stuff.

The body is smart - rather than being heavy-handed with it and thinking we know better (a very allopathic approach), I've found it's best to listen to it, find out what it wants, and give it to it, and at some point it actually does become satisfied.

The sensitivity is not the illness. The illness is toxicity and the sensitivity is like a scab to help us recover. It's like if you had pain from a broken bone - the solution is to give the bone rest and support so it can heal; not to "desensitize" the "pain reaction" so you can continue hurting yourself while your bone is not strong enough to handle it.

Lisa Petrison

I agree with A.M. Runyan. Also, while I've heard of people being helped by this for chemical sensitivities, I've yet to hear of anyone report that they were helped for mold sensitivities.
Q. 26:10 - Nutritional Supplements

Is it worth it to pursue nutritional protocols or supplements when you aren't able to be in a totally "clean" environment? Or is it a waste of time and money? Should I wait until I'm able to move to a safe home?

Lisa Petrison

I think it's a mistake to delay moving from a bad environment in the hope that the hyperreactivity can be fixed with supplements or nutrition. I've never seen that happen.

In general, from what I've seen, it's basically always the case that whatever treatment people try, it works better in a better environment. "Everything goes better without mold."

But I don't see anything wrong with taking strengthening supplements or eating well regardless of the environment. I would be a little cautious especially with pathogen killers or detox agents while in a bad place though, since I have seen a lot of people get worse (sometimes for quite a long time) trying that.

Janis Bell

In my experience, you won't get well from the supplements in the bad environment, but you can make some progress and build up your strength so that you can make better decisions and eventually find another place to live

Melanie

I would have to say support your body. It has taken us a year to find all the hidden mold. So glad I started nutritional supplements last year. I am fortunate to have a doctor who treats using western and holistic methods.
Q. 26:11 - Antivirals

I am about to start Valtrex for a possible shingles flare. Or at least a viral flare of some sort, causing similar symptoms. Just found out I am positive for HHV6, so have been advised by doctor to do a six-month course of Valtrex.

I know some others have had worsening of reactivity with initial use of antiviral drugs, particularly while in the early stages of avoidance, or while still being exposed to an environment that is over tolerance. I am in a geographic location that seems too much for me. I was hoping I wouldn't have to do anti-virals until I got my reactivity down and detoxed further, but it seems kind of necessary now.

I'm not sure what to expect, but I am definitely a bit concerned about increased reactivity as an effect of this drug, given my heightened reactivity to begin with. But I think I need to try this treatment because of my symptoms.

Of course the funny thing is that this virus activation (or symptoms that look like it) are probably due to biotoxin exposure and being extremely toxic! All paths lead to extreme avoidance, it seems. But in the meantime?

Just wondering if other avoiders with ME/CFS can share experiences with antivirals during various stages of avoidance?

Lisa Petrison

In Summer 2009, I was at the height of my hyperreactivity, I had been tent camping for several months and then was slammed hard by the "Mystery Toxin" while camping near Lake Tahoe. I was reacting to traces of it on my belongings and feeling like I was going to have to get rid of everything and start over.

At this point, I did an experiment with the antiviral Famvir, which had made me much sicker when living in the moldy house. My reactivity went up for three days, then decreased substantially below baseline. It certainly didn't go away, but small contaminations that I previously was unable to tolerate became unnoticeable.

About six months later, I added Valcyte. (At this point I was taking full strength Famvir and full strength Valcyte.) My reactivity did go up a bit (and I also got much more fibromyalgia, apparently as my body cleared the dead viruses...
through the lymph). But I was able to tolerate the drug by staying in super-clear locations. Eventually, my brain function improved somewhat and my reactivity went down somewhat.

I ended up taking Valcyte for somewhat over a year and Famvir for somewhat over 18 months. Eventually, after doing a lot of detox, they felt less necessary and I stopped them.

I've heard of other people doing extreme avoidance who did not feel that antivirals were helpful for reactivity though.

Audrey

Lemon balm herb is great for all herpes viruses. Apply the tincture topically several times per day as well as taking internally 3x per day. I'd also take astralagus and a 7 mushroom blend to support immune system. Activated charcoal take and separate time will help with mold detox

Dana

Valtrex made me way worse. I only took it one day then my doctor took me off and said to never take it again. I use Olive leaf now!
Q. 26:12 - Vitamin A Palmitate

I seem to experience reduced mold sensitivity after supplementing Vitamin A Palmitate. Has anyone else experienced this?

Lisa Petrison

I haven't heard that before but it is interesting. The GAPS diet suggests cod liver oil, I think mostly because of the Vitamin A present. That seems to be a slightly different form, but it does suggest that Vitamin A may be a more important factor in "mystery diseases" than has been recognized. I'd like to hear more reports on this.
Q. 27:1 - Best Kind of Home

What is the best kind of home to look for after experiencing toxic mold? And what should I look for in a conventional home?

Erik Johnson

A mobile one.

Because you never know when the shit might hit the fan at your neighbors’ house.

Christine

Ideally one that was built with care, built not too fast with natural building materials. Usually one well maintained, 10-15 years seems to work best here. No crawl space, good windows/frames, no leaks or history of leaks (anywhere). No attached garage, or carpeting

Julie Rehmeyer

My house is straw bale, and it meets Christine’s descriptions. No problems with it beyond occasional transient cross-contaminations. My reactivity has gone way down now, so I think that it would take something really bad happening for it to no longer work for me.

Lisa Petrison

Ensuring that a home (including the outside air) will stay good enough for a sensitized Moldie to remain healthy in is, from what I have seen, an almost impossible task. You might get lucky, but then again you might not. So I think that the best kind of home is one that feels good at present, and that you can abandon on a turn of a dime without a lot of loss of money or fuss if it goes bad (e.g. lease with an out clause, RV with high resale value, home that you can sell to a non-Moldie for the amount of money you put into it).
Janis Bell

There is not one right answer. Obviously the house has to be completely without mold. But most people develop sensitivities to formaldehyde and other environmental toxins. Since we all have different genetics, the sensitivities vary from one person to another. There are several healthy home specialists all over the country. They are called Bau biologists. They specialize in helping people with sensitivities find housing or build housing.
Q. 27:2 - Small Changes

I live in the UK. I am interested in the effect mould may be having on my health but it seems really hard for me to do much about it. I rely on my partner for income and we have a decent standard of living where we are. Not great, but decent. We have considered moving elsewhere but his career would suffer which means our income as a family would suffer too.

Has anyone made changes to their living environment which has helped without having to move abroad? The only other possibility that exists is for me to spend a few months in the winter near the coast, once finances permit.

I do understand the whole argument for moving away from where you live and leaving your possessions behind. But for some, I would imagine this is incredibly difficult from a financial perspective.

Lisa Petrison

England is a difficult country, from what I have heard. But it doesn't seem quite impossible (though almost).

Note that while the outside air in some places may be problematic, indoor building mold seems to be a bigger problem there. I have heard from a couple of people that there is a particular toxin that is very problematic in even tiny amounts, and that tends to be present in a high percentage of public buildings. One person called it the "Itch Toxin," because skin issues can be the biggest warning symptom for some people. (It causes other problems beyond that though.)

The working theory is that it is created by certain kind of mold present only in a few places, but then is spread easily around. And of course, England also has a lot of ordinarily moldy buildings, which may be okay for most people but can be problematic for ME patients.

So as a strategy for living in England, the first thing I would do is try to find a building that was unusually good, and preferably in a good location (or at least not in London). Then I would try to keep that building quite clean, and to make sure that I scrupulously decontaminated (put clothes in a bag to be washed; took a shower and rinsed/washed my hair) every single time I returned from going out. I think that if I did those two things, I probably would get a good bit of benefit even if the outside air was not really pristine.
The problem here is finding that building as well as a location with at least not-terrible air quality. If there were more guaranteed good places in England, then you could go there. Having to follow Sarah Myhill's suggestion and go abroad to get clear makes everything a good bit more difficult. But it still could be worth it, to give you a sense of what you are looking for.

Giles Meehan

I am certain that I have really benefitted from mold avoidance, still living in the UK. I was living in a fairly good house in probably one of the "least bad" towns in the UK, just a 2 minute walk from the sea. When I started to practice a certain degree of "avoiding mold", ie spending less time in fusty buildings when possible, and after any dubious exposure at all, having a full shower / bath and hair rinse *and* change of clothes *and* sealing the old clothes in a plastic bag in another room, then I did notice an improvement and noticed more of a pattern of what to avoid.

Around a year ago, I was fortunate to be able to move into a new property that has never had any mold, in a location where there has never been any toxic waste or chemicals, still in the same town, still a 2-3 minute walk from the sea. Here, I use almost only natural toiletries and household cleaners etc, almost nothing with any synthetic perfumes, and my bedroom furniture etc is all chemical-free (and mold-free!). I only moved things into the new home if I was sure they weren't contaminated.

I still do the avoidance, and the decontamination, and know how important it is to do it as quickly and thoroughly as possible. And it has really helped my health - I actually ran for a train the other day!!
Q. 27:3 - Finding Mold-Free Homes

How do you find these places to live that are completely mold free, including your home? There are so many places within a house where mold can be found, although not always are they obvious. Just curious.

A.M. Runyan

Once you go to low-mold places without your things, if you are sickened by mold/mold-poisoned, the body will react when around mold. After that it becomes really easy to tell when you are around it, whether a house is ok, etc. Testing is a good add-on, but a lot of it is just noticing whether the body reacts.

I've found a variety of low-mold places, including a renovated apartment, a hotel, and a luxury apartment complex. My housing costs definitely went up when I realized I had mold illness and needed to avoid mold, since I can no longer live in less expensive apartments like the one that initially gave me a lot of mold poisoning/had chronic water damage and a leak the landlord did not fix.

Erik Johnson

I built my own out of mold-resistant materials.

Beatrice Latherings

I bought a Camplite.
Q. 27:4 - Basements and Adobes

I just moved to Santa Fe and am looking for affordable housing, which is pretty scarce here. One place I found has the bedroom in a basement. Are basements always a no-no for Moldies?

Another place is an adobe house--not sure if it is new or old adobe. Are both of those necessarily moldy?

Any other things to avoid that are particular to the Southwest? I need to find a place to rent and cannot camp permanently or live in a trailer.

Lisa Petrisson

I stayed in an adobe house in NM for a while and it felt fantastic to me. However, the key here was that it was adobe with no drywall (all plaster interior walls). Adobe very frequently leaks like a sieve, but if there is no drywall (and of course there is no wall insulation), it usually doesn't matter in terms of mold because there's nothing it can grow on. But add drywall (which a lot of adobes do), and it's a nightmare.

This home was built in the early 1970s, I was told.

I don't know that I would go so far as to say all basements are moldy, but I find it hard to believe that many would be pristine enough to be an ideal place.

In general, Santa Fe does not seem to be a great choice in terms of outdoor air. About 10-15 years ago, it was fantastic. But it's fairly problematic now.

The only person I know who has done really well there lives outside the city (near the opera house), where the air is much better, and decontaminates every time she comes home from visiting town.

If you could live on the other side of the mountain, driving toward Las Vegas, that might be much better. On the other hand, Espanola and that area feels much worse than Santa Fe itself, so I wouldn't advise going that way.

Julie Rehmeyer

True adobe is fine. It's pretty much never got drywall or batt insulation. The big problem, though, is that so many adobe buildings have flat roofs, which are leak-
prone. Many modern buildings are faux adobe, with all the downsides of conventional construction -- plus, in Santa Fe, often a flat roof.

And almost all buildings have drywall on interior walls.

**Beatrice Latherings**

Flat roofs and swamp coolers are indications that you should be wary.

**Roger**

You couldn't pay me to live in a basement. I have lost all my belongings four times. I would hate to chance another.
Q. 27:5 – Feeling Respiratory Symptoms

I just moved a couple days ago from a small 2 bedroom apartment that had several molds in it. We did the at-home testing including one that you attach Petri dishes directly to the vents for a set amount of time, then let sit covered for several days. Over 8 different molds appeared and continued to grow.

The apartment complex had been done for black mold in some apartment a few years ago. But mine was not. And I was getting sick then.

For roughly five years, my son and I have been getting sick. Now we have moved to a 3 bedroom that the landlords had the air company come blow out the vents prior to me moving in.

Sadly by my second night here, I don't have the headache, but I have chest congestion, nasal drainage, pressure, and stuffy nose, as well as a sour stomach.

Now being that I had never lived in a house with mold in it before, I do not know what it’s like for a person to pretty much detox from mold. For the past year I have had living room size air purifiers in my room and son’s room. My son only seems to have a sore throat since he has been here. The house smells completely different. The nose bleeds stopped, and the headaches are no more. So we know the air is clean.

I just wanted to ask what the detox from a mold home to a clean home is like. Pretty much is what I am experiencing normal? (The sinus/congestion, cough, drainage, stuffy nose, sneezing, etc). Thanks for any answers you can give me.

Betty Keen

Different mold toxins can cause different symptoms. It sounds like you are in another moldy place. Did you spend some time in it before you signed the lease to see if you would have symptoms?

Lisa Petrison

No, chest congestion, stuffy nose etc. do not seem likely to be detox symptoms to me. They seem more like you have an allergy to something in your new
apartment, whether it be to "regular mold" (nontoxic or less toxic) or to something else.

I don't know if your new place is great, but (since the headaches and nosebleeds have stopped) it seems like it may be better than your old place. I would consider at minimum getting new bedding and pajamas for both you and your son, so that you can lower your exposure to those toxins while sleeping.
Q. 27:6 - A Clean Place

I just found out I'm likely sensitive to mold after moving to Coway, Arkansas, to an apartment that had mold in the bathroom.

Since being here I have been sicker. New sore throat symptoms, new itchy skin, new joint pain symptom, increased brain fog, etc

I'm looking for a new place. Literally wondering if I should buy a "new house"? Or is it even possible to get a mold free home in humid Arkansas?

Don't seem to feel bad outside, just indoors so far that I have noticed.

If I get a clean place, anything I can do to keep it clean?

A.M. Runyan

It seems like you might have mold-sensitive genes, if you are getting those kinds of symptoms from mold.

Welcome to the percentage of society who has to avoid mold to be healthy.

Take this seriously. With genes like this you could become extremely ill if you got more exposure. See this documentary trailer for an idea of what could happen (these people in the trailer lived like this for five years):

http://www.youtube.com/watch?v=1dkMK8Mbs8

Now that you've had this experience of getting strange symptoms from mold (not just allergies, but brain fog, etc.), you need to inspect everywhere you live in the future for mold, to make sure you do not get more exposure and develop full-blown environmental illness.

When I originally got sick from a moldy house I stayed in the same humid part of the country and didn't really get worse but also had trouble detoxing the mold that had already gotten in my body. When the summer came around and the humidity got higher/mold started growing again (it grows better over a certain temperature), I couldn't live there anymore and had to move out west to a less humid climate, and like many people here (lots of people move here because of mold sensitivity, allergies, etc.), I feel healthier out here. In fact, almost everyone I talk to here says they feel healthier here than in humid climates.
If you had to stay in a humid state there are probably things you could do to keep the humidity in your home very low and use ERMI or HERTSMI tests to choose low-mold homes.

Mold is something that will take from you everything you give it. Some of us find that keeping our exposures low and detoxing what we’ve already accumulated is one of the most important things we can do for our health.

**Lisa Petrison**

I would look at alternative building styles, such as log cabins with no drywall. In general, but I think especially in a damp climate, it's extremely difficult to keep drywall from getting moldy.
Q. 27:7 - Exchange for Rent

I moved out of my moldy home in Chicago and tried moving in with a relative. That home was moldy too. For the past few months I have been living with a roommate in Florida, but I have to move on. I am scared because I have nowhere to go and no money to try another place, and I can’t move back home.

I’d really love to find a caregiving position in exchange for rent, especially for a Lyme patient or someone in a similar situation as me. I’ve tried posting things but no luck. I don’t know what to do. No one seems willing to help.

What should I do?

Lisa Petrisin

In general, I don’t think it’s a terribly good idea for people with this illness to seek out other people with the same illness (especially people who are more ill than they are). My experience is that most people who are very sick with this sort of illness are living amongst really bad toxins, either from their current residence or cross-contaminated possessions from previous residences. And also, other patients have the same reactivated infections that people with this illness are susceptible to, providing another way to make things worse.

If I were looking for a caregiving situation, it would be with someone who had a totally different kind of illness. Though I have suspicions that things like broken hips or strokes can sometimes be related to mold exposures too, that seems a lot safer to me than trying to be a caregiver for someone with “mystery disease,” when they already know that they are hyperreactive to toxic mold.

Corinne

There is a work-trade position just posted on the EI Safe Housing group with someone who is mostly healthy
Q. 27:8 - Going on Vacation

I have an apartment that's been working well for me. I'm planning to leave for two or three weeks.

What can I do to keep mold/toxins low when I'm gone?

I'm thinking of having all the windows closed, running a small continuous room ionizer/ozonator, and having some DampRid and activated charcoal bags to absorb humidity.

Last time I left for a week I felt like my blankets got a bit musty here. I'll vacuum a lot before I leave.

Lisa Petrison

I guess that the reason that homes start to feel musty when people are away is because of the lack of air circulation. Bringing in outside air generally seems healthier, from what I have read and experienced. But whether you can keep a window open a little without fear of getting rain inside depends on the layout of your place, I guess.

Julie Rehmeyer

Continuous ozonation doesn't sound like a good idea to me. Concentrations won't be high enough to kill the bad stuff unless it really damages other stuff. But cracking a window, activated charcoal, and maybe a fan to keep air moving would make sense.
Q. 27:9 - Burst Pipe

Let's say you find yourself a 'good' house. Get rid of all your old belongings. Start from scratch in the good house. You start getting better, detox etc. Then a pipe bursts, you don't realize and suddenly you have some mold growing. Does this mean that this house is now bad for you and you have to move again?

A.M. Runyan

I'm renting. If there is a leak here I would get out of the lease with a disability note from a doctor. I can't afford to buy a home anyway, but for now it feels better to be able to move if anything happens to this place mold-wise.

Lisa Petrison

I saw this recently with a CFS patient who got sick from a work exposure but apparently was living in a good house. She increasingly realized that she was reactive to mold but had never had to move to get to a fairly recovered level of functioning (using a variety of other treatments). Then there was a roof leak and mold growth, and her health declined substantially. Things seem to have improved since a remediation and thorough cleaning, but in general it's been tough to get back to the level that she was at before.

Beatrice Latherings

It all depends on how it affects your health. If the pipe bursts, you get it fixed, you feel fine, all is well. If that last one isn't true....you don't feel well, then all is not fine and it's a case of "here we go again." Extreme avoidance, when required, is extreme.

Jeff Charlton

Moisture is the key to any mould growth and it doesn’t have to be in the form of liquid. It can be humidity and result in dew point condensation in or out of sight. Just because mould grows it doesn’t necessarily mean that it will be toxic or as toxic as the last property.

Typically mould growth type will depend on environmental conditions and the
substrate which is wet and which life form won the battle to dominate and this could be bacteria or different species and genus of mould.

I have been in a home where every wall was covered in active mould growth three feet up the wall. The occupants had absolutely no health issues because the mould was alive and happily growing without stress. It seems to me killing mould or trying too is often the trigger for health issues.

www.buildingforensics.co.uk

Janis Bell

This scenario is why we are trying to design mold safe homes where pipes are not hidden inside envelopes full of mold food.
Q. 27:10 - Water Pipes

I have a question that is a bit of a stretch. I just moved to a new place. I do not smell mildew or see signs of mold. (I know for me that means nothing.) But when I run the water it has a faint mildew like smell. Is this possible? That there is a type of mold that grows in the pipes?

Janis Bell

Could be mold in the hot water tank. Is it both hot and cold that smells? Also if plastic pipes leading to faucet, can get some mold if dust (food) and air once got in. I have no idea how to deal with this possibility.

I had a situation like this but the house had been unoccupied for awhile so It was sewer gases. Take 1/2 c baking soda and pour into drain. Follow with the same amount of white vinegar. Let bubble Pour down very hot water. See if thus helps. Do it more than once.

I also kept the plug closed when I wasn't using the sink.
Q. 27:11 - Keeping Drains Mold-Free

How do you keep drains and pipes mold free?

Julie Rehmeyer

Personally, I haven’t had problems with this. Each pipe will have a trap on it, which holds water and prevents sewer gases from coming into the house. So the only issue would be from the trap up.

Lisa Petrison

I’ve not found this to be a problem. If I suspected that it was a problem or feared that it might become one, I probably would make homemade milk kefir and then periodically pour some down into it.

Andrea

We use white vinegar and baking soda and a hanger works just fine!
Q. 27:12 - Inspection Schedule

Does anyone have a checklist or inspection schedule to ensure that there is no excess moisture or mold growth sneaking up on a home? Humidity meters, etc.?

Lisa Petrison

The engineer named Rock Cogar who lives near Colorado Springs regularly uses air tests for this. As has been mentioned many times before, air tests are useless when it comes to gauging whether a house is bad enough to make people sick (for instance, rarely catching Stachy). But Rock is using the air tests to make sure that there is NO mold growing in the house, and says it is much more helpful than an ERMI for that. He buys the air test kits from a company and does them himself. (He also periodically hires a mold dog.)

Janis Bell

Some remediers have moisture meters that use technology to read behind the wall surface. You can also bring a mold dog over for visits.
Q. 27:13 - Selling a Problematic Home

For those of you who have sold a moldy or potentially moldy home as part of getting away, how did you handle this? I don’t have an obvious mold problem to know what to remediate and have heard horror stories about people spending many thousands of dollars on remediation that didn’t even work. But the thought of causing this to unknowingly happen to someone else makes me physically ill. I have to sell my house, and not lose money to afford to move. It feels like there is no good way out.

Lisa Petrison

I think there is a difference between a moderately moldy home that can keep people with this disease sick and the small percentage of homes that are problematic enough to make people sick.

Of people who suspected that the home was responsible for causing their illness, I have known some who have just sold without looking into it; some that have sold to buyers who planned to totally gut or demolish the home; and some who have remediated before selling.

If you're not sure how bad your home is, you could get an ERMI done. If it comes out not-terrible, maybe you would feel more okay about selling. Of course, if it came out terrible, then in some states you would be supposed to disclose that.

A.M. Runyan

Some people are far more affected health-wise by mold than others. I'm starting to see CFS and mold illness as more or less genetic disorders that are caused by a combination of genes, in a set of genes, rather than a single gene. People with this "genetic disorder" need a much cleaner environment than most people and standards that work for most people (like regular remediation) might not work for them.

Beatrice Latherings

Disclose and sell. I have someone who offered to be the agent to sell my house to a contractor, who presumably would rip out what he thought was moldy (not visible in my house) and then sell it to an unsuspecting buyer even though he knew it had mold. I'm not sure how to handle that particular situation when I do
sell, and I share your concerns.

I have a friend who just bought a fix-up with a known mold problem. He's all enthusiastic to make it gorgeous. I hope I don't have to pick up the pieces later (although he is one of the ones who likely would not even believe me anyway, if he got sick from it.) And you can bet I'll never go inside that house, either.

Janis Bell

Disclose what you know. If there is a history of water leaks or poor drainage, let the buyer decide what risk they wish to take. 95% of US houses are moldy or potentially moldy.
Chapter 28

Construction
Q. 28:1 - Building from Scratch

Based on what you know now, if you were going to build a house from scratch to live in yourself, what would you do and why?

Beatrice Latherings

I am doing just that. The house will be made primarily of AAC blocks and panels (autoclaved aerated concrete.) I was sent a small block of this to try out, and it is really inert. That will be covered with plain old plaster. The roof will be metal; there will be no wood or cellulose products in the house. The AAC has a high R factor and so it meets energy codes without the need for additional insulation. I decided on PTAC units for heating/cooling because they fit in a metal sleeve in the wall, one per room, and can be removed if they need to be decontaminated or replaced. These are the units you see in the wall under the window in a hotel. I spent six hours visiting someone in a hospital room that had one of these, and it was the first time I was able to be in a building without a mold reaction. I figured if this ancient one was not molding me, it was the way to go.

The house has no duct work, no rooms share air, and there are breezeways under roof between the rooms, all to keep fresh air available and to ensure that if one room develops a problem, the whole house will not be contaminated.

Lisa Petrison

I think a simple log home, without any drywall. Those have consistently felt good to me, and I've gotten consistently good reports about them from some of the most reactive and successful mold avoiders I know. And since it would not be anything unusual, I could sell it to a non-Moldie if the air quality in the area went downhill without losing money.

Jeff Charlton

The main issue with any mould risk is moisture. Control humidity and or moisture you cannot have a mold problem. Ventilation is a key although humid environments may require air to be conditioned (cooled and dried before entering the home).

I would make ventilation not necessarily building materials my main priority. This should be emphasized because mold will grow on steel, glass and plastic if a bio
film exists and they almost always develop.
Q. 28:2 - A Safe Home

For those who have built or considered building a safe home, what essentials would you include? What would you leave out? What materials would you use? Places to research? Someone on this page mentioned designing homes without pipes hidden in spongy walls. Another person mentioned minimal plumbing. What would this look like?

Lisa Petrison

I increasingly think that for avoiding mold, if you just use no drywall at all and no wall insulation, pretty much any style building would be fine. Log cabin would be at the top of my list.

Corinne

I think exposed plumbing is a good idea. Another strategy I was going to use is to have all your plumbing in one wall (back the kitchen to the bathroom - leave that wall un-insulated and make a little door to look into that wall. I've been researching non-toxic building materials and am writing a blog about it. I am just putting the finishing touches on my chemical-free house

mychemicalfreehouse.blogspot.ca
Q. 28:3 - Monolithic Domes

I am considering building a home and I came across monolithic domes. Do you know anything about them as far as chemical sensitivities and mold, or do you know of some resources for building mold resistant homes? On their website they specifically mention how good they are for not encouraging mold growth and have some extra precautions you can take to make it even better. They even claim that they can stand up to an EMP...that's cool. Here's their website. www.monolithic.com"

Lisa Petrison

These sound good on the surface, but I'm very concerned that the company is located near Dallas. I fear that the plastic components of the structure especially, but really the whole thing, will get cross-contaminated by the "?" that is so prevalent in the outside air in Dallas. That would seem to have the potential of bringing a severe reactor down for years, without them having any understanding of what the problem was.

One time, I was camping in the Nevada desert and a new mold avoider came to visit. This person had told me that their car had only been to Ohio and Los Angeles, so I thought it was probably okay. But the car gave me the same sensations as the "?" toxin, which I only have found to the extent necessary to cross-contaminate like that in a few places (e.g. Ann Arbor, Tahoe, Dallas). Then he revealed that the car had spent a month in Richmond, CA (near Berkeley), which a number of people have told me is a real problem spot. The car threw me so much off balance that he had to move it several spots away. So I would not underestimate the cross-contamination risk with these Monolith domes.

Erik Johnson

When considering materials for my "mobile environmental control unit," I considered fiberglass.

The variables of the catalytic process, persistent off-gassing and known potential of fiberglass exposure to sensitize people removed it from consideration.
Chapter 29

Remediation
Q. 29:1 - Floor Drain Backup

Dirty water started rising up from our floor drain in the basement last night. Was 1" standing water on concrete. I had been down there 4 hours prior, so it sat a max of 4 hrs. All boxes have been disposed. Roto-rooter cleared drain, but happened again this morning. Assuming they get it this time, what’s our next step? Fans are going. Is there a type of disinfectant that won’t aggravate MCS? I’m taking detox meds/supplements, antihistamine, and using 'Super Good Stuff Nasal Wash.' "

Jeff Charlton

This is a difficult situation for MCS people. The sewage (or black water) flood event will leave a residue of surface and absorbed bacteria. Applying disinfectant may or may not kill them but dead bacteria result in endotoxins which have cell walls and cause IgE issues AND these can multiply the effects of mould exposure.

Lisa Petrison

Based on my limited knowledge of remediation type issues, it sounds to me like you did everything right and that things will be fine. But certainly information from people more knowledgeable than me would be really great.

In general, sewage backups do concern me. Sewers have a lot of bad things in them. However, my guess would be that if people with this illness are generally feeling good, then the sewer system in their neighborhood probably is not very contaminated with the really problematic mold toxin(s) and thus that a backup might not be as problematic as it could be in a generally problematic location.

Erik Johnson

In 1986 I realized that when the toxins lashed out, or "amped up", I simply could not remain in a house.

The toxin level was overpowering. I had to have a "Plan B."

After years of unsuccessful attempts to get back to a normal life, "Plan B" became my primary lifestyle.
Janis Bell

I've found Nasal crom and myrrh and peppermint oils useful to mitigate neural excitatory reactions from inhalants. One the entire drain issue is resolved I would look into a deep cleaning of both floor and walls and ceiling. Mycotoxins are almost impossible to remove by cleaning although a good cleaning will reduce the quantity. If the space still triggers you things to try are ozonation and sealing all surfaces with something that will block toxins from entering the airspace Cohen filter and UV the air to clear it.

Avoiding Mold

An update a week later from the person who asked the question:

> So far so good. They tore out carpet and sheetrock. Then disinfect, used the zero air deal, having 7 fans in the 1 room blowing all air through only one window out. I've limited my time downstairs, but knock in wood I'm ok.

> They used a water-based disinfectant called ShockWave to deal with the bacteria on sewer water. They sprayed the basement as well as all carpets in the house(as in early stages we inadvertently trampled through the house). I stayed in a clean hotel for 2 days and was fine when I came home. No fumes.

> No MCS to the product, thank goodness!

> I'm a little tired, but that's just from moving back and forth and other outside stressors. It doesn't feel MCS or mold related to me.

> A couple links about Shockwave."

http://www.fiberlock.com/mold/8310.html

http://www.midwestcleaningtech.com/wfm.asp
Q. 29:2 - Indoor Environment

What sort of environment is best to have inside your home? I've been seeing figures saying humidity must be kept below 50% to stop moulds growing. Is it that simple? Should carpets be removed? Old sofas etc?

Julie Rehmeyer

If a home has a history of water damage, or is in a location that's especially bad for mold, there's probably nothing you can do to make it safe for someone who's already sick.

If you're starting with a house that feels good to a sick person, on the other hand, the key is to keep it from going bad, and that's mostly an issue of keeping it from getting water damaged through a leak, either from pipes or from outside.

Also, objects in the home can pick up contamination brought in from outside, so at least during the period when the person is hypersensitive, it really makes sense to shower when you get home, at least if you've been in a moldy building and possibly always.

Carpets do tend to hold mold. I had to cover the carpet in my now-husband's bedroom with plastic because it started bothering me. (We put reed mat on top of that so that we weren't walking on yucky plastic and damaging it.) And sofas get contaminated quite easily. We've had to put the cushions of my sofa out in the sun to clear transient contaminations a number of times.

Lisa Petrison

It's my understanding that toxic species of mold, such as Stachybotrys, tend to grow well at a lower level of humidity than many other species of mold.

Apparently this is one of the reasons that modern buildings with climate control tend to be breeding grounds for toxic molds -- because they do great at average building levels (e.g. 70 degrees and 60% humidity).

Even if you are in a place with 10% humidity, mold can still grow anywhere that there is water and cellulose (e.g. as a result of leaking windows, leaky pipes, leaky roof, condensation in HVAC system, drains backing up, bathtub overflowing).
If there already is mold growing and you dry it out by using a dehumidifier, it will remain just as toxic. In addition, it will release a bunch of dead toxic spores all at once (in the hope that they will find new growth spots elsewhere), which means that your house actually may feel worse to you.

I’m not sure what to say about the carpets and sofa. If they are contaminated from being in a bad building (or certainly if they have had mold growing on them!), it’s unlikely they will be able to be cleaned to the point where a sensitized person can tolerate them.

A lot of people with mold illness or MCS end up avoiding carpets or sofas in general. They tend to be pretty toxic from chemicals and can’t be easily cleaned. But I do know Moldies who have lived with them successfully too.
Q. 29:3 - After a Flood

(Note: This question is from Fall 2013 from an experienced and mostly recovered mold avoider living in Boulder.)

I'm okay after the floods but many people are not and I'm trying to help them by posting accurate information on how to clean up after a flood, how to prevent mold, and how to deal with wet crawl spaces and basements. Do you have basic info I can post? A big thing is what sprays to use or not use (I say no bleach of course).

Many people want to use concrobium. Is that toxic? Good or bad idea? Others ask what to put on wet dirt in crawl space -- I was thinking borax or grapefruit seed extract, after drying out as much as possible. Then when totally dry sealing off crawl spaces with vapor barrier. They are also desperate for legit remediation companies.

Do you have any information about the information in this?

https://sites.google.com/site/hurricanemoldcleanup/

Thanks for any advice. This will help thousands. I looked at info on Sandy Hurricane but so much says to use bleach.

Erik Johnson

I have been worried about what kind of damage will happen to the water table if thousands of people all start drenching their environment with every mold killing chemical they can buy. I don't know about concrobium.

I think the Bible had it right. Anything with mold growing on it after being dried out must be removed to an unclean place outside the city.

Most molds won't continue growing when deprived of water. If they do, I don't think chemicals are likely to stop it, and may actually make the problem worse in the long run.

For the future of our environment, we have to stop messing it up.

I know this is not what people want to hear. It would be nice to spray some killer
crap on mold and solve our problems.

But it looks like mold is a much tougher customer that we bargained for.

Vapor barrier is another word for "Condensation trap"

Don't think for a moment that mold toxins from the happy colonies underneath can't come right up from around the edges.

Increase ventilation as necessary to decrease humidity.

Dehumidifiers and space heaters (watch the carbon monoxide - have to be out of the place) can help temporarily, but the best solutions are long term solutions.

After a while, people forget, the machine breaks.. etc.

Rock Cogar

People in and around Boulder need to be reminded that just because Colorado is arid almost all the time does not mean that climate will prevent mold in any way.

It is crucial that wet sheet rock be removed, the wooden studs need to be left open for complete drying, then only much later after careful inspection (with air testing or Mark's mold dog Mollie) should new sheet rock be installed.

Chris Copeland

Concrobiun is nontoxic, but I and several others have found it ineffective against mold, even with mild contamination. I had tried it when my mold doctor recommended it for cleaning hard surface items that had no visible mold but came out of a moldy home. I think the doctor was just trying to suggest a nontoxic mold cleaner but had no positive testimonials from his patients, only from the company's website. I naively trusted the doctor's advice and ended up cross-contaminating the apt I moved into with my supposedly clean items. As for *preventing* mold, I don't know if Concrobiun works, as it claims, but I wouldn't trust it.

Avoiding Mold

Here is an updated report from the person who asked the question above:
I posted some information and someone ripped out all her drywall then was told it could have asbestos and now the city is giving her a hard time. Oh this is so hard! I should have a caveat for everything to check with the city first perhaps? Or another idea?
Q. 29:4 - Do It Yourself

Where's the best place to get advice on removing mold from my apartment by myself? I can't afford to hire somebody.

A.M. Runyan

If you are ill with anything of this nature, probably best not to do it yourself. I heard of someone who did her own remediation and became bedbound from it. Even a few hours or days of exposure can take months or a very long time to detoxify and can leave long-term damage. How would you treat the apartment if it had nuclear radiation contamination? Treat mold like that. It's serious.

We don't know from this question what your health status is or what kind of mold is in the house (just mildew in a shower or was there water damage or is it behind walls) so it's hard to say really, but in general sick people should not be around mold and certainly should not be remediating mold.

Lisa Petrison

If you're sick with one of these "mystery" illnesses, and especially if you got sick in your current place, I wouldn't bother remediating. The return on investment will be much higher if you can figure out a way to get out. And definitely it's very dangerous for sick people to try to do remediation themselves, even using protection such as masks.

Julie Rehmeyer

If you're currently sick from mold, chances of remediating it well enough for it to be ok for you are slim. Better to put that energy into finding somewhere new and replacing your belongings. If you're not yet sick, or if you're only mildly sick, you have a shot at it.

Beatrice Latherings

Find Heather Plude's blog. She successfully did it herself. It's not easy.
Q. 29:5 - Re-Doing Basement Bathroom

This is a question from a highly health-conscious friend of mine, with four small children, in the city I just moved from. They just bought a new house last spring. I stayed in their basement for a week this summer and it was slightly mouldy, too much so for me. A slight smell of sewage gases was emanating from the bathroom floor drain, and a strong (to me) mould smell was coming from the shower drain. They have no known history of mould exposure or susceptibility, that I know of.

> Help! I am redoing my basement bathroom because I suspect mould - they are ripping it up as I write this. I am now paranoid that the spores will be released into the house. Should I be doing something? Air purifier? Open windows, do they travel in the air? Did I just make the problem worse? I am in a panic.

> I sneeze every time I go in there! How do I contain it?

> If I keep the windows open will it dissipate?

Lisa Petrison

In theory, if there is a belief that the mold is toxic, then the room should be sealed off with plastic from the rest of the house while the remediation is being done and the moldy materials should be packed up carefully for disposal.

So it sounds like they didn't do this.

It sounds like these people are healthy though. That makes it a different situation than if people who were already sick were there.

I would certainly try to air things out, use air filters, etc. And clean everything very thoroughly. And stay away from parts of the house that seem contaminated until they are cleaned.

But if a sensitized person did not feel really bad before the walls were opened up, probably it is not the worst kind of mold anyway.
Q. 29:6 - Covered By Insurance

My husband owns a house which he rents out (so we don’t live there). The renter left a window open and then left town, with the result that a pipe froze and burst and flooded the house. It’s covered by insurance, and at least it’s clean water. A company came in and removed all the wet drywall and insulation and flooring. They certify that the moisture is below some limit, but they don’t do any mold testing. The house was too moldy for me to tolerate before the flood, and it actually feels a bit better to me now. Is there any other sort of testing that would make sense in this situation? We could do ERMI, but I’m not sure whether it’s something that an insurance company would pay attention to.

Lisa Petrison

Happy that the insurance company paid for the problem. I have a rental/vacation home in Illinois, and when it flooded, the insurance did not pay for it at all. No point in even having insurance, it seems.

If you had a test done and it came up as problematic, that would not necessarily suggest that the mold was due to the flood. So I wouldn’t be surprised if insurance companies (which to my knowledge at most cover problems from acute problems) were not interested in seeing those results.

Probably your knowing that it does not feel worse to you than before the flood is the best reassurance, I would think.
Q. 29:7 - Thieves Oil

I've been diffusing Thieves Oil in my apartment to get rid of cross contamination effects. It seems to work pretty well. Does anyone have comments on Thieves Oil?

Karen Dean

Been beaten to death many times on many sites. Usually the effect is caused by the spores being made heavy and dropping to the ground, easier to vacuum up. Don't depend on it to cure a toxic environment. Only getting rid of the growing mold will help that.

A.M. Runyan

Beyond just killing mold, I find that essential oils do seem to help clean up toxins somehow in environments, so I could believe that observation. When I get some nasty toxin contamination (with toxins, but not even necessarily spores or anything) spreading lemon oil and orange oil around has often helped. Not sure why. I find that I sometimes get a little sensitive to clove and cinnamon oil, so I prefer to just use citrus oils, and they are often cheaper per ounce. Who knows exactly how any of this works; but yes, I find that essential oils are nice. Not an excuse not to try to keep mold at the absolute lowest level possible; but a real help when you mess up and need to clean up. Might have some beneficial properties when inhaled as well.

Lisa Petrison

In general, I feel the same way about this that I do about ozone.

* It seems to have some effectiveness in killing mold.
* It might have a little effectiveness in denaturing (some) mycotoxins, or maybe not. But in any case, it seems to be at most only a little effective, not particularly effective.

Thus, it's probably not a good idea to use this in a bad building at all. If it kills the mold without really effectively denaturing it, this has the potential of making things worse (since colonies release dormant spores into the air when they die).

For someone already practicing avoidance effectively, they can try this if they
want with small contaminations to see if it helps.

Personally, I think that Thieves Oil smells nice and I occasionally diffuse it or spritz it around. But I've not found that it does enough to make a difference to make me think of using it very often.

David Ou, M.D.

Some people have been known to have negative reactions to Thieves’ Oil. For some, the reaction is even worse than mold.
Q. 29:8 - Soy Candles

A.M. Runyan mentioned using soy candles to clear toxins from the air. I would like to hear more about that.

A.M. Runyan

Candles are really astounding for cleaning the air. I've gotten many reports of them being helpful. In the past, when my home was contaminated, having a candle on would make a huge difference in the air quality (particularly if I had to have the windows closed, like in the winter). Just be careful that you don't burn anything down, and try to leave them in closed containers where they can't fall over and set stuff on fire, and make sure there is nothing for several feet above them that could catch on fire.

I used to make my own candles using Mason jars, cotton lead-free wicks, and this wax from amazon:

http://www.amazon.com/Natural-Soy-444-Wax-pound/dp/B001QMXKN0/

It can be messy making them though. One way to make them is to pour the wax in the jar and then heat it very slowly inside a pot with water. You don't want it to ignite. You can also use a double boiler. Then I used to use plastic forks to get the wick to stand up straight in the jar while the candle was setting. There are instructions online.

If making them sounds too daunting, two brands I have liked are Beanpod candles and Tru Melange (beeswax and soy), which I believe are just natural ingredients and essential oils. In theory it's not great to use scented candles since burning even essential oils can be a little toxic, but I feel like I handle it fine even when I'm sensitive to things like fabric softener, and it can feel nice to have some anti-fungal essential oils getting diffused by the candles (peppermint, cinnamon, etc.). Vanilla usually feels helpful for cleaning spaces.

I've also heard of people using flamethrowers or lighters to clean air - basically the fire burns up stuff, whether spores or toxins, so that it does not go in your lungs. I guess it's a similar principle to ozone (oxidation), but it seems to have more predictable output - I have never had candles make toxins worse or seem to create new toxins or strip chemicals from the walls, like I've had happen with ozone.
Chapter 30

Filtration
Q. 30:1 - Best Face Masks

For those occasions where we must enter a mold contaminated building, what have others found to be the best face masks for protection?

Lisa Petrison

After a few experiments with using masks, I concluded that it was better just not to go into buildings that my body didn't like.

Beatrice Latherings

Well-fitted respirator ("gas mask") with acid gas/VOC/P100 filters. So far I've been ok with half face but some people need full face because mycotoxins can enter through the eyes.

In milder situations, I've used the I Can Breathe honeycomb mask

Jessica Grow

I have been trying the vogmask (in the photo) and RZmask. The vogmask is actually certified N99 and is more comfortable and cute but you cannot replace the filter. The RZ mask is not certified yet, is not as comfortable, but it seems to have a better seal and you can replace the filters.

I only use it for quick trips into places that I don't know if they are moldy, i.e, rest stop, gas station, doctor’s office. If I know a place is moldy I don't even go in with the mask.

I'm getting ready to go on a trip to Puerto Rico and I am going to test my C4a before and after the trip. I will wear it in every building I go in. We'll see how it goes!

Kathryn Chastain-Treat

I wear a mask and a Tyvek suit to avoid contamination of my clothes.
Q. 30:2 - True HEPA Mask

I've noticed that the only time I really get issues now is when I've gone into a building somewhere. So since sometimes it's unavoidable, I've decided to buy a True HEPA mask that i can carry out and use when needed. I'd rather look silly than damage my body any more. Do you know anyone who has gone that road, and found a convenient mask that does the job (filters spores and mycotoxins out)? I saw someone wearing a mask, but can't remember who.

A.M. Runyan

I used to wear two of those doctor's office masks on top of one another. Still have to wash clothes (ideally with 10 drops of grapefruit seed extract) and wash hair after going in these places. The stuff really seems to stick to hair. I use tea tree oil shampoo if I've been somewhere with lots of spores. Ideally though is just avoiding the buildings in the first place, while in the detox phase.

Julie Rehmeyer

I used one similar to this:

http://www.northerntool.com/.../product_200395637_200395637

It was very helpful, but be careful not to let the filters get shot. I had my very worst reaction ever in a tow truck when wearing a respirator with old filters, and I think it was the filters that did me in more than the tow truck. I put a respirator like this on once in a moldy airplane, and it pretty much saved me. I've also used it to be able to watch movies in a somewhat moldy movie theater. I wouldn't rely on it in a truly terrible situation, but it's a useful tool. I haven't found a charcoal mask to make a difference, though I have found a charcoal blanket to be helpful. Good for wrapping around oneself in a moldy building, or for laying on a hotel bed.

Lisa Petrison

I never liked wearing even regular hospital masks, and so I never tried anything else.
Dena


It's charcoal not HEPA but has been great for short mold exposures and I couldn't be without it for chemical exposures.
Q. 30:3 - HEPA Filters

Where is the best place to get HEPA filters, and does it matter what kind you get? Also, any good suggestions for remediation help in the Bay Area that doesn’t cost a fortune?

Lisa Petrison

If people are not already sick with ME/CFS/Lyme/FM/Mold illness, then remediating a home in the Bay Area may be worth doing. For people who are already sick, I would not bother to remediate a problematic home because the likelihood that the home is going to be good enough for health improvements to be made even if the remediation is "successful" is extremely low. Just living in the Bay Area at all is too much for many people to be able to tolerate, though some parts are much worse than others.

I would not bother to use a HEPA filter to try to protect myself from either the mold in a bad home or from the problem substance (which I believe to be a particular kind of mold, possibly one making the toxin Penitrem A) in the Bay Area. Some places with milder outdoor mold problems (e.g. agricultural areas of the Midwest) may be appropriate for the use of a HEPA filter, but I wouldn't do it in the Bay Area. The only use for a HEPA filter there might be if you are very MCS and trying to filter out chemicals rather than mold, but even then, I am suspicious. Once the air filter gets contaminated with toxic mold of whatever sort, it will be useless for pretty any purpose, for people who are hyperreactive.

Jessica Grow

I just bought a HEPA filter and one thing I learned while shopping for one is that some advertise "HEPA-like filter" and these are not actually HEPA filters. So make sure it says "true HEPA filter."

Also if you don't want ozone, make sure you read the description carefully.
Q. 30:4 - Filters Harbor Mold

Can HEPA filters harbor mold? What about charcoal filters? I have a Summit HEPA/UV/charcoal/ozone machine that I want to bring when moving to a new apartment (the current one is proving a bit of a moisture/mold challenge), and I don’t want to cross-contaminate. Should I just send the whole machine back, or just get a new HEPA filter to place in it?

Lisa Petrison

Erik advised very strongly not to bother with air filters, but like many mold avoiders, I decided to experiment with a few anyway. My experience is that the whole machine becomes cross-contaminated very easily (which makes sense since mold has a strong affinity for plastic), to the point that they are soon the worst item in the house. So that makes them pretty much useless, in my opinion.

When I was in the Midwest agricultural areas, I felt like the entire outdoors was moderately contaminated with a toxin that felt like a moderately moldy building to me. (I believe that was trichothecene from the Fusarium mold known to grow in the wake of Roundup usage.) Admittedly, air purifiers helped considerably there, in my trailer. So if I were reactive and being forced to stay in a place like that, I might consider buying an inexpensive air purifier for my sleeping space (e.g. $50) and then replacing the whole unit periodically.

Other than that, with regard to mold, I am finding it hard to imagine them being useful. In particular, the "?" toxin that is outdoors in Tahoe and other cities cross-contaminates air purifiers permanently almost immediately, even when just a small amount is present. It is too expensive to keep throwing those out, under those circumstances.

Forebearance

I would start over with a new machine, just based on my experiences of ruining rental homes.

Janis Bell

Adding to Lisa: mycotoxins and mold VOCs are not picked up by any filter because they are too small. The filters catch spores and dust particles which only
helps a little to keep those things out of the air. Some people are using an expensive aranizer which claims to neutralize the mycotoxins and was tested effective against tricothecene toxins.
Question 30:5 – Filter Goes Bad

We just moved from a bad house into a new place. Have been doing pretty well here. We threw pretty much everything away.

We had an IQ Air HEPA system with activated charcoal in our previous house. It helped for a while but then it seemed to make things worse. It is an expensive unit so we decided to clean it thoroughly and replace all three filters on it (pre-filter, charcoal filter, and hyper-HEPA) which cost about $300.

When we turned it on I started to feel bad. I had read that air filters can go bad in places but I was not expecting a problem after the cleaning and all the replacements we made. The only part that we could not clean is the fan blade because it is encased - but that is before the air flows through the charcoal and HEPA.

Any thoughts?

Lisa Petrisaon

Yes, Erik has talked about this and I have experienced it as well.

It seems to have to do with the ability of plastic to absorb mold toxins and magnify their effects, especially when running (e.g. being affected by electrical current).

So it's not just the contaminated filters that are a problem. It is the plastic in the unit itself.

The only thing that I can think of that might help is to take the whole unit to a higher altitude (such as 1000 feet higher or more), wait a couple of hours, and then bring it back down.

If that doesn't work, probably it will take years to die down.

Erik Johnson

I got a new HEPA vacuum when I was still trying to fight "the bad place.” It was a nice one, a Miele.
Seemed to help for a while. But a strange thing happened. The vacuum itself started to hit me.

Of course I changed bags, blew out the inside, washed it... but it just kept getting worse and worse. Finally I couldn't get within ten feet of the damn thing.

It was about this time when I started asking myself, "Haven't I tried hard enough? What more can I do? I think it's time to get the hell out of here."

**Daliya Robson**

To remove mold odors as well as spores you need UV. Also the carbon or the HEPA you have might not be good for you. Some people react to certain blends or carbon and some heaps that have been treated specially for mold.
Chapter 31

Ozone
Q. 31:1 - Words of Advice

Please tell me more about using an ozone generator. Has anyone here had success using one for slightly moldy rooms or contaminated possessions? Any words of advice?

Julie Rehmeyer

Yes, I have found it useful for quickening the process of getting rid of transient contamination that I picked up from elsewhere.

A.M. Runyan

I got a GT low-power ozone generator that I run all the time in my house to replenish ozone that is present in outdoor air but depleted in indoor air. Gives the air a little boost to stay clean. This is not so much to clean contamination as it is to just provide good indoor air quality. (Some people are sensitive to low-level ozone in air - MCS people tend to be - but I am not.)

For things that happen to an apartment/house once I move in, during avoidance, I use soy candles (which burn off offending VOCs) and open windows/circulation. The same goes for if I get any new furniture or if I'm in a new building or anything that involves VOCs.

Ozone has done strange things for me before (made some things worse) so I rarely if ever use an actual high-power ozone generator in my living space, and I would not rely on it to clean contaminated items from one's former moldy location, since some of these toxins are not cleaned by ozone (or barely cleaned by anything, frankly).
Q. 31:2 - Ozone Experiences

What experiences have people had using ozone to remediate their environment (either moldy buildings/cars or cross-contaminated items)? If I am considering buying an ozonator for this purpose, are there any that people particularly recommend?

Karen Dean

Read your warranty. Most warranties have so many stipulations on the use that you can only use it in a way that will never be strong enough to degrade toxin. If they say open the room up every couple of hours you know that won't work. The way to use a generator is to put it on a ladder with its butt outside. Have a filter on the intake so you are no bringing in more spores to the room, tape up the door, then let it rip for several days. Make sure you cleaned the room really well first, and removed mold colonies, and as many spores as possible. Afterwards, air out for several days, the ozone dissipates after 6 min, but the chemical by-products created by the ozoning may take much longer.

Ozone will degrade mold toxin. But it can also degrade things like rubber really badly, and plastic so it leaches toxic chemicals. I remember one guy who had a really strong ozone generator who left it in his car all weekend, it disintegrated the dashboard. Don't do that.

This is the company I recommend if you are going to buy an ozone generator.

http://www.ozonegenerator20000.com/...

Julie Rehmeyer

I have used the Max Blaster for cross-contaminations and found it helpful. I've never used it for an active mold infestation. I've had mine for more than a year, and I'd guess I've had it on for a few weeks' worth of continuous time, and it still seems to function well. I haven't had difficulties with it getting contaminated by the contamination in the room -- though again, I've only used it for cross-contaminations. Also, I haven't noticed any appreciable deterioration of objects in the room. I've used it in a car overnight, again without noticeable degradation to the car’s interior. Ozone definitely tends to degrades things, though, so I think caution is appropriate.
Q. 31:3 - Moldy Basement

What can anyone share regarding the use of an ozone generator to clear mold spores in a moldy basement? I hear it doesn't directly kill the mold but can go a long way in removing many of the spores. Does anyone have experience here?

Lisa Petrison

I actually do think that ozone (in high enough quantity) is helpful in killing mold. However, that is not the key here, since we are concerned not with live mold spores but with the toxins they make. Moreover, if you kill a mold colony, it will release a bunch of dormant spores all at once, which can make the environment even more toxic. Plus mold will spring back to life, if the pre-existing problems (water + cellulose) are not fixed. So to address a mold toxin problem, you need to actually remove the colony and fix the water problem.

After my house was extremely thoroughly remediated and repaired, the remediators ran an expensive professional ozone machine (along with some HEPA filters) for more than a week. The house felt a lot better after that (though somewhat worse after I started doing things like opening drawers and cleaning out closets). And the house has felt increasingly less toxic over the five years since (suggesting that mold did not grow back....one fear here was that the particularly bad kind of mold that we had would spring back into existence at the first opportunity, including in the HVAC system).

So despite the fact that the ozone may have been bad for electronics etc., I think it may have been a good idea to use it in combination with professional thorough remediation. On its own, I feel sure it would have been a mistake though.

David Ou, M.D.

See http://www.survivingmold.com/.../ozone-generators-and... at Dr. Shoemaker's website.

Jeff Charlton

Killing mould does not remove it BUT does make it more easy to inhale. I am now measuring dust particulates in the air as a guide to spores, fragments and general particulates. I have now firmly come to the conclusion that most
contractors and people are misguided in their approach to mould decontamination. The air must be cleaned, after removing the moisture source and visible or surface mold. There are various methods of cleaning air but almost no established method works. A new low cost process is Aerosolver.com which is a salt that is fogged into the air and this coagulates debris and brings it down to horizontal surfaces for wiping up. I believe people should use a professional company to fog this product but can do the cleaning up themselves to save cost and probably do a better clean up.
Q. 31:4 - How Long is Enough?

Talk to me about ozoning moldy buildings or houses. In my experience it's been helpful, but I'm hearing that it can be a disaster if not done long enough. How do you know how long is long enough?

Karen Dean

It depends on a number of issues. How big you generator is, how well it is functioning, how big or complicated the thing you are trying to detox is. What happens is the ozone will implode even ambient spores, causing a toxin release. If there is a mold colony in the wall of a room, massive amounts of toxin will be released by ozoning for one or 2 days, even with a big generator, you would have to ozone past this point, and then degrade all the toxin. If you open the door, more spores are brought in. Most generator manufacturers tell you to open and air out the room every 4 hrs. This is counter-productive. I have a 14,000 an hr generator. I would ozone the cab of my truck overnight, for about 8-10 hrs. Always ozone with the business end taped in a window or door, with the back end bringing in fresh air to make ozone. Put the generator on a ladder as ozone falls to the ground. Open a small hole on the other side to release air pressure. I ozone objects outside taped up in a garbage bag, overnight works for me. I would never do a room in less than 5 days. I would never attempt to do a whole house, unless I had a few strong generators. When I left the moldy house, I took all my jobs, which I could not toss, put them in a small bedroom, ozoned it for 2 weeks, everything except rubber came out clean, ozone destroys rubber. You must air out a room for several days after ozoning, to remove chemical byproducts. Ozone dissipates in 6 minutes.
Q. 31:5 - Worse from Ozone

Why is ozone making toxins worse, and how can I clean up? Twice in the past two months, I've tried to treat mild contaminations with ozone, and the ozone seems to have made it worse and spread the toxins. This is the same room ozonator that has worked really well on general mold, cigarette smoke, etc. For clean-up, orange and lemon essential oils seem to help. But whatever this is seems really persistent. This is the second night in a row I'm having trouble sleeping in the apartment because I'm wired, even though I cleaned about 4 hours today and had large box fans going all day to air it out.

Lisa Petrison

At the very beginning of my experience, Erik suggested that it was a waste of time to try to clean things and that instead it would be better to take a pure avoidance strategy. So that's what I've done.

Basically, this has meant for me taking two tacks:

1) Learning to quickly and efficiently identify toxins that are likely to be very problematic (especially in terms of lasting contaminations) and pulling out all the stops to keep them from cross-contaminating my living space.

2) Insofar as my living space (including the car) did get contaminated, pulling out all the stops in terms of getting away from the contamination until it died down (e.g. sleeping in a tent, not using the car much, spending the daytime hours in super-good places to "balance the books").

I used ozone once, on the moldy house after it was remediated (in the hope that I would be better able to tolerate it to give instructions to people about what to do with my stuff) and never even considered trying it again even though it did seem to make somewhat of a difference. I've never used essential oils (except just to freshen the air generally). I never use anything to wash clothes except ordinary mild laundry detergent (and threw away things that still bothered me after a wash). I never tried to clean my environment with anything except water and Dr. Bronner's.

Occasionally I did put bothersome things in the sun, and that did seem to help. And the altitude trick, as I described, has seemed very helpful.

But in general, I think that my decision to eschew trying to clean things has been
the right one for me. If nothing else, the hours that I would have spent cleaning things have been an equal amount of hours that I instead have spent being really clear (instead of being exposed to the bad contaminant trying to get rid of it).

Getting clear for enough time seems to fix just about anything, in my experience. And then the contaminations that do exist feel less bothersome.

Of course, this is an extreme strategy not suited for everyone's personality, regardless of how well it works.

Bennett

Some toxins are neutralized when oxidized, others are made more toxic, that's why your liver has two detox phases oxidation and conjugation

Erik Johnson

Prof. Harriet Ammann told me that ozone does not denature mycotoxins, and residual ozone can not only damage the lungs, but diminish olfactory sensitivity, which fools people into thinking smells have been neutralized, when it was their ability to smell that was decreased.

Karen Dean

There are 2 things to consider.

#1, if you have an ozonater that you cannot open and clean the grids with alcohol, the unit may have reduced output. They really do not last that long at full strength. All the first ones made you had full access to the plates, I used to have to clean my first one every 2 weeks. Now most are made not to be user serviceable, I have no idea why.

#2, ozone implodes the spores, and they dump all their toxin before they die. So you must ozone past this point, way longer than you would ozone just to remove smells from a room. I would never do a room for less than three days. But it also depends on how strong your generator is. I recently did my work room for a week straight with a pretty strong one.


Julie Rehmeyer

Gah! That's terrible. I've never had that experience, and I'm not sure what to suggest.
Q. 31:6 - Car Ozoning

I'm planning to ozonate my car for a mild mold problem (from water that has since been dried out). Any tips on car ozonating? Anything to watch out for? And is there any danger in renting an ozone machine to ozonate the car (from a health company in town that does ozone treatments of all sorts) while waiting for the one I ordered to arrive?

Lisa Petrison

One of the first horror stories that I heard about avoidance was from someone who moved out of her moldy apartment (she'd been sick for two decades and tests suggested this was just moderately bad mold, not even Stachy) to a long-term hotel room as a transition. There happened to be a leak and she was worried about mold, so the management fixed it and then brought in a high power fan to dry things out. The fan happened to be contaminated with a horror toxin (far worse than anything that was at her old apartment), and it cross-contaminated all her possessions. Then the computer that she was using there sprayed the same toxin all over the next room she was at. Then, she repotted some of her plants that had been in that room (without washing the roots) and gave them to her aunt. They felt okay to her a year later, so she put them on the patio where she was living. And then when a big storm kicked up and some of the dirt got knocked over, that same toxin reappeared and forced her to have to flee again, and get rid of everything.

In general, I do not want to be around anything that has been in a building bad enough that people feel it necessary to rent special tools to remediate, because those buildings very often have extraordinarily bad toxins in them. And I also am suspicious about using ozone in general, in proximity to electrical systems that could get ruined by it (i.e. especially in the car). So if it were me, I would just clean, dry and vacuum the car thoroughly; eventually take it up to the mountains to see if I could reduce the problem that way; drive with the windows down and decontaminate afterwards if necessary; and (if necessary) buy a different car. (If that last sounds excessive -- the reason I bought a used Toyota 4Runner is because I felt like I could sell it in without much of a loss if I needed to. That's why I chose a used Casita rather than some other RV, too.) But based on what I know of your problem (brief water event immediately dealt with, very mild mold issue) I think it will calm down within a week or two so that you don’t notice it anyway.
Jeff Charlton

Ozone destroys rubber so be prepared for a car to fall apart if you put enough ozone in it. Ozone may kill spores so you now have the dead fragments left which are as toxic or allergenic and more easily inhaled. The type of ozone machine you likely can buy will produce ozone from the air which contains Nitrogen and this will turn this gas in Nitrogen Hydroxyls which is toxic. I have tried oxygen fed ozone (No nitrogen but have varying results also fogged a new car with Hydrogen Peroxide and this had a better effect. Be careful ozone is very toxic but has a half life of 15 minutes so if you try make sure you leave the vehicle for 5 hours after turning off (from mains ) and then open the doors before a few hours, also ventilate the car with fans to blow out debris and fragments.

www.builidngforensics.co.uk

Karen Dean

There is a chance the unit could contain really bad spores if it has not been cleaned really well. Ozone is really good at degrading toxin, but less able to de-nature spores, although it will "kill" them (make them non-viable), they will still be allergenic.

Chris

I've ozoned my car a few times when it seemed mildly contaminated and used a brand that was recommended from a fellow moldie that successfully used it it her house and van with no degrading of materials. I was advised to clean car with ammonia/water mix after ozoning to get rid if the dead but toxic spores. It worked like a charm each time! Many people like myself have no problems using ammonia because it disintegrates so fast. But if you do not tolerate ammonia, use hydrogen peroxide.
Chapter 32

Environmental Testing
Q. 32:1 - Best Kind of Test

I would like to know if mold is a problem in my apartment. What kind of testing should I use to find out?

Lisa Petrison

* The most accurate test with regard to whether your apartment is a problem for you is to get away from it for a while and then return to it. This is a similar test to the one doctors recommend about omitting gluten from the diet and then reintroducing (which makes sense since both gluten and mold toxin are very inflammatory). But this is a difficult experiment, since you have to consider all sources of exposure you might be getting during your "sabbatical," including a) building mold, b) outside air mold, and c) cross-contamination of items.

* The most recommended test currently is the ERMI. It is a genetic test looking at the specific molds in the environment (toxic vs. non-toxic). Here is a research proposal looking at whether living in a place with a problematic ERMI score is a risk factor for getting CFS. There is a good bit of background info about the ERMI in it.

http://www.paradigmchange.me/ermi-study-proposal.pdf

* Air tests are very inaccurate and also very expensive. Stachy will almost never come up on an air test even when it is a huge problem (since it makes a sticky heavy spore that is released in waves and falls rapidly to the ground, disintegrating into toxic dust that cannot be identified in the air test pictures).

* Mold-sniffing dogs have been known to be very successful at finding problem spots. But it is hard to find a mold dog, and some people have concern over the health of the dogs (since dogs may be even more susceptible to mold toxins than humans).

* Tape lift tests can identify accurately specific types of mold that you might find in your home. However, just because you see one kind of mold does not mean that others are not also present (and the most toxic kinds of mold tend to hide the best). So this is generally not that helpful.

* The little petri dish kits that you find at, say, Home Depot are inaccurate when it comes to detecting toxic mold problems.

Note: The ERMI seems to be used appropriately to detect particularly
problematic buildings (e.g. ones that are bad enough to make people sick). However, the margin of error on the scores means that they are not very good at differentiating great buildings from good ones, or good ones from okay ones. For sensitized people, this may not be specific enough information. Also, cross-contamination of possessions and outdoor toxic mold problems are not measured by the ERMI.

A.M. Runyan

Three kinds of testing:

1) Consider your current symptoms. Do you have classic biotoxin illness symptoms of low circulation, low exercise tolerance (can't exercise heavily more than 15 minutes), brain fog, fatigue, food sensitivities, chronic leaky gut that won't heal, poor adrenal function, need 9 or more hours of sleep a night, rage, depression, suicidal thoughts, frequent injuries that don't heal, chronic inflammation, weak skin that is not firm and lacks elasticity, etc.

2) Leave the apartment for as long as possible, go somewhere that is not moldy, and see how you feel when you return (similar to elimination trials for food allergies). Could mean going out for a day, or going camping for a weekend or doing the whole camping in the desert thing. Chain coffee shops and grocery stores tend to be non-moldy since they clean a lot and have good ventilation, and outdoor areas are usually less moldy than the buildings in that given area.

3) Also, just common sense tests - if the building is old, if there is high humidity, if there's been water damage in the building history (you can ask! I didn't know there had been major water damage in the apartment where I got sick, before I moved in), it could have mold. Lots of us with mold illness have developed a sense for whether buildings are moldy after "testing" hundreds of buildings ourselves by walking into them and seeing how we feel. Perhaps you could post some pictures and get a visual read on it.

Erik Johnson

Once I realized that I was having a profound reaction to objects that had been in a moldy place, but immersed in soapy water and thoroughly washed, I realized that no testing applied to someone at my level of sensitivity.
Beatrice Latherings

If you want to test before leaving (although leaving is your best indicator) I recommend the HERTSMI-2, which you do yourself by collecting dust, and it costs $125. Don't have some professional come in and charge you a zillion dollars to do air testing; air testing is inadequate for someone with actual or potential mold illness.

Erik Johnson

Having determined that the very notion of testing was ludicrous for someone at my level of reactivity, I wanted to find out if others were the same. Accompanying them into exposures soon gave the answer.

They would point at small areas which were stable and had no effect on us beyond a few feet.

Unless the tester were as sensitive as we, they would never find these areas. I demonstrated this to Dr Vincent Marinkovich by locating a mold colony in his own reception room by pointing at a very small area in one wall and insisting it was there. Dr Marinkovich led me through his office had had me check each room, which were all clear.

The next visit, he told me he had put mold plates in every room and several in the reception room. The only one that came up positive was the one directly under where I indicated.

Needless to say, he was shocked. "I've never seen anyone do that before"

Considering that I had found others who were like me, it seems clear that we are encountering a paradigm shift that has outstripped both our technology, and our conceptual framework of what to expect.
Q. 32:2 - ERMI and Cross-Contamination

In a previous question, Julie wrote, 'Even if the house comes out okay on ERMI, I'd be very cautious about using the shower during an experiment camping in the garden. Most likely, your possessions are contaminated with something quite bad, and therefore your whole house is now contaminated with it.' If the whole house had become contaminated, wouldn’t that show up on an ERMI?

Erik Johnson

Guttation droplets are exudates of a crystalline structure.

They cannot be cultured, recognized by examination of air samples, or detected on tape lifts by conventional means.

Mold test reports appear to have been more of a loose guide than a reliable measure of toxic exposure.

It might even be that an ERMI means almost nothing in terms of whether one is being exposed.

*  

Guttation droplets of Penicillium nordicum and Penicillium verrucosum contain high concentrations of the mycotoxins ochratoxin A and B

Abstract: Eight of eleven ochratoxigenic isolates of Penicillium nordicum and Penicillium verrucosum produced guttation droplets when grown on Czapek yeast extract (CYA) agar for 10–14 days at 25C. Parallel cultivation of one strain each of P. nordicum and P. verrucosum on malt extract agar demonstrated that higher volumes of exudate are produced on this agar. However, HPLC analyses revealed higher concentrations of ochratoxin A (OTA) and B (OTB) in droplets originating from cultures on CYA. For quantitative determination of the mycotoxin contents, triplicates of three isolates each of P. nordicum and P. verrucosum were grown as single spot cultures on CYA for up to 14 days at 25C. Guttation droplets were carefully collected between day 11 and 14 with a microliter syringe from each culture. Extracts from exudates and corresponding mycelia as well as fungal free agar were analyzed by HPLC for the occurrence of ochratoxin A (OTA) and B (OTB). Mean concentrations ranging between 92.7–8667.0 ng OTA and 159.7–2943.3 ng OTB per ml were detected in the guttation fluids. Considerably lower toxin levels were found in corresponding samples of the
underlying mycelia (9.0–819.3 ng OTA and 4.5–409.7 ng OTB/g) and fungal free agar (15.3–417.0 ng OTA and 12.7–151.3 ng OTB/g). This is the first report which shows that high amounts of mycotoxins could be excreted from toxigenic Penicillium isolates into guttation droplets.

(Thanks to Greg Weatherman for providing this information)

Julie Rehmeyer

Erik's info is fascinating.

Here's my basic understanding of things: An ERMI is good for detecting active mold colonies in a house, but it's not good at detecting mycotoxins. Mold itself is probably bad for us, but the toxins they produce are worse. If a house isn't water-damaged, an ERMI isn't going to pick up much. But there are particular mycotoxins that can be extraordinarily bad for us, even in remarkably small quantities, and they are endemic to particular areas. So a house in Berkeley, say, that's very well-built and has never had a leak will come out just fine on an ERMI, but living in it would make me in particular very, very sick.

So, the summary is that you definitely don't want to live in a house with a bad ERMI, but a house with a good one isn't necessarily a place that you'll be able to heal. The best way to determine that is to get clear by going somewhere really pristine, ideally someplace other moldies have felt good in, with none of your own belongings. Once you're clear, you'll be able to tell pretty definitively when places are OK for you and when they're not.

Lisa Petrisen

To my understanding, this is what happens.

Dormant spores of, say, Stachy are released from the colony. They fall to the ground and disintegrate into poison dust ("spore fragments"). Then the dust is blown all over the house, with some of it lodging itself in furniture, pillows, sweaters, etc. Then, the poison from the dust attaches itself permanently to the items that the dust is touching. This could be wooden furniture, inside the computer, clothing, whatever.

The ERMI is a genetic analysis of the mold (including the spore fragments). It does not measure the toxins at all.
If you moved all your possessions to a new place wholesale, you'd probably bring alone some of the dust with you. (Especially since CFS/mold patients tend to be too sick to clean thoroughly, their possessions tend to be especially dusty, I would guess.) Then the dust might cross-contaminate the new dwelling (e.g. transferring its toxins to walls, carpets, etc.).

At that point, even if you threw away all the possessions you brought with you and cleaned thoroughly, there might be enough cross-contamination to be problematic, even though at that point the ERMI would look fine (and might have looked fine even with the poison dust present, if there was not very much of it).

Shoemaker's instructions (dispose of items that can't be washed, wash everything else) do a reasonably good job of getting rid of spores and spore fragments. They don't get rid of mycotoxins that have already stuck to things, though. Another good thing about these instructions is that mycotoxins that are stuck to things cross-contaminate less easily than spore debris.

Beatrice Latherings

There is some urine test that detects some mycotoxins. However, people who *don't* have the mold gene (and who are not sick) might have higher levels of these toxins in their urine that people who are sick, because they are better at detoxing the toxins. The sicker people will retain the toxins, which is why they are sicker. I'm no expert on this; just commenting on things I've read.

Erik Johnson

Here is something I wrote in 2002:

> My experience was that Joe is absolutely right about the necessity of sensitized individuals to avoid mycotoxins.

> I tried low level ozone and other products that claimed to denature the toxins in addition to killing the spores and they didn't work.

> But, I find that many of my possessions that I had horrible reactions to have lost their toxicity over a period of years.

> Don't destroy anything that is precious to you. Just pay the cost of storage. The toxins seem to "adsorb" onto certain plastics (see Van der Waals forces) and cannot be washed off.
It has taken between three and five years of storage for me to be able to use these items (depending on the quality of plastic), but there is almost no object that I cannot now tolerate. (The only exception is a computer)
Q. 32:3 - My Son’s House

I have mold illness and my own house has been fixed. Now I am concerned about my son's house (a remodel). Is there any test that I can do to find out if it is okay?

Lisa Petrisin

The ERMI doesn't seem to be foolproof, but it seems worth doing. Or for a less expensive version, maybe Shoemaker's HERTSMI test.

If people are in a relatively clear environment and are mold sensitive though, then they should be able to identify really bad buildings just by being exposed to them. If they can't do that, then probably they are still getting exposures in their own home (e.g. through cross-contaminated possessions).

Julie Rehmeyer

ERMI is the only worthwhile test that I know about.
Q. 32:4 - Doing the ERMI

Is it possible to do the ERMI test yourself? If so, please direct me to a quality product.

Lisa Petrison

I would be hesitant to go with a lab other than Mycometrics, since that is the one that Shoemaker recommends. The HERTSMI-2 is less expensive and possibly more accurate with regard to the sorts of symptoms suffered by "mystery illness" patients since it is based off of Shoemaker's patients, but it's not been in peer-reviewed papers. So whether you choose it or the ERMI is dependent on how much you trust Shoemaker, I guess.

A.M. Runyan

I was going to do HERTSMI-2 but decided I would try to move even if it came up negative/ok.

Beatrice Latherings

Shoemaker also recommends HERTSMI-2, which is about half the price. Don't use any lab but Mycometrics.

Forebearance

I did the ERMI test on my parents' house. I used the company Dr. Shoemaker recommended. It was pretty easy to do.

David Ou, M.D.

Dr. Shoemaker recommends that you run an ERMI from Mycometrics yourself. There's no need to have anyone else do it for you. All other labs run the ERMI differently from Mycometrics.
Q. 32:5 - Petri Dish Test

I am struggling from Lyme and mold in my home. I had my house treated for the mold by a company called bio science and they used an enzyme called tm100 to kill the mold. They hvac my furniture and fogged my home. I came back home and my hands and feet are swelling like before I left the house to go to Florida to get detoxed of the mold. I did a mold test by Lowes that is Petri dish thing before and after treatment. Before it had a lot of mold and after had just a little on it. How else do you suggest testing the home?

A.M. Runyan

If you got sick there, your body has already absorbed a lot of whatever was in that particular house, so you are probably going to react to even very small amounts of it from now on or at least until you get it out of your body, levels that remediation won't eliminate.

If you've already been sick from mold and have Lyme and all, you probably need a place that does not make you react at all in order to get inflammation down and detox adequately.

It might seem daunting but sometimes it's possible to get by with a lot fewer possessions. I try to buy things from places with flexible return policies, too, in case stuff gets contaminated (in my eyes, but still fine for other people), so I can return it.

In my own experience, I'm extraordinarily sensitive to any toxins from my former living places. I just drove by a place where I lived a few months ago this morning, and I reacted to it even from inside my car maybe 100 feet away, simply because my body is so attuned to that particular toxin that I got exposed to there (it was not a bad place but I accidentally contaminated it soon before leaving, but that's another story). Anyhow, I felt my detox symptoms stop immediately when I drove past that old place, just from the infinitesimal amount of toxins that were coming through my car. If I were living around that, even that small amount, regularly, it would be very hard to detox.

I also had a bad case of Lyme, where that was my primary diagnosis, and staying away from mold really helps me to have less of a problem with Lyme. I haven't needed any specific Lyme treatment since doing a year of ozone saunas and then starting mold avoidance, just general immune support. It can be really hard to heal from Lyme around mold.
**Julie Rehmeyer**

Once you're sick, remediation is unlikely to be sufficient to make it a place where you can heal. No testing will pick up the mycotoxins that are so problematic for us. ERMI is a more effective test for mold growing from water damage than the petri dish things, but it still doesn't detect mycotoxins. The fact that you're getting symptoms when you go back is definitive that it still isn't a good place for you to heal.

**Jeff Charlton**

This Bio Science company has in my opinion misled you. Killing mould results in greater health risks than live mould according to all recognised agencies including EPA CDC and WHO. The moisture source should have been eliminated and the mould removed (not killed).

I would ask a legal company to assess your rights as to the company's failure to remediate and possibly make your home more toxic. Petri dish will only respond to live mold and they killed it, If they followed international standards and recommendations they would have sampled for total spores which includes dead and fragments of spores.

[www.buildingforensics.co.uk](http://www.buildingforensics.co.uk)

**Lisa Petrison**

Killing mold is not that difficult, but just because you kill the mold does not mean that the place is going to be any less toxic than before. It may be even more toxic since once the colonies start to die, they release larger numbers of dormant spores into the environment in the hope of starting new colonies. (Which they will, if any more water issues emerge.)

I think that the test that you've already done -- noting that the home is still making you sick -- is the best one that you could possibly do and that you don't need any more testing. Based on what you're saying, I doubt you're going to get this remediated to be good for you.
Q. 32:6 - Air Testing

Recently, our home was checked for mold. I have severe CFS/ME and our 5 year old son has had continuing upper respiratory problems, as well as frequent bouts with pneumonia. Our test revealed the following: large amount of Bipolaris/Drechslera in Child's room. The guest room had the same amount as found outside. Windows are closed. Master bedroom had very high levels of Cladosporium. No black mold. We are all symptomatic, especially our son. Any advice would truly be appreciated. Do we need an air purifier? If so, could anyone recommend a brand? Addendum: According to company's mold analyst, the levels that I thought were quite elevated were not significantly elevated when compared to outdoor sample.

Erik Johnson

During the 1985 Tahoe Mystery Malady outbreak, I found that certain areas were so bad that just the amount I brought home on my clothing were enough to keep me sick.

I told doctors that no testing could possibly address my situation. In all the years since our outbreak led to the creation of "Chronic Fatigue Syndrome," my prediction to Dr. Cheney - "There will be millions of people like me" - have only grown more horrifyingly accurate.

It wasn't until I abandoned the idea that this could be tested for, and acted on perceptions alone, that I could take control of it.

A.M. Runyan

That kind of mold testing isn't always that accurate. I had similar results on a house that had made me extremely sick which was so bad that upon returning to meet the person for testing, I had to stand several blocks away from the house in order not to have symptoms.

The ERMI and HERTSMI tests are supposed to be more effective but I don't have any experience doing them myself

It rarely hurts to:
-diffuse essential oils, e.g. from one of those candle diffusers (pretty cheap) (put a candle underneath it) or nebulizing diffuser
-get more air flow from outdoors
- keep humidity low
- spend some time away from the house without many belongings and return to see if symptoms increase upon returning (the way people avoid gluten and then bring it back to see if it's causing effects)

**Julie Rehmeyer**

I agree with A.M. Runyan. The test you're describing doesn't indicate much. The most effective way to test is to spend a couple of weeks away, in a place that's very mold-free, with none of your own belongings, and then go back to see if your symptoms get worse.

**Lisa Petrison**

The only commercial test that I've heard of that seems to be at all accurate for testing for molds is the ERMI, and even it sometimes can miss big problems. The one you are discussing seems basically worthless, based on what I've heard.

I'm not a fan of air purifiers with regard to trying to compensate for indoor mold. People can waste a lot of time like that and never get anywhere.

**Kathy**

Cladosporum makes me incredibly ill. It is a toxic mold.

**Christine**

According to doctors I went to who treated mold, the indoor/outdoor mold level argument is irrelevant. Was told by doctors that outdoor molds have a way to keep each other in check. Indoor molds do not. Based on my experience, if one is having symptoms as you describe, no air purifier will be able to tackle improving these symptoms (in my opinion). I am not a doctor but if it were me, I would seek out another living environment.

**Damien Blenkinsopp**

Shoemaker puts little credibility in those tests and only recommends the ERMI. I find the ERMI convenient to do and accurate (correlation with my symptoms).
Lab technicians at Mycometrics have been very helpful in understanding the results.
Chapter 33

Mold Characteristics
Q. 33:1 - Toxin Names

What are the names of the toxins that are bad and the moulds that produce them?

Lisa Petrison

Mold: Toxin.

1. Stachybotrys chartarum: satratoxins, other trichothecenes, atranones. Mostly grows on cellulose; generally indoors, sometimes outdoors (e.g. on straw).

2. Certain species of Aspergillus (e.g. flavus, parasiticus): aflatoxin. Grains, peanuts; sometimes indoors.


4. Penicillium Crustosum, others: Penitrem A. Mostly outdoors, sometimes on spoiled food. Known to grow in sewers.

5. Some aspergillus and some penicillium: ochratoxin. Mostly foods (e.g. coffee), sometimes indoors.

These are the toxins mentioned most frequently. There are a few more (e.g. citrinin, zearalenol, nivalenol) occasionally mentioned as well.
Chapter 34

Medical Testing
Q. 34:1 - Mold Susceptible Genotypes

Why are some mould susceptible genotypes supposed to be worse than others?

Lisa Petrison

Multisusceptible are thought to be especially problematic because people have a hard time detoxing Lyme toxins as well as mold toxins. And some multisusceptible genotypes are supposed to be worse than others.

Of the people I've seen with severe CFS, the only genotypes I have seen are 1) Multisusceptible (on its own or in combination with something else) or 2) Mold + 1-5 (which Shoemaker periodically calls "Low MSH" or leaves off the chart entirely).

I've seen that latter genotype fairly frequently in this population, whereas I almost never seen anyone with just Mold Susceptible get this sick. I am Mold/MSH myself, and so I am especially interested in this.

Shoemaker says about this genotype:

"Remembering that low MSH is seen in 98% of cases, it is safe to say that once an individual has a CIRS and they have a 1-5 HLA, we can reasonably predict that their MSH levels will be lower than other affected patients. This does not mean that they are condemned to a life of chronic fatigue and misery. It simply means that we expect their MSH to be low and are no surprised if it shows up that way."

I'm a little suspicious of the idea that all the other haplotypes would be associated with susceptibility to particular toxins and this one would be just associated with 'Low MSH.' I think it more likely is associated with susceptibility to a toxin that Shoemaker is not currently aware of and not testing for.

Consistent with this, occasionally I see people who are moderately ill with CFS like illness who have susceptible genes such Lyme (alone), Low MSH (alone) or Lyme/Mold. So far, these people seem to be only moderately susceptible to mold (able to tolerate small amounts of it and to recover quickly from exposures to bad building) but very susceptible to "supertoxins" such as the "Tahoe Toxin" or what is sometimes called the "Itch Toxin."
Vicki

I am guessing that since some mold genotypes are also susceptible to other things (blue-green algae, pfisteria, ciguatera, lyme, etc.) that makes them "worse" in the sense that you have more things to avoid. Even though I am multi-susceptible, I still think mold is the hardest to avoid because it can be invisible. I know not to swim in freshwater lakes to avoid blue green algae; I don't always know which buildings to avoid.

I want to add that while I was sick for at least 15 years due to mold exposures, when I got Lyme and then a few weeks later was exposed to late summer Blue-green algae, the effects were definitely cumulative and multiplied. That may be why so many multi-susceptible people are so very sick. Too many toxins from many different exposures and difficulty detoxing, as Lisa suggests. I must say I am so thankful to know that I am multi-susceptible so that I can make informed choices.

I also want to remind folks of something I just read from Dr. Shoemaker. If you have two "bad" genotypes instead of just one, it will not make you sicker than if you had only one. It's a small piece of good news, but with our illness, any good news is welcome!

Dr. David Ou, M.D.

I wrote about this on my blog at http://www.drdaveou.com/blog/?p=406
Q. 34:2 - Mold Sensitivity Gene

How do you get tested for the mold sensitivity gene? Is there a test I can ask my doctor to run?

Lisa Petrison

Here is the information about this from the Surviving Mold site.

http://www.survivingmold.com/diagnosis/lab-tests
Q. 34:3 - Importance of Genetics

Would testing positive for the HLA-DR gene mean that I need to start extreme mold avoidance because of my previous exposure to toxic mold? And does a negative HLA-DR mean that I need to forget about mold?

Lisa Petrison

I don't think that the genetics are predictive of being hyperreactive, necessarily. What seems much more predictive is having "mystery illness" (such as ME/CFS or Chronic Lyme). From what I have seen, just about everyone with those conditions reports being hyperreactive to toxic mold, if they really look. Genetics seem to be somewhat correlated as well, but they definitely are not a sure predictor.

Many people with multisusceptible genes are not hyperreactive to toxic mold. If you think about what multisusceptible means, that makes sense. People with this gene may not have gotten enough exposure to make them sick; or they may have managed to detoxify the problem substances in some other way (such as sweating); or there may be factors that we don't know about (such as pathogens) that also are required to create a severe level of illness.

For people who do have mystery illness, what I have seen is that Multisusceptible, or Mold Susceptible + Low MSH, tend to be reactive to very small amounts of a wide variety of toxic molds. People who are Lyme susceptible (or Lyme + Low MSH) may be somewhat less reactive to certain kinds of mold but just as reactive to others.

So far, I've not seen anyone with just a mold susceptible gene be made permanently sick by mold or have severe "mystery disease." My suspicion/observation is that those people may feel bad when in a moldy building, but after removal quickly detoxify the mold from their system. I would like to see more case studies (or preferably systematic research) on this though.

I have known only one person with "mystery illness" who got those tests done and did not come up with a multisusceptible, mold susceptible or Lyme susceptible genotype. He had two low MSH genes. His reactivities seemed to be like the ones typically demonstrated by Lyme susceptible patients -- able to tolerate some exposure to some molds but quite reactive to a few more unusual kinds (including the "weather effect"). He said that for him, the old-fashioned mothball napthalene was a bigger problem -- with even tiny amounts causing him to pass out and be taken to the emergency room.
Q. 34:4 - Homozygous

My HLA test results from LabCorp translate into 4-3-53. This is one set of numbers. Should I not have two sets of numbers? I thought genes came in pairs.

Lisa Petrison

One thing that I know is that when the genes are the same, sometimes the laboratory will just supply one number. I don't know if there is any other reason they might just give one score though.

Heather Plude

You must be homozygous. You got the same gene from your mom and your dad.

My son is a double 4-3-53 also, the worst of the worst. Your 4 gene (HLA-1) came as 4 digits. What were the last 2? I have a list of which are the worst of the 4's. I can look it up for you. Remember, this is a guideline, not a death sentence. My son is 100% well despite his genetic code."

David Ou, M.D.

If you only have a 4-3-53, it means you are homozygous meaning that you have two copies of the same gene.

Steve Lyles

An HLA with only 401 3 53 on the test means that the gene is homozygous and like me you are extra-special in that you have two copies of the 4-3-53 genotype. Sorry to be flip about this, but I imagine this is why for me life is quite "different" than the average human.
Q. 34:5 - Negative VCS

Is it true that a negative VCS means that I don’t need to worry about mold?

Lisa Petrison

When I was living in the moldy house, I failed the VCS really badly, getting all but maybe 1-2 wrong in each eye. I was almost blind. After about 3 months away from the moldy house, without contaminated possessions but living in Chicago in what I later found out was a mildly contaminated area, I passed consistently in both eyes. And it was true that I was doing better. But I still got dramatic improvements after I moved from that "moderate avoidance" to extreme avoidance.

Shoemaker says that some small percentage -- I think 5% -- of mold illness patients that he sees pass the VCS.

Also, conceivably you could fail the VCS and not have mold poisoning. He talks about someone who was being poisoned by a particular automobile (some kind of fluid leak, maybe air conditioner fluid) failing it in Desperation Medicine, for instance. But that person did not have specific biotoxin illness symptoms.

Jeri McClure Kurre

There are a small percentage of biotoxin patients who do pass the VCS test.

Vicki

If I remember correctly, Dr. Shoemaker says that there is a 5% false negative rate, generally people who make their living in areas where visual acuity is needed, i.e. artists.

Andrea

I passed and am or was moldy.

I was poisoned by 50,000 toxic spores for only 7 weeks, in my opinion. I believe it’s got to do with being exposed over a long period.
Shoemaker has said there is a 7-8% false negative rate. Those people tend to be people who have an "eye" for what they do such as painters, artists, pilots, interior designers, etc. At baseline, they have a higher than average VCS so if they are exposed to mold, their VCS worsens but not to the point of failing. However, when they get better, their VCS improves.
Q. 34:6 - Serious or Irreversible

Which of Shoemaker's tests are best for showing (a) how serious the problem is (b) how serious the problems which might be irreversible are?

A.M. Runyan

High TGF-beta seems to be a consistent finding. I think it goes down with detox since I am seeing my lungs changing a lot from detox... probably related to less TGF-beta and less lung remodeling.

What makes you think this would be irreversible? Doesn't the body remake most cells every seven years or so? It can take really deliberate and extreme action to rectify the situation, but to me so far it seems somewhat fixable. There might be some hysteresis/chaos theory issues where once you go into a certain state it's hard to go back to before it happened, even if you reverse all the steps that took you to that place, but that part of things might be fixable with nutrigenomics or emotional/psychoneuroimmunology work.

Doesn't seem to help any medical condition to think it's irreversible; I like to always have hope. The body can be amazing if we listen to it and give it the right conditions to perform.

Lisa Petrison

C4a seems to be a measure of how much over tolerance the environment is. It can go down very dramatically if people get close to getting clear.

MMP9 is an inflammation measure that is related to environmental biotoxins and Lyme infections. It can go down pretty fast too, if people can get clear.

TGF-beta seems to go down more slowly. The hormones (MSH and VIP) in affected people seem to go up quite slowly. Avoidance doesn't seem to be the answer to fixing them, at least in the short term.

Vicki Nelson Slosson

I believe that Dr. Shoemaker says that in some people who have been exposed many times, that MSH sometimes does not come back up to normal levels.
Damien Blenkinsopp

Vicki, yes, that's correct. Shoemaker says that in the worst affected MSH is at the lowest end of the spectrum (non detectable) and may not come back up again. However he also notes that taking VIP fixes most of the issues surrounding insufficient MSH - so this enables people to surpass that issue - like a workaround, not ideal, but eliminates associated symptoms.
Q. 34:7 - My Son’s Bloodwork

I just got my son's blood work. He had a mold exposure in the past and typical mold lab tests. This time, his TGF Beta1 is 12,420, cortisol high. But they did not run MSH, VEGF or MMP9 because medicare no longer pays for them. His western blot lyme showed negative except on igg P 41 Ab shows present. What does this mean?

He does have the dreaded halo type 4-3-53. I figured he wouldn’t show any antibodies because of our bodies not being able to recognize antigens. So is this pointing to a less recent infection so will it still cause him problems?

Vicki

I, too, am one of the dreaded (11-3-52) and I did not make many antibodies to Lyme. A few, I guess. Enough that my doc felt it was positive result.

You are right that we don't make antigens to attach to the lyme toxins, but we still make some antibodies to fight the lyme spirochete. At least that is my understanding.

Ig G antibodies mean that it is not a recent (last few weeks or so) infection. Ig M antibodies are the first to respond to an infection. Band 41 is a band to which all spirochetes will respond positive. Many of us with Lyme showed very few positive Ig G bands when tested because our immune system was so overwhelmed it just made very few antibodies. Lyme is a clinical diagnosis made by the doctor based upon symptoms, but maybe these test results will help the doctor decide how to treat your son.

I would guess the IgG antibodies are pointing to a long term type infection instead of a recent tick bite and infection. If the doctor diagnoses Lyme from this test result, it would need treatment. Possibly long-term treatment. There are may methods of treatment, herbals, antibiotics, and immune boosters.

Also, since he is 4-3-53, he will need cholestyramine or some other toxin binder to remove circulating toxins from the lyme as well as toxins from the mold exposure. So, treatment for the lyme infections and treatment for the lyme toxins both if he is diagnosed. I'm not sure I was clear, but ask again if I wasn’t.
Q34:8 – Which Shoemaker Labs

I will have an opportunity to have some of the Shoemaker labs done soon. I can't do them all, but would like to do some of them, to get a sense of what is going on in my body, and where I stand after attempting to do avoidance for the past year, and being out of my mouldy apartment for a year and a half. I have only done TGF-beta in the past, while still living in the mouldy apartment. Which would be the most important tests to do in order to get a sense of what exactly is going on and where I stand? I am aiming for TGF-beta, MMP-9, and MSH at minimum. I am including MSH in particular because of my severe dehydration symptom, and TGF-beta to compare with last time. C4a seems important but may be more difficult to do since it requires going to a different lab (Dr Shoemaker says Quest only for C4a), and also seems to be a marker that fluctuates a lot, from what previous commenters on Avoiding Mold have said.

Betty Keen

If you're having dehydration symptoms then definitely do ADH. I think there's a specific panel for that but I can't recall what it is. Dr. Gray runs it.

Beatrice Latherings

Dr. Mary Ackerley ran a few tests after two years of avoidance. Because my C4a was low and my MARCoNS negative, I was offered VIP, and although I decided against it at this point in time, it was worth it to find out I had progressed far enough to attempt the last step in the Shoemaker protocol.

Gia MP

Just get your ADH levels checked and adrenal tests

Lisa Petrison

I have not seen much evidence that getting those tests done after pursuing avoidance at whatever level gives people much useful information.
Jennifer

I agree with Lisa....my experience has been after an exposure of "any type" once I remove myself completely from that exposure and any other exposure it is taking my body approximately 9-10 months to start seeing any recovery. This is why I am so careful about my surroundings and pay more attention to ERMI levels and moisture readings than I do taking more medical tests.
Q. 34:9 - Connection Between CD57 and Mold

Does anyone know if there is a connection between cd57 scores and mold?

Lisa Petrison

This is one of those tests that seems to often be abnormal in Lyme patients, in mold patients and in ME/CFS. Of course, in late stage all those diseases look exactly alike, both clinically and in a variety of tests. So that is not a surprise.

I've not found much in the literature that suggests that dysfunctions with Natural Killer Cells or Natural Killer T Cells can be caused by mold toxin. But that may be because no one has thought to look. Lyme and CFS doctors don't look at mold toxicity, and mold researchers don't look at those immune abnormalities present in mystery illness. So we never get anywhere.

Beachy Keen

I had the cd57 test before we knew about mold and were investigating Lyme. Mine came up normal range, but just on the border. Curious to see what other think.

Susan

I had the CD57 test twice and both times it was normal even though I was very sick for 8 years with mold illness. It is not a Shoemaker test.
Q. 34:10 - Urine Mycotoxin Test

Should I get the urine mycotoxin test done? I am positive my family is reacting to our home and that it is making me sicker."

Lisa Petrison

I think the Real Time Labs test could be useful for showing that certain populations (e.g. AIDS, ME/CFS, etc.) are more likely to be poisoned by mycotoxins than the general population if a good control group were used. Unfortunately, the papers looking at the Real Time Labs test have used very poor control groups, so far.

Regardless, I'm not sure that would be a helpful test for diagnosing mold illness, since healthy people working in a bad building will show mycotoxins in their urine (as they detoxify the poisons) and many really sick people living in bad places do not show at least some of these toxins in their bodies (because their detox mechanisms are shut down, due to the exposure or other reasons). Some people who move from bad buildings to good environments have their urine tests become positive once they are out, and then have it stay positive for a long time afterwards. So it's hard to know what to make of any test results, except to say that at some point, toxic exposure has occurred.

David Ou, M.D.

Dr. Shoemaker recommends that you run an ERMI from Mycometrics yourself. There's no need to have anyone else do it for you. All other labs run the ERMI differently from Mycometrics. Many mold doctors (not Dr. Shoemaker) like to run urine mycotoxins from Real Time Labs. One limitation is that it only checks for 3 mycotoxins when there are hundreds of them. Another limitation is that some very sick people who detoxify poorly won't release any mycotoxins into their urine so one can be mislead into believing you're fine.

Beatrice Latherings

Ditto of Dave Ou on the urine test. The only use I've seen for it is people who need to prove mycotoxin exposure for insurance, workman's comp, or litigation. If you can't detox the stuff, it might not show up but still be in your system. The tests on survivingmold.com will show where you're at in terms of whether toxins are causing you problems, and they have normal ranges listed right along with
the tests.

Janis Bell

To reply to Dave Ou's comment about mycotoxin testing: it is like any other lab test. It has to be considered together with the patient's symptoms. Slow detoxifiers also don't show metal load, but that doesn't mean we can't find ways to test for them. Mycotoxin load can indicate a high body burden from focal infection or from Dr. S's theory that they cannot be eliminated by those of us with certain HLA-DR alleles. I found the RealTime Lab test useful, and my retest correlated well with my improvement. But first line of testing should be home ERMI via Mycometrics and the core of the Shoemaker testing protocol: C4a, MMP-9, and VCR.
Q. 34:11 - Mycotoxin Test Results

I just got tested by Real Time Lab for mycotoxins and it came back positive for Tricothecene, at the top of normal for Aflatoxin and off the charts positive for Ochratoxin. My doctor didn't give me much information about what this meant (even though the test cost $700 and he charged me $120 to tell me the results). Do you have any insight? Is it definitely environmental? Could it be food? What do I do next?

Lisa Petrison

The control group for that test is people from the U.S. who have been screened carefully for lack of exposure to a water-damaged building. According to the authors of the studies about that test, 0% of those people had detectable mycotoxins in their urine. (By comparison, in one study, 93% of a sample of CFS patients had mycotoxins in their urine.)

The authors use this to suggest that if mycotoxins in foods were influencing the results, the % of the people in the control sample would have been greater than 0%. They also suggest that if random fungal infections that anyone could get were influencing the results, than higher than 0% of the control group would have showed up with the toxins. (They do suggest that fungi growing internally in the wake of toxic exposures obtained from buildings can add to the problem though.)

I'm not sure that I entirely trust these authors with regard to their methodology. However, based on the information that I have at my disposal, high results on this test (especially in someone who is ill with a chronic disease such as CFS or Lyme) do suggest to me mycotoxin exposure.

Unfortunately, doctors (whatever they call themselves) are generally not very good at helping people who have moderate or severe ME/CFS move toward recovery. Mold avoidance (and especially the more extreme avoidance approach pioneered by Erik Johnson) thus far seems to produce much better results. I would suggest reading the "Mold Blogs" and "Erik Johnson" sections on the Paradigm Change website and the "Back from the Edge" book to start.

Erik Johnson

When Dr Shoemaker asked me to do his HLA DR testing, I refused, having lost all confidence in doctors.
I told him that if his tests did not reflect my reality, I would simply be forced to conclude that the tests are wrong.

I got more bang for the buck by flying by the seat of my pants.

**Beatrice Latherings**

What you do is get out of where you live/work and find someplace that is not moldy. It is a daunting task but the *only* thing that will get you well. Medical treatment cannot keep up with exposure. You can leave for a few weeks and see how much better you are and then make some decisions from there. But you have to use extreme care not to jump from one moldy situation to another.

**Janis Bell**

Those are two pretty bad toxins to have in high amounts. Dr Janette Hope has two online full text articles, one on ochratoxin A and the other on mycotoxins and treatment, the first and most important step of which is avoidance. There are also ways to get the toxins out. Dr Hooper at the RealTime Lab also did biopsies to see how urinary mycotoxins correlated to tissue loads and found a high correlation. This condition is called mycotoxicosis.
Q. 34:12 - Allergy Testing

If you take a regular allergy skin test and it shows high on both types of mold. Does that mean that you were exposed to it; or just allergic to it?

Lisa Petrisin

If you go to an allergist, there are two kinds of mold allergy tests that they can do: IgE and IgG.

IgE is for standard allergies, like the kind people have to pollen or dust mites, with runny nose, red eyes, maybe breathing issues. I've not seen anything to indicate that mold toxic people have more of these symptoms than anyone else. I didn’t have any of these symptoms.

IgG suggests that you have had recent exposure to a particular kind of mold spore. This could be mold in your external environment, mold growing in your body or mold in food. (Note that Stachybotrys does not appear to colonize and is not a big food contaminant, and so a high IgG to that suggests environmental exposure.)

If people are living in a bad building, they may have high IgG regardless of whether they are being affected by the toxins.

Some/most/all (we need research to find out for sure which of these choices!) CFS patients have hyperreactivity to the toxins made by mold. This means that they may be very affected by mold toxins in the environment even when there is not much of the mold that makes them present. (Or, if cross-contamination of the toxins alone is driving response, then there may not be any of the mold spores that originally made the toxins present.)

Some people do come back from allergy testing with very high IgG levels and find that informative (particularly with regard to their environment being bad). But IgE type allergies (observed or tested) seem to be totally unrelated to toxic problems, as far as I have seen and heard.

David Ou, M.D.

I tell my patients there are two major reactions to mold. One is a mold allergy which is a localized reaction involving the sinuses and upper respiratory tract. Chronic Inflammatory Response Syndrome from the metabolites of water
damaged buildings causes a systemic reaction of the entire body affecting multiple systems and organs. People sensitive to mold can have one or the other or both.

Karen Dean

Thirteen years ago when I wasted $5,000 on traditional allergy testing, friends of mine in the health care industry tried to dissuade me, saying that a lot of health care providers now considered that treatment modality archaic and painful for no purpose. I wish I had listened to them.
Chapter 35

Symptoms
Q. 35:1 - Viral Symptoms

Can you get viral symptoms from a mold exposure?

A.M. Runyan

Yes, I've had this happen. I've had cases where I felt I was dealing with a low-level cold, and when I would go to a moldy place I'd get sick, but when I'd leave I'd feel well. I almost never get sick if I am doing mold avoidance, even if I do things that in the past would have caused me to get sick (sleep deprivation, being cold, high stress, being exposed to coughing people). So sure, if you have latent viruses, a mold exposure could suppress your ability to keep it at bay. Lots of mold toxins/biotoxins inhibit protein synthesis, which I assume is needed for fighting viruses. Biotoxin reactions can also cause mast cell issues which I imagine might feel somewhat like a virus/cold.

Lisa Petrison

When I went to visit Erik in Lake Tahoe in 2008 (sleeping in a tent), I woke up in the middle of one night thinking that I was getting a viral infection. My throat felt sore and my lymph nodes swelled up. This had happened to me periodically throughout my illness -- it would feel like I was starting to catch a cold but would rarely slip all the way into full-blown illness. I would feel a lot worse, like I was fighting something really nasty off, but never actually get sick.

But then after some discussion with Erik, I realized that the problem toxin in Truckee was acting up in the middle of the night and causing my symptoms. And as time went on and I got more experienced at avoidance, I realized that this "fighting off a cold" experience that I'd periodically had could be totally thwarted by staying away from that one toxin (which is almost never inside and which I dislike the most). Building mold does not give me that kind of experience though --- just the outdoor "Lake Tahoe stuff," whatever it is.

So I now think that all those times that I thought I was fighting off a viral infection, I actually was being hit. But on the few occasions where I actually did come down with a full-blown cold or flu, I'm not sure that had anything to do with being hit.

Brenda

My poison was CO and it diminished my immune system causing chronic
infections to remain alive in me for ever

Erik Johnson

Dr Shoemaker says that mold can mimic a viral infection.

* 

Mold Warriors By Dr Ritchie Shoemaker Gateway Press 2005.

Chapt.23. Mold at Ground Zero for CFS "History doesn't remember the critics" page 447 -Answers from Abroad: Vindication for Erik

One of the researchers who was well represented at the CFS meetings was Dr Kenny DeMeirleir from Belgium. He has published extensively on the different mechanisms that contribute to Chronic Fatigue Syndrome. Before I could talk to him, however, Dr.Robert Suhadolnik presented his data on the enzyme complexity involving RNase-L. He had been working with Drs Peterson and Cheney for some time.

I asked him about mold and CFS. Making me fall to the floor, he said, "Oh yes, we know a lot about mold exposure in the original cohort in Incline Village. The source of activation of the endopeptidase that cleaves RNase L is increased response of a cytokine, alpha interferon."

"Now wait," I said, "our data is very clear that alpha interferon levels are increased like crazy in mold patients compared to controls. Can we say that mold exposure doesn't change RNase L like you have reported in putative viral CFS patients?"

Dr DeMeirleir chimed in, "We know that cytokine increases are important activators of the subsequent increased activity of these enzymes. Given your data, we need to look again at our data in which we clearly see changes in innate immune responses in CFS. Mold could be the common denominator. The issue for me was that while DeMeirleir knews about MSH, innate immune response activation, including complement, coagulase negative Staph and changes in exercise tolerance and reduced VO2 max, he didn't know about VEGF.

But he knew about mycotoxin binding to Toll receptors (no one else did), in fact, he said that a Toll 3 receptor, a mycotoxin receptor, was critical to the abnormalities in CFS. When I said that the interferon and IL-1B increases could
be mycotoxins, binding to the Toll 3 receptor, activated excessive cytokine responses that then altered genes expressing autoimmunity, VEGF and erythropoietin and lowered MSH with all its downstream physiologic changes, Kenny just smiled.

"Yes, when we can put in the changes in the other findings (increased elastase is just one example) that I know to be true, alongside yours, then we might begin to understand Chronic Fatigue Syndrome," he said.

Let’s look again at the chronic fatigue from a mold perspective, looking at patients like Erik. Was there the potential for mold exposure at Incline Village? Sure, but no one looked properly. Was there a distinctive grouping of symptoms? Sure.

Was there a disciplined "ruling out," a differential diagnosis of all variables that led to the viral diagnosis. No.

Now that we know the biomarkers for the viral cause of CFS are not specific for viruses and indeed they’re also affected by mold, can we rule out mold as the source of the illness? Of course not.

Beatrice Latherings

I’ve had this happen. The mold clobbers my immune system, and anything that is hanging around takes advantage of that.
Q. 35:2 - Vulnerability to Infections

Is it common for people to be increasingly vulnerable to viruses and bacteria when they are in a moldier environment? I have had two colds in two weeks. This is not normal for me. For the past year I have almost never caught anything, now it's like all the time. I will have to incorporate some preventative tactics until I'm able to move, I think.

Lisa Petrison

In the 20 years since I first started showing signs of this illness, I've had a total of four colds/flus (three before practicing avoidance and one since). They were all really bad ones, and the three I had while living in the bad house all led to permanent health declines.

A.M. Runyan

Yes, of course.

Beatrice Latherings

Yes. I don't think my immune system is ramped up, though, I think it is so busy trying to deal with mold toxins that the other things just have a party.

Erik Johnson

From what I have seen, the TH1/TH2 shift can go either way.

Some who never got a cold or flu for years suddenly switched and catch everything. What remains a constant is that they cannot tolerate the mystery substance.

Karen Dean

Exposure to mold always activates my EBV. But my ramped up immune system has kept almost all colds and flus away for many years, go figure.
Q. 35:3 - Gut Problems

Did anyone find that avoiding mold helped them with candida or gut problems?

Lisa Petrison

Yes, it definitely helped me, and I have seen many others who also have reported this.

However, detoxing mold intensively through the gut can make gut problems come back even if there are no new exposures. This seems to be why Erik prefers to release toxins through sweat and breath rather than the intestinal tract.

There is a great deal of literature from agricultural researchers suggesting that trichothecenes are very toxic to the gut. "Exquisitely toxic" is how one paper phrased it. They have been shown in many papers to cause leaky gut and also cause dysbiosis by killing off good bacteria (allowing yeast and bad bacteria to grow).

Karen Dean

With my first Stachy exposure, my stomach became a basketball whenever I ate. It went away as I healed.

David Ou, M.D.

I have found that most people with candida or gut problems also have mold problems.
Q. 35:4 - New Exposures, Detox and Infections

Have you found a way to distinguish symptoms of new toxic exposures vs. detox symptoms vs. infections? For instance, recently I have been having some gut problems. I feel like maybe I picked up something from a raw juice bar, but maybe it's related to detox. How can I tell?

Lisa Petrison

My conclusion after doing a whole lot of detox is that the process really does a number on the gut. Some of the problem may be directly due to the toxins -- e.g. there are at least a dozen studies that show that trichothecenes cause leaky gut as well as other gut problems in both animals and humans. (One article states that these toxins are "exquisitely toxic" to the gut, for instance.)

But I think an even bigger problem may be that the toxins cause dysbiosis -- killing off good bacteria and allowing bad bacteria, toxin-producing yeast and other pests to thrive. After all, the reason that environmental mold produces toxin to begin with is to kill off a wide swath of environmental bacteria and fungi so that the species that produces the toxin can take over. The idea that it might cause similar dysbiosis in the gut should be obvious, though so far I've only found a few articles that have examined this topic. (In general, study of the microbiome is quite new, with scientists thus far expressing puzzlement over what might cause some people to be more healthy in this area than others.)

There are a few studies that show that mercury can contribute to dysbiosis as well. In addition, intestinal worms thrive in the presence of heavy metals -- published studies show that they are able to sequester enormous amounts of metals in their systems, and Dr. Klinghardt is now reportedly suggesting that they use it to develop a protective coat that will keep the white blood cells from attacking them (since WBC's die in the presence of mercury). And it definitely has been my experience that detoxing metals can cause parasites to become more problematic. (In 2007, Rich van K's methylation protocol caused a life-threatening intestinal blockage that I now believe was due to a growth of an intestinal tapeworm, for instance.)

In general, getting out of a bad environment can help a lot of people with gut problems. However, intensive detox can make them return, in some cases (such as mine) worse than ever. I think in the long run, it's still worth getting the toxins out, but the gut is so important that it's worth thinking about how to minimize the harm.
So I'm not sure this is an either/or question: "Is this detox or is it a bug?" I more think it could be both, that intensive detox can make people more susceptible to bugs.

A couple of thoughts.

First, probably insofar as toxins can be removed through the body in ways other than the gut (through breath, sweat or urine), that would be preferable to removing them through the gut.

Second, keeping things moving through the gut seems important. It's bad enough to have toxins moving through the gut; letting them sit there seems even worse.

Third, I'm increasingly wondering if taking proactive measures against intestinal pathogens while detoxing might not be a good idea. For instance, recently I've been experimenting with ozonated water (both drinking and in enemas) and am feeling like it's quite potent and with a broad spectrum of action, with less harmful effects than many other ways of killing pathogens. I think I might have had an easier time of keeping my digestive tract in shape if I'd been using it all along. And it's cheap!

Fourth, I've found it beneficial to reintroduce good bacteria into the gut, mostly through fermented foods (including as much as 1-2 quarts of homemade kefir made with really good milk per day). This was especially the case when I was intensively detoxing mold poison, not quite as essential (but still helpful) when detoxing metals.

Whether any of this is applicable to this particular question though, I'm not sure.

Corinne

I've had this dilemma as well. While the stomach is an ongoing project to figure out.... I think you have to try and hold things constant. If I am sniffing paint to test it I should try and make sure I'm preparing my own food and it's the same stuff I always eat and I'm not introducing other exposures at the same time. I'm still working on it!

Janis Bell

I've been thinking that this is not an either or situation as Lisa wrote. Reading recently about metal detox, it seems that every chelating agent, whether a
beneficial antioxidant as ALA or glutathione, for a chemical treatment like DMSA or DMPS, has a trade off between how much is pulled out safely and how much unbound toxins reinjures. This is even true for something as gentle as sauna. So I realized that taking binders is really crucial, Even though CSM and charcoal will help a lot of healthy nutrients. Ideally detox moves slowly enough to avoid more reinjury than the body can repair overnight. When it speeds up, sometimes as we impatiently push it in this direction, we need more rest and more nutrients than normal.

Skin is safe route for detox and bowels are also safer than kidneys which are very susceptible yo damage from Ochratoxin A and certain metals. But I think it's best to support all outlets so that nothing gets blocked.

**Family of the Way**

Are you taking any probiotics? Try Renewlife Ultimate Flora- 15 million, that is what is on the box. And try colloidal silver.
Q. 35:5 - Breathlessness

Is breathlessness at rest a common symptom of mould illness? What causes it?

A.M. Runyan

Yes. I believe it is caused by elevated TGF-beta, lung remodeling, and just constriction in the lungs (the body trying to reduce how much mold you breathe in), and also by capillary hypoperfusion from low VEGF (the body trying to reduce where the toxins go in the body).

I had shortness of breath like this for years at a time during Lyme and mold illness. During acute mold illness it would feel like my lungs would close off a lot whenever I got a whiff of mold.

Even when I thought my breathing was back to normal lately, I realize I still had farther to go, since with some recent detox treatment I've done, my lungs have opened up even more and feel more moisturized/lubricated and my breathing is very different. Now my lungs feel more like an expansive rainforest in the body, rather than a small plastic bag that only blows up a little. Lungs are supposed to be large and healthy.

Lisa Petrison

Maybe some of the mold doctors have a physiological explanation. Intuitively, it feels to me like one of those things that my body does on purpose to try to protect me from getting too much exposure, and thus something that may not be good to override.

David Ou, M.D.

Low VIP also contributes to "air hunger" --Dr. Ou
Q. 35:6 - Fungal Ball

Doctors removed a fungal ball from my sinuses two months ago and it seems to be coming back. I am concerned that the mold has entered my brain and is causing me to tremble in my sleep. Doctors do not believe it is mold related. Utah doctors do not believe in mold poisoning. What should I do? How do I get it out of my brain?

Lisa Petrison

I've only heard of a few other people who have had that surgery for a fungal ball done, and I've not heard anyone say that it made a big difference for them. I'd like to have more information if people have had success stories.

I found the best solution to addressing candida was to get to a really good location in terms of the outside air. I would suspect the same principle would apply to any other fungal infection you might have. (Though it's not a 100% guarantee for all fungal infections no matter how bad. I do know one healthy person who was staying in an extremely good building in a good location, with no bad stuff, who got Valley Fever, for instance. But she did recover from it well.)

Since you are in Utah, it would be easy for you to go camping! If you were interested. Snow Canyon State Park (near St. George) would be nice at this time of year, for instance.

Megan

You may want to search out an LLMD (Lyme literate medical doctor) they often deal with mold issues in the process of attacking a myriad of other tick born diseases in their patients. They think outside the box and are sort of used to odd symptoms. Good luck.

Andrea

I don't know the answer to your question sorry but I would nix any doctor who tries to convince you they don't believe mold causes illness!!!!!
Jessica Grow

I have biotoxin illness and I live in Utah. I found Doctor Wright in Provo who works with patients with biotoxin illness. I have not gone to him yet though because so far my doctor in CA has been able to do my visits through Skype.

Ruth

Air purifier?
Essential oils?
Neti pot?

Melanie

Have you used the BEG antibiotic spray?
Q. 35:7 - Ear Canal

Is it possible one could develop a mold infection in their ear canals? i have chronic ear canal itching since my mold exposure and i’m wondering if it’s mold.

Lisa Petrison

When i was still living in the moldy house, I got ongoing severe vertigo that made it difficult to do anything. Even lying in bed, I would have to put my head in a certain position or the room would start spinning around. It is called BPPV, if I remember correctly.

So I went to an ER doctor who said that he had been to a seminar that said that candida infections could press up against the inner ear and cause dizziness. Then another doctor told me that the candida could grow into the inner ear. I used Diflucan and the dizziness did go away. But after a while, the Diflucan stopped working as well and I got afraid. At that point, I became extremely strict about being on the anti-candida diet and used other things to keep the candida in check. And the dizziness did not come back.

At this point, no amount of sugar will cause any candida problems at all. But that is after a lot of avoidance and a lot of detox.

So I do believe that fungal infections can grow in the ear. Whether that is your problem and, regardless, how to solve your problem, I am not sure.

A.M. Runyan

I've had that happen to me when I get exposed to mold. Just as mold exposures seem to mess up my gut flora, they also seem to mess up my ear canal flora.

I can tell when I've gotten away from the exposure, or when I've taken something anti fungal that's working on my ears, because my ears will sometimes fizzle and then feel better.
Q. 35:8 - Brain Function

What causes the deterioration of brain function when you go somewhere bad? The higher level of neurotoxins themselves, or a jolt of inflammation?

Lisa Petrison

At one point, when I was very reactive, I checked my clothes every time I thought that I might have been exposed to see if they were okay. I would be perfectly clear, then pick up a garment, hold it against my nose and take a sharp whiff. In less than one second, my cognition would become fuzzy. That was how I could tell if there was a problem. Provided that I didn't get any further exposure though, my cognition would clear up pretty fast.

So whatever is happening, I think that the it's pretty clear that the toxins are sailing directly into the brain. This is where we get into Erik's hypothesis that mold-made nanoparticles may be serving as a drug-delivery device for the secondary metabolites commonly known as mycotoxins, and why even small amounts of the toxins may have the potential of causing harm.

I feel like hidden in that question is the idea that if the inflammation is the problem, then maybe we can turn off the inflammation and get better. I tend not to think that's a good idea though. It seems to me that the inflammation is serving a purpose here (to destroy the toxin and serve as a warning to get away), and that the toxin will do more damage if that inflammation system is turned off. Unless of course, the body can quickly eliminate the toxin or otherwise deal with it in a less damaging way.

Erik Johnson

In my "Sick Thermal Syndrome" story in Surviving Mold, I was becoming increasingly aware that the places which slammed me were never "just normal mold."

In each and every case, the mold had access to human-produced chemicals.

I immediately began telling doctors that this was no normal mold toxin, and was probably something new, so it would be misleading to look in their mold literature. All that would do is confirm to them that no such toxin exists.

And even cause them to fight to say that there is no need for any investigation,
because, "You have no evidence. You can't prove it. Your stories are anecdotal"

I told them to just wait a while.

**Michele**

I always felt that the neurotoxins caused the inflammation, as it can be immediate and somewhat long lasting in cases.
Q. 35:9 - Neurotoxicity

Something strange happened today, and I thought I would share to see if anyone else has had similar experiences. I was in a car and the driver bumped into a pole while trying to park. Not too hard, probably was insignificant to her, but my body immediately went into some degree of shock. It was partly that my neck and head felt bad from the sudden bump, but I think it was more than that, because after I got out and walked a couple blocks, I totally lost it, going into one of my exposure reactions. Unable to speak, walk, rocking back and forth, etc. Felt horrible. It cleared up with a bunch of emergency vitamin C & TriSalts, (which I now carry with me everywhere I go no matter what), and some time sitting and resting. Meanwhile the driver of the car was totally fine.

My theory is that I have horrific amount of toxicity in my brain and spinal cord, and probably all my tissues, and that this little incident released some of that. Like an internal re-exposure of toxins being kicked up. I have found, during reactions like that, that moving makes things worse. Almost like it recirculates the toxins. Sitting or lying perfectly still is best. This pattern would fit with that theory, in that it makes sense that a sudden violent jolt would stir up some toxins. Have others experienced this type of thing? I feel so vulnerable, like I'm a walking danger if anything unusual happens, given how much toxicity I am carrying around.

A.M. Runyan

I've heard of people recovering through MCS largely through craniosacral therapy or with CST as a major treatment. perhaps you could use a still point device or get other kinds of head manipulation.

I used to be highly intolerant of any kind of head manipulation and would not let people touch my head, but in the past week with Nrf2 activators and high dose Vitamin C and ALA (which I can tolerate without mercury detox symptoms), I notice it no longer hurts when people touch my head, and all sorts of cartilage areas in my body are firmer now (ears, nose, etc.). Perhaps things that alleviate oxidative stress and promote collagen could help the head be strong enough to handle manipulation or a still point device.

Julie Rehmeyer

Have you tried Natrum Sulphuricum? From what I've heard from others, it can be
helpful for draining toxins that are stuck in the brain and spinal cord.
Q. 35:10 - Valley Fever

I have mold and chemical sensitivity. I am exploring drier regions with a small travel trailer. I'm now concerned about Valley Fever in Arizona and surrounding states. I'm wondering if mold sensitive people contract this fungal infection more frequently, and whether the complications are worse. I'm willing to risk a little in this regard (little is key word) if the benefits of the Southwest make up for it.

Lisa Petrison

I got to know someone in California who had Valley Fever and was made sick by it, and I actually am somewhat concerned about it. It is particularly problematic in southern Arizona and the San Joaquin Valley of California, but possibly other places too. I suspect that people with mold illness are especially susceptible to it, and there do not seem any particular ways to protect oneself from it.

On the other hand, people with mold illness seem to be susceptible to a wide variety of other illnesses as well, including many that will re activate easily if they are in a problematic place. All things considered, I still think that looking for pristine air is factor number 1, by a long shot, for people with this illness.

FWIW, I lived in prime Valley Fever territory for almost a year and did not get sick with Valley Fever. But that doesn't mean that I wasn't just lucky. But I would consider living in the same place again, and my moving elsewhere had nothing to do with the possibility of getting it.

A.M. Runyan

Have had no problem with valley fever. I think doctors who don't want their patient base to move out of humid areas like to say "but the molds in the dry areas are stronger/worse" to make it seem like humidity is of no consequence for this disease.

But in my experience, being in a lower humidity area has made everything easier for dealing with this disease.

It's a big deal when your clothes dry in an hour rather than overnight, and when the bathroom barely gets foggy when you take a warm shower.
I got so spoiled living in Albuquerque that even Denver felt very humid to me when I moved here (and most people here complain about it being dry). It's just great to breathe very dry air.

Plenty of people live out here and never get Valley Fever.

Living at high elevation seems to help too for a variety of reasons, and much of the west near the Rockies is 5,000 feet and above.

Beatrice Latherings

I've lived in S AZ for 26 years and have not to my knowledge gotten Valley Fever. And I've spent a lot of time outside in blowing dust too.
Chapter 36

Multiple Chemical Sensitivity
Q. 36:1 - More Than Mold

Is anyone else avoiding more than mold? I have one of the multi-susceptible genotypes and would love to dialogue with others who have similar situation. It seems the list is growing as to other biotoxins to avoid.

Corinne

I try and avoid all toxins even the ones I don't know if I react to, like tannins in scented wood. Decreasing the overall load of toxins in the body I can only assume will help. Also once you start avoiding something, like perfume, you do then unmask and can find out if it's problematic for you.

A.M. Runyan

I avoid not just mold but also whatever non-smelling toxin seem to give me problems. For example, whatever is in Dallas/Fort Worth, or things that trailers from certain states bring into my apartment complex. The non-smelling stuff, which might not be mold, is often much worse in terms of symptoms and cross-contamination.

I also try to minimize Lyme and other microbial biotoxin exposure by simply keeping Lyme and other infections in check.

In general, you learn what toxic reactions feel like and try to avoid those, prioritizing avoiding the really bad toxins found in certain cities.

Lisa Petrison

I've had negative reactions to certain lakes/rivers/streams, which I think is cyanotoxin. I had a remarkably bad reaction drinking water in the Chicago area (and found that this particular city takes water from areas of Lake Michigan where cyanobacteria are growing profusely and does not do adequate filtration to remove the toxin). There was a time one summer in Chicago that I definitely felt bad showering in that water, to the point that I started rinsing my hair with bottled water after showering.

In general, I avoid chemicals. But I don't seem to have to worry about them producing horrific reactions, if I don't avoid them as scrupulously as I have had to avoid biotoxins.
Yes. Also algae (I don't go near lakes or streams), formaldehyde, solvents, whatever I can that is known to be toxic.
Q. 36:1 - MCS Reversal

Do you know if MCS caused by mold exposure can be reversed? I've already been treated for Lyme disease and am avoiding mold, now on Candida diet. I was exposed to mold 13 years ago but still sensitive to the chemicals.

Lisa Petrison

Quite a few people have reported that their chemical sensitivities have gone down as a result of extreme mold avoidance and detoxification. This can take a while though (in some cases several years), and the chemical sensitivities can come back if people get a particularly bad exposure to certain mystery toxins that we believe to be mold toxins (such as the one that Erik talks about in the "Back from the Edge" book). Also there are no guarantees that this will happen for everyone, especially if they don't manage to effectively detoxify. But still, in many cases the reactivities do go down, and often substantially before the mold reactivities do.

Forebearance

I don't know the answer for sure, but my MCS has gotten better since I've been avoiding mold.
Chapter 37

Increasing Tolerance
Q. 37:1 - Does This Last Forever?

For those of you now well that are/were severe reactors, once out of the mold, how long did it take you to not react severely everywhere you went and what did you do to lessen these reactions? I'm fine outside in my little tent, but soon as I go anywhere (car, building, house, etc), 99% of the time I feel back to where I was a year ago, sick as a dog. Does this last forever? I feel like I might as well get a bubble and call it a day!

Julie Rehmeyer

Took me a year.

I had an odd experience that brought down my reactivity enormously. I went to see a psychic that a friend had had a very positive experience with. That's not at all my thing, but I figured, "What the heck! It'll be an interesting experience in any case." He did a reading, and then I did a session of "energy work" with him. He said that my hyperreactivity came from having experienced trauma when I was child (between 4 and 6) while I was in the presence of mold, and that my mind had made a false association between the mold and the trauma. He was right about the trauma, and in fact my bedroom at the time was in the basement and could easily have been moldy. He had me re-experience that and think about what my "higher self" -- that is, my grownup, most thoughtful self -- would say to myself then. At the end of the session, he said, "The association with mold is completely broken!" I was extremely skeptical, but it brought an immediate and dramatic reduction in my reactivity. Before that, exposure to mold could be quite dangerous; after it, it has been little more than a considerable nuisance.

That said, it didn't eliminate the reactivity entirely, and it didn't eliminate the need for detox. Here's how I understand it at this point. I think that the process of learning to avoid mold essentially taught my body to be super, super reactive, through a kind of "power of suggestion" process. I was paying attention to the slightest symptom to know when to get the hell out of there. I think that was exactly the right thing to do, but it was part of what increased my reactivity to sky-high levels. (To the point of having a seizure once!) When I'd thoroughly learned to detect mold, and when my body had had a chance to heal a bit, then it was appropriate to break the mental part of the reactivity.

By the way, though the psychic's reading was pretty impressive and it's hard to come away from it not feeling like he has some kind of real gift there, the energy work he did was nothing at all supernatural or strange. It's ultimately much the...
same kind of thing as happens in therapy, bringing our more "evolved" selves to meet the wounded parts of ourselves.

I also think that detox is really key to reducing reactivity. I'm very doubtful that if I'd seen the psychic a year before, or even six months before, that he would have had the same impact on me (though, as with any such hypothetical, I have no way of being sure). And since we all have different amounts of toxins in us, and our bodies are able to get rid of them to varying degrees, and we have varying degrees of success in figuring out what will help our particular body get rid of the stuff, it takes different amounts of time to detox enough to reduce reactivity.

My guess -- though of course I'll never know -- is that my reactivity would have gone down without the psychic too.

A.M. Runyan

I went through about two months of really severe reactivity. Then I met a guy I was interested in and realized I wanted to get healthy quickly so that he could visit and I'd have less chance of reacting to him. So I threw everything I had at detox, particularly coffee enemas, juicing, methylation, taste sensitive minerals and keeping my minerals up, and infrared light, and sweating. At first it made me extremely nauseous since I was detoxing so much, and I'd get incapacitated by how much I was detoxing, but the different layers of stuff poured out, and after a while it was harder to get as much out at a time. Going through that took me down from severe reactivity to where, well, a wider range of buildings and areas are ok. That treatment also greatly improved my balance, which I hadn't realized that up until then was really poor.

The interesting thing is that mold sensitivity can get worse temporarily during detox, because you simply have so much in your system while it's coming out. But it's a clear sign that you are detoxing when, as people say, you go to the bathroom and notice that you feel more clear-headed afterward. Some people propose that is from getting histamine out of the body, but it tends to coincide with improvements in vision or balance for me so I think it has to do with removing toxins. Other signs of effective detox for me are that my eyes feel healthier, I have less Candida in my ears, my skin gets stronger, liver is less tender, heart feels healthier.

It seems that if you are able to detox, then the reactivity goes down over time. That could be because the mold toxins influence gene expression and tend to promote chronic inflammation and all those changes we know so well - high NfkB, high TGF-beta, high TNF-alpha, etc. So if you get the mold toxins out you
get less of those negative gene expression issues.

I think the body has a goal, and it's to get you detoxed and to let things come back into balance, and that's a higher goal for it than that you can go anywhere without symptoms.... so I think we have to submit to the body and address its priorities - detox and homeostasis - before addressing our own goals or social goals. The body tends to win.

**Lisa Petrison**

December 2007: Moved out of moldy house and away from contaminated possessions.

September 2008: Camping with Erik, got really clear (then back to Chicago)

November 2008: Moved to house in Las Cruces.

February 2009: Spent six months living in tent (with sporadic hotel stays), then got an RV. Hyperreactivity peaked in July 2009.

August 2009: Famvir brought down reactivity a little bit (able to handle cross-contamination a little better).

December 2009: Added Valcyte. Reactivity increased and then decreased a bit beyond baseline.

Summer 2011: Following intensive detox (spurred by homeopathic remedy), reactivity dropped substantially.

2012-2013: With continued detox (and nothing else), reactivity dropped gradually until almost no cross-contamination was problematic and almost no buildings felt very problematic. There are still certain outdoor toxins that are problems, but not nearly as much as they were even 18 months ago.

**Beatrice Latherings**

I'm not long out of mold, and probably not completely clear, although I'm functioning much of the time now. I can make quick forays into bad buildings but cannot make lengthy forays into bad buildings. Still could not imagine living in the housing I used to live in, and assume that will be a permanent change in my life.
Q. 37:2 - Cure

Who are the people you know of who have healed mold *sensitivity* the most (it's ok if it's you) - not just recovering from the initial toxic effects which lots of people do, but also who can be around reasonable amounts of mold and have a life, and if you had to speculate on a cure for mold illness that would take less than one year, what would it be?

Lisa Petrison

Based on the cases that I've seen, I think that for people who are severely ill, less than a year is not enough time. Of course, maybe if "science" put its energies toward solving this problem, that could change. I've seen no cases that make me think that it's possible with the available tools no matter how skillfully used though.

From the cases that I've seen, detox is very slow but provides sustainable results. It doesn't seem to matter what type of detox it is. From a severe level of illness, 3-5 years of intensive successful detox sounds like a possible goal to shoot for (though no guarantees here no matter what).

Killing bugs can result in much faster improvements, but people who focus their energies on that rarely do not relapse.

I've not seen any big success stories with people who have attempted to control symptoms with immune modulators or similar drugs/supplements, though they can perhaps help a little.

As we all know, dietary changes help some people a lot.
Q. 38:1 - Location vs. Buildings

Is it more important to prioritize getting away from cities and civilization (including buildings), or to prioritize getting to a good geographic location (and maybe then living in a building)?

It seems there are a few different approaches -- on the one hand, going camping, and on the other, living within society, but in a good geographic location. Which would I do better to focus on?

Up until now, my attempts to avoid mould by living in “better” housing within a bad city have been futile.

Beatrice Latherings

A good geographic location while getting away from moldy buildings would be my choice. The outside environment doesn't matter if the inside environment is killing you. And the inside environment doesn't matter if the outside environment is killing you.

Lisa Petrison

On the Locations Effect board, people are asked to rate the places that they've been on a scale of 1-5, with 1=Awful and 5=Excellent. And that's mostly how I think about locations, in my own mind.

(Note that while I have had disagreements with people in the MCS community about good vs. bad locations, when I've visited locations at the same time as other CFS patients or Moldies, the reactions tend to be very similar. So I think that just as buildings can be quantified as good or bad with regard to toxic mold, outdoor environments can be too. Of course, environments can change due to seasons, things getting overall better or worse. And of course, we need research to confirm.)

I think it's a mistake for a Moldie (especially if very sick and in early recovery) to live in location that's a 1 or a 2. It puts too much stress on the system and people just don't get anywhere.

I think a place that's a 3 ("Fair") is one where people can make some strides toward recovery, if they take care of the other two parts of the equation (finding a decent place to live and not bringing along contaminated possessions). I think of
Reno and (at least in the non-winter months) Chicago as falling into this category. A lot of people do reasonably well in these places, but I wouldn't expect anything spectacular (unless doing skilled Erik-style avoidance).

It's preferable to get to a place that's a 4 or a 5 (and there are a lot of these places). People who do that have the potential to get to "mostly recovered" and to start doing a lot of detox (which is hard to do in a not-great place). Though of course, building mold and cross-contamination is still a factor.

The same basic principle applies for housing. From what I've heard of the HERTSMI, it seems to do a good job of screening out living accommodations that would be a 1 or a 2 (Awful or Poor) on my scale. Definitely you don't want to be in one of those. Anything better that that (3=Fair) would give a person a chance to make some recovery.

But if you want to get a lot better and move toward an actual recovery, then finding a place that is a 4 or a 5 (whether it be a house or a tent or an RV or whatever) on all dimensions is probably going to be necessary, for someone at an advanced stage of illness.

Q. 38:2 - Severely Limited Finances

Is it unrealistic to try to do avoidance with severely limited finances? For example, living on very minimal state benefits from disability assistance?

I struggled to pay rent and eat before I ever had to evacuate my apartment or lose my belongings. If I have to lose everything I own again, I'm not sure how I will manage with basic of survival. I do have resources in the form of friends and community who help me with things (second-hand clothes, food banks, rides to places I need to go-- but I realize that those specific things are not necessarily going to be accessible to me once I get clear, because they might be moldy! Then what will I do?).

I am caught in a situation where I need to move to get better, but also don't know how to be sure I will not end up with nothing, or really being in a dangerously tight spot. The place I'm planning to go seems to allow legal outdoor sleeping in public parks. I'm hoping I don't have to do that. But maybe I'm underestimating the finances it takes to do this right.

A.M. Runyan

One thing I noticed with avoidance is that I didn't need supplements the way I used to. Supplements can help the detox go faster, but the body does know how to balance things out eventually if it gets some clear space.

Something I do to save money while doing avoidance is that I try to buy most of my stuff from places with good return policies, where I can return without a receipt or where returns are easy, so if stuff gets contaminated (by my criteria) and I can't fix it or clean it enough I just take it back.

Also, I really don't eat much food. I realize that autophagy (cellular recycling during intermittent fasting) is a really amazing, free way to detox and throw the cell ingredients back in the pool and remake cells. Not eating much during detox seems to be fine by my body, so long as I'm getting enough fats, particularly grass-fed butter and some other oils.

I feel also that baking soda/Alka Seltzer/alkalizing stuff might be a really strong treatment, and it's very cheap. Who knows though; you never know what to expect for the first few months of doing this.
Lisa Petrison

Just some random thoughts -- not suggesting that you should do this. And a lot of people who are starting off will need to stabilize in a decent place (as I did) before even considering something like this.

Here is an article by Joey of HealClick about his own cargo trailer, built to Erik's specifications and costing $7k. The second link shows a photo of a similar trailer.

http://blog.healclick.com/build-toxin-free-home-on-budget/

http://mychemicalfreehouse.blogspot.ca/.../mobile-homes...

Obviously, purchasing a trailer like this and a vehicle to tow it with requires an upfront investment. On the upside, campgrounds to park it (outside of city areas) tend to be quite reasonably priced even when full hook-ups are used.

At my own level of reactivity (which was pretty high), I mostly only had to throw away items when I ventured into bad places. If I had just stayed in a place that I knew was good rather than being so adventurous in traveling around so much, I would have had to throw almost nothing away due to contamination.

The main drawback to living in the middle of nowhere is that fresh organic produce is a challenge, especially if you want to have a lot of it for juicing. Places like Joshua Tree (CA), which have a farmer's market twice a week and an organic grocery to buy produce are fairly rare, unfortunately.
Q. 38:3 - Children

Has anyone done extreme avoidance with children? Does this seem impossible with a family?

Heather Plude

I moved out of my house with two kids, two adults and a dog. We took very little with us. What we had to take was sealed in plastic Ziploc bags, clothing (we cleaned it in 1-2 cups of ammonia). We threw out most of what we owned. We lived between motel rooms and tents for 10 1/2 months while we fixed our house and searched for safe housing elsewhere in case we could never live in our house again. My son went from zero quality of life, wheelchair, seizures, extreme pain to 100% well in 4 months. It took me 18 months to get well. We are still careful about exposures and what comes into the house. We were able to fix the house we got sick in and live there now. We test for air quality/mold frequently and will never be blindsided by environmental illness again.

Lisa Petrison

I've encountered a number of people with kids who have experienced substantial health improvements and/or successfully gotten to "mostly recovered" status through avoidance and other treatments, including several who have actively pursued "extreme avoidance" (using personal reactions to eliminate exposures of even tiny amounts of particularly problematic toxins). In general, this journey is not easy for anyone, but the health improvements that have allowed them to better care for their children seem to have been an especially large motivating force for them, as has the idea that (since this seems to be a genetic disease) living in a better environment likely will have long-run health benefits for the children as well.

All the mold avoiders with children that I've seen have made it a priority to find a conventional home that they could live in. There also tends to be a preference for places with good school systems (which makes sense since most people who have been willing to try avoidance so far are extremely well-educated themselves).

In my opinion, this makes getting clear so that small toxic exposures can be easily detected particularly important. An important goal here seems to be to choose a particularly good home in a place with particularly good outside air.
(compared to other similarly attractive places in terms of community/schools), so that maximum functionality can be obtained as quickly as possible. In order to obtain that heightened sensitivity quickly, spending a few weeks in a particularly good location without contaminated possessions (either tent camping or in a known good building or RV) is very helpful.

Choosing a location that is good year-round (e.g. that does not decline dramatically in winter) also is important. And especially if a home is purchased, working with a knowledgeable building professional who can focus on prevention of potential problems also is helpful.

**Julie Rehmeyer**

Yes, quite a few people with children are doing it. I don't have children myself so I can't speak from personal experience, but it's certainly clear that it's quite challenging. On your own, it's much easier to make your life very, very small for a while, focusing on avoidance and healing, while your reactivity is really high. It's harder to do that with kids, because of school and because of the sense that you don't want to shut down their lives completely. Nevertheless, I know of people who have made substantial health improvements through avoidance while raising kids.
Q. 38:4 - Work and Money

Two of my children recently had to quit their jobs because of mold issues. Another daughter is having hallucinations at the supermarket where she works and knows she has to quit. We had mold in our house and left, but now we're reacting everywhere. Two children also had to leave college. My question is: What does everyone do for work and money? Things are getting desperate around here.

A.M. Runyan

I used the Job Accommodation Network and Americans with Disabilities Act to get to work remotely. I actually work from a different state now, online.

The way it's supposed to work, you can apply for any job you are qualified for, not tell them in advance you have a disability, and then if you react to the building in theory you can request to work remotely if you can do the essential job functions remotely. They offer free help on the phone.

Also there are listings for online jobs. And some workplaces aren't moldy. And lots of online college courses that can be transferred to most colleges.

But yeah, it's tough. At least environmental illness (and MCS as well) is recognized as a disability under the ADA.

Julie Rehmeyer

For about a year, I relied on help from family-like friends. Since then, I've been well enough to support myself. I'm lucky to have flexible work that I can do from home as much as I'm up for.

Beatrice Latherings

I was damn lucky to be near retirement, and my employer carried me the last six months. I showed up but was unable to do very much.

Christine

I had to go on disability.
Q. 38:5 - Earning A Living

Any ideas for a young person who wants to combine mold avoidance and earning a living? I am well-off and still (just) managing to hold down a job.

Julie Rehmeyer

I am a freelance science writer, so I have the great blessing that I can work from home and that I can work as much or little as I’m able. Being able to work remotely makes an enormous difference.

A.M. Runyan

I work remotely (online) doing statistical analysis and research design. It helps to have a profession that lends itself to consulting or that kind of work relationship where you have a specific skill.

Mark Manson has a decent article on ways to make money online (that are real). In theory you can even work online while camping, but you’d need a good internet connection. It enables me to move where I need to move and keep working.

There are 100% online jobs, and you can request remote work as an environmental illness disability accommodation for any job that can be done online.

See the Job Accommodation Network

From FlexJobs, some of the top work online jobs:

http://www.flexjobs.com/blog/post/5-top-work-from-home-jobs/
Q. 38:6 - Fishing

Might fishing be a good job for a mould reactor? Good air, but I am afraid the damp on the boat might foster bad moulds.

Julie Rehmeyer

I would expect most boats to be moldy, but perhaps some are ok.

Lisa Petrisson

I know one CFS patient who said that when he was out on a boat on the ocean for long periods of time, he eventually would get to the point where he would feel totally normal. It would take about a week, he said. He thought it was a result of being away from mold. So he was considering buying a boat and living on it permanently.

Of course, it would depend on the boat. If the boat was moldy itself, then it wouldn't work.
Q. 38:7 - Prompt Action

How important is prompt action on mould avoidance?

A.M. Runyan

I used to say a lot when I was worse off, that I never wanted to let myself get so bad off that I couldn't travel or move or do research to take care of myself, since I had to depend on myself to cure myself. There's a point of no return, and I wanted to stay far away from that.

The other thing I think about is that life is uncertain. You never know when some sort of emergency could happen that would require you to be healthy, like what happened in CO where lots of people had to stay in shelters, etc. I made it a project to get a lot better early last year, and then I suddenly had to move out of my apartment due to a dangerous situation there with a neighbor, and because I'd acted like it was urgent to get healthier, I had the health to make the moves necessary.

In my experience - this is an emergency we are living in, where our bodies are toxic, and when you have an opportunity to take care of it, it's good to take care of it. The future is uncertain, but having fewer toxins in oneself usually makes the future better.

Lisa Petrison

If you're living in a bad place, the sooner you get out the better. For susceptible people, trying to detox this stuff out is infinitely more difficult than just avoiding it to begin with.

If you are talking about getting hit, the sooner that you get away and decontaminate, the more grief you will save yourself.

Susan

Seconding everything that A.M. Runyan wrote. The longer you let a situation go, the more damage is being done to your body and brain and the harder it is to reverse that damage. The longer you let a situation go, the less prepared you are physically, intellectually and emotionally for any other challenges that come up in your life, from car accident to family crisis to natural disaster to pathogens.
making the rounds. By being proactive, you stop a snowball from becoming an avalanche.

Beatrice Latherings

Some damage is permanent. Get out as soon as possible, even if you have to live in a tent. Just get out. I've never heard anybody say, "On I wish I had not left so soon." What I've heard people say is "Oh, I wish I had gotten out sooner."
Q. 38:8 - Having Children

Given what you know about toxicity in humans, and the state of our world today, how would you advise a seemingly-healthy sibling of a sick Moldie who has 'this illness,' if that seemingly-healthy sibling wishes to have children in the next few years (and may or may not share the Moldie sibling's detox genes)? What type of regime and what degree of rigour in preparatory detoxification would you think appropriate?

Would you advise more rigorous detox regime before pregnancy for that sibling than you would for a regular person not genetically related to someone with 'this illness'?

Also, in theory, if a sick Moldie with 'this illness' spends several years doing extreme avoidance and detoxing very thoroughly, do you think they could get to a point of being detoxed enough to be able to have children and not pass along toxins? Or do you think that having children even after thorough detox would be risky for someone in this category, because of toxins or their damage?

Underlying this question is: Do we think that people who are recovered from this illness eventually reach a state of detoxification comparable to that of truly healthy people, or perhaps they are more detoxed than average healthy people, or maybe they still have some degree of problematic toxicity lingering, even when fully recovered?

Connie

Dave Asprey's book *The Better Baby Book* really addresses this question. He goes through some detox methods that would be good. Sibling of a mould sensitive person likely has CFS and autism in the family.

Lisa Petrison

Considering how toxic the world is and how many children have diseases that seem possibly related to toxicity (such as autism, obesity or ADHD), I think it is probably a good idea for any woman thinking about conceiving toconcertedly pursue detoxification beforehand, regardless of whether she has a sibling with mystery disease.

It's my belief that a lot of people with mystery disease do a lot of things to try to
detoxify but do not manage to be successful at this. So I would suggest that if people are still sick (including having hyperreactivity), then that likely means that their systems are still especially toxic. If people get to the point where they are recovered, I would probably guess that that means that they are no longer more toxic than other healthy-appearing people. Which does not mean that they are not toxic enough to have an effect on a child. Again, toxicity in the world is such a problem that people who never have had mystery disease may be passing along enough toxins to have effects on their children too.

**Beatrice Latherings**

This will not be a popular comment. I think anyone with a known genetic defect that produces the kind of life-changing illness that the mold gene does, should not have children. It's not as if we are underpopulated and it's not as if there are not children out there begging for parents. Some in your own city. (No, I do not have children.) Why produce a child that you know ahead of time may have extreme health difficulties in an ever-increasingly toxic world? Why produce someone who is very likely to have an uncomfortable, frightening, and restricted life?
Q. 38:9 - Brain Down

A risk for me occurs during those times after some exposure when I am feeling better but my brain is still down (like power grid). That is when I usually have great ideas about cleaning or trying to retrieve things from my house or trying out a new space I might potentially react to but really want to visit. If others have this problem, how do they stop themselves from doing the dumb things? Write themselves notes? I was thinking of trying to practice an action plan exercise whenever I leave new safe place, regarding what I plan to do, what I won't do even if I problem or opportunity arises. Maybe if I do it all the time, even when I am not brain dead, it will be a habit I undertake even of I am brain dead. Have others figured out strategies to handle this problem?

Lisa Petrison

Certainly, I have had some experience with what you mention. But eventually, after enough bad experiences, I became more cautious.

What I had more difficulty with was in managing interpersonal relationships when still hyperreactive. What would generally happen when I was hit with certain kinds of toxins (especially that outdoor stuff that is especially associated with Tahoe but also with particularly bad indoor molds) is that I would become very emotionally hypersensitive and feel angry with people for doing relatively small problematic things -- to the point that I felt it necessary to express my anger toward them. That was not necessarily the best strategy much of the time, even though I think most of the time I actually did have some reason to be upset.

So I usually tried very hard to remind myself when I felt overwhelmed with emotions toward someone that I likely was reacting to something in the environment and probably would be best off if I dropped the topic for a while, until I felt more calm. Which probably is a good thing to do in general, in situations where people become really upset. It worked somewhat, though not entirely.

Life has become a lot easier now that I have regained so much emotional equilibrium that people can do incredibly problematic things and I still don't get emotionally upset about them. The possibility of losing that equilibrium makes me extremely hesitant to go to places that I know are problematic (like the Bay Area for the IACFS/ME conference), even though I think I probably could at this point without any serious non-emotional repercussions.
Karen Dean

As with the previous poster, I have experienced times when I am toxic that I take it out on people who certainly do not deserve it. Now that I have much experience with the nuerotoxic effect on emotions, I am very careful not to react. It can be controlled.

As for making mistakes, making checklists can help. Running a plan past someone else is a good idea.

Having protocols in place ahead of time is the best idea. Know what you are going to do if you end up in a bad place. Explain to people you are with that if a certain building is bad for you, you will have to leave.
Q. 38:10 - Consultation

Do you think there are any experienced mold avoiders who might be open to consultation in real time about particular activities one is contemplating that might be risky?

I did something yesterday that made me pretty sick: able to have only one thought (at a time) emotional, zombielike. Not sure what. But find that others, no matter how well-meaning, keep pushing me to do this and that and logically (without established science info) it seems reasonable.

I think after enough times of running into trouble I may ultimately figure it out but I am so afraid that each exposure is injuring me further and I may end up in state from which there will be no recovery.

My exposure was really intense. Probably was eating this mold on my toothbrush 3 times a day before and after spent day cleaning furry mold off stuff.

Scared, sad and disoriented. Feel unbelievably alone.

Lisa Petrison

It is extremely challenging to counsel people who are starting avoidance. Having done quite a bit of it myself (without being paid), I can say that with quite a lot of confidence.

In addition to the difficulty of doing this kind of work, there also is a question of whether charging someone for help without having a license as a medical practitioner or psychotherapist is appropriate. Certainly there are lots of people these days who charge for "life coaching" services, but the specifics do need to be considered carefully.

Although I do not have enough time to continue to counsel people without being paid, I am getting enough email pleas for such counseling that I am considering setting things up to provide services for a fee. The question is how to do that in a way that would provide an at least okay experience for all concerned.

Erik Johnson

Paradigm shifts are very hard to come to grips with.
It's wonderful to have reinforcement from others that you are not exaggerating this in any way.
Q. 38:11 - Motivation

How do you motivate yourself while doing mold avoidance? How do you make life gentler or easier to balance out how psychologically demanding mold avoidance can be?

Further details:

It requires a high level of attentiveness and responsibility, small mistakes can have devastating consequences, and there aren't a lot of people who you can talk to who will understand or believe the difficulty of something like making a mistake and contaminating your living space.

Also, in contrast to illness, where bad days often happen randomly, during mold avoidance you often know exactly why you are feeling bad, and it's often either 1) your fault, where you contaminated something or 2) a situation where people are bringing mold or toxins into your space and you either can't do anything about it or have to uproot yourself to avoid it, which can contribute to feelings of powerlessness or trauma.

Additionally, while going through the difficult times, you are also typically reacting to mold, which can make you more negative and emotional.

I do find that mold avoidance is worth it, in terms of getting "myself" back, but in those times when I mess up and get exposed again or ruin my living space for a few days, I'm really curious how other people keep (or kept) themselves going.

I'm looking for anything that people find helps. I realize I've been running at an emotional deficit while doing mold avoidance, where I'm just accepting the hard things about it and not doing much self-care to balance out the difficulty.

Karen Dean

I just got through another mold clean up after a neighbor, who is my handyman and had been here many times w no issues, came to measure for a new chimney, and contaminated my space. The most important thing I think is to have a system already set up for what to do in such a situation. A bag of clean bedding in a safe place is great. A checklist of what to do really helps, you may not be thinking clearly, it really helps. Make sure you never run out of the cleaning supplies you need. Having a back up sleeping spot is most ideal, especially when
you discover your regular place is too contaminated to risk sleeping in. Being sick and having to do 8 hrs of work is no fun, try not to beat yourself up about mistakes, we all make them.

**Lisa Petrison**

A few things that were helpful for me:

1) Finding a super-pristine, reliable spot in the wilderness and then spending time there. Everything seems much easier when the system is calmed down totally. And by breaking the response by getting away from the toxins for a while, they often start to be much less noticeable.

2) Simplify life. Many things that seem like they would be nice to do risk getting hit. Eventually it started to seem not worth it, a lot of times. A goal for me was to find places that felt good and that I enjoyed for other reasons, and then to stick with those places rather than experimenting with variety.

3) Don't focus too much on the end goal (getting rid of the illness and being totally better). I actually have been very goal oriented, but to the extent that I could find ways to make my life better despite still being reactive and having other symptoms, that really was a lot better.

**Beatrice Latherings**

It becomes a habit. We all continue to occasionally make stupid mistakes. I was just at a band rehearsal in town that ended at 9 PM. I turned on the hot water heater before I left to drive down the mountain, so I wouldn't have to wait for it to heat after I got back. It took over an hour to drive back up the mountain, so I got here about 10:15. Then I took my shower and could have gone to bed by about 10:45. This is so different from when I lived 20 minutes from the rehearsal and went home and fell into bed. You just get used to it.
Q. 38:12 - Social Connections and Work

I picked up the mold avoidance threads last year and have improved my health significantly since last fall with mold avoidance, detox, and lots of fresh air. No small set of sacrifices made this possible - I left my job, my partner, my dogs, and our home to get clear. I moved into a relatively new apartment with a few items of clothes, a cot, and a stadium chair. I reached a point last summer, living in Atlanta, where I was convinced that if I did not leave there would be no end to my problems and I would develop CFS or some other autoimmune problem.

At this point I would describe myself as a moderate to 'can actively manage' mold responder - provided my exposures are not too long and my clothes and sleeping place are free of mold.

Q1: How have people dealt with the isolation and distance required to get clear? I am not just talking about physical distance - I am talking about relationships. One of the most difficult parts of this process has been friends falling away and the looks I get when I talk about mold as a cause for my health problems. I have largely stopped talking about it which only increases my sense of isolation.

Q2: Getting clear and deliberately minimizing exposures seems to be the best path for keeping your immune system in order. What have people done to return to the workplace and be more active in the world? Hotels, offices, restaurants, airplanes, airports are all problematic and all required for me in my career. Have others shared their process for navigating these? I want to go back to work somewhere soon and I keep running into offices that are moldy where I am fine for a few hours but don’t think I could spend 40-50 hours a week.

Lisa Petrison

Q1: I wish there were a good way to talk about mold illness issues with people in a way that would be easily understood and accepted. I got to the point where I stopped talking about it with people at all, in terms of both people that I was just meeting as well as most people from "before." Fortunately, I did have a few people who I was able to talk with honestly and that did help. I once heard someone say that it's not that important that a child have lots of friends -- the key is whether s/he has at least one good friend. And I think that was true for me as well, going through this experience.
Eventually after I joined Facebook, some people from "before" started to find me on Facebook. And I talk about mold so much on there that eventually some of them started to understand that this was a real phenomenon and that I wasn't just nuts. Hopefully as we get more media coverage of the topic, the reaction of people to the idea that mold can be something that people can become sensitized to and need to avoid will be more like, "Oh, yeah, I've heard of that before" and they will be more accepting. But unfortunately, that hasn't happened yet.

Q2: Admittedly, many of the people who have been most successful in returning to work have been those who have been able to arrange a situation where they are able to work on their own rather than in an office. In many cases this includes people doing freelance work, but I know at least one person who got a current employer to allow remote work.

Possibly you will get lucky and find an employer in a building that is good enough for you. An alternative would be to pursue the course that Erik did -- to get as clear as possible at night and on weekends, in order to build up strength in the system to tolerate more exposure during work.

This might be easier in certain places out west. I don't have any reports that Atlanta is a particularly problematic city, but the air quality in any city is not ever going to be great. And my experience is that anywhere east of the Mississippi, the air quality outside the cities is not going to be good enough to really make a difference. At least in some places out west, you might be able to more easily live in an area where the air quality is really good and more easily get out to the Godforsaken desert to refresh on weekends -- and as a result be able to tolerate more, in terms of doing some travel or working in a less-than-great office. So that would be another possibility to consider, if moving is an option for you.

Erik Johnson

As long as my sleep area is free of neurotoxicants to the point of allowing regenerative REM sleep, I have been able to build up enough tolerance to operate in what would otherwise be completely unacceptable buildings. Rather than being a sacrifice that prevents interaction, it was the reverse. Extreme Avoidance is a trade-off that allows more.

Julie Rehmeyer

Yes, as time goes on with avoidance, one is able to handle more short-term
exposures, which helps with these issues. I've been fortunate in getting surprisingly little resistance from my friends about mold. My improvement was so dramatic that no one could really doubt it. It also probably helps that I'm a science writer and a mathematician. But also, the internet really helps in finding like-minded folks. I have a number of different social networks online that provide my most central communities, and I can take them wherever I go. I work for myself freelancing, and that's made a huge difference for me. Even now, when I'm nearly recovered, I really need the flexibility of working from home,

Giles Meehan

Strangely (or maybe not strangely?), almost all my ME friends think I'm crazy for doing mold avoidance and can't make any sense of it at all... But all my non-ME friends think it makes sense and don't have a problem with it - although a few might think I'm a bit "obsessive" about it!

Beachy Keen

Really curious to see how others handle this. The isolation is killing me, and I miss my family but can't be around them.
Q. 38:13 – Writing a Health Care Proxy

Any advice on writing a Health Care proxy?

Beatrice Latherings

The organization Final Exit has a service to help you write a health care proxy.
Chapter 39

Others’ Responses
Q. 39:1 - Tips for Explaining

Any tips for explaining mold injury and mold avoidance to friends and family members? Clearly those in the mold community know that people tend to think you're crazy and blow you off. Are there ways to approach others that will make them more likely to believe your story or understand your situation?

A.M. Runyan

http://momsaware.org/mold-video-series.html

Lisa Petriso

Some of the mold avoidance blogs listed on the Paradigm Change site have been persuasive to people.

Forebearance

That's a tough question. I tell people who just need a quick explanation that I have a messed up immune system and am easy to poison. If they need more explanation, like a family member, then I add that I have genes that make me especially vulnerable to mold toxins. so those kinds of poisons bother me the most. (It doesn't seem to help at all to mention ME/CFS because people either don't know what it is or have misconceptions about it.)

If you didn't have ME/CFS or chronic Lyme Disease, you could just say you have mold poisoning from living in a bad place. In my experience, most people understand that and have heard of it.

Kathleen

I found that most people need a visual to help them understand. Sometimes a photo like this one or even a video if they are will to take some time to watch and understand.

http://www.drdaveou.com/blog/?p=402
Q. 39:2 - Lost Relationships

How many of you have lost relationships because of mold illness? I have a suspicion many people with this issue are in isolation and have lost partners. I've seen countless people in the Lyme community abandoned either directly or indirectly because of their illness. I would imagine the numbers to be equally high here if not higher. It saddens me to see this happen to so many good people simply because of a condition.

Lisa Petrison

If you're looking at the disease from the point of view of "CFS" or "Lyme" (meaning advanced chronic Lyme), then there are going to be limited things that you are likely going to be able to do to help yourself to make substantial progress. Therefore, people are chronically pretty sick. And so the concept of "abandoned" makes sense.

The mold avoidance paradigm is one where people are making a decision to trade having a conventional life for the possibility of reclaiming a substantial part of their health. At that point, the relationship conflict usually is not framed as the sick person being abandoned. Instead, it is framed as, "I want to do XYZ to get better, and my partner is really pissed about it because s/he feels like s/he is being abandoned by me and/or thinks I'm insane." Which is quite a different scenario, psychologically speaking, than lying sick in bed for years until one day having the partner announce that it's over.

Of the people in relationships that I've seen who have pursued avoidance, a few of those relationships have ended. But a much higher percentage of them have gone on long-term "hold," with the partners living apart for extended periods of time while the affected (or more severely affected) person figures out avoidance, does some detox and other things to regain strength. And then eventually they come back together, periodically or permanently.

The unfortunate thing here is less the emotions felt by the people in the relationship (obviously this is stressful and demanding) but rather the emotions of people looking at the marriage. It is rather amazing to me how many people just simply do not like the idea of partners in a long-term relationship or marriage not living together for extended periods of time. They will try to push the issue, suggesting that you either should get a divorce or live together, and that being apart for extended periods of time is "no kind of marriage." When really, it's none of their business.
A.M. Runyan

I think it will become more respected as time goes on and there will be more social support for being with people with this condition, even if partners need to live separately or something. And healing does seem possible; people who detox seem to be less impacted than they were before. There are lots and lots of illnesses that are hard on relationships; hopefully as time goes on this will be less hard, between greater recognition/acceptance (particularly as more high-profile people experience it and see the truth of it) and better treatment/figuring out detox protocols better.

I "lost" two relationships because I had severe emotional symptoms from biotoxin illness in general (Lyme/mold) and I would have rage/anger and had to live with my partners. Now I'm living alone and having a much better relationship, 1) because I'm far less toxic and far, far more emotionally balanced, and 2) because I have time on my own to handle my own body and see my partner only occasionally and can make him a priority when I do see him. I think this is all I can physically manage now, and I would have to be a lot healthier and have my health working more on autopilot in order to live with someone again. Also, Skype is a lot like being together in person.

Just also wanted to comment that mold avoidance, and also the clarity and calmness people can get from it, can make people really great partners. I have a lot of personal traits and strength that are really valuable in my current relationship that I wouldn't have if all of this hadn't happened.

May Leen

These are the loneliest diseases ever, lost the family.

Beatrice Latherings

I was divorced but on good terms with my ex when the mold illness hit. He tried to be helpful, but told me that if we had still been married and I would have had to start living outside, that he would not have been able to handle it and would have bailed. At least he's honest. Secondly, I think the psychiatric effects of mold toxins on the brain will strain any relationship. People can only take a certain amount of helpless anxiety, depression, and rage in a partner.
Christine

In the last years I have found you can maintain more friendships by simply saying, “I'll stay outside while you go inside” (when you and a friend approach a contaminated shop/building). Initially I tried to explain the reasons and the physical compromises from exposures (mold/chemical), but it fell on deaf ears. No one really wants to know (until it is too late), so the secret for me to keeping more contacts now is saying less.

Joseph Salowitz

I lost two relationships with two wonderful women, due to mold illness, at two different times in my life. Life goes on.

During one of my home mold exposures, I moved in with another ex-girlfriend and her live-in boyfriend (he was great about that). After a few days, she told me I had to leave, because the sight of my coughing up blood, constantly, was upsetting them. I am still in touch, because I realized that my suffering was beyond anything that a friend, or lover, could endure.
Q. 39:3 - Seeing a Toxicologist

I have been sick from working in a water damaged building for about two years. I have worked out of my office for 6 months and am getting significantly better.

I finally get to see a toxicologist in about a week. I don't know if he knows about mold related illness. My trichothecene level was 1.75 after being out of the building for 4 months. I know it was significantly higher when I was working in the building and was way sicker.

Does anyone know how to approach an MD who possibly has no experience with mold exposure? Can I ask for certain labs?

I don't want to offend him and have him blow me off because he thinks I think I should be running the show. I have seen eight doctors and none know anything about this.

Lisa Petrison

A collection of informational resources appropriate for sharing with clinicians is on this page of the Paradigm Change website.

Janis Bell

No point in going to a doctor who won't listen to you. If he/she is open to being educated on how to address this illness, you can refer him to the paper, to Shoemaker's website, to Speight's chapter in a recent book on illness (well documented study), or to Hope's recent articles on diagnosing and treating mold illness. He/she just has to show the compassion and interest to follow through.

Vicki

I've never been very good at what you are asking, but I do have an idea for a Plan B if you need it. Dr. Shoemaker will consult with a PCP who is then guided on what labs to run and how to treat the illness.

On Dr. Shoemaker's website he has published research papers available for downloading also. survivingmold.com
Q. 39:4 - Medical Journal Articles

Can anyone recommend specific medical journal articles about mold illness and corresponding chemical sensitivities? A scientific viewpoint would help dispel the skepticism of friends and family members, since it sounds so implausible to them.

Julie Rehmeyer

This review article is one of the best I've seen:


And this one is good too, with the exception of the very first sentence, which is totally unwarranted:

http://www.hindawi.com/journals/tswj/2013/767482/abs/.

And this brand-new paper in PNAS is good too:

http://www.pnas.org/.../early/2013/11/06/1318830110.abstract

It doesn't give an overview the way the first two do, though. It shows that (at least in fruit flies) the VOCs from mold can cause Parkinson's-like symptoms, and also that the same VOCs are toxic to human cell lines. That's a pretty interesting result in itself, and I cite it here mostly because it's in PNAS, which is about as good as it gets in terms of journals.
Q. 39:5 - In-Laws Visiting

My in-laws, who live in another state, unfortunately have developed a big mold problem in their living space - including their closet with all their clothes.

They are not sensitive, but I'm hypersensitive to mold, and even a package they sent me made me very sick and had to be removed from our house immediately.

They are coming into town for a visit and I'm terrified they will cross contaminate us, our cars, our home, etc. I have dealt with that so many times since my first poisoning and lost homes just due to cross contamination - literally even after all I did was walk into a moldy house and then washed my clothes (which then ultimately ruined our condo from mycotoxins).

I'm wondering the following:

1. I'm thinking of doing an ERMI test just to know if whatever was there is still there in high levels that would show up, and what it is (Stachy is the big one that poisoned me), etc. Do you recommend a company for that?

2. Would ozoning their house and car help at all?

3. What can we do about their clothes? They dry cleaned them, which is only worse for me. I'm sure their machine is cross contaminated. I told them to wash with borax, but that actually never worked for me.

Any thoughts or test ideas or referrals welcome. I'm in a tough situation because they want to see their grandchild of course.

Lisa Petrison

The main reason that I can see to do an ERMI on their home is for their own benefit, since no one should be living in a really moldy house. I doubt that it would be of help for you though. Even if the house were remediated -- or actually even if they moved -- probably they are not going to get rid of all their possessions. And that will likely mean that you will have a hard time visiting their house, or dealing with the cross-contamination if they visit.

I don't have much personal experience with the ERMI, but Shoemaker seems to
I recommend Mycometrics. Here is the page on his website.

http://www.survivingmold.com/diagnosis/ermi-testing

After my own house was remediated from Stachy, I had it ozoned with high strength for a long time. It became slightly more tolerable to me, enough to be able to go inside for short periods of time. But not substantially. In this case, I really don’t think it's going to make enough of a difference.

If they are obliging, the easiest thing to do would be to have them purchase new clothing and other personal items to use during their visit to see you. They could mail order what they wanted from a place that you find okay (e.g. I would choose LL Bean) and you could wash them in advance. And then they could use a rental car or one of your cars during their stay. But of course, they would have to be agreeable.

Beatrice Latherings

The last paragraph of what Lisa said seems the best compromise if you are willing to expose yourself to them at all. I reached a point where losing my living space, my car, and all my possessions was absolutely not worth the alternative of possibly pissing someone off due to a refusal to submit to cross contamination.
Q. 39:6 - How is this Possible?

I have a question regarding mold avoidance. My girlfriend apparently has this 'mold illness' thing, and it seems plausible enough. But there are certain times we get into arguments about whether or not she is psychologically healthy.

One such instance: For a while, she was staying in a hotel. At some point, her mom mailed her an identification card from home, and she accidentally 'ozoned' it with an ozone machine all night. Soon after she said the entire hotel room was contaminated, and threw out most of her stuff and left the hotel. Now, a month 1/2 later, even if she just drives past the hotel, which is backed up from the street by a few hundred feet, she states that she can detect the after-effects of this incident. Apparently something that started as a small piece of paper that contaminated a single hotel room in a large complex has now contaminated a large-sized city block. This is also in a desert city with very little moisture.

We've gotten into multiple arguments about this, as I want her to be the best person she can be. I have told her she's being lazy, and walling herself off from the responsibility of life by making up some illness to pretend she's occupied. She insists it's just the way her body works.

I guess my question is, how is this possible? I understand the people that need to leave their homes, but I barely understand an ID card contaminating a room, much less large outdoor city blocks!

Julie Rehmeyer

I haven't had anything quite like this happen to me, though I've heard stories that aren't so terribly different from that from people who seem reliable to me.

A few things occur to me about it. An ID card is especially likely to cause a really extreme reaction, because it probably came from the environment in which she became sensitized. Whatever is in that environment is likely to be what bothered her most. Also, reactions can escalate to frightening degrees, so that something that is initially somewhat bothersome when close can become incredibly bothersome even when far away.

There may well also be a psychological component to all this. When learning to avoid mold, you have to trust your intuition and pay attention to the tiniest voice that suggests something might be bad for you. It makes sense to me that this
process would tend to exaggerate one's reactions with a kind of nocebo effect, because you're putting all this energy into recognizing and avoiding things that are bad.

So, perhaps, your girlfriend is subject to that kind of thing at the moment. But! I think that's a necessary part of the process. Our bodies really do need time to heal without mold exposure, and the only way, at this point, to give them that is through being hyperaware. Eventually, through avoidance and detox, her body will start to calm down, and her mind will start to calm down too, and those two effects will feed off one another.

The question at the moment is how you can deal with all this and how you can be helpful to her. Partners to people with this illness have a big challenge, no question. It ultimately doesn't matter at the moment whether her reaction has a psychological component to it or not, and frankly, neither she nor you will ever know whether that's the case; regardless, avoiding things that feel bad to her is what she needs to do right now in order to get better.

The question for you is whether you can support her in that. It's hard to throw out possessions over and over, particularly when you're not the one who has any sense that they're bad. But to be helpful to her, you're going to have to find a way of trusting her in that.

Lisa Petrison

This does sound like an unlikely story, doesn't it? I would have had a hard time believing it myself, for the first year or so that I was doing mold avoidance. But the more stories that I have heard about the particularly bad toxins, from people who are otherwise extremely reasonable and well-educated and successful at recovering their health through avoidance, the more I think that these toxins are really screwy.

Here are some stories that I have heard:

* Two of the mold avoiders who have experimented with these toxins the most have come to the conclusion that the toxins are acting as a "locus of attraction." They think that if you place a contaminated object in a living space, it has the potential of attracting more of the toxin from the air and thus of getting worse.

* I have a number of reports of people who are convinced that not only can toxins blow for several hundred miles (e.g. from Dallas to Wichita), but that this can permanently contaminate entire buildings in the distant city so that they cannot
go into them even when the outside air is okay.

* I've heard several stories that go like this: "I had one item contaminated with the bad toxin, and I needed to transport it. So I put it in three layers of plastic bags and put it in my car. Now the entire car and everything in it is totally contaminated, and it feels as bad as the original item. How can that be?"

* I've had a number of people say things like this: "Our family got sick in a moldy house and moved out, abandoning everything that we owned and being careful not to take any of the toxin with us. We're doing okay now. The problem is that we cannot be around any of our relatives or friends whose homes that we visited when we were in the house, because all their clothes and their other possessions are contaminated with the toxin. Just talking to them on the street is enough to make us sick for days, so we hide if we see them."

* One person was doing well on remote desert land but then invited a person with MCS to visit her. His trailer was contaminated. After he left, it took a whole year for the land to recover enough that this person was able to get back to enough health to return to work again.

Are these stories true or are they imagining that the toxins are acting that way? I don't know for sure. But the extent to which I was made sick by ridiculously tiny amounts of toxin when I was especially reactive is hard to believe even for me.

And the idea that someone might be even more reactive to particular toxins than I was doesn't seem totally implausible either. Especially since apart from their claims that they are reacting to these infinitesimal amounts of toxin, all of these people (who I have met personally) seem entirely sane.

The problem here seems to be a paradigm where decreasing the amount of the toxin exponentially does not result in decreased toxic effect on people whose protective mechanisms against the toxin are broken. That is a weird paradigm. Although in my opinion, it actually is not as weird as the paradigm now being reported in the literature about certain other toxins, such as BPA, which are worse at lower doses than high:


Regardless, based on my own experience with doing avoidance for the past six years, I think that a "better safe than sorry" approach to the really bad toxins is the best approach (e.g. led me to eventually recover my health and to be the best person that I could be under these very challenging circumstances).
At the beginning, when I ignored my warning signals about the toxins, I would almost always end up being sorry. I would be punished by spending weeks feeling horrible and trying to recover; my body stopped detoxing; and I ended up throwing even more things away than if I'd just been careful to begin with.

So I became more careful. And then my reactivity went down, to the point where I now can spend extended periods of time in places that I know are problematic. I never did brain retraining or stopped being vigilant -- my system just detoxed and healed. Which is the goal, in my opinion.

A.M. Runyan

This is only one of a number of hard-to-believe stories I've heard or encountered myself while doing this.

The bottom line is that we seem to be gathering reports to suggest that whatever these "toxins" are do not act in a purely chemical, dose-dependent way. There are some unusual aspects such as:

- Reactions to infinitesimal amounts
- Unbelievable cross-contaminations
- Very large radii of effects around toxic objects, proportional to the level of toxicity
- Some people essentially perceive a distance-squared effect in a sphere around toxic objects, where the effect increases the closer they get
- Electrical effects, like being shocked
- Reacting to objects or bad areas even when there is no air transfer possible (e.g. reacting to a city while landing in a plane over that city, even with minimal air transfer into the plane, which several people have reported)

This suggests a possibility that a chemical toxicity paradigm is incomplete, and these toxins might be exerting other effects, perhaps involving EMFs, electricity, or interaction with the body's electrical system. It is recognized in science that the body is not just chemical but also electric - see Robert Becker's research and excellent book:


The best analogy I've heard for how these toxins work is that they are like radiation. If you consider that analogy, then almost all of the stories make more sense.
If you imagine instead that humans are electrical beings, and certain objects get somehow imbued with something like radiation, then it could make sense that people whose electrical systems are very fragile could sense the presence of these electricity-disrupting objects very acutely. Perhaps if we look at it from this perspective and try to heal our systems from an electrical perspective we will make more headway with this disease.

I already notice that some of the most helpful treatments include Tri-salts and Alka Seltzer Gold, which impact the body electrically and seem to be able to shut off reactions dramatically (I've experienced this); electrolytes (a major part of the Patricia Kane protocol, and a major aid for detoxification seemingly): and BodyBio phosphatidylcholine, which impacts cell membranes. Even ozone works by changing the body electrically, involving electrons and cell membrane potential.

Examples:

I've heard of people getting electrically shocked by walls containing mold, being able to point to where mold was in a house when it was behind walls, being able to feel toxins through HEPA filters, reacting to other biotoxin-sensitive people's bodies even after they had been doing avoidance for months, and reacting to items that had spent time in particularly bad cities, especially those in which they had lived formerly.

One time, I took contaminated items from my former apartment and put them in a mini-fridge at a hotel, thinking keeping them sealed off would keep me from reacting to them. On the contrary, collecting them into a small area seemed to make them worse, and I still felt a reaction.

Early on, I also reacted to my sealed hotel room where these contaminated items were, when approaching it from a distance, even though there was very little air transfer.

When my mom visited from Fort Worth, I was not expecting to have any reactions and thought having her shower would be enough, but as soon as I opened my hotel room door when she arrived, I could feel the toxins and after spending a little time with her I had a major reaction that people thought I needed to go to the emergency room, I was completely red and having dry heaves and trouble breathing.

I've had it happen that biotoxin people stayed in the same hotel as I was in and I got very sick and affected simply from their presence in a room maybe 50 feet
away.

It was not just a placebo effect. There have been about four times I could tell something toxic was near my living space, but had no idea what it could be and doubted anything was there, and then I investigated and found that it was true.

I've also been able to confirm when toxic things have left my vicinity, because I sensed a noticeable shift in my body all of a sudden, and then upon checking it was confirmed that the people or trailer had left exactly when I thought they did.

One afternoon, I was busy with something and suddenly felt like I was getting mild paralysis. I closed the windows and went on with my day but kept having strange symptoms. I later saw that someone had parked a trailer about 50 feet away, and that probably coincided with my sudden onset of paralysis symptoms. I later found the person whose trailer it was and asked them to move it. I could tell exactly when it got moved since I suddenly was able to relax, and looked outside and saw them in the process of moving it down the street. Once it was down the street, I felt better, but sometimes it seemed the wind would shift and I'd feel it transiently and then it would die down.

I've had a number of unbelievable things happen, like apparently contaminating items through third-party object contact (I put something contaminated on the ground, and then a week later put something else on that same area and it got contaminated).

Or items that had been exposed to bad toxins still seem to be able to spread contamination to other things, even a month after being removed from the bad location.

I've heard of one box of photographs contaminating a person's new home.

I've learned that almost anything is possible with these toxins. You learn to clean/avoid first and ask questions later, because it is very obvious that the old/chemical paradigm is not sufficient for these. Whatever this is simply cannot be cleaned up or diluted in the way you can deal with chemical toxins.

It makes me think people might be on the right track when they wonder if molds are creating nano particles or crystalline structure toxic effects.

It is already well-known that the mold toxins in question are ionophores with presumably electrical effects in the body, rather than straight chemical/molecular effects.
Much of what we see happening could have far more in common with radiation, electricity, etc. than with chemical toxicity. I've heard crystal formation proposed elsewhere on this Avoiding Mold page. Also the way it is reacting with the body could have to do with altering electricity in the body, rather than with straight chemical toxicity effects. (It is a greatly overlooked area of science that the body could almost be seen as more electrical than chemical. Robert Becker was an excellent researcher ahead of his time and wrote the excellent book, The Body Electric.)

The electrical theory could help to explain why a lot of this does not make sense from a purely chemical toxicity point of view.

If you imagine instead that humans are electrical beings, and certain objects get somehow imbued with something like radiation, then it could make sense that people whose electrical systems are very fragile could sense the presence of these electricity-disrupting objects very acutely.

The shift could be in fact some sort of mild shift in the electrical activity of the brain or nervous system that then impacts detox, or a shift that causes a mild change in mast cell behavior.

This isn't too far from what people already observe who are EMF-sensitive, and mold toxins seem to be able to create greater EMF sensitivity. I don't have severe EMF sensitivity, but I don't like to have cell phones near my head, and it's been that way since I started having biotoxin illness in earnest when I got Lyme.

As for what to do for this, perhaps there are other things that can calm down these electrical situations. I find that chaga mushroom seems to be able to save some clothes that had really bad toxins on them. If I add it, I notice a sudden downgrade in the electrical feeling from the toxic object.

Butter also seems to be powerful, perhaps because many of the ionophore toxins are fat-soluble, and several people have agreed that butter seems to act like a sponge for these particular toxins, whether used on wet, warm skin or on toxic objects.

It's an exciting field and, as usual in medicine, the forefront/vanguard is in the repeated accounts of otherwise sane, intelligent people. It's one thing if one person reports this, but if dozens of people report it, it's worth considering, no matter how unbelievable it seems from the current paradigm.

The fact that it seems it's unbelievable means there is a problem with the current paradigm, not with the people reporting it. This goes for many cases where
multiple intelligent people report more or less the same thing.

Beatrice Latherings

I have met people who have "mold radar." Apparently mold sends out photons (I have no other explanation) and some people can detect these photons. They are so sensitized from prior experience that their systems go on Red Alert to warn them to stay away from this danger. I had one person who had never been to my house, point, from out in the driveway, to exactly where in my house the mold was. He had zero way of knowing that, and his perception was 100% accurate.

Karen Dean

Seeing the bizarre, sci-fi things that have happened to me with this illness, I would now believe anything. There is a block on my town I cannot walk on. One object has contaminated my entire environment. And mold exposure can so change my personality overnight that my best friends are frightened. Remember, first and foremost, mold is a mind bender.

I was told by a mycologist from Texas A&M many years ago to think of mycotoxin like radiation, and I would have more understanding. I have received large electrical shocks from mold. It is very hard for people not afflicted, or not having the same experiences to understand, or believe the issues.

Getting a boyfriend willing to accommodate my needs is difficult. The most understanding came from one who grew magic mushrooms and understood the behavior of spores.
Q. 39:7 - Cultish Detox Center

(Note: This note is from someone who just moved out of a moldy home on her doctor's suggestion.)

I need help. I'm at a detox center and it's not going well. It is very cultish, very condemning, very dogmatic, very horrendous all around. They are pissed that they couldn't convert me and that my body isn't responding the way it 'should.' They blame it on me not surrendering to (their) god, not doing everything they say (i.e., taking loads of supplements, eating processed foods and other foods that flare up my uc and cause me to bleed). They believe my health issues are caused by demonic possession and even did an exorcism on me. They convolute my words and make me feel like I'm going insane or that the devil is controlling me. That the only way I'll get healthy is by some miraculous spiritual enlightenment with their god. That yoga and meditation are satanistic and allow demons to possess the mind and body.

They don't understand chemical sensitivities, food intolerances, supplement reactions. They say that God will take it all away if you surrender. Well, I tried to surrender and follow their plan, but i got so sick the first week from doing the water fast, loads of supplements, and rapid detox, that i had to slow it down in order to stop losing weight and prevent myself from getting sicker.

I got so sensitive here that I had to wear a mask when i urinated because the smell of my own urine made me nearly vomit. Even the smell of water was nauseating.

I have nowhere to go but I don't know how much longer I can stay. They gave me till next Friday, but they are making it hell to be here. I was praying that a health institute would give me a great scholarship, but haven't heard back.

My only option is to go back home and stay with my grandmother until I find something. Her basement is moldy and she's a bit difficult to live with. I'm so afraid of getting recontaminated. Camping isn't an option.

Lisa Petrison

It is a nice thought to think that people who are sick with mold illness could just pay a lot of money and check into a treatment place, and then let the doctors
take over and fix things. That does not seem to be the way it works though. And after thinking about the topic a whole lot myself over the years, I don't think it's going to happen. There are too many pitfalls in creating and running a place like that for it to be a reasonable venture for anyone.

If Dr. Rea's clinic were in a reasonably good location rather than horrible Dallas, that might have a shot at helping people. But I do not think that people who are mold sensitive have a chance of getting much better in Dallas, no matter how skilled Dr. Rea may be. Sometimes people will insist to me that they were helped at Rea's clinic and that they know that they are sensitive to mold, but when I probe, what I find out is that the improvements were something like "I was totally unable to get out of bed and now I am able to take a shower every few days, and so I think I'm on the road to recovery." Which is not the level of recovery that I personally think is acceptable, compared to what people routinely get when they make the effort to do even moderate avoidance according to the instructions.

Since I know this questioner's goal was to get out of Chicago because she has a hard time with winters there, I would not especially recommend going back there at this moment. And I would not especially recommend moving into a known moldy home either, even temporarily. (The fact that chemical sensitivity has increased may suggest that this detox place, if unpleasant, is at least not moldy and thus that intensification reaction has set in. That means that going back to a bad place may be more problematic than before.)

I think that the easiest thing to do would be to go to a city like Wichita, which is not too far from the Midwest and which a number of Moldies have done well in. I would try to find an apartment that wasn't moldy, using a combination of the ERMI and my own reactions. And then I would just sit there for a while and see what happened. Provided that belongings are not contaminated and that the apartment is decent, hopefully some progress over the winter would occur, and then other more long-term options could be considered in the spring.
Chapter 40

Case Studies
Q. 40:1 - Case Study 1

I have been fatigued since I was 13/14 years old but not badly enough to stop me living my life. Moved from Zimbabwe (where I grew up) at age 16 to the UK, where I live now. Started having more severe fatigue but again didn't stop me going to uni/going out with friends etc.

17 years old got chicken pox for first time - was very ill. 18 years old got a 'virus' which made me tired, dizzy, off balance, couldn't see clearly for 2 months at a time. Doctor told me it was a virus. It would go away for several months and then come back.

At uni started to get more ill - fatigue, weight gain etc.

Fast forward to 3 years ago - had multiple vaccines for India. Got very ill with viral gastroenteritis while there. Came back and took months to feel better(ish). But health continued to decline fast. Started having brain fog, forgot things etc. Fatigue increased.

Finally March 2010 I got off the train and started walking home - thought I'd never make it. Fell into bed. Didn't move for days. Never returned to work. Was like the worst flu ever.

At the time I fell ill I was working in a school which was being rebuilt and there must've been loads of mould in the old building I worked in. Also the house I lived in at the time, we found a huge amount of black mould in the pantry - about 3 square metres of the stuff.

I now live in an old cottage. We did recently have a burst pipe which caused some mould in the kitchen and bathroom but we have finally managed to dry things out.

My partner and I have spoken about going away next summer for 2 months to see if we can get clear of the mould. Around that time we would also be looking to move if this house was a problem. Seeing as that's a year away, I found myself wondering about the garden. We have a pretty long garden and if I was at the bottom of it I would be pretty far away from the house.

I would buy new clothes and a new tent. Would cook and shower outside too.
I have tried: diet (has made the biggest change to my health), supplements, herbs, pacing, rest, acupuncture, osteopathy, Bowen, Perrin

At my best I am at 40% functioning on the ME scale, at my worst 10%. At the moment I'm 10 to 20%.

I do much worse in winter. I do worse in humid conditions.

I have all the classic ME symptoms - brain fog, fatigue, PEM, migraines, painful joints and muscles, insomnia, nightmares, adrenal fatigue, hormonal imbalances, weight gain, forgetfulness etc etc

Can you give me any more specific advice based on this information?"

Lisa Petrison

Purely anecdotally, it seems to me that CFS sufferers almost always first get sick or experience permanent substantial health declines when they are being exposed to relatively large amounts of particularly bad toxins. In addition, you know that the house that you were living in had a great deal of black mould (probably Stachy, which makes a variety of toxins depending on the circumstances but generally ranges from bad to super-bad). And you have suspicions about your workplace at the time as well.

It doesn't seem to me from this story that your health has declined since moving into your current cottage. And though there is mould in there, we don't have any specifics about it that make me especially suspicious.

So one hypothesis here is that your belongings may be contaminated with particularly bad toxins from your previous residence or workplace. If that is the case, then they certainly could be keeping you sick all by themselves, even if your current residence is not problematic at all.

When people feel much worse in winter, that often seems to correlate with problematic outdoor air (and specifically the toxin that I find most problematic). Depending on the extent of the problem, it can be hard for people to make much or any progress in places with that toxin in the outdoor air.

It would be interesting to see an ERMI or HERTSMI on your house, to try to get a sense of whether it is a problem (in addition to the assumed cross-contaminated possessions).
Especially if the house comes up as reasonably okay on the ERMI/HERTSMI, I would consider focusing attention on distancing yourself from possessions as much as possible. If you don't feel like you can get rid of everything (which would probably be the choice with maximum effectiveness), you could try replacing clothes and linens; moving all suspicious possessions out of your sleeping space (and showering before getting into bed each time to minimize cross-contamination dragged in from the rest of the house); and thoroughly washing everything.

Especially if the house comes up okay on the ERMI/HERTSMI, you might be able to use the shower during a camping experiment (though it probably would still be better not to). If you are suspecting that the outdoor air is problematic at certain times, then I wouldn't bother camping outdoors then. (Probably you would want to do this experiment during warmer months anyway.)

Eventually you may want to experiment with different locations, to see if there are any places that you feel more intuitively happier or calmer in. If so, then those might be a good place to consider moving to when you are able to move.

Julie Rehmeyer

Even if the house comes out okay on ERMI, I'd be very cautious about using the shower during the garden experiment. Most likely, your possessions are contaminated with something quite bad, and therefore your whole house is now contaminated with it.

From your story, when you get to the detox stage, parasites and heavy metals are probably worth considering.
Q. 40:2(1) - Case Study 2

(Note: This was post by a person with limited finances living in Canada.)

Grew up in a hundred-year-old house with roof leaks. SW Ontario

As a child - immobilizing melancholia: i recall lying on the bed smelling the 'fresh' air coming in the window from outside, and feeling a dark deep ugly feeling in the pit of my stomach that paralyzed me so i could not move. like existential pain felt physically. strange visual illusions of the room moving farther away from me, especially when sitting on a particular couch in a particular room. also experienced shortness of breath while sitting on that couch. had a period of this shortness of breath which lasted maybe a half year, unexplained. Odd, recurrent nightmarish experience, just upon falling asleep, of getting caught in a particular, strange, dream-dimension experience that I could not escape, and fought to wake up from.

Benign polyps growing in my colon at age 7-8, required repeated removal. As a teenager, sleeping too much on weekends. More than any other family member. First episodes of unexplained rage at age 12/13. Miserable and depressed throughout high school. Increasing sensitivity to coffee brewing smells in the morning - would make me irritable and furious. In 2004 I had the beginnings of chronic dehydration and frequent urination, not absorbing the water I drank, feeling worse for drinking it.

I recall being irritated by the school bus I rode to school for two years. I felt it had a smell (but no one else smelled it), and often changed my clothes upon getting home.

Sept 2004 - move to SW Quebec:

Began university (very old, grimy building where I spent all of my time)

I had constant three-month virus the entire duration of the semester (a simple cold), which i could not shake.

Dec 2004 - SW Ontario:

appendicitis. emergency appendectomy. prophylactic Cipro, then switched to Flagyl.

Jan/Feb 2005 - back to school in SW Quebec:
diagnosed with C Difficile. dehydration. treatment with flagyl failed. Treated with oral Vancomycin fixed the symptoms of c diff, but triggered the onset of severe crushing fatigue.

Symptoms at that time: abdominal pain (adhesions from surgery and trauma from the infection), 'post-infectious IBS,' severe weakness. feeling like the Vancomycin would kill me. going to sleep and wondering if i would wake up. awake/asleep confusion. unable to walk at more than a snail's pace. struggling/unable to climb stairs. unable to carry backpack.

by late 2005, symptoms included: depression, frequent crying, sense of crisis and life falling apart, inability to walk several blocks to bus stop, panicking from motion sensitivity while riding the bus, inability to concentrate at school, feeling of profound emotional and physical vulnerability. Dizziness from playing musical instrument (woodwind). Became too ill and weak to continue with school. Dropped out mid-year.

Dec 2005 - Moved back to SW Ontario:

Slow improvement with diet change, naturopathic and homeopathic treatment, attention to emotional healing, non-toxic lifestyle insofar as i knew how. Began anti-depressants and later a tiny dose of an anti-psychotic for 'mood stabilizing.' Made me feel I was 'losing it.' Felt desperate at times.

worked part time in a library and took several courses at the university there. felt unwell in the library. hated touching the books. needed to wash hands often to feel ok.

felt fine in the new-ish university buildings

Sept 2007 - move back SW Quebec:

Shocked upon my return to the city by the smell of car exhaust on regular streets. Assaulted by it. Couldn't believe how it affected me, but dismissed it.

Symptoms: severely unstable mood, prone to crises. learning disorder-type difficulty in school, total inability to take in information, distraction, unhappiness. Fatigue. Prone to hitting my own head, could not control this. Noticed that I could not learn or process information the way I used to. Struggled with auditory processing (was cultivating this at a very advanced level as part of my studies). Felt hugely impaired because of this issue.
September 2009 - began working in an ice cream shop and a basement library, part time.

The ice cream shop had a smell to it which I would eventually begin to notice upon entering the building. No one else seemed to notice it or care, but I remember now that those other people still felt suddenly desperately, urgently thirsty while working. we all did. I felt deeply depleted and dehydrated (oxidative stress-type feeling) after my shifts. The place was full of freezers and industrial fans and cooling systems. Side note: I walked in there two weeks ago just to see (2013), and left within 30 seconds, coughing and gasping.

The public library I worked in was in the basement just a few blocks from the ice cream shop. I was shelving books. I had to crouch on the ground, with my face close to the old carpet, to get at the lowest, ground-level children-sized shelves and read the call numbers. Difficulty pushing book cart.

Symptoms: Visual trouble, difficulty reading the call numbers on books, had to strain to do so. Exhaustion after my shift. Had to eat something and rest before biking home.

Was living in a very dingy apartment during this time. Had my first instances, that I recall, of waking up suddenly, scared, in the night.

Required at least nine hours of sleep per night. If not I would simply fall asleep -- in a seminar, while participating, while studying with a partner.

June-July 2010 - Western MA:

living in very dank and grimy student housing building

studying in a new and good quality building, but around ancient historical books. The administration even talked about the mould issues they had previously had in the warehouse where they used to store the books before they got their own building!

Symptoms: quickly worsening fatigue. could not ride my bike to my place of study anymore. needed to sleep on couches during lunch time. needed to lie down rather than sit. emotional crisis, felt very vulnerable.

Sept 2010 - moved to New York City:
studied in a somewhat stale building. seemed generally in good condition. lived in an average apartment with cockroaches and mice in a typical urban NYC neighborhood. no visible leaks.

Symptoms: Would wake up at night screaming, feeling there were ghosts around me. fatigue increased immediately. Could not keep up with the school schedule. Had to start missing classes almost immediately.

By January I was only able to attend half-time. Then I couldn't even attend half-time. Began a stricter diet for healing and started having liver pain. Needed to lie down and nap after getting to my school. Especially suffered when riding the subway - felt that deeply dehydrated/depleted feeling which I associate with oxidative stress. Too exhausted to leave my apartment some days. Unable to concentrate on my studies, emotionally distracted, worsening vision issues. First-ever castor oil pack caused me a detox reaction so severe it sickened me for days, making me mostly unable to walk or stand until the reaction ended.

May 2011 - return to SW Quebec:

living in various random basements, dirty sublets, then finally a nice place, clean good environment. slept on a memory foam pad atop a futon which I suspect was poisoning me.

Began work part time in a bookstore. Old building. New books, not used.

Health worsened. My illness became neurological. Vision was getting worse, had to stop doing microfilm research. After wearing glasses full time since age 5, gave up on my glasses completely because they made the neurological processing worse. Extreme brain fog, only alleviated when immersing my head in an epsom salt bath. Headaches with light-sensitivity. Post-exertional malaise. Agonizing fatigue riding the bus home from work, falling asleep, not being 'with it.' Balance issues.

Jan 2012- move to a worse apartment:

Started waking up at night with worse screaming and terror. would stay up until the sun rose because I was too scared to sleep. began going to sleep with a light on. first instances of severe heart pain and sense of cardio-distress, feeling like my body was at the edge of what it could handle. this was first triggered by overexertion.
May 2012:

Moved into a terrible building with a discernible smell, and leaks under both sinks.

One month in, I was having instances of my left leg/ankle/knee just giving out on me without warning. At first I would fall. Then I learned to hang onto railings, walls, etc while walking. Eventually needed to use a cane for support. My left knee would suddenly buckle. Fatigue worsened. Could not leave my apartment for 4-5 days at a time. Even then, sometimes when I tried to leave to walk to the park, I could not make it down the block, and had to turn around. Severe sensitivity to motion, would panic on buses, especially going down hills. Went away for a week and upon returning, was convinced there was mould in there, got out immediately.

Sept 2012:

Moved into new apartment. brand new building, two years old
Began developing breathing issues. Shortness of breath. could not sleep. needed windows wide open to even have a chance of sleeping. increasing sensitivity to car exhaust and fumes on the street. nosebleeds after vacuuming or cleaning at home. waking screaming during the night more often. Instances of tachycardia during the night, jerking and twitching at random times at rest, stabbing head pain which would make me grab my head and cry out. MCS reactions worse than ever to roommate’s shampoo. ERMI showed a score of 12. Stachybotrys showed up. Knew I needed to get out but didn’t know how. Delayed getting out.

April 2013:

After a three-week visit to SW Ontario, I returned to my apartment in QC and could not stand it for more than several hours. Realized many of my neurological symptoms were due to the apartment. It poured rain that night and I heard water dripping inside the wall, which was damp. That was my last night there. Evacuated that week. Left behind all porous possessions. Went to live with friends. Followed decontamination protocols for non-porous items. Inspection by public health agency confirmed abnormal humidity levels in the walls.

From that day onward, I became hypersensitive to buildings. Have stayed with six different friends since then. Tented in a backyard in SW Ontario (no good). Have been sleeping outside on a balcony for the past month. I react to the current space, mostly due to chemicals, I believe - the carpets
are the worst part, but there was a small bathroom flood while I was here. I am shocked at the outdoor air quality in this city. On hot humid days I now have Stachy-type symptoms just from going outside (jerking, convulsing, can't see or perceive properly or stand up or walk much at all).

Current Symptoms:

Involuntary grimacing, left-to-right proprioceptive confusion, occasional nighttime seizures which wake me from sleep (no loss of consciousness). Fatigue, though not as extreme as it used to be. Chest pain, feeling of cardio-distress. Severe brain fog and confusion. Word mix-ups, poor memory. No awareness of passing of time. Insomnia. Loss of appetite, low-level constant nausea. Vision problems.

This is a longer list of symptoms. Not all are present all the time. Some go away when I avoid mould exposures. So this list varies day-to-day.

GI:

- mild to moderate nausea, ongoing
- loss of appetite
- constipation
- diarrhea
- pain in colon; stomach
- bloating

Neurological:

- Multiple Chemical Sensitivity
- stabbing head pain
- headaches in forehead with light sensitivity
- intracranial pressure
- changes in handwriting
- left leg gives out while walking (knee buckles, whole leg goes weak)
- burning sensation in fingers when touching something cold
- sudden tinnitus in left ear (loud)
- acute ear pain, stabbing pain
- pulse pounding loudly/squeaking in left ear
- dizziness, unsteadiness (need to hold onto walls at home)
- veering to one side when walking
- coordination problems
- dyslexic typing
- muscle jerks, trembling
- staggering stumbling
- recurrent minor muscle spasms lasting several minutes (biceps, large muscle groups in legs, arms)
- uncontrollable jerking of limbs or torso
- violent trembling as if cold
- minor motor seizures during sleep which wake me up

Cognitive:

- difficulty finding words
- stuttering on first consonant before finding word
- brain fog
- distraction
- inability to process information
- forgetfulness
- very poor short-term memory (what I did today, or this week)
- confusion, disorientation
- difficulty concentrating
- forgetting where I am, what season it is, what month, for longer than normal

Cardiovascular:

- chest pain, sense of hand squeezing my heart
- stabbing pain in sternum/heart
- orthostatic hypotension
- low-ish blood pressure (around 96/66 or so)

Respiratory:

- sore throat, narrowing of throat
- shortness of breath; air hunger
- pain in lungs
- breath getting ‘caught’ in lungs
- coughing, followed by gasping (when exposed to mould)
- shallow, quick breathing (when exposed)
- sense of not getting enough oxygen, but blood oxymeters measure perfect scores
Visual:

- floaters
- blurriness
- seeing black spots; seeing stars, squiggly lines
- visual hallucinations
- light sensitivity
- difficulty reading (glasses make it worse)
- needing to turn head, use one eye or another, bring things abnormally close to focus on them, needing to make font large on computer
- difficulty reading books (very low tolerance of the great visual effort required)

Urinary

- frequent urination
- bladder pain
- recurring unexplained hematuria
- pieces of body tissue expelled with urination
- infection

Other:

- liver pain
- kidney pain
- spleen pain
- gallbladder discomfort/pain
- lower abdominal pain
- rash on torso over liver area (comes and goes)
- tendon pain in forearms
- muscle pain in legs and feet; tingling
- muscle fatigue - difficult/exhausting to lift arms
- extreme exhaustion, weakness
- faintness
- sore, stiff neck (back of neck especially)
- poor sleep
- insomnia
- night terrors with screaming
- sensitivity to noise
- heat intolerance
- total intolerance to alcohol
Oral:

- tooth grinding
- painful, swollen gums
- tooth issues. teeth appear to be dissolving by the day, pits getting bigger, teeth getting smaller

General:

- agonizing constant dehydration, inability to absorb water
- post-exertional malaise (PEM)
- sense of right/left side confusion in my body
- sticking out tongue to concentrate hard on fine motor movements
- random sudden strong pulsating pains in parts of my body that last a minute or two (fingers, feet, toes)
- bone pain
- sense of itchiness and irritation in/under my skin
- sensory processing issues (vestibular, difficulty with certain clothing, sound, music, light, needing people to repeat themselves, cannot concentrate with background noise, especially on telephone)

Lymphatic System:

- swollen/inflamed lymph nodes in armpits
- tender, swollen glands in throat
- thyroid pain and swelling

Psychological:

- anxiety
- irritability
- rage (when exposed)
- uncontrollable sobbing out of frustration
- nighttime fear

Lisa Petrison

When I read people’s case studies, I'm largely playing a game of "find the really bad mold." My hope is that if people can remove that particularly bad mold from
their lives -- by moving to a different building (and leaving behind possessions), or by getting rid of possessions from a previous exposure, or by getting out of a particularly bad outdoor area, or by decontaminating carefully after casual exposures -- they will be able to make substantial health improvements.

Probably some of this really bad mold is present here. But what is more striking to me here is that just about _everywhere_ seems to be problematic, in different ways. That makes me feel like this is less a problem of exceptionally bad toxins present and more a really advanced degree of hyperreactivity.

The other things salient to me about this story are that the person got sick very early in life and is still very young (20's) and that I don't see any mention at all here of places that I think have even decent air quality. (NYC may be the best, but there are some bad plumes there that could be rough for a really sick person.)

This is sounding to me like the level of toxicity that Erik was at when he developed extreme avoidance, or like I was at when I moved out of my moldy house. It's definitely possible to come back from that degree of toxicity, but it's also definitely a challenge.

Especially for someone still in their 20's, there seems to me a lot of upside to pursuing it though. Even if it took 5+ years to get back to functionality, there would still be a lot of years of life left to reap the rewards.

Ideally (though I hate to actively suggest this to anyone), I think you would be best off getting to the cleanest desert imaginable and tent camping for at least a year. I think that the air quality would be a revelation to you and that your body would automatically go into massive detox (which I would help along as much as possible; my guess here is that methylation pathways are totally shut down at the moment, for instance).

Canada seems to be a challenging country. Parts of Vancouver and Victoria (from reports) seem to be somewhat better if you can find a really mold-free residence, but I'm not convinced that they're a lot better than Chicago (where I started avoidance). For someone at a very advanced stage of illness, my guess here is that that sort of place might provide some stabilization and symptom relief, but likely not a move toward real wellness.

**Erik Johnson**

Totally classic in all respects.
I told Dr. Shoemaker that I would rather live in a dumpster than spend a single night in a moldy mansion.

Not doing avoidance was simply not an option.

Vacuuming without a HEPA filter can be extremely hazardous to your health.

"nosebleeds after vacuuming or cleaning at home."

Desperation Medicine by Dr Ritchie Shoemaker page 236.

I've always believed that facts are the best antidote for gratuitous criticism and closed-mindedness. And yet the arrogance of some of our most highly placed physicians and health researchers seems to be so great that even the light of hard, cold facts cannot reach it.

It's difficult to believe that most of these chronic-Lyme-denying physicians cannot be moved by the endless reports of patients who describe symptoms that range from severe joint pains to stiffness, to "lightning-like" pain that explodes deep in muscles and then jabs like white hot needles into every nerve along their pathway.

It's also difficult, as a practicing family physician, not to respond to these descriptions of searing sensitivity to bright lights (and especially to blue tones), along with the harrowing reports of nightmares full of death, blood and dismemberment.

And what about the patients who complain so often of two-day bouts of exhaustion—merely after completing such simple chores as vacuuming the living room rug?

Beatrice Latherings

It also sounds like you have Bartonella and perhaps other pathogens associated with Lyme, even Lyme itself. These are complicating to mold illness.

I've had many of your symptoms at one time or another. There is not enough attention paid to the psychiatric symptoms of mold exposure, what the cause is. People get diagnosed with a psychiatric disorder and sometimes even committed
to a psychiatric facility, which itself may have mold. My own first symptoms of exposure are depression and nightmares.

There can be, unfortunately, "real" psychological problems on top of the mold exposure, because if the child in the family has a mold gene, quite clearly at least one of the parents does also, and that leads to an upbringing by an emotionally unstable (due to mold exposure) parent.

Jeff Charlton

HEPA filtration is essential but it will not stop the VOCs and chemicals being ejected by vacuum exhaust aerosolised and becoming aerosolized
Q. 40:2(2) - Case Study 2 (Follow-Up)

I moved to a new location two weeks ago, the best one I could find in Canada, according to reports.

I expected the air to be a revelation that would blow my mind upon arrival. Even non-Moldies and mostly-healthy people had raved to me about the quality of the air in this location, compared to the part of the country I moved from, saying their asthma went away, they "didn't know what it meant to breathe air" until they moved here, and so on.

But the air quality here is not a revelation to me. It was not when I landed here, and it is not now. It is maybe better right on the water, but even then, it is no revelation. There have been a few evenings downtown when I liked the air quite a bit, but even then the enjoyment was interrupted by car exhaust, and I might have been imagining it in the first place, wanting to convince myself of it.

I don't know what this means. On the one hand, Lisa has mentioned some reports of things getting worse on the West Coast in late August. Maybe that happened here. I don't know because I only arrived the second week of September and have no comparison.

On the other hand, maybe this location would never have felt like a revelation to me. Maybe it is just not good enough.

And the problem is I don't know where else to go.

Lisa Petrison

In re-reading my response the original question, that is still what I think.

Of course, finding a way to get to a really clean place for a while could be a challenge.

Beatrice Latherings

I realize that camping in Canada year round is close to impossible. If you moved to the BC coast it wouldn't be below freezing much but would still be pretty miserably wet. I don't know if you can afford to make the move to the USA desert southwest, but the advice to try to camp in the desert for a year is the best advice
you will get in terms of eventual recovery as much as is possible. If I felt young enough to do that, and could afford it, I'd personally get a pickup truck with either a camper shell or a Camplite truck camper on it (allowed to detox, throw out the soft stuff). That would give you mobility and a place to sleep.
Q. 40:3 - Case Study 3

I am not certain mold toxicity is to blame for my symptoms, so I would like to share the story of my illness here. Maybe you would have a better idea of whether mold is to blame, and perhaps which strains of mold.

I am 33, female, grew up in rural Texas. Always had constipation and depression issues for as long as I can remember.

Lived in cheap apartments in Austin during college.

Spent my 20s living in cheap housing in Mexico and Central America, and a damp house in the woods of northern Minnesota.

Ages 29 and 30 I spent in Peru and Brazil; lots of cheap rental houses and hotels. During the year and a half I was there I had only two menstrual periods. I attribute this to the low-fat vegan diet I was eating (animal products were unavailable where I lived). I got very thin and acne and insomnia increased.

In 2010, age 30, I returned to Texas and rented a 100 year old house in Austin; it was possibly moldy. Convinced my amenorrhea was due to candida, I went on an extreme diet: zero carbohydrates. Just meat, fat, and green veggies. My period returned, but I got some new, severe symptoms: constant hunger, more acne, 30 pound weight gain that made me borderline overweight, heart palpitations, anxiety, insomnia, severe fatigue and worse depression. But I thought those symptoms were die off" and I liked having my period back, so I stayed on that diet a year.

In 2011, I moved to a coastal town near Cancun, Mexico. I soon went off the zero-carb diet and added in fruit, potatoes, corn. The awful symptoms went away! Felt great, lost weight, could sleep and didn’t have to eat constantly.

In Oct 2011, a tropical storm hit my house while I was away for several days and I returned to find black mold growing on every single porous surface. I couldn’t find new housing, so I cleaned it all as best I could and continued living in the house with the mold invasion.

In Dec. 2011, my old symptoms suddenly returned, even though I was still eating a moderate-carb balanced diet. Felt like something broke in my body.

I left Mexico August 2012 and returned to Austin, Texas to live in the same
old house I had lived in 2010-2011 when I first developed all the symptoms. I've moved out and am looking for housing in New Mexico now.

So it's been two years since I went off the diet that initially caused all the symptoms that I still have today. I am on Armour thyroid, which helps with sleep and anxiety, but I still have to eat constantly. And I have to eat about 2 pounds of meat a day even though it's disgusting to me, or else I literally cannot function or sleep (nausea and heart palpitations). I guess I have a problem with amino acids, since animal flesh is the only thing to make me feel okay.

I did some of Shoemaker's labs in spring 2013. Lab range in ().

MMP-9 647 (high)
TGF-b1 8760 (344-2382)
ACTH, Plasma 25.5 (7.2-63.3)
VIP, Plasma 53.9 (0-58)
Melanocyte Stimulating Hormone 28 (0-40)

The strange part is that I developed all my symptoms when I went on the zero-carb diet, and they went away once I added carbs back in, but they returned two months (not immediately) after the mold invasion. Maybe the mold threw off my thyroid and adrenals, and it took a couple months to hit me?

Since mold avoidance is an extreme undertaking, I would like to be relatively sure it is worth the expense and sacrifice. Thanks so much for reading this and for any advice.

A.M. Runyan

Well, we are not doctors here so we can't diagnose, but I can say just in my experience with myself, these things sound like mold symptoms:

gaining weight suddenly

losing weight and remission of symptoms in Cancun, which I hear often has good air (depending on the building)

The change in symptoms might have had to do with the change in air/buildings, rather than change in diet. I found I could eat a lot more carbs than usual when in Peru at high elevation, probably because there wasn't much mold around, but it
wasn't that a high carb diet was helping; it was the lack of biotoxins compared to where I'd been before that.

-having more symptoms after black mold in the building - yes, warning sign

-high TGF_beta - this is very related with mold illness.

If it were me, with that history with the black mold and TGF-beta, I'd definitely assume I had severe mold illness and would try to avoid mold as much as possible and upon finding a clean place, do detox treatments.

It can be more clear what was wrong as you heal, and as the toxins come out - and then you can see what symptoms were related to them, and you (how fun) get to feel what was in you as it comes out. (That is what I'm going through now. It doesn't cause the same inflammatory symptoms as when it's going in, but I'm definitely aware of dumping toxins. Infrared in particular makes me do this, and then it's overwhelming clear I was more or less poisoned over time with this stuff that is coming out now.)

Many people avoid mold in increasingly intense ways until they realize they just need to do actual mold avoidance. It might save some time to just do it right the first time.

Also, after a learning curve, mold avoidance becomes much easier. I have worked with people on changing their diets, and I tell them, once you get used to it, it becomes second nature. You can get used to things like washing contaminated clothes as soon as you get home, showering if you need to, etc. People are very adaptable and things that seem daunting now might seem like a small price to pay for how good you can feel when detoxed/clear.

I wanted to also comment that I don't like the air in Santa Fe. but outside Santa Fe even by 30 minutes (Tesuqe) was good, and places further down the highway seem good, like in Bernalillo.

As for apartments, they are supposed to let you out of the lease if you have a doctor's note saying your condition requires it, if they are not able to remediate the apartment to the standards your disability (environmental illness) requires. Some people ask for short initial leases (to test the apartment) because of their condition.
Lisa Petrison

One of the many things that throws people off about this paradigm is that rarely do people who are doing well move into a bad place and collapse on the first day.

Certainly, for people who are already sick and doing well only by practicing extreme avoidance, that will happen dramatically if they move to a bad place.

But for people who are in that gray zone between wellness and illness, the collapse from moving to a bad place usually isn't immediate. It takes a while.

I have seen that very clearly as my own system has become stronger. At this point, I could stay in the vast majority of buildings for a while. But too much exposure to a bad place and eventually I would collapse again.

Logically this does make sense. If the problem is that our bodies become overloaded with toxins, then it is reasonable to think extended exposures would result in more symptoms. And if indeed (as is suspected) the reason that these toxins are so damaging is because they affect the immune system, allowing pathogens to run wild, then it also makes sense that we would underestimate the effects of the toxins when initially being exposed to them.

Just as a hunch, it feels to me like your body is comparatively able to recover from these toxins, as long as you give it half a chance. Assuming for a moment that the Austin house was problematic, you seemed to recover quickly when you got to a different environment (even though presumably you had some of your possessions with you). And though I'm not a doctor, it seems to me that your VIP and MSH scores are somewhat higher than those that I frequently see in catastrophically reactive ME/CFS patients (though lower than Shoemaker would like), which again suggests that you possibly may be able to recover more easily than some people.

I've yet to encounter anyone with any of these mystery diseases (ME/CFS/Fibro/Lyme) who didn't turn out to be extremely reactive to small amounts of particular mold toxins, when they went through the protocol of systematically trying to find out. And there have been quite a few people (including me) who didn't believe that mold was a problem for them but turned out to be really reactive when they decided to try anyway. But I'm not going to diagnose anyone with mold reactivity, without their going through that exercise.

Whether you are reactive enough at this point to your possessions that you will be unable to make progress while keeping them, I don't know. Many people who
have gotten away from their possessions for the "sabbatical" have reported that being around them indeed would have kept them permanently totally sick though.

A few other random comments:

When I was living in the bad house and was about 36, my periods stopped. I thought it was early menopause. Then for no apparent reason, still in that bad house and more sick than before, they returned. I don’t know what to say about that.

Many patients with CFS/mold illness do report needing animal protein, and industrial animal products are indeed disgusting (aka toxic). You may want to consider seeking out really high-quality animal products -- organic feed or 100% grass-fed, pasture raised by small farmers where you can look at the farm (at least from the road). Of course, this is expensive.

New Mexico has some very good areas, but the northern settled part (especially Santa Fe/Espanola) is problematic. Whether you can live there, I don’t know. But this would not be a good place to try the "get clear in the desert" experience, because many people have found the outside air in that part of NM plenty bad enough to keep them totally sick.

Misha Kogan, M.D.

Over 50% of mold is not visible, no stains. Obvious mold growth does not mean that Stachybotrys is present

Do not do it yourself and do not order ERMI test despite Shomaker’s recommendations - it cannot be clinically used very easily.

You did not do most important tests VCS and C4a, the ones you did are not specific. TGF can be elevated with other conditions.

Get VCS at Shoemaker's site. If it is negative (passed) stop worrying about mold.

Lastly look into your methylation, likely that is the root cause of issues in your case. I have been following your posts for some time.

Ideally you would do some Yasko type test either through her website or through 23 and me, this last one is 5 times cheaper but you will need to figure out how to get raw data through one of the free online programs to get your methylation profile out of it. You can also start with just MTHFR using ICD9 270.4 (only that
one, otherwise it will not get covered by your insurance).

David Ou, M.D.

There's a 7-8% false negative rate for the VCS. In addition, monitors vary in quality so the false negative rate could be even higher.
Q. 40:4 - Case Study 4

(Note: This question is from someone who is living in an RV near Palm Springs.)

I was feeling great here and pretty good up in Joshua Tree National Park over the summer -- just a bit of congestion at night when the wind blew in and the temperature dropped. About six weeks ago, my healthy boyfriend and I went to a new juice bar and we both got sick the next morning from these green drinks. It was a minor G.I. thing with nothing extreme so we didn't follow up on it with medical visits.

It seems like it really ran me down now and a few weeks later I got sore throat, swollen glands and ended up with a lot of congestion in my sinuses. That is what I would call a cold, although I have heard that a cold only last 4 to 7 days. It starts to go away and then comes back.

Last night lying in bed it occurred to me that maybe I was starting to react to something in the trailer. Or maybe the RV park has gone bad? This isn't my typical reaction though, which usually has insomnia and palpitations.

Just before it started I really ramped up my detox protocol to increase my coffee enemas to two a day plus sauna. And hot pools.

The day I went into the doctor for a vitamin C glutathione IV, I already had a mild sore throat and swollen glands. Because the blood test came out normal, she didn't think it was an infection, but with my CFS I never show anything weird in the blood and I have tons of infection, so I don't really trust that.

For a while, I felt like I was just getting some pretty intense detox. But now that it's dragging on and moving into my chest I'm wondering how to figure out what might be in the environment inside or out.

I feel like such a wimp because the thought of camping on BLM land with the temperatures going down to 50 at night just scares me away. I don't have the equipment for that cold weather anymore, And when I go to stores the smells just overwhelm me, So I don't relish going out and buying new equipment when I'm no longer sure what I can tolerate and what I can't.

So I would like to see if this sounds to you like it could be detox or environmental reaction to something or just being rundown from stress.)
Corinne

I get colds that go on for months because CFS means you are immunocompromised. Regular doctors won't explain it. The colds just take longer to go away and when you have a cold you are susceptible to getting another one. And I get those two that never quite hit fullblown status. I have to been extremely careful with hygiene and can't eat at restaurants or be around anyone with a cold. It takes weeks of just resting, you have to treat it more seriously than other people would.

Lisa Petrison

I've never had that kind of symptom from detox. I would think it could be an infection or that it could be an exposure, or (and this might be my first guess) a mild exposure driving my body down on the power curve and making it less capable of handling an infection.

I've mentioned before here that Erik and I have gotten a whole bunch of reports of people suggesting that their local area has gotten worse since about the end of August (and coinciding with all the rains over the past few months). We've heard reports from both the western parts of North and South America, and a few scattered reports from other places as well. It possibly may be getting better now; I'm not sure. Whether that corresponds with your timeline of feeling worse, I don't know.

If I had that symptom, my first instinct would be to try to tackle the presumed infection by flooding my body with vitamin C (either oral to bowel tolerance or with an IV) and taking some goldenseal. And drinking a lot of citrus juice. And my favorite cold remedy: hot tea with lemon, honey and bourbon.

Another tack would be to presume that I had introduced some contaminated item into my living space and try removing things that I had obtained recently and then wiping things down with water.

If you don't feel like camping right away, you could try just going for a long day to somewhere that you feel confident is good and just sitting there. You may find just by doing that for a few days, it will boost you up on the power curve and also possibly get you clear enough that you will be able to better tell what is going on in your sleeping environment.
**Beatrice Latherings**

I'd guess that the green drink had something moldy in it, and that you acquired an intestinal mold infection. That is definitely a guess, but it happened to me. You could try oregano oil or olive leaf or something else that is against intestinal mold and see if it helps. I don't know what you can take and what you can't.

**Sábra Gypsydancer**

They spray a lot of stuff down here you know, particularly in the agricultural areas northwest of Palm Springs, and as soon as that wind kicks up... (?)

Generally what happens is we get 'sick' when our bodies are vulnerable (such as from food poisoning), and we become more reactive to our environment, chemicals or bacteria while we are in this state, and our body then begins trying to detox via 'cold' or flu symptoms.

I understand that when one is chronically ill they forget that some of this stuff is part of what being an imperfect 'normal-healthy' human is also. I know that it's rough when you were just feeling so awesome too!

There are parasites also that can be carried by the desert winds. Maybe something to check out.
Q. 40:5 - Case Study 5

I have CFS. Although not housebound, I don’t get out much because it’s too hard. I like to think of myself as moderate, but honestly it’s worse than that. I am getting progressively sicker and need to find some answers asap. I live in WV so the weather is crap right now.

I started having increased all over body pain, muscle stiffness and difficulty sleeping in 2007. I was diagnosed with Fibromyalgia. It kept getting progressively worse and none of the meds meant to treat it helped.

It should also be noted that I got the Gardisil vaccine series Dec 2011, March 2012, and June 2012.

September 2012 I caught a weird virus that lasted about 5 days, completely incapacitating me. I never recovered and got progressively worse. Fatigue, pain, cognitive dysfunction, swollen lymph nodes, mood swings/irritability, headaches, PEM, depression/anxiety, sleep dysfunction, etc.

I saw Charles Lapp Dec 2012 and was diagnosed with CFS. I had increased viral loads, IgG subclass 1 and 3 deficiency, CPET showed VO2max 14.1 (qualifies as stage III heart failure). He didn’t test NK cell function for some reason. I was working as a PT in Home Health and had been for 10 years. I visited multiple homes a day, many that were less than stellar. I went on medical leave Jan 2013 and have never returned. I am currently applying for SSDI.

We had purchased our house in April 2006, it had a roof leak at the time. We put a new roof on and thought that was the end of it. Storm damage caused it to leak again several years later in the exact two places. We repaired it multiple times over the years but it kept coming back.

I finally chased down the real problem this past summer and found the mold. It was leaking behind the siding, and much of the structural wood of the house where the leaks are is involved. At this point I was having constant headaches, nausea, hair loss, cognitive dysfunction, continued fatigue, depression and anxiety and more.

We moved to a hotel in October, then moved in with my parents late November. My symptoms improved some the 6 weeks at the hotel once we bought all new things and switched rooms. They got worse again shortly after moving in with my parents. I tested my parent’s house and HERTSML-2
is 16, with 3 stachy spores detected.

I am still trying to repair my house but am not hopeful I can return to live there. We certainly can't afford to live anywhere else until we can sell it. We have a mortgage, plus expensive land to eventually build on. That has always been my dream and now I am terrified of it.

Most days I spend in bed. Attempting the grocery store makes me crazy, I can't make decisions, my brain shuts down and anxiety skyrocket. What is it about the store that does this, are they all toxic? I do very little and need frequent rest breaks. I would say I am functioning at <50% pre-illness level.

Last summer we traveled for over a month. I felt like there was no way I could cope, but once we left things got surprisingly better. I did things I hadn't done in ages. Our last day I spent 8 hours walking in NYC. It wasn't easy, and I had a lot of pain and fatigue after but I still did it! 24 hours after being home I was deathly ill again.

Nobody else is really sick but me although there are mild symptoms. My son had developed a vocal tic that went away weeks after we left. My husband still has temper issues, I'm convinced it's the mold. My youngest son has behavioral issues. Is it third child syndrome or that he was born into toxicity? My dog has skin issues. I am getting sicker by the day at my parents.

I have tried CSM and charcoal, both significantly increase my symptoms which I just cannot tolerate right now.

I am planning a camping trip for April. But I am afraid I will get sicker when I come home or hyper-reactive and unable to come home. I have three kids so homelessness is not really an option. I would appreciate any and all advice.

Lisa Petrison

Compared to a lot of the stories that I hear where people have no idea if mold is a problem for them, your case history seems pretty straightforward. The mold in the house where you got sick seems to have been a big issue for you, and your current house appears to be way over tolerance.

Based on everything that I have seen and what you say about your illness, I don't think that you are going to be able to move back into your house and have any
sort of recovery. You would be much better off selling the home for what you can get for it and moving into whatever sort of better home that you can afford, even if it is not nearly as large or (apart from the lack of mold) not nearly as nice.

Andrea Fabry's blog details how they dealt with downscaling themselves, when she and her husband and their nine children fled their own lovely (but horribly moldy) home. A link to her blog and a PDF listing some of the particular blog posts on this topic is here.

http://www.paradigmchange.me/mold-illness-info/mold-blogs/

So I think a priority for you may be putting that house behind you and moving forward with your life.

It sounds like your parents' house is bad enough that the additional exposure has the potential of being substantial enough to add to your toxic burden, making it more difficult for you to recover in the long run. So again, I think it's a good idea to put as much attention as possible into getting things in order so that you are able to move to a better environment.

The main reason for people to go camping is so that they can get unmasked enough so that they can know if they are unknowingly being affected by toxins in buildings, in the outdoor air or on their cross-contaminated possessions. However, in your case, I think that you already know that the toxins in the home where you are staying are affecting you. The difficulty at present is sorting out your life so that you can get away from them.

Another reason for people to go on a mold sabbatical of whatever sort is to see how much better they would be in a different environment, and thus to feel more confident about putting the effort into making changes. But I think that you already did that, in the trip that you took last summer. And the fact that you felt that good in places like NYC suggests that you might be able to feel just as good in WV, if you are able to get to make some changes.

Mostly, I think, what a camping trip at this point would do for you would force you to make some changes when you came home from it, I suspect. Maybe that would be a good thing.

That is how Jeri Kurre did this, for instance. And it turned out to be a really good thing for her, once she managed to get the life changes made.

The other possibility is for you to move from your current home to a better one (according to the ERMI and/or your own reactions) with a short-term lease, and
then see how you are doing there. (At minimum I would bring no unwashed possessions from your parents' place, or maybe start over again.) At that point, a camping trip to get really clear would allow you to go home and make specific changes (such as moving to a house that felt even better to you, getting rid of bothersome possessions, or identifying places where the air was problematic).

Beatrice Latherings

You have to confront the impossible and find another place to live. Don't try to fix your house; it likely is not fixable in any way that will allow you to live in it. Also know that toxic mold exposure tends to cause women to collapse and men to become belligerent. So if your husband is acting that way it is very likely his physical response to exposure.

I know it is winter, but one thing you can do is pick a room on the opposite side of wherever there is water damage, and seal it off, put in a space heater, and then put in something that will bring in outside air 24 hours a day. There are heat-exchange units that will help keep some of the heat. Don't leave this room unless you are wearing a respirator. I found that even the time spent in a moldy house to use the bathroom was enough to keep me completely ill.

Paula

I had all the same symptoms as you and turned out that wasn't just toxic mold of my house (that I had to leave for good and not take anything that was once in there besides my own body). I also had Lyme disease. So moving out of the house, and doing a year of detoxification, to a completely mold free new house helped a lot but was not sufficient. I had to look for a Lyme specialist (hard to find a really good one) that knows how to read the western blot test and many others. I was also disabled 3 years ago and now I am pretty close to healthy (still on last phases of Lyme treatment and of course that if I get re-expose to mold by going to a store I have to address that immediately).