

Quick start MOLD GUIDE

I realized that when people have mold issues they aren't in their right mind. Thus, the cautionary advice I give is often executed in the exact opposite fashion of how it was described or forgotten all together. This is common and not on purpose by the pitiful person suddenly aware of what mold is doing to their life and health. In order to avoid that I've compiled this QUICK START guide that summarizes what you need to do and what you need to avoid simply. You can read the mold guide after to understand why.

Don't PANIC and grab a bottle of bleach. Bleach is not the answer and makes the problem worse. It does nothing about mold toxins and can hurt you. Stop, put the spray bottle down and back away. Let me say this again. **DO NOT USE BLEACH UNDER ANY CIRCUMSTANCE!**

Many in the mold remediation businesses are out to make a quick dollar off the panic the knowledge of mold in your home or work brings and will quickly take your money and worse not fix the problem and even make you sicker. Don't be suckered.

Test kits

We now have the kits here in the office. We have mostly the "Swiffer" kind because it's the easiest and cheapest. It's \$130. We have one vacuum type and they're \$150. We are now going through Envirobiomics, the company most recently endorsed by Dr. Shoemaker and with much better customer service than Mycometrics. You pay for the kit and send it when you've collected your sample. They email us the report and they may email you at same time. If not, we'll send it to you.

If we're out of kits you can also buy them directly from Envirobiomics.

<https://www.envirobiomics.com/product/hertsmi-2/>

Just follow this link and order your kit, I recommend going with the \$130, unless you just have to know sooner.

For the Swiffer test you simply wipe 10 horizontal surfaces or backs of computer monitors or computers anywhere you can find a decent amount of dust. If you clean weekly, you may need to not dust a couple weeks then dust with this Swiffer. You do NOT want to wipe mold up directly or go in especially grimy places like behind toilets or under sinks. The point is to capture dust that's settled over the past 2-3 weeks. You want 5 surfaces in living room and 5 surfaces in bedroom preferably about 3 feet off floor.

Inspectors

Martine Davis is an amazing inspector and was doing mold before Shoemaker even knew about mold. She trained in Europe because the USA was so behind in building science. However, she is travelling less and has trained an inspector now here in Peoria for Central Illinois patients. His name is Ben Kunze and he can be reached at 919-402-7670. Ideally you will test your house before having an inspection because that helps direct the inspector of what mold we're concerned about. The test has limitations especially with respect to Stachybotrys. Stachybotrys is very sticky and doesn't typically show up in the HERTSMI test and just should be ruled out by visual inspection. So even though the HERTSMI reports a score for Stachy we assume it's erring on the low side.

Inspector Martine Davis, BBEC, Certified Building Biologist, Indoor Environmental Testing Inc.

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(608) 241-9883

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Ben Kunze

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If you're concerned about mold inside walls, Martine has new fancy schmancy machine that is called **Instascope** and tests inside walls along with air and carpet and what not and you have the results immediately because it's a lab in a box. She still comes down 2-3 times a year and is especially excited to use her new machine so if you're interested in that give her a call.

When and Why to TEST?

1. First we test to find proof of exposure. I can't treat you for mold illness until I have proof you're being exposed. Sure, if you just moved from a house that smelled musty we aren't going to test the prior house BUT we still must test the current house to make sure you're not STILL being exposed.
2. I don't want to treat any Lyme Disease anymore without mold testing. Of course, you present with acute Lyme Disease we treat first ask questions later. Time is of the essence then but if you think you need ongoing antibiotic treatment you will have to prove you're mold free first.
3. Musty smell does equal mold. But lack of musty smell doesn't equal no mold. There are mold species of concern that do not smell. So, telling me your house smells fine is not sufficient. Plus, you've all seen the commercials, you could be nose blind. So far those most resistant to testing are scoring the worst for mold. Don't be fooled and do molds bidding. It can make you it's minion if you let it.
4. After remediation, I will need a HERTSMI2 score again to be sure the house is now safe. We will not initiate VIP treatment without this result. So, you must test again after remediation. I admittedly forgot this one in the beginning and quickly realized its importance. Trust me you don't want to waste money on VIP only to have it not work because your mold exposure hasn't stopped.

Remediation Companies

Remediation Company in Peoria and Bloomington has recently changed. Mike Lanius was our go to guy but he sold his company in December and retired to Florida with his mold dogs. That company was Indoor Environmental Professionals Inc. 309-670-6653 and I can't stand by their work anymore since I have no clue now who's running the show. Ben Kunze has been recommending Calep from Advanced Mold Control out of Bloomington, 309-287-5607, but you can discuss this with Ben if you use him as your Indoor Environmental Professional. Some of you may be able to also do it yourself. I'm working on

writing up the “typical steps” for a remediation plan, but that’s what you get from Ben as well after an inspection.

If you have a great experience with another company, please let me know. The HERTSMI2 before and after will prove they were effective. I’ve had many use other people but no one has stood out and many have not had impressive results.

I can’t emphasize enough to not cut corners and skip the inspector if you hire a remediator. The remediator will not test properly to show proof of a complete job. Even Mike Lanius that I recommend does air sampling afterwards. Air samples are insufficient to prove the home is safe. They are useful but don’t rely on only them. You should still ALWAYS have an independent inspector to check on the work performed by the company and make sure they did it right and adequately. They can take their air samples and if you’re moving and they say clear that’s good enough to sell the house. It is not good enough to live in and remember that when you move as well.

Starting Treatment with Questran (Cholestyramine) Vs. Welchol (Colesevelam)

Treatment is typically starting cholestyramine (CSM), a resin that comes as a powder, daily and slowly working up to 4 scoops a day. Welchol (Colesevelam) I'll abbreviate as WC is also a choice. It's a capsule and you can take up to 6 capsules daily with meals. Most people think capsule! Sign me up. It's only ¼ of the potency of CSM so it'll take much longer to get better using it and it's very expensive if insurance doesn't cover it then it's out of reach for most. It's not generic and it's usually prescribed for Diabetes Mellitus or high cholesterol. THERE are other "binders" out there but when tested by Dr. Shoemaker using very precise methods only these two worked for his patients with statistical significance. He's used this with over 10,000 patients. Therefore, we should try what worked for him first. However, there is at least one patient I have that is intolerant to both. So clearly, we'll have to try some other approach with this person. But she tried them. You must try them first.

Another option that is working well for some is to use both. They use the CSM before 2 meals and take 2 WC with 2 meals. Either way there is timing this with your medications, supplements and such to be figured out as well. Samples of how to time and titrate up can be found on our website when it goes up and for now on our Facebook group page. On FB group I uploaded as excel files first and recently as a pdf. I can email them to you as well. Specify if you want excel file or pdf.

<https://www.facebook.com/groups/KCIHBiotoxinSurvivors/815742658598082/>

Please join us!

BUT some of you are sensitive types and will need to go slower than that. Also, if you have Lyme also or it's suspected you may need to start Fish Oil first. One third of Shoemaker's Lyme patients had intensification of their symptoms on starting CSM. (But two thirds did just fine.) He found if he pretreated with Actos or high dose Fish Oil for 10-30 days this was drastically reduced.

Lymies or anyone that symptoms get worse (called intensification) when they take CSM. Stop. Call office for further instructions or start Fish Oil*. I now know it's much more likely to occur also in those with an MMP9 over 1000 or elevated Leptin levels. Lowering Leptin helps reduce the symptoms intensification and is done with Actos and following the No-Amylose Diet that's included in this handout.

***Fish Oil Regimen:** Start taking 4 grams of Fish Oil daily for at least 10 days before starting the CSM again. Also need to follow No-Amylose diet if your MMP9 is high or Leptin is over 13 for men and over 25 for women.

***High Leptin Regimen:** Start Actos 45 mg a day and follow No Amylose Diet (if not attached ask for this sheet).

Start Cholestyramine at ½ or 1 tsp a day, heck you can do 1/8 tsp every other day if you like. That's it. Start slow and go lower if you must. There's no glory in taking it too fast and feeling horrible. If you have an intensification of your symptoms when you take the CSM stop it. Start taking Fish Oil daily for at least 10 days before starting the CSM again. If you have a problem with constipation we also must address

that BEFORE starting the CSM. You will need to take magnesium salts, vitamin C powder or Miralax to ensure you have a bowel movement daily. Daily is the minimum.

Constipation, just say no!

Constipation really messes up the CSM treatment. If your baseline is constipation and you don't have a BM daily then you might want to start WelChol instead. CSM is typically used as treatment for diarrhea so if your baseline is constipation then you need to have a bowel movement daily before starting CSM. Many with CIRS have diarrhea but that's not the case for everyone. The recommended approaches to constipation that starts AFTER taking CSM is to add magnesium salts or vitamin C powder. Titrate it up until your stools are loose and then resume increasing your CSM. If you're not going regularly before you even start it then you should start Miralax daily to get going regularly if you're not already on it. If you already take aloe vera or another stimulant laxative* and have for a long time you will have to remain on it. Your bowels are unfortunately dependent on it now. We can work on that later now is not the time.

*Further help with constipation see appendix

What to Expect from Cholestyramine (CSM) from survivingmold.com

Cholestyramine (CSM) is an FDA-approved medication used to lower elevated levels of cholesterol. It has been used safely for over forty years in millions of patients who have taken the medication for extended periods of time. You have been given a prescription for CSM to be used for only a short period to treat your chronic, biotoxin-associated illness. The FDA (6/28/99) ruled that there was no reason to expect an increased risk to health from use of CSM in a group of patients who have biotoxin illnesses (such as Pfiesteria, ciguatera, mold, Post-Lyme) and blue green algae syndromes compared to those who don't. Therefore, such use is exempt from repeating FDA clinical trials to show safety. Your prescription is given to you under this FDA exemption.

This use of CSM is called "off-label." Off-label use is completely legal, ethical and is part of standard medical practice. There might be a few physicians somewhere in the US who don't use drugs off-label but I haven't met any yet. You need to know that your prescription is for CSM being used off-label.

Cholestyramine is not absorbed. It helps you get better but it adds nothing to you. All it does is take things away. If CSM is not taken with food, it binds cholesterol, bile salts and biotoxins in the small intestine. Because it binds biotoxins tightly, the biotoxins cannot be reabsorbed; the CSM-biotoxin complex is excreted harmlessly in the stool. Provided there is no re-exposure to sources of biotoxin or reacquisition of biotoxin, the CSM treatment will remove the biotoxin from tissues over time, providing the first step needed to resolve the chronic, biotoxin-associated illness. The illnesses of some patients can be resolved in two weeks, but depending on the amount of biotoxin in your body, and the inflammatory problems initiated by exposure to biotoxins and inflammagens, the time to regaining health may be longer. (I've personally never seen two weeks yet but I have seen a lot of improvement at 2-3 months.) CSM will not correct presence of MARCoNS, low VEGF, high TGF beta-1 or low levels of CD4+CD25++ cells, for example. MARCoNS should not be underestimated and are the most common reason for not improving.

Used at the FDA approved dose of 9 grams of CSM, or 4 grams of Questran Light (note this product contains aspartame), taken 4 times a day, there are gastrointestinal side effects that are potentially annoying but are usually not dangerous and should not interfere with your treatment program. Some people who are sensitive to chemicals might want to have compounded form of CSM ("MCS-CSM") that has nothing other than Stevia in it. Some people who tend to be constipated even before using CSM will need to be very careful to prevent CSM making their stools become too hard, as such brick-like stools can cause bleeding from the rectum when they pass out of the body. We try to anticipate the possible troublesome side effects; so we recommend additional medications to keep on hand "just in case." You will want to considering using magnesium citrate or slow-mag, Miralax, and/or vitamin C powder.

Reflux of stomach acid, also called heartburn or indigestion, is commonly experienced early on in treatment. The symptom abates spontaneously in most patients within a few days. A medication to stop over-production of stomach acid, taken before beginning the CSM doses, can prevent heartburn. Mixing the CSM in apple juice, cranberry juice or dissolving CSM, first in luke-warm water and then adding ice, helps reduce heartburn. Bloating and belching can also be cause initially by CSM. Fortunately, those side effects are rarely a major problem. As mentioned, constipation is commonly seen. Many patients simply increase their consumption of fruit or fiber products, such a psyllium (Metamucil), to avoid this problem. A non-absorbable, sweet tasting liquid, Miralax, available without a prescription, can hold water in stools, making bowel movements soft, thereby preventing constipation. Even though Miralax tastes sweet, it will not make your blood sugar rise or make you gain weight.

Cholestyramine Timing! Per Shoemaker, you don't need the huge space that the package insert calls for. He recommended 30 minutes before your meals and bedtime. An hour away from most medications suffices. Exceptions are hormones and a few others. But many of you are on thyroid or oral contraceptives. Those you want an hour for sure and best to take the thyroid or hormone pill first wait and hour than CSM then 30 minutes pass then eat. Most other medications a 30 minute window is fine. The other medications that are cause for particular concern are blood thinners, digoxin, propranolol, and diuretics. But even these don't require more than two hours before window between them and cholestyramine unlike the package insert that says 4-6 hours. Taking longer than 6 months would also require taking extra fat soluble vitamins.

Because many patients with chronic biotoxin associated illnesses have diarrhea or more frequent, softer stools, the constipating side effect of CSM can become a welcome, early benefit. CSM has been extensively tested in multiple clinical trials involving patients with chronic, biotoxin associated illnesses. The benefit of use of CSM has been confirmed by two double-blinded, placebo-controlled crossover studies. To date we have looked for, but not found benefit from CSM substitutes such as charcoal, chitosan, clay in several forms or any herbal remedy. We will use Welchol as a CSM substitute for those unable to take CSM. It is taken with food in a pill form. It is far easier to take but it is only 25% as effective as CSM.

Your physician (myself) will be following your case carefully. If you have questions regarding any phase of your treatment, please notify our office promptly. You will be given special tests of visual contrast sensitivity (VCS) on a regular basis. Your treatment will continue until your symptoms have resolved, your biomarkers have improved and your VCS is normal. Your physician will review your case in detail as your treatment progresses.

CSM Protocol

1. On an empty stomach, take one scoop of CSM (9 grams) or starting dose*, mix with water, or juice, 4-6 oz. You will clear the most toxin by taking it 20-30 minutes before a meal that contains fat or taking a spoonful of coconut oil chaser. The fat stimulates bile flow which is where the toxin is hanging out so it helps to get it flowing.
2. Stir well and swallow. Add more liquid, repeat 1 above until done.
3. Drink an extra 4-6 oz. of liquid.
4. After 30 minutes, you may eat or take meds (wait at least 2 hours after taking thyroxine, digitalis, theophylline, Coumadin and oral contraceptives before taking CSM; ask your doctor for information).
5. Take CSM 4 times a day! (Unless you weigh less than 120 lbs. then 3 times a day adequate)
6. If you eat first, wait at least 60 minutes before taking your next CSM.
7. Reflux, constipation, bloating and bowel distress are not unusual.
8. Use acid blocking medications as needed.
9. Use Miralax to relieve constipation. You can also use magnesium products and/or vitamin C powder. I've put a protocol for constipation in the appendix.

**Don't hesitate to start with much less than a scoop (1 and ¾ tsp) and just once a day. Then slowly go up from there. I have many who start with as little as 1/8 tsp if they're super-sensitives and go every third day and slowly work up to daily then increase dose slowly. It's whatever works. I would rather see people do that and go super slow but stick it out with CSM then try it once and ask for Welchol. Welchol will react very similarly but is only removing ¼ the amount of toxin that CSM does and costs 4 times as much.*

Don't hesitate to call if you have any questions. If you get to feeling so bad you don't know which way is up, then take a break for a week or two. If you feel better off the CSM during that time you would likely benefit from coming to the office once a week for IV glutathione. It's one of our super detoxifiers and this helps replenish it. If you feel worse when you take a break from the CSM then restart it right away and just go slower.

I recently had a patient's husband tell me how he removes the sugar and artificial and natural orange flavoring to make it pure cholestyramine. Cholestyramine is not water soluble but the sugar and flavoring are so he adds water to dissolve those out of the resin. Then filters the resin back out by pouring through a coffee filter. Easy peasy. Better than spending \$400 for compounded.

Appendix 1 Stimulant Laxatives and constipation protocol

Many like Aloe Vera because it's "natural". That's true but it is a stimulant laxative and discolors the lining of the colon. This is a big problem as it interferes with colonoscopy. We now have an alternative to colonoscopy that would work BUT if that test comes back positive then you will need a colonoscopy and must get off the stimulant laxatives. Stimulant laxatives are also bad because regular use leads to dependency such that if you don't take them you won't go at all. So, they should only be used sparingly. If it's too late and you are already on them daily then we'll work on that later.

Along with increasing fruits and vegetables, good water intake and being more active. If you can do yoga and learn some twisting postures that really helps. You can also self-massage your tummy.

1. Increasing fiber is important but must be done gradually and accompanied by more water. If you don't drink more water then you are in danger of the fiber forming concrete and water is essential for constipated folks (everyone). Aim for 10 glasses a day unless you don't have heart disease, kidney disease or low sodium.
2. Magnesium sulfate or magnesium citrate are "natural" and are not stimulants. They are OSMOTIC Laxatives#.
3. Vitamin C supplements. Usually takes 2000-5000 mg but you start with 500 mg a day and go up by 500 mg per day to gradually ramp up or you'll get horrible gas, cramps and diarrhea. Ester C is less acidic and gentler on the stomach.
4. Miralax daily, start with one packet may need 1/2 packet if you are going too frequently or too loose. May need 1 ½ packets. Basically, titrate until you are going daily. You can play with the dose.
5. Sennokot* S 2 tabs in evening if haven't had BM that day. If goes 2nd day without BM then 4 tabs in evening.
6. If above still doesn't work 30 cc of Milk of Mag every 2 hours until has BM x 2-3
7. If above not working do enema (sorry)!
8. Can use this as well if stools remain hard. Docusate Sodium 100 mg Tab but stool softeners really do nothing more than make stool softer. They don't make you go but softness is important if you've had bleeding hemorrhoids or a fissure.



Great option instead of Golytely for Colon Procedures and doesn't cost \$\$\$\$

Just add 10 packets (servings) of Miralax powder to 64 oz. of Gatorade and drink over 2 hours. If they want you to do the split dose methods. Like Moviprep add 5 packets (servings) of Miralax, a 5000 mg of vitamin C to 32 oz. of Gatorade and drink the night before and next day mix another 5 packets of Miralax, a 5000 mg of vitamin C and 32 oz. of Gatorade and drink starting 3 ½ hours before colonoscopy and finish by 1 and ½ hours before procedure time. Moviprep costs \$98 with godrx coupon. It's just vitamin C plus halflytely. Don't pay that when GI orders it. It also got aspartame and phenylalanine in it. Blech!

Fiber Additives

Metamucil, Citrucel, Benefiber are for adding to your diet. BUT it's much better to get fiber from real food. If you ever see cellulose in the ingredients, skip that fiber bar, it's sawdust. Yes, Big Food can add sawdust to our food to increase the fiber content and it doesn't help us at all. ☹️

Stool Softeners

Colace, docusate

*Stimulant Laxatives

Aloe Vera, Senna, Senokot, Correctol, Dulcolax, Ex-lax, Feen-a-mint, Super Aloe. Not to be used daily. But if you've already used daily for long time for now you're stuck on them.

#Osmotic Laxatives

Fleet Phospho-Soda, Kristalose, Milk of Magnesia (MOM), Miralax.

Prescription Medications for Constipation

Amitiza for chronic idiopathic constipation and IBS-constipation predominant.

Linzess for chronic idiopathic constipation.

Relistor is only for opioid induced constipation.

Prunes

Contain sorbitol which is an osmotic laxative. They also contain fiber. Sorbitol is often not tolerated by people with Celiac Disease. It can be malabsorbed when there is intestinal inflammation.

Appendix 2 The No-Amylose Diet

From survivingmold.com

If you have an elevated MMP9 level, it may be recommended that you follow a no-amylose diet to help bring this level down as part of your treatment program. Many of us are familiar with the low-carbohydrate diets that are so popular today including Atkins and South Beach. While it might seem on the surface to be similar, the amylose-free diet is slightly different from this mainstream approach. Fresh fruit is encouraged, and the only fruit that is restricted is bananas. The goal of this diet is to avoid foods that contain amylose and glucose which in turn cause a rapid rise in blood sugar when ingested.

The diet is easy to follow and does not require you to count calories or measure portion sizes. You might even be surprised at the foods that are on the list of allowed foods for you to enjoy. While lima beans and butternut squash are full of starch, amylose isn't one of them, and you are free to enjoy these starchy vegetables as often as you like. For more detailed information on the diet including using it for weight loss, please see [Lose the Weight You Hate](#) by Dr. Shoemaker.

NO-AMYLOSE DIET FORBIDDEN FOODS

Roots and tubers including white and sweet potatoes, beets, peanuts, carrots, and other vegetables that grow underground. The exception here is onions and garlic.

Bananas (the only forbidden fruit).

Wheat and wheat-based products including bread, pasta, cakes, and cookies.

Rice.

Oats.

Barley.

Rye.

Foods with added sugar, sucrose, corn syrup, or maltodextrin.

ALLOWED FOODS

Allowed foods include basically anything that is not on the list of forbidden foods including:

Corn.

Onions.

Garlic.

All vegetables that grow above the ground including lettuce, tomatoes, beans of all types, peas, cucumbers, and celery.

All fruits except bananas.

Meat, fish, and poultry.

Condiments (avoid low-fat varieties as they usually contain added sugar).

Spices.

Eggs.

Dairy (avoid sugar-laden products).

Nuts.

Sunflower, pumpkin, and squash seeds.

This diet is based on the 0-0-2-3 rule and is an easy way for you to remember what should or should not be included in your diet each day. You should have 0 sugars (glucose or sucrose, including corn syrup), 0 amylose, 2 servings of protein that total at least 6 to 8 ounces, and 3 servings each of vegetables that grow above the ground and fruit (except bananas) per day. This diet allows for sufficient quantities of food so that you won't be hungry and can enjoy good-tasting, high-quality meals. It just involves adjusting some of our habits and thought patterns when it comes to food. For instance, you can still eat a hamburger, just not the bun. Why not try some melted cheese and a hearty slice of tomato on top instead? Soups can be a nutritious and filling meal or snack but not when they are loaded with pasta, potatoes, or rice. Why not try some delicious black bean soup or maybe a homemade cream-based tomato soup without the added sugar so often found in canned varieties?

The other benefit of this diet is that it is also a gluten-free diet. The avoidance of wheat, oats, rye, and barley is the same for both diets. If you have also been advised to be on a gluten-free diet, no adjustments need to be made for you to eat gluten-free. Just follow the 0-amylose rule and you will automatically be avoiding gluten-containing products. One key difference to note is that this diet does not allow rice while gluten-free products often use rice as a substitute for wheat. This makes the no-amylose diet slightly more restrictive than a no-gluten diet. If your MMP-9 is less than 600 and you have a normal Leptin then you may only need to be gluten-free or neither. But many Moldies and Lymies do much better when they are at least gluten-free.