

What to Expect from Cholestyramine (CSM)

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 of time 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. Provided that 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. CSM will not correct presence of MRCoNS, low VEGF, high TGF beta-1 or low levels of CD4CD25 cells, for example.

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. Our treatment protocol attempts to anticipate the possible troublesome side effects; you will be given additional medications to keep on hand "just in case."

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 caused 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 as 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.

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 will be following your case carefully. If you have questions regarding any phase of your treatment, please notify your doctor's 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 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), mix with water, or juice, 4-6 oz.
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 before taking thyroxine, digitalis, theophylline, Coumadin and others; ask your doctor for information).
5. Take CSM 4 times a day!
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