

FAQ'S For "Newbies"

Question: How will I feel when I start the Guaifenesin Protocol?

Answer: When you start guaifenesin there are several things you may experience. Some people actually feel better for 24-48 hours. This is not a common reaction, but it happens because the guaifenesin begins to help the body excrete phosphate right away, if it isn't blocked. You may feel nothing at all. Remember that you won't feel differently until you get to your therapeutic dose. This means that the majority of people won't feel anything for the first week on guaifenesin simply because a dose of 300 mg twice a day (the recommended dose for the first week) isn't high enough to begin reversal.

Once you've hit the dose that works for you (most people will experience this at 600 mg. twice a day, and ninety percent will feel it by 1800 mg. of guaifenesin a day) your symptoms should exacerbate. You'll be more tired, achier -- as if you are coming down with the flu. You may be more emotional, your irritable bowel may flare, or you may be absolutely exhausted. Your symptoms, any and/or all of them, can get distinctly worse. When this happens you'll know you're at the correct dose.

Some people do reverse without a distinct worsening. Their symptoms might get only slightly worse for a short period. But their maps will show clearing. These people feel as if they have a straight line of clearing instead of the up and down cycling. These people are in the minority, but if a mapping confirms you're making progress, even though you haven't felt much worse, you may be one of the lucky ones.

Question: What is fibromyalgia?

Answer: Fibromyalgia is a syndrome, meaning that it is a collection of symptoms that occur together, and not all patients have all of them. Women are affected more than men--only about 20 percent are male--and it also occurs in children. Fibromyalgia means "pain in muscles and fibers." This pain must be present in all four quadrants of the body for three months. Diagnosis is made by the presence of tender swollen areas that hurt when a small amount of pressure is applied. However, not all patients have significant pain. For some, fatigue is the primary complaint. Other symptoms include headaches, irritable bowel syndrome, irritable bladder, vulvodynia, problems with memory and concentration, nervousness, depression, and sensitivity to sound, light and odors.

Question: What causes fibromyalgia?

Answer: We believe it is an inherited trait and that from birth phosphates very slowly build up in your tissues. At puberty and other accelerated growth times your body uses more of the phosphate you ingest. The build up might completely stop at that time. However, at some point, depending on your genetic trait, you become symptomatic: i.e. the phosphates have built up to the point where they cause an impediment in making energy. Eventually this lack of energy causes our symptoms.

You will reverse one year of build-up with about 2 months of guaifenesin. If you stop taking guaifenesin when you stop feeling symptoms, the build up will begin again and in time your symptoms will come back. That's why we stay on guai for life, despite the fact that we feel better.

Question: What is the difference between Fibromyalgia and Chronic Fatigue Syndrome?

Answer: Chronic Fatigue is a symptom of Fibromyalgia. All pain is diagnosed by a subjective scale - "Does this hurt?" If a person has a high pain threshold, "this" wouldn't necessarily hurt. Yet CFS patients have all the cognitive symptoms and many others of classic fibromyalgia. They don't fit the

usual FM classification because pain is a minor rather than major complaint. It doesn't however make their illness different than ours.

It helps to think of all illnesses, especially ours, as a bell shaped curve. In the middle, where most patients are--is a mixture of pain and fatigue. At each end are the extremes: a few patients with only pain on one side, and on the other, a few patients with only fatigue.

Question: What is the proper way to find my correct guaifenesin dosage?

Answer: When you start guaifenesin there are several things you may experience. Some people actually feel better for 24-48 hours. This is not a common reaction, but it happens because the guaifenesin begins to help the body excrete phosphate right away if it isn't blocked.

The proper way to start your guaifenesin is 300 mg. twice a day. If this is your dose, you will feel worse rather quickly. You may feel achy, fluey, crabby, more fatigue... usually you will only experience your personal symptoms made worse. In other words, if you've never had a headache, it's unlikely that you'll have headaches. Use your own list of symptoms to guide you. (Don't use pre-printed symptoms from any list) You will know within one week if you feel worse.

If you feel about the same after a week, then it's time to raise your dose. You should go up to 1200 mg, or 600 mg. twice a day. Some people are frightened that they will be incapacitated and prefer to be cautious. If this is the case, yes, you can raise your dose to 900 mg. instead of 1200 mg.

Now the process begins the same. You might feel a bit better for 24-48 hours. (You might not). Then, if this is your dose, you will feel worse. You should wait three weeks this time -- to finish your first month on guaifenesin and evaluate your situation. If you have someone mapping you, at the end of this first month, get checked again. If you don't, look at your calendar or your symptoms and see if you feel worse. You can use a chart. Remember the less you write the easier it will be to track your progress.

If at the end of the first month, you don't feel worse, it's time to raise your dose again, this time up to 1800 mg a day. This dose works for 90 percent of patients, so you have an excellent chance to respond. If for some reason, after another month, you have not felt worse, recheck your products very carefully. While it's possible you may need more than 1800 mg. of guai to reverse your FM, especially if you usually require large doses of medication---this dose works for 90 percent of patients. That's why you should check your products before raising your dose.

Question: How do I store guaifenesin correctly?

Answer: Guaifenesin, like nearly all other medications, should be stored in an area that has a temperature between 59 and 86 degrees Fahrenheit, not in the refrigerator or in a very warm room. Store it away from moisture and sunlight. Do not store in bathroom where it can be damp and humid. Do not refrigerate syrups or freeze liquid forms. Keep the LID ON TIGHT. The good news is that recent potency trials by Adams Pharmaceuticals have demonstrated that despite expiration dates guaifenesin quite probably retains full potency for ten years, and may have only a slightly diminished potency after that period.

Question: What is the quick salicylate screening test?

Answer: Read your product ingredients list and do this:

1. Look for any plant name (aloe, chamomile, coconut, etc.) and see if it is followed by the word oil, gel or extract. If you do not see any plant names skip to step 3. If you see any plant oil, gel or extract go to step 2.
2. If there is a plant oil, gel or extract, and the plant is NOT soy, wheat, corn or oats you cannot use the product. If it IS soy, wheat, corn, or oats (soybean oil, oat extract) go on to the next step.
3. Check the product for octisalate, octyl salicylate, salicylic acid, camphor or menthol. If it's a sunscreen, look for homosalate. If you see one of these you can't use the product.
4. If the product has mint flavor, or any flavor that contains mint, you can't use it.
5. If the product is a supplement of any kind and contains bioflavinoids, you can't use it.

Question: What does CROWS mean?

Answer: CROWS is an easy way to remember these salicylate-free plant ingredients: Corn, Rice, Rye, Oats, Wheat, Soy. These are seeds or grains that do not contain salicylates. You need to avoid all oils, gels and extracts with a plant name EXCEPT if the name is Corn, Rice, Rye, Oats, Wheat, or Soy.

Not all parts of all plants produce salicylates. These grains do not. But you still have to avoid the plants they grow on: wheat grass, for example IS a blocker, but wheat germ oil isn't. Thus, if an oil comes from the grain and ONLY the grain of corn, rice, rye, wheat, oats, or soy it is OK.

Question: How do I check my medications for salicylates?

Answer: Checking your medications is really very easy. If the medication is a salicylate, it will say so in the chemical name. All you need to know then, is the chemical name of your medication. For instance, Zelnorm is a product name. The chemical name is tegaserod maleate. That doesn't include salicylate, so it's okay. Urised (the product name) is a blocker because the chemical name, phenol salicylate reflects this. Tylenol with Codeine is Acetaminophen with Codeine and neither of those is salicylate. The aspirin and codeine compound is acetylsalicylic acid and codeine. Migraine medications such as Imitrex (sumatriptan) are fine, but ones that contain aspirin (acetylsalicylic acid) are blockers.

Question: What does the term "cycling" mean?

Answer: "Cycling" refers to the cyclical nature of symptoms when reversing. Reversal cycles are generally intensified symptoms of whatever YOU have. Your symptoms will repeatedly increase then decrease in intensity as you cycle through them.

Question: What is blocking?

Answer: When salicylates enter the body one of the things they do is travel to the kidney where they occupy receptor sites designed for them. Unfortunately, since these are the same sites guaifenesin needs, salicylates block the ability of guaifenesin to help the body excrete phosphates.

Question: What is the Blocking Test?

Answer: The Blocking Test is one of the tools we use to help find answers when someone is concerned about a lack of progress on the protocol. In conjunction with mapping, checking your products, and a symptom diary it can provide important clues. For example, when a map doesn't show much progress it can be hard to know whether or not you are blocking or if you are simply clearing in areas that are not palpated such as the brain or bowels.

If you are blocking, no amount of guaifenesin will change your symptoms. If you are not blocking, and you increase your dose, you should hurt more within a week. To properly use a blocking test do the following:

1. Increase your dosage 600 mgs a day for a few days.
2. If the increase in dosage causes an increase in any of your symptoms, you are NOT blocked.
3. If you DON'T experience any increase in symptoms you MAY be blocked, or you may have reached your kidney's capacity for elimination. Remember that the higher your dose, the less dramatic your response to a blocking test will be.
4. To ascertain which is the case, stop using any non-essential products and check all your products for salicylates.
5. If you experienced change when you eliminated products then you were blocking because of those products. If you didn't experience any change, then it's likely you were not blocking and have probably reached your kidney's capacity for purging.
6. If you were blocking you can continue using any products which were confirmed as Salicylate Free and go back to your previous dose of guaifenesin.
7. Discontinue using any of your other products which cannot be confirmed as completely Salicylate Free and continue focusing on your experience.
8. Don't add any product to your daily regimen unless it can be ruled salicylate free.

NOTE -- For those on the higher doses the blocking test isn't as definitive and will require a longer test period. Any changes will be subtle.

Question: Why do people feel worse when they block?

Answer: It is as though you were taking no medication. The natural course of fibromyalgia is to get worse if left untreated. Insufficient dosage or blocking are just like not treating at all and the illness begins to cycle back in the unfavorable, worsening direction.

Question: Why is it important to map the left thigh?

Answer: Dr. St. Amand's office finds that 100% of adult patients have significant lumps in their left thigh that significantly shrink or clear within a month on the patient's cycling dose. Therefore, these lumps are the most reliable indicator to help determine when a patient has reached the proper dose of guaifenesin.

Question: If my left thigh is partially cleared, why are there still lumps there?

Answer: It's normal for other, smaller round lumps to come and go in the left thigh. These lumps are different from the long left thigh lumps used to determine your cycling dose. Their appearance is not a sign that you need to increase your dose or that you are blocking.

Experienced guaiers sometimes talk about the "left thigh clearing" when you reach your cycling dose. Do not be confused; they are only referring to the lumps that were in the vastus lateralis and rectus femoris. People often use the phrase "left thigh clearing" as a short-hand. Or sometimes they themselves don't understand that other lumps in the left thigh are normal.

In addition, some mappers prod too deeply into tissues and end up mapping the tiny fatty and muscular nodules that are quite normal. Proper examination is done with a slightly firm, sweeping motion as though trying to iron out the muscle and felt with the pads, not the tips of the fingers. Mappers that feel too deeply often produce maps with multiple tiny dots or lines. Dr. St. Amand only finds larger, contracted bundles of muscle.

Question: If my left thigh has cleared, why am I finding new lumps and/or swelling in my body?

Answer: It's a normal part of the clearing process for lumps to swell and shrink and come and go. When a lump is being actively worked on, it often swells with fluid, then shrinks again when the cycle ends. Lumps often go through repeated cycles before they are completely gone, so you may experience cycling in the same location more than once. This is a normal part of reversal and does not indicate you are blocking or on too low a dose. However, if you continue to see more lumps and bumps and are feeling progressively worse you should do a blocking test.

Question: What will my map look like when I am clearing?

Answer: If you are clearing, your lumps will become progressively softer, smaller, and more mobile. Larger lumps, such as those around the hips and the tops of the shoulders, often break up into smaller lumps before disappearing. Although they will come and go, the overall trend is toward smaller and fewer lumps.

Question: What is mapping and how is it done?

Answer: A map is a diagram of the human body that shows the size, location and hardness of a patient's "lumps and bumps" of fibromyalgia. These lumps and bumps are nodules in the muscles that are characteristic of the syndrome. In addition to the lumps in muscles, tendons and ligaments can swell. Such swellings are also mapped.

Mapping is a tool to determine whether a person has reached his or her cycling dose. Maps are also done to monitor progress on the protocol and to detect blocking.

The mapper feels for the contracted portions of muscles, tendons and ligaments and draws them onto a blank map. Dr. St. Amand uses darker markings to indicate hard lumps, and lighter markings to indicate those that are softer.

Question: What will my map look like if I am blocking?

Answer: When a person blocks, their map shows an overall increase in the size and number of lesions. Lesions in the shoulder muscles are particularly likely to re-grow when a person blocks. This is very different from the normal swelling/shrinking and moving around that lumps do when you are cycling. With normal cycling, there is an overall trend towards smaller, fewer, softer, more mobile lumps. When someone blocks, the overall trend is towards larger, harder, more widespread lumps.

Question: Why are my maps changing so slowly now that I've been on the protocol for a while?

Answer: This is normal. Clearing slows down later in the protocol as you begin to cycle tendons and ligaments. These structures receive less blood flow than muscles. Therefore, it takes longer for them to clear than the lumps in muscles. Maps change very slowly later in the protocol compared to maps done earlier in the protocol.

Question: Which tendons commonly swell when cycling?

Answer: Tendons can swell anywhere. However, swollen tendons are especially common in the right upper arm (the deltoid tendon), the front of the right ankle, and often the soles of the feet. They often swell on the outside of the lower legs, the left more than the right. The inguinal ligaments in the groin are usually swollen for part of their length only, the left more than the right and more often in women than men.

Question: If my map is completely clear, why do I still have cycles and/or symptoms?

Answer: A map only shows the lumps and bumps that can be felt. There are many other structures affected by fibromyalgia that are too deep to feel. In addition, the mapper can only feel the lumps on the tops of your muscles. Others are located on the edges and underside but cannot be felt. These areas continue to cycle even after the obvious lumps have cleared up. Another possibility is that since even healthy people have small lumps and bumps from everyday wear and tear, if your map is completely clear, your mapper may be using a different technique than Dr. St. Amand uses.

Also, guaifenesin cannot reverse damage done by osteoarthritis. Nor does it ease the symptoms of other medical problems. If you have another condition that causes pain for example, guaifenesin will not reduce or eliminate that pain. However, people with multiple medical problems in addition to fibromyalgia can still benefit from the relief guaifenesin provides from the symptoms caused by their fibromyalgia.

Question: Who can map me?

Answer: Although there are medical doctors in addition to Dr. St. Amand who follow the protocol and are willing to map, their numbers are few. Some people discover their own doctors are willing to learn if they are asked. Others may feel uncomfortable, but there are alternatives. Massage and physical therapists, chiropractors and others who work with their hands may be willing to learn if you ask. Some fibromyalgics even find family members to map them. Others map their own left thighs, although most report this is difficult to do. Check with your support group leader to get the list of trained mappers working in your area.