

Debbie Johnson's Tips for Newcomers and FAQs

I put my name on this file to distinguish it from Deborah Cusack's documents. It was based on her writings, with what I've learned in the group and my own experience mixed in. I'm a layperson, so everything I offer is conversation, nothing is medical advice. Listen to your body; your mileage will ALWAYS vary.

The protocol lists adult dosages; parents can adjust to an appropriate level for their children.

Like just about everything else with Ehlers Danlos Syndrome (EDS), it's all about trial and error, to see what works best for you.

Where do I start?

You start with LGG (Lactobacillus rhamnosus GG) in Culturelle Health & Wellness (C H&W) formulation. This formulation contains no inulin, which can cause nasty side effects for people with MCAS, the super-common comorbidity to EDS, sensitive GI tracts, ragweed allergies... there's a list of folks who can't tolerate inulin. In general, it's just safer to start with C H&W.

If you can't find C H&W in your country or want a less expensive solution, look for a product with around 10-15 billion CFUs of LGG as a single strain (not combined with other strains), and avoid inulin unless you know you can tolerate it.

People who are sensitive to C H&W might do better with Pure Encapsulations. Some Custom Probiotic and Kefir products contain only LGG; read the labels!

If you want to start at a lower dose of LGG, you could use Culturelle Kids Chewable Daily Probiotic. It contains 5 billion CFUs, and the adult protocol calls for 10-15 billion. Please check the label to ensure it has no inulin.

Next is PQQ. If you have GI issues, wait two weeks. If you don't, then you can begin the PQQ and Culturelle H&W simultaneously. If you have *any* GI issues, or MCAS symptoms, then stop the PQQ, and wait to weeks before starting the PQQ again.

This combination of LGG (e.g. Culturelle Health & Wellness) and PQQ will do a LOT of things, which is probably why it's recommended for starting:

- 1) Culturelle H&W has LGG (Lactobacillus rhamnosus GG), called the King of probiotics, because it can bring all the other bacterial levels into a healthy balance.
- 2) Culturelle H&W is a mast cell down-regulator, which decreases your Mast cell reactions.
- 3) PQQ replenishes the epithelial lining of your GI tract (mouth to anus)

Together, they help heal the leaky gut which is common to so many of us EDSers, since the GI tract has a lot of connective tissues and a concentration of mast cells. You begin to absorb more of the nutrients from your food. Fewer reactants - and in less quantity - enter the bloodstream, which makes your entire body less reactive.

AND they allow your body to absorb and adequately process the supplements to come. (Tip: alcohol will kill the cultures, so take it hours away from wine, beer, spirits, etc.)

You may feel relief from the LGG (C H&W) in a few days, but PQQ can take 90 days to heal your GI tract.

And then what?

The next supplement for those of us with muscular-skeletal problems would likely be the polysaccharide. Here you have three choices:

- 1) Aloe - a very specific kind of Aloe called George's fractionally distilled (very important). An alternative is the PharmAloe capsule. Most people do well, but some are estrogen dominant, so prefer #2
- 2) Maitake mushroom. The Host Defense capsules are out of stock, so try the liquid extract or another brand.
- 3) Almost everyone does well on one or the other, but a few people need both.

You wait two weeks, and if all is well, you add the next supplement, which you choose based on your next most bothersome issue.

And so on. You keep adding supplements slowly. Each supplement targets a missing factor, which causes a lot of EDS symptoms. Several types of collagen are targeted with this protocol.

Why can't I start them all at once?

The primary reasons you wait two weeks are:

- 1) See how your body is doing. Most folks can jump into the full dose, but some may need to start with a lower dosage, and progress upwards slowly to the full dose on one or two of the supplements.
- 2) Let your body adjust to one new thing at a time.
- 3) When you dive in all at once, your body is more likely to react, and you have to stop everything to figure out what is causing it.

Can I take them at the same time?

You can take everything together EXCEPT... food-grade diatomaceous earth (DE) is best taken on an empty stomach

- 1 hr after eating, for better absorption, and by itself

- 1 hr before eating or taking supplements or medications because it has a 'sweeping' action.

And if you take both L-Arginine and the anti-viral L-Lysine, they need to be taken on opposite ends of the day or they'll cancel each other out. (Example. If you take 250 mg L-Arginine at night, take 500 mg L-Lysine in the morning.)

With food or without?

With one exception (DE above), the supplements can be taken on either a full or empty stomach, including Culturelle, which is unusual for a probiotic.

When you're starting out, or if you have a delicate stomach, you might want to take them with food.

What time of day is best?

D-ribose often brings energy, so that's best taken in the morning. Shelly says Lion's Mane is most effective when taken in the morning.

Otherwise, when you take them depends on how they make you feel. Some people find that some supplements energize them, or make them sleepy. One member said a supplement

changed after a few months, from making them sleepy to giving them energy so as always, watch your body.

What is a healing curve?

My family didn't, but some people have 'die off' or 'healing curve' symptoms, in which whatever they're trying to correct, gets a little worse before it begins to get better. Some people have reported feeling flu-ish, e.g. general malaise. Restarting, then 'low and slow' might be needed for that supplement. Some people tough it out for a few days. I can't stress enough that everyone is individual.

Low and slow means starting as low as you need to, to have no reaction symptoms. (You'll know it if you see it!) Many people use 1/4 dosage as their 'low' starting point. Then increase slowly, again to avoid reaction symptoms.

Do I have to take all of them?

Cusack says to take only what you need. For example, a child doesn't have joint pain, so doesn't need DE. They probably don't have muscle wasting, so won't need Astragalus.

Some people pick and choose the supplements, but the more I read, the more value I see in taking the complete protocol. There are overlapping benefits, so I believe this protocol is much more than the sum of its parts. For example, Cusack put hyaluronic acid on the protocol for eye flashers and floaters. However, the label of the product I buy stresses its importance for joints, connective tissues, and skin health.

How long until I start to feel better?

You may feel relief from the LGG (e.g. Culturelle Health & Wellness) in a few days, but Cusack said that PQQ and Astragalus can take 90 days in which to see symptom relief. A ~very~ general rule of thumb is to wait 90 days before expecting to see symptoms. This varies a great deal. It often happens sooner, and for the more severe issues it can take a year. For example, some scoliosis has been reversed with the George's Aloe Vera after a year or so.

Deborah Cusack's wisdom is to use the least dosage that's effective, and the recommended dosage is often ½ what the manufacturer recommends. If you're not seeing as much relief as you'd like, you could increase to the manufacturer's "Serving Size" listed on the label.

The DE is giving me a scratchy throat. What do I do?

First, be very sure you are taking food-grade Diatomaceous Earth. Industrial or garden-grade can be harmful and is not recommended.

If DE gives you a scratchy throat, try diluting the mixture more. I use 12 ounces for 2 tablespoons DE. It tends to settle to the bottom, so I use a straw to blow bubbles before I sip, to keep it mixed. Some people need to begin taking it with a small amount of applesauce or chocolate milk. It's most effective when mixed into a clear liquid, though.

What about the medications and other supplements I'm taking?

Cusack has said to continue taking whatever you're currently taking, and to add in the protocol supplements, starting with LGG (e.g. Culturelle Health and Wellness), then PQQ, and so on.

Will this work for all kinds of EDS?

Cusack 10-31-14.

"Regarding EDS as a whole, please know I choose to stay away from the labels typically called "EDS Types". I have chosen to approach EDS as a "whole body systems" metabolic biosynthesis dysfunction with DNA/RNA signaling deficiencies in the cells of the extracellular matrix of connective tissues. The old system only looks at the collagen rather than recognizing the many molecules involved in the several different cell types which are responsible for multiple layers of connective tissue production."

Some of our members have heritable connective tissue disorders (CTDs) other than EDS, like Sticklers, Loeys Dietz and Marfan Syndrome, are seeing relief with this protocol.

How did Deborah Cusack develop this protocol?

This last section is offered to those who are curious about the Cusack went about researching the issues involved with EDS, and how to supplement the substances our bodies lack.

Cusack 3-31-16.

"Please know when I first developed the protocol I began at ground zero by researching stem cells (the genesis of the beginning life) and proceeded from there. Taking apart each type of resident stem cell of each organ system tissue, the organelles, the mitochondria, ribosomes. etc., I searched for the molecules that open up signaling pathways to increase the production of connective tissues."

Cusack 9-16-14

"Here is an excerpt of what I have learned from 6 years of research regarding stem cells in connective tissues and connective tissue collagen production.

Because Ehlers Danlos Syndrome is caused by a metabolic biosynthesis dysfunction and a dysfunction of DNA and RNA signaling pathways, we can choose to supplement our bodies with:

1. Polysaccharides to target the genes COL1A1 and COL3A1 in fibroblast cells of connective tissues type I and III.
2. D-Ribose to target the genes COL4A1 and COL5A1 in Schwann cells of the myelin of the peripheral nervous system by increasing ATP activity. Connective tissue collagen type IV and V.
3. L-Arginine to target the epithelial cells of the intestinal tract lining and the endothelial cells of veins, arteries, and heart. L-Arginine opens signaling pathways of DNA and RNA of connective tissue collagen type IV.
4. Probiotic to restore Flora in digestive tract, enhance food digestion and control mast cell activation as well as improve compromised immune system."

This protocol isn't limited to the genes listed above, but was developed for all Types of EDS.

Again, everything I write is conversation, not medical advice.

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