



Helping Our Family & Friends Understand

Celiac Disease and the Gluten-Free Diet

To My Family and Friends

I want you to know – I will be okay! BUT I need your support and understanding. I have “celiac disease” and I have to eat gluten-free (GF) to get well – that is all I have to do.

Celiac Disease (CD)

Celiac Disease (pronounced SEE-lee-ack) is an auto-immune disease which means the body mistakes something as a pathogen and attacks its own cells. With celiac disease, the primary target is the villi in the small intestine.

Even though I do not understand everything about it yet, I know I want to stop that “attack” on my own body. This is NOT an allergy and I will not treat it like an allergy. I want to get well.

I have been told that the villi are like a shag carpet (simple lay terms). They are finger-like projections sort of like the strands in the shag carpet – more micro size. The immune system attacks that “shag carpet” and in time it damages or destroys the villi so it becomes like a tile floor – missing the villi (shag carpet). Guess what? It is through the villi that my nutrients are absorbed so if my villi have been destroyed, I cannot absorb those needed nutrients (e.g. vitamins, calcium, iron, magnesium, potassium, zinc, selenium, copper and more).

That is why celiac disease is called a “multi system disorder.” It begins to affect other parts of the body since the nutrients are not absorbed to keep the body healthy. Now for the **good news!**

Since I am taking this seriously and going gluten-free, the shag carpet/villi should grow back and my body will once again absorb the nutrients.

What causes the immune system to attack? CD is hereditary – not contagious. Those genes caused my body to permanently react and so my diet will be forever changed. I do not need to have medicine or any serious treatments. I just have to eat GF because gluten, which is found in wheat, barley, rye and often oats, causes the immune system to attack. Without those grains the immune system behaves itself! If I eat even an itchy bitsy bit of an itchy bitsy crumb, the immune system will wake up quickly and begin the damage again.

So please do not say that “A little bit of cake, etc., will not hurt me.” It will hurt me because the immune system does not sleep through a crumb.

Gluten-free Diet (GF)

The only “fix” for celiac disease is to eat NO gluten – which means I eat gluten-free. You surely have heard those words in today’s vocabulary. I do not know everywhere that gluten is hiding, but I do understand it can be in food without me knowing it – hidden. It is hard to believe that it might be in licorice, ice cream, malts, soups, soy sauce, nut mix, many more. I have to care about everything that goes in my mouth so I will have to learn from others who know more about what foods are gluten-free. Celiac support groups are helpful resources as well as national organizations (*see www.csaceliacs.org*). Celiacs are very good about helping other celiacs. They learn it and live it.

Just because a label does not appear to have any wheat, rye, barley, or common oats in it does not necessarily mean it is GF. It might have been processed in a plant with wheat flour, for example. Calling the toll-free telephone number on the product can help confirm if it is GF.

If I do not eat something that you have prepared, please do not be offended. It will take me time to feel safe because I want to

keep that immune system happy. You see, if you put your knife in your butter dish and spread the butter on your wheat bread and then put your knife back in the butter, that is enough gluten to have my immune system say, "I am back." The same is true if you have used flour in your kitchen and it comes in contact with my food. Other examples are: putting my GF bread in your toaster (wow! Look inside any used toaster); stirring my pasta with the same spoon that you stirred your pasta with while cooking. By reading the label, you believe it is GF when it really is not – wheat has to be declared on the label but barley and rye do not. You may believe I am exaggerating, but the experts know more than I do, so I have to trust what the experts say.

Getting Well

I am really excited about getting well. The experts say it will take several days but my villi will start growing back. It may take even a year or more to feel really, really good again, but I will be patient. I know that all I have to do to achieve good health again is to just eat safely – 100% GF! If I cheat or am not careful, the villi may become blunted and unhealthy again – it is not worth it to me to have that bite of gluten.

Thank You

I know you want me to be well so I thank you for your support and understanding. I want to learn more about CD and GF eating so I can help others myself. Feel free to ask me questions. I will find the answers.

WHAT CAN I EAT?

I am surprised how many foods I can eat that are just naturally gluten free. Most are also healthier because they do not have so many additives.

For example:

- Fresh fruits and vegetables
- Meat prepared by the butcher – no additives
- Most sodas, coffees and teas
- Most canned or frozen fruits and vegetables
- Eggs, milk, natural cheeses
- Air popped popcorn
- Many, many more

There are many foods that *might* be GF but it takes a phone call to the company or a celiac who confirmed with a company the GF status. "It just depends" is what I am often told when asking others about a product. One company can add gluten to some products where another company may not. It can just get cross-contaminated, such as stuffing a turkey with your wheat bread in the stuffing versus GF bread in the stuffing. That causes that little bit of gluten to contaminate the turkey. "Here comes the immune system." Wow is it sensitive.

You can see that I have lots of foods I can eat. I may wish I had one of your foods at times – maybe more than "sometimes" at first, but I have to care about my longevity. I will probably try and take something GF I really like when going to potlucks or family dinners since I will not know what is in the other dishes.

Oh, yes, there are several restaurants where I can eat! Yea!! Many of them have GF menus.

Thanks for caring about me. It means a lot.

SYMPTOMS OF CELIAC DISEASE

At this time, it is said that 1 out of every 141 have celiac disease and only 20 percent of those are correctly diagnosed. I am one of the lucky ones who now knows what to do. Below are some of the symptoms of CD. There are so many symptoms and celiacs do not all follow the same symptom list. It can even be silent but still doing the damage. Again, I am lucky.

- Diarrhea OR constipation
- Abdominal bloating/cramping
- Fatigue/weakness
- Joint pain
- Weight loss
- Skin rash
- Mouth sores
- Anemia
- Depression
- Irritability – especially in a child
- Stunted growth – child

These are just a few. I hope this helps you to know some of the symptoms. Maybe you will make a difference in someone's life who has these symptoms. If you know someone who does, it is very important for them to NOT go on the GF diet without a diagnosis. Unless the researchers find a way to solve the immune system from attacking the body, it is a life-time diet. No one should be on a restrictive diet without knowing they need to be.

Once on the diet, the testing will not give true results because that "shag carpet" will start growing back and it will fool the labs.

Have them see a doctor. It might save their life.