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Celiac Disease: The Tale of the “Chip Dilemma” and Cross Contamination

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Celiac Disease: The Tale of the “Chip Dilemma” and Cross Contamination

Author Bio

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Celiac Disease: The Tale of the “Chip Dilemma” and Cross Contamination

LAKEN FRANCHETTI

I have quite a wide range of anxieties: spiders, losing the people I love, unfulfilled potential, getting called out in class to answer a question when my hand wasn't raised, disappointing people, failure, forgetting to turn my phone on mute before class starts, tripping in front of people, and Celiac Disease. That last one is essential. It has to be.

When my sister was a few months old, she ended up in the NICU. My parents had been struggling to find a formula that agreed with her, but what they didn't know was that her body was fighting against itself on the inside. Her body had begun to shut down due to the gluten that she was ingesting, and doctors had not yet considered Celiac Disease as a possible culprit. My parents were given a “liquid gold” formula that my sister could live off of (nicknamed due to the expensive price tag that came with it). She wasn't diagnosed with Celiac Disease until she was three years old, and doctors then credited Celiac as the cause for her near-death experience.

I was tested for Celiac in the third grade because I had started to show some of the classic symptoms: a bloated stomach and frequent bouts with constipation and diarrhea (which is obviously no fun). I was quickly diagnosed with Celiac, and we later found out that my mom was the parent who carried the gene, yet she only started showing symptoms years after I had been diagnosed. My dad's the only one who doesn't have Celiac. You could say he's the only “normal” one.

Celiac Disease is an autoimmune disorder, and it's estimated that 1 in 100 people have Celiac. When people with Celiac Disease eat gluten, their body activates an immune response that attacks the small intestine. This in turn damages the villi, which line the small intestine and promote nutrient absorption, so when the villi are damaged, nutrients cannot be absorbed properly. According to The Celiac Disease Foundation, eating gluten can cause the following symptoms: abdominal pain, bloating, anxiety (go figure), headaches and migraines, joint pain, nausea and vomiting, peripheral neuropathy, and more. Untreated Celiac Disease can lead to more drastic health conditions: heart disease, infertility, liver failure, malnutrition, seizures, and more.

Growing up, I didn't think much of it. I knew I had to be gluten-free, but the only way that ever affected me was when I went to birthday parties and had to bring my own food. No one else in my childhood friend group had allergies, so I was the only one carrying around a lunchbox at parties. My mom did her best to pack what everyone else would be having, so typically, my meal would contain a few cold slices of pizza (it never stayed hot, no matter how hard my mom tried) and a cupcake that crumbled with one touch. I didn't mind. I was still getting pizza and a cupcake like all of my friends, so that was enough to please ten-year-old me.

But, once I got older, I started to recognize the differences between my friends and me. They got to have delicious, fluffy pizza while I ate stale slices with a crust that became rock hard. My sister didn't know what she was missing out on because she was diagnosed so young, but I knew. I knew all about the food that I was no longer allowed to eat. Now that I'm twenty, I feel that some of that has faded away. I'm so accustomed to gluten-free meals now that I can't remember much about regular food and how it tasted.

Growing up also allowed me to recognize all the things my parents were constantly doing to ensure that my sister and I were safe. They had to make separate meals for us to take to parties when everyone else was provided with free meals, had to check with other parents to make sure we had food and snacks during sleepovers, and had to organize our 504 plans for school. There was another constant chore they had to uphold: checking the ingredients on all the items they were buying, even priorly known gluten-free products. This is something I like to call "The Chip Dilemma" because it's constantly happening with popular chip companies like Doritos, Utz, and Lay's.

One week a bag of chips will be gluten-free, chips that have been gluten-free for years, so you would automatically assume there will be no issue when you decide to grab it again the following week. *Wrong*. Now the chips are suddenly not gluten-free because they changed their ingredients. And of course, there isn't a good substitute that fills the void of the chip that you so desperately wanted. Instead, you have options for a chip that crumbles too easily, is rock hard, or tastes too much like vegetables. The other fun thing companies do is remove their gluten-free certification off their packaging, but when you check the ingredients, everything appears to be the same. That's when you suddenly notice the small print right under the ingredients: "This product was made in a facility containing wheat." Some people with Celiac can stomach the small changes and move on.

Others, not so much. For my mom and I, we would be spending an unpleasant amount of time in the bathroom, and it would take a few hours for our stomachs to settle. For my sister, she would break out into hives, be sick for multiple days, and need about a week for her stomach to feel completely normal.

“The Chip Dilemma” is more so an annoyance than anything (although it does pose a threat if the consumer is unaware of the changes, which has unfortunately happened to me and landed me in the bathroom for quite some time). Something like cross contamination is an example of a higher-level threat. In the case of cross contamination, you have to make sure that none of the gluten-free food comes in contact with anything containing gluten. For example, you have to make sure that restaurants don’t put their supposed gluten-free fries in the same fryer as their breaded chicken tenders.

If they do, those aren’t gluten-free fries.

I follow some gluten-free “influencers” on social media. Aside from their recipe ideas and restaurant reviews, they often talk about their run-ins with cross contamination. Lauren, otherwise known as @eat.gluten-freewithme, made a video about how she found that a restaurant’s nachos, which had been labeled gluten-free on the menu, were not gluten-free as the chips were prepared in a fryer that contained gluten items. It’s what I imagine a bad date to be like. You’re really excited to see those nachos ever since you read about them on the menu, and now, it’s all you’re thinking about. But then you ask too many questions, and it all comes toppling down, and the nachos are revealed to be a glutenated jerk.

Lauren made the video to teach the Celiac community about awareness, and people began sharing their own similar stories in the comment section. As I was going through them, and laughing at the relatability of it all, I read one comment that was gaining some traction: “Don’t go out then.” This commentor then argued with people in the comments that Celiac Disease wasn’t a disability: “A disability is something that **DISABLES** you. The world doesn’t adapt itself to every person and this entitled mindset is what leads to suffering.”

Entitled mindset? We gluten-free people simply want a meal that has been advertised and labeled as gluten-free to actually *be* gluten-free! Quite frankly, I don’t think that is much to ask for! And no, I am not going to ostracize myself to my room and never go out into the world because I’m gluten-free. What kind of a life would that be? Yes, going out to eat with Celiac has its apprehensions, but I have to take that chance! I won’t give Celiac the satisfaction of encasing me into a bubble that I’m scared to

leave, and I'm not going to let my disability stop me from having a social life and trying new places.

Disabilities come in all different shapes and sizes. Due to mine, I have to protect myself constantly and make sure that the food that goes into my body is properly broken down and digested. Some people just brush Celiac off as a gluten-free diet, but it is so much more than that. I have to remain vigilant when going out to eat, and I always have to pack snacks in case what someone offers isn't gluten-free. I have to check the ingredients of all my food products, and I have to speak up when I notice that something isn't truly gluten-free.

At college, I watch the people who prepare my food in order to ensure that it's safe for me to eat. The pizza station has its own gluten-free crust that I personally think is some of the best pizza I have ever eaten. The salad bar is another safe option for me that I like, but the sandwich line, however, is a different story. I've had to remind two student workers to cut my sandwiches with a clean knife so that I can avoid cross contamination. One day, I happened to not be paying attention, and the worker cut my sandwich with a glutened knife. Luckily, their supervisor was watching and told them to remake the entire sandwich because it was now unsafe for me to eat. I found myself then apologizing to the worker for not paying attention to what she was doing. I apologized to *her*.

I shouldn't have to watch my food be made. I should be able to respond to a text or have a conversation with the person next to me, but I can't. I can't slip up because I can't afford to. On the inside, I was kicking myself that I let that happen to my food. My heart rate automatically picked up, and my palms grew overly sweaty, and I was itching to get my food and get out of there. Although the anxiety can get on my nerves, it's my survival mechanism. It's necessary for me to recognize my anxiety about Celiac because it prevents situations like the one I just described. I have to be cautious, and I have to stay aware, even if it means that I feel like I am sweating actual buckets.

And that anxiety is not going to force me into a bubble and not go out as that commentor had suggested. Yes, going out can be difficult with Celiac Disease, but it's manageable, and it's nothing that I should feel ashamed of or embarrassed by. My anxiety pushes me to recognize the dangers related to my Celiac Disease, but it also allows me to confront those issues so that I can eat comfortably and feel as normal as possible. Yes, "The Chip Dilemma" can be a nuisance, and it does suck when I can't eat fries with a burger at a restaurant, but I'm protecting myself.

I don't think that any of this means I have an "entitled mindset." I

simply want to be able to get through a meal without experiencing excruciating pain after eating. My anxiety helps me to make that possible.

My anxiety due to Celiac Disease is not an anxiety called to attention like when I see a spider or get a bad grade. This anxiety is always there. It has to be.