



Kyla Simone Brandenburg
PharmD student, University of Findlay,
Findlay, OH, USA
Email – brandenburgk@findlay.edu

CRUMB BY CRUMB: NAVIGATING LIFE WITH CELIAC DISEASE

Introduction

The gluten free diet has been praised and pushed by celebrities, athletes, and influencers with the promise of weight loss, improved performance, and clearer skin. Over the years the ability to avoid the gluten free diet fad has been nearly impossible with its presence covering food boxes in grocery stores, surcharges on restaurant menus, and social media before and after posts. Yet, how much does a gluten free diet really change in patients with celiac disease or gluten sensitivity? Over the last 5 years I have been following a gluten free diet I have been able to research heavily over the importance of a gluten free diet, how to listen to my body regarding the foods I eat, and how to navigate a socially and financially aware gluten free lifestyle.

My Journey to a Celiac Diagnosis

From a young age I can remember visiting with my grandfather and there being very specific rules about what snacks could be brought with us. The visit would typically start with a trip to the store to buy snacks for my siblings and I, that were gluten free and were

made in a gluten free facility. My grandfather is a celiac and his allergy is severe, which eventually lead to his gluten free household. I have many memories from my childhood of walking down grocery store isles learning how to read the back of food packaging to see if something contained wheat or gluten. This then led to being taught about cross contamination and the impact the food industry had on my grandfather's everyday life. This is often not something children or even adults learn until they are forced to research themselves when they are faced with their own dietary struggles.

My freshman year of college I lived in a dorm room and had a meal plan that included 2-3 meals a day from the dining hall, which typically included hot deli sandwiches, salads, burgers, and fries. The first few months of this diet was fine, and I had no noticeable symptoms. Around January of that year, I ended up getting the flu for the first time in my life and was sick for nearly 2 weeks, ever since I recovered, my stomach was never the same. Every time I ate I would get severe bloating, nausea, cramps, irregular bowel movements as well as joint pain, hives, and struggling with mental clarity. Knowing these were many of the symptoms my grandfather experiences when he eats gluten and the severity my symptoms had on my everyday life, I decided to do some research into the disease.

I started eliminating gluten in June of 2019, I was still struggling with the cravings of following a gluten free diet while also trying to decide how beneficial avoid gluten really was in my life. After about 6 months of going back and forth of trying to eat gluten free and "cheating" the diet I decided to go 100% gluten free. When going gluten free I noticed a tremendous change in my gut health, brain fog, and joint pain. Yet new struggles began to arise with the increased cost, limitations of quick options, increased planning when traveling, and the lack of education I had about this disease.



Celiac Disease: Definition and Diagnosis

One of the many things I found while researching is the difference between celiac disease vs. gluten sensitivity. Celiac disease is an autoimmune disorder that affects the small intestine in response to the ingestion of gluten, a protein found in wheat, barley, and rye. The gluten triggers antibodies to attach the small intestine and will eventually lead to permanent damage. Celiac disease is composed of many varying symptoms such as gastrointestinal symptoms, fatigue and weakness¹, dermatological symptoms, nutritional deficiencies, bone and joint pain, neurological symptoms and even developmental issues in children.² Celiac disease has been linked to a genetic component, specifically HLA-DQ2 and HLA-DQ8, is associated with an increased risk of developing celiac disease.³ When diagnosing celiac disease, serology studies are the first step, IgA TTG antibodies will be tested for⁴, yet the downfall is the patient must be eating a gluten containing diet at the time of testing.⁵ This is a downfall for many patients as they have already identified gluten is a source of discomfort and it is not worth eating for a potential positive diagnosis. While around 38% of the population carries the genes for celiac, only around 1% will develop celiac disease.² Current research suggests this is due to the ability of the gene to stay dormant in some individuals and can turn on when the body experiences high stress such as overexposure to viruses. This could be why I began experiencing symptoms after recovering from the flu. Gluten sensitivity has similar gastrointestinal symptoms but differs in the inflammation-based symptoms. This is because gluten sensitivity does not have an autoimmune component and has no genetic markers.⁶ Gluten sensitivity is more common at around 6% of the population⁷ and is diagnose based on symptoms.

Navigating the Challenges

There are many challenges due to living with celiac disease that are not visible and unexpected to the public. Some of these challenges include the financial burden, making and planning social events, communicating needs while trying not to feel like a burden, and the anxiety that surrounds having an allergy. Gluten-free products tend to be more expensive than their gluten-containing counterparts in both grocery stores and in restaurants.⁸ The desire for gluten free substitution items and the limited products labeled contribute to higher grocery bills, impacting the economic aspect of managing celiac disease. Fast food, a staple for many years prior has now become a challenge. The limited availability of gluten-free options and the risk of cross-contamination in fast-food establishments forces individuals to carefully select where and what they can eat, restricting choices significantly compared to the general population. In addition, most of the time, when gluten free substitutes are offered, it costs significantly more than a standard meal for someone else. This makes it difficult when needing a quick lunch at work, running errands, or needing something quick for dinner due to a busy schedule.

My fiancé's family like to eat out a lot for special events; birthdays, anniversaries, job promotions, and before/after school productions. This becomes a challenge to communicate that I need to eat somewhere that has a gluten free menu. Due to the increasing conversation around a gluten free diet, many chain restaurants are aware and can accommodate. Yet, there are still many times the only gluten free menu item is a salad with the croutons removed. To navigate these situations, I typically will call the restaurant prior to ensure they can accommodate and always carry a gluten free protein bar just in case.



Another challenge that is not always talked about with a food allergy is the anxiety that typically accompanies. When trying out a new restaurant, eating a meal not cooked in a gluten free home, or communicating your needs with friends and family often feel like walking on eggshells. At times others do not understand the importance and severity of cross contamination as you cannot see the gluten and it is not often talked about. Yet the feeling of being a burden or not wanting to cause a scene overpowers the hesitancy in eating the meal—that on occasions lead to being exposed and the wrath of symptoms that follow for days after.

Over the years of eating a meal I knew wasn't handled properly or I was hesitant about, followed by the uncomfortable symptoms that wreaked havoc days after, I finally made the change to start listening to my body. The more I listened the more I was able to uncover practices in my day-to-day life that were causing problems. Gluten was not only affecting my GI tract but also my skin and eyes. I realized I had been using products that contained oatmeal and flour in beauty products that were contributing to the skin irritation. The process of overanalyzing my daily routines, helped solidify the need to advocate for my needs and listen to my body when it was unhappy.

Summary

My journey with celiac disease has had its ups and downs but has taught me to listen to my body and be confident in my needs and proud of the journey I have faced. Through my personal experience and research over the years, I have learned how to navigate the complexities of living gluten-free and the significant impact it can have on everyday life. While the gluten-free diet fad may be highlighted in today's society, for those of us with celiac disease, it's not just a choice but a

necessity for our health and well-being. Despite the challenges of managing this disease, from financial burdens to social complexities, I've learned to navigate these challenges and inspire others to listen to their bodies. By sharing my story, I hope to shed light on the realities of living with celiac disease and inspire others to advocate for their health, embrace self-care, and find strength in their journey toward wellness. Due to this personal experience, I have with celiac disease, I feel like I am better equipped to help counsel patients on the importance of diet and the corresponding challenges and successes to their health.

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