

My Journey with Celiac Disease: Living with an Invisible Condition



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Introduction: Life Changed by Celiac Disease

When I first learned I had celiac disease, I felt a mixture of relief and anxiety. Relief because I finally had an answer to the constant digestive issues, fatigue, and skin rashes I'd been dealing with for years. Anxiety because it meant making life-altering changes, most notably adopting a strict gluten-free diet. Like many people with celiac disease, my path to diagnosis was long and filled with confusion. But now, after years of living with this condition, I've learned not only how to manage it but also how to live a fulfilling life despite the challenges.

What Is Celiac Disease?

Celiac disease is a chronic autoimmune disorder that occurs when the body mounts an immune response to gluten, a protein found in wheat, barley, and rye. When someone with celiac disease eats gluten, their immune system attacks the lining of the small intestine, causing inflammation and damage. This impairs nutrient absorption and can lead to a host of symptoms, both physical and emotional. According to the Celiac Disease Foundation, it's estimated that 1 in 100 people worldwide have celiac disease, though many remain undiagnosed due to the broad range of symptoms (Celiac Disease Foundation, n.d.).

The Symptoms: A Hidden Struggle

The symptoms of celiac disease are often misunderstood or misdiagnosed, which is why I struggled with my health for so many years before receiving a diagnosis. Common symptoms include chronic diarrhea, abdominal bloating, weight loss, and fatigue (National Institutes of Health, 2021). But in my case, the signs were more subtle. I suffered from fatigue, joint pain, and recurring rashes on my skin, all initially attributed to other conditions. For some people, neurological symptoms like headaches and brain fog can also be common (Green & Cellier, 2007).

It wasn't until I began experiencing severe stomach cramps — and realized I couldn't eat a meal without feeling miserable — that I finally sought a diagnosis.

The Diagnosis: A Long Road to Answers

Getting diagnosed with celiac disease is not always straightforward. In my case, it took multiple visits to doctors and many tests before I finally got the answer. The process usually starts with blood tests to check for certain antibodies associated with the disease, such as tissue transglutaminase (tTG) antibodies (Rubio-Tapia et al., 2013). The gold standard for diagnosis, however, is an intestinal biopsy, where a small sample of the small intestine is taken to confirm damage caused by the immune response to gluten.

I was relieved to finally have an answer but also overwhelmed by the thought of living without gluten. The next hurdle was adjusting to life with a strict gluten-free diet, which remains the only known treatment.

The Gluten-Free Diet: A Lifeline and a Challenge

The gluten-free diet is the cornerstone of managing celiac disease. At first, it seemed like an impossible task. Gluten is in so many foods that it's easy to feel isolated when dining out or attending social events. However, over time, I've learned that living gluten-free is not just about avoiding foods containing wheat, barley, or rye. It's about becoming hyper-aware of hidden sources of gluten and managing cross-contamination risks.

I remember feeling both liberated and stressed when I first started shopping for gluten-free foods. On one hand, it felt great to find snacks and meals I could eat without fear. On the other, I had to read every label carefully and educate myself about what was safe. It wasn't just food I had to worry about—gluten can be found in medications, cosmetics, and even some cleaning products. I had to rethink everything I used daily, not just what I ate.

Navigating the Challenges: Beyond the Diet

Being a celiac patient isn't just about managing food choices. It's about navigating the challenges of living with a condition invisible to most people.

One of the hardest aspects of living with celiac disease is dealing with social situations. Whether it's a family gathering, a work event, or a night out with friends, there's always the risk of cross-contamination or being served food that isn't safe.

The emotional toll can also be significant. I've often felt like an outsider when others enjoy meals I can't have or when I've had to turn down invitations because I'm unsure about food safety. This constant vigilance can lead to feelings of frustration and isolation.

But over time, I've learned how to advocate for myself and find support through online communities and local celiac groups. These communities have been invaluable in helping me feel less alone.

Living Well with Celiac Disease: Tips for Success

Although the journey with celiac disease is challenging, I've found several strategies that have helped me live a happy, healthy life:

- **Plan Ahead:** Whether I'm traveling or attending a dinner party, I always bring my own food or contact the host in advance to discuss gluten-free options. Having a backup

plan reduces the anxiety that often accompanies social events.

- **Educate Myself:** The more I learn about gluten and its sources, the more confident I feel in managing my condition. Staying informed about new products and medical research has helped me feel empowered on my health journey.
- **Lean on Support:** Finding people who truly understand the struggles of living with celiac disease has been a game-changer. Support groups, both online and in person, have provided practical tips and emotional encouragement.
- **Focus on the Positive:** Instead of feeling restricted by the gluten-free diet, I focus on all the foods I can enjoy. There are so many delicious, nutritious options available, and I've learned to get creative in the kitchen.

Conclusion: Embracing a New Normal

Living with celiac disease is not easy, but it's also not the end of the world. It's about making a few adjustments, embracing a new lifestyle, and being proactive about your health. Though it requires careful attention and planning, the gluten-free lifestyle is essential for managing the disease and living a healthy, fulfilling life.

And with each day, I continue to learn how to balance my health with my happiness, knowing that I am in control of my well-being.

References

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Biography:

Dr. Ewa J. Kleczyk is a healthcare executive with extensive experience in healthcare research, analytics, and operations. She is a nationally recognized leader, published scholar, and Editor-in-Chief of the *Universal Journal of 21st Century Women's Entrepreneurship, Leadership, Technology & Publishing* (UJWEL). In addition, she is pursuing a Business Excellence Graduate Certificate at Columbia University, expanding her expertise in organizational leadership and innovation. Dr. Kleczyk is a frequent speaker at premier academic and industry forums, including the Pharmaceutical Marketing Sciences Association (PMSA), Intellus Worldwide, the WomenTech Global Conference, and Harvard's Conference on Business and Economics. Widely published in peer-reviewed journals and academic volumes, she also serves on multiple editorial boards across healthcare, economics, and leadership disciplines.

Committed to advancing education and equitable healthcare access, she co-founded the Kleczyk-Strout Foundation, which supports community initiatives through advocacy, mentorship, and outreach. She also contributes her leadership through service on nonprofit boards and community councils, and by engaging audiences via podcasts and public forums.

Her contributions have earned her numerous honors, including the Presidential Lifetime Achievement Award by President Joe

Biden, the WomenTech Data Science Award, and recognition among the Top 50 Women Leaders in Healthcare Technology. Originally from Wroclaw, Poland, Dr. Kleczyk earned her Ph.D. in Agricultural and Applied Economics from Virginia Tech and both her M.S. and B.A. degrees in Economics from the University of Maine.