



Restaurants and Relationships: Varied Experiences with Celiac Disease

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What is celiac disease?

Celiac disease is an autoimmune disorder that can occur in genetically predisposed people where the ingestion of gluten leads to damage in the small intestine. Celiac disease is “the most common genetically-induced food intolerance in the world” (Rivera, Assiri & Guandalini 2013).

The Celiac Experience

The complications related to celiac disease and gluten intolerance have become more visible in recent years, leading to largely inaccurate representations in the media.

During the summer, we conducted interviews for Professor Hillary Crane with people who either had celiac disease or gluten intolerance. It quickly became apparent that people experience celiac disease in vastly different ways.

There is no typical celiac experience.

Symptoms

There are common symptoms associated with celiac disease and gluten intolerance, including anxiety, depression, trouble concentrating (commonly described as “brain fog,”) chronic fatigue, various stomach and digestive problems, and headaches. Many experience some or all of these in varying degrees of severity.

Kurt: “I stopped eating gluten and 24 hours later I didn’t feel like that [constant fatigue] anymore . . . I was 30 years old when I went gluten free—I went from feeling like I was probably a little older than that to feeling like I was 17 again.”

Diana: “The urgent diarrhea thing makes it very difficult to be social and to go someplace with people who don’t understand why you spent 15-20 minutes in the bathroom ten minutes after you finish eating the meal.”

Nancy: She had been healthy her whole life but started losing weight during menopause, she took a bone density test, found that she had severe osteoporosis and began medication but it didn't help. She brought up celiac disease to her doctor who said she didn't think Nancy could have it because she was so healthy but the doctor ordered the blood work and was very surprised when she did have celiac.

Restaurant Experiences

When people with celiac disease/gluten allergies go out to eat or are invited to an event, they typically face challenges in regards to ordering, accepting food, and deciding whether or not to disclose their symptoms when eating gluten.

Helen: “We’re a real eating society and when we have communal events, we eat. For example, somebody having a birthday at work: there’s a birthday cake, and you can’t eat it...So, you know, you just don’t make a big deal out of it and I never bring it up.”

“I usually motion [the waiter] over to me. I don’t want to scream it across the table and you feel like...you’re seeking attention. It made me uncomfortable to have to talk about it in front of my table full of friends.”

Lukas: “My whole family...it’s not fun when I try to go out to eat with them...They’ll try to help me like ‘you can eat this. You can eat this. Yah or you can eat this this way.’”

Trudy: “I would say, ‘I can’t eat gluten’ and if they got a blank look on their face, I would say, ‘That means I can’t eat bread, pasta, sauces thickened with flour.’ . . . I would have to be specific about what they needed to avoid for me.”

Relationships

Romantic relationships can be difficult with and affected by celiac/gluten allergies. Some interviewees dealt with relationships ending due to their disease. People with celiac in relationships (as well as those looking for relationships) struggle with things such as figuring out how to share a kitchen space with a partner who can eat gluten, how to deal with intimacy, and where to go out to eat.

Barbara: “You’ll be out on a date with someone and they’ll get a beer, and you’re like, ‘Oh no,’ that’s basically like, ‘I can’t kiss you now because you have gluten all over you and in you.’ It’s just like another level of that you have to disclose way quickly all of these weird rules that you have.”

“...it limits you in ways that you don’t necessarily want to fully have a whole conversation about right after someone’s like, ‘Hey you wanna go on a date?’ or ‘Hey you wanna go get a drink?’ You don’t wanna be like, ‘Yes and I have these insane limitations in my life, do you wanna sign up for that shit?’”

Laura: “if your partner does not go gluten free, they can keep contaminating you during intimacy, just plain old kissing. Can you imagine how that would make a person feel? It makes for terrible self-esteem. I am divorced and I was in a committed relationship when I was diagnosed . . . But my boyfriend stuck with me for about eight months but it’s part of the reason he broke up with me I’m absolutely positive because it’s so horrible”


“Well me being a woman and my partner was a man, he actually is supposed to wash around his mouth area . . . to brush his teeth with gluten free toothpaste and floss his teeth with gluten free dental floss . . . and so it’s such a turn off for intimacy and romance and love, it just kills that. So that’s one of the things for sure that’s been the most upsetting to me.”



Conclusion

Media representations tend to oversimplify the experience of those who cannot eat gluten. This is an easy trap to fall into because other diseases are defined by a set of common symptoms but there are few universal symptoms associated with celiac disease. Almost everything is contradictory and no one has the same experience. People generally do not know what it is, because it is difficult to define a disease without a strict set of symptoms.

Celiac is an indefinable disease in terms of its social impact. The symptoms people experience, the ways people deal with restaurants, and personal relationships vary, making it an elusive disease. Our research broaden the understanding of celiac disease—though there is no common experience—and these narratives help combat the stereotypical media representation of celiac disease and gluten intolerance.



BRACE YOURSELF



THE GLUTEN IS COMING

AT A RESTAURANT

A man with dark hair, wearing a red polo shirt, is shown in a state of intense frustration. He is holding a small, white piece of paper (likely a menu) in his right hand, looking at it with a pained and angry expression. His eyes are squinted, and his mouth is open in a grimace. The background is a green chalkboard with faint, illegible handwriting. The overall scene is set in what appears to be a restaurant or dining area.

**SEARCHING FOR GLUTEN FREE VEGAN
ITEMS ON THE MENU**

YES, WE HAVE

A

"GLUTEN FREE" MENU



**I DON'T KNOW WHAT
GLUTEN IS**

**AND AT THIS POINT, I'M TOO
AFRAID TO ASK**

YOU CONTAIN GLUTEN!

2004

**AND YOU CONTAIN
GLUTEN!**

**AND YOU CONTAIN
GLUTEN!**

EVERYTHING HAS GLUTEN!

Works Cited

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- <https://i.imgur.com/R5fIKIW.png>
- Rivera, E., Assiri, A., & Guandalini, S. (2013). Celiac disease. *Oral Diseases*, 19, 635-641.