

Surviving Celiac Disease in a World Full of Gluten By Lindsay Neal

I am a real, live, diagnosed celiac. Celiac disease is an autoimmune disorder, not an allergy, or a sensitivity. This means that if I were to knowingly, or unknowingly eat gluten, or kiss my partner after he took a sip of beer, my small intestine would get damaged, and it could lead to some less-trendy health concerns in my future. These less-trendy health concerns range from rheumatoid arthritis to cancer. Celiac disease is not the fashionable diet that the world has romanticized through its cutting-edge weight loss effects. Whoever was surprised that cutting out breads, beer and cakes would cause weight loss, needs a serious reality check. Being celiac is not something that I can choose to forget and have a gluten-party; unless I am already dying in the hospital and choosing to euthanize myself by eating pastries and pasta (which I will do on my deathbed). Celiac disease is not a choice, because believe me, if I could choose to eat a donut, I would eat a donut. A diagnosed celiac who stops eating gluten, is on a quest for survival.

If you aren't already educated on what gluten really is, please take this opportunity to google it. I'll wait. I am not going to pretend to scientifically explain the properties of this mysterious protein, that is found in most things that make you smile, or taste like the fondest memories of your childhood. The internet will quickly reveal to you, that gluten lives inside of most foods that are processed or created by Italians or the French. The world wide web will then present to you several diets that are gluten free, and recipes that contain several types of flours, xanthan gum, and are also vegan. Because why cut out one important ingredient, when you could cut out three? Now that we are on the same page, we can agree, that removing gluten from your diet for fun, is pure insanity; and frankly insulting to those of us who cannot eat it due to wanting to survive an autoimmune condition.

Surviving celiac disease in a world full of gluten is a hellish nightmare; but not for the reasons you may assume. Social obligations make surviving celiac disease a painful ordeal, because of the pressure to eat things that are impossible to trust as being celiac friendly. Finding options to eat, is like finding hay in a haystack. The hard part is distinguishing which foods are gluten free for the fad dieters, versus which foods were manufactured in a celiac-safe, non-cross contaminated facility. As a celiac, seeing people eat gluten is not offensive. The offensive part is watching them eat something gluten free and being physically repulsed it. Living with gluten-eaters is not a challenge; the real challenge is cleaning up the crumbs that trail behind them, or teaching them to not double-dip their bread covered knife in the peanut butter jar.

Social events make surviving celiac disease a pain in the butt, because they force me to be a rude guest. As a well-educated, and prepared celiac, I am always ready, and happy to bring my own food to events. I still must be prepared to turn down every single gluten-free food that someone made, because they knew I would be there, and they couldn't handle me eating my own food, or drinking wine in the place of dinner. I must be prepared to be a pretentious a-hole. This is because, as sweet as it was for my friend, let's call her Lucy, to bake black bean brownies for me, I cannot trust her. This is not because Lucy cannot be trusted. It is because her cross-contaminated kitchen, her gluten-ridden brownie pan, her boyfriend who snacks on crackers in the same kitchen space while she baked them, and her crumb infested butter are not to be trusted. Her intentions are good, but her utensils are not. It is not the food at social events that I must endure, it is the people who insist I try their gluten free quiche. Disclaimer: My friends and family can attest that I put them through a lot of questioning and training before I consume their food. I am incredibly grateful for whoever tries to feed me, whether I eat their food or not.

There are countless options of celiac safe food to eat, almost anywhere. The tricky part is deciphering the “gluten free” labels on each of the products, to find which is legitimately celiac safe, versus which brand created their own symbol for “celiac certified” and is really full of sh*t (or I guess gluten in this case). Not all “certified gluten free” or “certified celiac safe” stamps are legitimate. Why? Because labeling something gluten free (even if it’s a banana) is like pasting Oprah’s face on it. It sells. For this reason, being current on the most up to date design of the Canadian Celiac Associations’ Celiac Certified symbol, as well as the American Certified symbol is very important. There are symbols out there that try to fool the untrained eye or attract the consumer who is avoiding gluten because Gwyneth Paltrow doesn’t eat it. Making the right choice on foods that claim to be celiac safe, is essential to survival. One cracker that claims to be celiac safe or gluten free, yet is produced in the same facility as Premium Plus crackers, and I am stuck on the toilet for the next month.

Watching others eat gluten is not heartbreaking, it is like watching someone eat an eraser. Sure, I ate a few erasers when I was a child, but I now know that is not good for me, nor is it appropriate or appealing when I think about the effects it will have on my system. The difficult part that nobody considers is watching your gluten-eating peers eat a gluten free product and watching them die a little with each bite. Surviving the judgement in someone’s eyes of your new standards in food is burdensome. Of course, my gluten free scone doesn’t live up to your standards, you are able to digest the most important ingredient in most baked goods, and therefore your scones probably wouldn’t put a hole through the wall if you threw them, nor would they taste like cement. Witnessing the avid gluten-eater encounter a hamburger bun that crumbles in their hands is like a slap in the face. It is a special type of degrading to see your favorite muffin rejected by someone who can still enjoy flour-filled muffins.

Cross contamination is no joke. The smallest crumb can wreak havoc on the small intestine, introduce a myriad of unbecoming immediate side effects, and invite in a variety of future health issues. But to the innocent person who makes a sandwich a day, and leaves a crumb or two on the countertop, these crumbs don’t even cross their minds. They are counter-top landmines, just waiting for my food to touch them, only to explode in my gut later. It is so hard to emphasize that something so modest in size, will create so much destruction for a celiac. Surviving a shared kitchen with a gluten-eater is a constant battlefield, and a great case for becoming obsessed with cleaning countertops or being extremely possessive of food. I not only clean the countertop before and after I use it, but I now am so possessive of food that I will either hide it, or refuse to share. When my partner makes toast, I am there waiting with a paper towel. When he spreads the peanut butter on his toast, he uses his own jar. Survival of the breakfast.

Survival as a celiac in a world full of gluten is not for the weak. You must question every label and person who prepares your food. You must adopt obsessive habits and (happily) abandon sharing. You must accept that rice flour will never measure up to white flour. Though eating gluten free is not a choice for me, I have chosen to make the best of it, and thrive. I have found recipes that not only taste good to me, but have blown gluten-eaters out of the water. I have found gluten free pizzas in towns that have only one grocery store (shout out to Mayo). I have rehearsed and performed my most polite way to turn down food, and my most dainty way to exit a party, while rushing to the nearest commode to hurl from cross contamination. Surviving all the inconveniences introduced by the gluten free fad has only made me better at surviving as a celiac. As Robert Service would say, the diagnosis exiled me at first, and I hated it like hell for a season. Over time I learned to persist, and survived for good reason.