

# Living with Celiac Disease

Category: Loss

written by Andrea Eisenberg | July 13, 2025

Two years ago, I received diagnosis that I'm still grieving from and struggling to accept. After an endoscopy and colonoscopy to determine the cause of my anemia at age sixty, I was told I had celiac disease. Somehow after sixty years, my gene for celiac was activated, and now I had to make drastic, lifelong changes.

Giving up gluten is a huge lifestyle change. It's the obvious things like sourdough bread and bagels, croissants and pastries, cookies and cakes. But it's also the not-so-obvious things: managing every minuscule amount of gluten entering my mouth. Gluten can be in lipstick, chapstick, toothpaste, soy sauce, licorice, salad dressings, barbecue sauce. Gluten-free pizza in a place that makes gluten pizza will be cross contaminated with the flour in the air and on the prepping surfaces. Gluten-free ice cream can be contaminated from a scoop used in cookies and cream. When a friend bakes me something that is gluten-free, I have to somehow politely decline, because their kitchen is not gluten-free. At restaurants, I have to trust that when I tell the waiter they have to change gloves and use a clean surface to prep my food, that they actually do it.

But the biggest losses are the ability to grab lunch spontaneously with a friend, to find a snack in an airport, to attend a wedding, or to gather around a table and share food. It requires constant vigilance to maintain food safety, food availability, and food awareness, not to mention the extra cost of gluten-free food. When I'm too tired or anxious about an upcoming dinner or party, it feels easier to say "no" than to plan ahead and figure out what I need to bring or make, and to monitor every second of the meal, so that someone else doesn't contaminate it with their fork that just had pasta on it, or drop gluten crumbs on my food as they grab some bread on the other side of the table. When I say "no," I miss that time with friends or family, and that's a loss to my heart.

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