

THEN AND NOW

How being newly diagnosed with celiac disease has changed since 1997

BY JENNIFER HARRIS

I CAN HARDLY BELIEVE it has been 20 years since my celiac disease diagnosis. If you had told me then that I would turn that life-altering diagnosis into a career as a writer, consultant and natural foods buyer, as well as an advocate for the gluten-free community, I never would have believed you. But somehow it happened. I managed to go from a state of feeling alone, overwhelmed and hungry to one of belonging, achievement and satisfaction, including a job that gives me as much joy today as it did back then.

After the initial shock subsided of being diagnosed with an autoimmune disease almost no one had ever heard, I learned how to feed myself safely—a journey filled with mistakes, inedible food and plenty of tears.

THINGS WERE DIFFERENT BACK THEN

Perhaps the most notable difference is that the medical community as a whole did not have much knowledge about celiac disease 20 years ago. It took an average of seven to 11 years to receive a celiac disease diagnosis. A great deal of uncertainty led to ingredient misinformation. For example,

at the time, vinegar-based products were considered unsafe, so I didn't eat pickles, salad dressing or ketchup for five years. The myth that envelope glue and stamps contained gluten was alive and well, and even most dietitians weren't particularly helpful.

In 1997, the Food Allergen Labeling and Consumer Protection Act (FALCPA) was still seven years away from being enacted. This act guarantees that if food contains wheat in any form—including any ingredient like modified food starch or hydrolyzed vegetable protein—the word "wheat" will appear on the label. No certification system such as the Gluten-Free Certification Organization existed, and very few items were labeled gluten free. Safeguards to hold manufacturers accountable for the allergen status of products didn't exist, either. For example, labels didn't list the source of food starch, cereals didn't identify barley as a byproduct of wheat, and there was no information about what was kept in the manufacturing facility or whether products were run on shared lines. One could only contact the manufacturer to obtain these answers. And no one was talking about the risk of cross-contamination.

Grocery stores offered, at best, a quarter of the gluten-free products on shelves today, and many of those products were subpar, to put it as diplomatically as possible. The selection of gluten-free products at health food stores was also limited because they didn't carry a lot of products with sugar or additives. Online shopping wasn't centralized, meaning gluten-free items had to be ordered directly from manufacturers, and typically that dictated paying exorbitant shipping costs for food that tasted only slightly better than cardboard.

Gluten-free bakeries were about as common as a purple unicorn, so baking had to be done at home. Gluten-free flour blends didn't exist, but rice flour was prevalent. My boyfriend (now husband) had a terrible time trying to bake me a cake doing a one-to-one flour substitution. No one knew how to use xanthan gum, making us dependent on the few available gluten-free cookbooks to figure out how much to use. Add too much xanthan, and the cookies wouldn't even spread when baking; too little, and they would disintegrate after just one bite.

After recognizing that I really didn't know how to cook, just how to boil and heat, I spent Saturdays going from health food store to health food store for ingredients, then home to cook and pack lunches for the week. I got very cozy with my George Foreman Grill and learned how to make cheese sauce, chop vegetables and prepare meals.

WHAT I ATE

I had a very regimented diet that consisted of key products like macaroni and cheese mix with the starchiest rice pasta ever, flimsy and tasteless brown-rice crackers, Lundberg rice cakes, lots of Amy's Kitchen's enchiladas, and Food For Life rice bread toasted and topped with peanut butter. Pamela's Products' chocolate chip and shortbread cookies were a bright spot in my day and remain a trusted brand. Fresh fruit, vegetables, rice and meat rounded out my daily caloric intake. Boring, but safe.

It wasn't until I found Kinnikinnick Foods, which only charged—and still charges—a flat \$10 shipping rate, that I discovered gluten-free bread could taste good without toasting. The company also offered waffles, doughnuts and many other tasty treats made in a dedicated facility for people with celiac disease.

WHERE TO TURN FOR HELP

I was pretty much the only person my local friends and family knew with celiac disease, so I was on my own. I didn't find a support group until 2003, and it turned my

whole life around. Just being with people who shared and understood my experiences was such a high. I joined the board of the support group and started getting active in the local and national community, scheduling speakers, attending events and coordinating gluten-free vendor fairs. I also started working as a buyer at a local health food store, then launched a blog and began freelance writing for local and national publications.

WHAT HAS CHANGED

If you had told me in 1997 that following a gluten-free diet would become a trend, I would have laughed in your face. But that is just what happened when celebrities began recommending that people try the gluten-free diet to lose weight, sleep better and feel more energized. Why anyone would choose to pay two to three times as much for a loaf of bread is beyond me.

Now, too, people who don't have celiac disease but benefit from a gluten-free diet are diagnosed with the relatively new condition called non-celiac gluten sensitivity. Of course, as you probably know, in spite of all the progress that has been made, misinformation abounds. People still mix up the terms "gluten intolerant" and "gluten sensitive," which describe two entirely different ailments. And while often referred to as an "allergen," gluten in fact triggers an autoimmune reaction, not the histamine response characteristic of allergies.

As a result of this "trendy fad diet" nonsense, servers at restaurants ask diners if they are gluten free by choice or for medical reasons. And manufacturers slap a gluten-free label on pretty much everything that is made with gluten-free ingredients, like canned corn and ketchup. Times are better, and yet somehow there is still much confusion.

FALCPA is in full effect, with manufacturers practically overcommunicating the allergen status of products. We are even seeing a return to natural products made without additives, artificial colors and flavors, and unnecessary fillers. And with the priority placed on gut health, products are now often fortified with nutrients such as protein, fiber and probiotics.

IT'S A LIFESTYLE, NOT A DIET

Pretty much any food product you can think of is probably available in a gluten-free version at any health food or grocery store in town—or ordered from online retailers like Amazon. In stark contrast to 1997, Atlanta alone boasts six gluten-free bakeries, four dedicated gluten-free restaurants and a slew of places to dine on gluten-free fare. Health food stores

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and even mainstream grocery stores label their gluten-free products with shelf tags, making it easier to quickly identify suitable items. That's right—for those of you who remember what it was like back then, today there is no need to shop only the perimeter of the store because aisles contain gluten-free products made by both start-ups and established companies. And believe it or not, prices have stayed about the same, but are beginning to increase as manufacturers search for organic sources of raw ingredients.

Product certification is at an all-time high, with national support groups leading the charge. The Gluten Intolerance Group and Beyond Celiac both offer product and restaurant certification programs with steadily growing clientele.

I dine out more now than I did before my diagnosis, and I have traveled across the states and abroad enjoying the most gorgeous and readily available gluten-free cuisine. The natural products industry is exploding with innovation that can be seen in categories across the board. Twenty years ago, the idea of a portable device that can identify gluten in food sounded like something from science fiction—and today, the first of its kind is making headlines for its impact on gluten-free living.

Celiac awareness is at an all-time high and diagnosis times have decreased. While it's not perfect, I will take an eye roll from a server over my gluten-free status any day over the blank stares of 20 years ago. However, the stigma attached to the gluten-free diet, courtesy of fad dieters, needs to fade away pronto.

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