



## Adapting to Change: What I Learned After the Diagnosis

Not long ago I didn't have to think much about food allergies: sending special snacks to school, checking labels obsessively, bringing one cupcake to a birthday party - these were things other families had to do, not ours. We have friends whose children have severe, life-threatening allergies, so we understood (at one level), their cause for caution and concern. My kids missed their peanut butter and jelly sandwiches when they couldn't bring them to school, but we adapted easily. It wasn't until I had my own increasing symptoms and diagnosis, that food ingredients took on a whole new, more personal meaning.

My symptoms were not particularly dramatic at first and I attributed most of them to being a busy mom. Fatigue and brain fog, primarily - most moms can relate to that! I had some bloating, but hey, that's normal too, right? When my son was in the toddler phase, I was sleeping, eating and exercising pretty well, but the sleepiness was getting intolerable and the lack of focus and poor memory was frustrating. I saw a holistic nutritionist and chiropractor and my doctor. I learned a lot, but no one put all the pieces together. Probably, because I didn't recognize and describe enough of my symptoms. Moms out there, did you know that you should see your doctor if you are bloated for more than 2 weeks? I learned it can be a symptom of ovarian cancer - scary! After nurse relatives confirmed my belly did not look normal. "See what my stomach looks like at night? I think it might be related to wheat..." "Don't stick your stomach out." "I'm not!" They urged me to see my PCP right away, who ordered ultrasounds, blood tests, and then an endoscopy.

I now have celiac disease. This is actually an autoimmune disorder, not an allergy, however, like an allergy, my body can't tolerate a common ingredient in many foods. It was most likely triggered by the stress of my second pregnancy (and the adjustment to two children!) and I now need to go to great lengths to avoid gluten, a protein found in wheat, barley and



rye. The disease can take many years to diagnose due to the variety of symptoms. In fact 1-3 percent of the population has celiac disease, but 97% of those people do not know they have it! After seeing several traditional and non-traditional practitioners over the course of a year, I finally had an answer. I could never eat foods with gluten if I wanted to avoid serious symptoms, malnutrition (caused by damage to the intestines resulting in malabsorption of nutrients), and the increased possibility of cancer.

My husband and I knew we needed to test our kids since it is a genetic disorder that can be present even without symptoms. However, the testing for celiac disease can be complicated and we were unsure of how to proceed with their nutrition for awhile. As it turns out, they don't have celiac disease now. I feel so fortunate that we only had a few months with our kids on a gluten-free diet - it was not easy! It takes effort and a more expensive grocery bill to accommodate special foods! I definitely have a new appreciation for families whose children have allergies...especially with multiple ingredients to avoid. As for now, my children can go back to having graham crackers and goldfish at school or pizza and cake at a party, although we do limit gluten and will test them regularly. My husband thought it might be easier for our kids to go "gluten-free" than for me, because "it's all they will know". I disagree. It's hard to be different than your peers and not be able to participate in childhood social events in the same way- but its hard for me too!

When it is just me, I feel a bit selfish. It is not a life-or death allergy, my kids are healthy and I don't have a terminal illness. I "shouldn't" have anything to complain about, right? Well, I do value recognizing and owning our feelings, rather than denying them. In any situation, we can always find those less fortunate with whom to compare ourselves, but in order to be truly authentic, I needed to process, own and then keep moving through my feelings.



As I went through the process of adjusting to a life-long change and a new way of shopping, cooking, and eating, the five stages of grief developed by Elizabeth Kubler-Ross kept popping into my head. You know the ones. They've even been used in sitcoms and SNL like skits and are well known and applied to all kinds of situations. Well, they seemed to fit for me, even if it wasn't the original intent of the stages. Perhaps you'll see yourself in these if you are adjusting to a life change.

**Denial:** I knew acquaintances who had celiac, but didn't think I would have an actual diagnosis. Even months later, I thought the tests must have been wrong. It just couldn't be that I could never have many of my favorite foods again! However, the longer I was away from gluten, the more obvious the symptoms became. It was confirmed for me when I had about 1/2 cup of regular pasta by accident. I thought all the spaghetti in the fridge was gluten-free and added it to my chicken parmesan with GF bread crumbs. By the end of the meal, my husband asked, "what have you been eating, because you've said about five of the wrong words?" (we determined that was another symptom - my brain really doesn't work properly when I have gluten). "Well, I haven't eaten gluten in months, so it must just be 'mommy brain'".

That night, I was so sleepy, I went to bed about an hour after dinner, the next morning I looked like I was 5 months pregnant, and 24 hours later the joint pain in my shoulders and hands kicked in. Yep, that's my reaction to gluten. We figured out there was regular pasta in the fridge from a night I worked late and they had "gluten-full" spaghetti. I had grabbed it unknowingly and suffered the consequences! Now it is sinking in...it is not even psychosomatic.

**Anger:** "OK, this is just beyond ironic and not fair!" As a teenager I had struggled with an eating disorder and so much of my recovery involved having "no forbidden foods". I felt that I had made peace with food and the ideas of "moderation" and letting go of the "all or nothing thinking" continue to be helpful for so many women I see in my therapy practice



who struggle with eating issues. This is just ridiculous. I don't even want to "cheat" or I'll suffer for days after. The worst is when I am trying so hard and a crumb in the silverware drawer or a new vitamin I forgot to check brings on symptoms. Sometimes I never figure out the culprit.

In rebellion (during the early days after a frustrating tour of the grocery store), I bought Twizzlers. Yes, red dye, corn syrup and everything I knew wasn't the healthiest, and I didn't even check the label. True story - I didn't realize until days later that they contain wheat. Flour is the second ingredient - who knew?

**Bargaining:** Fine, I'll do this gluten-free thing for awhile, and maybe it will cure itself..I'm still not sure it can actually be an auto-immune disorder. The tests weren't completely thorough and maybe they were wrong. Maybe if I get more medical opinions...there are treatments out there that can cure allergies, right?

To be honest, I couldn't seriously stay in this phase long. If bargaining worked and I did have ovarian cancer, I would have traded that for celiac disease in a heartbeat. If given the chance I would take upon myself any illness that my children could possibly have. So there you have it, I would have chosen my current fate over many other options.

**Depression:** I've definitely had my share of pity-parties. This especially happens while grocery shopping when I calculate about 75% of the foods probably contain gluten, even in trace amounts. If you have never checked labels for the common allergens, you would be surprised! If you have, you know nuts, dairy and soy are everywhere too. Today I wanted dried cherries....too bad they were processed in a factory with wheat! In the past I've almost had a crying meltdown before a dinner party- what could I possibly eat in someone else's home without feeling high-maintenance or bringing my own food? I never fell into a deep depression, but there are moments of sadness as things keep sinking in. Little things like not being able to have the pretzel my son offers from his



plate, never being able to have a girl scout cookie from my daughter's brownie troop, or needing to make special birthday cakes for the family if I want to participate.

**Acceptance.** In my life and in my work with clients, this concept has become so powerful to me. Sometimes it feels like "radical acceptance": why would we want to accept something negative? It seems we are taught to fight or avoid what we don't like in our lives. I'm realizing it is often our resistance that brings us suffering, and it is only through acceptance that we can find peace. When we start accepting "what is", we can move on instead of staying stuck in the other stages. This process of grieving an "old life" and adjusting to a new way of being is an ongoing one. There are still times it hits me. "Oh..that is another food I can never have." As I learned in a seminar years ago, sometimes we re-cycle through those stages in waves.

Most days I try to recognize all the wonderful foods I can eat. This is a perspective shift I can choose daily. When I look at foods found in nature, I have tons of delicious choices to enjoy. Fortunately for anyone with gluten intolerance or food allergies, we live in a time with many alternatives and better food labels. I am starting to experiment more with "G-free" baking, I will bring my own cones to our favorite ice cream stand again this summer, and my supportive husband just moved the silverware drawer away from the gluten toaster oven (yes, we have two!)

Michelle Wilson, MA, LMHC is a psychotherapist and life coach in private practice in Andover, MA. She's grateful her husband enjoys cooking and she treasures hugs and kisses from her kids even with gluten-covered fingers or faces. Michelle has over 15 years experience helping women reach their goals and create a life they love and is the founder of Inner Oasis Counseling and Coaching. She enjoys working individually with women to help them manage stress and find more calm and joy in their lives as well as workshops, retreats and teleclasses on her MOM OASIS principles for women around the world. She is also trained to lead workshops based on the highly acclaimed book by Abby Seixas, "Finding the Deep River Within: A woman's Guide to Recovering Balance and Meaning in Everyday Life". Please visit [www.InnerOasisCounseling.com](http://www.InnerOasisCounseling.com) or [www.TheMomOasis.com](http://www.TheMomOasis.com) for more information and FREE RESOURCES to create more peace and joy in YOUR life!

