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I'm Not Crazy After All

I recognize the familiar cramping in my stomach and lower back. Waves of intense pain warn me that I have a few minutes to find a washroom. A few hours later depression overtakes me and I sink into a dark mood. I believe that my life is falling apart, that I am destined for failure, that there is no point in living. My stomach bloats and hardens; I feel nine months pregnant. I cannot keep my eyes open. I fall into bed. Exhaustion overwhelms me, yet it's just after three p.m. I fall asleep, longing for relief. I want to sleep through until morning, but my children wake me, hungry for dinner. I struggle to find the energy to make soup, clean up the dishes, help with homework, and tuck my daughters into bed.

The next morning, I awake before the alarm clock rings at six a.m. My head is no longer in a fog. The early morning sun peaks through the slats of the blind and I smile, anticipating a beautiful day. I can think clearly again. I run my hand over my flat stomach. As I make coffee I look back at my diet over the past thirty-six hours to try and determine what caused this attack. I knew the chicken salad was safe. So was the rice bread and peanut butter. What about the red licorice Nibs? I ate a few of those with my daughter while we watched a movie. I pull the bag from the pantry and read the label. The third ingredient listed is flour. One of my enemies.

This attack lasted less than twelve hours, but I had suffered these symptoms daily for over three years. My life became unmanageable. I wanted to exercise, but didn't have

the energy. I wanted to walk, but I had to be close to a washroom. I wanted to lose weight but I was always hungry. Work exhausted me. Even emptying the dishwasher or doing a load of laundry felt like climbing Mt. Everest. Much of the time I believed I lacked the will power to get well again. I was sick of being sick.

I visited the doctor every few months, complaining about the fifty pounds that I gained in a short period of time, the pain in my feet when I walked, the chronic diarrhea, the depression, and the fatigue. He advised that the weight gain put added pressure on the feet. “Lose the weight,” he said. “But I’m tired all the time,” I told him. He prescribed iron for the anemia and Zoloft for the depression.

I consulted an alternative doctor. He said that antidepressants might have affected the lining of my lower intestine, causing a sieve-like reaction to food. He offered a natural remedy to heal the damage. Yet my problems continued. Words like hypothyroidism, irritable bowel syndrome, anemia, and depression swirled around me for years.

I managed to continue my studies at the University of British Columbia, operate my bed and breakfast, write a food column for a local paper, and take care of my two daughters. Each day I struggled to survive. I forgot what life was like without exhaustion and diarrhea. By the end of the school term, I thought about stepping in front of a truck. If I was to live like this for the rest of my life, what was the point?

On a warm day in May, I interviewed my cousin, Lawrence Sawatzky. He and his wife Lori had just opened Emily’s Edibles, a gluten-free bakery, and I thought their story worthy for my readers. “Thirteen years ago, I was a skeleton,” he said. “I was technically dying from malnutrition and no one, not even the top specialists at Vancouver General

Hospital, knew what was wrong.” Lawrence listed his symptoms – fatigue, depression, fog, bloating, rapid weight loss, rash of white dots on his knees, and diarrhea – and each word resonated with me as I wrote it down.

Lawrence had undergone a small intestinal biopsy in which a fibre-optic tube, called an endoscope, was inserted in his mouth, down his throat, through his stomach and into the upper part of his small intestine to take tissue samples. Doctors found that the millions of finger-like projections on his intestinal wall, called “villi”, which absorb nutrients, were destroyed by gluten, the surface area reduced to a fraction of that of a healthy intestine. To visualize the damage think of changing a shag rug into linoleum. His gut could absorb only five percent of the nutrients, proteins, fats, carbohydrates, vitamins and minerals that he ingested. The rest he eliminated. Doctors told Lawrence he had celiac disease. Unlike a wheat allergy, which can cause sneezing and skin problems, celiac disease, caused by an intolerance to gluten, is not an allergy, but a hereditary, autoimmune disease. Lawrence carries a gene that mistakenly identifies gluten proteins as bacteria-like invaders. Celiac disease is incurable.

Lawrence required no drugs. He experienced a miracle cure by simply cutting out the gluten. He changed his eating habits. No more wheat, barley, rye, or oats. No more crackers, rice krispies, hamburger buns, pretzels, pre-shredded cheese, commercial salad dressings, icing sugar, baking soda, dry roasted peanuts, deli meats, beer, hot cocoa mixes, noodles, croutons, lasagne, muffins, whole wheat flour, soy sauce, and a host of other glutinous products.

Within days of eliminating gluten from his diet, Lawrence felt better. He eventually gained back the seventy pounds he had lost. All his symptoms disappeared.

I digested this information. I had never thought that what has been touted as the “staff of life” could be the source of my suffering but I made my next meal, and all those that followed, gluten-free. During the first few days my diet consisted of rice pasta, salads with lemon juice and olive oil, grilled fish and chicken, fresh fruit, and no gluten. Two weeks later, I marveled at my restored health. I walked for miles, I didn’t need to nap in the afternoon, and I ate without bloating. Here I had spent thousand of dollars to get well and all I needed was a diet change. I felt reborn.

When I told my doctor my findings, he said “Good for you for figuring it out.” I based my self-diagnosis on the fact that I felt good when I didn’t eat gluten and I was sick when I did. But I don’t know definitively if I am celiac because I haven’t undergone the invasive “gold standard” intestinal biopsy. Nor have I had the blood tests for gluten sensitivity: Endomysial Antibodies and Anti-Gliadin Antibodies (AGA) or the Tissue Transglutaminase (TTG). Unfortunately, because I now avoid gluten grains, these tests would be negative even if I am gluten intolerant.

In my desire to learn about gluten intolerance and celiac disease, I attended a seminar by Dr. Arjuna Veeravagu, a naturopathic physician and founder of Sage Clinic in Vancouver. His interest lies in the condition of non-celiac gluten intolerance. He pointed out that a person does not go from perfect health to end-stage celiac overnight, but as far as the medical community is concerned, outside of the celiac definition – originally identified and described by Dr. Samuel Cree in 1888 as a disease of malabsorption – there is nothing else. Blood tests are only accurate for those with end-stage intestinal damage, so those with mild to moderate gluten intolerance are missed. “Gluten intolerance describes the overall condition,” he said, “Celiac is just a small subset of

gluten-induced damage. Are the only people with heart disease those who have heart attacks?”

Dr. Veeravagu recommends non-invasive tests such as the new stool and saliva tests, which are far less invasive and expensive than a biopsy. A saliva test can detect all forms of gluten intolerance, although the longer one avoids gluten the less accurate the test becomes. I haven't taken the saliva test. If I ingest gluten I know it and that's enough of a test for me.

While my self-diagnosis took three years, the average diagnosis of gluten intolerance or celiac disease in Canada takes eleven years. Some people live a lifetime without relief. If I lived in Italy, where doctors screen children on a regular basis, and the awareness is much greater, I would have been diagnosed within three weeks of first visiting a doctor.

Lawrence and I are not the only ones to suffer intolerance to gluten. Far from being a rare problem, gluten intolerance is a common condition, affecting a significant proportion of the population. Recent research puts the figure as high as one in every thirty-three people. Yet most of these people don't know they have it. Many people just don't feel well or their doctors, many of whom are unfamiliar with the disease, misdiagnose them and it is this undiagnosed intolerance to gluten that can become the root cause of many cancers and chronic pain. In their book, *Dangerous Grains*, Drs. James Braly and Ron Hoggan say that intolerance to gluten is associated with over 150 diseases and symptoms, including Crohn's disease, colitis, learning difficulties, bone and muscle “growing pains”, hives, lethargy, infertility, miscarriage, epilepsy, insulin-dependent diabetes, inability to concentrate, coldness, clumsiness, recurring middle-ear

disease, short stature, nosebleeds, bed-wetting, autism, and migraines. Doctors prescribe antibiotics or drugs for these symptoms, but they never address the fundamental cause – food – and the cycle perpetuates. As for diagnosing celiac or gluten intolerance, many doctors still define the disease by Dr. Cree’s identifying features of a body wasting away. For years doctors have told patients that celiac disease was rare, affecting one in ten thousand people. Perhaps, if I had appeared to my doctor as skinny and pale, complaining of abdominal ailments, he might have been suspicious. Instead, I am overweight, like many gluten intolerant people today. The truth is that the range and variability of symptoms differs with each individual and, because of its diverse nature, gluten intolerance is the leading misdiagnosed or underdiagnosed disease in Canada.

I suspect that I have been gluten intolerant since childhood. I slept through most of my high school classes and wondered why I always seemed to get food poisoning when no one else did. Then, for years, I would be symptom free, only to have the symptoms return without warning. Research shows that trigger events can cause gluten intolerance to manifest, sometimes overnight. I experienced several stressful triggers in a short period of time: a move, a divorce, surgery, a car accident, and the death of a loved one. Any one of these could have contributed to my most recent onset of gluten intolerance. The events themselves were enough to make me feel as if I was going crazy, without the physical manifestations of pain and discomfort.

I have been gluten-free for three years now. When colleagues and friends learn about my dietary restrictions, the most common response is pity. “No chocolate cake, no pizza, no beer,” they say. “That must be difficult.” I agree that it is, but I live a full life without gluten. I cannot count on my friends or family to operate a gluten-free kitchen

and office party planners don't take my needs into consideration. So I plan my meals ahead of time and bring along my own food. I patronize restaurants where I can enjoy gluten-free food or I ask the waiters to query the kitchen about ingredients. I am not yet sufficiently diligent in reading the label of every bag I open, every can I buy, or asking what's in every bite I take. I also worry about cross-contamination. I have my own toaster, butter, and jam, for my rice bread, but my kids still don't fully realize the consequences of dipping their knife in the butter, on their whole wheat bread, and then into my jam. One half of the counter is mine for chopping, one half for them, but the boundaries are still new and as careful as we all try to be, crumbs and residue transfer to the gluten-free food.

For support, I joined the Canadian Celiac Association. Their monthly newsletters include information such as the latest research, anecdotal stories told by celiacs, and safe food products. Dr. Veeravagu now offers a support group for gluten intolerant people, whether celiac or not.

But, some days I still crave a cinnamon bun, made without rice flour. I long to pull apart the sticky dough and savour every mouthful, allowing the fluffiness that comes from gluten to melt on my tongue. I dream of a Boston Crème donut. A bagel with cream cheese and lox. Macaroni and cheese. Seafood lasagne. Apple pie. Turkey stuffing. But I won't indulge because I don't want to waste one more day of my life close to a toilet, in bed, or under a cloud of depression. I will make mistakes, perhaps out of habit, like licking the seal of an envelope, swallowing a vitamin, or brushing my teeth, before I realize that gluten shows up in trace amounts in hidden and surprising forms. By living a

healthy gluten free life, I believe that I will enjoy a long life span and make up for the years I thought I was going crazy.