

# Celiac Disease: Giving You the *Key* to Better Health

By Danna Korn

*At first, a diagnosis of celiac disease can be daunting (to say the least) and for some people, even devastating. It means giving up some of your favorite foods—pasta, bread, pizza, cakes, cookies, and pretzels—at least as you know them now. So why should you consider yourself lucky if you’ve been diagnosed with celiac disease? Because you’ve been given the key to better health.*

When our first child, Tyler, was born, he was perfection and miracle all wrapped up in an adorable little bundle, as all babies are. My husband and I never would have dreamed that our son was anything but perfectly healthy. Yet at about nine months old, he began to get sick—very sick—and we had no clue that the food we were feeding him was the cause.

We now know that our son has *celiac disease*, or a genetic intolerance to gluten (which is found in wheat, rye, and barley). Yet most people who have celiac disease aren't as lucky as our son. Hold on—he has a chronic disease that he'll never outgrow and we call him lucky? Absolutely. His health has been fully restored by dietary changes alone—no drugs, no surgery, no ongoing doctor's visits. Most people who have celiac disease suffer a torment of poor health for years, if not for their entire lives, because they've never been diagnosed. They don't have the key to better health: a gluten-free diet.

Our story began when Tyler developed more than just a touch of diarrhea at about nine months of age—not coincidentally, that was about the time we began to introduce solid foods such as crackers and cereal into his diet. Doctors attributed his condition to the antibiotics he was taking for ear infections, too much apple juice, teething, and the fact that babies get diarrhea. ”

When time was up on our allotted four-minute visit to a pediatrician, we were told to load him up on crackers, bread, and other starchy foods that would plug him up. We had no idea at the time that the prescribed dietary recommendations would just end up making him sicker.

Nine months and three pediatricians later, we were still being told that there was nothing wrong with our son. Yet the diarrhea continued, his belly had grown extremely distended due to malabsorption, and his disposition had changed from that of an easygoing, good-natured baby to an irritable, clingy toddler. Finally, he was referred to a pediatric gastroenterologist who, after testing for cystic fibrosis, blood diseases, cancer, and various other grave conditions, gave us the bittersweet diagnosis: “your son has celiac disease.”

### ***What is celiac disease?***

That’s what we asked. Having never heard of it, we were especially stunned that our son had this condition when we learned that it’s genetic. Celiac disease is the most common genetic condition of humankind<sup>1</sup>, yet few people have heard of it, and most people who have it don’t know it. Doctors often misdiagnose it as being irritable bowel syndrome, fibromyalgia, chronic fatigue syndrome, or any number of other conditions. Sadly, people who are misdiagnosed or undiagnosed are at great risk of developing severe complications and serious associated conditions. For every one person diagnosed with celiac disease, 90 will go undiagnosed<sup>2</sup>.

The beauty of this condition is that it’s fully treatable by dietary modification. Celiac disease, also known as *sprue*, is a genetic intolerance to gluten. When gluten is completely eliminated from the diet, health is fully restored, and the risk of complications and associated conditions is reduced.

While classic symptoms are generally gastrointestinal in nature (bloating, gas, diarrhea, constipation, weight loss/gain), most people have extra-intestinal symptoms, feeling only mild

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<sup>1</sup> *Gastroenterology and Endoscopy News*, September 2002

<sup>2</sup> [www.celiaccenter.org](http://www.celiaccenter.org)

signs, such as fatigue, headaches, irritability, or a lack of ability to concentrate. These symptoms, along with others such as infertility (or inability to maintain pregnancy), autoimmune conditions (such as Type-1 diabetes and autoimmune thyroid disease), joint and muscle pain, early onset osteoporosis, Down syndrome, lactose intolerance, and short stature are considered by most experts to be red flags that celiac disease may be present, and may therefore be considered justification for testing.

If celiacs continue to ingest gluten, their risk for associated conditions increases dramatically. Furthermore, while eating gluten, their bodies are not properly absorbing important nutrients such as iron, calcium, folic acid, and other vitamins and minerals, and they can become malnourished—circumstances that can have serious long-term health consequences. That's why early diagnosis is so important.

### ***A Rare Condition? Not At All!***

Since few people have heard of celiac disease, it's thought to be rare. But researchers are finding that this couldn't be further from the truth. Recent studies indicate that as many as 1 in 133 people—that's millions of Americans—has celiac disease<sup>3</sup>, yet for every person diagnosed with the condition, 90 go undiagnosed<sup>4</sup>.

### ***Why Isn't It Diagnosed More Often?***

In all fairness, it's difficult to diagnose a condition that has symptoms as widely varied as celiac disease. While classic symptoms include diarrhea, weight loss, anemia, and lethargy, some people have very different indications of the disease: constipation, vomiting, inability to concentrate, low bone density, headaches, lack of dental enamel formation, or infertility, to name just a few.

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<sup>3</sup> Archives of Internal Medicine, 2/10/03

<sup>4</sup> [www.celiaccenter.org](http://www.celiaccenter.org)

Another reason the diagnosis is often missed is because awareness, even in the medical community, is lacking. Very little time is spent in most medical schools discussing the condition, and what *is* discussed is often out of date, portraying the condition as being extremely rare, found only in children, and present only if classic symptoms exist—all inaccurate information.

Until a few years ago, the diagnosis was invasive and expensive, relying only on intestinal biopsies that showed specific damage to the lining of the small intestine. While biopsies are still required for a positive confirmation of the condition, today there is a simple blood test that can screen for antibodies that strongly suggest the presence of celiac disease.

### ***Fact vs. Fiction***

Another reason that celiac isn't diagnosed more often is because it is so misunderstood. There are many inaccurate perceptions about celiac disease, including:

**Myth:** Gastrointestinal symptoms are the most common indicators of celiac disease.

**Truth:** Classic symptoms of celiac disease *are* gastrointestinal in nature, but a majority of people suffer from non-specific symptoms, such as fatigue, headaches, infertility, joint or muscle pain, early onset osteoporosis, and myriad other symptoms.

**Myth:** Celiac disease is found only in children.

**Truth:** Celiac disease may present itself at any age, commonly being diagnosed among people in their 50s.

**Myth:** Kids outgrow celiac disease.

**Truth:** While symptoms may come and go, the celiac condition is lifelong.

**Myth:** Celiac disease results from eating too much gluten (or too many potatoes, or whatever the myth du jour may be).

**Truth:** Celiac disease is a disorder with very strong genetic susceptibility. It may have environmental triggers, but eating certain foods does not cause celiac disease.

**Myth:** The gluten-free diet lacks nutrients, so people are better off continuing to eat it, thus ensuring that their diets are balanced.

**Truth:** The gluten-free diet is very healthy. Many people tend to over-restrict themselves, eating only rice and potatoes, which are not terribly nutritious. It's important to eat a variety of foods, and to include whole grains such as brown rice or quinoa.

### ***The Gluten-Free Diet***

To many embarking upon the gluten-free lifestyle, it seems at first to be nearly impossible. After all, the American diet is loaded with breads, cookies, cakes, pizzas, pastas, and other gluten-laden goodies. But with a little bit of homework, it becomes apparent that the list of things you *can* eat on a gluten-free diet is a lot longer than the list of things you *can't*.

Meat, poultry, fish, and fresh vegetables are staples of the gluten-free diet. Rice, potatoes, and corn provide the carbohydrates that at first seem to be so difficult to get, and interesting grain alternatives such as quinoa, amaranth, and buckwheat are nutritional, delicious gluten-free alternatives. These days there are a variety of online resources with gluten-free mixes for cakes, cookies, and other treats once unavailable in the gluten-free world.

The gluten-free diet is extremely healthy, and is even found to be useful in treating people with a variety of conditions other than celiac disease. Some people, for instance, are simply gluten intolerant, without actually having the autoimmune disease. One of the newest and most exciting areas of research concerns autistic children, who in many cases show dramatic improvement when put on a gluten-free/casein-free diet.

### ***What To Do If You Suspect You Have Celiac Disease***

You most definitely should be tested, which means seeing a doctor who can order the appropriate tests. You'll need to educate yourself about the condition, and be prepared for your doctor's visit by keeping track of your symptoms, including the less-classic ones. Arm yourself with facts and information by visiting Websites such as [www.celiac.com](http://www.celiac.com) or [www.niddk.nih.gov](http://www.niddk.nih.gov). Sometimes physicians are reluctant to test for celiac disease, but be prepared to persist and insist.

The first step in testing for celiac disease is a blood test that looks for the antibodies that are usually present in this disease. The blood can be drawn at any lab, but it should be done by a lab that specializes in celiac disease, or one that at least has extensive experience with celiac disease testing, since the incidence of false negatives by labs inexperienced with the test is significant. For celiac testing to be accurate, you must be on a gluten-*containing* diet.

Ideally, the lab will do at least two blood tests:

- IgA EMA (anti-endomysial antibody)
- IgA tTG (anti-tissue transglutaminase)

EMA and tTG are antibodies that are produced when gluten is ingested by someone with celiac disease. They're very specific to the condition, which is why they are such valuable tests in screening for celiac disease. Doctors sometimes test for the presence of antigliadin (AGA) IgA and IgG, but because they're less specific to celiac disease (and can therefore be present in people who do not have the condition), these are much less valuable in detecting celiac disease than EMA and tTG.

If disease is still suspected, and the antibody tests above are normal, then the laboratory should test for the serum IgA level (this is to determine if you're IgA-deficient, which would lead to a false negative on the IgA EMA and anti tTG tests).

If the blood test is positive, you should have an intestinal biopsy done. Celiac disease causes specific damage to the villi on the lining of the small intestine, and that damage is only

definitively characterized by a biopsy done through an endoscopy. The damage from celiac disease can be spotty, so it's important that several biopsy samples are taken, and sent to a pathologist knowledgeable about the varying degrees of damage that can be classified as resulting from celiac disease.

A genetic test now widely available to the public through Prometheus Laboratories is helpful in ruling out celiac disease. The test identifies patients with a set of human leukocyte antigens (HLAs) called DQ2 and DQ8. Some people have these HLA types and do not develop celiac disease. The test is most valuable in excluding celiac disease in at-risk people, including family members and patients with autoimmune disease. There is a greater-than 99% *negative* predictive value<sup>5</sup> with these tests, meaning that if someone does not have DQ2/DQ8 alleles, they will not develop celiac disease.

***If you are diagnosed with celiac disease, remember that while it can be difficult to embark upon a gluten-free lifestyle, it's important to be diligent about sticking to the diet. Most important, remember that you're fortunate to have the diagnosis. You've been given the key to better health!***

This article has been reviewed by Martin Kagnoff, M.D.; Professor of Medicine, University of California at San Diego; member of the American Gastroenterology Association.

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<sup>5</sup> Kaukinen K, Partanen J, Maki M, et al. HLA-DQ typing in the diagnosis of celiac disease. *Am J Gastroenterol*, 2002; 97(3):695-9.