



# The Health and Social Impact of Celiac Disease

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“Breaking bread” represents community and connection, gathering with family and friends around the table. Whether a crusty accompaniment to soup, the crunchy crust of fried chicken, cakes and cookies or the foundation of pizza and sandwiches, bread—and gluten—can be unavoidable. That makes the need to avoid gluten in all forms all the more difficult and isolating. In addition to the health concerns for those living with celiac disease, dietary restrictions can make gatherings feel exclusive and possibly risky.

## What is Celiac Disease?

Celiac disease is a genetic, autoimmune disease where the ingestion of gluten leads to symptoms and damage of the small intestine. Gluten is the protein in wheat, rye and barley that allows bread to rise and stretch. However, with celiac disease, gluten causes the body’s immune system to attack the small intestine. Over time, this damage can prevent the small intestine from absorbing nutrients, as well as increasing the risk for coronary artery disease and bowel cancers. It can even lead to other serious conditions like multiple sclerosis, type 1 diabetes, osteoporosis, infertility and epilepsy.<sup>1</sup>

The specific cause of celiac disease is unknown, but doctors have identified a genetic component, meaning an individual must have certain genes to develop the disease. Even then, only a small percentage of those with the genes develop celiac disease.<sup>2</sup>

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*Those with an immediate family member with celiac disease have an estimated 1 in 10 risk of also developing it.*

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It is commonly estimated that globally 1 in 100 people live with celiac disease, though it is commonly confused with or misdiagnosed as other conditions. This misunderstanding could mean as many as 2.5 million Americans are undiagnosed.<sup>3</sup>

In addition to the genetic cause, researchers from the New York University School of Medicine may have found an environmental link that can cause those with the celiac-related genes to develop the disease. They published a small pilot study that tied elevated blood levels of toxic chemicals found in pesticides, nonstick cookware, and fire retardants to an increased risk for celiac disease in young people.<sup>4</sup>

## Symptoms, Diagnosis and Treatment

Celiac disease can cause both digestive and non-digestive symptoms. Digestive symptoms include diarrhea, fatigue, weight loss, bloating, gas, abdominal pain, nausea, vomiting and constipation. Most adults with celiac disease also have non-digestive symptoms which can range from joint pain and headaches to anemia, fatigue and skin rash. Children with celiac disease are more likely than adults to have digestive symptoms, and the inability to properly absorb nutrients can cause additional problems like irritability, slow growth and neurological symptoms.<sup>5</sup>

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<sup>1</sup> [Celiac Disease Foundation](#), “What is Celiac Disease?”

<sup>2</sup> [American Academy of Allergy, Asthma & Immunology](#), “Celiac Disease, Non-Celiac Gluten Sensitivity, and Food Allergy: How are they Different?”

<sup>3</sup> [Celiac Disease Foundation](#), “What is Celiac Disease?”

<sup>4</sup> [Eureka Alert](#), “Celiac Disease Linked to Common Chemical Pollutants”

<sup>5</sup> [Mayo Clinic](#), “Celiac Disease”

A celiac disease diagnosis can be confirmed through a blood test or endoscopy. The blood test will look for certain antibodies or the genes associated with celiac disease. An endoscopy involves using a tiny camera to inspect the small intestine and taking a sample to check for damage. Since celiac disease is hereditary, family history is important for diagnosis as well.

Sometimes someone will experience the symptoms of celiac disease but have these tests come back normal. In this case, it could be non-celiac gluten sensitivity (NCGS). NCGS can look a lot like celiac disease and requires reducing or eliminating eating gluten, though it may not need to be as strict as the diet for celiac disease.<sup>6</sup>

Treatment for celiac disease is a dramatic diet transformation, eliminating all gluten. Even small amounts or cross-contamination can cause symptoms and potential damage. Treatment may also involve working with a nutritionist to maintain a healthy diet despite restrictions.

### Living with Celiac Disease

While the treatment for celiac disease may sound simple, it can make everyday social events difficult or even dangerous. Researchers at the Celiac Disease Center of Columbia University in New York found that the majority of participants (adults and teenagers living with celiac disease) often “experience social and emotional stress around eating out due to fear of cross-contact, embarrassment about having to ask a lot of questions, and frustration with the gluten-free diet being perceived as trendy.” Many participants also expressed that they didn’t feel comfortable being spontaneous because of unknown food options in unfamiliar situations.<sup>7</sup>

One story on BeyondCeliac.org illustrates this stress. The writer shares that her family struggled to accept the severity of the condition: “I have had to sit at restaurants and watch my family eat while I had

nothing. They couldn’t understand why I couldn’t just order a salad or pick the croutons off.” Often, she says, restaurant employees didn’t know what gluten was, making these situations more uncomfortable and riskier.<sup>8</sup>

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*The strict gluten-free diet of celiac disease requires constant vigilance.*

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Often those living with celiac disease need to come prepared with their own food options or settle for a disappointing alternative. While the obvious gluten sources would be flour and breads, they also need to look out for hidden gluten, such as sauces or gravies where flour is often used as a thickener. Even some medications and cosmetics can contain gluten.<sup>9</sup>

Those with celiac disease and other gluten sensitivities can now choose from more products than ever before, but a gluten-free diet may not be right for everyone. Gluten-free diet and products have become a trendy choice as some perceive it to be healthier, but there is little published medical evidence that a gluten-free diet benefits individuals without a gluten intolerance or allergy. In fact, research suggests that “individuals who avoid gluten may increase their risk of heart disease, due to the potential for reduced consumption of whole grains.”<sup>10,11</sup>

If untreated, celiac disease can cause severe symptoms and serious health complications. While it can be effectively managed with a strict gluten-free diet, these dining requirements can create other forms of stress. Understanding this difficulty and providing accommodations and alternatives—or even just information on ingredients—can help assure everyone a comfortable seat at the table.

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<sup>6</sup> [University of Chicago Medicine](#), “Two Conditions that Seem like Celiac Disease, but Aren’t”

<sup>7</sup> [Celiac Disease Foundation](#), “Gluten-Free Diet and Quality of Life”

<sup>8</sup> [Beyond Celiac](#), “Voices of Celiac Disease: Emily”

<sup>9</sup> [Celiac Disease Foundation](#), “Dining and Social Eating”

<sup>10</sup> [Harvard School of Public Health](#), “Gluten: A Benefit or Harm to the Body?”

<sup>11</sup> [Harvard Medical School](#), “Ditch the Gluten, Improve Your Health?”