



**GLUTEN
INTOLERANCE
GROUP**



Celiac Disease

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What you need to know about celiac disease

Celiac disease is a chronic, autoimmune disease which is the result of an immune system response to the ingestion of gluten (a protein found in wheat, rye, and barley) in susceptible individuals. This response to gluten damages the small intestine, leading to malabsorption of nutrients and related health issues. To develop celiac disease, a person must inherit the genetic predisposition, be consuming gluten, and have the disease activated. Activation triggers may include stress, trauma (surgeries, etc.), and possibly viral infections and other environmental factors. Celiac disease may be diagnosed at any age, from infancy to later adulthood. Approximately 5-15% of first-degree relatives of those with celiac disease have the condition triggered in their lifetime. The disease is permanent and damage to the small intestine will occur every time gluten is ingested, regardless of whether or not symptoms are present.

Celiac disease affects about 1 in 100 individuals worldwide, or over 3 million people in the United States alone. Over half of those with celiac disease in the U.S. are undiagnosed.

Symptoms

Classical symptoms are those related to malabsorption and can include diarrhea, bloating, weight loss, anemia and growth failure. Non-classical symptoms may include a wide range of non-intestinal symptoms including: migraines, infertility, fatigue, joint pain, premature osteoporosis, depression and seizures. Up to 200 symptoms have been associated with celiac disease. Many people do not have classical gastrointestinal symptoms, some may have just one symptom and some individuals have no obvious symptoms at all.

Diagnosis

Initial screening for celiac disease is a blood test ordered by your physician. Blood tests look for the presence of the following antibodies. Because no one of these tests is ideal, panels are often used.

- Anti-tissue transglutaminase (tTG)
- Anti-endomysium (EMA)
- Anti-deamidated gliadin peptides (DGP)

Questions to ask your doctor:

Should I take nutritional supplements?

Could I have associated food intolerances?

Where can I have a bone density study?

What other concerns should I have?

How can I find out about the diet?

How often should I follow-up with the doctor? With the dietitian?

If this screening test suggests celiac disease, a small intestine biopsy is the next step to confirming diagnosis. A positive small intestine biopsy (showing damaged villi) is the “gold standard” for a diagnosis of celiac disease. In some cases a haplotype test for HLA DQ2 and DQ8 may be recommended prior to biopsy to confirm presence of the genes necessary to develop celiac disease. Starting a gluten-free diet before testing is not recommended and makes later diagnosis difficult. Tests to confirm celiac disease could be negative if a person were on a gluten-free diet for a period of time. For a valid diagnosis to be made, gluten would need to be reintroduced for at least several weeks before testing.

Treatment

Strict adherence to a gluten-free diet for life is the only treatment currently available. This involves elimination from the diet of wheat, barley, rye and foods made with these grains or their derivatives. Medication is not required unless there is an accompanying condition, such as osteoporosis or dermatitis herpetiformis (a skin manifestation of celiac disease). It may take several months or longer for the small intestine to completely heal. Improvement is measured by regular monitoring of the antibody blood tests used for screening, and by improved health. When you are on a gluten-free diet, blood tests should eventually come back to normal. This indicates good control of celiac disease - not a cure. You will always require a gluten-free diet until another form of treatment is discovered.

The Diet

The gluten-free diet must be adhered to strictly. Even tiny amounts of gluten can cause damage to the small intestine and related health issues. Fortunately, a large range of delicious and nutritious foods are naturally gluten-free, and there are gluten-free substitutes widely available for items like bread and pasta. In addition to choosing gluten-free foods, it is important to avoid cross-contamination of your gluten-free foods from foods that contain gluten. Find details about the gluten-free diet in the following educational bulletins:

- <https://gluten.org/resources/getting-started/getting-started-gluten-free-diet/>
- <https://gluten.org/resources/diet-nutrition/gigs-gluten-free-diet-and-drug-instruction/>
- <https://gluten.org/resources/diet-nutrition/healthy-gluten-free-eating-guidelines/>
- <https://gluten.org/resources/cross-contamination/>

Prognosis

Generally excellent, if a strict gluten-free diet is maintained. The small intestine will steadily heal and start absorbing nutrients normally. You should start to feel better within days; however, complete recovery may take from several months to several years.

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Other helpful information is available at www.GLUTEN.org.

Advances in celiac disease are fast-paced. If this document is more than 2 years old, please visit our website for updated documents.

This information should not be used to diagnose or treat gluten-related disorders or other medical conditions. For questions about these conditions consult your healthcare team when considering this information.

Please consider your local GIG support group as another resource.

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The Mission of the Gluten Intolerance Group is to empower the gluten-free community through consumer support, advocacy, and education.

To make a donation or become a volunteer to GIG, visit our website or call the office at 253-833-6655.