



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. Common activation triggers include stress, trauma (surgeries, etc.) and possibly viral infections. Approximately 10-20% of first-degree relatives of those with celiac disease will 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 is a genetic disorder affecting about 1 in 133 individuals in the United States, potentially 3 million people. For every person diagnosed with celiac disease, approximately 80 people have the condition but are undiagnosed.

Symptoms

Classic 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. Many people do not have 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:

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

Because no one of these tests is ideal, panels are often used.

If this test suggests celiac disease, it is often recommended that a haplotype test for HLA DQ2 and DQ8 be performed to confirm presence of the genes necessary to develop the condition. If this test is positive, a small intestine biopsy is done. A positive small intestine biopsy (showing damaged villi) is the “gold standard” for a diagnosis of celiac disease.

Celiac disease is an inherited autoimmune digestive disease and confirmation of celiac disease will help future generations be aware of the risk within the family.

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

Treatment

Strict adherence to a gluten-free diet for life is the only treatment currently available. This means elimination from the diet of wheat, rye, barley and foods made with these grains or their derivatives. Medication is not usually required, unless there is an accompanying condition, such as osteoporosis or dermatitis herpetiformis. Thriving or showing improvement on the gluten-free diet is the second half of the “gold standard” of diagnosis. 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 is a lifelong commitment and should not be started before being properly diagnosed. Starting the diet without complete 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.

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 Branch 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.