



## What you need to know about celiac disease

Celiac disease (CD), also referred to as gluten sensitive enteropathy (GSE), or celiac sprue, is a chronic, inherited digestive disease that can lead to malnutrition if untreated. CD is the result of an immune system response to the ingestion of gluten (a protein found in wheat, rye, and barley) that damages the small intestine. When the small intestine is damaged, nutrients pass through the small intestine, rather than get absorbed. To develop celiac disease (CD), you must inherit a gene, be consuming gluten, and have the disease activated. Common triggers include stress, trauma (surgeries, etc.) and possibly viral infections. Approximately 10% of first-degree relatives could have CD triggered in their lifetime. The disease is permanent and damage to the small intestine will occur every time you consume gluten, regardless if symptoms are present.

Celiac disease is a genetic disorder affecting 1:133 persons in the United States, potentially 2 million people. For every person diagnosed with CD, approximately 80 people are undiagnosed.

## Symptoms

Classic symptoms include: diarrhea, bloating, weight loss, anemia, chronic fatigue, weakness, bone pain and muscle cramps. Other symptoms may include constipation, constipation alternating with diarrhea, or premature osteoporosis. Over weight persons may also have undiagnosed celiac disease. Children may exhibit behavioral or concentration problems, diarrhea, bloated abdomen, growth failure, dental enamel defects, or projectile vomiting.

Many people will not have classic symptoms and some people may have just one or more symptoms. Other symptoms can include anemia, chronic fatigue or pain syndromes, migraines, nerve problems, infertility or miscarriages, and other apparently unrelated conditions. Patients are frequently misdiagnosed as having Irritable Bowel Syndrome (IBS), spastic colon/bowel, or Crohn's disease.

## Diagnosis

Initial screening for CD is a blood test ordered by your physician. The following tests should be included in the screening test:

- Tissue Transglutaminase IgA and IgG (tTG-IgA and IgG)  
or Anti-endomysial Antibodies IgA (EMA IgA)
- IgA Deficiency Test

If these tests suggest celiac disease, it is then recommended that an HLA genotype test for HLA DQ2 and DQ8 be performed. If this test also suggests celiac disease, then a small intestine biopsy is done. A positive small intestine biopsy (showing damaged villi) is the "gold standard" for a diagnosis of celiac disease.

## 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?



## Treatment

Strict adherence to a gluten-free (GF) diet for life is the only treatment currently available. This involves the elimination of wheat, rye, barley, and foods made with these grains from your diet. Medication is not normally 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 being diagnosed with CD. It may take several months for the small intestine to completely heal. Improvement is measured by regularly monitoring the blood tests for celiac disease and showing improved health. When you are on a GF diet, blood tests should eventually come back to normal. This indicates good control of the 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 (GF) diet is a life long commitment and should not be started before being properly diagnosed with CD. Starting the diet without complete testing is not recommended and makes later diagnosis difficult. Tests to confirm CD could be negative if a person were on a GF diet for a period of time. For a valid diagnosis, gluten would need to be reintroduced for several weeks before testing. Celiac disease is an inherited autoimmune digestive disease and confirmation of CD will help future generations be aware of the risk within the family. For further information and more details about the diet, please contact GIG to obtain the Quick Start Diet Guide for Celiac Disease.

## Prognosis

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

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Other helpful information is available at [www.GLUTEN.net](http://www.GLUTEN.net).

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

This information should not be used to diagnose or treat anemia or celiac disease. For questions about anemia and celiac disease consult your healthcare team when considering this information.

Please consider your local GIG branch as another resource.

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GIG is a nonprofit 501c3 national organization providing support for persons with gluten intolerances, in order to live healthy, productive lives. GIG Branches provide support at a local level.

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