

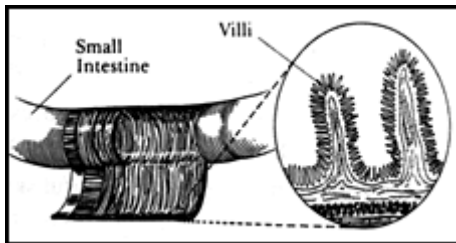


CELIAC SPRUE

Celiac Disease (CD) is a lifelong, digestive disorder affecting children and adults. When people with CD eat foods that contain **gluten**, it creates an immune-mediated toxic reaction that causes damage to the small intestine and does not allow food to be properly absorbed. Even small amounts of **gluten** in foods can affect those with CD and cause health problems. Damage can occur to the small bowel even when there are no symptoms present.

Gluten is the common name for the proteins in specific grains that are harmful to persons with celiac disease. These proteins are found in **ALL** forms of **wheat** (including durum, semolina, spelt, kamut, einkorn and faro) and related grains **rye**, **barley** and **triticale** and **MUST** be eliminated.

What Happens With Celiac Disease



When individuals with CD ingest gluten, the villi, tiny hair-like projections in the small intestine that absorb nutrients from food, are damaged. This is due to an immunological reaction to gluten. Damaged villi do not effectively absorb basic nutrients -- proteins, carbohydrates, fats, vitamins, minerals, and, in some cases, water and bile salts. If CD is left untreated, damage to the small bowel can be chronic and life threatening, causing an increased risk of associated disorders -- both nutritional and immune related.

Some long-term conditions that can result from untreated CD:

- Iron deficiency anemia
- Early onset osteoporosis or osteopenia
- Vitamin K deficiency associated with risk for hemorrhaging
- Vitamin and mineral deficiencies
- Central and peripheral nervous system disorders - usually due to unsuspected nutrient deficiencies
- Pancreatic insufficiency
- Intestinal lymphomas and other GI cancers (malignancies)
- Neurological manifestations
- Gall bladder malfunction

Other associated autoimmune disorders:

- Dermatitis Herpetiformis (DH)
- Insulin-dependent Type I Diabetes Mellitus
- Thyroid Disease
- Systemic Lupus Erythematosus

- Liver Diseases

Less commonly linked to CD:

- Addison's Disease
- Chronic Active Hepatitis
- Down Syndrome
- Rheumatoid Arthritis
- Turner Syndrome
- Williams Syndrome
- Sjögren's Syndrome
- Fibromyalgia
- Alopecia Areata
- Scleroderma

Cause of Celiac Disease

The cause of Celiac Disease, also known as gluten sensitive enteropathy (GSE), is still a mystery. One out of 133 people in the United States is affected with celiac disease. CD occurs in 5-15% of the offspring and siblings of a person with celiac disease. In 70% of identical twin pairs, both twins have the disease. It is strongly suggested that family members of a diagnosed celiac be tested, even if asymptomatic. Family members who have an autoimmune disease are at a 25% increased risk of having celiac disease. Celiac Disease is **not** a food allergy - it is an autoimmune disease. Food allergies, including wheat allergy, are conditions that people can grow out of. This is not the case with Celiac Disease.

Celiac Disease Symptoms

Adults

Celiac Disease may appear at any time in a person's life. The disease can be triggered for the first time after surgery, viral infection, severe emotional stress, pregnancy or childbirth. CD is a *multi-system, multi-symptom* disorder. Celiac Disease symptoms are extremely varied, can often mimic other bowel disorders and are not always gastrointestinal.

Children

Infants, toddlers, and young children often exhibit growth failure, vomiting, bloated abdomen and behavioral changes.

Symptoms of Celiac Disease May Include One or More of the Following:

- Recurring bloating, gas, or abdominal pain
- Chronic diarrhea or constipation or both
- Unexplained weight loss or weight gain
- Pale, foul-smelling stool
- Unexplained anemia
- Bone or joint pain
- Behavior changes/depression/irritability
- Vitamin K Deficiency
- Fatigue, weakness or lack of energy
- Delayed growth or onset of puberty
- Failure to thrive (in infants)
- Missed menstrual periods
- Infertility male & female

- Spontaneous miscarriages
- Canker sores inside the mouth
- Tooth discoloration or loss of enamel

Have You or a Family Member Been Diagnosed With the Following?

- Type 1 Diabetes
- Chronic Fatigue Syndrome
- Fibromyalgia
- IBS
- Eczema
- Sjogren's Syndrome
- Peripheral Neuropathy
- Thyroid Disease
- Dermatitis Herpetiformis
- Osteoporosis

Dermatitis Herpetiformis (DH) is skin manifestation of celiac disease characterized by blistering, intensely itchy skin. The rash has a symmetrical distribution and is most frequently found on the face, elbows, knees and buttocks. DH patients can have gastrointestinal damage without perceptible symptoms.

Celiac Disease Diagnosis

A person seeking preliminary diagnosis **MUST** be eating gluten. Specific antibody blood tests help identify the presence of CD and are the initial step in screening and should include the following tests:

- Endomysial antibody (EMA-IgA)
- Tissue transglutaminase antibody (tTG - IgA/IgG)
- Anti-gliadin antibody (AGA-IgG, AGA-IgA)
- Total serum IgA

The exception is children under the age of 2 years in which tTG and EMA may not be present. Consult your physician. It is essential that patients with positive antibody tests, and those with an IgA deficiency have a small bowel biopsy (which is performed endoscopically) to confirm the diagnosis and assess the degree of damage to the villi in the intestinal lining.

Blood tests can only screen for RISK of celiac disease and cannot confirm it. When blood tests and biopsy are inconclusive, testing for specific HLA (human leukocyte antigen) DQ2/DQ8 genes associated with celiac disease may be helpful. As an autoimmune disease, CD is the result of the interaction between genes and the environment (gluten). All the necessary genes to develop CD are not known; however, HLA DQ2 and/or DQ8 are absolutely necessary to develop CD. Since one-third of the population also have these genes, the presence of DQ2 or DQ8 does not imply that the person will develop CD, rather, that they have a genetic compatibility with CD. Genetic testing does not diagnose celiac disease – the absence of DQ2/DQ8 almost always rules it out. Patients should always consult with a physician to ensure proper diagnosis.

Dermatitis Herpetiformis (DH) is the skin manifestation of celiac disease characterized by blistering, intensely itchy skin. The rash has a symmetrical distribution and is most frequently found on the face, elbows, knees and buttocks. DH patients can have intestinal damage without obvious GI symptoms.

Dermatitis Herpetiformis (DH) is diagnosed by a biopsy of a skin lesion and staining for IgA in the tissues. More than 85% of DH patients have small bowel sensitivity to gluten. Everyone with DH needs to follow a gluten-free diet.

Treatment of Celiac Disease

Because CD/DH is a chronic disorder, the only treatment is the lifelong adherence to the gluten-free diet. When gluten is removed from the diet, the small intestine will start to heal and overall health improves. Medication is not normally required. Consult your physician regarding specific nutritional supplements to correct any deficiencies. The diagnosed celiac should have medical follow-up to monitor the clinical response to the gluten-free diet.

Dietary compliance increases the quality of life and decreases the likelihood of osteoporosis, intestinal lymphoma and other associated illnesses.

Because osteoporosis is common and may be profound in patients with newly diagnosed CD, bone density should be measured at or shortly after diagnosis.

Adapting to the gluten-free diet requires some lifestyle changes. It is essential to read labels and learn how to identify foods that are appropriate for the gluten-free diet and do not contain toxin gluten.

Potential harmful ingredients include:

- unidentified starch
- modified food starch
- binders
- fillers
- excipients
- extenders
- malt

Gluten may also be used as a binder in some pharmaceutical products. Request clarification from food and drug manufacturers when necessary.

For More Information

Celiac Disease Awareness Campaign

National Digestive Diseases Information Clearinghouse
2 Information Way
Bethesda, MD 20892-3570
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Email: celiac@info.niddk.nih.gov
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