

UNIVERSITY STUDENT HEALTH SERVICES • Fact Sheet

CELIAC DISEASE**WHAT IS IT?**

Celiac disease is a condition in which the immune system reacts abnormally to gluten, a protein found in wheat, rye, and barley. This abnormal immune response causes damage to the lining of the small intestine, which can lead to difficulty absorbing important nutrients. Eliminating gluten from the diet usually stops injury to the small intestine and the problems associated with it.

Previous names for celiac disease include gluten-sensitive enteropathy and celiac sprue.

WHAT CAUSES IT?

Celiac disease is believed to be an immune disorder triggered by environmental factors (ie. exposure to gluten) in genetically predisposed individuals. You are more likely to have celiac disease if a family member (especially a first-degree relative) has it. Other individuals at higher risk include those with Type 1 Diabetes and other autoimmune disorders.

Celiac disease can occur in people of any age, sex, or race. It commonly presents between the ages of 10 and 40 years and rarely affects people from sub-Saharan Africa, China, Japan and northern parts of Asia.

WHAT ARE THE SYMPTOMS?

Symptoms vary from person to person:

- ❖ Classic symptoms include diarrhea (often with bulky, foul-smelling, floating stools), abdominal pain, bloating, flatulence/gas, nausea, lack of appetite, and weight loss. Blood in the stool is less common.
- ❖ In many cases, there may be no obvious symptoms.
- ❖ Most cases of celiac disease are diagnosed in patients who present with non-gastrointestinal symptoms. Examples include fatigue, headaches, joint pain, mouth ulcers, numbness/tingling in the hands and feet, etc.
 - Many of these symptoms are due to the poor absorption of nutrients from the small intestine.
 - Some of these symptoms may be related to the autoimmune disease process itself. For example, the body's abnormal immune response may lead to an itchy, blistering rash called dermatitis herpetiformis; the presence of this rash makes the diagnosis of celiac disease extremely likely.

WHAT ARE POSSIBLE COMPLICATIONS?

- ❖ Malnutrition from untreated celiac disease is the primary concern. Even in cases where symptoms are not present, the small intestine may not be absorbing nutrients adequately. Bloodwork may show:
 - A low blood count (anemia) due to decreased absorption of iron, B12, and/or folic acid. B12 deficiency can also lead to neurologic abnormalities.
 - Vitamin D deficiency, which can result in weakening of the bones (osteopenia or osteoporosis).
- ❖ Studies also suggest that untreated celiac disease can modestly increase the risk of lymphoma and gastrointestinal cancers. A gluten-free diet can decrease cancer risk.
- ❖ A range of medical conditions has also been linked to celiac disease, including Type 1 Diabetes, thyroid disease, liver disease, neurologic disorders, and others.

HOW IS IT DIAGNOSED?

Celiac disease can be difficult to diagnose because of its wide variety of symptoms. Fortunately, testing is available to help confirm the diagnosis:

- ❖ **Blood tests that measure antibody levels** specific to celiac disease are usually checked first. It is important to continue a normal gluten-rich diet for 2-12 weeks before labs are drawn because these tests may be negative if gluten has been eliminated from the diet.
 - Over 95% of people with celiac disease have elevated IgA tissue transglutaminase levels. Tests for IgA or IgG deamidated gliadin peptide may also be high.
 - First-degree relatives of individuals with celiac disease should consider antibody testing since they are at higher risk of having the disease.
- ❖ **Biopsies of the small intestine** are taken, if blood tests are positive, to confirm the diagnosis. In patients at high risk of developing celiac disease, both blood tests and biopsies are recommended.

- ❖ **"Potential" celiac disease:** People with positive antibody testing but a normal small intestine biopsy are considered to have potential celiac disease. These patients are **not** usually advised to eat a gluten-free diet. However, they are at risk of developing classic celiac disease. Therefore, follow-up antibody testing is recommended and a repeat biopsy may be advised if symptoms develop.
- ❖ **"Silent" celiac disease:** People with a positive blood test and an abnormal small intestine biopsy but no symptoms are said to have "silent" celiac disease. It is unclear if these patients should avoid gluten. However, if blood tests show evidence of malabsorption, then a gluten-free diet is recommended.

FOLLOW-UP TESTING

Once a diagnosis of celiac disease has been made, your medical provider will order further tests to look for nutritional deficiencies:

- ❖ **Common blood tests** include iron, folic acid, vitamin B12, and vitamin D levels.
- ❖ Baseline labs may also check for anemia, thyroid problems, and cholesterol levels.
- ❖ **A bone density scan** to evaluate for bone loss is often recommended after being on a gluten-free diet for 12 months.
- ❖ **Antibody levels** are checked periodically to determine if the gluten-free diet is working. Levels should be decreasing after 4-6 weeks on a gluten-free diet. Once celiac antibody levels have returned to normal, antibody testing is generally repeated yearly.

WHAT IS THE TREATMENT?

The cornerstone of treatment is complete elimination of gluten from the diet for life. More than 70% of people begin to feel better within 2 weeks of avoiding gluten.

- ❖ Strict adherence to a gluten-free diet is recommended since small amounts of gluten can worsen the disease. It is important to avoid both eating gluten & being exposed to large amounts of flour particles in the air.
- ❖ A gluten-free diet is also necessary to avoid complications, such as nutritional deficiencies and the increased risk of developing lymphoma and certain gastrointestinal cancers from untreated celiac disease.

GLUTEN-FREE DIET

- ❖ **Nutritionist consult.** It's a good idea to meet with a registered dietitian to learn about what foods to avoid, as well as what foods to add, for a nutritionally balanced diet. A dietitian can also provide education on shopping & food preparation, as well as recommendations for gluten-free vitamins and supplements if needed. VCU students can schedule free individualized consultations with Student Health's registered dietitian by calling 804-828-8828; no referral is needed.
- ❖ **Avoid wheat, barley, rye, malt, oats, brewer's yeast, yeast extract, and autolyzed yeast extract** (unless the source is identified as "gluten-free"). Don't forget to look for these ingredients in condiments, medications, dietary supplements, and oral care products.
- ❖ **Look for "gluten-free" labels.** Per the FDA, foods labeled as "gluten-free" must contain less than 20 parts per million (ppm) of gluten, which is considered a safe limit for people with celiac disease.
- ❖ **Naturally gluten-free foods** include rice, wild rice, corn, potato, and other foods listed on the next page. Because these foods may be contaminated with wheat, barley, or rye, choose "gluten-free" labeled versions when possible. Exceptions are fresh corn, fresh potatoes, plain rice, and plain wild rice. It is also best to choose "gluten-free" labeled dried beans, lentils, other legumes (such as chickpeas), nuts and seeds.
- ❖ **Oats.** A small percentage of people with celiac disease cannot tolerate gluten-free oats. If you choose to eat oats, first consult with your medical provider who can check antibody levels and monitor symptoms. Only eat oat products that are specifically labeled "gluten-free." Limit intake to 50 grams (1/2c dry rolled oats or 1/4c dry steel-cut oats) per day. If tolerated, you may be able to increase your intake under medical supervision.
- ❖ **Alcohol and vinegars.** Distilled alcoholic beverages, wine, and distilled vinegars are gluten-free unless gluten-containing flavorings have been added. Beer, other malt beverages, and malt vinegar are not considered gluten-free. However, gluten-free beers that do not use malted barley can be consumed on a gluten-free diet. Avoid beer labeled as "gluten-removed" or "gluten-reduced".
- ❖ **Dairy products.** Some patients have difficulty tolerating dairy products initially, while their small intestine is healing. If you were able to tolerate lactose before your diagnosis, you may be able to tolerate it again after the intestine heals. Choose gluten- and lactose-free products, such as Fairlife milk and non-dairy alternatives such as rice, soy, and nut (almond, hazelnut) beverages that are fortified with calcium and vitamin D. Gluten-free lactase enzyme supplements are also available.

- ❖ **Constipation** is a common issue in individuals with newly diagnosed celiac disease due to an increased intake of low-fiber and low-nutrient foods, like rice, corn, and potatoes. Adding some high-fiber gluten-free whole grains (quinoa, amaranth, teff, buckwheat, sorghum, and millet) can help improve bowel movements and also increase your nutrient intake.
 - Increase high-fiber foods slowly to avoid cramping and gassiness.
 - Be sure to drink plenty of water. High fiber intake will not result in soft, regular stools if you are not drinking enough water.
 - Don't forget to include lots of fruits, vegetables, nuts and seeds, legumes and beans (navy, pinto, black, cannellini, etc) in your diet.
 - If needed, add fiber supplements like psyllium (Metamucil) to help with constipation.

MEDICATIONS

- ❖ If lab results identify any nutritional deficiencies, your medical provider will make specific recommendations about vitamins and other supplements.
- ❖ A small percentage of people with celiac disease do not improve with a gluten-free diet and may require treatment with medications that suppress the body's immune system.

RECOMMENDED WEBSITES:

- ❖ www.beyondceliac.org
- ❖ www.celiac.org
- ❖ www.gluten.org
- ❖ www.mayoclinic.org
- ❖ www.nationalceliac.org
- ❖ wakegastro.com/patient-info/patient-education/celiac-disease (has helpful list of foods to choose/avoid, divided into food groups; also has good "hidden gluten" chart)

Gluten Foods
Wheat (durum, einkorn, faro, graham, kamut, semolina, spelt, wheat bran, wheat germ, cracked wheat)
Rye
Barley, barley malt, barley extract
Malt, malt flavoring, malt vinegar (generally made from barley; verify source)
Triticale (a cross between wheat and rye)
Bulgur, couscous, farina, orzo, panko
Gluten-Free Foods
Amaranth
Arrowroot
Beans/bean flours (garbanzo, black bean, etc.)
Buckwheat
Cassava
Coconut flour
Corn (popcorn, hominy, grits, meal, starch, bran)
Flax and Chia
Legumes (lentils, peas, chick pea, etc.)
Mesquite flour
Millet
Nuts/nut flours, peanut butter, Nutella
Potato, starch, flour; potato vodka, wine
Quinoa
Rice, wild rice, rice bran, rice crackers, rice cakes, puffed rice, Kellogg's Rice Krispies, cream of rice
Sago, sorghum
Seeds, seed flours (pumpkin, sunflower)
Soy beans, soy flour, tofu
Sugar (white & brown), honey, molasses, gelatin, jam
Tamari soy sauce
Tapioca
Teff
Yucca

Overlooked Foods & Products That May Contain Gluten
<ul style="list-style-type: none"> ▪ Flour or cereal products ▪ Breading, croutons, communion wafers ▪ Matzo ▪ Rice pilaf, packaged rice mixtures ▪ French fries (shared fryers or gluten containing ingredients)
<ul style="list-style-type: none"> ▪ Brown rice syrup ▪ Sauces, gravies, marinades, salad dressing, mayonnaise, mustard, ketchup, soy sauce, smoke flavoring ▪ Canned & dry soups, bouillon
<ul style="list-style-type: none"> ▪ Self-basting poultry ▪ Processed lunch meats, hot dogs, sausages, canned meats ▪ Imitation bacon, imitation seafood
<ul style="list-style-type: none"> ▪ Processed cheese foods and spreads ▪ Non-dairy creamers, chocolate milk ▪ Cake frosting
<ul style="list-style-type: none"> ▪ Candy ▪ Licorice ▪ Energy bars
<ul style="list-style-type: none"> ▪ Flavored teas and coffees ▪ Drink mixes ▪ Ales, beers, lagers, porter, stout, sake ▪ Whiskey, scotch, grain vodka, gin ▪ Flavored hard cider/hard lemonade/wine coolers containing malt
Herbal medications, probiotics, vitamins, supplements, over-the-counter medications
Toothpaste, lipsticks, gloss, lip balms
Play-doh, crayons, paint
Glue, paper mache, postage stamps