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.

Celiac disease is also known as gluten-sensitive enteropathy, celiac sprue, and non-tropical 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.

Celiac disease occurs primarily in whites of northern European descent. However, it also occurs widely in other parts of Europe, the Americas, Australia, North Africa, the Middle East, and South Asia. It is rare in people from other parts of Asia or sub-Saharan Africa.

Celiac disease affects all genders and ages, though studies describe an increasing prevalence in older individuals.

WHAT ARE THE SYMPTOMS?

Symptoms vary from person to person. In many cases, there may be no obvious symptoms. Classic symptoms include diarrhea (often with bulky, foul-smelling, floating stools), abdominal pain, bloating, flatulence/gas, nausea, and weight loss. Blood in the stool is less common.

However, 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, blistery rash called dermatitis herpetiformis, whose presence makes the diagnosis of celiac disease extremely likely.

WHAT ARE POSSIBLE COMPLICATIONS?

Malnutrition is the primary concern. Even in cases where symptoms are not present, the small intestine may not be absorbing nutrients adequately. For example, blood work can show:

- A low blood count (anemia) due to decreased iron, B12, and/or folic acid absorption. B12
 deficiency can also lead to neurologic abnormalities.
- Vitamin D deficiency, which can result in weakening of the bones (osteopenia or osteoporosis).

Untreated celiac disease can also increase the risk of certain gastrointestinal cancers. The exact risk of cancer in those with minimal symptoms is not known but appears to be lower than in those presenting with malabsorption symptoms. A gluten-free diet is key in decreasing cancer risk levels back to normal.

A range of medical conditions has also been linked to celiac disease, including Diabetes Mellitus Type 1, thyroid disease, liver disease, neurologic disorders, and others.

HOW IS IT DIAGNOSED?

Suspicion for celiac disease is high if symptoms improve with a gluten-free diet. Lab tests are available to 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.

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 may be recommended after being on a gluten-free diet for 12 months.
- **Antibody levels** may be checked periodically to determine if the gluten-free diet is working. Once celiac antibody levels have returned to normal, antibody testing should be repeated yearly.
- "Potential" celiac disease: People with positive antibody testing but a normal small bowel biopsy are considered to have potential celiac disease. These patients are **not** usually advised to eat a gluten-free diet. However, follow-up antibody testing is recommended and a repeat biopsy may be advised if symptoms develop. Biopsies are usually taken from several areas of the small bowel since abnormal changes in the lining can be patchy.
- "Silent" celiac disease: People with a positive blood test and an abnormal small bowel 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.

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 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 certain types of gastrointestinal cancers from untreated celiac disease.

■ Gluten-Free Diet

- 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.
- 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, nuts and seeds in their shells, dried lentils (legumes), and dried beans.
- Oats. A small percentage of people with celiac disease cannot tolerate uncontaminated gluten-free oats. If you choose to eat oats, consult with your medical provider first. 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.
- 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. Gluten- and dairy-free alternatives include rice, soy, and nut (almond, hazelnut) beverages that are fortified with calcium and vitamin D. Gluten-free lactase enzyme supplements are also available.
- 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.
- **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. Your dietitian can also educate you on shopping & food preparation, as well as recommend gluten-free vitamins and supplements if needed.

■ Medications

- If your lab results identify any nutritional deficiencies, your medical provider will make specific recommendations about vitamins and other supplements.
- If constipation is a problem, fiber supplements like psyllium (Metamucil) can reduce symptoms.
- 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.com
- www.nationalceliac.org
- <u>www.wakegastro.com/services-procedures/celiac disease</u> (has helpful list of foods to choose/ avoid, divided into food groups; also has good "hidden gluten" chart)

Gluten Foods
Wheat, wheat germ, bran (durum, einkorn,
farro, graham, kamut, semolina, spelt), wheat
germ, bran
Barley, barley malt, barley extract
Rye
Bulgur, couscous, farina
Triticale
Orzo, panko

Overlooked Foods & Products That May
Contain Gluten
Flour or cereal products
Breading, croutons, communion wafers
Energy bars
Rice pilaf, packaged rice mixtures
Brown rice syrup
Sauces, gravy, marinades, salad dressing,
mayonnaise, mustard, ketchup, soy sauce
Canned & dry soups, bouillon
Self-basting poultry
Processed lunch meats, hot dogs, sausages,
canned meats
Imitation bacon, imitation seafood
Processed cheese foods and spreads
Non-dairy creamers, chocolate milk
Flavored teas and coffees
Drink mixes
Ales, beers, lagers
Whiskey, scotch, grain vodka, gin
Toothpaste, lipsticks, gloss, lip balms
Play-doh, crayons, paint
Glue, paper mache, postage stamps

Gluten-Free Foods
Amaranth
Arrowroot
Beans/bean flours (garfava, etc.)
Buckwheat
Cassava
Corn, popcorn, cornmeal, hominy, grits
Flax
Job's tears
Legumes (lentils, peas, etc.)
Millet
Nuts/nut flours, peanut butter, Nutella
Potatoes, potato starch, potato 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
Soy beans, soy flour, tofu
Sugar (white & brown), honey, molasses,
gelatin, jam
Tamari soy sauce
Tapioca
Teff
Yucca