Celiac Disease

Overview

- What is Celiac Disease (CD)?
  Celiac disease (CD) is a chronic (long-term) digestive disease during which patients have irritation (inflammation) of the small intestine, which causes difficulty with absorbing nutrients from food. Patients with CD often have other family members with the condition and are therefore susceptible to this disease. Inflammation in the intestine occurs when a patient with CD begins to eat food that contains gluten. Gluten is the name given to certain types of proteins found in wheat, barley, rye and related grains. Oats are currently considered not to be dangerous to persons with CD. However, due to the high possibility of contamination with other gluten containing grains, oats are typically not recommended for people with celiac disease.

  When food containing gluten arrives in the small intestine, the immune system reacts against the gluten, causing an inflammatory reaction in the wall of the intestine. The small intestine lining is covered by millions of villi (**see figures 1–3**), finger-like projections that increase the surface area of the intestine allowing greater absorption of nutrients. The inflammation in CD damages the villi, resulting in decreased nutrient absorption. When gluten is removed from the diet, inflammation is reduced and the intestine begins to heal. The time when a patient develops symptoms varies from patient to patient after their first contact with the gluten protein. In many cases, it may be decades before symptoms and signs develop, often precipitated by a trigger.

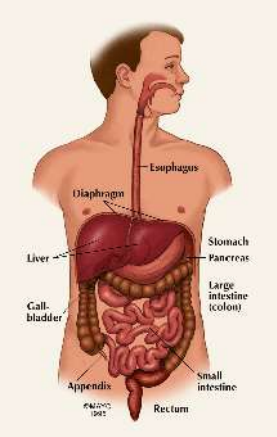

Figure 1. Normal Activity

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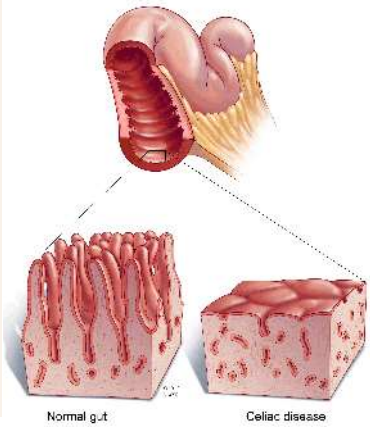

Figure 2. Normal Villi

Figure 3. Damaged Villi

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- How common is Celiac Disease?
  In the U.S., approximately 1 out of every 100 people may have CD, though only 1 out of 5 people with celiac disease may be actually diagnosed and are aware that they have this disease. Some of these patients have mild forms of the disease and may have no symptoms or only mild symptoms. There may be as many as 2–3 million people in the United States and 20 million in the world with CD.

- Who does Celiac Disease affect?
  CD affects many ethnicities, with the highest prevalence in Caucasians. Infants and children may have celiac disease, but CD is more commonly diagnosed in adulthood, and people can be diagnosed even in their seventies or eighties. Female patients are more likely to be diagnosed with celiac disease than male patients. Individuals that have type 1 diabetes, thyroid disorders, or relatives with CD are at greater risk for developing CD.

Symptoms

- What are the main symptoms of Celiac Disease?
  The symptoms or signs of celiac disease are highly variable. Some people have mild inflammation with few symptoms. Even though they may feel quite well, there is still damage occurring to the lining of the intestine. Other people have more severe inflammation, which causes symptoms that may be severe enough to lead them to visit their doctor. Occasionally, individuals will not have any symptoms at all even though their small intestine is severely inflamed.

  The most common symptoms and signs (consequences) are:

  1. Abdominal pains
  2. Bloating and gas
  3. Diarrhea
  4. Stools that may float or smell very bad
  5. Weight loss
  6. Poor growth or weight loss in children
  7. Anemia (low blood count)

  Other symptoms and signs (consequences) are:

  1. Feeling weak
  2. Fatigue
  3. Low vitamin levels—especially iron, calcium and folate
  4. Bone and joint pains
  5. Osteoporosis (bone thinning)
  6. A skin rash that lasts
  7. Infertility or reproductive difficulties
  8. Neurological deficits (neuropathy)
  9. Liver enzyme abnormalities

  Someone with celiac disease may have a variety of the above symptoms, and different people with celiac disease may have completely different symptoms. Celiac disease can mimic the symptoms of more common problems and be misdiagnosed as irritable bowel syndrome (IBS). It is now recommended that patients with IBS symptoms such as abdominal pain and changes in bowel movements (especially diarrhea) be tested for celiac

disease.

Screening/Diagnosis

- How is Celiac Disease diagnosed?
  It is important to remember that most patients with abdominal pain, bloating or diarrhea do not have celiac disease. When the doctor thinks that celiac disease is possible, but not very likely, then blood tests alone are done. If the blood tests are normal, other tests are rarely necessary. Sometimes the doctor strongly suspects that the symptoms are due to celiac disease or another similar illness, and will request an endoscopy and biopsy (sampling of the tissue of the small intestine). All tests for celiac disease, except for genetic tests, must be done while the patient is on a normal diet that contains gluten. Patients who are concerned that they may have celiac disease should not restrict their diet prior to seeking medical evaluation because this may cause false negative test results.

  Blood tests:
  Specific antibody blood tests are used to diagnose patients with CD. These blood tests are also used to test people who may be at risk for having CD but have no symptoms (relatives of patients with CD). The 2 most accurate tests used are the endomysial antibody and tissue transglutaminase antibody tests. Other tests, such as tests for deamidated gliadin peptide antibodies, may be used in restricted circumstances, but are not as accurate because they can be abnormal in healthy patients who do not have celiac disease or in people with other digestive problems. The original anti-gliadin or anti-gluten tests are no longer used for the diagnosis of celiac disease. Other tests for allergies will not detect celiac disease. Tests on saliva or stool for antibodies are not good substitutes for the blood-based tests. Genetic tests are available to assist doctors when the blood tests are unclear, or when patients continue to have symptoms while on a gluten free diet. However, simply carrying the genes that enable celiac disease does not mean that the patient will get celiac disease, only that it is possible. Not having the genes is a very good way to rule out the possibility of having celiac disease and may be used when the certainty of diagnosis is in doubt.

  Endoscopy:
  Establishing a firm diagnosis of CD requires taking biopsy samples of the small intestine using endoscopy. Endoscopy involves insertion of a thin flexible tube through the mouth into the stomach and small intestine. Tiny samples are taken from the wall of the small intestine and are examined under a microscope for changes of CD. This test is usually performed with the aid of sedatives.

Treatment

- How is Celiac Disease treated?
  Celiac disease is treated by avoiding all foods that contain gluten. Gluten is what causes inflammation in the small intestine. When this is removed from the diet, the intestine will heal and return to normal. Dieticians with expertise in gluten-free diets are essential for educating patients and tailoring diets. Medications are not normally required to treat CD except in occasional patients who do not respond to a gluten-free diet. There are many CD support groups available for patients and family members.

Gluten-Free Diet

The following grains **contain Gluten** and are **NOT ALLOWED IN ANY FORM**:

- Barley
- Einkorn
- Kamut
- Rye
- Spelt
- Triticale
- Wheat, , including bulgur, farro, wheatberry, durum, and others

Frequently overlooked foods that often contain gluten

- Basting
- Pastas
- Breading
- Imitation bacon
- Broth
- Imitation seafood
- Coating mixes
- Marinades
- Commercial cereals
- Processed meats
- Communion wafers
- Sauces
- Croutons
- Stuffings

Getting used to the gluten free diet requires some lifestyle changes. The key to understanding the gluten-free diet is to become a good ingredient label reader. If a food has questionable ingredients avoid it and find a similar product that you know is gluten-free. Foods containing the following ingredients are questionable and should not be consumed unless it is verified that they do not contain or are not derived from prohibited grains. These products are:

Unidentified:

- Modified food starch
- Hydrolyzed vegetable protein (HVP)
- Hydrolyzed plant protein (HPP)
- Malt vinegar
- Soy sauce or soy sauce solids
- Brown rice syrup
- Dextrin
- Textured vegetable protein (TVP)
- Vegetable gum

Be aware that medications may contain gluten ingredients. Gluten containing fillers may be in both prescription and over the counter medications. It is essential to ensure that any medications being taken are gluten free.

Allowed:

- Bean
- Quinoa
- Buckwheat
- Rice
- Corn
- Sorghum
- Coconut leaves
- Millet
- Soy
- Nut Flours
- Tapioca
- Potato
- Tef

Foods labeled as gluten free must have less than 20 parts per million of gluten.

- For how long do you remain on the gluten-free diet?
  Once a diagnosis of CD is established, these individuals **need to remain on the gluten free diet for the rest of their lives**. While this may be difficult at first, patients usually adapt quite well over time. Dieticians will assist in the dietary transition.

- Is there any other way of treating Celiac Disease?
  No. There is no other treatment currently available. All patients with CD must remain on a strict gluten free diet. Medications are not normally required. Supplemental vitamins, calcium and magnesium may sometimes be recommended but patients are advised to check with their physician about these supplements. Rarely steroids or other drugs are used to suppress the immune system but only in the most severe of cases.

Complications

- What will happen if you don't adhere to the gluten-free diet?
  Patients with CD who do not adhere to the gluten-free diet usually continue to suffer from symptoms such as abdominal pain, bloating, gas and diarrhea. In addition, these patients are at higher risk for developing complications of CD such as cancer of the small intestine and esophagus, and narrowing in the intestine due to inflammation.

- What are other complications of Celiac Disease?
  Other complications of CD that may be avoided by strictly following a gluten-free diet include fatigue, poor growth, decreased adult height, osteoporosis, bone pain, joint pain, difficulty having children, narrowing of the intestine, cancer of the esophagus (food tube) and small intestine, lymphoma (another type of cancer) and neuropathy (unsteady walking and confusion which may be severe). Patients may have deficiencies of certain vitamins (iron, vitamin B12, folate, zinc, copper, vitamin D and calcium. Usually it is a good idea to check for these deficiencies, especially in adults. Also, a test to determine the density of a person's bones is routinely done, when an adult is diagnosed with celiac disease.

- How should celiac disease be followed up?
  It is important that the symptoms get better. If they do not, then the patient should contact their doctor. Annual follow-up should include a blood test to follow the celiac activity. Patients with ongoing or recurrent symptoms need to be rescoped. Some specialists will rescope to make sure that healing has happened, even if the symptoms are gone.

- What does it mean for my family members?
  Immediate family members (blood relations), brothers, sisters, parents and children should be tested for celiac disease, even if they appear healthy as celiac disease is a genetic disease and may be hidden.

Author(s) and Publication Date(s)

Patrick McCabe, MD, Reno, NV – Updated April 2021.

Connor G. Loftus, MD, and Joseph A. Murray, MD, FACG, Division of Gastroenterology and Hepatology, Mayo Clinic, Rochester, MN – Published June 2004. Updated July 2010. Updated June 2016.

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Patient Links

- Celiac Disease Foundation
- Celiac Disease Awareness Campaign
- National Celiac Association.
- North American Society for Pediatric Gastroenterology, Heptology and Nutrition
- Children's Hospital of Philadelphia (links to https://www.beyondceliac.org)
- Cleveland Clinic
- University of Chicago
- Mayo Clinic
- Society for the Study of Celiac Disease