

## FAQ – General

[What is celiac disease?](#)

[How common is celiac disease?](#)

[Who gets celiac disease?](#)

[What are the symptoms of celiac disease?](#)

[When does celiac disease usually develop?](#)

[What is the difference between celiac disease, gluten intolerance, and wheat or gluten allergy?](#)

[When will I feel better?](#)

[Are there any concerns about pregnancy and celiac disease?](#)

[Are there any unique considerations for children with celiac disease, or children of celiac disease patients?](#)

How does having a problem with candida affect celiac disease (CD)?

Are high eosinophil levels connected to celiac disease (CD) and/or allergies (such as pollen, mold, mildew and dust mites) or asthma?

[Can a person with celiac disease donate blood?](#)

### **What is celiac disease?**

Celiac disease is an autoimmune disorder. In people with celiac disease, the body responds to gluten, the protein that comes from certain grains, by causing damage to the small intestine. Specifically, the body's immune system reacts to the gluten by causing inflammation of the lining of the small intestine, leading to malnutrition and other conditions. Other terms for celiac disease are celiac sprue, non-tropical sprue, and gluten-sensitive enteropathy.

Classically, the disease is described by villous atrophy (a wasting away of intestinal villi), malabsorptive symptoms like steatorrhea (fat globules in the bowel movement), weight loss, or nutritional deficiencies (like low levels of iron or calcium), and a resolution of symptoms and intestinal damage after stopping the ingestion of gluten-containing foods. Looking under a microscope you would see a loss in height of the villi (finger-like projections in the intestine which are important for digestion). In severe cases of celiac disease, the villi can be completely destroyed and flattened by the immune system's reaction.

There are a number of different symptoms that people with the disease may show. Some people are entirely without symptoms, while others can have chronic fatigue, abdominal pain, weight loss, malnutrition, anemia, diarrhea, and other gastrointestinal problems. Symptoms that are not gastrointestinal include depression, bone weakness, dermatitis herpetiformis (DH), and possibly increased risk of certain cancers. These symptoms, clinical manifestations, and increased risk of cancer as well as the actual damage to the intestine resolve after gluten is removed from the diet.

### **How common is celiac disease?**

According to a study by the University of Maryland, as many as 1 in 133 Americans may have celiac disease.<sup>1</sup> The number of patients that have been diagnosed or have symptoms of celiac disease, though, is far fewer. Approximately three million Americans have celiac disease.

### **Who gets celiac disease?**

Celiac disease is most common in people of North American or European descent, but is also found in people from the Middle East, North Africa, Turkey and India. The disease is believed to be rare among people of purely African-Caribbean, Chinese, or Japanese background. Although large epidemiologic studies are lacking from China and Japan, a prevalence of positive celiac antibodies was noted in 1% of patients with irritable bowel syndrome (diarrhea predominant) in China.<sup>2</sup> Celiac disease has a genetic component. Individuals who get celiac disease must have the HLA-DQ2 or HLA-DQ8 genes which are important in the immune system.

There is also a non-genetic, or physiological, component of celiac disease. In individuals who are genetically predisposed, celiac disease may develop after a period of acute or chronic stress, trauma, surgery, physical injury, or pregnancy. Celiac disease is also more likely to develop in individuals who were exposed to gluten before 3 months of age. Additionally, 7-10% of immediate family members of a patient with celiac disease also have the disease. Between 3% and up to 8% of individuals with Type I diabetes has celiac disease. People with Down's syndrome, Sjogren's syndrome, autoimmune thyroid disease, and other autoimmune conditions have an increased risk of also having celiac disease.

### **What are the symptoms of celiac disease?**

There are many symptoms of celiac disease. Some individuals will have many of these symptoms, and some will have no symptoms at all. The following are some of the most common symptoms experienced by individuals with celiac disease:

- Diarrhea - due to improper digestion and absorption of food nutrients; stools may be watery or oily in appearance and have a characteristic foul odor
- Iron deficiency anemia
- Abdominal pain
- Weight loss - varies in patients due to differences in severity of intestinal damage and since some patients may be able to compensate for the absorption problem by increasing dietary intake
- Malabsorption - improper absorption of fat results in the excessive fat in the large bowel (colon); bacteria then produce a compound (hydroxy fatty acids) that causes secretion of fluids into the intestine
- Fatigue - results from poor nutrition; anemia in some patients can contribute to fatigue and low energy
- Bloating/Gas - results from the release of gas produced in the intestines by bacteria that are breaking down undigested food
- Osteopenia or osteoporosis (thin bones)
- Vitamin D deficiency
- Constipation

Some less common symptoms are:

- Liver enzyme abnormalities ("bystander hepatitis," often with fatty changes in the liver)
- Aphthous stomatitis (canker sores)
- Nausea/vomiting

- Heartburn/GERD
- Hyposplenism (poorly functioning spleen)
- Myalgias (muscle aches)
- Arthralgias (joint pains)
- Neuropathy (most often numbness or tingling in fingers and/or toes)
- Alopecia (hair loss)
- Headaches
- Poor concentration
- Asthma
- Problems with fertility or pregnancy

It is important to realize that while the symptoms described above may suggest that you have celiac disease, you should always consult a physician for a complete examination. Often the symptoms can be related to some other process in the body and do not mean you have celiac disease. You should discuss the possibility of celiac disease with a physician comfortable with the diagnosis and treatment of celiac disease BEFORE starting a gluten free diet.

### **When does celiac disease usually develop?**

Celiac disease can develop at any time, from infancy through old age. The average age of diagnosis in America is around 40 years. Most patients have celiac disease for many years before they are diagnosed. If you are experiencing any of the symptoms listed above, you should contact your physician to see if you could have celiac disease.

### **What is the difference between celiac disease, non-celiac gluten sensitivity, and wheat or gluten allergy?**

Celiac disease is an autoimmune disease. Gluten causes a reaction that triggers the body to attack itself, specifically, the lining of the intestines. If you have a gluten or wheat allergy, the body launches an exaggerated response to the gluten or other wheat (cereal) proteins, but the damage to the small intestine is mild. Some symptoms of celiac disease and gluten or wheat allergy are the same, but often times an allergy will result in immediate, life-threatening symptoms, such as swelling and hives. Patients who have been told that they have an allergy by their physician should consult with an allergist.<sup>3</sup>

Non-celiac gluten sensitivity (NCGS) is a recently described condition with symptoms similar to those in celiac disease.<sup>3</sup> Unlike celiac disease, there is no known genetic susceptibility to NCGS, there are no auto-antibodies to damage the lining of the small intestine, and there is no association with other autoimmune diseases.<sup>4,5</sup> We don't know yet if NCGS is a type of functional disorder or whether some people with NCGS actually have a very mild immune reaction to gluten.

Tests for NCGS include skin and blood tests whose diagnostic accuracy is low, and more specific provocation tests that are only performed in a few specialized centers. Instead, the recommended way to diagnose NCGS is by excluding celiac disease and wheat allergy.

Patients with NCGS in whom celiac disease has been ruled out are encouraged to follow a gluten-free diet to the extent necessary to avoid symptoms. Some people find they can tolerate gluten in varying amounts; others find they can tolerate none.

### **When will I feel better?**

Patients should feel better within 1 week to six months of being on a gluten-free diet. Two thirds of them improve after only 2-3 weeks. Often times, patients continue to experience symptoms such as bloating, gas, and diarrhea or loose stool, even while on the gluten-free diet. These symptoms could be caused by lactose intolerance. Individuals with celiac disease often become temporarily lactose intolerant because of the damage to their intestine. If this is your case, by avoiding products made with milk, or reducing the amount of dairy (milk products) you eat, you will probably notice that your symptoms go away. Within a few months of starting the gluten-free diet, most people find that they are able to consume dairy products again. If you try avoiding dairy and still do not feel better after six months of being on a gluten-free diet, you should contact your gastroenterologist.

Another possibility is fructose malabsorption, the limited ability to digest fructose, a sugar molecule. The symptoms of fructose malabsorption mimic lactose intolerance - gas, bloating and loose stools. Testing for fructose malabsorption can be done with a breath test or a home trial on a low fructose diet under the supervision of your dietitian or doctor. There are also several other types of sugar molecules that can be poorly absorbed in people with celiac disease or other gastrointestinal conditions.<sup>6</sup>

In addition, there are a number of other causes for continuing symptoms in people with celiac disease on a gluten free diet. These people are referred to as patients with non- responsive celiac disease. The most common cause is poor adherence to celiac disease and other intestinal disorders such as microscopic colitis and pancreatic exocrine insufficiency. Rarely may you have a condition called refractory celiac disease needing medications in addition to a gluten-free diet.<sup>7</sup> These continued symptoms are best evaluated jointly between your doctor and your dietitian.

It is important to note that while untreated celiac disease is rarely lethal, it can be life threatening and result in severe complications and morbidity. An earlier study showed that by following a gluten-free diet the mortality rate of those with celiac disease decreased.<sup>4</sup> Many complications can affect individuals with untreated celiac disease, such as nutritional deficiencies, anemia, autoimmune diseases, electrolyte imbalances, neurological disorders, and osteoporosis. Rarer complications include celiac disease that is not responsive to a gluten-free diet (refractory celiac disease), ulcerative enteritis (formation of small ulcers along the small intestine), malignancies (cancers), and pancreatitis. Many complications can be avoided with the prompt initiation of a gluten-free diet.

### **Are there any concerns about pregnancy and celiac disease?**

Undiagnosed celiac disease may have negative effects on pregnancy and fertility in general. Undiagnosed celiac disease is associated with an increased risk of growth retardation, low birth weight, preterm birth, miscarriage, and cesarean section. However, once patients are diagnosed with celiac disease and are on a gluten-free diet, they do not experience any negative outcomes associated with pregnancy. This is most likely the result of compliance with a gluten-free diet. In

general, women with celiac disease tend to be older at the age of their first childbirth than women without celiac disease.<sup>8</sup>

It is important that pregnant women who are gluten-free maintain a healthy diet in order to have a healthy pregnancy. Your diet should include approximately 3000 calories per day (depending on your weight and trimester), but it is important that these calories come from healthy, vitamin rich foods. Eat foods rich in vitamins A, C, and D, calcium, iron, and folic acid, as these vitamins are extremely important for your health during pregnancy, as well as the health of your baby. Also eat foods that are high in omega-3 and omega-6 fatty acids, such as oily fish (salmon, sardines) and nuts. You should additionally take a gluten-free prenatal vitamin supplement, as well as calcium and vitamin D supplementation after consultation with your physician or dietitian. Pregnant women with celiac disease should see a dietician for further instructions on how to maintain a healthy diet during pregnancy.

### **Are there any unique considerations for children with celiac disease, or children of celiac disease patients?**

We do not treat children at BIDMC. If you are a parent with celiac disease, it is important that your children be screened for the condition. For more information, you may visit the Children's Hospital Celiac Disease Program at <http://www.childrenshospital.org/ceciac>.

### **How does having a problem with candida affect celiac disease (CD)?**

Candida albicans is a yeast that is part of our normal digestive and skin flora. In certain cases when the immune system or the normal flora is altered (such as antibiotic use, malnutrition, diabetes, etc.), this usually harmless yeast can cause inflammation of the skin as well as digestive and genital mucous surfaces. It may even get into the bloodstream. Although there is some cross reactivity that has been evidenced between gluten peptide and proteins on candida, actual causation is difficult to establish at this time.<sup>9</sup> Hence, this theory is not widely accepted.

### **Are high eosinophil levels connected to celiac disease (CD) and/or allergies (such as pollen, mold, mildew and dust mites) or asthma?**

Asthma, allergic rhinitis (hay fever) and atopic dermatitis are all part of a common spectrum of diseases called atopic diseases. A common finding in the blood work of people with this spectrum of diseases is a high eosinophil count. Some researchers have found that asthma and CD tend to happen together often. Nevertheless, based on our current knowledge, CD and atopic diseases are separate diseases with different biologic mechanisms.

### **Can a person with celiac disease donate blood?**

Yes.

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