Celiac Disease

National Digestive Diseases Information Clearinghouse

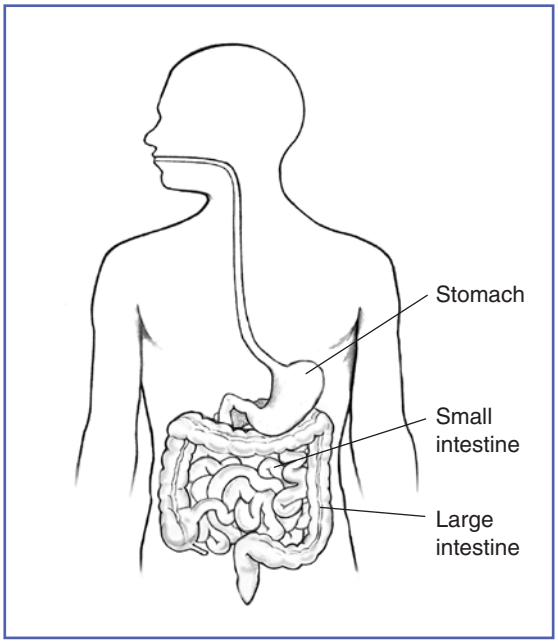
National Institute of Diabetes and Digestive and Kidney Diseases

What is celiac disease?

Celiac disease is an immune disorder in which people cannot tolerate gluten because it damages the inner lining of their small intestine and prevents it from absorbing nutrients. The small intestine is the tube-shaped organ between the stomach and large intestine. Gluten is a protein found in wheat, rye, and barley and occasionally in some products such as vitamin and nutrient supplements, lip balms, and certain medications.

The immune system is the body's natural defense system and normally protects the body from infection. However, when a person has celiac disease, gluten causes the immune system to react in a way that can cause intestinal inflammation—irritation or swelling—and long-lasting damage.

When people with celiac disease eat foods or use products containing gluten, their immune system responds by damaging or destroying villi—the tiny, fingerlike projections on the inner lining of the small intestine. Villi normally absorb nutrients from food and pass the nutrients through the walls of the small intestine and into the bloodstream. Without healthy villi, people can become malnourished, no matter how much food they eat.



The small intestine is the tube-shaped organ between the stomach and large intestine.

What causes celiac disease?

Researchers do not know the exact cause of celiac disease. Celiac disease sometimes runs in families. In 50 percent of people who have celiac disease, a family member, when screened, also has the disease.[1]

A person's chances of developing celiac disease increase when his or her genes—traits passed from parent to child—have variants, or changes. In celiac disease, certain gene variants and other factors, such as a person's exposure to things in his or her environment, can lead to celiac disease. Read more about genes and genetic conditions at *www.ghr.nlm.nih.gov*.

For most people, eating something with gluten is harmless. For others, an exposure to gluten can cause, or trigger, celiac disease to become active. Sometimes surgery, pregnancy, childbirth, a viral infection, or severe emotional stress can also trigger celiac disease symptoms.

How common is celiac disease and who is affected?

As many as one in 141 Americans has celiac disease, although most remain undiagnosed.[2] Celiac disease affects children and adults in all parts of the world and is more common in Caucasians and females.

Celiac disease is also more common among people with certain genetic diseases, including Down syndrome and Turner syndrome—a condition that affects girls' development.

What are the signs and symptoms of celiac disease?

A person may experience digestive signs and symptoms, or symptoms in other parts of the body. Digestive signs and symptoms are more common in children and can include

- abdominal bloating
- chronic diarrhea
- constipation
- gas
- pale, foul-smelling, or fatty stool
- stomach pain
- nausea
- vomiting

Being unable to absorb nutrients during the years when nutrition is critical to a child's normal growth and development can lead to other health problems, such as

- failure to thrive in infants
- slowed growth and short stature
- weight loss
- irritability or change in mood
- delayed puberty
- dental enamel defects of permanent teeth

Adults are less likely to have digestive signs and symptoms and may instead have one or more of the following:

- anemia
- bone or joint pain
- canker sores inside the mouth
- depression or anxiety
- dermatitis herpetiformis, an itchy, blistering skin rash
- fatigue, or feeling tired
- infertility or recurrent miscarriage
- missed menstrual periods
- seizures
- tingling numbness in the hands and feet
- weak and brittle bones, or osteoporosis
- headaches

Intestinal inflammation can cause other symptoms, such as

- feeling tired for long periods of time
- abdominal pain and bloating
- ulcers
- blockages in the intestine

Celiac disease can produce an autoimmune reaction, or a self-directed immune reaction, in which a person's immune system attacks healthy cells in the body. This reaction can spread outside of the gastrointestinal tract to affect other areas of the body, including the

- spleen
- skin
- nervous system
- bones
- joints

Recognizing celiac disease can be difficult because some of its symptoms are similar to those of other diseases and conditions. Celiac disease can be confused with

- irritable bowel syndrome (IBS)
- iron-deficiency anemia caused by menstrual blood loss
- lactose intolerance
- inflammatory bowel disease
- diverticulitis
- intestinal infections
- chronic fatigue syndrome

As a result, celiac disease has long been underdiagnosed or misdiagnosed. As health care providers become more aware of the many varied symptoms of the disease and reliable blood tests become more available, diagnosis rates are increasing, particularly for adults.

Dermatitis Herpetiformis

Dermatitis herpetiformis is a chronic, itchy, blistering skin rash—usually on the elbows, knees, buttocks, back, or scalp—that affects about 5 to 10 percent of people with celiac disease.[3] Men with dermatitis herpetiformis may also have oral or genital lesions. People with dermatitis herpetiformis may have no other signs or symptoms of celiac disease. Skin deposits of antibodies—proteins that react against the body's own cells or tissues—common in celiac disease cause dermatitis herpetiformis. Ingesting gluten triggers these antibodies.

Read more about dermatitis herpetiformis in *Dermatitis Herpetiformis: Skin Manifestation of Celiac Disease* at *www.digestive.niddk.nih.gov.*

Why are celiac disease signs and symptoms so varied?

Signs and symptoms of celiac disease vary from person to person because of numerous factors, including

- the length of time a person was breastfed as an infant; some studies have shown that the longer an infant was breastfed, the later the symptoms of celiac disease appear
- the age a person started eating gluten
- the amount of gluten a person eats
- age—symptoms can vary between young children and adults
- the degree of damage to the small intestine

Some people with celiac disease have no signs or symptoms; however, they can still develop complications of the disease over time. Long-term complications include

- malnutrition
- liver diseases
- intestinal cancer
- lymphoma

What other diseases can people with celiac disease have?

People with celiac disease may also have autoimmune diseases, including

- type 1 diabetes
- autoimmune thyroid disease
- autoimmune liver disease
- rheumatoid arthritis
- Addison's disease, a condition in which the immune system damages the glands that produce critical hormones
- Sjögren's syndrome, a condition in which the immune system destroys the glands that produce tears and saliva

How is celiac disease diagnosed?

A health care provider diagnoses celiac disease with

- a medical and family history
- a physical exam
- blood tests
- an intestinal biopsy
- a skin biopsy

Medical and Family History

Taking a medical and family history may help a health care provider diagnose celiac disease. He or she will ask the patient or caregiver to provide a medical and family history, specifically if anyone in the patient's family has a history of celiac disease.

Physical Exam

A physical exam may help diagnose celiac disease. During a physical exam, a health care provider usually

- examines the patient's body for malnutrition or a rash
- uses a stethoscope to listen to sounds within the abdomen
- taps on the patient's abdomen checking for bloating and pain

Blood Tests

A blood test involves drawing blood at a health care provider's office or a commercial facility and sending the sample to a lab for analysis. A blood test can show the presence of antibodies that are common in celiac disease.

If blood test results are negative and a health care provider still suspects celiac disease, he or she may order additional blood tests, which can affect test results.

Before the blood tests, patients should continue to eat a diet that includes foods with gluten, such as breads and pastas. If a patient stops eating foods with gluten before being tested, the results may be negative for celiac disease even if the disease is present.

Intestinal Biopsy

If blood tests suggest that a patient has celiac disease, a health care provider will perform a biopsy of the patient's small intestine to confirm the diagnosis. A biopsy is a procedure that involves taking a piece of tissue for examination with a microscope. A health care provider performs the biopsy in an outpatient center or a hospital. He or she will give the patient light sedation and a local anesthetic. Some patients may receive general anesthesia.

During the biopsy, a health care provider removes tiny pieces of tissue from the patient's small intestine using an endoscope—a small, flexible camera with a light. The health care provider carefully feeds the endoscope down the patient's esophagus and into the stomach and small intestine. A small camera mounted on the endoscope transmits a video image to a monitor, allowing close examination of the intestinal lining. The health care provider then takes the samples using tiny tools that he or she passes through the endoscope. A pathologist—a doctor who specializes in examining tissues to diagnose diseases—examines the tissue in a lab. The test can show damage to the villi in the small intestine.

Skin Biopsy

When a health care provider suspects that a patient has dermatitis herpetiformis, he or she will perform a skin biopsy. A skin biopsy is a procedure that involves removing tiny pieces of skin tissue for examination with a microscope. A health care provider performs the biopsy in an outpatient center or a hospital. The patient receives a local anesthetic; however, in some cases, the patient will require general anesthesia.

A pathologist examines the skin tissue in a lab and checks the tissue for antibodies that are common in celiac disease. If the skin tissue tests positive for the antibodies, a health care provider will perform blood tests to confirm celiac disease. If the skin biopsy and blood tests both suggest celiac disease, the patient may not need an intestinal biopsy for diagnosis.

Genetic Tests

In some cases, a health care provider will order genetic blood tests to confirm or rule out a diagnosis of celiac disease. Most people with celiac disease have gene pairs that contain at least one of the human leukocyte antigen (HLA) gene variants.[4] However, these variants are also common in people without celiac disease, so their presence alone cannot diagnose celiac disease.

If a biopsy and other blood tests do not give a clear diagnosis of celiac disease, a health care provider may test a patient for HLA gene variants. If the gene variants are not present, celiac disease is unlikely.

Do health care providers screen for celiac disease?

Health care providers in the United States do not routinely screen patients for celiac disease. However, since celiac disease sometimes runs in families, blood relatives of people with celiac disease should talk with their health care provider about their chances of getting the disease. Some researchers recommend the routine testing of all family members, such as parents and siblings, for celiac disease.[1,5] However, routine genetic testing for celiac disease is not usually helpful when diagnosing the disease.

How is celiac disease treated?

Most people with celiac disease have a significant improvement in symptoms when they follow a gluten-free diet. Health care providers typically refer people to a dietitian who specializes in treating people with the disease. The dietitian will teach the person to avoid gluten while following a healthy and nutritious diet. The dietitian will give the person instructions for how to

- read food and product labels and identify ingredients that contain gluten
- make healthy choices about the types of foods to eat
- design everyday meal plans

For most people, following a gluten-free diet will stop symptoms, heal existing intestinal damage, and prevent further damage. Symptoms may improve within days to weeks of starting the diet. The small intestine usually heals in 3 to 6 months in children. Complete healing can take several years in adults. Once the intestine heals, the villi will absorb nutrients from food into the bloodstream normally.

Some people with celiac disease show no improvement after starting a gluten-free diet. The most common reason for poor response to dietary changes is that people are still consuming small amounts of gluten, which can damage the small intestine—even in people without symptoms. Most people start responding to the gluten-free diet once they find and eliminate hidden sources of gluten from their diet. Hidden sources of gluten include additives made with wheat, such as

- modified food starch
- preservatives
- stabilizers

Did you know that medications and nonfood products may contain gluten?

Medications, supplements, and other products may also contain lecithin, a hidden source of gluten. People with celiac disease should ask a pharmacist about the ingredients in

- prescription and over-the-counter medications
- vitamins and mineral supplements
- herbal and nutritional supplements

Other products can be ingested or transferred from a person's hands to his or her mouth. Reading product labels can help people avoid gluten exposure. If a product's label does not list its ingredients, the manufacturer should provide a list upon request.

Products that can contain gluten include

- lipstick, lip gloss, and lip balm
- cosmetics
- skin and hair products
- toothpaste and mouthwash
- glue on stamps and envelopes
- children's modeling dough, such as Play-Doh

Some people who continue to have symptoms even after changing their diet may have other conditions or disorders that are more common in people with celiac disease. These conditions may include

- small intestinal bacterial overgrowth, which happens when too many bacteria grow in the small intestine
- pancreatic exocrine insufficiency, in which the pancreas does not produce enough digestive juice
- microscopic colitis, an inflammation of the colon that a health care provider can see only with a microscope
- IBS
- lactose intolerance, a condition in which people have symptoms after consuming milk or milk products
- other food intolerances, which may occur because of continued damage to the intestine

In some cases, people continue to have difficulty absorbing nutrients despite following a strict gluten-free diet. People with this condition, known as refractory celiac disease, have severely damaged intestines that cannot heal. Their intestines are not absorbing enough nutrients, so

they may need to receive nutrients intravenously. Researchers continue to evaluate medications to treat refractory celiac disease.

Depending on a person's age at diagnosis, some complications of celiac disease will not improve, such as short stature and dental enamel defects.

For people with dermatitis herpetiformis, skin symptoms generally respond to a gluten-free diet and may recur if a person adds gluten back into his or her diet. Medications such as dapsone can control the rash's symptoms. Dapsone does not treat intestinal symptoms or damage, so people with dermatitis herpetiformis should maintain a gluten-free diet, even if they don't have digestive symptoms. Even when a person follows a gluten-free diet, the skin lesions from dermatitis herpetiformis may take months or even years to fully heal and often recur over the years.

Eating, Diet, and Nutrition

Eating, diet, and nutrition play a significant role in treating celiac disease. People with the disease should maintain a gluten-free diet by avoiding products that contain gluten. In other words, a person with celiac disease should not eat most grains, pasta, and cereal, and many processed foods.

People with celiac disease can eat a well-balanced diet with a variety of foods. They can use potato, rice, soy, amaranth, quinoa, buckwheat, or bean flour instead of wheat flour. They can buy gluten-free bread, pasta, and other products from stores, or order products from special food companies. Meanwhile, "plain"—meaning no additives or seasonings—meat, fish, rice, fruits, and vegetables do not contain gluten, so people with celiac disease can eat these foods.

In the past, health care providers and dietitians advised people with celiac disease to avoid eating oats. Evidence suggests that most people with the disease can safely eat small amounts of oats, as long as the oats are not contaminated with wheat gluten during processing. People with celiac disease should talk with their health care team when deciding whether to include oats in their diet.

Eating out and shopping can be a challenge. Newly diagnosed people and their families may find support groups helpful as they adjust to a new approach to eating. People with celiac disease should

- read food labels—especially canned, frozen, and processed foods—for ingredients that contain gluten
- avoid ingredients such as hydrolyzed vegetable protein, also called lecithin or soy lecithin
- ask restaurant servers and chefs about ingredients and food preparation
- inquire whether a gluten-free menu is available
- ask a dinner or party host about gluten-free options before attending a social gathering

Foods that are packaged as gluten-free tend to cost more than the same foods containing gluten. People following a gluten-free diet may find that naturally gluten-free foods are less expensive. With practice, looking for gluten can become second nature.

The Gluten-free Diet: Some Examples

The Academy of Nutrition and Dietetics has published recommendations for a gluten-free diet. The following chart illustrates these recommendations. This list is **not** complete, so people with celiac disease should discuss gluten-free food choices with a dietitian or health care professional who specializes in celiac disease. People with celiac disease should always read food ingredient lists carefully to make sure the food does not contain gluten.

Table 1. Gluten-free foods and foods that contain gluten

Foods and Ingredients That Contain Gluten	
barley	brewer's yeast
rye	dextrin
triticale (a cross between wheat and rye)	malt (unless a gluten-free source is named, such as corn malt)
wheat, including • einkorn, emmer, Kamut, spelt • cracked wheat, hydrolyzed wheat protein, wheat bran, wheat germ, wheat starch	modified food starch oats (not labeled gluten-free) starch

Other Wheat Products That Contain Gluten		
bromated flour	graham flour	self-rising flour
durum flour	phosphated flour	semolina
enriched flour	plain flour	white flour
farina		

Processed Foods That May Contain Wheat, Barley, or Rye*		
bouillon cubes	communion wafers	sauces
brown rice syrup	french fries	seasoned tortilla chips
candy	gravies	self-basting turkey
chewing gum	imitation fish	soups
chips/potato chips	matzo and matzo meal	soy sauce
cold cuts, hot dogs, salami, sausage	rice mixes	vegetables in sauce

*Most of these foods can be found gluten-free. When in doubt, check with the food manufacturer.

Food Products and Ingredients Made from Barley*		
ale	malted milk	other fermented beverages
beer	malt extract	porter
malt	malt syrup	stout
malt beverages	malt vinegar	

*People should only consume these foods if they are labeled gluten-free—such as sorghum-based beer—or they list a grain source other than barley, wheat, or rye—such as corn malt.

Foods That Do Not Contain Gluten			
amaranth	legumes	quinoa	tapioca
arrowroot	lentils	rice	tef (or teff)
buckwheat	millet	sago	wild rice
cassava	nuts	seeds	yucca
corn	oats (labeled gluten-free)	sorghum	
flax	potatoes	soy	

Adapted from: Thompson T. *Celiac Disease Nutrition Guide.* 3rd ed. Chicago: Academy of Nutrition and Dietetics; 2014.

Food Labeling Requirements

On August 2, 2013, the U.S. Food and Drug Administration (FDA) published a new regulation defining the term "gluten-free" for voluntary food labeling. This new federal definition standardizes the meaning of "gluten-free" foods regulated by the FDA. Foods regulated by the U.S. Department of Agriculture, including meat and egg products, are not subject to this regulation. The regulation requires that any food with the term "gluten-free" on the label must meet all of the requirements of the definition, including that the food should contain fewer than 20 parts per million of gluten. The FDA rule also requires foods with the claims "no gluten," "free of gluten," and "without gluten" to meet the definition for "gluten-free."

If a food that is labeled "gluten-free" includes "wheat" on the ingredients list or "contains wheat" after the list, the following statement must be included on the label: "The wheat has been processed to allow this food to meet the Food and Drug Administration requirements for gluten-free food." If this statement is included, people with celiac disease may consume foods labeled "gluten-free."

Points to Remember

- Celiac disease is an immune disorder in which people cannot tolerate gluten because it damages the lining of their small intestine and prevents absorption of nutrients.
- When people with celiac disease eat foods or use products containing gluten, their immune system responds by damaging or destroying villi—the tiny, fingerlike projections on the inner lining of the small intestine.
- A person may experience digestive signs and symptoms, or symptoms in other parts of the body.
- Recognizing celiac disease can be difficult because some of its symptoms are similar to those of other diseases and conditions.
- Dermatitis herpetiformis is a chronic, itchy, blistering skin rash—usually on the elbows, knees, buttocks, back, or scalp—that affects about 5 to 10 percent of people with celiac disease.
- Signs and symptoms of celiac disease vary from person to person because of numerous factors.

- Some people with celiac disease have no signs or symptoms; however, they can still develop complications of the disease over time. Long-term complications include malnutrition, liver diseases, intestinal cancer, and lymphoma.
- A health care provider diagnoses celiac disease with a medical and family history, a physical exam, blood tests, an intestinal biopsy, and a skin biopsy.
- Since celiac disease sometimes runs in families, blood relatives of people with celiac disease should talk with their health care provider about their chances of getting the disease.
- Most people with celiac disease have a significant improvement in symptoms when they follow a gluten-free diet.
- Health care providers typically refer people to a dietitian who specializes in treating people with the disease.
- The dietitian will give the person instructions for how to read food and product labels and identify ingredients that contain gluten.
- Medications, supplements, and other products may also contain a hidden source of gluten.
- People with celiac disease can eat a well-balanced diet with a variety of foods.

Hope through Research

The National Institute of Diabetes and Digestive and Kidney Diseases' (NIDDK's) Division of Digestive Diseases and Nutrition supports several programs and studies devoted to improving treatment for people with diseases of the small intestine, including celiac disease.

Clinical trials are research studies involving people. Clinical trials look at safe and effective new ways to prevent, detect, or treat disease. Researchers also use clinical trials to look at other aspects of care, such as improving the quality of life for people with chronic illnesses. To learn more about clinical trials, why they matter, and how to participate, visit the NIH Clinical Research Trials and You website at *www.nih.gov/health/clinicaltrials.* For information about current studies, visit *www.ClinicalTrials.gov.*

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For More Information

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The Celiac Disease Awareness Campaign

The National Institutes of Health Celiac Disease Awareness Campaign provides current, comprehensive, science-based information about the symptoms, diagnosis, and treatment of celiac disease, also known as celiac sprue, nontropical sprue, and gluten-sensitive enteropathy. The Awareness Campaign is an initiative of the National Digestive Diseases Information Clearinghouse, a service of the National Institute of Diabetes and Digestive and Kidney Diseases.

Download this publication and learn more about the Awareness Campaign at *www.celiac.nih.gov.*

You may also find additional information about this topic by visiting MedlinePlus at *www.medlineplus.gov.*

This publication may contain information about medications and, when taken as prescribed, the conditions they treat. When prepared, this publication included the most current information available. For updates or for questions about any medications, contact the U.S. Food and Drug Administration toll-free at 1–888–INFO–FDA (1–888–463–6332) or visit *www.fda.gov.* Consult your health care provider for more information.

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