

Celiac Disease

Definition & Facts

What is celiac disease?

Celiac disease is a digestive disorder that damages the small intestine. The disease is triggered by eating foods containing gluten. Gluten is a protein found naturally in wheat, barley, and rye, and is common in foods such as bread, pasta, cookies, and cakes. Many pre-packaged foods, lip balms and lipsticks, hair and skin products, toothpastes, vitamin and nutrient supplements, and, rarely, medicines, contain gluten.

Celiac disease can be very serious. The disease can cause long-lasting digestive problems and keep your body from getting all the nutrients it needs. Celiac disease can also affect the body outside the intestine.

Celiac disease is different from gluten sensitivity or wheat intolerance. If you have gluten sensitivity, you may have symptoms similar to those of celiac disease, such as abdominal pain and tiredness. Unlike celiac disease, gluten sensitivity does not damage the small intestine.

Celiac disease is triggered by eating foods containing gluten.

Celiac disease is also different from a wheat allergy. In both cases, your body's immune system reacts to wheat. However, some symptoms in wheat allergies, such as having itchy eyes or a hard time breathing, are different from celiac disease. Wheat allergies also do not cause long-term damage to the small intestine.¹

How common is celiac disease?

As many as one in 141 Americans has celiac disease, although most don't know it.²

Who is more likely to develop celiac disease?

Although celiac disease affects children and adults in all parts of the world, the disease is more common in Caucasians and more often diagnosed in females. You are more likely to develop celiac disease if someone in your family has the disease. Celiac disease also is more common among people with certain other diseases, such as Down syndrome , Turner syndrome , and type 1 diabetes.

What other health problems do people with celiac disease have?

If you have celiac disease, you also may be at risk for

- Addison's disease
- Hashimoto's disease
- primary biliary cirrhosis
- type 1 diabetes

What are the complications of celiac disease?

Long-term complications of celiac disease include

- malnutrition, a condition in which you don't get enough vitamins, minerals, and other nutrients you need to be healthy
- accelerated osteoporosis or bone softening, known as osteomalacia
- nervous system problems
- problems related to reproduction

Rare complications can include

- intestinal cancer
- liver diseases
- lymphoma, a cancer of part of the immune system called the lymph system that includes the gut

In rare cases, you may continue to have trouble absorbing nutrients even though you have been following a strict gluten-free diet. If you have this condition, called refractory celiac disease, your intestines are severely damaged and can't heal. You may need to receive nutrients through an IV.

Symptoms & Causes

What are the symptoms of celiac disease?

Most people with celiac disease have one or more symptoms. However, some people with the disease may not have symptoms or feel sick. Sometimes health issues such as surgery, a pregnancy, childbirth, bacterial gastroenteritis, a viral infection, or severe mental stress can trigger celiac disease symptoms.

If you have celiac disease, you may have digestive problems or other symptoms. Digestive symptoms are more common in children and can include

- bloating, or a feeling of fullness or swelling in the abdomen
- chronic diarrhea
- constipation
- gas
- nausea
- pale, foul-smelling, or fatty stools that float
- stomach pain
- vomiting

For children with celiac disease, being unable to absorb nutrients when they are so important to normal growth and development can lead to

- damage to the permanent teeth's enamel
- delayed puberty
- failure to thrive in infants
- mood changes or feeling annoyed or impatient
- slowed growth and short height
- weight loss

Celiac disease in children may lead to weight loss.

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

- anemia
- a red, smooth, shiny tongue
- bone or joint pain
- depression or anxiety
- dermatitis herpetiformis
- headaches
- infertility or repeated miscarriage
- missed menstrual periods
- mouth problems such as canker sores or dry mouth
- seizures
- tingling numbness in the hands and feet
- tiredness
- weak and brittle bones

Adults who have digestive symptoms with celiac disease may have

- abdominal pain and bloating
- intestinal blockages
- tiredness that lasts for long periods of time
- ulcers, or sores on the stomach or lining of the intestine

Celiac disease also can produce a reaction in which your immune system, or your body's natural defense system, attacks healthy cells in your body. This reaction can spread outside your digestive tract to other areas of your body, including your

- bones
- joints
- nervous system
- skin
- spleen

Depending on how old you are when a doctor diagnoses your celiac disease, some symptoms, such as short height and tooth defects, will not improve.

Dermatitis herpetiformis

Dermatitis herpetiformis is an itchy, blistering skin rash that usually appears on the elbows, knees, buttocks, back, or scalp. The rash affects about 10 percent of people with celiac disease. The rash can affect people of all ages but is most likely to appear for the first time between the ages of 30 and 40. Men who have the rash also may have oral or, rarely, genital sores. Some people with celiac disease may have the rash and no other symptoms.

Why are celiac disease symptoms so varied?

Symptoms of celiac disease vary from person to person. Your symptoms may depend on

- how long you were breastfed as an infant; some studies have shown that the longer you were breastfed, the later celiac disease symptoms appear
- how much gluten you eat
- how old you were when you started eating gluten
- the amount of damage to your small intestine
- your age—symptoms can vary between young children and adults

People with celiac disease who have no symptoms can still develop complications from the disease over time if they do not get treatment.

What causes celiac disease?

Research suggests that celiac disease only happens to individuals who have particular genes. These genes are common and are carried by about one-third of the population. Individuals also have to be eating food that contains gluten to get celiac disease. Researchers do not know exactly what triggers celiac disease in people at risk who eat gluten over a long period of time. Sometimes the disease runs in families. About 10 to 20 percent of close relatives of people with celiac disease also are affected.³

Your chances of developing celiac disease increase when you have changes in your genes, or variants. Certain gene variants and other factors, such as things in your environment, can lead to celiac disease.

References

[3] Ruiz AR. Celiac disease. The Merck Manual website. www.merckmanuals.com . Updated May 2014. Accessed June 5, 2016.

Diagnosis

How do doctors diagnose celiac disease?

Celiac disease can be hard to diagnose because some of the symptoms are like symptoms of other diseases, such as irritable bowel syndrome (IBS) and lactose intolerance. Your doctor may diagnose celiac disease with a medical and family history, physical exam, and tests. Tests may include blood tests, genetic tests, and biopsy.

Medical and family history

Your doctor will ask you for information about your family's health—specifically, if anyone in your family has a history of celiac disease.

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Physical exam

During a physical exam, a doctor most often

- checks your body for a rash or malnutrition, a condition that arises when you don't get enough vitamins, minerals, and other nutrients you need to be healthy
- listens to sounds in your abdomen using a stethoscope
- taps on your abdomen to check for pain and fullness or swelling

Dental exam

For some people, a dental visit can be the first step toward discovering celiac disease. Dental enamel defects, such as white, yellow, or brown spots on the teeth, are a pretty common problem in people with celiac disease, especially children. These defects can help dentists and other health care professionals identify celiac disease.

What tests do doctors use to diagnose celiac disease?

Blood tests

A health care professional may take a blood sample from you and send the sample to a lab to test for antibodies common in celiac disease. If blood test results are negative and your doctor still suspects celiac disease, he or she may order more blood tests.

Genetic tests

If a biopsy and other blood tests do not clearly confirm celiac disease, your doctor may order genetic blood tests to check for certain gene changes, or variants.⁴ You are very unlikely to have celiac disease if these gene variants are not present. Having these variants alone is not enough to diagnose celiac disease because they also are common in people without the disease. In fact, most people with these genes will never get celiac disease.

Intestinal biopsy

If blood tests suggest you have celiac disease, your doctor will perform a biopsy to be sure. During a biopsy, the doctor takes a small piece of tissue from your small intestine during a procedure called an upper GI endoscopy.

Skin biopsy

If a doctor suspects you have dermatitis herpetiformis, he or she will perform a skin biopsy. For a skin biopsy, the doctor removes tiny pieces of skin tissue to examine with a microscope.

A doctor examines the skin tissue and checks the tissue for antibodies common in celiac disease. If the skin tissue has the antibodies, a doctor will perform blood tests to confirm celiac disease. If the skin biopsy and blood tests both suggest celiac disease, you may not need an intestinal biopsy.

Do doctors screen for celiac disease?

Screening is testing for diseases when you have no symptoms. Doctors in the United States do not routinely screen people for celiac disease. However, blood relatives of people with celiac

disease and those with type 1 diabetes should talk with their doctor about their chances of getting the disease.

Many researchers recommend routine screening of all family members, such as parents and siblings, for celiac disease.⁵ However, routine genetic screening for celiac disease is not usually helpful when diagnosing the disease.

Treatment

How do doctors treat celiac disease?

A gluten-free diet

Doctors treat celiac disease with a gluten-free diet. Gluten is a protein found naturally in wheat, barley, and rye that triggers a reaction if you have celiac disease. Symptoms greatly improve for most people with celiac disease who stick to a gluten-free diet. In recent years, grocery stores and restaurants have added many more gluten-free foods and products, making it easier to stay gluten free.

Your doctor may refer you to a dietitian who specializes in treating people with celiac disease. The dietitian will teach you how to avoid gluten while following a healthy diet. He or she will help you

- check food and product labels for gluten
- design everyday meal plans
- make healthy choices about the types of foods to eat

A dietitian can help you make healthy food choices.

For most people, following a gluten-free diet will heal damage in the small intestine and prevent more damage. You may see symptoms 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, which were damaged by the disease, regrow and will absorb nutrients from food into the bloodstream normally.

Gluten-free diet and dermatitis herpetiformis

If you have dermatitis herpetiformis—an itchy, blistering skin rash—skin symptoms generally respond to a gluten-free diet. However, skin symptoms may return if you add gluten back into your diet. Medicines such as dapsone, taken by mouth, can control the skin symptoms. People who take dapsone need to have regular blood tests to check for side effects from the medicine.

Dapsone does not treat intestinal symptoms or damage, which is why you should stay on a gluten-free diet if you have the rash. Even when you follow a gluten-free diet, the rash may take months or even years to fully heal—and often comes back over the years.

Avoiding medicines and nonfood products that may contain gluten

In addition to prescribing a gluten-free diet, your doctor will want you to avoid all hidden sources of gluten. If you have celiac disease, ask a pharmacist about ingredients in

- herbal and nutritional supplements
- prescription and over-the-counter medicines
- vitamin and mineral supplements

You also could take in or transfer from your hands to your mouth other products that contain gluten without knowing it. Products that may contain gluten include

- children's modeling dough, such as Play-Doh
- cosmetics
- lipstick, lip gloss, and lip balm
- skin and hair products
- toothpaste and mouthwash
- communion wafers

Products that may contain gluten include skin and hair products.

Medications are rare sources of gluten. Even if gluten is present in a medicine, it is likely to be in such small quantities that it would not cause any symptoms.

Reading product labels can sometimes help you avoid gluten. Some product makers label their products as being gluten-free. If a product label doesn't list the product's ingredients, ask the maker of the product for an ingredients list.

What if changing to a gluten-free diet isn't working?

If you don't improve after starting a gluten-free diet, you may still be eating or using small amounts of gluten. You probably will start responding to the gluten-free diet once you find and cut out all hidden sources of gluten. Hidden sources of gluten include additives made with wheat, such as

- modified food starch
- malt flavoring

- preservatives
- stabilizers

If you still have symptoms even after changing your diet, you may have other conditions or disorders that are more common with celiac disease, such as irritable bowel syndrome (IBS), lactose intolerance, microscopic colitis, dysfunction of the pancreas, and small intestinal bacterial overgrowth.

Eating, Diet, & Nutrition

What should I avoid eating if I have celiac disease?

Avoiding foods with gluten, a protein found naturally in wheat, rye, and barley, is critical in treating celiac disease. Removing gluten from your diet will improve symptoms, heal damage to your small intestine, and prevent further damage over time. While you may need to avoid certain foods, the good news is that many healthy, gluten-free foods and products are available.

Avoiding foods with gluten is critical in treating celiac disease.

You should avoid all products that contain gluten, such as most cereal, grains, and pasta, and many processed foods. Be sure to always read food ingredient lists carefully to make sure the food you want to eat doesn't have gluten. In addition, discuss gluten-free food choices with a dietitian or health care professional who specializes in celiac disease.

What should I eat if I have celiac disease?

Foods such as meat, fish, fruits, vegetables, rice, and potatoes without additives or seasonings do not contain gluten and are part of a well-balanced diet. You can eat gluten-free types of bread, pasta, and other foods that are now easier to find in stores, restaurants, and at special food companies. You also can eat potato, rice, soy, amaranth, quinoa, buckwheat, or bean flour instead of wheat flour.

In the past, doctors and dietitians advised against eating oats if you have celiac disease. Evidence suggests that most people with the disease can safely eat moderate amounts of oats, as long as they did not come in contact with wheat gluten during processing. You should talk with your health care team about whether to include oats in your diet.

When shopping and eating out, remember to

- read food labels—especially on canned, frozen, and processed foods—for ingredients that contain gluten
- identify foods labelled “gluten-free;” by law, these foods must contain less than 20 parts per million, well below the threshold to cause problems in the great majority of patients with celiac disease

- ask restaurant servers and chefs about how they prepare the food and what is in it
- find out whether a gluten-free menu is available
- ask a dinner or party host about gluten-free options before attending a social gathering

Foods labeled gluten-free tend to cost more than the same foods that have gluten. You may find that naturally gluten-free foods are less expensive. With practice, looking for gluten can become second nature.

If you have just been diagnosed with celiac disease, you and your family members may find support groups helpful as you adjust to a new approach to eating.

Is a gluten-free diet safe if I don't have celiac disease?

In recent years, more people without celiac disease have adopted a gluten-free diet, believing that avoiding gluten is healthier or could help them lose weight. No current data suggests that the general public should maintain a gluten-free diet for weight loss or better health.^{6, 7}

A gluten-free diet isn't always a healthy diet. For instance, a gluten-free diet may not provide enough of the nutrients, vitamins, and minerals the body needs, such as fiber, iron, and calcium. Some gluten-free products can be high in calories and sugar.

If you think you might have celiac disease, don't start avoiding gluten without first speaking with your doctor. If your doctor diagnoses you with celiac disease, he or she will put you on a gluten-free diet.

Gluten-free food labeling requirements

The U.S. Food and Drug Administration (FDA) published a rule defining what "gluten-free" means on food labels. The "gluten-free" for food labeling rule requires that any food with the terms "gluten-free," "no gluten," "free of gluten," and "without gluten" on the label must meet all of the definition's requirements.

While the FDA rule does not apply to foods regulated by the U.S. Department of Agriculture, including meat and egg products, it is often still observed.