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Patient information: Celiac disease in adults (Beyond the Basics)

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CELIAC DISEASE OVERVIEW — Celiac disease is a condition in which the immune system responds abnormally to a protein called gluten, which then leads to damage to the lining of the small intestine. Gluten is found in wheat, rye, barley, and a multitude of prepared foods. Celiac disease is also known as gluten sensitive enteropathy (enter-OH-pathy), celiac sprue, and nontropical sprue.

The small intestine is responsible for absorbing food and nutrients. Thus, damage to the lining of the small intestines can lead to difficulty absorbing important nutrients; this problem is referred to as malabsorption. Although celiac disease cannot be cured, avoiding gluten usually stops the damage to the intestinal lining and the malabsorption that results. Celiac disease can occur in people of any age and it affects both genders.

This topic discusses celiac disease in adults. Celiac disease in children is discussed separately. (See "[Patient information: Celiac disease in children \(Beyond the Basics\)](#)".) More detailed information about celiac disease is available by subscription. (See "[Pathogenesis, epidemiology, and clinical manifestations of celiac disease in adults](#)" and "[Diagnosis of celiac disease](#)" and "[Management of celiac disease in adults](#)".)

CELIAC DISEASE SYMPTOMS — The symptoms of celiac disease vary from one person to another. In its mildest form, there may be no symptoms whatsoever. However, even if you have no symptoms, you may not be absorbing nutrients adequately, which can be detected with blood tests. As an example, you can develop a low blood count as a result of decreased iron absorption.

Some people have bothersome symptoms of celiac disease, including diarrhea, weight loss, abdominal discomfort, excessive gas, and other signs and symptoms caused by vitamin and nutrient deficiencies.

Some conditions are more common in people with celiac disease, including:

- Osteopenia or osteoporosis (weakening of the bones)
- Iron deficiency anemia (low blood count due to lack of iron)
- Diabetes mellitus (type I or so-called juvenile onset diabetes mellitus)
- Thyroid problems (usually hypothyroidism, an underactive thyroid) (see "[Patient information: Hypothyroidism \(underactive thyroid\) \(Beyond the Basics\)](#)")
- A skin disease called dermatitis herpetiformis (see '[Skin conditions](#)' below)
- Nervous system disorders

- Liver disease

CELIAC DISEASE CAUSES — It is not clear what causes celiac disease. A combination of environmental and genetic factors is important. Celiac disease occurs widely in Europe, North and South Americas, Australia, North Africa, the Middle East and in South Asia. Celiac disease occurs rarely in people from other parts of Asia or sub-Saharan Africa.

CELIAC DISEASE DIAGNOSIS — Celiac disease can be difficult to diagnose because the signs and symptoms are similar to other conditions. Fortunately, testing is available that can easily distinguish untreated celiac disease from other disorders. (See "[Diagnosis of celiac disease](#)".)

Blood tests — A blood test can determine the blood level of antibodies (proteins) that become elevated in people with celiac disease. Over 95 percent of people with untreated celiac disease have elevated antibody levels (called IgA tissue transglutaminase, or IgA tTG), while these levels are rarely elevated in those without celiac disease.

Before having these tests, it is important to continue eating a normal diet, including foods that contain gluten. Avoiding or eliminating gluten could cause the antibody levels to fall to normal, delaying the diagnosis.

Small intestine biopsy — If your blood test is positive, the diagnosis must be confirmed by examining a small sample of the intestinal lining with a microscope. The sample (called a biopsy) is usually collected during an upper endoscopy, a test that involves swallowing a small flexible instrument with a camera. The camera allows a physician to examine the upper part of the gastrointestinal system and remove a small piece (biopsy) of the small intestine. The biopsy is not painful. (See "[Patient information: Upper endoscopy \(Beyond the Basics\)](#)".)

In people with celiac disease, the lining of the small intestine has a characteristic appearance when viewed with a microscope. Normally, the lining has distinct finger-like structures, which are called villi. Villi allow the small intestine to absorb nutrients. The villi become flattened in people with celiac disease. Once you stop eating gluten, the villi can resume a normal growth pattern. More than 70 percent of people begin to feel better within two weeks after stopping gluten.

One way to determine if the gluten-free diet is working is to monitor the levels of antibodies in your blood. If your levels decline on a gluten-free diet, this usually indicates that the diet has been effective.

"Potential" celiac disease — People with a positive IgA endomysial antibody test and/or a positive IgA-tTG test and a normal small bowel biopsy are considered to have potential celiac disease. People with potential celiac disease are NOT usually advised to eat a gluten-free diet. However, ongoing monitoring (with a blood test) is recommended and a repeat biopsy may be needed if you develop symptoms. Biopsies should be taken from several areas in the bowel since the abnormality can be patchy.

"Silent" celiac disease — If you have a positive blood test for celiac disease and an abnormal small bowel biopsy, but you have no other symptoms of celiac disease, you are said to have "silent" celiac disease. It is not clear if people with silent celiac disease should eat a gluten-free diet. Blood tests for malabsorption are recommended, and a gluten-free diet may be needed if you have evidence of malabsorption.

Testing for malabsorption — You should be tested for nutritional deficiencies if your blood test or bowel biopsy indicates celiac disease. Common tests include measurement of iron, [folic acid](#), or vitamin B12, and vitamin D. You may have other tests if you have signs of mineral or fat deficiency, such as changes in taste or smell, poor appetite, changes in your nails, hair, or skin, or diarrhea.

Other tests — Other standard tests include a CBC (complete blood count), lipid levels (total cholesterol, HDL, LDL, and triglycerides), and thyroid levels. Once your celiac antibody levels return to normal, you should have a repeat test once per year.

Many clinicians recommend a test for bone loss 12 months after beginning a gluten-free diet. One method involves using a bone density (DEXA) scan to measure your bone density. The test is not painful and is similar to having an x-ray. If you have significant bone loss, you may need calcium and vitamin D supplements, an exercise program, and possibly a medicine to stop bone loss and encourage new bone growth. (See "[Patient information: Bone density testing \(Beyond the Basics\)](#)".)

CELIAC DISEASE COMPLICATIONS

Nonresponsive celiac disease — Approximately 10 percent of people with celiac disease experience ongoing symptoms despite adhering to a gluten-free diet. There are many causes including other food intolerances or food allergies, bacterial overgrowth in the small intestine or conditions such as microscopic colitis, irritable bowel syndrome, or refractory celiac disease. However, the most common cause is ongoing, often inadvertent, gluten ingestion. Thus, an essential first step in evaluating nonresponsive celiac disease is consultation with an experienced celiac dietitian.

Refractory celiac disease — A small percentage of people develop intestinal symptoms that do not improve despite use of a strict gluten-free diet. In other cases, intestinal symptoms initially improve with dietary changes but then return.

People who have these problems may have refractory celiac disease. The cause of this problem is not known. Treatment involves medications that suppress the immune system's abnormal response (eg, steroids). Treatment is important because people with untreated celiac disease can develop anemia, bone loss, and other consequences of malabsorption.

Ulcerative jejunitis — People with refractory celiac disease who do not improve with steroids (glucocorticoids) may have a condition known as ulcerative jejunitis. This condition causes the small intestine to develop multiple ulcers that do not heal; other symptoms may include a lack of appetite, weight loss, abdominal pain, diarrhea, and fever. This condition can be difficult to treat. Treatment may require surgery to remove the ulcerated area.

Lymphoma — Cancer of the intestinal lymph system (lymphoma) is an uncommon complication of celiac disease. Avoiding gluten can usually prevent this complication.

Skin conditions — Celiac disease is associated with a number of skin disorders, of which dermatitis herpetiformis is the most common. Dermatitis herpetiformis is characterized by intensely itchy, raised, fluid-filled areas on the skin, usually located on the elbows, knees, buttocks, lower back, face, neck, trunk, and occasionally within the mouth.

The most bothersome symptoms are itching and burning. This feeling is quickly relieved when the blister ruptures. Scratching causes the area to rupture, dry up, and leave an area of darkened skin and scarring. The condition will improve after eliminating gluten from the diet, although it may take several weeks to see significant improvement. In the meantime, an oral medication called [dapson](#)e may be recommended. Dapsone relieves the itching but does not heal the lining of the small intestine; thus, the gluten-free diet is the most effective therapy for those with dermatitis herpetiformis.

CELIAC DISEASE TREATMENT

Gluten-free diet — The cornerstone of treatment for celiac disease is complete elimination of gluten from the diet for life. Gluten is the group of proteins found in wheat, rye and barley that are toxic to those with celiac disease. Gluten is not only contained in these most commonly consumed grains in the Western world; it is also hidden as an ingredient in a large number of prepared foods, as well as medications and supplements.

Maintaining a gluten-free diet can be a challenging task that may require major lifestyle adjustments. Strict gluten avoidance is recommended since even small amounts can aggravate the disease. It is important to avoid both eating gluten and being exposed to flour dust in the air. (See "[Management of celiac disease in adults](#)".)

Get help from a dietitian — Working with an experienced celiac dietitian can help you to learn how to eat a gluten-

free diet, what foods to avoid, and what foods to add for a nutritionally balanced diet.

Your celiac dietitian can also educate you on shopping, food preparation and lifestyle resources. Excellent resources are also available from celiac medical centers, organizations, and support groups. (See ['Where to get more information'](#) below.)

Fortunately, life on a gluten-free diet becomes increasingly easier each year due to the rising popularity of gluten-free foods among those with celiac disease, non-celiac gluten sensitivity, and wheat allergies. Excellent gluten-free substitute foods are now widely available in supermarkets, health food stores, and on-line.

General tips

- Avoid foods containing wheat, rye, barley, malt, brewer's yeast, and oats (unless pure, uncontaminated, labeled gluten-free oats).
- Naturally gluten-free foods include rice, wild rice, corn, potato, and other foods listed in the table ([table 1](#)). These foods may be contaminated with wheat, barley or rye. Therefore, wherever possible choose "gluten-free" versions of these products. According to the US Food and Drug Administration (FDA) regulations issued in August 2013, foods with "gluten-free" labeling must contain less than 20 parts per million (ppm) of gluten.
- Read labels on prepared foods and condiments carefully, paying particular attention to the "Contains" statement and the ingredient list. The word "wheat" will be included if the product is FDA regulated and it contains wheat protein. The following table has a list of prepared foods that sometimes contain gluten ([table 2](#)).
- Distilled alcoholic beverages and vinegars, as well as wine, are gluten-free unless gluten-containing flavorings are added after production. However, malt beverages, including beer, are not considered gluten-free. There are specially produced beers that do not use malted barley that are labeled gluten-free and can be consumed on a gluten-free diet. Please note that malt vinegar is not gluten-free.
- You may not tolerate dairy products initially while your intestines are healing. If you tolerated lactose before your diagnosis, you may be able to tolerate it again after the intestine heals. In the mean time, choose lactose-reduced or lactose-free products if your symptoms are worsened by dairy products. Choose labeled gluten-free, dairy-free alternatives, such as rice, soy, or nut (almond, hazelnut) beverages that are enriched with calcium and vitamin D. Keep in mind that gluten-free rice and nut milks have minimal protein per serving compared with cow's or soy milk. Gluten-free [lactase](#) enzyme supplements are also available, which may help you to tolerate foods that contain lactose.
- Discuss your need for calcium and vitamin D supplements with your healthcare provider or dietitian.
- A small percentage of people with celiac disease cannot tolerate oats. If you choose to eat oats, consult with a healthcare provider or dietitian, who can help to monitor your symptoms. In addition, you should avoid oats unless the package specifically indicates that the product is gluten-free and was processed in a gluten-free facility. Do not eat more than 50 grams (about 1/2 cup dry rolled oats, 1/4 cup dry steel cut oats) of oats per day.

Is gluten avoidance really necessary? — People who have no symptoms of celiac disease often find it difficult to follow a strict gluten-free diet. Indeed, some healthcare providers have questioned the need for a gluten-free diet in this group. However, certain factors support a gluten-free diet, even in those without symptoms:

- Strictly following a gluten-free diet sometimes helps you to feel more energetic and have an improved sense of health and well being.
- Some people with celiac disease have vitamin or nutrient deficiencies that do not cause them to feel ill, such as anemia due to iron deficiency or bone loss due to vitamin D deficiency. However, these deficiencies can cause

problems over the long term.

- Untreated celiac disease can increase the risk of developing certain types of gastrointestinal cancer. This risk can be reduced by eating a gluten-free diet.

IMPLICATIONS FOR THE FAMILY — Eliminating gluten requires a major lifestyle change for you as well as your family. However, with time and practice, it will be easier to know which foods, medications, supplements, and oral care products contain gluten and what alternatives are available. Although eating out can be challenging initially, restaurants have become increasingly interested in serving people with celiac disease by offering a gluten-free menu or ingredient substitutions.

Families also need to be aware of their increased risk of celiac disease. Thus, your first-degree relatives (parents, brothers, sisters, children) should consider being tested, especially if anyone has signs or symptoms of the condition. Testing is typically done with a blood antibody test, as described above (see '[Blood tests](#)' above).

WHERE TO GET MORE INFORMATION — Your healthcare provider is the best source of information for questions and concerns related to your medical problem.

This article will be updated as needed on our web site (www.uptodate.com/patients). Related topics for patients, as well as selected articles written for healthcare professionals, are also available. Some of the most relevant are listed below.

Patient level information — UpToDate offers two types of patient education materials.

The Basics — The Basics patient education pieces answer the four or five key questions a patient might have about a given condition. These articles are best for patients who want a general overview and who prefer short, easy-to-read materials.

[Patient information: Celiac disease \(The Basics\)](#)

[Patient information: Microscopic colitis \(The Basics\)](#)

[Patient information: Gluten-free diet \(The Basics\)](#)

Beyond the Basics — Beyond the Basics patient education pieces are longer, more sophisticated, and more detailed. These articles are best for patients who want in-depth information and are comfortable with some medical jargon.

[Patient information: Celiac disease in children \(Beyond the Basics\)](#)

[Patient information: Hypothyroidism \(underactive thyroid\) \(Beyond the Basics\)](#)

[Patient information: Upper endoscopy \(Beyond the Basics\)](#)

[Patient information: Bone density testing \(Beyond the Basics\)](#)

Professional level information — Professional level articles are designed to keep doctors and other health professionals up-to-date on the latest medical findings. These articles are thorough, long, and complex, and they contain multiple references to the research on which they are based. Professional level articles are best for people who are comfortable with a lot of medical terminology and who want to read the same materials their doctors are reading.

[Diagnosis of celiac disease](#)

[Management of celiac disease in adults](#)

[Pathogenesis, epidemiology, and clinical manifestations of celiac disease in adults](#)

The following organizations also provide reliable information for people living with celiac disease or nonceliac gluten sensitivity.

- Academy of Nutrition and Dietetics (formerly American Dietetic Association)

(www.eatright.org)

- American Celiac Disease Alliance

(www.americanceliac.org)

- American Gastroenterological Association

(<http://www.gastro.org/patient-center/digestive-conditions/celiac-disease>)

- Celiac Center at Beth Israel Deaconess Medical Center

(www.celiacnow.org)

- Celiac Disease Foundation

(www.celiac.org)

- Gluten Intolerance Group of North America

(www.gluten.net)

- National Foundation for Celiac Awareness (NFCA)

(www.celiacentral.org)

- National Institute of Diabetes and Digestive and Kidney Diseases

(www.niddk.nih.gov)

- National Library of Medicine

(www.nlm.nih.gov/medlineplus/celiacdisease.html)

- North American Society for the Study of Celiac Disease

(www.nasscd.org)

Patient support — There are a number of online forums where patients can find information and support from other people with similar conditions.

- Celiac.com

(www.celiac.com)

- Celiac List-serv
 - Send email message to: celiac@listserv.icors.org
 - Leave the subject line blank
 - Text: type SUB celiac your first name your last name (eg, "SUB celiac Joan Smith")

[1-5]

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Topic 1999 Version 8.0

GRAPHICS

Gluten-free foods

Amaranth	Legumes	Sorghum (milo)
Arrowroot	Millet	Soy
Beans/bean flours (garfava, etc)	Nuts/nut flours	Tapioca, tapioca starch
Buckwheat	Potato, potato starch, potato flour	Teff
Cassava	Quinoa	Wild rice
Corn	Rice	Yucca
Flax	Sago	
Job's tears	Seeds	

The foods listed above are naturally gluten-free. However, naturally gluten-free grains, flours, nuts, seeds, and products made from them may be contaminated with wheat, barley, and/or rye. Whenever possible, choose labeled gluten-free versions of these products.

Reproduced with permission from: Dennis M, Case S. Going gluten-free: a primer for clinicians. Pract Gastroenterol 2004; 28:86.

Graphic 54353 Version 6.0

Overlooked sources of gluten or potential gluten

Foods and products that contain or MAY contain gluten, depending on their ingredients or how they are derived. This is not an all-inclusive list.

Ales

Beer/lagers

Breading

Brewer's yeast

Broth/bouillon

Brown rice syrup

Cake frosting

Candy

Coating mixes

Communion wafers

Condiments

Croutons

Dates (if rolled in oat flour)

Drink mixes

Flavored teas and coffees

Flavored spirits (eg, raspberry vodka)

Flour or cereal products

Gravies

Imitation bacon

Imitation seafood

Licorice

Marinades

Malt, malt flavoring, and malt extract (avoid unless made from a gluten-free grain, such as rice malt, sorghum malt or corn malt; if so, it will be labeled as such)

Malt vinegar

Matzo/matzo meal

Medications (prescription and over the counter)

Oats (avoid unless pure, uncontaminated, labeled gluten-free oats)

Panko (Japanese bread crumbs)

Pasta

Play-Doh®, paper maché, glue, and many art supplies*
Processed luncheon meats
Rice pilaf and other packaged rice mixtures
Roux
Salad dressing
Sauces/spreads
Seasonings (or spice blends)
Seasoned chips, nuts, and seeds
Self-basting poultry
Smoke flavoring
Soup stock
Soy sauce (commonly made with both soy and wheat)
Stuffing (for poultry)
Supplements
Not allowed in any form
Wheat (einkorn, durum, faro, graham, kamut, semolina, spelt)
Rye
Barley
Malt, malt flavoring, malt extract derived from barley
Malt vinegar
Triticale

* The gluten protein does not pass through the skin. Avoid cross contamination by washing hands after handling and before eating.

Adapted from: Dennis M. Inadvertent gluten exposure. In: Real Life with Celiac Disease: Troubleshooting and Thriving Gluten-Free, Dennis M, Leffer D (Eds), AGA Press, Bethesda, MD 2010.

Graphic 56053 Version 3.0

Disclosures

Disclosures: **Ciarán P Kelly, MD** Consultant/Advisory Boards: Cubist Pharmaceuticals [C. difficile infection (Fidaxomicin)]; Merck [C. difficile infection (Anti-toxin HuMabs)]; Sanofi-Pasteur [C. difficile infection (toxoid vaccine)]; Astellas [C. difficile infection (Fidaxomicin)]; Claremont BioSolutions [C. difficile (diagnostic assay)]; Medimmune [C. difficile (Anti-toxin HuMabs)]; Regeneron [C. difficile (Anti-toxin HuMabs)]; Stellar Biotechnologies [C. difficile (Bacterial surface vaccine)]; Alba [celiac disease (Larazotide acetate)]; Alvine [celiac disease (Glutenase preparation)]; ImmunosanT [celiac disease (Gliadin-targeted vaccine)]. Grant/Research/Clinical Trial Support: Merck [C. difficile infection (Anti-toxin HuMabs)]; Sanofi-Pasteur [C. difficile infection (toxoid vaccine)]; Claremont BioSolutions [C. difficile (diagnostic assay)]; Alba [celiac disease (Larazotide acetate)]. Equity Ownership/Stock Options: Alvine [celiac disease (Glutenase preparation)]; ImmunosanT [celiac disease (Gliadin-targeted vaccine)]. **Melinda Dennis, MS, RD, LDN** Nothing to disclose. **J Thomas Lamont, MD** Nothing to disclose. **Shilpa Grover, MD, MPH** Employee of UpToDate, Inc.

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