

Understanding & Managing Celiac Disease

A Patient Guide to Diagnosis, Diet, and Long-Term Care

What Is Celiac Disease?

Celiac disease is an autoimmune condition in which eating gluten — a protein found in wheat, barley, and rye — triggers the immune system to attack the lining of the small intestine. Over time, this damages the finger-like projections (villi) that absorb nutrients from food, which is why untreated celiac disease can lead to deficiencies in iron, vitamins, and other nutrients even when a person is eating enough. Symptoms vary widely: some people have classic digestive symptoms like diarrhea, bloating, and weight loss, while others have subtler signs — fatigue, anemia, bone loss, or infertility — or no symptoms at all. The condition ranges from mild to severe, but the underlying intestinal damage and long-term risks are the same regardless of how noticeable the symptoms are.

What Causes It?

- **Genetics.** Almost everyone with celiac disease carries one of two gene variants, HLA-DQ2 or HLA-DQ8. However, roughly a third of the general population carries one of these genes and never develops celiac disease, so other factors must also be involved.
- **Family history.** A first-degree relative (parent, sibling, or child) of someone with celiac disease has about a 1-in-10 chance of developing it as well, which is why we often recommend testing close relatives, even without symptoms.
- **Other autoimmune conditions.** Celiac disease occurs more often alongside type 1 diabetes, autoimmune thyroid disease (such as Hashimoto's), and dermatitis herpetiformis — an itchy, blistering skin rash considered to be the skin form of celiac disease.
- **Environmental triggers.** The exact trigger that turns genetic risk into active disease isn't fully understood; it can develop at any age, including in people who previously tolerated gluten for years.

How Celiac Disease Is Diagnosed

Diagnosis starts with a blood test for tTG-IgA (tissue transglutaminase IgA antibody). This test only works while you're still regularly eating gluten — starting a gluten-free diet beforehand can cause a false-negative result, so please don't cut out gluten before testing or before your endoscopy without checking with us first. In adults, a positive blood test is confirmed with an upper endoscopy (EGD) and several biopsies taken from the duodenum (the first part of the small intestine), which remains the most reliable way to confirm the diagnosis and assess how much damage has occurred. Professional guidelines recommend against screening the general population, but do recommend testing anyone with suggestive symptoms, unexplained iron-deficiency anemia, a related autoimmune condition, or a first-degree relative with celiac disease.

How Celiac Disease Is Managed

A strict, lifelong gluten-free diet is currently the only proven treatment for celiac disease — there is no medication that treats the condition itself. Beyond the diet, management focuses on correcting nutritional deficiencies that are often already present at diagnosis, checking bone health, and following up over time to confirm the diet is working and healing is underway. A “pooled analysis” (also called a meta-analysis) mentioned below means researchers combined results from several studies for a more reliable answer than any single study could give alone.

Strict Gluten-Free Diet

Goal: eliminate the trigger completely — even small, repeated amounts of gluten can continue to damage the intestine and delay healing.

- **Avoid all wheat, barley, and rye**, and foods made from them — this includes most breads, pastas, cereals, and baked goods unless specifically labeled gluten-free.
- **Oats are naturally gluten-free**, but are frequently cross-contaminated with wheat during growing, transport, or processing — choose products specifically labeled “gluten-free oats.” A small number of people with celiac disease react to avenin, a protein in oats similar to gluten, so we recommend introducing them gradually and letting us know if symptoms return.
- **Watch for hidden sources of gluten** — soy sauce, malt, some sauces and gravies, beer, and certain supplements or medications can all contain gluten as a filler or ingredient. Reading labels (or checking with the manufacturer) becomes second nature over time.
- **Reduce cross-contact at home** — use a separate toaster or clearly designated section of the toaster, separate cutting boards and colanders, and fresh oil for frying gluten-free foods.
Evidence: Even trace amounts of gluten, well below what most people would notice, can be enough to keep the immune reaction active in someone with celiac disease.
- **Ask for a referral to a registered dietitian** experienced in celiac disease, especially in the first year — this is one of the most effective ways to shorten the learning curve and avoid accidental exposures.

Nutritional Deficiency Screening & Correction

Goal: identify and correct deficiencies caused by years of poor absorption, which are common even in people without obvious digestive symptoms.

- **Baseline lab work at diagnosis** typically includes a complete blood count, iron studies, vitamin B12, folate, 25-hydroxy vitamin D, zinc, and copper, along with thyroid and liver tests.
Evidence: Deficiencies are common at diagnosis: studies have found reduced iron stores in roughly 46% of newly diagnosed patients, anemia in about 32%, zinc deficiency in up to two-thirds of patients, and lower rates of folate, B12, and vitamin A deficiency as well.
- **Targeted supplementation** for any deficiency found, with repeat labs to confirm correction once you've been on a gluten-free diet for a while.
Evidence: Absorption of iron, B12, folate, and fat-soluble vitamins typically improves substantially as the intestinal lining heals on a gluten-free diet, though supplementation is still often needed in the meantime.

Bone Health

Goal: catch low bone density early, since reduced calcium and vitamin D absorption puts celiac patients at higher risk of osteopenia and osteoporosis.

- **A baseline bone density scan (DEXA)**, generally done around the time of diagnosis or after the first year on a gluten-free diet.
Evidence: Low bone density is common at diagnosis, with studies reporting osteoporosis or osteopenia in a substantial proportion of newly diagnosed adults, even in those without digestive symptoms.
- **Follow-up screening later in life**, particularly around age 45, when risk of bone loss rises further.
Evidence: A 2025 study found adults with celiac disease face an increased risk of lumbar spine osteoporosis in middle age, and suggested bone density screening at 45 as a reasonable checkpoint.
- **The gluten-free diet itself is the main treatment** for celiac-related bone loss in most patients, alongside adequate calcium and vitamin D intake.
Evidence: In many patients, especially those diagnosed at a younger age, a strict gluten-free diet alone is enough to halt further bone loss and allow density to recover over time.

Monitoring & Follow-Up

Goal: confirm the diet is working, catch accidental gluten exposure early, and support long-term healing.

- **Repeat tTG-IgA blood testing**, typically around 3–6 months after starting a gluten-free diet, and then periodically (often annually) afterward.

Evidence: Falling antibody levels are a useful sign that the diet is being followed closely and that the intestine is healing, even though antibody levels don't always perfectly track with biopsy findings.

- **Ongoing follow-up** with our office and, ideally, a dietitian — especially useful in the first year, during other major diet changes, or if symptoms return.

If Symptoms Don't Improve

Some patients continue to have symptoms, or persistently abnormal labs, despite reportedly following a gluten-free diet — this is called non-responsive celiac disease. Before assuming something more serious is going on, it's important to know that the most common cause by far is unintentional gluten exposure, not a more severe or treatment-resistant form of the disease.

- **Ongoing gluten exposure** — often from cross-contamination, hidden ingredients, or eating out — accounts for a large share of cases in studies that have looked into this, and is always the first thing we check.
- A detailed diet review with an experienced dietitian, sometimes paired with a stool or urine test that detects gluten breakdown products, is typically the next step before considering more involved testing.
- True refractory celiac disease — where the intestine stays damaged despite confirmed strict gluten avoidance — is uncommon and requires specialist evaluation, but this is only considered after other explanations have been ruled out.

Related Conditions to Be Aware Of

- **Type 1 diabetes** and **autoimmune thyroid disease** occur more often in people with celiac disease, and vice versa — your care team may check for these periodically.
- **Dermatitis herpetiformis**, an itchy, blistering rash usually on the elbows, knees, or buttocks, is a skin manifestation of celiac disease and usually improves with the same gluten-free diet.
- **Family members.** Because of the roughly 1-in-10 risk in first-degree relatives, it's reasonable for parents, siblings, and children of someone with celiac disease to be tested, even without symptoms.

When to Contact Our Office

- Unintentional weight loss, ongoing diarrhea, or new abdominal pain despite a gluten-free diet
- Signs of a nutrient deficiency, such as unusual fatigue, tingling or numbness, or unexplained bone pain
- Difficulty staying gluten-free, or you'd like a referral to a dietitian who specializes in celiac disease
- Symptoms that persist despite what you believe is strict gluten avoidance
- You're planning a pregnancy, as celiac disease that isn't well controlled can affect fertility and pregnancy outcomes
- A close family member is considering testing for celiac disease

This guide supports your personalized plan and isn't a substitute for individualized medical advice. Check with your provider before starting, stopping, or combining anything mentioned here.

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