FAQs: Medical Management of Celiac Disease (CD)

Are the villi permanently damaged in celiac disease (CD)? If not, how long will they take to recover?

No, the villi are not permanently damaged in CD. Once a person with CD starts a strict gluten-free diet (GFD), the small intestine begins to heal. Most people start feeling better within just two weeks of removing gluten from their diet. Symptoms like diarrhea often improve within the first couple of months.

However, full healing of the intestinal lining can take much longer—sometimes up to 3 years or more. Everyone heals at a different pace, and older adults may take longer to recover. The intestine itself renews quickly, but regrowing healthy villi takes time and good adherence to a gluten-free lifestyle.

Reference: Rubio-Tapia, A; Hill, I; Semrad, C; Kelly, CP; Greer, K; Limketkai, B; Lebwohl, B. American College of Gastroenterology Guidelines Update: Diagnosis and Management of Celiac Disease. Am J Gastroenterol. 118(1):p 59-76, January 2023.

How long does it take for the tTG-IgA blood test for celiac disease (CD) to be normal?

For most adult patients on the gluten-free diet (GFD), tTG-IgA levels normalize within several months to one year. tTG has a half-life of six months, which means it should drop by a half-fold in six months. Hence, if you started off at a tTG level in the thousands, it might take several years to normalize. With a GFD, 8 out of 10 patients will test negative (normal tTG) within a year. After five years on the diet, this increases to 9 out of 10 patients.

Many times, it is hard to predict when the test should become normal because some tTG tests don’t report values above a certain limit. For example, one test reports values up to 120 mg/dl after which all values, whether in the hundreds or thousands, are reported in the same manner. Whenever possible, it is recommended to have your tTG test done at the same facility to compare the level easily over time.

References:
Elli L, Leffler D, Cellier C, et al. Guidelines for best practices in monitoring established coeliac disease in adult patients. Nat Rev Gastroenterol Hepatol. 2024;21(3):198-215. doi:10.1038/s41575-023-00872-2

Kivelä L, Kaukinen K, Lähdeaho ML, Huhtala H, Kurppa K. Serologic follow-up of celiac disease in children and adults: a systematic review. Nutrients. 2021;13(10):3567.

Is it important to have repeat blood tests or biopsies to confirm that I have celiac disease (CD)?

It is important to be accurately diagnosed with celiac antibody blood tests and a biopsy before going on a gluten-free diet (GFD). After starting the diet, follow-up tests are individualized based on age, symptoms, and other health problems. Routine follow-up with a dietitian skilled in CD and a gastroenterologist is strongly recommended. In most cases, blood tests are performed regularly, while repeat biopsies are not as often as necessary. Your doctor will determine which specific tests are needed.

References:

Silvester JA, Kurada S, Szwajcer A, Kelly CP, Leffler DA, Duerksen DR. Tests for serum transglutaminase and endomysial antibodies do not detect most patients with celiac disease and persistent villous atrophy on gluten-free diets: a meta-analysis. Gastroenterology. 2017;153(3):689-701.e1. doi:10.1053/j.gastro.2017.05.015

Ribeiro CDS, Uenishi RH, Domingues ADS, et al. Gluten-free diet adherence tools for individuals with celiac disease: a systematic review and meta-analysis of tools compared to laboratory tests. Nutrients. 2024;16(15):2428. Published 2024 Jul 26. doi:10.3390/nu16152428

I think I have celiac disease (CD), but I had a negative blood test. How do I know if I have it?

It is possible to have CD even with a negative blood test. This is called “seronegative celiac disease” and it affects up to 5-16% of patients with CD. If you are on a gluten-containing diet and had a negative blood test for CD but still have symptoms, your doctor may recommend getting a biopsy of your small intestine.

If your blood tests and your small intestine biopsy are both negative on a gluten-containing diet, you can conclude that you do not have CD. However, if the biopsy does show damage, your doctor will then test you for the main celiac genes (HLA-DQ2 or DQ8).

If a person has intestinal damage on a biopsy but tests negative for the celiac genes (HLA-DQ2 or DQ8), it means that the damage is being caused by a condition other than CD. Therefore, your doctor will investigate other potential causes for the intestinal damage. If none are found, he/she may suggest trying a gluten-free diet for 12 to 24 months, followed by another biopsy to see if your intestine has healed. Remember that if new symptoms develop over time, you can always be rechecked. Visit Screening and Blood Tests on www.celiacnow.org.

Also, it is important to mention that some patients without CD may experience discomfort after ingesting gluten. These patients may feel better on a gluten-reduced diet. This condition is called “non–celiac gluten sensitivity” and is not the same as CD. Visit Non-Celiac Gluten Sensitivity on CeliacNow.org

References

Rubio-Tapia A, Hill ID, Semrad C, et al. American College of Gastroenterology Guidelines Update: Diagnosis and management of celiac disease. Am J Gastroenterol. 2023;118(1):59-76. doi:10.14309/ajg.0000000000002075

Schiepatti A, Sanders DS, Baiardi P, et al. Nomenclature and diagnosis of seronegative coeliac disease and chronic non-coeliac enteropathies in adults: the Paris consensus. Gut. 2022;71(11):2218-2225. doi:10.1136/gutjnl-2021-326645

Manza F, Lungaro L, Costanzini A, et al. Non-celiac gluten/wheat sensitivity-state of the art: a five-year narrative review. Nutrients. 2025;17(2):220. Published 2025 Jan 8. doi:10.3390/nu17020220

My doctor told me I have celiac disease (CD), but I feel fine. Should I start the gluten-free diet (GFD)?

The recommendation to start a GFD can be complex when a person has positive test results for CD but feels perfectly fine. The decision often depends on whether the intestine is damaged, which distinguishes between two different conditions: “silent celiac disease” and “potential celiac disease”.

A person with silent CD has no symptoms, but tests show both a positive blood test and intestinal damage on a biopsy. In this case, a GFD is typically recommended to heal the intestine and resolve other issues you may not be aware of, such as nutritional deficiencies.

On the other hand, a person with potential CD has a positive blood test but a normal intestinal biopsy. This diagnosis may be especially true in children with high-risk relatives who are frequently tested. This situation is more complicated and experts do not always agree on the next step. Some doctors will recommend a "watch and wait" approach with regular check-ups, while others may suggest starting the GFD due to concerns about future risks. Because the guidelines are not absolute for every situation, it's best to talk to a doctor specialized in CD about the pros and cons for your specific case.

References:

Caio G, Volta U, Sapone A, et al. Celiac disease: a comprehensive current review. BMC Med. 2019;17(1):142. Published 2019 Jul 23. doi:10.1186/s12916-019-1380-z

Nemteanu R, Clim A, Hincu CE, et al. Is there a time and a place for the gluten-free diet in potential celiac disease? Nutrients. 2023;15(18):4064. Published 2023 Sep 20. doi:10.3390/nu15184064

If a person with celiac disease (CD) does not follow the gluten-free diet (GFD) carefully, does it cause permanent damage?

Yes, if someone with CD does not follow a strict GFD, it can lead to serious and possibly long-lasting damage to the small intestine. Continued gluten exposure can destroy the villi leading to problems like malnutrition, anemia, bone loss, and an increased risk of certain cancers. Even small amounts of gluten can keep the intestine from healing properly, even if there are no obvious symptoms.

In some cases, the damage may become harder to reverse, especially in adults. That's why lifelong, careful adherence to the GFD is the only effective way to manage CD and prevent long-term complications.

Reference: Rubio-Tapia, A; Hill, I; Semrad, C; Kelly, CP; Greer, K; Limketkai, B; Lebwohl, B. American College of Gastroenterology Guidelines Update: Diagnosis and Management of Celiac Disease. Am J Gastroenterol. 118(1):p 59-76, January 2023.

If a person with celiac disease (CD) follows the gluten–free diet (GFD) very carefully but the IgA-tTG level continues to rise, what can it mean? Could dairy or fructose affect the IgA-tTG blood level?

After starting a GFD, doctors usually check blood tests after 4 to 6 weeks to make sure antibody levels are going down. If levels stay high or symptoms continue, it could mean the person is still being exposed to gluten—often by accident. Gluten can be overlooked in many processed foods, medications, or supplements, making it difficult to avoid completely. Meeting with a dietitian who understands CD can help find sources and make the diet easier to manage.

In some cases, other issues, such as small intestinal bacterial overgrowth (SIBO), may cause similar symptoms and high antibody levels. And, in rare cases, patients can develop refractory CD, where symptoms do not improve despite strict gluten avoidance. This may require medical treatment beyond diet alone. That's why regular follow-up with your healthcare provider is important to monitor progress and adjust care, as needed.

Reference: Patient education: Celiac disease in adults (Beyond the Basics). In: UpToDate. Post TW, ed. UpToDate; 2025. Accessed August 25, 2025.

Does a small or large amount of gluten elicit the same response? If so, why? Is it dose related?

Yes, once a person with CD eats enough gluten to cross a certain threshold, even a small amount can trigger the same immune reaction as a larger amount. Research shows that as little as 10 to 50 mg of gluten per day—far less than what's in a single slice of wheat bread—can damage the small intestine over time. This is why gluten-free products are required to have <20 parts per million (ppm) of gluten, which is considered a safe level for most people with CD.

After this threshold is passed, the severity of the damage and symptoms do not increase in a clear dose-related way. In other words, once the immune system is triggered, more gluten does not necessarily make the reaction worse. Everyone's sensitivity varies, but avoiding all gluten is the best way to stay safe.

Reference: Forbes GM. Safety of gluten in gluten-free foods. United European Gastroenterol J. 2016 Feb;4(1):152.

Why are people sometimes diagnosed so late in life? Could a person have had celiac disease (CD) for years and not known it?

The typical age of CD diagnosis among adults is sometime in their forties. It is very common for people to have had CD for a while before being diagnosed. The average time from the onset of gastrointestinal symptoms until diagnosis is 11 years. This lag time might be significantly higher in people who have CD but do not have symptoms.

Reference: Fasano A, Berti I, Gerarduzzi T, et al. Prevalence of celiac disease in at-risk and not-at-risk groups in the United States: a large multicenter study. Arch Intern Med. 2003;163(3):286–292. doi:10.1001/archinte.163.3.286

Shouldn't every person in the U.S. be tested for celiac disease (CD)?

Screening every person in the US for CD might not be cost-effective given that it is estimated to affect only about 1% of the general population. Nonetheless, most people who have CD are not aware of their diagnosis. This is due to insufficient screening in high-risk individuals and low disease awareness in the community.

To improve diagnosis rates, we recommend screening adults and second-degree relatives of people with CD as well as people with autoimmune diseases who have suggestive symptoms. It is also recommended that children of individuals with CD get screened once, even if they are not symptomatic.

Reference: US Preventive Services Task Force, Bibbins-Domingo K, Grossman DC, et al. Screening for celiac disease: US Preventive Services Task Force Recommendation Statement. JAMA. 2017;317(12):1252-1257. doi:10.1001/jama.2017.146

Does non-celiac gluten sensitivity cause visible damage in an endoscopy/biopsy?

No, non-celiac gluten sensitivity does not cause visible damage of the small intestine in endoscopy. But occasionally, the biopsy may show some inflammatory cells only. The presence of normal villous architecture is the characteristic feature of non-celiac gluten sensitivity, unlike in CD.

Reference: Manza F, Lungaro L, Costanzini A, et al. Non-celiac gluten/wheat sensitivity-state of the art: a five-year narrative review. Nutrients. 2025;17(2):220. Published 2025 Jan 8. doi:10.3390/nu17020220

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 bloodwork of people with this spectrum of diseases is a high count of a type of white blood cell called eosinophils. Some researchers have found that asthma and CD tend to occur together often. Nevertheless, based on our current knowledge, CD and these atopic diseases are separate diseases with different mechanisms in the body.

Reference: Kårhus LL, Skaaby T, Madsen AL, et al. The association of celiac disease and allergic disease in a general adult population. United European Gastroenterol J. 2019;7(1):78-89. doi:10.1177/2050640618811485

Can a person with celiac disease (CD) donate blood?

Yes, a person with CD can donate blood. There is no evidence that CD or its antibodies are transmitted through blood transfusion. As long as the person is in good health, a blood donation is safe.

Reference: Ludvigsson JF, Lebwohl B, Green PHR, Murray JA, Hjalgrim H, Edgren G. Is blood transfusion linked to celiac disease? a nationwide cohort study. Am J Epidemiol. 2018;187(1):120-124. doi:10.1093/aje/kwx210

What healthcare providers should I see for my celiac disease (CD)?

After being diagnosed with CD, it’s important to work with a team of healthcare providers to manage your condition. Start by seeing a gastroenterologist (a doctor who specializes in digestive diseases) to confirm your diagnosis and check for related health concerns. You may also need regular follow-up visits (e.g., at 3, 6, and 12 months, then yearly) to monitor your symptoms and recovery. Your primary care doctor will continue to support your overall health throughout this process.

One of the most important members of your care team is a registered dietitian who specializes in CD. They can help you follow a gluten-free diet safely and in a way that fits your lifestyle, culture, and nutritional needs. They'll also guide you in reading food labels, grocery shopping, preventing cross-contact in the kitchen, and selecting the right supplements, as needed. Depending on your situation, you may also see other specialists such as an endocrinologist for thyroid issues, diabetes, or bone health management. Additionally, a social worker or clinical psychologist can provide valuable support for emotional and social adjustments to living with CD. Ongoing education and support from your care team can make a big difference in helping you stay healthy and live well with CD.

The Celiac Center at Beth Israel Deaconess Medical Center has a listing of clinicians skilled in the management of CD. These individuals will aid in the diagnosis of the disease if you or your doctor suspects CD and will also provide long-term specialized care for you if you are already diagnosed with CD. Please visit Meet our Team and What to Expect from your Gastroenterologist's Visit on celiacnow.org.

Reference: Rubio-Tapia, A; Hill, I; Semrad, C; Kelly, CP; Greer, K; Limketkai, B; Lebwohl, B. American College of Gastroenterology Guidelines Update: Diagnosis and Management of Celiac Disease. Am J Gastroenterol. 118(1):p 59-76, January 2023.

Revision Date: November-25-2025
Authors: Matheus M. Berleze, MD, Maria S. Quines CRC, Javier Villafuerte MD,
Editors: Melinda Dennis, MS, RD, LDN