



**1. What are the recommended infant feeding practices for a child at risk of celiac disease?**

If the infant has the genetic predisposition for celiac disease, as documented by either a genetic test or suggested by being born into a family with a parent or a sibling with celiac disease, it is recommended that the child be breastfed for at least six months, and possibly up to 1 year. Gluten should be introduced, in very small amounts, while breastfeeding between 4-6 months of life.\*

\*Please note that research is ongoing that may alter these guidelines, suggesting that introduction of gluten should be postponed after the 6 month threshold, but at this moment this is not the recommendation.

**2. What is the difference between celiac disease, gluten intolerance, wheat allergy and gluten sensitivity?**

Gluten intolerance is a generic term encompassing any adverse reaction to gluten ingestion, regardless of the mechanism involved: it includes celiac disease, wheat allergy, and “gluten sensitivity”.

Wheat allergy is an allergic reaction to gluten ingestion, mediated by specific immune mechanisms that are common to other food allergies (e.g. milk, nuts...) and is totally different from celiac disease.

The last term, gluten sensitivity, is the most difficult to define, as it implies adverse reactions caused by gluten ingestion that do not fall into the two known and well characterized entities outlined above. Some individuals indeed manifest symptoms to gluten and yet no tests can identify a specific pathology in them. Research is active on this topic, including bench investigations carried out at The University of Chicago Celiac Center.

**3. Which blood tests are the best for screening for celiac disease and how accurate are they?**

For most people the serum Anti-Tissue Transglutaminase (tTG-IgA) is the best antibody blood test for screening for celiac disease; however, it is important to also get a Total Serum IgA. Having this total serum test will help bolster the reliability of the tTG test. The reason for this is that while the tTG test is very reliable, its reliability is dependent on the premise that the person being tested adequately produces IgA. If the individual does not produce sufficient amounts of IgA and is instead IgA deficient, then the tTG-IgG should be tested instead.



There is also a newer version of the old screening test that checked the levels of anti-gliadin antibodies, called DPG (for Deamidated Gliadin Peptides). While evidence shows these tests to be as reliable as the tTG, they are not necessarily better than the tTG.

NOTE: Dermatitis Herpetiformis (also known as DH, the skin version of celiac disease) is best diagnosed with a skin biopsy, that is sufficient for diagnosis. Patients with DH may in fact have normal serum tTG and occasionally even normal intestinal biopsy; yet they invariably need a strict gluten-free diet, just like every other celiac patient.

**4. Can someone with celiac disease eat oats?**

Oats as a grain do not contain gluten. Still, historically oats were not recommended for people with celiac disease because it was thought that avenin (the storage protein found in oats) was also toxic to gluten-intolerant individuals. However, abundant research in Europe and the U.S. has uniformly indicated that in fact oats are well tolerated by celiac children and adults when consumed in moderation and do not contribute to abdominal symptoms, nor prevent intestinal healing. That said, regular, commercially available oats are frequently contaminated with wheat or barley. PURE UNCONTAMINATED OATS, however, are available from several companies in the U.S. and Canada. These companies process oats in dedicated facilities and test the oats for purity. Pure, uncontaminated oats can be safely consumed by someone with celiac disease in quantities of <1 cup per day.

**5. Do lotions or hair care products need to be gluten-free?**

Consumption of gluten is what causes celiac disease to become active. Gluten in hair products or lotions are only dangerous if they are swallowed. Therefore it is important that lipstick, lip balm, toothpaste, mouthwash and hand lotion be gluten-free. Shampoos and hair products would only be of concern if they are ingested. These products do not cause damage if simply absorbed by the skin.

**6. How long after being gluten-free does it take for your intestine to heal and to have proper absorption of nutrients?**

The intestine is an amazing organ in that it is very quick to regenerate its lining once the gluten has been removed from the diet. In fact, most newly diagnosed celiac patients will notice a significant improvement in symptoms within days or weeks of starting treatment with a strict gluten free diet.



Even in those patients that do not notice their symptoms improving quickly, the intestinal lining does begin healing immediately and, without exposure to gluten completely re-generates in a matter of a few months.

The healing process may take longer in older patients or if there is more severe damage, and in some cases persistence of a low-grade inflammation is seen in spite of a rigorous gluten-free diet. It is however thought that even in these cases there should typically be no major problems with nutrient absorption and/or symptoms.

**7. What are the implications of a person with CD inadvertently ingesting gluten? Any long term effects? How long does it take to recover from the gluten?**

The ingestion of gluten—intentional or otherwise—reactivates the disease, triggering the abnormal immune reaction that causes damage to the intestinal tissue.

Each person has a different healing time, but typically the reaction gradually subsides after gluten is out of the system. While any ingestion of gluten is detrimental, it is repeated ingestion of gluten that will cause long term damage—keeping the disease in its active state and exposing to the risks that may occur in patient who just do not follow the diet.

**8. If you have tested positive for the genes associated with celiac disease, what is the proper protocol for further screening and diagnosis?**

If you have a gene associated with celiac disease and are having symptoms, you should have the antibody blood tests to screen for the disease immediately. If you have the gene and are a first-degree relative of a biopsy-diagnosed celiac, you should be screened every 2-3 years or immediately if you have symptoms. Nearly 30% of the population carries the genes associated with celiac disease. Only about 5% of that population ever actually develops the disease. Once it is found in a family it is very important to screen 1<sup>st</sup> degree relatives.

**9. If you have symptoms should you try the gluten free diet before being diagnosed?**

No. It is very important that all screening and diagnosis occur BEFORE experimenting with the treatment/gluten free diet. Once the treatment is started, within a couple of months it will make the anti-body screening tests and necessary biopsy unreliable and will prevent an accurate diagnosis.

**10. Is the gluten free diet recommended for healthy individuals or those with other diseases or disorders?**

The gluten free diet is mandatory for those with celiac disease. Although popular culture also promotes the diet as a “healthier” way to eat, there is no evidence that proves such a claim to be true. Some also claim that the gluten free diet is helpful to those who suffer from autism. So



far, scientific studies have failed to support this claim; a double-blind study is under way in the US that will likely shed more light on this controversial issue. For the time being, one should notice that studies have shown the risk of essential amino acids deficiency and bone mineral loss in autistic children on a casein and gluten-free diet.

**11. Are stool tests acceptable to screen for or diagnosis celiac disease or gluten intolerance or gluten sensitivity?**

No. There is currently no published evidence supporting the usefulness of any stool tests in screening for celiac disease or any forms of gluten intolerance. In fact, there is currently no medically accepted test—genetic, stool, blood or otherwise—that is considered valid in screening for gluten intolerance or gluten sensitivity.

**12. Should celiac patients have routine bone scans?**

It is not typically necessary for children with celiac disease to have bone scans as a strict gluten free diet should repair any loss of density within a year or so. It is generally a good idea for adults with celiac disease to monitor bone loss as it may require supplements to reverse damage.

**13. How is tooth enamel related to celiac disease?**

Enamel of the permanent teeth is formed during the first couple of years of the child's life. If during this time celiac disease occurs and remain undiagnosed, then the proper of several nutrients may be impaired. Among them, nutrients needed for proper formation of enamel may be missing, leading to its imperfect building, that will later shows itself when the permanent teeth finally erupt. While enamel defects can occur also in non-celiac individuals, they are manifolds more common in celiac patients.

**14. Should a nursing mother go on the gluten free diet if the baby's father has celiac disease?**

First, it is important to know if the child has the genetic predisposition for celiac disease, something that can be easily assessed by performing the genetic test. In any case, however, the best information known shows that it is not necessary for a non-celiac mother who breastfeeds a child at risk for celiac disease to be gluten free. From what we know, in fact the "gluten" (actually gliadin) that gets through to the baby in breast milk might actually have a protective, tolerance building effect.

**15. If the tTG-IgA number is very high, is the biopsy still necessary?**

The specificity of the tTG test is very high; in other words, someone with a very high titer of tTG-IgA can be considered to have about a 97% risk of being actually a celiac. However, false



positives occur; they are more frequent in subjects who have a liver disorder, an autoimmune disorder (such as type 1 diabetes) or Crohn's disease. It is for this reason that a confirmatory biopsy is considered necessary practically in all cases. Many GI specialists would also obtain a serum anti-Endomysium antibody test (EMA) in such cases, to add (or subtract!) diagnostic weight to the tTG and the intestinal biopsy.

**16. How is the biopsy done-where are samples taken from, how many samples, what do they show? My doctor said that he looked and saw no evidence of celiac so he did not do the biopsy. Is it possible he missed it?**

The biopsy is done during an upper gastrointestinal endoscopy (called "EGD" for Esophago-Gastro-Duodenoscopy). This is a 10 minute procedure usually done under deep sedation, that allows the endoscopist to obtain with a special forceps some specimens (of the size of a grain of rice) from the lining of the gut. It is important to obtain at least 4 biopsies from different parts of the duodenum to yield the highest diagnostic value. Even though the procedure itself may visually show changes suggestive of celiac disease ("scalloping" of the mucosa and others), these changes are very often absent in celiac patients; in other words, there is no way a diagnosis of celiac disease can be made or disproved only visually, without proper biopsy taking.