



Family Talk: Getting Your Family Tested for Celiac Disease

Celiac disease runs in families. Your family members are at risk even though they may have no symptoms at all. You can help them to understand the risk factors and the importance of getting tested. Celiac disease testing starts with a simple blood test and can help prevent a series of lifelong health problems.

Who is at risk for celiac disease?

1st or 2nd degree relative of a person with celiac disease

- 1 in 22 first-degree family members (parent, child, sibling) and 1 in 39 second-degree family members (aunt, uncle, niece, nephew, grandparent, grandchild and half-sibling) are at risk for celiac disease.
- Your risk may double if your brother or sister has celiac disease.
- You can determine your risk through genetic testing for the HLA-DQ2 and HLA-DQ8 genes.

You or your family have a history of autoimmune disease

- Having an autoimmune disease makes you more likely to develop other autoimmune diseases.
- Some autoimmune diseases are Type 1 diabetes, thyroid disease and some liver diseases, like primary biliary cirrhosis.
- An estimated 1 in 10 individuals with Type 1 diabetes in the U.S. has celiac disease.

What are the signs and symptoms?

- A 2012 survey found that 35% of people at risk for celiac disease had no reason to suspect that the symptoms they were experiencing may be due to undiagnosed celiac disease.
- Classic symptoms include diarrhea, anemia, weight loss or growth failure.
- Non-classic symptoms include constipation, abdominal pain, and foul-smelling and bulky stools.
- Other symptoms include skin rash, unexplained infertility, fatigue, headaches and nutritional deficiencies.
- Many people with undiagnosed celiac disease experience no symptoms at all.

What happens if celiac disease is left untreated?

- Left untreated, undiagnosed celiac disease can increase your risk of other problems, including: osteoporosis, infertility, recurrent miscarriage, thyroid disease and even certain cancers, like lymphoma.
- An early diagnosis of celiac disease can help to prevent the development of other autoimmune diseases.

Talk to your untested family members and tell them the facts.

www.CeliacCentral.org/family

You have a special role in informing your family members about celiac disease.

Getting tested is easy. You can lead the way.

Your experience and advice are hard to ignore. Explain to your untested family members that a simple blood test is the first step to diagnosis. Remind them to remain on a normal diet containing gluten until after all testing is complete.

- To start, your untested family members need to ask for an IgA-tTG along with a total IgA level.
- Most major health insurers cover the cost of testing.
- Let your relatives know to contact their primary care provider, family medicine doctor or OB-GYN about getting tested.



Personal risk information is easy to ignore.

- With so much health information in the news each day, it's easy to stop listening.
- This is especially true when someone feels perfectly healthy and is not aware of symptoms.

You give celiac disease a face.

- Your diagnosis of celiac disease makes it personal for your relatives. Your experience and advice are hard to ignore.
- In a 2012 study, 64% of those with a diagnosed family member said they would get tested for celiac disease if a family member asked them to.

Untested at-risk family members are difficult to reach.

- Without understanding the signs, symptoms and risk of celiac disease, getting your untested family members' attention is difficult.
- You play a key role in getting them the information they need to keep themselves healthy.



This guide was created by Claudia Dolphin, MA, as part of the Applied Learning Experience, Master's in Health Communication program at Emerson College. Educational guidance was provided by celiac disease experts at the National Foundation for Celiac Awareness and the Celiac Center at Beth Israel Deaconess Medical Center.