

Seriously, Celiac Disease.

If you have celiac disease, your family members might have it too. **Talk** to them about your experience and how celiac disease runs in families. **Tell** them the facts. Urge them to get a simple blood **test**.

NFCA research has shown that having a serious conversation about your family's risk of developing celiac disease can make a major impact in your family's health and future. This discussion guide can help you have a serious conversation about celiac disease using research-tested tips and tools.

Why talk to your family about testing for celiac disease?

If you have been recently diagnosed, you or your family may have some questions on what exactly celiac disease is. Celiac disease is a genetic autoimmune disease that damages the villi (small, finger-like projections that cover the lining of the small intestine) and interferes with absorption of nutrients from food. The disease has a variety of symptoms and can be very serious if mismanaged or untreated. Most people with undiagnosed celiac disease don't notice any obvious signs or symptoms.



talk.



tell.



test.



talk to your family.



Talking to your family immediately following your celiac disease diagnosis is important for several reasons. Your family might not be aware that they may be genetically at-risk or understand the severity of celiac disease. You can help them understand why getting tested is important for their own health.

Research shows that most family members only want to have this serious conversation once, so it's important that you use the right information and tactics when talking to them.

To have a memorable and impactful discussion, please **DO** the following:

DO initiate the conversation.

Start the conversation when you're in a comfortable setting where your family member doesn't feel caught off guard.

Have the conversation when both of you are free and focused.

Present the conversation in an open way where your family member can also ask you questions.

DO keep it conversational, but personal.

Talk face-to-face, or over the phone if that's not possible.

Pay attention to how your family member is responding to you.

Personalize the conversation based on your relationship with your family member and their personality.

Focus on wanting to help keep your family healthy.

DO ensure your family member feels comfortable and is interested, engaged, and actively participating in the conversation.

Pay attention to their body language and their mood, shifting the conversation based on their responses.

DO talk about symptoms and how serious celiac disease can be.

Talk about any symptoms that your family member can relate to. Stress that everyone has different symptoms and some have none at all.

Highlight the severity of celiac disease and reference certain diseases linked to celiac disease that might run in your family, such as:

- Lymphoma
- Small intestinal cancer
- Primary liver cancer
- Pancreatic cancer
- Autoimmune thyroid disease
- Type 1 diabetes

DO decide on an action plan.

Make sure you and your family member have next steps planned. Ask them how, if at all, they would like to have a follow-up conversation. For example, will your family member make an appointment to get tested? Or will you revisit the conversation in a few weeks?

talk to your family.

Research shows that certain actions or behavior can prevent your relatives from understanding the seriousness of celiac disease.

To have the best conversation possible, please **DON'T** do the following:

DON'T assume your family member will want to get tested right away.

The idea might make them nervous or scared.

DON'T have the conversation over e-mail or social media.

Celiac disease testing should be a personal conversation between family members.

DON'T have the conversation at a large family gathering or in a setting where a meal or food is the main focus.

Try to have a one-on-one talk with each family member in a private setting using an informative tone.

DON'T use statistics to talk about their celiac disease risk.

Most people cannot relate to these types of facts and instead prefer a conversation focused on their relevant personal experiences.

DON'T intimidate them by focusing on the details of a gluten-free diet.

Change can be scary for some people, so if they bring up the gluten-free diet, be sure to talk about it in a positive way.

DON'T simply share educational materials with them.

Family members are open to receiving education about celiac disease testing, but only when it adds to the conversation. Most family members prefer to use the material to prepare for their doctor's visit, and only some will consider sharing it with their healthcare provider.

DON'T be too casual about it.

Celiac disease is serious and deserves the time and attention for a focused conversation. If you talk about it too casually, your family member is less likely to understand the need to be tested.

DON'T bring up testing again unless you already chose a date for a follow-up conversation.

Some family members may tune out when approached more than once and when no new information is shared.

tell them the facts.



Since many people with celiac disease don't have any symptoms at all, it can be hard to clearly explain what undiagnosed celiac disease can do to your body. That's why it's important to tell them the facts. Your family needs to know that it is genetic and, if not properly diagnosed or treated, can lead to certain types of cancer and other autoimmune diseases. Help them understand the importance of a formal diagnosis and its long-term management with a team of knowledgeable healthcare providers.

When telling your family member about the facts of celiac disease, **DO** explain that:

- It's an autoimmune disease, which means that your immune system is attacking its healthy cells. This is different than a food allergy.
- It runs in families, and one person's diagnosis is reason for all blood relatives to learn more.
- Most people don't notice any signs or symptoms of celiac disease, but usually feel a big difference once they are properly diagnosed and managing their disease.
- Everyone is affected by celiac disease differently. Help your family member understand by talking about certain symptoms or associated conditions he or she may be experiencing.

Urge
them to
test.



Encourage your family member to ask for the celiac disease blood test at their next doctor's visit. This blood test – IgA tissue transglutaminase (tTG) – is the first step in learning if a person has celiac disease, can easily be ordered by most doctors and is covered by most insurance plans. The celiac disease blood test has a higher rate of identifying celiac disease than the genetic test, making it the test most family members prefer.

Talk to your family about staying on a regular, gluten-containing diet before being tested to ensure accurate results.

When you talk to your family, remind them that it is possible to continue to be at risk for developing celiac disease even if previous blood test results have been negative. **Because celiac disease can develop at any time and at any age, they should have a follow-up celiac disease blood test every two or three years.** Encourage them to pay close attention to any changes in their body so they can talk to their doctor about them in between the follow-up tests. If they ask, let your family member know you can help them find a knowledgeable doctor or handle any challenges they come across during the testing process.

Visit www.SeriouslyCeliac.org to:

- Download and share a free postcard with your family member so they can learn about the signs and symptoms of celiac disease and how to ask their doctor for the right celiac disease blood test.
- Get more tips and advice on how to have a serious and successful conversation about celiac disease with your family, including personal stories from others diagnosed with the autoimmune disease.

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