THE FACTS

about Celiac Disease & Gluten-Related Conditions

nca
National Celiac Association
Education & Advocacy for the Gluten-free Community

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What is Celiac Disease?

Celiac disease (CeD) is a genetic autoimmune disease where the body's immune system reacts abnormally to gluten. Gluten is a protein found in wheat, barley, and rye. When someone with CeD eats gluten, the villi on the lining of the small intestine become damaged and are unable to absorb nutrients properly.

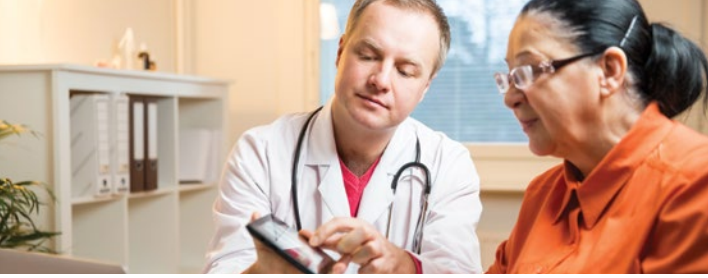
Treatment of Celiac Disease

Currently, the only treatment for CeD is the lifelong adherence to a strict gluten-free (GF) diet. All food that either contains gluten or might have had contact with gluten (known as cross-contact) must be avoided.

People with CeD must watch for cross-contact and/or items that have been used with gluten-containing food and cannot be sufficiently cleaned. For example:

- Toasters, toaster ovens, air fryers
- Food preparation surfaces
- Condiments and spreads
- Shared serving utensils
- Colanders/strainers
- Deep fryers

It can take time to heal, but it is vital to keep to a strict GF diet.



Who has Celiac Disease?

- CeD is common, affecting at least 1% of the population.
- Greater than 80% of people with CeD are undiagnosed.
- The genes known to be associated with CeD are HLA-DQ2 and HLA-DQ8.
- When a first-degree family member has CeD, the probability of developing it increases significantly.
- CeD can develop at any age.
- CeD affects individuals from all ethnic backgrounds.

Symptoms of Celiac Disease

There are over 200 symptoms of CeD and they vary so widely that **there is no such thing as a typical case**. Many people do not experience any of the gastrointestinal symptoms that were previously thought to typify the condition. These individuals often face a delay in diagnosis.

Physical symptoms may include:

- Abdominal cramping/pain
- Anemia/iron deficiency
- Bloating/distention
- Brain fog/inability to concentrate
- Canker sores
- Constipation
- Dental abnormalities
- Diarrhea
- Edema/swelling
- Electrolyte imbalance
- Elevated liver enzymes
- Fatigue
- Headaches
- Infertility/miscarriage
- Lactose intolerance
- Menstrual irregularities
- Nausea/vomiting
- Osteopenia/ osteoporosis
- Pain in bones/joints
- Peripheral neuropathy
- Rash (see dermatitis herpetiformis)
- Stool abnormalities
- Vitamin and mineral deficiencies
- Weight loss or gain

Emotional symptoms may include:

- Anxiety
- Depression
- Irritability
- Mood changes

Common symptoms in children:

Children with CeD may exhibit any of the previously listed symptoms as well as:

- Failure to thrive
- Delayed puberty
- ADHD-like symptoms

Other Gluten-Related Conditions

Non-Celiac Gluten/Wheat Sensitivity (NCGWS)

Symptoms are similar to those of CeD. Unlike CeD, however, there is usually minimal to no damage to the intestinal villi. Currently there is no test to diagnose NCGWS. A diagnosis of NCGWS can be made after CeD and wheat allergy have been ruled out. Eliminating gluten from the diet is the only treatment for NCGWS.

Dermatitis Herpetiformis (DH)

An itchy, blistering skin rash that is a form of CeD. In almost all cases, the small intestine of a person with DH is also damaged by ingesting gluten. DH is diagnosed via skin biopsy by a dermatologist. It is recommended to see a gastroenterologist as well. The treatment for DH is the GF diet and other treatments to manage symptoms.

Asymptomatic Celiac Disease

Classic clinical symptoms may not be present, but there is usually damage to the lining of the small intestine. Testing may have only taken place due to family history or an associated condition. However, as with symptomatic CeD, failure to keep to a strict GF diet can lead to long-term health complications.

Wheat Allergy

An allergic immune reaction to wheat ingestion that involves a different branch of the immune system from CeD. Wheat allergy should be diagnosed by an allergist. Treatment is a wheat-free diet and may include medications to manage symptoms.

Refractory Celiac Disease

A rare condition where the intestine does not heal and symptoms remain present despite 12 months on a strict GF diet. Potential treatment options exist in addition to the GF diet and should be discussed with a healthcare provider knowledgeable in CeD.

Diagnosis

It is important to continue to consume gluten throughout the testing process. Failure to do so can lead to a false negative or an inconclusive result.

The steps leading to a diagnosis of celiac disease are:

1. A thorough physical examination with complete medical history.
2. Blood work that will measure the amount of particular antibodies in the blood. It should include:
   - tTG IgA (tissue transglutaminase antibody immunoglobulin A) together with a total serum IgA

   Other available blood work includes:
   - DGP IgA and IgG (deamidated gliadin peptide immunoglobulin A and G): This test can detect CeD in people who have an IgA deficiency
   - IgA EMA (endomysial antibody)
3. An upper endoscopy with several biopsies of the small intestine, including the duodenum.

It is necessary to go through the testing process to get an accurate diagnosis since other serious medical conditions can present in a similar way to CeD and need to be ruled out.

Additionally, keeping to a lifelong, strict GF diet can be burdensome and is more difficult to maintain without a proven medical need. After you are diagnosed with CeD and begin a GF diet, your antibody levels will start to drop and your villi will begin to heal.

Follow-Up Care

Number One Goal: Keep to a Strict GF Diet

- Following a diagnosis of CeD, a baseline level of blood work should be taken to test for vitamin and mineral deficiencies as well as to check for medical conditions that are associated with, or can be caused by CeD. These include other autoimmune diseases (e.g., thyroid diseases, type 1 diabetes) and conditions such as osteoporosis and liver disease.
- Follow-up visits with a gastroenterologist and a registered dietitian who are well versed in CeD are recommended.
- First-degree family members should be tested for CeD regardless of the presence of symptoms due to the strong hereditary link. High-risk individuals should be tested at regular intervals as CeD can develop at any stage in life.

Thriving with Celiac Disease

Once you start the GF diet and work with your healthcare team, you can begin to thrive!

- You are on the road to recovery!
- You will discover GF recipes that are truly delicious.
- You will meet wonderful people within the gluten-free community.
- You will learn how to get out and enjoy the world, traveling and dining out at safe restaurants with friends & family.
- You've got this, and we've got your back.

NCA is Here to Help

NCA has a wide range of programs to help individuals understand their diagnosis, deal with the complexities of the GF diet, and manage its social impact.

Feeding Gluten Free℠

ROCK Raising Our Celiac Kids

Supporting Celiac Seniors

NCA NATIONWIDE SUPPORT NETWORK

nationalceliac.org

Visit nationalceliac.org

Learn More

- View our webinar, **"Understanding and Managing Gluten-Related Conditions."**
- Sign up for NCA's **free e-newsletter** to learn about celiac research, upcoming events, product recalls/alerts, advocacy, and more!
- Explore hundreds of **"Ask the Experts" FAQs** as well as recorded educational webinars.
- Plan your weekly meals with our comprehensive **recipes**.
- Access NCA's ***Gluten-Free Nation*** magazine.

Find Events

- Join our lively monthly **virtual meetings for all ages** as well as in-person events around the nation, found on our event calendar online.
- Register for upcoming **webinars** with national and international celiac disease experts.

Download Comprehensive Tools

- Take advantage of online access to ***The Complete Guide to Gluten-Free Living*** (hard copy available for purchase).
- Try recipes from our cookbook, ***Thrifty Gluten Free*** (hard copy available for purchase).
- Find money-saving strategies from our ***Budget Guide***.

Check Out Our Community Initiatives

- **Feeding Gluten Free:** disaster preparedness and pantry search
- **Raising Our Celiac Kids (ROCK):** child and teen-focused resources including a peer mentorship program with Celiac Chat
- **Supporting Celiac Seniors:** advocacy strategies and age-specific resources

"As a busy clinician, I have found the National Celiac Association a very helpful resource for my patients. The educational materials provided are excellent, along with resources and opportunities for support that are not always available in many communities. It's a great help for patients and providers alike!"

– David Limauro, MD, FACG, Pittsburgh Gastroenterology Associates and South Hills Endoscopy Center

"Because of the efforts by all of you, my diet, health, and my whole life has improved so much. THANK YOU."

– Anonymous

"The National Celiac Association has been a leading national advocate and educator, profoundly impacting individuals with celiac disease and other gluten-related disorders. In partnership with our team in Northern California, the NCA is addressing food insecurity in high-risk communities by identifying needs, providing education, and training food pantries in safe gluten-free food handling and distribution."

– Hilary Jericho, MD, Endowed Medical Director, Celiac Disease Program, Stanford Medicine Children's Health Center for IBD and Celiac Disease Division of Gastroenterology, Hepatology, and Nutrition Stanford University | Department of Pediatrics

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