



QUICK FACTS

about Celiac Disease
& Related Conditions

nca
National
Celiac Association

Education & Advocacy for the Gluten-free Community

nationalceliac.org | 617.262.5422



What is Celiac Disease?

Celiac disease (CeD) is a genetic autoimmune condition that mainly affects the gastrointestinal tract when gluten is ingested. Gluten is a protein found in wheat, barley, and rye. When someone with CeD eats gluten, the lining of the small intestine becomes damaged and is 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.
- Upwards of 83% 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 of all ethnicities.



⋮ 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
 - Amenorrhea
 - Anemia
 - Bloating/distention
 - Brain fog/inability to concentrate
 - Canker sores
 - Constipation
 - Dental abnormalities
 - Diarrhea
 - Edema/swelling
 - Electrolyte imbalance
 - Elevated liver enzymes
 - Fatigue
 - Headaches
 - Infertility/miscarriage
 - Osteopenia/osteoporosis
 - Pain in bones and joints
 - Peripheral neuropathy
 - Rash (see dermatitis herpetiformis)
 - Stool abnormalities
 - Vitamin and mineral deficiencies
 - Vomiting
 - Weight loss or gain
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Emotional symptoms may include:

- Anxiety
 - Depression
 - Irritability
 - Mood changes
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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

Dermatitis Herpetiformis (DH)

An itchy, blistering skin rash that is associated with 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. The treatment for DH is the GF diet and topical treatments to manage symptoms.

Silent/Asymptomatic Celiac Disease

No obvious symptoms are present, and 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.

Refractory Celiac Disease

A rare condition where the intestine does not heal and symptoms remain present despite 12 months on a strict GF diet.

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.

Non-Celiac Gluten Sensitivity (NCGS)

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



⋮ Diagnosis

The steps leading to a diagnosis of celiac disease are:

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

Other available blood work includes:

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

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.

It's important 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. Once you are diagnosed with CeD and a GF diet has started, 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, further testing should take place 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 caused by vitamin and mineral deficiencies (e.g., osteoporosis, anemia).
- 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

You are on the road to recovery!

- You can feel better.
- You may have more energy.
- You will discover GF recipes that are truly delicious.
- You will meet wonderful people within the celiac community.
- You will find restaurants that serve safe GF food and they will become your go-to when eating out with friends.



∴ **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 FreeSM

Supporting
Celiac Seniors

ROCK
Raising Our Celiac Kids



**NCA NATIONWIDE
SUPPORT NETWORK**

nationalceliac.org | 1.888.4.CELIAC

Learn More!

Check out our website at nationalceliac.org

- Sign up for NCA's **free e-newsletter** for information on research updates, recipes, food recalls, and more!
- Take advantage of online access to ***The Complete Guide to Gluten-Free Living*** (hard copy available for purchase).
- Explore the **"Ask the Experts"** resource and watch our **webinars with the Celiac Research Center at Harvard Medical School**.
- Learn more with our webinar, **"Going Gluten Free: Off to a Fresh Start."**
- Join our lively monthly **virtual meetings**, found on our event calendar online
- Plan your weekly meals with our comprehensive **recipes, free meal planner tool**, and cookbook, **Thrifty Gluten Free** (available for purchase).
- Read more about our important programs like **Feeding Gluten Free, Raising Our Celiac Kids**, and **Supporting Celiac Seniors**.
- Access NCA's **Gluten-Free Nation** magazine.





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

“Would like to say ‘thank you’ and give only positive feedback to NCA — everyone is helpful, professional, and friendly. I took advantage of a number of your programs to begin with and now feel so much better!”

“The National Celiac Association is a leading support group nationwide in providing cutting edge information and support for patients and families and in networking with academic celiac centers in order to provide the best support possible to the celiac community.”

- Dr. Alessio Fasano, Medical Director, Center for Celiac Research and Chief, Division of Pediatric Gastroenterology and Nutrition at Massachusetts General Hospital

“The National Celiac Association has long been a highly effective advocate and educator nationally. I applaud their foresight in their outreach and continuing educational activities. Their service to those with celiac disease and other gluten-related disorders has had such a significant impact.”

- Dr. Ciaran Kelly, Medical Director and Founder of the Celiac Center at Beth Israel/Lahey Health



**For more information visit us online at
nationalceliac.org or call us at 617.262.5422**

    **@nationalceliac**

NCA
20 Pickering Street
Needham, MA 02492

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