



QUICK FACTS

about Celiac Disease
& Related Conditions

nca
National
Celiac Association

Education & Advocacy for the Gluten-free Community

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What is Celiac Disease?

Celiac disease (CD) 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 CD 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 CD 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. Even levels of cross-contact that do not produce a noticeable reaction may cause damage to the intestine and should be avoided.

People with CD 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 utensils
- Colanders/strainers
- Deep fryers

It takes time to heal, but for most people, keeping to a strict GF diet can result in an improvement in symptoms.



Who has Celiac Disease?

- CD is common, affecting at least 1% of the population
- Upwards of 83% of people with CD are undiagnosed
- The genes known to be associated with CD are HLA-DQ2 and HLA-DQ8
- When a first-degree family member has CD, the probability of developing it increases significantly
- CD can develop at any age
- CD affects individuals of all ethnicities



📌 Symptoms of Celiac Disease

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

Physical symptoms may include:

- Abdominal cramping
- Amenorrhea (absence of menstruation)
- 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

Emotional symptoms may include:

- Anxiety
- Depression
- Irritability
- Mood changes

Common symptoms in children:

Children with CD 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 CD. 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” 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 CD, failure to keep to a strict GF diet can lead to long-term health complications.

Refractory Celiac Disease

A rare condition, 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 CD. 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 of NCGS are similar to those with CD. Unlike CD, 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 CD and wheat allergy have been ruled out. Eliminating gluten from the diet is the only treatment for NCGS.



⋮ Diagnosis

The steps leading to diagnosis of celiac disease are:

- A thorough physical examination with complete medical history.
- Blood work that includes a celiac panel. A celiac panel will measure the amount of particular antibodies in the blood. The most common tests include: tTG (tissue transglutaminase antibody) and total serum IgA. Other available tests include an EMA (endomysial antibody), DGP (deaminated gliadin peptide), IgA, and IgG.
- 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 CD 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 CD 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 CD, further testing should take place to check for medical conditions that are associated with or can be caused by CD. 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 CD are recommended.
- First-degree family members should be tested for CD regardless of the presence of symptoms due to the strong hereditary link. High-risk individuals should be tested at regular intervals as CD can develop at any stage in life.

📌 Thriving with Celiac Disease

Despite initial challenges understanding the diet, remember: 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.



**NCA NATIONWIDE
SUPPORT NETWORK**

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Your supportive membership includes online access to the **Complete Guide to Gluten-Free Living** and an annual subscription to **Gluten-Free Nation** magazine.

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“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



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