

**Patients must continue to consume gluten throughout the testing process. Failure to do so can lead to a false negative or inconclusive result.**

It is imperative that individuals who suspect they have CD go through a formal diagnostic process and do not self-diagnose or begin a GF diet because:

- Other serious medical conditions can present in a similar way to CD and need to be ruled out.
- Keeping to a lifelong, strict GF diet is a huge social and economic burden which is more difficult to maintain without a proven medical need.
- Once on the diet a correct diagnosis cannot be made without the reintroduction of gluten. This has substantial negative implications.



## Living with Celiac Disease

Living with CD and keeping to a strict GF diet affects an individual's life in many ways, including work, home, travel and social interactions. As well as receiving medical treatment it is important to recognize and seek help with these social and emotional consequences.

Follow-up visits with a gastroenterologist and a registered dietitian who are well versed in CD are helpful. Many individuals need assistance in managing the impact of a diet that drastically limits what can be eaten and makes it difficult to eat outside of the home or participate in food-related activities.

Studies show that the social and financial restrictions that result from being on a strict GF diet can be challenging.



NCA has a wide range of informational resources to help individuals understand their diagnosis, deal with the complexities of the GF diet, and manage its social impact. We also have many different outreach opportunities, including social groups, local experts and a telephone helpline. Together these provide education, advocacy, and empowerment during a difficult period of adjustment.



## Join the National Celiac Association

The National Celiac Association, a 501(c)(3) non-profit organization, is dedicated to helping those with celiac disease and their families live full lives. **Donations and memberships support these services:**

- Nationwide support groups
- Annual subscription to the *Gluten-Free Nation* magazine
- Monthly e-newsletter including "Ask the Dietitian" Q&A column
- National conference in partnership with the Harvard Medical School Celiac Research Program
- **ROCK – Raising Our Celiac Kids:** a fun and approachable program with nurturing and age appropriate educational materials and support
- **Gluten-Free Food Bank:** education and advocacy for those struggling to afford their gluten-free diet, including distribution of GF food staples to partner food pantries in Massachusetts.
- NCA is proud of its longstanding partnership with the following celiac centers:
  - Massachusetts General Hospital
  - Beth Israel Deaconess Medical Center
  - Boston Children's Hospital
  - The Harvard Medical School Celiac Research Program
  - University of Chicago Celiac Center

### For more information:

**Visit our website: [www.nationalceliac.org](http://www.nationalceliac.org)**

### Or call us:

**Toll Free: 1-888-4-CELIAC (888-423-5422)**

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## Follow-Up Testing

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 I diabetes) and conditions caused by vitamin and mineral deficiencies (e.g. osteoporosis, anemia).

It is also recommended that first-degree family members be tested for CD **regardless of the presence of symptoms**, as there is a strong hereditary link. High-risk individuals should be tested at regular intervals (3-5 years) as CD can develop at any stage in life.



Education & Advocacy for the Gluten-free Community

# Celiac Disease THE FACTS



Until there's a cure ... there's NCA

[www.nationalceliac.org](http://www.nationalceliac.org) • 1.888.4.CELIAC

# What is Celiac Disease?

Celiac disease (CD) is an autoimmune disease that mainly affects the gastrointestinal tract. Individuals who have CD are permanently intolerant to gluten, a group of proteins found in wheat, barley, and rye.



## Treatment of Celiac Disease

**Currently the only treatment for CD is the lifelong adherence to a strict gluten-free (GF) diet**, meaning that 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.

- Toasters & toaster ovens
- Food preparation surfaces
- Pasta cooking water
- Condiments and spreads
- Shared utensils
- Colanders/strainers
- Fryolater/deep fryer



Medications can also contain gluten and individuals must consult with their pharmacist to ensure prescription and over-the-counter products are safe to consume.



For most people, keeping to a strict GF diet results 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 the condition are undiagnosed
- One or both of these genes must be present to get CD: HLA DQ2 & HLA DQ8
- When a first-degree family member has CD, the probability of developing it increases significantly
- CD can develop at any time in life
- CD affects individuals from a diverse range of ethnicities

## Symptoms of Celiac Disease

There are at least 200 symptoms of CD and they vary so widely that there is **no such thing as a typical case**. It should be particularly noted that 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 / miscarriages
- Vitamin & mineral deficiencies
- Osteopenia / osteoporosis
- Pain in bones and joints
- Peripheral neuropathy
- Stool abnormalities (loose, hard, small, large, foul smelling, light tan or gray, frothy)
- Rash (see dermatitis herpetiformis)
- Weight loss or gain (unexplained)
- Vomiting

### Emotional symptoms may include:

- Anxiety
- Depression
- Irritability
- Mood changes

## Symptoms in Children:

Children with CD may exhibit any of the aforementioned symptoms as well as:

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



## Dermatitis Herpetiformis

Dermatitis herpetiformis (DH) is 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 exposure to 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

The intestine does not heal and symptoms remain present despite 12 months on a strict GF diet.

## Non-Celiac Gluten Sensitivity

People with non-celiac gluten sensitivity (NCGS) experience symptoms that are similar to those with CD. Unlike CD, however, there is minimal to no damage to intestinal villi. Currently there is no test to diagnose NCGS. A diagnosis of NCGS can be made after CD and a wheat allergy have been ruled out. Eliminating gluten from the diet is the only treatment for NCGS.

## Diagnosis

The earlier a diagnosis takes place, the more likely long term complications can be avoided.

The major steps leading to diagnosis of celiac disease are:

1. A thorough physical examination, personal interview including family history as well as blood tests including a **celiac panel**. This could include tissue transglutaminase antibodies (tTG- IgA) and total serum IgA. Other available tests include an EMA (endomysial antibody) or DGP IgA and IgG (deaminated gliadin peptide).
2. An upper endoscopy with a biopsy of the small intestine. At least 5 duodenal biopsies should be taken, with duodenal bulb samples labeled and submitted separately. For those with suspected DH, skin biopsies should be taken.

