

The Complete Guide

to Gluten-Free Living



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

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Dear Friend,

Welcome to the **National Celiac Association (NCA)**, a group dedicated to educating, advocating for, and empowering people with celiac disease, non-celiac gluten sensitivity, dermatitis herpetiformis, and gluten-related disorders. We are based in the Boston area, close to major celiac medical centers. Our collaboration with the Harvard Medical School Celiac Education & Research Program guarantees that we have the most up-to-date information about research and treatment of celiac disease. NCA offers support networks and maintains relationships with healthcare professionals throughout the United States.

This guide provides an overview of best practices, offering easy-to-follow tips on adapting your kitchen, shopping for gluten-free food, dining out, traveling, and entertaining at home. It also addresses many of the concerns you or your family are likely to have.

Visit our website, nationalceliac.org, for more in-depth resources. If you have additional questions, please don't hesitate to contact NCA by phone or email.

We're here to help!

National Celiac Association

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Celiac Disease

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 villi on the lining of the small intestine become damaged and are unable to absorb nutrients properly.

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 (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 (numbness/tingling in hands/feet)
- Rash (see dermatitis herpetiformis on page 10)
- 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 CeD may exhibit any of the previously listed symptoms as well as:

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



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)

For more information, please see the “Evidence and Rationale” section of the most recent guidelines from the American College of Gastroenterology.¹

3. An upper endoscopy with several biopsies of the small intestine, including the duodenum.

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

You must 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 gluten-free (GF) diet can be burdensome and is more difficult to maintain without a proven medical need. After you are diagnosed with CeD and begin to follow a GF diet, your antibody levels will start to drop and the villi on the lining of your small intestine will begin to heal.

Treatment of Celiac Disease

Currently, the only treatment for CeD is the lifelong adherence to a strict 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.

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



Did you know?

Some people have “asymptomatic” or “silent” CeD. With this, 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, you must keep to a strict GF diet to prevent long-term health complications.

Follow-Up Care

The 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, but are not limited to, other autoimmune diseases (e.g., thyroid diseases, type 1 diabetes) and conditions caused by vitamin and mineral deficiencies (e.g., osteoporosis, anemia). This is mostly done via blood work, however a dual-energy x-ray absorptiometry (DEXA) scan will assess bone density for osteopenia/osteoporosis.
- 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. These high-risk individuals should be tested at regular intervals as CeD can develop at any stage in life.



Suggested Timeline

AT DIAGNOSIS

- Visits with gastroenterologist and registered dietitian
- Blood work: complete blood count, alanine aminotransferase, vitamins (A, D, E, B12), copper, zinc, carotene, folic acid, ferritin, iron, thyroid function (may need additional tests)¹
- Bone density scan

3 MONTHS

- May need to see registered dietitian and/or gastroenterologist, depending on case
- Children are monitored for growth

6 MONTHS

- Visits with gastroenterologist and registered dietitian
- Blood work: celiac-specific antibodies (tTG IgA most common) and monitoring of micronutrient deficiencies
- Children are monitored for growth

12 MONTHS

- Visits with gastroenterologist and registered dietitian
- Some gastroenterologists may do a repeat endoscopy
- Blood work: celiac-specific antibodies, complete blood count, alanine aminotransferase, vitamins (A, D, E, B12), copper, zinc, carotene, folic acid, ferritin, iron, thyroid function (may need additional tests)¹
- Children are monitored for growth
- Those without complications may have annual follow-ups going forward

Notes

- The above are general suggestions; additional considerations specific to each individual may be required.
- Most people will heal within a few months but it is not uncommon for someone to take up to 2 years to heal.
- Non-responsive CeD and refractory CeD, which is rare, are conditions that may be present if healing is not seen within the first year while following a strict GF diet.
- Speak with your doctor or specialist if you are still experiencing symptoms 1 year after diagnosis.

Other Gluten-Related Conditions

Dermatitis Herpetiformis (DH)

DH is 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.

Wheat Allergy

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

Non-Celiac Gluten Sensitivity (NCGS)

NCGS is “a condition triggered by an adverse reaction to certain wheat components and characterized by gastrointestinal, namely irritable bowel syndrome (IBS)-like, symptoms, and by extraintestinal manifestations, occurring a few hours or days after the ingestion of foods made with gluten-containing cereals (i.e., wheat, rye or barley).”²

Symptoms of NCGS 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.



Making Adjustments

Many aspects of your life including cooking and shopping, going to work or school, traveling, dining out, and more will be affected by CeD. However, as you start to feel better, and learn to manage the changes, everything will fall into place!

While the GF diet can be overwhelming at first, it is essential to take one day at a time. Here are some other tips to consider:

Get good follow-up medical care

Because CeD is an autoimmune condition, it can affect many parts of your body. Finding a doctor and a dietitian who understand that and know how to help you will be important.

Learn from reputable sources like NCA

There are many places to get information online these days, but be wary of websites, blogs, social media, and any information not supported by scientific research.

Watch a webinar

NCA and partner organizations offer informative webinars.

Take care of yourself

Depression, anxiety, and feelings of isolation can be common with CeD. Don't hesitate to reach out to a mental health counselor, your doctor, or to find other productive ways to address these feelings.

Join a support group

There are so many others who are going through similar experiences. NCA offers a nationwide network of support. Check the NCA website for in-person or virtual meetings.

Find at least one person to be your close support

Even if this person doesn't have to eat GF, it is so important to be able to turn to someone to help get you through the bad days and to celebrate the good ones.



**Always remember—You are not alone.
NCA is always ready and willing to help!**



Your Kitchen

You can prepare delicious and healthy meals at home. Each household needs to decide what works best for them regarding how to set up the kitchen. Some people may choose to have a dedicated GF kitchen while others prefer to have a shared kitchen, taking steps to eliminate cross-contact.

First, take stock of your food:

- Begin by reading all food labels. (See page 26).
- Sort through the foods you have on hand in your freezer, refrigerator, and pantry shelves.
- Identify which foods contain gluten (all traditional bread products, pizza, pasta, cake, cookies, etc.). Check your packaged goods and sauces/condiments, looking for ingredients such as wheat as a thickener or malt (derived from barley) as a flavoring.
- Notice how many foods are naturally GF (fruits, vegetables, plain meats, fish and poultry, cheese, plain rice, and potatoes).
- Place items containing gluten in separate cabinets or on the bottom shelf, to avoid cross-contact with GF items.
- GF flour should be kept separately.

Next, consider your tools and utensils:

- Kitchen utensils, pots/pans, and other items that have had contact with gluten need to be washed carefully. If an item is too damaged or scratched to clean it effectively, consider replacing it.
- You may want items dedicated to GF food that are difficult to clean such as cast-iron pans, colanders, cutting boards, air fryers, and bread machines.
- A new toaster should be purchased for dedicated use with GF breads.

Lastly, consider other areas where cross-contact is common in the kitchen:

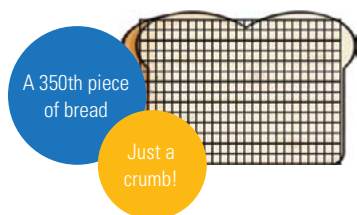
- Be careful of cross-contact from residue on knives and other utensils that have been used to spread peanut butter, mayonnaise, mustard, jellies, etc. No double-dipping! You might choose to keep two jars of such spreadables, making sure to label the GF one. Squeeze bottles are also a good option.
- Food preparation surfaces should be thoroughly cleaned between uses.
- It is not recommended to use the convection setting to cook gluten-containing items because particles may be blown around when cooking GF items in the future.



Watching out for cross-contact is an important part of staying GF.

Very small amounts of gluten can make someone with CeD sick. Research has shown that as little as 10 milligrams of gluten per day can cause intestinal damage.³ To put this into perspective, 10 milligrams of gluten is the equivalent of a 350th piece of bread, just a crumb!

How Much is 10 Milligrams?



Keep in mind that 10mg is the total limit for all foods combined for the entire day.

Cross-Contact vs. Cross-Contamination

Cross-contact occurs when one food inadvertently touches another; in this instance when gluten touches items meant to be GF. Cooking/heat does not “kill” gluten or reduce/eliminate the chances of exposure for a person with CeD.

Cross-contamination refers to bacteria or other microorganisms being unintentionally transferred from one substance or object to another, with harmful effects. Most dangerous bacteria can be killed through proper cooking.

About Ingredients

Grains, Flours, and Starches

Safe

Look for labeled gluten-free grains, starches, and flours made from the foods below (plain rice does not need to be labeled gluten free):

- Amaranth
- Arrowroot
- Bean flours
- Buckwheat
- Cassava
- Chia (seed, flour)
- Coconut flour
- Corn (grits, meal, starch, flour, bran)
- Flaxseed (meal, flour, whole seeds)
- Hemp
- Legume flours (chickpea, lentil)
- Mesquite flour
- Millet
- Nut flours (almond, hazelnut)
- Oats*
- Potato (flour, starch)
- Quinoa
- Rice (flour, bran, wild rice, rice blends)
- Seed flours (pumpkin, sunflower)
- Sorghum
- Soy (flour, soybean)
- Tapioca (flour, starch, pearls)
- Teff
- Yam flour
- Yucca flour

* See nationalceliac.org/oats for information on safety, selection, and introduction of labeled gluten-free oats under medical supervision.

Other Ingredients

Here is information about some ingredients that may cause confusion among people who have to eat GF.

Artificial Flavorings

These are blended from chemical compounds and are free from gluten.

Color Additives

These generally are derived from chemicals and dyes and are free from gluten.

Dextrin

Dextrin is a carbohydrate that is hydrolyzed from starches. It can be derived from wheat; however, most dextrin is derived from corn in the U.S. Dextrin from wheat should be avoided UNLESS the product is labeled gluten free. If a product is labeled gluten free and contains wheat dextrin, the product has to contain less than 20 parts per million (ppm) gluten and should be safe for those with CeD. For medications and products regulated under the United States Department of Agriculture (USDA), you should check with the manufacturer about the origin of the dextrin.

Distilled Alcohol

Distilled alcohol is an alcoholic liquor made from distillation of wine or other fermented fruit or plant juice, or from a starchy material (such as various grains) that has first been brewed. Even if distilled alcohol is made from wheat, barley, or rye, it is considered gluten free as gluten is removed in the distillation process.

Malt

This is a flavoring ingredient that is usually made from barley. It may be listed as malt, malt flavoring, malt extract, or malt syrup. Malt vinegar is fermented, not distilled, and contains gluten. Any product containing barley malt is not gluten free and must be avoided.

Maltodextrin

Maltodextrin is a starch hydrolysate that may be made from wheat starch but is usually made from cornstarch, especially in the U.S. Regardless of the starting material, maltodextrin is considered gluten free. Even if wheat or barley is listed as the source, it is highly unlikely that it would cause an otherwise gluten-free food to contain 20 ppm or more gluten.

Modified Food Starch

Most often, modified food starch is made from corn. If it is derived from wheat, however, modified food starch may not be gluten free. If a product regulated by the Food and Drug Administration (FDA) that is sold in the U.S. contains modified food starch derived from wheat, it will be clearly listed either in the ingredients list or in a “Contains” statement (or both). If wheat is not listed in either place, modified food starch can be considered gluten free.

In USDA-regulated products containing wheat-based modified food starch, wheat may not be stated on the label. If modified food starch is listed, and the product does NOT have a gluten-free label, it may be best to contact the manufacturer to ask about the source of their starch.

Monoglycerides and Diglycerides

These are fats used as chemical binding agents. They do not contain gluten, though occasionally wheat may be used as a “carrier.” If so, wheat will be listed in the ingredients list or the “Contains” statement on an FDA-regulated package.

Natural Flavorings

Natural flavors are products from sources of plant materials or animals with a primary function to flavor food. Unless wheat, barley, rye or malt is included in the manufacturer’s ingredients list, or the “Contains” statement lists (wheat) on the package, the natural flavoring is probably free of gluten protein.⁴

Oats

Most commercial sources of oats have had cross-contact with gluten. Some manufacturers are not adequately testing their oats for gluten, or are using methods to sort and test their products that are inadequate. Sound information about the safety of gluten-free oats is greatly in flux at this time. Please check nationalceliac.org/oats for the most up-to-date information available.

Smoke Flavoring

Smoke flavoring is derived from burning various types of woods. “When used as an ingredient in a food product, dry smoke flavoring may sometimes use barley malt flour to capture the smoke. It is not known at this time how often this occurs or how much gluten smoke flavoring may contain.”⁴ Contact the manufacturer if you have concerns about this ingredient.

Vinegar

Vinegar made from wine, balsamic, or apple cider is safe. Note that plain distilled vinegar such as white vinegar is safe even when made from gluten-containing grains. Gluten is removed during the distillation process, rendering the final product gluten free. Malt vinegar, which is usually made from barley, is not distilled and contains gluten and is not safe. Some flavored vinegars may also contain gluten.

Wheat Starch

Wheat starch is a finely processed powder derived from the endosperm (starchy portion) of the wheat plant.

Food containing wheat starch that is NOT labeled gluten free should not be eaten because it may contain high levels of gluten. A food labeled gluten free may contain wheat starch if the food contains less than 20 ppm of gluten.

The FDA has mandated that if a food labeled gluten free includes the word wheat in the ingredients list or “Contains” statement as required by FALCPA, then the food label must include the statement: “The wheat has been processed to allow this food to meet the Food and Drug Administration requirements for gluten-free foods.”⁴

Yeast

- **Baker's Yeast:** Instant and active, dry and wet (fresh) yeast used in baking are gluten free.
- **Brewer's Yeast:** Brewer's yeast is spent yeast from beer production and may contain malt or other gluten-containing grains. Brewer's yeast is not gluten free and should be avoided by those with CeD or other gluten-related disorders.
- **Yeast Extract/Autolyzed Yeast Extract:** Yeast extract and autolyzed yeast extract are ingredients that may be made from spent brewer's yeast which is used in food as a flavoring agent. They can also be grown on sugar beets which are gluten free. To be on the safe side, avoid yeast extract and autolyzed yeast extract or check with the manufacturer of the origin of the yeast extract UNLESS the product is labeled gluten free.⁴



Frequently Overlooked Sources of Gluten or Potential Gluten

- beer/ale/lager (unless labeled gluten free, NOT gluten reduced or gluten removed)
- breading and coating mixes
- candy
- Communion wafers
- drink mixes
- French fries (when cooked in shared fryers or if they contain gluten)
- herbals and nutritional supplements (e.g., probiotics)
- imitation meats/seafood
- licorice
- marinades, sauces, gravies
- malt
- matzo/matzo meal
- medications and vitamins/minerals
- panko (Japanese bread crumbs)
- Play Doh™
- processed deli meats
- salad dressings
- seasoned rice mixes
- soup base, broth, bouillon
- soy sauce, BBQ sauce, teriyaki sauce
- spice mixes, seasoning mixes
- thickeners (roux)
- wine coolers, some hard seltzers and flavored alcoholic drinks

This list is not comprehensive. When in doubt, contact the manufacturer.



Miscellaneous Information

Anything that gets ingested should be checked for gluten.

Cosmetics

There is currently no scientific evidence that gluten used in cosmetics that are NOT ingested is harmful to individuals with CeD, NCGS, or DH, particularly if hands are washed after applying. Hand lotion and products used in and around the mouth, such as lipstick and lip balm, are more suspect for potential, though likely minimal, gluten exposure.⁵ Cosmetics free of gluten-containing ingredients can be found in the marketplace. More studies are needed on the gluten content of cosmetics containing ingredients derived from wheat, barley, rye, and oats, particularly for the lips and hands.

Religious Observances

Several options for GF or low-gluten Communion wafers and unleavened, gluten-free matzo that are derived from various GF ingredients are available.

Wheat-Derived Ingredients

The following ingredients are safe even when derived from wheat because gluten is removed in the processing of the raw ingredient itself:

- distilled vinegar
- distilled alcohols
- citric acid
- glucose syrup



Medications

Gluten is sometimes used as a binder or filler in medications (although this is rare according to the FDA⁶).

You should always check your medications (over-the-counter (OTC) & prescription) for gluten ingredients. Note that the rules for labeling of medications are different from those for foods. Fillers can be derived from wheat without being declared on the label. The FDA has issued draft guidance for how gluten should be labeled on medications, however, labeling gluten is not currently required. You may see this statement indicating that the medication does not contain gluten:

“Contains no ingredient made from a gluten-containing grain (wheat, barley, or rye).”

Medication Research

Tips for investigating if your medications are GF:

- Inform your physician and pharmacist of your need to avoid gluten.
- Check pharmaceutical insert/ingredient listing for both prescription and OTC medications.
- Contact the pharmaceutical company for more information about ingredients.
- Check the National Institute of Health’s Daily Med website for ingredient lists.
- If unable to get GF medication, you may use a compounding pharmacist.

Other Important Notes About Cross-Contact

Cross-contact may occur anywhere GF food comes in contact with gluten, including the field or factory. Other GF foods are made in shared facilities and/or on shared equipment with gluten. This does not necessarily mean that the food is unsafe, but is why good manufacturing practices (GMPs) are required.

- **Many naturally GF foods** and beverages (for example, bottled water, a can of olives, plain diced tomatoes, olive oil) have little or no risk of cross-contact with gluten-containing grains. In these low-risk cases, it is generally safe to buy the food or beverage even without a gluten-free label.

- **Choose labeled gluten-free, grain-based food** (bars, breads, hot/cold cereals, etc.), grains, and packaged snacks and sweets. Of note, plain rice does not need to be labeled gluten free.
- **Avoid purchasing items from bulk bins** since there is a great risk of cross-contact with gluten-containing ingredients stored next to or above the GF ones. Scoops can also come into contact with gluten when used for items from a different bin. It is recommended to purchase GF foods that are packaged by the manufacturer.
- **Lentils and other legumes** are allowed by law to contain a certain percentage of foreign grain, including wheat, barley, and/or rye unless they are labeled gluten free. However, whether the lentils and other legumes you buy are labeled gluten free or not, it is necessary to take extra steps before using them. Rinse canned ones thoroughly under running water. Pour dry legumes onto a cookie sheet, pick through them, and then rinse thoroughly under running water.⁷
- **Nuts and seeds** may come into contact with gluten-containing grains in the facility. Choose labeled gluten-free nuts and seeds, when possible, particularly if they are seasoned or dry roasted.

It is important to note that wheat free does not necessarily mean gluten free. For instance, breads labeled wheat free might contain rye or other grains that are not allowed on the GF diet.

Good Manufacturing Practices, or GMPs, are guidelines that provide the minimum requirements that a manufacturer must meet to assure that their products are consistently high in quality, from batch to batch, for their intended use. The rules that govern each industry may differ significantly; however, the main purpose of GMPs is always to prevent harm from occurring to the end user.⁸

Shopping and Label Reading

How to Read a Label

What is considered gluten free

- Foods that are naturally GF
- Foods that contain gluten grains - i.e., wheat starch, but have had the gluten removed to below 20 ppm*
- Foods that do not contain more than 20 ppm of gluten AND any unavoidable gluten in the food due to cross-contact or migration of gluten from packaging material is less than 20 ppm gluten

Check product labels

1. **Look for a gluten-free label/statement.** Read the ingredients carefully. Wheat is required to be listed on the label on foods regulated by the FDA, but barley and rye are not.
2. For foods that are not labeled gluten free, check for these ingredients:
 - wheat
 - malt
 - rye
 - brewer's yeast
 - barley
 - oat ingredients
3. Any grain-based foods such as cereals and flour should be labeled gluten free due to the high risk of cross-contact with gluten.

If unsure, contact the manufacturer.

** There are concerns around the accuracy in testing for gluten in a product such as gluten-removed beer when the protein has undergone hydrolysis or fermentation. Therefore, at this time, gluten-removed beer is not recommended.*

How Can I Determine if an FDA Product is Gluten Free?

1. See if the product states that it is gluten free.
2. Look for allergen statements and ingredient listing - WHEAT must be declared if present.
3. Look at each ingredient carefully, particularly whether rye, barley/malt, brewer's yeast, or oat ingredients are listed.
4. Contact the manufacturer to verify GF status if unsure.

The FDA considers food to be GF when it contains less than 20 ppm of gluten⁴

How Can I Determine if an USDA Product is Gluten Free?

Unlike the FDA, there is no official standard for gluten-free labeling of USDA products, which cover:

- Meat products
- Poultry products
- Egg products
- Mixed food products that contain certain amounts of meat or poultry (e.g., some stews and some chili)^{9, 10}

However, USDA follows FDA's guideline that any foods claiming to be gluten free contain less than 20 ppm.⁹ Look for the USDA seal if you are unsure whether a product is regulated by the USDA.



Product Research

Tips for contacting the manufacturer:

- A contact number should be included on the product label. Ask to talk to customer service, and ask to speak to a manager if your questions are not answered.
- Visit their website and review their FAQs as the information might already be answered there.
- Email the manufacturer.
- Trust information received from the manufacturer rather than what other individuals may state about products.

Suggested questions to ask:

- Are there any gluten-derived ingredients in the food?
- Is gluten used on the same lines/equipment with GF items and if so, what are the cleaning protocols/GMPs used between batches?
- Do they store their GF ingredients away from gluten-containing ingredients?
- Do they verify raw ingredients are GF via testing, and do they test for gluten in the end product?



When in doubt – leave it out! Do not risk it!





Labeling Certifications and Statements

Gluten-Free Certifications

A gluten-free certification is different from gluten-free labeling as it is done by a third-party organization. Several different companies offer gluten-free certification. They vary in requirements, but all must adhere to the FDA standard of <20 ppm, at a minimum.

Advisory Statements

“Processed in a facility/on shared equipment that also processes wheat.”

Statements like the above are VOLUNTARY, and the manufacturers may or may not take the necessary steps to prevent cross-contact. The products have not necessarily come into contact with gluten. Under the FDA Gluten-Free Labeling Rule, foods labeled gluten free must contain <20 ppm of gluten regardless of ingredients or cross-contact. This rule applies even when an allergen advisory statement for wheat is also printed on the label.⁴

All food is required to be processed using current GMPs to prevent unintentional ingredients, such as allergens, from ending up in a product.

For foods that are NOT labeled gluten free, safety must be determined on an individual basis. We recommend that you contact the manufacturer for detailed information about their processing procedures.

Smartphone Applications (Apps)

There are many smartphone apps that may help to identify “safe” and “unsafe” food to eat. These apps may be helpful if used as one tool in a toolbox when navigating how to shop. However, please use caution with these as most are not updated on a regular basis and some may have incorrect information. It is critical that you continue to use your label-reading skills to ensure that you are purchasing and consuming safe GF food.



Labeling Laws: For Your Reference

Gluten-Free Labeling Rule

The FDA published the final rule for the labeling of food as gluten free in 2013. Food manufacturers are not required to use the term gluten free on labels. The rule specifies, among other criteria, that any foods that carry the label “gluten-free,” “no gluten,” “free of gluten,” or “without gluten” must contain less than 20 ppm of gluten. If manufacturers choose to label a product gluten free, the food must:

- Be naturally gluten free, such as bottled water or a bag of raw carrots, or
- Meet both of the following criteria:
 - The food does **NOT** contain an ingredient that is a gluten-containing grain (such as wheat).
 - The food does **NOT** contain an ingredient derived from a gluten-containing grain that has not been processed to remove gluten (such as wheat starch).

A GF food **MAY** contain an ingredient derived from a gluten-containing grain that has been processed to remove gluten (such as wheat starch), as long as use of that ingredient in the food does not cause the food to contain 20 or more ppm of gluten.

Food labeled gluten free must contain less than 20 ppm of gluten, regardless of whether the gluten comes from an ingredient in the food or is in the food unintentionally due to cross-contact.⁴

The Food Allergen Labeling & Consumer Protection Act (FALCPA)¹¹

FALCPA is a labeling law that requires the top major allergens be listed. These are: wheat, milk, eggs, soy, fish, shellfish, peanuts, tree nuts, & sesame. FALCPA does not require the disclosure of any information regarding cross-contact.

Barley and rye are not listed as major allergens. Wheat free does not necessarily mean gluten free!

Wheat will be declared in one of two ways:

- In a “Contains” statement following the ingredient listing.
E.g., Contains WHEAT
- In parenthesis following the ingredient containing the allergen within the ingredient listing. E.g., Modified food starch (wheat).

FALCPA applies to foods, beverages, and dietary supplements.

FALCPA does not apply to foods regulated by the USDA, alcoholic beverages regulated by the Alcohol and Tobacco Tax and Trade Bureau (TTB), prescription and non-prescription drugs, pet food, and cosmetics.¹¹

Of note, while USDA products are not subject to FALCPA, all ingredients are required to be listed on the label and they are encouraged to have allergen statements on the label as well.



The Restaurant Experience

There are a lot of opportunities to eat at restaurants that cater to people who follow a GF diet. While not all restaurants have safe options, many have GF menus and some are even entirely GF!

It is our responsibility to do our homework before dining out. The bedrock of this is our knowledge of the GF diet and how food is prepared. Our website (nationalceliac.org/restaurants) has a list of restaurants recommended by the community. Additionally, many smartphone apps are available to help you find suitable restaurants. Use caution with apps as most are based on reviews and each experience is unique. It is still recommended to do the preparatory work to ensure a safe dining experience.

Tips for Dining Out:

- Review menus in advance to get an idea of which items are likely to be safe.
- Call the restaurant at a quiet time to inquire if they can accommodate a strict GF diet.
- When you make a reservation, alert the host that you need to eat GF.
- When you arrive at the restaurant, telling the person who is seating you is optional. However, that person will often provide a GF menu, if available, and may bring this to the attention of the waitstaff and/or the manager.
- When the waitstaff arrives, let them know that you require a medically necessary GF diet.



- Bring a GF dining card that explains the diet. These are available through NCA, and one is located in the back of this booklet.
- Tell the staff that you must avoid food, sauces, soy sauce, marinades, and salad dressings that contain or come into contact with wheat, rye, and barley/malt, even in tiny amounts.
- Emphasize the need to avoid cross-contact.
- When your food arrives at the table, confirm that the order you are getting is, indeed, GF.

Special Caution

- If your salad arrives with croutons or your hamburger with a bun (not GF), insist that this dish needs to be re-made from scratch because of cross-contact.
- Soups may not be GF.
- Au jus almost always contains gluten.
- Some restaurants use bread to soak up the grease from bacon.
- Some restaurants add flour to mashed potatoes or eggs.
- Rice dishes are often enhanced by spices, broth, or other hidden gluten, such as orzo (wheat).
- If you are ordering GF fried food, make sure it is prepared in a dedicated fryer (one not used to fry anything with gluten).
- Make sure GF pasta or vegetables are cooked in fresh water rather than in water that was used to cook gluten-containing pasta.

Other Thoughts

- At some restaurants, it can be safest to order as plainly as possible (plain broiled fish, chicken or steak, plain steamed vegetables, and a baked potato).
- If the restaurant staff makes a genuine effort to respect your diet, make sure to show your appreciation by thanking them sincerely, by tipping generously, and perhaps by sharing a positive review online.
- If something doesn't look right, question it. It is better not to take chances. When in doubt, leave it out!

Being a Guest

With a little extra care, sharing a meal at a friend or relative's house will continue to be enjoyable.

Whether the event is a family gathering, barbecue, potluck meal, or formal dinner party, the questions will be the same: what will be safe to eat, and how will you communicate your GF needs? At many events, you will likely be able to find at least a few items that you can eat safely, such as some types of chips, most cheeses, fruit and vegetable platters, and undressed, crouton-free salads. However, your approach to eating at these events will depend on your comfort level, the kind of party it is, and the relationship you have with the host.

In order to eat safely:

- Check with the host or chef to determine which dishes are safe.
- Bring a contribution (GF, of course), ensuring that you can eat something.
- To avoid cross-contact at a buffet, it helps to be first in line.

These are new skills. Each one of us needs to assess our own comfort level as we ask for special consideration. Remember that it is never impolite to take care of your health. Avoiding gluten is your goal. And, don't forget to write a note to your host to thank them for their efforts.

Although being a guest can be a safe experience, there are times that may be more challenging, especially around holiday meals. Every family has its own traditions; when it comes to foods, many of those traditions include gluten. Some family members are willing to make the adjustment to make the stuffing GF, for example, but a GF pumpkin pie might not be welcome. Offering to bring a GF version of some of these traditional dishes can often be a good solution.

If someone is offended that you are not willing to taste “just a little bit” of a gluten-containing dish you ate for years, it is time to take a breath and remind yourself that a little bit of gluten is not worth the risk, even for the sake of family harmony. Navigating this with friends and relatives will become easier over time.



Traveling

If you love to travel, keep traveling!

There are ways to navigate a safe, GF trip. Finding GF shopping and dining options away from home is as easy as searching the internet, especially the websites of celiac organizations local to where you are visiting. Most places have stores that carry GF foods. If you are planning international travel, GF restaurant cards can be found on the internet in just about every language.

No matter how you travel or where you are going, bringing along a few of your favorite GF foods can be comforting. For convenience, you might want to carry GF cereals, snacks, breads, dry pastas, bars, and crackers.



A few additional tips:

- For car travel, fill a cooler with GF goodies. GF snacks, breads, bagels, energy bars, sandwiches, and cookies will ensure that you won't go hungry.
- Some international airlines offer GF meals. Ask and arrange for one when you reserve your flight (and identify yourself as soon as you get on the plane so someone else doesn't get your meal). Pack some GF staples in your carry-on in case you are delayed or your GF meal is not on the plane.
- At hotels/motels, ask for a room with a refrigerator and microwave. Some places may let you store your GF items in their kitchen refrigerators.
- Contact your tour company or travel agent before booking a trip to find out how your GF needs will be accommodated.
- Look for travel companies that cater to GF clients.
- If renting a house/apartment, make sure to wash the kitchen tools before you use them. Some people feel more comfortable bringing some of their own items like a cutting board and/or colander.
- Tin foil can be used to line toaster ovens, grills, baking sheets, etc.



NCA is Here to Help

We hope this guide has answered most of your questions!

NCA was founded in 1993 as a small group of people supporting each other with celiac disease in the Greater Boston area. As we have grown into a national organization, we haven't forgotten our roots. Most of us at NCA have celiac disease personally or in our families. We have all experienced tough times while also growing confident and comfortable with celiac disease and the gluten-free diet. NCA stands ready to be there for you on your journey to health as well.

Rest assured, our collaboration with the Harvard Medical School Celiac Education & Research Program ensures that we have the most up-to-date information about research and treatment for celiac disease. From the reliable and accurate resources we provide, you can put your trust in NCA that we exist to help you live your best self.

● ● ●
NCA welcomes you!
● ● ●

Contact us with any questions or concerns you may have.

(617) 262-5422 | info@nationalceliac.org | nationalceliac.org



Additional Resources

National Celiac Association: nationalceliac.org

- E-newsletter: nationalceliac.org/news
- Events: nationalceliac.org/events
- Webinars: nationalceliac.org/webinars

Going Gluten Free: Off to a Fresh Start

- Webinar: nationalceliac.org/GoingGF

Raising Our Celiac Kids (ROCK) resources: raisingourceliackids.org

- Downloadable School Packet: nationalceliac.org/school

The Celiac Center at Beth Israel Deaconess Medical Center: celiacnow.org

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Notes





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