

# Getting Started

## Celiac Disease & The Gluten-Free Diet

amaranth  
buckwheat  
chickpea  
corn  
flax  
legumes  
lentils  
millet  
potato  
quinoa  
rice  
sesame  
sorghum  
tapioca  
taro  
tef



[www.CeliacCentral.org](http://www.CeliacCentral.org)



## ABOUT GETTING STARTED...

Did you just learn that you have celiac disease or are gluten intolerant? If so, you probably are wondering what to do and where to turn. Perhaps you are thinking about all of the foods that you will miss and are unsure if you will ever be able to go out for dinner again.

### **Relax!**

Getting started on the gluten-free lifestyle can seem challenging at first, but you soon will find that it has become routine. And going gluten-free doesn't mean that you have to go without! Through my own personal experience, I learned that maintaining a gluten-free diet can be a positive life-changing experience

More than ever, there is a wonderful world of delicious gluten-free food available to all of us. The gluten-free marketplace is expanding exponentially offering more and more options. Major grocery chains have developed gluten-free sections of their stores, the online gluten-free industry is booming and, increasingly, restaurants offer gluten-free items as a staple part of their menus. You will find that you will not have to compromise on enjoying a delicious and healthy diet.

This Guide will give you the information you need to navigate these early days of your recovery. We provide tips throughout to help to ease what often feels like a difficult path to walk, Here is my personal tip: Shop the perimeter of the supermarket and work on incorporating naturally gluten-free and nutritious foods into your diet.

So, let's get started! Just imagine how much better you will feel when your health is restored and your life is reclaimed. Good luck!

Alice Bast  
Founder and President  
National Foundation for Celiac Awareness



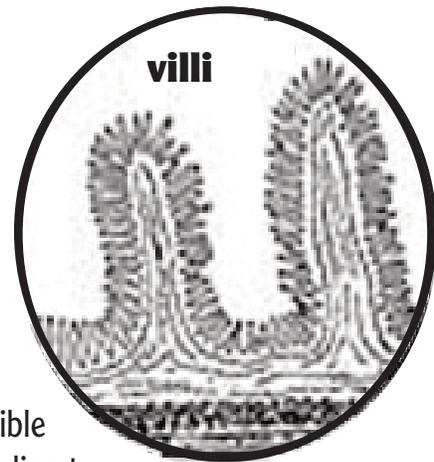
# Getting Started

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# WHAT IS CELIAC DISEASE?

Celiac disease (also referred to as celiac sprue, non-topical sprue, and gluten-sensitive enteropathy) is an autoimmune disorder—where the immune system attacks the tissues of the body—triggered by consuming a protein called gluten, found in wheat, barley and rye, which interferes with the absorption of nutrients from food by damaging a part of the small intestine called villi. Damaged villi make it nearly impossible for the body to absorb nutrients into the bloodstream, leading to malnourishment and a host of other problems including cancer, osteoporosis, infertility, diabetes, and the onset of other autoimmune diseases.



Tragically, 95% of people with celiac disease remain undiagnosed or misdiagnosed. This means that up to three million Americans have celiac disease and only about 150,000 know they have the condition.

## Who Gets Celiac Disease?

Nearly one out of every 100 Americans has celiac disease, equivalent to nearly 1% of the U.S. population. Celiac disease is a genetic disorder, meaning that it passes from parent to child via DNA. In some cases, stressful events like pregnancy, surgery, infection, or severe emotional distress can trigger the onset of the disease.

# SYMPTOMS OF CELIAC DISEASE

Celiac disease is a common autoimmune disorder with a wide variety of symptoms that can manifest in many typical and atypical ways. With nearly 300 symptoms associated with the disease, doctors often have difficulty diagnosing it and, in many cases, misdiagnose patients with other conditions such as irritable bowel syndrome. The most common symptoms of celiac disease are gastrointestinal and include:

- Abdominal pain
- Bloating
- Bloody or fatty stools
- Constipation
- Decreased appetite
- Diarrhea
- Gas
- Increased appetite in some
- Nausea

Prevalent non-intestinal symptoms include:

- Anemia
- ADD/ADHD
- Bone and joint pain
- Depression
- Enamel defects on teeth
- Failure to thrive/delayed growth in children
- Fatigue
- Infertility or pregnancy complications
- Itchy skin rash (dermatitis herpetiformis)
- Migraine headaches
- Osteoporosis/osteopenia
- Pale sore in mouth

People who suffer from unexplained symptoms for several months should speak to a doctor about celiac disease as a potential cause. A delayed diagnosis can increase the risk of developing new symptoms or other complications.

## DIAGNOSIS OF CELIAC DISEASE

With a wide variety of symptoms associated with celiac disease, gaining an accurate diagnosis can be difficult in many cases. To determine if a patient has celiac disease, a physician can screen by using an antibody test, genetic test or a small intestine biopsy. Although there are three options, the only definitive test is the small intestine biopsy.

### **Antibody Celiac Test**

When a physician orders an antibody test to screen for celiac disease, he or she is measuring anti-endomysium and anti-tissue transglutaminase. The antibody test will determine the response a patient's body is having to the gluten protein. A person with celiac disease will have higher-than-normal antibody levels.

The antibody test is made up of a panel consisting of Anti-Tissue Transglutaminase (**tTG-IgA**), Total Serum IgA and anti-endomysial antibody (**EMA-IgA**). In order for an accurate test, patients must be eating gluten regularly. If a patient has a positive antibody test, they will need a small intestine biopsy to confirm a celiac diagnosis.

### **Genetic Testing**

The genetic test is used for two reasons. The first is to rule out a celiac disease diagnosis if the **HLA-DQ2** and **HLA-DQ8** genes are not present. If a patient does not have these genes, it is nearly impossible for them to develop celiac disease. In this case, they would not need to have a follow-up antibody test or endoscopy.

The second reason for the genetic test is to determine a possible celiac diagnosis in patients that are already on a gluten-free diet. Having the HLA-DQ2 and HLA-DQ8 genes does not automatically mean a person has celiac disease, but it does put them in a high-risk group that requires further testing and follow up.

### **Small Intestine Biopsy**

If a patient receives a positive antibody or genetic test, it is recommended that he or she undergo a small bowel biopsy to determine if there is damage to the villi. The biopsy is taken using an endoscope, which is a long, thin tube that the physician weaves through the mouth and stomach to reach the small intestine.

# TREATMENT OF CELIAC DISEASE: A GLUTEN-FREE DIET

The treatment for celiac disease is simple: a gluten-free diet. There are no medications or surgeries that can cure the autoimmune disease. What is gluten? Gluten is a protein found in all forms of wheat, barley and rye.

The gluten-free diet is a lifelong commitment for people with celiac disease. Eating any amount of gluten, no matter how tiny, can cause damage to the villi of the small intestines and prevent patients from absorbing nutrients into the bloodstream.

A physician will typically recommend that a newly diagnosed celiac disease patient visit with a dietitian or nutritionist. These professionals can help someone with celiac learn to read food labels and identify foods that are acceptable on the gluten-free diet. They can also help patients network with local celiac support groups and find grocery stores that specialize in gluten-free food items. This will help a patient begin living with celiac disease in his or her daily life.

Most patients who strictly follow the gluten-free diet will experience relief of symptoms within a few weeks, although it will take up to six months for the small intestine to heal in children and up to two years to heal in adults.

A small number of patients will continue to experience symptoms even when following the gluten-free diet, and a small percentage of individuals may have unresponsive celiac disease resulting from significant damage of the small intestine. According to the National Institutes of Health (NIH), researchers are currently working to develop a drug therapy to treat patients with unresponsive celiac disease.

Due to the harmful and sometimes prolonged effects of gluten exposure, those with celiac may have severe nutrient malabsorption issues, and low levels of essential vitamins and minerals. These levels can gradually improve as you begin a gluten-free diet, but consulting a doctor or nutritionist during this critical restoration process is encouraged.

The goal is to stay gluten-free for life. Concentrate on what you CAN eat, and start simply! A first and simple step is to look for dishes that need very little customization, perhaps just the substitution of one gluten-free ingredient for one that is not gluten-free. For example, make macaroni and cheese or baked ziti with rice, corn, or lentil pasta, or prepare enchiladas with corn tortillas instead of the wheat flour variety.

Although single ingredient, fresh foods are a good way to start, choices are abundant in local stores. A surprising number of restaurants have gluten-free selections and even offer gluten-free menus. Food processors may change ingredients, so it is still important to read labels, visit websites and/or call manufacturers.



In order to maximize the health and nutritional benefits of a gluten-free diet, you should embrace a diet filled with a variety of naturally gluten-free such as fruits, vegetables, and lean meats. Remember that while the growing number of gluten-free products available is both exciting and tasty, a balanced diet containing a variety of healthy foods is best!

Many gluten-free products lack the B vitamins, calcium, vitamin D, iron, zinc, magnesium, and fiber essential to maintaining a healthy body. As a result, those on a gluten-free diet may continue to suffer from certain vitamin and mineral deficiencies, and become susceptible to complications resulting from obesity.

This guide provides suggestions for food during the early healing process and while exploring this fast-expanding marketplace. Yes, even beer and pizza! Most foods containing gluten have a gluten-free equivalent. These menus are not individualized to meet daily calorie, protein, mineral and vitamin needs. Work with a dietitian, as well as your physician, to determine individual nutrition needs.

## LIVING WITH CELIAC DISEASE

Many diseases require treatment with medication or surgery. Not celiac disease. The only treatment is a lifelong gluten-free diet, eliminating all forms of wheat, barley and rye.

Eating any amount of gluten can cause damage to the small intestines and prevent nutrients from being absorbed into the bloodstream.

Eliminating these popular foods from the diet can seem overwhelming when a patient is first diagnosed, but with a little extra effort in the kitchen, people with celiac disease can eat delicious food that tastes just as good as their glutinous counterparts.

# THE FIRST STEPS

## **1. Accept that you have celiac disease.**

The first step towards managing a successful gluten-free diet is accepting that this is a necessity for you in order to live a long and healthy life. Having a positive attitude will make managing the diet much easier!

## **2. Schedule an appointment with a dietitian or nutritionist.**

As soon as you are diagnosed with celiac disease, you should ask your doctor for a dietitian or nutritionist referral. These professionals can help you learn the basics of a gluten-free diet and make suggestions to get your body healthy. Dietitians also receive hundreds of samples from food vendors, so they may have gluten-free items for you to sample.

## **3. Learn which foods contain gluten.**

Gluten is a protein found in all forms of wheat, barley and rye, which means that most forms of bread, pasta and other baked goods found on grocery store shelves are off limits. You will also need to learn which grains are unsafe.

## **4. Learn how to read food labels.**

It is important to always read the labels of prepared, canned, and packaged foods to be sure that no gluten has been added to them. Plain meat, poultry, fish, fruit, and vegetables are all naturally gluten-free, as are rice, potatoes, corn, and quinoa.

## **5. Research gluten-free vendors.**

As more people are diagnosed with celiac disease, the gluten-free marketplace will continue to expand with better tasting products in more grocery stores. There are hundreds of gluten-free products available including breads, pizzas, pastas, cookies, cakes and crackers.

## **6. Read gluten-free cookbooks and learn how to make your favorite recipes gluten-free.**

There are hundreds of cookbooks available that offer tasty gluten-free recipes. Go to your local bookstore to browse through the cookbook section. To find more fantastic cookbooks, visit the NFCA website at [www.celiaccentral.org](http://www.celiaccentral.org).

## **7. Prevent cross-contamination at home by educating your family.**

Teach your family about the gluten-free diet. Learning to prevent cross-contamination is key to staying on track. This requires separating gluten-free products from other items in your pantry, as well as washing all cooking surfaces

before preparing gluten-free foods. Remind your family not to share utensils, pots and pans, toasters, or other cooking items without thoroughly washing them beforehand. For example, take precautions not to dip a knife in peanut butter that has already touched a piece of bread.

### **8. Attend local celiac support group meetings and Meet-Up Groups.**

Most cities in the United States have a celiac support group. Look up your local chapter and attend a meeting. Vendors send product samples to most meetings, so this is a great opportunity to taste gluten-free goodies. Also, Celiac Disease Meet-Up Groups are a new social phenomenon! In major cities, celiac patients have joined together to eat out at restaurants. You will meet people and learn which restaurants are celiac friendly.

American Celiac Disease Alliance

[www.americanceeliac.org](http://www.americanceeliac.org)

Celiac Disease Foundation

[www.celiac.org](http://www.celiac.org)

Celiac Sprue Association CSA/USA

[www.csaceliacs.org](http://www.csaceliacs.org)

Children's Digestive Health and Nutrition Foundation

[www.celiachealth.org](http://www.celiachealth.org)

Gluten Intolerance Group (GIG)

[www.gluten.net](http://www.gluten.net)

National Foundation for Celiac Awareness

[www.celiaccentral.org](http://www.celiaccentral.org)

R.O.C.K. (Raising Our Celiac Kids)

[www.celiackids.com](http://www.celiackids.com)

### **9. Schedule annual follow-up appointments with your doctor.**

To make sure your gluten-free diet is successful, schedule annual exams and take the celiac antibody test when directed by your doctor. If your blood test comes back normal, it will confirm that you are maintaining a completely gluten-free diet!

### **10. Eat at restaurants.**

Ask questions, but don't give up your social life! NFCA's website, [www.celiaccentral.org](http://www.celiaccentral.org), has a directory of national restaurant chains and locations that have gluten-free menu options!

## GLUTEN-FREE DIET 101

Sticking to a gluten-free diet can be difficult if you don't know what foods contain gluten. If you have celiac disease or a gluten intolerance you must avoid all forms of wheat, barley and rye.

You'll soon become an expert reading labels and inquiring about ingredients. It may take a little time, but with the right support system, you'll be able to navigate the gluten-free diet with ease.





## UNSAFE INGREDIENTS

**The following grains (and ingredients derived from them) should not be consumed and may be included as undeclared ingredients.**

Barley	Farro	Panko
Bran	Graham	Rye
Bulgur	Kamut	Spelt
Couscous	Malt	Triticale
Durum	Malt Vinegar	Udon
Einkorn	Matzo Meal	Wheat
Emmer	Mir	Wheat Germ
Farina	Orzo	Wheat Starch

### **Hidden Sources of Gluten**

Bullions and Broths	Imitation seafood	Play Doh
Chapstick	Licorice	Salad Dressings
Communion wafers	Lip gloss	Seasonings
Dairy substitutes	Lipstick	Soy sauce
Deli Meats	Lunch meats	Spice Blends
Dextrin	Medication	Toothpaste
Gravies	Modified food starch	Vitamins
Hydrolyzed protein	Natural Flavors	

### **Oats: A Special Caution**

While oats in their natural form do not contain gluten, an estimated 1%- 5% of celiac patients react to oats in their pure form. Some literature suggests that a protein in oats can trigger a similar response to gluten. Additionally, most mills that process oats also manufacture wheat, making the chances of cross contamination inevitable. The best advice we can offer is to take a great deal of care before introducing oats into your diet. There is no way to determine if you will react, so proceed with caution. Verify that the oats you are using are made in a gluten-free facility and are certified gluten-free.

# SAFE GLUTEN-FREE SUBSTITUTES

If you don't use the correct substitutes when replacing wheat flour in gluten-free recipes, your cookies may come out of the oven flat and tasting like rubber. Below is a list of the most useful gluten-free flours that can be used when substituting for wheat flour, and some tips on how to make your favorite recipes gluten-free!

## **Almond Meal Flour**

Almond meal flour is made from whole almonds that have been finely ground into a powder. It is used in cookies, cakes and other desserts. Be sure to store almond meal flour in the freezer.

## **Amaranth**

Amaranth has a very high protein and fiber content and adds a nutty flavor to gluten-free baked goods. It is most commonly used in combination with other flours to make breads, pasta, pancakes and other recipes.

## **Buckwheat**

Although buckwheat is a grain-like ingredient, it has no relation to wheat and is, in fact, gluten-free. Buckwheat is used throughout Europe to make pancakes and serves as a fantastic alternative for gluten-free cooking, especially when used to make breakfast cereal and lower calorie gluten-free breads.

## **Coconut Flour**

Coconut flour is a delicious and healthy alternative flour that has a high fiber content. It provides a natural sweetness and added moisture to baked goods.

## **Corn Flour**

Compared to cornmeal, corn flour has a blander taste, as well as a lighter and finer texture when used in baked goods.

## **Cornstarch**

Cornstarch is made by grinding up the starchy portion of a corn grain and turning it into a very fine powder. Cornstarch is typically used as a thickening agent, such as for soups, sauces and stews. It is also used in pre-made gluten-free flour blends because it creates a smoother texture.

## **Garbanzo Bean Flour (Chickpea Flour)**

Garbanzo bean flour, aka chickpea flour, is like all bean flours in that it is high in protein and fiber content. As opposed to rice, tapioca, and potato flours, bean flours more closely mimic the texture of white flour when used in baked products.

## **Guar Gum**

Guar gum is made from guar beans and has eight times the thickening ability of corn starch. It works well for thickening sauces and is often used to make gluten-free breads.



## **Potato Flour**

Potato flour is made by grinding potato roots and subsequently removing the fibrous material. Potato flour is most commonly used to thicken sauces and is generally included in gluten-free flour blends because it adds moisture to baked goods.

## **Quinoa**

Quinoa is one of the more nutritionally packed gluten-free substitutes. It is loaded with protein and a host of other vitamins and minerals. Quinoa is known for its mild nutty flavor. It can add both texture and moisture in baking.

## **Sorghum Flour**

Sorghum flour is a millet-like grain and adds a strong flavor to gluten-free baked goods. Add in about 1/8 cup to enhance the flavors of breads, cookies and cakes.

## **Tapioca Flour**

Tapioca flour can add chewiness to baked goods, and is wonderful thickening agent. Tapioca flour is known for being one of the more flavorless gluten-free flours, so it won't affect the taste of your dish.

## **White Rice Flour**

White rice flour is made from finely ground white rice and is most often used as a replacement for wheat flour in gluten-free breads.

## **Xanthan Gum**

Xanthan gum is used to add volume or fluffiness to gluten-free bread and other baked goods. It is made from xanthomonas and is a natural carbohydrate.

## **Cooking with Gluten-Free Flours**

Most gluten-free flours cannot be used as a 1 for 1 replacement for wheat flour in recipes, and are best used during cooking and baking in combination with one another. Here are some tips on how to use gluten-free flours, and how to create your own gluten-free flour mix that can serve as a 1 for 1 replacement in your cooking and baking. When replacing wheat flour in recipes, for every 1 cup use:

- Amaranth - 1 cup
- Almond Flour- ½ cup
- Bean Flour - 7/8 cup
- Corn Flour - 1 cup
- Potato Flour - 5/8 cup
- Rice Flour - 7/8 cup
- Quinoa – 1 cup
- Sorghum Flour - 1 cup
- Tapioca Flour - 1 cup

## How do you incorporate these gluten-free flours into your favorite family recipes?

### **All Purpose Flour**

Find a prepared gluten-free baking mix to keep handy in your refrigerator. These tried and true mixtures of gluten-free flours, starches, and leavening agents can usually be substituted with wheat flour on a one-for-one basis.

### **Flouring or breading meat and fish**

There are several companies that make gluten-free bread crumbs, but you can also season a gluten-free coating to taste. Try cornmeal, potato flakes or mixtures of gluten-free flours. Whirl some dry bread or corn tortilla chips in a food processor until fine. Some people enjoy crumbled gluten-free waffles or crisped rice. These are not usually sweetened and, when seasoned, create a tasty, crunchy coating using crushed nuts as a topping is also a great way to increase the nutritional value of your dish.

### **Gravy**

Use arrowroot starch as a thickener.

### **Pudding and pie filling**

Try gluten-free starches such as cornstarch, potato starch, tapioca or arrowroot.

### **Stuffing**

Make your favorite recipe with gluten-free cornbread or gluten-free white bread (homemade or store-bought) or experiment with rice stuffing.

### **Roux or white sauce**

Use rice flour...you will find that bean and soy flours have too strong a taste.



The gluten-free marketplace is expanding nearly 30% a year. Substitutes are now available for nearly all of your favorite gluten-containing foods. Even so, many people with celiac disease find that they enjoy freshly-baked breads, cookies, muffins and crusts. Learning to master gluten-free cooking and baking is also a great way to bring families together for quality time. Visit our recipe boxes and recipe of the week at [www.celiaccentral.org](http://www.celiaccentral.org).

# WHERE TO PURCHASE GLUTEN-FREE FOOD

Grocery stores and food distributors nationwide are responding to the skyrocketing demand for gluten-free products. Most locations of the following supermarkets have dedicated gluten-free aisles or printed guides that will help you easily identify products that are safe for a gluten-free diet.

## **Acme Markets**

Acme understands that food isn't just necessary to live. It's a necessity for living. So Acme is committed to making it easier for you to prepare and share for a great meal any night of the week. [www.acmemarkets.com](http://www.acmemarkets.com)

## **Giant Food**

Giant Food LLC was founded in 1936 in Washington, D.C. Today, the company serves customers in the Baltimore/Washington market area and in Delaware. The Giant Family now includes approximately 21,000 associates. In 1998, Giant became a member of the Royal Ahold international family of fine grocery stores. [www.giantfood.com](http://www.giantfood.com)

## **Publix Super Markets**

Founded in 1930, Publix Super Markets is the largest and fastest-growing employee-owned supermarket chain in the United States. Publix and our associates excel in community involvement, volunteerism and a commitment to our market areas and beyond. [www.publix.com](http://www.publix.com)

## **ShopRite**

ShopRite supermarkets are members of Wakefern Food Corporation, a retailer-owned cooperative with stores throughout New Jersey, New York, Pennsylvania, Connecticut, and Delaware. ShopRite serves more than 4 million customers each week.

[www.shoprite.com](http://www.shoprite.com)

## **Stop & Shop**

Growing from a single corner grocer to a chain of more than 375 stores throughout New England, New York and New Jersey, Stop & Shop has offered its customers the best selection, quality and value for more than 90 years. [www.stopandshop.com](http://www.stopandshop.com)

## **Wal-Mart Stores Inc.**

Saving people money to help them live better was the goal that Sam Walton envisioned when he opened the doors to the first Wal-Mart. Today, more than 40 years later with operations in 16 markets worldwide, we continue to deliver that promise to families around the globe. [www.walmart.com](http://www.walmart.com)

### **Wegmans Food Market**

Wegmans began in 1915 as a mom and pop grocery store in Rochester, NY. Wegmans works carefully to fulfill the needs of their customers with food allergies, intolerances and with other dietary restrictions (such as celiac disease). With dedicated expertise in our Quality Assurance Test Kitchen and better computer systems, we've been able to keep the lists of products safe for those with diet restrictions current for our grocery, dairy and frozen foods areas. We add new products, discontinue others, and watch out for ingredient changes from suppliers. [www.wegmans.com](http://www.wegmans.com)

### **Trader Joe's Grocery Stores**

Trader Joe's Specialty Stores are not your ordinary neighborhood grocery stores. Their shelves are stocked full of delicious foods and beverages from the basics like milk, bread and butter to more exotic fare like imported cheeses, organic produce and hand-tossed pizza from Italy. [www.traderjoes.com](http://www.traderjoes.com)

### **Whole Foods Market**

Whole Foods Market was founded in Austin, Texas, when three local businessmen decided the natural foods industry was ready for a supermarket format. To better serve our patients with celiac disease, we've put together extensive lists of gluten-free products available at each Whole Foods Market location. As your partner in good health, we're committed to bringing you the highest quality products available for any diet. [www.wholefoodsmarket.com](http://www.wholefoodsmarket.com)

## **SPECIALTY GF RETAILERS AND VENDORS**

There are so many fantastic retailers and vendors nationwide offering delicious gluten-free products. Many offer online ordering, and will ship them to your door! For a comprehensive and frequently updated listing of gluten-free retailers and vendors, visit NFCA's website [www.celiaccentral.org](http://www.celiaccentral.org).

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When shopping for a gluten-free diet, many grocery stores and chains publish frequently updated lists of the safe products they carry.

You can also visit [www.CeliacCentral.org](http://www.CeliacCentral.org) to learn about safe food manufacturers who have partnered with NFCA and to obtain a membership list for our GREAT Business Association.

## A NOTE ABOUT FOOD LABELING

The FDA Food Allergen Labeling and Consumer Protection Act requires labeling of the top eight allergens: milk, eggs, peanuts, tree nuts, fish, shellfish, soy and wheat. However, the absence of wheat on a label does not mean a food is gluten-free. Food manufacturers are also not required to notify consumers of product ingredient and recipe changes, so it is always important to double-check product labels each time a food is purchased since the gluten-free status of a particular product may change at any time.

Further complicating the situation, the FDA has no guidelines in effect to define the safety standard for companies wishing to specify “Gluten-Free” on the label. The proposed standard is 20 parts per million, which many people with celiac disease say is above their threshold.

Luckily, manufacturers are starting to see a market advantage by declaring the gluten-free status of their ingredients. Look for products that declare all of the source ingredients or label gluten-free. If the label is ambiguous, check out the manufacturer’s website or call the company. There are also guides available to use as resources.

## GUIDELINES FOR DINING OUT

Just because you have celiac, doesn’t mean you have to forgo dining out with your friends and family! Here are some suggestions to help streamline the process.

### **1. Make reservations, in person when possible.**

Speaking with the chef and restaurant manager ahead of time to discuss your dietary restrictions can be really helpful for everyone involved. Stop in during off-peak times when you are more likely to have their full attention.

### **2. Review menus online.**

Many restaurants post their menus online. Whether you have time to meet with a chef ahead of time or not, look over the online menu prior to eating out. This will help you to get ideas of what you want to order, and questions you have for the chef upon arrival.



### **3. Build relationships with local chefs.**

Frequent the same restaurants and make connections with the staff. They appreciate your patronage and truly want to please you, just as you value the security and comfort of a delicious, gluten-free meal!

### **4. Bring resources and information for chefs and restaurant staff.**

Providing information about celiac disease and the gluten-free diet can be another helpful way to raise education and awareness, but never let this replace a personal conversation with any chef or restaurant manager.

### **5. Communication, Compliments, and Kudos!**

Follow up with a quick “thank-you” before leaving the restaurant to let the chef know you appreciate the extra efforts that went in to accommodating your needs. A personal note highlighting the helpfulness of the staff is always welcomed. If you had an unpleasant meal, politely inform the manager or follow up with a letter.

### **6. Show your gratitude with a BIG tip.**

Budget this into your expected costs of dining out. By getting to know the chefs and tipping well, you will guarantee exceptional service in the future. Over time, you will develop strong relationships with local restaurants and you will find that you can eat out safely with confidence!

### **7. Be polite and informative.**

Even though celiac disease is becoming more and more common, many people still do not know about it. Be patient with chefs and waiters as you explain your needs. Do not be demanding or threatening with them, or they will be less willing to serve and accommodate you. Should there be a mistake or problem, try your best to be patient and understanding.

### **8. Ask questions.**

If you do not understand the wording of how something is prepared, do not be afraid to ask. If your plate looks suspicious, it is fine to double check (or even triple check).

### **9. BYOB - Bring Your Own Backup!**

Call and ask the restaurant if you are permitted to bring your own bread, pasta, crackers, etc. When providing your own additions to a meal, be sure to give the kitchen enough time and advanced notice to make it possible and convenient. Include cooking information so your meal is timed appropriately. And, just in case, pack a small emergency gluten-free snack stash (prepackaged nuts, crackers, or cookies).

### **10. Have fun!**

Celiac disease is not the end of social dining. It may seem like a burden and an inconvenience at first but, once you get the hang of it, you will be eating out in better style than you ever were before.

# GLUTEN IN MEDICATIONS

Although people with celiac disease are generally focused on the food they eat, it is important to remember that it is possible to be exposed to gluten when taking medication. Gluten is used in many medications as an excipient, which binds the pills together. There are several types of excipients that drug companies may use, so it is important always to check with the manufacturer to be sure that the particular medication you are taking is indeed gluten-free.

## **The problem:**

- There are currently NO requirements for labeling gluten or common allergens found in drug ingredients.
- There are NO specific precautions for individuals with celiac disease in labeling.
- Potential sources of gluten (medication excipients) are NOT well recognized by health professionals or patients.
- The botanical source of starch may not be specified.
- Generic formulations may include different excipients than brand-name drugs.

## **Starches Found in Medications:**

- Corn (most common)
- Potato
- Tapioca
- Wheat
- Modified starch (source not specified)
- Pregelatinized starch (source not specified)
- Pregelatinized modified starch (source not specified)

## **Other excipients:**

- Dextrimaltose (when barley malt is used)
- Caramel coloring (when barley malt is used)



**Resource for checking  
if medication contains gluten:**  
[www.GlutenFreeDrugs.com](http://www.GlutenFreeDrugs.com)

*List is maintained by pharmacists at  
Columbus Children's Hospital*

# UNIVERSITY MEDICAL CENTERS

## **Beth Israel Deaconess Medical Center at Harvard University**

Specialists at the Celiac Center at Beth Israel Deaconess Medical Center integrate diagnosis and treatment with nutritional counseling, and closely evaluate bone health and other food intolerances. The center specializes in evaluating patients where the diagnosis of celiac disease is difficult to confirm.

## **The Celiac Center at Paoli Hospital**

This new center provides a Philadelphia area resource to help manage and embrace the gluten-free lifestyle. Whether you believe you or a loved one have celiac disease, are newly diagnosed or have lived gluten-free for years, the team at Paoli is committed to helping you through it all, from screening and nutritional counseling to consultations with specialists.

## **Center for Celiac Disease at The Children's Hospital of Philadelphia**

The pediatric celiac experts at the Center for Celiac Disease at CHOP provide initial testing and diagnosis through long-term celiac disease management. Families receive the latest information, as well as support from physicians, nutritionists, nurses, educators, laboratory technicians and clinical researchers.

## **Celiac Disease Center at Columbia University**

The Celiac Disease Center at Columbia University provides comprehensive medical care for adult and pediatric patients with celiac disease. The center focuses its research on clinical epidemiology, and mechanisms of celiac disease.

## **Digestive Disease Institute at Thomas Jefferson University Hospital**

The Jefferson Digestive Disease Institute (JDDI) offers a full range of clinical services in gastroenterology and hepatology, including diagnostic and therapeutic endoscopy, motility and liver transplantation.

## **Kogan Celiac Center of Saint Barnabas Health Care System**

The Kogan Celiac Center, located at the Saint Barnabas Ambulatory Care Center, offers comprehensive testing and treatment for celiac disease for adults and children.

## **Mayo Clinic Celiac Center**

At Mayo Clinic Celiac Center, medical specialists from different specialties collaborate to diagnose and develop treatment plans for hundreds of adults and children with celiac disease.

## **Northwestern Memorial Hospital (NMH)**

Northwestern Memorial Hospital (NMH) is one of the country's premier academic medical centers and is a major referral center for the Midwest and beyond.

### **Stanford Hospital Celiac Sprue Clinic**

The Stanford Celiac Sprue Clinic offers long term follow-up care to diagnosed patients.

### **University of Chicago Celiac Disease Center**

The University of Chicago Celiac Disease Center was founded in 2000. The staff seeks to meet the needs of people diagnosed with celiac disease through education, research and advocacy.

### **University of Colorado Hospital**

University of Colorado Hospital is ranked among the nation's top programs for treating digestive disorders, including Celiac Sprue Disease.

### **University of Maryland Center for Celiac Research**

University of Maryland Center for Celiac Research is an institution engaged in clinical care, diagnostic support, education, and clinical and basic science research in celiac disease.

### **University of Virginia Health System – The Digestive Health Center of Excellence**

The goal of the center is to provide excellence and innovation in the care of patients, the training of health professionals and the creation and sharing of health knowledge.

### **William K. Warren Medical Research Center for Celiac Disease**

The William K. Warren Medical Research Center for Celiac Disease seeks to advance the knowledge of celiac disease and to develop diagnostic and therapeutic advances. The center also works to educate medical professionals and the local community about celiac disease.

## RESOURCES AVAILABLE FROM NFCA

### **Symptoms Checklist**

After submitting this simple on-line checklist ([www.celiaccentral.org](http://www.celiaccentral.org)), you will be able to download a printer-friendly form for your doctor that includes information on celiac testing, including the blood test and small intestine biopsy.

### **Getting Started Guide**

Download the guide online or request hard copies by mail.

### **Gluten-Free Resource Education Awareness Training (GREAT) and Train your Favorite Chef**

The GREAT program is a comprehensive tool to educate chefs, dietitians, cafeteria

workers and other hospitality industry professionals about celiac disease and the gluten-free diet. The GREAT Program is accredited by the American Dietetic Association (ADA) and the American Culinary Federation (ACF). You and your neighbors can even raise money to have your favorite local restaurant trained.

### **Gluten in Medications**

Current United States regulations do NOT require manufacturers to label the inactive ingredients in drugs. To learn all about the inactive ingredients in medications, download our one-page guide that was developed in partnership with the American Society of Health-System Pharmacists.

### **School Lunches**

The NFCA developed guidelines to help children and parents navigate their school's meal program. The guidelines explain federal laws and provide step-by-step instructions for getting a child special gluten-free meals at school.

### **Gluten-Free Lifestyle Webinar Series**

This series provides celiac patients and their families with valuable information and resources to help them manage their disease and diet, as well as improve their general health and wellness. Each webinar features presentations from esteemed doctors, nurses, dietitians, educators, industry experts and national leaders.

### **Monthly Newsletter**

NFCA's monthly online publication covers a variety of topics including: celiac disease news, lifestyle and wellness information, gluten-free product reviews, recipes and cooking, as well as NFCA programming and event updates!

### **Official Website and Lifestyle Blogs**

NFCA's official website provides celiac disease and gluten-free news updates, information on NFCA, registration for all NFCA events and programs, and hosts online versions of all NFCA resources for free access and distribution. Visitors can complete our online symptoms checklist, view our Public Service Announcements, read personal stories, and so much more! In conjunction with our website, NFCA boasts a diverse slate of unique blogs including 'Athletes for Awareness', a Gluten-Free Recipe Blog, and NFCA's Health and Medical Information blog.

### **Media Kit**

The National Foundation for Celiac Awareness is happy to provide members of the media with assistance as they put together news articles and on-air packages about celiac disease and the gluten-free diet. For information visit NFCA website press contacts page.

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# GET INVOLVED!

Dedicated volunteers, generous contributors, and involved community members are key players in the success of NFCA and its mission. Want to help us raise awareness and drive diagnosis of celiac disease? There are several ways you can get involved!

## **Donate**

It really is true that no amount is too small—or too large. Please consider a donation to the National Foundation for Celiac Awareness. Financial contributions support NFCA's mission to drive diagnosis, improve quality-of-life and advance research.

## **Community Fundraising**

If you like to have fun and raise money for celiac awareness at the same time, then planning a community fundraising event is the way to go. Whether by organizing an awareness night at your local sports venue, throwing a cupcake party, hosting a charity concert or a happy hour, you are sure to enjoy raising celiac awareness and money for the cause!

## **Distribute Educational and Awareness Materials**

Help NFCA spread awareness of celiac disease and get those who may have undiagnosed celiac tested and diagnosed. Have your local doctor's office, pharmacy, supermarket, health fair, or community event distribute NFCA brochures, flyers, or symptoms checklist.

## **Personal Stories**

One of the most powerful tools that we have in the fight to raise celiac awareness is the personal story of those who have it. These stories tell the public – in a way unlike any other- the impact that celiac disease has on an individual's life. Tell us yours!

## **Advocate for Awareness**

Many states have passed celiac awareness resolutions thanks to the help of passionate activists in the celiac community. You can help spread awareness in your state, too! Take action by contacting your state representatives and ask them to sponsor a similar resolution in your state focusing on May as Celiac Awareness Month. With your help, we can continue to spread the important message that celiac disease affects millions of Americans, yet most remain undiagnosed.





## NATIONAL FOUNDATION FOR CELIAC AWARENESS

The National Foundation for Celiac Awareness (NFCA) is a non-profit organization dedicated to raising awareness of Celiac Disease in order to gain a prompt and accurate diagnosis for those suffering, support the health and wellbeing of children and families with Celiac Disease and Gluten Intolerance and advance research by collaborating with thought leaders in the healthcare field. NFCA is the leading source for celiac information and conducts a rigorous nationally focused awareness campaign.

The NFCA website ([CeliacCentral.org](http://CeliacCentral.org)) offers free, comprehensive information and support materials for celiac patients, their families and health care professionals.

### **National Headquarters**

PO Box 544  
Ambler, PA 19002  
Main: 215-325-1306  
Fax: 215-643-1707  
[info@CeliacCentral.org](mailto:info@CeliacCentral.org)

### **Patient Information**

[info@CeliacCentral.org](mailto:info@CeliacCentral.org)

### **Media Inquiries**

215-325-1306 x103  
[whitney@CeliacCentral.org](mailto:whitney@CeliacCentral.org)

**[www.CeliacCentral.org](http://www.CeliacCentral.org)**



[thaikitchen.com](http://thaikitchen.com)

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