



GETTING STARTED

A Guide to Celiac Disease & the Gluten-Free Diet



BeyondCeliac.org





ABOUT GETTING STARTED

Did you just learn that you have celiac disease or non-celiac gluten sensitivity (“gluten sensitivity”)? If so, you are probably 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.

The first several months to a year after diagnosis can be difficult. This guide will be your road map to handling the gluten-free diet as easily and safely as possible.

Fortunately, there is a wonderful world of delicious gluten-free food available to all of us. The gluten-free marketplace is expanding daily, offering more and more options. Major grocery chains have developed gluten-free sections in their stores, the online gluten-free industry is booming, and many restaurants have gluten-free options.

Beyond Celiac has put together this guide to give you the information you need to navigate these early days of your recovery. We provide tips throughout to help ease what often feels like a difficult path to walk. Here is my personal tip: keep it simple and work on incorporating naturally gluten-free and nutritious foods into your diet.

As you go through the guide, you will see that we have left white space in the columns on each page, as well as a blank Notes section at the end. Use this space to track your own important messages, phone numbers and reminders.

Let’s get started!

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GETTING STARTED

A Guide to Celiac Disease & the Gluten-Free Diet

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Celiac disease
affects an
estimated
1 in 133
Americans.

WHAT IS CELIAC DISEASE?

Celiac disease is a serious, genetic autoimmune disorder where the immune system attacks the tissues of the body. It is triggered by consuming a protein called gluten, which is found in wheat, barley and rye. When people with celiac disease eat gluten, the body reacts as if there is a foreign invader and attacks itself. This causes damage to the villi in the small intestine, which are finger-like projections that absorb nutrients from food. Damaged villi make it nearly impossible for the body to absorb certain nutrients into the bloodstream, leading to malnourishment and a host of other problems, which may include anemia, bone disease, adverse pregnancy outcomes, and certain types of cancer.

Researchers estimate that 50–80% of people with celiac disease in the United States are not diagnosed or are misdiagnosed. The prevalence of celiac disease has increased fourfold since 1950, furthering the need for prompt diagnoses.

Who Gets Celiac Disease?

In the United States, 1 out of every 133 persons has celiac disease. Celiac disease is genetic, which means that it is more common in people with a family history of the condition.

Because celiac disease is genetically-based, biological relatives of people diagnosed with celiac disease are at an increased risk for developing the autoimmune condition. Family members of those diagnosed with celiac disease should be tested. Among relatives, celiac disease occurs in:

- 1 in 22 first-degree family members, such as parents, children and siblings
- 1 in 39 second-degree family members, such as aunts, uncles, nieces, nephews, cousins, grandparents, grandchildren and half-siblings.

Some doctors believe that stressful events like pregnancy, surgery, infection or severe emotional distress may trigger the onset of the disease in genetically-susceptible individuals.

Download your
free guide on talking
to your family about
their risk:
www.SeriouslyCeliac.org

Seriously, Celiac Disease

It's important to tell your family members about their risk for developing celiac disease. Beyond Celiac conducted research and learned that family members want to learn about it through a serious, in-person, one-on-one conversation. Beyond Celiac encourages you to talk to them. Tell them the facts. Urge them to get tested. We can show you how.

Visit **www.SeriouslyCeliac.org** to watch a video showing you how to have this important conversation. Beyond Celiac offers free downloadable guides at this link which contain all the dos and don'ts for talking to your relatives about getting tested.

Dermatitis Herpetiformis

Dermatitis herpetiformis (DH) is the skin form of celiac disease. It is characterized by an extremely itchy rash that is triggered when a person with DH eats gluten.

Not all people with DH will develop other signs and symptoms associated with celiac disease. In fact, up to 20% of patients with DH will actually have an undamaged small intestine. Regardless of the presentation or symptoms, a positive diagnosis of DH always indicates celiac disease.

DH is diagnosed through a biopsy of the skin. Treatment includes both a strict, lifelong gluten-free diet and medication specifically for the skin rash.

Non-Celiac Gluten Sensitivity

Sometimes referred to as gluten intolerance or non-celiac wheat sensitivity, gluten sensitivity is considered a non-autoimmune, non-allergic, symptomatic response to gluten. Preliminary research suggests that gluten sensitivity may affect up to 6% of the United States' population. Currently, there are no diagnostic tests for gluten sensitivity. A diagnosis may be made after celiac disease and other conditions are ruled out. The treatment for gluten sensitivity is a gluten-free diet.

SIGNS & SYMPTOMS OF CELIAC DISEASE

Celiac disease is a serious, genetic autoimmune condition. Because it affects multiple systems of the body, it has a wide variety of signs and symptoms. With nearly 300 symptoms associated with the disease, doctors often have difficulty diagnosing it and, in many cases, may misdiagnose patients with other conditions, such as irritable bowel syndrome.

Some of the most common presentations of celiac disease are often gastrointestinal and can include:

- Abdominal bloating
- Abdominal pain
- Constipation
- Diarrhea
- Foul-smelling and bulky stool
- Heartburn
- Nausea
- Vomiting
- Weight loss or weight gain

Prevalent non-gastrointestinal symptoms can include:

- Anemia
- Bone disease (osteopenia and osteoporosis)
- Brain fog
- Dental defects
- Depression
- Failure to thrive (children)
- Fatigue
- Headaches
- Irritability
- Itchy skin rash (dermatitis herpetiformis)
- Joint pain
- Pale mouth sores
- Peripheral neuropathy (tingling or numbness in hands and feet)
- Short stature
- Unexplained elevation in liver enzymes
- Unexplained infertility
- Unexplained miscarriage

People who suffer from unexplained signs or 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.

There may be an increased risk of celiac diseases among people with other autoimmune disease, like autoimmune thyroid disease, type 1 diabetes, Sjögren's, and autoimmune liver disease. An increased risk has also been associated with Down syndrome and Turner syndrome.

Celiac disease and
gluten sensitivity are two
different conditions.
Learn the difference.
**[www.BeyondCeliac.org/
ncgs](http://www.BeyondCeliac.org/ncgs)**



It's important to be on a **normal, gluten-containing diet** when getting tested for celiac disease.

DIAGNOSING CELIAC DISEASE

With a wide variety of signs and symptoms associated with celiac disease, getting an accurate diagnosis can be difficult. To determine if a patient has celiac disease, a physician will first order antibody tests (simple blood tests), followed by an upper endoscopy and small intestine biopsy. This combination of tests is considered the gold standard for diagnosis. Genetic testing may also be used to rule out a diagnosis of celiac disease.

Antibody Celiac Disease Test

Blood tests for celiac disease are used to determine whether at-risk individuals have elevated levels of certain autoantibodies—proteins that react against the body's own cells or tissues—in their blood. The antibody tests will determine how the patient's body responds to gluten. A person with celiac disease may have higher-than-normal antibody levels.

The celiac disease diagnostic panel consists of three tests: Anti-Tissue Transglutaminase (IgA-tTG), Anti-Endomysial Antibody (IgA-EMA), and Total IgA.

In order for the tests to be accurate, patients must be eating gluten daily. If a patient has a positive antibody test, they will need a small intestine biopsy to confirm a celiac disease diagnosis.

Small Intestine Biopsy

If the antibody tests are indicative of celiac disease, patients should undergo a biopsy of the small intestine to determine if there is damage to the villi, which is characteristic of celiac disease.

The biopsy is taken using an endoscope, a long, thin tube that the physician inserts into the mouth and weaves through the esophagus and stomach to reach the small intestine. Once the endoscope reaches the small intestine, several tissue samples can be taken.

Some research indicates that even if antibody levels are not elevated a follow-up endoscopy and biopsy may still be needed to confirm or rule out celiac disease when other notable risk factors are present.

Get more facts
on celiac
disease testing.
[www.BeyondCeliac.org/
gettested](http://www.BeyondCeliac.org/gettested)

Genetic Testing

When a physician orders a genetic test for celiac disease, they are looking for certain genes. About 95% of people with celiac disease have the HLA-DQ2 gene and most of the remaining 5% have the HLA-DQ8 gene. Some people with celiac disease have both DQ2 and DQ8. If a patient does not have either of these genes, it is nearly impossible for them to develop celiac disease. If these genes are not present, the patient would not need a follow-up antibody test or endoscopy.

While genetic testing can be used to rule out celiac disease, it is not very helpful in diagnosing celiac disease. Approximately 40% of the United States' population carries either DQ2 or DQ8, but a very small percentage of them actually go on to develop celiac disease.

Genetic testing may be a good option to try and rule out celiac disease for at-risk people who are already on the gluten-free diet.

If you have undergone the celiac disease blood panel and/or an endoscopy and biopsy in the past; have the genes for celiac disease; or have other risk factors (such as symptoms or other autoimmune diseases), you may want to ask your doctor to regularly screen you for celiac disease, which can start at any time. One negative test doesn't necessarily mean that you will always be free from celiac disease.



Learn more about the conditions
related to celiac disease.
**[www.BeyondCeliac.org/
related-conditions](http://www.BeyondCeliac.org/related-conditions)**

Other Lab Tests You May Need

Celiac disease damages the villi, which are finger-like projections in the small intestine. Villi are responsible for absorbing nutrients from food. Because of this, it is highly likely that people newly-diagnosed with celiac disease will be deficient in essential vitamins and nutrients. Laboratory tests should be done within three to six months following a diagnosis and then annually for the rest of your life.

Regular monitoring with blood tests can help answer the following questions:

- Is my small intestine healing?
- Am I being screened for common nutritional deficiencies and associated diseases?
- Am I getting better?
- Am I being exposed to gluten?

Laboratory tests to get in order to monitor your celiac disease include:

- Celiac disease antibodies (IgA-tTG)
- Nutritional anemia profile (hemoglobin, hematocrit, folate, ferritin, vitamin B12)
- Vitamin profile (thiamin, vitamin B6, 25-hydroxy vitamin D)
- Mineral profile (copper, zinc)
- Lipid profile
- Electrolyte and renal profile
- Complete blood count (CBC)
- Thyroid stimulating hormone (TSH)

Adults with celiac disease should have a bone mineral density scan within the first year after diagnosis.

The specific tests you receive will vary depending on your situation and your doctor's advice. Please use these tests as a guide to your lifelong management of celiac disease.

While blood tests are extremely helpful for monitoring your health, visiting a registered dietitian familiar with celiac disease and the gluten-free diet can help you understand how you may be getting accidentally exposed to gluten.





Learn more at
[www.BeyondCeliac.org/
Treatment](http://www.BeyondCeliac.org/Treatment)

TREATING CELIAC DISEASE: A GLUTEN-FREE DIET

The treatment for celiac disease is a strict, gluten-free diet. Currently, there are no medications or surgeries that can treat or cure this autoimmune disease.

However, researchers are working every day to find a better solution for celiac disease than the gluten-free diet alone.

What is gluten?

Gluten is a protein found in wheat, barley, rye and other grains. For a longer list of gluten-containing grains, see page 22.

Until there is a cure or until medication, or pharmaceutical treatment become available, the gluten-free diet is a lifelong commitment for people with celiac disease. Eating even tiny amounts of gluten can cause damage to the villi of the small intestine and prevent patients from absorbing nutrients into the bloodstream.

Focus on **what
you CAN eat**,
not what you
can't.

A good first step is to look for dishes that need very little customization, perhaps just the substitution of one gluten-containing ingredient for a gluten-free alternative. 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.

Single-ingredient, fresh foods are a great way to start but don't be afraid of the prepackaged gluten-free choices available in your local grocery stores. If you're concerned about the ingredients or preparation of these products, visit the manufacturer's website and/or call them for more information before purchasing the product. Above all else, don't forget to read the label on every product every time—food manufacturers may change ingredients without warning.

In order to maximize the health and nutritional benefits of a gluten-free diet, embrace a diet filled with a variety of naturally gluten-free foods, such as fruits, vegetables, lean meat, poultry, fish, dairy, eggs, nuts, seeds and legumes. While the growing number of gluten-free products available is both exciting and tasty, a healthy, balanced diet contains variety.

The gluten-free diet may be high in fat and low in carbohydrates, fiber, calcium, iron, folate, niacin, B12, phosphorus and zinc. As a result, those on a gluten-free diet may continue to suffer from low intakes of certain vitamins and minerals and become susceptible to unwanted weight gain.

To make sure you get the most nutrition from the foods you eat, follow these tips:

- Choose gluten-free whole grain products whenever possible. Read ingredients lists looking for whole grain corn, brown rice, teff, millet, sorghum, wild rice, amaranth, buckwheat, and quinoa as the first ingredient. Whole grains are sources of fiber, B vitamins, iron and zinc.
- Choose refined grain products (e.g., products made with refined flours, such as white rice flour and milled corn, and starches, such as corn starch and tapioca starch) that are enriched or fortified with B vitamins and iron over those that are not enriched or fortified whenever possible. You can tell if a product is enriched or fortified by reading the ingredients list. The added vitamins and minerals will be

named. Enriched grain foods are sources of B vitamins and iron.

- Use the Nutrition Facts panel to compare the total fat and saturated fat content of the grain foods you buy. Choose the versions with the lowest fat and saturated fat content.

- Eat and drink recommended amounts of milk and milk-based products (or their equivalents, such as calcium and vitamin D fortified soy milk). Milk is a source of calcium, vitamin B12, and phosphorus. Note that some people who are newly diagnosed with celiac disease may have an intolerance to lactose, which may resolve after time on the gluten-free diet. Read more at www.BeyondCeliac.org/lactose-intolerance.

When reading this guide, please note that any food product suggestions are not individualized to meet daily calorie, protein, mineral and vitamin needs. Work with a registered dietitian, as well as your physician, to determine individual nutrition needs.

When will you feel better?

Most patients who strictly follow the gluten-free diet will experience relief from symptoms within a few weeks, although it may take several months or sometimes years for the small intestine to heal. The time it takes for the small intestine to heal can vary; each person's body is different.

In a small number of patients, symptoms and intestinal damage may persist despite following a strict gluten-free diet. This type of celiac disease is called refractory celiac disease. According to the National Institutes of Health (NIH), researchers are currently evaluating drug treatments for patients with refractory celiac disease.

If you have been diagnosed with celiac disease, your goal is to stay gluten-free for life (or until a treatment or a cure is developed). Concentrate on what you can eat, and start simply!

Download a guide to
reading labels at
[www.BeyondCeliac.org/
reading-food-labels](http://www.BeyondCeliac.org/reading-food-labels)





Separate fact from
fiction. Visit
[www.BeyondCeliac.org/
ceeliac-disease/myths](http://www.BeyondCeliac.org/ceeliac-disease/myths)

LIVING WITH CELIAC DISEASE

Repeated exposure to even tiny amounts of gluten can lead to ongoing symptoms and persistent, significant and sustained intestinal inflammation. In other words, if you cheat on your gluten-free diet, you could prevent your intestine from fully recovering, which, research suggests, could affect your long-term health and well-being.

Eliminating gluten-containing foods from your diet can seem overwhelming when you are first diagnosed, but with a little extra effort in the kitchen, you can eat delicious food that tastes just as good as the gluten containing counterparts you are used to. Yes, even gluten-free beer and gluten-free pizza are available!

For more information
on which foods
are safe, visit
[www.BeyondCeliac.org/
is-it-gluten-free](http://www.BeyondCeliac.org/is-it-gluten-free)

THE FIRST STEPS

1. Accept that you have celiac disease (or non-celiac gluten sensitivity).

The first step to 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.

As soon as you are diagnosed with celiac disease, ask your doctor for a referral to a registered dietitian skilled in the gluten-free diet. These professionals can help you learn the basics of a gluten-free diet and make suggestions to get your body healthy again. As an added bonus, dietitians also receive hundreds of samples from food vendors, so they may have gluten-free items for you to try!

3. Learn which foods contain gluten.

Gluten is a protein found in the grains wheat, barley and rye, which means that most breads, pastas, breakfast cereals, baked goods and sweet and savory snacks found on the grocery store shelves are off-limits.

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 they do not include any gluten-containing ingredients. If a food is not labeled gluten-free, look for the words or ingredients "wheat," "barley," "rye," "oats," "malt" and "brewer's yeast" to indicate that the food is not safe to eat. Plain meat, poultry, fish, fruit, vegetables, eggs, milk, nuts, seeds and beans are all naturally gluten-free. There are many naturally gluten-free grains and flours including those made from corn, rice, millet, sorghum, teff, quinoa, buckwheat, and amaranth. Whenever possible, buy grains and flours that are labeled gluten-free.

5. Research gluten-free manufacturers.

As more people are diagnosed with celiac disease, the gluten-free marketplace continues to expand with more products available in grocery stores, natural food stores and online. 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 and browse through the cookbook section. To find more fantastic cookbooks, visit the Beyond Celiac website at www.BeyondCeliac.org/books. If you are new to cooking in general, spend some time watching cooking shows on the Food Network or check out a basic cookbook from the library that talks about the various principles of cooking.

7. Prevent cross-contact at home by educating your family.

Teach your family about the gluten-free diet. Learning to prevent cross-contact 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 and toaster racks, or other cooking items without thoroughly washing them beforehand. For example, take precautions not to dip a knife into peanut butter that has already touched a piece of bread. Do not use wooden cutting boards or wooden utensils that have touched gluten; the gluten proteins can get into the wood and stay there. Stick to unscratched metal, ceramic and plastic products.

8. Schedule follow-up appointments with your doctor and dietitian.

To make sure your gluten-free diet is successful, schedule follow-up exams and take the celiac disease antibody test when directed by your doctor. If your blood test comes back normal, it is an indication that you are staying gluten-free. If it remains elevated, you can work with your dietitian to determine how you may be accidentally eating gluten.

9. Eat at restaurants.

Ask questions, but don't give up your social life! See the dining tips section of the guide on page 37.

To learn more about cross-contact, visit www.BeyondCeliac.org/cross-contact

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 non-celiac gluten sensitivity, you must avoid wheat, barley, rye and all other gluten-containing grains. You'll soon become an expert at reading labels and inquiring about ingredients. It may take a little time, but with practice you'll be able to navigate the gluten-free diet with ease.

UNSAFE INGREDIENTS

Ingredients to avoid:

- All types of wheat ingredients, including wheat flour, wheat bran, wheat germ, and hydrolyzed wheat protein, plus wheat varieties including einkorn, emmer, kamut, spelt, bulgur, graham, farina, semolina and durum
 - Wheat starch, unless it is labeled gluten-free or is an ingredient in a food labeled gluten-free
- Barley grain and barley flour
- Malt, malt extract, malt flavoring (these ingredients are found in many foods, including malt vinegar, malted milk, and malt beverages, such as beer)
- Rye grain and rye flour
- Triticale grain and triticale flour (a cross between wheat grain and rye grain)
- Oats (unless labeled gluten-free)
- Brewer's yeast
- Modified food starch made from wheat (unless it is an ingredient in a food product labeled gluten-free)
- Dextrin made from wheat (unless it is an ingredient in a food product labeled gluten-free)

Packaged foods that may contain gluten

Read the labels of all packaged foods. The foods listed below are just a few of the many products that may contain gluten ingredients:

- Bouillon/broth
- Communion wafers
- Deli/lunch meat
- Gravies, sauces and marinades
- Imitation meat and seafood
- Licorice
- Salad dressings
- Seasoned potato/tortilla chips
- Seasoned rice mixes
- Soup
- Soy sauce
- Teriyaki sauce
- Vegetables in sauce
- Veggie burgers

It is not clear if “gluten removed” beer is safe for people with celiac disease. Read about the remaining questions about gluten-removed beer on our website.
**[www.BeyondCeliac.org/
gluten-removed-beer](http://www.BeyondCeliac.org/gluten-removed-beer)**

Other products that may contain gluten

- **Children's art supplies** While most children do not eat their art supplies, they often put their hands in their mouths before washing them. Play-Doh® contains wheat, but Aroma Dough (www.aromadough.com) is gluten-free. If your child's class is making macaroni necklaces or macaroni art, send a box of gluten-free noodles with your child that day.
- **Personal care products used on the mouth** Some lipstick, lip gloss, and other lip care products may contain ingredients derived from gluten. While these products are not eaten per se, they may be inadvertently ingested. Regardless, the amount of gluten they contain and the amount that may be "eaten" is likely very small. If you are concerned, read the ingredients lists carefully or contact the manufacturer. An increasing number of cosmetics manufacturers are labeling products gluten-free.
- **Alcoholic beverages** Malt beverages such as traditionally-made beer are NOT considered gluten-free. Specially manufactured gluten-free beers made with a substitute for malted barley are available. Pure distilled alcohol (e.g. vodka) and wine are considered gluten-free.
- **Vitamins, supplements and medications** Some inactive ingredients, like excipients and binders, may contain gluten. See page 40 of this guide for more information on gluten in medications.

Talk to your doctor before reintroducing oats into your diet. Choose only "certified gluten-free" oats.

Oats: A Special Caution

By definition, oats are naturally gluten-free. In their natural form, oats do not contain the gluten protein. However, fields where oats are grown and mills that produce and store oats may also grow and manufacture wheat, barley or rye. These practices result in cross-contact.

The good news is that cross-contact is preventable.

Current research suggests that the majority of patients with celiac disease can tolerate oats in their pure, uncontaminated form.

A small percentage of individuals with celiac disease do react to pure, uncontaminated oats. Although the cause for this reaction is not completely understood, some literature suggests that a protein in oats can trigger a response similar to gluten.

Individuals who would like to add gluten-free oats to their diet should do so under the guidance of their dietitian or physician. For persons with celiac disease, oat intake should be limited to the equivalent of ½ cup of gluten-free rolled oats per day. When shopping, look for oats that are specifically labeled "gluten-free."

Individuals who develop any new symptoms after adding gluten-free oats to their diet should bring this to the attention of their dietitian or physician.



BAKING WITH GLUTEN-FREE FLOURS

Gluten-free cooking and baking is all about experimenting! Gluten-free flours have different tastes and textures so gluten-free baked goods will usually turn out better if a combination of gluten-free flours and starches is used. In general, you do not want to substitute a single gluten-free flour for the wheat flour called for in a recipe. You may want to try substituting $\frac{3}{4}$ cup of a gluten-free flour and $\frac{1}{4}$ cup of a gluten-free starch (which is the carbohydrate portion of grain) for 1 cup of wheat flour.

However, when you're first starting out it may be easier to buy a premade, all-purpose baking mix and/or use a cookbook with tried and true recipes. Following tested recipes at first will help you learn about the various flours, including their tastes and textures. You can find a list of cookbook suggestions on our website at www.BeyondCeliac.org/gluten-free-diet/getting-started-store/books

It may be easiest to buy an all-purpose baking mix when you are first getting started (see next page under "All Purpose Gluten-Free Flour.") The gluten-free marketplace continues to expand with replacement options that can be substituted one-for-one with wheat flour. (Be sure to read intended use and instructions.)

When starting out, follow recipes exactly to get a sense of the different tastes and textures.

For recipes, videos
and tips on gluten-free
baking, visit
[www.BeyondCeliac.org/
baking](http://www.BeyondCeliac.org/baking)

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 unappealing. Below is a list of the most useful gluten-free flours when substituting for wheat flour and some tips on how to make your favorite recipes gluten-free.

Almond 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. Store almond meal flour in the freezer.

Amaranth Flour 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. Make sure to buy amaranth flour that is labeled gluten-free.

Arrowroot Arrowroot starch is made from tropical plants. It works well in both sweet and savory dishes and adds little to no flavor, making it an ideal thickener. Use it to thicken sauces and puddings.

Brown Rice Flour Brown rice flour packs a bit more of a nutritional punch than white rice flour. Use this flour in muffins and breads when a heartier product is desired. Be sure to buy brown rice flour that is labeled gluten-free.

Buckwheat Flour 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 gluten-free breads. Make sure that any products you buy containing buckwheat are labeled gluten-free.

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

Corn Flour Compared to cornmeal, corn flour has a blander taste, as well as a lighter and finer texture. Whenever possible, buy corn flour that is labeled gluten-free.

Cornstarch Cornstarch is made by grinding the starchy (carbohydrate) portion of a corn grain into a very fine powder. Cornstarch is typically used as a thickening agent 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 wheat flour when used in baked products.

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

Millet Flour Millet flour looks and tastes a lot like corn flour or cornmeal and is a great source of fiber. Use this flour in muffins and cornbreads. Be sure to buy millet flour that is labeled gluten-free.

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

Quinoa Flour Quinoa is one of the more nutritious 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. Be sure to buy quinoa flour that is labeled gluten-free.

Sorghum Flour Sorghum is a millet-like grain and adds a strong flavor to gluten-free baked goods. Be sure to buy sorghum flour that is labeled gluten-free.

Tapioca Flour Tapioca flour can add chewiness to baked goods and is a 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.

Teff Flour Teff flour is a nutritional powerhouse with a mild nutty flavor and a very soft, fine texture. It works well in cookies and pie crusts. Be sure to buy teff flour that is labeled gluten-free.

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. Be sure to buy white rice flour that is labeled gluten-free.

Xanthan Gum Xanthan gum is used to add volume or fluffiness to gluten-free breads and other baked goods. It is made from the fermentation of sugar by the organism *Xanthomonas campestris*.

TIPS FOR INCORPORATING GLUTEN-FREE FLOURS AND STARCHES INTO FAVORITE FAMILY RECIPES

All-Purpose Gluten-Free Flour

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

Gluten-Free Sourdough

If you have gluten-free flour and water, you have what you need to create your own sourdough bread starter!

There is some misinformation online about any sourdough being okay for people with celiac disease and gluten sensitivity. There is no research that supports that. While the natural bacteria may make sourdough easier to digest than regular wheat flour, it doesn't render it gluten-free.

If you have celiac disease or gluten sensitivity, be sure that you use gluten-free flour for the starter and gluten-free ingredients for all of the baked goods you plan to use your gluten-free sourdough starter in.

What is Sourdough Starter?

Sourdough bread starter is an ingredient needed to create sourdough bread. Think of it as a naturally occurring yeast that replaces packaged yeast and creates the "rise." It is a naturally-fermented ingredient that—because it releases gases like bubbles in beer—expands your bread and makes the air pockets characteristic of sourdough. The tangy taste of sourdough is a result of the fermented sourdough starter.

Once you create the starter, you can add it to flour and other ingredients to bake your own homemade gluten-free sourdough bread. It doesn't require anything other than gluten-free flour, water and salt. Other ingredients may be added to create a flavor you like.

Visit www.BeyondCeliac.org/make-sourdough to learn how to make your own!

To get started, you'll need to spend a few minutes a day for seven days to get your starter going. Then you'll be able to maintain it by "feeding" it more flour and water as necessary.

Flouring or Breading Meat and Fish

There are several companies that make gluten-free breadcrumbs, but you can also make your own gluten-free coating. Try cornmeal, potato or quinoa flakes or mixtures of gluten-free flours. Whirl some dry gluten-free bread or gluten-free corn tortilla chips in a food processor until finely ground.

Some people enjoy crumbled gluten-free waffles or gluten-free crisped rice. These are not usually sweetened and, when seasoned with salt, pepper, garlic powder, crushed red pepper flakes, etc., can 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 or all-purpose flour as a thickener.

Pudding and Pie Filling

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

Roux or White Sauce

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

Stuffing

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

**Get gluten-free recipes at
[www.BeyondCeliac.org/
gluten-free-recipes](http://www.BeyondCeliac.org/gluten-free-recipes)**



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WHERE TO PURCHASE GLUTEN-FREE FOOD

Grocery stores and food distributors nationwide are responding to the demand for gluten-free products. No matter where you live, you should be able to find many products that are labeled gluten-free in your local supermarket. Some grocery stores will have separate gluten-free sections, while others may have gluten-free items dispersed throughout the regular sections. Some supermarkets even have registered dietitians who are able to give you a store tour to help you find gluten-free items.

In addition to your regular grocery store, big box stores and even pharmacies are now offering gluten-free products. There is also an abundance of online stores that can ship gluten-free food right to your door.

GLUTEN-FREE FOOD LABELING

FOOD LABELING 101

The gluten-free marketplace is booming and new gluten-free products are filling grocery store shelves on a regular basis. Just as more gluten-free products have increasingly become available over time, so too has it become easier to identify gluten-free products.

The key to gluten-free food safety is not only learning how to identify gluten-containing ingredients by reading food labels, but also understanding which food products have a high-risk for cross-contact with gluten.

As you begin your gluten-free journey, follow these simple tips while navigating the grocery store:

- Choose fresh produce, eggs, dairy, beans and fresh or frozen meat – all of which are naturally gluten-free. This is not only safer and more nutritious, it may also be cheaper than gluten-free packaged meals and staples.
- Read through a product's entire ingredient list, especially on products labeled "wheat-free." Wheat-free does NOT necessarily mean gluten-free.
- Buy packaged and processed foods that have only a few simple ingredients—their labels are easier to read!
- Look out for less-obvious sources of barley, specifically malt and brewer's yeast.
- Whenever possible, purchase naturally gluten-free grains, flours and starches that are labeled or certified gluten-free by a third party.
- When foods containing "smoke flavor" aren't labeled gluten-free, verify their status with the food manufacturer.
- Avoid poultry and meat products that do not list the source of dextrin or starch on the product label.
- Avoid purchasing from bulk bins—cross-contact can easily occur with scoops and gluten-containing items.

FOOD LABELING 201

The Law—FALCPA

The Food Allergen Labeling & Consumer Protection Act (FALCPA) mandates that if a food or beverage contains any of the top nine allergens, the allergen must be named in either the ingredients list or a separate “Contains” statement immediately following or next to the ingredients list. The top nine allergens are milk, eggs, peanuts, tree nuts, fish, crustacean shellfish, soy, wheat and sesame. If you do not see the word “wheat” in the ingredients list or “Contains” statement of a packaged food product regulated by the FDA, none of the ingredients in that product include wheat.

However, barley, rye and other gluten-containing grains are not considered to be top nine allergens, so they are not constrained by FALCPA rules. Therefore, people with celiac disease need to read the whole ingredients list to look for these grains, too.

FALCPA regulations also apply to dietary supplements, such as vitamins and minerals. However, the rule does not apply to:

- Foods regulated by the U.S. Department of Agriculture (USDA), such as meat and poultry
- Alcoholic beverages regulated by the Alcohol and Tobacco Tax and Trade Bureau (TTB)
- Prescription and over-the-counter drugs
- Pet food
- Cosmetics

Even though USDA-regulated products are not required to comply with FALCPA, it's estimated that 80 to 90% of these products voluntarily comply. If there is any doubt about whether a USDA-regulated product is complying with FALCPA labeling, the following ingredients may be derived from wheat and need to be avoided or investigated: starch, food starch, modified food starch and dextrin. In USDA-regulated products, the single word “starch” can mean either “corn starch” or “wheat starch.”

Gluten-Free Labels

Per FDA regulations, if a product bears the label “gluten-free,” the food must contain less than 20 parts per million (ppm) gluten. The rule also applies to products labeled “no gluten,” “free of gluten,” and “without gluten. However, because labeling food products as gluten-free is a voluntary action, manufacturers are not required to test gluten levels of their products.

Gluten-free claims can also be applied to products that

- Do not contain a gluten-containing grain
- Contains an ingredient derived from a gluten-containing grain that has been processed to remove gluten as long as the food product contains less than 20 parts per million (ppm) of gluten (i.e. wheat starch). In such situations, the labeling must indicate, "the [ingredient] has been processed to allow this food to meet FDA requirements for gluten-free foods."

How Much is 20 ppm Gluten?

20 parts per million means there are 20 milligrams of gluten (or less) per 1 million milligrams (1 kilogram) of the product.

If a one-ounce slice of bread contains 20 ppm gluten, it contains approximately 1/2 milligram of gluten (0.56 milligrams). This is a very small amount.

Many celiac disease experts believe that up to 10 milligrams of gluten can be eaten each day without causing damage to the small intestine.

Allergen Advisory Statements

Allergen advisory statements are voluntary and not defined by any federal regulations. These types of statements generally refer to production procedures and read something like "processed in a facility that also processes wheat." Because these statements are voluntary, some manufacturers use them while others do not. You may come across a product labeled gluten-free that also includes an allergen advisory statement for wheat.

Foods with allergen advisory statements for wheat that are labeled gluten-free must comply with the FDA's gluten-free labeling rule. This means that if you come across a product labeled gluten-free that also includes the statement "processed in a facility that also processes wheat," the food is not mislabeled and must still contain less than 20 ppm gluten, even when the source of gluten is from cross-contact.

Label Reading

Allergen labeling is not optional. However, gluten-free labeling is optional, so products not labeled gluten-free may still be gluten-free. Therefore, reading the label to check ingredients remains an essential part of successfully managing the gluten-free diet.

If you are still unsure about a product after reading the ingredients list, don't be afraid to contact the manufacturer for more information. Contact information, whether it's a phone number or email, should be located somewhere on the package. Contact them and ask about preparation, ingredients, or packaging. If possible, specify the lot number of the food in question. State your needs clearly and be patient, persistent and polite.

Special Cautions

Some food products carry an increased risk for cross-contact with gluten, including oats and naturally gluten-free grains, flours and starches. Therefore, it is recommended that individuals with celiac disease purchase naturally gluten-free grains, flours and starches that are labeled gluten-free.

Additionally, while individual herbs and spices are naturally gluten-free, research has found that some spice mixtures may have small amounts of gluten-containing grains. For example, spices can be mixed with wheat flour or wheat starch to reduce costs. (If wheat-based ingredients are added to a spice or dried herb, U.S. food regulations require that wheat be included on the food label, or the spice will be deemed misbranded.)

It is also possible that spices and herbs may come into cross-contact with a gluten source during the manufacturing and packaging processes. However, because herbs and spices are typically consumed in small quantities during an average meal, researchers concluded that the trace amounts of gluten did not pose a health risk for individuals with celiac disease.

Gluten-Free Certification

Gluten-free certification is a process designed to protect consumers with gluten-related disorders by confirming that a food, drink or supplement meets strict standards for gluten-free safety. It assures consumers that there is third-party oversight confirming the legitimacy of the manufacturer's gluten-free claims, which can help consumers feel better about the product's safety, given that the FDA does not require testing to confirm the gluten-free status of a product.

Products that have been certified gluten-free will typically bear a symbol on the packaging so customers with celiac disease and other gluten-related disorders can quickly and easily recognize that the product is certified. Beyond Celiac endorses the Gluten-Free Certification Program (GFCP). Learn more about the GFCP at www.gf-cert.org.

Lastly, while federal regulations for gluten-free labeling cover food products and supplements only, some gluten-free certifications will allow for medications and non-food products like cosmetics to be certified gluten-free.





GUIDELINES FOR DINING OUT

Just because you have celiac disease or gluten sensitivity doesn't mean you have to forgo dining out with your friends and family! Here are some suggestions to help streamline the process and minimize the chance of gluten exposure.

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 restaurants online.

Scope out a restaurant ahead of time by reading about it online. Find the restaurant website and review their menu in order to get an idea of what you want to order and what questions you may have for the chef upon arrival. They may have an "about us" section where they elaborate on why or how they cook food or an "allergy menu" with certain menu items marked as suitable or unsuitable depending on food restrictions. Read independent reviews of the restaurants on websites like Yelp, Google Reviews, or FindMeGlutenFree to determine how well they accommodate people with food restrictions.

3. Ask about cross-contact.

Explain what cross-contact* is and ask what precautions are taken to prevent it. Make sure the kitchen staff uses clean utensils, cutting boards, pots, pans, etc. when preparing your meal. If a grill is used, request that they place a barrier like aluminum foil between your food and the grill surface, or ask that your food be pan-grilled. If condiments are included, like mayo on a gluten-free sandwich, ask if the staff uses squeeze bottles or has a dedicated set of gluten-free condiments.

4. Ask about how food is prepared.

Items to be especially wary of include:

- Soups and broths
- Grilled foods
- Anything with a sauce
- Items that may be breaded or include breadcrumbs
- French fries or other foods that may be cooked in a shared fryer (Those with celiac disease need food from dedicated gluten-free fryers. Shared fryers are a no-go)
- Soy sauce
- Marinated meats
- Rice made with stock

Make sure croutons are not included with your salad, and avoid malt vinegar. Also, confirm that vegetables are cooked in a separate pot. Some restaurants cook them in the same water as used for gluten-containing pasta, thus causing cross-contact and making them unsafe for those with celiac disease.

*Cross-contact is sometimes referred to as cross-contamination. Cross-contamination is the term used to indicate the spreading food-borne illnesses, so cross-contact is more accurate when referring to gluten.

Even if a restaurant offers a gluten-free menu, **it is still extremely important to ask questions** about ingredients and preparation practices.

5. Be polite and informative.

Even though celiac disease has become 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, 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.

6. 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!

7. Clarify and double-check.

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).

8. BYOB—Bring Your Own Backup!

Call and ask the restaurant if you are permitted to bring your own bread, pasta, sauce, 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).

9. 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 into 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.

10. Show your gratitude in your 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!

11. Have fun!

A diagnosis of celiac disease or gluten sensitivity 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 primarily focused on the food they eat, it is possible to be exposed to gluten when taking medication.

Wheat may be used in medications as an inactive ingredient. Inactive ingredients include excipients, which help bind pills together. There are several types of excipients that drug companies may use. It is important to check with the manufacturer, your pharmacist, or a reputable website such as www.glutenfreedrugs.com to be sure that the particular medication you are taking is free of gluten-containing ingredients.

Potential Concerns

- Prescription and non-prescription medications do not have to comply with the Food Allergen Labeling and Consumer Protection Act (FALCPA). This means that even if wheat is present in an ingredient, it does not need to be declared on the product label.
- Non-prescription medications include lists of both active and inactive ingredients on product packaging. However, consumers may not always be provided with the ingredients list of prescription medication. Ask your pharmacist for the package insert from the manufacturer.
- Starches and hydrolyzed starches may be ingredients in medications, and wheat may occasionally be used. Unfortunately, the source of the starch ingredient does not have to be named.
- Potential sources of gluten in medications are not well recognized by healthcare professionals.
- Inactive ingredients (and their sources) used in medications may vary between the name-brand drug and generic variety.

Grain Sources of Starches Found in Medications

- Corn (most common)
- Potato
- Tapioca
- Rice
- Wheat (not often used)

Starch Ingredients Used in Medications

- Starch
- Pregelatinized starch
- Sodium starch glycolate
- Maltodextrin
- Maltose
- Dextrates

Resource for checking if medication contains gluten:

www.GlutenFreeDrugs.com. This list is maintained by Steven Plogsted, PharmD

If you think you are being exposed to gluten through your medication, talk to your doctor or pharmacist about your concerns.



RESOURCES AVAILABLE FROM BEYOND CELIAC

Symptoms Checklist

After submitting this simple online checklist, you will be able to download a printable form for your doctor that includes information on celiac disease testing.

www.BeyondCeliac.org/checklist

Research News

Subscribe to stay up to date on all the latest celiac disease research. All research we write about has been reviewed by our Science Team so you know it's worth reading about.

www.BeyondCeliac.org/research

Monthly e-Newsletter

Beyond Celiac produces a free monthly e-newsletter that covers a variety of topics, including health and wellness articles, food and lifestyle tips, and gluten-free product reviews.

www.BeyondCeliac.org/subscribe

Non-Celiac Gluten Sensitivity

Find answers by expert researchers to frequently-asked questions about NCGS.

www.BeyondCeliac.org/celiac-disease/non-celiac-gluten-sensitivity

Gluten-Free Recipes

Find hundreds of gluten-free recipes at

www.BeyondCeliac.org/recipes

GET INVOLVED!

Dedicated volunteers, generous contributors and involved community members are key players in the success of Beyond Celiac and our mission.

Want to help us raise awareness and make gluten-free living easier? There are several ways you can get involved!

Donate

It really is true that no amount is too small—or too large. Please consider donating to Beyond Celiac. Financial contributions support our research initiatives and keep patient resources free, including this guide.

www.BeyondCeliac.org/donate

Participate in Research

Advance celiac disease research by telling your story. Visit Go Beyond Celiac at <https://go.beyondceliac.org>, register and complete the surveys. The data we collect is being shared with researchers so they can better understand the disease and develop treatment options.

Consider participating in a clinical trial. Visit www.BeyondCeliac.org/clinical-trials for more information.

Join The Fun

Sign Up for a Step Beyond Celiac 5K. Step Beyond Celiac 5Ks raise much-needed funds for celiac disease research... and they're fun too!

Learn more at

www.StepBeyondCeliac.org.

Raise Awareness

Follow us on Facebook, Instagram, Twitter and YouTube and like and share evidence-based, informative and helpful posts from Beyond Celiac.

Volunteer

Interested in volunteering or learning more about volunteer opportunities with Beyond Celiac and/or our events? Visit

www.BeyondCeliac.org/volunteer or contact volunteer@beyondceliac.org.

NOTES



ABOUT BEYOND CELIAC

Since 2003, Beyond Celiac has been the leading patient advocacy and research-driven celiac disease organization working to drive diagnosis, advance research and accelerate the discovery of new treatments and a cure.

By engaging with the top scientists in the field, awarding research grants, and supporting the community, Beyond Celiac envisions a world in which people with celiac disease can live healthy lives and eat without fear – a world Beyond Celiac.

Vision Statement

A world in which people with celiac disease can live healthy lives, free from social stigma and fear of gluten exposure – a world Beyond Celiac.

Mission Statement

Beyond Celiac unites with patients and partners to drive diagnosis, advance research and accelerate the discovery of new treatments and a cure.



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