

Gluten-Free Diet Guide for Families

Table of Contents

What Is Gluten?	2
Where Is Gluten Found?	2
What Can The Celiac Patient Eat?	3
What About Oats?	3
How Do I Start My New Diet?	3
Life Goes On!	6
Don't Blame The Gluten!	6
Gluten-Free Does Not Mean It Is Good For You!	7
Once The Diet Has Started	8

INTRODUCTION

If your child has just been diagnosed with celiac disease (CD), you may be experiencing mixed emotions. On one hand, no one likes to hear that their child has any kind of medical condition. However, you may be relieved to finally have the answer to your child's past medical problems. You may also feel better knowing that CD is a treatable disorder, and that intestinal damage from CD is reversible. You may also feel confused, overwhelmed, or unsure about how to start the healing process.

Therapy for CD is achieved through dietary avoidance of foods containing gluten. The purpose of this booklet is to help newly diagnosed patients with CD and their families get started with treatment—the gluten-free diet. This booklet is a starter guide that will help you through the initial days of the gluten-free lifestyle and is designed to help you and your family manage the emotional stress that you may be feeling right now.

The most important first step is to work with your physician and a knowledgeable registered dietitian (RD) who will individualize the gluten-free diet and any other specific nutritional needs of your child.



Before You Start The Gluten-Free Diet:

Before starting the gluten-free diet, be sure your physician has completed all testing necessary to correctly diagnose celiac disease. Starting the diet before all tests are completed will interfere with the results of the tests, so the diagnosis must be made while on a diet containing gluten.

WHAT IS GLUTEN?

Gluten is the general name for one of the proteins found in wheat, rye, and barley. It is the substance in flour that forms the structure of dough, the “glue” that holds the product together, and a leavening ingredient. When these proteins are present in the diet of someone with CD, they become toxic and cause damage to the intestine. This damage leads to decreased absorption of essential nutrients and, if left untreated, can lead to nutrient deficiency and increased risk for other diseases, like iron deficiency anemia, decreased bone density, unintentional weight loss, and folate and vitamin B12 deficiency.

WHERE IS GLUTEN FOUND?

Food/grains

The grains containing gluten include wheat, rye, barley, and products derived from them (see **Table 1** for a list of grains to be avoided). These grains are used in such items as breads, cereals, pasta, pizza, cakes, pies, cookies, and as added ingredients to many processed food items.

Table 1. Gluten-containing grains to avoid

Barley	Faro	Spelt
Barley malt/extract	Graham flour	Triticale
Bran	Kamut	Udon
Bulgur	Matzo flour/meal	Wheat
Couscous	Orzo	Wheat bran
Durum	Panko	Wheat germ
Einkorn	Rye	Wheat starch*
Emmer	Seitan	
Farina	Semolina	

**May be allowed in a labeled gluten-free food, however, “wheat” must be followed by an asterisk that links to another asterisk and the statement, “The wheat has been processed to allow this food to meet the Food and Drug Administration requirements for gluten-free foods.”*

Overlooked Sources of Gluten

To completely remove gluten from your diet, less obvious sources of gluten must also be identified and avoided. You may find gluten in products such as:

Table 2. Overlooked gluten sources

Ales	Sauces
Beer and Lagers, (including those labeled “gluten removed”)	Soup Base
Breading	Stuffing
Coating Mix	Malted products
Communion Wafers	Imitation bacon/seafood
CROUTONS	Soy sauce
Candy	Seasoned rice mixes
Protein/Energy Bars	Marinades, thickeners
Processed Meats	Prescription medications and over-the-counter medication*
French fries (shared fryers)	Nutritional supplements, vitamin & mineral supplements**
Broth	
Pasta	
Roux	Play-doh***

*Visit www.glutenfreedugs.com for information on gluten in medications

**Covered under FALCPA

***The gluten protein is not absorbed through the skin. However, hands need to be properly washed after handling Play-doh and before eating to avoid cross-contamination.

Be sure to read all labels carefully. Labels must be read every time you purchase food because ingredients in a product can change at any time without notice.

Food Allergen Labeling and Consumer Act (FALCPA)

There is good news to help make label-reading easier. Food products manufactured and labeled after January 1, 2006 fall under the “Food Allergen Labeling and Consumer Act” (FALCPA). This rule requires companies to identify in “plain English” the eight most prevalent food allergens including eggs, fish, milk, peanuts, shellfish, soybeans, tree nuts, and **wheat**. If wheat protein or a protein derived from wheat is used as an ingredient, even in small amounts (for example, in coloring, flavoring, or seasoning), it must be declared in the allergy statement as “Contains” or in parentheses next to the ingredient containing wheat. For example:

Including the ingredient list with parentheses

- **Ingredients:** Enriched flour (wheat flour, malt flavoring, niacin, reduced iron, thiamin mononitrate, riboflavin, folic acid), sugar... **OR**

Use a “contains” statement

- **Ingredients:** Enriched flour (wheat flour, malt flavoring, niacin, reduced iron, thiamin mononitrate, riboflavin, folic acid), sugar...

Contains: Wheat, Milk, Egg, and Soy

This law does not, however, address the use of barley (malt) or rye. If the label does not indicate in the allergy statement that wheat has been used, you must read the list of ingredients for other gluten-containing grains. If a product is **not** labeled as gluten-free, read the label carefully for the following gluten-containing ingredients:

Wheat
Rye
Barley
Malt
Brewer’s Yeast
Oats

USDA Foods

Products regulated by the U.S. Department of Agriculture (USDA; meat, poultry, and egg products and mixed foods products that generally contain more than 3% raw meat or 2% or more cooked meat or poultry meat) are not required to follow FALCPA rules (although the vast majority voluntarily follow FALCPA labeling). In those foods, possible problem ingredients may be: dextrin, modified food starch, and starch. It is worthwhile to inquire about meat, poultry, and egg products that contain these ingredients.

FDA Defines the Term “Gluten-Free”

FALCPA legislation also requires the Food and Drug Administration (FDA) to develop rules for the use of the term “gluten-free”. The rule defining the term “gluten-free” was enacted August 5, 2014. In part, this rule states that products labeled gluten-free must contain less than 20 parts per million of gluten. For more information about the rule, please see <https://www.fda.gov/food/food-labeling-nutrition/questions-and-answers-gluten-free-food-labeling-final-rule>.

WHAT CAN YOU EAT?

You may be uncertain about what to feed your child because it seems that there is so much that a person with CD can’t eat. Not to worry, there are many foods that will fit into your child’s diet that are naturally gluten-free (see **Table 3** for a list of gluten-free grains and starches). There are also a variety of gluten-free substitutes to replace old favorites like pizza, pasta, and bagels.

Table 3. Gluten-free grains and starches

Amaranth	Seeds	Rice
Arrowroot	Millet	Rice Bran
Buckwheat	Montina (<i>Milled</i>)	Sago
Corn	<i>Indian Ricegrass</i>	Sorghum
Flax	Potato Starch	Soy (Soya)
Flours made from	Potato Flour	Tapioca
Nuts Beans and	Quinoa	Teff

Distilled vinegars are gluten-free since all distilled products are free of any harmful gluten proteins. Malt vinegar, however, is not distilled and therefore contains gluten.

WHAT ABOUT OATS?

Many recent studies indicate that the protein found in oats may not be harmful to **most** people with CD. However, there is concern that the oats may be contaminated with wheat during milling and processing. **Please consult your physician or dietitian before adding oats to your child’s diet.**

HOW DO I START A GLUTEN-FREE DIET?

At Home

Your first instinct may be to stop at the grocery store on your way home from the doctors’ office and search the grocery store for all the gluten-free products you can find. This is an overwhelming task that initially may end in frustration and emotional distress.

Start the new diet by looking at the foods you already have in your home. Many of your favorite brands may already be gluten-free, eliminating the need to search all the brands of a particular product.

Start to plan your meals around naturally gluten-free foods. Plan a week’s menu around these foods and make a grocery list to help you stay on track once you get to the store. Try the following meal suggestions:

Breakfast

- Cream of rice cereal with nuts, seeds, or dried fruit
- Labeled gluten-free rice cereal (like Chex), milk, and fresh fruit
- Fruit and yogurt smoothies
- Cottage cheese with apples and cinnamon
- Egg, cheese, and veggie omelet with fried potatoes and ½ grapefruit
- Eggs, Canadian bacon or turkey bacon, and grits

Lunch and Dinner

- Loaded baked potatoes with cheese and veggies
- Salads with chopped veggies, toasted almonds, or sunflower seeds and lean meats (chicken, tuna, ham)
- Tuna fish on mixed greens with fresh fruit
- Stir-fry with meat, poultry, seafood, and chopped vegetables served over brown rice
- Meat or veggie fajitas or quesadillas made from corn tortillas
- Turkey or beef chili, corn chips, and veggie sticks
- Beef or chicken kabobs on rice or quinoa and ice cream

Snacks

- Rice cakes or rice crackers with cheese, hummus, and peanut butter
- Nachos made from corn chips with melted cheese and salsa
- Celery sticks with cream cheese, peanut butter, or cheese spread
- Pudding, ice cream, or yogurt topped with berries and whipped topping
- Baked apple
- String cheese
- Popcorn
- Nuts



Table 4. A Healthy and Nutrient-Rich Gluten-Free Diet

NUTRIENT	TIP FOR EATING MORE
Protein	Incorporate several sources of lean proteins daily, such as lean beef and pork, poultry, fish, nuts, beans, lentils, and tofu
Fiber	Choose gluten-free whole grains whenever possible, like brown rice instead of white rice. Fruits, vegetables, and beans are also great sources of fiber. Choose cereals with more than 3 grams of fiber per serving.
Calcium	Consume at least a few servings daily of milk products or substitutes, such as yogurt, cheese, or soy milk. Try to get calcium through food whenever possible, instead of taking calcium supplements.
Iron	Fortified gluten-free cereals, lean meats, and legumes are great sources of iron. Patients with profound anemia may require iron supplements as well.
Vitamins	Once your intestine is fully healed, a variety of fruits, vegetables, legumes, nuts, dairy, meats, healthy fats, and gluten-free whole grains should provide all of the vitamins that your body needs.

At the Grocery Store

As you step into your favorite grocery store, start with the fresh produce section. No need to worry here. Stock up on nutrient rich, low fat, low-sodium fruits and veggies.

Next, visit the fresh meat, poultry, and seafood section. Again, these are naturally gluten-free. Think about making a fresh turkey breast or lean roast for dinner and then using the leftovers as a filling for a corn tortilla for lunch. Use caution when choosing processed meats such as hot dogs and sausages. The processed meats may contain gluten as fillers or flavor enhancers, so read the label carefully.

After the meat section, you can visit the eggs and dairy section. These products are, for the most part, gluten-free. Calcium-rich desserts and snacks like ice cream, yogurt, and pudding may be good choices for a gluten-free diet. If your

child has lactose intolerance, try lactose-free milk, yogurt, and hard cheeses, which are usually well tolerated in those patients. Lactaid tablets can also be taken with dairy.

Within the inner isles of the grocery store, look for:

- Corn tortillas
- Plain rice
- Dried beans and legumes
- Spices and herbs
- Peanut butter
- Cooking oils
- Asian foods section for rice noodles and crackers

As the demand for gluten-free products increases, grocery stores are offering an increasing variety. These products include gluten-free pastas, flours, and baking products, bagels, breads, or brown rice pizza crusts to defrost and warm at home. Some frozen food sections have gluten-free frozen meals as a convenient option.

Gluten Free Shopping List

Produce	Fresh Fruits and Vegetables Apple, Avocado, Banana, Orange, Grapes, Berries, Mango, Melons, Pineapple Asparagus, Broccoli, Beets, Cabbage, Carrots, Celery, Corn, Green Beans, Tomatoes, Lettuce, Onions, Peppers, Potatoes, Squash, Spinach Canned/Frozen Plain Fruits and Vegetables Tofu
Dairy	Unflavored Milk Cream Cheese (use caution with processed cheese) Most Yogurts Butter, Margarine Cream Cheese Cottage Cheese Sour Cream

Packaged & Canned Goods	Plain Fruits and Vegetables Canned Tuna Dried Beans, Lentils, Peas, most Baked Beans Soups Labeled GF Olives, GF Salad Dressing, GF BBQ Sauce, GF Pasta
Cereals, grains	GF Cream of Rice, Chex, Grits, Puffed Rice Plain Brown or White Rice Corn Tacos, Corn Tortillas GF Oats
Meat, fish, poultry	Plain Beef, Pork, Poultry, Fish, Eggs, Bacon
Frozen foods	Plain Fruits and Vegetables Most Ice Cream and Sherbet Gluten-free Frozen Waffles
Beverages	100% Fruit Juice, Coffee, Tea, Cocoa, Soft Drinks
Snacks	Potato Chips (Caution: Flavored Chips), Corn Chips, Popcorn Rice Crackers, Rice Cakes Plain Nuts, Seeds Jello
Staples and Condiments	Jams and Jellies, Marmalade, Honey, Peanut Butter Corn or Potato Starch Corn and Maple Syrup, Molasses Brown, White and Confectioner's Sugar Spices and Herbs, Salt, Pepper Relish, Pickles, Olives Ketchup, Mustard, Distilled Vinegars Most Salad Dressing
Fats and Oils	Vegetable, Canola, Olive Oil, Shortening

Food Preparation

Once you are home with your groceries, you need to think about how your food is prepared. Gluten-free foods cannot come in contact with gluten-containing foods, so extra steps need to be taken to prevent cross-contamination. Here are several suggestions to help you avoid contaminating your food with gluten:

- Purchase separate jam, jelly, mayonnaise, and peanut butter to avoid wheat/bread crumbs in the shared jars. Or, purchase squeeze containers that do not require a knife to spread.
- Purchase a separate toaster for gluten-free breads, use a toaster oven that can be cleaned between uses, or place tinfoil on the rack to avoid contamination.
- Clean countertops and cutting boards often to remove gluten-containing crumbs. Prepare the gluten-free food item first, then follow with the gluten-containing item second.
- Cooking utensils, colanders, and pans need to be cleaned carefully after each use and before cooking gluten-free products.

LIFE GOES ON!

Eating Away from Home

A diagnosis of CD does not mean never eating at a restaurant again. Do not stay home for fear of making a mistake on the gluten-free diet. Dining out is a big part of our way of life and, with a little effort and planning, can continue to be enjoyed.

- Before leaving home, do some homework. Most restaurants have a website. Review the menu online to see if there is enough selection for you. Some restaurants have gluten-free menus or a list of common food allergens utilized in making their foods.
- Call ahead and talk to the manager or the chef and ask about specially prepared items that are gluten-free to determine if they are “Celiac Friendly”.
- Try to make your first visit to a restaurant outside of peak dining times.
- Always identify yourself as someone who cannot eat wheat, rye, or barley instead of saying gluten as most people have heard of gluten but do not know what it is. Also, an allergy is easier for most people to understand vs. celiac disease or autoimmune disease and indicates that this is a medical condition not a lifestyle choice.

- Don't be afraid to ask how the food is prepared. Meats may be marinated in soy sauce. French fries may be made in the same fryer as other breaded products. Hamburgers and hamburger buns may be grilled in the same area. All of these methods can lead to gluten contamination.
- Be pleasant and informative and thank your server/manager if you receive good service and a safe gluten-free meal.
- Bring your own GF bread or crackers.

www.findme glutenfree.com

www.glutenfreepassport.com

www.glutenfreetravel.com

DON'T BLAME THE GLUTEN!

On a strict gluten-free diet, gastrointestinal symptoms will begin to improve in a few weeks and may completely resolve after 6 to 12 months. After healing has occurred and antibody levels have returned to normal, symptoms may not be a reliable way to determine whether or not you have ingested gluten. You can eat gluten-containing foods and may not have symptoms and, conversely, you can have symptoms without ingesting gluten. The following items may cause gastrointestinal problems that are not gluten-related.

- *Acidic foods.* Vinegars, tomato products, and citrus juices can cause reflux symptoms.
- *Sorbitol, mannitol.* These sweeteners are found in medication and dietetic candy. As a non-digestible sugar, sorbitol can cause bloating, gas, cramping, and diarrhea.
- *Guar gums.* These gums are used in gluten-free products and may cause gas, bloating, and abdominal pain.
- *Lactose.* Before the intestine has healed completely, lactase, the enzyme needed to break down the milk sugar lactose may be deficient. Drinking milk or a large amount of other dairy products may cause increased gas, bloating, abdominal pain, and diarrhea.
- *Food allergens.* It is not uncommon to have additional food intolerances to foods such as milk, soy, nuts, yeast, eggs, corn, and fructose. Further testing maybe required.
- *Flax.* Flax can increase the number of bowel movements.

GLUTEN-FREE DOES NOT MEAN IT IS GOOD FOR YOU!

Today there are many specialty companies that produce good gluten-free products. Although these products taste wonderful, the ingredients used may not be healthful. Good nutrition is also important as you select foods in your diet. **Table 5** gives some examples for a healthy gluten-free diet.

Table 5. The Healthy Diet

Low Fat	Read labels carefully because many gluten-free foods may be higher in fat than their gluten-containing counterparts.
Calcium Rich Foods	Osteopenia and osteoporosis are common in people with CD.
Weight Gain/Loss	After the gastrointestinal tract has healed, it can now absorb all the nutrients in foods. Even though the calorie level has remained the same, this may be the cause of unintentional weight gain. Dietary changes to eliminate gluten-containing foods may also lead to a decrease in caloric intake.
Constipation/ Diarrhea	If only processed white rice is used in replacement of wheat flour, the low-fiber diet may lead to constipation. Conversely, if fiber-rich grains are added in the diet in large amounts too quickly, diarrhea can occur. It is important to include healthy high fiber sources in the gluten-free diet.
Vitamin Supplements	A vitamin/mineral supplement may be necessary when your child's diagnosis is first made. The damage done to the intestinal lining can lead to a decreased absorption of iron, calcium, folate, and other B-vitamins. In addition, processed wheat products such as breads, cereals, and pasta are fortified and enriched with B-vitamins, folate, and iron, while many gluten-free foods are not. This lack of fortification can contribute to vitamin and mineral deficiencies.

Vitamin Supplements continues —▶



It is important to select a vitamin/mineral supplement that is gluten-free (supplements are covered under FALCPA; therefore, if wheat is used, it will be listed in the ingredients) and meets 100% of the recommended daily allowances, or the daily-recommended intake (RDA or DRI). A well-balanced diet can usually provide adequate amounts of most nutrients, therefore a vitamin and mineral supplement may not be necessary long-term.

Table 6 provides a list of nutrient-rich foods to be included in the GF diet.

Table 6. Nutrient-Rich Gluten-Free Foods

Calcium	Milk, Yogurt, Cheese, Ice Cream, Sardines, Salmon, Broccoli, Spinach, Almonds, Figs, Calcium Fortified Soy Milk, and Orange Juice
Iron	Meat, Fish, Poultry, Nuts, Seeds, Legumes, Dried Fruit, Eggs, Amaranth, Quinoa
Folate	Broccoli, Asparagus, Orange Juice, Liver, Legumes, Bean Flour, Flax, Peanuts, Walnuts, Sesame and Sunflower Seeds
B12	Liver, Eggs, Milk, Meat, Poultry, Fish and Other Seafood

Getting School Accommodations

Children with CD qualify for accommodations under the Americans with Disabilities Act. Under this provision, a child with CD is entitled to receive a gluten-free lunch at school, at no extra cost to the family. Ask for a meeting with school administrators to discuss setting up a 504 plan that will list important accommodations needed during the school day, such as advanced notice of special parties that involve foods, field trips, and an accidental exposure notice to parents. If school lunch is not an option, pack lunch from home.

ONCE THE DIET HAS STARTED

Nutritional Consult

It is important to have the contact information of a dietitian with expertise in CD. You may need several sessions with a dietitian before feeling confident about dealing with a gluten-free diet. Periodic visits with the dietitian are required, especially if the repeat blood test is suggestive of gluten ingestion.

Gastroenterology Follow-Ups

The frequency of follow-up visits with the gastroenterologist depends on the age of the patient, the pace of symptom improvement, and the return of blood test results to a normal range. If there is a good response to the diet and blood tests return to normal within six to nine months, visits to the gastroenterologist can usually be less frequent, yearly follow-ups. A decline in antibody levels is expected after a six-month period on an appropriate gluten-free diet. With dietary compliance, the antibodies should eventually disappear. Continued detection of the antibodies suggests poor dietary compliance, either knowingly or accidentally. In this situation, a meeting with the dietitian is necessary to identify sources of gluten in the diet.

Should Other Family Members Be Tested?

First-degree relatives of patients with CD should undergo blood testing, and a gastroenterologist should further evaluate family members with positive blood test results. Upper gastrointestinal endoscopy with intestinal biopsy remains the gold standard for diagnosis. For those patients with negative celiac blood test results, genetic testing may be helpful in guiding the follow-up care and need for repeat celiac blood testing. In the absence of genetic markers there is no need to repeat blood tests.

Family Support

Family support of the gluten-free diet is vital. It is important that all family members are aware of gluten-free dietary requirements and become involved in both grocery buying and meal preparation.

Family support for dietary compliance is equally important. At home, gluten-free foods and flours must be stored separately to avoid cross-contamination and for younger children with CD, only their gluten-free foods should be easily accessible.

Emotional Aspects of The Gluten-Free Diet

Some patients are relieved when diagnosed with CD because it is a disease that can be managed with diet alone. However, others are concerned by the drastic diet and lifestyle modification. Fear of eating, particularly dining outside of the home, can occur and result in social isolation because so many social events are centered around eating. These concerns must be discussed with the dietitian and gastroenterologist. With appropriate teaching, the gluten-free diet can be maintained even when dining out. Some regional support groups have lists of local gluten-free restaurants with GF menus or menu items.

The sudden dietary and lifestyle change may induce depression to varying degrees, and involvement in support groups may be helpful, especially for teenagers. Within this group, they can share their feelings with others and learn coping skills. In some occasions, a referral to one-on-one counseling may be an option for dealing with change; be sure to ask your medical team for a referral.

The important thing to remember is that you are fortunate to be aware that you have CD, and the damage can be reversed through the gluten-free diet, reducing the impact the disease has had on your body. We hope this guide will help you, and we wish you good health.

→ Locate a Pediatric Gastroenterologist

IMPORTANT REMINDER: This information from the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) is intended only to provide general educational information as a definitive basis for diagnosis or treatment in any particular case. It is very important that you consult your doctor about your specific condition.

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