



Gluten - Free Diet Guide *for* Families



Children's Digestive Health and Nutrition Foundation



North American Society for Pediatric
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INTRODUCTION

If your child has just been diagnosed with celiac disease (CD), you may be experiencing mixed feelings. On one hand, no one likes to hear that his or her 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 celiac disease is a treatable disorder, that intestinal damage from celiac disease is reversible, and that therapy does not involve shots, pills, therapy or surgery. You may also feel confused, overwhelmed or unsure about how to start the healing process.

After getting nutritional advice, some parents head straight to the grocery store to stock up on gluten-free (GF) products for their child. They may spend hours in the grocery store, but leave with only a small bag of groceries and no idea of what to serve for dinner. They may experience the so-called "Celiac Meltdown"!

The purpose of this booklet is to help prevent newly diagnosed celiac patients and their families from experiencing "Celiac Meltdown. 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 review the gluten-free diet and any other specific nutritional needs of your child. The registered dietitian will be able to help you contact local support groups and direct you to reliable web sites.

For more information or to locate a pediatric gastroenterologist in your area please visit our website at:
www.naspgan.org

IMPORTANT REMINDER: This information from the CDHNF is intended only to provide general information and not 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.

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 is also the 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 subsequent disease (i.e. Iron deficiency anemia, decreased bone density, unintentional weight loss, folate and vitamin B12 deficiency).

Where is Gluten Found?

Food/grains

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

Table 1. Gluten containing grains to avoid

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

Hidden Sources of Gluten

In order to completely remove gluten from your diet, hidden sources of gluten must be avoided. You will find hidden gluten in products that may not be obvious to you at first, such as:

Table 2. Hidden gluten sources

Candy	Processed meats
Broth	Self-basting poultry
Imitation bacon/seafood	Soy Sauce
Marinades	Thickeners

Be sure to read all labels carefully. If a product has questionable ingredients, avoid it until the manufacturer confirms that the product is gluten-free. Labels must be read every time you purchase food because ingredients in a product can change at any time (see *Table 3* for a listing of ingredients on labels that may contain gluten).

Table 3. Ingredients to question as sources of gluten

Brown rice syrup	Caramel color
Dextrin	Malt/malt extract/flavoring
Modified food starch	Modified hop extract
Seasonings and spice blends	"Starch" in pharmaceuticals
Yeast-malt sprout extract	

New Food Label Laws

There is good news to help make label reading easier. By 2006, the *"Food Allergen Labeling and Consumer Act of 2003"* will require that companies identify in "plain English" the eight most prevalent food allergens including eggs, fish, milk, peanuts, shellfish, soybeans, tree nuts and wheat. If these ingredients are present, even in small amounts, in items such as colorings, flavoring, and seasoning, they must be identified. This legislation also requires the Food and Drug Administration (FDA) to develop rules for the use of the term "gluten-free".

WHAT CAN THE PATIENT WITH CELIAC DISEASE EAT?

You may be uncertain about what to feed your child because it seems that there is so much that a patient with celiac disease 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 4* for a listing of GF grains and starches). There are also a variety of gluten-free substitutes to replace old favorites like pizza, pasta and bagels.

Table 4. Gluten-free grains and starches

Amaranth	Arrowroot
Buckwheat	Corn
Flax	Flours made from nuts, beans and seeds
Millet	Montina
Potato starch, potato flour	Quinoa
Rice, rice bran	Sago
Sorghum	Soy (soya)
Tapioca	Teff

The following ingredients on food labels are also safe: starch (FDA requires that it should be corn starch), maltodextrin, vinegar, and alcohol (distilled vinegar and spirits are GF but avoid malt vinegar and malt beverages e.g. beer).

What About Oats?

Many recent studies indicate that the protein found in oats may not be harmful to most people with celiac disease. However, there is concern that the oats may be contaminated with wheat during the 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
- Puffed Rice cereal, 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

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 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

Table 5. Gluten- free shopping list

Fruits and vegetables (fresh, frozen, and canned)	Rice, cream of Rice, rice flake or puffed rice cereal, rice crackers
Fresh meat, fish, poultry Eggs Lentils, peas, beans, nuts, seeds, tofu	Corn, corn tacos, corn tortillas, corn chips, cornmeal, cornstarch, hominy grits, plain popcorn
Milk, cream, cheese, most yogurt and ice cream, cream cheese, cottage cheese, sour cream	Butter, margarine, vegetable oil, shortening, lard
Potato, potato starch, plain potato chips	Tea, coffee, cocoa, soft drinks, 100% fruit juice, distilled beverages
Jam, jelly, marmalade, honey, peanut butter, corn syrup, maple syrup, molasses, Sugar (brown, white and confectioner's)	Spices and herbs, salt and pepper, plain pickles, relish, olives, ketchup, mustard, tomato paste, distilled vinegars

At the Grocery Store

On your first trip to the grocery store, think about shopping the perimeter of the store. This is where you will find naturally gluten-free foods. 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 luncheon meat and other processed meats. 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 cheese as these 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 (canola and olive oils are low in saturated fats and contain healthy monosaturated fat)

While shopping for food, you will also need to think of other, non-food, items you purchase that may contain gluten (see Table 6).



Table 6. Other items to consider as hidden gluten sources

Lipstick gloss and balms	Mouthwash and toothpaste
Play Dough	Prescription and OTC medication
Stamps and envelope glue	Vitamins

As the demand for GF products increases, many grocery stores will begin to stock more products that are specifically gluten-free. Look in the Asian section for rice noodles and crackers. Check out the “organic” or “health food” section for GF pastas, flours, and baking products. Specialty health food stores typically have GF foods in the frozen food section. One can select GF bagels, breads, or brown rice pizza crusts to defrost and warm at home. Some frozen food sections have GF frozen meals as a convenient option.

Food Preparation

Once you get your groceries home, you need to think about how your food is prepared. 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.
- Purchase a separate toaster for gluten-free breads, or use a toaster oven that can be cleaned between uses, or place tinfoil on the rack to avoid contamination.
- Clean counter tops and cutting boards often to remove gluten-containing crumbs.
- 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 that can easily be found through a search engine. Review the menu on line to see if there is enough selection for you. Some restaurants have GF 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 GF.
- Try to make your first visit to a restaurant before peak dining times.
- Always identify yourself as someone who cannot eat wheat, rye or barley. Food items that you would never guess have flour in them, often do. (One large popular pancake house adds pancake batter to their omelets.) Salads may not have croutons, but may arrive at your table with a bread stick across the top.
- 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 these methods can lead to gluten contamination.
- Be pleasant and informative, but not demanding.
- Bring your own GF bread or crackers.



DON'T BLAME THE GLUTEN!

On a strict GF diet, gastrointestinal symptoms will begin to improve in a few weeks and will 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 taken in 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 GI problems that are not gluten related.

- *Acidic foods.* Vinegars, tomato products, and citrus juices can cause reflux symptoms.
- *Sorbitol.* It is 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.* In a recent survey of the Celiac Sprue Association, over half of the members reported having additional food intolerances to foods such as milk, soy, nuts, yeast, eggs, corn, and fructose.
- *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 they taste wonderful, the ingredients used may not be a healthy alternative. Good nutrition is also important as you select foods in your diet. Table 7 gives some examples for a healthy GF diet.

Table 7. The healthy diet

Low fat	Read labels carefully as many GF foods may be higher in fat than their gluten-containing counterpart.
Calcium rich foods	Osteopenia and osteoporosis are common in people with CD.
Weight gain/loss	After the GI 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 the fiber rich grains are added in the diet in large amounts too quickly, diarrhea can occur.

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, many gluten-containing breads, cereals, and pasta are fortified with B-vitamins and iron while many gluten-free foods are not and this can also contribute to vitamin and mineral deficiencies.

It is important to select a vitamin/mineral supplement that is gluten-free 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. Table 8 provides a list of nutrient rich foods to be included in the GF diet.

Table 8. 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 seafood

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 serology 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 the resolution of symptoms, and normalization of serology test results. If there is a good response to the diet and blood tests normalize 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 GF diet. With dietary compliance, the antibodies should eventually disappear. Persistence of the antibodies suggests poor dietary compliance, either knowingly or inadvertently. In this situation, a meeting with the nutritionist is necessary in order to identify sources of gluten in the diet.

Should other family members be tested?

First-degree relatives of patients with CD should undergo serological 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 serology results, genetic testing may be helpful in guiding the follow-up care and need for repeat celiac serology. In the absence of genetic markers there is no need to repeat serology tests.

Family support

Family support of the gluten-free diet is vital. It is very important that all family members are aware of GF 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 celiac disease, 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 of the 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 at varying degrees and involvement in support groups may help, especially for teenagers. Within this group, they can share their feelings with others and learn coping skills. In rare occasions, a referral to counseling may be necessary.

The important thing to remember is that you are fortunate to be aware of the fact that you have CD. Millions of people do not know they have the disease. You can reverse the impact the disease has had on your body through diet. We hope this guide will help you and wish you good health

RESOURCES

This is a representative but not a comprehensive list of resources for celiac disease.

MAJOR NATIONAL SUPPORT GROUPS

Gluten Intolerance Group

15110 10th Ave. SW, Suite A

Seattle, WA 98166

206.246.6652

Group: gig@gluten.net

Website: www.gluten.net

Celiac Sprue Association/USA

PO Box 31700

Omaha, NE 68131-0700

402-558-0600

402-558-1347 (fax)

Group: celiacs@csaceliacs.org

Website: <http://www.csaceliacs.org>

Celiac Disease Foundation

13251 Ventura Boulevard, Suite 1

Studio City, CA 91604-1838

818-990-2354

818-990-2379 (fax)

Group: cdf@celiac.org

Website: www.celiac.org

Canadian Celiac Association

5170 Dixie Road, Suite 204

Mississauga, Ontario

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Phone: 905-507-6208, 1-800-363-7296

Fax: 905-507-4673

Email: celiac@look.ca

INTERNET

American Dietetic Association:

www.eatright.org

Celiac Center at Columbia University

<http://www.celiacdiseasecenter.columbia.edu/CF-HOME.htm>

Celiac disease and gluten-free resource:

www.celiac.com

Celiac Frequently Asked Questions (FAQ):

www.enabling.org/ia/celiac/faq.html

Center for Celiac Research, University of Maryland School of Medicine

www.celiaccenter.org

Children's Digestive Health and Nutrition Foundation (CDHNF)

www.cdhnf.org

www.celiachealth.org

North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN):

http://www.naspghan.org/sub/celiac_disease.asp

<http://www.naspghan.org/sub/positionpapers.asp>

National Institutes of Health:

<http://digestive.niddk.nih.gov/ddiseases/pubs/celiac/>

University of Chicago, Celiac Disease Program: <http://www.uchospitals.edu/specialties/celiac/index.php>

BOOKS

Gluten-Free Friends: An Activity Book for Kids by Nancy Patin Falini, MA, RD, LDN
www.savorypalate.com

Gluten-Free Diet: A Comprehensive Resource Guide by Shelley Case, B.Sc. RD
www.glutenfreediet.ca

Kids with celiac disease: A Family Guide to raising Happy, Healthy. Gluten-free Children
By Danna Korn
http://www.celiac.com/cgi-bin/webc.cgi/st_main.html?p_catid=8

CELIAC PUBLICATIONS

Gluten-Free Living: National Newsletter for People with Gluten Sensitivity
www.glutenfreeliving.com

Sully's Living Without Magazine
www.livingwithout.com

COOKBOOKS

The Gluten-Free Gourmet-Living Well Without Wheat, Cookbook series by Bette Hagman
http://www.best-cooking-books.com/search_Bette_Hagman/searchBy_Author.html

Wheat-Free, Gluten-Free Cookbook for Kids and Busy Adults by Connie Sarros
www.gfbooks.homestead.com

Cookbooks and Informational Books by Carol Fenster
<http://www.savorypalate.com/>

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