

HOUSTON CELIAC-SPRUE SUPPORT GROUP

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Celiacs Helping Celiacs

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FOR THE NEWLY-DIAGNOSED CELIAC AND DH'er STEP-BY-STEP: BEGINNING THE GLUTEN-FREE LIFESTYLE©by Janet Y. Rinehart, Houston, and Lynn Rainwater, San Antonio

BEGIN

A definite diagnosis of Celiac Disease (screening blood tests plus endoscopic biopsies) and/or Dermatitis Herpetiformis (skin biopsy) means a lifetime commitment to a gluten-free diet.

- Take full advantage of your local chapter membership. Our group leaders and contacts have experience with the gluten-free diet. We can help you acclimate to the changes in your lifestyle. We welcome your questions.
- Join national celiac support groups, for example:

CSA/USA, P. O. Box 31700, Omaha, NE 68131-0700; www.csaceliacs.org. The full membership (\$33) includes a quarterly newsletter, *Lifeline*, and publications that can be an important part of your orientation.

GLUTEN INTOLERANCE GROUP (GIG), 3 1214 124 Avenue, SE, Auburn, WA 98092-3667; 253/833-6655

CELIAC DISEASE FOUNDATION, 13251 Ventura Blvd., #3, Studio City, CA 91604-1838; 818/990-2354

- Order the *CSA/USA Gluten-Free Product Listing* (\$30) from CSA/USA (www.csaceliacs.org). It will greatly simplify your task of identifying gluten-free products.

- Do research at reputable celiac disease centers:

University of Chicago Celiac Disease Program: Celiac Hotline: 773/702-7593; www.uchospitals.edu/specialties/celiac/ .

University of Maryland Center for Celiac Research -- 410-706-8021; <http://celiaccenter.org>.

Celiac Disease Center at Columbia U. www.celiacdiseasecenter.columbia.edu or 212-342-0251.

Celiac Center at Beth Israel Deaconess Medical Center, Boston, MA; Phone: 617-667-1272; Website: www.bidmc.harvard.edu/celiaccenter

National Institute of Health: <http://digestive.niddk.nih.gov/diseases/pubs/celiac/>

NASPGHAN: http://www.naspgn.org/sub/celiac_disease.asp

Gluten-Free Diet Guide for Families: www.celiachealth.org

FOOD ISSUES

- **Shop the perimeter of the grocery store.** Start your gluten-free diet using unprocessed fresh foods, like fresh fruit and vegetables, unmarinated poultry, beef and fish. Add new foods one at a time every 3 days. This way you should discover, perhaps, other food allergies, and what agrees best with you.
- **Start a Food Diary** with notations about both investigated “good” brands and those which do not seem to agree with you. Write down everything you put into your mouth – food, liquids, and medications – and questionable ingredients, as well as your body’s reactions. You may see a pattern indicating other food sensitivities.
- **Sort out your Pantry and refrigerator.** Stock with approved goods and produce. Give away non-gluten-free items -- like baked goods, pasta, soups, etc. or keep them on shelves for family members who are not gluten intolerant. You may want to use special stickers to differentiate gluten-free items.
- **Learn to read all labels to discern possible hidden gluten.** See more details later in this paper.
- **Start with mixes marked “Gluten-Free / Wheat Free.”** However, wheat free is not necessarily all gluten free. Different GF cookbooks seem to use a different set of flour ingredients. Rather than store a myriad of flours, you will discover **mixes** are an easy way to begin. Mixes will help you get a feel of baking in terms of new texture, feel, time for baking, type of ingredients, etc. Then go find some

good basic GF cookbooks (Hagman's, Fenster, etc.). Follow the recipes exactly.

- **Understand that you will make unintentional mistakes as you are learning and may cause some symptoms to reoccur.** Unfortunately, that's part of the process. Just get back to basics and do the best you can. Gluten is hidden in so many products.

READING LABELS

The Food Allergen and Consumer Protection Act went into effect on January 1, 2006. The top 8 allergens must appear in common terms on labels: **milk, eggs, fish, Crustacean shellfish, tree nuts, peanuts, wheat and soybeans.** Note that *gluten* is not one of the terms to be included yet. We will still have to look for malt (barley), oats (because of contamination with wheat), although they usually are on labels. Rye is generally only in rye bread, so we don't really have to look hard for that term.

This new labeling will help people with wheat and gluten sensitivities because wheat is the biggest challenge for us and used to be hidden under nebulous terms on labels. These allergens may appear directly (1) in the Ingredient List or as a source in parenthesis for an ingredient, or (2) in a "Contains" statement below the ingredient listing. (3) in an Advisory Statement near the ingredient listing. Also, an Advisory Statement may mention possibilities of cross contamination. If you are still confused, do continue to call manufacturers; there are a lot of 800 numbers on labels so that you can even call directly from the grocery store.

The USDA regulates meat and raw egg products. Although the USDA products are not covered by the previously-mentioned labeling law, the manufacturers are aware of the law and usually voluntarily comply.

- **DO USE: Uncontaminated flours from rice, corn, potato, nuts, beans, tapioca, sorghum, millet, Montina™, manioc (from yucca plant) or quinoa.** Start your GF diet using unprocessed fresh foods. Add one new food every three days to gauge your body's reaction. Wait to use the special gluten-free oats; most celiacs can tolerate the GF oats, but not all.
- **AVOID ALWAYS: Wheat, barley, rye, oats, spelt, triticale and kamut.**
- **The terms "modified food starch", "modified starch" or "gelatinized starch" are now believed to be less likely to contain wheat.** If there is any wheat, it should be labeled as such.
- **The word "starch" alone on a U.S. food label is supposed to indicate that corn is the source of the starch.**
- **The single word "vinegar" on a food label should denote apple cider vinegar on U.S. products.** All distilled vinegar should be tolerated by most celiacs.

- **These ingredients contain gluten:** Bran, bread crumbs, bulgur, cereal extract, couscous, cracker meal, durum, durum flour, enriched flour, farina, gluten, graham flour, gram flour, high gluten flour, high protein flour, malt or cereal extract, malt vinegar, matzo, semolina, soft wheat flour, pastas, gluten flour, vital gluten, wheat (bran, germ, gluten, malt, whole wheat berries, whole wheat flour, barley grass, orzo (rice-shaped pasta), matzo meal, and more.
- **These items usually contain gluten and should be questioned:** Most soy sauces, brown rice syrup, flavorings in meat products, coating mixes, communion wafers, imitation seafood (surimi), marinades, roux, sauces, self-basting poultry, canned soups and soup bases, bouillon, stuffings, thickeners.
- **AVOID: Malt flavoring**, a very common ingredient in cereals and elsewhere, is usually from barley. Do not use products with malt or malt flavoring. Also, question “grain vinegar.” Other distilled vinegars should be fine.
- **QUESTION: Dextrin and MSG if product is imported;** vegetable starch; perhaps artificial or natural flavorings in meats.
- **Pharmaceutical products are not covered by the labeling law.** Read labels carefully on your vitamins and medications, both active and inactive ingredients. Call manufacturers if sources of ingredients are unclear, as they often are. The single word “starch” on medications can mean any starch.
- **Some celiacs, and especially those with Dermatitis Herpetiformis, may be sensitive to gluten in lotions, cosmetics, or other topical products.** Read all labels and choose appropriate brands without gluten. Amazingly, gluten may be present in glue on envelopes and stamps; it would be best to moisten these with a sponge, rather than lick them with your tongue.
- **Other Sensitivities: Certain products are questionable for celiacs, not because of gluten, but some other issue having to do with an individual sensitivity.** For example: New fat replacers Olean and Olestra are not recommended for people with digestive problems; they may have a laxative effect. Similarly, guar gum does not contain gluten, but larger amounts may have a laxative effect. Likewise, sorbitol, mannitol and the like may cause diarrhea, even though the products are GF. Celiacs tend to have other food sensitivities.
- **Cross contamination is a real problem in terms of manufacturing,** conveyor belts, shipping; at restaurants and at home with bottled/canned products everyone uses (use one implement for dipping and another for spreading); toaster; cooking in restaurants on grills, using same spoons, picking off croutons instead of none to start with, etc. Be aware and vigilant.
- **Note that manufacturers may replace fat in some no-fat or low-fat products with starch of indeterminate source.** Therefore, no-fat products are probably not a good choice. Read labels.
- **IF IN DOUBT, LEAVE IT OUT!** Wheat free is not necessarily gluten free.

- **ALWAYS READ ALL LABELS!** Manufacturers may change ingredients frequently based on the lowest cost provider.

WAIT

- **You may want to wait 2 to 4 months to use milk products.** Many newly-diagnosed celiacs are intolerant to lactose (with similar symptoms to gluten ingestion). The lactose in milk does not damage the villi, but the gluten damage in the intestine may interfere with the production of the enzyme lactase, the enzyme used by the body to break down lactose (milk sugar). After the gut heals, celiacs who were not lactose intolerant before developing CD usually regain the ability to tolerate lactose to varying degrees.
- **Wait to use fatty foods like bacon & ham.** Sick celiacs tend not to digest fats well.
- **Wait to try any ‘pseudo grains’ like millet, amaranth, buckwheat.** Although these grains in pure form are gluten free, these may be contaminated with wheat. There are so many great recipes using the common substitutes that you need not use any of these at the beginning. Then test one at a time.
- **Celiacs tend to be susceptible to other food sensitivities.** After dairy, the most common one is soy intolerance.

TOOLS

- **Invest in good gluten-free cookbooks.** Bette Hagman’s *Gluten-Free Gourmet* series and Carol Fenster’s series (www.savorypalate.com) with food values and substitutions) are excellent resources. If your child is the celiac in your family, collect a variety of cookbooks and teach him/her to cook. Engage your spouse to learn to shop and cook gluten free. In order to stay committed on any special diet, you will be more satisfied with a variety of foods. You won’t feel so deprived if you find good substitutes for your favorite meals and dishes. Try at least one new recipe a week.
- **Get used to calling manufacturers.** An important tip when investigating products is to first ask whether the product contains wheat, barley, rye or oats, or any derivatives – rather than asking initially whether something is gluten free. (Some manufacturers lump corn gluten into a big “gluten” category, and that complicates the picture. Corn gluten is fine.) You will find most company representatives are friendly and helpful. However, many companies don’t want to be committed to saying something is gluten free because of possible litigation.
- **LABELS.** Manufacturers can and do change ingredients and suppliers at any time and without warning, so always read the labels! Unfortunately, at this time the label cannot be the final arbiter of what truly is gluten free and what’s not. When calling a manufacturer, first ask if something has any wheat, barley, rye or oats in it; hopefully, the representative will then ask you if you are inquiring about

gluten. Then you know that person probably knows what the real issues are.
Good luck.

MEDICATIONS

You can't necessarily tell by labels whether a medication is gluten free. Your local pharmacist does not know either. Most times the package insert also does not give you full information about starch binders in pills. Investigate with a manufacturer the source of any starch in both active and inactive ingredients.

- Access www.glutenfreedrugs.com, a free web site by pharmacist Steve Plogsted, Ph.D. with lists of GF medications.
- Access <http://homepage.mac.com/sholland/ceciac/GFmedlist.pdf> . Dr. Holland's Naperville celiac chapter medicine investigations (free). In Adobe format.

SYMPTOMS

Diarrhea:

If you're still having diarrhea, perhaps try a softer diet of mashed potatoes, bananas, well-cooked soft vegetables, apple sauce, GF bread (warmed in microwave or toasted), soft cooked chicken or fish, eggs, etc., for a couple of weeks. Avoid fatty foods like bacon or ham. Avoid milk products and ingredients, and of course, gluten.

A short course of the over-the-counter medication Imodium may be helpful. If symptoms persist, consult your GI specialist.

Constipation:

If you're suffering with constipation, gradually add more "al dente" vegetables and fruits that contain fiber. Drink more plain water. If possible, begin a walking plan. Exercise will help digestion. You may find Metamucil will balance out the system, as needed.

Dermatitis Herpetiformis:

Skin eruptions for celiacs with DH usually take longer to disappear than the digestive symptoms. Work with your dermatologist to ensure you use the smallest amount of Dapsone or other medication possible to provide relief from symptoms. Remember that the GF diet must be strictly followed to achieve remission. Iodine (in salt, some shellfish, etc.) may exacerbate symptoms.

MEAL PLANNING

- **Plan meals before you get to the grocery store.** Shop the perimeter of the grocery store to find fresh produce, meats, poultry and fish. The first couple of months will be frustrating and your shopping experience will be longer when going grocery shopping because you are new at reading labels. Yes, gluten-free specialty products are more expensive; that's just a fact.
- **To save time and trouble, plan to make as much of the whole meal gluten free as possible.** The celiac will appreciate not feeling different, and the cook will not have to make two meals. The "civilians" in the family can add gluten-containing bread or dessert items as they want.
- **Start out with simple meals,** rather than combination dishes like casseroles.
- **Pay attention to all food sensitivities of your family.**
- **Make a rough draft of your meals for the next week,** taking into consideration the family's schedule. Plan for balanced meals with a main entree, veggies, fruit & salad. Plan one new interesting GF dessert per week.
- **Use the *CSA Gluten-Free Product Listing*, *Triumph Dining's The Essential Gluten-Free Grocery Guide*, or *Cecilia's Marketplace Gluten-Free Grocery Shopping Guide*** to evaluate brand names of products. Then draw up a brand-name grocery list based on the recipes you plan to use. Working on a weekly basis helps you eliminate extra trips to the grocery store, which will in turn cut down on the frustration of looking at labels again and may save money.
- **Be sure to plan for the family's snacks, both gluten free and non-GF.** When you have GF items readily available (like nuts, popcorn, fruit, raw cut-up vegetables, etc.), you will be less tempted to "cheat" when you are starving.
- **Try at least one new gluten-free recipe a week.** Mark your cookbooks with comments, or develop a list of your favorites with the cookbook page noted. Include the family in meal planning. What kind of meals do they like? Try to find good gluten-free substitutes.
- **Make good use of your freezer.** Freeze single portions of dinner dishes to use as lunch items. Freeze dessert items for snacks.
- **There are many companies that manufacture gluten-free specialty products.** These products are more expensive than the comparable; that's just a fact. However, many of the mixes, frozen meals, and already-baked goods are quite good and make your life easier. On the Web there are several on-line grocery stores with extensive GF product lists.
- **ALWAYS READ ALL LABELS!!!**

SUPPLEMENTAL

- **Find a gluten-free multivitamin**; for example, Freeda brand, Nature Made, Theragran or others.
- **Have a bone density test (DEXA) as a base line right after CD diagnosis**, then subsequent tests every couple of years, unless more often suggested by your own doctor.

CONCLUSION

Continue your education about Celiac Disease and the Gluten-Free Diet. Attend a national celiac conference. Former Surgeon General Dr. C Everett Koop has said, “The best prescription is knowledge.” Your success in going gluten free will ultimately get you back to good health. Don’t cheat. Every single bit of gluten is doing some damage in your small intestine and promoting inflammation.

Never give up. You can do it. Foster a support system within your family and local celiac support group. Don’t forget to utilize your sense of humor; some day a guest will really ask for your recipe (GF)! Stem depression by thinking of, reaching out to, and helping others. Do unto others as you would have them do unto you.

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Janet Rinehart is founder (1989) and chairman of the Houston Celiac Support Group. This chapter publishes *HOUSTON CELIAC PERSPECTIVE* and maintains a website at www.houstonceliacs.org. Janet is a Former President of Celiac Sprue Assn./USA. Janet was the recipient of The Jefferson Award for public service to celiacs in 2008.