

FAQs: Gluten and the Gluten-Free Diet

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ANSWERS:

What is the difference between gluten and gliadin?

Gluten is the generic term for the storage protein found in grains. Gluten is what gives dough its elasticity, and allows bread to be leavened. Gliadin is the specific name of the protein found in wheat, and is a type of gluten. Different grains have different names for their specific glutes, but the general term gluten is most commonly used. Visit *Introduction to the Gluten-Free Diet Level 3* under Nutrition and the Gluten-Free Diet on www.celiacnow.org.

Can I cheat on my gluten-free diet (GFD)?

Unfortunately, the answer to this question is no. Even when you are sticking to a GFD, it is impossible to eat gluten-free 100% of the time. Research indicates that most people with CD can tolerate an exposure of only less than 50 mg gluten per day. This is equal to about 1/8 teaspoon of wheat flour, such a very small amount. This is why you need to be careful with cross contamination or intentional exposure to gluten since damage can occur above that safe level. Cross contamination can occur when food is processed, when dining out, or in your own kitchen at home. Follow the gluten-free diet as carefully

as you can to help heal your intestines. Visit Cross Contamination under Nutrition and the Gluten-Free Diet on www.celiacnow.org.

What are the consequences of not following a strict gluten-free diet (GFD)?

There can be serious consequences to not following a GFD when advised to do so by your physician. There will be continued damage to the lining of your small intestine. These changes will lead to decreased absorption of nutrients, possibly leading to other conditions such as osteoporosis and anemia. You will also be at increased risk for gastrointestinal cancers, as well as non-Hodgkin's lymphoma. Visit *How Celiac Disease is Treated Level 2* under Medical Management and *Common Nutritional Deficiencies in People with Celiac Disease (Levels 1-3)* under Nutritional Considerations on the Gluten-Free Diet on www.celiacnow.org.

I suspect I have celiac disease. Should I start on a gluten-free diet (GFD) now?

No, not immediately. If you are extremely ill and your doctor agrees that your symptoms may be due to celiac disease (CD), he/she may ask you to begin the GFD immediately. Your doctor will also plan to have blood work and biopsy done very quickly so that starting on the gluten-free diet does not affect the results. If testing is done after (or too long after) a GFD is started, blood tests and biopsies may appear normal, and your doctor will be unable to accurately diagnose CD.

Otherwise starting a GFD without first confirming the diagnosis of CD using blood tests and endoscopy with biopsy of the small intestine is not recommended. The reason is that CD is a lifelong illness. It requires keeping a life-long GFD; it also involves multiple parts of the body. A number of other tests including nutritional status and bone density scan (DEXA) may need to be performed. Again, if testing is done after a GFD is started, blood tests and biopsies may appear normal, and your doctor will be unable to accurately diagnose CD. Visit *Screening Level 1 -2* under Medical Management on www.celiacnow.org.

I've been on a gluten-free diet (GFD) for a while and I don't feel better. Why?

Most often the reason patients don't feel better is because they have not completely removed gluten from their diet. Once hidden sources of gluten are removed from the diet, patients often start to feel better. Other reasons for experiencing symptoms while on a GFD include: having a separate condition, such as irritable bowel syndrome (IBS), refractory celiac disease, lactose intolerance, fructose malabsorption, small intestine bacterial overgrowth, or microscopic colitis.¹ Consult with a skilled dietitian to be sure your diet is completely gluten-free and consult with your gastroenterologist if you are continuing to experience symptoms while on the GFD. If you began to feel well on the GFD, and then your symptoms returned, it is important that you contact your gastroenterologist, as this may be a sign of a more serious medical condition. Visit *Non-Responsive Celiac Disease Level 1 and 2* under Medical Management on www.celiacnow.org.

What if I don't experience symptoms when I eat gluten? Do I still need to be strict?

Most people with celiac disease feel the consequences of ingesting gluten, but there are some people who have no symptoms. Although more research needs to be done on exactly what the consequences of ingesting gluten may be over time, we do now that people who choose to eat gluten are at increased risk of developing another autoimmune disease, certain cancers, and vitamin and mineral deficiencies which can lead to bone disease and osteoporosis. So, even if you do not feel symptoms it is important to follow the gluten free diet strictly because, even 1/50 of a slice of bread has been shown to lead to inflammatory damage in the gastrointestinal tract.

Besides avoiding gluten, are there other changes I should make in my diet?

Many patients may need to avoid lactose-containing foods at first, such as milk, cheese, and other dairy products if they are having gastrointestinal symptoms such as diarrhea, bloating, cramping or gas. This is because lactase, the enzyme that digests the lactose sugar found in dairy products, is made on the tips of the villi in the small intestine. Celiac disease destroys these villi, also destroying the lactase enzyme. As the villi heal, tolerance to lactose usually returns. Once a patient follows the gluten-free diet for a few months, s/he may try reintroducing dairy products back into the diet, as long as they are tolerated. Yogurt and cheese are lower in lactose and may be tolerated. Gluten-free soy, rice, and nut milks (all should be labeled gluten-free) are good substitutions if lactose must be avoided. You should also avoid any other foods to which you are allergic or sensitive. Visit *Lactose Intolerance Levels 1-3* under Nutritional Considerations of the Gluten-Free Diet on www.celiacnow.org.

It is also important that your gluten-free diet is heart-healthy. Your diet should be low in fat and sodium, high in fruits and vegetables, and include lean proteins, such as chicken, fish, turkey, beans, plain or labeled gluten-free seeds and nuts, legumes, and lean meat. Add fiber in the form of gluten-free whole grains into your diet, such as amaranth, millet, brown rice, and quinoa (all labeled gluten-free). Most importantly, you should consult with a dietitian skilled in celiac disease to be sure that your new diet contains appropriate amounts of vitamins and nutrients, specifically iron, calcium, vitamin D, and B vitamins. Visit *Healthy Eating on the Gluten-Free Diet Levels 1-3* and *Fiber and the Gluten-Free Grains Level 1-3* under Nutrition and the Gluten-Free Diet on www.celiacnow.org.

Is a gluten-free diet (GFD) harmful or unhealthy to someone NOT diagnosed with celiac disease (CD)?

While the GFD is not harmful, it is low in certain important nutrients, specifically iron, calcium, vitamin D, B vitamins, and fiber, so attention must be paid to balancing a healthy GFD with these concerns in mind.² Fortunately, many foods that are naturally

gluten-free, such as vegetables, fruit, plain nuts and seeds, gluten-free whole grains, and lean proteins, are very healthy. Anyone who does not have CD or non-celiac gluten sensitivity who wishes to start a GFD should first consult his/her doctor and dietitian.

Why is fructose sometimes a problem for people with celiac disease? What does the low fructose diet involve? What are FODMAPs?

Some people with celiac disease discover that although they are following the gluten-free diet carefully, they have symptoms of burping, bloating, gas, cramping and loose stools and/or constipation. If gluten exposure is not the concern, the physician or dietitian may consider lactose intolerance or other poorly digested carbohydrates, such as fructose. Fructose is found naturally in some fruits and vegetables (pears, apples, asparagus, watermelon, mango, and sugar snap peas), honey, high fructose corn syrup, sweetened drinks, sweets and candy. Other examples of poorly absorbed carbohydrates are fructans (wheat, rye, garlic, onions), galactans (cabbage, legumes such as lentils and soybeans), lactose (milk, milk products) and polyol sweeteners that include naturally occurring sorbitol (peaches, plums, nectarines, cherries, apricots), xylitol, mannitol (cauliflower, mushrooms) and isomalt (an ingredient in sugar-free products). These polyol sweeteners are also commonly found in sugar-free products. Together, all of these poorly absorbed carbohydrates are called FODMAPs (fermentable oligo/di/polysaccharides and polyols).³

Two options for diagnosis include fructose and/or lactose breath tests or a dietary trial of avoiding most sources of these poorly digested carbohydrates. An elimination diet usually lasting 2-8 weeks, followed by a rechallenge trial should be supervised by a skilled dietitian to ensure a balanced and healthy diet during the trial.

If a food is labeled “gluten-free”, is it safe to consume? Are there small amounts of gluten in foods labeled “gluten-free?”

Foods that are labeled “gluten-free” are safe to consume if you have celiac disease. As of August 2013, the Food and Drug Administration has set guidelines for the labeling of gluten-free foods. While gluten-free labeling is optional, companies who decide to label their products gluten-free must comply with these FDA guidelines. In short, products labeled gluten-free must contain less than 20 parts per million gluten per serving. Less than twenty parts per million gluten has been determined to be too small an amount to cause villi damage in someone with celiac disease.

What are the basics of gluten-free grocery shopping?

Gluten-free shopping doesn't have to be difficult. By following some basic steps, you will become more familiar with the many products that are gluten-free.

- Most important! Learn to read the ingredients on all processed foods very carefully for gluten. Visit *Simple Start to the Gluten-Free Diet Levels 1-3* to understand how to choose safe foods when shopping. Visit *Simple Label Reading, FDA vs USDA Labeling, Allergen Advisory Statements, Food*

Ingredients You Don't Need to Worry About, and *Gluten-Free Grains Safety and Contamination* (find these topics under the Label Reading header under Nutrition and the Gluten-Free Diet on www.celiacnow.org).

- Look for fresh or frozen produce. Fruits and vegetables (without additives, sauces or gravies) are naturally gluten-free. Eat up!
- Plain meat, poultry, and fish are also gluten-free. To keep a healthy diet, try to consume lean proteins, and limit red meat intake.
- Legumes, such as chickpeas, lentils, and kidney beans, are excellent sources of protein and fiber. Many people find that they do not include enough fiber in their gluten-free diet, and legumes are an excellent way to add more fiber.
- Low-fat dairy products, if well tolerated, are an excellent source of calcium and vitamin D in the diet. If you cannot tolerate dairy products, substitute labeled gluten-free soy, rice, or nut (almond, hazelnut) milk that is fortified with calcium and vitamin D.
- Gluten-free whole grains are an excellent way to add fiber and other vitamins and nutrients into your diet. Try to eat grains (labeled gluten-free) like amaranth, millet, and quinoa, which are high in complex carbohydrates, iron, calcium, B vitamins, and minerals. The decision to include gluten free oats in your gluten-free diet should be discussed first with your doctor. You may also eat starches such as corn, potato, and white rice (a grain), but they are high in refined carbohydrates, low in fiber, and should be used in moderation. Visit *Fiber and the Gluten-Free Grains* under Nutrition and the Gluten-Free Diet on www.celiacnow.org.
- When you are not choosing gluten-free *whole* grains, look for *enriched* refined breads, pastas and baking mixes and *fortified* breakfast cereals. These products have more vitamins and minerals and are an important part of the gluten-free diet. Visit *Fiber and the Gluten-Free Grains* under Nutrition and the Gluten-Free Diet on www.celiacnow.org.
- Consult with a dietitian who specializes in celiac disease. A skilled dietitian will not only monitor your diet, but will also help you to identify hidden sources of gluten, and give you new ideas and recipes. Visit *Nutritional Consults* on www.celiacnow.org.

How should I choose a gluten-free multivitamin/mineral supplement?

A standard gluten-free multivitamin/mineral supplement is typically recommended for individuals with celiac disease since the gluten-free diet can be low in certain nutrients, including calcium, iron, folate, niacin, B12, other B vitamins, vitamin D, zinc and phosphorus. Women who are menstruating or who are anemic should choose a multivitamin/mineral supplement that contains iron (they may also need additional iron if so determined by their doctor). Men and postmenopausal women, unless they are anemic, do not need iron in their supplement. If you need more B vitamins, your dietitian or doctor may suggest that you choose a gluten-free B complex vitamin to take along with your multivitamin/mineral supplement. Check the label for “gluten free” or call the manufacturer to determine the gluten-free status of each supplement you would like to take. Most importantly, ask your doctor or dietitian to help you decide which, if any,

supplement you might need. Be sure to visit *Supplements* under Nutrition and the Gluten-Free Diet to learn many more important details on choosing the correct supplements.

Should I take a calcium and vitamin D supplement?

Calcium is required for the proper functioning of a number of systems in the body. Calcium is normally absorbed from foods through the small intestine. In celiac disease, the small intestine has been damaged and cannot adequately absorb calcium and many other vitamins and minerals. In order to keep the body working normally, calcium is released from bone into the blood stream, and is delivered to other parts of the body that need it. This process, in turn, can lead to osteopenia or osteoporosis (porous, fragile bones that are prone to breaking).

The problem of calcium malabsorption is also related to malabsorption of vitamin D and magnesium. Both of these are needed to absorb calcium from food. If vitamin D and magnesium are also not being absorbed because of intestinal damage, calcium will not be absorbed either.

If you have celiac disease and osteoporosis or osteopenia, speak to your doctor and dietitian to learn the correct amount of calcium and vitamin D intake from foods and supplements that you need. Be sure to visit *Supplements* under Nutrition and the Gluten-Free Diet to learn important details on choosing the correct supplements.

Should all individuals with celiac disease take a probiotic, even if they do not have any gastrointestinal symptoms on a gluten free diet (GFD)?

Probiotics, also known as “healthy” or “friendly” bacteria are living microbial food ingredients which can be beneficial to health when ingested in adequate amounts. Particular probiotics may be recommended by your doctor or dietitian based on your medical history and report of symptoms, such as gas, bloating, diarrhea or constipation. Any probiotic formula you take must be gluten-free. It is not necessary to take a probiotic, however, if you have no symptoms on a GFD. Visit *Probiotics Level 1-3* on www.celiacnow.org.

Are my medications gluten-free?

Medications are NOT required to declare “wheat” or other gluten-containing grains on their labels. Some medications have gluten-containing fillers or coatings. Since it is difficult to understand the ingredients on the label of any medication (prescription or over-the-counter), contact the manufacturer directly and ask if your medication is gluten-free. It is best to check directly with the manufacturer as website listings may not reflect the most current status of a drug. A very good resource, however, is www.glutenfreedrugs.com. This website gives helpful information regarding how to identify gluten in your medications, as well as a list of gluten-free drugs. Always remind

your healthcare provider to write “must be gluten-free” on any prescription and check with the pharmacy when you pick up or receive your medication.

What are my options if my medicine contains gluten?

You can ask your doctor if there is a reasonable substitute for your medication that does not contain gluten. You can also order your medication or supplement from a compounding pharmacy.

My health insurance won't cover access to a dietitian even though I have celiac disease. Can anything be done about this?

You can ask your doctor and dietitian to write a letter to your insurance company stating that Medical Nutrition Therapy (nutritional counseling) provided by a registered dietitian, as part of a team-based approach, is strongly recommended for individuals with celiac disease and results in improved patient self-management. Although costs of MNT sessions and reimbursement vary, these dietitian-led counseling sessions are essential for improved patient outcomes. The National Institutes of Health (NIH) Consensus Panel identified consultation with a skilled dietitian as one of the elements required for the management of celiac disease. The American Gastroenterological Association recommends that patients with celiac disease should be evaluated at regular intervals by a health care team, including a physician and dietitian. While there is no guarantee, this type of letter may help you in securing insurance coverage for your nutrition visits.

*For more detailed answers and additional information, visit www.celiacnow.org

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