

## **Common Reasons for Continued Symptoms on the Gluten-Free Diet**

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“I’m on the gluten-free diet and I still feel unwell.” This is a common scenario among my patients with celiac disease and non-celiac gluten sensitivity. Symptoms can include (but are not limited to) gas, bloating, cramping, abdominal pain, loose stool, diarrhea, constipation, abnormal stool patterns, fatigue, headaches, nausea, and the list goes on. So, let’s explore what might be causing these persistent symptoms.

### **Gluten is sneaking into the diet.**

More often than not, whether accidental or intentional, this is the most common reason for feeling unwell. Other than the obvious gluten-containing foods and beverages such as bread, crackers, baking mixes, beer, etc., gluten can appear in condiments, medications, supplements, Communion wafers, Matzo, and as fillers in processed meat, to name just a few. It can even be found in yeast extract or autolyzed yeast extract if it’s derived from barley. Or through cross contamination, such as a non-dedicated fryer, when dining out. You may be frustrated if you have gone over your diet with a fine-toothed comb to find and remove the gluten. Consider sitting down with a dietitian skilled in the gluten-free diet to help you search carefully for any exposure. In some cases, it is a matter of gaining a better understanding of the labeling laws and caveats. In others, it means asking more pointed questions in restaurants or carefully checking your own kitchen if you share it with others – do you have your own toaster or toaster oven? Do you have a system to avoid cross-contamination if you share condiments and butter, etc.?

For labeling law and cross contamination resources, visit:

[www.glutenfreedietitian.com](http://www.glutenfreedietitian.com) (Tricia Thompson MS, RDN)

Cross Contamination: Level 3 on celiacnow.org

<http://www.bidmc.org/Centers-and-Departments/Departments/Digestive-Disease-Center/Celiac-Center/CeliacNow/NUTRAGFD/CRSSCNTAM/Level3.aspx>

If you and your dietitian have reviewed your gluten-free diet and lifestyle and can find no gluten sneaking in, consider these other causes of persistent symptoms:

### **Food Intolerances and Sensitivities**

Sometimes my patients tell me that after going gluten-free they notice other foods have started to bother them. Some patients have a true food allergy that can be determined through allergy testing. In some cases, the food was

bothering them all along but they didn't realize it because gluten was still in the picture, masking the symptoms. In other cases, they have developed a reaction to a food they're now eating in greater quantities as they try to avoid gluten. Some of the most common foods I hear about are dairy, soy, eggs, corn, nuts and sugar (see FODMAPs below) but it is certainly not limited to these alone. The range of symptoms is very, very wide and can involve the gastrointestinal tract, brain, joints, skin and many other parts of the body. Let's discuss two – lactose and the other FODMAPs (including fructose).

### **Lactose intolerance**

A high percentage of those with celiac disease and non-celiac gluten sensitivity experience the symptoms of lactose intolerance. Lactose is the sugar found in milk products from a mammal. Lactose is broken down into smaller sugars by the enzyme, lactase, which lives in the villi (fingerlike projections) that line the small intestine. If there has been damage to the small intestine, such as through a gastrointestinal infection or celiac disease (and possibly gluten sensitivity), the production of lactase is temporarily decreased.

Without enough lactase enzyme, the lactose is not digested in the small intestine. It moves through to the large intestine where the bacteria ferment it leading to symptoms of gas, bloating, cramping, loose stools and diarrhea. If you are newly diagnosed, your doctor or dietitian may ask you to avoid lactose for a short period of time to give your villi a chance to heal and the enzymes to return.

The degree of severity of symptoms and amount of lactose tolerated will vary greatly by person. It's possible for many people to regain tolerance to lactose especially if they tolerated lactose in the past. Most people still produce at least a small amount of lactase and, thus, can tolerate small amounts of lactose in their diet without ill effects. Good news - in the long run, eliminating all dairy products is not the solution to lactose intolerance. If you enjoy dairy but are having some symptoms, choose gluten-free, lactose-free, or lactose-reduced products. Continue to introduce small amounts of lactose into your diet, spaced throughout the day, so that your body "remembers" to keep making the enzyme, lactase, for you.

Those who cannot tolerate lactose in any amount can turn to dairy-free beverages such as soy, rice, and almond milk labeled gluten-free.

References and further reading:

Lactose Intolerance. Level 3 on celiacnow.org.

<http://www.bidmc.org/Centers-and-Departments/Departments/Digestive-Disease-Center/Celiac-Center/CeliacNow/NUTRAGFD/NUTRCNSDRGFD/LCTSINT/Level3.aspx>.

Dennis M, Barrett J. Malabsorption of Fructose, Lactose, and Related Carbohydrates. In *Real Life with Celiac Disease: Troubleshooting and Thriving Gluten-Free*. AGA Press. Bethesda, MD, 2010.

<http://theceliacmd.com/2012/11/top-5-reasons-for-persistent-symptoms-after-going-gluten-free/> (Amy Burkhart MD, RD)

### **FODMAP malabsorption**

FODMAP is an acronym that stands for **F**ermentable **O**ligosaccharides, **D**isaccharides, **M**onosaccharides **A**nd **P**olyols. The FODMAPs are a group of small chain carbohydrates (sugars and fibers) that are commonly poorly absorbed in the small (upper) intestine. These FODMAPs are naturally found in many, many foods such as apples, pears, mangoes, honey, agave syrup, milk products, watermelon, cauliflower, legumes, mushrooms, onion, garlic, wheat, rye, and barley, to name a few. They are also found in some medications and supplements as well as in artificial sweeteners (sorbitol, xylitol, mannitol, etc.) and so appear in sugar-free or diet drinks, foods, chewing gum, mints and candies.

These poorly absorbed FODMAPs (the most commonly known ones being “fructose” and “lactose”) are carried to the colon (large intestine) where the normal bacteria quickly consume them. The bacteria produce gases and chemicals which cause the intestine to swell, prompting the feelings of bloating and distension, cramping, gas, fatigue, nausea and abdominal pain. Diarrhea and/or constipation are also common symptoms. As you can see, the symptoms of fructose malabsorption can mimic those of gluten exposure.

Malabsorption of FODMAPS is widespread among the irritable bowel syndrome (IBS) population and, from the literature, it appears that a high percentage of those with IBS see good results from a Low FODMAP diet trial. FODMAP malabsorption can also be seen in patients with celiac disease, gluten sensitivity, inflammatory bowel disease, and in other individuals with a sensitive gastrointestinal tract. Specific breath tests can diagnose malabsorption of fructose and lactose; malabsorption of the other groups is best detected through a careful review of the patient’s diet and symptoms by a skilled dietitian.

The Low FODMAP diet is a **temporary** diet that begins with a strict restriction of all high FODMAP foods followed by a reintroduction of the FODMAPs one group at a time. In this second phase, the type and amount of FODMAPs an individual can tolerate are identified with the goal of a varied, balanced diet for the long-term. An experienced dietitian should be consulted to help balance nutrient and fiber intake since each phase involves many specific diet changes.

For many more details on the diagnosis, symptoms, and treatment of FODMAP malabsorption, please review these excellent resources/references:

Monash University Website: <http://www.med.monash.edu/cecs/gastro/fodmap/>

Monash University Low FODMAP App for I-phone and Android:  
<http://www.med.monash.edu/cecs/gastro/fodmap/iphone-app.html>

<http://shepherdworks.com.au/disease-information/low-fodmap-diet>

Sue Shepherd B.App.Sci, M.Nut. & Diet., PhD

*Shepherd, S. The Low FODMAP Diet Cookbook.* The Experiment, 2014.

<http://blog.katescarlata.com> (Kate Scarlata, MS, RDN)

<http://theceliacmd.com/2013/02/fructose-malabsorption-is-is-the-cause-of-my-tummy-troubles/> (Amy Burkhart MD, RDN)

<http://theceliacmd.com/2013/12/move-gluten-free-low-fodmap-next/>  
Amy Burkhart MD, RDN

<http://theceliacmd.com/2013/09/gluten-really-culprit-gluten-sensitivity/>  
Amy Burkhart MD, RDN

<http://www.ibsfree.net/>  
Patsy Catsos, MS, RDN

Barrett JS. Extending our knowledge of fermentable, short-chain carbohydrates for managing gastrointestinal symptoms. *Nutr Clin Pract* 2013. Jun; 28(3):300-6.

### **Small intestinal bacterial overgrowth (SIBO)**

People naturally have hundreds and hundreds of different bacterial species in their colon and much fewer in their small intestine. In SIBO, there are large numbers of bacteria or the wrong type of bacteria in the small intestine. There are many medical conditions and treatments that can predispose someone to SIBO, including celiac disease and small bowel dysmotility. People with celiac disease may have a higher incidence of SIBO.

SIBO leads to symptoms that mimic gluten exposure such as severe abdominal bloating (a major complaint), abdominal distension (visible protrusion of the abdomen), increased gas, diarrhea and/or constipation. Other symptoms can include nausea, weight loss, and early satiety (feeling full after eating a small amount of food), to name a few. In addition, these bacteria compete for nutrients

such as Vitamin B12 and other B vitamins, vitamin A, D, and E, iron, fat, protein and carbohydrates (starches).

There is no single validated testing method for SIBO; currently the ones most often in use are the lactulose or glucose breath tests which measure a person's output of hydrogen and methane gas to diagnose SIBO. Treatments vary greatly among practitioners regarding the use or avoidance of antibiotics (traditional or herbal). Generally accepted are recommendations to monitor and treat nutritional deficiencies and to consume easily digested foods that have modest (not high) amounts of fiber. Moderate, regular exercise and adequate fluid intake can help to normalize bowel patterns. Spacing meals ~4 hours apart (if possible) allows the body's migrating motor complex to cleanse the small intestine with intestinal juices, washing away bacteria. This meal spacing time frame varies in the literature and also by a patient's medical status. Use or avoidance of probiotics varies widely among clinicians.

At this time, there are no research studies validating a specific diet therapy for SIBO. Several diet therapies have been suggested and are in use - most of them with the goal of reducing sugars that the bacteria favor. The low FODMAP diet and the elemental diet (short-term use of a predigested, easily absorbed nutritional oral supplement) seem to be the most commonly used ones in clinical practice. The priority is on a nutritionally balanced diet that can be achieved long-term. Consultation with a skilled dietitian is important to ensure nutritional balance.

SIBO is not a symptom; it is a diagnosis. The finding of SIBO may suggest an underlying problem. The goal is to identify and treat the cause. This brief description only scratches the surface of SIBO. For information on conditions that increase the risk of SIBO and a variety of clinical testing approaches and treatment options that appear in the literature, please visit these resources/references:

<http://blog.katescarlata.com/2014/01/22/small-intestinal-bacterial-overgrowth/>  
(Kate Scarlata MS, RDN)

<http://theceliacmd.com/2013/11/november-2013-sibo-gluten-ibs-connection/>  
(Amy Burkhart MD, RDN)

<http://drmarkpimentel.com/index.htm>  
(Dr. Mark Pimentel)

<http://siboinfo.com> (Dr. Allison Siebecker)

Tursi A, Brandimarte G, Giorgetti G. High prevalence of small intestinal bacterial overgrowth in celiac patients with persistence of gastrointestinal symptoms after gluten withdrawal. Am J Gastroenterol. 2003 Apr;98(4):839-43.

<http://www.webmd.boots.com/digestive-disorders/small-intestinal-bacteria-sibo>  
(WebMD)

### **Nutrient Deficiencies**

If you were undiagnosed with celiac disease for years, chances are good that one or more of your vitamin and mineral levels are low due to malabsorption over a long period of time. Nutrient deficiencies can also be seen in non-celiac gluten sensitivity. These deficiencies can lead to symptoms that can be extensive and hard to pin down. Here are just a few:

Fatigue can be blamed on low vitamin D, iron, magnesium, folate, B6 or B12, for example.

Twitching, spasms and muscle cramps? Likely low magnesium.

Poor health of skin, hair and nails? Check your zinc level.

(The symptoms above can be related to other deficiencies or conditions, as well, which are not listed here.)

The list goes on and on. Fortunately, lab testing can help identify vitamin and mineral deficiencies and your health care practitioner can recommend foods and supplements to help you restore them. At diagnosis, the typical celiac blood panel includes:

Complete blood count (hemoglobin, hematocrit, etc.)
25 OHD (Vitamin D)
Vitamin B12
Folate (often depends on the region)
Iron and/or ferritin
Zinc
IgA-tTG; DGP (deamidated gliadin peptide) may also be tested
TSH (thyroid stimulating hormone)

(Courtesy Beth Israel Deaconess Medical Center, Celiac Center, 2015)

This is an enormous topic, like all the others in this article, and I will address it in more detail in a later article.

References and further reading:

Common Nutritional Deficiencies in Patients with Celiac Disease

<http://www.bidmc.org/Centers-and-Departments/Departments/Digestive-Disease-Center/Celiac-Center/CeliacNow/NUTRAGFD/NUTRCNSDRGFD/CMMNNUTRPTNTS/Level3.aspx>

<http://theceliacmd.com/2012/11/top-5-reasons-for-persistent-symptoms-after-going-gluten-free/>

Amy Burkhart MD, RD

**Other Reasons:**

Less common causes of continued symptoms on the gluten-free diet include, but are not limited to, microscopic colitis, pancreatic enzyme insufficiency, and refractory celiac disease (very uncommon) and can be discussed with your doctor.

**Bottom line:** Don't assume it's normal to be feeling unwell. I hear many patients say "I just assumed everyone had diarrhea twice a day and I got used to living with it." If you are still experiencing symptoms, talk to your doctor and ask for testing. You deserve to be in excellent health.

**Disclaimer:** As Nutrition Coordinator of the Celiac Center at Beth Israel Deaconess Medical Center, I am the lead writer and editor of the website [www.celiacnow.org](http://www.celiacnow.org) and co-author of the book *Real Life with Celiac Disease*. Otherwise, I have no business/financial stake in the resources listed in my article above.

Note: The References and Further Reading resources above represent only a portion of the excellent information available on these topics. I recommend PubMed, in particular, for the multiple peer-reviewed journal articles you will find.

## Highly Educational Gluten-Free Wellness Retreats



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<http://www.deletethewheat.com/WellnessRetreatsv2.html>

[or email me for more information: MelindaRD@DeletetheWheat.com](mailto:MelindaRD@DeletetheWheat.com)

## About Melinda

Melinda Dennis, MS, RDN, is a registered dietitian specializing in celiac disease and gluten-related disorders, author, nationally acclaimed speaker, and the Nutrition Coordinator of the Celiac Center at Beth Israel Deaconess Medical Center in Boston. She offers gluten-free consulting through her private firm, Delete the Wheat, LLC.

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