



I'm Eating Gluten Free— Why Do I Still Have Symptoms?

An excerpt from *Real Life with Celiac Disease*



Nonresponsive celiac disease (NRCD) is a general term clinicians use to describe people with celiac disease for whom the gluten-free diet (GFD) does not appear to resolve all the symptoms or problems that were initially attributed to the celiac disease. NRCD is not a diagnosis itself; it is just a description that is used until we can find the root of the problem and make a firm diagnosis. You would need to be on a GFD for at least 6 months without significant improvement before we would decide that you were not responding and look for other reasons. There is a great deal of variability in how long it takes people to feel fully better on a GFD, so as long as there is some continual improvement, even if it seems very slow, a full evaluation for NRCD is usually unnecessary.

As we discuss in the book, there are many reasons for NRCD. The first step is often to get confirmation that you do indeed have celiac disease. Many people are aware that celiac disease can be mistaken for other disorders such as irritable bowel syndrome. But you may be surprised to know that the reverse often occurs as well, that is, celiac disease can be mistakenly diagnosed when the true problem is something else. If you are having continued symptoms on a GFD and either blood tests or intestinal biopsy were normal before going on GFD, you should talk to your doctor about the possibility that you do not actually have celiac disease.

Causes of Nonresponsive Celiac Disease

Cause	Typical Features/Tests	How Common
Gluten exposure (see Chapter 20)	Evaluation by dietitian skilled in celiac disease	Very common
Irritable bowel syndrome (see Chapter 38)	None	Very common
Lactose intolerance or fructose malabsorption (see Chapter 37)	Trial of lactose or fructose restriction; lactose or fructose breath testing	Somewhat common
Microscopic colitis (see Chapter 39)	Biopsy of colon	Somewhat common
Small intestinal bacterial overgrowth (see Chapter 40)	Breath testing and or a response to antibiotic therapy	Somewhat common
Refractory celiac disease (see Chapter 43)	Biopsy of small intestine	Rare
Eating disorder (see Chapter 30)	None	Rare
Inflammatory bowel disease	Biopsy of small or large intestine, imaging studies of intestine	Rare
Pancreatic exocrine insufficiency	Stool levels of chymotrypsin or elastase	Rare
Motility disturbances (too slow or too fast movement of food through the intestine)	Gastric emptying study, intestinal transit testing	Rare
Food allergy (see Chapter 35)	Allergy testing (skin or blood)	Very rare
Cancer	Endoscopy, imaging studies of intestine	Very rare

From Shailaja Jamma, MD, and Daniel A. Leffler, MD: Nonresponsive Celiac Disease. In *Real Life with Celiac Disease: Troubleshooting and Thriving Gluten Free* by Melinda Dennis, MS, RD, LDN, and Daniel A. Leffler, MD.

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