

Follow-up testing.

Follow-up testing is conducted to ensure that antibody levels are returning to normal, indicating that the intestine is healing as a result of the gluten-free diet. For this reason, repeat intestinal biopsies are no longer necessary if the antibodies decline as expected and symptoms improve. These tests also are reasonably good indicators of the extent to which a celiac patient has been avoiding gluten, and can detect when hidden gluten has entered the diet.

How often should follow-up testing occur?

We recommend that new celiac patients receive follow-up testing twice in the first year after their diagnosis. The first appointment should occur 3 to 6 months after the diagnosis, and the second should occur after 1 year on the gluten-free diet. After that, a celiac patient should receive follow-up testing on a yearly basis.

What tests are needed at follow-up appointments? How are they interpreted?

Guidelines on the diagnosis and treatment of celiac disease from both ESPGHAN and the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) advise that tTG-IgA be used for follow-up care. Interpreting this test result is straightforward—a celiac patient on the gluten-free diet for at least several months should have a negative test.

The University of Chicago Celiac Disease Center recommends additional testing because the tTG test can sometimes be inaccurate in people with autoimmune disorders such as Type 1 diabetes. For this reason, the newer anti-deamidated gliadin peptide (DGP) tests are recommended. The two key tests are the DGP-IgA and DGP-IgG. These antibodies are actually more promptly and fully responsive to a strict gluten-free diet, so their numbers should be as close to zero as possible, indicating a minimal antibody response to gluten. The additional advantage of these tests is that the blood can be drawn by any physician and sent to any laboratory.

While a negative test is what most celiac patients want to see sometime after beginning the gluten-free diet, a normal value can sometimes be reached only after a year or more on the diet, especially if the initial value was very elevated. What really matters is that the number declines consistently over time.

I've been having joint pain and I think it's from celiac disease. I follow the diet very carefully.

This raises a common issue with celiac patients who are on a strict gluten-free diet: sometimes the symptoms they had before diagnosis do not seem to resolve, or at least not completely. In general, this can be due to 1 of 3 circumstances: 1) there is still gluten in the diet; 2) the symptoms are not due to celiac disease; or 3) the symptoms are due to celiac disease but in rare instances may persist even when following a gluten-free diet.

In the first instance, it is imperative that, in addition to the blood tests (see above), a careful dietetic review be done; it is rare, but possible, for the tests to be normal even when a small amount of gluten may have unknowingly been introduced. Sometimes the doctor may want to repeat the biopsy to be absolutely sure that celiac disease is in remission.

In the second instance, it is common for joint pain to be due to another cause, such as arthritis, rather than celiac disease, so changing the diet won't help alleviate the symptoms. Likewise, people with irritable bowel syndrome (IBS) will have symptoms that persist on a gluten-free diet, which is an indication that the symptoms may not be due to celiac disease. Thus, an accurate search for alternative causes for the symptoms must be performed.

Finally, there are health issues that originate because of celiac disease but do not resolve on a gluten-free diet. For instance, some patients with peripheral neuropathy will continue to have problems even when on a gluten-free diet.

From a practical standpoint, you need to first make sure that the diet is completely gluten-free; then ask your doctor if your symptoms could be due to other causes and have him or her address them appropriately. Only at that point, after a negative search, may you conclude that your symptoms are due to celiac disease, which unfortunately may persist, so have your doctor treat the symptoms appropriately.