

Diagnosis of celiac disease.

If antibody tests and symptoms suggest celiac disease, the physician needs to establish the diagnosis by obtaining tiny pieces of tissue from the upper small intestine to check for damage to the villi. This is done in a procedure called a biopsy. The physician eases a long, thin tube called an endoscope through the mouth and stomach into the small intestine, and then takes samples of the tissue using small instruments passed through the endoscope.

Biopsy remains the most accurate way to diagnose celiac disease.

The endoscopic biopsy

This procedure is always performed by a gastroenterologist, and is conducted most often in an outpatient surgical suite. The procedure lasts less than half an hour, and sedation and local anesthesia are generally used.

The procedure involves a long, thin tube with a small camera on the end. The physician will insert the tube into the patient's mouth, down the throat, and into the esophagus. When the tube reaches the patient's stomach, the physician finds the entryway into the small intestine (the duodenum) and inserts the tube there. As the tube is making its way to the small intestine, the camera on the end sends a video image to a monitor in the procedure room. On the monitor the physician can visually assess any evident abnormalities such as ulcers or gastritis.

In the small intestine, the physician examines most of the duodenum, the area affected by celiac disease. However, in many celiac

patients, their duodenum appears normal at the time of biopsy. This is why the surgical removal of tissue is so important—it is only under a microscope that a definitive diagnosis of celiac disease can be made.

To take some tissue for biopsy, the physician inserts a tiny surgical instrument through the endoscope tube. Working in concert with a surgical nurse, the physician will take 5 to 6 biopsies. Each one is taken by grasping sections of the small intestine and slicing them gently away from the walls of the intestine. Multiple tissue samples are vital to make an accurate diagnosis—celiac disease can cause patchy lesions in the duodenum, which can be missed if only one or two samples are taken. Results of the biopsy will confirm if a patient has celiac disease. There are no nerve endings in the lining of the intestine, so this procedure does not cause any pain. Afterward, some patients experience a sore throat, but most have no memory of the procedure.

How is dermatitis herpetiformis (DH) diagnosed?

DH is diagnosed by a skin biopsy, which involves removing a tiny piece of skin near the active rash and testing it for the IgA antibody. DH is treated with a gluten-free diet and medication such as dapsone or sulfapyridine to control the rash. Drug treatment is short term, usually until the gluten-free diet starts to relieve symptoms. It is not necessary to perform an intestinal biopsy to establish the diagnosis of celiac disease in a patient with DH; the skin biopsy is definitive.

I'm concerned about my child having this procedure. Is it really necessary in children? Can my child have the biopsy when he is older?

The biopsy procedure must be performed to ascertain the diagnosis. However, there are selected cases where the experienced physician may decide to forgo this procedure. In keeping with the European guidelines set

forth by the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN), diagnosis in the absence of a biopsy may occur when a child who has symptoms consistent with celiac disease also has extremely elevated celiac autoantibodies known as tTG and autoantibodies known as EMA that are also clearly positive. It is necessary to also confirm the genetic predisposition is consistent with celiac disease. In all other circumstances, the biopsy is necessary for a final diagnosis. While it is understandable for parents to be concerned about this procedure, there are several important facts to consider. The procedure takes 10 to 15 minutes, during which the child is under general anesthesia and being closely monitored by a team of anesthesiologists. The child will have an experienced physician who has done many of these procedures, which will also help to ensure that everything goes smoothly.

The longer a child is on the gluten-free diet, the more difficult it becomes to correctly diagnose the child with celiac disease. (This is also true for adults.) A child may have to eat gluten for 4 to 8 weeks (a gluten challenge) in order to have a biopsy that reflects how the body would respond when on a regular, gluten-containing diet. A gluten challenge in adults can last 3 months.

Clinical experience also shows that children and adults who have not had a biopsy as part of their diagnosis for celiac disease tend to take the diet less seriously and eat gluten when they shouldn't. While many people who have not had a biopsy may not have celiac disease, this approach to the gluten-free diet is concerning for those who do in fact have celiac disease but don't really know it.

Can you see celiac disease?

Because the damage caused by celiac disease is microscopic, in a majority of cases it is not possible to confirm the diagnosis of celiac disease just by looking at the walls of the intestine. That's why a biopsy is needed.

Are you scheduled for a biopsy? Are you eating gluten?

Any changes in your diet can affect the accuracy of your biopsy results. You must be eating gluten every day, in an amount equivalent to at least 1 slice of bread, for at least 2 to 3 weeks before the procedure. If you are scheduled for a biopsy and are not eating gluten, talk to your doctor about what is necessary to obtain accurate results. If you have eaten gluten only a short time before the biopsy, you and your physician will not know if a negative test result is accurate or due to your diet.