



Diagnosis

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 instruments passed through the endoscope.

Biopsy of the small intestine is the only 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 ½ an hour, and for adults, sedation and local anesthesia are 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 gastritis, or other inflammation (such as acid reflux).

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

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

At this point, the physician will insert a tiny surgical instrument through the tube. It reaches the small intestine, and working in concert with a surgical nurse, the physician will biopsy 5-6 areas of the small intestine. The biopsy is taken by grasping very small sections of tissue and slicing them gently away from the walls of the intestine. Multiple tissue samples are also vital to 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 intestine, so this procedure does not cause pain in the gut. Afterwards, some patients experience a sore throat, but most have no memory of the procedure.

How is DH Diagnosed?

DH is diagnosed by a skin biopsy, which involves removing a tiny piece of skin near

the rash and testing it for the IgA antibody. DH is treated with a gluten-free diet and medication to control the rash, such as dapsone or sulfapyridine. 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?

It is. While it is understandable for parents to be concerned about this procedure, there are several important facts to consider.

First, the procedure takes 10-15 minutes, during which the child is under general anesthesia and closely monitored by a team of anesthesiologists. This team will adjust the anesthesia your child receives during the procedure to just the right amount. Ensuring that your child has an experienced physician who has done many procedures will also help to ensure that everything goes smoothly.

Second, research shows that children diagnosed before the age of four reduce their risk of developing additional autoimmune disorders. This advantage is tremendous, as children who are diagnosed between the ages of 4 and 12 have a 17% risk; from 12-20 years of age the risk goes up to 27% and an individual diagnosed above the age of 20 has a 34% chance of developing another autoimmune disorder.

Third, the longer a child is on the gluten-free diet, it becomes more difficult to correctly diagnose the child with celiac disease. (This is also true for adults.) A child may have to eat gluten for 4-8 weeks (a gluten challenge) in order to have a biopsy if that child has been eating gluten for several months or more. A gluten challenge in adults can last three months.

Clinical experience also shows that children and adults who have not been biopsied 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 been biopsied 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 the biopsies are needed.

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

Any changes in your diet can affect the accuracy of your biopsy results. It is necessary for you to be eating gluten every day for at least 4-8 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 a biopsy and have eaten gluten only a short time before the test, you and your physician will not know if a negative test result is accurate or due to your diet.

For more information contact the University of Chicago Celiac Disease Center at 773.702.7593 or www.CeliacDisease.net.