

Celiac Disease: Far More Common Than We Knew

Dr. Todd Huffman, for the Eugene Register-Guard, March 2010

Our understanding of celiac disease (CD) has undergone significant change in the last four decades. Once considered primarily a disease of early childhood, CD is now recognized to be a lifelong intolerance to gluten in wheat, and related proteins found in barley and rye.

CD occurs in genetically susceptible persons who ingest these gluten proteins, and is much more common – perhaps 100 times more common – than once recognized. Recent studies have revealed that 1 in 133 Americans likely have CD, which could mean that two or three million people in this country are affected. The number of confirmed cases in the US is only in the tens of thousands, which suggests that many cases in children and adults remain undiagnosed.

Celiac disease was recognized as early as 250 AD, and by the early 1920s a dietary cause was suspected. However, it was not until 1952 that wheat was finally confirmed to be “toxic” factor leading to the illness.

Today, we understand that CD is an autoimmune disorder, a disease in which the immune system attacks the body’s own tissues. In the case of CD, it is the lining of the small intestine that is attacked in response to the consumption of gluten and related proteins. Over time, the small intestine is chronically inflamed and damaged, rendering it unable to carry out its normal function of breaking down food and shunting nutrients across the intestinal wall to the bloodstream for delivery throughout the body.

The signs and symptoms of CD are highly variable, as is the age of onset. Because CD damages the lining of the small intestine, symptoms are often gastrointestinal. However, we now understand that CD can affect other body systems, and that some patients (up to 50% of adults, in fact) first come to medical attention for signs and symptoms not related to the GI tract.

Gastrointestinal symptoms of CD may include diarrhea, loose fatty stools, chronic abdominal pain, abdominal distension and bloating, excessive gas, nausea and vomiting, constipation, and recurring mouth sores. One in ten children diagnosed as having CD presented only with chronic abdominal pain.

Non-GI symptoms may include iron-deficiency anemia, vague recurrent joint aches, delayed puberty, unexplained numbness or swelling of hands and feet, short stature, infertility or recurrent miscarriages, elevated liver enzymes, skin or oral cavity lesions, generalized low energy, and weak bones and poor dental enamel.

Untreated CD is also associated with a greater risk of cancer – in particular, small intestine lymphoma in adults. Non-GI symptoms are present in about half of all newly diagnosed cases of CD.

A strong association exists between CD and a number of other conditions, including diseases such as Addison disease, autoimmune thyroid or liver disease, and type 1 diabetes (8% of insulin-dependent diabetics have Celiac Disease); and genetic abnormalities such as Down Syndrome, Turner Syndrome, and Williams Syndrome. First-degree relatives of a patient with confirmed CD are also at increased risk; the condition occurs in 5% to 10% of immediate family members.

In what is sometimes referred to as “classic” Celiac Disease, gastrointestinal symptoms predominate, typically beginning between 6 months and 2 years of age, after the introduction of gluten into the diet. The young child experiences diarrhea or fatty, smelly loose stools, accompanied by poor weight gain or possibly weight loss. Some children begin to eat much less, and become more chronically irritable.

However, the “classic” presentation of CD occurs in only a small percentage of children with the disease. More often, GI symptoms appear later in life, with onset any time from childhood to adulthood. Symptoms vary, occur singly or in combination, and may be mild or intermittent initially. All which helps to explain why CD is such a difficult disease to recognize.

When Celiac Disease is suspected, blood tests (tissue Transglutaminase/tTG and Endomysial Antibody/EMA) may be used for screening purposes, but the diagnosis can only be definitively made by a small intestine biopsy that demonstrates the characteristic features of CD, followed in one year by a biopsy that demonstrates resolution of the disease after twelve months of a strict gluten-free diet.

So who should be tested for Celiac Disease? Any child or adult with major chronic gastrointestinal symptoms, especially if coupled with growth delay, short stature, or delayed puberty. Additionally, children with type 1 diabetes, with Down Syndrome or Turner Syndrome, or with a first-degree relative with confirmed CD should undergo blood screening for the disease. If blood tests are positive, a referral to a gastroenterologist should be made.

Once the diagnosis is confirmed, the patient will need to adhere to the healthy but difficult to maintain gluten-free diet (GFD) for life. The GFD excludes all products that contain proteins derived from wheat, rye, and barley. Oats were once believed to contribute to CD, but we now know that pure oats do not cause the condition; problems with oats arise from the fact that they are often contaminated with wheat flour during harvesting and milling.

Strict exclusion of gluten will result in complete healing of the gut lining and resolution of symptoms over weeks or months. But following a strict GFD is much easier said than done.

Gluten from wheat and related proteins from barley and rye are found in many commercial food products, and their presence is not always apparent. Gluten-free products are not widely available and are more expensive than their gluten-containing counterparts. A good source of information for initial dietary management of CD is the Web site www.celiachealth.org.

Because wheat is one of the largest sources of starch in the diet of developed countries such as the U.S., and because traditional bread products and pastas will need to be eliminated from the diet, patients and parents have to quickly become educated about safe alternative sources of starch, such as rice, corn, potato, amaranth, legumes, quinoa, and soy.

Again, with so many cases of Celiac Disease likely remaining undiagnosed, parents of children with chronic (more than 6 months) abdominal pain, bloating, constipation, diarrhea, nausea/vomiting or even weight loss or growth delay should discuss the condition with their child's physician. The earlier that CD is recognized, the more that can be done to alleviate symptoms and prevent lasting and serious consequences.