



CELIAC DISEASE

and the Gluten

By Jessica Schulman, PhD, MPH, RD



Free Diet

Throughout Connor's early years, his mother, Wendy, noticed periods when he stopped gaining weight and did not grow. She took her son to doctors, who invariably recommended high-calorie diets and patience, and indeed these periods passed and Connor resumed growing normally. When Connor was 10 years old, it happened again. Wendy remembers: "He weighed only 45 pounds." They were referred to a pediatric gastroenterologist, who, finding no obvious problems, was prepared to send them home, suggesting that he had a "weak stomach." Then, just before the appointment ended, Wendy mentioned that her grandmother had celiac disease (CD). They decided to test Connor for it, and the results were positive. ➤



Connar, who has CD, is his family's main gluten-free baker.

What Is CD?

CD, which is also known as celiac sprue or gluten-sensitive enteropathy, is a lifelong autoimmune disorder characterized by an immunologically toxic reaction to gluten—the storage proteins found in wheat, rye, barley and triticale. The disease has a genetic basis, but genes alone will not cause symptoms of CD, nor will eating too much bread. Instead, CD arises through the interaction between the environment and genetics, similar to diabetes.

When people with CD consume foods containing gluten, the gluten particles are broken down to form a “complex.” The body misreads this complex as a dangerous invader, producing immune cells to fight against it. The antibodies that are the product of this autoimmune reaction cause microscopic damage to everything in their path. This overreaction leads to the inflammation, intestinal damage, and all of the short-term and long-term problems associated with the disease. The disease's current treatment is a gluten-free diet. Undiagnosed and untreated, CD can lead to other conditions, including osteoporosis and anemia.¹

What Are CD Symptoms?

CD manifests in various ways. Individuals can have the classical form (obvious gut problems), failure to thrive,

atypical CD (subtle symptoms), or silent CD (no symptoms). Classic symptoms in children include diarrhea, bloating, anemia and failure to thrive. For adolescents and adults, symptoms often include diarrhea, constipation, weight loss, weakness, short stature, gas, bloating and vomiting.^{1,2}

CD, which can masquerade as other problems, also can look different depending on age, the severity of the disease, and the presence of health problems outside of the gut (extraintestinal manifestations). For example, dermatitis herpetiformis is a skin manifestation of CD that looks like little blisters on the face, elbows, knees or bottom.

Absence of these problems does not rule out CD. According to CD expert Mary Niewinski, MS, RD, “Atypical clinical manifestations of celiac disease are characterized by few or no gastrointestinal (GI) symptoms, instead, extraintestinal symptoms.”¹ Looking back, Wendy was able to associate CD with various problems during the 10 months it took for diagnosis. She says: “I realized that Connar had several other symptoms the whole time, like emotional instability and very small stature. Also, he had stopped functioning academically.”

How Common Is CD?

In the general population, between 1 in 100 and 1 in 300 people live with CD. In specific groups, such as European immigrants and those with certain autoimmune conditions, rates are much higher.² Moreover, because symptoms of CD can be mild or nonspecific, the disease is underdiagnosed in the United States, and patients are frequently diagnosed with other conditions first.³ Once health professionals are more aware of the disease and more accustomed to screening for it, the true prevalence will likely be higher.

When Does CD Occur?

As the Celiac Disease Foundation noted in 2006: “Celiac disease may appear at any time in a person's life. The disease can be triggered for the first time after surgery, viral infection, severe emotional stress, pregnancy or childbirth.” It might become noticeable in babies when food is introduced. Symptoms can persist throughout childhood and decrease in adolescence. Other factors such as viruses (adenovirus and relapsing rotavirus infections), other genetic syndromes, drug treatment such as interferon and intestinal permeability may increase risk for CD as well.⁴

¹ Niewinski, MM. Advances in Celiac Disease and Gluten-Free Diet. *J of the Am Diet Assoc.* 2008;108:pp.661-672.

² Wolters VM and Wijmenga C. Genetic Background of Celiac Disease and Its Clinical Implications. *Am J Gastroenterol.* 2008;103(1):pp.190-195.

³ Niewinski, op.cit.

⁴ Wolters and Wijmenga, op.cit.

Examples of Extraintestinal Problems Associated With CD

Iron deficiency anemia

Decrease in red blood cells (hematocrit and hemoglobin) due to inadequate iron. May have small red blood cells, low serum ferritin, low serum iron, high iron binding capacity, blood (visible or microscopic) in the stool.

Reduced bone

Less bone as measured by bone mineral density (BMD) testing. Predicts bone strength, mineral density and its ability to bear weight. A reduced BMD correlates with risk of fracture.

Chronic fatigue

May be mild or an incapacitating fatigue that isn't improved by bed rest. Exacerbated by physical or mental activity. Associated with cognitive dysfunction, impaired memory, decreased concentration, joint or muscle pain, headaches, swollen lymph nodes and shortness of breath.

Irritable bowel

Abdominal pain or discomfort. May include cramping, bloating, swollen abdomen, gas, diarrhea, and/or constipation. Affects the large bowel. Some people are relieved by a bowel movement and others have the sensation that they have "not finished." Mucus may appear in the stool.

Dyspepsia

Pain or discomfort in the upper abdomen, belching, nausea, bloating, feeling of fullness, abdominal bloating.

Infertility

Not being able to conceive after one year of trying or the inability to carry a baby to term, when no other cause is found.

Miscarriage

The natural or spontaneous end of a pregnancy. Usually occurs prior to 20 weeks gestation.

Hypertransaminasemia

Blood test that indicates a liver disorder. Chronic and otherwise unexplained.

Coagulopathy

Problems with the body's ability to clot blood. This may be caused by impaired absorption of vitamin K (prothrombin deficiency). May lead to prolonged bleeding after an injury.

Short stature

Below-average growth in childhood or height is not progressing at a fairly steady pace over time. Bone age lags behind chronologic age.

Pubertal delay or hormonal disorders

When child has passed the normative age when puberty begins and there are no physical signs that it has started—usually no later than age 14.

Arthralgia

A form of joint pain that is not usually accompanied by inflammation.

Aphthous stomatitis

Occasional and self-limited ulcerations or canker sores that can last for one week. Some can become more long-term or debilitating.

Folate deficiency

Reduction in red blood cells. Megaloblastic anemia (red cells are abnormally large). Symptoms include fatigue, headaches, sore mouth and tongue, and pallor (pale color).

Zinc deficiency

Delayed growth and maturation, hair loss, eye and skin lesions, diarrhea, loss of appetite or weight, delayed wound healing, taste abnormalities, and mental lethargy, depression of immune function (reduced activation of T-cells).

Dental enamel hypoplasia

Decreased quality and quantity of the enamel on one or many teeth. May look mild (small pits that may or may not be discolored) or may be more noticeable (dents or misshapen teeth). Contributes to tooth sensitivity and susceptibility to cavities.

Unexplained neurological disorders

Unusual sensations such as tingling, burning and numbness in the hands and feet. Some people feel pain sensations in their arms or legs. Associated with weakness and cramping.

Psychological or behavioral

Problems with concentration or memory, depression, mood disorders, irritability.

Unfortunately, CD usually persists throughout life and will often reappear when the individual is in their 30s or 40s. Due to delayed diagnosis and nonspecific symptoms, the diagnosis of CD might not be given until much later in life. Niewinski reports that symptoms may be present for "an average of 11 to 12 years" before properly diagnosed.⁵

How Can You Get Correctly Diagnosed?

Blood tests are an important first step. IgA endomysial antibodies, IgA tissue transglutaminase, and IgG tissue transglutaminase may be useful in identifying patients at risk for CD. However, for people with antibody defects, such as an IgA deficiency (or more extensive primary ➤

⁵ Fasano A. Celiac Disease in the Clinical Spotlight: What's New and What's the Path Forward? Medscape. www.medscape.com/viewarticle/533251.

immune deficiencies), and for children under 5 years of age, results will not be reliable. In these cases, or if there is suspicion of CD, a small intestinal biopsy is recommended.⁶ An individual with CD will usually have distinctly patterned small lesions in their intestine. After dietary treatment,

biopsies should show that lesions are healing or in remission.

Genetic tests can also help to identify who is at risk or who is unlikely to have the condition, but genes do not always predict who will develop symptoms. Human leukocyte antigen (HLA-DQ2 or HLA-DQ8) are required to develop the disease but are not the only factors. People who do not carry these genes tend not to develop CD; however, one out of three individuals is a genetic carrier and most carriers do not develop the disease. Furthermore, non-HLA genes may also contribute to CD, and additional regions of the genome are under study but their associations are not well known.⁷

To get an accurate blood test or biopsy, the patient must be consuming gluten. This is one reason why it is important to consult with a qualified healthcare professional if you or a loved one is seeking evaluation for CD.

What Is the Gluten-Free Diet?

Strict adherence to a gluten-free diet is the only available treatment for CD. Some patients might develop tolerance to gluten over time but scientists don't know whether this is temporary. Distinguishing between patients who need life-long adherence to the gluten-free diet from those who don't is not yet possible. For now, a gluten-free diet remains the cornerstone of treatment. Many patients report relief from symptoms after a couple of weeks on the diet. Full recovery, confirmed by biopsy, may take months or, in complicated cases, years.

Wendy explains that adjusting to the diet was initially difficult: "I was frustrated because nothing I was

Allowed Grains Vs. Foods to Avoid in CD

Gluten-Free

Amaranth
Arrowroot
Bean flours
Buckwheat
Corn
Fava
Flaxseed
Garbanzo bean
Garfava™ flour
(garbanzo & fava bean)
Hominy
Mesquite
Millet
Montina™ flour
Nut flours and nut meals
Oats (uncontaminated and if approved by patient's physician)
Pea flour
Potato flour
Quinoa
Rice
Sago
Sorghum flour
Soy flour
Tapioca (manioc, cassava, yucca)
Teff (or tef) flour

Toxic With Celiac Disease

Barley
Bulgur
Cereal binding
Chapati flour (atta)
Couscous
Dinkel
Durum
Einkorn
Emmer
Garina
Farro (or faro)
Fu
Gluten, gluten flour
Graham flour
Kamut
Malt (malt extract, malt flavoring, malt syrup, malt vinegar)
Matzoh meal
Oats
(most commercial brands, oat bran, oat syrup)
Orzo (a pasta that looks like a rice)
Rye Seitan ("wheat meat")
Semolina
Spelt
Triticale
Wheat
(wheat bran, wheat germ, wheat starch)

Adapted from and reprinted with permission from Case, *Gluten-Free Diet: A Comprehensive Resource Guide*, 2006.

⁶ Celiac Disease Foundation. Brochure: Celiac Disease, 2006.

⁷ Wolters and Wijmenga, op.cit.



used to cooking tasted the same. Connor also felt very isolated.” With the support of a friend who was on a gluten-free diet, Wendy says, “I began to get my footing on gluten-free.” Families with CD are strongly encouraged to meet with a dietitian or gastroenterology nurse who has experience with CD, and to participate in a CD support group.⁸ Learning the gluten-free diet, which may be lacking in certain nutrients, takes time.

Wendy says that most people were supportive and understanding and Connor has been great about sticking to the diet. “He now reads every label and knows exactly what to look for ... he is our main gluten-free baker.” The Celiac Disease Foundation, www.celiac.org or (818) 990-2354, provides a “Quick Start Diet Guide for Celiac Disease.” What follows is an overview:

- Read labels. Become a good ingredient label reader and avoid the foods that are toxic for patients with CD (see table on Page 28). Labels must be read every time food is bought. Wheat-free is not gluten-free.
- Verify ingredients. Contact the food manufacturer and specify the ingredient and the lot number of the food in question (e.g., breading, brown rice syrup, croutons, energy bars, flour or cereal products, imitation bacon, imitation seafood, marinades, pasta, luncheon meats, sauces, gravies, self-basting poultry, soy sauce, soup bases, stuffings, dressing, thickeners, communion wafers, herbal supplements, drugs and over-the-counter medications, vitamins, nutritional supplements).
- When in doubt, go without!
- Keep a diary. Healing may take time. Not all adverse food reactions are due to CD.

Looking Ahead

The prognosis for patients who are correctly identified and treated for CD is excellent. However, a small number of individuals who implement a gluten-free diet still may not feel better; these individuals may require steroids or other treatments. An individual living with CD has an increased risk for structural damage and cancers in the small intestine, as well as lymphomas.

Eighteen months after his diagnosis, Connor is a different child. Wendy reports that he has gained 15 pounds and has grown. She says: “He doesn’t look sickly anymore. His positive attitude has returned. He is progressing again academically and he now has physical control over his body, which he has never had before.”

Connor’s fondest hope is to help families and find a cure for this condition. According to Wendy, “Many days he wonders why he has to have celiac, but he always turns it around with the idea that maybe he can find relief for others someday.” ■

Editor’s Note: The author is a credentialed dietitian, holds a doctorate in health behavior, and is a visiting scholar in the Department of Psychology at the University of California, Los Angeles. This article is intended for general information only. Individuals with medical conditions should consult a physician to determine what eating pattern is right for them.

Support Groups

Gluten Intolerance Group

www.gluten.net

Celiac Disease Foundation

www.celiac.org

Canadian Celiac Association

www.celiac.ca

Celiac Sprue Association

www.csaceliacs.org

Gluten-Free Diet Information

www.celiac.com

Celiac Disease Online Support Group

www.geocities.com/HotSprings/Spa/4003/delphi.html

⁸ Raymond N, Heap J, Case S. The Gluten-Free Diet: An Update for Health Professionals. *Practical Gastro*. 2006; Sept:67-92.