

# Celiac Disease

## Still Vastly Under-Diagnosed

**Shelley Case**, Registered Dietitian  
Case Nutrition Consulting, Inc.



### What is celiac disease?

Celiac disease is a common, inherited disorder estimated to affect as many as 1 in 100 persons in North America. In genetically susceptible individuals, the ingestion of gluten triggers this autoimmune disease. Continued exposure to specific proteins (gluten) contained in wheat, rye, and barley damages the tiny finger-like projections (villi), which line the small intestinal tract. These villi eventually become inflamed and flattened (villous atrophy). Malabsorption of nutrients such as iron, folate, calcium, fat-soluble vitamins A, D, E, and K, and protein can occur, leading to nutritional deficiencies (e.g. anemia and osteoporosis). The poorly-functioning villi may decrease their production of lactase, an enzyme necessary for digesting lactose, the sugar found in milk. This may result in temporary lactose intolerance. Additional complications of untreated celiac disease include infertility in women and men, miscarriage, lymphoma, and the possible development of other autoimmune diseases.

### Presentations of celiac disease

Symptoms of celiac disease can appear at any age from infancy well into senior adulthood. The average age of diagnosis is between the 4<sup>th</sup> and 6<sup>th</sup> decades of life, with approximately 20% of cases diagnosed in those who are more than 60 years of age. In the *Canadian Celiac Health Survey*<sup>1</sup> of 2,681 adults with biopsy-proven celiac disease, the mean age at diagnosis was 46 years. A gastrointestinal or viral infection, surgery, pregnancy, or severe stress can sometimes trigger onset of the disease.

Medical scientists now recognize that while celiac disease clearly affects the gastrointestinal system, it also affects the musculoskeletal, hematological, endocrine, neurological, cutaneous, and reproductive systems. The symptoms of celiac disease are highly variable depending on age, the duration, and extent of the disease, and the presence of extra intestinal manifestations. Celiac disease may also be associated with other conditions including type 1 diabetes, autoimmune hepatitis, autoimmune thyroid disease, Down syndrome, and Turner syndrome.

### Symptoms of Celiac Disease\*

- Iron, folate, and/or vitamin B12 deficiency
- Other vitamin and mineral deficiencies (A, D, E, K)
- Chronic fatigue and weakness
- Abdominal pain, bloating, and gas
- Indigestion/reflux
- Nausea and vomiting
- Diarrhea, constipation or intermittent diarrhea and/or constipation
- Lactose intolerance
- Weight loss (note that celiac can also occur in obese individuals)
- Bone/joint pain
- Easy bruising of the skin
- Edema (swelling) of hands and feet
- Migraine headaches
- Depression
- Mouth ulcers (canker sores)
- Menstrual irregularities
- Infertility (in both women and men)
- Recurrent miscarriages
- Elevated liver enzymes
- Peripheral neuropathy, ataxia, epilepsy

### Additional symptoms in children:

- Irritability and behavioural changes
- Concentration and learning difficulties
- Failure to thrive (delayed growth and short stature)
- Delayed puberty
- Dental enamel abnormalities

\* These symptoms can occur singly or in combination.

### Diagnosis

The varied presentations of celiac disease and similarities of its symptoms with other diseases often lead to misdiagnoses such as irritable bowel syndrome, diverticular disease, gastric ulcers, allergies, chronic fatigue syndrome, or fibromyalgia. Individuals frequently see numerous physicians before receiving a correct diagnosis. The *Canadian Celiac Health Survey*<sup>1</sup> revealed

that 37% of respondents had consulted two or more family physicians, 27% saw three or more physicians and 14% consulted two or more gastroenterologists before reaching a diagnosis of celiac disease. The mean delay in diagnosis was 11.7 years after onset of the symptoms.

Specific blood tests are now available to screen for celiac disease, including IgA tissue transglutaminase (TtG) and IgA endomysial (EMA) antibody tests. False negative results can occur with these tests. IgA TtG and EMA will be falsely negative in individuals with IgA deficiency, which occurs in 3-5% of persons with celiac disease. If these tests are negative and the patient has symptoms of celiac disease, then they should also be tested for IgA deficiency. IgA and IgG anti-gliadin antibody tests are no longer recommended screening tests for celiac disease, since they are not as sensitive or as specific as the TtG and EMA.

Health Canada has approved a home blood test screening kit that identifies IgA TtG, which is now available in Canadian pharmacies. Sold under the name Biocard™ Celiac Test, it costs \$50 and uses a fingertip blood drop, providing results within about ten minutes.

Regardless of whether accessing laboratory analysis or using a home test kit, **a small intestinal biopsy is required to confirm the diagnosis of celiac disease.** It is important to know that a **gluten-free diet should NOT be started before the blood test and biopsy have been**

**completed** as it can interfere with making an accurate diagnosis.

### Treatment

The only treatment for celiac disease is a **strict gluten-free diet for life.** Upon diagnosis, it is essential the individual and family members/caregivers consult a registered dietitian with expertise in celiac disease. The dietitian will do a complete nutritional assessment and provide comprehensive diet education. This includes assisting with meal planning, label reading, shopping, finding specialty food products, locating recipes, eating out, travelling, finding credible resources, and using supplements. Joining a patient group like the Canadian Society of Intestinal Research ([www.badgut.org](http://www.badgut.org)) or the Canadian Celiac Association ([www.celiac.ca](http://www.celiac.ca)) is also highly recommended to receive valuable information and ongoing support.

### Gluten-Free 101

Celiac patients must avoid all forms of wheat, rye, and barley on a gluten-free diet (**See Table 1: NOT SAFE**). Historically, oats were also on the list of prohibited grains as it was thought that the oat protein (avenin) caused the same toxic reaction as in wheat, rye, and barley. However, new research reveals that moderate amounts of pure, uncontaminated oats are

**Table 1: NOT SAFE<sup>4</sup>**  
Gluten-Containing Foods & Ingredients

Ale	Lager
Atta <sup>i</sup>	Malt
Barley (Flakes, Flour, Pearl)	Malt Extract, Malt Syrup, Malt Flavouring
Beer	Malt Vinegar
Brewer's Yeast	Malted Milk
Bulgur	Matzoh, Matzoh Meal
Couscous	Modified Wheat Starch
Dinkel (also known as spelt) <sup>ii</sup>	Rye
Durum <sup>ii</sup>	Seitan <sup>iv</sup>
Einkorn <sup>ii</sup>	Semolina
Emmer <sup>ii</sup>	Spelt (also known as farro or faro; dinkel)
Farina	Triticale
Farro or Faro (also known as spelt) <sup>ii</sup>	Wheat
Fu <sup>iii</sup>	Wheat Bran
Graham Flour	Wheat Flour
Hydrolyzed Wheat Protein	Wheat Germ
Kamut <sup>ii</sup>	Wheat Starch

i A fine whole-meal flour made from low-gluten, soft-textured wheat used to make Indian flatbread (also known as chapatti flour).

ii Types of wheat.

iii A dried gluten product derived from wheat and sold as thin sheets or thick round cakes; used as a protein supplement in Asian dishes such as soups and vegetables.

iv A meat-like food derived from wheat gluten used in many vegetarian dishes, sometimes called 'wheat meat.'

safe for most individuals with celiac disease. Producers grow these specialty oats on dedicated fields and then harvest, transport, and process them on dedicated equipment to prevent cross-contamination with gluten-containing grains. Cream Hill Estates Ltd. (Lara brand)<sup>2</sup> in Montreal and FarmPure Foods Ltd. (Only Oats)<sup>3</sup> in Regina are the only two Canadian companies currently producing pure oats. All other regular commercial oats might contain wheat, rye and/or barley and thus do not conform to the gluten-free diet. A very small number of individuals with celiac disease may not tolerate pure oats; however, the mechanism causing this intolerance remains undiscovered. Physicians recommend that a person be well established on a gluten-free diet before they introduce pure oats into their diet.

Most individuals find that changing lifelong eating habits and adapting to a gluten-free diet is a major challenge for a number of reasons, including that wheat, and to a lesser extent, rye and barley, are the staple cereals used in the North American diet. They serve as the basis for a wide variety of foods such as cereals, pasta, breads, and other baked products. Many soups, sauces, salad dressings, seasonings, prepared meats (e.g. deli meats, hot dogs, meat patties), snack foods, some flavoured coffees and teas, beer, candies, and chocolates contain gluten. Due to busy lifestyles, eating out, and use of packaged, convenience foods, it is increasingly common for gluten to find its way into our diet, even where we least expect it. Current Canadian food labelling regulations do not require manufacturers to declare all components of ingredients on the package label (e.g. modified food starch, seasonings, hydrolyzed vegetable protein) making it difficult to determine whether products containing these ingredients are gluten-free.

Fortunately, there are many varieties of foods that are naturally gluten-free, including plain meat, poultry, fish, eggs, nuts, seeds, legumes, milk, cheese, yogurt,

## Celiac Resources

Please contact our office for more information about celiac disease and the gluten-free diet. The following resources may also be helpful:

- Health Canada's extensive technical review on the safety of oats: [www.hc-sc.gc.ca/fn-an/securit/allerg/cel-coe/oats\\_cd-avoine-eng.php](http://www.hc-sc.gc.ca/fn-an/securit/allerg/cel-coe/oats_cd-avoine-eng.php)
- The Canadian Celiac Association (CCA), 1-800-363-7296 or [www.celiac.ca](http://www.celiac.ca)
- *Acceptability of Foods and Food Ingredients for the Gluten-Free Diet Pocket Dictionary (CCA)*
- *Guidelines for Consumption of Pure and Uncontaminated Oats by Individuals with Celiac Disease*: [www.celiac.ca/Articles/PABoatsguidelines2007June.html](http://www.celiac.ca/Articles/PABoatsguidelines2007June.html)
- *Gluten-Free Diet: A Comprehensive Resource Guide* by Shelley Case, RD, Case Nutrition Consulting: [www.glutenfreediet.ca](http://www.glutenfreediet.ca)
- Canada Revenue Agency celiac disease medical expense information: [www.cra-arc.gc.ca/tx/ndvdl/tpcs/clc-eng.html](http://www.cra-arc.gc.ca/tx/ndvdl/tpcs/clc-eng.html)

fruits, and vegetables. Additionally, there are many gluten-free flours, starches, and grains that can replace wheat, barley, and rye (**See Table 2: SAFE**). Distilled alcoholic beverages, wine, and liqueurs are safe, however beer derived from barley is not. All vinegars except malt vinegar are gluten-free.

There are also increasing varieties of gluten-free specialty products available, such as ready-to-eat baked products (e.g. breads, bagels, buns, muffins, cakes, cookies, pies, and pizza crusts), baking mixes and specialty flours, hot and cold cereals, snack foods, entrees, pasta, soups, sauces, communion wafers, snack bars and gluten-free beer. Products are available in health food and grocery stores, as well as from mail order companies.

The cost of gluten-free products is usually considerably higher than gluten-containing foods and

**Table 2: SAFE<sup>4</sup>**  
Gluten-Free Flours, Cereals, and Starches

Amaranth	Potato Starch
Arrowroot	Quinoa
Buckwheat	Rice (black, brown, glutinous/sweet, white, wild)
Corn	Rice Bran
Flax	Rice Polish
Indian Ricegrass (Montina™)	Sago
Legumes Flours (bean, chickpea/garbanzo, lentil, pea)	Sorghum
Mesquite Flour	Soy
Millet	Sweet Potato Flour
Nut Flours (almond, hazelnut, pecan)	Tapioca (cassava/manioc)
Potato Flour	Teff

they are not as readily available as gluten-containing products. A small percentage of individuals with celiac disease may qualify for a tax rebate from the Canada Revenue Agency for the incremental cost of purchasing gluten-free foods. Additionally, many gluten free items are available in bulk form for cost savings. See sidebar for more resources.

Good compliance with the diet is essential to reduce the risk of complications and to improve the health and quality of life for those with celiac disease.

Shelley Case, a registered dietitian, is a leading international nutrition expert on celiac disease and the gluten-free diet. She is a member of the Medical Advisory Boards of the Celiac Disease Foundation and Gluten Intolerance Group in the United States and the Professional Advisory Board of the Canadian Celiac Association. Visit her website at [www.glutenfreediet.ca](http://www.glutenfreediet.ca).

In recognition of Shelley's major contributions to the celiac community and dedication to educating health professionals and individuals with celiac disease in Canada and the United States, she was awarded the Queen Elizabeth Golden Jubilee Medal. Shelley also recently received the Canadian Celiac Association's Honourary Life Member Award.



### Here's what you'll find in the new *Gluten-Free Diet*

- Detailed food and ingredient information
- Latest breaking news on oats, including position statements from various organizations around the world, guidelines for use, and references
- New food and GF labeling regulations in the US, Canada, Europe and Australia/NZ, as well as the international Codex Alimentarius
- More than 3,100 gluten-free specialty products listed by company name, product name, and package size
- Directory of more than 270 American, Canadian, and international companies divided into 3 categories: manufacturers of GF products, GF bakeries, and GF stores & distributors
- Nutrition information and practical strategies for healthy gluten-free living
- Creative ideas for meals and snacks
- Gluten-free recipes with nutritional analysis
- Prevention of cross-contamination
- Resources such as books, cookbooks, magazines, celiac groups around the world
- Tips for eating out, and more!

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 855 West 12th Avenue  
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 Fax 604-875-4429

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