

Celiac Disease, Gluten Sensitivity and the Gluten-Free Diet

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Celiac Disease

Celiac disease (CD) is one of the most common inherited disorders, with an estimated prevalence rate of 1:100. Originally thought to be a rare disorder, a multi-center study revealed that 1:133 people in the US have CD (1). This translates into 3 million Americans with the disease, although it is estimated that 90 to 95% remain undiagnosed. Prevalence of CD in Canada is thought to be similar as in the US. A high prevalence of CD is also found in individuals with other disorders such as Type 1 diabetes (T1D), autoimmune thyroid disease and Down syndrome. The prevalence of CD in T1D populations around the world ranges between 2.4% to 16.4% (2).

Celiac disease (CD) is an autoimmune disorder in which the villi of the small intestine are damaged by specific prolamins from the grains wheat, rye and barley (collectively called gluten). Symptoms of CD are highly variable, may occur at any age (including the elderly) and involve not only the gastrointestinal system but many other organ systems. Infants and young children can present with bloating, gas, diarrhea, weight loss, poor growth, irritability, dental enamel defects and/or anemia. In older children and adults, symptoms can vary from mild to severe. Some may present with only a few symptoms while others can have many different symptoms. These include anemia, nausea, reflux, bloating, gas, diarrhea or constipation (or both), lactose intolerance, weight loss (note that CD can also occur in obese individuals), mouth ulcers, extreme fatigue, irritability, bone and joint pain, easy bruising of the skin, menstrual irregularities, miscarriage, infertility in both women and men, migraines, depression, ataxia, seizures, neuropathy and elevated liver enzymes.

Another presentation of CD is the skin condition called dermatitis herpetiformis (DH) that is characterized by an intense burning, itchy rash that is symmetrically distributed. Initially, groups of small blisters are formed that soon erupt into small erosions. Areas affected can include the elbows, knees, back of the neck and scalp, upper back and buttocks. Most people with DH will also have varying degrees of small intestinal villous atrophy, although many will have no bowel complaints.

Untreated CD can result in nutritional deficiencies; osteoporosis; increased risk of intestinal cancers; reproductive complications such as infertility and miscarriage; and development of other autoimmune disorders. Because the symptoms of CD vary so widely in the nature and severity, especially among adults, misdiagnoses such as irritable bowel syndrome, lactose intolerance, fibromyalgia, chronic fatigue syndrome and ulcers are common. Also, diagnosis is often delayed for many years after symptoms appear. Studies by Columbia University in New York and the Canadian Celiac Association (3) revealed that adults suffer from the disease for an average of 10-12 years before being correctly diagnosed.

There are specific serological tests (IgA tissue transglutaminase and IgA endomysial antibodies) that can be used to screen for CD, however the only definitive test for diagnosis is the small intestinal biopsy. Diagnosis for DH is a skin biopsy from unaffected skin adjacent to the blisters or erosions. In DH, an intestinal biopsy is not essential if the skin biopsy is positive. **A gluten-free diet should never be started before the blood tests and biopsy are done as this can interfere with making an accurate diagnosis.**

The only treatment for CD is a strict gluten-free diet (GFD) for life. It is essential that individuals with CD be referred for an initial assessment, education and follow-up with a registered dietitian with expertise in CD and the GFD (4). Individuals should also be encouraged to join a local and/or national celiac group for ongoing support.

Type 1 Diabetes and Celiac Disease

A high prevalence of CD in T1D has been documented in many studies around the world. Both diseases have common autoimmune origins and are associated with the HLA class II genotype DQ2. In addition to this shared genetic basis, there is evidence that consumption of gluten and/or local microbial factors can result in altered gut permeability and mucosal immunity that may be a factor in the development of T1D and other autoimmune disorders (2, 5).

Clinical manifestations of CD in T1D vary considerably. Gastrointestinal symptoms, anemia, weight loss or poor weight gain, growth failure, delayed puberty, unexplained hypoglycemia or erratic blood glucose levels, low bone mineral density and other symptoms may be present. However, many individuals are asymptomatic or have mild or subtle symptoms that may not be recognized as CD until after diagnosed and treated with a GF diet (6). In the majority of patients T1D is usually diagnosed before CD (7).

North American medical and diabetes associations have different celiac screening protocols and treatment recommendations for T1D (2,8,9,10,11). Some do not recommend screening for CD unless symptoms are present. Others routinely screen all individuals with T1D at diagnosis and follow up at regular intervals with repeated screening if the initial tests are negative. Most organizations recommend a GFD for individuals with symptomatic and asymptomatic CD, although debate still continues regarding treating those with asymptomatic CD (2,10). Individuals with symptomatic CD often see a resolution or improvement of symptoms on the GFD. In symptom-free cases, response to the GFD is variable, with benefits frequently limited to changes in growth parameters and bone mineral density (12). Further long-term studies are needed to determine the effectiveness of a GFD for individuals with T1D and asymptomatic CD (2, 12).

Gluten Sensitivity (GS)

Recent research has revealed that it is possible to be sensitive to gluten and not have celiac disease. Although the exact mechanism and prevalence of GS is not known at this time, Dr. Fasano from the Center for Celiac Research in Baltimore has recently published several papers on this topic (see below). There appears to be differences in gut permeability and the immune system of those with CD compared to individuals with GS. GS is not an autoimmune disease, is not accompanied by elevated TTG antibodies and does not result in increased intestinal permeability or severe intestinal damage. Symptoms of GS can be similar to CD such as abdominal pain, bloating, gas, diarrhea, unexplained anemia, muscle cramps, leg numbness and bone or joint pain. Currently there are no specific tests for diagnosing GS. The only way to determine if someone has GS is by ruling out CD and wheat allergy, then seeing the response to a gluten-free diet and a gluten challenge. It is not known whether someone with GS must strictly avoid gluten for life like those with CD. The Center for Celiac Research estimates that GS may affect 6% of the population compared to 1% for those with CD.

<http://www.biomedcentral.com/content/pdf/1741-7015-9-23.pdf>

<http://somvweb.som.umaryland.edu/absolutenm/templates/?a=1474&z=5>

<http://www.biomedcentral.com/content/pdf/1741-7015-10-13.pdf>

<http://www.biomedcentral.com/1741-7015/10/13>

Gluten Defined

Gluten is the common name for storage proteins (prolamins) found in wheat, rye and barley. The specific names of the toxic prolamins are gliadin in wheat, secalin in rye and hordein in barley. All forms of wheat, rye and barley must strictly be avoided, including spelt, kamut, einkorn, emmer, faro, durum, couscous, semolina, bulgur and triticale. Barley malt, barley malt extract, barley malt flavor, brewer's yeast, malt vinegar, as well as barley-based ale, beer and lager must also be avoided.

The avenin prolamin in oats was originally thought to trigger the same toxic reaction as wheat and other gluten-containing grains. Research in Europe and the US over the past 17 years has revealed that consumption of moderate amounts of oats is safe for the majority of children and adults with celiac disease. Most of these studies used pure, uncontaminated oats, but it should be noted that a very small number of individuals with celiac disease may not even tolerate pure oats. The mechanism causing this intolerance has yet to be established.

Based on this research, many celiac organizations and health professionals around the world now allow consumption of moderate amounts of pure, uncontaminated oat products in diet. An extensive technical review on the safety of oats is published on Health Canada's website:

www.hc-sc.gc.ca/fn-an/securit/allerg/cel-coe/oats_cd-avoine_e.html

Unfortunately the majority of commercial oats products on the market are cross contaminated with wheat, barley or rye which occurs during harvesting, transportation, storage, milling, processing and packaging. The good news is that there are companies in the US, Canada and Europe who produce pure, uncontaminated specialty oat products. The North American companies are:

Bob's Red Mill	www.bobsredmill.com
Cream Hill Estates (Lara's brand)	www.creamhillestates.com
Avena Foods (Only Oats™)	www.onlyoats.com
Gifts of Nature	www.giftsofnature.net
Gluten-Free Oats	www.glutenfreeoats.com
Legacy Valley	www.mtmonstermunchies.com

Sources of Gluten

Gluten is found in a wide variety of foods such as breads and other baked products, cereals, pastas, soups, sauces such as soy sauce which is often made from wheat and soy, seasonings, salad dressings, snack foods, prepared meats (e.g., deli meats, hot dogs, hamburger patties, imitation seafood), beer, flavored coffees and teas, some candies (e.g., licorice) and chocolate bars, as well as some nutrition supplements and medications.

Foods Allowed on a Gluten-Free Diet

A wide variety of foods that are naturally gluten-free include plain meat, poultry, fish, eggs, pulses (pulses), nuts, seeds, milk, yogurt, cheese, fruits, vegetables, as well as many gluten-free flours, cereals and starches that can be substituted for wheat, rye and barley (see below). Distilled alcoholic beverages and wines are also allowed, however beer derived from barley must be avoided. All vinegars are gluten-free except for malt vinegar (made from barley and is not distilled).

Gluten-Free Flours, Cereals and Starches

- Amaranth
- Arrowroot
- Buckwheat
- Corn
- Flax
- Indian ricegrass
- Pulse flours (*bean, chickpea/garbanzo, lentil, pea*)
- Mesquite flour
- Millet
- Nut flours (*almond, hazelnut, pecan*)
- Potato Flour
- Potato Starch
- Quinoa
- Rice Bran
- Rice Polish
- Sago
- Sorghum
- Soy
- Sweet Potato Flour
- Rice (*black, brown, glutinous/sweet, white, wild*)
- Tapioca (*cassava/manioc*)
- Teff

Gluten-Free Specialty Products

A growing number of gluten-free specialty products from companies in the USA, Canada and Europe are available in health food and grocery stores, as well as mail order companies. Examples include ready-to-eat baked products (e.g., breads, buns, bagels, muffins, cakes, cookies, pies, pizza crusts), baking mixes and specialty flours, hot and cold cereals, crackers, snack foods, entrees, pastas (corn, pulses, quinoa and rice), bread crumbs, coating mixes, gravy mixes, soups, sauces, communion wafers, ice cream cones and snack bars. Gluten-free beer made from rice, buckwheat and/or sorghum is also available in the US, Canada and some European countries.

Gluten-Free Labeling

There is no single world-wide definition for the term “gluten-free”. Various countries have different gluten-free labeling regulations, terminology allowed and acceptable levels of gluten. Unfortunately, these differences have caused great confusion within the celiac community and food industry, resulting in various interpretations of gluten-free and labeling of food products.

On August 2, 2004, the *US Food Allergen Labeling and Consumer Protection Act* (FALCPA) of 2004 became law. This legislation required manufacturers to identify the eight major food allergens, including wheat (but not barley and rye) on the food label effective January 1, 2006. The FALCPA also mandated the FDA to issue a proposed rule to define and permit the use of the term “gluten-free” on food labels by August 2006, with the final ruling by August 2008. The proposed gluten-free regulation was released January 2007 and the FDA reviewed comments from consumers, industry, health professionals and others. The final rule to establish a regulatory definition for the term “gluten-free” was expected in August 2008; however it was delayed. The FDA completed a safety assessment report on gluten exposure in individuals with celiac disease and sought comments from the general public, health professionals and the food industry. The comment period closed October 2011. After reviewing the comments the FDA will finalize the gluten-free regulation. It is unknown at this time how long this process will take but is estimated for fall 2012.

<http://www.fda.gov/Food/LabelingNutrition/FoodAllergensLabeling/GuidanceComplianceRegulatoryInformation/ucm077926.htm>

<http://www.fda.gov/downloads/Food/ScienceResearch/ResearchAreas/RiskAssessmentSafetyAssessment/UCM264152.pdf>

<http://www.fda.gov/downloads/Food/ScienceResearch/ResearchAreas/RiskAssessmentSafetyAssessment/UCM264150.pdf>

Canada has a specific regulation B. 24.018 for products labeled “gluten-free” that was established in 1995. Due to recent advances in the understanding of celiac disease and the gluten-free diet, including the safety of pure, uncontaminated oats, Health Canada communicated that the gluten-free regulation required further revisions. On May 13, 2010, *Health Canada’s Proposed Policy Intent for Revising Canada’s Gluten-Free Labelling Requirements* was released for comments from consumers, industry and other stakeholders. www.hc-sc.gc.ca/fn-an/consult/gluten2010/index-eng.php Health Canada reviewed these comments and will be publishing a summary of these results very soon. Stakeholders will have an opportunity to comment on this. Further regulatory changes will be proposed following the consultation.

Health Canada also passed a new regulation on February 16, 2011 entitled *Schedule 1220 Enhanced Labelling of Food Allergen and Gluten Sources and Added Sulphites*. This will require manufacturers to declare on the food label the major food allergens, all gluten sources and sulphites when present as ingredients or components of ingredients in prepackaged foods sold in Canada effective August 4, 2012. As a result of changes to Schedule 1220, a consequential amendment to the gluten-free regulation B.24.108 occurred (see below). A guidance document for this new gluten-free regulation that will include threshold levels, gluten testing methodologies and other background information will be finalized before August 4, 2012 after consultation with key stakeholders.

<http://www.gazette.gc.ca/rp-pr/p2/2011/2011-02-16/html/sor-dors28-eng.html>

<http://www.hc-sc.gc.ca/fn-an/label-etiquet/allergen/index-eng.php>

Nutritional Concerns

The nutritional status of people with newly diagnosed CD can vary considerably depending on the length of time delay between onset and diagnosis and the degree of malabsorption. For many with delayed diagnosis, which is the majority, there is a significant risk for a variety of vitamin and mineral deficiencies. In severe cases of CD, malabsorption of fat, fat-soluble vitamins A, D, E and K, iron, folic acid, calcium and magnesium, as well as secondary lactose intolerance can occur. In order for the intestinal villi to regenerate and reverse the nutritional deficiencies, it is important to follow these dietary guidelines:

- 1) **Follow a strict gluten-free diet for life.** Eliminate all forms of wheat, rye and barley. Response to the GFD varies greatly among individuals. Symptoms may resolve within a few weeks; however the intestinal villi can take months to several years to normalize.
- 2) **A temporary lactose-free diet may also be necessary.** Although data on prevalence of lactose intolerance in individuals with CD is limited, it is estimated that 30-60% may develop secondary lactose intolerance. There are several options to manage lactose intolerance and ensure adequate calcium intake: a) Lactase enzyme drops or tablets when consuming dairy products, b) lactose-reduced milk products, and c) soy, rice, nut and potato beverages are lactose-free. Check the ingredients since some brands may contain barley malt as a flavoring agent, which contains gluten. Choose products that are enriched with calcium, vitamin D and other nutrients.
- 3) As chronic iron deficiency anemia is common, **encourage consumption of iron-rich, gluten-free foods.** Red meat is an excellent source of heme iron. Chicken and fish provide lesser amounts, but still contribute to overall intake of heme iron. Good sources of non-heme iron include many gluten-free flours, cereals and starches (e.g., amaranth, pulse flours, millet, quinoa, rice bran and teff), nuts, seeds, pulses, dried fruits (apricots, prunes and raisins), and blackstrap molasses.
- 4) **Ensure adequate amounts of calcium and vitamin D.** Early bone disease, including osteopenia and osteoporosis, is common in people with CD. For those unable or not willing to consume enough calcium and vitamin D through dietary sources, encourage gluten-free supplements.
- 5) **Choose more nutritious ingredients** such as amaranth, brown rice flour, buckwheat, flax, nut flours, oats (pure, uncontaminated), quinoa, pulse flours (e.g., garbanzo/chick pea, Garfava™, yellow or green pea, bean {black, cranberry, soy} and teff when preparing or purchasing gluten-free foods.
- 6) **Look for enriched gluten-free products.** Most gluten-free products are not enriched and/or are made from refined flours and starches that are low in vitamins, minerals and dietary fiber. However, some companies enrich their gluten-free products with iron and B vitamins at the same levels as gluten-containing breads, cereals, pastas and flours.
- 7) **Consume adequate amounts of dietary fiber.** People with newly diagnosed CD may initially present with diarrhea due to malabsorption. Once a gluten-free diet is introduced and the gut heals and diarrhea subsides, constipation often occurs due to the absence of high-fiber, gluten containing foods such as wheat bran and whole-wheat breads and cereals. Emphasize fiber-rich gluten-free products such as fruits, vegetables, nuts, seeds, pulses and their flours, amaranth, flax seed, mesquite flour, oats (pure, uncontaminated), quinoa, rice bran, rice (brown and wild) and teff. Gradually increase fiber and increase the consumption of fluids, especially water.

Dietary strategies for T1D and CD

- 1) Refer to a **dietitian with expertise in both diseases**. If two dietitians are involved (one for CD and one for diabetes) ensure good communication and consistent treatment goals and guidelines are given to the patient. Frequent follow up visits are essential to educate the patient about celiac disease and the gluten-free diet (GFD), as well as how to integrate the GFD with diabetes meal plan, monitoring and insulin adjustment.
- 2) **Achieve and maintain blood glucose control** by balancing carbohydrate with insulin administration. Frequent blood glucose monitoring and insulin adjustments are necessary as GF products are often higher in carbohydrates, sugar and fat and lower in fiber than gluten-containing counterparts. Also absorption of GF carbohydrates will increase once intestinal villi begin to heal. May need to modify portions based on blood sugars, CHO counts and weight goals.
- 3) Use **accurate and practical resources** on managing both diseases. There is a lot of misinformation about the GFD on the internet and from other sources. For accurate and practical information see suggestions in the “Resources” section.

Resources

Gluten-Free Diet: A Comprehensive Resource Guide by Shelley Case, RD

This 368 page book is written for consumers, health professionals, culinary professionals and others needing accurate and practical information about the gluten-free diet. Includes detailed information about safe foods/ingredients and those to avoid; labelling; meal plans; recipes (with nutritional analysis); cooking hints and substitutions; nutrition information (including CHO content of GF grains, flours, starches and other foods); practical strategies for healthy gluten-free living; over 3100 GF specialty products; directory of more than 270 companies; and resources. The website has information and free downloadable handouts on the gluten-free diet and celiac disease. www.glutenfreediet.ca

Celiac Disease for Dummies by Dr. Ian Blumer and Dr. Sheila Crowe

This 384 page book is written for people with celiac disease and their family members. Very comprehensive and practical information about celiac disease including symptoms, diagnostic tests, associated conditions (including diabetes), complications, treatment, nutritional considerations, alternate and complimentary therapies, follow up and frequently asked question.

Celiac Disease: A Hidden Epidemic by Dr. Peter Green and Rory Jones

An authoritative guide to celiac disease co-authored by Dr. Peter Green who is the director of the Celiac Disease Center at Columbia University. It covers proper diagnosis, treatment and management, including a section on coping with the psychological aspects of chronic illness and the gluten-free diet. It looks at the latest research, complications and related diseases – including infertility, autoimmune diseases e.g., diabetes, thyroid disease, liver disease and cancer.

Real Life with Celiac Disease: Troubleshooting and Thriving Gluten Free by Melinda Dennis, RD and Dr. Daniel Leffler, MD.

This 369 page book includes 53 chapters on a wide variety of topics about celiac disease, gluten sensitivity and the gluten-free diet. The authors and more than 50 international celiac experts feature cases studies and recommended treatment options, lifestyle changes and outcomes. Published by the American Gastroenterological Association. www.reallifewithceliacdisease.com

Canadian Celiac Association Pocket Dictionary: Acceptability of Foods and Food Ingredients for the Gluten-Free Diet

This 60 page pocket-size dictionary contains more than 300 foods and food ingredients and over 300 food additives listed in alphabetical order for easy reference. Easy to understand description of each item and food ingredients classified by category (allowed, not allowed, or to check). Written by dietitians with expertise in celiac disease who did extensive research into ingredient manufacturing practices and food labelling regulations in the USA, Canada and Europe.

Gluten-Free Passport

GlutenFree Passport® is a series of books and Apps focused on promoting awareness and helping those with celiac disease, food allergies and special diets who eat out and travel. www.glutenfreepassport.com

TheCeliacScene.com

Canada's only comprehensive listing of celiac-endorsed restaurants. Owned, operated and maintained by individuals with celiac disease in cooperation with Chapters of the Canadian Celiac Association. All recommendations are reviewed and must meet specific standards to be listed. Free maps plus links to celiac-friendly fast-food chains across North America.

BeFreeForMe.com

Free website for consumers with gluten intolerance or food allergies that offers coupons, savings and samples. Also includes product reviews, articles, extensive database of recipes and the "AskBeFeeForMe" column by Shelley Case.

Pulses and the Gluten-Free Diet

This booklet contains information about the various types of pulses and their nutritional and health benefits. It also features tips on buying and preparing pulses, practical ways to incorporate them into meals and snacks and includes 26 delicious gluten-free recipes.

<http://www.pulsecanada.com/pulses-and-the-gluten-free-diet>

Cookbooks

There are many excellent gluten-free cookbooks available. These are a few examples:

1,000 Gluten-Free Recipes by Carol Fenster

www.savorypalate.com

125 Best Gluten-Free Bread Machine Recipes by Donna Washburn and Heather Butt

www.bestbreadrecipes.com/glutenfree.htm

250 Gluten-Free Favourites by Donna Washburn and Heather Butt

www.bestbreadrecipes.com/glutenfree.htm

Magazines

Here are a few magazines featuring recipes, celiac disease and gluten-free diet information:

Allergic Living www.allergicliving.com

Gluten-Free Living www.glutenfreeliving.com

Living Without www.livingwithout.com

National Celiac Associations

Canadian Celiac Association www.celiac.ca;

- website section for health professionals: www.celiacguide.org

Celiac Sprue Association www.csaceliacs.org

Celiac Disease Foundation www.celiac.org

Gluten Intolerance Group of North America www.gluten.net

National Foundation for Celiac Awareness www.celiaccentral.org

Diabetes and Celiac Disease Resources

Managing Diabetes and Celiac Disease...Together by Canadian Celiac Association and Canadian Diabetes Association

This is 50 page booklet includes an overview of diabetes and celiac disease, meal planning, CHO content of GF flours and recipes with nutritional analysis. Available from www.celiac.ca

Combining Diabetes and Gluten-Free Dietary Management Guidelines by

Cynthia Kupper and Laurie Higgins, available at:

http://www.medicine.virginia.edu/clinical/departments/medicine/divisions/digestive-health/nutrition-support-team/copy_of_nutritionarticles/KupperArticle.pdf

Double Trouble - Counseling Clients with Diabetes and Celiac Disease by

Maggie Moon, MS, RD (*Today's Dietitian*, Vol. 11 No. 8 P. 32). Available at:

<http://www.todaysdietitian.com/newarchives/072709p32.shtml>

Counting Gluten-Free Carbohydrates: a Dietitian Resource for Counseling Individuals with Diabetes and Celiac Disease by dietitians Tricia Thompson and Suzanne Simpson

Includes the American Dietetic Association's evidence-based practice guidelines for celiac disease and Type 1 Diabetes, as well as an extensive alphabetical list of gluten-free manufacturers and products. The grams of CHO, sugar, fiber, protein and fat are provided for each product. Lists GF cookbooks that provide nutrition information for recipes. Download this free resource from:

<http://www.glutenfreedietitian.com/registration.php?id=cgfc>

Gluten-Free Certification Programs

Canadian Celiac Association Gluten-Free Certification Program

<http://www.celiac.ca/index.php/about-the-cca/certification/>

Gluten-Free Certification Organization

www.gfco.org

National Foundation for Celiac Awareness Gluten-Free Product Certification

<http://www.celiaccentral.org/gluten-free-certification/>

Celiac Sprue Association Recognition Seal Program

http://www.csaceliacs.info/csa_recognition_seal.jsp

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