Celiac Disease & the Gluten-Free Diet

Shelley Case, BSc, RD
Consulting Dietitian, Speaker and Author of
Gluten-Free Diet: A Comprehensive Resource Guide
Case Nutrition Consulting Inc.

* Website: www.glutenfreediet.ca * Email: scase@accesscomm.ca * Phone: 306-536-7716

Celiac Disease

Celiac disease (CD) is one of the most common inherited disorders, with an estimated worldwide prevalence rate of 1:100 – 1:200. Originally thought to be a rare disorder, a multi-center study revealed that 1:133 people in the US have CD. This translates into 3 million Americans with the disease, although it is estimated that 97% remain undiagnosed. A high prevalence of CD is also found in people with Type 1 diabetes, thyroid disease, Down syndrome and other disorders.

Celiac disease (CD) or gluten-sensitive enteropathy is an autoimmune disorder in which the villi of the small intestine are damaged by specific peptides from 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 abnormalities and/or anemia. In older children and adults, symptoms vary from mild to severe, with some presenting with only a few symptoms and others with many symptoms such as anemia, nausea, bloating, gas, diarrhea or constipation (or both), lactose intolerance, weight loss (note that CD can also occur in obese individuals), mouth ulcers, extreme fatigue, bone and joint pain, easy bruising of the skin, menstrual irregularities, miscarriage, infertility in both women and men, migraines, depression 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.

If untreated, CD can result in nutritional deficiencies; increased risk of osteoporosis, intestinal cancers, neurological disorders (ataxia, seizures and neuropathy), reproductive complications such as infertility and miscarriage, and development of other autoimmune diseases. 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 revealed that patients suffer from the disease for an average of 10-11 years before being correctly diagnosed.

There are specific serological tests 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. Individuals should also be encouraged to join a local and/or national celiac group for ongoing support.

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 and are listed in Table 1.

Gluten-Containing Foods & Ingredients To Avoid

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

* fine whole-meal flour made from low-gluten, soft-textured wheat used to make Indian flatbread (also known as chapatti flour)
** Types of wheat
*** A dried gluten product derived from wheat that is sold as thin sheets or thick round cakes. Used as a protein supplement in Asian dishes such as soups and vegetables.
**** A meat-like food derived from wheat gluten used in many vegetarian dishes. Sometimes called "wheat meat."

The avenin prolamin in oats was originally thought to trigger the same toxic reaction as wheat and other gluten-containing grains. New research in Europe and the US over the past 12 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 new research, a growing number of 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 was recently published on Health Canada's website. http://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 are now producing 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
FarmPure Foods (Only Oats™)	www.onlyoats.com
Gifts of Nature	www.giftsofnature.net
Gluten-Free Oats	www.glutenfreeoats.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, legumes, nuts, seeds, milk, yogurt, cheese, fruits, vegetables, as well as many gluten-free flours, cereals and starches that can be substituted for wheat, barley and rye (see below). Distilled alcoholic beverages and wine are also allowed, however beer derived from barley must be avoided. All vinegars are gluten-free except for malt vinegar.

Gluten-Free Flours, Cereals and Starches

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

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 has been delayed.

Health Canada proposed a new regulation on July 26, 2008 entitled *Enhanced Labelling of Food Allergen and Gluten Sources and Added Sulphites* which would 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. Until the final mandatory amendments have become law, Health Canada and the Canadian Food Inspection Agency strongly urge manufacturers to declare on their food labels the allergens, gluten sources and sulphites. Canada already has a specific regulation for the term "gluten-free" and monitors the gluten-free label claim by testing for gluten.

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, as well as secondary lactose intolerance. In severe cases of CD, malabsorption of fat, fat-soluble vitamins A, D, E and K, iron, folic acid, B12, calcium and magnesium can occur. In order for the intestinal villi to regenerate and reverse the nutritional deficiencies, it is important to focus on the following 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 patients as villi recovery can take several months to years in adults with CD.

2) **A temporary lactose-free diet may also be necessary.** There is no concrete data on the incidence of lactose intolerance in people with CD; however, gastroenterologists estimate that 30-60% of people may develop secondary lactose intolerance, especially if they present with severe malabsorption. There are several options to manage lactose intolerance and ensure adequate calcium intake:

    - Lactase enzyme drops or tablets can be used when consuming dairy products.
    - Lactose-reduced milk products (milk, yogurt and ice cream) are available.
    - Soy, rice, nut and potato beverages are lactose-free. Check the ingredients since some brands contain barley malt as a flavoring agent, which is a source of 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 with 2.5 to 3.5 mg per 3.5 ounce serving. 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, legume flours, millet, Montina™, quinoa, rice bran and teff), nuts, seeds, legumes, 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, Montina™, nut flours, quinoa, teff and legume flours (e.g., garbanzo/chick pea, Garfava™ and soy) 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, there are several companies that are now enriching 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, legumes and their flours, amaranth, corn bran, flax seed, mesquite flour, Montina™, oats (pure, uncontaminated), quinoa, rice bran, rice (brown and wild) and teff. Gradually increase fiber and increase the consumption of fluids, especially water.

8) **Avoid cross contamination of gluten-free foods** with gluten-containing foods/ingredients. Key points to emphasize to clients:

- Store all gluten-free products in separate, labeled covered containers
- Buy separate containers of items such as peanut butter, jam or mayonnaise for the exclusive use by the person with celiac disease.
- Use squeeze bottles of condiments such as ketchup, mustard and relish
- Have a separate butter dish and cutting board that are used for gluten-free foods only
- Keep a second toaster or use a toaster oven where the rack can be removed and washed
- Avoid buying products from bulk bins

Celiac disease and gluten-free diet resources

Resources are available from a variety of sources such as health professionals, complimentary health practitioners, celiac support groups, the internet, food companies, family and friends. Unfortunately there is a significant amount of outdated, inaccurate and conflicting information from many of these sources. As the knowledge of celiac disease and gluten-free diet is rapidly expanding, it is essential that information being disseminated is evidence-based and current. The following are just a few examples of some recommended resources for health professionals and those with celiac disease.

Gluten-Free Diet: A Comprehensive Resource Guide - Revised and Expanded Edition, 2008
Shelley Case, RD
Case Nutrition Consulting Inc. ISBN 978-1-897010-54-9
www.glutenfreediet.ca

Celiac Disease: A Hidden Epidemic
Dr. Peter Green and Rory Jones
Harper Collins ISBN 0-06-0766693-X
www.harpercollins.com

Celiac Disease: The Road to Diagnosis
Dr. Mohsin Rashid
http://celiacstories.ca/

National Institute of Health Celiac Awareness Campaign
www.celiac.nih.gov

Acceptability of Foods and Food Ingredients for the Gluten-Free Diet Pocket Dictionary
Canadian Celiac Association
www.celiac.ca

Gluten-Free Living Magazine
www.glutenfreeliving.com