

# Celiac Disease & 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 to 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 90-95% 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, autoimmune thyroid disease and Down syndrome.

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, 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 revealed that adults suffer from the disease for an average of 10-12 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, including spelt, kamut, einkorn, emmer, faro, durum, couscous, semolina, bulgur and triticale. Barley malt, barley malt extract, barley malt flavour, 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. New research in Europe and the US over the past 15 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 is published on Health Canada's website:

[http://www.hc-sc.gc.ca/fn-an/secure/allerg/cel-coe/oats\\_cd-avoine\\_e.html](http://www.hc-sc.gc.ca/fn-an/secure/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                    | <a href="http://www.bobsredmill.com">www.bobsredmill.com</a>           |
| Cream Hill Estates (Lara's brand) | <a href="http://www.creamhillestates.com">www.creamhillestates.com</a> |
| Avena Foods (Only Oats™)          | <a href="http://www.onlyoats.com">www.onlyoats.com</a>                 |
| Gifts of Nature                   | <a href="http://www.giftsofnature.net">www.giftsofnature.net</a>       |
| Gluten-Free Oats                  | <a href="http://www.glutenfreeoats.com">www.glutenfreeoats.com</a>     |

## 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, flavoured 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 and food industry, resulting in various interpretations of gluten-free and labelling.

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 until a safety assessment report on gluten exposure in individuals with celiac disease has been published.

Health Canada proposed a new regulation on July 26, 2008 entitled *Enhanced Labelling of Food Allergen and Gluten Sources and Added Sulphites* which 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. Until the final mandatory amendments 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 has a specific regulation for the term "gluten-free" that was established over 25 years ago. On May 13, 2010 Health Canada announced that the gluten-free regulation (B.24.018) is under review, including the labelling of pure, uncontaminated oats.

## 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, B12, 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.** 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: 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 flavouring 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, legume flours, millet, Montana™, 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, Montana™, nut flours, quinoa, legume 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 fibre. 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 fibre.** 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-fibre, gluten containing foods such as wheat bran and whole-wheat breads and cereals. Emphasize fibre-rich gluten-free products such as fruits, vegetables, nuts, seeds, legumes and their flours, amaranth, flax seed, mesquite flour, Montana™, oats (pure, uncontaminated), quinoa, rice bran, rice (brown and wild) and teff. Gradually increase fibre and increase the consumption of fluids, especially water.

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

- Store all gluten-free products in separate covered containers labeled gluten-free. One tip is to buy bright stickers and put them on everything that is and/or should remain gluten-free. In addition, you may want to keep all gluten-free foods in a separate place in the cupboard and refrigerator. Another tip is to store gluten-free products on the upper shelves of the pantry or cupboards ABOVE the gluten-containing products to prevent flour dust and crumbs from falling onto the packages and containers of gluten-free items.
- Buy separate containers of items such as peanut butter, jam or mayonnaise and label them with a sticker saying "gluten-free" to prevent them from being cross-contaminated by other family members preparing gluten-containing products (e.g., toast, sandwiches).
- Use squeeze bottles of condiments such as ketchup, mustard and relish.
- Have a separate butter or margarine 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. Another option is to use special toaster bags for gluten-free bread that can be placed in a regular toaster. The bags can be washed and re-used. Available from [www.celinafoods.com](http://www.celinafoods.com), [www.elpeto.com](http://www.elpeto.com) or [www.glutenfree.com](http://www.glutenfree.com)
- Always make sure the counter space used to prepare gluten-free foods is freshly washed to ensure it is free from crumbs or flour dust.
- Do not boil gluten-free pasta in the same water that previously had gluten-containing pasta. Also use a separate colander to drain gluten-free pasta, as it is difficult to remove traces of pasta from colanders.

## **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 the gluten-free diet is rapidly expanding, it is essential to use evidenced-based and current resources.

### **Books**

**Gluten-Free Diet - A Comprehensive Resource Guide, Revised and Expanded Edition, 2010**

Shelley Case, RD. [www.glutenfreediet.ca](http://www.glutenfreediet.ca)

**Celiac Disease for Dummies:** Dr. Ian Blumer and Dr. Sheila Crowe

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

**Real Life with Celiac Disease -Troubleshooting and Thriving Gluten-Free:** Melinda Dennis, RD and Daniel Leffler, MD [www.reallifewithceliacdisease.com](http://www.reallifewithceliacdisease.com)

**Celiac Disease - The Road to Diagnosis** <http://celiacstories.ca>

**The Gluten-Free Nutrition Guide:** Tricia Thompson, RD

**Gluten-Free Friends - An Activity Book for Kids:** Nancy Falini, RD

## ***Cookbooks***

**1,000 Gluten-Free Recipes:** Carol Fenster <http://1000glutenfreerecipes.com/default.aspx>

**250 Gluten-Free Favourites:** Donna Washburn and Heather Butt [www.bestbreadrecipes.com/glutenfree.htm](http://www.bestbreadrecipes.com/glutenfree.htm)

**The Gluten-Free Gourmet Bakes Bread:** Bette Hagman

**Wheat-Free Gluten-Free Cookbook for Kids and Busy Adults:** Connie Sarros

## ***National Celiac Associations***

**Canadian Celiac Association** [www.celiac.ca](http://www.celiac.ca) and [www.celiacguide.org](http://www.celiacguide.org)

**Celiac Disease Foundation** [www.celiac.org](http://www.celiac.org)

**Gluten Intolerance Group of North America** [www.gluten.net](http://www.gluten.net)

**Celiac Sprue Association** [www.csaceliacs.org](http://www.csaceliacs.org)

**National Foundation for Celiac Awareness** [www.celiaccentral.org](http://www.celiaccentral.org)

**American Celiac Disease Alliance** [www.americaneliac.org](http://www.americaneliac.org)

## ***Other Resources***

**National Institute of Health Celiac Awareness Campaign:** [www.celiac.nih.gov](http://www.celiac.nih.gov)

**Acceptability of Foods and Food Ingredients for the Gluten-Free Diet Pocket Dictionary**  
Canadian Celiac Association [www.celiac.ca](http://www.celiac.ca)

**Gluten-Free Living Magazine** [www.glutenfreeliving.com](http://www.glutenfreeliving.com)

**Allergic Living Magazine** [www.allergicliving.com](http://www.allergicliving.com)

**Living Without Magazine** [www.livingwithout.com](http://www.livingwithout.com)

**Gluten-Free Passport** [www.glutenfreepassport.com](http://www.glutenfreepassport.com)

**Triumph Dining Resources** [www.triumphdining.com](http://www.triumphdining.com)

**Gluten-Free Restaurant Awareness Program** [www.glutenfreerestaurants.org](http://www.glutenfreerestaurants.org)

**Gluten-Free Drugs** [www.glutenfreedrugs.com](http://www.glutenfreedrugs.com)

**Gluten-Free Certification Organization** [www.gfco.org](http://www.gfco.org)