

Celiac Disease and Lactose Intolerance

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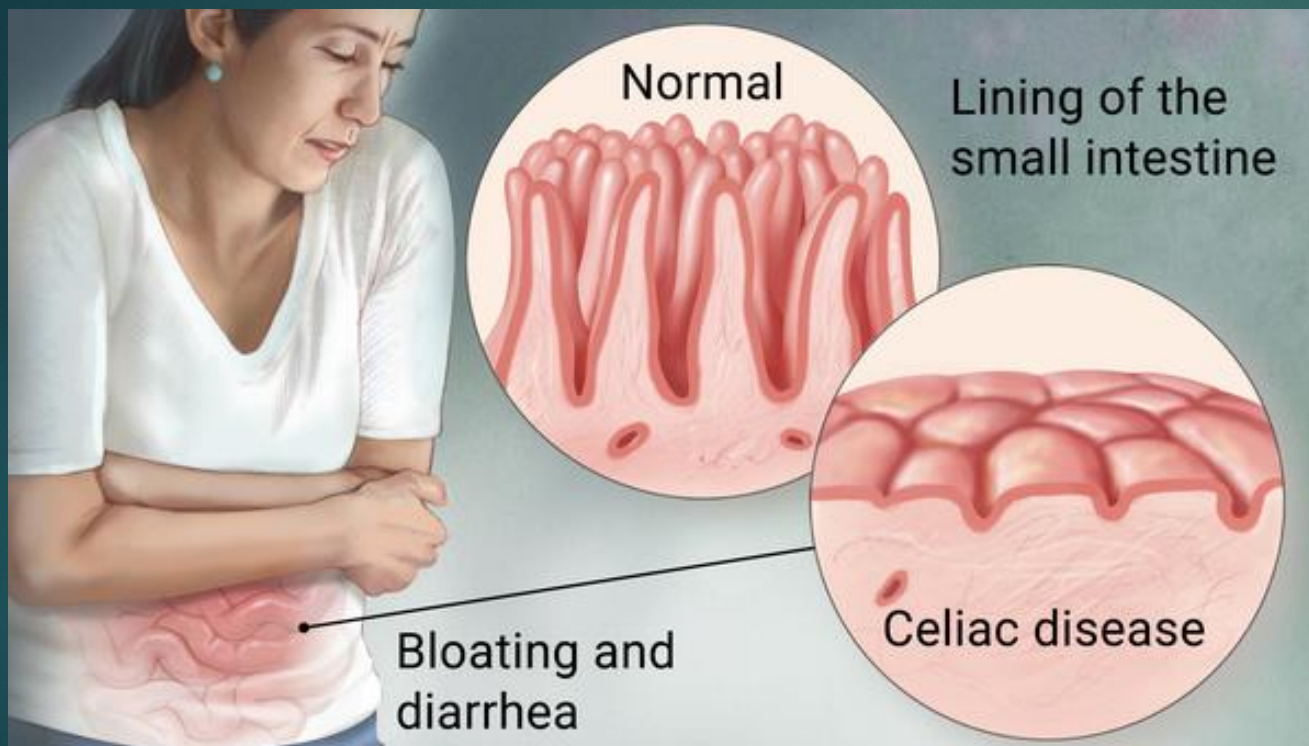
Celiac – Definition

- ▶ Celiac, also known as coeliac disease, celiac sprue, gluten-sensitive enteropathy, and non-tropical sprue is a genetic, hereditary autoimmune disorder.
- ▶ *attributed to the specific genetic markers known as HLA-DQ2 and HLA-DQ8 that are present in affected individuals.*

Characteristics

- ▶ Sensitivity to amino acids found in the prolamin fraction of wheat (gliadin), barley (hordein), and rye (secalin), commonly known as glutens.
- ▶ When these grains are consumed by persons with celiac disease, they trigger an immune response that results in damage to the person's mucosa of the small intestine.
- ▶ This damage causes the malabsorption of macronutrients and micronutrients.

Source: Nutrition Care Manual. Academy of Nutrition and Dietetics. 2019: Gastrointestinal Disease: Celiac. Available from [\[https://www.nutritioncaremanual.org\]](https://www.nutritioncaremanual.org)



Comparison of
lining of the
small intestine in
healthy
individual and
person with
Celiac disease

Prevalence of Celiac in the United States

- ▶ 1% of population ~ 3 million Americans
- ▶ It's about the same number of people living in the state of Nevada.
- ▶ In the general US population: 1 in 133 people
- ▶ In people with first - degree relatives (parent, child, sibling) who has celiac: 1 in 22
- ▶ In people with second degree relatives (aunt, uncle, cousin) who has celiac: 1 in 39

Source: Nutrition Care Manual. Academy of Nutrition and Dietetics. 2019: Gastrointestinal Disease: Celiac. Available from [\[https://www.nutritioncaremanual.org\]](https://www.nutritioncaremanual.org)

Prevalence of Celiac Disease (CD) in Down Syndrome (DS)

- ▶ Ample of studies suggest that CD is higher in individuals with Down Syndrome.
- ▶ The meta-analysis study ¹ (31 studies included 4383 individuals) showed that individuals with DS are at very high risk of CD.
- ▶ More than **one in twenty patients** (children) with DS have CD, at least in Europe and America.
- ▶ Conclusion: the high prevalence of CD in DS patients should motivate screening for CD in patients with DS.

1. Yang Du, Ling-Fei Shan, Zong Ze Cao, Jin-Chao Feng and Yong Cheng. Prevalence of celiac disease in patients with Down syndrome: a meta-analysis. Oncotarget. 2018 Jan 12; 9(4): 5387–5396.

Sign and Symptoms of Celiac

Classic symptoms

- ▶ Diarrhea
- ▶ Weight loss
- ▶ Fatigue

Gastrointestinal symptoms

- ▶ Flatulence
- ▶ Constipation
- ▶ Bloating
- ▶ Indigestion
- ▶ Steatorrhea
- ▶ Abdominal pain
- ▶ Diarrhea

Sign and Symptoms of Celiac (non gastrointestinal)

- ▶ Unexplained, chronically high levels of transaminases
- ▶ Unexplained short stature
- ▶ Unexplained delayed puberty
- ▶ Unexplained iron-deficiency anemia
- ▶ Mineral/vitamins deficiency
- ▶ Repeated fetal loss
- ▶ Infertility
- ▶ Anxiety
- ▶ Depression
- ▶ Bone disease
- ▶ Joint pain
- ▶ Neurological condition

Celiac Disease and Medical Diagnosis

- ▶ Until the recent years Celiac was treated as an uncommon condition.
- ▶ Studies showed that Celiac is often confused/misdiagnosed with different conditions before person is tested for Celiac². Currently, Celiac Disease is considered as an underdiagnosed condition.
- ▶ Individuals with IDD present even more difficult cases because they may not be able to describe their symptoms properly due to impaired verbal communication. Therefore we should pay strong attention for facial expression, body language, behavior and those unexplained sign and symptoms we just discussed.

².Source: Marisa Spencer, Adrienne Lenhart, Jason Baker, Joseph Dickens, Arlene Weissman, Andrew J. Read, Seema Saini, Sameer D. Saini. Primary care physicians are under-testing for celiac disease in patients with iron deficiency anemia: Results of a national survey. PLoS One. 2017; 12(9).



Diet prescription

PERSON WITH CELIAC
DISEASE IS ADVISED TO
ADHERE TO LIFELONG
GLUTEN FREE DIET.

Ingredients to avoid with Celiac disease

- ▶ Wheat (all types, including einkorn, emmer, spelt, and kamut)
- ▶ Barley
- ▶ Rye
- ▶ Malt
- ▶ Oats (unless they are gluten-free)



Gluten can be found in many products

A) The most popular are flours, breads, pasta, breakfast cereals, pizza, cakes, and cookies.

B) Hidden sources of gluten:

- ▶ Alcohols
- ▶ Cosmetics
- ▶ Medication and Supplements
- ▶ Processed meats
- ▶ Seasonings and condiments

The Food Allergen Labeling and Consumer Protection Act (FALCPA)

- ▶ Become law in 2004, went into effect on January 01, 2006.
- ▶ FALCPA updates the labeling requirements for all food products regulated by the FDA. FALCPA requires that foods are labeled to identify the eight major food allergens (milk, egg, fish, crustacean shell fish, tree nuts, wheat, peanuts and soybeans).
- ▶ **Examples:** "lecithin (soy)," "flour (wheat)," and "whey (milk)"
- ▶ **Examples:** "Contains Soy, Wheat and Milk."

Source: <https://www.kidswithfoodallergies.org/page/label-law-food-allergen-labeling-consumer-protection-act>

FDA's Regulation of “Gluten-Free” Claims (2013)

Established Criteria:

- ▶ Any foods that carry the label “gluten-free,” “no gluten,” “free of gluten,” or “without gluten” must contain less than 20 parts per million (ppm) of gluten.
- ▶ This level is the lowest that can be reliably detected in foods using scientifically validated analytical methods.
- ▶ Source: <https://www.fda.gov/food/nutrition-education-resources-materials/gluten-and-food-labeling>

How to make sure that the food is gluten free?

- ▶ - Read the ingredients, in some cases you may need to call the food company.
- ▶ - Look for the gluten free logo on the product.
- ▶ - In a restaurant inform that you require gluten free meal.
- ▶ - At home, watch for cross contamination.



Nutritional Adequacy

- ▶ Many of the gluten free products are made from refined flours. As a result, a gluten-free diet may be lacking in B-vitamins, iron, and fiber.
- ▶ However, the quality of gluten free products has been improving and there are many tasty and high quality nutritious gluten free foods.
- ▶ If properly planned, gluten free diet is safe and doesn't present any adverse nutrition outcomes.

Lactose intolerance

Lactose intolerance description

“Lactose intolerance is an impaired ability to digest lactose, a sugar found in milk and other dairy products. Lactose is normally broken down by an enzyme called lactase, which is produced by cells in the lining of the small intestine.”

► Source: <https://ghr.nlm.nih.gov/>



Primary source material:

NUTRITION CARE MANUAL. ACADEMY OF NUTRITION AND DIETETICS. 2019:
GASTROINTESTINAL DISEASE: LACTOSE INTOLERANCE. AVAILABLE FROM

[[HTTPS://WWW.NUTRITIONCAREMANUAL.ORG](https://www.nutritioncaremanual.org)]

Symptoms

Abdominal pain

Bloating

Flatulence

Nausea

Diarrhea

The symptoms usually occur between 30 minutes to 2 hours after consuming dairy.



Which foods contain lactose?

- ▶ All dairy food products contain lactose unless indicated that is lactose free.
- ▶ It also can be a part of food additives and medications.

Hidden sources of lactose

- ▶ Lunchmeats
- ▶ Hotdogs
- ▶ Baked goods
- ▶ Instant potatoes
- ▶ Instant soups
- ▶ Beverage mixes
- ▶ Margarine
- ▶ Salad dressings
- ▶ Candies
- ▶ Pancake and cake mixes

Nutritional concern of avoiding dairy

- ▶ Nutrients of concern are vitamin D, calcium, and riboflavin—all of which may be low with avoidance of milk and dairy products.

Reasons for nutritional assessment



Successful elimination of lactose-containing foods

Appropriate reduction of lactose

Change in the manner in which lactose is consumed

Adequate intake of nutrients which are regularly provided by dairy products

Nutritional goals when working with lactose intolerance patients

Alleviate	Alleviate symptoms
Restrict	Restrict lactose intake to less than 12 g/day (NIH, 2010).
Instruct	Instruct the patient on appropriate use of lactase enzyme supplements
Assist	Assist the patient with appropriate nutrition education to ensure an adequate intake of all nutrients.

Guidelines to improve tolerance of lactose containing foods:

- ▶ Start with small amounts of lactose-containing foods ($\frac{1}{4}$ cup milk or $\frac{1}{2}$ oz cheese)
- ▶ Start with foods lower in lactose content
- ▶ Only include one dairy food a day and gradually increase the amount as the days go by
- ▶ Only eat one lactose-containing food/meal
- ▶ Drink milk or eat dairy foods with a meal or a snack, but not alone
- ▶ Consume lactose-containing foods several hours apart

Guidelines to improve tolerance of lactose containing foods:

- ▶ If drinking milk, heat the milk as it may improve tolerance
- ▶ Try lactose-free milk
- ▶ Take lactase enzymes when eating dairy foods
- ▶ Consume aged cheeses that are naturally lower in lactose than processed cheeses
- ▶ Consume yogurt, which contains bacteria that break down the lactose, as it may be easier to digest
- ▶ Consider buttermilk; it may also be easier to tolerate as it is a fermented dairy food

"THERE IS NO REASON FOR PEOPLE
WITH LACTOSE INTOLERANCE
TO PUSH THEMSELVES TO DRINK MILK."

-PHYSICIANS COMMITTEE FOR RESPONSIBLE MEDICINE



Challenges to adhere to the specific diet among individuals with IDD

A. Majority of them can't read food labels

B. Family or staff (caregivers) may not be properly trained on reading food labels and planning gluten free meals or lactose free meals.

C. Peer pressure:

- Sharing food with other individuals may cause cross contamination

- Buying the same meals or snacks as other individuals (snack is usually a processed one) presents the risk of consuming food which is not allowed in the diet.

- Belief that having just “a little” of forbidden food doesn't hurt.

- Belief that it's OK to eat if someone else offers the food which otherwise is not allowed.

- Lack of awareness of hidden ingredients and their adverse health effects.

Success story - Case # 1 Celiac Disease

Michael, 18 y/o, male with intellectual and developmental disabilities was referred for nutrition services with Dx of morbid obesity and Celiac Disease. Michael was coming with his mother for nutrition sessions. His vocabulary was limited and most of the information was provided by his mother. She was highly concerned that regardless of her effort to keep Michael on a gluten free diet he was constantly having episodes of diarrhea and she was called at work to pick him up from the program which he was attending.

At one point she realized that his condition was getting worse when they were waiting for the bus next to a bakery. Even though he was not eating any products from this bakery his condition was getting worse just being there. As a further precaution they kept a distance from the bakery.

The mother claimed reading carefully all ingredients to avoid any gluten in Michael's meals. However, diarrhea persisted.

Since the family claimed that all foods he has been eating are gluten free, the dietitian suggested that he may have some other undiagnosed food sensitivities and advised to start FODMAP. During the FODMAP diet the diarrhea decreased, but was not resolved. About the same time his father noticed that Michael's favorite hot dogs may have ingredients which may have contributed to his condition. The parents stopped giving him hot dogs; however diarrhea didn't improve much.

At one of the sessions, the dietitian pointed out that gluten can be a part of seasoning and cosmetics. The mother called all cosmetics companies to check if Michael's cosmetics are gluten free. On the next sessions she informed the dietitian that Michael's body lotion contains gluten. After discontinued using the lotion his

Success Story - Case # 2 Lactose intolerance

Erick, 44 y/o, male with intellectual and developmental disabilities was referred for nutrition services with Dx of obesity and lactose intolerance. Erick denies having typical dairy products such as milk, cheese, butter, yogurt, ice cream or sour cream. However, he struggles with abstaining from food containing dairy.

Erick attends a day program when he participates in community activities. He loves to volunteer at senior citizen day program where he helps to serve food. After food is served the facility provides lunch to all volunteers.

When I met Erick, he was an independent traveler. Unfortunately, after leaving the day program, instead of going home, he was going to McDonald begging for money. Eventually he was getting enough money to buy whatever meal he wanted. At the same time his wt was going up as well all the issues associated with lactose intolerance. When his family learned about his activities, they assigned him to take a bus which was bringing him to the day program and then back home.

When Erick's "source of income" disappeared, he figured out another profitable revenue. He realized that when he volunteers at the places when food is served he is not only getting extra meal, but the workers can give him extra food to take home. He took full advantage of the situation. He started bringing food to the day program. Some of the food he was able to sell to other individuals or exchange for the processed snacks. Meanwhile he experienced significant increase of bloating and diarrhea. Many times, the bus had to wait for him, and his nutrition services was cancelled because Erick was spending long time in the bathroom.

Currently, the program staff is closely watching his activities and Erick was asked to discontinue his business. The senior citizen facility was informed about his medical condition and asked to be mindful about giving him extra food. Erick denies having diarrhea, for the last few months.