



Diagnosis Crisis of Celiac Disease

Celiac Disease

Celiac disease (CeD) is a serious autoimmune disorders **affecting 1:100** Canadian children and adults. It is recognized as one of the most common inherited disorders especially in those from North American and European decent, but also individuals from India, Pakistan, North Africa, the Middle East and Latin America.

When an individual with CeD consumes gluten (a protein found in wheat, barley, rye and related hybrid grains) it triggers an immune reaction damaging the small intestinal tract. As a result, the body's ability to absorb nutrients, especially iron, vitamin D, calcium, folate and other B vitamins is impaired causing nutritional deficiencies.

In addition to gastrointestinal issues, many other organ systems in the body are affected leading to **over 200 symptoms and complications**. These can include anemia, chronic fatigue, weight loss, bone and joint pain; easy bruising of the skin, an itchy blistering skin rash, muscle cramps, osteoporosis, infertility, neuropathy, ataxia (balance issues), migraine headaches, seizures, depression, development of other autoimmune disorders and even some cancers. Additional symptoms in children are often failure to thrive, delayed puberty, irritability and behavioural changes; concentration and learning difficulties; and dental enamel defects.

Currently the only known treatment for CeD is a **Medical Nutrition Therapy (MNT)** of a strict gluten-free diet for life – **food is our medicine**. This can be very challenging as gluten is found in many different items such as breads and other baked goods; cereals, crackers, pasta, soups, sauces, salad dressings, processed meat products, plant-based meat substitutes, snack foods, chocolates and other candies, some alcoholic beverages and nutrition supplements.

Underdiagnosed and Delayed Diagnosis

Although there has been increased awareness regarding celiac disease, it is estimated that **70-80%** of individuals remain undiagnosed - approximately **300,000 Canadians**.

A 2022 research study, *State of Celiac Disease in Canada* has revealed continued significant delays in individuals who eventually received a correct diagnosis of CeD. The mean duration of symptoms before diagnosis is still approximately **10 years**, only a slight improvement from 2002 and 2008 of **11.7 and 12 years respectively in adults**.

Individuals with longer delays to diagnosis had more symptoms and complications of which some were irreversible despite following a strict MNT. Of note, **neurological complications dominate** the list of complications. Regardless of the symptoms and complications, additional ongoing medical visits, medications and other treatments not only greatly reduces the quality of life and can result in loss of work or increased sick time but results in further costs to the healthcare system.

It is interesting to note that individuals **consulted multiple physicians** and other health care professionals in the quest for confirmation of their health issues. In the CCA pediatric survey almost one third consulted two or more pediatricians and 6% consulted two or more gastroenterologists before confirmation of diagnosis.

There are a variety of reasons for the underdiagnosed and delayed diagnosis rates. Some of these include:

- Presentations and symptoms of CeD vary greatly among individuals
- Some individuals have asymptomatic CeD
- Symptoms overlap with many other conditions and disorders
- Lack of knowledge of CeD by physicians and other health care professionals
- Inappropriate diagnostic testing
- Misdiagnosis with other disorders
- Long wait times for a gastroenterologist appointment and small intestinal biopsy procedure
- Lack of CeD specialists (gastroenterologists, dietitians, nurse practitioners and others)

Benefits to Earlier Diagnosis

- Prevention of complications and associated conditions.
- Reduce the burden of disease and improved quality of life.
- Reduced health care visits and associated costs.
- Reduced costs of unnecessary diagnostic testing.

Celiac Canada Recommendations

1. Develop a national celiac disease strategy to reduce diagnosis wait times and improve health outcomes. Greater investment in celiac disease research and support by federal agencies to advance treatments, and potential cure for celiac disease.
 - a. Improve the health data strategy in Canada to better link personal health data and disease tracking to improve health outcomes.
 - b. Recommend the development of Canadian-based clinical practice guidelines by the Canadian Association of Gastroenterology to improve diagnosis rates and standards of care.
 - c. Add celiac disease to all provincial medical laboratory requisition forms to promote more serological screening of the disease where appropriate.
 - d. Increase medical education for primary care physicians and other healthcare professionals to understand the current clinical presentations of the disease, including but not limited to, neurological and mental health presentations to reduce wait times, complications and unnecessary hospitalizations, doctor visits and testing.
 - e. Improve funding availability for more endoscopy procedures to reduce wait times.
 - f. Support a national public awareness campaign.