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**Subject: Safe Long Term Care Act**

On behalf of Celiac Canada, we are pleased to make a written submission in response to your public consultation into the development of a **Safe Long Term Care Act**. We represent over 400,000 Canadians with, or at risk of, celiac disease.

For 50 years, Celiac Canada (formerly Canadian Celiac Association) – a federal registered charity - has been the only national voice for people with celiac disease, a common lifelong autoimmune condition that impacts one percent of the population.

### **About Celiac Disease**

For a person living with celiac disease, gluten ingestion damages the wall of the small intestine. This damage can lead to a variety of symptoms and results in the inability of the body to absorb nutrients.

**Following a strict gluten-free diet is the only medical treatment option available for individuals living with celiac disease.** There are no pharmacological drugs or medications.

Gluten is a protein found in wheat, barley, regular oats, and rye. Individuals diagnosed with celiac disease may experience immediate symptoms upon consuming a food item containing gluten or one that has been cross-contaminated. These symptoms can vary from mild to severe gastrointestinal discomfort (diarrhea, vomiting, constipation, severe bloating), skin rashes, joint pain to neurological complications (headaches, migraines, anxiety, tingling, unsteady gait, or depression). Symptoms vary greatly among individuals, but all affect quality of life.

Gluten cross-contamination is a very real concern for people living with celiac disease. Over time, even very small amounts of gluten will cause damage to the small intestine, affecting an individual's short and long-term health outcomes. Complications from repetitive gluten exposure can include longer term damage such as anemia, non-fatty liver disease, osteoporosis, ataxia and other neurological conditions and even cancer. On a stable, safe gluten-free diet, people with celiac disease can live long healthy lives with similar lifespans of other individuals and avoid the painful conditions and side effects.

Gluten is found in a wide array of foods from sauces, spices, dressings, condiments and more. Fortunately, Canada has robust, internationally recognized standards for food, and now natural health products for labelling to help identify gluten.

## Impacts on Long Term Care

As described above, individuals with celiac disease often experience a range of symptoms due to gluten cross-contamination, and these symptoms can be difficult to control, leading to significant distress. For those individuals living in long-term care, cross-contamination may result in increased needs to use the bathroom and/or increased diaper and linen changes, which increases the workload for nursing and care staff. Symptoms could also result in an increased need for urgent toileting, thereby increasing fall risk. Additionally, if gluten cross-contamination occurs, it can manifest as gastrointestinal symptoms, potentially necessitating isolation while diagnostic tests are conducted. Isolation can contribute to feelings of depression or anxiety for the resident, further decreasing quality of life measures.

The right to safe food is a foundational element of human rights, crucial for the overall well-being of all individuals living in Canada. Safe food not only supports physical health but upholds the principles of human dignity and equality. Those living in long-term care should not live in fear that the food they are provided with may cause harm or illness. And of equal importance, they should not be denied access to care because the long-term care home feels they cannot accommodate a gluten-free diet, which has happened to many in our community.

There needs to be equal access to specialized therapeutic diets for all disease states and religious requests in Canada. Just as individuals with diabetes and heart disease have access to safe, therapeutic diets, or individuals with religious beliefs granted their specific food preparations, people living with celiac disease should be granted the same opportunity. Gluten free is not a choice.

Accessing facilities has also been a concern for our community. We have individual stories of families being turned down or refused care because of the facilities' simple lack of knowledge of celiac disease.

## How Can the Federal Government Help?

**Funding is a big concern.** In British Columbia, food budgets include an allowance of \$7.78 per resident. This is very low and often this funding is not increased commensurate with inflation. Despite the higher cost of gluten-free products, no extra funding is allocated. Based on recent research conducted by Celiac Canada, it was found that following a gluten-free diet can cost over 200% more than a regular diet. Low funding levels impact the safety, quality and potentially the nutritional adequacy of food service for those with celiac disease in long-term care.

When living in a facility where meals are prepared by others, it is **imperative that the staff providing meal service have education to ensure meal service is gluten-free as well as education regarding how they can make meal service palatable and enjoyable for residents with celiac disease.**

Our objectives to improve the quality of life for celiacs in long-term care align with the patient-centered approach advocated for by the proposed Safe Long-Term Care Act. This includes the need for a high-

quality standard of care, ensuring the safety of all clients, and promoting equity and accessibility to healthcare services.

To realize these objectives, we ask that you achieve results for Canadians by supporting the following commitments:

- **Ensure Adequate Funding for Food Service Staffing and Food Budgets:** On average, the gluten-free diet is 200% more expensive than a general diet and takes more care and time to prepare. To ensure safe and palatable food, and nutritional adequacy, additional funding needs to be allocated for both food supplies and staffing. Food budgets need to rise annually with the Consumer Price Index. Companies that supply food to long-term care facilities can accommodate pre-packaged gluten-free food that is even certified gluten free for facilities with appropriate funding.
- **Make Education Regarding Gluten-Free Meal Service Mandatory for Food Service and Other Staff in Long-Term Care:** Working with Celiac Canada, launch an education program for all long-term care food service and clinical staff who have role in providing food service to residents with celiac disease. This includes education on gluten sources, how to prevent cross-contamination and how to make food service palatable and enjoyable for these residents. Celiac Canada has recently developed education resources for the healthcare sector. Make this, or similar education, a mandatory part of training.
- **Enforce Mandatory Accreditation for all Provinces and Territories:** Hold facilities accountable for patient safety, quality, equity and accessibility. As part of accreditation, ensure that the requirement to provide all medically required diets are met. Suggestions include, but are not limited to, checking menus for dietary compliance, ensuring preparation and cooking areas minimize gluten contamination, and ensuring that all staff members have completed all necessary dietary education modules.
- **Implement Indicators of Long-term Dietary Compliance:** Not every patient with celiac disease is symptomatic when exposed to gluten. Therefore, another marker to ensure facility compliance and patient safety is required. One of our current monitoring tools is an annual TTG-IGA level. For clients with celiac disease, it is our recommendation that this blood work become part of their annual medical review to ensure safe foods are being provided.
- **Ensure Inclusivity in Gatherings:** Ensure gluten-free offerings at all facility events that have food offerings, including, but not limited to tuck shops, snack wagons, parties or other celebrations.

- **Ensure Variety:** Ensure that those requiring a gluten-free diet meet the same rotational meal standards of other residents. By doing so, this will also ensure that a variety of nutrients are being offered and residents do not develop ‘menu fatigue’, a contributing factor to weight loss.
- **Ensure that the Gluten-free Diet has Texture Modified Options:** These modified options need to provide choice, variety, and palatability to optimize intake and quality of life.
- **Ensure that Menus are Planned by a Professional:** Professionals include Registered Dietitians or members of the Canadian Society of Nutrition Management, with the education, knowledge, and skills to plan a safe, nutritious, and varied menu that meets the needs of residents.

By addressing the above issues and working together with Celiac Canada, we can significantly enhance patient-centered care and the quality of life for individuals with celiac disease living in long-term care. We will also promote inclusivity and optimize health status.

Thank you for your attention to this very important within our community.

Sincerely,

*Melissa Secord*

Melissa Secord, CAE  
Executive Director  
Celiac Canada