

CELIAC DISEASE:

Combatting gluten-free food insecurity

BY JENNIFER BLYTH

For Islanders living with celiac disease, having access to a gluten-free diet isn't a fad – it's essential to effectively treating a genetic autoimmune condition.

Affecting 1 in 100 Canadians, celiac disease causes numerous debilitating health issues for individuals who consume any foods containing gluten, such as wheat, rye, barley or regular oats.

Ingesting gluten causes the body to attack itself, damaging the small intestine and resulting in malabsorption of vital nutrients. Damage can lead to a variety of more than 260 possible gastrointestinal and extraintestinal symptoms, with the most common 'non-gut' symptoms including anxiety, brain fog, and headaches and migraines.

Celiac disease also commonly occurs in patients with other autoimmune disorders such as thyroid disease and Type 1 diabetes and can run in families, both in first- and second-degree relatives, notes Celiac Canada.

Beyond potentially life-altering effects of CD, long delays in diagnosis can also cause co-morbidities and early death from complications.

However, the physical symptoms are not the only challenges for those living with celiac disease.

The food costs associated with a gluten-free diet can be significant. Gluten-free products can be difficult to find, and those that are available are often significantly more expensive, notes Ellen Bayens, from The Celiac Scene in Victoria.

In addition, "our community is more vulnerable to food supply chain shortages due to their highly specific and required gluten-free diet."

Those challenges are in the spotlight this spring as May marks

Celiac Awareness Month. Amid rising prices and ongoing financial challenges for many families, the demand on food banks remains significant and, unfortunately, the dietary needs of people with celiac disease can be overlooked, Ellen says.

That's why this May, Country Grocer will donate partial proceeds from the purchase of a variety of gluten-free products to the Mustard Seed Food Bank in Victoria, Loaves & Fishes in Nanaimo and the CMS Food Bank in Mill Bay, serving Cobble Hill, Mill Bay and Shawnigan, so they can better support their gluten-free families.

The local reality of the challenges for families is borne out in the recent release of the survey, *State of Celiac Disease in Canada: 20 Years Later*.

Two decades after the first effort to explore the experiences of those with celiac disease, the survey of 7,500 Canadians with CD indicates little has changed for hundreds of thousands living with the condition.

The new results show the condition remains largely underdiagnosed, that the gluten-free diet is often not affordable, and many risk being exposed to unsafe food.

"Sadly, the biggest challenges haven't improved in 20 years – like getting people with celiac disease properly diagnosed early, and en-

suring they're able to afford gluten-free foods that won't do them harm," explains Melissa Secord, National Executive Director of Celiac Canada, which funded the survey.

"Celiac disease is a common genetic disorder that affects about one per cent of the world's population, but up to 80 per cent still don't even know they have it. So, they're living with painful, life-disrupting symptoms and unwittingly causing themselves harm. For those who have been diagnosed, the unaffordable cost of gluten-free foods often means having to skip meals, change the food they purchase or make sacrifices in other areas of their spending."

Among the key findings of the Celiac Canada survey:

Delays in diagnosis: In the last 20 years, there's been no significant reduction in the amount of time it can take for people with symptoms to be properly diagnosed – as long as 10 years.

Changing symptoms: 4 out of the 10 top symptoms in more recent years are neurological, such as anxiety, brain fog, mood swings/irritability, headaches and migraines, versus more traditional celiac disease symptoms like bloating, gas and diarrhea.

Affordability: Most respondents (75 per

cent) say the cost of gluten-free food is their top concern, and impacts the dietary choices they make. Gluten-free foods can cost from 150 to 500 per cent more than their conventional counterparts, representing an average additional cost of \$1,000 per year per adult. Only 20 per cent of respondents have taken advantage of tax relief offered by the federal government; and those in the lowest income categories – and who need help the most, the association notes – don't even qualify.

Risk of unsafe foods: Three-quarters of respondents who have been in hospitals or care homes say it's difficult getting gluten-free food in those settings.

Mental health: More than half reported feelings of frustration and isolation from having to follow a gluten-free diet. They also say it affects their participation in social events and causes stress in food preparation and interactions with friends, family and work colleagues. Respondents continue to be wary of or fear options in restaurants using confusing and unregulated language such as "gluten-friendly" or "gluten aware" menu items.

To learn more, visit celiac.ca or theceliacscene.com and to help local families, watch for specially marked products in your Country Grocer this May 🌾



Ellen Bayens, The Celiac Scene, Victoria

Looking for Gluten-Free products at your Country Grocer? Watch for this tag:



Symptoms of celiac disease

Celiac Canada notes that patients with CD can present with a variety of symptoms, including "classic" CD symptoms like: chronic diarrhea; abdominal pain; malabsorption; and weight loss.

However, many patients now also present with atypical symptoms including:

- anemia
- osteoporosis
- extreme fatigue
- oral ulcers
- liver enzyme abnormalities
- constipation
- infertility
- dental enamel defects
- neurological problems, etc.

And in children, CD can present with:

- constipation
- chronic diarrhea
- swollen belly
- gas
- pale, foul smelling stools

- nausea and vomiting
- The inability to absorb nutrients can result in: short stature; irritability; failure to thrive in infants; anemia; delayed puberty; damage to tooth enamel; neurological symptoms such as headaches, learning disabilities, lack of muscle coordination; seizures, etc.

Since many patients with CD do not present with classical symptoms, delays in diagnosis can occur.

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DID YOU KNOW?

- Celiac disease is an autoimmune disease that affects 1 in 100 Canadians.
- CD prevents individuals from consuming any foods that contain gluten, such as wheat, rye, barley or regular oats. Doing so, even inadvertently, can bring numerous debilitating health issues, both physical and neurological.
- Gluten-free foods can cost from 150 to 500 per cent more than their conventional counterparts, notes Celiac Canada. This represents an average additional cost of \$1,000 per year per adult.

RESOURCES:

- On Vancouver Island, The Celiac Scene: theceliacscene.com
- Celiac Canada: celiac.ca