

Older Adults Living with Celiac Disease in Canada

Purpose

To seek support for three federal actions to improve the health and longevity of seniors living with celiac disease (CeD).

Overview

- Seniors with CeD face **major health and affordability pressures**: diagnostic delays, ongoing symptoms, and the high cost of medically required gluten-free food.
- Existing tax relief is not working for most: **74%** of older adults in Celiac Canada’s national survey report not claiming gluten-free food expenses on income tax.
- Federal leadership can quickly improve outcomes through a **flat-rate refundable** medical expense tax credit, advancing the **Safe Long-Term Care Act** with funded provincial implementation/training for medically required diets, and targeted **Ageing Well with Celiac home** supports to keep seniors safely at home longer.

The Issues

Celiac disease is an autoimmune condition that can strike at any time of life and requires lifelong Medical Nutrition Therapy consisting of a strict gluten-free (GF) diet. Without standardized education, training, and safe food service processes in hospitals and long-term care, residents are at high risk of gluten exposure that can lead to illness, faster decline, and higher care needs. At the same time, GF food remains significantly more expensive, and the current medical expense tax process is administratively burdensome and excludes many vulnerable seniors.

- **Diagnosis delays impact long term health and recovery**: Among older adults in Celiac Canada’s national survey, 27% reported waiting more than 20 years for diagnosis; quality of life improves after diagnosis, but ongoing symptoms persist for many if diagnosis delayed.
- **Affordability impacts are widespread**: 90% of older adults report GF food costs increased vs. pre-pandemic, with greater impact on lower-income households.
- **Low uptake of current tax relief**: Only 26% of older adults reported claiming the incremental difference of gluten-free food as a medical expense on their income tax due to complexity and high burden.
- **Institutional food safety gap**: There are currently no enforceable standards governing GF food service in hospitals and long-term care facilities; recurring cross-contamination can worsen health and increase care burdens, and some facilities have declined admission due to dietary requirements.
- **Educational support needed**: Celiac Canada was supported for a New Horizons grant in 2025 to create a “Ageing Well with Celiac” pilot program to fund a seniors-led program to help keep our seniors safely at home as long as possible.

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Recommendations

1) Tax Fairness & Affordability: Implement a flat-rate, refundable tax credit for CeD

Recommendation: Support amending the Income Tax Act to provide a flat-rate, fully refundable tax credit to offset the medically required GF diet: \$1,000 per adult with CeD (\$600 per child)

Rationale:

- Current framework (s.118.2(2)(r)) requires extensive receipt tracking, price comparisons, and proration, and is non-refundable, limiting benefit for many low-income seniors.
- Uptake is low: older-adult survey data show 74% do not claim GF costs
- Optional interim action (administrative): Direct CRA to implement short-term administrative relief (e.g., a “deeming provision” concept raised by Celiac Canada) while legislative changes are pursued.

2) Safe & Inclusive Congregate Care: Table the Safe Long-Term Care Act and fund provincial standards + education tools for gluten-free food service

Recommendation: Support federal tabling of the Safe Long-Term Care Act and provide targeted funding to provinces/territories to implement standards and training/tools that ensure inclusive, equitable access to medically required diets, starting with GF food service in assisted living, long-term hospital settings and LTC.

Rationale:

- Health Canada engagement emphasizes equity/inclusivity, transparency, accountability, and LTC as part of a supportive care continuum that includes home care.
- Celiac Canada evidence indicates recurring cross-contamination in care settings can accelerate decline; lack of standardized practice, especially with food handling, creates avoidable harms.

3) Aging Well with Celiac: Fund targeted at-home supports for seniors with celiac disease

Recommendation: Expand/extend *Aging Well with Celiac* pilot to keep seniors with CeD at home as long and as safely as possible—prioritizing safe meal supports, navigation, and practical services.

Rationale:

- Offers peer supports, dietitian-led and developed education, caregiver/family resources are essential to seniors who need a medically safe diet.
- Navigation assistance - connecting seniors to reliable GF food resources, menus, meal plans, nutrition and medical management advice.

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State of Celiac Disease in Canada – Seniors Edition

Demographics of Older Adults in State of Celiac Disease Survey (n=1396)

	N (%)
Gender	
Female	1069 (76.6%)
Male	298 (21.3%)
Prefer not to disclose	2 (0.2%)
Household Income Before Taxes (1363)	
Under \$49,999	266 (19.5%)
\$50,000 - \$99,999	442 (32.4%)
\$100,000 - \$150,000	154 (11.3%)
Over \$150,000	62 (4.5%)
Prefer not to disclose	439 (32.2%)

Reported Time to Diagnosis (n=1357)

	N (%)
Less than 6 months	90 (6.6%)
6 months to less than 2 years	198 (14.6%)
2 years to less than 5 years	206 (14.9%)
5 years to less than 10 years	199 (14.7%)
10 years to less than 20 years	202 (14.9%)
More than 20 years	366 (27.0%)
I did not have any symptoms (asymptomatic)	96 (7.1%)

Among older adults with celiac disease (n=1357), time to diagnosis is often prolonged. The largest group (27%) reported waiting more than 20 years before receiving a diagnosis. Only 6.6% were diagnosed within 6 months of symptom onset. Roughly 60% experienced delays of 2 years or longer.

	Older Adults	Younger Adults
Less than 6 months	90 (6.6%)	183 (5.0%)
6 months to less than 2 years	198 (14.6%)	682 (18.7%)
2 years to less than 5 years	206 (14.9%)	644 (17.7%)
5 years to less than 10 years	199 (14.7%)	627 (17.2%)
10 years to less than 20 years	202 (14.9%)	568 (15.6%)
More than 20 years	366 (27.0%)	739 (20.3%)
I did not have any symptoms (asymptomatic)	96 (7.1%)	197 (5.4%)

Time to diagnosis differed significantly between older adults and younger adults ($p < 0.001$). Older adults were more likely to report prolonged diagnostic delays, with 27% experiencing symptoms for more than 20 years prior to diagnosis, compared to 20% of younger adults.

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Ongoing symptoms despite gluten-free diet (GFD)

Symptom	Recovered After Starting GFD	
	Yes	No
Diarrhea	506 (69.4%)	223 (30.6%)
Constipation	235 (46.6%)	269 (53.4%)
Bloating	438 (54.0%)	373 (46.0%)
Gas/Flatulence	362 (43.8%)	465 (56.2%)
Abdominal Pain/Discomfort	484 (60.6%)	315 (39.4%)
Nausea	230 (70.1%)	98 (29.9%)
Vomit	181 (83.8%)	35 (16.2%)
Large, Pale Foul Stools	346 (76.2%)	108 (23.8%)
Lactose Intolerance	126 (31.6%)	273 (68.4%)
Iron Deficiency Anemia	434 (78.3%)	120 (21.7%)
Iron Deficiency	432 (76.7%)	131 (23.3%)
Vitamin B12 Deficiency	290 (70.4%)	122 (29.6%)
Extremely weak and tired	366 (56.9%)	277 (43.1%)
Dizziness	128 (44.8%)	158 (55.2%)
Ataxia	80 (29.0%)	196 (71.0%)
Bone Joint Pain	122 (23.9%)	388 (76.1%)
Muscle Cramps	150 (31.7%)	323 (68.3%)
Swollen Extremities	84 (33.1%)	170 (66.9%)
Bruising	117 (29.8%)	276 (70.2%)
Itchy Skin	166 (32.9%)	339 (67.1%)
Skin Rash	156 (42.5%)	211 (57.5%)
Numbness and Tingling	87 (27.5%)	229 (72.5%)
Mouth Ulcers	253 (58.3%)	181 (41.7%)
Headaches and Migraines	203 (46.2%)	236 (53.8%)
Brain Fog	188 (40.9%)	272 (59.1%)
Mood Swings/Irritability	218 (45.5%)	261 (54.5%)
Anxiety	125 (26.9%)	340 (73.1%)
Depression	147 (37.5%)	245 (62.5%)
Insomnia	92 (21.3%)	339 (78.7%)

While many gastrointestinal and nutrient deficiency symptoms improve following a GF diet, a substantial proportion of older adults continue to experience persistent neurological and systemic symptoms, including insomnia (79%), anxiety (73%), and bone/joint pain (76%).

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Quality of life (Before vs After)

	Quality of Life Before Diagnosis	Quality of Life After Diagnosis
Poor	356 (26.3%)	16 (1.2%)
Fair	388 (28.4%)	128 (9.4%)
Good	347 (25.4%)	431 (31.6%)
Very Good	216 (15.9%)	583 (43.0%)
Excellent	56 (4.1%)	202 (14.8%)

Self-reported quality of life improved significantly after diagnosis ($p < 0.001$). Prior to diagnosis, over half of older adults (55%) rated their quality of life as poor or fair. Following diagnosis and adoption of a strict GF diet, this dropped to just 11%, with the majority reporting good to excellent health (89%). Despite these improvements, a small proportion of older adults continue to report fair or poor quality of life (11%), indicating ongoing challenges even after diagnosis.

Medical Expense Tax Credit

Do older adults claim the incremental cost of GF food expenses on their income tax?

- Yes: 354 (26.0%)
- No: 1007 (74.0%)

Household Income Before Tax	Yes – Claims GF Food Expenses on Income Tax	No – Does not Claim GF Food Expense on Income Tax
Under \$50,000	74	190
\$50,000 - \$99,999	125	313
\$100,000 - \$149,999	34	119
Over \$150,000	5	57

Only about one in four older adults (26%) reported claiming GF food expenses on their income tax. Uptake varied significantly by income level ($p = 0.004$), with similar rates among those earning below \$100,000 (~28% use claim) but lower uptake among high-income groups, particularly those earning over \$150,000 (~8%).

Major take-away:

Three quarter of older adults are not claiming a tax credit designed to offset medically necessary dietary costs of the GF diet.

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Affordability - Costs of Gluten-Free Foods

*Older adults' opinions on the cost of GF foods now compared to the pre-pandemic cost.
(Do you feel the cost of GF food is now more expensive compared to the pre-pandemic cost?)*

	N(%)
No, I don't think there has been a significant change.	134 (9.9%)
Yes, and this has affected the type of gluten-free food we buy.	197 (14.5%)
Yes, and we have had to access a food bank	3 (0.02%)
Yes, but this has not been a problem for me personally.	574 (42.3%)
Yes, but we have continued to purchase similar gluten-free food as in the pre-pandemic era and adjusted our finances in other ways.	449 (33.1%)

Ninety percent of older adults agree that the cost of GF food now is more expensive than before the pandemic. 197/1357 (14.5%) of older adults' report that rising gluten-free food costs changed the type of gluten-free foods they buy.

Income Before Tax	N (%)
<\$50,000	79 (29.8%)
\$50,000 - \$99,999	50 (11.4%)
\$100,000 - \$150,000	11 (7.2%)
>\$150,000	1 (1.6%)

The impact varies significantly by income ($p < 0.001$), with nearly one third of older adults earning less than \$50,000 reporting changes, compared to just 1.6% of those earning over \$150,000. These findings suggest that lower income older adults are disproportionately affected by rising GF food costs.

Despite significant differences in how rising food costs impact purchasing behaviours, adherence to a GF diet remains high across all income groups. This suggests that while lower-income older adults may modify the types of foods they purchase, they continue to prioritize maintaining a gluten-free diet (See findings below on "Adherence to the GF Diet").

Adherence to the Gluten-Free Diet

Self-reported GF diet adherence	N (%)
No gluten	666 (48.7%)
Usually GF/rare accidental gluten (<1 month)	620 (45.3%)
Usually GF/rare intentional gluten (<1 month)	59 (4.3%)
Occasional gluten (1-3 times/month)	17 (1.2%)
Frequent gluten (>1/week)	5 (0.04%)