Living with Celiac: Why Teens Struggle to Stay Gluten-Free

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Abstract

This study explores the struggles that teenagers with celiac disease (CD) experience as a result of their condition. Currently, there is limited research on why teenagers struggle with CD, which may contribute to unnecessary challenges for affected individuals. This study reports on the results of a 34-question survey distributed to adolescents via Celiac Canada's nationwide mailing list. Survey respondents identified three primary challenges: limited access to gluten-free options in social settings, heightened anxiety over cross-contamination, and difficulty maintaining dietary adherence. The findings also highlight the prevalence of extraintestinal symptoms in teenagers with CD and the improvement in their quality of life (QoL) following diagnosis. These results emphasize the urgent need for improved gluten-free accessibility, increased awareness of atypical symptoms amongst primary care providers, and stronger support systems to enhance the well-being of teenagers managing celiac disease.

Keywords: Celiac Disease, Autoimmune, Diet, Teenagers, Condition

Problem

As celiac disease (CD) is a chronic, life-long condition, teenagers often struggle to adhere to the strict gluten-free diet (GF), which is currently the only treatment. These challenges are likely multifactorial, such as their desire to fit in, inadequate education/support around the GF diet after diagnosis, lack of safe GF food, and possibly socioeconomic factors. Regardless of the specific reasons, adolescents need access to assistance to manage this chronic disease, as the gluten-free diet is essential to preventing both immediate and long-term complications of untreated CD.

Method

The project was carried out using an online 34-question survey created on Google Docs by Simon Gidrewicz and distributed through Celiac Canada's mailing list and social media platforms (Meta/Facebook and Twitter). Additionally, a poster advertising the study was posted at the pediatric gastroenterology clinic at the Alberta Children's Hospital and South Health Campus. This survey was targeted towards adolescents between the ages of 12 and 19 who had a confirmed diagnosis of celiac disease. Survey questions covered demographics, diagnosis and medical history, intestinal and extraintestinal symptoms, peer pressure, eating habits, lifestyle, and quality of life.

Research

Celiac disease is a genetic, chronic autoimmune condition involving the small intestines. It commonly affects about 1-2% of the North American population. When people with celiac disease eat gluten (a protein found in wheat, rye, and barley), it triggers a reaction in the small intestines, ultimately leading to damage (i.e., flattening) of the intestinal villi (*Celiac Disease - Symptoms and Causes*, 2023). The diagnosis is made with screening blood work (i.e., celiac screen) and often confirmed with an intestinal biopsy performed via upper endoscopy. Currently, there is no known cure for celiac disease, and the only treatment is adhering to a strict, lifelong gluten-free (GF) diet. Though this may sound simple, the GF diet can be very challenging as gluten is commonly found in many foods. In most cases, reviewing with a skilled dietician as well as yearly or bi-yearly blood work is required for disease monitoring.

The Body's Response to Gluten

In a person with celiac, the body responds to gluten ingestion in various ways, including activation of the immune system in the small intestine, which leads to damage to the villi. Unhealthy intestinal villi are unable to absorb nutrients and people develop many various symptoms such as abdominal pain, weight loss, diarrhea, or constipation, as well as extraintestinal symptoms (symptoms that do not directly relate to the intestine) such as fatigue, joint pain, skin rashes like dermatitis herpetiformis, anemia, or other neurological symptoms such as headaches (*Celiac Disease - Symptoms and Causes*, 2023).

Diagnosis

Even in 2025, many Canadians struggle to get a diagnosis of CD in a timely way, as many primary care physicians are unaware of atypical, extraintestinal features of CD and may not screen adolescents who present outside of the usual symptoms of abdominal pain and diarrhea. Furthermore, wait times to see a gastroenterologist to confirm the diagnosis can be long. This delay in the diagnostic process greatly harms the individual as they remain sick for longer, without a known cause. According to Celiac Canada, studies indicate that approximately 85% of individuals with celiac disease in Canada remain undiagnosed, posing a major public health concern. Addressing the issue of undiagnosed celiac disease requires concerted efforts from healthcare professionals, public health organizations, and the general population. Raising awareness about the disease, its symptoms—both intestinal and extraintestinal—and the importance of timely diagnosis is critical for improving outcomes. Furthermore, healthcare professionals should be encouraged to include celiac disease in their diagnosis when evaluating patients with compatible symptoms, regardless of age. By improving education, enhancing diagnostic tools, and promoting early detection, it is possible to reduce the proportion of undiagnosed cases and ensure that individuals with CD in Canada receive the necessary medical support and dietary guidance for an improved quality of life. Sadly, despite the major efforts taken by organizations such as Celiac Canada, the wait times for a CD diagnosis remain unacceptably long for many people. Even a 2-year wait from symptom onset to diagnosis is a long time in the life of a teenager who is going through puberty.

Another major hurdle in the diagnostic process is the fact that many general practitioners don't associate extraintestinal symptoms with possible CD and do not order the celiac screen blood work. Thus, the adolescent may go a longer time with these atypical symptoms, such as headaches and fatigue, affecting their school performance, or even missing school or other extra-curricular activities.

Common Misdiagnoses

There are two steps to diagnosing celiac disease. First a person needs to have blood work measuring a celiac screen (IgA TTG), and this is often followed by an intestinal biopsy performed by a gastroenterologist. CD can sometimes be passed off as a different disease or condition because of their similarities, such as irritable bowel syndrome (IBS), as they both can present with abdominal pain, but IBS does not cause intestinal inflammation or flatten the villi in the intestine. Other times, it can be passed off as a gluten intolerance or wheat allergy because they may also share similar symptoms. Other common conditions that may be misdiagnosed include gallbladder disease, stomach ulcers, parasitic infections, and lactose intolerance (Adams, 2015).

Psychological, Neurological, & Cognitive Effects

Emotions, cognitive abilities, and behaviors are some of the most common mental and psychological effects of untreated CD. According to a 2021 study conducted by Beyond Celiac in collaboration with Northeastern University and Beth Israel Deaconess Medical Center, 89% of adult survey participants with CD had brain fog after consuming gluten, and 72.7% stated that their brain fog impaired their ability to concentrate. Also, 47% of responders stated that their brain fog lasted for 1 to 5 days (Beyond Celiac, n.d..). According to the researchers, "this suggests a potentially significant impact on activities including work and school" (Avery, 2021). This impact can be quite far-reaching, as it can reduce school success and performance in extra-curriculars, such as sports and peer relations, leading to significant problems for the adolescent. Depression, anxiety, irritability, and social anxiety are other neurological effects that are associated with CD, but many general practitioners do not associate them with CD.

Lasting Effects

People with CD can have major lasting physical effects, such as anemia (low hemoglobin), bone loss/osteoporosis (Lebwohl & Rubio-Tapia, 2021), or even intestinal cancers. These serious side effects are caused by continuous gluten consumption after a celiac diagnosis, such that the intestines are unable to fully heal. They could also have many major neurological disorders, such as ataxia, brain fog, seizure, muscle twitches/spasms, and even peripheral neuropathy (numbness and tingling in the hands and feet). These can be caused by a lack of nutrients and vitamins or maybe the inflammation in the intestines triggering problems in other organs, like the brain. Females are more likely to develop other autoimmune complications such as thyroid disease, while men are more likely to develop neurological complications and osteoporosis, but if CD is diagnosed quickly and people follow a strict GF diet, then they are less likely to develop those serious complications.

Gender Differences

Teenage boys and girls develop quite different personalities and boundaries when going through puberty, which can change their adherence to the GF diet in many important ways. According to Ljungmand and Myrdal in a Coeliac review, ninety-one percent of the girls in the study reported strict adherence to the diet when at school compared to 75% of boys (White et al., 2016), which can likely be attributed to peer pressure. When taken into consideration, peer pressure can unduly harm teenage boys, as they are also more susceptible to other outside influences (peer pressure, etc.). When worries about food or diet become disproportionate, it can lead people to create unnecessary restrictions or avoid social situations, like eating out altogether. This kind of mindset can increase stress and make adolescents feel even more isolated.

Effects on Teens

Puberty is a challenging time, with so many physical and emotional changes happening at once. For a teenager dealing with a celiac diagnosis, it can feel especially overwhelming, not only to navigate the usual struggles of adolescence, but also to manage the strict gluten-free diet, which can feel isolating, frustrating, and confusing. Fear of Missing Out, FOMO, further contributes to the struggles of adhering to a strict GF diet. In some cases, teens eat gluten to “fit in” with their friends at school (eg, cake or pizza at birthday parties, cookies from friends). In many cases, adolescents do not fully understand the harm they are causing their bodies by eating gluten, and possibly ignoring or underestimating certain symptoms and side effects. One overlooked side effect is stunted growth, as teenagers may think they still have years to keep growing while failing to realize they might never reach their full genetic height potential. A 2018 study conducted by the Columbia University Medical Center at the Celiac Disease Center in

New York highlighted several challenges for teenagers with celiac disease, the most notable being;

> In the context of being asked about barriers, 56% of adults and 70% of teens explicitly referenced the adverse social impact of adhering to a GFD. Words that came up included “misunderstood,” “embarrassed,” “different,” “stigmatized,” “left out,” “awkward,” and “guilty.” Some suspected they were not invited to events or homes because of their dietary restrictions (Wolf et al., 2018).

This study showcases the unique mental challenges that adolescents with CD face, including their concerns about feeling embarrassed, different, or excluded from their peer group. These struggles likely contribute to breaking their GF diet (Chung et al., 2021).

In some other cases, teenagers don’t break their GF diet but instead experience anxiety, which can feel overwhelming. According to a discussion in Swedish adolescents in a review about Coeliac Disease;

> Foods consumed by teenagers with CD made them feel visible in public, placing them at risk of social devaluation; thus, they preferred to eat at home where GFD was accepted (i.e., they withdrew from social situations). They felt guilty about not accepting food offered by others and commented that peers thought they were ‘making it up’ or were ‘self important’ because the condition was not visible. Many adolescents with CD lacked knowledge or had misconceptions about CD and GFD, although they felt that stigma was reduced by having a good understanding of the diet, as well as practical or social support (Ljungman & Myrdal, 1993).

Many people feel that a lack of knowledge about the GF diet contributes to the stigmatization of individuals. In many cases, the more individuals understand a particular issue, the more likely they are to accept it.

Results

The 34-question survey was completed by 134 adolescents, all of whom provided consent to participate in the online survey.

Demographics and Clinical Data

The survey was completed by 90 females (67%), 39 males (29%), and 5 participants who preferred not to state their gender (4%). The mean age was 15.2 +/- 2.3 years (median = 15 years). The respondents spanned across Canada from coast to coast: 22 (16.4%) from British Columbia, 24 (17.9%) from Alberta, 6 from Saskatchewan and Manitoba (4.5%), 54 from Ontario (40%), 11 from Quebec (8.1%), 15 from the Maritimes (11.2%) and 1 from Northwest Territories (0.8%). The majority of respondents were diagnosed via blood work and intestinal biopsy (81, 60.4%), while 46 (34%) were diagnosed via blood work alone, and 9 (6.7%) were diagnosed using another method of diagnosis. 61 (45.5%) adolescents had been experiencing symptoms for 2 or more years before diagnosis. Only 22 (16.4%) had been experiencing symptoms for less than 6 months before diagnosis, and 51 (38.1%) were symptomatic for 6 months to 2 years before their diagnosis.

Table 1. Demographics of survey respondents

Gender	**Number**	**Proportion**
Female	90	67.2%
Male	39	29.1%
Other/Would rather not say	5	3.7%
Province		
British Columbia	22	16.4%
Alberta	24	17.9%
Saskatchewan	1	0.8%
Manitoba	5	3.7%
Ontario	54	40.3%
Quebec	11	8.2%
Prince Edward Island	2	1.5%
New Brunswick	1	0.8%
Nova Scotia	12	9.0%
Newfoundland and Labrador	1	0.8%
Northwest Territories	1	0.8%
Year of Birth		
2006	35	26.1%
2007	18	13.4%
2008	10	7.5%
2009	12	9.0%
2010	16	11.9%
2011	21	15.7%

2012	22	16.4%
Diagnosis		
Bloodwork alone	44	32.8%
Biopsy and Bloodwork	81	60.5%
Other	9	6.7%
Duration of symptoms before diagnosis of celiac		
Less than 6 months	22	16.4%
6 - 12 months	27	20.1%
1 - 2 years	24	17.9%
2 - 5 years	38	28.4%
5+ years	23	17.2%

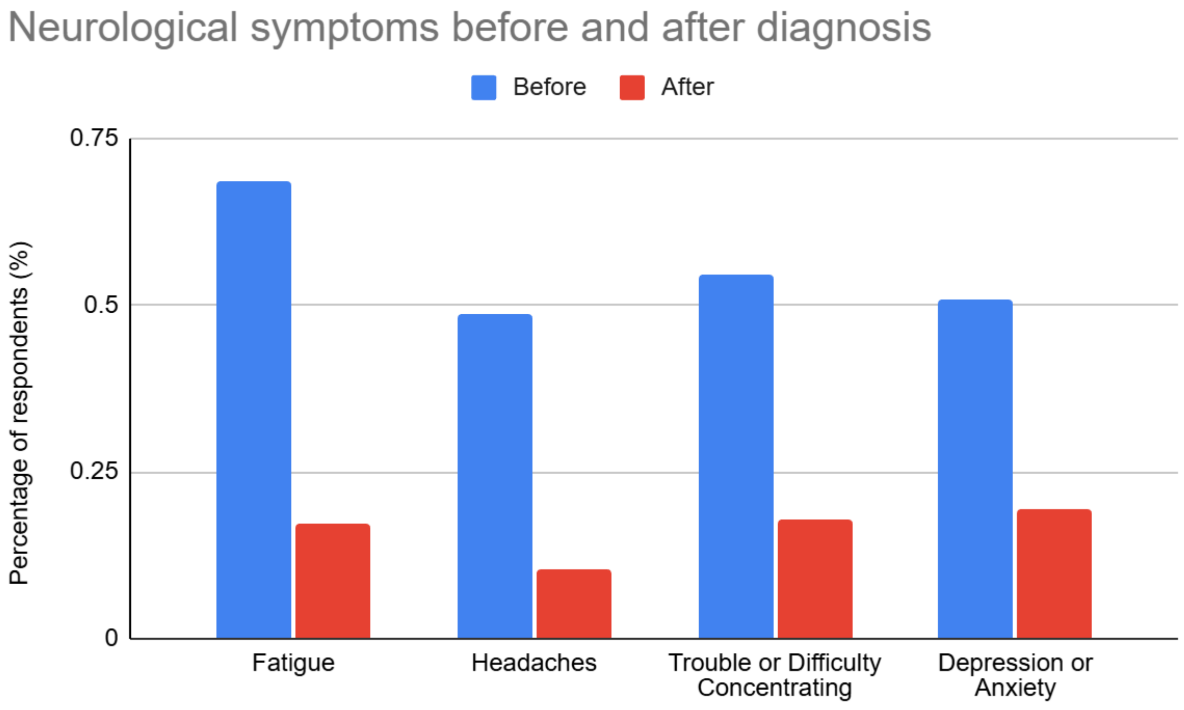
The clinical symptoms at diagnosis, as well as persistent symptoms on a GF diet, are shown in Table 2. Gastrointestinal symptoms were commonly reported at diagnosis, including chronic diarrhea (57 respondents, 42.5%, and 4 reporting ongoing symptoms on a GF diet), constipation (78, 58.2%), bloating or gas (90, 67.2%, 16 reporting ongoing symptoms on a GF diet), abdominal pain or cramping (100, 74.6%), nausea or vomiting (67, 50%). Extraintestinal, or non-gastrointestinal, features were also commonly reported among adolescents at diagnosis. Most commonly, adolescents reported fatigue (92, 49.3%; 23 reporting ongoing symptoms on a GF diet), followed by poor weight gain and stunted growth (81, 60.5%; 15 reporting ongoing symptoms on a GF diet). Many individuals presented with neurological symptoms that may be difficult to attribute to celiac disease, such as headaches or migraines, depression, or difficulty concentrating. Headaches and migraines were reported by 66 respondents at diagnosis (49.3%), and 73 (54.1%) reported difficulty concentrating. Mental health concerns were also often reported, with 68 (50.7%) adolescents struggling with depression or anxiety at the time of diagnosis, and 26 (38.2%) reported ongoing symptoms on a GF diet. In this study, 8 (6.7%) teens presented with only GI symptoms, while the vast majority also presented with atypical symptoms. According to one response,

> I had been having constant headaches for like a year and a half, and they weren't getting better. My mom took me to our family doctor, and he found nothing wrong with me and told me to just take Advil and Tylenol, which is what I had been doing. My mom had told him about Celiac… …and there was no doubt I was Celiac.

Table 2. Clinical symptoms of respondents at the time of diagnosis. Respondents were able to select multiple symptoms.

Symptoms at Diagnosis	Number	Proportion
Abdominal pain or cramping	100	74.6%
Bloating or gas	90	67.2%
Chronic diarrhea	57	42.5%
Constipation	78	58.2%
Nausea or vomiting	67	50.0%
Fatigue	92	68.7%
Headaches or migraines	66	49.3%
Trouble or difficulty concentrating	73	54.5%
Poor weight gain/growth	81	60.5%
Depression or anxiety	69	51.5%

Figure 1. Neurological symptoms at the time of diagnosis and ongoing symptoms on a GF diet.

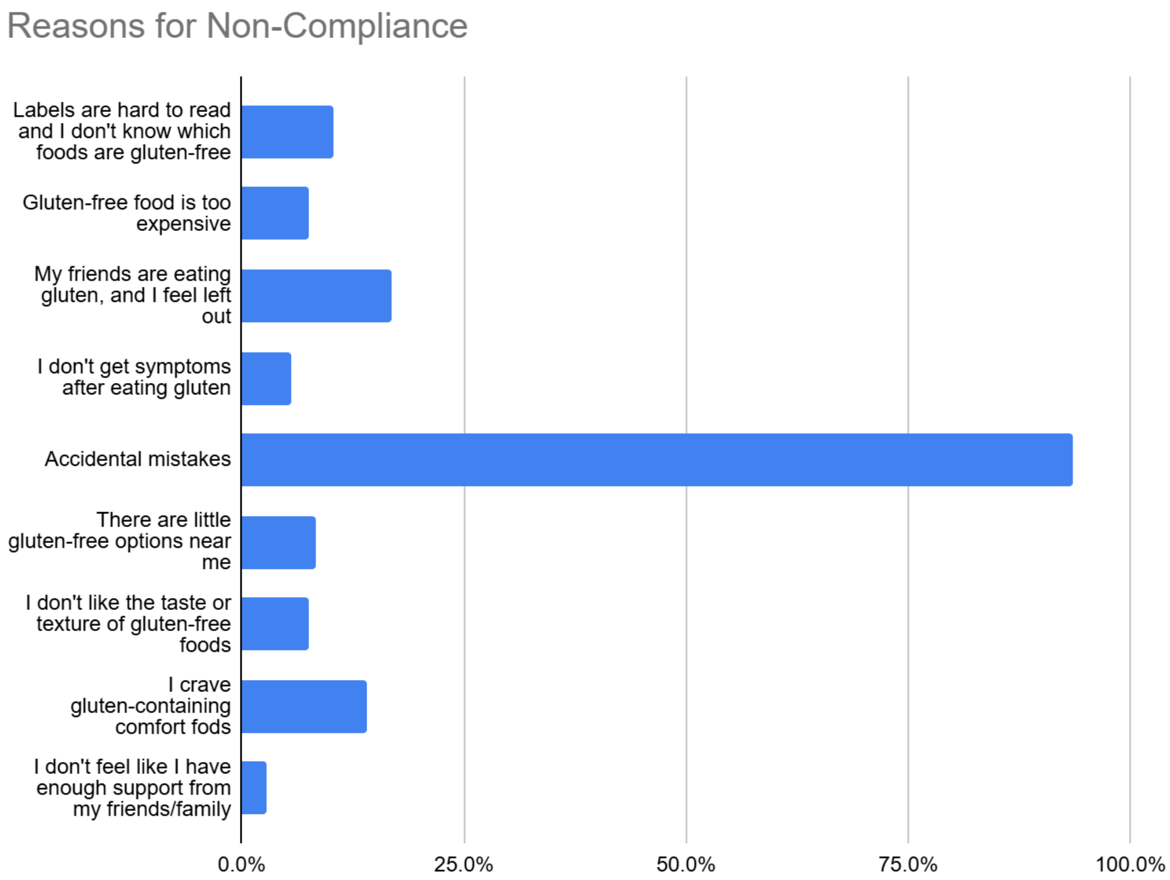


Adherence

Adherence to a GF diet was enquired by asking respondents to rate on a scale of 1-10 how carefully they adhere to a GF diet. The majority of respondents reported always sticking to the GF diet (10/10) (107, 79.9%), while 5 respondents (3.7%) reported not sticking to the GF diet at all (1/10). In another question, they were asked to rate how hard it was to maintain a GF diet. One-third of respondents experience major difficulties adhering to their diet (44, 32.8%), while 66 (49.3%) reported minor difficulties staying GF. When exploring reasons for breaking their GF diet, 101 (75.3%) respondents stated they ate gluten accidentally, however, 18 (13.4%) respondents stated that peer pressure contributed to breaking their GF diet so that they could fit in.

Figure 2. Reasons for non-compliance to a GF diet.

Respondents were able to select multiple choices.



Financial reasons also contributed to lack of adherence to the GF diet as 21 (15.6%) of respondents stated that GF food is too expensive, making it harder for them to be GF as their families consume large amounts of non-GF food (Figure 2). Many respondents felt incredibly excluded when others shared non-GF food (90, 66.7%), and 39 (43.3%) adolescents stated that feeling excluded causes them to break their GF diet. Female participants born in 2008, 2009, or 2010 (i.e., 16, 15, and 14 years of age) reported that they felt more excluded when others shared non-GF than their male counterparts, which also caused them to feel significantly more likely to break their GF diet to fit in (Figure 3).

Figure 3. Feelings of isolation when surrounded by others sharing non-GF food.

On a scale of 1 to 5, individuals were asked how excluded they felt when others shared non-GF food around them. 1 represented not feeling excluded at all, while 5 represented feeling incredibly isolated. The light blue line represented the male trendline, while the light red line represented the female trendline.

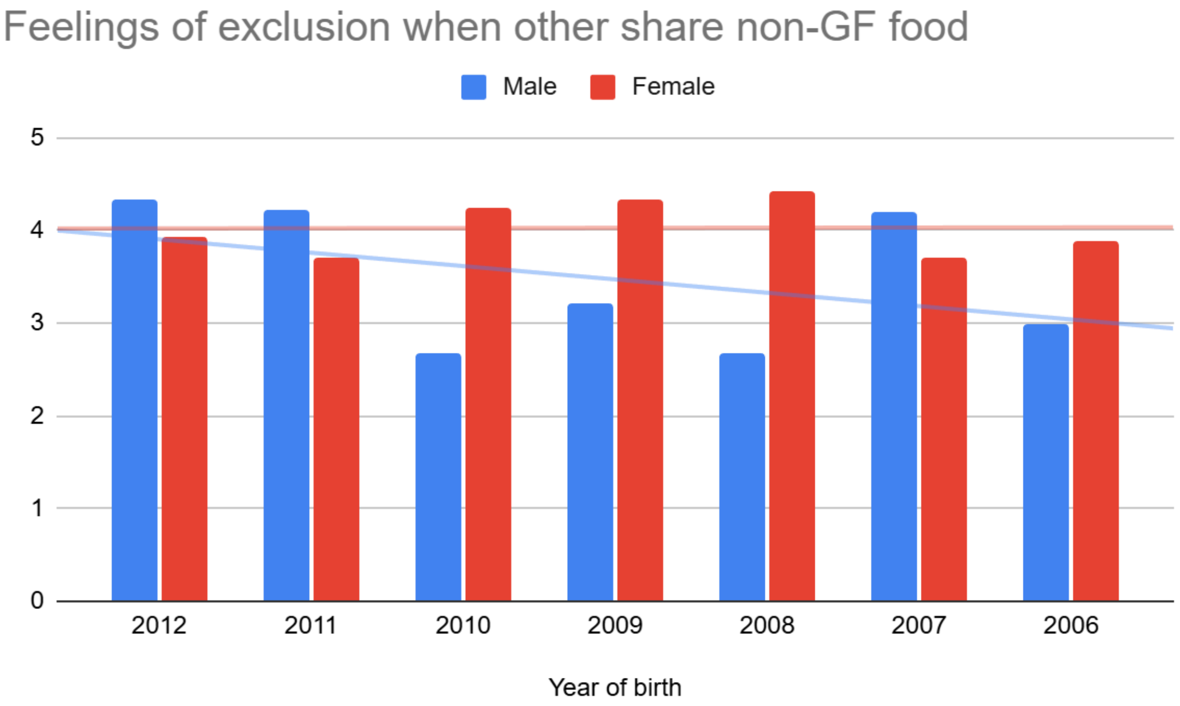
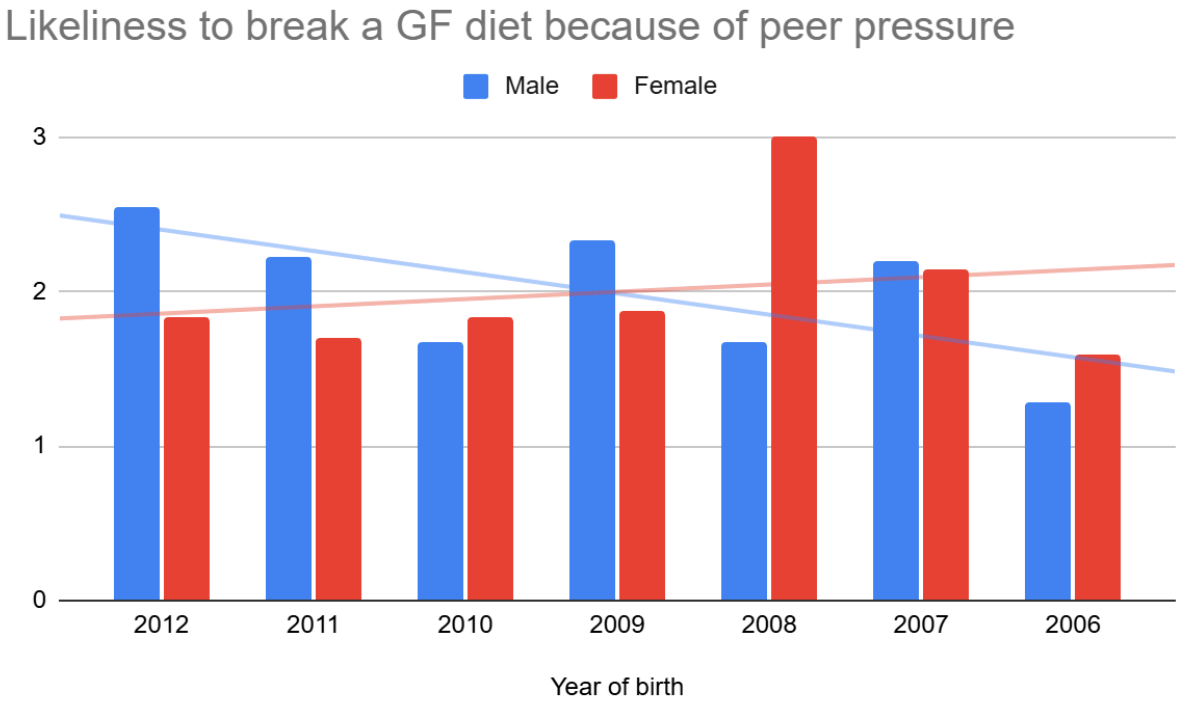


Figure 4. Likeliness to break GF diet as a result of peer pressure.

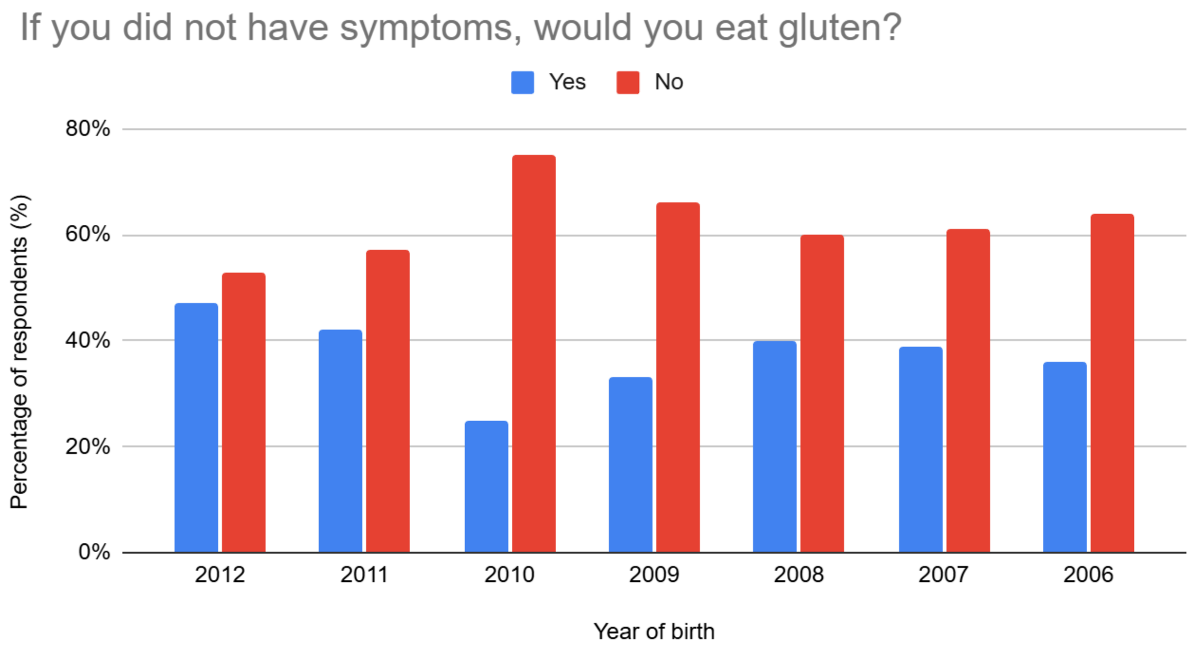
On a scale of 1 to 5, individuals were asked how likely they were to break their GF diet as a result of peer pressure. 1 = rarely/never breaking it, 3 = breaking in more than 3 out of 10 peer pressure instances, 5 = frequently breaking it.

The light blue line represents the male category's trendline. The light red line represents the female category's trendline.



As shown in Figure 4, respondents born in 2012, 2011, and 2010 (12, 13, 14) were a lot more likely to break their GF diet than their female counterparts, while females born in 2006 and 2007 (18 & 17) were more likely to break it than their male counterparts. Many individuals also reported that they experienced major difficulties following a GF diet, and males born in 2012 appeared to experience the most struggles. Quite surprisingly, females born in 2010 and 2011 do find the GF diet more difficult than males born in 2011 and 2010, but they do not feel more excluded than their male counterparts (Figure 6). Most interestingly, 52 (38.8%) respondents stated that they would break their GF diet if they did not have symptoms of gluten ingestion (Figure 5). Furthermore, 47% of 12-year-olds (i.e., respondents born in 2012) stated that they would eat gluten, which was larger than the other age groups.

Figure 5. Respondents would eat gluten if they remained asymptomatic.



Lifestyle and Quality of Life

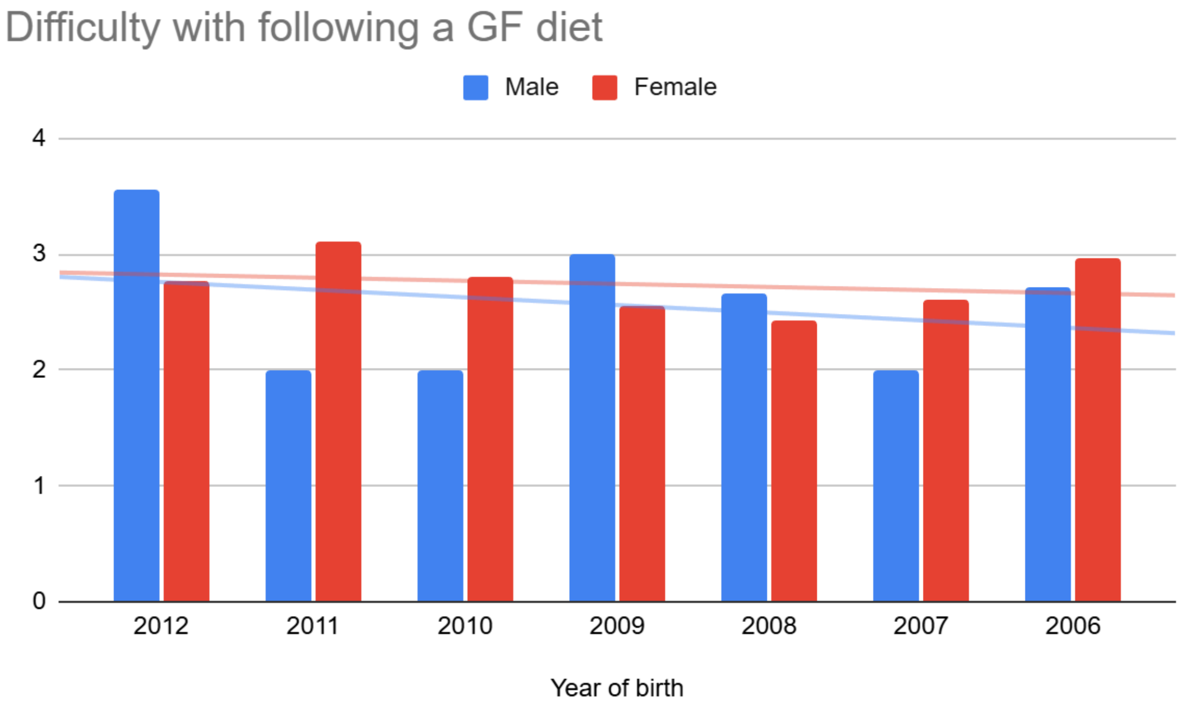
The respondents were asked five questions related to eating out, such as at the school cafeteria and/or fast food, including how often they eat out, which fast food places they frequent, and concerns about food labeling at these fast food restaurants. According to one response;

> Last year, I had to miss meals on the bus because Tim Hortons does not offer a gluten-free breakfast, and the school cafeteria refused to let me store pre-made meals in the fridge. Post-game meals made by the cooks at the cafeteria were often not gluten-free, so I would have to eat cereal instead of pasta or chicken. My teammates would often make fun of me for having to go behind the counter in the cafeteria to grab my meals or having a meal labelled "Gluten-free." Most people do not realize the serious effect eating gluten has on my health; it's a necessity, not a preference. Often, I miss out on lunch breaks with my friends because the restaurants or fast-food places do not have anything

> for me; it makes me feel left out at times. Overall, managing my diet is a burden that creates lots of stress and anxiety, whether it is constantly wondering if the food I am eating is safe or having to plan every event in my life around what I am going to eat.

Figure 6. Difficulty following a GF diet.

On a scale of 1 to 5, respondents were asked how hard following a GF diet was, with 1 representing that they found following the GF quite simple and 5 representing that they found following the GF diet incredibly difficult. Many individuals attributed this difficulty to the risk of cross-contamination. The light blue line represents the male linear trendline, while the light red line represents the female linear trendline.



Many individuals stated that they ate out less as they were worried about cross-contamination.

This caused them to eat more at home, and if they went out, they would bring their food. Many respondents also stated that they were in “financial-savings mode” as they could not afford to eat out GF, which also limited eating out with their friends and peers. According to one response, “Going gluten-free is the easy part. Avoiding cross-contamination is hard... this is the part that causes so much confusion and stress when explaining it to folks… …there are no activities for GF folks”. Respondents state that sometimes, they don’t eat breakfast, or they only eat one meal a day to save money. Another respondent described their struggles with ostracization and bullying;

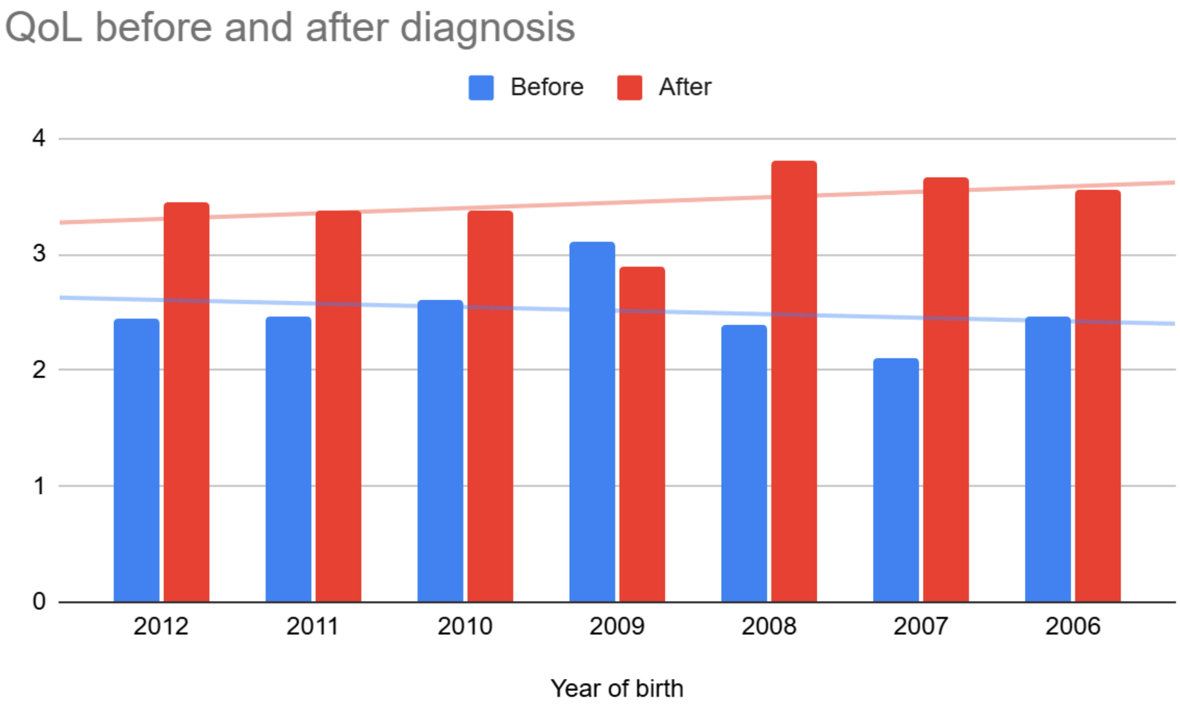
> “My dietary needs were forgotten or seen as unimportant. My teammates would often make fun of me for having to go behind the counter in the cafeteria to grab my meals or having a meal labelled "Gluten-free." Overall, managing my diet is a burden that creates lots of stress and anxiety, whether it is constantly wondering if the food I am eating is safe or having to plan every event in my life around what I am going to eat.”

This response captures the significant social struggles that adolescents with CD experience and their effects on many aspects of their lives, including extra-curricular sports.

Individuals were also asked to rate their quality of life (QoL) before and after their diagnosis on a scale of 1 to 5 (1= horrible, 5= amazing. The average QoL before the diagnosis was 2.49 +/- 1.2, while after the diagnosis, the average QoL was 3.46 +/- 0.9. Many individuals reported that their QoL improved as they no longer struggled with painful symptoms (Figure 7).

Figure 7. QoL before the diagnosis and at the time of the survey.

On a scale of 1 to 5, respondents were asked how they would rate their quality of life (QoL) before and after their diagnosis. 1 represented poor, while 5 represented amazing. The light blue line is the before trendline, while the light red line is the after trendline.



Discussion

To the author's knowledge, this is the largest survey of adolescents with celiac disease exploring their symptoms, diagnosis, and struggles with the GF diet in Canada.

Extraintestinal Symptoms

This study highlights the need to teach doctors that celiac disease very often presents with extraintestinal symptoms, such as fatigue, trouble concentrating, anxiety, and depressive symptoms, even in adolescents. In 2022, Celiac Canada conducted a State of Celiac Survey in adults with over 7500 respondents. Their survey demonstrated that 62.0% of adults experienced fatigue at diagnosis (Celiac Canada, 2024). Our survey demonstrates that fatigue is very common in adolescents as well, but could be easily attributed to something else such as long nights studying for exams. (69% of teenagers presented with fatigue). According to the World Health Organization, depression is estimated to occur among 1.4% of adolescents aged 10–14 years, and 3.5% of 15–19-year-olds (*Mental Health of Adolescents*, 2024). In this study, 50.8% of respondents presented with depression at the time of their diagnosis, and 19.4% of respondents reported unresolved self-reported depression when completing the survey. Our survey reveals that many teenagers experience mental health concerns at the time of celiac diagnosis. However, our reported rates of depression may be higher than WHO statistics, as our data is based on self-reported depression and anxiety. In contrast, the WHO figures likely reflect physician-diagnosed cases. Suffering from a major chronic illness can contribute to depression and/or anxiety as it can affect your mental state. Therefore, primary care professionals who take care of teenagers need to be aware of these neurological features of CD to prevent a delay in diagnosis.

Delay in Diagnosis for Teenagers

A delay in diagnosis exists in Canada for adolescents today despite an easy-to-access celiac blood test, as over 45% of respondents reported experiencing symptoms over 2 years before their diagnosis. This delay in diagnosis affects patient care and increases healthcare costs as patients seek out frequent medical assistance before they receive a diagnosis of CD. According to a 2015 Swedish population study, patients with undiagnosed CD had a 1.40 times higher mean annual cost than reference individuals 5 years before diagnosis (Bozorg et al., n.d.). This extra cost burdens the healthcare system, which is already underfunded and overburdened. By educating doctors and the public that celiac disease can often present with atypical and extraintestinal symptoms, we can save individuals with CD a lot of pain and struggles awaiting a diagnosis, and direct the health care funds to improving life after the diagnosis, such as long-term follow-ups.

Complacency

It is commonly recognized that individuals with chronic conditions may become complacent about treatment after a certain period. In this study, individuals who have had CD for over 5 years tended to struggle the most with peer pressure and exclusion and found staying GF the hardest. This may also suggest that healthcare professionals should follow up with CD patients 2-3 years after their diagnosis, and follow up again 4-6 years after diagnosis, as currently they are not commonly followed up with 1 year past their diagnosis with CD.

Lack of Safe GF Food

A common theme in this survey was the lack of availability of safe GF food in school cafeterias and fast food restaurants. Many respondents stated that they felt that areas near them did not have GF food that was not at risk of being cross-contaminated. In some cases, school cafeterias were not able to provide GF food, which can greatly affect teenagers' lives as they may not have fast food places near their school that are safe to eat. This may leave them with nowhere to go. According to one response, "I can't eat at most chain restaurants, and searching for safe places in the area takes a lot of forethought (I use the Find Me GF app to tell me GF restaurants in the area)". This can cause them to eat at places that may run the risk of cross-contamination, which is detrimental to an individual's health. In other common scenarios, such as potlucks, individuals can feel excluded as some of the GF items run the risk of cross-contamination.

Social Burden

Teenagers with CD also struggle with the social burden that comes with eating differently than their peers. Respondents reported feeling excluded when others around them ate food that was not GF are, and they also reported feeling bad about being GF when others tried to share non-GF food with them, not knowing that they were GF, so they had to turn down their food. This immense social burden is exasperated when teenagers cannot buy food at their comfort spots (cafeterias, fast food places, etc.). Currently, a large part of Celiac Canada advocacy targets grocery store labeling, but teenagers do not shop at grocery stores. Instead, more of their advocacy efforts should go towards providing GF options at school cafeterias and fast food places. A major takeaway from this is that by not offering GF food at local cafeterias or schools or by not providing enough education about it, we can cause individuals to feel excluded and ostracized because they are GF.

Limitations of this Survey

Though this large survey included adolescents across Canada, I could only reach out to the members of Celiac Canada's mailing list. The parents of those adolescents on this mailing list are generally described as more motivated to learn and maintain a GF diet. Also, this survey asked people about symptoms at diagnosis, which may have been many years ago, thus leading to recall bias as it may have been difficult to recall all their symptoms. Finally, this survey was only conducted in English, therefore, we had very few participants from Quebec. Possibly, their experiences on the GF diet, but their symptoms before and after the diagnosis would not likely be vastly different than other Canadians.

Conclusion

This study hopes to provide new information concerning the presenting symptoms and life on a GF diet in adolescents with celiac disease, while also influencing new legislation concerned about CD so that it can better aid teenagers with CD. The majority of teenagers present with extraintestinal symptoms, and the survey also highlights many of the pressing issues of teenagers with CD. In today's society, teenagers struggle with ostracization and social distancing because of their differences, and they struggle to find safe GF places to eat. This is a critical issue that requires immediate attention, and this study marks the first step toward addressing it.

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Appendix

Living With Celiac 2024-2025 Response Form

Find out more about the survey here. Please put time and effort into answering all the questions, as they greatly benefit us.

A1. Do you give consent to having your responses recorded and tracked for the purposes of this study?

Select one

○ Yes

○ No

A2. Does your Parent/Guardian give consent to having your responses recorded and tracked for the purposes of this study?

Select one

○ Yes
○ No

A3. What is your first name, and the first initial of your last name?

____

Eligibility

1. Do you have celiac disease?

Select one

○ Yes
○ No

General Information

2. What is your year of birth?

Select one

○ 2006
○ 2007
○ 2008
○ 2009
○ 2010
○ 2011
○ 2012

3. What is your gender?

Select one

○ Male
○ Female
○ Other
○ Would rather not say

4. What province/territory do you live in?

Select one

○ British Columbia
○ Alberta
○ Saskatchewan
○ Manitoba
○ Ontario
○ Quebec
○ Prince Edward Island
○ New Brunswick
○ Nova Scotia
○ Newfoundland & Labrador
○ Nunavut
○ Northwest Territories
○ Yukon

Diagnosis and Medical History

5. My diagnosis of celiac disease was based on the following:

Select all that apply

☐ Blood work only
☐ Blood work and Biopsy (Intestinal)
☐ Other

6. If you selected other, please specify

____

7. How many years have passed since your diagnosis of celiac disease?

Select one

○ Less than 6 months
○ 6-12 months
○ 1-2 years
○ 2-5 years
○ More than 5 years

8. Do you have other autoimmune issues (eg. Type 1 diabetes, hypothyroidism), other medical or mental conditions?

Select one

○ Yes
○ No

9. If you answered yes to the question above, please specify.

Select all that apply

☐ ADHD
☐ Asthma
☐ Skin issues, like eczema
☐ Food allergies (i.e. nuts)
☐ Inflammatory bowel disease (I.e. Crohn's Disease, Ulcerative Colitis, etc.)
☐ Mental health concerns (Depression, etc.)
☐ Thyroid issues that need extra treatment
☐ Type 1 diabetes
☐ Other

Symptoms

10. Were you feeling unwell or had symptoms when you were diagnosed with celiac disease?

Select one

○ No, I was screened after someone else in my family was diagnosed with celiac.
○ Yes, I had symptoms that triggered by doctor to order celiac blood work

11. Did you have any of the following symptoms before starting a gluten-free diet? If so, did you recover from it?

Select one per row

	Never had symptom	Not recovered	Partially recovered	Fully recovered
Chronic diarrhea	○	○	○	○
Constipation	○	○	○	○
Bloating or gas	○	○	○	○
Abdominal pain or cramping	○	○	○	○
Nausea or vomiting	○	○	○	○
Fatigue	○	○	○	○
Headaches or migraines	○	○	○	○
Trouble or difficulty concentrating	○	○	○	○

Poor weight gain or poor growth	○	○	○	○
Depression or anxiety	○	○	○	○

12. If you had symptoms that were not stated above, please specify.

____

13. How long did you experience symptoms before your celiac diagnosis?

Select one

○ Less than 6 months
○ 6 - 12 months
○ 1-2 years
○ 2-5 years
○ More than 5 years

14. Do you currently experience symptoms if you eat gluten?

Select one

○ Yes
○ No

15. If yes, how long after eating gluten do you start to have symptoms?

Select one

○ Less than 30 minutes
○ 30 - 60 minutes
○ 1-2 hours
○ More than 2 hours later
○ Not sure

16. If you have symptoms after eating gluten, how long do reactions usually last?

Select one

○ Less than 30 minutes
○ 30 - 60 minutes
○ 1-2 hours
○ More than 2 hours
○ Not sure

17. On a scale from 1 to 10, how painful are your symptoms with gluten exposure?

Painless ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10 ○ 11 Incredibly Painful

18. If you did not have symptoms, would you eat gluten?

Select one

○ Yes
○ No

Dietary Practices and Management

22. 19. How carefully do you stick to the gluten-free diet?

Eat gluten many times a week ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10 ○ 11 Always eat gluten-free food

20. How hard is it for you to follow a gluten-free diet?

Very Easy ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 Very Hard

21. If you eat gluten-containing foods, why?

Select all that apply

☐ Labels are hard to read and I don't know which foods are gluten-free
☐ Gluten-free food is too expensive
☐ My friends are eating gluten, and I feel left out
☐ I don't get symptoms after eating gluten
☐ Accidental mistakes
☐ There is little gluten-free options near me
☐ I don't like the taste or texture of gluten-free foods
☐ I crave gluten-containing comfort foods or favorite dishes
☐ I don't feel like I have enough support from parents/siblings and/or friends to manage a gluten-free diet
☐ Other

21a. If you selected too expensive, what parts of the GF diet are too expensive?

____

22. If you selected other, please specify.

____

23. After you were diagnosed with celiac, did your parents/guardian speak with a dietitian?

Select one

○ Yes
○ No
○ I don't known

24. Have you received information about the gluten-free diet? [such as handouts, links to videos, teaching classes].

Select one

○ Yes
○ No
○ I don't know

25. If yes, rate its usefulness.

Useless ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 Very Useful

26. In what ways has being gluten-free impacted your eating habits?

____

____

Eating Out

27. Do you eat out? [eg. school cafeteria, fast food]

Select one

○ Yes
○ No

28. If so, how many times a week do you eat out?

Select one

○ 1
○ 1-2
○ 2-5
○ More than 5

29. Do you find gluten-free labeling at restaurants and fast food places confusing?

Not confusing at all ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 Very confusing

30. Which restaurants do you think have incorrect/confusing labelling? Select all that apply.

Select all that apply

☐ A&W
☐ Boston Pizza
☐ Burger King
☐ Dairy Queen
☐ Dominos
☐ Edo Japan
☐ McDonalds
☐ New York Fries
☐ Papa John's
☐ Pizza 73
☐ Pizza Hut
☐ Popeyes
☐ Subway
☐ Taco Bell
☐ Wendy's
☐ Tim Horton's
☐ Other

30a. If you selected other, please specify

____

30b. If you selected an option above, which item on their menu do you think is not GF?

____

31. How have your eating out habits changed since having celiac disease?

____

____

Impact on Personal Life

32. Do you feel excluded when others share non-GF food (eg. at school, sports events, parties)?

Never ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 Always

33. Do you feel pressured to break your GF diet when others share non-GF food?

Never ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 Always

34. How has celiac made your personal life harder (eg. feeling ostracized/excluded, constant pressure to break GF diet, etc.)?

____

____

34a. How do you find that peer pressure has affected your GF diet? (eg. Breaking it to fit in, etc.)

____

____

34b. How many time in a week does this happen, if at all?

Select one

○ Once
○ 2-4 times
○ 5-9 times
○ 10+ times
○ Never happens

Quality of Life

35. How would you rate your overall health and quality of life before and after your diagnosis?

Select one per row

	1	2	3	4	5
Before	○	○	○	○	○
After	○	○	○	○	○

36. How has your quality of life changed after your diagnosis of celiac?

____

____

37. Did it get easier to be gluten-free after having Celiac for a long time?

____

____

Extra Information

38. Is there anything else that you would like to tell us to help us understand your struggles with having celiac disease.

____

____