



Overview of Findings: New England Celiac Organization (NECO) Spring 2016 College Survey

Abstract

This document provides a summary of findings and recommendations from an online survey conducted by NECO in the spring of 2016 to document the dietary, social and educational issues faced by college students with celiac disease or significant gluten intolerance.

About New England Celiac Organization:

New England Celiac Organization (www.neceliac.org) is a 501(c)(3) non-profit organization dedicated to educating and advocating for individuals with celiac disease and non-celiac gluten sensitivities, their families, and communities throughout New England. NECO provides education, awareness, and support for persons with celiac and the medical community through in-person events and the online community.

What is Celiac Disease?

Celiac disease (CD) is an autoimmune disease that mainly affects the gastrointestinal tract. Individuals who have CD are permanently intolerant to gluten, a group of proteins found in wheat, barley, and rye.

Gluten is toxic to those with CD. In a person with undiagnosed or untreated CD, the finger-like ridges that line the walls of the small intestine known as villi become flattened and unable to absorb nutrients properly. CD may also affect other organ systems.

What is Gluten Intolerance or Non Celiac Gluten Sensitivity?

Gluten Intolerance (GI) or Non Celiac Gluten Sensitivity (NCGS) encompasses a collection of medical conditions in which gluten has an adverse effect on the body. Unlike celiac disease, damage to the small intestine does not occur, but symptoms can range from mild to severe and include diarrhea, vomiting, and migraines.

Following a gluten free diet can reduce or eliminate these symptoms.

Study Methodology

NECO hosted an online survey instrument with SurveyMonkey and invited participation through a number of channels, including email, Facebook and other social media. The survey was opened on April 1, 2016 and closed 60 days later, on June 1, 2016. Participants were emailed multiple times to ensure participation and survey completion.

For More Information

For more information about this study or to learn more about coping with Celiac Disease, please visit www.neceliac.org.

Special thanks to Ian's Natural Foods (www.iansnaturalfoods.com) for their financial support of this survey.

Introduction

For some, the diagnosis of celiac disease provides the answer to a series of health questions:

- Why can't I lose weight?
- Why can't I gain weight?
- Why do I always feel like crap after eating?
- Does everybody feel like this after a meal?
- Why do I have brain fog?
- Is this *normal*?

The diagnosis also comes with a set of rules for eating safely. No foods with gluten. No food that has been prepared using the same implements or cooking oil that has been used with "regular" food (containing gluten).

Some celiacs react strongly to being "glutened"; others may have no reaction even though the gluten will continue to damage their system.

And gluten hides in a variety of foods, such as sushi rice or fried food. If the rice has been prepared with malt vinegar, it contains gluten. If fried food has been prepared in a fryolator that has also been used to prepare foods containing gluten, cross contamination will occur.

Cutting boards, cooking implements, or a cook's hands will also create cross contamination. Many celiacs have to play "detective" to find out why they get sick after eating out.

For adults, the process of refining one's diet, playing detective, keeping oneself safe, is challenging enough. For a young adult, who may have been recently diagnosed, or may be heading off to college for the first time, responsible for their own well-being, the challenges can be overwhelming.

In the spring of 2016, the New England Celiac Organization set out to document the issues faced by college students. The study authors and advisors have lived this firsthand...one study advisor was diagnosed shortly before going off to her first year in college and had to advocate strongly for herself to be able to receive "safe" food on a regular basis. Her experience is not uncommon in the celiac community.

Our research corroborated our personal experiences. College students with celiac disease face overwhelming complications, including:

- Untrained food service employees
- Food service and administration personnel unwilling or unable to help
- Limited and repetitive food choices
- Social isolation
- Inability to participate in group social, educational or team activities

The respondents reported significant, perhaps devastating, social and educational impact, at a point in their personal development when they are particularly vulnerable. First time away from home (and the parental and long term support systems), making new friends, trying to adjust to new social norms, taking on more challenging educational loads.

And boom...they get sick. Boom...they have to pre-order food. Boom...they have to eat separately from their new friends. Boom...they miss classes. Boom...they have to advocate for themselves. Boom...they end up double paying for food (no refund on the meal service, no safe cooking facilities, not much more than junk food available outside the cafeteria.)

This is a recipe for personal, developmental and educational disaster.

And the data suggests that those that have been recently diagnosed are at greater risk. Their answers skew towards “poorer” responses, reflecting greater impact as they are just learning about the disease, how to manage it, and how to advocate for themselves.

Our research documents how broadly the problem exists and the extent of the impact on the student. For educational institutions, there is a corresponding financial and brand impact.

Financial and Brand Impact on the Institution

As one measure of the impact, a full 60% of the celiacs would not be “very” or “extremely” likely to recommend their school to others with celiac disease. This question, phrased using the standard “NetPromoter Score” methodology, represents a failure on the part of those schools to meet the needs of their “customers”.

The social and educational impact on the student with celiac disease will lower his or her likelihood to graduate on time...or at all. And the resulting lower four-year graduation rates affect a school's ability to attract future students.

While a few schools have established separate gluten free cooking facilities for the use of students, we believe that this does not effectively address the problem.

- Students, particularly first or second year, may not have the time, ability or inclination to shop off-campus or to cook for themselves
- Other students may try to use the facility, contaminating it with gluten
- While separate facilities may work for those students following social or religious dietary guidelines, this approach has the effect of separating celiacs from their peer groups

NECO Recommendations

NECO recommends the following actions:

- Schools and universities must acknowledge the extent of the problem and its impact
- While eating gluten-free may be a “fad” for some, gluten and cross-contamination cause serious health issues, including cancer, for celiacs
- School administrations and food service organizations must properly develop and operate “safe eating practices”, ensuring that celiacs can eat safely, with a choice of selections across the major food groups
- Food service organizations must address the challenge of continuous retraining of an hourly work force
- School administrations and food service organizations must take steps to “mainstream” celiac support, allowing affected students to eat with their friends, social and study groups
- As newly or recently diagnosed celiacs are at greater social and educational risk, they should be identified prior to matriculation and provided direct support by a school staff member
- Similarly, those with no other family members diagnosed with celiac are at substantially greater social and educational risk and need additional support

Major Findings

Of the 415 total qualified respondents (those with celiac disease or significant gluten intolerance), just over half (215) completed the entire survey. Only college or university students with current or recent meal plans were included in the analysis.

- 37% identified as having a formal celiac diagnosis.
- 18% specified a gluten sensitivity
- 36% indicated that they choose to eat gluten free
- 8% reported an “other” need to eat gluten free

74% of the celiacs had been diagnosed five or more years ago, and 61% reported that one or more other family members also have celiac.

44% of celiacs reported that eating gluten free had been a problem “the entire time I’ve been here.” Another 26% reported that it was a problem at first, but got better over time.

Only 30% of the celiacs reported that their diet at school was “well-rounded,” while 48% of respondents choosing to eat gluten free reported that their diet was well rounded.

16% of celiacs reported that they are supplementing their diet with snacks, while only 5% of those choosing to eat gluten free reported having to supplement.

20% of celiacs reported that the food service needed more than 30 minutes to prepare gluten free food.

A full 40% reported that their eating experience on campus was “poor – challenging, frustrating.”

32% report that they still expect to be glutened once in a while.

Almost 20% say that they simply stay away from the food service, as it’s “not worth the risk.”

71% reported that their efforts to eat GF were having “some” or “major” impact on their social life.

The following are some of the verbatim comments provided by respondents:

I feel weird and bad when I have to keep being like 'yall I can't eat at any of these restaurants' or not being able to reliably eat at a certain dining hall and people get upset and then I feel like a bad person and some times end up going places where I can't eat anything.

People do not want to put in that little bit of extra effort to make sure that I can eat and eat safely. They think it's a joke and not a serious medical condition. I've been told to either eat before I go out or bring my own food along because no one else can be bothered to go to a restaurant where I can eat or make sure that I can have like a bag of chips at a party.

Many of my friends do not understand the severity of celiac disease. Because of this, I am often excluded from social events with friends, and I am rarely invited out to eat. If I am invited, I bring my own food, which leads to a further sense of social isolation. Friends and family will offer to make me food, but this gives me severe anxiety, because I do not know the state of their kitchen, or the segregation of ingredients or utensils. Because of this, I tend not to eat when going out with friends or when attending events at other people's houses.

I don't have a social life LMAO sorry I stay in the classroom during meals and work through them. It's a better use of my time than going up to the dining hall only to find there's nothing to eat.

It's frustrating because all my friends have meal plans and want to eat at the cafeteria, but I rather not. But, I also don't have access to a kitchen and cannot afford to go out to eat and end up eating minimal meals at the cafeteria.

Long wait time to get gf food, limited Options, no gf food at social events or food trucks on campus, friend complain they don't want to dine with me as it takes too much time.

I rarely can eat out with friends off or on campus because of incredibly limited selection and perpetual risk of cross contamination.

A lot of the academic events and social events provide food, which I usually cannot eat. This means that either I have to bring my own food or eat before/after. I can only be accommodated at one dining hall on campus, thankfully it is the main one, but this severely limits my meals "out" on campus with friends.

I can't enjoy going out, unless to a place I know is safe for me to eat. My friends are considered of where I can eat, but I feel awkward always choosing the places to eat.

I have to request food in advance and have to wait for it to be prepared. This leaves me alone or away from my friends for part of our meal time.

My friends won't wait for me to get my food. So I have to eat alone.

I avoid community gatherings because I know there will be no gluten-free options.

Feeling awkward or isolated because of my dietary needs.

I hold back from going to certain events because everyone is eating and I hate being that awkward person just standing around

Making me feel excluded Making my friends not want to be around me because I'm sick

Conversely, only 4% of those choosing to eat gluten free felt a substantial social impact.

32% indicated that having to find GF food is having "some" impact on their educational success, while 5% indicated that it was having a "major" impact.

I have wasted a lot of my time, that I could have spent studying or with friends, meeting with the cafeteria staff and emailing them.

At times food wasn't able to be prepared in the time frame I had and was forced to eat prepackaged snack food for the day

When I first came here and lived on campus, I was getting sick frequently and had to miss a few classes. I haven't had any problems lately

After being glutened, the brain fog I experienced often made concentrating in class nearly impossible. Those days I may as well not been in the classroom.

I am extremely sensitive to gluten and it causes major brain fog, belly aches, diarrhea to the point I have to miss classes.

I have had to miss class from being "glutened" more than once, without a doctor's note excusing me for that day specifically, I get points deducted from my average for missing class.

23% of celiacs report skipping 1-2 meals a week due to gluten concerns, while 30% report skipping 3-5 meals a week.

25% reported that they worked with the food service to improve the situation. The largest percentage, however, 30%, indicated that they found no solution; they were just "winging it."

58% of the celiacs report that the food choices at school are "limited and repetitive."

8% report that they are glutened "frequently", while 17% report being glutened at least a couple of times each month.

Over half, 51%, had no idea whether the food service workers had been properly trained in food preparation (with regard to cross contamination). Another 18% guessed that perhaps one or two workers had been properly trained.

Family Matters

Those with other family members with celiac handle the situation better at school, reporting that access to GF food is better. 38% of those with family history of celiac report having a well-rounded diet, versus only 17% of those with no other family members.

Those with family members more actively advocated for themselves and reported better results. 66% of those with family members reported that having to eat gluten free was having "some" or "major" impact on them socially, while a full 80% of those with no other family members reported this impact.

Next Steps

NECO suggests that colleges and universities form a Gluten Free Task Force to formally address the issues raised in this research. While some schools have had success in providing pockets of “safe” dining for celiacs, not a single school received an “excellent” rating from our respondents.

Plenty of room exists for improvement – from the support of newly matriculated students, to better training of food prep employees, to a formal and systemic approach to handling the concerns raised by those requiring a gluten free (and safe) diet.

When the overall situation is improved, the results will be significant for those with celiac disease, including:

- Overall better health
- Better social and educational development
- Sense of empowerment rather than isolation
- Greater likelihood of educational success

And for the institutions, potential results include:

- Lower on-campus health care expenses
- An empowered student body
- Higher academic success and graduation rates

With these results available, schools must act now.