Calgary Chapter Celiac 101







Meet our volunteers

Disclaimer: Please note that the volunteers at Celiac 101 and the information in this presentation are for informational purposes and should not be taken as direct medical advice for your individual case/needs, always consult a medical practitioner





Introductions

Health and Celiac Disease

Resources

Daily Living

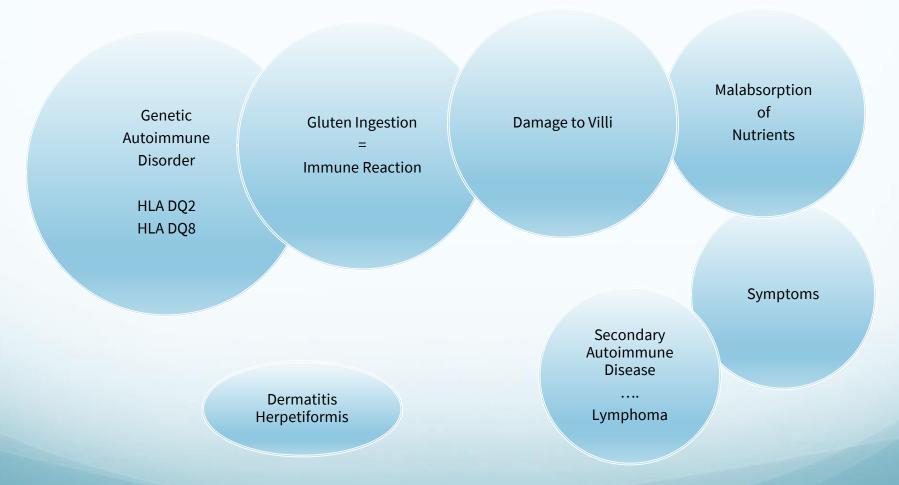
Social Life

Q&A











Gluten in the Gut

Wheat - Rye - Barley - Oats*

Ingestion Gluten

Enzymatic Breakdown (Zonulin)



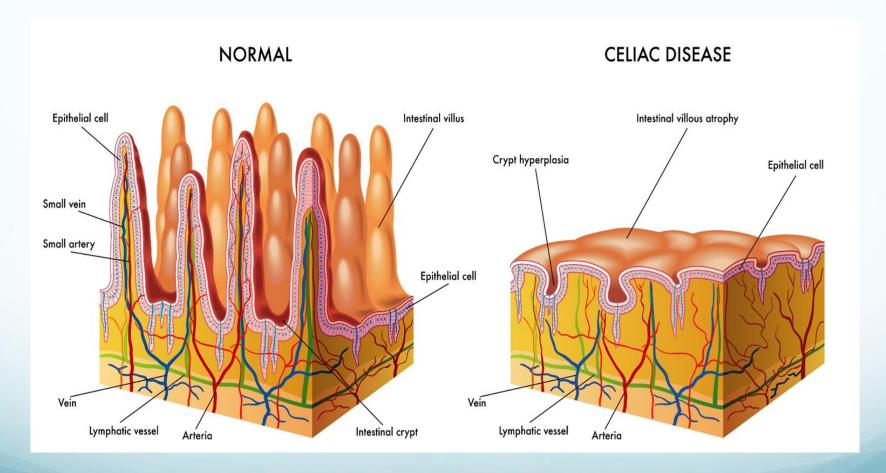


Please refer to Gluten Free 24/7 app, Pocket Dictionary or Celiac.ca for complete list of Gluten containing ingredients.

*Oats may not be suitable for all Celiacs

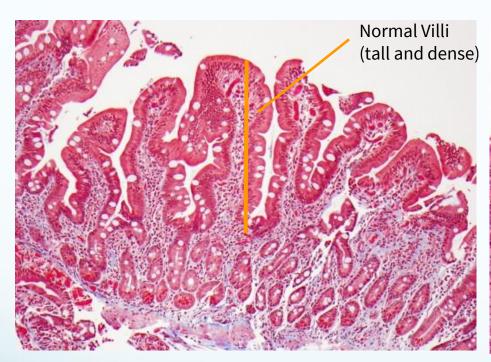


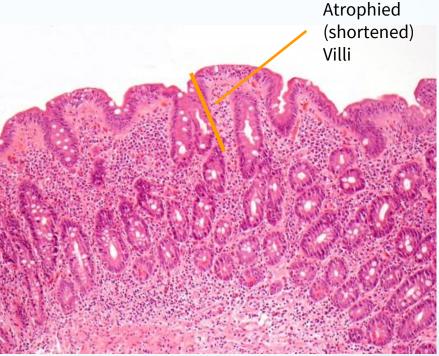
Villi - Normal vs. Celiac











Normal Villi

Villi of Celiac Patient

CD – What causes it? Genetics --> Exposure --> Trigger



- Genetic Predisposition
 - > HLA-DQ2 & HLA-DQ8
- Gluten Ingestion
 - > resulting immune response
- Environmental Factors
 - > trigged by major life event
 - gut microbiome



Celiac Disease Facts

- The onset can occur at any time
- It is a lifelong disease with NO current cure
- CD affects ~ 1% of the population
 May be as high as ⅓ in certain populations
 Highly under diagnosed, only ~1/250 Celiacs know they are Celiac
 - 56% of Celiacs are SILENT Celiacs, seemingly without gut based symptoms
- Chance of developing CD in relatives is high, and all 1st degree relatives should be screened
 - 1st degree is 5 20%
 - 2nd degree is 5 8%
- On average it takes 6-10 years before a correct diagnosis is made
 It used to be ~14 years in the early 2000's
- A strict GF Diet is the only way to manage CD and DH
 - Even a tiny amount of gluten will damage your intestines, with or without
 symptoms/pain



CD Symptoms



- There are approx. 300 symptoms that can impact any part or organ of the body such as gastrointestinal, skin, reproductive, oral, psychological, joint, neurological, nutritional deficiencies etc....
- The # of symptoms and intensity vary among each person

Classic Celiac Disease: GI symptoms, anemia, failure to thrive

Silent Celiac Disease: Few symptoms until educated

Atypical Celiac Disease: Gluten ataxia, seizures, broken bones



CD – (Mis)Diagnosis



- Celiac Disease symptoms overlap many other conditions often leading to a <u>misdiagnosis</u> of *Crohn's*, *Colitis*, *Lupus*, *IBS*, *Unexplained Infertility*, *Fibromyalgia*, *Anemia etc*.
- A few examples of associated conditions that Celiac patients also have:
 - > Type 1 Diabetes (4 8 %)
 - ➤ Autoimmune Thyroid Disease (2 5 %)
 - ➤ Down Syndrome (2 5 %)
 - ➤ Unexplained Infertility (4 -8 %)
 - ➤ Multiple Sclerosis (11%)

What do I do now?



If Celiacs is SUSPECTED but Unconfirmed - Continue to eat gluten -

- 1) Complete Blood Test
- 2) Complete Intestinal Biopsy

Celiacs Confirmed - Stop eating gluten -

- Review current medications and supplements*
 Acute/singular tx vs. long term chronic meds
- 2) Complete Nutritional Counselling with a registered dietician
- 3) Re-organize your kitchen, educate family members sharing your kitchen
- 4) Arrange for DEXA scan

What do I do now? cont'd



Celiacs Confirmed - Stop eating gluten -

- 9) Encourage 1st (2nd) degree relatives to be tested
- 10) Continue or begin to exercise
- 11) Join support groups such as the Canadian Celiac Association and/or online reputable groups
- 12) Repeat blood work within 3 to 6 months after diagnosis; annually after that
- Repeat intestinal biopsy if symptoms do not improve after 6-12 months, or screen for other associated disorders
 Refractory Celiac Disease"



What's under the Gluten Umbrella?

	Celiac Disease	Non Celiac Gluten Sensitivity	Wheat Allergy
Autoimmune	*		
Intolerance		*	
Allergy			*
Genetic	*		
Dermatitis Herpetiformis	*		
Villi Damage	*		
IBS Symptoms	*	*	*
~% of pop.	1	0.6 – 6	0.1
Testing	*		*

Current Research

cca acmc

Unfortunately, there are no drugs approved to treat or cure Celiac Disease.



Research is ongoing, and there are a number of active clinical trials.

One of the best ways to help is to volunteer for a trial if you are able to, or participate in research studies online. Please see some of the links below for further information.

www.beyondceliac.org www.celiac.org www.clinicaltrials.gov



Resources

Please refer to "Celiac 101 Resource Sheet"

for further information.



Daily Living – Limits and Labelling



Allowable tolerance of gluten in food to be considered safe and to meet a Gluten Free claim is 20 ppm.

CCA provides this clarification for label reading:

Contains

= allergen is present

May Contain = allergen might be present, for wheat allergy

Made in Facility = hard to determine if present, very small trace amounts



Daily Living - Shopping



The Gluten Free Certification Program
is the only Cdn voluntary certification program,
manufacturer's are listed on the CCA website



- Recheck "ingredient list" and "labels" of food every time you purchase them
- "When in doubt go without"
- Avoid Bulk Bins
- Prepackaged foods not required to include allergy label i.e.) mini roasted chickens



Daily Living - Kitchen

It is important to prevent contamination of GF food with residue from gluten containing foods!!

- Airborne particles of gluten containing foods can contaminate GF foods.
 - Use boldly labelled, separate, air tight containers
- Designate a separate cupboard (top shelves) and preparation area in your kitchen for GF foods
- Thoroughly clean all food preparation surfaces, cooking surfaces, and cooking utensils
- Use a dedicated GF toaster or toaster bags

Daily Living - Cooking



- Always wash hands before handling GF products
- Prepare GF food before other food
- Use individual portions and/or squeeze bottles for condiments
- Prevent cross contamination when using:
 - Thermometers, BBQ grill and cooking utensils
- Use fresh water for boiling, poaching and steaming
- BBQ grill and utensils could be an issue



Daily Living – Oats, Fibre & Sugar

- Oats are naturally GF but can be contaminated through harvesting and packaging
- Purchase only certified GF oats and introduce to diet as per CCA guidelines (e.g. Only Oats brand)
- Most GF products
 - > HIGH in sugar
 - > LOW in vitamins, minerals & fibre



Daily Living – Non-food Items



- Gluten protein cannot pass through the skin.
- Many people with CD and DH use GF hygiene products (hand soaps, lotions, hair care products) as most have less harsh chemicals.
- OK to touch food (human or pet) with gluten in it but prevent cross contamination with your GF food.
- Any food or non-food item that you ingest should be GF
 - > Medication, vitamins and supplements
 - Lipsticks, lip gloss, chap-stick
 - Mouthwash, toothpaste, hairspray, hand sanitizer
 - Play-doh, paper mâché

straws in Canada are GF

- Ensure all health professionals are aware you have CD
- Kissing

Note: Paper

Impact To Social Life – Family & Friends



- Inform them of your diagnosis
- Provide them with information
- Offer to host dinners
- Offer to bring food when invited to house parties
- Be the 1st in line at potlucks and the snack table
- Do not expect everyone to accommodate you



Impacts To Social Life – Restaurants



- Gluten free/Gluten friendly/Gluten Aware
- Always precheck the menu
- Advise server you are Celiac
- "Glutened", call the restaurant and discuss this with the Chef or Owner.
- Be very careful of deep fried foods, buffets and kitchens that have airborne particles





Impacts To Social Life - Travel

- Always plan ahead
- Use translation cards/apps
- What are the GF standards and logos
- Always carry GF snacks
- Make sure you have a fridge or a kitchenette

















Certified

Gluten-Free

Impacts to Social Life - Alcohol

	Safe	Not Safe	Research
Distilled Alcohol			
Whiskey, Scotch, Brandy, Gin, Rum, Tequila, Vodka	*		*
Liqueurs (Cordials)			
Amaretto, Baileys, Cointreau, Grand Marnier, Kahlua	*		*
Wines			
Red, White, Rose, Sparkling, Port	*		
Beers			
Gluten Containing, Gluten Reduced, Deglutened		*	
Gluten Free	*		
Hard Ciders			
Fruit Based	*		*
Specialty Premixed Alcoholic Beverages			
Hard Lemonade, Coolers, Wine Coolers, Caesars			*



Q&A's and Questionnaire

Don't forget to sign up for the Calgary Chapter quarterly newsletter.

Email info@calgaryceliac.ca



References & Resources

- Pgs 3, 5, 8, 15, 21, 23, 24, 27 Pictures copied from CCA Toolkit (Shutterbug)
- Pg 6 Villi picture credit to <u>www.universityhealthnews.com</u>
- Pg 7 Villi biopsy credit to CCA 2017 national presentation
- Pgs 8-14, 18-24 CCA & Beyond Celiac (<u>www.beyondceliac.org</u>)
- Pg 9 Picture copied from Bing website (author unknown)
- Pg 10 Picture copied from <u>www.clipart-library.com</u>
- Pg 11 Verywellhealth.com (MS study)
- Pg 16 Alberta Health Services
- Pg 17 Limits & labelling details credit to Canadian Celiac Association (<u>www.celiac.ca</u>)
- Pg 25 various logos copied from Bing.com, CCA, and various European Celiac websites
- Pg 26 Shelley Case "Gluten Free the Definitive Resource Guide"
- Pg 27 https://clinicaltrials.gov, www.pvpbio.com, https://clinicaltrials.gov, www.pvpbio.com, <a hre
- Misc....
 - www.Celiac.com, www.Glutendude.com, www.Gluten.org (gluten intolerance group)
 - celiacdiseasecenter.columbia.edu (Columbia University) Pg 35 Burger JPW, de Brouwer B, IntHout J, et al. Systematic review with meta-analysis: dietary adherence influences normalization of health-related quality of life in coeliac disease. Clin Nutr. 2017;36(2):399-406.
- Resource handout credit to Calgary Chapter (CCA) 101 volunteers
- Symptoms handout credit to CCA