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Follow-Up of the Patient: Finding a Balance

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"It is far more important to know what sort of person has the disease than what sort of disease the person has."

- Hippocrates



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Four Strictly Adherent Patients

- John
 - Reads labels
 - Restaurants: only orders "safe" foods
 - Eats gluten-free oats
- Paul
 - Reads labels
 - Asks extensive questions at restaurants
 - Avoids all oats
- George
 - Reads labels
 - Does not eat at restaurants
 - Avoids all oats
- Ringo
 - Reads labels
 - Does not eat at restaurants
 - Avoids all packaged foods
 - Does not keep any gluten in the home



A Simple Validated Gluten-Free Diet Adherence Survey for Adults With Celiac Disease

- Derivation of the Celiac Disease Adherence Test
- Gold standard: standardized expert interview
 - Single dietitian, >10 years experience
 - 3-day food record
 - Food ingredient quiz
 - Dynamic clinical interview
- 6 point scale: composite of quantity and frequency of gluten exposure

A Simple Validated Gluten-Free Diet Adherence Survey for Adults With Celiac Disease

1. Excellent

- Participant eats gluten fewer than 3 times per year
- Uses only celiac-friendly restaurants or asks thorough questions when dining out
- Follows “when in doubt, leave it out” motto
- Review of diet reveals no obvious gluten sources
- Checks medications, supplements, and body care products that enter nose, eyes, and mouth
- Reads labels well
- Has eliminated cross-contamination potential in kitchen

3. Fair

- Participant eats gluten 2 to 3 times per month
- Does not ask questions in restaurants or when dining out—guesses or takes chances
- Checks some but not all medications, supplements, and body care products
- Shows some confusion over label reading
- Review of diet shows some obvious gluten exposure
- Consumes gluten on occasion—intentionally or unintentionally—per diet/lifestyle recall
- May rely on partner/family member for some caregiving regarding diet
- Has not eliminated cross-contamination potential in kitchen
- May have mental or behavioral issues that make following the diet more difficult
- May have language skills that make dietary adherence more difficult

Leffler, et al. Clin Gastroenterol Hepatol. 2009;7:530-6.

A Simple Validated Gluten-Free Diet Adherence Survey for Adults With Celiac Disease

Table 4. CDAT

Question
Have you been bothered by low energy level during the past 4 weeks?
Have you been bothered by headaches during the past 4 weeks?
I am able to follow a GFD when dining outside my home
Before I do something I carefully consider the consequences
I do not consider myself a failure
How important to your health are accidental gluten exposures?
Over the past 4 weeks, how many times have you eaten foods containing gluten on purpose?

≥13: Inadequate Adherence

Sensitivity: 73.7%

Specificity: 76.7%

PPV: 50%

NPV: 90.2%

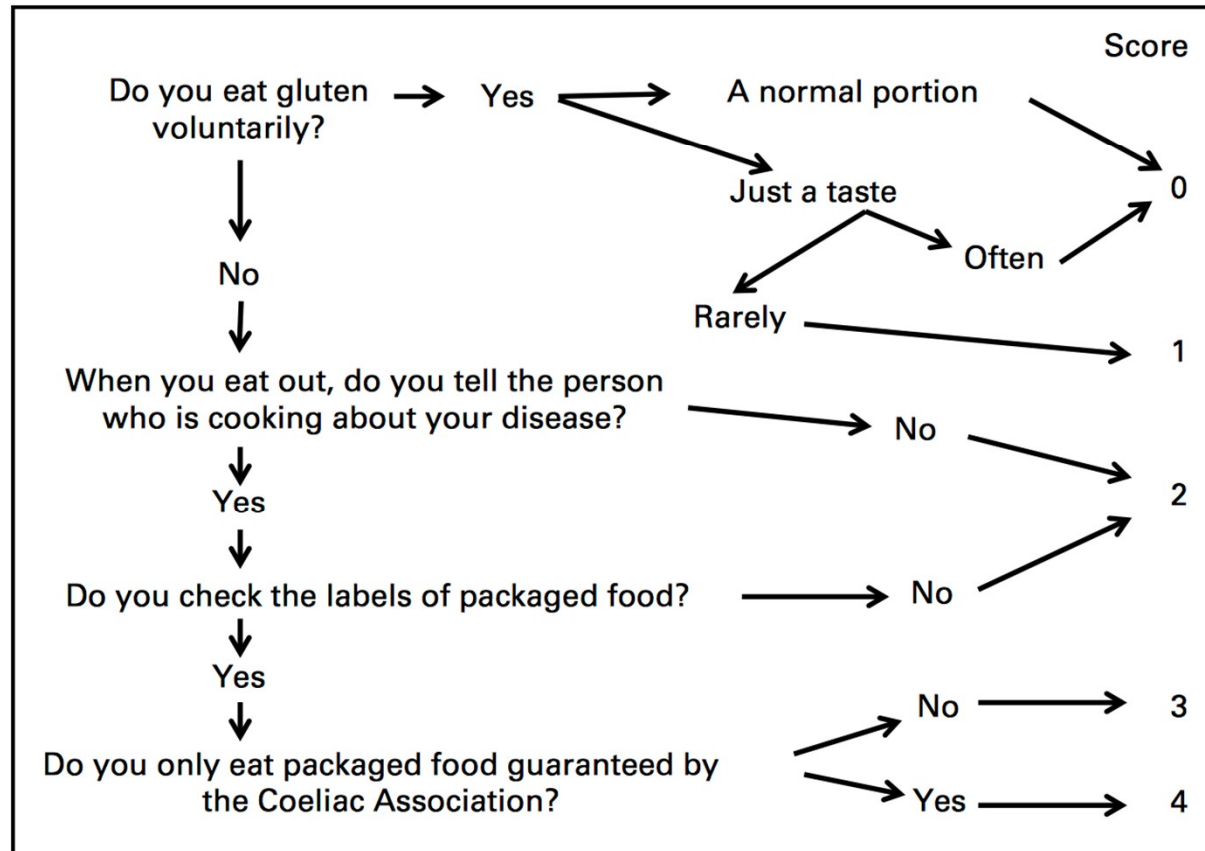
Gluten Free Eating Assessment Tool (GF-EAT)

Living gluten-free: adherence, knowledge, lifestyle adaptations and feelings towards a gluten-free diet

J. A. Silvester,^{1,2} D. Weiten,³ L. A. Graff,^{1,4} J. R. Walker^{1,4} & D. R. Duerksen^{1,5}

1. Please describe your *current* diet
 - i Unrestricted diet
 - i Unrestricted gluten, other foods restricted
 - i Gluten-free diet sometimes
 - i Gluten-free diet most of the time
 - i Usually gluten-free with rare intentional gluten consumption
 - i Usually gluten-free with rare accidental gluten consumption
 - i Trying to follow a gluten-free diet but not always sure
 - i Strict gluten-free diet

A score that verifies adherence to a gluten-free diet: a cross-sectional, multicentre validation in real clinical life



A score that verifies adherence to a gluten-free diet: a cross-sectional, multicentre validation in real clinical life

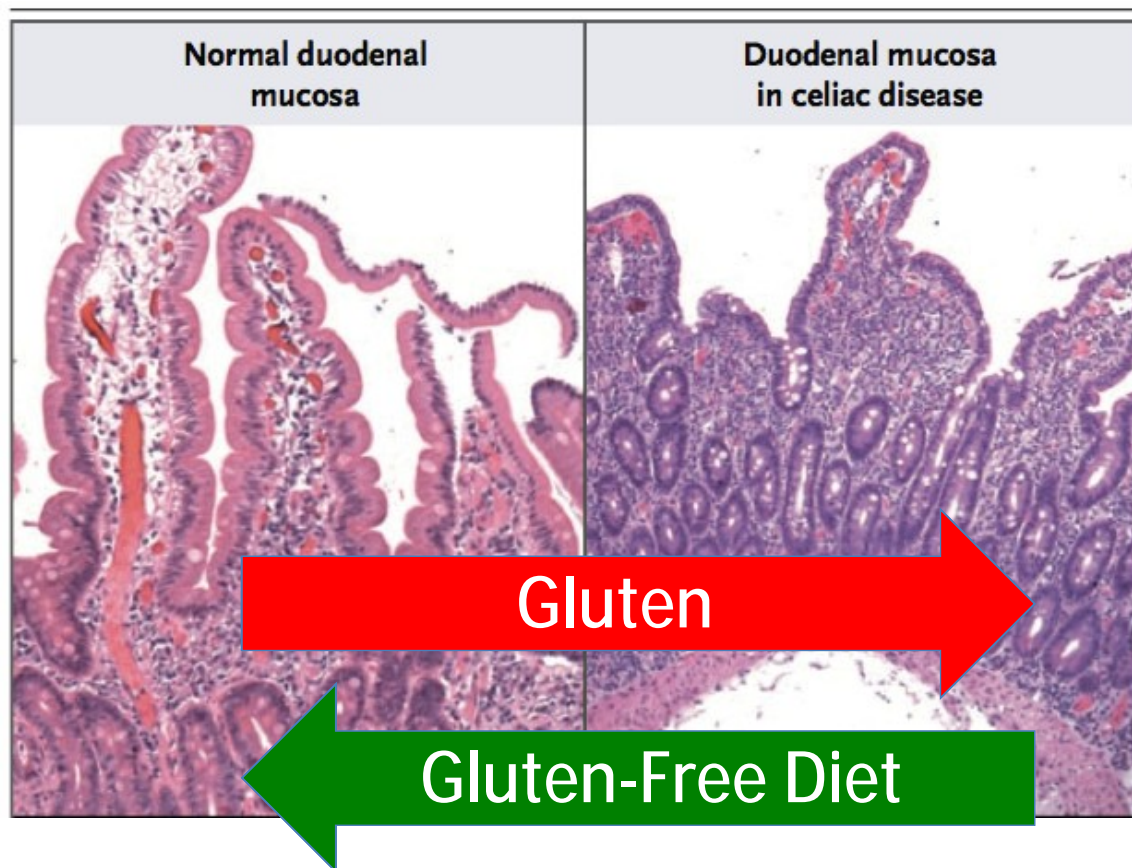
GFD score	<i>n</i>	Villous atrophy on a GFD		<i>P</i> *	<i>P</i> †	OR‡	95 % CI	<i>P</i>
		<i>n</i>	%					
0–1	18	11	61	<0.001	<0.001	–	0.00, 0.75	–
2	7	1	14			0.04		0.024
3–4	116	8	7			0.02		<0.001

- Short, easy to administer
- Time period?
- “Often,” “Rarely”
- “The Coeliac Association”



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Green and Cellier. N Engl J Med 2007;357:1731-1743.



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Consequences of Failing to Heal

Outcome	Hazard Ratio (95% CI)	Interpretation
Mortality (Aliment Pharmacol Ther 2013;37:332-9.)	1.01 (0.86-1.19)	No increased risk
Ischemic Heart Disease (PLOS One 2015; 30;10:e0117529.)	0.97 (0.73-1.30)	No increased risk
Low Birth Weight (Clin Gastroenterol Hepatol 2015;13:1111-7.)	0.98 (0.41-2.39)	No increased risk
Lymphoproliferative Malignancy (Ann Intern Med 2013;159:169-75.)	2.26 (1.18-4.34)	Increased risk
Hip Fracture (J Clin Endocrinol Metab 2014;99:609-16.)	1.67 (1.05-2.66)	Increased risk

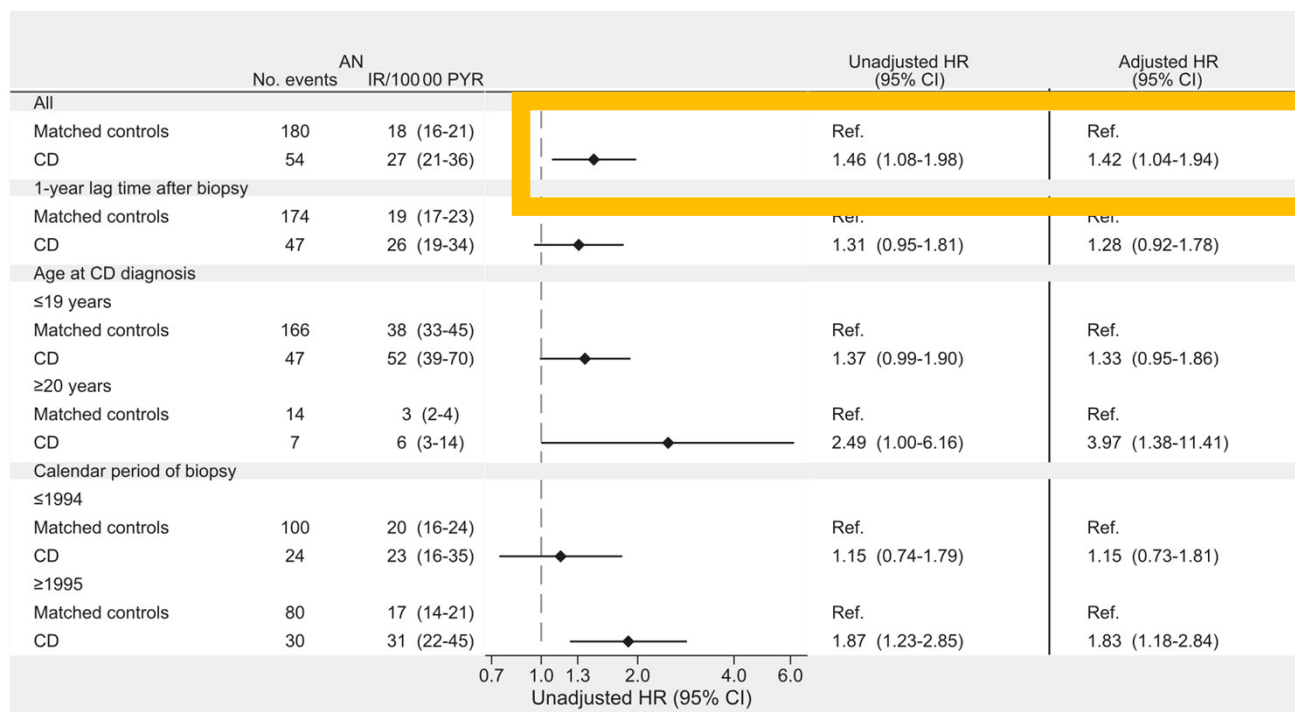
Anxiety after coeliac disease diagnosis predicts mucosal healing: a population-based study

Jonas F. Ludvigsson^{1,2,3,4}  | Benjamin Lebwohl⁴ | Qi Chen¹ | Gabriella Bröms^{5,6,7} |
Randi L. Wolf⁸ | Peter H. R. Green⁴ | Louise Emilsson^{7,9,10} 

- Mucosal healing associated with new diagnoses of anxiety (HR 1.49; 95%CI 1.12-1.96)
- History of anxiety associated with greater odds of mucosal healing (OR 2.51; 95% 1.33-4.74)
- Vigilance **↔** Anxiety?



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Marild, et al. Pediatrics. 2017;139.



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- Avoidant Restrictive Food Intake Disorder (DSM-V: 2013)
 - Persistent difficulty in meeting nutritional needs despite a lack of body image or weight concern
- Orthorexia Nervosa
 - Excessive preoccupation with healthy eating

Non-Celiac Avoiders of Gluten Often Avoid Other Foods

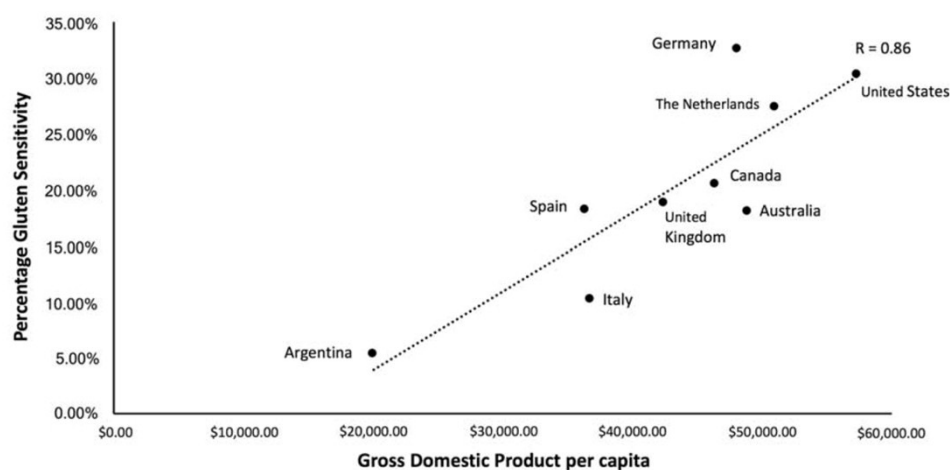


TABLE 3. Food Avoidance in Celiac Disease Versus Gluten Sensitivity

Food Avoidance	n (%)		<i>P</i>
	Celiac Disease	Gluten Sensitivity	
Shellfish	146 (2.3)	152 (5.9)	<0.0001
Eggs	177 (2.7)	211 (8.1)	<0.0001
Dairy	588 (9.1)	667 (25.7)	<0.0001
Other	230 (3.6)	231 (8.9)	<0.0001
Peanuts	212 (3.3)	234 (9.0)	<0.0001
Tree nuts	171 (2.6)	184 (7.1)	<0.0001
Soy	431 (6.7)	529 (20.4)	<0.0001

Zylberberg, et al. J Clin Gastroenterol. 2018;52:696-702.

Hypervigilance to a Gluten-Free Diet and Decreased Quality of Life in Teenagers and Adults with Celiac Disease

Randi L. Wolf¹  · Benjamin Lebwohl² · Anne R. Lee² · Patricia Zybert¹ · Norelle R. Reilly² · Jennifer Cadenhead¹ · Chelsea Amengual¹ · Peter H. R. Green²

- Definition: excellent adherence score for all 3 days of 24 hour dietary recalls
 1. **Excellent**
 - Participant eats gluten fewer than 3 times per year
 - Uses only celiac-friendly restaurants or asks thorough questions when dining out
 - Follows “when in doubt, leave it out” motto
 - Review of diet reveals no obvious gluten sources
 - Checks medications, supplements, and body care products that enter nose, eyes, and mouth
 - Reads labels well
 - Has eliminated cross-contamination potential in kitchen

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	Extremely Vigilant (n =12)	Less Vigilant (n=38)	p value
Overall CDQOL	64.2	77.2	0.004
Subscales			
Dysphoria	85.4	94.1	0.016
Limitations	56.7	73.8	0.004
Health Concerns	65.0	71.1	0.36
Inadequate Treatment	53.1	74.0	0.012
Knowledge	5.7	5.1	0.035

Research Article

Development and Validation of the Coeliac Disease Food Attitudes and Behaviours Scale

• Coeliac disease food attitudes and behaviors scale (CD-FAB)

	Strongly agree (7)	Agree (6)	Somewhat agree (5)	Neither agree nor disagree (4)	Somewhat disagree (3)	Disagree (2)	Strongly disagree (1)
<i>Because of my coeliac disease...</i>							
I get concerned being near others when they are eating gluten							
I am afraid to eat outside my home							
I am afraid to touch gluten-containing foods							
I get worried when eating with strangers							
I find it hard to eat gluten-free foods that look like the gluten-containing foods that have made me ill in the past							
I will only eat food that I have prepared myself							
My concerns about cross-contamination prevent me from going to social events involving food							
<i>Despite having coeliac disease...</i>							
I enjoy going out for meals as much as I did before my diagnosis*							
I am comfortable eating gluten-free food from other people's kitchens*							
Being contaminated by gluten in the past has not stopped me from enjoying restaurants*							
If I ask questions, I can normally find gluten-free food to eat*							

Reverse items with * and add all scores to make total score.

Satherley, et al. Gastroenterol Res Pract. 2018; in press.

Research Article

Development and Validation of the Coeliac Disease Food Attitudes and Behaviours Scale

	Low scorers	Medium scorers	High scorers	F statistic
<i>Demographic outcomes</i>				
Age (years)	32.3	29.0	29.0	1.75
BMI	22.6	22.7	21.9	0.29
<i>Psychosocial outcomes</i>				
Depression	8.6	13.5 ^a	13.5 ^b	3.81*
Anxiety	6.6	10.1 ^a	11.6 ^b	4.34*
Stress	11.6	16.9 ^a	15.8 ^b	4.13*
Total DASS-21	26.7	40.5 ^a	40.9 ^b	5.3*
FNS	27.4	31.3	33.9 ^b	10.7**
Total quality of life	71.1	57.9 ^{aa}	53.6 ^{bb}	16.03**
Limitations	31.4	24.4 ^{aa}	21.9 ^{bb}	17.32**
Health	17.1	13.6 ^{aa}	12.4 ^{bb}	10.92**
Treatment	5.5	5.5	5.5	0.032
Dysphoria	17.1	14.6 ^a	14.2 ^{bb}	7.12**

* $p = 0.05$; ** $p < 0.001$ for ANOVA across all three groups; ^a $p = 0.05$; ^{aa} $p < 0.001$ for t -test across low and medium scorers; ^b $p = 0.05$; ^{bb} $p < 0.001$ for t -test across low and high CD-FAB scorers.

Trace gluten contamination may play a role in mucosal and clinical recovery in a subgroup of diet-adherent non-responsive celiac disease patients

Table 1 Products allowed/disallowed in the Gluten Contamination Elimination Diet (GCED), targeting the elimination of gluten cross-contamination

	Allowed	Not allowed
Grains	Plain, unflavored, brown and white rice	Millet, sorghum, buckwheat or other inherently gluten-free grains, seeds, or flours
Fruits/Vegetables	All fresh fruits/vegetables	Frozen, canned or dried
Proteins	Fresh meats	Lunch meats
	Fresh fish	Ham, bacon
	Eggs	Other processed, self-basted or cured meat products
	Dried beans	
	Unseasoned nuts in the shell	
Dairy	Butter, yogurt (unflavored), milk (unflavored), aged cheeses	Seasoned or flavored dairy products
		Processed cheeses
Condiments	Oils, vinegar, honey, salt	Flavored and malt vinegars
Beverages	100% fruit/vegetable	
	Gluten-free supplemental formulas	
	Gatorade, milk, water	

Trace gluten contamination may play a role in mucosal and clinical recovery in a subgroup of diet-adherent non-responsive celiac disease patients

Patient	Serology before ¹	Serology after ¹	Symptoms before	Symptoms after	Biopsy before	Biopsy after
1	High	Neg	Abdominal pain	None		
2	High	Neg	Inadequate weight gain	None		
3	High	Neg	Diarrhea, fatigue	None	Marsh 3a (RCD)	Refused
4	High	Neg	Constipation	None	Marsh 3 (RCD)	
5	High	Weak Pos	None	None	Marsh 3a	Marsh 1
6	High	Weak Pos	Elevated transaminases	None	Marsh 2	
7	High	Weak Pos	Constipation, fatigue	None		Marsh 1
8	High	Weak Pos	Diarrhea	None	Marsh 1	
9	High	High	Diarrhea, abdominal pain, bloating	None	Marsh 3a (RCD)	Marsh 1
10	High	High	Fatigue, anxiety	Fatigue, anxiety		Marsh 3a (RCD1)
11	Weak Pos	Neg	Diarrhea, abdominal pain	None	Marsh 2	Marsh 0
12	Weak Pos	Neg	Diarrhea	None	Marsh 1	
13	Weak Pos	Weak Pos	Inadequate weight gain	Inadequate weight gain		
14	Neg	Neg	Diarrhea, bloating, fatigue	None	Marsh 0	
15	Neg	Neg	Abdominal pain, fatigue	None	Marsh 3a (RCD), VCE: Atrophy	VCE : normal
16	Neg	Neg	Diarrhea, weight loss	None	Marsh 3b (RCD)	Lost to follow-up
17	Neg	Neg	Diarrhea, abdominal pain, bloating	Diarrhea, abdominal pain, bloating	Marsh 3a (RCD)	VCE : atrophy

Hollon, et al. BMC Gastroenterol. 2013;13:40.



Figure 1 Proposed diagnostic algorithm for non-responsive celiac disease. 1. Dietary compliance should be assessed by an experienced dietitian to rule-out continued gluten exposure. 2. Consider colonoscopy with biopsies if symptoms clinically warrant. 3. To include testing for pancreatic insufficiency, small bowel bacterial overgrowth, lactose intolerance (based on clinical symptoms). EGD, esophagogastroduodenoscopy; RCD, refractory celiac disease; RCD1, refractory celiac disease type 1; RCD, refractory celiac disease type 2; GFD, gluten-free diet.



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Skepticism Regarding Vaccine and Gluten-Free Food Safety Among Patients with Celiac Disease and Non-celiac Gluten Sensitivity

Loren G. Rabinowitz^{1,6} · Haley M. Zylberberg^{1,6} · Alan Levinovitz² · Melissa S. Stockwell^{3,4} · Peter H. R. Green^{1,6} · Benjamin Lebwohl^{1,5,6}

Question	Answer	NCGS (%)	CD (%)	<i>p</i>
Are vaccines safe for CD pts?	No	41.3	26.4	.0001
Are you refusing vaccination?	Yes	30.9	24.2	.007
Are you refusing GMO foods?	Yes	47.0	27.8	.0001
Is your diet based only on organic products?	Yes	28.6	12.2	.0001
Is a gluten bad for everyone?	Yes	31.3	16.3	.0001
Is GFD improving energy and concentration?	Yes	40.3	20.7	.0001



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"Is Coffee Gluten-Free?"

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About 251,000,000 results (0.56 seconds)

According to Celiac Disease Foundation (CDF), **coffee** is **gluten-free** and safe for people with celiac disease to drink. ... The researchers concluded that drinking **pure coffee** that has not been contaminated with **gluten** may be safe for those with celiac disease or **gluten sensitivity**. May 12, 2018

[Can You Drink Coffee With a Gluten Free Diet? | Healthy Eating | SF ...](https://healthyeating.sfgate.com/can-drink-coffee-gluten-diet-5746.html)
<https://healthyeating.sfgate.com/can-drink-coffee-gluten-diet-5746.html>


www.glutenfreesociety.org

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Is Coffee Gluten-Free? (Not Always!) - Verywell Health
<https://www.verywellhealth.com> › ... › Digestive Health › Celiac Disease › Nutrition
Jun 18, 2018 · Yes, There Could Be Gluten in Your Coffee. Of course, it's also possible that you are, in fact, reacting to **gluten** in your **coffee**. Even plain **coffee** beans can be cross-contaminated if they're processed in a shared facility or on equipment that also processes **gluten**-containing ingredients.

Should celiacs drink coffee, whether it's gluten free or not? - Gluten Dude
<https://glutendude.com> › Celiac
Plus the article says it's still possible to be gluten sensitive and not cross react to **coffee**. But you'll have to do some expensive lab testing with a knowledgeable ...

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"Maltodextrin Gluten"

Top 10 ingredients you really don't need to worry ... - Gluten-Free Living

<https://www.glutenfreeliving.com/gluten.../top-10-ingredients-you-really-dont-need-t...> ▼

Jan 5, 2016 - Why it's on worry lists: **Maltodextrin** can be made from a variety of starches, including corn, potato, rice or wheat. Why you don't need to worry: The source does not matter because **maltodextrin** is such a highly processed ingredient that the protein is removed, rendering it **gluten** free.

Is Maltodextrin Gluten-Free? | BeyondCeliac.org

<https://www.beyondceliac.org/gluten-free-diet/is-it-gluten-free/maltodextrin/> ▼

The ingredient **maltodextrin** is **gluten**-free, despite including the word "malt," which is typically an indication that barley is used. **Maltodextrin** is a common food additive used in food production. ... **Maltodextrin** is typically **gluten**-free even when derived from wheat, due to the nature of its processing.

Maltodextrin - Gluten Free Dietitian

<https://www.glutenfreedietitian.com/maltodextrin/> ▼

Dec 7, 2007 - There seems to be a commonly held misconception about the ingredient **maltodextrin** and how it will be listed on the food label. Hopefully the ...

Gluten-Free 101: What You Need to Know - Celiac Disease Foundation

<https://celiac.org/blog/2016/01/gluten-free-101-need-know/> ▼

Jan 31, 2016 - **Gluten**-free ingredients you don't need to avoid: caramel color, **maltodextrin**, and maltose (these are all made from corn), dextrose, glucose ...

Is maltodextrin gluten free? - Canadian Celiac Association

www.celiac.ca/b/?wp_super_faq=is-maltodextrin-gluten-free ▼

Jul 2, 2013 - **Maltodextrin** is a highly processed starch product. Most **maltodextrin** is made from corn but it may also be made from tapioca or wheat. Even if the product is made from wheat, it is so highly processed that no wheat protein remains and it is considered safe for people with celiac disease and **gluten** sensitivity.

Q. I'm on a gluten-free diet. Does maltodextrin contain gluten ...

[https://foodwatch.com.au/Medical Diets](https://foodwatch.com.au/Medical-Diets) ▼

Jun 11, 2013 - A. Yes. It may contain small fragments of protein particles related to **gluten**. **Maltodextrin** is a starch which is used as a thickener or texture ...



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Conclusions

- Levels of adherence vary between individuals and we should not assume “one size fits all”
- Several validated measures of adherence have been developed, each with its own limitations
- Adherence scales do not take into account effect of vigilance on quality of life
- Excessive precaution should be identified and corrected
- “Too strict” varies between patients



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