



Gluten-Free Diet Adherence

How Gluten-Free Are You Really?

Gluten-Free Eaters Unknowingly Consume Up to 5x More Gluten Than What is Considered Safe!

A typical adult on a 'regular' American diet eats about 5-15 grams of gluten daily (a whopping 5,000-15,000mg of gluten!). Gluten intake as low as 50mg daily can cause symptoms in people with celiac disease.

[In a recent study analyzing gluten peptides and antibodies, as well as intestinal biopsy results found that GF eaters consume upwards of 244mg of gluten per day- up to 5x more than safe! This is enough gluten to produce symptoms in strict GF eaters.]



How Strictly Should People with Non Celiac Gluten Sensitivity Adhere to a Gluten Free Diet?

'Safe' intake in non-celiac gluten sensitivity (NCGS) is likely to vary for each individual. One study of non-celiac GF eaters found they were:

- ✓ more likely to intentionally eat gluten
- ✓ less knowledgeable about a GF diet
- ✓ less likely to consult with health care professionals about their health than people with celiac
- ✓ possibly associated with a greater risk of death due to intestinal inflammation

Self-Reports of Adherence Versus Expert Evaluation of Adherence

Most studies of gluten-free diet adherence have measured adherence through self-report and/or questionnaires. Estimates of adherence range from 42-91% depending on population studied, definitions of adherence, and length of time on a GF diet.

[Self-reports have been shown to be inaccurate and to overestimate adherence compared to a trained nutritionist's evaluation.]



Gluten-Free Diet Labeling Reading – Safe, Unsafe, and Suspect Ingredients...It's Complicated!

Label reading for gluten ingredients in foods can be confusing, even for long time GF eaters.

One study asked GF eaters, who were **gluten-free for an average of six years**, to read food labels to identify ingredients that were safe (allowed), unsafe (to avoid), or 'suspect' (to question). Of the long time GF eaters:

- ✓ **not one person was able to correctly identify all 17 foods**
- ✓ **only 30% were correctly able to identify 14 foods!**

Gluten-free eaters should consult with a gluten-free expert to learn about label reading for safe, unsafe, and suspect ingredients, and be sure to check medications, dietary supplements, and body care products for gluten.

What's the Harm of an Occasional 'Cheat Day' or 'Cheat Meal' on a Gluten-Free Diet?

Avoid Harmful Symptoms

People with celiac who do not adhere to a strict gluten-free diet have higher mortality and poorer quality of life. Following a strict gluten-free diet helps avoid:

- bloating and gas
- constipation/diarrhea
- heart attack and heart disease
- infertility
- intestinal lymphoma and other cancers
- iron deficiency anemia
- kidney disease
- osteoporosis
- thyroid disorders
- unintentional weight loss
- urinary tract infections

Even "a Little" Can Hurt A Lot- Trace Gluten Contamination Can Slow Recovery!

It is estimated that up to 20% of people with celiac disease have persistent symptoms while on a gluten-free diet. The most common reason for persistent symptoms is continuing to ingest gluten, intentionally or unintentionally. Gluten-free eaters who have persistent symptoms despite strict adherence to the gluten-free diet may be reacting to gluten cross contamination:

- in their kitchen
- in restaurants
- in foods that are naturally gluten-free
- even in foods labeled gluten-free!

People with celiac disease and NCGS may require a 'gluten contamination elimination diet' for 3 to 6 months to help promote full recovery.



▶ Test, Don't Guess To Assess Gluten-Free Diet Adherence and Monitor Health Outcomes!

Testing is NOT "one and done"! The Celiac Foundation recommends routine testing to monitor gluten-free diet adherence and health outcomes in celiac. Currently the recommendation is test at diagnosis, 3-6 months later, at 12 months, and annually thereafter.



▶ Additional Laboratory Testing

The Celiac Disease Foundation also recommends additional laboratory testing at diagnosis including family screening, CBC, iron and anemia panel, thyroid tests, liver tests, vitamin D, and additional micronutrient testing.

If any tests are abnormal, retesting is recommended at the 3-6 month visit and annually thereafter. Until clinical guidelines and best practices are established for NCGS (and wheat sensitivity), follow the Celiac Disease Foundation *Celiac Disease Treatment and Follow-Up Guidelines*.

References

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Assessing Gluten Free Diet Adherence and Assigning an Adherence Rating*

Gluten Free Adherence Rating	Consumes Gluten Intentionally or Unintentionally	Ability to Follow GF Diet When Dining Out	GF Diet Knowledge, Label Reading, and Barriers	Trace/Cross Contamination	Checks for Ingredients in OTC/Rx Medications, Dietary Supplements, & Body Care Products
Excellent	Less than 3 times per year	Uses only GF restaurants or asks thorough questions when dining out	Reads labels well; adheres to " <i>When in doubt, leave it out</i> " motto	Has identified and eliminated <u>ALL</u> contamination sources	Checks <u>ALL</u> products
Good	1 time per month	Asks useful questions in restaurant	High level of confidence; reads labels well	Has identified and eliminated <u>most</u> contamination sources	Checks <u>ALL</u> products
Fair	2-3 times per month	Guesses or takes chances when eating out	Shows some confusion over diet and label reading	Has not identified and eliminated contamination sources	Checks <u>some</u> , <u>but not all</u> products
Poor	1-2 times per week	Does not ask questions when eating out	Lacks knowledge of GF diet and label reading, may partially or entirely rely on caregivers or others for GF diet, may have other barriers	Has contaminated kitchen area	Does not check products
Very Poor	More than 2 times per week	Does not ask questions when eating out	Lacks knowledge of GF diet and label reading, may partially or entirely rely on caregivers or others for GF diet, may have other barriers	Has contaminated kitchen area	Does not check products

*Criteria and ratings adapted from Celiac Dietary Adherence Test (CDAT)