

SYMPTOMS

Many people with celiac disease suspect that they have accidentally ingested gluten when they experience symptoms. Symptoms can mimic other conditions, so it can sometimes be hard to determine if gluten exposure has occurred.



Neurological symptoms like fatigue, headache, brain fog and tingling skin are common signs of gluten exposure for people with celiac disease and gluten sensitivity.



Many people associate gluten exposure with intestinal distress like bloating and abdominal pain. Not everyone with celiac disease has GI symptoms when they are exposed to gluten, and even those without symptoms may have intestinal damage.



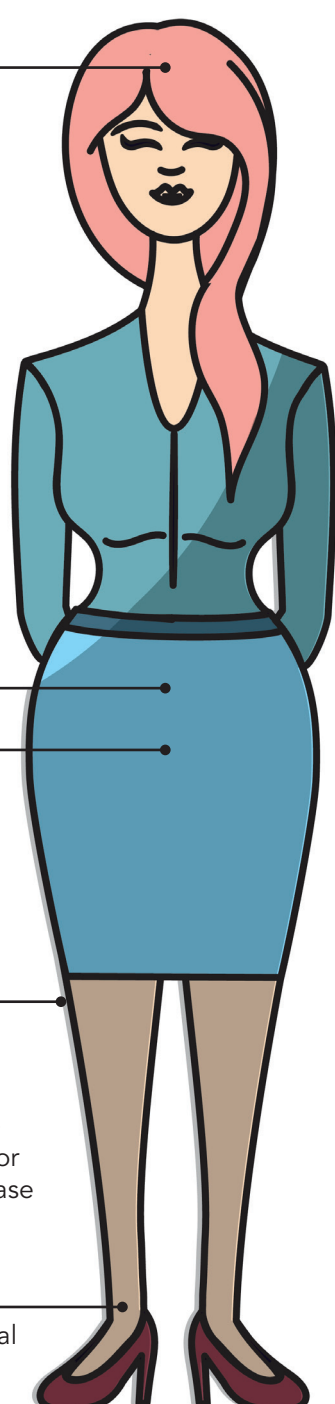
Cramping and diarrhea are also common symptoms for people who have been exposed to gluten.



People with dermatitis herpetiformis, a form of celiac disease that affects the skin, may get itchy rashes when they have ingested gluten. It is a common myth that gluten can break the skin barrier, so ingestion must occur in order for these symptoms to be related to a celiac disease immune reaction.



Joint pain can be another signal that accidental gluten ingestion has occurred. Not everyone with celiac disease experiences the same symptoms or severity of symptoms.

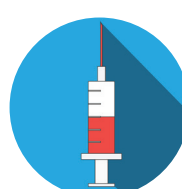


EVERYDAY RISKS



People with celiac disease face risks when they eat outside of the home and purchase processed foods. Gluten can be hidden in ingredients and can get into gluten-free food exposed to gluten-containing food or a shared preparation area. It's impossible to be 100% gluten-free and scientists have concluded a trace amount of gluten up to 20 parts per million is safe for most people with celiac disease. There are now testing kits available for home use that can test for gluten in food before it is consumed, but it is unclear how those tests align to food safety standards.

MONITORING TOOLS



MEASURING THE EFFECT OF GLUTEN
Doctors sometimes use blood tests to monitor antibodies triggered in those who have celiac disease when a damaging amount of gluten gets in the diet. The blood tests, which work well for diagnosis, are not foolproof in monitoring celiac disease but are currently the only ones available.



MEASURING THE AMOUNT OF GLUTEN IN THE BODY
New tests can actually measure gluten fragments—called GIPs—that are found in the urine and stool of anyone who eats gluten. GIPs can be detected in urine for 24 hours after gluten is ingested and in stool from 2-6 days after ingestion. Currently, urine tests are positive if you have consumed a fairly significant amount of gluten, while stool tests will pick up a trace amount.

LONG-TERM HEALTH IMPLICATIONS

ONGOING GLUTEN EXPOSURE HAS LONG-TERM HEALTH EFFECTS FOR PEOPLE WITH CELIAC DISEASE

4X INCREASE IN
EARLY DEATH

70%

24%

of people with celiac disease are exposed to gluten despite their best efforts to adhere to the gluten-free diet

of those diagnosed after age 10 suffer from other autoimmune diseases (also known as "autoimmune cascade")

1 in 5

CHILDREN STILL HAVE INTESTINAL DAMAGE AFTER 12 MONTHS OF EATING GLUTEN-FREE



SUMMARY OF ACG GUIDELINES FOR MONITORING CELIAC DISEASE

THE AMERICAN COLLEGE OF GASTROENTEROLOGY IS A PROFESSIONAL ASSOCIATION FOR GASTROENTEROLOGISTS IN THE UNITED STATES. THEIR GUIDELINES FOR CELIAC DISEASE WERE RELEASED IN 2013.

ACG guidelines recommend that people with celiac disease need to actively manage the condition by:

- Getting follow-up care from a doctor and dietitian knowledgeable about the disease
- Paying attention to symptoms and adherence to the gluten-free diet

The guidelines advise doctors treating patients with celiac disease to:

- Use patient reported information about symptoms and diet and blood tests to determine if celiac disease is under control, particularly looking for a return to normal blood test levels following diagnosis and adoption of the gluten-free diet
- Recommend an endoscopy to determine if intestinal damage is occurring in patients whose symptoms can't be controlled by the gluten-free diet

Despite these recommendations, a recent study by Beyond Celiac and other researchers found that more than one out of four celiac disease patients diagnosed at least five years ago have not had follow-up healthcare for the condition in the past five years.



WHAT'S WRONG WITH THIS PICTURE?

The guidelines for monitoring celiac disease are nearly five years old. Unfortunately, it takes more than 10 years from research to enter everyday practice. There are new tools available to detect gluten in food and to monitor accidental gluten exposure, such as using glutendetective.com. That means that the average gastroenterologist may not be aware of this new technology for a decade or more. Be proactive. Learn about these tools and work with your healthcare providers to use them appropriately to improve your long-term health outcomes.

RELEVANT RESEARCH

- Rubio-Tapia A, Kyle RA, Kaplan EL, et al. *Increased Prevalence and Mortality in Undiagnosed Celiac Disease*. *Gastroenterology*. 2009;137(1):88-93. doi:10.1053/j.gastro.2009.03.059. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2704247/>
- Herman M, Rubio-Tapia A, et al. *Clin Gastroenterol Hepatol* 2012; 10: 893
- Greco, Magazzu G, *Duration of exposure to gluten and risk for autoimmune disorders in patients with celiac disease*. SIGEP Study Group for Autoimmune Disorders in Celiac Disease.
- Leonard, Maureen & Weir, D.C. & Degroote, M & Mitchell, P.D. & Singh, P & Silvester, J.A. & Leichtner, A.M. & Fasano, Alessio. (2017). Value of IgA tTG in Predicting Mucosal Recovery in Children with Celiac Disease on a Gluten-Free Diet. 64. 286-291. 10.1097/MPG.0000000000001460.

www.BeyondCeliac.org



Is It Gluten?

uncover if you are truly gluten free



**Gluten
DETECTIVE**

GlutenDetective.com