



[ REALITY IS THE BEST MEDICINE ] HARRIET HALL

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## Understanding Gluten



Until a few years ago, few people had even heard of gluten. Now going on a gluten-free diet has become a popular fad. People diagnosed with celiac disease must avoid gluten to prevent symptoms, but others are avoiding gluten for questionable reasons—or for no reason at all. I watched a TV program where the host stopped random people on the street to ask them about gluten. Many of them didn’t even know what gluten was, but nevertheless, they were convinced it was unhealthy and should be avoided. Although only 1 percent of Americans have celiac disease, 30 percent of Americans reported that they were trying to avoid gluten. An article on NPR called it “the dietary

boogeyman du jour” (Fell 2015).

### Celiac Disease

Other names for celiac disease are celiac sprue, non-tropical sprue, and gluten-sensitive enteropathy. The classic symptoms are diarrhea, abdominal pain, bloating, weight loss, malabsorption, and failure to thrive. Other gastrointestinal symptoms may include mouth sores, gastroesophageal reflux, and recurrent nausea and vomiting. There are countless extraintestinal manifestations, including rash, arthritis, amenorrhea, anemia, chronic fatigue, osteoporosis, depression, infertility, epilepsy, fractures, neuropathy,

miscarriage, and more.

Screening is not recommended. No test is diagnostic; the diagnosis is established by a combination of blood tests, esophagogastroduodenoscopy with small bowel biopsy, and the patient’s response to a gluten-free diet. It has been estimated that up to 83 percent of Americans with celiac disease remain undiagnosed or misdiagnosed (Beyond Celiac n.d.). Some patients have no symptoms but still have pathognomonic damage to the small intestine. Some groups are at increased risk: first-degree relatives of patients with celiac disease (10 percent risk), type 1 diabetics (2–8 percent), people with certain genetic disorders (Down syndrome 8 percent,

Turner syndrome 6 percent, etc.), and those with immunoglobulin deficiency (2–8 percent) and autoimmune thyroid disorders (6 percent) (Williams et al. 2022).

Blood tests are useless if patients have already chosen to go on a gluten-free diet; they must first go back on a gluten-containing diet for two to six weeks. The best blood test for screening those at risk is an immunoglobulin A tissue transglutaminase test (IgA tTG), which has a high sensitivity (95 percent) and specificity (95 percent). Total IgA levels should be measured, because 2–3 percent of celiac patients will have an IgA deficiency. Low IgA levels should be followed by IgG testing (IgG deamidated gliadin peptides and IgG tTG). And the IgA endomysial antibody test is useful for confirmatory testing. Human leukocyte antigen (HLA) alleles DQ2 and DQ8 are not used for diagnosis, but they represent a major genetic risk factor, and a negative test for both rules out celiac disease, with a negative predictive value of greater than 99 percent.

In celiac disease, there is atrophy and flattening of the villi in the small intestine, causing malabsorption. Biopsies demonstrate this atrophy as well as other typical pathological findings of celiac disease. Endoscopy can be done as an outpatient. Four to six biopsies are taken from the duodenum. For patients unwilling to undergo endoscopy, another option is video capsule endoscopy. One in four patients with celiac disease develop an itchy, blistering rash called dermatitis herpetiformis, most commonly on the buttocks, elbows, knees, scalp, or lower back. The rash responds quickly to treatment with dapsone, but long-term management requires a gluten-free diet.

#### **What Is Gluten? Safe and Unsafe Alternatives**

Gluten is a protein with viscoelastic and adhesive properties that makes up 75–85 percent of the protein in bread wheat. Gluten is developed as the dough is kneaded. It helps the dough rise and contributes to its chewy texture. Grains to be avoided for those sensitive to gluten are wheat, barley,

malt, rye, kamut, semolina, triticale, and spelt. Safe grains that are gluten-free are amaranth, buckwheat, corn, millet, oats, quinoa, rice, sorghum, and teff.

Flour alternatives include:

- Any of the safe grains
- Legumes, such as chickpeas, kidney beans, lentils, navy beans, pea beans, peanuts, and soybeans
- Nuts, such as almonds, cashews, chestnuts, hazelnuts, and walnuts
- Seeds, such as flax, pumpkin, and sunflower
- Tubers, such as arrowroot, jicama, potato, tapioca, and taro

#### **Effects of Popularity**

A lot of people have jumped on the gluten-free bandwagon. When a friend of mine joined a gluten-free support group, he learned that he was the only one there who had been diagnosed by

### **When a friend of mine joined a gluten-free support group, he learned that he was the only one there who had been diagnosed by a doctor.**

a doctor. The popularity of gluten-free diets has been both good and bad for patients with celiac disease. Gluten-free products are now much easier to find, and awareness has brought acceptance by restaurants and the public. But the association with fad diets has also brought many people to suspect that those claiming to have celiac disease are just faddists who are making things up.

#### **Other Diagnoses**

Some people who follow a gluten-free diet do so in the belief that they are treating an illness that is not celiac disease. They have symptoms that subside when they follow a gluten-free diet, but they have not been diagnosed with

celiac disease. They may think they have a wheat allergy or a non-celiac gluten sensitivity (NCGS). Estimates of the prevalence of NCGS vary; it may be as low as 0.6 percent or as high as 13 percent of the general population.

Wheat allergy is real. It involves IgG and mast cell response. Within minutes to hours of eating something with wheat in it, allergic patients typically develop swelling or itching in the mouth or throat, a skin rash or hives, nasal congestion, headache, problems breathing, cramps, nausea, vomiting, or diarrhea. They could even have an anaphylactic reaction, a medical emergency that could be fatal. There is some overlap between the symptoms of wheat allergy and celiac disease, but they are not the same thing; it should be fairly easy to distinguish them from each other on clinical grounds. An allergy specialist can diagnose wheat allergy with skin tests, blood tests, food challenges, and elimination diets. Gluten is not the only allergen in wheat: it also contains twenty-six other potential allergens (Sotkovský et al. 2011). When diagnosed in children, over half of wheat allergies resolve spontaneously as they get older.

If celiac disease and wheat allergy can be ruled out, symptoms that respond to a gluten-free diet could be due to NCGS. The diagnosis of NCGS is controversial and is still being debated. Many investigators question whether it is real. It may be confused with irritable bowel syndrome (IBS).

And then there are FODMAPS: fermentable oligosaccharides, disaccharides, monosaccharides, and polyols. That's quite a mouthful; it's easy to see why people prefer to use the acronym, which reduces the syllable count from twenty-three to two. These short-chain carbohydrates tend to absorb water and ferment in the colon; the resulting distention causes discomfort in some people. No inflammation is involved. Low FODMAP diets improve symptoms in people with functional bowel disorders, but they could disrupt the intestinal microbiome and may carry a risk of nutritional inadequacy. Low FODMAP diets restrict the carbohydrates in certain grains, while gluten-free diets restrict the protein. So far there have been

no studies comparing the gluten-free diet to the low FODMAP diet.

A gluten-free diet is difficult to follow, although the new widespread availability of foods labeled *gluten-free* has made it easier. Avoiding gluten is not only difficult for the individual but also creates problems for others around them, including family members, those who prepare their food, and those who serve them or eat with them at restaurants. They may face misunderstanding and ridicule from those who think of gluten-free diets as a food fad and assume celiac patients are just confused or are imagining things.

Some people give reasons for avoiding gluten that simply don't make sense:

- "Wheat is a common allergen." Sure, but it's far more common to *not* be allergic to wheat. Wouldn't it be better to find out whether you belong to the small minority or the vast majority before you commit to life-long dietary restrictions?
- "Gluten can be inflammatory." But that's only if you are sensitive to gluten.
- "Gluten may cause thyroid problems." That's questionable. There is some research suggesting that a gluten-free diet can help reduce antibody levels in autoimmune thyroid disease. Do you have autoimmune thyroid disease?
- "Gluten products aren't necessarily nutrient dense." So what?
- "It is estimated that up to 13 percent of the population has NCGS." Which would mean that at least 87 percent of the population does not.
- "Gluten may block nutrient absorption." But that's only if you have gluten sensitivity or celiac disease.
- "Weight loss." It doesn't work.
- "Autism." Not supported by research.

#### Elimination Diets

Because people are avoiding gluten for questionable reasons, more research is needed. Well-designed studies with control groups can provide credible evidence, but patients will try to do their own research by experimenting



with elimination diets, and that's a mistake. If they respond well, it could be a placebo effect. They are proud of taking control, want to feel better, and may convince themselves they feel better in some way. But they may still be eating problem foods without realizing it. They can't control the way food is prepared in other people's homes and in restaurants. Meals eaten away from home may include ingredients they are trying to avoid. A restaurant that offers a gluten-free menu may inadvertently include trace amounts of forbidden foods, such as flour used to thicken gravy, or there could be cross-contamination from other foods cooked on the same grill. If people feel worse on an elimination diet, it might not be due to the target food but to the absence of other foods they are in the habit of eating.

#### Follow Science, Not Fads

In short, there are two groups of people currently following a gluten-free diet:

those who have been properly diagnosed by a doctor with celiac disease and who really need to avoid gluten to maintain good health and those who have self-diagnosed and who may or may not benefit from avoiding gluten. There are others with undiagnosed celiac disease who should avoid gluten but don't yet know it. ■

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