

CELIAC DISEASE DIAGNOSIS & MANAGEMENT

Celiac disease is a genetic autoimmune condition that damages the lining of the small intestine and interferes with absorption of nutrients from food. It is triggered by gluten—a protein found in wheat, barley, rye and their derivatives—and can develop at any age with exposure to gluten.

Untreated or mismanaged, celiac disease can lead to:

- Osteoporosis
- Low vitamin levels
- Anemia
- Some cancers, such as lymphoma

CELIAC DISEASE by the NUMBERS

AFFECTS **1** in **133** AMERICANS

up to **40%**
OF THE POPULATION HAVE CELIAC DISEASE GENES HLA-DQ2/DQ8

but...
only **2-3%**
GO ON TO DEVELOP IT

40's
AVERAGE AGE OF
DIAGNOSIS IN ADULTS

83%
PEOPLE UNDIAGNOSED
OR MISDIAGNOSED

10 to 11
AVERAGE # OF YEARS PEOPLE
SUFFER BEFORE A DIAGNOSIS

4-fold
ONE'S RISK OF PREMATURE DEATH
IF LEFT UNDIAGNOSED



CELIAC DISEASE RUNS IN FAMILIES

- Risk increases to **20%** in family members with symptoms.
- Risk may **double** if a brother/sister has celiac disease.

SIGNS & SYMPTOMS

- **28-50%** of those newly diagnosed have iron deficiency.
- Having **1** autoimmune disorder makes someone more likely to develop **another**.
- Up to **38%** of those diagnosed have no outward or noticeable symptoms. Some only realize how poor they felt once diagnosed and on the gluten-free diet.
- Consider celiac disease when there are persistent signs and symptoms not explained by another condition.

TESTING & DIAGNOSIS

DON'T JUST GO GLUTEN-FREE!

Stay on a normal, gluten-containing diet when being tested.



0 = # OF FDA-APPROVED TESTS FOR GLUTEN SENSITIVITY

STEP A panel of **blood tests** can start the process:

1 Total IgA | IgA-tTG | IgA-EMA

5% of people who have IgA deficiency also have celiac disease, which means they must use the IgG-DGP or IgG-tTG tests instead.

2

Positive Blood Test? Upper endoscopy + small intestinal biopsy with multiple tissue samples can confirm celiac disease.

Negative Blood Test? Consider gluten sensitivity, a condition that can only be diagnosed once celiac disease is completely ruled out.

Follow-Up Testing

- IgA-tTG
- Complete blood count (CBC)
- Thyroid-stimulating hormone (TSH)
- Liver function tests (LFTs)
- Iron studies
- Vitamin D
- Vitamin B12
- Bone mineral density scan after 1 year

HLA TYPING

GENETIC TESTING THAT CAN RULE OUT CELIAC DISEASE BY USING A BLOOD TEST OR CHEEK SWAB

THE GLUTEN CHALLENGE

1.5 SLICES OF REGULAR BREAD DAILY FOR 2 WEEKS UNDER THE GUIDANCE OF A PHYSICIAN, THIS CAN HELP DIAGNOSE CELIAC DISEASE IN PEOPLE ALREADY EATING GLUTEN-FREE.

BARRIER TO DIAGNOSIS

"GOING GLUTEN-FREE" BEFORE GETTING TESTED

About 80% of Americans on a gluten-free diet do not have celiac disease.

DISEASE MANAGEMENT

STRICT, LIFELONG GLUTEN-FREE DIET

THE ONLY TREATMENT
FOR CELIAC DISEASE

- Meet with a dietitian experienced in the gluten-free diet.
- Get long-term medical follow-up with skilled doctors and a dietitian.
- Become educated on celiac disease and the gluten-free diet.
- Join an advocacy or support group.

JUST AS IMPORTANT...

- Talk with your family members about getting tested.
- Consider meeting with a psychologist to help with coping and acceptance.
- Don't be surprised if your physician suggests a pneumococcal or flu vaccine.
- Realize that gluten may be found in medications.

A FEW BREADCRUMBS
ARE ENOUGH TO CAUSE
INTESTINAL DAMAGE

QUESTIONS? ASK
YOUR HEALTHCARE
PROVIDER AT YOUR
NEXT VISIT.



JEFFERSON.EDU/CELIAC



NATIONAL FOUNDATION
FOR CELIAC AWARENESS

CELIACCENTRAL.ORG/DIAGNOSIS