



Celiac Disease Patient Guide

Celiac disease is a **lifelong condition** where the body's immune system reacts to gluten, a protein found in wheat, barley, and rye. This reaction damages the small intestine and can cause a wide range of symptoms, or sometimes no symptoms at all.

How common is celiac disease?

Celiac disease affects about 1% of people worldwide. It can develop at any age and is more common in women. Many people with celiac disease are not diagnosed, often because symptoms can be mild or mistaken for other problems.

What causes celiac disease?

Celiac disease happens in people who have certain genes. The main genetic risk comes from HLA-DQ2 and HLA-DQ8 genes. About 90% of people with celiac disease have HLA-DQ2, and most of the rest have HLA-DQ8. Having these genes does not mean you will definitely get celiac disease, but it is necessary for the disease to develop. If a close family member (like a parent, child, or sibling) has celiac disease, your risk is higher—about 5-15%.

What are the symptoms?

Symptoms can vary significantly. Some people have classic symptoms like diarrhea, weight loss, and stomach pain. Others may have less obvious symptoms such as tiredness, anemia (low iron), bone problems (like osteoporosis), skin rashes, or even trouble getting pregnant. Some people have no symptoms at all.

How is celiac disease diagnosed?

Diagnosis usually starts with a blood test for antibodies called TTG-IgA. If this test is positive, most people will need a small intestine biopsy (done during an endoscopy) to confirm the diagnosis. In some children with very high antibody levels, a biopsy may not be needed. Genetic testing for HLA-DQ2 or DQ8 may be used in special cases, especially if the diagnosis is unclear. It is important to keep eating gluten before testing, as stopping gluten can affect the results.

How is celiac disease managed?

The only treatment is a **strict, lifelong gluten-free diet**. This means avoiding all foods and drinks that contain wheat, barley, or rye. Most people feel better within weeks of starting the diet, and it helps prevent long-term problems. It is important to learn about hidden sources of gluten and how to avoid cross-contamination. Seeing a dietitian and joining support groups can be very helpful. Regular follow-up with your healthcare team is important to check your health and make sure the diet is working. If symptoms do not improve, your doctor may check for other causes or rare complications.

What is the outlook?

Most people with celiac disease do very well on a gluten-free diet. Sticking to the diet helps heal the intestine, improves symptoms, and lowers the risk of serious problems like certain cancers. Ongoing research is looking for new treatments, but for now, avoiding gluten is the best way to stay healthy.

If you have questions or need help with your diet, talk to your healthcare provider or a dietitian who specializes in celiac disease.

References

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