# Celiac Disease

Celiac disease is a digestive disease that damages the small intestine. It interferes with absorption (taking in) of nutrients from food. Celiac disease is also known as celiac sprue, nontropical sprue, and gluten-sensitive enteropathy. People who have celiac disease cannot tolerate gluten. Gluten is a protein found in wheat, rye, and barley. With time, celiac disease will damage the cells lining the small intestine. This leads to *malabsorption* (being unable to absorb nutrients from food), diarrhea, and nutritional problems.

## CAUSE

Celiac disease is an autoimmune disease. You have a higher likelihood of getting the disease if someone in your family has had it. If you inherit this condition, exposure to gluten causes your body's immune system to react against its own cells.

## SYMPTOMS

The symptoms of celiac disease vary from person to person. Some people are affected as children. Others may not have symptoms until adulthood. A few factors can affect when you may develop symptoms. Whether you were breastfed as a baby, and your age when gluten-containing (wheat, etc.) foods were introduced into your diet are 2 examples. The symptoms generally are digestive or nutritional.

Digestive symptoms occur when the body is unable to properly absorb food from the intestine. This results in:

- Recurring abdominal bloating and pain
- Gas
- Chronic diarrhea
- Pale, foul smelling, greasy or oily stool

**Nutritional symptoms include:**

- Failure to thrive in infants
- Delayed growth in children
- Weight loss in children and adults
- Missed menstrual periods (often due to extreme weight loss)
- Anemia
- Osteoporosis
- Fatigue and weakness
- Peripheral *neuropathy* (tingling and other signs of nerve damage).
- Depression

## DIAGNOSIS

If your symptoms and physical exam suggest that a digestive disorder and/or malnutrition are present, your caregiver may suspect celiac disease. You may have already begun a gluten-free diet. If symptoms persist, testing may be needed to confirm the diagnosis. Some of these tests are best done while you are on a normal, unrestricted diet. Tests may include:

- Blood tests to check for nutritional deficiencies.
- Blood tests to look for evidence that the body is producing antibodies against its own small intestine cells.
- Biopsy of the small bowel. While you are sedated, a specialist can place a long, thin tube through your mouth that will reach all the way into the small intestine. With this tube (*endoscope*), the specialist is able to remove a small piece of the lining of the small intestine. This specimen is then examined under a microscope for evidence of celiac disease.
- Other tests may include x-rays of the small bowel; evaluation of the stool for fat, or tests of nutrient absorption from the intestine.
- Genetic testing is sometimes useful.
- Tests are sometimes needed to exclude conditions that can be confused with celiac disease: irritable bowel syndrome, Crohn's disease, ulcerative colitis, diverticulosis, intestinal infections, chronic fatigue syndrome, and depression.

## PREVENTION

There is no way to prevent celiac disease. Avoiding all gluten may help reduce the damage the disease causes to the small intestine. In this way, digestive and nutritional symptoms may be reduced.

This is a genetic disease. Up to 10% of your close relatives (parent, sibling, child) may also have the disease. These relatives can have blood tests for the small intestine antibodies of celiac disease. If the tests are positive, discuss the situation with a caregiver to try to reduce the effects of the disease.

## PROGNOSIS

The prognosis of celiac disease depends on when the disease was diagnosed. If you were diagnosed in the early stages, following a gluten free diet can allow you to live a long, relatively symptom-free life. If serious malnutrition has occurred, you will need to discuss the prognosis with your caregiver.

## RISKS AND COMPLICATIONS

- Untreated celiac disease can cause all of the problems listed in the 'symptoms' section above. Growth problems (in children), anemia, osteoporosis, and peripheral neuropathy are of special concern.
- If you are an untreated pregnant woman with celiac disease, you have a higher risk of miscarriage and of having a child with a congenital problem.
- Some people can develop disease that does not improve with avoidance of gluten. This is called Refractory Sprue. It may require treatment with strong medicines aimed at the immune system.
- There is a link between celiac disease and problems with the spleen.
- Overall, a person with celiac disease does not have a higher risk of cancer. There may be a slightly higher risk of certain kinds of cancer (lymphoma and cancer of the bowel).

People with celiac disease tend to have other autoimmune diseases, which may be genetic, as well, including:

- Dermatitis herpetiformis
- Thyroid disease
- Systemic lupus erythematosis
- Type 1 diabetes
- Liver disease
- Collagen vascular disease
- Rheumatoid arthritis
- Sjögren's syndrome

## TREATMENT

- The only treatment for celiac disease is to follow a gluten-free diet. All foods containing gluten must be avoided. For most people, following this diet will stop symptoms. It will heal existing intestinal damage and prevent further damage. Improvements begin within days of starting the diet. The small intestine is usually completely healed. This happens within 3 to 6 months. It may take up to 2 years for older adults.
- The gluten-free diet is a lifetime requirement. Eating even a small amount of gluten can damage your intestine. This is true for anyone with the disease, even people who do not have obvious symptoms. Depending on your age at diagnosis, some problems, such as delayed growth and discolored teeth, may not improve.
- A small percentage of people with this disease do not improve on the gluten-free diet. These people often have badly damaged intestines that can not heal. Because their intestines are not absorbing enough nutrients, they may need to receive intravenous (injected into the veins) nutrition supplements. Drug treatments are being tested for unresponsive celiac disease. These patients may need to be evaluated for complications of the disease.
- Your caregiver may recommend a pneumonia vaccination.
- Nutrients and other treatments may be recommended for any nutritional deficiencies.

Your caregiver can provide you with more information on a gluten-free diet. Discussion with a dietician skilled in this illness will be valuable. Support groups may also be helpful.

## HOME CARE INSTRUCTIONS

Care at home focuses on a gluten-free diet. This diet must become a way of life. Eating outside the home will be a challenge and will require preparation. Regular follow-up with your caregiver is important. You will need to monitor your response to the gluten free diet and treat any nutritional deficiencies. Family members may want screening tests to look for early signs of the disease.

## SEEK MEDICAL CARE IF:

- You continue to have digestive symptoms (gas, cramping, diarrhea) despite a proper diet.
- You have trouble sticking to the gluten-free diet.
- You develop an itchy rash with groups of tiny blisters.
- You develop severe weakness, balance problems, menstrual troubles, or depression.

## MAKE SURE YOU:

- Understand these instructions.
- Will watch your condition.
- Will get help right away if you are not doing well or get worse.

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