

understanding
**CELIAC
DISEASE**

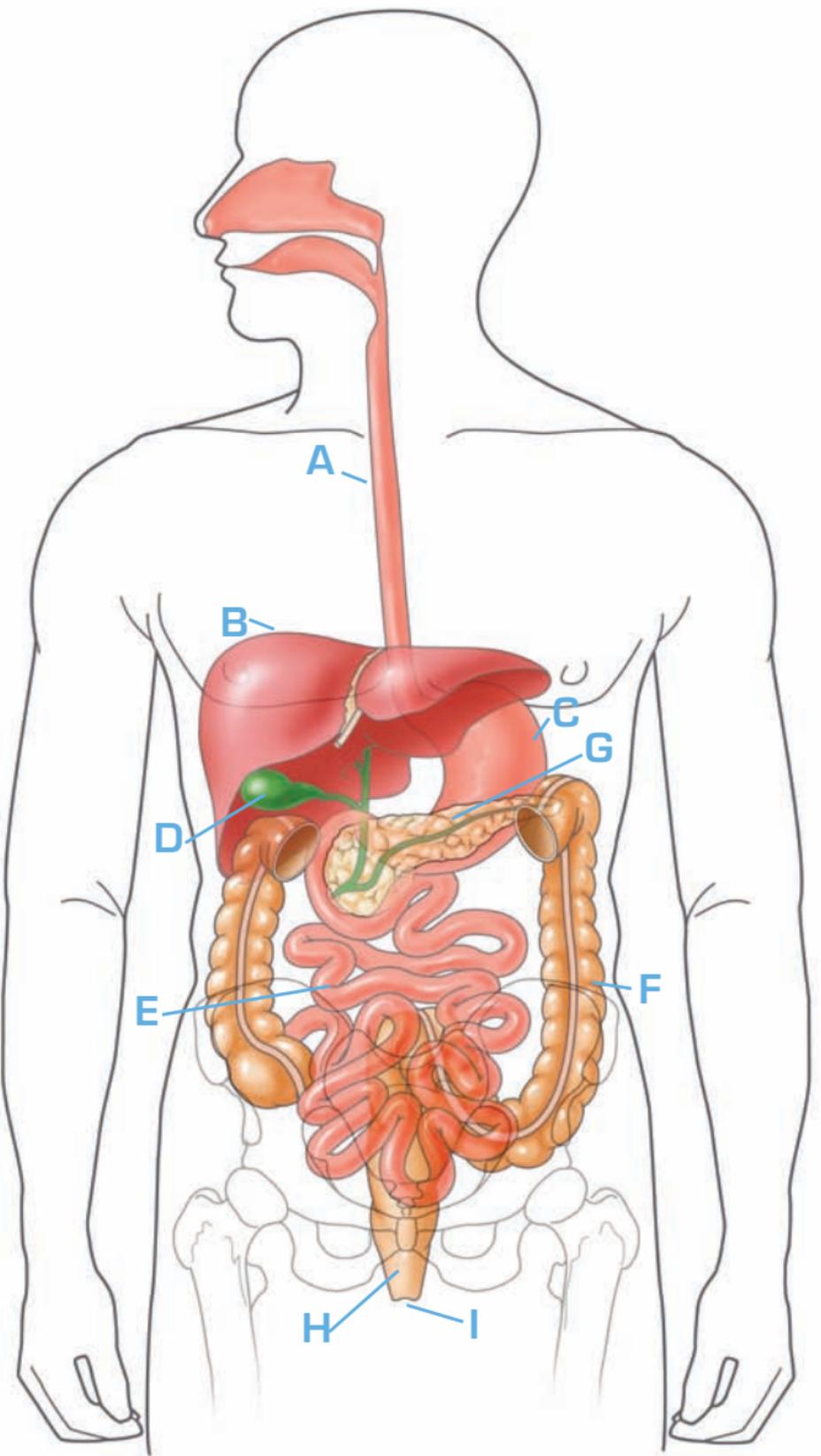
A patient's guide from your doctor and



Celiac Disease Basics

- Celiac disease is an autoimmune disorder that causes your immune system to interfere with the proper function of the small intestine.
- Celiac disease is considered a malabsorption disease because it prevents the body from collecting nutrients as food passes through the small intestine.
- Although the disease can be tricky to diagnose, treatment is straightforward and relief of symptoms generally begins within days of adopting a gluten-free diet.

Your Digestive System



A. Esophagus

B. Liver

C. Stomach

D. Gallbladder

E. Small Intestine

F. Large Intestine

G. Pancreas

H. Rectum

I. Anus

A Gluten-Free Diet

Grains, including wheat products, are a major source of nutrients in the basic American diet. The U.S. Department of Agriculture recommends individuals eat between 3 and 8 ounces of grains a day depending on age and activity level. For instance, this is one slice of bread, 1 cup of ready-to-eat cereal, or a half a cup of cooked rice, cooked pasta or cooked cereal.

Once you are diagnosed with celiac disease, your gastroenterologist will work with you to help develop a diet program that will be free of gluten-containing products, but still ensure you are receiving the correct balance of nutrients. You will need to learn how to read nutrition labels to ensure that the products do not contain gluten or other ingredients that may affect you. While the introduction of a gluten-free diet can seem overwhelming, especially for a child, there are many foods that can be substituted for traditional wheat-based foods.

Some foods you will be allowed to eat include:

- ▶ Amaranth
- ▶ Arrowroot
- ▶ Brown rice
- ▶ Buckwheat
- ▶ Corn
- ▶ Flax
- ▶ Legumes
- ▶ Millet
- ▶ Nuts
- ▶ Potatoes
- ▶ Quinoa
- ▶ Seeds
- ▶ Soy
- ▶ Tapioca
- ▶ Wild Rice

Foods to avoid include:

- ▶ Wheat, including durum, graham, spelt, kamut, semolina.
- ▶ Wheat starch, wheat bran, wheat germ, cracked wheat, hydrolyzed wheat protein.
- ▶ Barley.
- ▶ Rye.
- ▶ Triticale (a cross between wheat and rye).

Many products thought to be gluten-free are often contaminated with gluten, such as oat products. For this reason oats are not allowed in the initial diets of those with celiac disease.

There are many processed food products that are made using wheat, barley and rye. While many of these products are available gluten-free, read the nutrition label or contact the manufacturer to learn more.

- ▶ Bouillon cubes
- ▶ Chips/potato chips
- ▶ Candy
- ▶ Cold cuts, hot dogs, salami, sausage
- ▶ Communion wafer
- ▶ French fries
- ▶ Gravy
- ▶ Matzo
- ▶ Rice mixes
- ▶ Sauces
- ▶ Seasoned tortilla chips
- ▶ Self-basting turkey
- ▶ Soups
- ▶ Soy sauce



To help you understand and manage your condition, the AGA Institute provides you with the following information, designed to give you some basic facts, to help you better understand your condition and to serve as a starting point for discussions with your doctor.

Celiac Disease

While you may initially be relieved to receive a diagnosis for the unexplained symptoms you may have been experiencing, you may also be scared by hearing you have celiac disease. It is important to know that **by working with your gastroenterologist, you can develop an eating plan that can help control your symptoms and may reverse the damage of your disease, allowing you and your loved ones to live healthy lives.**

Celiac disease occurs in the digestive system when people cannot tolerate a protein called gluten. Gluten is found primarily in wheat, barley and rye, but may also be in products you use every day, including some medicines and vitamins and even in stamp and envelope glue.

Celiac disease was, until recently, thought to be a rare disease. However, recent research has shown that as many as 2 million people in the U.S. may have celiac disease. It is very common among first-degree relatives, who include siblings, parents and children, meaning it is a genetic disease. Celiac disease can be diagnosed in both children and adults and people may live for years without knowing they have it. In some patients with the genetic predisposition, the disease reveals itself after an event such as surgery, pregnancy, viral infections or severe emotional stress.

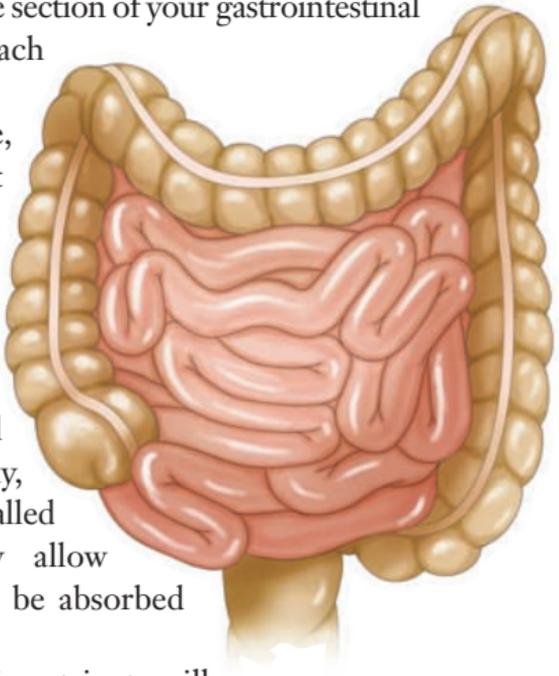
Many people living with celiac disease are undiagnosed for a number of reasons:

- ▶ The symptoms associated with celiac disease are often attributed to other problems.
- ▶ While many health-care providers have learned about the disease, they may not think first about celiac disease as a potential diagnosis when presented with the list of symptoms.

Biology of Celiac Disease

Celiac disease causes your immune system to damage the lining of the small intestine, the section of your gastrointestinal tract between the stomach and the large intestine.

The small intestine, which is about 20 feet long, finishes the process of digestion, absorbs the nutrients and passes the residue on to the large intestine. The small intestine is lined by tiny, fingerlike protrusions, called villi. These normally allow nutrients from food to be absorbed into the bloodstream.



Without healthy villi, nutrients will pass through the small intestine without being absorbed, and you will become malnourished, regardless of how much food you eat.

Celiac disease is a permanent disease. It is classified as both an autoimmune disorder, because the body is damaged by its own immune system, and a disease of malabsorption, since your body cannot absorb the nutrients it needs to function properly.

With celiac disease, when you eat foods or use products containing gluten, your immune system responds by damaging cells and destroying the villi lining the small intestine. However, if you change your habits and adopt a gluten-free lifestyle, you can reverse the damage associated with celiac disease.

Symptoms

Celiac disease affects people differently and the symptoms are wide and varied. Experiencing these symptoms does not mean you have celiac disease, just as some patients with the disease may not show any symptoms. However, if you have one or more of these symptoms and a relative with celiac disease, you may want to talk to your gastroenterologist about getting tested.

- ▶ Gas, recurring abdominal bloating and pain
- ▶ Chronic diarrhea or constipation; pale, foul-smelling or fatty stool
- ▶ Weight loss/weight gain
- ▶ Fatigue
- ▶ Unexplained anemia (a low count of red blood cells causing fatigue)
- ▶ Behavioral changes; irritability is common in children
- ▶ Tingling numbness in the legs (from nerve damage)
- ▶ Bone or joint pain
- ▶ Muscle cramps
- ▶ Delayed growth in children or failure to thrive in infants
- ▶ Pale sores inside the mouth, called aphthous ulcers
- ▶ Itchy skin rash called dermatitis herpetiformis

Diagnosing Celiac Disease

Since the symptoms of celiac disease often mimic other diseases, such as irritable bowel syndrome, Crohn's disease and diverticulitis, it is often difficult to recognize whether you may have the disease. In discussing your symptoms with your gastroenterologist, he or she may order a **blood test** to determine whether you have high levels of autoantibodies, which are antibodies that react to your own body's tissues.

If the blood test comes back positive, your gastroenterologist may perform an **endoscopy** to obtain a sample of the tissue (**biopsy**) from your small intestine to test the damage to the villi. An endoscopy is performed by your gastroenterologist using a long, thin, flexible tube with a tiny video camera and light on the end. The gastroenterologist can safely guide the instrument to carefully examine the inside lining of the small intestine. Tiny instruments are passed through an opening in the endoscope to obtain tissue samples for the biopsy. To learn more about endoscopy, read the AGA Institute brochure on that topic in your gastroenterologist's office or visit www.gastro.org/patient.

Before you undergo any test to determine whether you have celiac disease, it is important that you continue your normal diet so the results are accurate.

Treatment

The primary treatment for celiac disease is the strict following of a gluten-free diet. A life-long gluten-free diet will help protect your small intestine.

In many patients with celiac disease, even a small amount of gluten is enough to cause intestinal damage, even though you may not be experiencing symptoms.

While you may be tempted to cheat, and may not notice much of a problem when you do, it is important to remember that you may run the risk of long-term problems.

**Good news:
Improvements in
symptoms should begin
within days of changing your diet.**



While you will never be completely cured of celiac disease, after adopting a gluten-free diet your small intestine should heal in two years for adults and within a few months in children and young adults.

Your gastroenterologist may want to take an intestinal tissue biopsy about six months after diagnosis to confirm your new diet is helping to improve the intestinal tissues.

Being healed from celiac disease means that your small intestine returns to normal function and can begin absorbing nutrients properly; however, it does not mean that you can stop eating gluten-free products. Some patients with celiac disease may experience symptoms if the same cookware is used to cook their food and food containing gluten.

Complications of Celiac Disease

- ▶ Due to damage of the small intestine and nutrient absorption problems, people with celiac disease are at increased risk of developing malnutrition, anemia and other diseases and health problems.
- ▶ After years of being undiagnosed, some adults may experience “refractory” celiac disease, which means that the body does not respond to a gluten-free diet and that symptoms continue and can lead to intestinal damage.
- ▶ Patients with celiac disease may develop osteoporosis (weak and brittle bones) or short stature in children. This is due to lack of nutritional absorption.
- ▶ Patients may experience an increased risk of lymphoma and intestinal cancers.
- ▶ Some patients with celiac disease may have other autoimmune disorders including type 1 diabetes, thyroid disease, rheumatoid arthritis and liver disease, among others.

Much research is being conducted on celiac disease to increase understanding and awareness that will lead to earlier diagnosis and treatment of the disease.

Go to www.gastro.org/patient for more information on digestive health and tests performed by gastroenterologists and to find an AGA member physician in your area.

The American Gastroenterological Association (AGA) is dedicated to the mission of advancing the science and practice of gastroenterology. Founded in 1897, the AGA is one of the oldest medical-specialty societies in the U.S. Our 16,000 members include physicians and scientists who research, diagnose and treat disorders of the gastrointestinal tract and liver. The AGA Institute runs the organization's practice, research and educational programs.

The content in the series of AGA Institute patient education brochures was reviewed by the following gastroenterologists:

John I. Allen, MD, MBA, AGAF

*Minnesota Gastroenterology
Chair, AGA Clinical Practice & Quality
Management Committee*

Harry R. Aslanian, MD

Yale University School of Medicine

Stephen J. Bickston, MD, AGAF

University of Virginia Health System

Joel V. Brill, MD, AGAF

*Predictive Health LLC
Chair, AGA Practice Management
& Economics Committee*

Marcia I. Canto, MD, MHS

Johns Hopkins University

Richard Davis, Jr. PA-C

University of Florida College of Medicine

Mark H. DeLegge, MD, AGAF

Medical University of South Carolina

Kenneth DeVault, MD

Mayo Clinic, Jacksonville

Stephen W. Hiltz, MD, MBA, AGAF

TriState Gastroenterology

Lawrence R.

Kosinski, MD, MBA, AGAF

Elgin Gastroenterology, S.C.

Linda A. Lee, MD, AGAF

Johns Hopkins School of Medicine

Stephen A. McClave, MD, AGAF

University of Louisville School of Medicine

Kimberley Persley, MD

Texas Digestive Disease Consultants

John Schaffner, MD

Mayo Clinic, Rochester

Joanne A.P. Wilson, MD, FACP, AGAF

Duke University Medical Center

Cynthia M. Yoshida, MD, AGAF

University of Virginia Health System

Atif Zaman, MD, MPH

Oregon Health and Science University



AGAINSTITUTE
AGA Education, Practice and Research



The Digestive Health Initiative® (DHI) is an AGA Institute initiative that offers educational programs on digestive disorders for individuals who are affected by a digestive disease, in an effort to educate the larger health-care community.

This brochure was produced by the AGA Institute and funded by a grant from TAP Pharmaceutical Products Inc.



For more information about digestive diseases, please visit the AGA Web site at www.gastro.org.

The AGA Institute offers the information in these brochures for educational purposes to provide accurate and helpful health information for the general public. This information is not intended as medical advice and should not be used for diagnosis. The information in these brochures should not be considered a replacement for consultation with a health-care professional. If you have questions or concerns about the information found in these brochures, please contact your health-care provider. We encourage you to use the information and questions in these brochures with your health-care provider(s) as a way of creating a dialogue and partnership about your condition and your treatment.