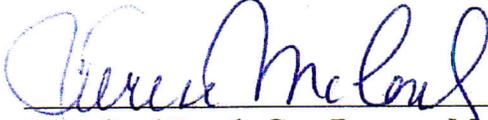


**SPECIALIZED FAMILY CARE
Provider Training**

Category:	Health Issue
Title:	Celiac Disease
Materials:	Articles: "What Is Celiac Disease?" from National Foundation for Celiac Awareness and "Celiac Disease" from National Digestive Diseases Information Clearinghouse
Goal:	To increase awareness of celiac disease
Credit Hours:	2 hours
Date Developed:	July 2014
Developed by:	Donna McCune, MSW, Specialized Family Care Program

This Training Packet was approved for the Specialized Family Care Training Program by:

 8/2/14
 Specialized Family Care Program Manager Date

Training Objectives:

- Provider can define celiac disease
- Provider knows common symptoms of celiac disease
- Provider knows complications which can result from celiac disease
- Provider knows foods recommended for a gluten free diet

Training Procedures:

- Provider initiated self study
- Test completed by Provider
- Review of test responses by Family Based Care Specialist and Provider

I certify that I have completed all the materials associated with this training module. I feel that I have a basic understanding of the material completed.

 Specialized Family Care Provider

 Date

Reviewed by: _____

Family Based Care Specialist

 Date

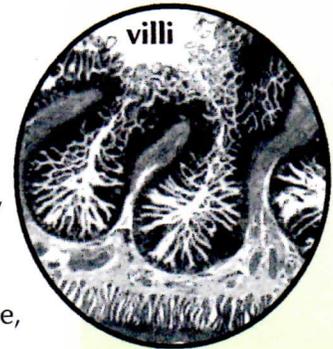
This Program is funded by the WV Department of Health & Human Resources, Bureau for Children & Families and administered by the Center for Excellence in Disabilities, West Virginia University.

WVDHHR/CED/SFC/CELIAC DISEASE/AUGUST 2014



what is celiac disease?

Celiac disease (also referred to as celiac sprue, non-tropical sprue, and gluten-sensitive enteropathy) is an autoimmune disorder triggered by consuming a protein called gluten, which is found in wheat, barley and rye. When a person with celiac eats gluten, the protein interferes with the absorption of nutrients from food by damaging a part of the small intestine called villi. Damaged villi make it nearly impossible for the body to absorb nutrients into the bloodstream, leading to malnourishment and a host of other problems including some cancers, thyroid disease, osteoporosis, infertility and the onset of other autoimmune diseases.



Who Gets Celiac Disease?

One out of every 133 Americans has celiac disease, equivalent to nearly 1% of the U.S. population. Unfortunately, 83% of the 3 million Americans living with celiac disease remain undiagnosed or misdiagnosed. Celiac disease is a genetic disorder, meaning that it passes from parent to child via DNA. In some cases, stressful events such as pregnancy, surgery, infection, or severe emotional distress can trigger the onset of the disease.

How Is It Diagnosed?

With a wide variety of symptoms associated with celiac disease, gaining an accurate diagnosis can be difficult. To determine if a patient has celiac disease, a physician can screen by using a simple antibody blood test, sometimes combined with a genetic test. If a celiac diagnosis is still suspected, the doctor will likely perform a small intestinal biopsy for confirmation.

Treatment of Celiac Disease: A Gluten-Free Diet

The treatment for celiac disease is simple: a lifelong gluten-free diet. There are no medications or surgeries that can cure the autoimmune disease. Eating any amount of gluten, no matter how tiny it is, can cause damage to the villi of the small intestine and prevent patients from absorbing nutrients into the bloodstream.

Eliminating popular foods from the diet can seem overwhelming when a patient is first diagnosed, but with a little extra effort in the kitchen, people with celiac disease can eat delicious food that tastes just as good as their gluten-containing counterparts.

COMMON SYMPTOMS

- Abdominal Pain
- Anemia
- Bloating
- Delayed Growth
- Depression
- Dermatitis Herpetiformis
- Diarrhea
- Dental Enamel Defects
- Fatigue
- Gas
- Infertility
- Joint Pain
- Pale Sores in Mouth
- Migraines
- Nausea
- Numbness in Legs
- Osteopenia
- Osteoporosis
- Weight Loss

GLUTEN-FREE = NO WHEAT, RYE OR BARLEY

NFCA
PO BOX 544
Ambler, PA 19002
info@CeliacCentral.org
215-325-1306

CeliacCentral.org

celiac facts

1. One in 133 Americans has celiac disease.

2. Three million Americans across all races, ages and genders suffer from celiac.

3. Celiac disease is hereditary, so all first and second-degree relatives should be screened.

4. 83% of celiacs are undiagnosed or misdiagnosed.

5. 6-10 years is the average time a person waits to be correctly diagnosed in the United States.

6. The burden of undiagnosed celiac disease over a four-year period is estimated to be almost \$4,000.

7. Celiac disease can lead to a number of other disorders including infertility, reduced bone density, neurological disorders, some cancers, and other autoimmune diseases.

8. There are NO pharmaceutical cures for celiac disease.

9. A strict gluten-free diet is the only treatment for celiac disease.

10. The gluten-free marketplace is doubling every three years!

3
million
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National Foundation
for Celiac Awareness

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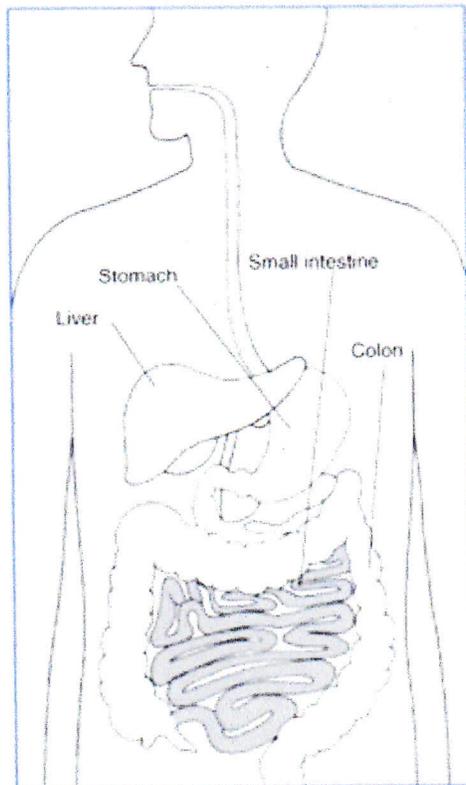
CeliacCentral.org

restoring health...
reclaiming lives...

Celiac Disease

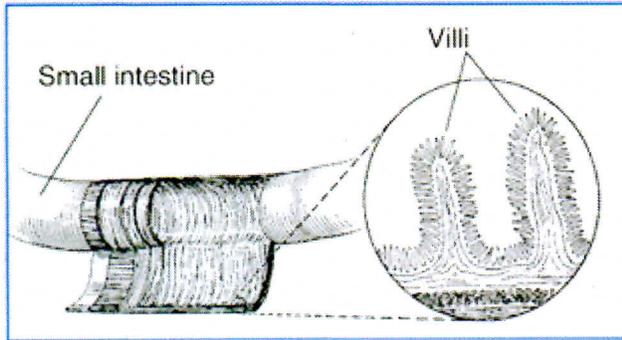
What is celiac disease?

Celiac disease is a digestive disease that damages the small intestine and interferes with absorption of nutrients from food. People who have celiac disease cannot tolerate gluten, a protein in wheat, rye, and barley. Gluten is found mainly in foods but may also be found in everyday products such as medicines, vitamins, and lip balms.



The small intestine is shaded above.

When people with celiac disease eat foods or use products containing gluten, their immune system responds by damaging or destroying villi—the tiny, fingerlike protrusions lining the small intestine. Villi normally allow nutrients from food to be absorbed through the walls of the small intestine into the bloodstream. Without healthy villi, a person becomes malnourished, no matter how much food one eats.



Villi on the lining of the small intestine help absorb nutrients.

Celiac disease is both a disease of malabsorption—meaning nutrients are not absorbed properly—and an abnormal immune reaction to gluten. Celiac disease is also known as celiac sprue, nontropical sprue, and gluten-sensitive enteropathy. Celiac disease is genetic, meaning it runs in families. Sometimes the disease is triggered—or becomes active for the first time—after surgery, pregnancy, childbirth, viral infection, or severe emotional stress.

What are the symptoms of celiac disease?

Symptoms of celiac disease vary from person to person. Symptoms may occur in the digestive system or in other parts of the body. Digestive symptoms are more common in infants and young children and may include

- abdominal bloating and pain
- chronic diarrhea
- vomiting
- constipation
- pale, foul-smelling, or fatty stool
- weight loss

Irritability is another common symptom in children. Malabsorption of nutrients during the years when nutrition is critical to a child's normal growth and development can result in other problems such as failure to thrive in infants, delayed growth and short stature, delayed puberty, and dental enamel defects of the permanent teeth.

Adults are less likely to have digestive symptoms and may instead have one or more of the following:

- unexplained iron-deficiency anemia

- fatigue
- bone or joint pain
- arthritis
- bone loss or osteoporosis
- depression or anxiety
- tingling numbness in the hands and feet
- seizures
- missed menstrual periods
- infertility or recurrent miscarriage
- canker sores inside the mouth
- an itchy skin rash called dermatitis herpetiformis

People with celiac disease may have no symptoms but can still develop complications of the disease over time. Long-term complications include malnutrition—which can lead to anemia, osteoporosis, and miscarriage, among other problems—liver diseases, and cancers of the intestine.

Why are celiac disease symptoms so varied?

Researchers are studying the reasons celiac disease affects people differently. The length of time a person was breastfed, the age a person started eating gluten-containing foods, and the amount of gluten-containing foods one eats are three factors thought to play a role in when and how celiac disease appears. Some studies have shown, for example, that the longer a person was breastfed, the later the symptoms of celiac disease appear.

Symptoms also vary depending on a person's age and the degree of damage to the small intestine. Many adults have the disease for a decade or more before they are diagnosed. The longer a person goes undiagnosed and untreated, the greater the chance of developing long-term complications.

What other health problems do people with celiac disease have?

People with celiac disease tend to have other diseases in which the immune system attacks the body's healthy cells and tissues. The connection between celiac disease and these diseases may be genetic. They include

- type 1 diabetes
- autoimmune thyroid disease
- autoimmune liver disease

- rheumatoid arthritis
- Addison's disease, a condition in which the glands that produce critical hormones are damaged
- Sjögren's syndrome, a condition in which the glands that produce tears and saliva are destroyed

How common is celiac disease?

Celiac disease affects people in all parts of the world. Originally thought to be a rare childhood syndrome, celiac disease is now known to be a common genetic disorder. More than 2 million people in the United States have the disease, or about 1 in 133 people.¹ Among people who have a first-degree relative—a parent, sibling, or child—diagnosed with celiac disease, as many as 1 in 22 people may have the disease.²

Celiac disease is also more common among people with other genetic disorders including Down syndrome and Turner syndrome, a condition that affects girls' development.

¹Fasano A, Berti I, Gerarduzzi T, et al. Prevalence of celiac disease in at-risk and not-at-risk groups in the United States. *Archives of Internal Medicine*. 2003;163(3):268–292.

²Ibid.

How is celiac disease diagnosed?

Recognizing celiac disease can be difficult because some of its symptoms are similar to those of other diseases. Celiac disease can be confused with irritable bowel syndrome, iron-deficiency anemia caused by menstrual blood loss, inflammatory bowel disease, diverticulitis, intestinal infections, and chronic fatigue syndrome. As a result, celiac disease has long been underdiagnosed or misdiagnosed. As doctors become more aware of the many varied symptoms of the disease and reliable blood tests become more available, diagnosis rates are increasing.

Blood Tests

People with celiac disease have higher than normal levels of certain autoantibodies—proteins that react against the body's own cells or tissues—in their blood. To diagnose celiac disease, doctors will test blood for high levels of anti-tissue transglutaminase antibodies (tTGA) or anti-endomysium antibodies (EMA). If test results are negative but celiac disease is still suspected, additional blood tests may be needed.

Before being tested, one should continue to eat a diet that includes foods with gluten, such as breads and pastas. If a person stops eating foods with gluten before being tested, the results may be negative for celiac disease even if the disease is present.

Intestinal Biopsy

If blood tests and symptoms suggest celiac disease, a biopsy of the small intestine is performed to confirm the diagnosis. During the biopsy, the doctor removes tiny pieces of tissue from the small intestine to check for damage to the villi. To obtain the tissue sample, the doctor eases a long, thin tube called an endoscope through the patient's mouth and stomach into the small intestine. The doctor then takes the samples using instruments passed through the endoscope.

Dermatitis Herpetiformis

Dermatitis herpetiformis (DH) is an intensely itchy, blistering skin rash that affects 15 to 25 percent of people with celiac disease.³ The rash usually occurs on the elbows, knees, and buttocks. Most people with DH have no digestive symptoms of celiac disease.

DH is diagnosed through blood tests and a skin biopsy. If the antibody tests are positive and the skin biopsy has the typical findings of DH, patients do not need to have an intestinal biopsy. Both the skin disease and the intestinal disease respond to a gluten-free diet and recur if gluten is added back into the diet. The rash symptoms can be controlled with antibiotics such as dapsone. Because dapsone does not treat the intestinal condition, people with DH must maintain a gluten-free diet.

Screening

Screening for celiac disease means testing for the presence of autoantibodies in the blood in people without symptoms. Americans are not routinely screened for celiac disease. However, because celiac disease is hereditary, family members of a person with the disease may wish to be tested. Four to 12 percent of an affected person's first-degree relatives will also have the disease.⁴

³Rodrigo L. Celiac disease. *World Journal of Gastroenterology*. 2006;12(41):6585–6593.

⁴Ibid.

How is celiac disease treated?

The only treatment for celiac disease is a gluten-free diet. Doctors may ask a newly diagnosed person to work with a dietitian on a gluten-free diet plan. A dietitian is a health care professional who specializes in food and nutrition. Someone with celiac disease can learn from a dietitian how to read ingredient lists and identify foods that contain gluten in order to make informed decisions at the grocery store and when eating out.

For most people, following this diet will stop symptoms, heal existing intestinal damage, and prevent further damage. Improvement begins within days of starting the diet. The small intestine usually heals in 3 to 6 months in children but may take several years in adults. A healed intestine means a person now has villi that can absorb nutrients from food into the bloodstream.

To stay well, people with celiac disease must avoid gluten for the rest of their lives. Eating even a small amount of gluten can damage the small intestine. The damage will occur in anyone with the disease, including people without noticeable symptoms. Depending on a person's age at diagnosis, some problems will not improve, such as short stature and dental enamel defects.

Some people with celiac disease show no improvement on the gluten-free diet. The most common reason for poor response to the diet is that small amounts of gluten are still being consumed. Hidden sources of gluten include additives such as modified food starch, preservatives, and stabilizers made with wheat. And because many corn and rice products are produced in factories that also manufacture wheat products, they can be contaminated with wheat gluten.

Rarely, the intestinal injury will continue despite a strictly gluten-free diet. People with this condition, known as refractory celiac disease, have severely damaged intestines that cannot heal. Because their intestines are not absorbing enough nutrients, they may need to receive nutrients directly into their bloodstream through a vein, or intravenously. Researchers are evaluating drug treatments for refractory celiac disease.

The Gluten-free Diet

A gluten-free diet means not eating foods that contain wheat, rye, and barley. The foods and products made from these grains should also be avoided. In other words, a person with celiac disease should not eat most grain, pasta, cereal, and many processed foods.

Despite these restrictions, people with celiac disease can eat a well-balanced diet with a variety of foods. They can use potato, rice, soy, amaranth, quinoa, buckwheat, or bean flour instead of wheat flour. They can buy gluten-free bread, pasta, and other products from stores that carry organic foods, or order products from special food companies. Gluten-free products are increasingly available from mainstream stores.

“Plain” meat, fish, rice, fruits, and vegetables do not contain gluten, so people with celiac disease can freely eat these foods. In the past, people with celiac disease were advised not to eat oats. New evidence suggests that most people can safely eat small amounts of oats, as long as the oats are not contaminated with wheat gluten during processing. People with celiac disease should work closely with their health care team when deciding whether to include oats in their diet. Examples of other foods that are safe to eat and those that are not are provided in the [table](#).

The gluten-free diet requires a completely new approach to eating. Newly diagnosed people and their families may find support groups helpful as they learn to adjust to a new way of life. People with celiac disease must be cautious about what they buy for lunch at school or work, what they purchase at the grocery store, what they eat at restaurants or parties, and what they grab for a snack. Eating out can be a challenge. When in doubt about a menu item, a person with celiac disease should ask the waiter or chef about ingredients and preparation or if a gluten-free menu is available.

Gluten is also used in some medications. People with celiac disease should ask a pharmacist if prescribed medications contain wheat. Because gluten is sometimes used as an additive in unexpected products—such as lipstick and play dough—reading product labels is important. If the ingredients are not listed on the label, the manufacturer should provide a list upon request. With practice, screening for gluten becomes second nature.

New Food Labeling

The Food Allergen Labeling and Consumer Protection Act (FALCPA), which took effect on January 1, 2006, requires food labels to clearly identify wheat and other common food allergens in the list of ingredients. FALCPA also requires the U.S. Food and Drug Administration to develop and finalize rules for the use of the term “gluten free” on product labels.

The Gluten-free Diet: Some Examples

In 2006, the American Dietetic Association updated its recommendations for a gluten-free diet. The following chart is based on the 2006 recommendations. This list is **not** complete, so people with

celiac disease should discuss gluten-free food choices with a dietitian or physician who specializes in celiac disease. People with celiac disease should always read food ingredient lists carefully to make sure the food does not contain gluten.

Allowed Foods		
amaranth arrowroot buckwheat cassava corn flax Indian rice grass Job's tears	legumes millet nuts potatoes quinoa rice sago	seeds sorghum soy tapioca teff wild rice yucca
Foods To Avoid		
wheat <ul style="list-style-type: none"> • including einkorn, emmer, spelt, kamut • wheat starch, wheat bran, wheat germ, cracked wheat, hydrolyzed wheat protein 		barley rye triticale (a cross between wheat and rye)
Other Wheat Products		
bromated flour durum flour enriched flour farina	graham flour phosphated flour plain flour	self-rising flour semolina white flour
Processed Foods that May Contain Wheat, Barley, or Rye*		
bouillon cubes brown rice syrup candy chips/potato chips cold cuts, hot dogs, salami, sausage communion wafers	French fries gravy imitation fish matzo rice mixes sauces	seasoned tortilla chips self-basting turkey soups soy sauce vegetables in sauce

* Most of these foods can be found gluten-free. When in doubt, check with the food manufacturer.

Source: Thompson T. *Celiac Disease Nutrition Guide*, 2nd ed. Chicago: American Dietetic Association; 2006. © American Dietetic Association. Adapted with permission. For a complete copy of the *Celiac Disease Nutrition Guide*, please visit www.eatright.org.

Points to Remember

- People with celiac disease cannot tolerate gluten, a protein in wheat, rye, and barley.
- Untreated celiac disease damages the small intestine and interferes with nutrient absorption.
- Without treatment, people with celiac disease can develop complications such as osteoporosis, anemia, and cancer.
- A person with celiac disease may or may not have symptoms.
- Diagnosis involves blood tests and, in most cases, a biopsy of the small intestine.
- Since celiac disease is hereditary, family members of a person with celiac disease may wish to be tested.
- Celiac disease is treated by eliminating all gluten from the diet. The gluten-free diet is a lifetime requirement.
- A dietitian can teach a person with celiac disease about food selection, label reading, and other strategies to help manage the disease.

Hope through Research

The National Institute of Diabetes and Digestive and Kidney Diseases conducts and supports research on celiac disease. Researchers are studying new options for diagnosing celiac disease, including capsule endoscopy. In this technique, patients swallow a capsule containing a tiny video camera that records images of the small intestine.

Several drug treatments for celiac disease are under evaluation. Researchers are also studying a combination of enzymes—proteins that aid chemical reactions in the body—that detoxify gluten before it enters the small intestine.

Scientists are also developing educational materials for standardized medical training to raise awareness among health care providers. The hope is that increased understanding and awareness will lead to earlier diagnosis and treatment of celiac disease.

Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available, and help others by contributing to medical research. For information about current studies, visit www.ClinicalTrials.gov.

For More Information

American Celiac Disease Alliance

2504 Duxbury Place

Alexandria, VA 22308

Phone: 703-622-3331

Email: info@americanceliac.org

Internet: www.americanceliac.org

American Dietetic Association

120 South Riverside Plaza, Suite 2000

Chicago, IL 60606-6995

Email: hotline@eatright.org

Internet: www.eatright.org

Celiac Disease Foundation

13251 Ventura Boulevard, #1

Studio City, CA 91604

Phone: 818-990-2354

Fax: 818-990-2379

Email: cdf@celiac.org

Internet: www.celiac.org

Celiac Sprue Association/USA Inc.

P.O. Box 31700

Omaha, NE 68131-0700

Phone: 1-877-CSA-4CSA (272-4272)

Fax: 402-643-4108

Email: celiacs@csaceliacs.org

Internet: www.csaceliacs.org

Children's Digestive Health and Nutrition Foundation

P.O. Box 6

Flourtown, PA 19031

Phone: 215-233-0808

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Email: mstallings@naspghan.org

Internet: www.cdhnf.org

www.gastrokids.org

Gluten Intolerance Group of North America

31214 124th Avenue SE

Auburn, WA 98092-3667

Phone: 253-833-6655

Fax: 253-833-6675

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Internet: www.gluten.net

National Foundation for Celiac Awareness

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North American Society for Pediatric Gastroenterology, Hepatology and Nutrition

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www.cdhnf.org

The Celiac Disease Awareness Campaign

To meet the need for comprehensive and current information about celiac disease, the National Digestive Diseases Information Clearinghouse (NDDIC), a service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), launched the Celiac Disease Awareness Campaign. The Awareness Campaign is the result of the combined ideas and efforts of the professional and voluntary organizations that focus on celiac disease, along with the NIDDK, the National Institutes of Health, and the Centers for Disease Control and Prevention.

Visit www.celiac.nih.gov to learn more about the Awareness Campaign.

You may also find additional information about this topic by visiting MedlinePlus at www.medlineplus.gov.

This publication may contain information about medications. When prepared, this publication included the most current information available. For updates or for questions about any medications, contact the U.S. Food and Drug Administration toll-free at 1-888-INFO-FDA (1-888-463-6332) or visit www.fda.gov. Consult your doctor for more information.

National Digestive Diseases Information Clearinghouse

2 Information Way

Bethesda, MD 20892-3570

Phone: 1-800-891-5389

TTY: 1-866-569-1162

Fax: 703-738-4929

Email: nddic@info.niddk.nih.gov

Internet: www.digestive.niddk.nih.gov

The National Digestive Diseases Information Clearinghouse (NDDIC) is a service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The NIDDK is part of the National Institutes of Health of the U.S. Department of Health and Human Services. Established in 1980, the Clearinghouse provides information about digestive diseases to people with digestive disorders and to their families, health care professionals, and the public. The NDDIC answers inquiries, develops and distributes publications, and works closely with professional and patient organizations and Government agencies to coordinate resources about digestive diseases.

Publications produced by the Clearinghouse are carefully reviewed by both NIDDK scientists and outside experts. This publication was reviewed by Ciaran Kelly, M.D., Beth Israel Deaconess Medical Center; Mitchell Cohen, M.D., Cincinnati, Children's Hospital Medical Center; Walter Reed Army Medical Center; National Foundation for Celiac Awareness; Celiac Disease Foundation; Celiac Sprue Association/USA, Inc.; and Centers for Disease Control and Prevention staff. The gluten-free diet chart was reviewed by Alice Bast and Nancy Dickens, National Foundation for Celiac Awareness; Cynthia Kupper, R.D., C.D., Gluten Intolerance Group; and Elaine Monarch, Celiac Disease Foundation.

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