

Jump Start Your Gluten-Free Diet!

**Living with Celiac / Coeliac Disease
& Gluten Intolerance**



BROUGHT TO YOU BY THE UNIVERSITY OF CHICAGO CELIAC DISEASE CENTER

eBook Edition

Jump Start Your Gluten-Free Diet!

Living with Celiac / Coeliac Disease &
Gluten Intolerance

The University of Chicago Celiac Disease Center



THE UNIVERSITY OF CHICAGO
CELIAC
DISEASE CENTER

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Intention of eBook

The University of Chicago Celiac Disease Center is dedicated to raising awareness, increasing diagnosis rates and meeting the needs of people affected by celiac disease nationwide through education, research and advocacy.

The contents of this eBook are not intended to diagnose or recommend treatment for celiac disease. Please consult your healthcare provider with questions about your condition.

The gluten-free diet is the primary treatment for celiac disease and should be maintained to achieve maximum health. This information should be used as a resource but is not the only source that should be used to succeed with the gluten-free diet. Please take caution with all foods that are ingested and, when in doubt, do not consume.

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For more information about The University of Chicago Celiac Disease Center, please contact our office at 1-773-702-7593 or www.CeliacDisease.net.

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Introduction

Overview of Gluten-Free Diet

Celiac disease, spelled Coeliac outside of North America, is an autoimmune disorder, which means the body “attacks itself”, rather than attacking a foreign substance as in an allergy. Celiac disease mainly affects the small intestine, specifically the upper third of the small intestine.

The medical treatment for celiac disease consists of strict adherence to a gluten-free diet. In this guide you will learn what gluten is, where gluten is found and how to avoid gluten. The word gluten is a general name to describe the storage proteins, or prolamins, found in wheat (gliadin), rye (hordein), barley (secalin), and derivatives of these grains. Gliadins are the proteins mainly involved in the pathophysiology of celiac disease.

When people with celiac disease eat foods containing gluten, their immune system responds by damaging the small intestine. Specifically, the villi (small finger-like protrusions), which are found on the lining of the small intestine, become damaged. Without villi, a person is unable to absorb nutrients in food and becomes malnourished, regardless of the quantity of food eaten. Celiac disease can present with as many as 300 symptoms or with no symptoms at all.

Strict adherence to the gluten-free diet will stop symptoms including bloating, diarrhea, weight loss, fatigue, and delayed growth in children and begin the healing process. Improvements can begin within days of starting the diet, and research has found that, in children, the small intestine is usually completely healed within 12-18 months. The healing time can be longer for adults. Lactose intolerance, which can be caused by intestinal injury, often improves with intestinal healing. However, not all people with celiac disease have lactose intolerance.

The University of Chicago Celiac Disease Center

The University of Chicago Celiac Disease Center is dedicated to raising awareness and diagnosis rates nationwide and meeting the critical needs of people affected by celiac disease through education, research and advocacy.

The University of Chicago Celiac Disease Center is the first center of its kind in the nation, offering a comprehensive approach to the disease: including reliable and accurate patient and professional education, expert diagnosis and treatment for both children and adults, ground-breaking bench and clinical research and active leadership in advocacy efforts.

Mission

The University of Chicago Celiac Disease Center is dedicated to raising awareness and diagnosis rates nationwide and meeting the critical needs of people affected by celiac disease through education, research and advocacy.

History

The University of Chicago Celiac Disease Center was the first organization of its kind in the United States. Founded in 2000 by Dr. Stefano Guandalini, a world-renowned pediatric gastroenterologist and Celiac Disease expert. Largely meant to combat the misconception that Celiac Disease is a rare disease and to properly educate both the general public as well as the medical profession, the Celiac Disease Center got its start as The University of Chicago Celiac Disease Program with the help of Robin Steans and Leonard Gail, parents of one of Dr. Guandalini's celiac disease patients at the University of Chicago. Dr. Guandalini, originally from Naples, Italy, was shocked to learn how few Americans were diagnosed with Celiac Disease when he came to the US in the early 1990's. Dr. Guandalini quickly discovered the reason for the lack of diagnoses in the US. It wasn't that it was less common (in fact, current research shows the prevalence of celiac disease is approximately 1 in 100 Americans); rather it was that U.S. medical doctors had for years been taught that celiac disease was extremely rare and were therefore not screening patients for the disease.

Determined to raise awareness, education, diagnosis rates and get research underway, Dr. Guandalini joined forces with the Steans-Gail Family, established a passionate advisory board and a bold mission: to raise diagnosis rates for celiac disease and to meet the critical needs of people affected by this condition through education, research and advocacy. As a result of its success, in 2007 the organization was renamed The University of Chicago Celiac Disease Center.

In addition to conducting leading research and providing education and patient services for celiac disease, The University of Chicago Celiac Disease Center consists of a network of doctors who specialize in infertility, thyroid disease, dermatology, diabetes, cancer and other diseases and disorders that are often associated with celiac disease. These specialists collaborate to offer comprehensive diagnosis and treatment of the disease.

The University of Chicago Celiac Disease Center is well known for some of the best programs and services for celiac disease in the country including:

- **Gluten-Free Care Package Program** delivers a gift basket of gluten-free foods, educational materials about the disease and the diet to newly diagnosed Celiacs across the nation.
- **Celiac Disease Preceptorship Program** is the only intense hands-on medical professional celiac disease education in the US.
- **Annual Free Blood Screening** is a program that screens more than 500 people each year who are at risk for celiac disease often because their doctors refuse to carry the tests, insurance does not cover the cost or they are uninsured.
- **Information Hotline** is available five days a week to answer any questions related to the diet or disease.
- **Benefit and Events** occur throughout the year to build awareness and raise funds for the Center. Signature events include the Spring Flours Benefit, which attracts attendees from across the country for an evening of gourmet gluten-free fare and entertainment.

The University of Chicago Celiac Disease Center is led by the medical director and executive director and is supported by a talented advisory board consisting of doctors, dietitians, nurses, business and lay people, each of whom has a special interest in celiac disease and is dedicated to the mission of the organization.

As of January 2011, The University of Chicago Celiac Disease Center has directly assisted more than 350,000 people throughout the United States and the world with continued advancements in order to maintain its status as the leading authority on celiac disease. The University of Chicago Celiac Disease Center is a part of The University of Chicago, a 501-c3 non-profit organization. The Celiac Center is completely funded by donor contributions.

Pioneering Research Initiatives

The University of Chicago Celiac Disease Center is at the forefront of research and professional education regarding celiac disease. Our team is led by Dr. Bana Jabri who has contributed to groundbreaking celiac research and who has also been awarded the coveted 2009 Wm. K. Warren Prize in Celiac Disease - a first for anyone in The United States.

At The University of Chicago Celiac Disease Center, our predominant research vision is to develop an alternative to the gluten-free diet for medical treatment of celiac disease. We are also concerned with improving the diagnosis of celiac disease and gluten sensitivity, as well as treating patients that respond poorly to a gluten-free diet. In addition, we are working to identify treatments to prevent the development of celiac disease in at-risk children.

We benefit from a unique infrastructure combining pediatric and adult gastroenterologists dedicated to improving the life of patients with celiac disease, our Celiac Disease Center that supports forefront patient care and research, and an outstanding research group, which is the first to have received the international Wm. K. Warren prize for outstanding celiac disease research. Our group has published on celiac disease in the most high impact journals such as Nature, Immunity, and the Journal of Experimental Medicine. Our approach is unique because we combine human research with the development of mouse models, which gives us an exceptional depth, power of analysis, and ability to make groundbreaking discoveries. Obtaining an endowment for celiac disease research would provide a unique opportunity to continue and expand pioneering work on celiac disease with the goal to treat and prevent celiac disease.

Developing curative and preventive therapies for celiac disease

- **Mouse models of celiac disease.** In order to test new therapeutic strategies, it is critical to have mouse models of celiac disease that actually reproduce the human disease in a relevant manner. In addition, mouse models allow us to create a direct cause-effect relationship and hence allow us to identify the critical targets for therapies.

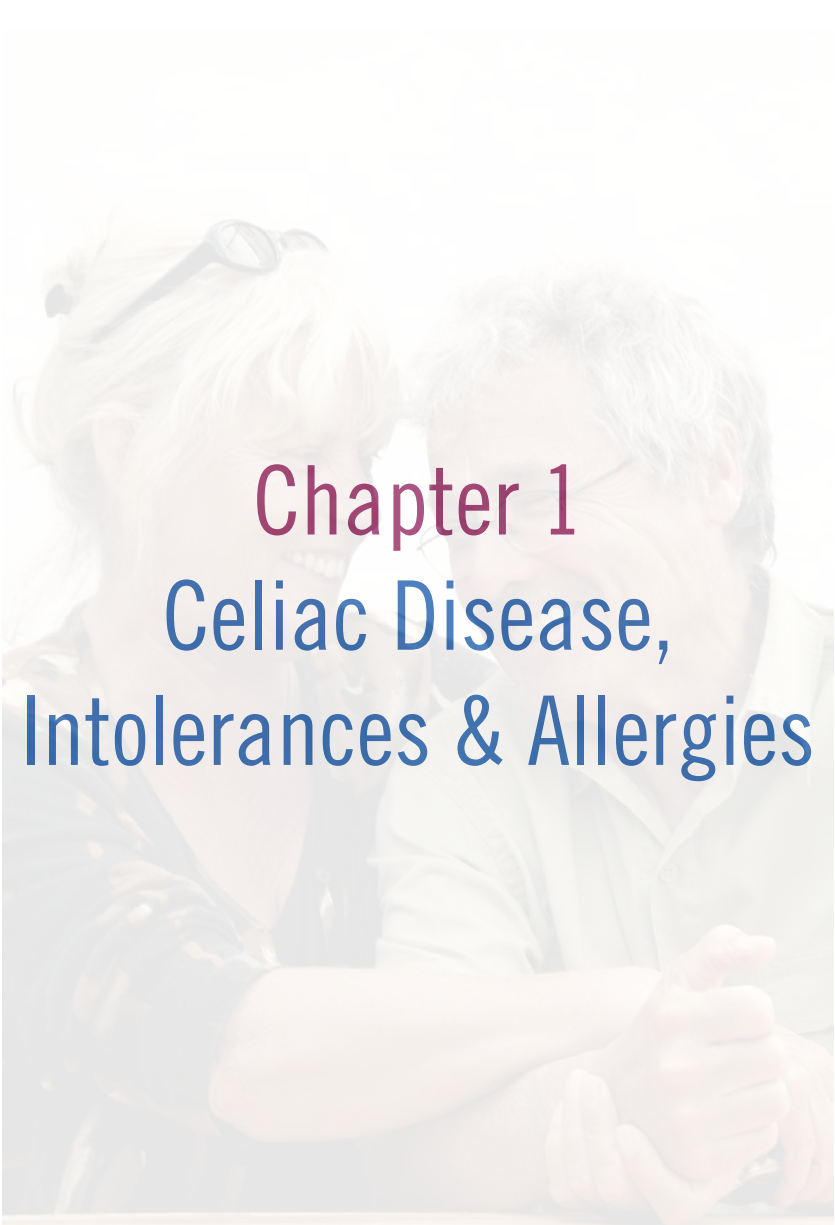
- **From human basic research to clinical trials.** Our research has identified a killer pathway responsible for the destruction of the intestinal layer. We can target these pathways with appropriate pharmacological compounds. Such examples exist for Crohn's disease and rheumatoid arthritis, where development of anti-TNF therapies has changed the lives of patients touched by these diseases. We have identified such an effector molecule implicated in celiac disease and are working in collaboration with a pharmaceutical group to set up clinical trials.
- **We are creating a comprehensive research program with chemists to develop a treatment that can prevent and cure celiac disease.** The idea is that celiac disease results from a bad destructive response to gluten and that if we could reorient this response to a good, tolerogenic, and beneficial response, we could prevent and cure celiac disease. To do this, it is necessary to have a comprehensive analysis of the intestinal immune system and a strong understanding of how it is deregulated in celiac disease. A mouse model is also necessary to test and adjust therapeutic avenues. Our background, past work, and mouse models put us in the position to achieve this.
- **Efficacy of a probiotic treatment in celiac patients with partial response to the gluten-free diet.** A small portion of patients with celiac disease continue to present symptoms of gastrointestinal distress even after beginning the diet, as a result of an ongoing mild degree of inflammation. In addition, the microflora of celiac patients has been shown to be different from that of healthy individuals. Probiotics are known to beneficially affect intestinal inflammation and may normalize abnormal microflora. Thus, this study aims to assess the efficacy of a scientifically validated probiotic treatment in normalizing the microbial composition and ameliorating symptoms in celiac patients on the gluten-free diet.

Improving the Diagnosis of Celiac Disease and Gluten Sensitivity

- **Gluten Sensitivity: myth or reality?** People suffer from gluten sensitivity and yet do not have the classical markers of celiac disease. Because they lack both anti-transglutaminase antibodies and in some cases also the right genetic make-up (HLA-DQ2 or HLA-DQ8), their suffering is dismissed as being psychological. We have evidence that gluten sensitivity is a real disease. In gluten sensitive patients, gluten is viewed as a danger signal and virus by the body. Consequently, the body mounts an inappropriate stress response that results in alterations of the intestinal linings, abdominal pain, and diarrhea. Our goal is to develop diagnostic markers and understand how gluten can induce such a stress response, and to improve the diagnosis and treatment of patients suffering from gluten sensitivity.

- **Celiac disease and autoimmune diseases.** Celiac disease is associated with an increase in autoimmune disorders such as type-1 diabetes. It is also known that the longer patients have untreated celiac disease, the higher their risk of developing an autoimmune disorder. Our group is working to identify the cause of this increased risk of developing autoimmunity in celiac disease. We have identified a factor in the blood that we believe can help identify at-risk patients and creates the possibility of developing therapeutic tools to prevent the development of autoimmune diseases in celiac disease patients.
- **Associating genetic studies with patient phenotyping.** We know now that celiac disease is a complex genetic disorder and that there are different forms of celiac disease. Some patients suffer from destruction of their intestinal lining (they have villous atrophy), some have a skin disease or neurological symptoms, while others have general fatigue. Understanding how the genetic make-up and environmental factors such as viral infections and gluten lead to different forms of celiac disease is critical to advance the diagnosis and treatment of celiac disease.
- **Efficacy of rapid finger-prick test in diagnosing celiac disease.** This trial will test the accuracy of a finger-prick test for celiac disease. The product is currently sold in Europe, and gives a tissue transglutaminase antibody reading in under ten minutes.
- **Timing of gluten intake in infant nutrition and risk of celiac disease autoimmunity.** Studies have shown that breast feeding at-risk infants at the time of gluten introduction may delay or prevent the development of celiac disease. The risk of developing celiac disease is reduced by prolonged breast-feeding, introduction of gluten during breast-feeding, introduction of gluten in the right “time window,” and introduction of gluten in small amounts. The University of Chicago Celiac Disease Center is partnering with the University of Maryland Center for Celiac Research on an international, multi-center study (25 centers in all) to further investigate the effects of early versus late gluten introduction in at-risk infants on the development of celiac disease.

In conclusion, we have a unique infrastructure, an extraordinary expertise, distinguished clinical and research programs, and exceptional tools that allow us the possibility to make a notable difference in the life of celiac disease patients and their families. Given the right resources, we believe that we can find a cure for celiac disease in the coming 10-15 years.



Chapter 1

Celiac Disease, Intolerances & Allergies

Overview of Celiac Disease

What is celiac disease? Celiac disease is the world's most common genetic autoimmune disorder which affects the digestive process of the small intestine. When a person who has celiac disease consumes gluten, a protein found in wheat, rye and barley, the individual's immune system responds by attacking the small intestine and inhibiting the absorption of important nutrients into the body. Undiagnosed and untreated, celiac disease can lead to the development of other autoimmune disorders, as well as osteoporosis, infertility, neurological conditions and in rare cases, cancer.

Celiac disease affects the digestive process of the small intestine which is connected to the stomach—the first part of the small intestine, the duodenum and the jejunum are where celiac is commonly found. Specifically, tiny finger like protrusions, called villi, on the lining of the small intestine are lost. Nutrients from food are absorbed into the bloodstream through these villi.

What is dermatitis herpetiformis (DH)?

Dermatitis herpetiformis (DH) is an itchy, blistering skin condition that is a form of celiac disease. The rash usually occurs on the elbows, knees, and buttocks and is characterized by its bilateral nature; both knees (and/or both arms) are affected, seldom just one. Many people with DH have no digestive symptoms and only about 40% of them have the positive blood tests (serology) for celiac disease: however, they almost always have the same, gluten-dependent intestinal damage as people with celiac disease.

Unless otherwise specified, the information pertaining to celiac disease also pertains to people with dermatitis herpetiformis. In addition to following a strict gluten-free diet, DH is also commonly treated with a medication called Dapsone.

Is celiac disease a rare condition?

No. Celiac disease affects at least 1% of Americans, or nearly 3 million people in the United States. By comparison, Alzheimer's disease affects approximately 2 million people. In addition, research has shown that celiac disease is becoming more and more prevalent with time. It is possible to be diagnosed with celiac disease at any age.

Is it possible to have celiac disease and NO symptoms?

YES. Recent research has demonstrated that a significant percentage of children and adults with positive celiac blood tests had no, or minimal, symptoms when they were tested.

Further, there are a few patients that carry the gene for celiac disease, have no or minimal symptoms and negative blood tests, yet a positive biopsy showing that the disease is active.

Why is it difficult to find a doctor that knows about celiac disease?

Most physicians learned during medical school that celiac disease was so rare they would never see a patient with symptoms in their entire medical career. Lectures on celiac disease in medical schools, even today, are few and far between. When your doctor was in medical school, he or she may have heard a 20-30 minute celiac disease lecture during four years of classes. Medical textbooks still contain outdated information.

Additionally, celiac disease often presents with seemingly unrelated symptoms, such as fatigue, joint pain, anemia and infertility, making diagnosis that much more difficult. The University of Chicago Celiac Disease Center is working hard to properly educate doctors about celiac disease so that those at risk for the disease are screened immediately.

What is the prevalence of celiac disease in the United States?

- In average healthy people: 1 in 133
- In people with related symptoms: 1 in 56
- People with first-degree relatives who are celiac: 1 in 22
- In people with second-degree relatives who are celiac: 1 in 39
- Estimated prevalence for African, Hispanic and Asian-Americans: 1 in 236
- In the landmark prevalence study on celiac disease, investigators determined that 60% of children and 41% of adults diagnosed during the study were asymptomatic (without any symptoms).
- Researchers found that 21% of patients with a positive anti-endomysial antibody test couldn't receive a biopsy due to the refusal of a physician to

perform the procedure or the insurance company to pay for it.

- Only 35% of newly diagnosed patients had chronic diarrhea, dispelling the myth that diarrhea must be present to diagnose celiac disease.

Source: A multi-center study on the prevalence of celiac disease in the U.S. among both at risk and not at risk groups. Fasano et. al., Archives of Internal Medicine February 2003.

- Celiac disease affects 3 million Americans.
- The average length of time it takes for a symptomatic person to be diagnosed with celiac disease in the US is four years; this type of delay dramatically increases an individual's risk of developing autoimmune disorders, neurological problems, osteoporosis and even cancer.

Source: Characteristics of adult celiac disease in the USA: results of a national survey. Green, P.H. et.al. American Journal of Gastroenterology, 2001, 2006.

- The incidence of autoimmune diseases in the general US population is 3.5%. In a 1999 study, Ventura found that those diagnosed with celiac disease between 2-4 years of age had a 10.5% chance of developing an autoimmune disorder. Additional findings are outlined in the table below:

Age at Diagnosis	Chance of Developing Autoimmune Condition
4 – 12 years	16.7%
12 – 20 years	27%
Over 20 years	34%

- Early diagnosis of celiac disease thus is important, as it might prevent complications, and awareness is the key. A recent study in North America shows that an active case-finding strategy in the primary care setting is an effective means to improve the diagnostic rate of Celiac Disease: by screening with the blood test all subjects belonging to known “at-risk” groups such as those listed above, the diagnosis rates increased more than 40-fold.

Source: Duration of exposure to gluten and risk for autoimmune disorders in patients with celiac disease. SIGEP Study Group for Autoimmune Disorders in Celiac Disease. Ventura A, et.al. Gastroenterology 1999 Aug;117(2):297-303. Rampertab SD et al. Trends in the Presentation of Celiac Disease Am J Medicine 2006. Catassi C et al. Detection of Celiac disease in primary care: a multicenter case-finding study in North America. Am J Gastroenterol 2007

What other chronic illnesses are common in the United States?

- Epilepsy affects 2.7 million
- Cystic Fibrosis affects 30,000 people
- 17,000 people are living with hemophilia
- Parkinson's disease affects 1,000,000 individuals
- Ulcerative colitis affects 500,000 people

- Crohn's disease affects 500,000 Americans
- 2.1 million Americans are living with rheumatoid arthritis
- Lupus affects 1.5 million people
- Multiple sclerosis affects 400,000 people in the United States

What are the statistics on the amount of people affected by celiac disease?

- Type 1 Diabetes affects 3 million people; up to 10% (300,000) of those diagnosed also have celiac disease.
- 610,000 women in the US experience unexplained infertility; 6% (36,600) of these women might never learn that celiac disease is the cause.
- 350,000 people in the United States are living with Down syndrome; up to 12% (42,000) of them also have celiac disease.
- The number of people with celiac disease in the U.S. would fill 4,400 Boeing 747 airplanes.
- It would take 936 cruise ships to hold every American with celiac disease.
- Americans with celiac disease could fill Comiskey Park (now US Cellular Field, with 40,000 seats) to watch the Chicago White Sox 55 times.
- U.S. fans with celiac disease could fill Soldier Field, the home of the Chicago Bears, 37 times.
- The number of people with celiac disease in the U.S. is roughly equal to the number of people living in the state of Nevada.
- Alaska, Delaware, Washington DC, Hawaii, Idaho, Maine, Montana, Nebraska, New Hampshire, New Mexico, North Dakota, Rhode Island, South Dakota, Utah and Vermont all have populations that are less than 2,200,000 the number of people living with celiac disease in the United States.

Intolerances & Allergies

The way that celiac disease, gluten sensitivity & wheat allergy are defined means a lot to the person with the gastrointestinal condition as well as to that person's family. Fortunately, medical research has allowed us to define these entities. However, a medical professional who does not know how to diagnose celiac disease may provide an incorrect diagnosis of gluten sensitivity or wheat allergy.

First, it is important to recognize that celiac, gluten sensitivity and a wheat (or gluten) allergy are all food intolerances. There are several classifications of food intolerances: food allergy, autoimmune-mediated, congenital digestive disorders and metabolic diseases. Metabolic diseases, like fructose intolerance, affect 1 in 10,000 people. For purposes of this publication, only celiac disease, gluten sensitivity and wheat (or gluten) allergy are defined.

What is celiac disease?

Celiac is an autoimmune-mediated disorder and occurs when the immune system acts to destroy the body's own tissues. The tissue damage created by an autoimmune disorder can lead to medical complications and an increased risk for other disorders. The development of an autoimmune disorder is affected by genetics (there are two established genetic factors for celiac disease: DQ2 and DQ8) and factors in the environment.

Celiac disease is the only autoimmune disorder where the trigger is known; remove the trigger and the autoimmune response does not occur. This means that a person with celiac disease who is following the gluten-free diet has as healthy an immune system as any average person walking down the street.

If an individual feels they may not have received a correct diagnosis, and is on a gluten-free diet, the HLA gene test for celiac disease could be helpful. This is a blood test that should be performed by a qualified laboratory, like Prometheus or Mayo Clinic.

An individual has a 65% chance of not having the genes for celiac disease. If the genes are not present, a symptomatic individual could have an allergy or intolerance. If the genes are there, the individual possibly has celiac disease.

What is gluten sensitivity?

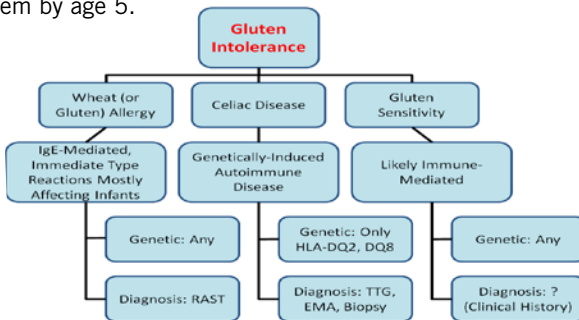
Gluten sensitivity is an adverse food-induced reaction, possibly immune-mediated, but for which we have no diagnostic test available. This is a reaction in the digestive tract that causes gastrointestinal symptoms just like irritable bowel syndrome (IBS). It may also lead to other body systems problems, such as fatigue, headache, etc. Unlike celiac disease however, it is not restricted to people that are HLA-DQ2 and/or DQ8, and it might be transient. Also, there is no known association with autoimmune conditions, and it is not known to be associated, if untreated, with long-term risk of malignancies.

Although there is currently no diagnostic test (even an intestinal biopsy would be normal!), the University of Chicago Celiac Disease Center is actively involved in research to define a biological marker that could be used to support such diagnosis.

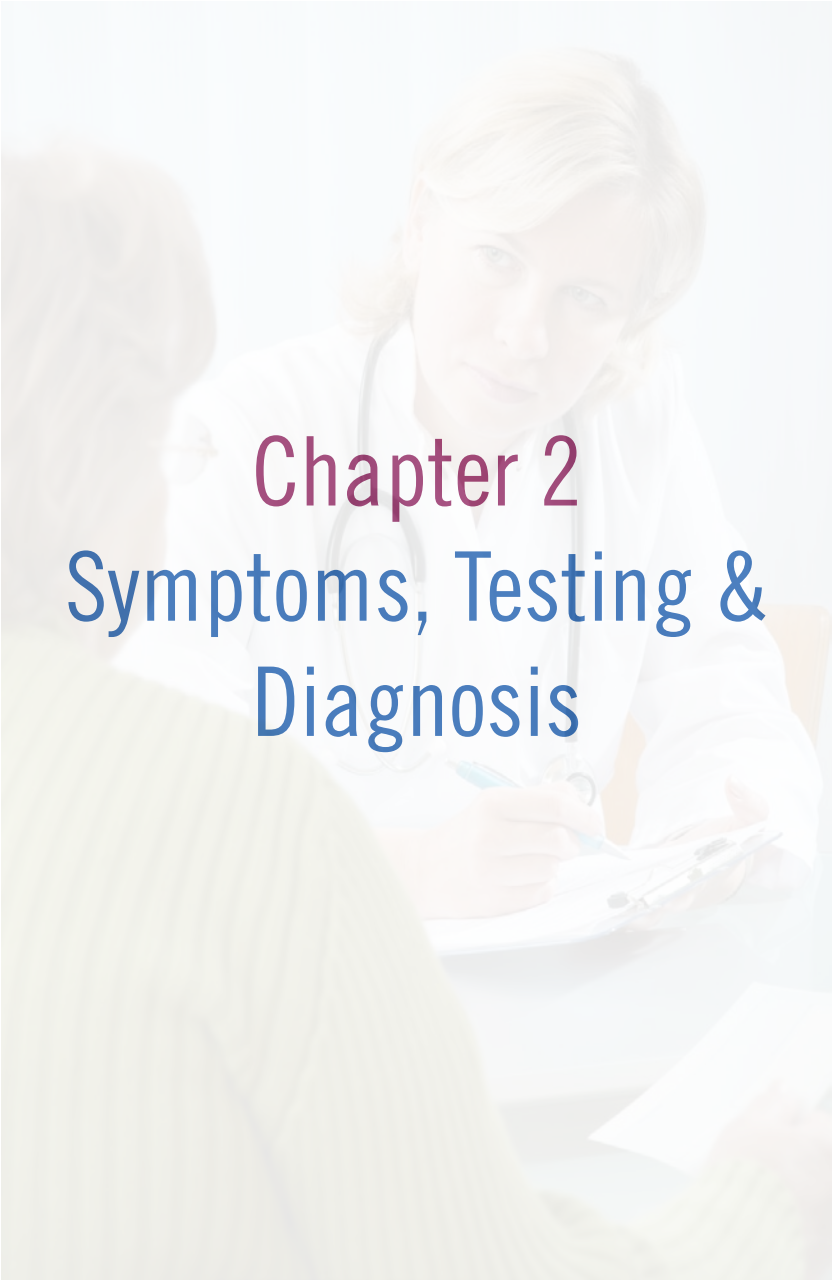
What are food allergies?

Food allergies affect 3-5% of the population. In 20% of those cases, people with food allergies have an IgE mediated immune reaction to the trigger food. There is a blood test that can detect IgE mediated food allergies called the RAST test. Unfortunately, most people have food allergies that cannot be detected by this test, as they are mediated by immune mechanisms other than IgE. These types of allergies are diagnosed with a food elimination diet.

Trigger foods produce an immune response towards the particular food protein – the immune system has determined that the offending food is dangerous to the body when in fact it isn't. The symptoms that are caused by the immune response are time-limited and do not cause lasting harm to the body's tissues. (The exception is the immediate response to peanuts or other foods that produce an anaphylaxis response—where the individual can stop breathing and the allergy is life-threatening). Food allergies can be temporary; many children outgrow them by age 5.



A schematic representation of the three possible adverse reactions to gluten ingestion



Chapter 2

Symptoms, Testing & Diagnosis

Symptoms

Celiac disease affects people differently. There are more than 300 signs and symptoms of celiac disease, yet a significant percentage of people with celiac disease have no symptoms at all. The undamaged part of their small intestine is able to absorb enough nutrients to prevent symptoms. However, people without symptoms are still at risk for some complications of celiac disease.

What are the symptoms of celiac disease?

- Recurring abdominal bloating/pain
- Chronic diarrhea/constipation
- Vomiting
- Liver and biliary tract disorders (“Transaminitis”, fatty liver, primary sclerosing cholangitis etc.)
- Weight loss
- Pale, foul-smelling stool
- Iron-deficiency anemia that does not respond to iron therapy
- Fatigue
- Failure to thrive or short stature
- Delayed puberty
- Pain in the joints
- Tingling numbness in the legs
- Pale sores inside the mouth
- A skin rash called dermatitis herpetiformis (DH)
- Tooth discoloration or loss of enamel
- Unexplained infertility, recurrent miscarriage
- Osteopenia (mild) or osteoporosis (more serious bone density problem)
- Peripheral Neuropathy
- Psychiatric disorders such as anxiety, depression

How do these symptoms tend to appear in children & adults?

Children tend to have the more classic signs of celiac disease, including growth problems (failure to thrive, chronic diarrhea/constipation, recurring abdominal bloating and pain, fatigue and irritability).

Adults tend to have symptoms that are not entirely gastrointestinal in nature. Recent research has demonstrated that only a third of adult patients diagnosed with celiac disease experience diarrhea. Weight loss is also not a common sign. The most common sign of celiac disease in adults is iron deficiency anemia that does not respond to iron therapy.

Who should be tested for celiac disease and how often?

1. Children older than three years of age and adults, regardless of symptoms, if related to a close relative with biopsy confirmed celiac disease. A close relative is considered to be a parent, sibling or child. An aunt/uncle, grandparent or cousin with celiac disease may raise an individual's risk for celiac disease somewhat, but not much higher than the risk of the average population.
2. In children younger than three, with symptoms, antibody testing may not always be accurate. However, young children with symptoms (especially failure to thrive or persistent diarrhea) should be evaluated by a pediatric gastroenterologist. Children need to be eating wheat or barley based cereals for some time, up to one year before they can generate an autoimmune response to gluten and have their blood tested.
3. Any individual who has a related autoimmune disorder, regardless of celiac symptoms, should be tested for celiac disease and if negative the test should be repeated on a periodic basis. These conditions include insulin-dependent diabetes mellitus (requiring insulin therapy), Hashimoto's thyroiditis, Turner's syndrome, Williams syndrome, Graves disease and Sjogren's disease.
4. Any person with Down Syndrome should be tested on a periodic basis.
5. Any individual who has experienced persistent miscarriage or infertility where a medical cause could not be found needs to be tested for celiac disease.
6. There are many other symptoms that could indicate the presence of celiac disease, including persistent gastrointestinal symptoms, bone density problems, dental enamel hypoplasia, fatigue, and others. If you are concerned about your symptoms, ask your doctor about testing.

Why do I need to be tested more than once?

Celiac disease can develop, in a person at risk, at any time. There are three factors that come together to cause celiac disease to occur—an over-responsive immune system, genetic predisposition, and factors in an individual's environment.

We know that people are born with the genes for celiac disease, and that gluten is what turns on the autoimmune response. However, the factors in an individual's environment act in unpredictable ways.

Some people can eat gluten for fifty years and then develop celiac disease, while others eat gluten for only nine months before they are diagnosed. Many individuals have silent celiac disease, which means that the absence of symptoms does not indicate they are healthy.

What is known is that the early diagnosis of celiac disease can prevent the development of other autoimmune disorders and additional complications in many people. Regular antibody testing is the key to early diagnosis.



Genetic & Antibody Blood Testing

When a person is diagnosed with celiac disease, the entire family learns that they must be tested for the condition for they are now at risk. First degree relatives (parent, child, sibling) have a 1 in 22 chance of developing celiac disease in their lifetimes; second degree relatives (aunt, uncle, cousin, grandparent), have a 1 in 39 chance. A simple genetic test can determine if further screening is needed or can completely rule out the possibility of developing the disease. If the genetic test is positive, the individual should have antibody screening regularly to help determine if the disease is active. Research has also shown that people with celiac disease who eat gluten have higher than normal levels of certain antibodies in their blood.

What is genetic testing and who can benefit from it?

DNA testing is available (either via blood test, cheek swab or saliva) to determine whether or not an at-risk individual carries the genes responsible for the development of celiac disease. These genes are located on the HLA-class II complex and are called DQ2 and DQ8. Almost every case of celiac disease has been found to show these so-called “haplotypes”; therefore, a negative gene test indicates that celiac disease would be extremely unlikely to develop in that individual.

There are two main reasons for using the genetic test when evaluating an individual for celiac disease. The first case is to “rule out” celiac disease, which is a medical term that indicates an individual does not possess a necessary risk

factor for the development of celiac disease, genetic predisposition. Without this factor, it is impossible that the individual with a negative gene test will develop celiac disease in the future. People who test negative for the gene would not be required to have regular antibody screening for the remainder of their lives.

In individuals with symptoms who have not had a biopsy to diagnose celiac disease, but have been on the gluten-free diet for a significant period of time, the gene test is often the only way to determine if symptoms could possibly be related to celiac disease. For a person who faces this situation, a negative gene test would indicate that symptoms are not the result of celiac disease. A positive gene test, however, does not diagnose the disease but increases the likelihood that it is present.

If I have a gene for celiac disease, does that mean I have celiac disease?

The gene test does not diagnose celiac disease. It places an individual into an “at-risk” group for celiac disease, which indicates the individual should be closely monitored with antibody testing in the future. When the genetic predisposition for celiac disease was detected (on Chromosome 6) researchers noted that the genes were a necessary but not sufficient condition for the disease to develop. People with DQ2 or DQ8 can develop celiac disease at any time.

How is genetic testing different than antibody testing for celiac disease?

The blood tests that most people with celiac disease are familiar with are the antibody tests. These tests, such as the tissue transglutaminase test (tTG) or the antiendomysial (EMA) antibody test, measure the autoimmune response triggered by gluten that occurs at a point in time. (Think of it as a photograph.) These are important tests because they characterize the extent to which the immune system is responding to gluten.

Unlike antibody testing, the HLA gene testing for celiac disease measures the presence or absence of genetically-programmed molecules that are found on the surface of some cells. The HLA gene test for celiac disease can be performed at any time after birth (and even in the cord blood at birth!)—an individual is either born with or without these factors and they do not change over time.

How is genetic predisposition for celiac disease inherited?

Inheriting the genes for celiac disease occurs differently than the manner in which many genetic traits are passed on. We are accustomed to thinking in terms of dominant or recessive genes which are inherited from both parents and form sets to determine hair color, height and other human health characteristics. In fact, even though DQ2 and DQ8 are passed on similarly, they are not sufficient to determine the occurrence of the disease, even if they are in double doses.

Because 35% of the American population have either DQ2 (more commonly) or DQ8, it is possible for two affected people to marry each other. The genes can be passed on by males as well as females. Therefore, one person's gene test doesn't necessarily mean that the other side of the family is not affected as well.

Who can order the gene test?

Genetic testing is available through most doctors. More and more insurance companies are covering the cost for the test, especially if the individual being tested has a risk factor for the disease. Genetic testing kits are available for at home use from both Prometheus Laboratories (www.MyCeliacID.com) and Kimball Genetics (www.KimballGenetics.com).

What is antibody testing?

To help diagnose celiac disease, physicians first test blood to measure levels of certain antibodies. These antibodies are anti-endomysium and anti-tissue transglutaminase. A positive antibody test indicates only that a person needs a biopsy; it is not a diagnosis in and of itself.

Antibody tests measure your immune system's response to gluten in the food you eat. Your doctor may order a panel of tests to aid in diagnosis, or order one or several to see if you may need further evaluation. The blood for these tests are usually sent to one of only a few labs in the country that are best suited for conducting the test and interpreting the results. These laboratories include Prometheus Labs, Quest Diagnostics and the Mayo Clinic.

Which tests do I need?

If antibody tests and/or symptoms suggest celiac disease, the physician needs to establish the diagnosis by obtaining tiny pieces of tissue from the small intestine to check for damage to the villi. This is done in an endoscopic biopsy procedure. The physician eases a long, thin tube called an endoscope through the mouth and stomach into the small intestine, and then takes samples of the tissue using instruments passed through the endoscope. Biopsy of the small intestine is the only way to diagnose celiac disease.

Why is it necessary to have the endoscopic biopsy?

It is important to know that the blood testing can only confirm that you do not have celiac disease. This is why the biopsy is necessary if your test results are positive, to confirm the results. It is important to definitively establish the presence of celiac disease and rule out the presence of other conditions, including food allergies, a far more common condition.

What do I do if I have a negative blood test (or panel) but I'm still having symptoms?

While it is rare, it is possible for patients to have a negative antibody test results and still have celiac disease. IgA deficiency is one example where this could occur. Further medical evaluation is important for anyone who is still experiencing symptoms, to establish the diagnosis or to rule out celiac disease as a part of establishing another diagnosis.

Should I stop eating gluten before getting tested?

Antibody tests are only accurate when a patient is on a gluten-containing diet. Those concerned about celiac disease are strongly discouraged from starting a gluten-free diet without having had a firm diagnosis. Any change in the diet, even for as little as a month, can complicate the diagnostic process.

What is a screening test?

A screening test is commonly used when an individual is in a risk group for celiac disease, whether or not he/she has symptoms. This test is usually the one offered for celiac screening events. Other tests include:

- Total Serum IgA to test for IgA deficiency (this health condition can affect accuracy of antibody test)
- Anti-endomysial antibody test (EMA-IgA) - EMA-IgA are very specific for celiac disease but they are not as sensitive as the tTG-IgA.
- HLA-DQ2 and HLA-DQ8 gene tests for celiac disease

The “gene tests” are not antibodies: they can be used to exclude celiac disease (if negative) in doubtful cases. Anti-gliadin Antibodies (AGA-IgG and AGA-IgA) are no longer used to test for celiac disease due to a low level of accuracy in people who haven't been diagnosed.

Does this apply to you?

It is important to note that some people with Type 1 Diabetes, Hashimoto's thyroiditis and autoimmune liver conditions can have a falsely positive tissue transglutaminase test. For this reason, it is important that tTG test results in people with these conditions be checked with the EMA test. People with IgA deficiency require a different version of the antibody tests listed above. The tTG and EMA tests have IgG versions and these tests will then be accurate for someone with IgA deficiency. IgA deficiency is diagnosed when someone has a total serum IgA test and the results are very close to zero.

Diagnosis

If antibody tests and symptoms suggest celiac disease, the physician needs to establish the diagnosis by obtaining tiny pieces of tissue from the upper small intestine to check for damage to the villi. This is done in a procedure called a biopsy: the physician eases a long, thin tube called an endoscope through the mouth and stomach into the small intestine, and then takes samples of the tissue using instruments passed through the endoscope.

What is an endoscopic biopsy?

Biopsy of the small intestine is the only way to diagnose celiac disease. This procedure is always performed by a gastroenterologist, and is conducted most often in an outpatient surgical suite. The procedure lasts less than ½ an hour, and for adults, sedation and local anesthesia are used.

The procedure involves a long, thin tube with a small camera on the end. The physician will insert the tube into the patient's mouth, down the throat and into the esophagus. When the tube reaches the patient's stomach the physician finds the entryway into the small intestine (the duodenum) and inserts the tube there. As the tube is making its way to the small intestine, the camera on the end sends a video image to a monitor in the procedure room. On the monitor, the physician can visually assess any gastritis, or other inflammation (such as inflammation of the lower esophagus due to acid reflux).

In the small intestine, the physician examines the entire length of the duodenum, the area affected by celiac disease. However, in many celiac patients, their duodenum--at the time of biopsy--appears normal. This is why the surgical removal of tissue is so important, for it is only under a microscope that a definitive diagnosis of celiac disease can be made.

At this point, the physician will insert a tiny surgical instrument through the tube. It reaches the small intestine, and working in concert with a surgical nurse, the physician will biopsy 5-6 areas of the small intestine. The biopsy is taken by grasping very small sections of tissue and slicing them gently away from

the walls of the intestine. Multiple tissue samples are also vital to an accurate diagnosis—celiac disease can cause patchy lesions in the duodenum which can be missed if only one or two samples are taken. Results of the biopsy will confirm if a patient has celiac disease. There are no nerve endings in the intestine, so this procedure does not cause pain in the gut. Afterwards, some patients experience a sore throat, but most have no memory of the procedure.

How is DH Diagnosed?

DH is diagnosed by a skin biopsy, which involves removing a tiny piece of skin near the rash and testing it for the IgA antibody. DH is treated with a gluten-free diet and medication to control the rash, such as dapsone or sulfapyridine. Drug treatment is short term, usually until the gluten-free diet starts to relieve symptoms. It is not necessary to perform an intestinal biopsy to establish the diagnosis of celiac disease in a patient with DH; the skin biopsy is definitive.

I'm concerned about my child having this procedure. Is it really necessary in children? Can my child have the biopsy when he is older?

It is. While it is understandable for parents to be concerned about this procedure, there are several important facts to consider.

First, the procedure takes 10-15 minutes, during which the child is under general anesthesia and closely monitored by a team of anesthesiologists. This team will adjust the anesthesia your child receives during the procedure to just the right amount. Ensuring that your child has an experienced physician who has done many procedures will also help to ensure that everything goes smoothly.

Second, research shows that children diagnosed before the age of four reduce their risk of developing additional autoimmune disorders. This advantage is tremendous, as children who are diagnosed between the ages of 4 and 12 have a 17% risk; from 12-20 years of age the risk goes up to 27% and an individual diagnosed above the age of 20 has a 34% chance of developing another autoimmune disorder.

Third, the longer a child is on the gluten-free diet, it becomes more difficult to correctly diagnose the child with celiac disease. (This is also true for adults.) A child may have to eat gluten for many weeks (a gluten challenge) in order to have a biopsy if that child has been eating gluten for several months or more. A gluten challenge in adults can last three months.

Clinical experience also shows that children and adults who have not been biopsied as part of their diagnosis for celiac disease tend to take the diet less seriously and eat gluten when they shouldn't. While many people who have not been biopsied may not have celiac disease, this approach to the gluten-free diet is concerning for those who do in fact have celiac disease but don't know it.

Can you see celiac disease?

Because the damage caused by celiac disease is microscopic, in a majority of cases it is not possible to confirm the diagnosis of celiac disease just by looking at the walls of the intestine. That's why the biopsies are needed.

Are you scheduled for a biopsy? Are you eating gluten?

Any changes in your diet can affect the accuracy of your biopsy results. It is necessary for you to be eating gluten every day for at least 12 weeks before the procedure. If you are scheduled for a biopsy and are not eating gluten, talk to your doctor about what is necessary to obtain accurate results. If you have a biopsy and have eaten gluten only a short time before the test, you and your physician will not know if a negative test result is accurate or due to your diet.





Chapter 3

Healing The Gut

Treatment

Once an individual has been confirmed, through a biopsy, to have celiac disease they are instructed to begin following the gluten-free diet. This can often be difficult, at first, because so many foods contain gluten in them. However, through support and guidance from experienced celiacs and a skilled dietitian, many newly diagnosed patients learn that the gluten-free diet requires some creativity and planning, but that great tasting food isn't out of reach.

The only treatment for celiac disease is to follow a gluten-free diet--that is, to avoid all foods that contain gluten. For most people, following this diet will stop symptoms, heal existing intestinal damage, and prevent further damage. Improvements begin within weeks of starting the diet, and the small intestine is usually completely healed--meaning the villi are intact and working--in 6 to 18 months. (It may take up to 2 years for older adults.) Left untreated, celiac disease may result in:

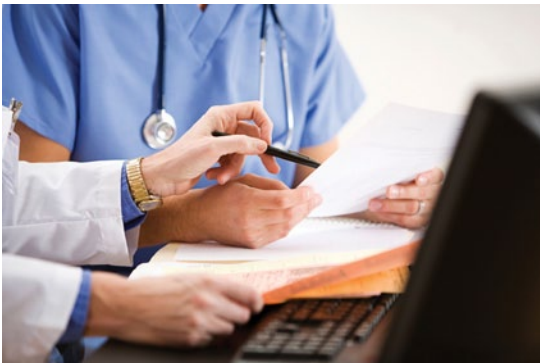
- Vitamin and mineral deficiencies
- Osteoporosis
- Anemia
- Increased risk of infertility or miscarriage
- Lymphoma
- Adenocarcinomas of the intestinal tract
- Depression

The gluten-free diet is a lifetime requirement. Eating any gluten-containing food, no matter how small an amount, can damage the intestine. This is true for anyone with the disease, including people who do not have noticeable symptoms. It can take weeks for antibody levels (indicating intestinal damage) to normalize after a person with celiac disease has consumed gluten. Depending on a person's age at diagnosis, some problems, such as delayed growth and tooth discoloration, may not improve.

A gluten-free diet means avoiding all foods that contain wheat (including spelt, triticale, and kamut), rye, and barley. Despite these restrictions, people with celiac disease can eat a well-balanced diet with a variety of foods, including gluten-free bread and pasta. For example, instead of wheat flour, people can use potato, rice, soy, or bean flour.

Unprocessed meat, fish, rice, fruits, and vegetables do not contain gluten, so people with celiac disease can eat as much of these foods as they like. The gluten-free diet requires a completely new approach to eating that affects a person's entire life. People with celiac disease have to be extremely careful about what they buy for lunch at school or work, eat at cocktail parties, or grab from the refrigerator for a midnight snack. Eating out can be a challenge as the person with celiac disease learns to scrutinize the menu for foods with gluten and question the waiter or chef about possible hidden sources of gluten. However, with practice, identifying potential sources of gluten becomes second nature and people learn to recognize which foods are safe and which are off limits.

A dietitian, a health care professional who specializes in food and nutrition, can help people learn about their new diet. It is important to find a dietitian who specializes in celiac disease. You can find one at www.EatRight.org. Also, support groups are particularly helpful for newly diagnosed people and their families as they learn to adjust to a new way of life. Over time, the diet becomes easier—even second nature. If you find that the diet is still difficult after several months, or you are still sick, talk to your doctor, your dietitian and your support organizations. You may be eating gluten accidentally and need an outside perspective to identify foods that are keeping you from regaining your health.



Ingredients to Avoid (CONTAIN GLUTEN)

- Abyssinian Hard (Wheat Triticum duran)
- Avena (wild oat)
- Barley (Hordeum Vulgare)
- Barley malt, barley extract
- Beer, ale, porter, stout, other fermented beverages
- Blue Cheese**
- Bran
- Bread flour
- Broth**
- Bulgur (bulgur wheat and nuts)
- Bouillon
- Cereal (cereal extract, cereal binding)
- Cracker meal
- Croutons
- Couscous
- Dinkle***
- Durum***
- Einkorn, wild einkorn***
- Emmer, wild emmer***
- Edible starch
- Farina
- Farro***
- Filler
- Fu
- Flour (Including but not limited to: all-purpose, barley, bleached, bread, brown, durum, enriched, gluten, graham, granary, high protein, oat, wheat, white)
- Germ
- Gluten, Glutenin
- Graham Flour
- Hordeum, Hordeum vulgare
- Hydrolyzed oat starch, hydrolyzed wheat gluten, hydrolyzed wheat protein
- Kamut ***
- Malt, malt beverages, malt extract, malted milk, malt flavoring, malt syrup, malt vinegar, maltose
- Matzo (Matzah)
- MIR (wheat, rye)
- Miso (may contain barley)
- Mustard powder**
- Oats, oat bran, oat fiber, oat gum, oat syrup*
- Oriental wheat
- Rice malt, rice syrup, brown rice syrup**
- Rye
- Soy Sauce**
- Seitan
- Semolina
- Spelt***
- Sprouted wheat
- Tabbuleh
- Triticale
- Udon
- Vital gluten
- Wheat, wheat berry, wheat bran, wheat germ, wheat germ oil, wheat grass, wheat gluten, wheat starch, whole wheat berries

*Historically, oats were not recommended because it was thought that avenin was toxic to gluten-intolerant individuals. However, research in Europe and the US has found that oats are well tolerated by most people when consumed in moderation and do not contribute to abdominal symptoms, nor prevent intestinal healing. PLEASE NOTE: Regular, commercially available oats are frequently contaminated with wheat or barley. However, "pure, uncontaminated" oats have become available from several companies in the US and Canada. These companies process oats in dedicated facilities and are tested for purity. Pure, uncontaminated oats can be consumed safely in quantities of less than 1 cup per day. It is important that you talk to your physician and your registered dietitian prior to starting oats.

** May be made with wheat - call company to verify.

*** Types of wheat

Gluten-Free Ingredients (SAFE)

- Acorn
- Almond
- Amaranth
- Arborio rice
- Aromatic rice
- Arrowroot
- Basmati rice
- Brown rice, Brown rice flour
- Buckwheat
- Calrose
- Canola
- Cassava
- Channa
- Chestnut
- Chickpea
- Corn, corn flour, corn gluten, corn malt, cornmeal, cornstarch
- Cottonseed
- Dal
- Dasheen flour
- Enriched rice
- Fava bean
- Flax, flax seeds
- Garbanzo
- Glutinous rice
- Hominy
- Instant rice
- Job's tears
- Millet
- Modified corn starch
- Modified tapioca starch
- Montana™
- Peanut flour
- Potato flour, potato starch
- Quinoa
- Red rice
- Rice, rice bran, rice flour
- Risotto
- Sago
- Sesame
- Sorghum
- Soy, soybean, tofu (soya)
- Starch (made from safe grains)
- Sunflower Seed
- Sweet rice flour
- Tapioca
- Taro flour
- Teff
- Wild rice

Gluten-Free Additives (SAFE)

- Acacia Gum (gum Arabic)
- Acetic Acid
- Adipic Acid
- Algin
- Annatto
- Aspartame
- Baking Yeast
- Benzoic Acid
- Beta Carotene
- BHA
- BHT
- Brewers Yeast
- Brown Sugar
- Calcium Disodium EDTA
- Carrageenan
- Caramel Color¹
- Carboxymethyl cellulose
- Carob Bean Gum
- Cellulose
- Corn Syrup
- Corn Syrup Solids
- Cream of Tartar
- Dextrose
- Ethyl Maltol



- Fructose
- Fumaric Acid
- Gelatin
- Glucose
- Guar Gum
- Invert Sugar
- Karaya Gum
- Lactic Acid
- Lactose
- Lecithin
- Malic Acid
- Maltodextrin²
- Maltol
- Mannitol
- Methylcellulose
- MSG – monosodium glutamate
- Papain
- Pectin
- Polysorbate 60; 80
- Propylene Glycol
- Psyllium
- Sodium Benzoate
- Sodium Metabisulphite
- Sodium Nitrate; Nitrite
- Sodium Sulphite
- Sorbitol
- Stearic Acid
- Sucralose
- Sucrose
- Sugar
- Tartaric Acid
- Tartrazine
- Titanium Dioxide
- Tragacanth
- Vanilla Extract
- Vanillin
- White Vinegar³
- Xanthan Gum
- Xylitol
- Yam
- Yeast

¹Caramel color is manufactured by heating carbohydrates and is produced from sweeteners. Although gluten-containing ingredients can be used, they are not used in North America; corn is most often used, however it is important to check with food manufacturers.

² Maltodextrin is made from cornstarch, potato starch, or rice starch.

³ Distilled white vinegar is safe to consume on the gluten-free diet. Vinegar is a solution made of acetic acid and flavoring materials such as apples, grapes, grain, and molasses. For example, cider vinegar is made from apple juice; malt vinegar is made from barley malt, balsamic vinegar is made from grapes. Distilled vinegars are gluten-free because the distillation process filters out the large gluten proteins so that they do not pass through to the end product. Therefore, the finished liquid is gluten-free. Patients with celiac disease should not be concerned about distilled white vinegar or foods such as pickles, which may contain it. The exception to this rule is MALT VINEGAR, which is not distilled, and therefore is not safe to consume.

Road to Recovery

The first step in managing the gluten-free diet is to understand which foods contain wheat, rye and barley so they can be eliminated from the diet and intestinal healing can begin. It may seem overwhelming at first as wheat, rye and barley are common food ingredients.

However, there is a wide variety of foods that are naturally gluten free. Fresh foods, without any processing or additives, from the fruit, vegetables, dairy products, and meat/meat alternatives food groups are all **NATURALLY GLUTEN FREE**. That is five out of the six food groups.

Refer to Introduction - Overview of Gluten-Free Diet for a list of ingredients to avoid as they contain wheat, rye, barley or derivatives of these grains. It is important to look for words such as these on all food ingredient labels. Check for words like these every time you shop. In order to become completely gluten-free, it is important to start in the kitchen.

1. If you plan to have both gluten-containing and gluten-free food in your household, it is important to determine which foods are “SAFE” for the family members who have celiac disease. Use a laundry marker and label “GF” (gluten-free) on all safe foods and condiments.
2. Start by taking out everything in the pantry, refrigerator and freezer (not all at once!) and reading labels.
3. In addition to the previous gluten-containing grains, there are also many ingredients to question. These ingredients **MAY** contain wheat, rye, or barley. If you have any questions about an ingredient, then contact the manufacturer to learn about where these products are derived. (Instead of asking whether the product contains gluten, ask the question, “Does this product contain: wheat, rye, or barley?”)

Commonly Questioned Ingredients

- **Seasonings and Spice Mixes:** Pure spices do not contain wheat, rye or barley. Spice mixes, when 2 or more spices are blended together, do not commonly use wheat. Alternatively, seasonings are a blend of spices, herbs or proteins that are combined with a carrier including: salt, sugar, milk powder, cereal flours (wheat) and starches.
- **Dextrin:** May be derived from corn, waxy maize, waxy milo, potato, arrowroot, WHEAT, rice, tapioca, and/or sago; however, two large U.S. manufacturers use cornstarch in their production.
- **Flavorings:** Gluten-containing grains are rarely used. Flavorings are mostly derived from corn; exceptions include barley malt flavoring or flavorings in meat products. However, natural flavor may be made from a variety of plant materials and should be confirmed with the manufacturer.
- **Modified Food Starch:** The FDA requires manufacturers to state if starch comes from wheat using a parenthetical statement (ie: "Wheat" or will state: "Contains wheat").
- **Starch:** The FDA regulations state that "starch" implies cornstarch, and if alternative starch is used, it will be identified as such.
- **Mono & Diglycerides:** An emulsifier made from specific fats or oils heated at high temperatures. Previously in question because wheat can be added as a carrier with this food ingredient; the label will state if wheat is present.

Reading Food Labels

As a result of the Food Allergen Labeling and Consumer Protection Act of 2004 (FALCPA), food manufacturers must label food products that contain an ingredient that is or contains protein from a major food allergen (milk, egg, soy, peanut/tree-nut, fish/shellfish and WHEAT) in one of two ways:

- **Include the Name in Parenthesis:** Food manufacturers will include the name of the food source in parenthesis following the common or usual name of the major food allergen in the list of ingredients. This is when the name of the food source of the major allergen does not appear elsewhere in the ingredient statement.
- **Place the Word "Contains"** followed by the name of the food source from which the allergen is derived. Food manufacturers will also use this method of food labeling after or adjacent to the list of ingredients. For example: Contains Wheat, Milk, Egg and Soy. Please note this law does not address the use of barley (malt) or rye. Therefore, this further reinforces the importance of reading food labels for "ingredients to avoid".

Follow-Up Testing & Medications

Follow-up testing is conducted to ensure that antibody levels are returning to normal, indicating that the intestine is healing on the new diet. For this reason, repeat intestinal biopsies are no longer necessary. These tests also indicate the extent to which a celiac is avoiding gluten, and can detect when hidden gluten has entered the diet.

How often should follow-up testing occur?

New celiacs should receive follow-up testing twice in the first year after their diagnosis. The first appointment should occur three to six months after the diagnosis, and the second should occur after 1 year on the gluten-free diet. After that, a celiac should receive follow-up testing periodically, and possibly on a yearly basis.

What tests are needed at follow-up appointments? How are they interpreted?

Guidelines on the diagnosis and treatment of celiac disease by the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition state that tTG-IgA testing should be used for follow-up care. Interpreting this test result is straightforward—a celiac on the gluten-free diet should have a negative test. The numerical value of the test is not important.

The University of Chicago Celiac Disease Center recommends additional testing, because the tTG test can sometimes be inaccurate in people with autoimmune disorders like Type 1 diabetes and thyroid disease. In addition, the tTG can sometimes become negative before a celiac has actually experienced significant healing.

For these reasons, Deamidated Anti-Gliadin Antibodies (DGP) are also important. There are two types that need to be run: DGP-IgA, and DGP-IgG. In this circumstance, the numerical values of the tests are very important. The numbers should be as close to zero as possible, indicating a minimal antibody response to gluten. The additional advantage of these tests is that the blood can be drawn by any physician and sent to any laboratory.

Follow Up Test #1:

tTG-IgA: This test result should be negative - the numerical value of the test doesn't matter as long as the result is negative. However, it may take time for the test to become completely negative. In cases where the test numbers were very high to begin with, this time may be up to a whole year or even more.

Follow Up Test #2

Deamidated Anti-Gliadin Peptides IgA and IgG: These results should have a very low negative value. In this case, the numerical value does matter, because a high negative test result still indicates that a patient is eating gluten. A low negative indicates that the diet is working well.

I was diagnosed 15 years ago, and have never received follow-up testing. Why should I start now?

It's never too late to begin follow up testing and to learn from the results. Food manufacturing practices change often, and even the most diligent celiac cannot keep up with all the changes. In addition, some celiacs find that current health problems may be related to celiac disease, such as anemia or bone density. The reverse is also true—some find that current health problems they've attributed to celiac disease aren't related, because their antibody levels indicate that celiac disease isn't active. In either case, the patient and physician have received valuable information.

While follow-up testing is especially important for people in the first five years after diagnosis (this is when the most serious complications of celiac disease can occur) testing can help all celiacs know that they are doing well with the diet or need to make changes to protect their health.

I worry that I might be feeding my child the wrong foods. How can I tell if her stomachaches are from celiac disease or something else?

For concerned parents, and for anyone who worries if they are making the right food choices for themselves or their child, follow-up testing can be very helpful. Negative test results reinforce that the family's approach to a child's gluten-free diet is working well.

I've been having joint pain, and I think it's from celiac disease. Am I right?

Follow up testing is important, and can be performed when there is a question about whether or not a health condition, like joint pain, could be related to celiac disease. A series of positive antibody tests (indicating gluten in the diet) may indicate that a complication of celiac disease exists, in this case, joint pain. When antibody tests are negative, indicating a strong level of compliance

with the diet, it is unlikely that celiac disease is contributing to the worrisome symptom. While this is not an exact science, follow up testing can often clarify whether or not a health condition could be a complication of celiac disease.

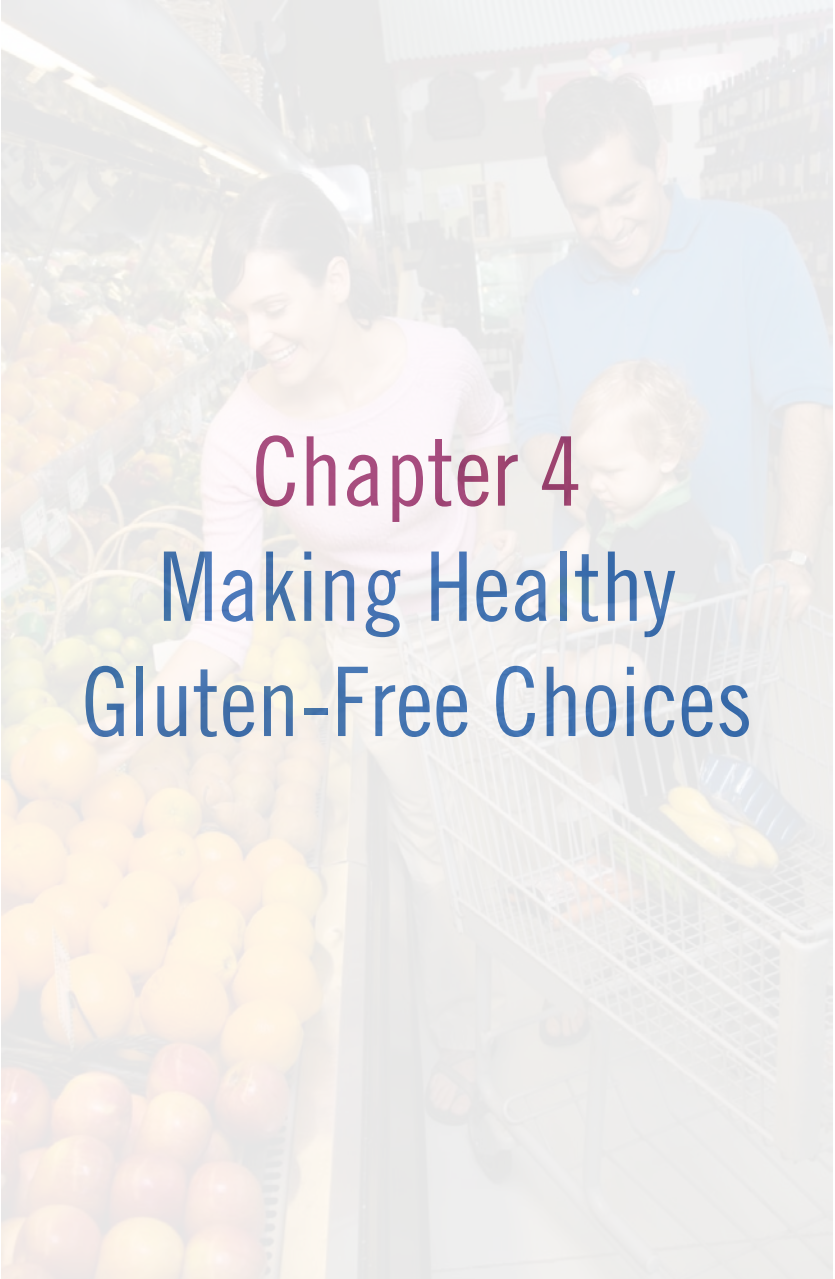
Please use your own discretion to determine what products are safe to use. Some product lines may produce gluten-containing supplements as well. Please use caution when purchasing.

What medications can I take?

As with vitamins and mineral supplements, it is important to ensure that over the counter and prescription medications are gluten-free. Potential sources of gluten contamination occur when filler (excipient) ingredients are added to the active drug. In medications, excipients form the bulk of the product and are designed to perform several functions such as: providing bulk, act as lubricants for the powder or absorb water, which causes the tablet to swell and disintegrate.

How do I know what medications are safe?

1. Read the label or package insert to determine the ingredients of the medication. If still in question, check with the pharmacist to determine if your medication is gluten-free. If a product contains the word “starch”, the source must be identified. Corn, rice, potato and tapioca starch are safe for celiac patients. Alternatively, call the 1-800 phone number listed on the package to speak to a customer service representative.
2. In products that do not contain excipients derived from starch, the likelihood of gluten contamination is small.
3. Internet resources may provide some help. We especially recommend www.GlutenFreeDrugs.com as reliable and periodically updated, but caution should be taken regarding this source.
4. When following a strict gluten-free diet, it is important to optimize intake of vitamins and minerals. Gluten-free products such as cereals and breads, are not commonly fortified similar to their gluten-containing counterparts. Therefore, it is important to supplement a gluten-free diet with a daily multivitamin with minerals. Additionally, upon initial diagnosis, especially in adults, the damage to the intestine can lead to decreased absorption of iron, calcium, folate and other B vitamins.

A photograph of a family shopping in a grocery store. A woman in a pink shirt is looking at produce, a man in a blue shirt is pushing a shopping cart, and a young child is sitting in the cart. The store is filled with various fruits and vegetables.

Chapter 4

Making Healthy Gluten-Free Choices

Grocery Shopping

The first trip to the grocery store after a diagnosis of celiac disease may be difficult. It is good to go prepared. First, start by making a list of foods that you know are safe.*

Dairy Products

- Eggs, Egg Substitute
- Milk (unflavored), Butter
- Cream Cheese, Cottage Cheese
- Swiss, Cheddar, Mozzarella
- Plain Yogurt

Vegetables

- Lettuce, Tomatoes
- Carrots, Broccoli, Corn
- Red and Green Peppers
- Potatoes

Fruit

- Apples, Grapes
- Oranges, Melon
- Berries, Cherries, Peaches, Plums (when in season)

Meat and Alternatives

- Fresh Poultry (take caution with self-basting types)
- Fresh Fish/Shellfish
- Fresh Beef
- Beans, Lentils, Peas

Miscellaneous

- Peanut Butter
- Jelly, Jams, Marmalade
- Ketchup, Mayonnaise
- Canola and Olive Oil

*This is just a sampling of many naturally gluten-free items you can purchase at your general grocery store.

Grocery Store Considerations

1. Purchase pre-sliced deli meats. Some deli items may contain marinades and seasonings containing wheat that can contaminate the slicer, especially during busy times. It is best to purchase pre-sliced deli meats and cheeses.
2. Avoid bulk bins when purchasing flour, dried beans and cereals. These storage containers are difficult to clean & are at risk for cross contamination.
3. Stick to the list! It's easy to become overwhelmed (and distressed) when considering options. It takes time to read food ingredient labels, so if you prepare ahead of time, a trip to the grocery store will take less time.

Gluten-Free Convenience Foods

After filling your cart with natural gluten-free choices, gluten-free alternatives to your regular breads, cereals and snack foods are important to find. There are a wide variety of gluten-free options to choose from. However, you want to make sure you know what is out there first.

What Does Gluten-Free Mean?

The FDA proposed the FALCPA to assist food-allergic consumers in deciding the safety of food products. In part with FALCPA, the FDA proposed to define the term “gluten-free” for voluntary use in the labeling of foods.

Will Gluten-Free Be On All Products?

Because it is voluntary, the term “gluten-free” does not need to be on every product available to consumers. However, approval of this rule means that the food does not contain any of the following:

- An ingredient that is any species of the grains wheat, rye, barley or a crossbred hybrid of these “prohibited grains”
- An ingredient that is derived from a prohibited grain and that has not been processed to remove gluten (e.g. wheat flour)
- An ingredient that is derived from a prohibited grain & has been processed to remove gluten (e.g. wheat starch), if the use of that ingredient results in the presence of 20 parts per million (ppm) or more gluten in the food
- 20 ppm or more gluten in the food

How is the FDA Regulating this?

If a food product bears the claim “gluten-free” in its labeling and fails to meet the conditions above, it will be deemed misbranded.

Are Mislabeled Products Recalled?

A food product that contains an undeclared allergen may be subject to recall. Additionally, if a food product is found to be improperly labeled, it may be misbranded and subject to seizure and will be removed from the market place.

How Much Inadvertent Gluten Exposure is Safe?

Avoiding all gluten is extremely difficult, if not impossible. Celiac disease patients are exposed to products containing trace amounts of gluten, even when the products are sold as naturally gluten-free. In order to estimate the safe threshold for daily gluten intake, the amount of residual gluten in gluten-free products and the total intake of these products must be considered.

A calculated daily intake of 30 mg of gliadin seems not to harm the intestinal mucosa of celiac disease patients. Therefore at present, a safe limit could be set between 10 and 100 mg. On the contrary, data also indicates that a certain proportion of naturally gluten-free products may contain gluten. The overall potential daily intake of gluten should be considered in setting a safe limit for the claim "gluten-free", taking into account all foods which contain gluten, whether naturally gluten-free or rendered gluten-free.

How Much Gluten is too Much?

Research shows that anyone with celiac disease will have a reaction to ingestion of gluten when it reaches just 100 mg per day. Some people have been shown to react with as little as 10 mg per day. In either case, we are talking about a very small amount: the equivalent of 1/8 to 1/64 of a teaspoon of flour. There are about 600 mg of flour in 1/8 teaspoon, and in it there are about 80 mg of gluten. Thus, 10 mg of gluten is just 1/64 of a teaspoon.

Gluten-Free Meal / Snack Ideas

Breakfast Ideas

- Gluten-free cereal mixed with fruit and milk (add some ground flax seed for additional fiber)
- Yogurt mixed with fresh fruit and nuts
- Gluten-free bread, bagel or muffin topped with cream cheese, peanut butter, preserves or honey
- Homemade French toast prepared with gluten-free bread, made with egg and topped with gluten-free syrup and fruit
- Fruit smoothie made with yogurt and fresh or frozen fruit (check ingredients on frozen packaging)
- Cooked cereal mixed with chopped dried fruit such as raisins or dates, mixed with brown sugar or cinnamon

Lunch Ideas

- Sandwiches made with gluten-free bread (choose ones with more than 3g fiber per slice) topped with vegetables, gluten-free lunchmeat
- Homemade pizza with a gluten-free crust topped with gluten-free pizza sauce, cheese and fresh vegetables
- Leftovers (casseroles, pasta, meat, potatoes, chicken, rice, quinoa)
- Wraps made with lettuce or corn tortillas stuffed with rice noodles, meat, vegetables or cooked rice
- Rice cakes topped with peanut butter, banana or cheese
- Baked potatoes topped with cheese, vegetables and chili
- Gluten-free hot dog with gluten-free bun
- Gluten-free crackers, hummus, raw vegetables and fresh fruit

Dinner Ideas

- Gluten-free lasagna
- Meatloaf made with lean turkey or beef, gluten-free bread crumbs, egg and herbs/spices
- Barbecue chicken, beef, pork, seafood, fish with rice pilaf, quinoa or buckwheat salad
- Gluten-free pizza
- Gluten-free tacos made with corn tortillas
- Oriental stir fry made with fresh vegetables, gluten-free soy sauce, served over rice

Snack Ideas

- Yogurt
- Gluten-free pretzels with peanut butter or cheese
- Fresh, dried, or canned fruit
- Popcorn
- Fresh vegetables & gluten-free dip
- Gluten-free snack bars
- Homemade gluten-free trail mix (gluten-free cereal, raisins, nuts and gluten-free chocolate candies)



Serving Suggestions & Tips for Healthy Eating

Breads, Cereal, Rice and Pasta (6-11 Servings) (Depending on age & weight)

- 1 slice brown rice bread
- ½ cup cooked quinoa, buckwheat
- ½ cup cooked cereal
- ¾ cup ready-to-eat gluten-free cereal

Look at the Nutrition Facts Food Labeling on foods to determine the fiber content of the product. A good choice would contain more than 3 grams fiber per serving. Choose grains such as quinoa or buckwheat more often than foods made with rice flour; these products contain more fiber and protein than products made with white rice.

Vegetables (3-5 Servings)

- 1 cup raw leafy vegetables
- 1 cup cooked or chopped raw vegetables
- ¾ cup vegetable juice



Choose dark green leafy vegetables (romaine or baby spinach) instead of lighter colored varieties (iceberg). Cook vegetables for a short amount of time in shallow water (1 inch) in a covered pot to retain nutrients – vegetables should still have a bite to them.

Fruit (2-3 Servings)

- ½ cup fresh, frozen or canned fruit
- 1 medium sized apple, orange, pear
- ¼ cup dried fruit
- ½ cup juice (4 oz)



Choose fresh fruit for snacks. If eating canned fruit, choose fruit in its own juice, instead of in heavy syrup. After a trip to the grocery store, wash and cut up produce so it is ready to eat and can be grabbed quickly from the refrigerator.

Milk, Yogurt, Cheese & Other Dairy Products (3 Servings)

- 1 cup milk (8 ounces)
- 6 ounces yogurt
- 1 ½ ounce cheese
- ½ cup cottage cheese



Choose low-fat dairy products. Try white cheese instead of yellow varieties (Swiss is a better choice than cheddar). If dairy products are not tolerated well, try lactose-free milk or Lactaid tablets when eating dairy products. If unable to consume milk or alternative dairy products, calcium should be replaced in the form of supplement such as calcium citrate.

Meat, Poultry, Fish, Beans, Eggs and Nuts (2-3 Servings)

- 3-4 ounces cooked lean meat, poultry or fish
- ½ cup cooked legumes (beans, peas, lentils)
- 1/3 cup tofu
- 2 Tbsp peanut butter
- 1 egg = 1 ounce lean meat (limit to approximately 2-3/wk)



Choose lean meats more frequently. Trim all visible fat from meats, take the skin off poultry. Limit high fat processed meats such as sausages, bacon, bologna, salami and cold cuts.

Fats, Sweets and Oils (Use Springly)

- 1 tsp margarine, butter
- 1 Tbsp oil



Choose oils such as canola (rapeseed), olive or safflower instead of palm and coconut oil. Try light margarines with no trans fat – trans fats tend to increase blood cholesterol. Consume baked products and sweets in moderation



Chapter 5

Preparing Foods Inside The Home

Food Preparation & Kitchen Clean Up

It is not only important to eat the right foods, but it is also important to take a look around at where the food is prepared. Especially in the case where there will be other gluten-containing foods in the household, it is very important the person with celiac disease does not receive any source of contamination from gluten-containing products.

Recommendations

1. A separate toaster should be used for gluten-free products. Even a crumb is a source of gluten, which will cause harm to a person with celiac disease.
2. A separate colander (strainer) should be used with gluten-free pasta because the small crevices are a good hiding place for the glutinous substance of wheat, rye and barley protein. Make sure to clean other cooking utensils, such as pots and pans, after each use and before cooking gluten-free products.
3. Bread makers may be a good purchase for families who want to make their own gluten-free bread. The same bread maker should not be used with both gluten-free bread mixes and gluten-containing mixes.
4. Be careful with your sponges! Sponges are not only a large source of bacteria, but also are very likely to spread gluten around the kitchen. Use disposable paper towels, and disinfect frequently to ensure the surfaces are clean and free of gluten.
5. Purchase and mark a separate peanut butter, jam, mayonnaise, butter or other spreadable condiments which can be contaminated with gluten-containing products.



RECIPES

These recipes are both gluten and dairy/casein free. Casein is a protein found in milk. Ingredients may be listed as GFCD; for example, GFCD bread crumbs indicates gluten-free and dairy-free bread crumbs. If your diet allows dairy, you may substitute regular dairy products whenever the recipe specifies a nondairy ingredient. These recipes were provided by renowned chef and cookbook author Sueson Vess. For many more gluten-free and dairy-free recipes, see her cookbook, *Simple, Delicious Solutions for Gluten-Free & Dairy-Free Cooking*, published by Special Eats. To order, visit www.SpecialEats.com.

Chicken Noodle Soup

- | | | | |
|---|--|-------|---|
| 1 | tablespoon olive oil | 2 | quarts homemade chicken broth, recipe follows (you may also use purchased GFCF chicken broth) |
| 2 | medium carrots, cut into 1/4 inch slices | | |
| 2 | celery ribs, halved lengthwise, and cut into 1/2 inch slices | 1 1/2 | cups shredded cooked chicken |
| 4 | fresh thyme sprigs | | Salt and pepper |
| 1 | bay leaf | 8 | ounces GFCF noodles |

1 Place a soup pot over medium heat and coat with the oil. Add carrots, celery, thyme and bay leaf. Cook and stir for about 5 minutes, until the vegetables are softened but not browned. Pour in the chicken broth and bring the liquid to a boil. Add the chicken, and continue to simmer for another couple of minutes to heat through; season with salt and pepper.

2 In a separate pot of boiling salted water cook GFCF pasta according to package directions. Drain and add to the simmering soup. Serve immediately. Serves 4

Chicken Broth

- | | | | |
|---|---|-----|--|
| 3 | to 3 1/2 pounds free-range chicken pieces, mostly backs and wings, rinsed (Do not use giblets.) | 1/2 | teaspoon whole black peppercorns |
| 2 | carrots, cut in large chunks | 1/2 | teaspoon whole cloves |
| 3 | celery stalks, cut in large chunks | | Cold, purified water |
| 2 | large white onions, quartered | 2 | tablespoons vinegar or fresh lemon juice |
| 1 | bay leaf | | Salt |
| | Handful of parsley and/or thyme sprigs (fresh) | | Optional: 3-4 dried juniper berries (available at Penzeys Spices: www.Penzeys.com) |

1 Place the chicken and vegetables in a large stockpot over medium heat. Pour enough cold water to cover chicken. Add vinegar or lemon juice. Add bay, parsley/thyme, peppercorns, and cloves and slowly bring to a boil. Lower the heat to medium-low and gently simmer for 1 to 1 1/2 hours, partially covered. As the broth cooks, skim any impurities that rise to the surface; add a little more water if necessary to keep the chicken covered while simmering.

2 Remove the chicken pieces and discard. Strain the broth through a fine sieve into another pot to remove the vegetable solids. If not using the broth immediately, place the pot in a sink full of ice water and stir to cool. When cool, cover and refrigerate or freeze. Yield: 2 quarts

There are more than 200 signs & symptoms of celiac disease, yet a significant percentage of people with celiac disease have no symptoms at all.

Pancakes

Use ¼ cup less liquid (milk or orange juice)

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| 2 | cups GF flour blend | 3 | large eggs |
| 1 | tablespoon GF baking powder | 2 | tablespoons agave syrup (may use honey or sugar) |
| ¼ | teaspoon salt | 4 | tablespoons coconut oil, melted (may use vegetable oil) |
| ¼ | teaspoon nutmeg (ground) | | |
| 1½ | cups GF/CF nondairy milk (or half water and half orange juice – if using orange juice, reduce sweetener by half) | | |

1 In a large bowl sift or whisk all the dry ingredients. In a medium bowl, whisk GF/CF milk substitute, eggs, agave syrup and coconut oil until blended well. Add the egg mixture to the flour mixture and stir. The mixture should have small lumps.

2 Heat a non-stick griddle wiped with a small amount of oil over medium heat (if using electric griddle heat to 300-325 degrees). Pour 2-3 tablespoons (a ladle works well) onto the hot griddle and cook until the surface is covered with small bubbles that begin to pop about 1 ½ to 2 minutes. Turn pancakes and cook the other side for another minute or until golden brown. Transfer to a warming oven while you cook the remaining pancakes.

Serve with pure maple syrup, fresh fruit, Blueberry Syrup (see recipe). Serves 4 (16-20 4 -inch pancakes)

Variation: Blueberry Pancakes

Fold 1 cup fresh or frozen (slightly thawed) blueberries to the batter after mixing all the above ingredients and make as indicated above. Alternatively, you may drop blueberries directly onto the pancake batter after spooning desired amount onto the griddle – about 8 blueberries per pancake. Adding blueberries to the batter will color pancakes a lovely blue shade.

Blueberry Syrup

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| 2 ½ | cups blueberries picked over (reserve ½ cup) | ¼ | cup fresh orange juice (or apple juice) |
| ½ | cup agave syrup (honey or sugar may be substituted) | | |

In a large saucepan, combine the 2 cups blueberries, agave and orange juice and simmer over low heat covered, for 10 minutes. Puree the mixture in a blender or food processor. Add the reserved ½ cup of blueberries. Serve the syrup warm over pancakes or GF/CF ice cream.

Variation: Chocolate Chip Pancakes

Fold 1 cup GF/CF chocolate chips to the batter after mixing all the above ingredients and make as indicated above. Alternatively, you may drop chocolate chips directly onto the pancake batter after spooning desired amount onto the griddle. Chocolate lovers beware! Note: Enjoy Life Foods makes GF/CF and soy-free chocolate chips, see www.EnjoyLifeFoods.com.



French Toast with Orange Syrup

For best results, prepare this breakfast the night before to allow the bread to absorb the flavorful ingredients.

French Toast

- 4 large eggs, slightly beaten
- 2 cups GFCF nondairy milk
- 1 tablespoon honey or 2 teaspoons agave
- 1 teaspoon vanilla
- $\frac{1}{4}$ teaspoon cinnamon
- $\frac{1}{4}$ teaspoon nutmeg
- 8 thick slices GFCF bread

Ingredients Orange Syrup

- $\frac{1}{2}$ teaspoon orange zest (outer peel of an orange, grated without the white pith)
- $\frac{1}{2}$ cup orange juice, freshly squeezed
- 1 tablespoon honey or 2 teaspoons agave
- 1 teaspoon cornstarch or arrowroot
- $\frac{1}{4}$ teaspoon cinnamon

1 Prepare a 9 x 13-inch baking dish by spraying with GFCF oil. Arrange bread slices in 2 rows, overlapping the slices.

2 In a large bowl, combine the eggs, milk, sweetener, vanilla, cinnamon, and nutmeg and mix with a whisk until blended. Pour mixture over the bread slices, making sure all are covered evenly with the egg mixture. Cover and refrigerate overnight or for at least an hour. Preheat oven to 350 degrees and bake for 40 minutes, until puffed and lightly golden. Serve with orange syrup or pure maple syrup.

3 Mix all syrup ingredients in a small saucepan on medium heat. Cook, stirring constantly until mixture thickens and comes to a boil. May add additional orange juice to attain the consistency of syrup. Serves 4

Tuscan Chicken with Pasta

- | | |
|---|---|
| 1/4 cup olive oil | 1/3 cup Madeira wine or other dry wine |
| 3-4 cloves garlic sliced | 1 cup gluten-free marinara sauce (bottled or your own homemade sauce) |
| 1/4 teaspoon crushed red pepper flakes (more or less to taste) | 1/2 pound gluten-free penne pasta |
| 3 single boneless, skinless chicken breasts (about 6 ounces each) | 1/2 cup dairy-free Parmesan cheese (optional) |

1 Bring large pan of water to boil to cook pasta. Cook pasta al dente following package directions.

2 Sauté in a large skillet over medium heat:

3 1/4 cup olive oil, garlic and crushed red pepper flakes for about 3 minutes. Watch carefully so that garlic does not brown.

4 Add 3 boneless skinless chicken breasts cut into 1 inch x 2 inch chunks and sauté for 5 minutes until chicken is cooked through. Remove chicken from skillet and place in a warming oven.

5 Add wine to the skillet and bring to a boil. Add marinara sauce and return to simmer. Add chicken, drained pasta and cheese to skillet and stir. Serve with additional cheese if desired. Serves 4-5

Buffalo Meat Loaf

- | | |
|-------------------------------------|--|
| 1 large onion, finely chopped | 2 tablespoons gluten-free ketchup (or pureed roasted peppers) |
| 2 celery ribs, finely chopped | 1 tablespoon gluten-free Mr. Spice Garlic Steak Sauce (or GF Worcestershire sauce) |
| 1 large carrot, finely chopped | 2 teaspoons salt (divided) |
| 3 teaspoons vegetable oil (divided) | 1/4 teaspoon freshly ground pepper |
| 3/4 cup fine GFCF bread crumbs | 2 pounds ground buffalo (may substitute other ground meet such as beef, ostrich or turkey) |
| 1/2 cup chopped parsley | |
| 1 large egg | |

1 Preheat oven to 375 degrees. Lightly oil 9 x 5 inch loaf pan.

2 Sauté onion, celery and carrots in 2 teaspoons oil in a large skillet over moderate heat until softened. Transfer vegetables to a large bowl and stir in GFCF bread crumbs, parsley, egg, ketchup, Garlic Steak Sauce, 1 teaspoon salt and pepper. Gently mix in buffalo (do not over mix or meatloaf will be tough). Bake in preheated oven for 1 hour 10 minutes, or until a thermometer inserted 2 inches into the center registers 160 degrees F.

3 Transfer meat loaf to a platter and let stand 10 minutes before slicing. Serves 4-6



Turkey Chili Molé

- | | | | |
|---|---|-----|--|
| 2 | tablespoons vegetable oil | 1 | 28 ounce can crushed GF tomatoes in puree |
| 2 | pounds ground dark turkey (may substitute other ground meat: beef, buffalo, chicken, ostrich) | 1 | 15 ounce can black beans, drained and rinsed |
| 1 | large onion, chopped | 2 | teaspoons chili molé seasoning (see below) |
| 1 | large red pepper, chopped | 1/2 | teaspoon salt |
| | | 1/2 | teaspoon fresh ground pepper |

In a large skillet, heat oil and sauté ground meat, onions and red pepper over medium-high heat until turkey is cooked through (no pink remains). Add tomato sauce and seasoning. Simmer for at least 15 minutes. Taste and adjust seasoning. Serve with white rice, guacamole or GFCF Nondairy sour cream or yogurt Serves 8

Sueson's Chili Molé Seasoning

Individual spices are available in bulk food section of natural or grocery stores making this seasoning blend easy and inexpensive.

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|-----|-------------------------|---|----------|---|
| 1/4 | teaspoon cayenne pepper | 1 | 1/2 | teaspoon marjoram |
| 1/4 | teaspoon white pepper | 1 | 1/2 | teaspoon cinnamon |
| 1/4 | teaspoon allspice | 3 | teaspoon | cocoa (unsweetened, not Dutch processed) |
| 1/4 | teaspoon nutmeg | 2 | teaspoon | chili powder (single chili, like Ancho Chili Peppers, not chili powder blend) |
| 1 | teaspoon thyme | | | |



The Best Minestrone Ever

This minestrone is more than soup – it is a hearty meal. It will be even better the next day. It is labor intensive due to chopping all the vegetables, but well worth the work. Make this on a cold, leisurely Sunday afternoon.

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|---|---|---|---|
| 2 | tablespoons olive oil | 1 | large potato cut in large pieces (unpeeled OK) |
| 1 | large onions, chopped | ½ | head curly Savoy cabbage (or green head cabbage), cut into 1-1 ½ -inch pieces |
| 1 | clove garlic, minced | ½ | cup green beans, cut into bite sized pieces |
| 1 | leek, sliced including part of light green top | 1 | bunch swiss chard, chiffonade cut (strips) |
| 2 | zucchini, chopped | 1 | teaspoon dried basil |
| 1 | carrot, chopped | | Salt and pepper to taste |
| 1 | 28 ounce can GF chopped tomatoes in juice, include juice | | GFCF Pasta (2 cups uncooked) |
| 2 | 15 ounce cans kidney beans, adzuki beans or other small red beans, drained and rinsed | 2 | tablespoons chopped parsley |
| 2 | 15 ounce cans navy beans, or other white beans, drained and rinsed | | Optional: GFCF Parmesan cheese |

1 In a large stockpot over medium temperature heat olive oil, add onions, garlic and leek; cook until onions are transparent, about 4-5 minutes. Add zucchini and carrot, tomatoes and juice and bring to simmer uncovered.

2 In a food processor or blender puree white beans until smooth, adding 1/2 cup of water if necessary. Add pureed beans, red beans, potato, cabbage, green beans and 4 cups of water; bring to a slow simmer. Cook for two-three hours stirring occasionally. Add swiss chard and basil, salt and pepper and cook for another 15 minutes. Taste and adjust seasoning.

3 To Serve: In a large serving bowl, mix cooked pasta with a little olive oil and (2 tablespoons) chopped fresh parsley. Serve soup over GFCF pasta. Bi-Aglut makes Ditalini pasta, small tube-like pasta from Italy that is wonderful with Minestrone; however, any GFCF pasta will work. Serves 6-10

Oven “Fried” Chicken with Apricot Dipping Sauce

- 3 cups Rice Crunch ‘Ems gluten-free cereal (may substitute other unsweetened brown rice cereal)
- 2 tablespoons GF flour blend
- 1/2 teaspoon salt
- 1/2 teaspoon fresh ground pepper
- 1 teaspoon dried thyme
- 1 teaspoon dried sage
- 1/2 teaspoon paprika
- 2 pounds boneless, skinless chicken breasts
- 1/2 cup vegetable oil

Dipping Sauce Ingredients:

- 1 jar apricot or peach jam (fruit juice sweetened)
- 1 tablespoon lemon or lime juice
- 1 teaspoon horseradish

1 Preheat oven to 400 degrees.

2 Combine in food processor or blender: cereal, GF flour blend; salt; pepper; thyme, sage and paprika. Place crumb mixture in a shallow bowl.

3 Cut chicken breasts into bite-sized (or finger-sized) pieces. Put oil in a shallow bowl. Dip chicken in oil and then into the crumb mixture.

4 Place chicken pieces on a pan lined with aluminum foil brushed lightly with oil. Pour any remaining oil over chicken pieces and place in the preheated oven for 15-20 minutes until cooked through.

5 Heat apricot jam in microwave for 1-2 minutes to soften. Mix jam, lime juice and horseradish in a bowl and set aside until ready to serve. Refrigerate unused sauce.

6 Serve chicken fingers with apricot dipping sauce, bottled GF BBQ sauce, ketchup, honey or agave syrup. Chicken is also good added to your favorite salad. Serves 4

Antibody tests are only accurate
when a patient is on a gluten-containing diet.

Pasta Salads

Cook 1/2 pound GF/CF pasta in boiling salted water according to manufacturer's directions. Tinkyada's brown rice penne is very good for pasta salad (available at many supermarkets and health food stores, visit www.TinkYada.com for more information). It does not get mushy when cooked slightly al dente (underdone). After cooking pasta rinse under cold water to stop the cooking, and drain well. Here are variations for making different pasta salads. May substitute cooked rice (day-old is best). Each pasta salad serves 6-8 and may be doubled.

Asian Pasta Salad

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|--|---|
| 1 bunch green onions, sliced | Vinaigrette ingredients |
| 1 cup broccoli, cut into bite-sized pieces | 2 cloves garlic, minced |
| 1 cup carrots, chopped | 1/2 teaspoon salt |
| 1 cup bean sprouts | 1/2 teaspoon Chinese five-spice seasoning |
| 1/2 cup pea pods, cut into bite sized pieces | 1 tablespoon gluten-free soy sauce |
| 2 tablespoons fresh ginger root, minced | 2 tablespoons red wine vinegar |
| | 6 tablespoons olive oil |

Asparagus Pasta Salad

- | | |
|--|-------------------------------|
| 1 cup grilled, roasted or steamed asparagus cut into bite-sized pieces | Vinaigrette ingredients |
| 1 can artichoke hearts, drained (not marinated) coarsely chopped | 2 cloves garlic, minced |
| 1 bunch chopped arugula (or watercress or other green to your taste) | 1/2 teaspoon salt |
| Zest of fresh lemon (use juice in vinaigrette) | 1 tablespoon vinegar |
| | Juice of one lemon |
| | 6 tablespoons olive oil |
| | Optional: 1 teaspoon tarragon |

Mexican Pasta Salad

- | | |
|---|---|
| 1 15 ounce can black beans, rinsed and drained | Vinaigrette ingredients |
| 1/2 sweet onion chopped | 1 shallot minced |
| 1 cup organic corn, frozen or fresh cut off cob | 1/2 teaspoon salt |
| 1 large sweet pepper cut into bite-sized pieces | 1/2 teaspoon GF chili powder (or cumin depending on personal taste) |
| 2 pounds tomatoes cut into bite-sized pieces | Fresh ground pepper to taste |
| 1/4 cup cilantro, coarsely chopped | 2 tablespoons cider vinegar |
| Optional: 1 chopped jalapeno pepper | 6 tablespoons olive oil |



Pizza Pasta Salad

- 2 pounds tomatoes cut into bite-sized pieces
- 1/2 red onion chopped
- 1 cup mushrooms, sliced
- 1 large sweet pepper cut into bite-sized pieces
- 1/4 cup sliced olives – green and/or black
- Cooked GFCF sausage or pepperoni cut in bite-sized pieces

Vinaigrette ingredients

- 2 cloves garlic, minced
- 1/2 teaspoon salt
- Fresh ground pepper to taste
- 2 tablespoons balsamic vinegar
- 6 tablespoons olive oil

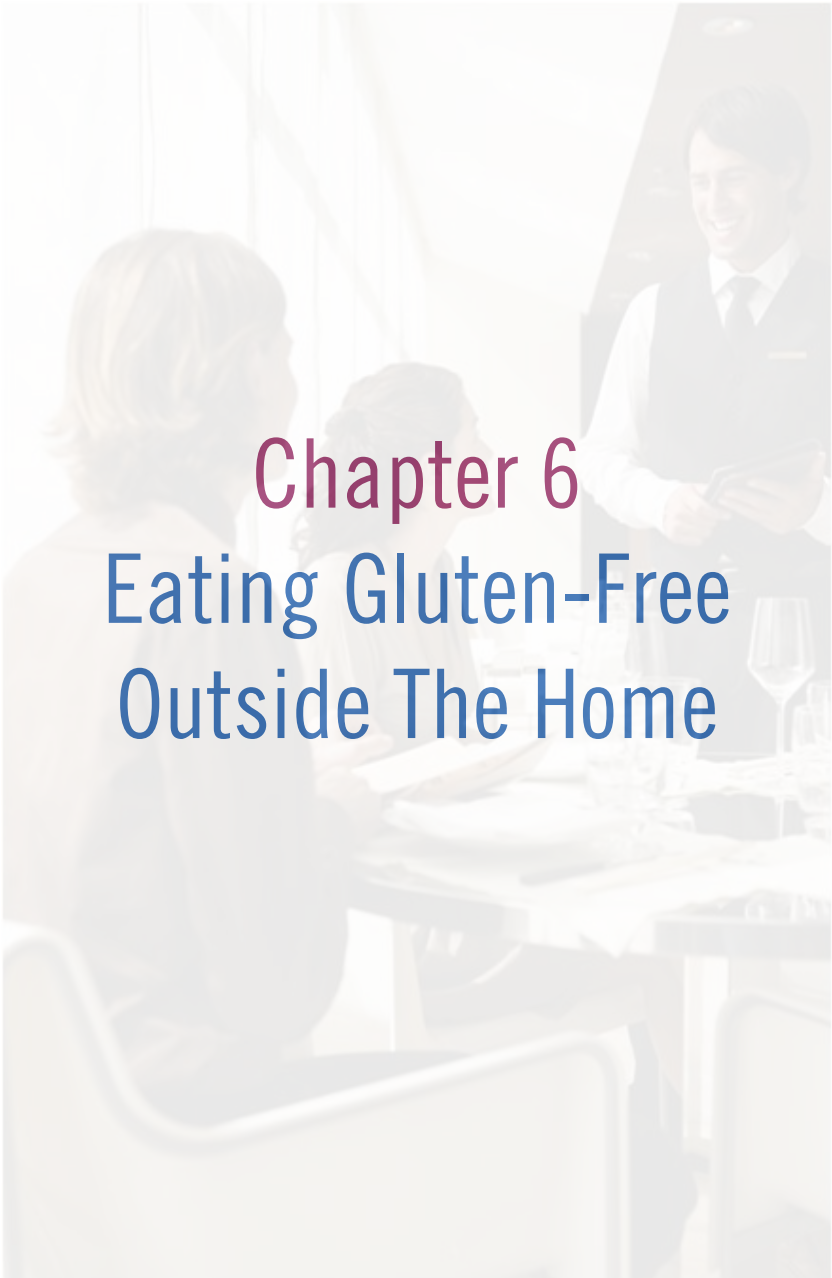
Gazpacho Pasta Salad

- 2 3 ribs celery cut into bite-sized pieces
- 1 large red or yellow sweet pepper cut into bite-sized pieces
- 1 cucumber cut into bite-sized pieces
- 2 pounds tomatoes cut into bite-sized pieces
- 1 bunch green onions sliced
- 1/4 cup cilantro, coarsely chopped
- Optional fresh basil leaves

Vinaigrette ingredients

- 2 cloves garlic, minced
- 1/2 teaspoon salt
- Fresh ground pepper to taste
- 2 tablespoons red wine vinegar
- 6 tablespoons olive oil
- Grilled Vegetable Pasta Salad
- Use your favorite grilled vegetables including zucchini, eggplant, peppers, onions, etc.
- Use balsamic vinaigrette.

ADDING PROTEIN Modify pasta salad and make it a main course by adding bite-sized pieces of cooked chicken, turkey, shrimp, or other protein. Allow 1/4 cup protein per person.



Chapter 6

Eating Gluten-Free Outside The Home

Social Gatherings & School

After mastering the gluten-free diet, it is important, especially with children, to try to get back to the life you were used to. Some tips on managing difficult social situations are as follows.

Family Parties / Holidays / Birthday Parties

- Call ahead to determine food being served
- Offer to bring similar items to ensure people with celiac disease have something to eat
- Skip cake, eat ice cream
- Keep gluten-free cookies or cupcakes on hand in the freezer to decorate as needed

School / Day Care

- **Get Involved:** You may want to think about becoming the “room parent” in order to understand more about the daily activities at school associated with food. Additionally, provide a letter to school specifically indicating details about celiac disease and what restrictions are important to maintain the safety and good health of your child.
- **Bring Lunch to School:** Keep snacks in the room. Food service companies are not always equipped to handle dietary restrictions. Food handling practices and education on ingredients is essential. It is important to find out if gluten-free foods can be purchased in substitution for the gluten-containing counterparts.
- **Monitor Food Activities:** Children should also avoid using play dough, finger paints, pasta or any other gluten-containing food products for art projects in school, due to the fact that these products also contain gluten. However, it is equally as important to ensure that the child does not feel ostracized from the rest of the class.
- **Wash Hands Thoroughly:** Another great risk for patients with celiac disease is cross-contamination from foods or other products that other children are using that contain gluten. Let teachers know that it would be helpful if a hand-washing policy was instituted to ensure that your child remains safe after the other children use these gluten-containing products.

College Bound

For young adults going off to college, it is important to learn how universities manage dietary restrictions during the application process.

1. Arrange meetings with the food service director, dining hall manager, and/or dean of students to discuss your child's needs during school. Bring education materials to help the food service to understand your dietary needs and the importance of the diet as medical treatment.
2. Inquire about housing options available such as dormitories with full or modified kitchens including appliances such as refrigerators, microwaves or hot plates that would enable your child to prepare meals for him/herself if necessary.
3. Determine if alternative meal options are available. Some college dormitories have meal plan options in which students are allotted a certain number of meals per week in the school food service. However, if most of the meals cater to a "non-gluten-free" lifestyle, the cost can seem excessive.
4. Determine if the food service is able to prepare gluten-free items and alternatives. Proper education is essential to understand cross contamination and how to maintain a safe environment.
5. Be prepared! Send along non-perishable gluten-free alternatives so that the student can have snack foods on hand.

On the Job

- **Be Prepared:** To ensure lunchtime is not a source of stress at the office, come prepared with lunch and snacks to have on hand. If brown-bagging is not within your office culture, make sure to investigate the local restaurants ahead of time to determine which establishments meet your needs. It would be helpful to look at the menu prior to venturing out, in order to prevent an unintentional ingestion of gluten-containing foods.
- **Educate Catering Company Food:** Service companies that provide hot meals in workplace cafeterias should have ingredient information available. Speak to the manager to determine if alternative food products can be ordered to ensure that your food is gluten-free.

Restaurants

There is a learning curve for individuals who are guests in eating establishments managing gluten-free diets as well as for the restaurants who cater to them. The process of gaining the necessary knowledge to successfully handle special dietary requirements is similar for both parties.

Learning Curve

The learning curve associated with special diets includes the following four key steps, for individuals and restaurant professionals alike:

- Awareness
- Information
- Knowledge
- Empowerment



1. To gain awareness, you, as an individual, need to first educate yourself to understand exactly what you are allergic to or what special diet you are required to follow. You may be asking, “What have I been diagnosed with? Where do I begin my research? What resources are available to me and what do I do next?” These are all common questions associated with learning about your new way of life. On the other side of the table, restaurant professionals go through a similar experience. “What type of special diets may be required by our guests? What do we need to learn to better understand their needs? What resources are available to help us?”
2. The next step in the learning curve is information. As an individual, you must learn what you can and cannot eat on a fundamental level. Once this is understood, it is important to investigate where problematic allergens can be hidden in foods and what you need to do to adjust for this unexpected variable. Likewise, restaurant professionals follow a similar thought process. “What can this guest eat and what is not allowable? What ingredients and food preparation techniques can be an issue and how can we adjust to suit their requirements?” The parallel is undeniable.

3. Once this understanding is accomplished, the third step is knowledge. Individuals need to apply what has been learned to safely eat in restaurants, as well as at home. Furthermore, you must learn to communicate your special requirements and determine an effective strategy for ordering safe meals in order to develop a comfort level with various cuisines and dishes. As a restaurant, you have a different set of concerns to address, such as how to train both front and back of the house staff. You also need to determine how to accurately convey this information between all employees involved in the process and identify what protocols need to be in operation. Through effective training efforts, an establishment can teach their staff how to assist special diet guests by guiding them through the menu, taking into consideration ingredients, food preparation techniques and hidden allergen concerns.
4. The final step of the learning curve is empowerment. As the guest, you need to know where and what you can eat, as well as what modifications can be made to easily accommodate your dietary requirements. Once this is achieved, you can focus on enjoying your eating experiences while remaining diligent about the foods you eat. For the restaurant, the focus becomes how to simplify menu options to adjust for special dietary needs. This allows the restaurant to concentrate on providing safe and delicious meals for their guests, while ensuring a high standard of service, ultimately resulting in repeat and loyal business.

Guest Approach to Eating Outside the Home

Based upon years of research, personal experience and extensive discussions with hospitality professionals, the following approach is designed to help you, the person managing gluten-free lifestyles, eat out safely.

The objective is to enjoy safe eating experiences regardless of your choice of restaurant, cuisine or location. These suggestions include eight key steps on how to safely eat outside the home:

1. Educate yourself about eating outside the home with special diets
2. Assess your dining comfort level for the meal
3. Identify your eating options and preferences
4. Determine desired level of pre-planning efforts
5. Communicate your special dietary needs with the restaurant
6. Order your meal
7. Receive order and appreciate your meal
8. Provide feedback on dining experience

Each of these eight key steps are described in detail to guide you in developing your own approach to eating outside the home. The questions to ask yourself, as the guest, may be helpful in assessing your level of preparedness along the way. If you are new to your diet, these ideas may give you some food for thought during the early stages of your learning curve.

For those who have been following a gluten-free diet for some time, you might find it interesting to reflect upon your previous experiences, correlate them to this recommended approach and, perhaps, learn something new in the process. These ideas are also provided for restaurants who want to understand the guest's perspective of how to handle special dietary needs.

1. Educate yourself about eating outside the home with special diets

a. Read applicable materials:

- Review books, restaurant reviews and awareness programs
- Research the Internet, databases and other reference materials

b. Talk with other individuals managing gluten-free lifestyles

c. Attend educational sessions:

- Participate in associated conferences and cooking classes
- Hire a personal chef for consultation

2. Assess your dining comfort level

a. Identify your safety factors:

- Determine how you feel physically
- Assess how safe you feel with eating out

b. Evaluate what cuisines are low & high risk

c. Assess specific cuisines:

- Determine what type of cuisines satisfy your comfort level and tastes
- Identify your level of understanding about preparation techniques



3. Identify your eating options and preferences

a. Determine the desired type of establishment:

- Fine dining or family-oriented restaurant
- Fast food/quick service or carry out/take away

b. Assess what type of cuisine you prefer:

- New and different
- Familiar with cuisine menu items

c. Determine important factors based on your comfort level:

- Recommended and new restaurant

- Familiar and where you have eaten before
 - Features specific gluten-free menu
4. Determine desired level of pre-planning efforts
 - a. Conduct research as necessary on:
 - Cuisine ingredients and preparation techniques
 - Potential hidden allergens
 - Restaurant menu options and items
 - b. Determine the best time for your meal:
 - Decide to walk into a restaurant when convenient
 - Reserve a desired time
 - Reserve a time that is typically not crowded
 - c. Determine the level of communication necessary prior to your meal:
 - None required
 - Review menu on the Internet
 - Call ahead to discuss your requirements
 5. Communicate your special dietary needs with the restaurant
 - a. Determine your approach:
 - Have celiac / coeliac
 - Susceptible to anaphylaxis and life threatening conditions
 - On a special diet
 - b. Initiate your first contact with restaurant:
 - Go to restaurant without prior communication
 - Call ahead prior to walking in the door
 - Pre-order your meal based upon your concerns
 - c. Discuss requirements with restaurant and request manager if needed
 6. Order your meal
 - a. Determine reference materials required to order meal:
 - Assess if a dining card outlining dietary requirements is needed based upon your comfort level or language considerations
 - Refer to your notes, books, quick reference guides, translation cards and foreign language phrase books as needed
 - b. Discuss the menu with the restaurant:
 - Ask appropriate questions to determine meal choices based upon cuisine, dishes and preferences
 - Explain your concerns to the restaurant
 - Ask staff to verify and validate ingredients and preparation techniques as needed

- c. Place your order:
 - Request special food preparation
 - Confirm your order with restaurant
- 7. Receive order and appreciate your meal
 - a. Confirm your order upon delivery:
 - Reiterate your special order request
 - Receive dish and assess preparation
 - b. Enjoy your meal:
 - Accept the dish
 - Request dish be returned if special request is not met
 - c. Relax and appreciate the dining experience:
 - Compliment the staff if your special requests are met
 - Include a generous tip for good service, if appropriate
 - Frequent the restaurant again based on experience
- 8. Provide feedback on dining experience
 - a. Provide constructive feedback to restaurant on your experience
 - b. Recommend the establishment to your friends and family, as appropriate
 - c. Notify applicable on-line database resources and/or restaurant awareness programs about your experience

Note: Gluten-free restaurant advice excerpted from the 10-time award winning *Let's Eat Out with Celiac / Coeliac & Food Allergies!* series of books, eBooks and applications.

For mobile app listings of gluten-free restaurants throughout Chicago and across the US as well as for additional information, visit www.GlutenFreePassport.com.



Gluten-Free Travel

Safely traveling while managing special diets is very doable and highly rewarding. You can discover new places and experience safe gluten-friendly journeys with careful planning and a little extra effort! The best way to expand your own personal comfort and reduce the stress associated with traveling is three-fold: education, preparation and communication.

Overall Travel Considerations

Educate yourself on your travel and eating out options based upon what you can and cannot eat. Be prepared with snacks, medications and back-up plans in the event of a mistake, accident or emergency. Communicate your special dietary requirements effectively with airline, hotel, cruise line, restaurant and hospitality professionals as needed.

Achieving empowerment when eating out and traveling anywhere in the world requires due diligence, taking proper precautions and asking the right questions.

Airline Guidelines and Checklists

Eating gluten-free while traveling by air is possible. The best approach to gaining that often elusive comfort level when flying is a combination of at least three key areas of consideration, and possibly four if at risk to anaphylaxis.

These “how-to” guidelines and checklists are designed to assist you throughout your planning efforts, and while on board the airplane, to enjoy safe and comfortable flying experiences. The key four points, depending upon your concerns, include:

1. Bring your own carry-on snacks for your flight(s)
2. Understand standard airline meal codes
3. Order your special meal(s)
4. Communicate your life threatening condition, if applicable

Guidelines for Carry-On Snacks through Airport Security

Your first step, and your safest option, is to bring your own snacks to eat during your flight. You need to ensure that your snacks are portable and tasty as well

as allowable based upon the respective airport security regulations for each departing and arriving country.

For example, when traveling within some countries, you may need to understand requirements such as:

- If you are bringing packaged salad dressings or sauces, ensure that it falls within the liquid carry-on requirement.
- Remember to have liquid items available for inspection in an approved, re-sealable package.
- Products such as canned fruit may be considered liquid and may be confiscated at security.
- It is recommended that you do not bring cooling packs, as they are typically filled with chemical liquids or gels, and will likely be confiscated at security check points.
- Purchase your beverages for the flight after you have cleared security.
- Fill up your re-sealable baggy or travel-size cooler with ice, if needed, AFTER you go through security either at a food stand or on the airplane.

Standard Airline Meal Codes

Many global airlines cater to those who need gluten-free meals when traveling by air. The selection & quality of these meals significantly varies from each airline. The standard code used by the airlines for a gluten-free meal is GFML (Gluten-Free Meal) which indicates no wheat, rye, barley or their derivatives will be included.



International Travel Tips

When venturing overseas, following these travel guidelines will help to make your journey more enjoyable and increase your comfort level while staying in both English and foreign-language speaking destinations.

1. Research on-line global databases and resources about eating out and traveling overseas.
2. Contact the local celiac / coeliac associations for suggestions on eating gluten-free in that specific country.
3. Understand country specific regulations regarding standards on allowable products packed in carry-on luggage.
4. Review food product labeling regulations for your destination, which may differ from your home country.
5. Determine the availability of safe gluten-free snacks for future purchase during your travels.

Foreign Language Translation Cards

For those visiting foreign-speaking countries, it is also important to communicate your needs in the native language.

1. Ensure any medical documentation that may be needed has been translated into the language of each country included in your travels.
2. Carry pocket-size gluten-free translation cards which identify your special dietary requirements by allergen, key ingredients and critical food preparation techniques. For free downloadable dining cards, visit www.GlutenFreePassport.com.

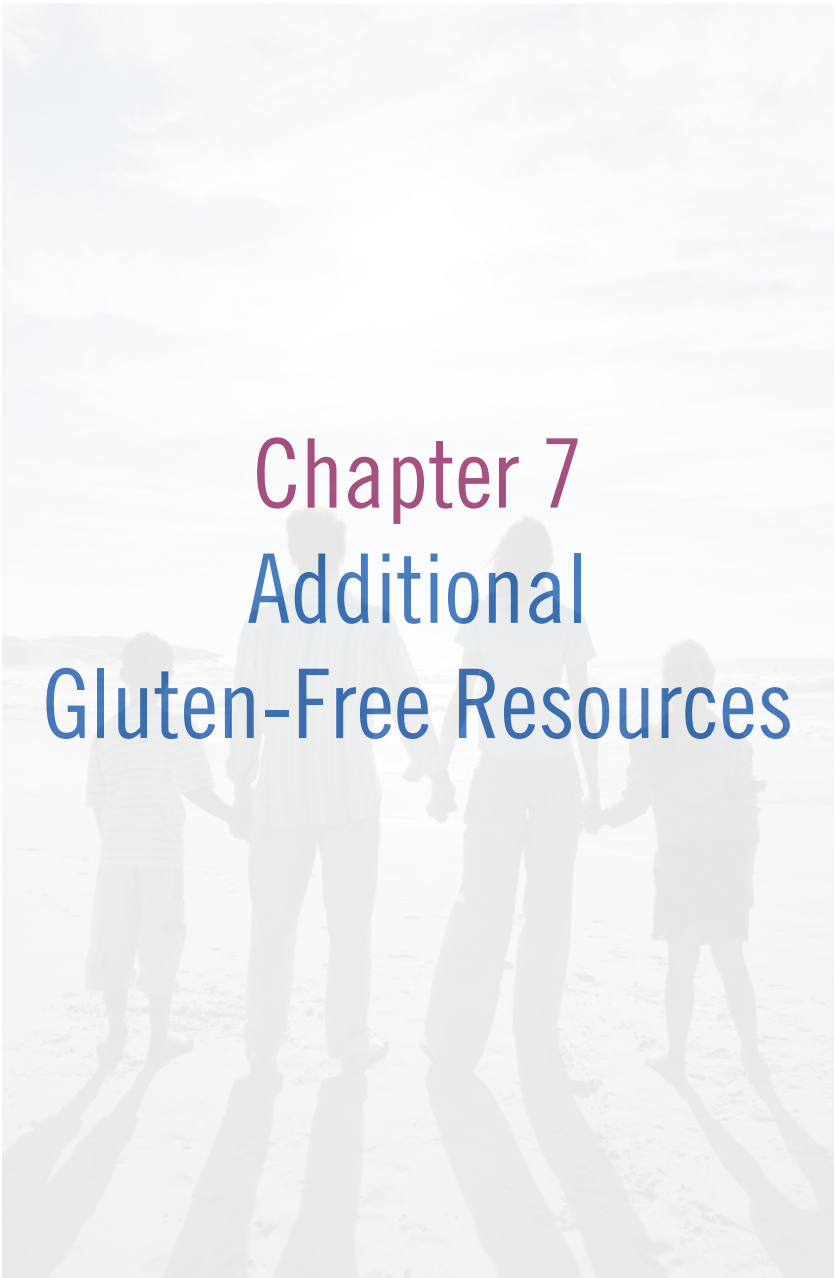
In order to navigate your way in foreign-speaking countries, it is important to effectively communicate your needs in the native language even if you can't pronounce the words or speak the language.

It is recommended that you present the appropriate card to the wait staff and/or chef at your selected eating establishment in the foreign-speaking country to communicate your special dietary requirements. It may also be helpful to print extra copies of the cards in the event that the restaurant staff or chef want to keep them for future reference!

Note: Gluten-free travel tips excerpted from the 10-time award winning *Let's Eat Out with Celiac / Coeliac & Food Allergies!* series of books, eBooks and applications.

For mobile app listings of gluten-free restaurants throughout Chicago and across the US as well as for additional information, visit www.GlutenFreePassport.com.





Chapter 7

Additional Gluten-Free Resources

Reference Materials

More Information

- Section 504 Complaints: Office of Civil Rights
www.ed.gov/ocr
- ADA: Equal Employment Opportunity Commission
www.eeoc.gov
- Other ADA Complaints: U.S. Department of Justice
www.usdoj.gov/crt/ada

National Celiac Disease Organizations

- American Celiac Disease Alliance
www.AmericanCeliac.org
- Celiac Disease Foundation
www.Celiac.org
- Celiac Sprue Association
www.CSACeliacs.org
- The Gluten Intolerance Group
www.Gluten.net

Doctors

- University of Chicago Medical Center
www.UCHospitals.edu
- University of Chicago Comer Children's Hospital
www.UChicagoKidsHospital.org

Section 504 and the ADA protect people with allergies because legally, they are disabled. People with celiac disease fall into this category as well.

Section 504 is enforced by the Department of Education's Office for Civil Rights which requires all schools, private or public, that receive federal funding ensure that all individuals with disabilities have full access to all facilities, programs, goods and services. This prohibits discrimination against students, faculty and staff at educational institutions.

The ADA extends the obligations of Section 504 to other public accommodations such as hotels, museums, non-religious private schools, restaurants or doctors' offices, whether they receive federal funding or not.

This prohibits discrimination at all public accommodations including employment related activities including recruitment, hiring, firing, compensation, layoff, leave, etc.

Contributions & Contact Information

Please visit contact us for additional information about our leading programs and services:

- Gluten-Free Care Package Program
- Annual Celiac Disease Preceptorship Program
- Annual Free Blood Screening
- Information Hotline
- Benefits & Events
- Research Initiatives
- Education & Outreach

The work of the University of Chicago Celiac Disease Center is entirely funded by private donations.

We are pleased to be able to accept your contributions via our website at www.CeliacDisease.net.

If you prefer to send a check, kindly make it payable to The University of Chicago Celiac Disease Center, and mail to us directly. An acknowledgement will be sent to you for tax purposes.

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Find Us on Facebook and Follow Us on Twitter at CureCeliac
www.CeliacDisease.net

Thank You For Your Continued Support!