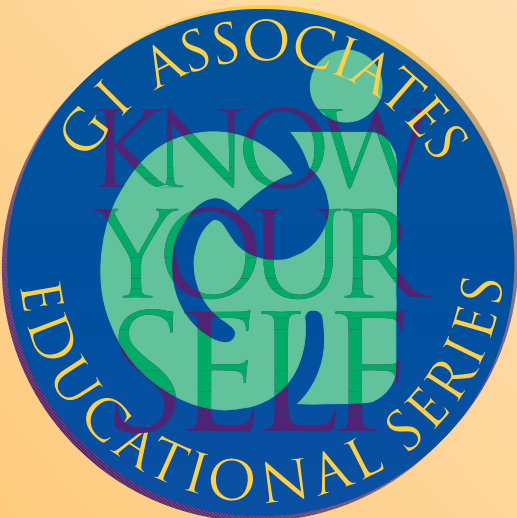


Celiac Sprue



Table of contents

What is it?	1
What causes it?.....	2
Symptoms	3
Diagnosis.....	4
Treatment	5
Complications.....	6
Points to remember	7
Taking care of yourself	8
Supplementary information.....	9
Patient resources	12



Celiac Sprue

The following information will help you understand the condition known as *celiac sprue sprue, nontropical sprue* and *gluten-sensitive enteropathy*. To make it simple in this brochure, we will call it **sprue**.

What is it?

Sprue is a digestive problem that damages the small intestine. Since nutrients in food are absorbed in the small intestine, sprue interferes with that process. People who have this problem cannot tolerate *gluten*, which is a protein found in wheat, rye, barley and often, oat products.

When a person with sprue eats foods that contain gluten, the immune system responds by damaging *villi* in the small intestine. *Villi* are tiny hair-like projections along the inside wall of the small intestine, through which nutrients pass into the bloodstream. Once in the bloodstream, nutrients are transported to all parts of the body to maintain good health.

Without the action of healthy villi, (and the transport of nutrients to the body) a person can become *malnourished* no matter how much food is eaten.

Sprue is an *autoimmune* disorder, causing the body's own immune system to "turn against" or damage the body. It is also considered to be a *disease of malabsorption* because nutrients are not absorbed into the body the way they should be to maintain good health.

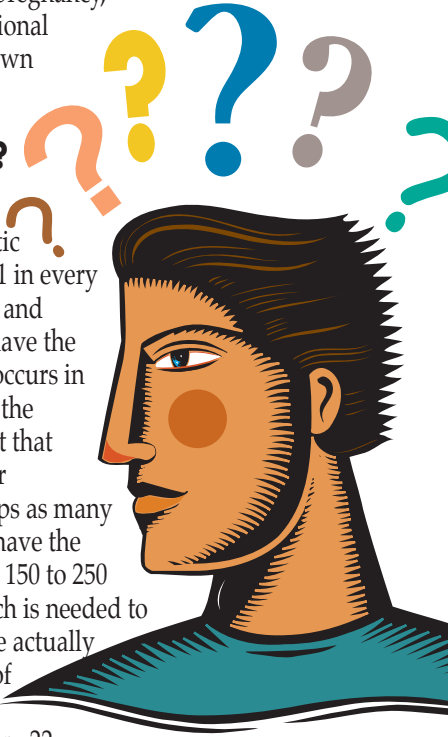


What causes sprue?

Sprue is a genetic problem, which means that it runs in families and the tendency to have it is inherited. Even though the potential is there, sometimes it may not become active until a person has an extreme health challenge such as a severe infection, injury, surgery, pregnancy, childbirth, or severe emotional stress. Much is still unknown about the disease.

How common is it?

We now realize that it is the most common genetic disease in Europe. About 1 in every 250 people in Italy have it and about 1 in 300 in Ireland have the problem. It almost never occurs in Africa, China or Japan. In the United States, it is thought that the problem may be under diagnosed and that perhaps as many Americans as Europeans have the problem (about 1 of every 150 to 250 persons), but more research is needed to find out how many people actually have sprue. For relatives of those who are known to have sprue, about 1 in every 22 persons have been found to have the problem.



What are the risk factors?

Those at a higher than average risk for developing sprue include people of European descent and people with other disorders of the immune system, such as:

- **Lupus Erythematosus**
- **Type 1 diabetes (juvenile or insulin-dependent diabetes)**
- **Rheumatoid arthritis**
- **Autoimmune thyroid disease**

What are the symptoms?

Sprue affects each person differently, so symptoms vary a lot and may seem similar to many other health problems. Sometimes symptoms develop in childhood or may not develop until adult years.

Symptoms may be within both the digestive system or in another body system. For instance, one person may have diarrhea and bloating, but another person's primary symptoms may be irritability and depression. And some people with sprue do not notice any symptoms, because some of the small intestine still functions *enough* to maintain a fairly good level of nutrition. For those reasons, sprue may be difficult to diagnose. Many people have sprue for years before it is diagnosed.

Children who have sprue may have anemia, delayed growth and weight loss, all signs of malnutrition.

Symptoms may include one or more of the following:

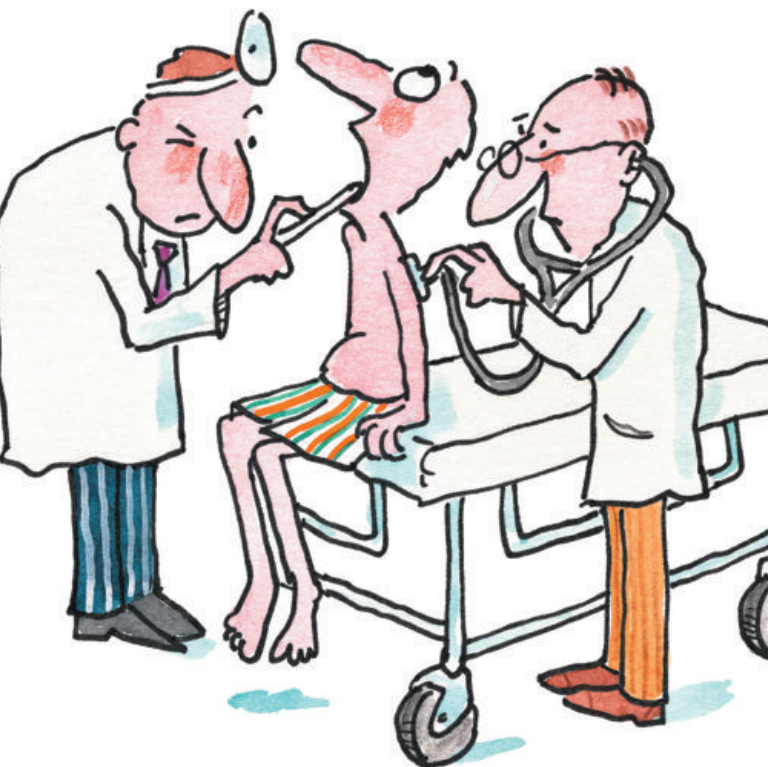
- **Bloating and pain in the abdomen that recur**
- **Chronic diarrhea**
- **Weight loss**
- **Light-colored or grayish, foul-smelling stool (bowel movements) that may be fatty or oily-appearing and may float**
- **Anemia (low red blood cell count)**
- **Gas**
- **Bone pain**
- **Behavior changes**
- **Muscle cramps**
- **Fatigue (feeling tired) or general weakness**
- **Delayed growth or failure to thrive in infants**
- **Pain in the joints**
- **Seizures**
- **Tingling numbness in the legs**
- **Pale sores in the mouth (aphthous ulcers)**
- **Painful skin rash (dermatitis herpetiformis)**
- **Tooth discoloration or loss of tooth enamel**
- **Missed menstrual periods in women**

How is *Sprue* diagnosed?

Researchers have discovered that people with sprue have higher blood levels of specific antibodies (*antigliadin*, *anti-ientomysium*, *anti-tissue transglutaminase* and *antireticulin*), that have been produced by their bodies in response to eating gluten.

If blood tests are positive for elevated antibodies, it suggests that a person has sprue. Then, a biopsy of intestinal villi, using an endoscope, can be done to check for damage. *Biopsy of the small intestine is the best way to confirm a diagnosis of celiac sprue.*

Because sprue is hereditary, most experts agree that first degree (blood) relatives should be screened for the problem. Early diagnosis and treatment may prevent intestinal damage.



The treatment for *sprue*... what you eat is the key!

The only known effective treatment for sprue is to follow a gluten-free diet — avoiding all food and food products that contain gluten. When gluten is eliminated, the small intestine begins to heal and symptoms will go away. Further damage can be prevented by staying on a meal plan to avoid gluten.

Only a very few people with sprue *do not* improve with a gluten-free meal plan. Usually it is because they have severely damaged intestines. These few individuals may need nutritional supplements for life to help prevent malnutrition and other complications of sprue (see the discussion below).

The benefits pay off right away!

Many people who have sprue notice improvement within days of eliminating gluten. Villi usually become completely healed within three to six months, but it may take longer in older adults.

Change requires

dedication... The person who has been diagnosed with sprue must make many life changes and eat differently to make sure that all gluten is avoided. Generally, this means avoiding all foods or food ingredients made from any of the grains (or types of the grains), including wheat, barley, and rye.

See page 9
for tips on
how to have
a successful
gluten-free
diet.

A complete listing of foods that contain gluten is a good start, so you will know what foods to stay away from. In addition, a listing of “hidden” gluten sources will help you to become a *very smart reader of food labels*. By carefully reading labels, you can also avoid ingredients used in manufacturing foods that might cause you harm. (See the section at the end of the brochure for more information.)

What happens if sprue is not treated?

Untreated sprue can lead to the following complications:

Malnutrition Malabsorption of nutrients caused by damaged villi in the small intestine can cause malnutrition.

Malabsorption can also cause a deficiency of the essential vitamins A, B-12, D, E, K, and folate, which can result in anemia and weight loss. Stunted growth in children and delayed development are also complications of sprue.

Lactose intolerance Since there has been damage to the small intestine, even some foods that don't contain gluten may cause pain and diarrhea. Some people with sprue have problems tolerating milk products and other products that contain lactose. Often, after sprue is treated with a gluten-free diet, patients may be able to tolerate lactose-containing products better.

Osteoporosis Because of poor calcium absorption, bones may become weak, brittle and prone to breaking.

Kidney stones of a certain type (*calcium oxalate stone*) can also result from lack of calcium absorption

Miscarriage and congenital malformation Pregnant women who have untreated sprue run a greater than average risk of having a miscarriage or babies with major birth defects.

Cancer People who do not follow a gluten-free meal plan have a greater than average chance of developing several forms of cancer, including lymphoma and adenocarcinoma of the intestine.

Neurological conditions Disorders of the nervous system can also result from untreated sprue. Those conditions include seizures (*epilepsy*) and nerve damage (*peripheral neuropathy*).

Remember these points...

- **People with sprue must avoid all gluten, a protein found in wheat, barley, rye and some oat products. This must be a life-long, lifestyle change.**
- **Sprue damages the villi in the small intestine and interferes with nutrient absorption.**
- **Sprue can be diagnosed by blood tests and biopsy of the small intestine.**
- **People with sprue may or may not have symptoms.**
- **Treatment is important to avoid serious health problems.**
- **Since sprue is an inherited health problem, family members should be tested.**



How to take care of yourself when you have sprue.

Changing *the way you eat* and *what you eat* is a major challenge. To avoid gluten, you must first learn all the foods that contain gluten, then avoid them. This can be pretty frustrating because *many* common foods do have gluten.

In addition to changing the foods you, eat consider these tips that will help you cope with sprue:

- ***Use the information sources listed in this brochure to find out more about the problem.***
- ***Talk with others who have sprue and share ideas and concerns.***
- ***Support legislation for better food labeling.***
- ***Read food labels carefully to stay away from food that contains gluten.***
- ***When you don't know, ask. Registered dietitians are great resources. Also, if a food label is unclear about whether or not the food contains gluten, usually a phone number is listed and you can call to find out.***
- ***When eating out, ask the waiter to find out for sure whether or not the food contains gluten. If in doubt, don't eat it.***
- ***Remember that all major food groups that are necessary for good health contain foods that are gluten free, so you can have a very healthy diet without gluten.***
- ***Feeling better and living successfully with sprue will require some commitment and changes on your part, but need not interfere with having a healthy life. Working together with your doctor, you can expect the best possible treatment outcome!***

Supplementary information

Tips to avoid gluten

Avoiding all foods that contain gluten is the goal for those that have sprue.

AVOID THESE:

Wheat and wheat products, rye, barley and some oat products: most grain, pasta, cereal, baked goods, most crackers, breads and many processed foods. This includes:

- ✗ Spelt
- ✗ Triticale
- ✗ Kamut
- ✗ Wheat-based semolina
- ✗ Wheat germ
- ✗ Bran
- ✗ Graham and graham powder
- ✗ Wheat starch
- ✗ Oat bran
- ✗ Bulgur
- ✗ Farina
- ✗ Malt extracts
- ✗ Malt flavorings
- ✗ Malted milk
- ✗ Some milk drinks and hot cocoa mixes
- ✗ Some flavored and frozen yogurt
- ✗ Beer
- ✗ Liquor and other alcoholic beverages that are distilled from grain
- ✗ HVP/HPP (preservatives made from wheat protein)



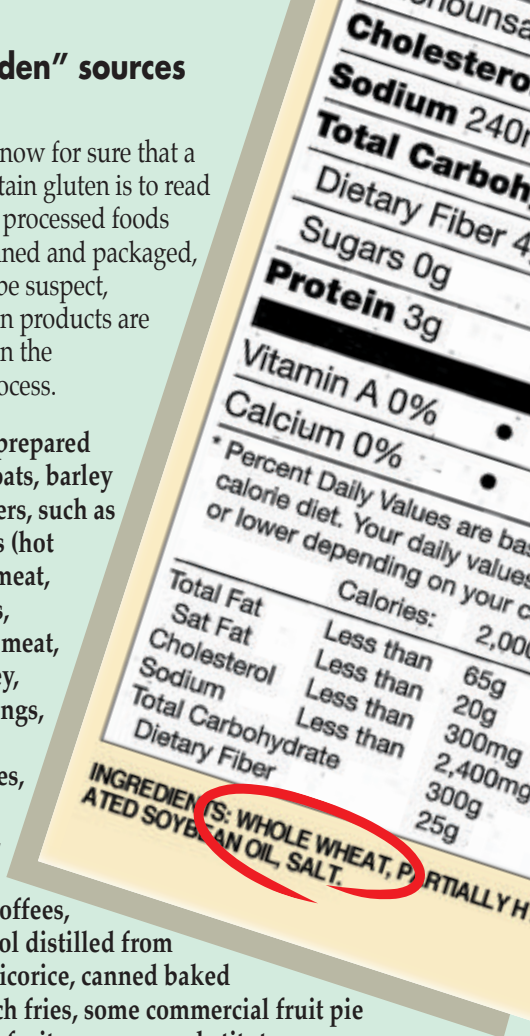
Beware “hidden” sources of gluten

The only way to know for sure that a food does not contain gluten is to read the food label. All processed foods (those that are canned and packaged, not fresh) should be suspect, because often grain products are used somewhere in the manufacturing process.

Avoid any foods prepared with wheat, rye, oats, barley or gluten stabilizers, such as some frankfurters (hot dogs), sandwich meat, sandwich spreads, sausages, canned meat, self-basting turkey, some salad dressings, prepared soups, condiments, sauces, seasonings, hot cocoa mixes, non-dairy creamers, flavored instant coffees, herbal teas, alcohol distilled from grains, beer, ale, licorice, canned baked beans, some french fries, some commercial fruit pie fillings and dried fruit, some egg substitutes.

Even medicines and mouthwashes can contain gluten.... So remember to ask your doctor or pharmacist if an over-the-counter or prescription medicine has gluten as an ingredient.

This is not by any means a complete list— you must learn to read labels even on foods that you don’t think will have gluten!



There are many substitutes that you can eat!

The list of foods to avoid is pretty large, but there are many foods that are gluten free and shopping for them has become easier.

All plain, fresh, frozen or canned vegetables with allowed ingredients can be eaten. All fruits and fruit juices; all milk products except those with gluten additives; aged cheese; all fresh meat, poultry, shellfish, fish and eggs; dry peas and beans, nuts, peanut butter; cold cuts, hotdogs and sausage (that do not have fillers or additives that contain gluten) can be eaten.

Breads or bread products that are made from corn, rice, soy, arrowroot, corn or potato starch, pea, potato or whole-bean flour, tapioca, sago rice bran, cornmeal, buckwheat, millet, flax, teff, sorghum, amaranth and quinoa do not have gluten.

Hot cereals made from soy, hominy, hominy grits, brown and white rice are gluten-free. Puffed corn, rice or millet, rice and rice noodles made from gluten free ingredients are also OK to eat.

The bottom line on food choices is that you can eat most anything as long as it does not contain gluten as a main ingredient or an additive/filler. Read the label to be sure.



Patient Resources:

American Celiac Society
59 Crystal Avenue
West Orange, NJ 07052
Phone: (973) 325-8837
Email: amerceliacsoc@netscape.net

Celiac Disease Foundation
13251 Ventura Boulevard, #1
Studio City, CA 91604-1838
Phone: (818) 990-2354
Email: cdf@celiac.org
Internet: www.celiac.org

Celiac Sprue Association/USA Inc.
P.O. Box 31700
Omaha, NE 68131-0700
Phone: (402) 558-0600
Internet: www.csaceliacs.org

Gluten Intolerance Group of North America
15110 10th Ave. SW, Suite A
Seattle, WA 98166-1820
Phone: (206) 246-6652
Email: info@gluten.net
Internet: www.gluten.net

National Center for Nutrition and Dietetics
American Dietetic Association
216 West Jackson Blvd., Suite 800
Chicago, IL 60606-6995
Phone: 1-800-366-1655
Email: hotline@eatright.org
Internet: www.eatright.org

Gluten-free Living (bi-monthly newsletter)
P.O. Box 105
Hastings-on-Hudson, NY 10706
Phone: (914) 969-2018
Email: gfliving@aol.com

Vendors of Gluten-free products:

'Cause you're Special, Inc.
Phone: (866) No wheat (866-669-4328)
Internet:
www.CauseYoureSpecial.com

Authentic Foods
Phone: 800-806-4737
Internet:
www.glutenfree-supermarket.com

Dowd & Rogers Baking Mixes
Phone: 916-451-6480
Internet: www.dowdandrogers.com

Gluten Free Mall
Internet: www.glutenfreemarket.com

Gluten Free Market
Phone: 847-419-9610
Internet: www.glutenfreemarket.com

Gluten Free Pantry
Phone: 800-291-8386
Internet: www.glutenfree.com

Gluten-free cookbooks

Wheat-free Gluten-free Reduced Calorie Cookbook

Wheat-free Gluten-free Cookbook for Kids and Working Adults

Wheat-free Gluten-free Dessert Cookbook

All written by Connie Sarros and can be ordered at
www.wfgf.homestead.com/gfhtml

