

Dear School Nurse,

A student in your school has been diagnosed with an autoimmune disorder called celiac disease (CD). While this will affect some aspects of classroom and school management, patience and understanding can bring about the necessary changes that will quickly become a natural part of the school experience for all involved.

What is celiac disease?

Also known as celiac sprue or gluten-sensitive enteropathy, CD is a genetic disorder that can affect both children and adults. Once considered extremely rare, an epidemiological study has now shown that in otherwise healthy people, CD occurs in about 1 in 133 people.¹ This study was replicated in 2004 by a Casper, Wyoming gastroenterologist, in conjunction with Mayo Clinic.²

In people with CD, eating certain types of grain-based proteins sets off an autoimmune response which causes damage to the tiny fingerlike protrusions, called villi, on the lining of the small intestine. Because nutrition is absorbed into the bloodstream through these villi, a person with CD can become malnourished--regardless of the quantity or quality of the food eaten. The proteins that cause these difficulties are collectively called gluten and are found in wheat, barley, rye and, oats* (WBRO), as well as all of their derivatives.

What are the Symptoms?

Exposure to WBRO results in a variety of symptoms which may include diarrhea, abdominal distention, anemia, fatigue and inability to concentrate. For a small number of people with CD, the disease manifests itself in small itchy blisters on the skin called dermatitis herpetiformis (DH). It is interesting to note that in the United States, non-classical symptoms tend to be more prevalent.

Symptoms may or may not occur in the digestive system. For example, one person might have diarrhea and abdominal pain, while another person has irritability or depression. In fact, irritability is one of the most common symptoms in children. Symptoms of celiac disease may include (but are not limited to) one or more of the following:

abdominal bloating and pain	joint pain
anemia	legs (tingling/numbness/nerve damage)
behavior changes	menstrual periods missed (often because of excessive weight loss)
bone pain	mouth - pale sores, called aphthous ulcers
concentration difficulties	muscle cramps
dermatitis herpetiformis (painful rash)	seizures
diarrhea	stools - pale, foul-smelling
failure to thrive in infants	tooth discoloration or loss of enamel
fatigue	weight loss
gas	
growth delays	

Symptoms can present themselves almost immediately or up to as many as 24 hours after exposure to the offending grains. In some cases the patient may not exhibit any visible symptoms. Because no two celiacs exhibit exactly the same symptoms, please refer to the back cover of this booklet to see a list of those particular to this student. Contact the parent/guardian or CSA for a more extensive list of possible symptoms.

How is CD treated?

This is a lifelong disease and the only known treatment at this time is the total elimination of WBRO from the diet. This might sound like an easy solution at first. WBRO may be hidden, however, in things like food additives, flavorings, personal care products, school supplies and more. Therefore, some adjustments may need to be made in the classroom and other areas of the school to reduce the risk of inadvertent contact.

How will I be involved?

Because this is a health-related issue, faculty, staff and parents may seek your guidance as they learn to make the necessary adjustments. You may be called upon to:

- review the child's health record.
- identify a core team to work with the family in order to establish a safety plan for the child while at school.
- train any and all staff who will interact with the child, making them aware of his/her special needs.
- provide a process for identification and resolution of the child's specific health care needs.
- handle a response. (Note: anaphylaxis is rare.)
- ensure that the school is prepared for emergencies involving the child. (Note: For a few celiacs with DH, Latex and/or Iodine are not well tolerated. Communicate with the parent/guardian to see if it is an issue with this child and make any arrangements needed.)

Whose responsibility is it?

Ultimately, it is the responsibility of the student to decide what he or she will eat and touch while at school, knowing the consequences of those decisions. However, a newly-diagnosed celiac may need help to enforce the prescribed lifestyle change. The goal is to help provide the child with adequate information in order to increase confidence in living a lifestyle that is free of WBRO.

Where do I find out more about celiac disease?

The information contained in this material is not intended to be all-inclusive. It is provided to help you understand the importance of caution and preparation when working with a person with CD. More details on the disease and its management are available from the Celiac Sprue Association. (See the back cover of this material.)

The goal is to provide an environment where the child with CD can learn self-management skills without being consumed by the illness. An atmosphere designed to

foster responsible decision making will ultimately help the child perform well both in and out of the classroom.

Thank you for your help and support.

¹Fasano et al., *Archives of Internal Medicine*. 2003 Feb 10;163(3):286-92.

²Katz et al., Awaiting publication

*Clinical studies have shown that pure oats can be tolerated by some people with celiac disease. Pure, uncontaminated oats sources are not readily available at this time and therefore, it is suggested that oats be avoided, especially by those who are newly-diagnosed.

Helpful Resources

Student: _____

Symptoms most often exhibited upon exposure to WBRO: _____

Parent/Guardian(s): _____

Phone: _____ Work: _____ Cell: _____

Pediatrician: _____ Phone: _____

Dietitian: _____ Phone: _____

Additional notes: _____

For more information on celiac disease or its implications in the areas of insurance and The Americans with Disabilities Act contact:



P.O. Box 13700
Omaha, NE 68131-0700
1-877-CSA-4-CSA
www.csaceliacs.org

The Celiac Sprue Association (CSA) is the nation's largest non-profit organization dedicated to helping people with celiac disease (CD) and the related skin response dermatitis herpetiformis (DH). With local chapters and resource units across the United States, CSA serves nearly 9,000 members worldwide through information, education, and research.

This material is provided through:



CSA's *Cel-Kids Network* is specifically designed for children with CD/DH and the adults who work with them.
www.csaceliacs.org/CelKidsNetwork.php