

Dear Principal,

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. In people with CD, eating certain types of grain-based proteins sets off an autoimmune response which causes damage to the small intestine. This, in turn, interferes with the small intestine's ability to absorb the nutrients found in food, leading to malnutrition and a variety of other complications. The offending proteins 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 of CD?

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). 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.

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.

Intercession should rarely be necessary for older children. For a younger child, however, it is vitally important for members of the school staff to encourage self-management by making sure that the student either reads the ingredients or has someone else read the ingredients to him or her. 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.

The grieving process

As with many other forms of loss, a child diagnosed with CD must give up many of his or her favorite foods and thus may experience some level of grief. During this period, you may see signs of sadness, denial, shock, confusion, anger, irritability, loss of appetite,

physical complaints, loss of concentration, depression and/or withdrawal from friends. Occasionally, as part of the denial process, the child may take risks with foods or other products known to contain WBRO (this is especially true in the teen years). It is important to remember that such action might dramatically impact present and future health. All research indicates that even a small amount of exposure to WBRO can evoke an undetectable immune reaction, increasing a celiac's chances for future health problems and conditions including other autoimmune diseases, osteoporosis, and cancers such as T-cell lymphoma.

It is important for a child with celiac disease to be able to share the feelings and frustrations he or she might have because of the disease. By sharing, other students will be able to learn about similarities and differences that exist in people's health situations.

Family and close friends, striving to help the newly diagnosed child, may also experience some stages of grief. Patience and understanding are needed to move those involved from these feelings of loss to a place of acceptance. Feel free to contact the child's parent/guardian if you have questions or concerns in this area.

Who needs to know?

Teacher/Substitute Teachers: The information included for the teacher points out possible risk areas in the classroom and gives tips to encourage self-management by the student. It is intended to serve as a guideline to use when looking for hidden WBRO, but it is by no means all-inclusive.

It is imperative that the classroom teacher both realizes the seriousness of this condition and is willing work with the special needs it demands. Because there will be times when the student will be taught by other faculty and staff members, please ensure that all those who interact with this student have been made aware of these special needs. Contact the parent/guardian or CSA for help in this area.

Cafeteria Staff: One of the areas of greatest concern for any student with CD is the cafeteria. Material is available to help educate the kitchen staff about this disease and encourage them to ensure that, when possible, safe options are available for this student. When is not feasible, the parent/guardian may provide a packed lunch. Lunchroom supervisors might need to remind the child not to swap food or touch other foods which could cross-contaminate his or her meal. In the end, the child will need to learn to make appropriate choices, but a friendly reminder may occasionally be necessary.

Counselor: As stated above, when a person has been diagnosed with this disease, it is common for him or her to experience the typical stages of grief. It is important for the school counselor to be aware of this possibility and be prepared to help as needed.

Custodial Staff: For some with CD, especially those with DH, the soap available in school restrooms will need to be free of WBRO. It is best to contact the manufacturer for a list of the ingredients and their sources. If it is not possible to offer the appropriate

supplies in every school restroom, please designate one that will be “celiac friendly”, and allow access to it as needed.

Field Trip Chaperones: When a student with CD is involved in off-site events, it is important that the chaperones be informed of the special needs that may be involved.

Hall Monitor: Sometimes students are allowed to use the restroom only a certain number of times during a day, or only during certain activities. It is important to remember that if a child with celiac disease should come into physical contact with any of the offending grains, it will be necessary to remove all protein residue as quickly as possible. There also may be an urgency to use the toilet due to the possible onset of uncontrollable diarrhea. His or her instant reaction may be to “run” to a sink or toilet without asking for permission. Because of this, special restroom privileges may be needed.

Healthcare Professionals/School: Information is available for the healthcare professional working in your school. It is provided as both an informational and a reference tool so the appropriate care can be offered to the student when visits to the nurse's office are necessary.

School Secretary/Attendance Monitor: Depending on how recently a child has been diagnosed, attendance can be an issue. Although a child with CD should maintain attendance, some emergencies may occur that keep him or her out of class at times. Medical appointments with specialists and dietitians might also be necessary and will sometimes need to be held during school hours. It is also understood that the child may come into contact with WBRO during the course of the school day which possibly will cause disruptive symptoms. Feel free to contact the child's parent/guardian if you have questions or concerns in this area.

Others: Enclosed with this information is an example of a memo that can be given to all the faculty and staff of your school. It provides basic information about CD and encourages each employee to consider how his or her job may be affected by the presence of a student with this disease. Please refer to the booklet provided for the teacher to determine which staff may need more explicit instructions in this regard, i.e. art, science, or drama.

The information contained in this brochure is not intended to be all-inclusive. It is provided to help you begin to understand the importance of caution and preparation for those working with a person with CD. It is most important 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 in advance for your help and support.

*Clinical studies have shown that pure oats can be tolerated by some people with celiac disease. Pure, uncontaminated oats sources are not readily available in the United States 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:



CSA
Celiac Sprue Association®

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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