

Dear Student,

You have celiac disease or the related skin response, dermatitis herpetiformis and are learning to live with new foods and new ways of doing things at home and with your friends. It's time to make some changes at school, too, to make sure you stay healthy and safe while you're there.

At school you are part of a very important team. Your parents, teacher, principal, counselor, nurse and cafeteria staff are all concerned about you and want to help you get the most out of your time at school. However, *you* are the most important member of this team. You are the only one who completely understands the specific challenges of having celiac disease. You are the only one who can help the other team members understand your needs.

You already know you have special challenges that none of your classmates will experience. Some of those challenges include your need to use special supplies and materials in your classes. You and your family need to work with your teacher to reduce the risk of exposure to things that can make you sick. It is also important for you to learn to recognize the ingredients listed on labels that might cause problems for you. Once you understand the things you need to avoid, you will be more confident in your abilities and willingness to participate in special activities in your classroom and school.

Remember, it took time for you and your doctor to figure out that you have celiac disease. It will also take time to adjust to this new lifestyle. Here are some things that might help you through this time of change.

Grief

Certain feelings are natural when people lose something important to them, like a pet dies or a grandparent moves away. The process of working through these feelings is called "grieving". When you found out you have celiac disease, you "lost" something – your old way of doing things. Because of this, you may be going through this grieving process, too. Grieving is important and is a very normal thing for people to do after learning they have a disease. The grieving process is different for everyone, but it always involves the same five stages: denial, anger, bargaining, depression or sadness, and acceptance.

Denial

Denial is what happens when a person tries to believe or pretend that they don't really have celiac disease. "The diagnosis is just not true!" You might feel numb, or shocked. Denial is one way that your body tries to protect you when something in your life seems too overwhelming to deal with all at once.

Anger

When a person finally believes that they really do have celiac disease, they can become very angry. They wonder why this had to happen to them. One of the best ways for you to deal with your bursts of anger is to exercise or do some kind of physical activity. Talking with family and friends, other people with celiac disease, or members of the school team, may also help. You might try expressing your anger through therapeutic play, talking to other people your own age, drawing pictures of how you feel or writing in a journal.

Bargaining

In the bargaining stage, you might be asking, "Why me?" and "What did I do to deserve this?" These are very common questions. You also might try making "a deal" with yourself, or with the person or being you believe has control over things, in hopes that this will make your celiac disease go away. For instance, you might tell yourself, or them, that you promise not to do something you've done before (such as arguing with family members), or to start doing something you haven't done before (such as going to church regularly), in exchange for recovery from this disease.

You may start to think it is your fault you have CD and search for something you did that caused you to get this disease. It is important to remember that there is *nothing* that you or your family has done which gave you celiac disease. It is not anyone's fault. It just happened.

Depression or Sadness

Once a person realizes that the disease will never go away, they may become very sad. This is normal. This sadness may bring physical changes such as trouble sleeping, or sleeping too much, changes in appetite, difficulty with concentrating on simple daily activities, or feeling a constant fear that someone else in the family will be diagnosed with celiac disease. Take time to talk about your sadness with someone like your parents, doctor or school counselor, or meet with a support group to help you cope with these feelings.

Acceptance

After a while, the disease and the changes it brings will become "normal". A person in this stage accepts the new way of doing things and is able to see them as ordinary parts of life. It doesn't mean that you will never feel the other emotions again, but usually you can handle them more easily.

Give yourself permission to go through this grieving process. It will help you cope with having celiac disease and prepare you to live the rest of your life in your new "normal" mode. Remember to give your family and friends the same permission. Many things will change for them, as well. Your patience with their mistakes and misunderstandings will go a long way to helping them learn to help you. Also, humor is a great way to get through awkward situations. When people see that you are comfortable with who you are and the unique needs you have, they become more comfortable, too.

Remember – you are not alone. Many people are concerned about you and want to help. Turn to your family, friends or school team for support. If they don't have answers to your questions and concerns, work with them to find the resources you need.

You are Special

Most of all, remember that you are a very special person with talents and abilities all your own. Don't let celiac disease or anything else keep you from accomplishing your goals and following your dreams!