SPRING 2013

CenterLines

Center for Disabilities and Development *Useful News for Families*

What the heck is Celiac Disease?

Celiac (see-lee-ack) disease is a disease that damages the small intestine. It makes it hard to absorb food. About one in 133 people has it. It is one of the most common problems in children's health. It is genetic so if you or your parents have it, you and your children are likely to have it too.

People who have celiac disease can't eat gluten (glue-tin). What is that? It is a protein found in grain like wheat, rye, and barley. You can find gluten in all kinds of food, like bread, pasta, and even pizza. Some people can eat gluten and not have any trouble. But not people with celiac disease.

In your small intestine you have these tiny finger-like projections called villi (vill-eye).They are really tiny, so small you need a microscope to see them. These villi absorb nutrients from the food you eat. Celiac disease causes an autoimmune reaction. For most people, your immune system is what keeps you from getting sick. When a virus or bacteria gets in the body, the immune system attacks and stops it. Autoimmune means that your immune system attacks parts of your body instead. So, if someone with celiac disease eats bread, the body starts attacking and destroying the villi. Without villi, the body can't absorb vitamins and nutrients from food. Without enough nutrients, a kid's body has a tough time staying healthy and growing. You can even eat a lot of food and still lose weight. It can affect many parts of the body, such as the skeleton, nervous system, intestines and teeth.

Gluten is not only in food, you can find it in many everyday products like vitamins, lotion, and shampoo.

What does it feel like?

If you have celiac disease you may have diarrhea, stomach aches and gas. You may lose weight. Some people have skin rashes and mouth sores. Some have trouble with their memory. You may be moody or grouchy. Kids can show signs as early

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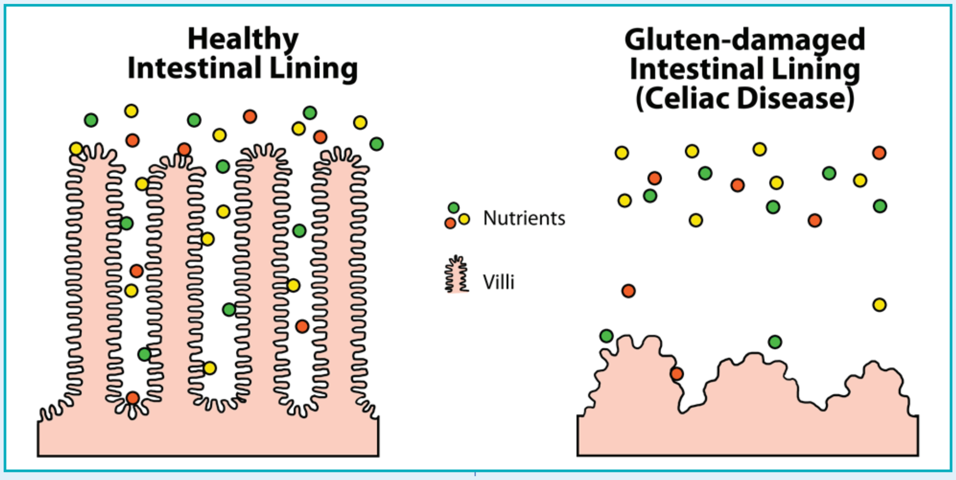

University of Iowa
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Celiac Disease

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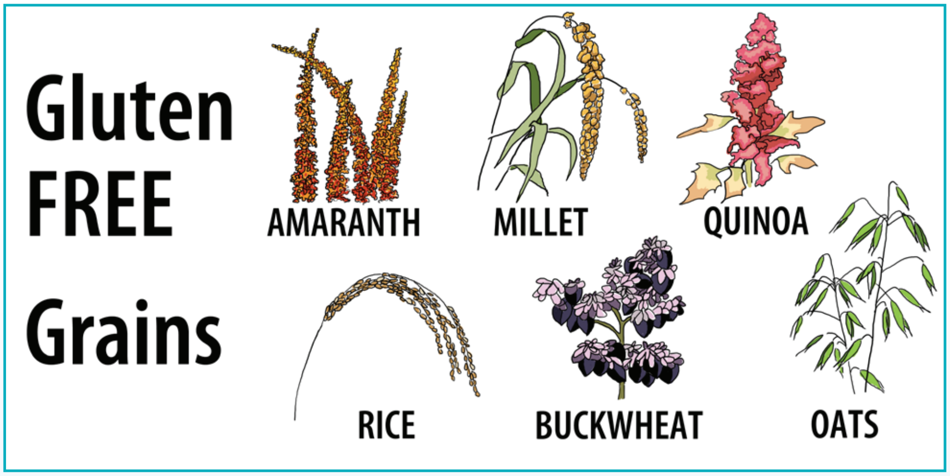
as 6 months. That's about the time they start eating food with gluten. You can have really bad symptoms and then sometimes no problems at all. It is chronic, which means you will always have it.

If you are worried about you or your child, go to your doctor and talk to him/her. The doctor will talk to you about your symptoms, do an exam, and even test your blood. To confirm it, they may do a biopsy of your small intestine to look at the villi.

Many people may have celiac disease and not even know it. However, we are learning more every day.

What if I have it?

The only real way to treat celiac disease is to change the way you eat. You can't eat food with gluten. This can be hard at first because gluten is in many foods. A dietitian can help you learn what foods have gluten and how to change your diet. They can teach you how to read labels on your food. Now you can even find special isles in the grocery store where they have gluten-free food.



Do not start a gluten-free diet or put your child on one until you talk to your doctor first.

When you stop eating food with gluten your small intestine can heal. But that doesn't mean you can start eating the old way again. For someone with celiac disease, gluten will always cause problems and the diarrhea, stomach aches, and other symptoms will return.

Support Groups

Just because you have celiac disease you don't have to give up all your favorite foods. It just means changing the way you make them so they are gluten free. A support group can help keep you with that. The group can keep you up-to-date on any new information about the disease. They are also a great place to get to know other adults or kids who have celiac disease. You learn that you are not alone. The Celiac Disease Foundation at Celiac.org has lists of local support groups.

For more information, you can go to the Celiac Disease Health Center on Web MD. The address is www.webmd.com/digestive-disorders/celiac-disease/.

You can also visit gikids.org or KidsHealth.org. At KidsHealth.org they have a section just for celiac disease. They provide the information in different ways, for kids, teens, parents, and even teachers. But always remember, your best local source is your own doctor.

Wheelchair & Seating Service

Our Wheelchair and Seating Service (WSS) has been here to serve you for more than 25 years. We have clinic appointments here in our building, but we also offer an Outreach Clinic in local communities. Our current clinics are in:

- Burlington
- Keokuk
- Marshalltown
- Newton
- Ottumwa

We always work closely with you, your family, your community providers, and your vendor. Our service is for all ages. At your visit, we will:

- ☐ Perform an evaluation led by a PT or OT who are ATP (Assistive Technology Professional) certified
- ☐ Discuss your concerns and needs for a wheelchair
- ☐ Recommend options for wheelchairs and seating
- ☐ If needed, write a letter of medical necessity for a wheelchair and seating
- ☐ Complete molding for special seating for more complex needs
- ☐ Provide education on how to use and care for your new chair

Referrals

We can take a referral from you, family, doctors, or any other service provider. All you have to do is contact us to make an appointment.

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319-356-1515 (direct)
Email: deanna-daugherty@uiowa.edu

You can also contact our Scheduling Center at:

877-686-0032 (toll free)
cdd-scheduling@uiowa.edu

Iowa Assistive Technology Professional Development Network

Hi, I'm Jim Stachowiak, the Associate Director of the Iowa Center for Assistive Technology

Special Webinars

The Iowa Assistive Technology Professional Development Network or ICATER is hosting a series of webinars on assistive technology (AT) and the assistive iPad. These webinars were developed by Jim Stachowiak, the director of ICATER. They are open to anyone and free. The webinars are archived so if you can't watch them live, you can watch them later.

The AT Webinars are one Monday a month from 11:00 am to noon on a variety of subjects. The iPad webinars are every Tuesday starting at 3:00 pm, and are about 10-15 minutes long. In these, they will go over several features of the iPad and then a number of helpful apps.

For more information or to register for upcoming webinars, go to the ICATER website at www.education.uiowa.edu/centers/icater then click on Webinars in the heading.

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New Mobile Apps Make Your Job Search Easier

The US Department of Labor's CareerOneStop website now offers five mobile web applications you can use on your smartphone, tablet computer, and other mobile device. These mobile apps can help you locate an American Job Center near you, search job listings and find local education and training programs.

Visit Disability.gov for more career planning and job search tools, as well as information about job accommodations that can help you succeed in the workplace.

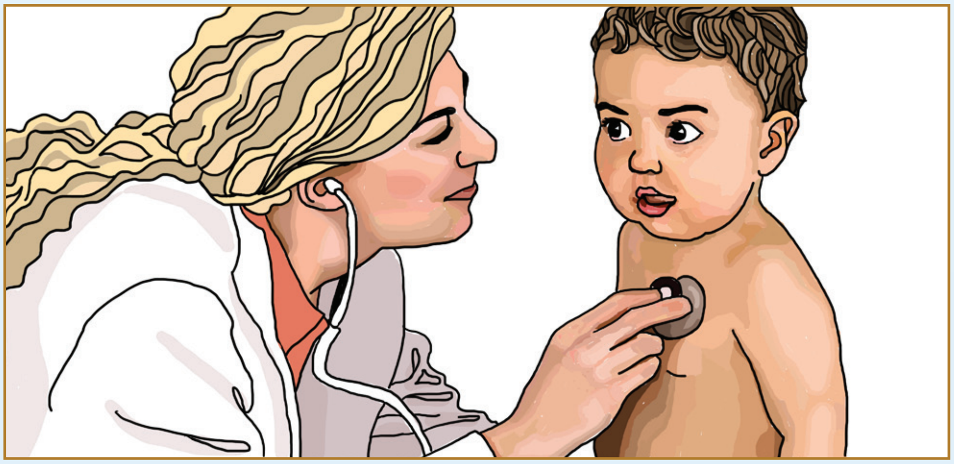
Pediatric Cardiology

Mark Olson, PA
Pediatric Cardiology, UI Children's Hospital

Heart problems can affect young children, teens, or a baby in the womb. If you are worried about your child's heart health, your doctor may have you see a "pediatric cardiologist." This is a doctor who specializes in finding and treating heart disease in infants, children and teenagers. Here at CDD, we see kids with heart issues, and we send them to the pediatric cardiologists at University of Iowa Children's Hospital, dedicated to providing the best care to children and young adults.

Pediatric Cardiology has everything needed to diagnose and treat heart problems that children are born with or problems that show up as they grow. These are called "acquired heart diseases," that develop after birth. They can be caused by infection or other disease. They can affect the heart muscle, heart valves, or coronary arteries. The doctors work with children who have abnormal heart rhythms, heart murmurs, adolescent cardiology, heart transplants, cholesterol disorders, high blood pressure in children and heart defects. We also offer special ultrasounds during pregnancy to discover heart disease before birth.

Cardiologists also work with pediatric heart surgeons. They do special ultrasounds of the heart called echocardiograms. You may have heard them called EKGs. They also work with pacemaker management, heart catheterizations, and correcting abnormal heart rhythms. For more information about our services you can go to: www.uichildrens.org/cardiology/.



Having *That Talk* with your teen who has ASD

Melissa Lehan Mackin PhD, RN
College of Nursing, The University of Iowa

Talking about sex is difficult and talking about sex with your teen with autism may be even more difficult. It's hard to have certain talks with your teens. However, being able to talk about sexuality is important for several reasons. First, teens with autism have a hard time communicating and understanding the intentions of others. This puts them at a greater risk of sexual harm. They may be targeted by others or just find themselves in a place where they do not have the skills or know how to make good choices. Talking about okay touches, how to say "No," and how to understand what might be a sexual situation may reduce the risk of harm. Second, research has shown that rates of STDs and accidental pregnancy may be higher in teens with autism. Talking to your teen about how bodies work, birth control, and safe sex could prevent health issues that can occur with sexual activity. Lastly, parents are in the best position to provide sexual education to their children. This may be truer for teens with autism. Their parents are their advocates and in a position of trust and authority. You know best about how your child reacts to challenges in social situations and communication. This will help you give the best information about sexual issues.

There are not a lot of resources specific to teens with autism. But there are some things parents can do. Start by thinking about how comfortable you are talking about sex. If you aren't comfortable, think of things that might help you make it easier. You can start by talking to a spouse or close friend. This can be a great way to start and make you feel more comfortable. It may also help you identify issues you have to overcome. This may give you the words to be able to make it useful for your teen. It might also be a good idea to know what sexual health information your child is learning at school. This gives you a starting place to understand what your child already knows. You can then reinforce what he or she learned in school and build from there. The best thing you can do is be prepared. Talking about public masturbation or learning about your child's first sexual experience may be a stressful time to start talking about sex.

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or by regular mail:

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In this issue

Centerlines for Families is published quarterly. CDD encourages subscribers to read partner newsletters ***Iowa COMPASS News*** and ***Possibilities in Education and Training***. You can find them all by going to our website at **www.uichildrens.org/cdd** and then clicking on the link for newsletters on the right.

CenterLines for Families, the newsletter of the Center for Disabilities and Development at the University of Iowa Children's Hospital, is published four times a year. It provides families with current information on child and adult development, issues affecting people with disabilities, and CDD resources available to them and their families. The newsletter is available in print, in Spanish, and also online at www.uichildrens.org/cdd. Click on Centerlines for Families.

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