

TOPICS IN LIVING WITH TYPE 1 DIABETES

Celiac Disease & Type 1 Diabetes

If I had known about celiac, I might have connected the dots sooner,” says JDRF volunteer Renee Burnett, whose 21-year-old daughter—diagnosed with type 1 diabetes at age 9—was diagnosed two years ago with celiac disease after years of unnecessarily suffering from stomachaches, anemia, fatigue, and depression.

A medical disorder once thought to be rare is now being called one of the most underdiagnosed common diseases in the U.S. today. About 1 in 10 people with type 1 diabetes in the U. S. are affected by celiac disease—compared with an estimated 1 in 100 in the general population. The incidence of celiac among people—particularly children—with type 1 diabetes has led an increasing number of healthcare professionals and parents to call for routine screening of all people with type 1 to look for the presence of celiac. What is celiac disease, and what should you, as parents of children with diabetes, know about it?

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ASK A MEDICAL PROFESSIONAL

New Diabetes and School

The new diagnosis of type 1 diabetes in a child is a life-altering experience that creates many new stresses for the family. High on the list is how to deal with school. Arranging proper care in the school environment is a critical step. Columbia University pediatric endocrinologist Barney Softness, MD, covers critical concerns, including: Maintaining metabolic control to maximize your child’s learning experience, identifying individuals to supervise your child’s diabetes management needs, and developing a care plan with school personnel.

[READ A DOCTOR’S ADVICE ON DIABETES AND SCHOOL.](#)

ASK A PARENT

Help from JDRF's Volunteer Families

Q: My teenage daughter has gone through periods when she has been defiant, in denial, and noncompliant. Recently she has done much better with regular blood sugar checks and taking insulin, but she still resists eating appropriately. She does well at diabetes camp in the summer, but she struggles the rest of the year. We need some help.

A: *from a 21-year-old college senior and JDRF Online Diabetes Support Team volunteer with type 1 diabetes:*

It isn’t uncommon for teens to feel diabetes is very demanding. It’s when kids start taking “complete” control over managing their diabetes and it can be a lot to handle. It seems you’re trying your hardest to take care of your daughter and you really deserve a pat on the back for that—she is lucky to have a supportive family. Make sure you remind yourself of that when you are feeling stressed out too.

Being a teenager can be tough enough, and then to have to add meal planning, insulin and finger sticks on top of it all can sometimes just be chaotic and stressful! In my senior year of high school, I did not want to be bothered with counting every piece of food I put in my mouth. My friends at school didn’t have to read nutrition labels at the lunch table for carbohydrate counts, why should I? I wanted just *one* day off.

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dLife Network Premieres

A new integrated media network dedicated to diabetes was recently launched. Focused on people living with diabetes, their families and caregivers, and those at risk for the disease, the network includes a weekly television show featuring celebrity hosts and correspondents, a website, a radio program, and a direct mail newsletter. “We believe that dLife will help reduce the isolation and silent suffering of millions of people living with diabetes and their caregivers,” says Howard Steinberg, CEO of LifeMed Marketing, the network’s parent company, who himself has type 1 diabetes. dLife TV will air Sunday evenings at 7 p.m. EST on CNBC.

FOR KIDS AND FAMILIES

JDRF Kids Online is designed with help from medical professionals and kids who have type 1 diabetes. Sections include [Role Models](#), currently featuring cross-country ski champion Kris Freeman, and [Have Your Say](#), where you can do just that—and find out what other kids have to say.

WHAT A JDRF CHAPTER CAN DO FOR YOU

JDRF Chapters are places to go for one-on-one support, family networking, support groups, and useful tools like the Bag of Hope and Teen Pak. View what [one JDRF Chapter](#) offers newly diagnosed families and [find a JDRF chapter](#) in your area.

CELIAC DISEASE & TYPE 1 DIABETES, *continued from page 1*

What is celiac disease?

Like type 1 diabetes, celiac is an autoimmune disease. In celiac, the immune system reacts to gluten proteins found in wheat, rye, and barley, triggering inflammation in the small intestine and an attack on the villi, the tiny hair-like projections that absorb nutrients from foods. If untreated, the small intestine cannot absorb food and nutrients, leading to serious health consequences that can include neurological disorders, vitamin deficiencies, malnutrition, osteoporosis, and cancer.

Symptoms may be silent

Complicating and often delaying the diagnosis of celiac disease, its symptoms vary greatly. In children, these may include frequent stomachaches and other gastrointestinal problems that do not resolve, general malaise, muscle cramps, fatigue, anemia, weight loss, and weakness. The condition may even cause depression or irritability, and failure to grow and thrive. Making diagnosis all the more difficult, as many as one-half of those diagnosed with celiac show no symptoms at all, as was the case with 6-year-old Cassie Maxwell, daughter of JDRF volunteers Red and Marinda Maxwell.

Cassie had lived with diabetes for more than five years and was completely asymptomatic until tests confirmed she had celiac disease. “It was a routine test in our pediatric endocrinologist’s office, when a biopsy confirmed that she did in fact have yet another autoimmune disease,” says Marinda.

Celiac disease is now considered to resemble a multi-system disorder rather than a mainly gastrointestinal one. “The majority of people with the disease remain undiagnosed, because celiac masquerades as many different medical problems, or presents without overt symptoms,” says Peter H.R. Green, M.D., professor of clinical medicine at Columbia University Medical Center and director of the Celiac Disease Center.

Blood sugar control: the celiac connection

Getting tested for celiac is important to people with type 1 diabetes especially because celiac’s symptoms can be confused with problems caused by unstable blood sugar levels. At age 11, about a year after Katelyn Miller was diagnosed with type 1, she began to have frequent headaches and stomachaches, which were attributed to her unstable blood glucose levels. “When she developed a rash, it was one again thought to be caused by her wide swings in blood sugar levels. Looking back, if they had just screened her blood for celiac they could have prevented the unnecessarily difficult period we all went through,” says Katelyn’s mother, Karen. After Katelyn’s diagnosis, because celiac is genetically-based and can run

in families, the whole family was screened for celiac, and none of them had the disease.

JDRF volunteer Renee Bennett requested a celiac test for her daughter Melissa when she was 19, ten years after her type 1 diagnosis, because she had heard of other children with diabetes testing positive. “I had absolutely no idea that depression, irritability, anemia, fatigue, and the stomachaches that plagued Melissa for years weren’t just blood sugar-related,” says Renee. “If I had known about celiac, I might have connected the dots sooner. Instead, we treated each of Melissa’s symptoms as yet another side effect of diabetes.”

Routine screening becoming the norm

Dr. Green’s research shows that it takes an average of 11 years before celiac is correctly diagnosed, often only after serious damage is done. That is why many endocrinologists and diabetes treatment centers have begun to routinely screen their type 1 patients for celiac every one or two years. According to Dr. Green, there are two peak times of celiac disease onset, one in childhood from around 3 to 5 years of age and one in adulthood during the 30s and 40s.

How is celiac treated?

The “good” news about celiac is that although there is no complete cure, it can be successfully treated and controlled without need for injections, blood checks, and record-keeping as in type 1 diabetes—only a change in diet that completely removes gluten from the diet. While acknowledging the extra burden put on children already coping with diabetes, experts and families report that improvements in quality of life occur almost immediately.

After eating gluten-free for only one week, Melissa had no stomachaches, and felt less fatigued and emotionally steadier. “Today, Melissa is following the gluten-free diet as a college student in New York City, not an easy task,” she adds, “but the continuing improvement in all her symptoms is rewarding compensation. Life is still a banquet, but today’s banquet features foods like rice, potatoes, fruits, vegetables, meats, and salads, instead of a pizza, wrap, or pretzel on the way to class. Life is not only easier for Melissa, it’s also a lot healthier.”

NEW DIABETES AND SCHOOL, *continued from page 1*

By Barney Softness, M.D.

Dr. Softness is a board-certified pediatric endocrinologist with a special interest in diabetes. As an assistant clinical professor of pediatric endocrinology at Columbia University’s College of Physicians & Surgeons, he treats children with all types of diabetes. He is currently involved in clinical trials focused on reducing diabetes

in children genetically at risk, looking at the risk of siblings with diabetes, and demonstrating the safety of insulin pumps in young children. He is also participating in an oral health project with Columbia University's Dental School, investigating periodontal disease in children with diabetes.

A new diagnosis of type 1 diabetes in a child is a life-altering experience that creates many new stresses for the family, ranging from learning to inject or pump insulin to counting carbohydrates and calculating insulin doses. Once these basics have been learned, you'll need to confront a number of other complex challenges. High on the list are finding qualified babysitters, and most importantly, arranging proper care in the school environment:

Since abnormalities in blood sugar may affect your child's attention or behavior, it is vitally important that he maintain metabolic control as close to normal as possible. At the least, fluctuations in blood sugar can cause disruptions in classroom participation: High blood sugars can cause frequent urination, and low blood sugars require a snack and frequent testing. How will the school deal with these everyday medical situations?

If you are like most parents, it will be necessary for you to substantially increase communication with your child's school. Educating school personnel about diabetes and your child's individual needs is the first important step. All children with type 1 diabetes are protected by a federal statute called Section 504 of the Rehabilitation Act of 1973, and you are entitled to arrange for specific services for your child through written agreements known as a Section 504 plan or an Individualized Education Program (IEP). Topics that a written plan might include:

- **Full-time nursing supervision in the school**
- **Eating whenever and wherever necessary**
- **Going to the bathroom or drinking water as needed**
- **Participating fully in all extra-curricular activities, including field trips**
- **Eating lunch at an appropriate time**
- **Absences related to medical visits**
- **Schedule of blood glucose monitoring and insulin injections, with personnel properly trained in the technique, as well as particular doses**
- **Phone numbers of emergency contacts**

Your next job is to identify personnel in the school who will be responsible for your child's care and develop a positive relationship with them right from the start. In effect, you must become your child's advocate, making sure that teachers and other personnel understand and meet your child's needs. In most cases, you

should first meet with the school nurse and perhaps the principal to identify your child's individual needs, discuss components of your care plan, and develop an agenda for a larger meeting later, involving a wider range of school personnel, who may include, in addition to the family and nurse, the current classroom teacher(s), past teacher(s), the food service manager, the physical education teacher, the counselor or social worker, bus drivers, and any other staff with direct responsibility for the child. Members of the child's health team may also be invited. The agenda should cover an overview of diabetes and its management, identification and hierarchy of staff expected to respond in emergency situations, and the individual components of your plan, whether a "504" or your version of one. This is also an opportunity to be sure that the appropriate staff members know the location of food kits, glucagon and other supplies. Normally, the nurse trains the staff, but on occasion, the child's health care team, for instance if there is a new insulin pump, may come in to train. I recommend a meeting at least once year, preferably in the spring to map out plans before the start of the new school year.

Finally, remember to maintain open communication with the school, especially if your child's needs or doses change. Most schools try hard to be accommodating to students with diabetes, and there is every reason to believe that with some careful planning your child will have a fulfilling educational experience.

Read more about the [rights of children with diabetes in school.](#)

ASK A PARENT

Help from JDRF's Volunteer Families, *continued from page 1*

How did I get back on track? First of all, I thought about it. I saw I was putting myself at risk for developing long-term complications. I also talked with my endocrinologist. I also realized that I should be lucky to have *just* diabetes since there are so many other things that are worse. The support of my family and friends was great too.

As for "eating appropriately," a lot has changed since I was diagnosed. When I was younger I had a set amount of carbs to eat at each meal, whether I was hungry or not. I never ate anything that wasn't sugar free.

As I got older, carbohydrate counting was introduced, along with sliding scales of insulin that depended upon how many grams of carbohydrate person ate. So I now can eat the same things as my friends, provided that I am responsible and read nutrition labels.

Has your daughter talked with a dietician? Perhaps seeing one would help her to make healthy and responsible choices.