

4 Steps to Help Kids With Diabetes at School

By Lindsey Wahowiak
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It may be summer now, but the crisp fall days of a new school year are fast approaching. While children across the country are picking up new Transformers backpacks and SpongeBob SquarePants lunch boxes, the families of kids with diabetes have a longer list of supplies to gather and tasks to complete. Whether children are recently diagnosed or already pros at managing diabetes at school, they may need help getting back into the swing of things as school nears. Parents and administrators need to be aware of the school's legal responsibilities in caring for students with diabetes (box, p. 45), but it's important to prepare the child, too.

Planning for your child's diabetes management at school may seem at first like a big job, or even a little scary, but there's plenty of advice and help available. The American Diabetes Association's **Safe at School program** provides information for parents of kids at all stages of their education. ADA books and **message boards** can also be a valuable resource. And other parents who have "been there, done that" have experience to share, for the newly diagnosed child or for one who is entering a new school or a new stage, like adolescence. We've gathered tips from them and other diabetes experts to come up with this four-step back-to-school game plan.

Doing Your Homework

Parents can help teachers and administrators prepare for children's care

School hasn't started yet, but that doesn't mean that parents don't have homework to do. Crystal Jackson, associate director of legal advocacy with the American Diabetes Association (and mother of a teenage daughter with type 1 diabetes), offers these suggestions for starting the year off on the right foot.

Learn about your legal protections. Federal and many state laws protect students with diabetes and their families against discrimination and set out the legal responsibilities of the school. To learn about these laws as well as available training resources and tips for resolving challenges in school, see diabetes.org/schooldiscrimination.

Make sure you have a Diabetes Medical Management Plan (DMMP). This plan, developed by your child's health care team, provides essential information on how school personnel should care for your child. It also explains what your child can do independently and when he or she requires more help from a trained adult. For a sample DMMP, visit diabetes.org/assets/pdfs/schools/dmmp-form.pdf.

Put together a draft Section 504 Plan or Individualized Education Program (IEP). While the DMMP specifically addresses how a child's diabetes is managed, a 504 Plan or IEP is designed to ensure that children with diabetes won't be discriminated against and that they'll have the same opportunities and education as children without diabetes, in accordance with federal law. You can see a sample 504 Plan at diabetes.org/504plan.

Meet with school staff to discuss the DMMP and come to agreement on the Section 504 Plan or IEP. These documents must specify who will provide diabetes care for your child. They ensure there is always someone available who has been trained to provide routine care for children who need help with tasks such as checking blood glucose and administering insulin, as well as emergency care for all children, such as administering glucagon. "It is also important that the plans spell out your child's level of self-management, required level of assistance from trained school staff, and accessibility to medication, supplies, and equipment," Jackson says.

The ADA's Safe at School campaign can help parents and school personnel make sure students with diabetes are treated fairly and get the care they need. In addition to outlining effective school-based diabetes management, the campaign also provides support for families who may have communications or compliance issues with their schools. For more information, visit diabetes.org/safeatschool or contact your local ADA office; you can find the office nearest you at diabetes.org/zip.

Step 1. Help Your Kids Get Involved

The best way to prepare your child to go back to school, experts say, is to include him or her in the planning process. As kids grow older, they should take increasing responsibility for handling their diabetes as they feel comfortable doing so. Parents should be open with their children so that families can problem-solve together, says Jill Weissberg-Benchell, PhD, CDE, a pediatric psychologist and diabetes educator who specializes in working with children with chronic illnesses. Families should discuss back-to-school plans well before the academic year begins. "If the parents sit down with the child and say, 'What are your thoughts about this?' . . . I think that's really helpful," she says.

Brandon Schmidt, 15, of Jacksonville, N.C., was diagnosed with **type 1** at 12 months old, so his entire school career has included diabetes care and explaining the disease to classmates and teachers. It can be tough at times, he says. "They'll make fun of me over something stupid, like my meter. Some people said, 'That's the goofiest-looking cell phone ever.' I've tried [to explain], but sometimes they just don't listen." It helped a lot when, in sixth grade, he met another student with type 1. They were friends through middle school and will enter high school together as ninth graders this year. "He understands what it's like to deal with life with diabetes," Brandon says.



Joyce and Alexis Boudoin

Joyce Boudoin of Apopka, Fla., involves her 8-year-old daughter, Alexis, in just about every aspect of back-to-school preparation. Boudoin says she tries to find age-appropriate ways for Alexis to take some control of her diabetes care, such as picking her pump site, and Alexis sits in on her parents' meetings with teachers and school administrators. And when Tracy Milligan's 9-year-old son, Jared, starts fourth grade this year in Jacksonville, Fla., he'll also begin the next phase of taking responsibility for his diabetes management: He is learning to count carbs. "He's . . . beginning to understand the numbers and what needs to be done according to the numbers," Milligan says. "While it is great, we haven't relinquished that [task] all together, of course. He takes his lunch to school every day, and I include the carb count in his lunch box for him."

Marilyn Clougherty, the diabetes program coordinator at Children's Hospital of Pittsburgh of UPMC, says the children who take an active role in their care tend to do best in managing their diabetes. "All kids mature differently, but I think it is difficult for kids whose parents have always spoken for them," she says.

At the same time, managing diabetes can be tiring for a child (as it is for an adult, too). Parents who stay involved have a greater chance of making sure their children succeed, Clougherty says, even with high school students. Weissberg-Benchell notes that a child's self-care can ebb and flow throughout adolescence, and kids should not feel punished or as if they've let their parents or health care providers down if they need to relinquish some responsibilities. "The most important thing is to listen to your child," she says. "It's just as important to give them permission to say to you, 'I don't want to do this anymore. I want to give this back to you.' Because it's really hard."

That said, it's worth remembering that even the most independent kid needs to have at least

one adult at school who understands his or her diabetes management and can be called on in an emergency.

Step 2. Assemble the Team

Preparations for diabetes care at school should start well before the first bell chimes. "It is very important to make sure that you are prepared to discuss the diabetes management plan for the impending school year at your child's visit with the physician and/or clinic," says Linda Siminerio, RN, PhD, CDE, executive director of the University of Pittsburgh Diabetes Institute and chair of ADA's Safe at School task force. "It is a good idea to come ready with ideas and questions to talk about with the diabetes team." For example, you should review your child's blood glucose target ranges and make a plan for when the school staff needs to take action or calls to alert you. You may want to chat with the dietitian about healthy snacks or the best treatments for low blood glucose. Or you might talk to the nurse educator about whether your child is ready to be unsupervised when giving pump boluses. If you come prepared with all of the questions you want to ask (preferably written down), you're less likely to forget something.

Clougherty says it's also key to get in touch with teachers, administrators, and nurses as soon as you know where your child will be going to school. Paperwork and the management plan should be filed several weeks in advance of the first day of class, and the adults who will be taking care of your child should feel prepared to fulfill that duty. "It's really important that everyone knows what to expect from each other," she says. "That's something you can't do on Day 1 of school." (For more information about what schools are legally required to do for kids with diabetes, click [here](#).)

If your school doesn't announce which teacher your student will have until a few weeks before classes start, you still have some options. Tracy Milligan works with the principal of her son's school to try to get the name of Jared's teacher as early as possible, so she can send the teacher a letter or e-mail to set up a meeting before the school year begins. She also talks with the school nurse to make sure school staff members have been trained to handle any diabetes care, including emergencies. She says some teachers have volunteered for extra training, so they can supervise Jared while he administers his insulin.

By law, schools are responsible for making sure there is always either a school nurse or another trained staff member available to provide routine care for students who cannot yet manage their diabetes on their own and emergency care for any child with diabetes. Encouraging others to get involved in your child's care can be nerve-wracking, Milligan says. However, the better informed school nurses, teachers, administrators, and coaches are, the better off your child will be. "It's very scary as a parent to really push control to other people for your child's health and well-being," she says. "However, as long as they're trained, then your child will be safe, and as long as you keep the line of communication open, then your child will be in safe hands."

Opening those lines early may even help you find surprising allies. When searching for caregivers for her son, Casey Horrell of Conway, Ark., made sure to discuss diabetes with potential providers—and found one who had **type 2** herself. That familiarity with the disease helped Horrell and her son Tracey, now 6 years old, feel more comfortable.





Lauren and Monica Lanning

It's important, too, to make sure that those who are caring for your child with diabetes are at ease doing so. Lauren Lanning of Highlands Ranch, Colo., has worked with teachers, nurses, and administrators throughout the schooling of her 17-year-old daughter, Monica, and she says gauging their comfort level is key. "If someone isn't comfortable, like . . . watching your child do a blood test, see if there's someone [else] who can come down and watch," she says. "Don't put someone in an uncomfortable place, because it doesn't turn out too well." And that includes your kid: While children should be allowed to self-manage to the extent they are able, they certainly should not be pushed to do so when they cannot.

Setting up diabetes care plans, meeting with teachers and administrators, and putting the right tools in place before classes begin are important steps. But they are only the first steps. Managing diabetes is a round-the-clock job, day in and day out, so it's critical to keep in touch with the school throughout the year. Back-and-forth communication helps both family and school meet a child's needs.

Step 3. Put Tools in Place

Your child's diabetes care team at school should be prepared by the time your child sets foot in the halls. That means a Diabetes Medical Management Plan, a Section 504 Plan, and other paperwork (box, p. 45) should ideally be filed already with the school, or the process to develop care plans should be well under way.

Parents can safeguard their children in small, practical ways, too. Wearing a medical alert bracelet can be a great help in emergency situations. Packages of glucose tabs or appropriate snacks to treat lows should be placed in your child's classrooms and the school office. Milligan puts juice boxes, Smarties, and simple instructions for dealing with highs and lows into large plastic zip-top bags and delivers them to all her son's teachers. Jared also carries a bag of supplies with him at all times.

While many children do just fine with insulin injections, Boudoin has found that her daughter's **insulin pump** has helped Alexis maintain better blood glucose control and made her more independent. At 8 years old, she can now deliver mealtime boluses and explain some aspects of diabetes to adults and students alike. Boudoin, who has received advanced school advocacy training from the ADA, came to class in kindergarten and first grade to read *Rufus Comes Home: Rufus, the Bear With Diabetes* to her daughter's classmates, and then Alexis showed how her

pump worked. The visits helped the other children understand diabetes. "Her peers in the class ended up watching the clock and saying, 'Lexi, it's time for your snack.' They knew, and it wasn't a big deal," Boudoin says.

Brandon's mother, Brandy Schmidt, says her son's pump helped ease her mind and gave him more independence. "There really is a fine line that you have to walk when you have a teenager. As a parent, you want to be protective and know every single aspect of his diabetes care, but if he's not with you, you can't." Schmidt says Brandon tests his blood glucose, but his parents download information from his meter to check on how he's doing.

Step 4. Be Your Own Advocate—and Teach Your Kid to Be One, Too

The greatest tool children can have when it comes to managing diabetes is being able to speak up for themselves, at school and later in life, says Crystal Jackson, the ADA's associate director of legal advocacy. While it's important that teachers, coaches, school administrators, and friends can read the warning signs of a high or low (and staff members be trained to respond), she notes that even young children can and should learn to recognize these signs in themselves and alert others when necessary. Hayden Desborough, 12, of Thousand Oaks, Calif., says that sometimes it's frustrating to have to explain diabetes to people, but that it's not difficult to do. Children with diabetes "can sometimes be annoying—that's when we're low. They can also be normal. They're normal kids, they just have an exception," he says. "If [friends or teachers] do ask . . . just say, 'I have the disease, it's called diabetes, and it's where one of my organs doesn't work.' "

Older children, especially those in high school, can start taking on responsibilities of implementing 504 Plans—as well as carrying a cell phone to report highs and lows to their diabetes care team, as Monica Lanning does—but younger children can be involved, too. Joyce Boudoin asks daughter Alexis to describe how she feels both when she is high and low. She also encourages her to speak up when an adult provides care that doesn't meet her 504 Plan's requirements, such as telling her not to eat something. "We tell her, 'You live with diabetes, and you actually know more than a person who doesn't deal with it every day.' It's OK to respectfully say, 'That's not the steps you should take,'" Boudoin says.

The same holds true when schools don't abide by laws designed to protect students with diabetes by forcing them to test blood glucose or administer insulin outside of the classroom, or keeping students from class parties or field trips because of their diabetes. Lanning says she wishes someone had told her it was appropriate to educate school officials and insist that they comply with the law; sometimes, she says, they simply don't know what the law entails. The ADA's Safe at School campaign provides materials parents can use to educate schools about these laws and to form a good working relationship with teachers, administrators, and other staff members.

Lanning has advocated not only for her own daughter but also for another child with type 1 diabetes, who was left out of a school field trip because her mother wasn't able to chaperone. It's illegal for a school to exclude a child with diabetes from activities based on a parent's ability to attend. "I felt so bad for her," Lanning remembers. "I had to educate them all about how they need to make accommodations. I had to talk to her mom and let her know about it. Our kids can't be denied the same education all the other kids are getting."

As parents get supplies ready and prepare schools for their children's return to classes, the most important back-to-school task is talking with your children. Chances are they'll tell you what they're ready to take on by themselves—and what they'll need your help with. Schooling both kids and adults now about proper diabetes care can make the rest of the coming school year smooth sailing.

American Diabetes Association, 1701 N. Beauregard St., Alexandria, VA 22311

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