

The Day-Care Dilemma

Know your rights
and how to
fight child-care
discrimination

BY TRACEY NEITHERCOTT



Child-care issues for kids with diabetes can be complex and confusing, but worry not. *Diabetes Forecast* has grilled experts about your child's rights, how to fight discrimination, and ways to ensure your kid stays safe.

Your Child's Rights

Despite what a day-care facility may tell you, your child cannot be turned away simply because of diabetes. "There's no right to attend day care," says Ed Kraus, professor of law at Illinois Institute of Technology Chicago-Kent College of Law and supervisor of the Center for Diabetes Research and Policy there. "But what there is for kids with disabilities is a right to not be discriminated against." And under the Americans with Disabilities Act, refusing a child's acceptance into a day-care facility or after-school program counts as discrimination. (Religious institutions, however, are not covered under the law unless they receive federal funds. Neither are private nannies or babysitters.)

Acceptance, however, isn't the major issue most parents face. Getting child-care workers to help manage your child's diabetes is a tougher task. While Section 504 of the Rehabilitation Act of 1973 requires publicly funded schools to provide the assistance kids with diabetes need to manage their disease, the provision often doesn't apply to child-care facilities. (The



Head Start program and after-school programs held on school grounds, though, are subject to Section 504.)

Most day cares and aftercare programs are privately run, but they still have legal obligations to provide diabetes care. However, “if your kid needs insulin during the day, [a day care] might not be legally required to hire nurses or train a layperson,” says Kraus. “If a day care shows it’s an undue burden, it’s not discrimination.”

So what’s an undue burden? Well, it’s a legal term up for interpretation, but child-care facilities could use it as a reason not to provide diabetes care. For instance, a day care may say it is too understaffed to inject a kid’s insulin.

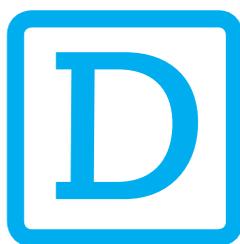
Things get tricky when the undue burden is based on state laws that maintain only nurses can provide medical care. Under those laws, a day care would have to hire a nurse to care for your child’s diabetes—which may not be financially feasible.

“[Educating day-care facilities] is especially important where there are state laws or people think there are state laws that say, ‘You can’t do this as a program that doesn’t staff nurses,’” says Larisa Cummings, an attorney with the Disability Rights Education and Defense Fund. The good news is that the federal Americans with Disabilities Act trumps state laws. “There really is no state law that can stand in the way of federal law,” says Cummings. “The Department of Justice agrees with us.”

Little Kids, Big Worries

Decisions on whether staff members perform children’s diabetes management tasks vary on a case-by-case basis. Smaller day cares with few employees may say they don’t have enough workers to thoroughly care for a child with diabetes, while larger centers are more likely to have policies on giving medication. How long a child will be at the center, as well as the child’s age, may also play a role in the day care’s decision.

Many kids in day care are too young to do even the simplest of diabetes-care tasks. “We’re dealing with a group of children who are 100 percent dependent on the adults around them,” says pediatric



Day-care centers may be wary about caring for such young children with diabetes, and the fear of harming the child can motivate them to refuse care.



● When you step out as a Red Strider, you get cool swag, such as this baseball cap. You also meet other people with diabetes, just like you! diabetes.org/stepout

endocrinologist Larry Deeb, MD, a clinical professor at Florida State University, past president of the American Diabetes Association, and cochair of the Association’s Safe at School® working group. “The child is perhaps incapable of saying how he or she feels. A 7-year-old might come to you and say, ‘I’m low.’ A 3-year-old might get tired.” Caregivers need to recognize the signs of hypoglycemia (lows) and hyperglycemia (highs) and know how to treat accordingly.

Day-care centers may be wary about caring for such young children with diabetes, and the fear of harming the child can motivate them to refuse care. “It’s a big job for a day care to take on,” Deeb says. “It’s a big job for a parent to take on.”

But parents with newly diagnosed infants and children manage, and with the proper training, day-care workers can, too. “There’s nothing that difficult in diabetes [management] that can’t be taught,” says Marilyn Clougherty, RN, MSN, CDE, coordinator of the Children’s Hospital of Pittsburgh’s diabetes program.

Care That Needs Covering

For kids with diabetes, staying safe during the day or even for a few hours after school comes down to diabetes management. As soon as your child is accepted by a center or program, schedule a chat with staff to discuss which diabetes-care practices caregivers will need to follow.

At least one person at the day care or after-school program should be prepared to check your child’s blood glucose. The caregiver must be able to recognize and treat the symptoms of high and low blood glucose. Most often that includes giving kids fast-acting glucose to treat a low and keeping watch on their glucose levels. But any place you leave your child should be willing to provide emergency care, such as giving glucagon.

It’s important for parents to iron out the details of emergency care early on. Day-care providers may resist giving glucagon, so parents may have to fight a little harder to educate and negotiate emergency care for their child. If you’re adamant about your

child receiving a glucagon injection for a severe low blood sugar causing seizure or loss of consciousness and the program refuses, it may be time to seek an alternative child-care solution.

While some children may not need staff to administer insulin—such as those who will be in day care for only a couple of hours or kids in an after-school program—most parents look for child-care programs that agree to count carbs and inject insulin. Even children at a center for just an hour or two may need insulin if snacks or meals are served.

How to Fight

If a day care or after-school program refuses to accept your child, you have two options: Search for another center or fight back. Parents who plan ahead will have the best outcomes. “Go in knowing what your rights are, and don’t take no for an answer,” says Katie Hathaway, managing director for legal advocacy at the American Diabetes Association. Because refusing to accept a child based on diabetes alone is considered discrimination under the Americans with Disabilities Act, you should have a strong position in fighting for your child’s place at day care.

If a center still refuses your child, there are legal actions you can take. And you don’t have to go at it alone. “It’s important for parents who are running into these obstacles to reach out and get assistance as soon as possible,” says Cummings. Your best bet is to contact the American Diabetes Association, which can answer questions and put you in touch with an expert in your area for guidance.

You may be advised to file a complaint with the Department of Justice. “It can take a while, but there are so many good outcomes,” Cummings says.

Fighting back is a little trickier when it comes to child-care programs that accept kids with diabetes but won’t tend to children’s basic diabetes-care needs. If that’s the case, your first action should be talking with the staff or administration to see if adjustments can be made. “They

BATTLING

THE MILITARY

Katina Mein fights child-care discrimination on military bases

When Katina Mein’s son, Steven, was diagnosed with diabetes last year, he’d been attending preschool since he was 2 years old. The family moved to the military base where Mein’s husband worked, planning to send Steven to the on-base preschool. But that’s not what happened.

In Hawaii, where the Meins lived at the time, preschool is considered child care and therefore doesn’t fall under the state’s Department of Education umbrella. So unlike state-funded elementary schools and beyond, Hawaiian preschools aren’t necessarily required to care for the needs of students with diabetes. When Mein broached the topic with administrators at her son’s preschool, she was shocked at their reaction. “We left that meeting very upset, heartbroken,” she says. “Every brainstorming thing we put out there was met with rolling eyes, met with sighs.”

The on-base preschool wouldn’t budge. Administrators refused care even though the preschool staff was large and included two nurses shared with two other child-care centers. Financing staff education wasn’t an obstacle either because the Meins’ diabetes educator offered to teach staff for free.

Frustrated with the center’s refusal of care, Mein submitted a complaint that was discussed by an Army subcommittee, and she attended with an American Diabetes Association representative in tow. The committee’s finding: Insulin is too dangerous a drug for preschool employees to administer. That, plus the training involved in teaching staff diabetes management, wouldn’t be realistic, it decided. “If we could learn to take care of our child in two days, why couldn’t they?” Mein asks.

For a year, Mein has been fighting the system and pushing for her son, now 4, to return to preschool. Eventually, her husband reconsidered his military career. “This was sort of an eye-opener for us,” Mein says. “The Army talks about taking care of their families, and we saw that isn’t the case.” Mein’s husband is in the process of leaving the military, and in the meantime she has recently moved with her son and baby daughter to Texas, where the family hopes to have better luck with child care and education.

Though Steven was learning with 4- and 5-year-olds by age 3, he hasn’t been to school in a year. To make sure her son’s education doesn’t get tied up in military red tape, Mein has hired a tutor.

As for her complaint, Mein asked to be updated as it progresses through various military channels but hasn’t heard anything yet. That doesn’t mean she’s giving up. “I’m still pursuing it,” she says. “I never want another parent to have to sit through that assessment meeting and feel so belittled and so helpless. I never want another child to have to sit through that and hear what he or she can’t do.”

need to see if they can modify their practices,” says Hathaway.

If that fails, you can file a complaint with the Department of Justice (for details, go to [justice.gov/crt/complaint](https://www.justice.gov/crt/complaint)), and there’s a good chance you’ll get a ruling in your favor.

“Based on what we’ve seen in other cases, it’s likely the Department of Justice will require most child-care centers to provide needed diabetes care,” says Hathaway.

Depending on your situation, an American Diabetes Association representative might recommend you hire a lawyer. Is getting an attorney involved worth it? If you’re fighting a larger company, the answer may be yes. “When you have those bigger entities, you can use the law,” says Kraus. “You can argue, ‘Come on, all you’re asked to do is check glucose.’”

Of course, sometimes all it takes for a day care to comply is a sit-down meeting during which you educate staffers about diabetes. “There’s still a lot of misunderstanding,” says Sarah Blenner, director of the Chicago-Kent law school’s Center for Diabetes Research and Policy. “There’s still a real need to understand what a child may need.”

By explaining exactly what goes into caring for a child with diabetes, you can put child-care administrators’ fears to rest—and reassure them that diabetes management isn’t such a daunting task.



In need of a good day care? Ask other parents of children with diabetes for referrals.

“If you’re willing to approach it in the right way, there are a lot of day cares across the country that will care for young kids with diabetes,” Blenner says.

The Parents’ Role

Once a day care or aftercare program agrees to be responsible for your child’s diabetes, be prepared to help find someone to educate the staff or do it yourself. “It’s not a ‘drop the kid off and see you in three hours’ situation,” says Blenner. “Parents have to help the day care navigate through.” Focus on four major areas:

TREATMENT PLAN: Start with your child’s endocrinologist. He or she should be able to give you a treatment plan the day care can follow. A Diabetes Medical Management Plan, which details all elements of diabetes care a child needs, can be useful for child-care staff. (Find an example at diabetes.org/childcare.)

Staff unfamiliar with diabetes may need diabetes education, and it’s the parent’s job to help provide it. “Pediatric centers may be able to provide education for day-care or aftercare places,” says Clougherty. Sometimes diabetes educators will teach a child-care facility for free, but often there’s a cost involved. “A lot of times, parents pay that cost. Sometimes the aftercare places do.”

Another alternative is to bring the caregiver responsible for your child’s diabetes management to your diabetes center or practitioner’s office for a free diabetes education class. Or parents can educate the staff, which is what happens in many cases.

SUPPLIES: Providing the day care with the necessary diabetes supplies is an important step in ensuring your child’s safety. “A day care can only provide care with the tools they’re given, and the tools are there to keep your child safe,” Clougherty says. So be sure to pack a meter and test strips, extra insulin and syringes, pump tubing and adhesive, urine ketone test strips, fast-acting glucose, glucagon kit, and any snacks or meals your child should eat. Make it easy for day-care workers to dose insulin by writing the number of



carbohydrate grams in a snack or meal on the outside of the plastic baggie.

FOOD: When it comes to eating, be specific about your desires. Should your child be allowed to partake in special snacks, such as cupcakes for a birthday? Or would you rather he or she only eats the food you provide? What happens if the regular mealtime is pushed back? Instructions for staff should take all scenarios into consideration.

OUTINGS: Details are also crucial when it comes to other aspects of child care. Many programs take children on field trips; they might bar a child with diabetes from going unless a parent or guardian tags along. Discuss the issue at the outset so you're not blindsided the day before (or the day of) a field trip.

Once the details have been determined and your child is successfully cared for, stay alert. Make sure the staff is following your child's treatment plan by reviewing the history on your child's meter, pump, continuous glucose monitor, or logbook you ask the center to keep. Don't be afraid to raise questions or concerns as they arise. And, above all, remain available throughout the day.

Managing Expectations

The idea of child care is to provide safe and reliable care for a child when a parent can't be there. But parents of children with diabetes need to be available at all times in case of emergency. "When parents have a child with diabetes, they know they're at a different level of being available," says Clougherty. "There's always the understanding that we might need you to come to get your child."

It's also a smart idea to allow staff members to call you with questions about your child's care. "This is a time when parents have to be involved, and it may be that you have to be involved over your lunch hour," says Deeb. For hardworking parents, that may seem unreasonable, but it's necessary to keep your child safe.

"It's a tough situation," says Kraus. "There's no obvious solution. In a lot of cases, it requires parents make a lot of hard

choices and sacrifices." One option Clougherty says some parents find helpful is to ask the day care or aftercare program to contact your child's diabetes center or endocrinologist's office if you can't be reached. It's a safeguard many doctors and diabetes educators will agree to.

Points to Ponder

Most parents weigh the pros and cons of sending their children to day care, but parents of kids with diabetes have a few other issues to consider. For starters, it's rare for a day care or after-school program to staff nurses, so you'll need to work with the day care to make sure there's at least one staff member available on-site who is trained to meet your child's diabetes needs.

What's more, there's often a high turnover rate at child-care centers, making it hard for management to assign one person the job of learning diabetes care. And depending on employees' schedules, the staff member you leave your child with may not be there when you pick up. "You have to remember that day care is a different industry," says Blenner.

Parents forced to battle a day care to tend to their child's needs may want to consider whether relying on that center is a good idea, says Deeb. "I'd want my 3-year-old wanted by a place," he says. "I wouldn't want my 3-year-old forced on somebody." That is, if a center grudgingly agrees to care for your child's diabetes, you'll have to determine whether reluctant care will be up to the standards you expect.

That said, day cares and after-school programs across the country successfully manage diabetes care for children of all ages. "We have wonderful day cares that have taken it on," says Clougherty. "They call when they need help. They provide a wonderful, safe environment. For the most part, people who work in day cares want to help children." ▲



Ask the day care to contact your child's health care provider if you can't be reached.

More

YOU DON'T HAVE TO FIGHT DISCRIMINATION ON YOUR OWN. Ask for the American Diabetes Association's help by calling 1-800-DIABETES (1-800-342-2383).