



WHEN THE Parent has Diabetes

😊 Children with Diabetes*

When the Parent has Diabetes

Written and clinically reviewed by Marissa Town, RN, BSN, CDCES

Your role as a parent is to teach your children as much as you can to prepare them for their future independence, or something like that. Your kids look to you for answers and guidance to many of life's challenges. You teach them how to talk, walk, feed themselves, read, show empathy, wash dishes, do algebra, and hundreds of other things in their lifetime. You try to protect them from getting hurt in any way that you can, while knowing you won't be able to keep them safe from many of life's typical hardships.

When you're a parent with diabetes, you must teach them things that can cause them to have added emotional stress. This is difficult to do as a parent; it goes against your instincts to protect your babies from hard things. But if you don't teach them these hard things, you could be putting your life at risk.

It's hard to teach them that when mommy's blood sugar is low, she can't help you do your homework or get a snack for you. That if mommy's blood sugar goes too low, it's dangerous and she could need your help. That if mommy's blood sugar is high, she may be grumpy or need to go lie down for a little while. That if mommy could choose to not have diabetes, she would so she could keep playing with you. That mommy doesn't choose to have high and low blood sugars; it's just part of the never-ending game of trying to manage blood glucose levels.

Let's start at the beginning

The work going into becoming a parent with diabetes starts early for women (or people with a uterus) with t1d. We must plan to become pregnant before we know if we can even conceive a child. The doctors ask you to have blood sugars with an average HbA1C of less than 6.5%, but they'd prefer less than 6%, before you even get pregnant. While you're pregnant, you should keep it between 4-6% — the same as someone without diabetes. Piece of cake, right? Mmm cake...

Let's say you get pregnant before you thought you would actually get pregnant, and your HbA1C is 6.5%, which is pretty damn close to 6%, in all honesty. But what happens is you panic because all the horror stories doctors and other people have told you throughout your life are in your head now. You are terrified that by trying to get pregnant and assuming it would take more time, you have sentenced your child to a life with complications from your diabetes because you weren't as prepared as you should have been.

You call your mentor who has t1d and has been through pregnancy – long before they had CGMs and even rapid acting insulin. She talks you off the proverbial ledge and reminds you that you are in really good control, and you can do this. That many women get pregnant with blood sugars that are nowhere near target and may babies end up just fine. She encourages you and helps you throughout the whole thing.

You spend 40 weeks, or 37 in my case, working your butt off to keep your blood sugars in as tight a range as possible. You keep a paper log, because this is what your team demands, experience all kinds of lows in the first trimester, use mini-glucagon more than you ever thought you would, have a low of 24 mg/dl on an airplane – because of course it's on an airplane – and spend the pregnancy trying to keep your fetus safe. Trying to give the baby the same risks as if you did not have diabetes, but you do have it. Hoping with all your might that your baby will come out healthy, and that you won't live with guilt for the rest of your life because you didn't have perfect blood sugars during your pregnancy.

Then it's a baby

Congratulations! You're the proud owner of a brand new little being who is entirely dependent on you for survival. It doesn't matter what your blood sugar is to this little being, they can't understand any of that. Then you decide to breastfeed, which was your choice don't forget that, and your blood sugar drops every time you feed the baby. It should be no surprise, the baby sucked out all your energy during pregnancy, why not keep it going?

But no fear, you'll figure it out! You stash juice boxes and fruit snacks all over the house where you feed the baby, so you have something to grab. If you're lucky, you have support from your partner and family to help with diaper changes, laundry, dishes, and allow you to nap when you can. You adapt like all new parents do to this enormous shift of reality, to the reality where your life is not all yours anymore, but something you must share with this tiny human you have created.

There are some heart wrenching moments, when your partner is at work, and you are the only parent at home. When your baby is crying, and your blood sugar is low, so you must wait to pick them up and soothe them. These are the moments where you curse your pancreas for not being normal. But they are not the majority of the time, thankfully. You also want to keep an eye on where you put your infusion set and tubing when you're holding the baby...and maybe you make some changes to your usual patterns there.

As they grow

As your child gets older, you explain things to them about your diabetes. They ask more questions, and you're happy to answer most of them. The toddler "why" phase can get a little fun for any parent, so we decided to take advantage and impart some diabetes knowledge during this phase for our children. Many young children are very happy to help their parent with diabetes tasks, such as getting fruit snacks when you're low, or carrying fruit snacks in their bike basket when you're going on a bike ride. It's really endearing, honestly.

I've let my children go through the cartridge fill process on my insulin pump. They excitedly push the buttons for me on the pump and watch as I insert my infusion set. They love to push the button on my sensor, which inserts it into my body for me. It's honestly helpful when I'm doing it on the back of my arm to have an extra set of hands – even if they're little hands. They love to be a part of my diabetes experience, most days.

As they have gotten older, we've been able to explain more details of diabetes to them. We've talked about their risks of getting diabetes, even though one of our babies isn't genetically ours, so we don't know her risks. We try to allow them to have mommy's fruit snacks on occasion so that they don't feel deprived. They have never, ever snuck fruit snacks from us. (I guess that we know of...) They know it's "mommy's medicine" and that we'll get them other treats if they want them, but to make sure we always have fruit snacks for mommy at home.

Emotions about diabetes

I'd be lying if I said it was all positive. Of course it's not, it's diabetes, and it's a real pain that none of us want. Recently, we took our son to a psychologist because we were concerned he was experiencing anxiety. During the visit, my pump alerted that my blood sugar was high (busted) so I told him sorry it's my insulin pump, and he then asked Connor how he felt about his mom having diabetes. His answer was, "I worry about her a lot." I was floored.

He then told the psychologist this story, which happened a little over 2 years ago: "I especially get worried when my mom wakes me up in the middle of the night to watch her because she's low. But at least she let me watch cartoons."

We had just moved cross-country, during the pandemic. I had flown with the two kids, and my husband was still with the dog finishing cleaning up the rental and would arrive 5 days later. We moved from a different time zone, had gone through a crazy stressful day of pandemic traveling, including a search because I set the bomb material alert off when they swabbed my hands after touching my pump (thanks, hand sanitizer), and us running to our flight after extensive time at security.

It's 10 pm or so, after the kids were in bed in the next room, but I was the only adult in our apartment where we were staying. My brother-in-law and his wife were upstairs, asleep, and they didn't fully understand glucagon or how to help. I was also afraid to climb the stairs to get them because what if I fell? My blood sugar was 50 with double down arrows and I've been low enough times to know that I want to have a safety plan in place. A back-up plan in case I lose consciousness.

I'm a nurse and clinical diabetes care and education specialist, and I've given glucagon to people with low blood sugars experiencing seizures enough times to have the fear of severe hypoglycemia embedded into my brain. I weighed my options: Risk the stairs to inform the adults or wake my kids up. In my low brain, waking the kids up seemed safer. I'm not sure if it was, but here we are. I woke Connor up,

but Everly was in the same room, so she also woke up, and told him that I was very low, and I needed him to come watch me just in case. That I would probably be fine, but having a back-up was important.

Then, I let them watch Spongebob Squarepants so that they weren't just stressed watching me sit there waiting for the carbs to get into my system. I tried to explain what could happen and told them if I fell over or started to shake to go upstairs and get Uncle Ben. I got the glucagon out with the instructions just in case. I had the nasal glucagon and gave Connor the instructions as well, but he was only 7 years old. It was the only glucagon I had, so I didn't want to use it unnecessarily, and I didn't have the red kit to mini-dose.

After a few minutes of waiting for the carbs to kick in, Everly put her hands on my knees. I asked her, "what are you doing sweetie?" and she said, "I'm trying to hold you so you don't fall off the couch." At just 4 years old, she was doing what she could to help keep me safe. She didn't totally understand what was happening, but she heard that I may fall off, and didn't want that to happen.

My blood sugar of course eventually came up, and I decided because I had woken them up to let them watch the full episode that they were watching and do my best to make sure they were okay emotionally after this. They said they were fine, told me they loved me, and were glad I was okay. I think Connor even said something like, "It was fun I got to watch TV" to help make me feel better.

Where to go from here

After the visit with the psychologist, I asked Connor in the elevator, "Buddy, why didn't you tell me you were worried about my diabetes?" and he broke my heart with his reply, "You never asked, mom." These words were gut-wrenching for me. As I said before, I am a nurse and diabetes education specialist. I have grown up through Friends for Life conferences learning about how much diabetes impacts the whole family. I know that kids, like siblings of people with diabetes, have their own emotional experiences with diabetes.

Our kids come to Friends for Life Orlando with us every year, but due to COVID, have not attended in three summers. (SHAKES FIST) So they have not had an opportunity to talk to kids whose parents have t1d or a diabetes psychologist in three years. I immediately signed them up to come with me to the FFL Seattle conference, which is only a couple of months away, and have been proactively having conversations with both children about their feelings related to my diabetes.

Is it easy to ask my children how my condition negatively affects them? Absolutely not. Is it necessary? Without a doubt. Has diabetes only negatively affected them? I don't think so at all. They are used to me living with medical devices and additional needs compared to people without diabetes, and I believe it has helped foster their empathy and compassion for others. They're still school-aged, so this will probably change when we enter teenage years and they start being angsty about everything, but who knows.

At the end of the day, whether we like it or not, diabetes is a part of our family's life. So, we try to make the best of it. All we can do is try and hope for the best. Everyone has their own stressors in life, diabetes or not. And there's always therapy for the stuff we screw up in their childhood anyway.