

## What It's Like to Have a Child with Type 1 Diabetes

"I can do this," I thought as I listened to the doctor explain how our daughter, Erin, had just been diagnosed with type 1 diabetes. My mother had T1D. Yes, there had been a lot of advances in technology since her passing 15 years before, but the basics were still the same. It was all about numbers – measuring food, counting carbohydrates, blood glucose levels, insulin dosages, body weight, hours of activity, hours of sleep, etc. What I didn't understand at the time was the mental and emotional toll this focus on numbers can have on a person, especially someone predisposed to an eating disorder.

Every three months we went to the endocrinologist, and every visit felt like sitting for an exam. Her blood sugar log would be checked, her HbA1c measured (a blood test that indicates your average blood glucose for the last three months), her weight taken. She would be quizzed on how and what she was eating, how and when she was exercising. She would then receive an evaluation from each of three "examiners": the doctor, the nurse and the dietitian. How well she performed would determine whether or not she was sent to the diabetes educator which always felt like being sent to the principal's office. These appointments also determined how I felt and behaved over the next three months. If they went well, I was a good mother and could relax a little. If they did not, I was a bad mother and had to double down on my efforts the next three months. For Erin, this probably felt like being sent to boot camp.

I remember clearly the appointment that should have been our first red flag. Erin's weight had gone down significantly, but her A1c had gone up. The doctor commended her on her weight loss, lectured her on her A1c, and sent us home. I knew enough about the biology of T1D that I should have been able to put the pieces together, yet there was no mention of the connection between the two. When a person doesn't take enough insulin, their body can't utilize the food they are eating. The glucose stays in their bloodstream causing their blood sugars to run high until they literally pee out the calories. And since the person isn't getting any energy from their food, their body starts to eat itself. Unfortunately, without insulin the body still can't utilize this energy resulting in continued high blood sugars and an accumulation of ketones.

Erin, however, had figured it out. If she didn't take insulin, she would lose weight and get praise from the man who had become a second father figure to her. Now all she had to do was figure out how to bring down her A1c while still not taking insulin. Restricting food, thus restricting the need for insulin, is a common method; also a common path to disordered eating. There exists multiple ways to fake a blood sugar reading on a meter, and multiple ways to appear to be taking insulin even on an insulin pump. Erin became quite expert at many of these ways. She would then shrug during her endocrinology appointment stating she had no idea why her logs would be so disparate from her A1c test.

Instead of lecturing, her doctor moved into problem solving mode. Of course, everything was still about numbers – changing dosages, changing basal rates, changing carbohydrate ratios, testing blood sugars more often, etc. Still no mention of a possible psychological problem; no questions about how she was feeling emotionally. By now, Erin had been dealing with type 1 diabetes for five years. Yet no one on her treatment team had talked about the emotional side of diabetes, what it must be like for someone to be diagnosed with a chronic, life-threatening disease, a disease that you never get a break from. Every bite you take, every activity you do comes with a calculation – what is my blood sugar now, is it too high/low to go for a run, how much insulin is on board, how many carbs are on this plate, what kind of carbs are they (pizza is different from an apple is different from...), am I going to the gym later? And even when you do everything "right", you can still get an unexplained blood sugar because weather, hormones, a virus, any number of things beyond your control will also impact that number. It's no wonder that people with diabetes are twice as likely to develop depression and women with T1D are 2.4 times more likely to develop an eating disorder than their non-diabetic peers.

After two years of struggling with Erin's diabetes management, her endocrinologist labeled her non-

compliant and dropped her as a patient. He said that he couldn't reason with her. Of course not, you can't reason with a starving brain. As we began looking for a new doctor, we also began looking for a broader answer to what was going on. At one point, I even took her to a therapist and specifically asked about an eating disorder. I thought if it looks like a duck and quacks like a duck, it must be a duck. The therapist told us that she did not have an eating disorder, that she was a rebellious teenager. For the next two years, this poor child endured countless experiments in parenting techniques; none of which worked because they weren't addressing the actual problem. Erin had diabulimia, an eating disorder affecting people with type 1 diabetes where a person omits or restricts their insulin in order to lose weight.

It wasn't until Erin went into recovery that I began to learn about the connection between diabetes and eating disorders. In addition to the constant evaluation and pursuit of perfection that a person with diabetes experiences, the focus on food and numbers causes the person to imbue them with values of good or bad rather than just see them as information. Dr. Ann Goebel-Fabbri from Joslin Diabetes Center has said, "Teaching a person to be a good diabetic is akin to teaching them how to have an eating disorder." Interestingly, 18 of the 40 questions on the EAT-40 eating disorder test, when answered affirmatively indicating risk for an eating disorder, would also be an indicator of good diabetes management.

I learned that most people with T1D lose their hunger cues because they no longer eat intuitively. Many doctors and educators still promote eating on a fixed schedule or as close to one as possible; some even specify a specific number of carbs to eat at each meal or snack. Even with a more flexible treatment plan, people are more likely to choose when or what to eat based on their current blood sugar and plans for the day. That complex calculation and need to constantly ponder "how will this affect my blood sugar" never goes away.

I have also come to understand what "feeding my insulin" means to someone who already has fears about weight and/or food. This can happen when you dose insulin for a certain number of carbohydrates, then get full before you finish your meal. If you don't finish, you know you will end up with a low blood sugar so you find yourself eating food you don't want. It can also happen when you have an unexpected low. This feeling has been described to me as your brain screaming, "Eat or Die!" Again, you find yourself eating food you don't want and often experiencing a bounce back high blood sugar. In either case, a person is likely to feel betrayed by their body, and if they already struggle with food or weight issues, may choose to compensate by skipping their insulin at the next meal or simply skipping the meal altogether.

My daughter developed diabulimia in her teens, one of the highest risk periods for a person with T1D. In anticipation of college or adulthood, parents are trying to responsibly hand over the reigns of their child's diabetes management. They are doing so at the same time the child is wrestling with their self-image, trying to define who they are, wanting more than anything to fit in. How easy to skip testing and dosing at lunch so that no-one asks questions? How tempting to omit for a couple weeks to fit into that homecoming dress? First year away from home is another high risk period as young adults are truly on their own for the first time. Nevertheless, please be aware that an eating disorder can arise at any age. Multiple studies report that 30%-35% of women with type 1 diabetes will omit or restrict their insulin at some point in order to control weight.

After a long fought battle, with a lot of trial and error, Erin is now happy and healthy and fully recovered, though she will live with some of the consequences for the rest of her life. This is the most insidious aspect of ED-DMT1 - that most complications such as neuropathy and gastroparesis are irreversible. Hopefully, armed with a little knowledge about the co-morbidity of diabetes and eating disorders, your battle won't be so hard. The best advice I can give you is to be loving and supportive without being the diabetes police, to intervene immediately if you suspect disordered eating behavior and to be your loved one's strongest advocate.

