JAKE’S STORY — Living with Type 1 Diabetes

Jake is a 12-year-old boy who was diagnosed with diabetes at age 8. The following narrative was written by his mother.

Living with Type 1 Diabetes: Jake’s Story

On school days, I wake up Jake at 6:30 AM. He tests his blood sugar by pricking his finger until it bleeds and sticking a test strip into the drop of blood. Then, he inserts the strip into a small hand-held glucometer and waits 3-5 seconds for a reading of his blood sugar. If this is 120 mg/dL or higher, he gives himself insulin 10-15 minutes before breakfast. I calculate how many carbohydrates (sugar, starch, and fat) he will have in his breakfast so that he can bolus [give himself enough insulin to cover the food he will eat] correctly. He has an insulin pump [see Figure 18-18] so he types in the amount of carbohydrates he will eat plus his current blood sugar reading. The pump calculates how much insulin he needs to cover the carbs and any extra insulin he may need to bring down a high blood sugar. After he boluses he waits 15 minutes to eat breakfast. If his blood sugar is less than 120 mg/dL he will not bolus until he starts eating, because if the insulin acts too rapidly his blood sugar can drop too low.

As I cook his breakfast, I count carbs exactly—3 eggs (he needs protein to keep his blood sugar stable throughout the morning), 15 carbs of fruit (15 grapes, ½ banana, ½ small apple, or 1½ clementines), one 8-oz cup of low-carb juice, and 3 waffles. If he is still hungry/thirsty after he eats, he counts carbs of whatever else he eats and boluses for it.

I then count carbs for his lunch and place an index card in his lunch bag to show the nurse before his lunchtime bolus. At school, he visits the nurse if he feels high or low, and at lunch as well... I worry about his exposure to all the sick kids at school when he visits the nurse. At school, if his blood sugar is high, he drinks water and tests his urine for ketones to make sure he does not have ketonuria, which may indicate ketoacidosis. If it is positive for ketones, he is sent home from school (fortunately, this has never happened).

At lunch, he leaves class early to test his blood sugar and does the same calculations as at breakfast. He waits for the nurse to manually compute the amount of insulin he needs to make sure that it matches the calculation of the pump. Then he boluses and goes to lunch. If his blood sugar is less than 70, he can’t go to lunch with his friends. He eats or drinks some fast-acting sugar (Skittles, Smarties, or Sprite) and waits for his blood sugar to rise to an acceptable range.

FIGURE 18–18  Insulin pump. This device can be programmed to deliver doses of insulin according to varying body needs. Basal insulin is delivered continuously over 24 hours and mimics the normal secretion by the pancreas. Bolus insulin is delivered or injected at mealtimes to “cover” a specific amount of sugar or starch ingested. (Courtesy Ruthellen Sheldon.)
We plan ahead for all field trips and food snacks that are brought into the classroom. If Jake is playing sports, he times his meals with the start of the activity so his blood sugar is around 150. He disconnects his pump during sports. Jake is an avid soccer player. At half-time he tests his blood sugar. If it is low, he needs to eat. If it is high, he needs to reconnect his pump and get more insulin. After sports, his blood sugar usually spikes because of an adrenaline [epinephrine] rush and then crashes down 3-10 hours later. This is unpredictable and never consistent, so it takes guesswork to keep him in range after a sports game or practice.

During the night, his Dad and I set alarms to wake up every few hours to test him. If his blood sugar is high while he sleeps, we use his pump to give him a correction. If it is low, we wake him and have him drink Sprite or eat Smarties. Sometimes we check him four or five times during the night. Even if his numbers are stable, it’s not a guarantee that he won’t drop suddenly and have a seizure (this happened in March after we had tested him at 11 PM and 2 AM and he was steady). He never complains about all the interruptions to his sleep and does a great job of falling right back to sleep when awakened.

Every 2 days he changes his insertion site for the insulin pump. He can’t do this alone. The pump is connected to his body with a small cannula [tube]. It is inserted manually via a needle into his hip region. The needle is then removed and the tiny Teflon cannula remains in his body, delivering fast-acting insulin under the skin. Plastic tubing clips into the cannula and then attaches to the side of his pump. He clips his pump to his waist or places it in his pocket. When he bathes, he disconnects from his pump, and when he sleeps, he places it on the mattress next to his body.

His body naturally rejects the Teflon cannula, so after 2 days his pump site must be changed. We realize this because his blood sugar numbers start rising for no apparent reason. Typically, we will change out the pump site and notice that it is red and sometimes the cannula tip is bent. Although changing the pump site is time-consuming and expensive, a bad site means that not enough insulin is getting into his body, which can quickly spiral into stomach pains, ketonuria and ketoacidosis [DKA].

Jake has just started to wear a continuous glucose monitoring system [CGMS]. This has a small sensor that is inserted into his arm to measure blood sugar in his interstitial fluid every minute. It is new technology that will actually beep at night if his blood sugar is dropping. Jake doesn’t like the system because it is painful to insert and is cumbersome to carry. Plus, it doesn’t replace fingersticks for blood sugar readings.

In general, Jake’s diabetes doesn’t disrupt his life other than the nighttime checks, wearing an insulin pump, and paying attention to how many carbs he eats. We encourage him to make good nutritional choices (not always easy for a kid) and to limit certain foods (donuts, Slurpees, candy) for special occasions. He must also carry a glucometer with him at all times and a sugar to take when his blood glucose is low.

Having a child with diabetes forces me to carefully plan the preparation and timing of meals. I always have certain foods and medical supplies in the house and I carry snacks and sugar sources wherever I go. I am always available to Jake and to the school nurse. I don’t always have a good night’s sleep. I think I would sleep better if I were not so driven to keep his blood sugar in a healthy range. Right now, my body has adjusted to this new sleep pattern and I’m happy to wake up for him. I try to be at all his sports events to help him manage his blood sugars properly before, during and after games. He can’t go to a friend’s house for a sleepover and he cannot attend overnight camp. His Dad or I must always be in town. Keeping Jake’s blood sugar in tight control hopefully means that he will avoid many of the complications frequently encountered later in life by people with type 1 diabetes.