When You Have a Toddler With Type 1 Diabetes

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Sholom in Maimonides Hospital at the diagnosis.

ne year ago, our lives were changed forever when we sat in a Hatzalah ambulance, just a few minutes before Shabbos, and were told that our precious seventh child Sholom, only 22 months old at the time, had Type 1 Diabetes (T1D). My pediatrician had called me Friday afternoon letting me know that the blood test we took the day before because Sholom seemed sick so we wanted to "rule out diabetes" actually looked worrisome and she urged me to go the ER immediately.

My husband and I spent the next 25 hours at Maimonides Hospital processing this new reality, together, just the three of us. Just the three of us and plenty of kind hospital staff, monitoring our son, checking on him, asking if we had any questions. We didn't even know what to ask. Since it was Shabbos, there was no calling anyone and no Googling anything (thank G-d for Shabbos!) so instead, we spent that Shabbos communicating with each other, with Sholom, and with Hashem. There was lots of davening from the siddur and in our own words too, lots of singing, lots of tears, and also lots of hope and bitachon that it will all be okay. Honestly, we took Sholom's lead. He was comforting us with his innocent

and naive smiles; we just knew he would be okay.

When he was younger, we had had another scare with Sholom (an almost-accident) that *b"H* turned out okay, and after that I started saying, "Thank You, Hashem," before saying his *kapitel* every day. After the diabetes diagnosis it felt like I should keep saying those words because I just knew that as hard as this journey would be, Hashem would have our backs.

I feel that Sholom has a special *malach* watching over him. We parents can't possibly do this alone. Even unrelated to diabetes, I know the *malach* is at work. On another occasion, on Chanukah, his hair caught fire while lighting the menorah, and he was completely



Mommy & Me for kids with T1D. L-R: Chava Menczer with Baila. Leah Winner with Sholom. Toby Gaida with Chanie. Temima Dean with Tziporah.



When Sholom was extremely low due to the babysitter accidentally pumping excess insulin, he needed a whole lot of sugar.



Sholom at the endocrinologist.

unharmed. It feels like every day involves constant miracles and I'm thankful to Hashem for all of them, the ones I know about and the ones I don't.

Type 1 Diabetes means that the pancreas isn't functioning as it should and isn't producing insulin for the body to break down sugar. Sholom needs insulin to be injected or pumped into his body many times a day to be sure the carbs he eats (which are in almost every food, even fruits and vegetables) will be broken down in his bloodstream. Of course, we humans trying to recreate Hashem's systems can't manage blood sugar as efficiently as the healthy human body does on its own, so sometimes there's an excess of insulin which makes the blood sugar level drop too low, and then we need to bring it up urgently—with food. Sometimes the sugar can drop too low if there's excess exercise; for a toddler that can mean jumping on the couch for an hour or scooting at the park or swimming, so even when there's no eating happening, his blood sugar must be monitored 24-7. That's T1D in short.

It's good for people to know what the clues are for T1D—please pay attention and see a doctor if you hear someone complain about a child who is constantly starving, or has signs of unquenchable thirst, sudden weight loss, or frequent urination. The earlier it is detected, the better.

Because Sholom was not yet two years old at the time of his diagnosis, there were a lot of unknowns, even to the experts. Like should I keep breastfeeding or should I wean him? Should we give him insulin before he eats or only once

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he starts eating, since he can't tell us how much he plans to eat? We got lots of conflicting instructions.

B"*H*, within a few days of his diagnosis, we got a sensor and a pump for Sholom. The sensor lets us see where his blood glucose is at all times. It's inserted into his skin on his arm or thigh and needs to be changed every seven to ten days. It's miraculous and lifesaving. The pump attached to his skin as well, changed every four days, pumps insulin as needed-all without needles and without him even knowing about it! The joys of technology! Except, as we know, technology isn't Hashem, and when it fails us, it's frustrating. But for the most part, the technology makes life with T1D a lot more manageable than it was for kids who had T1D even just 10 or 15 years ago.

Sholom is now almost three years old and knows a lot more than the typical toddler. He opens a bag of chips and hands it back to me, pointing at the nutrition facts and asking, "How many carbs?" He notices his pump wires

tangled around his diaper and says, "Mommy, fix my pump, it's stuck!" Of course, like any typical toddler, he says he wants to eat a huge bowl of pasta, so we give him plenty of insulin, only to realize a few minutes later that he actually doesn't want even one bite and now he has way too much insulin in his body which will cause him to go low, and the roller coaster continues. Of course I try to keep *nosh* out of his way and offer fruits and veggies before other options but when we're at a party, and on shlichus there are many, and he wants to have a donut or birthday cake, I don't deprive him. I give him insulin and allow him to be like any other kid his age and enjoy.

It's like he's on a seesaw all day: Sugar too high, sugar too low, and on those rare occasions—sugar just right and in range.

Sholom is a champ—he's chatty about all his supplies and giggles when he gets a finger prick—so we keep it all happy and steer away from stress, too. Recently he learned how to prick his finger himself and he is so proud of himself.

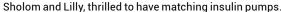
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Some examples: In August we were told that Sholom's insurance was inactive until October, which would mean six weeks of not receiving his diabetes supplies! I was frantic... for about a minute. I immediately posted on a few different WhatsApp groups of fellow Jews with T1D and within 60 seconds got SEVEN people messaging me, offering to share their supplies! They asked for nothing in return. It was just straight-up kindness. My cousin Frumi Marozov sent me some sensors by overnight shipping and refused to allow me to pay her for the supplies or the shipping. Other Crown Heights families came to the rescue too.

Toby Gaida, who's saved in my phone as T1D mom, is actually more of a friend by now. Toby's kindness is hard to put







The Uber package from Toby at 1:00 a.m.



Leah Winner with Zlaty Tyrnauer, a fellow T1D toddler mother, outside of a *melaveh malkah* arranged by Friends With Diabetes, an incredible organization run by *frum* people who support T1D patients and their families.

into words. The first time I needed to change Sholom's sensor and the technology was totally overwhelming, she didn't go to sleep until after 2 a.m., waiting to hear from me that he was okay. And a million other times she answered my beginner's questions. She FaceTimed with me minutes before Shabbos when I had an urgent question. She gave me about a dozen insulin vials when I was in need and offered more. Last week when I needed a sensor urgently when Sholom's sensor failed at 1:00 a.m., I posted on our toddler chat and Toby sent an Uber package not only with sensors but also chocolate and a sweet note, "Hope your night gets better."

Perhaps more than anything, the greatest gift Toby gave me is that she created a network of fellow *frum* moms who have toddlers with diabetes. We post our questions and support each other at all hours.

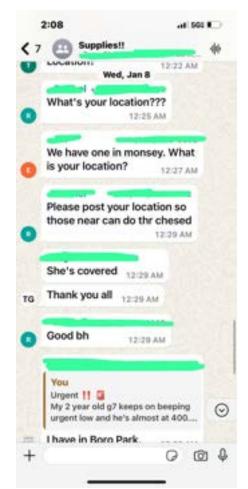
The chat is invaluable! My family and friends are always there for me but there's something about the support of others in the same situation who just really get it. We can vent there, get real answers, and find the encouragement we can't find anywhere else.

We even met up twice for an exclusive Mommy & Me for toddlers with T1D and plan to meet again soon. We share helpful tips and commiserate on the challenges. We laugh a lot and share videos of our toddlers so they can see they're not the only kid getting a pump change. (If you know of a mom of a toddler with T1D, please let me know, c/o the *N'shei Chabad Newsletter*, so I can invite her into our circle.)

I've been running Mommy & Me at our Chabad House in



Mommy & Me for kids with T1D. L-R: Leah Winner and Sholom. Toby Gaida and Chanie. Elana Barer and Lilly.



The overflowing *chessed* from fellow T1D mothers.

West Brighton Beach, NY, for over a decade but the Mommy & Me for kids with diabetes holds a special place in my heart. The joy that Sholom has when seeing other kids wearing insulin pumps and sensors is something I try to give him as often as I can. He talks about his "diabuddies" as we call them. He'll randomly announce, "Chanie and Lilly and Baila are my friends."

There are several chats for *frum* Jews with T1D with close to 1,000 members where everyone discusses the perks and downsides of different pumps, offers leftover supplies, and asks for supplies when in need. I find myself reading the chat and literally saying out loud: *Mi k'amcha k'Yisroel!*

Our endocrinologist was preparing us for how much we would have to spend on supplies during the insurance lapse and she was shocked to hear I was totally covered by my fellow Jews—for more than two months!

Going back to the time of Sholom's diagnosis, right before Shabbos, Hatzalah members (dressed in their Shabbos clothes) left their families' Shabbos meals to escort us so we'd get the best care at Maimonides, and returned again hours later on a Friday night to check on us.

The Bikur Cholim at Maimonides gave us bags full of food—a bag for each of us with *kiddush*, challah, and complete Shabbos meals. They dropped the bags at our curtain without even making eye contact, not looking for thanks.

My family listens endlessly to my sagas and offers support and babysitting whenever they can.

My sister-in-law Sara Silver runs Neshama Preschool and makes sure Sholom is in good hands even on days that our babysitter isn't able to be there with him. The staff doesn't mind getting my calls and messages throughout the day.

My older kids, Sholom's siblings, are all in love with him, distracting him and hugging him during pump and sensor changes, making sure to hide their treats, and convincing him to have treats when his sugar is low.

Last but definitely not least, I am grateful to my husband Moishe Dovid. He hears the beeping at night indicating high or low blood sugar and is my partner in this enormous responsibility. To simply know that I am not alone in managing Sholom's T1D is a *brachah* I don't take for granted.

Thank You, Hashem, for my sweet Sholom. I would never exchange him for any other child. He's my delicious boy and every day, when I say his *kapitel*, I mean it when I say "thank You Hashem," because he is the cherry on top of my life.

I daven for Moshiach when everyone in the world will be in full health. I daven for a cure to diabetes. And until that happens, I thank Hashem for technology, good doctors, and the generous hearts of my fellow Jews, my extended family. Am Yisroel Chai!