

Sisters Share



By: Ruchama Schnaidman

Three women, who each have a sibling with Down syndrome, share their experiences - the ups, the downs and the joy their siblings have poured into their lives.

Strength, insight and inspiration – those were my three main takeaways from my wonderful conversations with three women – all sisters of siblings with Down syndrome who agreed to share their experiences. I heard three stories, each one unique in its details and emotions and learned from there how individual every one of our experiences are.

Age, personality, location, knowledge – these all play huge roles in our life experiences, how we process them, understand them and ultimately grow from them.

When it comes to emotions, there is no one way that's right. Your way is right because you're the one living it.

And so, I invite you to join me in hearing from women who have experienced what you've experienced. You may find yourself nodding in understanding, feeling relieved to be understood and laughing along with those who really get it.

However, you feel, I hope there's something here that you can relate to, understand or feel uplifted from.

Gitty Abrahams speaks...

"My delicious sister, Shevi, the youngest of our family of nine, was born when I was in 3rd grade," Gitty Abrahams shares. "Thinking back to that time, I remember the worry that enveloped our household for the first six weeks of her life when she was in the hospital dealing with medical issues. I knew that part was scary, because my newborn sister wasn't home with us, but I didn't know that much more. In fact, I only found out that Shevi had Down syndrome a few weeks after she was born and by then I already knew her as the delicious and adorable baby sister she was."

Since I was so young, when Shevi was born, for me, Down syndrome was never scary, sad or something to hide. Sure, it was unsettling for me to watch my parents look so serious, to see my older siblings feel devastated, but I was so young, I didn't really understand. To me, Shevi was always just the cutest little sister."

Once the baby came home from the hospital, the entire family adored her. "She was the most loveable baby, the easiest, most delicious girl and we were all crazy

over her. Once my older siblings came to terms with Shevi having Down syndrome, our house became more relaxed and we were just obsessed with her. There's some special *chein* that kids with Down syndrome have and within a short time, Shevi totally won over all of our hearts. From that point on having Shevi in our lives was all positive. We were fortunate that after those first few weeks, Shevi didn't suffer from medical issues. She was just this easy, fun, hysterical and delicious kid who we adored. As the youngest, we poured all of our energies into her and *baruch Hahsem* she was very advanced."

But as much as Gitty's entire family loved Shevi from the day she came home from the hospital, Gitty always felt and still feels that she has a special, amazing connection to her.

"I was always crazy over her, we were so close, I can honestly say that Shevi was the happiness of my childhood."

Did Gitty ever feel embarrassed or ashamed of Shevi? "As a kid I was always proud of Shevi but of course, there were times that I felt embarrassed. I knew she wasn't regular and it was uncomfortable to see people stare at her, but our bond is so deep and we love her so much, my overwhelming feeling about Shevi has always been pride."

Gitty goes on to explain that although there can be challenges involved in having a sister with Down syndrome, the bond she built with Shevi is unlike most regular relationships. "I was always super close to Shevi and that very deep bond was mutual. Kids with Down syndrome just have this amazing *koach* to connect deeply with others. My friends loved her; she was always the star of the show. She was always there for me, I used to lay in her bed and put her to sleep and when I was in seminary, I was truly homesick for her. It was very hard for Shevi when I got married. She missed having all of my attention. In our eyes, Shevi is our precious, youngest sister who can do no wrong."

"If there's one message, I can give over to other siblings of children with Down syndrome it would be this: Whenever I hear of a family with a child who has Down syndrome, I know it can be hard, but honestly, I just think that they are the luckiest people in the world. There is something so deeply loving and special about these children – they change your life in a way that no other person can. All I can say is if you have a sibling with Down syndrome, you're going to end up being so crazy over and obsessed with this sibling, you will forget any hardship from the beginning. You will love this child so, so much."

Tziporah Friedman shares...

"I was in seminary, tucked away in Eretz Yisroel when Shloimy, my youngest brother was born with Down syndrome," Tziporah shares. "Interestingly, one year before Shloimy was born, two other families on our block had boys with Down syndrome and so in the back of my mind, I was worried about Shloimy even before he was born. My mother also worried that if she had a child

with Down syndrome, she would scare others. But the doctors kept reassuring her that everything was fine and so when he was born with Down syndrome it was a big shock for my parents. For me, though, it wasn't. I had a strange feeling that something was wrong with the baby and so even when my father called to tell me the good news that my mother had a baby (before he knew that Shloimy had Down syndrome) my first question was, 'Is everything okay?' My father's reassurance that everything was fine

● didn't calm me down. I decided I wouldn't tell my friends yet because I felt that something was wrong with the baby."

● When her father actually called back a few hours later to tell her that Shloimy had Down syndrome, Tziporah almost felt relieved that at least, it was only that.

● But the strongest memory, Tziporah has is the conversation she had with her father shortly after he gave over the news. "I asked him, 'What did you tell Bubby?' and he answered simply, 'What do you mean? I told her the truth.' My parents were so accepting, upfront and forthright about Shloimy, it set the tone for our entire family.

● I realized that the way I react is the way others are going to treat me, so I took my father's cue and told everyone the truth. I preferred for everyone to hear it from me than to be talking behind my back. Some people were taken aback by how open I was but ultimately it was the best thing I could have done. I didn't feel like a *nebach*, I wasn't hiding a secret and everyone around me was so supportive, nice and there for me."

● Many years later, Tziporah still hears from seminary friends how much *chizuk* her reaction to Shloimy's birth gave and continues to give them.

● "My friends from seminary never forgot my reaction and I feel it was a gift from Hashem. He showed me how to act and it inspired a lot

of people. Of course, a lot of the credit for my reaction goes to my parents.

From the moment my parents heard the news about Shloimy and my father pointed his finger upwards, indicating that it is all from Hashem, Down syndrome was never something we hid or were embarrassed of. Over the next few years, my parents would go with Shloimy to other families who had Down syndrome babies to give them *chizuk*."

Tziporah speaks of the incredible qualities Shloimy has. "People with Down syndrome are so genuine," she says. "Shloimy doesn't hide his emotions, he's full of compliments for others and you feel really good when he compliments you. He breaks out in massive smiles whenever he's complimented and he is so sincere. He calls to check on my kids, asking if they ate supper, if they went to sleep nicely. He loves to *schmooze* and he calls me often to do just that. Shloimy brings so much joy into our family – he is definitely the favorite among the siblings and nieces and nephews."

Tziporah's message is: "The first few years can be hard. In the beginning, you're essentially dealing with blank slate and it's so unknown how far a child with Down syndrome will go. Life can also be hectic then with constant therapy, but as time passes, children with Down syndrome are pure joy. I can't begin to describe how much Shloimy does for our family."

In Fraidy Stern's Words...

"I'll be honest," Fraidy says. "When my sister, Tova was born with Down syndrome when I was in 8th grade, I was devastated. We were living in an out-of-town community and I knew absolutely nothing about Down syndrome. I had never even seen a person with Down syndrome. None of my friends had siblings with Down syndrome and I had no idea what to expect. There was also nothing set up in the frum community to help parents of children with Down syndrome – no frum schools or therapy programs. I had real fears for our future. I had a great family and a great life and I didn't know what would change now that we had Tova. At the time, I was also very embarrassed of her."

Fraidy remembers her friends telling her that Tova was so cute and she thought, *don't say that, you're only saying that because you feel you have to.*

"It was a rough beginning," Fraidy says. "But now I can honestly say, that today, my family wouldn't trade Tova for anything


in the world. Literally, for anything. She's amazing, she recently moved with my parents to a new community where she found a job. She's just off and going!"

"How?" I ask Fraidy. "How did you reach this point of such deep love for Tova when you were so sad in the beginning?"

Fraidy has a two word formula for that: "Love and time," she says.

"Time is a great healer and *ahavah* – love is giving and when it came to Tova, we gave and gave and we all just love her to pieces. In those first few years, we rallied around her – her early intervention therapists were amazed by us, this huge Jewish family of nine children *kah* who cheered Tova on. When she was a little older, she went out for therapy and our mother allowed us to take off from school to go with her."

Fraidy shares how her family learned to appreciate milestones. "Our simcha and excitement as Tova reached her milestones – sitting, crawling, walking, talking was



absolutely incredible. Baruch Hashem she is high-functioning and the only thing she did to our home was make it a better place to be.”

“Today, we can’t imagine life without Tova. She keeps us on our toes and she fills us with her unending *simcha*. She’s so *geshmak* to be around because her self-esteem is sky high, she’s also so happy and sincere.”

Amongst her nieces and nephews, Tova is regarded with true respect. “Having Tova in our family taught the nieces and nephews to be sensitive, caring and respectful. We taught our kids, ‘She may be different but she is still our Tanta. When we go to Bubby’s house, it’s also Tova’s house, we have to be respectful or her needs and her space.’ The nieces and nephews adore her – she is the favorite of the family.”

Still, with all of the joy that Tova fills her life with, Fraidy remembers the early days and the way she felt when she heard the news about Tova’s Down syndrome. “It’s important to realize that however you react to the news is

absolutely okay. You can be devastated but you don’t have to be. There are no abnormal feelings and you shouldn’t feel guilty for anything you may feel or anything you’ve felt in the past. A sibling with Down syndrome can be a big shock, it’s different than what you expected and it’s okay to feel however you may feel.”

Her parting message though is optimistic. “We all view Tova as a tremendous asset to our family. Even with the challenges involved, we adore her and wouldn’t trade her for anything in the world. She’s fun and funny and just so super-enjoyable to be around. People with Down syndrome are happy – they change you for the good and teach you to be happy with what you have. But, remember these feelings didn’t just come. They took time and *ahavah* – the two things that show us all just how special children with Down syndrome truly are.”