Growing up with my Daughter

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While packing, in a carton of personal memorabilia, I came across an old birthday card. A hummingbird in flight soars on a turquoise background. The message reads, "A bird does not sing because it has an answer, it sings because it has a song". Written inside: "It is my first wish in your path of independence and happiness. Always sing your own song my dearest daughter, and never compromise in the song of your life and your intentions. I bless you and wish you success in your journey". Rather philosophical for a first birthday!

It is dated October 4, 1978. The card is as good as new and the feelings as fierce as they were then. However, Nafisa cannot read my message nor does she quite understand my fervour for her. She is not a bubbly 22-year-old, enjoying adulthood, she is caught in a state of permanent childhood. Her mental age is that of a five-year-old. Physically, she looks around 6 years with a delicate build, sad eyes and thick, curly hair.

After the initial shock of being a parent of a spastic child, I realised that the advice given at school to treat her like a "Normal" child is worth its weight in gold. Quite early, I decided that I wasn't going to do just that but also treat her as a special gift. So what if she had a faulty gait, failing eyesight, acute dental problems, poor immunity, partial hearing loss, faltering speech, problems grasping? So what, at least she's mine! She is generous to a fault, loves shopping, and has the memory of an elephant. Her large motherly heart loves/hates and bosses over her brother, Anees. She has numerous traits that single her out as a very special person.

The truth is that she isn't really trapped in her childhood. She has grown in many ways and, more importantly, we have grown with her. We have grown in sensitivity, to her and to humans around us. I wonder if we could have savoured this had we not opened our minds to a child like Nafisa. I'm sure I would have gone through life skimming the surface.

You mustn't think of her as some poor frail thing. She could be quite a tough cookie! She demanded equal rights with Anees. Each year when the new school session began and we went through the ritual of covering books with brown paper, fancy nametags, she wanted all of that too. We often used to get into these mother daughter tiffs, and the final line from her was, "I'm going to get myself a new mama". Once when I refused to make French fries for her as she had a bad throat, she got cross and declared, "I'm not your daughter, I'm going to the sky to stay with Hanumanji." I continued in the same vein. "Okay, but don't call me to wash you." I wasn't prepared for her answer: "I won't call you! Sita will wash me." I was stunned.

This happened several years ago when the Ramayana was being televised every Sunday morning. And from the whole array of colourful characters she had picked out the right one, the one with a mother's image. Her understanding was more impressive than I had assumed.

My worst fears were realised when I discovered she was suffering from progressive hearing loss, though she wasn't born deaf. I was miserable at the thought of hearing aid cords entwined with the springs that keep her thick spectacles behind the ears. When she got the hearing aid set, I explained how it worked. She turned to me laughingly, and said, "Is this my remote control?" I learnt how brave she is about her disabilities. I need to match her growing confidence.

As part of Nafisa's home programme, developed by the Spastic Society, we had to do a lot of activities for her fingers and hands. She began with paper tearing, painting with fingers, and threading wooded beads. But after a while, the monotony set in and her mind was racing ahead. She would get the scissors and try cutting paper. I was hesitant at first lest she hurt herself, but she proved me wrong. So, we launched into cutting bits of cloth and making small collages. After that, it was the knife she wanted to help me cut vegetables. Within a short time, she mastered the art of cutting vegetables into small, almost regular, pieces. Everyday she would chop the veggies for our vegetarian dog's food. How well she had adapted her therapy to useful work at home.

I shall never forget the day when she showed the little mother in her. She was barely six and Anees was not yet two. I wanted to visit my next-door neighbour. Both kids were sleeping. I shook Nafisa, and explained that I was going next door and that she should not get out of bed. I must have been away for about 20 minutes. I returned to find Anees sitting at the small kitchen table, and a bright orange river flowing from the table across the floor into an orange lake. In halting words she told me, "Mama, little brother has got up and I'm making him a drink." She had poured a whole bottle of water into a more than half full 2.5 kg tin of Tang, and both of them were pouring the liquid into his feeding cup. She looked so content. Anees has, naturally, over the years shot into a strapping young man while Nafisa has remained almost where she was in physical appearance.