

Family Needs to Get Involved

Bringing up a daughter with Down syndrome

Falguni Doshi

My life was moving in a smooth, straight line, just like the way I had drawn it for myself – studied computers, got a job in a multinational firm, married a tall, dark, handsome and caring husband, had an extremely loving family and a lovely daughter.

When I was going to be a mother for the second time, everyone in the family agreed that we would not get sonography test done and will accept whoever comes into our lives – whether a daughter or a son and will give her or him a happy life and a good upbringing. I have to say this because at that time, the old ideology of preferring a son and a sonography test to find the gender prevailed. Even as I write this, I am unable to control my anger. What sort of mothers are those who can destroy a part of their own being due to their own mindsets or under family's pressure? Anyway.

The day Stuti came into my life, God lifted me from my smooth, straight line and put me on an unknown path. Since it was a normal delivery, I was able to listen to the conversation of the doctor and the nurse. As soon as Stuti cry was heard, the nurse said, 'Look, doctor, she is looking like an angel, and look at her eyes, this child is so different!' I could make out that I have got a daughter and she is as cute as an angel. All these things are etched in my mind like a picture... as if it happened only yesterday. On the second day, the paediatrician came for rounds and was discussing something with my gynaecologist. I did not understand what they were saying and when I asked, they said that certain tests have to be done since they suspect Stuti to be a Mongolⁱ. I was a student of science, so I understood that they were talking about Down syndrome. Stuti's blood test was done. The report was supposed to come in a month. And for that whole month, I kept convincing myself that the doctor might not have understood Stuti's problem properly, there may be some mistake somewhere and that God will never do this to me. My behaviour has been always good with everyone, nothing will ever go wrong with me. I even tried to bribe God, I thought, Oh, God! Please see that Stuti's reports are normal, I will chant Gayatri Mantra everyday...

When the reports finally came, the doctor's suspicion was correct and Stuti was born with trisomy 21. My eyes were filled with tears and it was all quite painful. But then, immediately, it struck me that now that we know about it, what next? I lost my mother when I was a child, so I was used to solving all my problems myself and that helped me. The first thing I did was to meet the geneticist, a doctor who is an expert in genealogy, to try and understand the reasons for this and what the strengths and weaknesses are. He told me that bright colours, happy atmosphere and constantly talking with Stuti would be very beneficial. Babies with Down syndrome have low muscle tone and that has to be taken care of. He explained about various therapies. Everything can be learnt with patience. Then, I went to a centre where they work with special children, and I broke down there...so many children... each one having a different problem and the distressed faces of their mothers. I somehow controlled myself and decided that I would bring up Stuti with all my might and try to give her a good life.

Stuti's physiotherapy started when she was six months old. I learnt from the therapists all that was necessary for her and repeated it at home. I had studied computers to make it my career but now it was very helpful for me in getting information about Down syndrome. There were some changes in life and my work started on 'Mission Stuti'. I gave up my job and spent my time, energy and knowledge in raising my children. I was lucky that I got good people everywhere—good teachers, good therapists, good neighbours, good relatives and a good family.

Stuti is 17 years old today, very cheerful and composed, has passed the tenth standard exam, uses computers, mobiles, and all other gadgets with ease. She can do a lot of household chores and today, I am not her support rather she is my support. I have learnt many things in my journey while walking on this path. I compare Stuti with herself, not with other children. If she does any activity with a little improvement than before, I feel happy. A therapist can help us, but ultimately, it is we who must persist. So even though the teachers used to help Stuti with play therapy, speech therapy and studies, and I also did and got accustomed to doing everything that was needed for her. When the whole family gets involved in the process, then the positive results can clearly be seen. Stuti can learn everything that a normal person can learn, only the learning period may be longer, or the method of learning may be different. During all this, I have come to understand that miracles will not happen overnight, this is life and the struggle of each life will go on. If we want good results, then we have to be happy and keep on trying. I am happy that my family supported me at every step and has encouraged me wherever required.

I am still walking on an unknown path, have crossed many stages, many more are still to come, but the pleasure lies not only in reaching the destination but also in walking on the path that takes one to his or her destination.



¹ An old term, now unacceptable, used for Down Syndrome.



Falguni Doshi
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