

A Special Gift from Allah

By Shyrose Jaffer-Dhalla

The ominous tone of the doctor's words shattered the cheerful atmosphere of the hospital maternity room where Sukaina (Dungersi) Syed had given birth to a beautiful baby boy, just two days earlier. She recalls the scene vividly for it is a moment of her life that is forever etched in her memory.

"Mrs. Syed," said the doctor. "There is something important that I must discuss with you in private." Sukaina remembers the doctor's serious face and that sickening feeling of dread that had suddenly come upon her. "My mother was sitting across from me, my husband was by my side and the baby was playing in the bassinet at the foot of the bed. The doctor asked my mother to leave the room but I said, 'No, whatever you have to say, you can say it in front of her', and that was when he said the words that changed our lives forever. He said, 'Mrs. Syed, we strongly suspect that your child has Down's Syndrome.'"

"We were completely rooted to the spot. I felt as if I had become paralyzed and I couldn't hear anything else that he was saying to me. My mother and my husband's eyes were wide with shock as we watched the doctor place the child on the examining table and remove the baby's clothes. And then he looked at us and slowly nodded in confirmation. More tests were needed, he said, but all the signs indicated that the initial diagnosis was correct. And then he left the room to order the tests."

Sukaina takes a deep breath as she remembers that fateful scene. "Each of us was just stunned. We were unable to even speak. And then, the baby started to cry. We saw him there, small and totally naked, his arms and legs kicking away like little babies do, crying his eyes out. And we just couldn't move to pick him up. I think the world was just spinning around me, I could hear him crying and I felt as if the earth should open up and just swallow me. He cried and cried and I summoned up all of my inner strength and told myself that I must pick him up. I went towards him and my

legs were wobbling. I felt as if someone had thrown freezing cold water on me. I took him in my arms and I held him close to my heart and I thought to myself, "this is my child, this is my Abbas" and I said to Allah (s.w.t), "If you have given me this challenge, then I shall face it."

Down's Syndrome (referred to as Mongolism in earlier literature) is a genetic, chromosomal disorder that occurs in approximately 1 in 700 births in Canada. A child with Down's Syndrome has 47 chromosomes in each cell instead of 46. This extra chromosome material is present at conception and may be contributed from the father's sperm or the mother's egg, each of which contributes 23 chromosomes. Although it is not known for sure what exactly causes this extra chromosome, it is possible that it may be due to an error in cell division. Since the defect occurs at conception, nothing done by the mother during pregnancy will alter the condition in any way.

The chance of having a child with Down's Syndrome increases significantly with age (odds are 1:32 for women over age 45). However, statistics show that 80% of babies born with the syndrome are born to women under 35 yrs of age, as these are the prime childbearing years.

Newborns with Down Syndrome may look like babies who do not have Down's Syndrome while others may clearly exhibit the features that are characteristic of this condition. These may include chubby cheeks, large, round eyes, larger tongue, smaller limbs and smaller face. Other features range from small ears, flattened bridge space between the two eyes and short neck, to a protruding tongue and webbed or connected fingers and toes.

The child may also (but not always) face health complications such as some life-threatening congenital malformations of the heart, hypothyroidism, hearing loss, vision problems, upper respiratory problems and other medical conditions. Some degree of

mental retardation is also common and the child may function at a mental capacity below their age and have difficulty with speech and comprehension. The life expectancy of children with Down Syndrome can be up to and over 40 yrs depending on the degree of medical complications.

"At first, I just couldn't see anything different about my child," says Zehra Hashem, whose has a twelve year old daughter with Down's Syndrome. "During my fifth month of pregnancy the doctors had done a routine amniocentesis (test for fetal abnormality) due to my age (40 yrs at the time). The results indicated that the child would be severely abnormal and I spent the whole pregnancy just totally devastated. When the child was born, I was scared to even look at her because of all the fear within me. I just did not know what I would find. It took me three days to finally take her in my arms and then I saw that she was just so beautiful! She was just very red. And I kept looking at her for the first few weeks just asking myself, 'could it be true? I don't see anything wrong with her. Maybe there has been a horrible mistake. Even doctors can be wrong.' I would just keep staring at her and I'd show her to relatives and ask them, 'do you see anything different about her?' and they would politely reassure me that the baby is ok. And I spent that whole time just denying it, convincing myself that everything would turn out alright." "It is very common," says Sukaina Syed

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whose son Abbas is now 10 years old, "to wonder if you, as a mother, are to blame for your child's condition. For me, the questions were even more difficult, because I was barely 30 when I gave birth to Abbas and that's not too old at all. Lots of people have children at that age. Was I being punished? But I quickly reasoned with myself that that can simply not be true. I vowed then, to myself, that I would never be ashamed of my child. He was a special gift from Allah (s.w.t) and not a punishment but a blessing. There were going to be challenges ahead, but I would face them because Allah (s.w.t) has said in the Quran that our souls will be tested to the extent to which we can bear and not beyond that."

The challenges involved in parenting a child with Down's Syndrome are so varied, that the full commitment and time of the whole family is required. For the Syeds, who already had a 6 year old daughter, Zahra, life took up a frantic pace. "I realized that I would have to empower myself if I wanted to be of any help to my son," says Sukaina. "The hospital had given us a phone number for help but it was totally up to us to follow up on it. I registered with the Downs Syndrome Association of Toronto and with various other organizations, I read every newsletter, books and everything else possible about Down's that I could find. I went to workshops, conferences, activities for mother and child. I took speech therapy and behaviour management courses to deal effectively with

Abbas and I also researched whatever type of funding was available out there to help him. Abbas became my focus but I had to also make time for Zahra and for my husband. The daily routine of life had to go on as well, of course. This is when it becomes difficult to find a balance and to decide how to share your time. In terms of the effect on our marriage and family life, alhamdulillah, we were able to pull together closer. My daughter matured very quickly because of all the challenges in our lives. I think that when you are confronted with a situation like this, it can either make or break a marriage. There are many spouses who can't take the pressure and end up leaving. I am glad that my husband is religious which helps a lot. There are times when he feels neglected, of course, but then we try to make an effort to spend some time alone together and go out. I must admit that whenever I take time out for myself, I can't help but feel guilty because I tell myself that my first priority should be Abbas, but then I have to remind myself that I need a change of scenery too so that I can be rejuvenated."

Both time and individualized attention are crucial when dealing with children who have Down's Syndrome. Parents interviewed spoke of the need for constant reinforcement coupled with regular repetition and reminders since low memory retention is an acute problem faced by such children.

"Like all parents, we had certain expectations from our first child, Zahra," explains Sukaina, "we knew that someday she, like any other child, will dress herself, read, write etc. With Abbas, everything he learned was a big milestone for us because we had no idea if he was capable of it. It took so much more effort to teach him how to button his shirt, or to count or to write something. And if after teaching him something we leave it for a week, then he forgets everything and it means starting all over again."

Zehra Hashem struggles with the same challenges. "The doctor has said that it is important to keep talking to Ferwa, even if she doesn't appear to understand because she needs constant stimulation in order to learn. He

has recommended that we make her watch children's TV programs as well because it will help with her speech development. Her memory is low but if she is interested in something then she makes an effort to learn it. Right now she is very interested in fishes and she has memorized names of all sorts of whales and can recognize their pictures. She goes to a regular school and has a special TA (teaching assistant) who simplifies the concepts for her. She never ceases to amaze me with her willingness to learn. Even as a baby, she made the effort to walk, became toilet trained, learned her alphabet. She can speak very clearly, understands everything that is said to her and makes an effort to communicate with those around her. I am so proud of her!"

A firm believer in her son's abilities, Sukaina has taken an active role in Abbas's education. He attends grade 5 in a regular school, and also has a TA to simplify concepts for him although his intellectual capabilities are not quite that of a 10 year old child's. "I have fought hard for his rights and will continue to do so," she says resolutely. "His therapists, his teachers, everyone tells me that I am a wonderful advocate for my son and I believe that it is my duty to do whatever I can for him. It is not always easy. Sometimes my husband cautions me to be

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less vocal because I often end up arguing or even crying when I am trying to win his case but I tell him, 'if you would be in my situation, you would react the same way'. My goal is to make my son as independent as possible so that one day he can live on his own, or go to the bank and write a cheque. I have to help him reach that goal."

Perhaps equally daunting as the goal for self-independence, is the goal for social integration that the parents of children with Down's often dream of. The social stigma faced by the children leaves them isolated from their peers, a fact that breaks their parents' heart. "Now that Abbas is older," says Sukaina, "I can see him becoming aware of the fact that kids his own age don't include him in their games. I can see him getting depressed and how it is affecting his self-esteem and I wish that I could make things better for him. Sometimes it causes me to go into a depression too and then I tell myself, 'Sukaina, you can't let every little thing bother you like this. There are other bigger challenges to worry about.' But I just can't help worrying that people would treat him like an individual and try to understand and accept him instead of ignoring him."

"If people took the time to know Ferwa," says Zehra Hashem, "they would see that she is like any other child who loves to play dress up, put nail polish on and braid her hair with fancy hairstyles. She even loves to put on *mendhi!* Two and a half years before Ferwa was born, I lost my 14 month old daughter in a car accident right outside the mosque. Those were the darkest years of my life and I never thought I would ever smile again. Then Allah (s.w.t) gave me Ferwa. And she has given me a reason to live again. She has fallen so much in love with this sweet girl. I wonder now why I was so scared before. I have given birth to her, she is mine, no matter what she has. And she is always by my side. She has become my partner, my friend, my companion. I love her so deeply, I think with her I would have died with grief. She has

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this wonderful ability to win everyone's hearts. She is so kind and loving. She may have Down's but she is a living, breathing, human being who responds to those around her."

The pure love that such special children tend to give and evoke is something that the Syed family has been touched with, as well. "My husband claims that only Abbas has the power to make me laugh," says Sukaina with a chuckle. "You know, when I see his face, I forget everything. Nobody makes me happy like Abbas can. He is so cute and loving and with him, there is just so much to look forward to in life. I cannot describe to you the joy that I feel when he is able to do something new. Little things like when he manages to button his own shirt by himself just gives me so much delight and I just exclaim with joy, 'Abbas, you did it!'"

For most parents of children with special needs, the future well-being of their children is a gnawing concern that is always in the back of their minds. "I worry about what will happen to little Ferwa once I am gone," says Zehra quietly. "I wish that we had a foster or adoption system in our com-

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munity so that such children can be taken care of after the death of their parents. I want to keep Ferwa in this community. I even wish we could have some sort of madressa system for children like her. Or even arrangements for outings and events to foster friendships. Imagine if we set aside a unit or two at the Jaffari Islamic Housing complex so people like her can live alone within the supportive environment of the community? We have to start somewhere."

"Having a child like Abbas has actually strengthened our faith and changed our outlook of life," says Sukaina philosophically. "There are some realities of life that you can't escape but you can at least improve things by doing a little bit of hard work. You have to reach out to others who may be able to give some advice, steel yourself from becoming too sensitive and try to open up to others too. There are times when I am just so exhausted in every way, my heart, my head, my body, everything is just numb but I have to push myself to go on. I have no choice. I can't afford to give up."

The selfless devotion of women like Sukaina and Zehra enhances the notion that paradise lies at the feet of a mother. There is no doubt that the strong presence of Allah (s.w.t) in their lives and acceptance of His decrees constantly nourishes their spirits.

"A woman caught sight of Abbas in my arms at the mosque one day," recalls Sukaina. "She asked me in Urdu, 'Is something wrong with your child?' I answered, 'Yes. He has a cold... And he is not like you and me.' Her face just changed and my mind was silently saying, 'don't feel sorry for me'. Then I looked at her in the eyes and said something that has given me peace, ever since. I said, 'aur hum apne Allah se Raazi hein'. (I am in agreement with my Lord. I accept, and I am satisfied with what He has chosen for me.)"

Author's Note:
With sincere gratitude to the families who so willingly agreed to share their stories. May Allah (s.w.t) shower his blessings upon you, Ameen.