

Narrative Medicine

Arya's mother

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'Madam, I have come,' said a sweet voice — one that I am used to hearing once every month. It was five year old Arya. This time though, she was on her feet, standing independently at the gate of our department. While she smiled as usual, I could see far greater happiness on her mother's face. In the three years that I had known them, it was the first time that I had seen Arya stand without support and I could not resist the impulse to rush and embrace her.

Mrs Kulkarni, Arya's mother, stood behind her to hold her in case she fell.

"I am so happy today that Arya is standing on her own. It is like a dream come true for me after all that struggle," said Mrs Kulkarni, as we walked towards my chamber. Meanwhile, Snehal, my therapist, took Arya off for her treatment.

I was aware of the struggle Mrs. Kulkarni had gone through. It could not have been an easy task traveling alone, 170 km, carrying Arya in her arms, once every month for three years. Once a month only because she could not make it more often than that due to financial constraints. Ideally, considering the profound developmental delay, Arya

needed daily treatment sessions. Instead, Mrs Kulkarni would learn the exercises from us and meticulously follow the given home exercise program under the guidance of a local Physiotherapist.

"For the first six months there was absolutely no difference in her physical activities," Mrs Kulkarni recalled. "When I helped her do the exercises at home, I doubted if they would work, but her sweet smile when she was able to achieve the next milestone would make me more determined about my efforts. Thank you for everything".

By this time we had reached my chamber and were sitting down. I could see that Mrs Kulkarni was very emotional. Today, finally, she was able to savour the fruits of her struggle. My mind went back to the day, three years ago, when she first brought Arya to our department.

Arya, then, was two years old but was unable to hold her head up. Mrs. Kulkarni was overly worried as Arya was her only child and the most awaited gift after a barren marriage of seven years. I personally liked treating Arya since she was a quiet

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child, even during exercises. She was very shy and never threw tantrums or showed any reluctance towards the exercises, no matter how many times they were repeated. Her mother meant everything to her and had to be with her during the complete one hour session.

I felt Mrs Kulkarni's gratitude was misplaced. "No, Mrs Kulkarni, you are the real hero for your daughter. What we did was just to guide you. It was you who followed our advice strictly and kept up the exercise prescription at home. Many other parents are not able to do that," I said.

"Yes," Mrs Kulkarni said. "I did that because it probably was the only option for us. I wanted Arya to be able to stand, walk and run like other children. I still remember how many times we haven't had anything but dal roti for lunch and dinner." By this time Mrs Kulkarni had started crying and I got up and went to her.

Putting my arm around her, I asked "How did you manage everything at home all these years?"

She replied in a very low tone, "Mr. Kulkarni met with an accident two years ago and lost the use of both his legs, and he lost his job too. I gave up all hope for anything. I thought everything was over. I couldn't imagine how I'd ever be able to look after both, my husband and Arya. It was a difficult time mentally as well as physically."

Mrs. Kulkarni continued. "But Arya's smiling face gave me the courage to fight against all odds. My husband helped me every moment in every possible way with Arya's treatment. You won't believe it, but despite his newly limited ability he helped me with all the household work. Financially, now things are

better since he has started a small business that he runs from the house.

The spark had come back into Mrs Kulkarni's eyes by this time. I was happy to see her mood change.

whirl Her storv sent me into introspection. reminded It me of the numerous instances, during the course of treatment of other children, when I get frustrated. My frustration is due to many factors which include regression in the child's development, lack of perseverance on the part of parents, and non-compliance of other therapists. Some of these factors are under my control but some are not; but just as Mrs Kulkarni persisted on her determined path despite staggering odds, I learned in that moment that I should not get deterred or disheartened. I should not allow hindrances to stop me or divert me from moving towards my goal.

Our conversation and my introspection was interrupted by Arya's giggling. She was enjoying her exercises. It was her first time on the parallel bars.

Mrs Kulkarni watched Arya, then turned back to me. "You see how happy she is while doing the standing exercises? I am proud of my child!"

"And we are proud of you, Mrs Kulkarni. It is thanks to your perseverance that Arya is standing today."

If Mrs Kulkarni taught me anything it was this - never give up on anybody, not even on yourself.

Just then, three year old Ram, who is cranky all the time, clapped for Arya and I saw him smile for the first time in six months. Happiness is infectious!

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