

A PARENT'S PERSPECTIVE

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I am a parent of a child with cerebral palsy. I had no idea what it means and how many people in the world suffer from it until life made me come face to face with it in the form of my only child , my son, Banraj. In the beginning when the mile stone were delayed, we were consulting doctors for answers; none of them diagnosed the problem as CP. In all case sheets I was told that he was having delayed milestones and thus would eventually come out of it. After consulting a dozen doctors and getting the same response, I was sure that it is delayed mile stones and so when a doctor said that it was not delayed mile stones but CP, I thought he was a quack and didn't know any thing about medicine. But he was the doctor who turned me towards a developmental neurologist and once I was there I came to know what actually was wrong with my baby.

Meanwhile, on the other side of medicine, which is the people who think that they knew more than most of the doctors and unfortunately were also my relatives who started giving me tips on what should be done to make Banraj walk with in a month. I was even directed towards holy men claiming to have the magical powers and could restore what ever had gone wrong.

At the developmental clinic, I was taught the right way to handle my child and to understand his needs and insecurities, his behaviour patterns, his exercises and every other detail that I had never come across during my consultation with various doctors, physiotherapist and other supernatural beings. I started developing something that was lacking in me for a very long time- FAITH.

Today my son is seven years old He walks with the support of a walker & modified floor reaction orthotic (swash and AFO)
He rides a bicycle with full rotation of peddle and at a normal speed.
Climbs on bicycle and climbs down on his own,
He is very intelligent, goes to a normal school, has done well in the KG2 final examination and has been promoted to 1st standard.
He swims with full hand strokes with the help of a tube but no other support,

He is very good with orals and is extremely talkative. Climbs bed and other furniture of same height. All this we have been able to achieve because we were all moving in the right direction under the right guidance with the right knowledge of what we are doing and what all is possible.

He goes to clinic 4 times a week and exercises for a period of 1 hour with the help of rings, wooden balls , blocks, rods pyramids, wooden pyramids, big bolsters and big exercising balls. The whole exercise program is designed to exercise every muscle of the body in different postures. Followed by strengthening exercises done with weights in prone, leg lifts etc.

At the clinic we also concentrate on group behaviour & activities related to schooling so that children know how to behave in school and other public places & perform at school like other children.

WHAT NEEDS TO BE DONE-

I wish that more doctors were aware of what CP is and what needs to be done to help parents who go to them with such children. The misguided parents keep spending money on wrong treatments and before age surgeries and wrong kind of exercises and end up doing more harm to the child than good.

I wish that the new researches and developments in the field of CP should reach the patients at a faster speed than it is being done right now.

I wish that the stem cell therapy could be developed faster and applied in CP so that the children can take maximum help from the treatment and lead a life which is better in quality.

I wish that steps were taken to help children in mainstreaming as the teachers do not know what should be done and maximum of the kids with CP who have normal intelligence remain ill-treated and ignored.

I know that awareness is the key to all the problems and so I wish that doctors and general public were more aware as to what needs to be done to special children with CP. As a parent member of IACP, I will support any initiative that is taken by IACP family forum group & join hands with doctors , therapists & educators towards this end. Parents will be the biggest beneficiaries of such efforts.