

Attitudes

I WISH I WERE NORMAL

Mithu Alur



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(This has been written for young people, so that they can understand spastic children better. The author has tried to look at her daughter Malini's body through 10 year old Malini's eyes)

I am a spastic girl. My brain is damaged. The result is I cannot speak too well as the co-ordination which is necessary for speaking has been affected and people cannot understand quickly what I am saying. My hands do not always obey me; they sometimes strike out all over the place; even if I want to drink a glass of orange juice when I am thirsty, my hands do not have the power to reach out for it, bring it to my lips and sip it.

The brain not only controls our thinking powers, but all the functions of the body. That part of my brain which controls physical movements got damaged when I was born. That is why anything which needs a motor skill, I cannot do very well. I suffer from all kinds of jerky, unco-ordinated movements which affect me from top to toe. I am what is known as a 'multiply handicapped child'.

'Spastic' is merely a jargon term to describe the medical condition of cerebral palsy. The brain being as nebulous as it is, with one area overlapping the other, the spastic does not sustain a clear-cut damage of one area. Many parts of

the brain can get affected and this disturbs the functions of walking, talking, feeding or working with our hands. Cerebral palsy is not a disease, it is a condition and it is not infectious. I specially mention this because quite often, when I go swimming with my mother, people come up and ask about me. They stare at me and begin these interminable questions. " What is wrong with her? She cannot walk? She can't even talk? But you shouldn't bring her for swimming, she may pass on her disease to the other children. " And I hear my mother explaining that I am not contagious! That anybody's child can be a spastic. There are many reasons, but the main one is a lack of oxygen to the brain during birth and it can happen to anybody.

I can understand everything. That part of my brain which controls the thought processes is not damaged. Therefore, my powers of observation, retention, memory and intelligence are normal. In fact, studies show that 50% of spastics have average intelligence. Somebody described us graphically when he defined our condition as "an intelligent mind trapped in a disobedient body".

I started reading when I was three years old. I attended a special school in England, where I had to work very hard from early in the morning. At school, I had to have exercises with the physio, speech and occupational therapists. The physiotherapist made me do all kinds of physical exercises - to learn balance and to control my unruly muscles. With the speech therapist, I had to learn

to eat and drink properly and to use the muscles of my lips, tongue and jaw, to articulate words correctly. The occupational therapist taught me to control my hand - to dress and undress myself. My teacher in the classroom taught me reading, writing and numbers. My whole body was broken up with demands from various individuals. Sometimes, I found it very hard. The simplest task of rolling over and crawling took me two years to accomplish. To stretch out and eat food with a spoon is a skill I still haven't mastered. I am still learning to drink from a cup. Although my childhood was such a lot of hard work, I felt thrilled and jubilant when I mastered a small task. The feeling of achievement was wonderful to experience. Naturally, I often feel sad when I cannot do many things after years of trying.

I am now 10. I still cannot walk on my own. But after all these years of work, I can walk with crutches. I have a tricycle on which I love to cover space. I also love swimming. I go to a special school in Bombay where I get education as well as therapy. In school, there are many children who are better than me and a few worse. We do enjoy our school very much. The children go home in the afternoon at 3 o'clock.

Unfortunately, unlike normal kids, I have very few friends. Its difficult to make friends if you cannot speak.

Sometimes I think if I work tremendously hard and listen to all my therapists and teachers, maybe I'll get cured. I'll become normal. Free to run around, jump, climb a tree,

dance, sing, shout, make a friend. Nobody will stare at me again when I go out.

I can get lost in a crowd.

I can be ordinary and not different.

I can be like you - free! gloriously free, from this dreadful body in which I am trapped and caged.

But this is not to be.

You see, if any brain cells get damaged, it cannot be repaired. Brain damage has no cure. The idea of getting treatment day after day is to teach the other parts of the brain to perform the functions of the damaged parts.

We can improve. We can contribute to the community. There are many stories of people like me, who have achieved terrific feats. They have become doctors, journalists, research fellows in Universities as well as accomplished computer operators.

But when I hear people talk about me in front of me - comments which may spring from deep-rooted prejudice and ignorance - I feel like telling them that I can understand, I have eyes, ears, organs, senses, just like them. I can feel affection and pain, just like them. I can feel joy and suffering, just like them. If you prick me, I too will bleed. I am human, in spite of my incompetent body.

The condition of cerebral palsy lasts a life-time. It's a lifetime of struggle, as my mother tells me, to be faced bravely; that I should make best use of what I have and count my blessings. She says that both pain and pleasure, like good and evil, are a part of life. Success depends on what best use we make of what we have; it is our ability to win over our adversities which makes life more meaningful. And that I must be strong.....and pray to God to give me more and more strength.

Although, I try to accept my handicap, I cannot discipline my unruly thoughts. I secretly keep saying that I wish I could be cured.

"Who can blame me if I sometimes say to myself, I wish people did not stare at me and talk about me in front of me" I wish...I wish....I wish I could fade into the background and not stand out like this....

I agree with her and I am determined to stand up to it. I will make every effort to build up my courage and fortitude. I will try and be a soldier and face life with this trying body that doesn't work.

*I could go to a normal school and have normal friends,
"I WISH I WERE NORMAL".*

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