

# Grace Under Challenges

## A Sibling Speaks

Prema Raghunath

When I became an elder sister after several years of being the youngest, my first reaction was a mixture of excitement and pride and, it must be admitted, feelings of satisfaction of getting the opportunity, at last, to generally give instructions and have somebody obey them, as I had been doing.

As time passed, it did not quite work out like that.

My sister was diagnosed with Cerebral Palsy (CP) and the resultant bewilderment, confusion and consternation in the family took many months to subside. My parents were, understandably, worried and completely in the dark, because this was a time when nothing much was known about conditions like this, which resulted in multiple disabilities of movement, speech and development. Having a child with disabilities meant social ostracism of a very sophisticated kind - everyone was kind and appeared to understand, but in fact, nobody did. Invitations to social functions thinned out and, as we had decided that Gita (my sister) was not going to be tucked away out of sight but would be a fully participative member of the family, our appearance caused embarrassment. I am going to try and outline the issues that arose from this. Things have changed greatly from those times, but the human angle remains essentially the same. I think a lot of people reading this will recognise some of the aspects as relevant.

### Loss of childhood

The other children in the family have to all grow up overnight - outwardly at least. I lost my parents to the overwhelming changes that having a child with disabilities inevitably brings. Everything has to revolve around the many needs - the general routine has to accommodate the various therapies - physiotherapy, speech therapy and other demands. This could result in, unless parents are alive to this, the siblings taking on more responsibility than they can possibly handle at a very young age. Consequently, they are automatically excluded from their friends' circles.

Secondly, many of the achievements of the siblings are sometimes underplayed in an effort to protect the sibling with disabilities. Although today many things have changed for the better and definitions have altered, I still feel that younger and elder siblings need to be given the attention they require to reach their own potential.

Thirdly, these deficits may never be made up. In many ways, I have recognised in myself the effects of having had adulthood thrust on me - anxiety, some survivor guilt and confused emotions.

### Increased empathy

The good part of growing up in such a situation is that one is far more *tolerant* - the lesson that life throws up surprises is learned early. The early sense of responsibility can morph into accepting leadership positions as well as a sense of self-reliance. In my own case, I think it made me far more tolerant of *differences* - I did not think everyone had to be the same for me to get on with them. In one sense, making friends was easier, though in another, more difficult. At one stage, the acid test of friendship became how the other person accepted Gita. If they could include her, they were all right, if not, then there were fights which sometimes ended in tears.

### Great love

I must mention this as an important component of being sister to a person with disabilities. There is an enormous sense of *love, care and nurture* which can be nothing but good. People usually have to wait for the birth of their own children to feel all this, but I think we - a special category- experience these

things earlier. It is tied up to the lost childhood aspect which I mentioned earlier but is beneficial, all the same.

### **What parents could do**

One of the big facets of having a child with disabilities is that it impacts everyone's life - parents, siblings, grandparents and, though perhaps to a lesser extent, the extended family. Parents feel several things - sadness, denial, sometimes disavowal while all the time knowing inwardly that this is not going to go away. However, daily life has to be lived out – going to work, running the home, keeping up with social connections, taking care of other responsibilities as well as finding the time and energy for another child, older or younger. The list is quite challenging.

But here's the thing – the other child (or children) has also been presented with a new normal. Grades may drop (they did for me), there may be tantrums, new behaviour patterns. Here is where parents could get help so that the sibling can get some quality time and space with them. This is easier said than done, but with the wisdom of hindsight, I can see what could have been different.

In the end, I want to say that if parents of children with disabilities become very special themselves – two ordinary human beings develop a side of themselves that can only be described as heroic and draw on the strength they never knew they possessed, siblings too turn out to be very special indeed. They are special because of their unflinching support of decisions made by others, not quite knowing what they are all about, only standing by the side of the brother or sister whom they will do anything for.

That is some of what I learned from Gita, whose grace and lovely, generous nature more than made up for the upheavals. For it was grace that she too displayed – grace under tremendous challenges, both physical and emotional. She could cut through the externals of any person and know them for what they were and let me have the benefit of the knowledge! We were dear sisters who were best friends.



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