

# RELATING TO A child

## RATHER THAN A DISABILITY

BY FIONA PLACE

My relationship with Fraser as a newborn was strongly influenced by his physical features: his smaller than average head, his almond shaped eyes, his thickish neck and his body's low muscle tone. I knew these differences meant something. And every time I looked at him, every time I fed and changed him, I sensed their potency as negative medical signifiers.

Perhaps it was my experience as a paediatric student nurse, perhaps it was because he was my second child, perhaps it was because my husband was a doctor, perhaps it was because of the pessimistic attitude of the staff, I don't know, but for a while the differences spoke so loudly to me I couldn't experience him as a baby, but only as an object.

I wanted to strip the label Down syndrome off his tiny body and discard it (preferably outside the room). My way of doing this was to request it not be assumed he had Down syndrome until the results of the blood tests were known. (Although I knew full well this would be long after I had left hospital).

Over the next few days he had to spend some time in the intensive care unit because of an unrelated medical problem. In some ways this helped me enormously because it allowed me to focus on looking after him in the same way you would any sick baby. It was something I could do. I felt competent and capable. Once he was back with me he breast fed easily, slept well and was generally very accommodating.

Fraser couldn't, however, communicate as effectively or as robustly as his older brother. For example, he didn't smile,

gurgle or wave his hands nearly as early or as distinctively. And because it wasn't easy to discern the features that would eventually emerge to distinguish him personality-wise, I found it difficult to get to know him. It was difficult to describe him in ways that were separate from his disability.

I wanted to form a solid relationship with Fraser, to love him deeply, but I didn't find it straightforward. My early relationship with him was very much shaped by his disability; by an engulfing sense of lack. It seemed there were so many things he would never do or never be. While I didn't like these unpleasant thoughts I knew denying them wouldn't do me much good either. I had to accept and acknowledge my disappointment. After all if I didn't learn how to look through his physical and intellectual limitations and see Fraser, how could I expect anyone else to?



Fiona Place with Fraser (left) and Harrison.

“...with each new word his disability fades just that little bit further into the background”



Fraser at school on Father's day

Learning to see took time and patience. There was a quality of passivity I had to learn to ignore. A quality of awkwardness I had to ignore. This continued stage after stage. When Fraser was a toddler he had such low muscle tone he was unable to sit upright. This meant he could only be bathed if I sat and held him in the bath and he could only look around the room if I sat him upright in a specially made supportive chair.

When he was three he had to be placed in a standing frame twice a day, which he hated, and wear bands on his legs when he wasn't in the frame. He also had hearing aids, and once weekly speech therapy, as well as a patch over one eye! It wasn't easy but if I wanted to see him as a boy who would one day be in the driver's seat I had to believe there'd be a day when there'd be no aids, only Fraser.

Today at nine years of age Fraser can not only run and swim, he can also do the most spectacular dives and bombs. He no longer wears a patch over his eye or hearing aids – he grew out of his hearing loss thanks to grommets, wider ear canals and less infections.

And while he may not be the greatest talker with Down syndrome, (he usually only uses five word sentences when there is a reward), with each new word his disability fades just that little bit further into the background as he steps forward.

These days he can tell me if he wants a sandwich or milk while he watches the Simpsons. He can ask to go to the video store, the beach or say he is tired and wants to go to bed. These days what was once an overwhelming sense of lack has been replaced with a sense of hey, maybe he can. Maybe he can. 🌀