

## A Life Unwritten

Written by Liza Maloney

Wednesday, 19 August 2009

*Liza Maloney wonders why no manual could tell her what to expect when her child was diagnosed with autism...*

I remember the day our daughter was diagnosed like it was yesterday. We sat in the paediatric neurologist's rooms and tried to comprehend the words "your daughter has autism, a lifelong disability. I recommend that you contact disability services because you are going to need them for a very long time". It was like being hit with a stun gun and having your heart torn out simultaneously. We had only just celebrated her second birthday.

We returned home that afternoon to one of the worst storms our region had ever experienced. Our home was without power for the following three days. The irony was not lost on us. The darkness was symbolic of the pain we felt and of a journey into the unknown that we had only just begun.

That journey came without any teaching manual. Books such as *The First Five Years* and *Raising Toddlers* went into the recycling bin. We had to create our own parenting manual. Our story would be very different to we had imagined or read in any book. There weren't any books to tell us that this was going to be extremely difficult, that we would have to become an 'autistic family' in order to survive.

There was nothing to explain that we would still be changing nappies into our ninth year of parenting and perhaps beyond. We weren't warned of the hours we would spend visiting psychologists, speech therapists, occupational therapists... the list goes on. We couldn't find a single piece of literature that prepared us for having to fight for our daughter's rights every day.

There wasn't a parenting manual that told us that our house would need to be as bare as possible: no carpet, no rugs, the less furniture the better. Because furniture would be broken, chewed, urinated on and smeared with faeces. No manual explained to us that we would need to lock our external doors from the inside otherwise our daughter would escape and run naked down the road.

There wasn't anything that explained to us that we would have to spend countless hours teaching our daughter to use a speaking device because otherwise she would be unable to communicate her most basic needs to us. No-one informed us that something as simple as buying a loaf of bread would require a careful plan of action - because if it is not in the routine, it will cause a huge amount of stress. You just can't run out of anything, that's all there is to it.

Not a single text existed that could describe the loneliness and isolation that that came with having a child with a disability. Nothing to prepare us for the pain of realising that our child would never look us in the eye and call us Mummy and Daddy, or tell us that she loved us. That it would take more than seven years to teach our child to reciprocate a hug.

What is taken for granted in most families is cherished and celebrated in our world. If only we had been told this, all those years ago.

(posts)

Heather Golding

### **A Life Unwritten**

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From the moment I read Liza Maloney's story about there being no manual to tell her what to expect when her child was diagnosed with autism, I knew exactly where it was heading. The hairs on the back of my neck stood up! Virtually everything Liza described is exactly, if not similar, to what I have also experienced with my own child.

I have also read the books Liza mentioned, but found them too clinical and full of technical mumbo jumbo, which sadly lacked the soft human touch of just what it is like to raise a child with autism, let alone what to expect and how to face each moment as they occur. So I decided to tackle the huge task myself and am currently in the process of writing my own book on the subject - from a mother's perspective. Despite the fact that I have also read a few books written by parents of children with autism, I have decided to keep working on my manuscript, because not only is it helping me with my grieving process, I am learning more about my child and his world of autism, be documenting everything, both good and bad, the happy moments as well as all the crap I've personally had to deal with over these past few years.

Ironically, like Liza, I also describe the isolation and loneliness, the endless medical appointments, the strict routine and the polava that can simply unravel that routine when you do something totally different, like simply buying a loaf of bread, which requires a careful plan of action, as Liza said.

However, I am yet to find a publisher who is even remotely interested in my book idea, having already faced their rejection, let alone face the unfamiliar task of self-publishing.

