

An excellent account of the writer's candid experiences with her autistic sibling as well as daily struggles her family has to cope with. Free of jargon, it is an easy read that provides an insight into the autism world, and allows readers to peer into the mind and understand the idiosyncratic behaviours of an autistic individual.

– Dr Noel Chia Kok Hwee, Assistant Professor, Early Childhood & Special Education Academic Group, NIE

Just as with mental illness, there are many misconceptions about autism. This book, beautifully penned by the author that draws on the struggles of a family with an autistic child, brought tears to my eyes. And it leads me to ask: "Can't society learn to accept that children with autism are also God's children who need love, understanding and support to enable them to lead perfectly normal lives?"

– Raymond Anthony Fernando, Author, Motivational Speaker, Mental Health Activist

aqilah teo

ORDINARY  
STORIES IN AN  
EXTRA<sup>ORDINARY</sup>  
WORLD

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To my father *Paul Teo*, the scholar  
To my mother *Sabariah Teo*, the sage  
And to *Jan*, who sits beside me as *I* write.

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# Prologue

As I have mentioned to many friends, this is not a textbook on autism. That would be a very interesting textbook, and it has not been written yet. Perhaps it will never be. Nor is this a manual on special needs; no, nothing of that sort.

This is a true account of what the special needs world is like in Singapore. Here, I have covered merely a fraction of the thousands of stories that can be told in a thousand different ways.

I am only able to write from a second-hand point of view on autism. A first-hand account mapping out all the secrets of autism would probably be declared the next Wonder of the World. But Jan has so far not shown any inclination for writing.

One may jest, but in the special needs world, we are constantly fighting for awareness and provisions. Sometimes, it is simply about acceptance, one less sneer at, and one more open heart for a special needs child on the street. This is my part of the fight.

All the names mentioned in this book are real, except for those of children and my brother himself. Jan is not his real name. It does, however, hold a special significance for him.

Aqilah Teo

## Chapter 1

### A Tale Of Anomalous Childhoods

My mother groan'd! My father wept  
Into this dangerous world I leapt  
Helpless, naked, piping loud  
Like a fiend hid in a cloud

– William Blake, *Infant Sorrow*

## The 1<sup>st</sup> Step: Into the Dangerous World

My brother Jan had not come with a manual.

My memories of the events surrounding his birth are somewhat fuzzy today, but I recall my parents had not said to me, ‘Congratulations, you’ve a new baby brother. We’ve got a manual too, so we’ll figure out how to operate him soon enough.’

I had lived as an only child for the first six years of my life, and did not fully understand the concept of a baby brother.

My parents seemed to be very busy and I knew that something important was going to happen. I knew what babies looked like, and someone had probably told me that we would have one in the house soon.

‘What is this new thing that is coming?’ I had wondered. ‘Is it for me? Does it run on batteries? Will it make a noise if I poke at it?’

Beyond that, however, it was all vague bits of uninteresting information as I went about my own daily business.

Then, one day, the new arrival came home. I resented the intrusion of this new member of the family, this reddish wailing thing wrapped in a large white napkin. I might have preferred a hotdog; it would have looked almost the same and posed a much lesser threat.

Nonetheless I soon grew fond of him in a shallow, childish way. He was cute, and fun to poke at and play with. But when it came to important matters such as who got to lie next to my mother at bedtime, I turned into a monster of a jealous sibling. Indeed, I would push him away and throw great

tantrums until my mother handed him over to the domestic help to rock him to sleep.

Jan soon grew to be a round, healthy, happy toddler and no one suspected anything different. He first sat up at six months. His first words were “mam mam” and “meow” at around the same time. He stopped saying anything else after that.

At one year and two months, Jan took his first steps. When he was two and a half years old, still not another word had come out of his mouth. The grown-ups suspected he was either a slow developer, or had tongue tie. Tongue tie happens when the membrane under the tongue is unusually short. It pulls at the tongue, which then cannot move as freely. People with tongue tie have trouble speaking.

Little Jan was brought to see the general practitioner. The doctor said Jan’s tongue was perfectly fine. It could be autism.

At the time, my mother had no idea what autism was or what the word meant, but she knew something was not right. She excused herself from the doctor’s office, went outside and began to weep. Now this really was something, because my mother is not a weepy sort of person.

My parents called doctors, and they called other doctors. My brother was carted all over the place like a wrongly-addressed parcel.

One Dr K B Phua, a gifted and respected paediatrician, arranged for speech therapy sessions for my brother. The therapists said that Jan was “ego-centric”, but they were not able to properly categorise him as autistic. In fact, he did not seem to really fit in any profile at all.



When Jan was three, the speech therapists contacted Balestier Special School. They arranged for assessments and ran him through a gauntlet of tests with cameras and videos and machinery.

Jan was also brought to see Dr Vera Bernard-Opitz at the National University of Singapore. But he simply did not fit into any of their programmes. They kindly advised us to bring him home. Knowing my brother's bossiness, he might have been trying to run a few programmes of his own over there.

All the while, Jan seemed perfectly normal aside from his not talking. He would help my mother with the household chores, like doing the laundry. When we were cooking for a function once, he helped spoon glutinous rice into the cups that were to be served to the guests.

Then out of nowhere, my brother began to show signs of hyperactiveness. I was in primary school at the time. I remember how he would ricochet about the house like a pinball gone loose. 'First he's here, suddenly he's there,' we used to say. You did not even see him move.

Jan also began to develop habits like hand-swirling and staring at ceilings. He liked anything circular and ran around in circles. Other times, he was just running everywhere. He was a whirlwind packed into a little boy, a human cannonball.

It seemed, too, as if he had to rebel against us every step of the way. If you wanted to get him to walk, he threw himself on the floor; if you picked him up, he would deliberately weaken his knees and let you drag him along; if you wanted to get him to sit down, he would leap up and dash off. When you wanted to stop, he would go; when you said up, he went down; when you said yes, he said no.

He once managed to single-handedly loosen the door frame to one of the bedrooms. I remember coming home from school every day and using a hammer to knock the sides back into place before we got it fixed.

And if there was any need to hold him down, it would look as though the grown-ups were trying to flatten a tiny tornado. Jan would twist and turn and wriggle his way out of their grip with fantastic skill. When he could not, he at least made sure not to go down without a fight.

Jan especially detested going to strange places. Or, at least, he seemed to detest visiting. He put up a spectacular performance one time – the small fearsome feisty thing, all elbows and knees and angry roars, when my father tried to get him out of the car. In the end, he won, and my father had a picnic with him in the car while my mother and I did the visiting.

The psychiatrists said he would outgrow the hyperactiveness. Finally, they made an official diagnosis of his autism. Jan was two and a half.

## **The 2<sup>nd</sup> Step**

Special schools have long waiting lists. About two years long, to be precise. My brother joined the list when he was nearly three. In the meantime he continued with his speech therapy and visits to the psychologists, developed bronchitis, and spent his time bossing everyone around.

The first time I was allowed to look after him by myself was when I was about ten. Jan was four. Mum had started her traction treatments at the hospital for her pro-lapsed intervertebral disc (PID). This is where the disc or discs

that help to hold a person's spine together gets punctured or torn, and can be really quite painful.

I was very excited at being given the responsibility. I would play with him and make sure that he ate his lunch and did not get into trouble. At showertime, I would wash him very thoroughly and after that proudly report to my parents that he was "squeaky clean". It was around this time we started calling him Squeaky, and the nickname stuck for the next ten years.

Jan liked showers and baths. He liked soap too, perhaps a little too much. He had seen a children's soap commercial on television in which the kids submerged themselves in mountains of suds, and decided he was going to do the same. He would sneak into the bathroom and squeeze out bottle after bottle of soap and shampoo until he and the entire bathroom were covered in thick foam and soapy water.

People have said, 'Why don't you just hide them or lock them up where he can't get them?'

Finding a place to hide things from Jan is a never-ending quest. He is very resourceful. So the search for the ideal hiding place carries on from one day to the next. It becomes such that we end up doing little else but look for places to hide our things. I reckon the only place we did not try to hide the soaps in were the ceiling light covers.

The days passed. Finally, at the age of five, my brother entered Balestier Special School.

## The 3<sup>rd</sup> Step

Jan used to be known fondly as "The Big Boss" at school, as if he were running a gang. He would boss his teachers, the aides, the school staff, the classroom doors and passing pigeons.

He liked school. He especially found the swimming and computer lessons to his fancy. Once, he insisted on instructing one of his computer teachers on how to operate a program being used. He had apparently decided that the latter was doing it all wrong, and spent the entire lesson showing the teacher what to do.

Jan was always very proud of his school uniform and his schoolbag and school lunchbox. He would wait eagerly for the school bus to pick him up from home. He definitely looked forward to school much more than his sister did.

My brother grew to be inseparable from some of his teachers. When he was assigned new teachers at the beginning of a new school year, the pint-sized dictator insisted vehemently on having his old favourites back. The school had to rearrange the teachers' roster, the grown-ups did a lot of scrabbling, and in the end, my brother nearly always got his way.

The teachers loved Jan very much, as they did with all their children. I suppose, too, that Jan has his own brand of sparkling charm. Folks have declared that once you spent some time with the boy, it is a matter of course that you ended up getting really fond of him. Jan's past caregivers have even called my mother over the phone to tell her how much they missed little Jan, and sniffled.

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## About the Author

Aqilah Teo is a preschool teacher and freelance writer who has worked with children ranging from preschoolers to teenagers. Her brother's autism led to her fascination with psychology and epistemology. She hopes to shine a spotlight on the special needs world through the stories in this book.