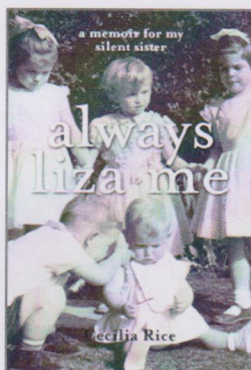


"Always Liza To Me" by Cecilia Rice



Allen & Unwin (2009)

Book Review by Katrina Clark.

Reading Cecilia Rice's book gave me a perspective on living with a child with a disability that shook my reality. As a mother of a 13 year old daughter with Rett Syndrome, I thought I knew it all. What I had never fully considered was the perspective of my other children as siblings to our Georgia.

The author, Cecilia Rice, grew up as a twin in a family of 6 children. Cecilia's parents' first child, a boy, survived only 5 hours. Their second, a girl christened "Elizabeth", was born with physical and intellectual disabilities and was also thought unlikely to survive. Cecilia and her twin sister were born only one year after Elizabeth. Their mother, an ardent Catholic, went on to have 3 more healthy children after the twins, each of whom had quite different reactions to growing up with Elizabeth as the focus of their parents' attention.

Cecilia describes how her parents dished out their love on a "triage basis", dealing with the demands of Elizabeth, who became more unpredictably violent and dangerous as each new baby was brought home from the hospital. Cecilia's account of growing up is honest, raw and frank.

I was personally able to identify all too easily with Cecilia's mother's desire to dictate routine and order in a house full of chaos, of flash tempers and of over-reactions at risky behaviour that might lead to a healthy child also suffering brain damage. I recognized and respected her mother's courage in seeking to hold her head up high whilst managing inappropriate and embarrassing behaviour in a shopping centre or clearing her daughter of excrement smeared in a split second of inattention.

With virtually no home help and 5 younger children to care for, Elizabeth was placed in care outside the family home from 6 years of age. I had expected this action to distinguish this family from my own in some way but, instead, I ached for Cecilia and her mother as I read of how traumatic it was to return Elizabeth to her place of care after each family outing.

Cecilia is honestly brutal about how placing Elizabeth in care outside the home made life easier for her and her siblings but also sensitively recognizes the ongoing pain and sadness that decision caused her parents. Elizabeth, referred to more fondly by her family as "Liza", was never

abandoned. Her parents love and concern for her crossed the boundaries of distance and her place as a member of the family was always paramount.

As Cecilia points out:

"There are many forgotten people in this world; not all of them live in institutions. And not all who live in institutions are forgotten." (p135)

What surprised me most when reading "**Always Liza to Me**" was how each sibling was so affected by Elizabeth, notwithstanding she had lived away from home from such a young age. How then are my own children affected by growing up with their youngest sister being so physically and intellectually disabled? Can I be so naïve to continue to believe it is just a co-incidence that my 18 year old has chosen to study Genetics at University, pretending to myself that my husband and I have shielded them as they grew? Should they worry about the future caring responsibilities ahead of them?

Do they look at me often as their "crazed mother", focused solely on the intense needs of her child with a disability, campaigning in any "spare time" to change policy and attitudes Australia-wide for a better future for all people with a disability and their families? Where do they fit into that picture?

I cried as I took comfort from Cecilia's reflection that, in her own experience & in speaking with other siblings, although they love their sibling deeply, the love of a sibling ***"is not the engulfing, stretched love of our mothers"***. She states, ***"It is a gentle, watchful love & we are not sorrowful."*** (p197)

Strangely, Cecilia Rice and I have walked similar paths in our professional lives – I was a summer intern in the law firm where she worked; we both specialized in the same area of law and share many colleagues as a result, but I never knew of her history until she wrote "**Always Liza to Me**" and I suspect she never knew of my more recent immersion in the world of disability until I saw her at a fundraising event organized last year at Parliament House.

Isn't that the way of the world though? Many, many more people are touched by disability in this world than is apparent on the surface. That is why, when a Government finds the courage to implement a scheme supportive of more funding and better services for people with a disability in this country, a National Disability Insurance Scheme, Australians will support it, and support it en masse.

Thank you to Katrina Clark for providing this review.