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## "A different Light"

### **A Different Light 27 July 2019 – WORLD TO RITES**

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Funerals and Powhiri. I instinctually tend to shy away from such formal and public events. Both occasions generally require me walking in front of a group of people I don't necessarily know. This combination of social intensity and mobilisation can often make my cerebral palsy go into overdrive making all four limbs rigidly hyper-extend. I used to disparagingly call this phenomenon 'rigor mortis'. In time I shortened the term, to the more casually catchy, 'riga' and then used to Dad joke with my daughters about getting 'riggy with it' after Will Smith's dance hit in the 90's.

This past week I had two such occasions. My wife's grandmother passed away days before her 101<sup>st</sup> birthday. The funeral was on Saturday. There were four generations who attended including our Isla, who was Grandma's Great Great Grandchild. I attended on my scooter so thankfully there was no 'riga'. It was however very moving. To bear witness to, and be a part of, the deeply felt loss of such an iconic special Grandma was sad. The ceremony did however celebrate and underpin the life of a gracious matriarch who united multiple generations around her. Following this were catch ups with relatives from near and far and shared memories of Grandma. I recalled a first Boxing Day celebration I attended at her place. I used stuff a hand in my jeans' pocket in those days to help me retain balance, especially when walking into unknown territory. On meeting Grandma, she quickly spied this and gave me the royal command to 'get your hands out of your pockets!' You did not defy Grandma, so out they came and I wobbled away for the rest of the event. I knew then, that if I could be told off, Grandma really embraced me as part of the family

The Powhiri was on Tuesday morning. My moko and her parents did the decent thing and moved back to permanently live in Aotearoa even better they have moved to our local neighbourhood. Yes Ruakaka; our answer to the Gold Coast. This week she started at her local pre-school, Bream Bay Kindergarten. We were duly invited to her Powhiri.

We waited by the doorway and then a group of littlies came and held our hands to lead us in. A little boy made a beeline for me. It was so natural I simply followed him to where we were seated, and my arms and legs pretty much behaved. The staff and some of the pupils at the kindy gave their pepeha, welcomed us and sang a waiata. My daughter and wife

responded, and we sung 'Te Aroha' back. While Sally was speaking on our behalf, Isla hid under her mother's scarf, reminding me of when I used to drive her mother to school and she would duck down in acute embarrassment. When we left Isla was happily playing-grounded in the playground and feeling at home. We felt welcomed.

Both events were a good reminder that rituals and occasions should not be shied away from but embraced – and you will be too.

*Jonny Wilkinson is the CEO of Tiaho Trust - Disability A Matter of Perception. A Whangarei based disability advocacy organisation.*