



Lydia

Richard Page

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This is the story of my late wife Lydia and our family's journey with Motor Neurone Disease/Amyotrophic Lateral Sclerosis (MND/ALS). Lydia presented symptoms in April 2009 and was diagnosed with MND in September 2009. She passed on 25 February 2011 and I dedicated myself since March 2011 to honour her memory and raise awareness of this terrible dreaded disease. I spent 2 years and 7 months writing the book at night and weekends. MND is very rare, terminal and untreatable and it was my mission to educate and inform Families with members who have been diagnosed with MND, Care Givers and Medical Practitioners of our experience through the various phases of the disease. As the primary Care Giver I accumulated first-hand experience of the symptoms and symptomatic relief of MND and how to maintain the Patient's quality of life. It is also a personal and detailed journey of how my wife as the patient, suffered from the progressive ravages of the disease and how I as the husband and Care Giver, experienced the journey. The book is composed of 8 sections chronicling the journey from humble beginnings during the Apartheid Group Areas and Job Reservations eras through the difficulties of self-realisation, career development to financial stability only for the disease to strike and deprive us from enjoying the fruits of our labour. The first three sections map the journey from humble beginnings to self-realisation. The fourth section maps our journey from April 2009 when she presented symptoms to diagnosis September 2009. The fifth section through to the seventh section maps our journey tracking the progressive degeneration month by month from September 2009 to February 2011 when she passed on. The eighth section chronicles lessons learnt and my understanding and coming to terms with Lydia's passing which I believe can offer comfort and coping mechanisms to the families left behind. I believe the fourth, fifth, sixth and seventh sections will benefit families, Care Givers and Medical Practitioners by describing the progressive degeneration phases and what to do to provide symptomatic relief. The eighth section offers insights from lessons learnt from the journey and will hopefully provide comfort and understanding for the families affected by MND/ALS.

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