

# Scleroderma - Jo's Journey

This journey starts long before I knew what the word meant even though I had nursed for a number of years. Many years later when I did know what it was, my nursing text book had a quarter of a paragraph with very vague description without a hopeful prognosis or treatment.

My mother was not well for many years. Doctors knew she was ill but couldn't find a cause she was a hard worker and I can remember her saying "don't tell your father" when she needed to lie down each afternoon and was becoming more breathless and losing weight. In time my father took her to Alice Springs to see if the drier air would help (my sister lived there at the time). The Doctor there was baffled and sent her to Adelaide after many tests they eventually diagnosed my Mother with progressive systemic sclerosis. Mother lived only 2 months after diagnosis and passed away at the age of 52.

The reason I mentioned this, is to point out how far our Medical research has come and today we don't have such a journey, although it is still a difficult disease to diagnosis but now we do now have successful treatment regimes.

My personal journey started in 1978, till then I was a very fit and healthy woman with two children and a good husband. I had an operation for a tumour in the frontal sinus and that seemed to begin my journey. My general health didn't pick up and again had to search for answers, one of which was to suggest I go to a Psychiatrist? I then saw an advertisement in the newspaper describing my symptoms and the invitation to attend a Scleroderma meeting. I had never heard the word before but thought I would go along. I was relieved to see old people there for I had feared that I would never reach old age as my Mother had died so young, it was really a huge weight off my mind. I do encourage the existence of a support group in whatever form because there you see how others cope with their symptoms and enjoy an interchange of encouragement.

With the advance in research of Autoimmune Diseases there are diagnostic procedures that enable quicker and more accurate diagnosis and the search continues for a cause and better understanding of the disease process.

Our opportunity to become informed is so much greater these days with access to the internet, our newsletters and support groups.

Where am I now? I am in my late sixties and coping very well. Yes I have good and bad days but I have a very supportive and understanding family, a very firm faith, attentive Medical Practitioners and an array of pills, so can look forward to a long and satisfying life.

*Thank you for sharing your story Jo*

**Juliet Roosendaal's Life Story**

<http://www.theherald.com.au/news/local/news/general/unsung-hero-juliet-roosendaal/2577844.aspx>