

Scleroderma - Cheryl's Story

Hi my name is Cheryl and I live on the Central Coast of NSW. I am married with 2 adult daughters and a wonderful husband. I was diagnosed with Diffuse Scleroderma in January 2007 age 49 years old. We lived a quite active life, bike riding approximately 100kms a week, regularly walking each week, regular camping trips and bush walking, plus working and looking after a family and also caring for my mother with dementia.

My symptoms started with my hands swelling and unable to make a fist, my G.P. ran the routine blood test, and then back we went for the results, to be told I need an experienced Rheumatologist as he thought maybe I have Scleroderma. So in March 2007 I had my first visit with the Rheumatologist, who ran more blood tests and started me on some medication. Being the kind of person not to run to doctors I hadn't gone back to my G.P. as my symptoms started progressing, so I was back at the Rheumatologist 2 weeks later for further results. On leaving after that first visit the receptionist commented that nobody comes back in 2 weeks I thought this must be serious. At my next visit they started me on stronger medication and watched my progress with blood test fortnightly and 6 weekly visits. Now this was a huge life style change.

In the July 2007 I had my first signs of Raynaud's Disease and I had never been so cold in my life. I had all the routine test for my Lungs and they were all clear. Then in October 2007 I went into Scleroderma Renal Failure. I spent 3 weeks in The Royal Newcastle Centre as they tried to stabilize my blood pressure, this was when I had my first contact with the Autoimmune Resource & Research Centre when one of the staff came down to have a chat. I sort of lost the plot when they told me my kidney function was 20%, but once I accepted this and things were explain by the Kidney Specialist it was time to get on with life. Now life became doctors and medication, then a reaction to the medication with a severe skin rash all over my body so back in hospital for another week just before Christmas of 2007. The Kidney Specialist thought my kidney function wouldn't get back to 30% but after about three months it was back to 36% and now is between 45-50%.

Things progressed fairly rapidly after this with the skin tightening starting all over my body, arms, legs and face. They also diagnosed me with Water Melon Stomach after losing 20 kilos quite rapidly, most women all their life try and lose weight and never can, mine just seem to melt away, people I had known for years would walk straight past me and not recognize me. The littlest things that I use to be able to do, like reaching my feet, washing my hair, putting clothes on, even putting my socks on or trying to pick things up off the floor, reaching the clothes line were all a real challenge now. So in February 2008 I started on some new medication which has been a great help, it has been a slow process, slowly starting to exercise again, at first I could only walk a small distance but with perseverance I now walk at least 4-5 kms regularly along our local beach and also ride my bike about 20kms but at a much slower pace.

This journey has been a challenge and for all the bad parts a lot of good has come out of it. It gave me the chance to spend more time with my family especially my husband who now helps care for me and does most of the housework, it also gave me the chance to spend more time with my mother before her dementia declined, as I was no longer working I could care for mum with the help of my Husband who is now only working 2 days a week. As mum's dementia declined I had to make the decision for permanent care which was a big decision for all my family, but now I have more time to spend quality time with mum. Since mums placement family and friends say I look so much better, so we must think of caring for ourselves, as most of us don't have the energy we once had and to do this we must

learn to put ourselves first. If I am not feeling up to some particular activity that day I now just change my plans to suit. My 2 daughters and their partners were also a great help with all family activities and this has also been a great change for them as well, it affects all members of our families. I look at life totally different now and I feel that there are more important things in life. My work was very supportive and didn't push for a resignation as I felt this wasn't a decision being made

by me, but made for me because of my health problems. I have only just resigned this year and have now accepted this decision. Some days are very hard and not knowing how this disease will progress sometimes gets me down but I just pick myself up and keep fighting as a positive attitude is so important.

As I've only had Scleroderma for 2 years I still have a lot to learn, but with each visit to the different specialists I learn something new every time. Also by talking to lots of different people with the disease and with the Autoimmune Resource & Research Centre I have gained a lot of knowledge. I realize there is hope and that tomorrow will be a better day, so don't give up.

Thank you so much Cheryl for sharing your story