

# ***My Journey with Scleroderma - by Yvonne Turner***

## ***Raynaud's***

In the winter of 1995 whilst touring UK, my fingers turned white on cold days for the first time. On returning home my GP diagnosed Raynaud's'. He treated me with medication and advice until late 2001 when he referred me to a vascular physician because of worsening finger ulcers. The VP diagnosed limited (crest) scleroderma. No medication was changed. In 2006 I lost the top of my right index finger to dry gangrene and in 2008 similar on my middle finger but this time I knew to seek help earlier. The best advice I have received is:

- Need for central heating at home to minimise temperature changes, hence avoiding pain.
- Wear gloves, I have found ski gloves/mittens indispensable and I wear gloves most of the winter even at home. I never leave the house without gloves, even in the summer.
- If pain is a problem get referred to a pain clinic. I received good advice on managing medication for pain and in 2006 and 2008 had a Stellar Ganglion Block to stop some of the pain in those bad years.

## ***Calcinosis***

In 2004 I had my first problem with calcinosis. Liquid calcium erupted on the tip of my left middle finger and continued for eighteen months until Christmas 2005. Three calcium crystals came out of the finger at that time. Since then I have had calcinosis eruptions/ulcers/scabs on all but three fingers/thumbs, some fingers in multiple spots - I can count 13 - some old, some current and the soreness is present at varying levels even on the oldest sites.

Late 2008 I noticed calcinosis on my left elbow. Unfortunately it became infected. I took 10 courses of oral antibiotics, had five days in hospital and 2 weeks at home with a pump (on intravenous antibiotics) with the APAC nurses attending every day. Surgery followed to clean the area. I continued to see the community nurse for the next year until the calcium ceased exuding and the wound healed. The best advice I received is:

- Take all steps to avoid infection
- Mexoplexlite as a dressing for ulcers and exuding sites. It is the thin sponge, sticky on the side that is placed on the wound. It draws the moisture from the wound and keeps it as dry as possible. Cover to keep in place. I have found it is best not to let the site dry out if it is still active.
- Same advice for pain as for Raynaud's.

## ***Gastrointestinal***

I see a gastroenterologist when required, but my problems do not require constant attendance. I take medication for reflux. I have a swallowing difficulty which I believe is due to 'motility'. Problems with the lower bowel are a "nuisance" and managed by suitable foods and medication.

## ***Pulmonary Arterial Hypertension (PAH)***

Late 2007 while on holidays noticed worse than usual breathlessness on walks and much distress up slopes/steps. On return an echocardiogram showed I had PAH. I saw a respiratory physician but no treatment was started at that time. I had an echo every 7 months to monitor progression. November 2007 figure quoted to me was 45, November 2008 - 55, May 2009 - 82 ie - severe. At this stage I was referred to a cardiologist, tests done and referred to an immunologist. In September 2009, I started taking Bosentan.

The condition was fairly stable until March 2011 when I noticed more than usual breathlessness, swollen legs and weight gain. The echo number was way

over 80. After much toing and froing with all my doctors I firstly put on oral diuretics followed by oxygen at home and finally hospital in May with Right Heart Failure for 12 days to receive intravenous diuretics. I lost 10 kilos in weight (fluid) while in hospital and a total of twenty kilos by the end of June. An ECHO in July- the figure was - 65, January, 2012 -60. I had gone from being someone who needed help doing many things to now feeling better than I have for some time. On this long hard road I have learnt:

- The most important thing to overcome from the experience is to watch fluid intake. I am currently on a limit of 1.5 litres a day and take 4x40mg of Lasix a day. Fluid is anything that runs at room temperature and includes ice-cream, yoghurt, sauces etc.
- It is a fine balance between fluid intake and diuretics as blood pressure can be affected.
- Daily weight watching is important to ensure that fluid retention is not returning. An increase of 2 kilos in 2 days is cause for concern.

## ***Sleep***

Over most of the summer, I have had trouble sleeping due to restless muscles. This may or may not be related to scleroderma. As there were similarities with the sleep problems leading to heat failure last year I was concerned. Thankfully I am now sleeping well again, and feel well but no reason was found for the problem.

## ***Telangiectasia***

I had an internal bleed in late January but no source was found. My immunologist believes it was due to telangiectasia, ie a blood vessel burst in my stomach. I required blood transfusions at the time and it left me anaemic. Regular blood tests show the blood count is gradually getting back to normal. As it is the red blood cells that carry oxygen to the body my oxygen use was increased from 16+ to 20 hours a day.

## ***In conclusion***

I am sure we have all found that one of the most difficult things about this disease we have is that we can look healthy - no cast, no crutches or other outward signs to indicate a problem. I am aware of odd glances on occasions I take my oxygen concentrator into public places and I am waiting for the day when I get challenged for parking in a disabled car park.

Exercise is problematic (everything has to be at a slow pace), but I try to go to cardiac gym at Gosford hospital once a week. I did a "Heart Failure" course there last year so now I am allowed to attend for an hour a week (free of charge). It is staffed with cardiac nurses and they check blood pressure, oxygen and will discuss any concerns anyone may have.

I have always been a positive person- look on the bright side of everything. Laughter is good medicine! LOL

Most of all I have a supportive family. My husband does the cooking, heavy work and drives me places if I'm not up to it. I still like to do a little gardening. My son and his wife are wonderful and of course their two children are the light of my life.

### ***Acknowledgements***

*My thanks go to my treating doctors over the past 17 years. I believe they have all served me well.*

- Gosford Hospital has played a large part in my path to better health and continues to do so through the cardiac rehab gym. I thank all the doctors and medical staff for their dedication and expertise.*
- My PAH Manager is Associate Professor Glenn Reeves and John Hunter Hospital. Through (ARRC) the Autoimmune Resource and Research Centre I am on a trial drug that will hopefully become main stream in the future.*
- On a more personal note I am grateful for the opportunity to attend support meetings run by the Scleroderma NSW. The friendly discussions with others with similar are very helpful.*

***ARRC thanks Yvonne for sharing her story***