

## Acromegaly – Norma



Being diagnosed with Acromegaly was quite a shock as it's often unheard of and quite a rare disorder to have, but it was also a relief to finally put a name to all the strange symptoms I had been experiencing for about 10 years prior. It is presumed by specialists that the pituitary tumour developed around the age of 40 years and became more active at about 50 years of age. Symptoms slowly crept up on me including facial changes with myself, my family and GP thinking it was due to weight gain.

After moving to Brisbane I was referred to a Physician to help control by blood pressure and to participate in a stress test due to breathlessness and arthritis that had also become quite painful. He questioned if I had to increase my shoe size and have rings enlarged and of course that was my exact problem. He was also clever enough to notice my large facial features; broader nose, larger ear lobes, lips, tongue, coarse skin and puffiness of face and upper body. After many blood tests and very high IGF1 I was referred to an Endocrinologist.

I had to collect photos of the past 10 years and the changes were obvious when all put together. My history of those years was a feeling of unwell but because of my very busy lifestyle, I just kept pushing myself when my body just wanted to stop. In my early forties I started early menopause of heavy periods, almost daily headaches sometimes migraines, night sweats and flushes. Hysterectomy was performed in my late forties as well as right carpal tunnel and trigger finger surgery.

Sleep Apnea was also diagnosed and the Doctor was embarrassed and later apologised for not diagnosing Acromegaly due to the large tongue and all the other symptoms. A C/PAP machine gave me some relief and helped control the snoring. My blood pressure/cholesterol was always difficult to control even with exercise and sensible diet and medication has been increased in the past years.

Initially the Endocrinologist recommended surgery, but the first MRI did not show any pituitary tumour but because of the elevated IGF1 I was prescribed bromocriptine tabs building up to a stronger dose over 3 months. This brought the levels down slightly but not to the acceptable levels for my age and the side effects of nausea, dizziness and depression/tiredness were too much to cope with so I was weaned off that drug.

A second opinion with a new Endocrinologist and a new more detailed MRI from a different hospital confirmed a microadenoma 0.5cm so I was happy to have a transphenoidal removal of tumour which was confirmed as an Acromegaly type tumour by pathology. Surgery was excellent but on the 6<sup>th</sup> day I was admitted back to hospital with low sodium levels. After 5 more days of treatment and levels returning to normal, I was discharged. Post op found my IGF1 levels falling slowly to the high thirties. I lost 10kg of fluid. Due to increased body fluid it was always a huge problem finding veins to take blood for blood tests and trying to inject contrast for scans and MRI. Since surgery this is no longer the case.

The headaches were not as frequent and my hands, feet, tongue, ear lobes were back to normal soon after surgery. About one year post op the IGF1 started to rise, as well as headaches returning and blood pressure too high. Radiation therapy was commenced due to the tumour possibly returning and 26 treatments were administered. Since the radiation, my taste/smell is not the best and I am excessively tired. While waiting for up to 2 years for the result of radiation I have a monthly injection of Somatuline Autogel 60 mg to reduce the excess growth hormone/IGF1.

The IGF1 is now in the upper limits of the normal range for my age. To date the Endocrinologist will continue to monitor the blood for Thyroid, Cortisol, IGF1 etc etc etc.

I am now in my 50's and looking forward to getting back to whatever life is like to be normal again. There is no doubt Acromegaly is an awful disorder to live with because we have different symptoms and all treatment seems to go slowly waiting for medication to work and then blood tests and results and dealing with many specialists required to monitor my progress. Being in the workforce would be almost impossible as no two days are the same with tiredness, aches & pains and headaches and nausea. Having good family support and trying to think positively helps get me through each challenging day. Simple exercise such as swimming, walking and gardening also helps physically and mentally.

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