



## Cushings – My Journey - Sue

My problems began in my 20's when I first began to put on weight, had irregular periods, noticed more body and facial hair, and had episodes of depression. Sweating was also a discomfort. Fertility was a concern as we were trying to start a family so I saw a Gynecologist who diagnosed Polycystic Ovarian Syndrome (physical symptoms present similarly to Cushing's Disease but is caused by a very different disease process). With the help of the drug Clomid I was able to have both my children with one miscarriage between the births.

Unfortunately in following years I put on more weight, perspired profusely and really couldn't cope with the heat, couldn't sleep, retained fluid in my ankles and felt exhausted most of the time. My blood pressure was through the roof and I really felt quite sick. During this time I felt I was micro-waving from the inside out, experienced heart palpitations and had a general feeling of "rushiness" inside. My face would always be bright red & covered with sweat, wearing makeup was a nightmare so I soon gave up. I do distinctly remember one morning where I looked at myself in the downstairs mirror and thought to myself "How could some-one love YOU" – the image was a bloated red coloured blob with almond shaded eyes.

I explored a couple of opinions from doctors, but the results were always the same – loose weight and it would help considerably; here's some anti-depressants; try some exercise; and a variety of drugs/hormones were used to try to fix up my increased androgens etc. At one point I visited a Menopause Clinic and tried Aldactone to assist with the hair growth but got a fairly severe reaction to it. Interestingly 3 months after the reaction I lost quite a quantity of my hair. It did come back but in a darker colour and curly.

The beginning of the diagnosis was when I went to my GP and said I was so exhausted I could not cope. I was at the end of my tether. A full blood test revealed excess white blood cells in my blood (Neutrophilia). The doctor explained this could be from an infection in my body somewhere and repeated the tests again 6 weeks later. Eventually I was sent to a hospital to have a bone marrow biopsy as the Neutrophilia was still active. I awoke from the twilight anesthetic in tears fearing the outcome. The oncology clinic had some good news and some not so good news. The good news was no blood cancers, the bad news was that cortisol was picked up in a urine sample and I could have a condition called Cushing's Disease. It was then off to see an Endocrinologist who then referred me to an Endocrine Clinic at a major hospital for further investigations after my tests were coming back inconclusive.

The MRI would not reveal a tumour, however it appeared to show that the gland's midline was swaying slightly to one side. The endocrinologist was wonderful. He spent up to 3 hours with us explaining the disease, the consequences and the outcomes of treatment.

I was booked to have a Petrosal Sinus Sampling operation. It's an amazing test/procedure where they place you under a scanning machine then insert catheters in your groin and then feed a "tube" up right to the area of your pituitary gland. Internal blood sampling is taken from different areas of your body while they also scan and take pictures. I always remember the sound in my head – it was like the sound of someone sucking the last remnants of a milkshake! You cannot move and have a panic button to signal if you are experiencing difficulty. At one point I had to use that button when I felt as if I was going to pass out.

I am also very grateful to the nurse who strategically placed a rolled up towel to preserve my dignity during the process. One outcome from having this disease is that being modest goes out the door for some – you understand that your body is a finely tuned machine and the doctors are there for one purpose – to repair where possible and maintain that machine. I had no reservations about showing my “Cushingoid” body to interested nurses who dropped by.

When the procedure was complete I was being taken back to my ward when my blood pressure rose rapidly. Immediately the nurses and doctors put pressure on my groin and stabilised me. I was then left to rest postured for 6 hours in my bed.

My results came back totally normal! I could not believe it! The disease seemed to be ‘episodic’ or ‘cyclical’ (it would switch on and off) and it appeared it had “turned off” some-where between my last blood test and the Sampling. To the Endocrine Department’s credit the doctors persevered with trying to reach a firm diagnosis - every day I did an early morning cortisol/creatinine sample and froze it for bulk delivery every week to the pathology department. This went on for just over 12 months and they started to scale the testing back.

While waiting for my next appointment I knew something was different. I got that “rushy” feeling again and was feeling out of sorts so I made an appointment with my GP to have a urine test. Sure enough the test came back with the cortisol very high. It was on again. It’s amazing how a person knows their own body.

The Endocrine department confirmed that the condition was active once again. I was booked to have another Petrosal Sinus Sampling, but this time they did pathology the day before and notified me that night around 8pm that the procedure would go ahead. No way I was going to go through that again to find it had shut off. Cushing’s Disease (as a result of an ACTH-producing tumour on the pituitary gland) was identified as the hormone to the right side of my gland was accelerated.

While waiting for surgery I took Ketoconazole to keep the excess cortisol under control. I got caught up in a hospital crisis time unfortunately, and waited for 4 months for the surgery. This was very distressing since I was told that some Cushing’s patients had a life expectancy of 5 years. When the hospital finally rang with a surgery date all I could do was weep. Was it relief or fear? To this day I am still not sure but I will never forget that feeling. I did have private health insurance and ventured away from the public health system during this time to see if I could proceed to surgery faster, but unfortunately I saw a neurosurgeon who wanted to have the whole thing re-diagnosed by an Endocrinologist. I have no idea why he would not take the public hospital referral, perhaps it was because the tumour was not identifiable on MRI. After the usual waiting period to get in to see some-one and all the time bloods and urine tests came back – the hospital had rung with the operation appointment. In hindsight I should have made an appointment with the surgeon who interviewed me for the operation thru the public system and seen him in his private rooms.

So at the age of 36 I had transsphenoidal surgery. Thankfully the tumour was successfully removed, as well as a considerable amount of my pituitary gland through an intricate operation through the nasal septum and into the frontal and mid sinuses. These days quite a few doctors go straight up the nostril instead of opening up the septum. By the end of my hospital stay I was developing sinusitis so stayed in for a couple of extra days. While home I was very unwell and my husband took me back to emergency. After an endoscopic examination they extracted part of a plastic sinus separator which had snapped off during removal by a nurse. The registrar had been called away during the packing being taken out and the nurse completed the job, and she did not notice the problem. As a result I spent another 2 weeks in hospital.

Initially I was deficient in Cortisol, and also took DDAVP for 3 months to replace missing Anti-diuretic hormone until it rectified itself. 5 months after surgery we went for a sea-side holiday and the whole caravan park was affected by a vomiting and diarrhoea virus. One evening I ventured down to the toilets and ended up having to lay my towel on the floor in the public area, lie on it and wait for my husband to retrieve me. Was it the effects of low cortisol or just dizziness from the virus? We were in a remote area called Woollahri and I was concerned I’d have to have my meds intravenously, but it did not come to that.

After being on replacement hormones for 2 years, I am now very grateful that I do not have to take any replacement hormone. The residual tissue of my gland appears to have recovered and has been able to maintain the needs of my body once again. My sex hormones never seemed to recover though – thankfully I had completed my family prior to treatment. Up until recently I have remained on a contraceptive pill to replenish my sex hormones, but I turn 50 this year and the doctor has suggested I stop.

I did not require radiation therapy and I now realize how lucky I have been and am very grateful for the skill of the specialists concerned. I still have regular pathology check-ups as this disease has a small reputation for raising its ugly head again, but so far so good. Of course I get the occasional paranoia that some-thing is not right, but I think most people who go through and survive an illness like this go through that. I once met a bloke whose tumour returned after 20 years.

It took quite a while, but things got better as time passed. The memory problems that plagued me were not as bad and my confidence started to come back. Initially I lost 13 kilos post op but the weight is still a problem, only because I have had difficulties shedding it due to polycystic ovaries and insulin resistance, and I do still become very tired. My diagnosis and surgery time was quite a big deal, and at that time I felt extremely isolated with this “rare condition”.

I have since trained and secured employment and feel I contribute to society. I consider myself to be one of the lucky ones.

Prior to my surgery I was not really aware of the pituitary gland, and had never heard of an “Endocrinologist”. Now I know I will always feel “different” from the average person. I don’t play on it, but I suppose I do expect considerations at times – mainly because of my fatigue which I have not been able to put right.

Sometimes I look at a room full of people and wonder what personal traumas some of them might have had, which are not physically noticeable. That’s where I have found being in touch with other people through the Pituitary Foundation has had a soothing effect on me; to know that I am not the only person to have gone through this. Everyone has a story to tell, so don’t be too judgemental when you first meet them if you notice something a little different.

My husband has also gained a wider understanding from talking with partners of people affected by pituitary disease, our involvement with the Foundation has been beneficial for us both.



1987  
before my  
journey began

1994  
2 years prior  
to surgery

Today  
Celebrating  
a full recovery

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