

Cushings – by Annie

Hi, I am Annie. I am in my early fifties, married with two teenage children.

It is still hard to believe that this has all happened. For about 15 years I knew that there was something wrong. I was plagued with 'things' like insomnia, mood swings, my periods stopped when I was 40, red itchy face that peeled, extreme lethargy, unable to concentrate, feeling down, loss of libido and I always felt hot. And the list went on. I went to dozens of doctors, specialists and alternative practitioners - nothing helped. I was diagnosed with many ailments - allergies, dermatitis, depression. I tried different diets, herbal remedies but nothing worked. In 15 years only two practitioners who were honest enough to tell me that they didn't know what was happening – my local GP at the time and an acupuncturist who I still see.

The final straw was when a Doctor told me that 'it was all in my mind and I should see a psychiatrist'. At this stage I decided that the only way I was going to survive was to accept what was happening with my body – learn to live with it. That was November 2002.

The biggest challenges for me were my face and the 'black cloud' that constantly seemed to hang over me. They both caused me grief. My face was always bright red – like it was permanently sunburnt - and burning. I would lose layers of skin. At times I couldn't close my eyes. I would walk around the house with sorbolene plastered all over my face to try and get some relief. Doing simple household chores like cooking and ironing was agonising. I started to iron outside in an attempt to alleviate the heat on my face. I tried to get into air conditioning as much as possible. I couldn't have water splashed on my face – so no swimming. Certainly not the way to be when you were the mum of small children.

The 'black cloud' was always there. Nobody, including me, understood what was happening. My personality changed – I lost my 'spark'. I became very withdrawn. I lacked confidence and this was made worse by the fact that I could not sustain anything I tried to do, jobs, study. I was self-conscious about my appearance and hated going out. This led to me withdrawing and becoming socially isolated. I lost friends. At times it was incredibly lonely.

Then just before my 49th birthday in March 2004 things got markedly worse. My mood swings became extreme and I was incredibly angry. I also noticed that I had an incredibly hairy stomach. And no matter how hard I tried I couldn't lose the weight from around my stomach. Menopause, I thought and tried to 'soldier on'!

Then a friend of mine suggested seeing yet another doctor, who was nearly an hour's drive away! After a while I decided, "well, why not, I have got nothing to lose". That is when things started to change for me. Tests revealed extremely high levels of testosterone, low levels of progesterone and bilateral adrenal tumours. I was referred to an Endocrinologist who did more tests and suggested that I had Cushing's. I had never heard of Cushing's. My adrenal tumours were secondary (benign) tumours. This Endocrinologist referred me to an Endocrine Unit within a public hospital for specialised tests to confirm the diagnosis of Cushing's and locate the primary tumour.



My first appointment at the Endocrine Unit was just wonderful. I was finally able to talk to someone who understood. The Endocrinologist listened for over an hour while I talked (and cried) about what had been happening for me over the last 15 years. Then he talked about what would happen next. I was totally overwhelmed. It was all too much for me – 15 years of not knowing what was happening and now I was looking at another 6 months of tests to actually find the tumour! BUT things were starting to happen. There were tests and more tests - tests like I never imagined. When I was in hospital, having tests performed, I would spend hours in the medical library reading and researching medical and endocrine journals for any information I could find on Cushing's. That helped me enormously – I tried to focus on the clinical side, as emotionally I was a wreck. Each test was an emotional roller coaster ride – would they find the tumour? During this period I relied heavily on the support of my family, friends and my counsellor.

Finally we got to the stage where it was *thought* my tumour was on the right side of my pituitary gland – yes, it still had not been spotted! Then off to see a Neurosurgeon. FINALLY surgery was scheduled AND delayed and rescheduled.

D-day arrived (November 2004) and I was as nervous as all hell. Even when the Neurosurgeon went in to operate, he couldn't see the tumour. So based on tests performed prior to surgery the right side of my pituitary gland was removed. Tests later showed that the tumour had been removed. After surgery I had Diabetes Insipidus and had to take DDAVP until I stabilised.

Then home! But not for long as I went back into hospital with Meningitis (a complication of surgery) and stayed for another two weeks. I had headaches like I have never experienced. It was like my head was going to explode. My Diabetes Insipidus returned.

FINALLY home. By this stage I was so nervous about going home and being without medical care. I had spent a month in hospital. I was slow. I talked slow, it was hard to think fast enough to communicate. It seemed like I did everything in slow motion.

I was on Cortate (cortisol replacement) and DDAVP (Diabetes Insipidus). My progress was slow and I had several set backs including bilateral frozen shoulders.

As I withdrew from the Cortate every bone in my body ached, it was hard to walk because my feet were so swollen and I felt incredibly alone. Nobody really understood what I was going through. Whenever I got down I would look at my face in the mirror - WOW - it was white and no flaky skin! I was still going to regular counselling. When I was diagnosed I stopped working as a counsellor and put myself into counselling!

After being home from hospital for about three months I decided to find a private Endocrinologist. The public hospital system was great for seeing me through to surgery, but now I felt that I needed to be able to see the same Endocrinologist every visit. I was feeling extremely vulnerable and very alone. This proved to be a good move for me. I saw her regularly, sometimes every fortnight. It was great to have someone to talk to that really understood what I was going through. On her advice I started hydrotherapy – my muscles had wasted as a result of having Cushing's. I went every day except for Sunday for six months and then twice a week.

Now over a year later, I no longer take any cortisol replacement. I am still on DDAVP and will be for the rest of my life. Some days I still struggle, but there are so many positive things that have happened. I have never lost any skin off my face since surgery and my skin is lily white and I just love it! I have lost over 10kgs, which is all the weight that I put on. Those "good looking hairs" on my stomach seemed to vanish over night. For the first time in 15 years I feel the cold and needed to wear long sleeves and I SLEEP! Every morning when I wake up I say thanks!

I exercise nearly every day - walking and I have a home program to help build up the muscle wastage. I go to hydrotherapy every Friday. Work – I am not sure that I will ever go back to being a Counsellor. I started working at a Bodywork/Shiatsu practice one day a week in November 2005 and also work a couple of hours a week at a shop.

I am enjoying being able to spend time with my family and friends and doing things I haven't been able to do for YEARS. The old 'spark' has started to come back and I just love it. I feel as though I have a new life and I cherish it.

For me, having Cushing's was an incredibly lonely experience, even with the great support network I had. I decided that I wanted to do something to support anyone affected by Cushing's – patient, family, friends. So I have recently formed the Qld Cushing's Support Group.

May 2007

Wow, it was amazing to read over what I had written and realise how far I have come in the last year. So much has happened.

In August 2006 I started working 3 days a week at a women's legal service with the best bunch of women you could ever imagine. They are just so supportive. Working has helped my recovery enormously. I am using skills I thought I had lost and once again I feel I am worthwhile and able to contribute. The dark clouds started to lift! What a wonderful feeling.

In January I progressed from walking and hydrotherapy to a gym program. At first going to the gym was incredibly difficult, but I have made amazing progress. I am no longer using pasta bake jars as weights – I use the real weights!

I have regular checkups with doctors. Once a month I visit my GP and have my blood pressure checked. It is still coming down and now I am on the lowest dose of medication – looking good!

I see my Endocrinologist every 6 months. My last blood tests were perfect and my scan showed my adrenal tumours are shrinking. The best news of all is that I am no longer on DDAVP for Diabetes Insipidus!

I was on DDAVP for over a year and doctors said that I would be on it for the rest of my life. I wasn't prepared to accept that – I just hated taking it! It was hard coming off it, and of course it meant that I had to spend a lot of time around home so I was close to a toilet and so I could closely monitor my fluid input/output - **BUT EVENTUALLY I DID IT!**

So I am now off all Cushing's related medications and my pituitary is fully functioning! I still have to wear a medical alert bracelet - I may need extra cortisol in emergency situations or for surgery.

Every so often my body crashes - especially when I try something that maybe my body just wasn't quite ready for! Guess it is like learning to live with a new body and that is quite an adjustment after having a Cushing's body for 15 years.

For a long time I was incredibly frightened of going places on my own and trying out things that I hadn't done for such a long period of time. Over the last year I have had several trips away on my own and that has been wonderful.

Emotionally I am in a much better place. Work, counselling and the support of family and friends has helped enormously. I am no longer seeing my counsellor but I still journal regularly.

Pretty awesome really! So for me life really did begin at 50!

December 2008

It has been 21 months since my last entry and I am just amazed at the changes in my life and the progress I have made.

In March this year I had a bit of a scare when blood tests came back with elevated ACTH levels. I had been working crazy hours and getting pretty tired and stressed. So I resigned and had a total break for about 6 weeks. I am now working back at the same place but as a casual, which seems to work so much better for me.

I had a checkup in August and my test results were perfect! The elevated ACTH level in March was put down to lab error! I am now on yearly checkups with periodic BP checks with my GP **AND** I no longer need to wear my medical alert bracelet.

My focus for the last 18 months has been working on my muscle wastage. That has proven to be a huge challenge. I started a pilates program in a rehabilitation centre and found that to be overwhelmingly tiring. I tried a number of other options – again professionals would try to push me further than what my body could cope with. I found that there was very little understanding on the impact of Cushing's on the human

body, muscle groups etc So I started giving talks to health professionals, like physiotherapists and exercise physiologists.

Eventually I found an option that worked for me. I spoke to my physiotherapist and she was happy to test all my muscle groups and provide a report for me to take to a personal trainer. She would review my progress every 3 months and provide an update on improvements and which muscles groups needed attention.

I had been attending a local gym for years and they were familiar with my journey, so they were able to source an appropriate personal trainer for me. After 6 months of intensive work most of my muscle groups are now working within normal range. I can now do a whole range of things I never imagined I would ever be able to do again, like pick up a saucepan, grate a carrot, stir a sauce...yes, all of those actions we take for granted.

I have started doing yoga, body balance and pilates at my gym and will continue the personal training program and my physiotherapist will review my progress every 3 months.

2009 I hope to travel overseas!

May 2009

It is always amazing to read back over what I have written and see the progress I have made.

Yet once again, I am thinking WOW! My life just continues to get better and better.

In March I traveled to Bhutan (near Himalayas). One of the pictures I have had on my wall every since surgery was of a monastery there called Tiger's Nest. I decided that I wanted to see it. So off I went, on my own, to Bhutan. I traveled around for 2 weeks doing lots of walking at altitudes way above anything I had ever endured – above 2500 ft. The hike to Tiger's Nest took me nearly 6 very slow hours -there and back, but I made it!

There were so many things about the trip that were amazing, challenging and confronting. Most amazing was that my body handled everything that was thrown at it. I had taken medicines for everything you could imagine and didn't have to use anything.

My next adventure is going to be somewhere not quite so confronting and challenging – like an Italian village for a few weeks!

My rehabilitation program continues! Yes, some of my larger muscle groups just don't want to work, but we will get there.

Work – I am still working as a casual and just love it. Some weeks I work nearly every day and other weeks maybe 2 days - usually for about 5 hours.

The journey continues.....

Copyright
Australian Pituitary Foundation Ltd
2009