



Cushings – Nikki

Timeline

My name is Nikki. I had Cushing's Syndrome, but now I'm cured and this is my story.

I gave birth to my son in May 2000. After 15 months of breastfeeding I had retained a lot of my pregnancy weight and I was beginning to gain weight.

I was concerned about other changes that were occurring. The hair on my upper lip was getting darker and longer like a mans. I bleached at first, then waxed to try and hide the hair growth. I just assumed it was due to birth, hormones and breastfeeding

One day I really looked carefully in the mirror and could see my body and face were definitely changing. I was developing a hunched back, my face was rounding, I was getting hairier, my toenails appeared thicker, the palms of my hands were yellow, my face was pasty. I just looked different, strange... In August, 2002 I decided to get my hormones tested. Apart from my testosterone levels being slightly up, all appeared fine.

***I didn't realize at the time that not ALL your hormones are tested, and it was basically left at that. I was left with this horrid feeling of, 'This is the future for me.'

In November that same year, my husband and I were watching "Today Tonight" and a segment came on about this woman with a condition called 'Cushing's Syndrome'. My husband turned to me and said, "That sounds like you darl." We jumped on the Internet and had a closer look at the symptoms.

Symptoms

These are the ones I had. Weight gain – abdomen, face (jowls), neck, upper back (hump) and generally my body, easy bruising, facial hair growth also on the upper arms & shoulders, fatigue, weakness in arms & legs; absolutely drained at times, increased thirst & urination – couldn't go anywhere without taking water and poor wound healing.

Other things I noticed: some trouble sleeping, funny sensation within my face, problems concentrating & with memory, hair condition poor and thinning at front, thickening of toenails, pasty complexion, rashes under my arms and on legs after shaving, hairy sideburns, yellow hands.

I didn't know if some of them were symptoms or not, but the one that clinched it for me was 'increased susceptibility to some infections including pneumonia...' Well that was it! I had had pneumonia the previous year. I felt I had enough symptoms to specifically ask my doctor for a cortisol test. But in my mind I already knew I definitely had 'Cushing's Syndrome'. It was around January 2003, I went to my doctor.

He had heard of Cushing's Syndrome, but had little knowledge of it, and was sceptical, which was fair enough. He felt it was more likely that I had Polycystic Ovarian Syndrome, but to his credit he listened and I had the test. It came back with a high reading of cortisol.

He referred me to an endocrinologist.

The testing began and with each test it became more and more conclusive (especially as far as I was concerned) that I did have it. Once it was confirmed I had Cushing's Syndrome I was referred to other Endocrinologists. At this stage, knowing that I was 34 and wanting to have another baby soon, I was very grateful to my doctors' diligence and swiftness. I was amazed at the willingness of my doctors to spend time with me, listen and talk. It made such a difference to my understanding of what was going on and my comfort and security level in the people I was trusting.

Within three months of a barrage of tests, I had exploratory surgery and it was discovered I had a growth on my pituitary gland. The next step was surgery to remove it.

Now this to me was a case of, well once it's gone then I'll be better. That was my expectation. I don't think I ever doubted that. I don't think I really knew the other possibilities and I'm glad I didn't because I was fixed on getting better and that was it!

So the date was set. 24th July 2003.

While having Cushing's I faced the horror of having to shave my chin every morning, and again at night if I was going out. I had stubble like a man. I had hairs growing on my neck and sideburns developing. I wouldn't leave the house without foundation and other make-up on. It was a struggle to maintain dignity and any sense of femininity. I did combat the hair growth initially with waxing, then moved onto major league work of IPL treatment, which is Intense Pulsed Light. Basically the intense light zaps the hairs killing most follicles. Now this is something I highly recommend for people to do if they have ongoing problems and are feeling depressed about it. It is certainly worth doctors mentioning to patients as an option.

My mind was also constantly focussed on food. I would think about what was on the menu for the upcoming week. Each meal as I was eating and planning what else I could eat later that day. I was fighting the fatty foods, but food was just there in my mind all the time. I was actually in some control; I think my weight situation may have been a lot worse had I not been active and fairly aware of what I was eating.

I was also drinking a lot of alcohol, not admitting the extent of it even during all the testings for fear of the doctors automatically assuming my problem was alcohol related. It was consuming though. Everything about Cushing's is...

My surgeon removed the tumour which was approx. 6 ½ mm. in diameter. A lesion was also found on the other side of my pituitary which he also removed.

The day after my surgery, I was not given any cortisone replacement, my levels went really low and as I virtually melted into the bed with weakness my endocrinologist took great delight in proclaiming me cured. I had headaches and tiredness which had to be expected.

The tiredness lasted at least 6 months, but I was amazed at how fast I recuperated from every aspect of Cushing's.

Cushing's is not a common illness. Generally, the public has never heard of it. I now pass quite a few women on the street and think, "Get your cortisol level checked."

As it stands for me, since the initial cortisol test I am now an active, rejuvenated person. All the major symptoms of Cushing's have gone and most things are as they should be.

I still take some medication. I have an MRI scan booked and then I should be free to start trying for my second child. Something I am extremely grateful for. One thing I did appreciate about having Cushing's Syndrome was that it was curable; not potentially life-threatening. I always believed I would be okay.

As a patient speaking to other patients who may be struggling to find answers, give yourselves every opportunity, ask questions, ask for tests, do what you can to help yourselves.

PHOTO 1 - October, 2002

This is a photo of me around about the time I first heard of a condition called "Cushing's disease".



PHOTO 2 - May, 2003

I first met with my Endocrinologist in March, 2003. Because I was apparently in the early stages, I was not displaying the full-blown symptoms of a 'typical' Cushing's patient. As such it was doubted I really did have it.



PHOTO 3 - three days prior to the operation - 24th July 2003

During the short six month period of testing my symptoms developed dramatically. This photo I'm showing you is just three days before my operation: July 24th 2003. I was roughly 74kg.

My humped back was humpier, my jowls bulging.

It was strange. I thought at times I was looking okay, then I'd see a photo like this and I just felt ugly. I was feeling depressed. I just couldn't believe what I was seeing was me. I did not identify my face as my own. It was a very confusing, depressing time in my life. I couldn't see how my husband could love me as I was.



PHOTO 4 - 16th August 2003

I took a photo every three weeks post op. to clearly see the progression. Already the pastiness was diminishing and the hair growth seemed slower. I generally looked healthier.

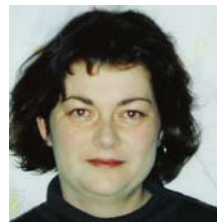


PHOTO 5 - 5th September

6 weeks post op: I may not look happy but I was. I'm 71kg, you can see the jowls are diminishing as well as some top weight. The hairiness around my chin was virtually gone too.



PHOTO 6 - 26th September

9 weeks on: looking brighter, more alert, more natural. The jowls continue to decline, as does the hair growth and weight. Down to 68.5kg.



PHOTO 7 - 17th October

12 weeks on: I was a much happier person. It was amazing how fast the hair growth, the jowls, the hump back all just gradually disappeared. I couldn't believe it.

