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HAYLEY'S STORY

Because of adrenal surgery to treat Cushings syndrome, Hayley is now an Addisonian

My name is Hayley Lewis. I am 39 years of age, no children, Andy is my husband. We were married in September 2001. We live in Wanganui. We both work, Andy at a meat company, and myself in a lawyer's office.

I have had Cushing's Syndrome. My adrenal glands were surgically removed, and so I take hydrocortisone and fludrocortisone replacement, the same as people with Addison's disease. This is my story leading up to and after diagnosis of this irritating condition.

In May 1998 I woke one morning to find my eyes had swollen, so much so that I felt my sight was slightly impaired. A week later the same puffiness was still there so I went to my local GP who prescribed eye drops which did nothing to make the swelling go down. I wondered then if I was allergic to something in my home or something I had eaten, so I began to eliminate things from my diet and change things within the home. I decided to have the 8 hours sleep I thought I needed. Still the eyes remained puffy.

Time went by and another visit to the GP in March of 1999. By this time my face was filling out and began showing redness. I can remember saying to my GP that I had been feeling out of sorts and I couldn't quite pinpoint the reason, and my eyes were still puffy, but he could not shed any more light onto the situation. He ordered a blood test and rang the result back as fine, nothing to worry about.



In September 1999 I changed GP's. About this time I noticed facial hair appearing and Andy noticed a "hump" type formation on the back of my neck. Most of the time my face and neck were red. I had noticed daily, that strands of hair had fallen out in large quantities - my hairdresser said it was natural for at least 100 strands a day to fall out. In the meantime I was working five days a week, feeling okay at work but when the weekends came around my eyes got puffy again, and I felt drained of energy and spent most of the weekend just sitting around at home. Going out and socialising with friends on the odd occasion was a real effort. I was subjected to criticism about my facial hair and

whether I was pregnant or not. This last remark was as a result of the increase in weight especially around the stomach area over several months.

Six months later, March 2000 I went to my new GP again. I was due for my annual smear test. At this consultation my GP prescribed another blood test which showed a discrepancy in the white blood cells. I then had five blood tests in five weeks and each time the result came back worse than the one before. My blood pressure was up a little and my cholesterol levels were up also.

I was advised at this time to cut out sugar, fat, oil, butter and salt from my diet to hopefully bring the cholesterol levels down a bit and lose a bit of weight. When I have done this before I have lost weight, but this time, it seemed I was putting on weight. My shape was changing - my upper torso was protruding further than my breasts and my stomach was becoming very rounded.

A daily pattern seemed to have emerged for me. First thing in the morning I didn't feel so bad, but as the day progressed, the aches and pains and skin stretching feelings I got, along with blurry vision, light headedness and tiredness just got worse. By 6pm at night I felt exhausted and like I was going to "pop".

My GP then referred me to a blood specialist. I had to wait another four weeks to see the specialist, and during that time my condition became progressively worse - instead of just the weekends feeling tired and lethargic, it was seven days a week.

At this time my legs had a reddish, blotchy look, I noticed that bruises on my legs and arms didn't go away in a hurry and were quite a deep purple colour. I developed "old age" blood spots on my arms which continued to appear. Striae (stretch marks), had vividly appeared on my lower stomach, also on the top of my left leg, under my arm and under my breasts.

My first meeting with the specialist was on 8th June 2000. My face and neck was swollen, my stomach felt like it was going to burst, it felt like I had something stuck in my throat, my eyes were watering all the time, my ankles, knees and fingers had swollen. I had aches and pains in my upper and lower back and behind my knees. My skin was still "blotchy" in appearance. April was the last time I had had a period. I was tired all the time and for the first time in my life that I can remember, had lots of dizzy spells. My family and friends commented to me that my personality was "not like it used to be".

At the end of the consultation the specialist prescribed another blood test, a chest x-ray and an Overnight Dexamethasone Suppression Test because he suspected Cushing's.

I, and my family had never heard of "Cushing's". My mother in particular was curious and having access to the Internet, typed in the word "Cushing's". She printed out all the information that she found on the Internet so I could read about

it. That I did and sent four e-mails to addresses I had found on the Internet. I had a response from Jeanette of New Zealand Addison's Network and also Laurens Mjinders of ACIF. At least two to three times per week I would e-mail my dear friends, the support I got was second to none.



My chest x-rays showed no signs of abnormality, but the results of the dexamethasone test showed I needed another, higher-dose test, which meant three days in Wanganui Hospital. At the conclusion of this test the specialist treating me left the employ of the Wanganui hospital. I was then referred to another specialist. Three weeks went by and the "new" specialist telephoned me at work to advise that the results appeared to indicate Cushing's Syndrome. He then referred me to an Endocrinologist in another city.

I was again in contact with Jeanette of NZAN to let her know what was happening. Jeanette mentioned a book called "Cushing Patients in the Netherlands" which she suggested might be of interest to me. At this time I wanted as much information I could get so Jeanette loaned me the book from NZAN's library.

I was booked into the Waikato Hospital for Monday 24 July 2000 to undergo a Cushing's Protocol for eight days. The night before my admission I read the book "Cushing Patients in the Netherlands" from front to back, which was ever so helpful. I felt fully prepared for everything that could possibly happen to me.

Part of the protocol was to undergo an MRI scan and CT scan. The MRI scan showed that both adrenal glands were two and a half times bigger than normal and full of nodules. I was immediately booked for surgery.

During the time leading up to surgery I experienced what I call a "chugging" sensation throughout my whole body, which was constant during the hours I was awake. Two days before surgery I got my period. It was so heavy I thought I was hemorrhaging. The next night, I had what appeared to be contractions for two hours. I was frightened. Then, 10 days after admission, I had a seven hour operation to remove both adrenal glands. It was intended and attempted, to do the laparoscopy approach but obviously the glands were too enlarged and therefore I had the big cut (64 staples later).

When in recovery after the operation on 3 August 2000, 99% of the symptoms I'd had, seemed to have disappeared.

I was discharged from Waikato Hospital a week later, and returned to work a couple of weeks after that. Most mornings for the first couple of weeks after my

discharge from hospital, I woke with a terrible headache and backache for which I took two disprins every two hours to relieve the pain. I got the odd shooting pain in the stomach and pelvic area and I often got quite lethargic by mid afternoon. Although some days I had the attitude of "can't be bothered doing anything", I was positive and wanted to return to my previous self as soon as possible.

I have had just one day after discharge and before I went back to work, where the symptoms were quite different from "every day" happenings. I was awake most of the night one night with excruciating knee pain. The knees just ached for about 10 hours. During this time it felt my stomach had subsided in size I didn't have that bloated feeling. My walking was a little wobbly, my knees and ankles were still swollen. I haven't had that since.

Originally I was told that recovery may take 12 to 18 months. Six months after surgery I began playing again the sports I love, squash, basketball, indoor netball. In April 2001, I came first in my grade at a local squash tournament. I played in the 2001 local basketball competition for 24 weeks from April to October. I was told by my team mates at Indoor Netball that I was a lot fitter now than before. I felt good. I felt normal then and I feel normal now. My weight reduction went from 76kg to 63kg in just a few months. I had always felt I was battling to reduce my weight for many years, however I'm quite content with my weight as it is now.

Approximately 12 months after surgery I had one night where I forgot to take my medication. It was 10.45pm at night when I felt drained of energy, could hardly move. I had a headache and pains were shooting down my left leg. I'd had a very busy day at work, I met a friend after work for a chat, then played squash a couple of hours later so by the time 10.45pm came I was extremely tired. It dawned on me then that I hadn't taken my medication at the regimental time of 5.30pm. I took my medication then, and woke up the next morning feeling great.

When I was diagnosed with Cushing's my job was quite routine, Receptionist/Telephonist for a local law firm. I often felt embarrassed greeting clients. I felt very conscious of how I looked. It was quite hard to cover a "moon face" and a rapidly expanding body. My appearance certainly did not give me much confidence in myself.

It's now 18 months since my adrenal glands were removed [May 2002]. My life feels like it's been kick started. I now find my employment more of a challenge as I now have the added duty of Legal Executive which I thoroughly enjoy. I am trying to be the best I can be at my position as Legal Executive. Some days I feel I suffer from brain drain, but I'm sure it's because there is so much to learn and not enough time to learn it in.

Outside working hours during the summer months, I have taken on co-ordinating games of basketball for 28 teams, which again is a challenge. The mind has to be quite alert. It is rewarding through hearing from players that the competition is exciting and well run.

For the past 18 months I feel I have been on a roller-coaster ride. The highs have been that I have continued to be better medically, I have gained promotion through my employment, I married a wonderful man who continues to encourage me in everything I do. The lows have been - my mother died of cancer, my father suffered a brain aneurysm, and my bridesmaid passed away with melanoma. My feelings of despair have encouraged me to work hard and play hard to bring about ultimate happiness that I strive for.

I am lucky to have had the support of family, friends, work colleagues, NZAN and fellow sufferers of Cushing's and Addison's to help get me through a "glitch" in my life. I look forward to tomorrow every day. It feels great to be back again.