



Cushings – Catherine - A patient's perspective

I have Cushing's disease or rather had it and now as a result of surgery have hypopituitarism and secondary Addison's disease. I had surgery nearly 12 months ago.

Like many people with pituitary tumours it took considerable time for the correct diagnosis to be made and, as a result of the delay, I had a least one possibly unnecessary major operation. The first person to realize I had a problem was my mother, of course! She told me that she felt something was wrong and that I should have some investigation done.

At the time, I had put on weight and my hair was thinning considerably. I would also get very moody. I put the extra weight and moodiness, at that time, down to the fact that I was doing postgraduate study, and perhaps was not exercising enough. Maybe I was also eating more with those cups of coffee I took to give myself a break away from the computer. I was also holding down a full-time job. I decided to join the University gym and before lectures would do a supervised workout twice a week, and walk at other times, as well as watching carefully what I ate. All to no avail.

I noticed swelling of my ankles and mentioned this and all my other concerns to my GP on several visits. She had no explanation and basically ignored my concerns. I finished the course of study I was doing and did not pursue further study at this time, but things were going from bad to worse. It was brought home to me with a vengeance how much I had changed physically when photos were taken at a family function. I looked awful and this affected my self-esteem badly. My hair was so bad I was considering a wig. I was having severe menstrual problems, mood changes, depression, headaches and continued weight gain. At times I felt suicidal and the only thing that stopped me was the devastation my family would feel at this course of action. At this stage I had been to several doctors and had numerous tests. Some tests coming back negative, some abnormal, but not hugely abnormal. I found myself running into many dead ends and I wanted to give up.

I do not wish to be critical of doctors but many were unsympathetic and in some cases downright rude. I was told to see a psychologist, and learn to accept myself as I was, and to eat 'lean cuisine' meals. In one instance I was told to be glad I did not have Cushing's because it would ruin my life. This sort of attitude was disappointing and unexpected as I felt I was not being unreasonable.

Meanwhile in the background I had a very supportive extended family network. In the 18-month period prior to having the pituitary tumour removed I had two other major operations. During this time I also found an endocrinologist who admitted that I had a problem but he didn't know what it was and was not sure he could find the answer. This doctor treated the symptoms. I was happy to live with this because I felt that finally someone believed what I was saying. Up to this point I was beginning to believe what I was being told, and was thinking that perhaps it was all in my head; that I was just a hypochondriac and very much overweight.

The end of the diagnostic road came with an uncle seeing a BBC television program on Cushing's and contacting the specialist in London. The London specialist gave me the name of a doctor at Westmead who had studied with him. That was the beginning of a fantastic doctor-patient relationship. The endocrinologist I see at Westmead is extremely patient, caring and tolerant of me. He puts up with my continual quest for knowledge and answers, and my lack of blind faith. We have some rather interesting discussions.

It is VERY important to find specialists as well as a GP that you feel comfortable with and whom you have confidence in. It's like most things in life; the right builder, the right plumber, the right mechanic, the right teacher. It may be difficult but I would like to offer some suggestions to finding the right doctor; ask a doctor you may already have whom you trust, talk to family and friends, ask people in a support group, contact the hospital. When you have found a doctor, have a list of questions ready you would like them to answer. I always write them down because when I get in there I forget half the things I want to say. My specialist always expects me to pull out a piece of paper with a list of things I want to know or question. I think he'll be disappointed if I turn up one day without one.

Since the tumour has been removed I feel that in some ways I have just swapped one set of problems for another set.

It has been a difficult period of adjustment learning to juggle medications and recuperation with lifestyle and family expectations. One of my children when I was discussing my fears regarding the surgery said to me, "I don't know what your problem is, finally you have an answer and all you have to do is have the surgery." I explained that I felt it was just the beginning of the tunnel but hopefully we could see the light. Nearly 12 months on I am only just feeling that I can see a speck of light.

I had severe generalised joint pain after the surgery, which at times made it difficult for me to walk and even get around. I still have some joint problems even now.

I have had 3 Addison's-like crises, one of which none of my family realized how serious it was and how sick I was. It was only sheer good luck that I came out of it as well as I did. After one of these episodes I again became very depressed and felt that my quality of life was lousy, and for a few days stopped taking my medication. I just wanted to give up fighting and pushing myself, as that was what I felt I had been doing for so long. I felt it was just all too hard. Eventually I saw reason and resumed taking the medication.

I get extremely tired and have to pace myself in my everyday life. How I will feel each day is unpredictable. In the mornings I cannot get going until I have had my medication. I used to be a morning person and have found it difficult to adjust to this. Some days I feel like I have achieved very little.

I have to be aware of stressful and potentially stressful situations, and increase my medication to deal with them. I laugh about the time my son had a car accident and, before I could deal with that, I had to take my medication. My family are very supportive of me, and are very aware of when I need medication and what to do if I have a crisis. I am a source of constant amusement to them. As my medication wears off I have trouble concentrating, and start to slur my words and mix them up. And all without a drink. My work colleagues know of my condition and are aware of times when I'm not well.

Living with and accepting Cushing's has been very difficult for me. Prior to diagnosis I was doing postgraduate study, working full time, doing voluntary work and raising three children. Having to recognize that I can no longer keep up this pace and that on some days I need to accept that I'll be lucky just to get the washing done, tidy the house and get the evening meal.

I have three teenage children, two at University and one in Year 11 at school. It has been a very traumatic period for them to see their mother so ill. They, and my husband, have had to see me undergo three major operations in 18 months. They have seen me struggle with each recovery period, which has increased with each operation. They have had to deal with me as I struggle to come to terms with the limitations my illness puts on me. I used to lead a very full life with many projects on the go. When I was going through the tests a friend told me that if I was any healthier I would be dangerous, that I exhausted her just talking about what I had to do. Yet I felt I was achieving very little compared to what I had been doing before I got sick. I now only work two days per week so that I have the energy to do other things. I take care of myself so that I have something left for my family. Going back to work has been important for me from a psychological point of view. It makes me feel as if I belong in the "real world". Prior to diagnosis and since the surgery I have on occasions consulted with a psychologist. I think it helps to have someone to talk to who is objective. Family and friends can get a little bit fed up with listening to us.

I am finally accepting of my disease. I realize I can lead a normal life, socialize, go on holidays, exercise, play sport, go to the theatre and all those other things that people who do not have an illness do.

A few final points. I would like to ask all health professionals to really LISTEN to their patients. To use all the skills required to be a good listener. Please do not belittle your patients or make light of their symptoms, hence making them feel they are at fault. Also respect that your patients are intelligent people. I joked with my endocrinologist, when I was in hospital having the tumour removed, that somehow you lose 50 IQ points when you walk through the hospital doors. Funny how you find them at home. I would also like to thank all those health professionals who have hung in there with us and been supportive. We cannot make it without you.

Also patients and families hang in there and have faith in yourself. You know yourself better than anyone. As I tell parents of gifted children, you know them better than any of us as you are with them all the time. You are living with your symptoms every day. Keep looking and searching for answers and support, it's there.

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2009