

I was diagnosed with Endometriosis whilst having a laparoscopy for a large ovarian cyst in September 2010. Strangely, the cyst had gone, but luckily for me the private surgeon, Dr Appanna, knew what the lesions and small growths were inside my abdomen. He was able to clear what he could at the time.

Unfortunately, as I had a pre-existing condition of heavy bleeding on my private insurance, they would not cover me for further endometriosis surgery. This was because their experts decreed that heavy bleeding is linked to endometriosis, so they refused to pay. Nothing I could do or say would change their mind. I then went through the process in January 2011 of being referred to Waikato DHB for an appointment and surgery.

Whilst I waited I read anything and everything on this new problem that I now had. I also joined Insight Endometriosis (formerly Endometriosis Waikato). I needed to find out what I was up against! They were so helpful, I can't thank them enough; especially for Annette making time for a one-on-one appointment.

Personal History

I didn't start my period until I was well into 15. Then they started to become heavy after about 1 year. I remember Mum always said to me "I hope you're not like me and have to wear a towel". She meant a bathroom towel! Because I was sporty I used tampons - super, whatever the biggest were, and eventually a back-up pad too. I had to keep checking myself just in case; leaks were common.

After having a baby, I went onto the low dose pill at about 21. My periods became so much different, lighter, it changed my life. I felt free. I had tried to come off the pill once since then; I was about 38 I think. My husband had had a vasectomy, so thinking, along with my GP it was about time, as I'd been on it a long time. Straight away I was in floods again. I could hardly walk with pain on my period, I was almost doubled over. I stuck it for about 6 months and my GP put me back on it.

When I came to NZ in 2006 I decided that, once I was settled in a house and a job I would come off the pill near menopause age. That was about July 2008, I was 42. By November 2008 I went from size 12 to 8 and was suffering. My job and career was at risk, I looked so bad I couldn't look at myself in the mirror. I had to resign my job as I couldn't cope with everything. I felt helpless, as a visit to a GP was fruitless. I told him how bad I was bleeding, if I stood up, I would feel it dripping from me. I couldn't use super tampons anymore as they hurt when I tried, sex (if I felt like it!) was painful, and sitting down hurt me inside too. Do you know what he said to me.....You'll just have to live with it! What did I do...? Walked away and thought oh, this must be normal then. I came home and cried.

I used maternity pads and had a shower curtain under the bed sheet. I would take spare clothes and pads out with me wherever I went. Thankfully a large handbag doesn't look odd these days!

Unsurprisingly, I started to get run down and depressed but carried on. I got part time work. I was prescribed some anti-depressants, but I didn't really want to take them; it didn't feel right. I knew myself that was not the answer. I went back to see a female GP, with the same information of course. I was advised to have a blood

test and consider the Mirena. It was actually funded for me as I was diagnosed with anaemia. It was fitted in March 2009.

Things became better for me, my periods didn't stop, but they were a lot more manageable. I still had bad back ache, unable to use tampons, cramps etc, and sore to sit down. But it was way better than before. This brings us back to the cyst. My back aches became continual and painful. A scan revealed a large cyst on my ovary. Thankfully, my health insurance was covered.

DHB and Health Insurance

I did not have to wait too long for an appointment with the DHB. Annette at Insight Endometriosis advised me of the top people in the area for endometriosis issues, one of which was Dr VP Singh. My appointment was to be with him so I was very happy. However, I did not see Dr Singh as my letter suggested, just a registrar. They didn't even need to examine me as they had a referral from Dr Appanna with all the details. Apparently, my endometriosis was severe and over the bowel so I needed two surgeons/specialists. I was advised that I would likely need a hysterectomy and bowel resection and would be on the waiting list as a priority.

This was April 2011. By October I had had enough, my pain was getting worse and I was getting symptoms of IBS now too. More reason to carry spare clothes around again! I had already rung the Gynae dep't a few times in the preceding months, trying to get an idea of how soon I would be seen. (My April letter had stated surgery within 6 months). I could not get an answer from them other than "we know you are on the list, it is not easy to arrange two surgeons, we will let you know..."

I decided to take action. I wrote an appeal to my health insurance and asked them to explain how they had linked my endometriosis to my heavy periods, as they based their decision on medical notes from 2008, therefore after my policy started! I also argued that medical science shows no conclusive evidence on what causes endometriosis, how long it takes to develop etc. At the same time, I contacted the Health & Consumer Service for help to complain to the DHB.

Consequently, in November I took a phone call from my health insurance to say they will definitely pay now, get it booked and sorted. I did get this in writing too, for future reference.

The DHB told me I was number four on their list of 30 and that they only do two surgeries a month. Why don't they tell you this straight off I wonder? You do the calculation for number 30! Anyway, they agreed to see me as soon as possible, and pencilled in January or February 2012 because of the time of year.

I have now had my Total Hysterectomy. The DHB did it early, on 8 December 2011; the private sector could not get me in sooner! I had Dr.Lakshmi Ravikanti as the surgeon and the surgery was done via laparoscopy. It transpires that I had adenomyosis, did not require bowel surgery, and all went well.

I am recovering very well and look forward to saying "I do not regret having it done!"

For more information:

Visit us at: www.InsightEndometriosis.org.nz or www.Facebook.com/InsightEndometriosis
or contact our Educator, Annette: 07 8555 123 info@InsightEndometriosis.org.nz
