

It all started with pelvic pain on my right side, and more intense after I had exercised vigorously. It started as a dull ache and progressed to sharp, stabbing pain at any time of the day or night. I decided to seek advice from my GP when it became too common a problem. The pain was more severe around menstrual time but nothing I couldn't tolerate at this stage.

My doctor sent me to get tests such as ultrasounds, blood test – but nothing came back positive, so I started to think that maybe, just maybe, it was all an hallucination... . Anyway my GP sent me to see a gynaecologist, because I'd had other operations in the past such as peritonitis and two c-sections. The diagnosis at this stage was that adhesions had formed and maybe we needed to have a look and get them sorted. So off to the specialist I went to undergo a laparoscopy.

The next thing I knew (and \$7000 later) I woke up in the comfort of my hospital bed and the surgeon was holding my hand apologising to me that I had severe endometriosis (Grade IV) and \$full hysterectomy was required and we need to get onto it as soon as possible.

As a personal trainer, endometriosis was not unfamiliar to me, but the logistics of it all was. Getting to the bottom of why? How? When? And the truth of it all was going to be a journey. I know I must accept the fact that endometriosis is going to change the rest of my life. Endometriosis is a lot more than a physical disease – it has become a mental challenge.

It's been three months now and no better. I have tried very hard to keep my sense of humour over this time and not letting those around me see my inner suffering. They don't need to hear me moan and I don't want to anyway, but it's getting tougher and tougher and I think I am going to have to ask for help in the end. This is a very difficult thing for me to ask for.

This disease is not only rotting away at my insides, it plays tricks with your mind and your sanity. I feel like it's a test – to see how strong I am. Unfortunately there are days I am losing the battle – my social life is becoming hard and making plans difficult as I have to take one day at a time. It's more than just sleepless nights and endless crying when not being seen by anyone. When the pain gets too bad, the pills just don't work anymore. There is also the feeling of heating up inside – like a burning sensation – which starts from the soles of the feet through to the top surface of the face.

My last period was an absolute nightmare. Mark was away and I really needed him. I thrashed around in the bed like something mad and uncontrollable. Desperate to call and ask him to come home, I realised that would be selfish on my part to ask to for some comfort to get me through the night.

I am dreading next month when my period arrives again. I am now armed with more potent painkillers after seeing my GP. I had to get stronger pills just to deal with the severity of the pain. I hate these pills – they really knock me out, make me feel drunk and more sick than I feel anyway – but at least it takes the pain away so I can copy through the day and night. The week of my period is a week taken out of my life, and a week of hell, a feeling of non-existing in the real world. The pain is nothing that I could explain to anyone, because they just wouldn't understand. Just to get up and put the jug on is a struggle during this time.

I used to have a good sex life – no problems having orgasms and no pain – things have changed now dramatically. I've started getting severe shooting pains, burning and numbness during sex. What used to take 5 minutes to have an orgasm now takes over 20

minutes, and the feeling is not as intense anymore. Sometimes it even hurts just to be touched. The pain is now becoming a fear.

This month I managed to have sex at least three times over three days because that's all I got in the month with no pain now. I try to make the most of it, as I know it could be different tomorrow.

I know more myself as a result of endometriosis than I ever knew before, both physically and mentally. Learning to live with the pain is a profound lesson; I am much less agitated about things that really don't matter. I am trying to be more flexible and make no long-range plans. I try to not let endometriosis become the most important thing in my life. But at the moment it is.

With just two months before my operation I am terrified. The feeling of not being there for my family and knowing there will be arguments with Mark and the kids to cope with the surrounding is going to do my head in big time. Somehow, being a Mum is the peacekeeper of the household. The fact that I will feel the blame for getting this disease is frightening me.

Being off work too is going to make me feel inadequate. How do I keep up the responsibility that a manager and owner needs to maintain? They say I need to take the time to recover and heal after the operation, but I think more stress is going to creep in when I see the people that mean the most around me not coping and will stress and argue over the tasks I normally do.

29 February 2008 I got engaged. But was it the right thing to do? Getting engaged brought some happiness for awhile – it was good to see my family smile. I do have my doubts though – I can't help feeling that Mark feels very sorry for me and the depression that endometriosis causes drives my mind into overdrive and think the worst.

27 March 2008 – went to an endometriosis meeting last night with one of the top gynaecologist in the country, Naylin Appanna. We are lucky in Hamilton to have some of the best.

There were only three or four things that he mentioned that still embed in my mind - the main one being that cancer is easier to remove than endometriosis, and the other was that if an operation is required which is normally the case, then within two years 30% of women will have the endometriosis come back and in five years 60%. I can just remember numbness and gazing at the window and looking at my reflection with the darkness of the night falling behind. I could have got up and walked out about now, but I really wasn't sure if my legs would have walked upright, so I stayed put and watched his video. Stunned by the sight of a Grade III photo – tiny black dots lined the walls – I knew I was in trouble, my black dots were black boulders compared to them and I knew I was a Grade IV – oh my God!

My period this week has been almost impossible to deal with – the pain extremely high and uncontrollable; the painkillers I got last month aren't working anymore. I found myself on all fours like a dog trying to get some sort of comfortable position, and Mark wondering what the hell he can do to help, feeling utterly hopeless to relieve the pain somehow. I hadn't slept for four days, feel absolutely drained. It's now causing me to have time off work.

My blood flow has been the worst I've had, flooding my clothes six times - three in one day - all I had to do was stand up from a seated position. I went through a box of 40 super tampons in three days. I might have to invest in pads next month – thank God it will be my last one, even so, I am not looking forward to it. It's not very nice to talk about, but the blood is black and congealed like liver.

If you ask yourself if you are ready to have a hysterectomy, chances are you are not. You will know when you have reached the end of your tolerance, when you have reached rock bottom. My time came when the pain stopped me from sleeping for four nights.

Papers arrived on the Friday before surgery and everything finally hit home that this is really going to happen now. I was sent for blood tests on Monday, and on Tuesday I had to take this rather awful-tasting powder to clean my bowels out; this left me on the toilet most of the day, not to mention I had to take another one on the morning of the surgery.

21 May 2008 – 12:35. I had two of the best surgeons, Stewart Hastie and VP Singh. I found it really hard, as for once in my life I didn't have control of what was going to happen to me – my body was going to be entrusted to two surgeons.

After the surgery, Dr Hastie was very pleased as he seemed to think that he had got everything that he could see. A large mass of endometriosis – bigger than a tennis ball - was taken out of the left-hand side close to the back, which was also pressed up against my bowel and would have been the reason for my lower back pain. Huge adhesions were also removed which had been holding and affecting everything they touched. Not very pleasant. One of the nurses that assisted the operation mentioned to me afterwards that she had never seen any that thick before.

On my third day, and wondering why I wasn't able to sit properly and feeling like I was sitting on a basketball, I found out that I had to have some packing removed from my vagina. Oh my God – someone should have warned me about this one! – I guess this is just one of those times they forgot to mention that this was part of the procedure that had to take place afterwards. What I didn't realise was that there was around 3m of it (if not more) and it wasn't the most pleasant experience while removing it, when the top of my vagina was covered in stitches. Not something I will forget in a hurry, but at least there was a feeling of relief afterwards.

Four days after, every time I ate I got large amounts of pain, like the food is rubbing the insides that have been cut and removed. My stomach bloats up badly, so I ate very small amounts of soft foods. Meats are out, except for fish, and so are vegetables which I find strange. My meals consist of mashed potato, fish, gravy, ice cream, jelly and soup.

It's been 8 weeks since my operation, and I still have pink urine which surprises me. I guess I thought it would be all over and healed by now. I guess when they say slow recovery, then that's what it really is. I have been back at work since the fourth week – some say too early, but I have been OK and even on a bike exercising for 30 minutes at a time. I feel good, but I just make sure I have a day or two off in between and don't rush things.

The hardest thing I would have to mention of all of this, is the intimacy with Mark. When you're sitting in the surgeon's office before the operation and they tell you that you have to wait 8-10 weeks before you have intercourse again, you take it with a grain of salt, but in reality I think Mark and I have found this the hardest thing to do. You can cuddle up together on the couch but it's just not the same and you find a slight drifting apart. It's been ten weeks now, and I get my clearance tomorrow hopefully. Sex will be our first question – will it hurt? I now have to deal with the reality of how we do this and how we go about it. It may sound strange, but we never thought of it at the time. My vagina was stitched at the top which has made it smaller than normal now, so the depth of penetration is going to change – or will it?

It's been 12 weeks now and finally we both got together in a sexual embrace. It was OK, but very strange at first. In fact, to be honest it was better than it used to be. Mark said I was tighter, and felt very pleasant for him. What a relief on my part. I had read so many books saying how after a hysterectomy women never get their sexual drive back. In my view I am more sensitive now than before and sex is also better. We both know more about my body than ever before – it has now brought us both closer together. We just had to get over the initial fear hurdle of it all.

In a year's time I guess I will be able to judge the success of my operation. The big question now is, how much of this unwanted friend is back.

To end this story of mind, it has been a learning experience. I look at life differently now and see others differently. Those little things don't bother me anymore. I have lots of living to do and I damn well am going to enjoy it! Endometriosis now, it's with me so just get over it and start living. Life is too precious to let it beat us. Don't put up with the pain – just get rid of it. It shouldn't be there. A SIMPLE DECISION.

For more information:

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