

My journey with endometriosis didn't start until I was 30 years old. I never had any of the issues with my period in my teenage years or 20's, as most women with endometriosis seem to do. I remember at around 29 or 30 years of age I started to get uncomfortable and sometimes slightly painful periods. The pain was only mild, certainly not keeping me bedridden or away from work.

However, over the next three-four years I started to experience other symptoms-more frequent trips to the bathroom and, more noticeably, sex became painful. After a year or two of regular visits to the GP and regular prescriptions for Urinary Tract Infections (UTI) I said "enough". I told my GP I didn't think I had UTI's, and I wanted to be referred to a specialist.

I was referred to a urologist. Thankfully I had insurance through work and I didn't have to stress about the financial stuff. During the examination I experienced a lot of pain. The first thing the urologist said was that he was going to refer me to a gynaecologist, Naylin Appanna. Off I went to see another specialist. During the internal exam I felt an incredible amount of pain which left me in tears and Naylin had no doubts I had endometriosis. I'd never heard of the disease before. It was quite a shock. Naylin explained that he would need to perform a laparoscopy to determine it for sure. I was booked in and a month later had the op.

When I woke from surgery, Naylin came in to tell me that I had stage IV endometriosis and that the disease had been on my bladder and bowel. That certainly explained a lot. However, I still didn't really understand this horrible disease. It was only over the next year that I was to learn how badly it can affect women. My partner and I had talked about starting a family only six months or so prior to my diagnosis and I was really worried that I wouldn't be able to conceive. Fortunately I was lucky, and only three months after my op I was up the duff.

I breastfed my daughter until she was 16 months old and then got pregnant three months later. I also breastfed my son until he was a year old so this kept the endometriosis at bay for those years. When my son was about five months old I noticed that my visits to the loo were increasing and I was also experiencing a lot of burning and pain. Once again I went through the vicious cycle of visits to a GP who kept treating me for UTI's. I changed GP and talked about my concern that the endometriosis had returned. I was referred to Waikato Hospital. I had changed insurance companies and was no longer covered.

It took a year to get an appointment just to see the gynaecologist who was going to see me and ask questions. I had to wait another seven months before I got the laparoscopy. This time they found a large adhesion attached to my bowel, which they thought was from my previous surgery five years earlier. They also found some scar tissue and discovered that my bladder had attached itself to the top of my uterus and been stretched to twice its normal size, which must have happened after my second c-section to deliver my youngest child. What they *didn't* find was any new growth of endometriosis.

I was really surprised because of all the pain and issues with the loo. About a month after my op the burning and frequent urination returned and I asked my GP to refer me to a urologist. Thankfully this was covered by my insurance. I had a cystoscopy and they found I have Interstitial Cystitis (IC). What?! I had never heard

of this before either! The cystoscopy was performed only three months after my second laparoscopy and I was kind of over it all by then. I found out that IC is fairly common with endometriosis. Who would guess?! I haven't experienced any problems with endometriosis for the last five months, but am on medication for IC. I'm on mild anti-depressants to try to help me sleep through the night and some anti-inflammatory medication as well. I'm still up two or three times a night going to the loo and going every half hour to an hour during the day. Some days are worse than others and I can be on the loo every 15 minutes when it's really bad.

I have recently discovered that one of my Mum's sisters has been suffering with IC for years, although she seems better now. Apparently her trigger is stress. Mine? Not sure yet. I've eliminated all the acidic foods from my diet including coffee chocolate, alcohol, most fruits and some veggies. I am also being treated by a naturopath.

It's been four months and I've noticed some change, but I still have really bad days. I don't get a chance to exercise or take my children very far from home because I need to be near a loo and when the burning is really bad I can hardly walk. I was told by VP Singh and my urologist that IC can get worse around menstruation.

I've been on Depo Provera for the last year and have only just come off it so will have to wait and see if that's the case. It's frustrating to know that most of us don't have to cope with just endometriosis (like that isn't bad enough), but that we can be affected by other, just as debilitating, diseases as well.

There are days when I think I can't cope with it anymore—until I look at my two beautiful children, then I truck on through another day. At the end of 2010 I was really struggling with coping with my symptoms of IC and endometriosis and went searching online for more info and someone to talk to. I came across the Insight Endometriosis website and felt encouraged to give Annette a call at the time and talk about my anxieties. Annette was really great and it was a relief to talk to someone who knew some of what I was going through. I called Annette a few times over the next few months expressing my frustration at how long the public health system was taking to get me sorted and again found her incredibly supportive and full of useful info. That's what helped me get through the year before my op. And since then I've wanted to contribute in any way I could to such a great and supportive group.

For more information:

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