

I was quite innocent to the possibility of having endometriosis for some time. The name had been floated around the family for ages when my only sister, who is 15 years older than me, suffered terribly from this endometriosis thing that I could not even pronounce! She was one of the many unfortunate ones who was misdiagnosed as having appendicitis, and had a perfectly good appendix removed, because as the surgeon explained, "there would have been a scar there and it would be confusing to any other members of the medical profession". She was and still is a very strong lady with a high pain threshold, yet she was in such pain she would faint, or be unable to walk 25 metres for help while she was out on her postal run.

Although she had told me that I did not have endometriosis because I was in no pain - at that stage anyway - I still made my GP aware that there was "this horrible disease in my family, that sounded like endometriosis something or other". Luckily he had been interested in gynaecological work so knew exactly what I was talking about.

My problems with endometriosis began when I came off the contraceptive pill while trying for a family. We were trying to conceive our second child, but were having problems. My GP had taken down some notes of my history of painful periods and heavy bleeding prior to being on the pill and suggested I seek advice from a gynaecologist. The gynaecologist actually suggested prior to performing a scan and a physical that I should have been sent to a general surgeon. (Just remember that for later...). On investigation, he was strongly convinced I did have endometriosis, which was confirmed following surgery. Following surgery he advised we had a window of about 6 months to try to conceive naturally, then the endometriosis would probably return and limit our chances to almost nil. The 6 months came and went without any baby news. I was extremely sad and frustrated that it was not my decision not to have further children, but nature's. My sister made a comment, "you may have been suffering from endometriosis when you conceived your first child and didn't know". So I just kept on trying and hoping. Against all odds of the gynaecologist and GP I did conceive for a second time. We decided that due to all the anxiety we went through for the No 2 child, we would not try for more. The trying to conceive naturally was hard on everyone around us, not just our nuclear family.

I was fortunate that the contraceptive pill does mask the endometriosis symptoms, and I have been on it again for the last 12 years. However in the next few years I will have to stop it. My osteopath advises she may be able to help my body adjust. However that was not the end of my medical problems... .

Although I had my endometriosis under control, I was still getting terrible bouts of pain, often making me incapable of performing any activity for 2 x per month at worst, to once per 15 months over a 7 year time period. The medical profession could not work out what was wrong with me. It was my osteopath who noticed something wrong with my digestive system, (I had gone to him for another problem). He sent me to a herbalist who suggested I visit my GP and demand a scan for gallstones, which were found to be the problem! Had the gynaecologist picked it up years before? My body was passing the stones before I was going for blood tests. It sounds as though gall bladder problems are common among endometriosis sufferers!

My main passion all these years after helping to set up the endometriosis group, is to support the sufferers. I have been there and know what you feel like, with people who don't believe you, or think you're a wimp, to doctors who think you are crazy. To also continue going to doctors if you are not well, just be persistent.

Also don't take specialists negative thoughts as being right, thankfully they can get it wrong! I often think that as I watch my youngest girl grow up. I have two girls, and one who is nearly 17 years. I am very proactive if she or her friends have painful periods etc... . It is not normal, spread the word to continue to seek help.

For more information:

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