

I first discovered the word endometriosis when I was fourteen. I had been experiencing extremely heavy and painful periods for two years. My periods were so heavy that I could soak through a 'super' pad in half an hour! The pain was like nothing I had ever experienced before – not just cramping - it was a gripping, twisting pain that radiated from my stomach to my legs. I experienced bad cramping and aches through my back throughout the month. I had many visits to our GP who prescribed Ponstan and anti-inflammatories, which didn't help much.

I first visited a gynaecologist when I was fourteen, who helpfully suggested that becoming pregnant might help my period problems! This was not something I wanted to consider at that age. I was instead put on the contraceptive pill to attempt to control the excessive bleeding every month. By this time, I was having a lot of time off school as the heavy bleeding and pain lasted for over a week each month. Although I attended a girl's school, I found it very difficult to explain to anyone why I was so unwell. Everyone else seemed to cope with their periods much better than I was, and it was something I felt embarrassed to talk about. I had a D&C when I was 14, which did not produce any diagnosis or any relief from heavy periods.

It was a very lonely time for me. I visited the library and searched on the internet, hoping for some guidance or help with my problem. It was then that I found the term endometriosis, and a checklist of possible symptoms – I had nearly every one of them!

I was excited to find some kind of explanation for the problems I had been experiencing. I visited a new gynaecologist who dismissed the idea of possibly having endometriosis – I was far too young! I was told that this only affected women older than me – I was only a teenager! I felt extremely confused, as I found it hard to convey to the doctors I saw exactly how bad my periods were. By this stage, I was becoming extremely anemic from my heavy menstrual bleeding. I felt sapped of energy and people frequently commented on my very pale skin. I chose not to take iron supplements as I didn't like their side effects. I struggle to remember events that happened at this time as I was so anemic, it was all I could manage to attend school as much as possible then come home and rest. I had few other interests as I just didn't have the energy, and I was embarrassed of my heavy bleeding and flooding. I remember attending a concert during the first day of my period and when I stood up at the end, I had completely flooded – blood through my jeans and all over the seat. I was embarrassed and mortified, and it wasn't the only time it happened! It was especially hard to cope with this at school. One particularly understanding and helpful teacher told me about her daughter who had similar problems, and gave me an advertisement for the endometriosis support group based in Hamilton.

My mother and I attended a support group meeting. I found it amazing and a relief to talk to other women experiencing the same thing as me. I could talk about what was happening and how I felt, and these other women understood. I found out more about possible treatments and side effects of medication. In the summer holidays before my 6th form year, I had laparoscopic surgery that diagnosed endometriosis. I was relieved to finally have this diagnosis confirmed. The operation did not go smoothly. The night after the operation, I was in a lot of pain and requested pain relief from the hospital nurses. They gave me Panadol, which I took, but it was not sufficient. Despite other pain relief being charted, they declined to give me any. I was not able to sleep that night and could only breathe with considerable pain. I later developed an infection in the surgery incision in my navel. I could also pull nylon stitches through the other incision sites for months afterwards, and this seems to have left keloid type scars.

Unfortunately, despite the diagnosis, I did not experience any relief from the pain or heavy periods after the laparoscopy. The gynaecologist prescribed medication - gonadotropin-releasing hormone (GnRH agonists) - to treat any remaining areas of endometriosis, but I was alarmed by the possible side effects – hair growth, voice lowering and acne. I chose to not take this medication and returned to taking the contraceptive pill continuously (skipping sugar pills) in an effort to reduce the amount of periods I was having. I was still very anemic and experienced breakthrough bleeding when taking the Pill continuously. I kept attending the support group meeting as I found the speakers and discussions with other women extremely helpful. I was relieved to know I was not the only one experiencing these problems.

I found it very difficult to attend school during this time, as I was frequently taking codeine pills or Tramadol to reduce the pain I was experiencing. These left me feeling 'fuzzy' and made it very hard to concentrate. I sometimes wonder how I sat some of my exams while on this medication! I managed to finish high school in 2002, having passed my Bursary exams. I did not plan any future study at this time, as I did not think I could leave home or complete tertiary study with my current state of health. I found full-time work in retail and had another laparoscopy operation in mid 2003. This was with Dr Hillary Liddell in Ascot Hospital, Auckland. I had read about Dr Liddell in a 'Next' magazine article, in which she mentioned treating many teenage girls with endometriosis. I found her to be an extremely warm, engaging doctor. She did not dismiss my concerns or fears – she actually took me seriously! I had a laparoscopy for removal of endometriosis, and an insertion of a Mirena IUD device.

I joke that I walked out of the hospital the day after having the laparoscopy feeling better than when I walked in – and I'm not really joking! Despite the discomfort of the surgery, I felt better almost immediately after the operation. Dr Liddell said that she had removed moderate deposits of endometriosis, as well as adhesions to the bowel and cul-de-sac. I had some bleeding for a couple of weeks, but recovered better than from the previous laparoscopy. I returned to work a week and a half later. Three weeks after the operation, I started bleeding which turned into extremely heavy flooding, and passing huge clots. I hurriedly left work as this began when I was standing on the shop floor. I was quite alarmed by the amount of blood and clots that I was losing. This continued for most of that day, but has never occurred again. I initially had monthly spotting, then spotting for a day every few months. Now I have spotting very infrequently, and it is very light. I have no menstrual-related pain whatsoever and my backaches are gone (these may be explained by the discovery that I have a retroverted uterus – sloping backwards instead of forwards). I am very pleased I chose to have the Mirena. It has proved its worth as contraception and period control, although I probably would not have chosen to use it as a contraceptive device if I was not requiring it for period control due to the endometriosis.

Since the second laparoscopy and Mirena insertion, I am no longer anemic and continually tired. I do not have to plan my life around my 'period week' each month. I don't have to sleep on towels in case I flood! I have realised that having a bowel motion no longer causes any pain.

I graduated with a Bachelor of Nursing in 2007 and am now pursuing my career as a paediatric nurse at Starship Hospital. I have no doubt that I would not have been able to work or study at a tertiary level without the treatment and removal of my endometriosis. At present, I am totally healthy and happy, and I urge other girls and women seek to help and knowledge around endometriosis and period-related issues.

For more information:

Visit us at: www.InsightEndometriosis.org.nz or [www.Facebook.com/InsightEndometriosis](https://www.facebook.com/InsightEndometriosis)
or contact our Educator, Annette: 07 8555 123 info@InsightEndometriosis.org.nz
