

Where exactly do I begin - the feelings of unknown fear, lack of control, disbelief, but mostly of anger. Why was this happening? What is wrong with me? Was I really sick or perhaps they could be right - perhaps it was in my head? Right down to the feeling of sudden relief, of finally having a future, a job, a relationship and basically just being a normal human being.

I guess from the age of 15 I had heavy periods and period problems, but was given the usual comment from doctors - everyone gets them, it's just part of being a woman. Participating in sports was almost impossible, as were the days off school with stomach cramps. While other kids enjoyed a social life, my best friend was my hot water bottle and a bottle of painkillers.

When I turned 19 I enrolled in the Air Force for a six-week course, and departed to Woodbourne Airbase located in Blenheim for what was supposed to be a lifetime experience. Here I was having the time of my life when suddenly, two days into the course I took sick. On day three they transferred me to Blenheim hospital where I stayed for a further seven days undergoing numerous tests. When nothing showed they released me from both the hospital and the Air Force on grounds of Home Sickness. Arriving at Hamilton airport to pick me up, Mum found a young pale size 8 daughter, whom she failed to recognise, instead of the healthy size 16 well-tanned lady that left just 10 days earlier.

After several months' rest I became well enough to continue working and gained employment at an accountant's office and even managed to enlist as a volunteer fire-fighter, but about six months into my career I again took sick. Again the diagnosis was slow and eventually I was diagnosed with endometriosis - a condition we later discovered my Mum had, but was never told.

Having a name was the ultimate and now on medication after extensive surgery, I figured this was the end never to return. Oh how foolish a person can be, because three months after I finished drug treatment my newly diagnosed friend was back; again they treated me with Dimetrioise followed by surgery. Surely this time it would work? By this time I had not only lost my accountant's position and volunteer firefighting role, but also been badly branded around my home town as a mental nutcase. Of course most people who don't know what endometriosis is automatically assume it's a mental problem. Needless to say I didn't have many friends left nor job prospects after that, and in fact six years later there are still people who choose to believe this - guess it shows the narrow-minded side to small communities.

For six months after this I was great - finally living a dream life - but then suddenly it happened again. By this time I was fortunate to have some supportive work associates who helped me continue to work. There were days when I was taking six different painkillers just so I could ease the pain enough to go to work. Most days I wanted to just roll over, and others where I thought I was being punished for something extremely bad I had done. Nothing in the world would have prepared me for what I had encountered and I thought nothing else could have been this bad. I was isolated, no-one else I knew had heard of this illness, struggling to understand what was happening to me or why, when we discovered an 0800 helpline who referred me to a support group based in Hamilton - one hour away.

That very first meeting was scary to say the least, but after meeting all the fabulous ladies I soon understood for the first time I wasn't alone, I wasn't crazy like the Brigade had labelled me - I was just a normal endometriosis sufferer. Each month as I went back it became easier to make decisions - I had facts from medical knowledge but I also had other peoples own personal experiences: advice of things which have helped; advice on

how to deal with the emotional, physical and social issues associated with suffering this illness.

At the age of 21, I decided having children wasn't for me; there were other ways to have kids - adoption, surrogacy - besides, who could have kids if they were too sick to look after them? At 23, single again after the second partner walked out because they couldn't stand the pressure of my constant sickness, I decided to fight for a hysterectomy. By this time I'd been handed over to a more experienced specialist and as much as he fought against it, I fought for it. As he presented evidence against the idea, I hit back with information for it, and before long we reached a compromise - he'd go in and remove the worst tube and ovary.

So at the age of 26, I had the right tube and ovary removed. For 12 months things improved - I had a new lease of life and finally started to see a future, something I hadn't seen for awhile. However, to my dismay, after those 12 months I started to have symptoms again. After another discussion with the specialist and with the support of my local GP I finally went for a psychology report, which supported my decision, and a week before my 30th birthday had a hysterectomy, keeping the left ovary, followed by Zoladex for six months. Although I knew that with the one ovary remaining and the possibility of endometriosis deposits left behind, nothing could have prepared me for the shock of what was to come.

It started with chest pains, fatigue, shortness of breath, and recently my throat has been swelling. I am prone to infections. Before I was a confident person, now I cry for anything. I draw away from things and have lost sight of my dreams and goals.

My illness has put a lot of pressure on my partner, who has supported me for the last 10 months, but it's very difficult when doctors ask if he's hitting you or abusing you in front of him. Or how I'm always pulling him out of bed or away from work because I'm sick and need help. The stress for him, watching me drive to work and then receive a call saying I've blacked out and need him to come get me. I guess after 10 months of the unknown and living life on egg shells he decided he couldn't take it any more and decided I should go home. Instead of my illness making our love stronger, the stress of the illness, the accusations, turned his love to hate. Although it's hard for me to accept and I'm extremely angry towards the doctors for it getting to this point, I don't blame him, nor have I stopped loving him. I guess he just feels that without him around they may just do something.

The financial stress has been huge and in just the last 10 months I have used my entire life savings of \$14,000 to cover medical bills and time off for loss of earnings. When people think of endometriosis, they think of the physical pain and suffering to the sufferer - what they don't comprehend is the emotional and financial aspects as well. The ongoing doctor/specialist fees, medication costs, and the emotional roller-coaster of feelings hidden away.

Endometriosis is described by many as a women's complaint, but let me tell you, it affects your partner, children, parents and anyone else who plays a part in your life. Some people cope, others need support. Partners and loved ones, they have a choice to leave, but for the sufferer we do not have a say and have to soldier on the best way we can.

My best advice for partners and sufferers: never be afraid to admit you can't cope and ask for support, get involved in your treatment, do your research, and remember that at the end of the day any decisions about your body are yours and only yours. And in Joe's departing words: be strong, don't give up, fight it every way.

For more information:

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