

Hi, my name is Amanda. I am 29 years and I have Crohn's Disease. My disease itself is only in the mild - moderate category, but the complications I have from years of having the disease unchecked have... complicated it.

I was formally diagnosed with the disease on April the 28<sup>th</sup> 2010 after (what my specialist predicts) suffering from the disease for 20 years... in silence.

I don't remember much about my childhood now, but I do remember constant stomach problems, ulcers on my tongue that wouldn't go away and having "low iron" on every blood test I ever had. I also remember GP after GP reassuring my parents there was nothing "actually" wrong with me that I was simply a child that didn't want to go to school. I visited 4 GP's in those 20 years... not one of them thought to send me for further testing. In fact, they made me feel like a lunatic... and they convinced my family that my constant health problems were a sign of hypochondria rather than considering I was actually ill. They made me feel so disgusted in myself I started to believe I was indeed crazy and stopped going to avoid the criticism.

In September 2005, I had what I now know to be my first bowel obstruction. I was on my first overseas trip when I became hideously sick. I managed to stay away from any form of doctor, and eventually, it passed. I wasn't to know at that point it was the first of many bowel obstructions I would have and the tip of the ice burg when it came to pain. It was about 12 months before I suffered my next obstruction... I was so violently ill; my family dragged me to our GP. He looked down his nose at me... and said I obviously had an allergic reaction to something I ate on both occasions. He was so convinced I was making it out to be much worse that it was; he didn't even give me an additional day off work. My obstructions continued... and they began to become closer together. I still refused to go back to a GP, "it must be something I'm eating" I thought. I started keeping a food diary – but there was no pattern, no logic.

It was December 2009 when my partner and close friends reached breaking point – I was experiencing all the symptoms of an obstruction every 3 weeks. It took them until February, after a good friend's birthday party, to convince me to go back for more mental torment. Back I went on February 21<sup>st</sup> 2010. I was forceful with the doctor – I think the constant illness had stopped me looking at them like "God's"... the sad thing is, a lot of people see them like that. Sadder still, I think some doctors themselves that way. He gave me the same attitude I always got "nothing serious can possibly be wrong with you". He diagnosed me with Giardia – a parasite, but I hadn't been to a "problem area" for them... ever. When I protested, he huffed and gave me a referral for a blood test – he decided not to bulk bill this test, because he was adamant I had Giardia. I took the treatment for the parasite and went for my test. It became blatantly obvious it was not Giardia when I became violently ill just 4 days after the "treatment that would end my problems". I returned to the GP my blood tests were back and they showed extremely low iron and vitamin d. He dismissed them, told me I wasn't eating right and to take some vitamins... I told him about my continuing pain and problems, he grunted and threw a referral for an abdominal ultrasound at me, again refusing to bulk bill it.

I went for the ultrasound the next day, on the table the operator informed me that I had a "thickened bowel wall" when I asked if that meant cancer, she nodded and said "possibly". I was almost destroyed, that afternoon I had reached my lowest point. I was depressed and tired and just wanted some answers. My next appointment was the very next day – he read the report, it said noting about Cancer. Instead it mentioned a disease I had never heard before – IBD. My doctor would still not concede that I was sick – but ordered a scope, at a private hospital – we were uninsured. I will remember the last words that GP said to me until the day I die – on

the way out the door, he said in front of a full waiting room, "harden up, I still don't think anything serious is wrong with you".

I went home that night – desperate for answers and googled IBD – I know you shouldn't but I needed to know. I looked at Crohn's Disease first... by the end of the second paragraph, I was in tears.... I knew at that moment, I had Crohn's disease... It explained my entire life to date. Before it was official though, I needed to have a test I was terrified of... a Colonoscopy. I rang up quickly – thinking if I could get it done in a few days time it wouldn't be so bad – you know like ripping a bandaid off? Alas because my GP had blamed my diet for my iron and ordered me to take supplements – I needed to wait two weeks before I was right to go.

In the grand scheme of things – the scope was nothing... a walk in the park compared to what I have been through since. When they woke me up – the specialist who performed the procedure was there... he opened his mouth, but sound came out of mine. "It's Crohn's Disease" I said without shifting my gaze – he nodded, handed me a referral and walked away. I told my partner when he arrived... I wasn't upset... I just was. I scheduled the SBS for the next day... it took 5 hours to perform because my bowel was so slow and so badly structured from years of abuse. I swear to whatever you believe in – I will never do that test again. After all the testing, doctors' appointments, bloods, and the whole shebang – I was \$1900 out of pocket, just 5 months after moving into my first house I had bought with my partner. I later found out every test could have been bulk billed and we would have been spared the financial hardship – by that stage though, I was too numb to be angry.

I was 6 weeks before the GI could see me again... I was still undedicated and flaring – so in-between times I obstructed again. When I saw him he very flatly told me how sick I was and that I would need surgery – perhaps soon if the medication he was prescribing didn't work. He told me about a medication that would be perfect for me. Then he told me the price, \$285 a month – at that time, I thought for the rest of my life (he didn't explain things well). I took the prescription thinking we were going to have to sell our house. I also took a referral for a specialist – I protested, just seeing that as him booking me into surgery. I was wrong.

I spent the next 3 months scratching together money to afford the expensive medication. I woke up for three months thinking "I am not sure I want to keep waking up if this is how I am going to feel every day for the rest of my life". I dragged myself to work and faked my way through every day while people who had no idea what they were saying kept congratulating me for having Crohn's rather than Cancer – I wish I had the balls then I have now, because I would have told them exactly what they were congratulating me for.

My life changed, for the better, the day I met the first doctor in my entire life to just sit down and talk to me... he examined my records, listened to my story – hell he even wrote my old GP a letter that really dressed him down... I talked to him for going on 2 hours – he didn't look at his watch once... he has been my saviour... both medically and mentally, I don't know where I would be today without him. Being an outpatient I was able to access medication cheaper – for the first time in a long time, I breathed out a sigh of relief – after meeting that man and the staff in Endoscopy at the hospital I knew I was going to be okay.

Here I am today – still no surgery. The medication worked to reduce the swelling in my bowel, in fact, I have only had one obstruction in the last 18 months and that was exactly 12 months ago yesterday.

I know that if you have Crohn's Disease, a good doctor can make a monumental difference. There isn't a day that goes by that I don't tell people how glad I am to be

under the care of Gold Coast hospital. The people there are amazing. My partner stayed with me while it felt like both our lives were falling apart... he is my hero. I was broken mentally and medically and I was breaking us financially, but he stayed by me – we are still together today and planning on getting married in August.

If I could give advice to anyone – it's to trust your own body and instincts. If you feel sick – force your GP to listen to you, force him to test and demand they are bulk billed. People can be seriously ill – IBD is not a joke and won't just go away.

Sometimes I sit and think about what I would have been like, how sick I would have been if they had of caught the disease earlier. Who knows, right? I know after the last 2 years of my life, there is nothing I can't handle and nothing I can't do. Mentally I have never been stronger – I guess I have Crohn's to thank for that?