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## Have Bag, Will Travel

### Symptoms, diagnosis, and letting go of dreams.

Not long after my 30th birthday, the first symptoms appeared. I remember clearly the first time I noticed blood in the toilet bowl. November 2009. I didn't think much of it at the time, but I thought I'd better see my GP. Some pro-biotics, stool samples and antibiotics later with no improvement, it was off to a specialist. Little did I know how big a role this man would play in the next four years of my life!

After a colonoscopy and banding for suspected haemorrhoids, I was told that I had Crohn's disease, a form of inflammatory bowel disease (IBD), and an illness which I knew nothing about. Even the fact that it was chronic didn't really register with me at first.

My doctors advised my Crohn's was only mild, and with treatment my plans to live and work in London with my partner Michael could probably go ahead. The first year was manageable. Gradually though, my symptoms worsened. I started having sudden urges to go to the toilet, the blood and mucus increased, and I was losing weight rapidly. We remained hopeful right up until a few weeks before our planned



Laura takes her bag all over the world.

departure. I'd even resigned and started packing. I think deep down I knew that our trip wouldn't be going ahead, but I didn't want to let go of our dream and let the disease win.

On the date of our intended departure, instead of sitting excitedly on a plane

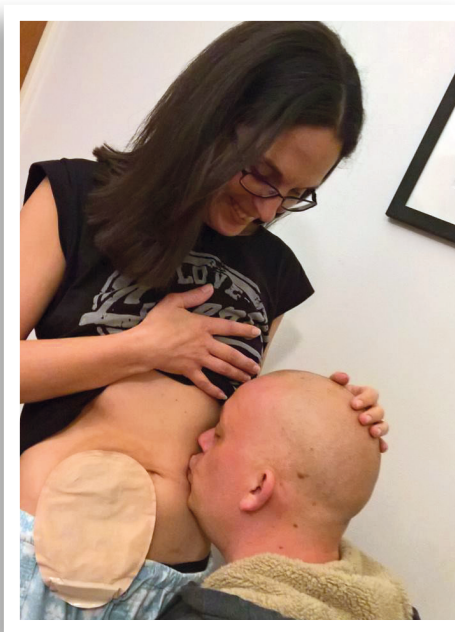
awaiting a new life in London, I was in hospital having a colonoscopy. Days later I was admitted with the worst flare up I had experienced.

## Years of pain and struggle

I continued to experience repeated flares. Some periods were better than others, but I never went into “remission”. I lost almost 20kg in weight, was rushing to the bathroom in excess of 20 times a day, and could barely hold down a part-time job. My life was put on hold as I struggled to do the normal, everyday things I had always taken for granted. As anyone with an understanding of IBD knows, it can be a daily battle to get out of bed, leave the house, and live a normal life. The symptoms take over and can be extremely debilitating.

I tried every medication available for Crohn's, including some less-common ones. At first, some of the medications did improve my symptoms, but this was always short-lived. I yo-yoed up and down from 1 - 50mg of Prednisone and had all the associated, fun side-effects. After a while even the steroids stopped helping. Worst were the nightly enemas I struggled to hold in because the perianal inflammation was so severe.

Complications and side-effects were rampant: fistulas, abscesses, osteopenia, achy joints, oral thrush and shingles, all due to my suppressed immune system. After my first hospitalisation, I experienced deep vein thrombosis, resulting in a pulmonary embolism, which could very easily have killed me.



Laura with her husband, Michael.

I tried Chinese herbs, acupuncture, and several different diets. I attended and later facilitated a support group for Crohn's and Colitis Australia, which really helped me through the early days. I saw psychologists and a hypnotherapist who were both extremely helpful in teaching me coping mechanisms for my symptoms and anxiety. But it seemed no matter what I tried, my Crohn's just got worse. Even a temporary loop ileostomy to rest my bowel and give the inflammation a chance to heal didn't work.

At my last colonoscopy, my gastroenterologist couldn't even get a clear picture from the scope. As soon as the blood was wiped away, more would appear.

On more than one occasion during these last few years I told myself my worldwide travels had come to an end. I had actually 99% resigned myself to this. Thank goodness for the 1% that still held hope!

## Decision made! Time for surgery...

In September 2013, I made the decision. I'd had enough. I was sick of feeling sick, the pain, anxiety, and daily struggle. I'd grappled over the decision for months. Should I keep fighting? Was I being weak? Was it really even a decision? It felt like I had run out of options.

A week later, I was back in the familiar surroundings of hospital, ready to have it all removed! It was a huge decision. There was no turning back from this one - a panproctocolectomy with permanent end ileostomy. I knew what living with a temporary ostomy was like, but this was something I would have for the rest of my life, until I was old (and quite possibly senile!). After six hours on the operating table, I woke up heavily sedated, minus a few pretty major body parts, and with the addition of a nifty little ostomy bag!

## A new me

Weird as it sounds, I almost immediately felt as if all the badness was gone. Within a week I was back home, on the road to recovery. Six weeks later I was at work, gaining weight, taking less medication than I had in years, eating all my favourite foods again, and getting out and about with a feeling of freedom I had forgotten was possible. Of course, having a stoma was a huge thing to get used to and wasn't

without its challenges, but compared to how sick I'd been and what my life had been like, I was just so grateful to be feeling healthy again.

A few months after surgery, with the green light from my doctors, it was time to revive our dreams and embark on the trip of a lifetime, not working, just travelling and living life!

There was so much to organise for our 10-month holiday! As well as all the normal things, there were the added considerations of travelling with Crohn's and an ostomy: stoma supplies, medication, doctors' letters, insurance. We got it all sorted, and a few days before leaving, even managed to get engaged! This was a huge shock to me, as Michael proposed after 17 years together. I said 'yes' of course!

At last, the day arrived. Over four years since being diagnosed, three years later than originally anticipated, and just over six months since having major surgery - it was real! Holding my fiancé's hand, I breathed a huge sigh and shed a few tears as we took off from Sydney.

## Have bag, will travel

So Michael and I, and my new ileostomy, were off on our adventure. There was a small part of me that held some trepidation about leaving Australia. I'd relied so heavily on my family, close friends and doctors for support, guidance, and strength for what seemed like such a long time, but after how far we had come, I knew we'd be okay.

Although I was worried to begin with, for me, travelling with an ostomy really had no significant issues. In some ways it was a benefit! Pre-departure planning, arranging and carrying supplies, emptying and changing the bag in foreign places, eating different foods, organising blood tests, all took some patience and stamina, but was ultimately smooth-sailing (or smooth-pooping!). While there may be challenges along the way, they are nothing worse than anything else we've overcome, and are well worth it to experience the joy of travelling!

I really wanted to share my story, raise awareness and reduce stigmas around IBD and ostomies, so I joined the [#GetYourBellyOut](#) campaign and got my belly and bag out for photos all around the world; even on my wedding day!

I am so grateful to be at the stage I am now. There is no way that I could have made the trip as I was prior to surgery. I am also very fortunate that I have not had any issues with my stoma and have adapted to being an ostomate very well, and this may not be the case for everyone. I try to acknowledge my thanks every day. I'm so blessed to have had this adventure - ten months travelling through three continents and 17 countries, experiencing incredible things, people, and places.

I hope my story helps and inspires others who may be struggling with their ostomies

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Laura 'gets her belly out' to raise awareness.

and shows that there is life after a stoma. For me, so far, it has given me my life back, and enabled me to fulfil some lifelong dreams that for a long time I feared would never be possible.

If you are interested in reading more about my experiences including the specifics and practicalities of travelling with an ostomy, please check out my blog and my Facebook page:

<https://stomalicious.wordpress.com/>

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