

Harriet Clayton
Suffolk

I'm a Nurse with a Stoma

My name is Harriet, I am 25 and I have a permanent ileostomy and a 'barbie butt'.

I am a registered nurse by profession, something which I have always wanted to do. I was a healthy child and teenager; I was in full time education until I was 21 and I was able to follow my aspirations of becoming a registered nurse. I went to college and off to university and undertook a degree in adult nursing. I qualified in 2015, aged 21.

Looking back, I always struggled with my tummy, joint pains, nausea, and extreme fatigue. I spent many trips going backwards and forwards to my GP. I always put down my struggles to maybe working hard, growing and generally being a busy person. However, following my degree, life slowed down. I had time to think, rest - and then my symptoms appeared.

I started to notice a decrease in my health drastically around January 2016, only 3 months after I achieved my life goal of becoming a nurse. Looking back on it, it is quite odd really. My very first placement as a student nurse was on an emergency gastro ward, taking care and learning about acutely unwell patients with chronic

diseases of their stomach, taking care of them post-operatively and helping them adapt to having a stoma fitted if need be.

I really noticed a difference in my health. I was permanently exhausted; I had no energy and my bowel movements changed. Growing up, I would go to the toilet roughly once a week (normal for me so I never thought anything of it), and suddenly, I was then going to the toilet over 15 times a day. I was a very busy nurse, didn't get much rest in between 12-hour shifts, both day and night, didn't eat properly and lived off caffeine. It was the new norm for me. I kept feeling progressively worse and my symptoms were getting more and more severe. I was then unable to keep going to work, I was absolutely exhausted and I was noticing blood in my poo.

I had lost around 4 stone in weight, I looked severely unwell and I had no energy. I went to my GP, who I have to say, was brilliant. That one question: 'Have your bowel movements changed?' was when I looked back and thought to myself, 'I think I am really quite poorly.' This is when things started to change and a plan looked possible; I thought the old me was in sight again.

My health continued to deteriorate. I was unable to be a nurse and took some time off for my health to try to get better as soon as I could. Little did I know at the time, I had a long road ahead of me.

I was sent for numerous tests, and the last, a colonoscopy - something I had witnessed as a student nurse. I was worried it wouldn't show anything, I was worried people thought I was making my condition up as it is an 'invisible disability'. I was worried people who had doubted me would be right, as some thought I was making it up.

The day before the procedure came and I had to drink what I can only describe as 2 litres of wallpaper paste, to clear my bowel completely to get a good picture of what was going on inside my stomach. At times, I did not think it would be possible for me to drink it all, and I would have wasted everyone's time at the over-stretched NHS. However, the morning of the procedure came and I went along to have this test I was so anxious about. I always remember brushing it off, saying my illness would be okay, but I remember I had two friends, also nurses, who pushed for me to get seen and the treatment I desperately needed. I was a very anxious patient (they say nurses make the worst patients!) but the nurses were so, so kind to me and put me at ease. I took all the medications and pain relief offered and before I knew it, the procedure was over.

Soon after I returned to the ward and was alert in recovery, I was given my results: I had ulcerative colitis, a form of inflammatory bowel disease affecting the



Harriet.

large bowel and rectum. In February 2015, it was seen in only my rectal stump - something to be treated with rectal meds, oral steroids and something which should improve. I was referred to a gastro consultant and put under his care, as well as an inflammatory bowel nurse specialist.

I took the medications, as prescribed, for a few weeks. Months went by. No improvement. I was deteriorating rapidly. I kept attending my GP, going backwards and forwards week after week. I then became steroid dependent; I was no longer able to manage without them. I got all the side effects, I was awake craving roast dinners at 3.00 a.m., my face was shaped like a moon despite me being so very unwell under the surface. I was then going to the toilet up to 30 times a day, overnight and often could not make the toilet in my own home; leaving the house was impossible. I was housebound more

or less, at 21 years old. Unable to work, my mood was low and I was very anxious about my future. I attended many out of hours appointments to try to get a treatment plan together, but nothing worked.

I changed my diet and ended up trying to survive on crisps. Even water would go straight through me. I was able to have another colonoscopy around September 2016, and it showed the disease had taken over my whole bowel and I had something called pan-colitis. The treatment plan changed; I had hospital admissions for intravenous steroids. These also did not work, and each week I felt more and more unwell. I was put on chemotherapy type medications; they did not work how they should and ease my symptoms. They wiped my immune system out so well, I was called around midnight to ensure I did not have a temperature or infection or I would need to go to hospital for further treatments.

I was then offered strong intravenous immuno-suppressant medications, in the form of an infusion every 8 weeks. It would completely wipe my immune system out and came with many risks in itself. However, I felt so unwell I agreed to everything. I started the treatments; no improvement there either. I then decided I needed and wanted to see a surgeon.

Quite swiftly, I was able to meet a colorectal surgeon, who went on to become my hero. He saved my life, and I owe him absolutely everything for that. I went along, severely unwell, to meet him in his clinic. Within around 10 minutes, he



Harriet, ready for work.

agreed, I had no option but to have a sub-total colectomy with end ileostomy, which meant I would have a stoma (a part of my bowel on the outside of my tummy where I would pass faeces). Being a nurse, I had researched it and knew this was something I desperately not only needed, but wanted. I agreed in the consultation and was put on the waiting list for surgery. I was counting down the days and I could not wait.

I got my date through for February 2018, and I was taken down to surgery. A four hour operation took six and a half hours. I woke up in the most horrendous pain I have ever experienced, but I was alive. I met my stoma, and named him Stanley. Stan the Stoma - sounds like a superhero, I thought. My surgeon removed my whole large bowel, and left my rectal stump in, should I opt for a reversal in the future. (Ed: *an internal pouch*) I was able to have my operation done laparoscopically, which meant it was done by 'keyhole'.

I had a very long road ahead of me; however, it was not the end. Me being me, I was ready for the next challenge. Three months went by. I felt amazing, had little to no symptoms and I had my life back. To be able to go out and not worry where the toilet was had to be the best feeling in the world. However, I then started to increasingly pass bloody mucous from my rectum - the ulcerative colitis was back in my rectum - the only bit left to attack. I endured yet more treatments which did not work.

I then saw my surgeon again, who agreed to complete a proctectomy, where he would remove my rectum and sew my bum shut, making me have a 'barbie bum', and my little Stan on my tummy would be made permanent for life.

The operation does not come without risk. There is a high risk of infertility, incontinence, bladder damage - however, for me, I would have rather been healthy than unwell and that poorly Harriet I once was. In May 2019, I had the four-hour operation, and my life has since got better and better.

I woke up with drains and pain, but three days post operation, I was home and recovering in my own bed, in time for my 25th birthday. I had been unwell since I was 21; for four long years I wasn't the Harriet everyone knew. I was a shell of myself.

I am now almost a year post-operative, and every time I look back, I know it was the right thing for me to do. Going forward, I hope to inspire and help other

people who may be in a similar position. One thing I have learnt from this experience, is that you never know what someone is going through and you must never judge someone for their looks. I aspire to help others and raise awareness and educate people where ever I go.

I have been lucky enough to also be in contact with the charity Purple Wings, who give confidence back to people who have had stoma surgery, and participated in a pin-up calendar for 2020. It did give me my confidence back, so I will be eternally grateful to the charity for that.

If I can help one person in a similar position, my job is done. I am Harriet, I am a nurse, and I live with an ileostomy.