

Victoria Hicks Age 35

My illness started on the 26th December 2015. A day I won't forget in a hurry! After being wrongly diagnosed for a year and a half I changed hospitals and was eventually found to have an anal-vaginal fistula, which, every six to eight weeks would get infected and cause agonising abscesses, which would often burst internally. I had to leave University, where I had just started my third and final year of a Paediatric Nursing Degree due to the amount of hospital admissions, pain and the difficulty in traveling to Bournemouth for lectures.

After more than thirty operations and a failed repair I was left with faecal incontinence through my fistula into my vagina. This caused chronic urinary and bladder infections. I also always needed to be near a toilet and washing facilities. I was placed on sick leave from my job as a veterinary receptionist.

On June the sixth 2019 I had planned elective surgery to form a defunctioning loop colostomy. I was well prepared by the Musgrove Stoma Nurses. They gave me regular counselling, exercises and a starter pack to practise wearing and changing a colostomy bag.

I spent just over a week in hospital, and again the Stoma Nurses were very supportive during my stay as well as after during many home visits. I was in a lot of pain during those first few weeks, but this eased as time went on.

While I was coping well physically during the first three months, emotionally I was struggling. I felt I could not leave the house or be around anyone that was not immediate family due to the fear of leaks, offensive smells and very noisy wind! I felt like I was completely alone, and no one understood how I was feeling.

Eventually, with the support of my family, I went to see my GP. Sitting in a quiet waiting room was just awful! I was diagnosed with anxiety and depression. I was prescribed anti-anxiety medication but felt my mental health issues remained despite religiously taking the pills as the underlying concerns had not been explored or discussed. Still feeling like an alien, not knowing anyone else with a stoma I felt completely isolated and alone.

It was at this lowest point that I started looking for support from other individuals with stomas, not even knowing if this kind of support even existed! After an extensive internet search, I found a website called Somerset Health Connections which contained details of an organisation called Stoma Heroes and an email address. So at 10pm one Friday evening I reached out and set an email outlining how I felt..... within five minutes a man called Shane had replied "I understand, you will get through this, can I call you in the morning for a chat?". The relief I felt can not be put into words, for the first time I felt there was light at the end of a very long tunnel.

My first group meeting with The Stoma Heroes was inspirational, it made me realise a 'normal' life with a stoma was possible. My new peers were a fountain of knowledge, through WhatsApp, Facebook and email they provide a friendly, informal support network where no question is silly or stupid. I still am in contact with my Stoma Nurse; but for those "is this normal" or "help" moments at the weekend or, most often, at 2am the Stoma Heroes WhatsApp group is particularly helpful. I also enjoy the social side of the group and the many fun and new activities my fellow ostomates and I have the opportunity to try and get involved in. Swimming was a complete no-go area for me with a colostomy bag, despite being a keen swimmer. Through the Stoma Heroes I have attended an Ostomy swim group and even had ago at Kayaking!

Roll on a year.... How time flies! I am now back at work full time, meeting with friends and extended family and attending a gym on a regular basis. I have come off my anxiety medication and I am happy! The Stoma Heroes have had such a positive impact on my life, to know you are not alone, having a support network and a friend who understands is absolutely life changing.

I am awaiting a date for a second attempt to repair my fistula, if this is successful my stoma will be reversed in a year or two. If the repair is not successful, my loop colostomy will be made into an end colostomy which will be for life. I feel now that I will be happy with either option and with the help and continued support from the Stoma Heroes I will be prepared, remain focused and move forward. Through the Stoma Heroes I feel I am now able to support and offer advice to fellow ostomates and individuals who may be struggling, something I would not have even thought to consider a year ago!