

Narcotic Bowel Syndrome and Me

Tori Davis - Cumbria

My name is Tori. I am 34, I have a metal jaw, lots of scars, and quite an unusual story to tell - oh, and I have a permanent ileostomy.

I am an Animation Art Director for LEGO. I have two pet house bunnies and a very energetic border collie. I live on the edge of the Lake District in Cumbria, with my incredible boyfriend; without his unconditional support I wouldn't be in the positive and fortunate position I am in today.

Our story began when we met online, though an Ostomy support group called "Meet an Ostomate". He, like me, has a stoma. We met when I was at my lowest point and needed support more than ever.

I was living and working in Denmark, which was difficult enough when you don't speak the language, but then trying to cope with my severely declining health, and having ongoing surgery too meant I had never felt more alone.

I had just had my 10th operation when I met Karl online. I had a loop ileostomy made, and I was really struggling, trying to come to terms with my "new normal".

Karl was coming to Denmark for a holiday and after talking online for a few months, we arranged to meet when he came to Denmark for his trip. From there, we never looked back!

We both instantly found our significant other; someone who just understood it and "got it". We completed each other. I was smitten from



the moment we met. He gave me my confidence back and the strength to accept my new life - a healthy life, and one he wanted to share with me.

Within six months of meeting each other, I left Denmark to move back home to the UK to be with Karl, and it was time for me to start making up for the many years I'd lost due to ill health.

First stop, we got a puppy. Our highly energetic border collie, "Benny". This supercharged pup keeps us on our toes and active, climbing mountains or running down the beach every day - something I could have only dreamed about a few years ago.

I have so much to be grateful for and despite a current global pandemic, I'm in a better mental

and physical place now than I have been for over 12 years.

The reason for my stoma is quite unusual; I have had my ileostomy since February 2018, but my problems all started 10 years earlier when I broke my jaw, eating a KFC!

I dislocated my jaw when biting into a chicken wing, and ended up snapping the TMJ joint. From there, I ended up having 7 separate operations to fix my broken jaw, with the last one resulting in a full titanium jaw replacement in 2012.

As much as my jaw now works very well, it came with a huge consequence: the side effects of the many years of strong opiate medication prescribed by doctors to manage the pain for my jaw, as well as the many operations I had to fix it, had damaged my insides and digestive tract.

My bowels could no longer function and were dependent on high doses of laxatives to work. The diagnosis was “narcotic bowel syndrome” (*ed: this is a subset of opioid bowel dysfunction. Symptoms include chronic or frequently recurring abdominal pain that worsens with continued or escalating dosages of narcotics*), and even after my body had been weaned off all the prescription opiates and other medicines, the damage had already been done to my colon and it couldn't be reversed.

After many years of suffering and trying to cope with the pain, embarrassment, living alone in a foreign country, trying to do a job that I loved but struggled to properly fulfil because of my declining health, I had to accept I couldn't continue.

Post jaw-replacement, I had to have my gallbladder removed, gave myself 2 hernias due to chronic constipation, had countless different treatments, medications, tests and lived with so many years of non-stop pain. I was on a downward spiral of depression, suffering severe weight loss, and my body was dependent on copious amounts of very strong laxatives just to be able to go to the toilet. I was living a nightmare. I had a huge fear of what long-term damage the laxatives would do to my body, as it became more dependent on them to work and the dose needed would continue to increase.

By the end of 2017 I had another operation to fix a hernia caused by chronic constipation. It was at this point the doctors told me I had no other choice. Hernias and other problems would continue and get worse if I didn't accept it: my only option left to give my colon any chance of functioning again was to have a stoma.

It was a huge thing to accept. I'd been warned about it a year beforehand but I refused to accept it. There was no way I wanted this...but now it had come to a point where I had no other choice.

I got a lot of support and help from my work and the stoma support team but it was still very difficult and daunting, when living abroad and struggling with the language.

That is where I couldn't be more grateful for the online community - support online, from people my age, who spoke my language. Without the online support, I wouldn't have found Karl.

My stoma (or as the Danish called it, a “stomi”) was completed over three surgeries. There had

been hope at first that I could maybe have a loop ileostomy, meaning I could get it reversed at a later date - but due to complications, it didn't work out that way. I had the final part of my surgery completed (a total proctectomy) in November 2019 here in the UK, and it was the best thing I could have done.

Now, nine months post surgery, I'm training for a 40-mile charity walk, currently postponed due to Covid-19. I continue to train and I am active every day, as I continue to get stronger - not just physically but mentally too.

After everything that has happened to me, I have a very different value and appreciation for life. I don't take anything for granted and try my hardest to make the most out of every day.

I won't be defined as the girl with a bag, and I won't let it stop me from living my life - but I do like to be able to help others learn from my own experiences wherever I can.

I have given presentations to doctors at my local hospital about the dangers of opiates and helped junior doctors with their studies.

I also work with the Grand Appeal charity running LEGO animation workshops for kids at the Bristol Royal Children's Hospital, teaching children the power of play during their hospital stays.

I still have moments when I get a little upset about my stoma; it is usually if I catch a glimpse of my bag, sticking out from under a pretty dress, or when I'm in the shower. However, I soon shake them off when I step back and look at the bigger picture: this bag has given me a life I could have only dreamed of. Less than 3 years ago, I was on the verge of giving up, but post-surgery it has given me opportunities I could never have imagined, introduced me to so many new people, taught me how to love unconditionally - and for the first time in over 12 years, I am healthy. Stay safe, and keep positive!



Tori and Karl at the beach with their beloved border collie, Benny.