



"... it could definitely be worse"

Hi I'm Jade. I had my first experience of artificial feeding at thirteen via a nasal tube. Being thirteen with braces, greasy hair and a feeding tube wasn't the most fun a girl could have. Nasal gastric feeding wasn't really the right feeding for me, as it still made me quite symptomatic. My main concern was the yellow tube (I wrote to the company and they explained it was due to the radio opaque material).

When I eventually moved onto a PEG with a jejunal extension I noticed a massive difference. I had minimal symptoms from my Crohn's disease, reflux disease and pan gut dysmotility. I went on my first girlie holiday at the age of seventeen with the assistance from PINNT. They helped me whilst I was fumbling around trying to figure out whether holidaying was even an option. I had a brilliant time and my feed was delivered directly to the hotel. The frustrating part was the constant movement of the jejunal end and I was forever having tube changes. In 2009 I met a surgeon who believed that a Roux-en-Y bypass would help me to tolerate food again. I was literally on the table the minute he mentioned it! The idea of eating without any symptoms was my dream come true. Unfortunately, the dream turned into a nightmare and I was eighteen and in hospital for six months having had septic shock three times, necrosis of the bowel twice, a pelvic abscess that burst, peritonitis three times, MRSA infection and klebsiella bladder infection. I was ventilated and in intensive care for around four weeks and had multiple surgeries. I was on TPN during this time. Eventually, despite the odds, I made it out alive! I was discharged with a jejunal tube, but unfortunately I began losing more and more weight. I was transferred to Salford Royal Intestinal Failure unit. It took six months to get a bed and I was in a bit of a bad way when I reached them in 2010. I had another six month stay with them whilst they investigated and were trying to avoid TPN for me. Eventually they diagnosed bacterial overgrowth which meant the bugs were stealing my nutrients which is why my weight was dropping constantly. The treatment allowed me to tolerate a feed called Emersigen. I had another operation to place a permanent jejunal tube and abdominal reconstruction. During this time I had been placed on strong levels of opiates but unbeknown to me, these were making life difficult for my digestive system and when I came off them in 2012 I had a significant improvement in symptoms allowing me to maintain a diet with oral supplements and grazing. This continued until last year when I had a significant relapse in symptoms. I required an NJ tube to refitted. I found this difficult and initially adjusting again was hard. However, the benefits outweigh anything else. I have energy to work part time, go to gigs and enjoy life. There are things that make it hard (connecting twenty hours a day and forgetting I'm connected is usually a favourite). The blocking of the tube is another pain in the backside (YouTube do great videos by the way to help unblock a tube), the tube disconnecting at night and waking up in a pool of feed, or waiting two weeks to have a replacement tube. At the moment I am waiting to have another JEJ tube fitted and although it isn't what I would have picked, a full life is possible and it could definitely be worse!

