

Life as a teenage ostomist

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Most people would disagree with the cliché that schooldays are the best of their lives. Teenage years are usually among the most turbulent and confusing of times. In this two-part series, two young women who experienced the added burden of bowel problems write about life with a stoma. In the next issue, Victoria Linke will pass on practical tips for making the most of your teenage years, but first Sarah Maill describes how she faced up to life after stoma surgery.

Do you remember how you felt when you were faced with the prospect of surgery, or when you looked at your appliance for the first time? Alone and scared? Distraught? As if your whole world had ended?

Ten years ago, aged 18, I had a total colectomy with ileostomy due to Crohn's disease, and I experienced all of those feelings. I thought I must be the only young person in the world with an ileostomy and, although my family, friends and medical team were supportive, nobody understood what I was going through.

Before my surgery, I had low self-esteem and lacked confidence, often comparing myself to my peers. I wasn't interested in clothes, going to parties, getting drunk or meeting boys. Instead, I was battling a disease I knew little about and trying to hide the unpleasant and embarrassing symptoms of inflammatory bowel disease. Crohn's disease soon began to dominate my life. I remember going on a school field trip armed with steroids and enema foam sprays. I realised I could no longer hide my illness from my friends and had to



It's not just the elderly who have stomas

explain why I kept running to the toilet. One friend even thought it was amusing that I was having bowel problems – if only she knew what my life was really like.

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I hated the constant visits to the hospital, the undignified tests, the medication, the pain, the nausea, being prodded and poked and feeling lethargic. I thought it would never end. My gastroenterologist explained that there was a possibility I would need an ileostomy in the future, but I naively thought it would never happen. When the time came, I was too ill to comprehend what life would be like after surgery. All I wanted was to feel well again and to have my life back.

Stoma surgery

The thought of having a stoma is incredibly daunting and frightening.

Nothing could have prepared me for seeing my stoma for the first time. It was not how I imagined it would be, and I struggled to come to terms with my emotions. I know people react differently and that not everyone can accept life with a stoma, but once I got over the initial shock, I realised that it offered me a whole new lease of life. I felt as if I had been given a second chance and was determined to recover as quickly as possible.

Body image

One of my major problems was my body image. I was convinced that people would be able to tell I had an ileostomy and, lying in hospital in a nightdress, I couldn't imagine how I would ever wear 'normal' clothes again. These concerns were reinforced when a friend admitted she couldn't understand how I would ever be able to wear clothes like hers.

After being discharged from hospital, I became paranoid and self-conscious. I wore baggy clothes to try and disguise any bulge from the bag. I also developed the habit of constantly touching my abdomen to see if my bag was secure.

The following weeks were difficult. My confidence and self-esteem hit rock-bottom as I developed terrible acne and my hair began to fall out (luckily, I didn't go bald). My GP was extremely sympathetic; he prescribed medication for my skin and explained that my body was reacting to the trauma of both my illness and surgery. Eventually, I had my hair cut as my new, healthy hair was growing through a completely different colour. Losing ten inches of my hair, which had taken me years to grow, was not an easy task, but it was another part of the acceptance process for me.

Building relationships

The change in body image after the formation of a stoma made me question my femininity. I no longer felt attractive and wondered how I would ever find a boyfriend. An intense fear of rejection terrified me. Unfortunately, I was rejected by the first person I tried to become close to and it was a steep learning curve, but I was able to move on. Despite being single for a long time, I have had relationships where my stoma has not been an issue.

For years I struggled with my feelings about my stoma. I hated seeing myself naked and wore big knickers and a cotton bag cover to hide my appliance. However, as I have grown older, undergone further surgery and dealt with the side-effects of Crohn's, I have become more daring. I now wear different underwear and the cotton bag cover is long gone. I'm lucky as my stoma is quite low and I also have a perfect scar (if there is such a thing). It looks like my consultant used a ruler when he opened me up. So I am able to wear the clothes I want, including fairly low-waisted jeans and trousers. My family often ask me which side my stoma is on as they are amazed by how discreet appliances can be. Four years ago, I finally plucked up the courage to wear a bikini (with short bottoms) on holiday, and although I was convinced people could tell I had an ileostomy, I had no embarrassing experiences. I even survived paragliding. Now I go swimming and to aqua aerobics every week.



After feeling at first that her life was over, Sarah now goes swimming every week

Moving on

Whether you are a new ostomist or are facing surgery, it is natural to feel apprehensive at first, but once you adjust to your stoma and begin to socialise, you will regain your confidence and your insecurities will fade

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away. I strongly believe you need to feel comfortable and be happy in yourself in order to be confident, so wear whatever styles and fashions you prefer. When you are fully clothed, no one need know that you

have a stoma unless you want to divulge it.

Ever since having my ileostomy I have been determined not to let it rule my life. I have been to university, passed my driving test, travelled (although I haven't yet built up the courage to go backpacking), worked in both the retail and charity sectors, volunteered with Oxfam and, more recently, worked with children with special needs. Now I have embarked on one of my biggest challenges yet – I am training to be a primary school teacher. My achievements so far prove that there is life after ostomy surgery and that having a stoma is not the end of the world.

*See page 18 for more information
about the Young is and for details
of how to contact Sarah*

Key points

- Although most ostomists are older, bowel disease and stoma formation can affect young people as well.
- Coping with adolescence can be difficult enough at the best of times, and adapting your body image to take into account your stoma can make things a lot harder.
- Over time, you will realise that nobody but you is aware of your stoma and that you can wear what you want and do what you feel like doing.
- Having your stoma formed can, eventually, lead to big improvements in the quality of your life.