

Pathways to a colostomy

Recto-Vaginal Fistula...can be caused by trauma during childbirth, symptoms of Crohns disease or Ulcerative colitis, or sometimes from complications during surgery



**Sarah Squire...
Research Assistant
wife and busy
Mum of two
first contacted the
Colostomy Association
in 2008. Talking to
Bob Buckley
CA volunteer and
others via the
CA Facebook site
Sarah was encouraged
to tell her story...**

I had my colostomy surgery in 2007 when I was 34 years old, due to a recto-vaginal fistula. A fistula is defined as an abnormal connection or passageway between two organs or vessels that normally do not connect. In my case, a hole between anus and vagina, so it is more accurately ano-vaginal. These fistulas can be caused by trauma during childbirth, symptoms of Crohns disease or Ulcerative colitis, or sometimes from complications during surgery. My cause is a bit of a mystery. I have two children, Oliver thirteen and Madison seven. Maddie was over 10lbs when she was born, and arrived rather swiftly, but nothing was apparent at the time after her birth.

In 2005 I had my ovaries removed as a precaution after losing my mum to cancer when she was just forty-five. I am told the surgery is unlikely to be the cause of my fistula but it was about six months after this I started to get symptoms. I assumed the HRT I was now taking was not quite right and I was getting breakthrough bleeding. I did what many of us do with 'downstairs business'. I ignored it. After a few months I got brave enough to go my GP and was referred to a gynaecologist. By now I was mortified to admit that I thought poo might be coming through the front. The doctor reassured me I wasn't a freak, or unique and diagnosed a fistula and referred me to colorectal surgeon Ian Lindsey.

Mr Lindsey told me he would put a seton in for a couple of months and

then repair the fistula. The draining seton is a loop of plastic which threads through the fistula and keeps the tract open, to reduce the risk of infection and allow healthy tissue growth in preparation for the repair. I was told the advancement flap repair had about a 70% chance of working. Not bad odds then I thought. The idea of the procedure is to excise a flap of healthy tissue next to the fistula, pull over the hole, suture, and jobs a good un. Or so it should be. Two days post op my symptoms were horrendous. This will definitely go down as the low point in my whole journey. Each time I went to the loo I leaked poo vaginally for hours. I find it hard to explain just how awful I felt. It's not the sort of thing you tell people. It's dirty. It's embarrassing. It's wrong. After two visits to my surgeon the option of a temporary stoma was suggested. In one way the thought of a bag was a relief. But will people know? Will I be able to go to work? Will it be noisy? Will it smell?

It was arranged that I would see a stoma nurse before the op, which I was to have two weeks after the failed repair. My stoma nurse Simon Turley in Oxford was fantastic. I was convinced I wouldn't get used to it but he explained everything and I realised this was the best option for me. We were due to go to Cornwall on holiday that week and after much discussion and tears we decided my husband Steve would take the kids on holiday and I would go for the full board offered at the John Radcliffe Hospital! I couldn't go on holiday like



Sarah pictured with husband Steve and children Oliver and Madison...enjoying the sunshine together

this and didn't want the kids to miss out. It was very, very hard waving them off but I knew they would be having fun instead of hospital visiting.

The evening they left I spent hours on the Internet finding out everything I could about colostomies. By chance I came across the Ostomyland forum. I had never been on a forum before and must admit I thought they were

for nerds. But I read and read and read. I dubiously posted a 'hello' message and was inundated with replies. One lady even had the same problem as me and was fixed, awaiting reversal. The relief to find someone I could relate to was enormous. I really wasn't a freak or unique! And you know, they didn't even sound or look like nerds! They were just normal people, with one

thing in common. They have, had, or are close to someone with a stoma. By the time I went into hospital a couple of days later I felt I had a very good understanding of life with a stoma. I actually began to look forward to it.

As it was I had to wait a few days to get the surgery as emergencies of course took priority. My dad and his partner became chief visitors, treating me to ice cream each night I got bumped off the list! After the surgery I had terrible trouble with nerve pain, but the stoma worked well. Simon was great. That man has a lot of patience! I had a few issues with bags sticking as my stoma is flat and it seemed nothing was going to keep a good seal. But, eventually we sorted it with the help of a barrier ring.

So the family came back from Cornwall and it was time to explain to the kids just why Mum had been so poorly. They seemed to easily accept that I wasn't going on holiday with them. Too easily now I think back! But I really think kids are great accepting things at face value. So I decided to be upfront about my stoma. They took it in, had a look, and got on with life! Maddie always asked – and still does – if she was hurting my 'poorly tummy bit' when climbing on me, but it didn't seem an issue that I now pooped out of my tummy. Kids really are great. Steve was, and is, amazing. I couldn't ask for a more understanding husband. My whole extended family bent over backwards to help and have been supportive all along.

Physically I was doing well. My fistula symptoms were finally gone and the stoma was OK. Now I had to think about going back to work. I work full time as a Research Scientist as part of a team developing therapies to treat Duchenne Muscular Dystrophy. At first I didn't want anyone to know, but inevitably with me being off, people asked where I was. I think the scientific environment helped me be

open. People understood the procedure and were interested in my problem and possible repairs. I lined up one workmate to take the blame if my stoma was noisy during lab meetings (which by the way, has never happened) and they were all great. It has been known for a bunch of us to crowd round a computer looking up the latest treatment options, including graphic videos! I went back to work eight weeks after the stoma surgery, and it would have been sooner if a skin ulcer hadn't knocked me back a couple of weeks. I did worry about smell, and even had Steve with his nose next to my stoma the night before I went back to work as I was convinced I could smell it! The things you do for love.

I start work early in the morning and wasn't overly happy about going off with my bag filling. I wasn't having any problems as such with the bag, but it was on my mind all the time. I had been spending more and more time on Ostomyland and had read about irrigation. It seemed very fiddly to me and a bit of a faff but with the encouragement of my new cyber friends I made an appointment with Simon to have some lessons. It did seem fiddly and I did regret the chicken korma the night before while enclosed in a small space with poor Simon, but the feeling of an empty bag for hours was nice. So I decided to give it a go at home. It was a bit tricky for the first week but then I got into a routine, and it really gave me my confidence back. I felt I had finally begun to accept the stoma. I developed a hernia about six months after the stoma surgery, which for the moment is not too much of a problem. By wearing jeans it stays comfy most of the time but I do find it plays up if I am on my feet too much or wear looser fitting clothes.

Unfortunately I am now three years on and have had six failed repairs on

the fistula. Most of the time I manage to stay positive about the situation, but I do get down, particularly as I seem to keep slipping through the system, and have to chase appointments. My surgeon was great, even when I kept turning up like a bad penny to tell him his latest handiwork had come adrift. I know they are tricky so and sos to mend, and that I have been unlucky. I have now been referred to a new consultant Bruce George, who has experience of using the leg gracilis muscle for reconstruction and I hope to have this surgery in early 2011. I'm not quite ready to give up on the fistula repairs yet and like to think I may have the chance to be reversed in the future. But as one of my good friends on Ostomyland said, 'A well irrigated stoma is often more convenient than a bum hole'. Life for me and my stoma is good. I work, I am a school governor, I travel abroad, and even hope to one day repeat the Cornwall holiday I missed out on!

I have continued to visit Ostomyland on a regular basis and was thrilled to be asked by webmaster Jason to join the 'team' as a moderator. I feel I have come full circle, from being new and needing much help to being in a position where I like to think I can help out new and potential ostomates overcome their fears and problems. I was also very proud to represent them at a Colostomy Association open day along with another member of the crew Kathy. Ostomyland offers an online support community in the form of a lifestyle guide, message board and live chat. I truly believe it was through the support of members that I managed to cope so well with my stoma, and I have made friends for life. I now have a very good friend through Ostomyland who has the identical problem and the same surgeon. We like to compare notes on him over a coffee! It is also great to see the CA have a Facebook page

now. The Internet has become such a big part of many people's lives and it is good to be able to find support and advice online. Not so long ago it was easy to feel very alone with a colostomy and hopefully now ostomates do not need to look far to find someone they can relate to.

About... Recto-vaginal Fistula

Ostetric trauma is the most common cause for the development of these fistula. Other causes include trauma, radiation damage, and inflammatory bowel disease, especially Crohn's disease.

A recto-vaginal fistula is an abnormal opening between the rectum and vagina which allows the passage of small amounts of waste, normally contained in the rectum, to pass into the vagina leading to possible infections.

The patient complains of passing flatus (wind) and faeces from the vagina. Vaginitis and recurrent urinary tract infections may also occur. Diagnosis is made via examination under anaesthetic at which time multiple biopsies are taken.

It is possible for some surgeons to attempt to repair the fistula, although it is generally considered better to leave them alone as they can be made worse.

However, surgical techniques have improved and if problems persist giving a poor quality of life, surgery may be considered.

Direct repair of the defect or advancement of a mucosal-submucosal flap of the vagina to cover the defect is often successful. Occasionally a bowel resection with or without a temporary defunctioning stoma is required.

References:
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