



The ileostomy & internal pouch

Support Group

Registered Charity

COMING BACK FROM STOMA SURGERY

Barbara Graves

Back in 1996, I felt I was the happiest, most fortunate person on earth. I was happily married, had two perfect children, a girl aged 3 and a boy aged 1 and I was doing my dream job. I was Headteacher of a brand new primary school on a small island off the West Coast of Scotland. Things just couldn't be better. Little did I know that in 2002, I would be attending an awards lunch in Manchester, where I would be sharing my story as part of the ConvaTec Great Comebacks Programme.

Pregnancy had left me with what I thought was piles. I was also suffering from loose bowel movements but was really delighted how quickly the extra weight gained during pregnancy was falling off. My GP referred me to the local hospital, where the piles turned out to be skin tags and the first of many scopes confirmed Crohn's Disease. I was able to cope until January 1997 when I was flown off by helicopter for the first of many weeks in hospital.

The story from then on was of aggressive Crohn's disease, with all the 'extras' - i.e. loss of weight and appetite, persistent diarrhoea with blood and mucus, arthritis, iritis and erythema nodosum (painful lumps on your legs). Nights were full of heat, not of passion but night sweats, necessitating 4 or 5 changes of t-shirt and sleeping on towels. My temperature would swing violently and the pain of the many visits to the loo, day and night, so bad that I was often sick. Due to the fact that a generator provided our electricity, my nocturnal antics were often in torch or candlelight. And then the last thing I needed, a perianal fistula.

If this wasn't bad enough, there were the investigations and drug treatments. Bowel preparations and scopes, barium enemas, scans and nuclear medicine. It seemed that everyone wanted to see your rear end. I was swallowing up to 16 tablets at a time and had drugs intravenously. I experienced strange side effects - moon face, increased hair on my face and arms and even curly hair! I suffered such a loss of dignity that as a friend once said I could stop a complete stranger in the street and ask them to administer an enema.

Life was on a downward spiral.

As the teacher in a one-teacher school, I could no longer get through a day without shouting instructions from the toilet. I had to give up the job I'd spent my life working for. Our home was tied to the job and I was the major breadwinner. Home life was spent in bed and activities with my children reduced to sharing books and quiet games. I could have qualified for air miles with the Air Ambulance service and was spending more and more time in hospital. My social life (and that of my family) had dried up, and even visiting neighbours required careful planning.

And then CRUNCH TIME.

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At the end of 1998 after even more investigations, blood transfusion, and a couple of weeks living on food supplements (protein drinks that taste like a cross between glue, the scrapings off a chemical factory floor, and the cheapest of cheap sweets) and surgery for a particularly nasty fistula.... the suggestion was made that I took the surgical option. Yes...remove it all... the whole of the large bowel and everything below it.

The end.....My end!

Well not quite. Being the brave and fearless person that I am, I refused surgery point blank, had a good cry, and set about to prove the experts wrong. I would find a way round this. I would search the four corners of the earth to avoid - *the bag*. I was only 36. I had two young children... I couldn't wear a bag!!!! I go sailing and camping and canoeing and climbing...I don't wear a bag.

I surfed the net looking for cures. People I really respected made time to see me, listened to my personal crusade, nodded and quietly pointed out that really surgery was becoming unavoidable. Still I kept on looking for alternatives and finally I spoke to the medical consultant I had first seen what seemed now like years before. As I left, again choosing not to hear his advice to take the surgical option, I grudgingly conceded to "I'll think about it". His parting shot was "What is there to think about?"

Terrified of the new vocabulary - 'ileostomy', 'stoma', and the sight of a bag, and feeling like I just couldn't quite do this, I set off to meet a lady who had recently had the operation. We talked about the disease that we had both been overcome by, of the pain, of the embarrassment, of the tears and frustrations. She delighted in telling me how good she felt and how her life had returned to normal. I was amazed! You couldn't tell she was wearing a bag. No one knew. She radiated good health and normality. I suddenly realised as I headed home just how far from normal my life had become. This could work for me. I had to give it a go.

Three months later I went in for surgery. The support of family and friends sustained me through first the preparations, the operation, and then the recovery. I was still having serious doubts as to whether this was really me, and could I ever get used to seeing and dealing with up front what had been passing from behind me somewhere for the previous 36 years? But here it was.

After 5½ weeks away, I came home. I felt well, I had an appetite and the pounds were coming back on.

Unfortunately, there were complications and I endured three bouts of obstruction. I survived all of these with the continued support of friends and family, the skills of the staff at the Belford Hospital in Fort William, and the superb services of the Air Ambulance and HM Coastguard. My surgery was revised and all started to go well.

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The psychological aspect of dealing with my new appendage took quite some time to deal with. I found myself fingering the seal on the pouch to make sure it was securely attached. I carried spares of everything everywhere I went. The bulges in my pockets producing far more odd looks than my wee concealed pouch ever would!

But I was now pain and virtually drug free. I could sleep. I gradually built up my strength and fitness and grew in confidence about my appearance and my newly rediscovered abilities. I again became a wife to my husband and a mother to my children. Life was good. Life was very good. And best of all life is still good. A whole new set of priorities began to formulate in my mind. We started to plan days out, nights camping and holidays. I went to France and to the USA to visit my brother. Although there are sometimes leaks and embarrassing noises, I've adopted the philosophy that those who matter don't care, and those who care, don't matter!

And that is just about where I am now.

I am doing all the things I did before the onset of Crohn's, and am now a member of the Coastguard and a Firefighter. Having given up teaching, I am now looking to work in the field of stoma support. People I meet for the first time have no idea about my stoma or what we've been through. My outlook on life has changed however. I value my family life above everything else and now focus on living for the moment and seizing opportunities when they arise.

I was recently honoured to receive an award for my 'Great Comeback', by ConvaTec, one of the suppliers of ostomy products. A fantastic event was held in Manchester in May. Simon, my husband, Jackie, my Stoma Nurse and I were flown to Manchester, where we were treated to a champagne reception and a slap up lunch. Laser lighting, inspirational music and an amazing computerised version of each person's comeback story preceded the twenty awards. These were presented by Rolf Benirschke, a fellow ostomist and professional American Footballer, who had set up the scheme in America in 1984. The atmosphere was so full of a zest for life, it was almost tangible. If you could have bottled it, you could have sold it for millions! Almost 700 nominations were received and I was overwhelmed to be selected as the overall winner. I hope that by sharing my story and those of the other award winners, those who face surgery can see that there is a light at the end of the tunnel. The common theme of all the 'Comebacks' stories, was the extra quality that life now holds and an enthusiasm for achieving the things in our lives that, before surgery, seemed to exist only in the lives of others.

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