

# Reaching for the summit

Kenny Graham

**It was just after the New Year festive period in 1991, a few months after I had married and just a few weeks after quitting smoking that I was struck with a bad attack of gastroenteritis. I recall sitting relaxing that evening with my wife, Karen, and saying that I was going to go to bed as I suddenly felt a bit unwell. A few hours later and I was violently sick, a scene that was to be repeated every hour or so during that night until our neighbour who was a nurse suggested that I should go to A&E. Once there I was checked over by a nurse and advised that I was experiencing a particularly bad attack of gastroenteritis and sent home to drink plenty fluids and to recover.**

This experience was to be the start of a 25-year long journey that has only just ended in September last year when I had bowel reversal surgery at my local NHS hospital. In this time, I was initially misdiagnosed with Irritable Bowel Syndrome before finally being diagnosed with ulcerative colitis in 2003, had my large bowel removed and an ileostomy formed in 2012, an Internal J-Pouch formed in February last year then finally the



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takedown in September 2016. A long journey with a few low points but a journey that I was determined to win.

It was after that attack of gastroenteritis that my bowel frequency started to change and I quickly noticed that I was making more frequent visits to the loo and after speaking to my GP was advised that I had IBS. This went on for about 11 years with healthy periods mixed in with periods of bowel problems until a particularly bad flare up in 2003 that required hospitalisation and at last a proper diagnosis of ulcerative colitis.

Nine years followed, most it being good and only an occasional flare up where intravenous steroids quickly cleared the inflammation in my large bowel and returned me to some normality. However, five years ago, I experienced a particularly bad flare up and for once the intravenous steroids did not work. The result was that surgery was recommended and quickly as my bowel was in danger of becoming cancerous, septic or even rupturing. I recall being left with very mixed emotions when being told this – one part of me being very concerned at the thought of surgery but this fear being outweighed by a bright light at the end of what had been a long tunnel and the start of the end game.

The surgery was a success and despite being left with an external pouch my attitude was one of positivity at my newly found freedom to do what I wanted to and when I wanted to. I was aware that I was going to be going back into hospital to have an internal J-pouch formed and then the final reversal stage of the process at some point in the future but for the time being I was in charge and I was going to make the most of it!

I have a great love of the countryside and living in Scotland gives me access to some of the most amazing scenery to be found in the world. Having walked The West Highland Way

(a 96 mile walk through the Highlands) with friends in 2002 my eyes were opened to the amazing scenery that existed in Scotland, particularly so when walking through Glencoe. I started climbing mountains again and completed several Munros (mountains 3,000 and above) as well as walking numerous other smaller hills and level walks.

My other main passion has always been music and I have always enjoyed listening to good music such as Queen, Marillion and Pink Floyd to name a few of my favourite artists. My new lease of life took me to The Netherlands for the biennial Marillion Convention, to London to see Kate Bush and to Liverpool to see Queen and Adam Lambert as well as many more gigs throughout Scotland. On one occasion prior to my operations I was fortunate enough to have met one of my musical favourites in the form of none other than Queen guitarist Brian May which was an amazing experience, particularly so as he was an absolute gentleman.

However during this time it was always on my mind that there was unfinished business to deal with in the form of two more operations and I decided to start the process off in February 2016 by going back into hospital to have the internal j-pouch formed. The decision came about due to a combination of knowing I'd eventually have

to have the rectum removed due to a cancer risk (if I didn't have this procedure within 10 years) and I was made redundant. It just seemed like the right time. Initially I had little interest in having a reversal, I was quite happy to live with the stoma as I had regained some freedom from the clutches of colitis. My surgeon had always encouraged me to go ahead however with the final reversal and I also no longer wished to live with a stoma so the decision had been made to go ahead with the procedures.

My surgeon informed me the surgery had taken over 6 hours as I had many adhesions that were to be treated and the recovery was longer than I had anticipated. I unfortunately succumbed to a post-operative paralytic ileus on two separate occasions a few days apart [editor: ileus is the lack of movement within the intestines which can lead to intestinal obstruction]. Being completely honest I would have to say that these few days were probably the worst experience of the whole experience as I was very ill at the time. Then 4 weeks after being discharged and just when I thought I was on the road to recovery, I became dehydrated and low in potassium and had to be readmitted to hospital, the reason for this being that I had a very high stoma output at first and losing too many fluids. I was on a drip for 2-3 days but after that



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I started to feel more like myself again.

I was still determined however to carry on enjoying the things that I loved doing and I continued my walking and gig-going although not to as great an extent as before. My walking outings became more of a relaxing nature rather than climbing mountains and I gained an increased appreciation of the peace and tranquility to be found around one of Scotland's most beautiful areas, Loch Lomond and The Trossachs, which is a short drive away from my home.

And on to my final takedown procedure in September last year and it must be said this was by far the easiest of the three procedures. The recovery was much quicker and I was discharged after seven days then returning to work five days later. I had a very understanding manager and was able to work from home for a few weeks which was most pleasing as it was a 75 minute drive to work. Being an accountant and office-based made

the return to work easier although I would imagine this would not be so straightforward for people who are employed in roles requiring a higher level of mobility.

It felt strange after 4½ years to suddenly have a bowel function again and although initially this was very frequent, things have settled down relatively quickly and I am delighted at only having to frequent the toilet about 5-6 times daily – a frequency that I have been informed is good so soon after this operation. It is early days though and I am trying to establish the foods and drinks that may cause a higher output. I still occasionally have a visit to the toilet during the night but this has become less frequent and seems to be related to what I've eaten in the few hours before bed.

One early issue that I have discovered in these early days is that one of my favourite drinks, white wine, gives me a bad attack of “butt burn” the next day! Another issue is that I only have confidence in passing wind while being on the toilet – so far, I am unwilling to take the risk in passing wind at other times just in case of some leakage. To me these are minor issues however as I am now in charge of my life again rather than colitis being in charge of me! The most pleasing outcome of all of this is that I now have no more appointments with doctors, surgeons or specialists for the first



Kenny (left) with Queen guitarist Brian May

time in 25 years! When I was given the all clear from my surgeon six weeks after the third operation it was quite an emotional moment as I looked back at the struggles over the years and to that night back in 1991 when I felt ill.

Special mention must be made to IA and the work that many people do in this fantastic organization. I was encouraged to join by my surgeon after having my total colectomy and it has been extremely beneficial in terms of information and support. I was initially put in contact with several people involved in the organization, people who I contacted and from whom I was given excellent advice and information. The chat room (IA forum) is a source of excellent information and the local bi-annual meetings within my group have a medical representative in attendance, something that I feel is both beneficial and reassuring. I myself have undertaken IA's visitor training course and in turn now support others who

are considering going down this route because their IBD is severe and badly affecting their quality of life. I thoroughly enjoy this role and have a desire to continue supporting others to help them and reassure them that they can get better.

My advice to anyone considering going ahead with this is to think seriously as to whether are you satisfied living permanently with a stoma? If you are, then I would seriously consider doing so. However, if you feel uncomfortable or self-conscious living with a stoma and are prepared to go through the complexities of surgery then from my own experience I would say go ahead.

If anybody reading this has any doubts about living with a stoma I would ask them to consider the following experience I had as an IA trained volunteer. I met a gentleman just over a year ago who had recently undergone a total colectomy [removal of the large intestine] but was not accepting having a stoma and wanted the internal pouch and takedown performed at the earliest opportunity. He was so upset about having the stoma that he was in tears discussing it with me. I tried to bring out all the positives such as him feeling much healthier now, no urgency to go to the toilet frequently and the ability now to be able to plan ahead and do what he wanted to in life – basically

being in control again rather than IBD being in control of you. Roll forward one year and I recently received a fantastic text from the gentleman offering me a massive thank you for my help and for being so positive with him. He has been on three holidays in the past year and is loving life again. In other words, life with a stoma is not so bad!

This whole experience has been something which has affected not just myself but also my family and close friends and thankfully I am blessed with a loving, supportive family and some of the best friends anybody could ask for. Karen has also lived with my experience of ulcerative colitis for 25 years and my two amazing children, Heather and Eoin, have also lived with this for 19 and 15 years respectively. The most important things in life are family and friends and without them we have nothing. It is something that has been said so many times but it is something that is so very true. To say that I am appreciative of the support of my family and friends would be a gross understatement.

As 2017 commences I am planning some more outings, once again to The Netherlands for the 2017 Marillion Convention with friends, a long distance walk along The Great Glen Way and a hillwalking outing to the roof of Britain, Ben Nevis. And when I reach that summit it will be on my

mind of the challenges which have been faced over the years and the fact that I have never given up hope of getting better. I am almost at that summit and it is not far away now.