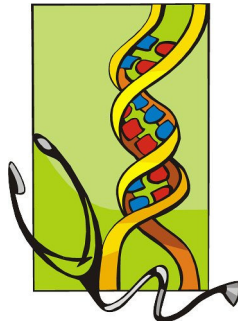


Beating Bowel Cancer:

My Genetic Journey



Mick Mason 2006

Introduction



My name is Mick Mason and in June 1999 at the age of 56 I had a planned operation to remove my colon due to multiple polyps. My wife Ann and I knew it would change our lives but were unclear exactly how. We also knew it was a big operation but without which I would eventually have colon cancer. Only ten days after my operation and still in hospital we found out, eventually meant now.

I have often been asked how cancer had changed my life but a more appropriate question would soon be “How has a genetic fault altered your life”? For when I was told I had colon cancer it was also mentioned that it could be through a faulty gene. At the time I never really took a lot of notice of the condition mentioned, Familial Adenomatous Polyposis (FAP) but that was soon to change.

The proceeds from the sale of this booklet will be shared between FAP Gene and The Beating Bowel Cancer Charity.

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Church Choirs

In Leicester the Groby Road separated the parish of St. Augustine's on Fosse Road North from St. Leonard's in Woodgate. St. Augustine's was quite a modern church whilst St. Leonard's was much older and more impressive as a building. Rather strange then that my father was a church warden at St. Augustine's although living the wrong side of the road. This had quite an effect on my later life, if you think the age of 10 is later life. From the age of about 7, I was in St. Augustine's church choir and the 32nd. St. Augustine's cub pack.

So far quite simple except when I was about 10 a dispute between the vicar a Rev. Daybell and the Choirmaster led to the choir getting the sack!! I think the choice of music had a lot to do with this and not our behaviour as it included the adults as well.



Before that fatal day I have fond memories of a Mrs Burton always pulling my leg whenever we sang hymns with 'Hallelujah' in them. We always had a smile at each other, pity it wasn't throughout the year though and not just for a few weeks. I had enjoyed singing in the choir and it was at this time at my primary school Alderman Richard Hallam on Anstey Lane, a member of St. Leonard's Church came looking for choirboys. It seemed a natural step to switch sides and never thought it would cause any bother. Trouble did brew when the Rev Daybell re-instated his choir and there was a heated discussion with my father about my being poached by St. Leonard's.

In the end I was asked to choose between the two and as St. Leonard's had a weekly choir club there wasn't really any doubt where I would continue. As well I think the pay was perhaps better. A regular income and extra for a wedding and for some reason even more for a funeral. The Reverend Daybell eventually became a Canon and lived in Bottesford until his death only a few years ago.

Our choirmaster at St. Leonard's was Mr Hill and the organist a small fellow Mr Dick Tuck who was quite a character and had played the piano quite seriously in his younger days. No wonder that the music was of a much higher standard and included over the years The Messiah and St. Matthews Passion. I remember later on singing at Somerby Village Church as a 17 year old and several of us being beaten into the pub by their vicar and Mr Tuck.



Before choir practice it wasn't unknown for us to pop into a small room at the side of the church and drain empty bottles of communion wine into one! There was enough to get a taste at least. Also Phillip, who later became my Best Man used to play some light hearted music on the organ. He had an exceptional talent and it was a sad loss when he died at the age of 42. His two brothers Richard and Christopher also sang in the choir and Richard will always be remembered for his rendition of 'Once in Royal David's City' at the Christmas midnight mass.

A more humorous moment was when for some reason about five of us decided to join the congregation for this service. We must have been about 18/19 as a tour of a few public houses, namely The Blackbird, Cricketer's and The Robin Hood preceded this moment. As I remember Phillip, Anthony, David, Malcolm, Barry and I sat in the congregation much to the surprise of the regulars. Mr Tuck came and we took up his invitation to don our robes. Funny that afterwards he commented that it was the best we had ever sung!!

I remember sometimes at a service one of us had to use a pair of bellows to keep the organ going and remember Mr Tuck giving some very forceful orders at times as the air supply dwindled which affected the magnificent organ. Another of Mr Tuck's lighter moments was in regards to his marking our music sheets with letters of the alphabet. This made it easy to return to a certain place even for the dimmest of us. Funny how many times it was to 'Letter B' as he looked at the lady members of the choir.



One of the merriest times for many reasons was the carol singing around the streets of the parish of St. Leonard's. This also included Groby Road Hospital and the infamous Blackbird Hotel. Each night we would start at someone's house and finish at another with mince pies etc.

Most welcome ending was at Mr Hessletine's who was a church warden and lived across the road from 'The Blackbird'. As we grew older it took quite a while to get through the pub and across the road to Mr. Hessletine's.

Also at Christmas we had a trip to the pantomime, preceded by a lush tea at the vicarage. I remember the Reverends Jaegar and Brain being very different with the Jaegers' being a family with a son in the choir and the Rev. Brain, unmarried with a passion for trains. Sadder moments were when St. Leonard's was demolished due to the demise of local homes and in 2004 St. Augustine's was burnt to the ground whilst awaiting planning permission for other uses. Both hold fond memories and will be missed for a variety of reasons.

Chess

How a game could be such a large part of someone's life is understandable but when it's Chess some might wonder. It all started when as a pupil at Ellis Avenue School in Leicester I came under the influence of an Austrian English teacher. I might add along with about 100 others.



The school catered for 11 to 16 year olds and in 1954 was classed as an Intermediate School. This was for those not up to grammar school status but above the secondary schools. There was a 5th year for those wanting to stay on for GCE's but most left at 15. Each school year had a chess team and there was a chess club every lunch time.

In the 1950's it was the most successful school for chess in Leicester and was awarded the British Chess Federation Shield for chess excellence during this period. This was all due to Mr Illesley. As important as the children were the mums who provided sandwiches for the many matches against other Leicester Schools.

In four years our team hardly lost a match and we were invited into the Grammar School League (under 18's) when in our 5th year. This was a lot harder but we at least gave our older opponents a run for their money.

Whilst studying for my GCE's I was playing in the evening league with several friends for an Old Boys team and also entered a Leicestershire Schools Chess Congress at Alderman Newton's School during the Easter holiday. This was split into groups of 6 players and at the end of a week all the group winners received a medal and played in a simultaneous game against a top player. I still have a coveted medal.

On leaving school I carried on playing for the old boy's team before giving up the game just before I entered the RAF. At the age of 18 the enjoyment had disappeared and everything revolved around winning and analyzing games.

My abstinence lasted until I was at RAF Sharjah in the Persian Gulf. With about 12 of us to a room our attentions turned to the Friday night WRVS games evenings. For a small fee each one of us entered a different competition and any winnings were pooled for a night out. Seemed they never had a chess player in the room before.

Chess always seemed a bit like poker to me with an important part being not to let your opponent sense any weakness or excitement in you. So on the first night I was told I would have the white pieces to give me a chance against the usual winner Tony!! Nobody asked about if I had ever played before or the option of a choice of colour. With my nerves a bit on edge and rather put off by being assumed to be there for the taking I not only beat Tony but won the competition that night.

I must give Tony his due as he then asked where I had learnt to play and afterwards we became keen but friendly opponents. Think on average quite a bit of money went in the kitty over the next year.

It wasn't until about 1972 when we moved to our own house in Melton Mowbray whilst serving at RAF North Luffenham that I was tempted to play again. The local chess club had moved premises and I eventually plucked up enough courage to have a look. Serious chess was far from my thoughts but found an ex-school mate one of the clubs star players. So I was hooked.

For about twenty years I played in the second team with a reasonable amount of luck. I say luck because my knowledge of the game was still there but tactics had changed and my opponents were often better players. I still managed a few surprises though and started to enjoy the game again.

The club had several good young players and in 1980 I started to help with chess at The Sherard Primary School in Melton Mowbray where our eldest son had offered to start a chess club - run by his dad!! This was the biggest move of my chess career for over the next 20 years I became heavily involved in Leicestershire Primary Schools Chess. This whilst playing for the county third team and at least one club match a week would eventually take its toll and I finished playing for the county before I became too weak a player for them.

The schools chess was a real helter-skelter. I progressed from the school chess club and then (mainly after the upheavals in education) to the county primary schools coach and lastly secretary. In that time I started an individual tournament which eventually attracted around 250 entries. Also the county mixed under 11 team was added to, by first the girls under 11 team and then a mixed under 9 team. We managed to get to the National Finals once with the U11 mixed team and had a pretty good day at Ross-on-Wye. A full bus load went down there and everyone had a medallion to commemorate the occasion even if we did come last.

The under 9 team also made a National Final when we hosted the event at The Ivanhoe School in Ashby-de-la-Zouch.

With the girls team there was no qualification and trips to Liverpool and Brean Sands for the finals found them recognised as perhaps not the best players but certainly the friendliest team around as were all our teams.

There were so many happy memories and the Melton club also benefited from the influx of young local talent with one team comprising of 8 to 13 year olds and holding their own against adult teams.

The end of my chess life really started after being diagnosed with bowel cancer. The primary schools association was proving a difficult thing to keep organising. I started to play again but found it hard to concentrate over a 2 hour game especially as the Melton Mowbray club had folded and I was travelling to Ashby which was a 35 mile round trip and then Birstall for home matches!!

Starting Work August 1959 at Hillcrest Hospital Leicester

This was the month when as a 17 year old I started my first job as a junior welfare clerk at what used to be Leicester's Workhouse and was now a geriatric hospital. After an interview at the Leicester City Council Welfare Office in Pocklington's Walk I was assigned to the hospital and a friend to the Pocklington Walk Office. I remember the look on people's faces when I said where I was to work and wondered what I was letting myself in for. My friend was soon gloating that he had the better job. He turned out to be quite envious. Hillcrest Hospital was just over Swain Street Railway Bridge in Sparkenhoe Street. What a daunting place for a 17 year old as I went through the gates into 'The Lodge'.



Things changed as a friendly porter took me to the Welfare Office, which was to the left of the main entrance. Such a small office painted green and cream if my memory is working OK. Here I was introduced to The Chief of the Welfare Office Mrs. Rayne and her staff Miss Cole and Mr Wright. Geoff looked about 35 and would be who I worked with. Quite a relief as Miss Cole and Mrs. Rayne seemed rather stern and frightening.

Whilst being shown around by Geoff on that first morning a mutual interest in football emerged as he had played for Walsall at one time. Also in the main office Mr Clegg was a local football referee. Then followed Mr Healey the Superintendent, Mr Booth his Deputy, Matron and Deputy Matron who might have been O'Hearne and MacAllister, Chief Clerk Mr Higginbottam, Mrs. Rayne's husband who was the chef and the 8 or so ward sisters. It was impressed on me, except by Geoff that I was an office junior and all of them were higher **in all respects**.

The Hospital had separate residential sides for male and female and 2 or 3 male wards which ran along the railway side. The female wards were in two blocks 3 high. My job was to help get pension books signed and hand out patients on the wards their weekly money allowance (if they were deemed fit enough), type out the account sheets and any standard letters that were needed.

This sounded boring but soon I was to realise that being so young compared to the patients and residents had its benefits as I suddenly had that many 'mums and dads' looking after me! It seemed an impossible task to remember names but several of the elderly ladies used to point out who was who and gradually over the months I could venture out on my own and find the majority of them.

On a Friday morning Geoff disappeared down the main post office with all the pension books and in a conference room every counterfoil was stamped and torn out by the PO staff. Woe betides us if the figures didn't tally up. How many books? Seemed thousands and thought about 5-8 hundred but haven't been able to find out an exact figure.



One of my duties was to man the lodge and its switchboard every 4th or 5th weekend. For this we had 2 days off in the week. So training on the marvels of a ball and socket switchboard was one of my first challenges. Interesting that even then you could arrange a 3 or 4 way conversation. Well others could. The days off were strange as all my pals were working and I started playing golf at the Western Park Municipal Course. Never that good but it's something I enjoyed.

At the weekend it was also the duty clerk's responsibility to issue the daily milk ration to the wards. Needless to say it was easy for the nurses to make sure they had more than enough milk from a very nervous young lad.

Christmas Day was a special time as it has been the only time I have ever worked on that day. As well it was voluntary with no pay.

I started with Geoff about 9am. Our job was to give sweets and things to the patients on the 8 or so wards. He warned me that it was very strenuous work and we were expected to wish everyone a happy Christmas and not refuse a drink from the ward sisters.

I remember accepting a few but not an awful lot after the first few wards. I do remember commenting afterwards that I found out a ward linen cupboard was big enough for two people.

Also I remember helping to ply the residents with ale from jugs filled in the kitchen at their Christmas Dinner a little later on. Again I seemed to serve the same fellows quite a few times as they insisted it was their first drink.

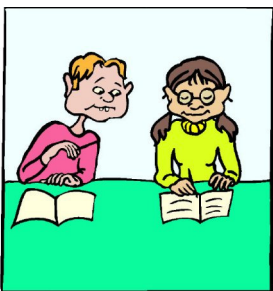
I had my first motorised bike whilst at the hospital. My older brother's Norman Nippy. It was the rich mans cycle master as it had fairings and a covered in chain. It was the days of no crash helmets until a cyclist was injured outside the hospital gates and Mrs. Rayn's insisted I wore one or didn't go to work on it!!

Workers Playtime the radio programme was recorded one lunch time with Tony Hatch and Jackie Trent. We were kept out of the way though so couldn't have been classed as workers.

A light relief was sometimes being allowed to help the Chief Clerk and Mr Clegg show a film on a Friday evening to the residents. The main canteen had a proper projection room and two large projectors with carbon arc lights. I also helped to sort out a couple of gramophone records for the pre-film entertainment.

There was a record by Pee Wee Hunt and his Jazz Men called Hawaiian War Dance I was crazy about and they must have been fed up of in the end. Another time we missed the middle reel out and played it at the end and hardly anyone noticed. The residents did notice however if we broke down and were worse than the youngsters at our local cinemas with their catcalls.

This was also the time to think of the future and promotion prospects. So with my pal from the main office we entered the delights of Night School. On a Monday I worked from 8.30 until 6pm but was allowed to leave at 5pm as evening lessons started at 6pm.



I began to learn about who paid for street lighting, the police, dustbins etc. The many acts of parliament that affected local government completely baffled me. After a while it was that boring we used to extend our tea break for a pint in a local pub. Then it was a case of not going back for the second part. This had a profound effect on me for after a chat with Mrs. Rayns about my lack of ambition I found out a little known exam taken at school gave me two increments on my starting pay and the need not to take the first two exams!!

This exam was The Local Government Entrance Exam and our Headmaster at Ellis Avenue School a Mr Date (Who had also taught my dad at The Wyggeston Grammar School) had made us take it before our GCE's. He thought this would get us use to the process of sitting exams and another exam he found for us was The College of Preceptors Exam, a trial for leaving school at 15 with some qualifications.

After just over 2 years I left this paradise when I decided to join the RAF even though National Service had finished. I just could not see myself doing the same thing day after day and after all I was only 18!

I did pay them a visit later when my Grandfather was moved from the Enderby Old Folks Home when in his nineties and not in such good health. It still looked and felt the same but felt I had made the right decision to move on.

My R.A.F. Life 1961 to 1973

National Service had finished and a pal from my school days had the brilliant idea of us joining The Canadian Air Force. Problem was we had to serve in the R.A.F. first and transfer or something similar afterwards.

After filling in forms at the recruiting office in Leicester my friend backed out but with my brother having enjoyed life in the R.A.F. as a national serviceman (he actually signed on for an extra year) I carried on. Then what happened next should have warned me to be careful with future decisions.

I had an 'A' grade in my maths GCE exam and opted for the accounts section. Imagine my surprise when told my maths wasn't good enough and was offered the proud sounding trade of 'Clerk Equipment Accounts'. This was the same as pay accounts or so I was told. Didn't take long to realise I was a Storeman to all intents and purposes and as it turned out was for the next 30 odd years of my working life.

My hope was to get away from the Leicester area and after being made welcome when signing the final paperwork was given my first orders which were virtually 'Here's a ticket to RAF Bridgnorth, don't miss your trains or else'.



The eight week square bashing course was a real roller coaster with about 20 of us in a hut and plagued by two corporal drill instructors. One was the kind friendly type, the other a bully. I think it took us about three weeks to work out this was all part of their fun and how they must have laughed over drinks in the local pub.

I remember taking Sandy a lad from the Highlands home on a weekend pass. I could just about understand him if he spoke very slowly but friends in Leicester were quite baffled. My trade training was another eight weeks at Kirton-in-Lindsay. The bonus was we had a civilian instructor and seemed to be treated slightly better. Then my first posting and dreams of Scotland, Cornwall or anyplace away from Leicester.

So where was RAF Cottesmore? Turned out 20 miles from Leicester!! Another sense of humour from my new masters. It had its benefits as Oakham had a decent pub, The Roebuck, where we would often be knocking on the door at opening time.



Another asset was it had a coffee bar at the rear where I met my eventual wife Ann who I married in 1967 after foolishly agreeing to do so if England won the World Cup!

Memories of Cottesmore were mostly happy ones and sharing a room with three Geordies was never dull. One Sunday we went down into Oakham and gave our pint of blood to pass away the time and get a free cup of tea and a biscuit. Also my first Vespa scooter bought for £10 gave valiant service around East Leicestershire and Rutland even though I could not manage to pass my test. Well not until I returned from my next posting in Germany and upgraded to a Lambretta.

In August 1963 I was posted to RAF Gutersloh in Germany just as Ann and myself were getting a little bit serious about each other. So for the next 30 months I seemed to spend more time travelling home on leave to Oakham than actually being in Germany. This was thanks to my brother Keith. I had wanted to sign on for 12 years but he explained if I signed initially for 5 years I would be enticed to sign for more whilst at RAF Bridgnorth doing my basic training. Then was the time to sign for the 12 and get 21 days re-engagement leave at the same time.



The Supply Squadron at RAF Gutersloh had one of the meanest looking football teams in the world. This was in stark contrast to The Admin Wing team. What a transformation that was when we only just lost 2-1 in the final to a star studded Engineering Wing



I finished my service at RAF North Luffenham only about 6 miles from Cottesmore. In between postings to Sharjah in the Persian Gulf; 16MU at Stafford and Waddington near Lincoln completed my 12 years. Highlights of my other postings were building a beer bar in a 'clothes drying room' for Christmas in Sharjah. 12 of us spent about a week lining it with plywood and converting it into a ships bridge. It even included a gang plank and ships bell. When we worked out the cost to the RAF we nearly ripped it all out for fear of several charges.

All the bars were judged by the Group Captain and ours won a barrel of beer and was opened straight the way. It eventually closed several days later and was the only one open 24/7 as they say now, with us working shifts behind the bar. My favourite customers were the RAF Police Dogs who appreciated a change in diet throughout the night.

The other high spot was ordering spares for the Lancaster Bomber whilst at Waddington. In the final stages of getting its air worthiness certificate it was actually given the same priority for spares as the stations V Bombers and several hours were spent with the MoD on the telephone trying to find bits and pieces.

A Funny Acting Bowel

In the late 1960's I used to smile when my father-in-law gave me instructions for getting down to Devon from Oakham by car. Every change of road was linked to a pub which made the trek quite easy to follow.

A few years later I had a different reason for remembering the locations of pubs, inns or hotels when I was diagnosed with ulcerative colitis and trips to the toilet became quite frequent.

I remember as a youngster in the early 50's getting out of the after dinner washing up regime by dashing to the toilet, it became a family joke. Now I realised that perhaps that was the first sign of things to come.



In the early 1970's I started playing chess again and usually left home soon after our evening meal. I thought it was nerves causing me to dash to the toilet before I left and having the same problem when I arrived at the venue. Some times this was after a visit to the toilet on the way. We even joked about ordering extra toilet rolls.

It never affected what I wanted to eat or my general health but always having to be aware of where toilets were was not what someone just turned 32 really needed in his life. I think then I almost shut my eyes to it and didn't mention to Ann when I first started to pass some blood.

I knew I should see my GP but wanted to believe it was normal for someone with ulcerative colitis to pass blood and eventually mucus as well. It was only when someone over the road and one of my cousins died of cancer that I plucked up the courage to see my GP again. This led to my first colonoscopy and a report that there was no sign of cancer. So I was left to monitor how I was and for about 20 years apart from another colonoscopy in 1993 things stayed much the same.

At this time I was working shifts as a process controller at Pedigree Petfoods in Melton Mowbray and gradually was spending more time visiting the toilet, which did have one benefit. This was listening to the conversations between managers as they paid a quick visit to the urinals. The information gained from some of them was quite useful to the small team I worked in.

I finished working at Pedigree Petfoods just before Christmas 1995 when an offer to take early retirement was too good to refuse even at the age of 53. There followed 18 months at an engineering firm in Leicester as a storeman again, before being made redundant in 1998.

It was after this that things went downhill with up to 15 toilet visits a day. This was starting to drain me physically and also mentally. The thought of cancer returned and I was referred to my first consultant who thought I should have a better quality of life. So the next twelve months were spent on varying doses of steroids and other medication, when only the higher doses showed only a slight improvement.



I never imagined things could get worse but at Christmas that year things did in a dramatic way. For the first time I had severe stomach cramps which left me in agony for a few moments each time I went to the toilet.

One check-up was quickly followed by another and laying on a hospital bed after a colonoscopy my consultant showed Ann and me a photo of my colon that looked like something from outer space. I think we had both been expecting the worst with the change in symptoms and were rather relieved in a way that there was the mention of an operation which would improve my waste system and prevent cancer. I did ask if that meant a bag which I didn't like the thought of and was told perhaps not.

A few weeks later I saw my future surgeon for the first time and another examination revealed that all of my colon and everything beyond it would have to be removed. He said because of all of the polyps it would be unsafe to leave any of the colon as it would eventually be covered in them as well with the risk of cancer. This would mean me having a stoma and a bag. I think my heart sank but at least I wouldn't get cancer or so I thought.

I couldn't really imagine how the operation would be performed and the idea of having no more need to sit on a toilet seat was beyond me. We must have been told but I think the shock of everything even though we suspected the worst, blocked our minds. We arrived back home and still could not really take it all in but did remember that someone called a stoma nurse would come and see us and help us understand what was to happen.

We knew very little of the various alternatives in surgery with stomas and internal pouches but all were explained and it seemed a permanent ileostomy due to the added complication of the multiple polyps was the best option. It was still left up to us to decide but reading between the lines there wasn't really a choice.

Looking back I am relieved that I didn't really have to choose because for those who do, even with help support of doctors and stoma nurses, it must, at times, be a very difficult decision to make. They cannot say how you will be after either operation as everyone is different. However at least mine would mean one major operation and not at least another one which would be needed if I were to have an internal pouch made out of part of the colon.

My stoma nurse came and at last we started to understand a bit more. The fact I would not have to pay for my prescriptions with having a stoma was a surprise and something that hadn't crossed our minds. All of my bags and any other stoma related items could be delivered to our door and I would be given a plastic box to hold them all. Her help and advice settled us a bit but all we could think of was when would we know a date.

At this time I had started to help with chess again at Langham Primary School in Rutland. The Head Teacher who had also taught our children in Melton at The Sherard had a friend for me to chat to about having a stoma. Her friend's stoma was seventeen years old!

The conversation with someone I didn't know lasted around two hours and answered many questions without really asking them.

My own thoughts were that at last I would be rid of the need to think toilets all the while. Towards the end we had noticed that on our breaks away for a few days there was no long walk in the evening as I needed to be even closer to them. This did spoil the breaks and only brought things to the surface when we were trying to forget them for a while.

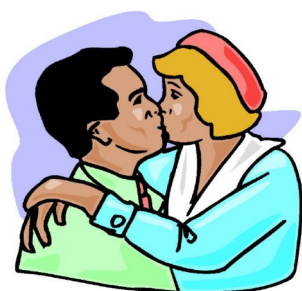
It was an anxious time for both of us as we waited for a date for my surgery. Our children were visibly upset as it all took time to sink in. They said it would be a matter of weeks and when the date arrived, our hearts sunk as the truth began to sink in even more. It was a very quiet household.

Surgery

The day I went into Leicester's Glenfield Hospital was a Bank Holiday Monday. I think the worst moment or rather first worst moment was the dreaded phone call to see if there was a bed available. I had not thought a lot about this beforehand but to Ann it was a very traumatic moment. At one time you just assumed there was a bed but with all the publicity about cancelled operations it can be as bad as actually going in!

I also was very aware that as I sat on the toilet before leaving that it would be for the very last time at home. I wondered how I would manage about reading the newspaper and also what to do with all the spare time which would hopefully be available.

The hospital is only about a 20 minute drive from Melton Mowbray and at least the car park was almost empty. It was a nerve wracking walk up to the ward and I felt even worse when I sat on 'my bed'. I think it was then that we both realised how serious the next few days would be and yet at the same time what a relief.



Ann stayed a while and wondered whether to stay the night. With my operation due about 12 noon the next day we decided it was best for Ann to return home and see me later the next day. This reminded me of when Ann had our three children. I used to take her to the hospital and couldn't wait to get back home.

There was a chap in the next bed who turned out to be a godsend. He was recovering from having an ileostomy reversed and in a very calming way explained about how he had coped with a stoma and about recovering from that initial operation four years ago. After the operation his encouragement and advice was something I will never forget.

They say uniforms give people character. Not surprising then I didn't recognise my surgeon when he sat on my bed in his jumper and casual trousers. I smiled probably for the last time in a few days when he offered to don his white coat. He went through the procedure again just to make sure I understood everything. Also that I would have two surgeons, one to do the upper part and he would contend with the nether regions. Then the anaesthetist came with his few words and checked the results of an ECG I had had earlier.

That afternoon and evening took a long while to pass. I think only the thought that in 24 hours time all would be over and I would be clear of the cramps and pain for ever kept me going. A frightening thought though was about having a stoma to think about, let alone the operation itself. How would I cope and what would life be with one for both Ann and me?



On the Tuesday morning it was all go. I bathed and shaved but missed having my usual breakfast. Then Sue the stoma nurse came and put a cross where she wanted the stoma to be sited. This seemed odd as I thought the surgeon would decide. However Sue explained that it helped and usually the surgeon asked her anyway. Then it was the jab that makes you drunk and I remember being on the bed travelling down corridors, round bends and in lifts before seeing the anaesthetist again. I think I counted to two and then vaguely remember being called too by one of the nurses before realising it was all over.

My operation had been due in the morning and Ann rang after lunchtime to be told I had just gone down to the theatre and to ring again about 5pm. Afterwards, she said how lonely this time was with her nerves all on edge. There was a further delay and eventually around 8pm she came to see me.

The first two days were a bit of a blur as I remember Ann seeing me a few hours after the operation and hearing her say she was amazed there were only a few tubes connected to me. I think we both expected all manner of things from watching Casualty and other hospital dramas. on the TV. Also amazing how quickly they recover in those programmes.

There were a few problems that first 24 hours as an added complication was my having Ankolosing Spondilitis. This is an arthritic condition and affected my neck and lower spine. To relieve the pain I had from this, my pain killing drugs for the operation were at a higher level. This gave the young lady doctor two sleepless nights as she tried to sort out my low blood pressure and then wondered where all the fluids were going the next night. Luckily she solved both problems. As for me, I couldn't care less for I was in a world of my own. I can vaguely remember being lifted so x-rays could be taken and mention of another ECG. Luckily nothing was amiss and I assume others then kept her up all night. What hours they work and yet still manage to look refreshed.

I must have been really tired a few days later, as it took Ann three hours to wake me up on her visit. All the suggestions from the nurses and other patients failed to work and eventually I woke up and was surprised Ann seemed a little fed up with me and was nearly ready to leave. She had tickled my feet, pulled my ears and many other things and we often smiled about it even now.

It was nice to repay her the next day when I met her along the corridor near my bed to show how I could walk. Those visits every day really helped in my recovery and I tried to be cheerful so as not to worry her. I also began to realise how much it had taken out of her. Not only visiting but from the time an operation had become a certainty. The focus was always on me and how it would affect me. When we looked back later we realised that the partner and other close relatives need just as much thought at a difficult time.

The worst problem was not being allowed to eat for about 7 days. I watched some of the others having their meals whilst I was allowed a few sips of water an hour. Imagine my delight when this water ration was doubled to 20ml an hour and then being allowed half a biscuit from the WI trolley service. The gods must have been smiling on me when I was at last allowed a meal. It was too late to order one but they had a Sheppard's pie and rice pudding, my favourite things.

The best moments apart from Ann's visits were when the tubes started to be taken away and I returned to being 'normal' again. I still had worries about coping with my stoma and although I was draining the bag I hadn't changed it yet and that scared me to death. However I never thought of myself as any different by having a bag and was already relishing not being tied to a toilet!

Sue changed my bag the first time and a few days later it was my turn. Just before that the registrar had mentioned I might go home that day a thought that terrified me. I needn't have worried for there was Sue behind him shaking her head. She explained that I would be going nowhere until she was satisfied I could cope with changing it. Boy was I relieved.

I didn't do too bad that first time but everything was done in a rush and I was afraid things would go wrong. I was pleasantly surprised when she said I had done OK. I had thought removing the bag would be like pulling a plaster off and about any hairs growing underneath. I likened it to pulling Velcro apart and another milestone had been passed.



Then the bad news really came, as although my operation was surgically a great success, whilst still in hospital, it was complicated by the finding of a tumour. In the days after the operation my surgeon kept a watch on me and I was pleased he didn't have a trail of others behind him. Often he would be alone and just sit with me for a quiet update. When after about ten days he did come with a few followers I sensed all was not well and was told I had colon cancer and it might be through a genetic fault. Luckily it had been caught early and was only in one gland near to where the cancerous polyp

had been. The prognosis was pretty good but all sorts of possibilities were racing through my mind.

This is when the words Familial Adenomatous Polyposis were mentioned for the first time. Sounds a grand name and luckily FAP is much easier to remember. Ann usually visited me after lunch and on that Friday morning when I was told by my surgeon that I had bowel cancer and would need further treatment. My first concern was at which hospital. My operation at Leicester's Glenfield Hospital at least made it a fairly easy journey for Ann to visit me and I hoped it would be there.

My hopes were dashed when they mentioned the 30 weeks of chemotherapy would be at The Leicester Royal Infirmary, notorious like many other hospitals for its parking problems. This would involve one treatment a week and take only a few minutes. However with the travelling and waiting it was expected to last all morning or afternoon.

I could also, if I wanted, go home that afternoon and thought it essential to be with Ann so both of us could cope together with the devastating news. Usually I rang her before she left for her lunchtime job at a local school and thought it best not to mention the news. It was also hard to sound cheerful and I mentioned I could go home later that day.

It was strange when Ann came and I had asked my surgeon to come and talk to both of us. The news stunned her as we all, including the surgeon expected no cancer to be present. Just shows you never know until all is looked at.

We had quite a wait for the paperwork to be completed before we were allowed to leave and all we seemed to do was sit there trying to comfort each other. We wondered how we would tell our children and their reaction to my uncertain future. It was worse because it had come so unexpected and we slowly realised how unprepared we were.

I cannot remember much of the 20 minute journey home. We were relieved to be together again but that word 'cancer' had changed all our dreams of a quick return to health. How would I react to the chemotherapy, would it be a success, would it affect my stoma, how long would I live and as important how would Ann cope with so much to think about?

Home Again

Both of us had assumed I would not be able to get up and down the stairs very easily but apart from a very sore backside with the stitches still in there was no problem. I did however find it extremely hard to get comfortable sitting in a chair.

We also had the task of letting our families and closest friends know of the depressing news. We will never be sure how we got through those first days especially as on the Sunday morning I was back in the same hospital bed when the wound on my backside started to leak.

It was about 4am after I had been to the toilet I noticed the dressing on my backside was rather wet and a pink colour. I hardly dare wake Ann but she came into the room just as I was getting into a bit of a panic. A call to the hospital help eased the fears a little as they mentioned the colour was a good sign that nothing serious was going on. I was also asked to return and ended up in the same bed about 30 minutes later. My old friend was still there in the next bed and wasn't too surprised to see me when he woke up as he had been dreaming I would return. Perhaps this was induced by our beds being near the nurse's area.

A quick check of my temperature and examination by a doctor showed no signs of an infection which was good news even before MRSA had started to appear. Although this calmed us down it was a disastrous start to our new lives and put an extra strain on Ann for although we had had a day to think about the future together we were soon back to the afternoon visits and being apart.

On a more humorous note there were only the two of us in the bay and my trusty friend pulled the curtains and added a sign 'Business Class'. Neither of us needed treatment and for a couple of days tried to put a lighter touch to our circumstances. We must really have confused the staff as we watched The Tellytubbies on the television. Luckily everything cleared up and on removing some stitches all the pressure was relieved and I was even able to sit without any pain on a chair. Then on the Wednesday Ann took me home for a second time.

There we were with the problems of coping with the news of the cancer, recovering from major surgery, the genetic possibility and getting to grips with a stoma which on its own was quite frightening at the time.

Whilst in hospital Ann mentioned that the telephone hardly stopped ringing but when I came home it seemed to almost stop and whether this was as news of my having cancer became known or not is something we might never know. I suppose it could be awkward knowing what to say as after all there was no mention of this before my operation, the main aim was to prevent cancer occurring.

At least we found who our true friends were. They were concerned for Ann and myself and not just wanted to know the full details to gossip with others about like one close neighbour.

We had never thought to ask about the simple things beforehand. Things like "Would I be able to get up the stairs"? How about walking and what energy would I have for the normal things in life. Now, how would chemotherapy and cancer affect me and what could it do to my stoma.

We did know it might be around 8 to 12 weeks before I could drive which would put the pressure on Ann as my taxi driver. It wouldn't be advisable to think of lifting much for three months but we also knew little things would become important and that sometimes there would be a step backwards to contend with. Now we had time to talk to our children and explain all of what we knew. It was a very quiet time as we all thought about how it would affect all of us. At times it was almost like a dream and we hardly mentioned the fact it might be a genetic fault which might affect some of them. This was not because of feeling scared but because we didn't really know much about it and other problems, were there to be solved.



Where to sleep? Would I wake the whole house up with any nightly ramblings? What would I eat? Would I be able to sit on a hard seat to watch Leicester City? Was it worth having a season ticket again? Would Ann be able to continue working? So many questions and as yet, not many answers.

There was also the fact of both of us coming to terms with my stoma. How would others see me and would I need a whole new set of clothes. I suppose it was all a bit clinical and when the time came to change my bag there was a huge feeling of relief when I had completed the task. Everything was to hand as I rushed through and tried to remember everything I had been shown in hospital. How different it was to be alone and almost panicking to get it all done. The thought that every two days for the rest of my life I would have to do this was hard to think about.

Draining the bag had been easy in the hospital as the output was very watery due to eating hardly any solids. It was almost self cleaning and now I was faced with adapting my skills to emptying a variety of different consistencies over the following weeks. However gradually I panicked less and started to realise that 5 visits a day totalling about 10 minutes was far better than 15 visits taking an hour or more.

Another important thing was for me to start the thirty weeks of chemotherapy which would hopefully kill any of the cancer which might have been left behind and get it out of the way. Also for five years I would be carefully monitored for any signs of it having spread. This was a worrying thought and something we had never thought of. Of course I was worried about losing my hair especially with many scars from having cysts removed on my head. What a relief when they said the chemotherapy I was to have would hopefully have few if any side effects.

Our daughter came to see us with her Newfoundland dog called Friday a few days after I came home. Normally I would be pounced on by this 8 stone friendly mass but for a few visits she calmly sat the other side of the room away from me. I found this a bit upsetting as I longed to give her a big bear like hug to prove in a way I suppose that nothing had changed.



It was a relief and a sign I was on the mend when on one visit her paw was offered to me for a shake and then the usual friendly assault. Amazing what they can perhaps sense about people and in a way act appropriately. Could she really have sensed that I was in a rather delicate state and needed time to recover? I like to think so.

I just wondered how long it would be before I could take her for a walk again and if I would be able to get her in the car.

Chemotherapy

Our first appointment at the LRI did nothing to ease our fears as the oncologist was delayed for a few hours with an emergency. It had a long lasting benefit though as we chatted to a couple in a similar position and found the lady had her operation straight after me with the same surgeon. We all agreed it was a most depressing place and did nothing to ease our worries about the treatment that was to come.

I was weighed and measured and eventually everything was discussed with us and how every four weeks I would see the oncologist. We soon learnt to use this to break the 30 weeks into 7 bits. Here we were in the summer and what a thought that it would be well after Christmas before it was over. Even then, would it be successful and what effects might it leave.

Our first visit for treatment was totally different to that first one. The area was almost new and very open. We were offered free drinks from a machine and sandwiches as we were there at lunchtime. Also everyone was so friendly and it became more like a coffee morning with friends. In a way it was our first support group as the tips that were passed around really helped. These included tips about caring for my new stoma which was still a rather daunting thing. Plus Ann was able to chat with other partners about how they were managing which is sometimes forgotten about.

The actual time to have the chemotherapy was only a matter of minutes with it injected into the back of my hand. The nurses and the receptionist's were so thoughtful for all their patients and over the weeks we chatted about everything apart from cancer really. One week we had to smile, a new nurse prepared everything with slightly shaking hands. I was her first patient and during the previous week she had been practising on other nurses to perfect her technique. The thought of them sitting around playing with needles and syringes was quite amusing.

Luckily I had very few side effects and only felt very tired for a couple of days each week. I even managed to spend a few months before Christmas working at the local Argos store. This was a real bonus as I enjoyed it the year before but thought the chemo had put paid to that. It was a boost when the manager said that wasn't a problem and if I felt tired just to go home. He couldn't have known what this meant to Ann and me as I had gone to see him and explain why I couldn't work. I waltzed home to give Ann the good news.

I did feel a bit of a fraud when people were so concerned about my treatment and its length. This was just a thought in my mind as some of the treatments are almost unbearable with the side effects. Mine was what I classed as mild and only when told no chemo is mild and also what major surgery I had had did I realise I was perhaps just fortunate. However I still feel for others facing any form of this treatment.

So the weeks went by during which I saw several friends starting their treatment or accompanying others and realised how many are affected by cancer. I never really believed the 'One in Three' people will be affected by cancer theory but I did after a few weeks there. The most heart rendering was seeing the daughter of one of them starting treatment for breast cancer. She was so young.

Some weeks when we saw the oncologist Ann would have the dinnertime off work and we would manage a light lunch somewhere. We found this made it feel as if the hospital visit was something during our day out and not something special we had to do.

When we came to our last day it was almost like a party with everyone congratulating us and wishing us the best in the future. All of the nurses found time to wish us well and it was funny because it seemed a rather sad time as well as being almost a time to celebrate. Our emotions were so mixed that it was hard to say what the tears were for.

We had seen so many others go through the same and hoped like them that the treatment would prove a success.

Also at this time we felt almost alone for the first time since I went into hospital. I had been in a cocoon, being looked after by so many people. It had become almost a way of life. Now although I had Ann keeping a very watchful eye on me it was a strange feeling that no weekly trip would leave a hole in our lives'

It was then that we realised there was no mention of any support groups either for the stoma or cancer and no literature to read about this genetic cancer. Perhaps our fault for not asking, which was understandable with so much to think about. However looking back it would have been so helpful to be able to sit and let it all slowly sink in instead of suddenly thinking of what might be in store for us.

Our visits to The Leicester Royal Infirmary for the chemotherapy had taken over our lives but hopefully it will have done its work.

Over the next five years regular checks were made on me and all went well as did our friendship with the couple we met that first time. We started having a pub lunch together about every three months and still do after six years.

It has been interesting how the conversation changed in that time as our lives gradually returned to what we saw as some normality. The medical chats had gradually disappeared as the four of us came to terms with our illness.

At first there were two distinct conversations going on. Ann and George would chat about how they were coping with looking after us whilst Elaine and I would pick each others minds about our treatment and stomas.

Now six years on the words cancer and stomas are very rarely mentioned as our thoughts have turned to their dancing holidays and our trips on steam trains. I think though that we all realise how lucky we were that our cancers were caught early and the treatment was a success.



During those years, I managed to reach little targets Ann and myself set. They always seemed to be under a wife's watchful eye. That first walk down the garden path was a tremendous boost and the most daunting walking the mile into town on my own. I had promised to ring her to bring me back in the car but I felt so good I walked home. This was my first real challenge and Ann was a bit worried I had overdone things, something that would often be on her mind even several years later.

One of the highlights was driving 40 miles to see, for the first time to see my telephone visitor Margaret. That was such an emotional time as we realised how much she had helped prepare us in such a positive way. Of course she was disappointed about the cancer but pleased her chat about her stoma had started me off in the right direction.

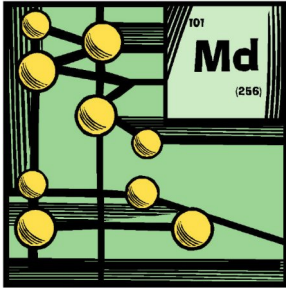
Another giant step was when Ann took me shopping in Grantham and I drained my bag for the first time away from home. Might sound trivial but to both of us it was a monumental step. The toilet was a bit small and a few weeks later I obtained a RADAR key for the disabled toilets. I don't see myself as disabled but it is better being prepared for a problem and this was always in the mind especially at first with carrying spare items in case of an emergency. Leaks and the bag actually falling off were all mentioned much to our concerns.

It is strange however that I have never stayed the night at any friend's houses. Whether this is because of the worry of leaks and being up in the night I am not sure. We have been asked several times and at first I just made excuses. Now I do say why and it is accepted without any questions.

So the treatment had finished but for the next four years I would have annual appointments to keep a check on my liver and kidneys. This was quite reassuring in a way that I wasn't as alone as I thought.

One worrying time was when I had my second annual Ultrasound Scan on my liver. It took about three times longer than the first one and I began to suspect all was not well. It just seemed that she was returning to the same area all the while. With everything I had been through I had got used to asking questions if I wasn't sure about something. So it was a huge sigh of relief I let out when it was explained this was a full abdominal scan whereas the first was purely on my liver. Also that everything was fine.

The Start of My Genetic Journey



This is where in June 1999 after my operation at the age of 56 my Genetic Journey began. My father and a sister had also had colon cancer and it was suggested by my surgeon that we saw a Professor in the Department of Clinical Genetics at the Leicester Royal Infirmary. It was mentioned that it could take quite a while perhaps over a year.

If I had the gene it was then a 50/50 chance that each of our children could be affected and if so, virtually certain that polyps would eventually appear and at least one turn cancerous. A frightening thought, but one which never really sunk in at the time. I suspect we were just pleased the cancer had been caught early enough for treatment to have a good chance of preventing it spreading into other places.

In November 1999 we had a nurse specialist from the Clinic visit us at home. I had seen a television programme about a couple who had to decide whether to have a genetic test or not and was instantly reminded of it. Going through a family history was quite a test of memory but only concerned those on my father's side of the family. I smiled at that for my mother's side of the family was enormous and would really have tested the memory.

We remembered a lot but afterwards a chat was needed with my brother and sister to complete the tree. It soon became apparent that if the test was positive it could affect around 50 relatives, right down to grandchildren of second cousins. The next step was a chat with the Professor to make sure we understand all the implications including the effect it might have for insurance purposes. Also he explained how rare this genetic cancer was which made us feel rather alone. He mentioned a figure of 1 in 8,000 being affected. How I wish he could have said there were two, three or four hundred which would have given us a better idea of how alone we really were or perhaps not. It was starting to get very complicated.

At the time nothing was mentioned of other problems this gene might have in store for me (Later the mention of polyps in the small bowel and stomach would cause concern) and we assumed the operation had also put paid to it in me. We felt there was no option but to have the test as if positive, others in the family would be able to make their own decisions and perhaps prevent them having colon cancer.

Whilst waiting for a result the Prof. mentioned that another indication was the finding of any freckles at the back of the eye. They were not dangerous but if found would help in the centres work.

Things were then quiet until January 2002 when I had the eye test but no freckles were found. I thought this was a good sign and although not the final answer was starting to think all was OK.

It was a surprise when within a week I was asked to see our Professor and was told I did have the faulty gene. The strange point was it usually starts to cause problems in the early teens. Another bit to our strange family. Looking back I wonder how we managed without any booklets or leaflets about FAP and had to try and remember all that was said. This is no criticism of the centre for there just wasn't the information available. This was something that would always be remembered and again was something that would have a strong bearing on my life when I decided to try and improve access to information on FAP.

Now I know it wasn't a fault that would cause the certain death of a relative like some genetic disorders but without surgery it was certain colon cancer would appear and it was a blow all the same.

However if relatives decided to have a blood test the results would be known in about six weeks instead of the eighteen months for the initial test. I was asked if I would contact 13 relatives on my father's side

on this rather sensitive issue. Although scattered around they all knew I had had cancer which made the initial call a little easier. I wondered how they felt at the news and possibility of being affected and asked them to ring the clinic if they had any concerns or questions but it was left up to them to decide.

They were all pleased my treatment seemed to have been successful but very mixed in their view on the genetic side, perhaps because they were mostly older than me and had no previous bowel problems. The main thing was that I had let them know and for them to decide what action to take.



A harder task was telling our three children and their decision about a genetic test. Only then did it really sink in when we realised the consequences. Another thought now was would I feel guilty if I had passed the gene onto my children? They all said I shouldn't and pointed out it could have started anywhere in the family history. I wasn't so sure and only time would tell, perhaps all three would be unaffected. However, even if they do not have a test, details of a possible genetic condition could be put on their medical records if they wished.

With the help of my family I realised that I shouldn't feel guilty but at times it gets very hard to remember this. The feeling that you have given a child something so devastating will never really go away.

Like so many things in life everyone at some time has to make decisions and whilst advice and help can be offered only one person can make the final decision. The feeling of guilt has gone but in some ways I will always feel responsible.



From the age of eleven I had about one hundred and twenty cysts removed from all over the place. This led to being asked to see another friend of the Prof. who would take an x-ray of my jaw for any problems. It seems they have a chance of being there and also cause other dental deformities.

It was a relief when none were found and I was given some free advice that a back tooth was rather large and my sinus cavities also large. This would mean if the tooth were ever extracted I would have to have an operation. There were as well some bumpy bits around but nothing needed doing about those. The only trouble was over the years I had three teeth out in the lower jaw and now it would not only be quite costly but perhaps a futile thing to have a plate or implants. I wish I could have something improve my looks but you cannot win every time and perhaps in the future something might be able to be done. I hope so.

I was also referred to a dermatologist about the cysts which were then referred to as a sign of Gardner's Syndrome (Now known as being part of FAP)

There are several things that might happen to you through FAP/Gardner's Syndrome but the chances vary and the view seems to be not to worry about everything as it might not happen. You have an operation to remove the certainty of colon cancer and are then left to realise that this pest of a gene has several tricks up its sleeve, which might affect you over many years to come. Even in the same family the effects can vary which sometimes makes it harder to understand and come to terms with.

All of this has led to two more consultants examining this strange person and a bit of minor surgery to remove a few more during the next year. One was actually inside the layers of my eyelid and this again added to their knowledge. Whilst having a check for this cyst they used some new equipment to re-check the back of my eye for freckles and on the very outer limits they found one!

At last I wasn't so strange, what a good feeling. In some ways I wondered why something was not asked before about why I might have had so many cysts. Perhaps I just hadn't seen the right person at the right time.

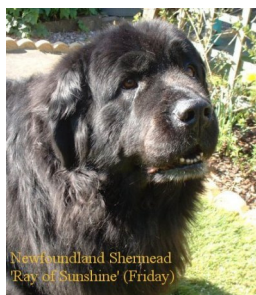
This is where I started, like others with the gene, to train others. In this case my dentist. She had not heard of Gardner's Syndrome which can cause some dental problems. Notes were made and I am sure now that it would help if she saw any of her patients with similar bumpy bits.

On looking back there were so many appointments that we were always aware of checking the calendar before planning any social activities. Sometimes it was just impossible to do this and at the time was far more important not to miss any which might delay my recovery.

It was in 2002 when one of my immediate family found out they had the gene and multiple polyps in the colon. It wasn't until a few days after receiving the news that I realised how it had affected me. For a while I had become a bit 'broody' and I suppose withdrawn, which is most uncommon for me. With the help of my wife Ann I have realised that these things happen and now look to the future and the support other members of our family might need. I knew it would be hard but how could I not help to repay all the support they had given me whilst knowing they might be carrying the gene themselves.

I had been asked on a number of occasions to help with articles on bowel cancer and FAP. However whereas the local Leicester Mercury and Melton Times were happy that I refused to make any comments other than about myself, a few other newspapers and magazines were only interested in the family as a whole. To me they wanted a sensational heading and soon disappeared when my position was made clear to them. Perhaps this was being a bit harsh on them but everyone to their own point of view.

So now I have ended up with my ileostomy, which has behaved quite well and I have also started on a journey that has been fascinating yet worrying. Obviously at times it had been eased by the knowledge that a positive result would not affect my own health and there are far more serious genetic faults, which others have to cope with.



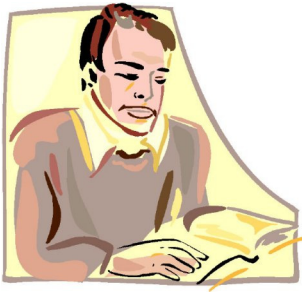
Also when my wife Ann is not around to give a cuddle there is always my 'Therapy dog' called Friday who was my daughter's seven-year-old Newfoundland. Unfortunately Friday died in July 2003 but she will never be forgotten.

In July 2003 my close relative had a successful operation to prevent colon cancer, which afterwards they found would have been a certainty within a couple of years. Again the feelings of guilt were around but at this time with the help of Ann my wife and our children I was better prepared.

Sometimes I wonder why after a colonoscopy in 1993 I wasn't given a date for any future checks. The report had mentioned multiple biopsies and mild dysplasia but as I looked well and had no pains it would be left up to me to return if the symptoms worsened. I didn't find this out until I asked for a copy from my medical records to give the Leicester Genetic Centre.

Initially my thoughts were that my cancer perhaps should or might have been prevented. On reflection was it better that through my own cancer it had been prevented in my relative. This way of thinking helps Ann and me to cope but again is something that will not go completely away. I suppose if our relative had also had cancer despite their operation our view would change.

I became involved with designing a websites for a Leicester Charity 'Coping with Cancer', who suffered from my new expertise. Not one for fundraising I was able to indirectly help as the work was done as a volunteer. Besides running the site I benefited from the support the charity gave to Ann and me. They had coffee mornings, social afternoons and also special events which gave us the chance to chat with others in a similar position to ourselves. It all helped to reduce the feeling of being alone even though the word cancer was often not mentioned. Not because of what it meant but there were far more important things in life to talk about.



In October 2003 a short clip of an article from CancerBACup appeared in one of Ann's magazines about cancer genetics. I was surprised that it mentioned the good news, which was that these genes in breast, bowel, ovarian and prostate cancer didn't mean you would get cancer. Not quite true for FAP I thought (Getting a bit knowledgeable by this time).

Upon contacting CancerBACup, I found out with limited room for the article it had been impossible to contain everything. I was also asked if I would be interested in reading a draft copy of their new Genetic Cancer Booklet with about 50 others.

At the time I never dreamt of what this might lead too as I found the booklet very enlightening and wished something similar had been available earlier. Then I was asked if I would be interested in my name being put forward to being part of a group of patients involved with some new genetic cancer projects, which the DoH and Macmillan were proposing. With so much going on with appointments and the usual family hiccups I wasn't sure and was left to think about it.

By November 2003 things had quietened down a bit and Ann knowing of my growing interest in trying to understand the FAP gene and its implications on our lives persuaded me to say yes and see what happened. It gave me a tremendous boost when they said they would have disappointed if I had said no. Suddenly I began to realise that my experience and the knowledge I was gaining could be used in a positive way to help others with a risk of having a genetic cancer.

The outcome was that I was one of about a dozen asked to form The National User Advisor Group for the projects. What a grand title. This gave me an interest and at the same time helped to promote the feelings of patients and relatives in regards to genetic cancer disorders. I felt like many that at times we were talked about but not to, as if our own thoughts were unimportant. Through the group I have made new friends and enjoyed the journeys to London, and York even if rather tiring. My confidence rose and I felt more at ease as we all gradually got to know each other and became more than just a committee, almost a support group at times.



At the end of 2003 I had about 10 appointments to go on our calendar for the next year even before it started. Mind you I had some hope as it might mean the last visits to my surgeon and oncologist. I knew by now the genetic checks would continue in some form for the rest of my life but saw these two as the main hurdles for the year. How those appointments ruled our lives though, with everything else fitted around them.

The most nerve-racking days were early in 2004 when I was waiting for the results of a CT scan after a niggling pain in the groin. I had been used to ultrasounds but this to me was serious stuff. Both of us were shaking as our oncologist came into the room with a smile and a look as if to say “what are you worried about”. The relief that nothing was wrong was almost as bad as the waiting. It was like a lead weight being lifted and he was as pleased as we were about the result.

When I started my treatment this consultant had been one of the junior ones and seemed to do a lot of walking about with folders. We had seen him climb the ladder and seen his confidence grow as well, all very reassuring to us. It gave us the trust in him that was so important for the future he might predict.

I did notice though that he had no notes with him and assumed that this would be a good sign if it happened again. It was only a few months later that we were shaking for a different reason when he told us that the next time he saw me he hoped it would be in a supermarket. The emotions were so mixed and it literally took days for the news to sink in and the fact that they were happy not to see me and in late 2004 I had my last appointment with my surgeon. There was going to be another one in 2005 but as I had a thank you card, which I said would be a pity to waste; he agreed to take me off his books.

The strange thing was we suddenly felt quite alone and wondered what would take up all the spare time we would have with hardly any appointments but as you will see other things were just starting which would again change our lives. Perhaps at the time it was lucky we didn't know about these things as we had time to enjoy life and think about holidays and just being ourselves again.

Later in 2004 a new cloud appeared on the horizon when polyps were found in my duodenum and stomach. I was told these were slow growing but would need annual screening to keep an eye on them. It was put to me that I was more at risk of heart problems from my type two diabetes and high blood pressure than the polyps.

I can live with that but just get a bit edgy when the check approaches. There is always the possibility of bad news afterwards and at times it is almost expected with having had so many different conditions to cope with.

My second endoscopy used a side viewing scope which is a bit thicker and more uncomfortable than the normal one. This is to see around a corner where the polyps are. I never bothered with any sedation only a spray on the back of my throat. Although I was able to have a cob and a pint of cider within half an hour I was thinking of the next one in a year's time already.

Since then I have decided to have the full sedation in an attempt to forget about it and so far it is working.

Bowel Cancer Awareness



Promoting awareness of bowel cancer was something I felt comfortable with. I still felt very lucky at an early diagnosis whilst a few friends I made along the way are no longer with us. I had been asked to help with publicity about bowel cancer with CancerBacup and Macmillan. Word must get around as Beating Bowel Cancer contacted the Leicester Mercury for an article and the Melton Mowbray Times have had their three pennyworths.

Perhaps the most intriguing was to help with the launch of The Prime Health Magazine for men. The editor from Dr. Foster (a website well worth a visit (www.doctorfoster.co.uk)) contacted me and asked if I would attend a film session to be used at its launch in Birmingham. My friends mentioned about being made up and my youngest son even thought the address in Marylebone sounded a bit dodgy. So imagine my state of mind when on arriving I was directed to the make-up room. I nearly died but was made to feel at home and ready for an interview before the camera. I think they told all of us involved how good we had been and I asked if I could take the 'new me' home instead of the older version. Mind you there was a funny look from one chap on the underground.



Although I was under the stoma department at Leicester Glenfield Hospital I was asked by the Leicester Royal Infirmary Stoma Department to do a bit of visiting for them. This led to coffee mornings for Loud Tie Day were spent giving a helping hand. It was here I found out about the bowel cancer support group 'Moving On' which meets once a month at the L.R.I.

During the year and until recently it gave both of us valuable support and knowledge about how to cope with cancer and the days out in Bridgnorth and Stratford on Avon not to mention post Christmas meals will always be remembered. It has a rather apt name for during 2004 I decided it was time to move on after given an OK by both my surgeon and oncologist and the interests of the genetic side of my cancer provided a different kind of support.



Another side to my story is volunteering as a patient for the student doctor examinations at Glenfield Hospital. There was an ulterior motive as it gave me the chance to mention the genetic side to these would be doctors and a hope for the future that a more general knowledge would be known about the subject. My fame must have been spreading as a couple of times the examiners seemed very interested in me before the days examinations started. I have also enjoyed giving a brief tale of my journey several times to health professionals taking the cancer care module course at the L.R.I.

The Café Royal and St. James's Palace.

As mentioned previously I had helped The Beating Bowel Cancer Charity with an awareness campaign and also kept in contact with the ladies from CancerBacup. However what a surprise and a pick me up when two invitations arrived within a few days of each other. CancerBacup were having an evening reception for their 21st Birthday at St. James's Palace with Princess Alexandra and Beating Bowel Cancer was launching its Patient Voices Forum with a day at The Café Royal. Even better was that Ann was invited as well to the Café Royal which initially put the fear of god in her. How did she think I felt about St. James's Palace?

Both days were something neither of us will forget and it was nice that things I had done to try and help others had been appreciated (with many others) in this way. Another good point was I ended up with a suit that fitted me and was quite surprised how comfortable it felt. To be honest my last suit had been years before for a rather formal dinner with my sister.



The Palace evening was from 6pm to 8pm and quite a chunk of that time I spent with a friend chatting to Wayne Sleep. He was a fascinating person to listen to and also was very interested in both of us as people. We also met several old friends and made a few new ones before it was time to leave. Later on we had a fish and chip supper in Kensington and the look from the Chippy was quite hilarious as we sat with our 'posh clothes' on squirting tomato ketchup on the chips!

Ann and me had not had much of a break for a while and decided to have a couple of nights in the centre of London's West End for our visit to the Café Royal. Quite amazing what the Internet can find at reasonable prices. Not a thing we would do very often but being able to step out the hotel virtually straight into Leicester Square was a real bonus.

The evening before we had a peek through the doors of The Café Royal and this did little for Ann's nerves at the time. As well we realised how small this part of London really is and spent the rest of the evening walking to a few of the familiar landmarks whereas in the past it was always via the Underground. Of course had to show off and take Ann past St. James's Palace! Our day with Beating Bowel Cancer gave Ann an idea of my other trips to similar events and after a nervous start soon found it interesting and rewarding especially as two of the speakers gave talks on Genetic Cancers and Endoscopies. It wasn't all serious talk as we found whilst listening to a couple of fundraisers with tales of the London Marathon in a diving suit and a trek in Peru off the beaten track. Also the lunch was something else to remember.

My FAP Website

I mentioned the lack of literature that was available for FAP patients and looked around The Internet. I found two, a discussion forum in the United States which virtually scared me to death and the first really helpful booklet from The John Hopkins Hospital in New York.

This made me think that I could have my own website and find information and links in an attempt to save others searching all over the place and finding what perhaps was not always suitable. However I was worried as to how the health professionals and especially those at the Leicester Genetic Clinic would view such a thought. I wouldn't want to tread on any toes, as I would be relying on them for the rest of my life.



The website nearly never happened and I must thank the genetic centre at the L.R.I. for their interest which eventually got me going what a relief that was. It was designed to put links in one place about FAP. I also worked closely with the Ileostomy and Internal Pouch Support Group. The IA already had a website and discussion forum and while they were thinking about adding an FAP section the matter was raised by one of the members. Saved me a lot of work and also helps promote the interests of both parties. Thanks to a member of the 'ia' - Diane.

What started as a few pages gradually grew as I found out more about a gene that in my layman terms is one that lets lumps grow. I added my articles which I had written for the 'ia' Journal, to give it a more human touch and also sought permission from newspapers, magazines and the person concerned to add further articles. I felt that these stories from those actually affected would be of tremendous use to others trying to cope. News items about cancer genetics also helped. All the while though I kept it strictly non-medical and even added a frequently asked questions page but without any answers. You may think this very odd but who could I find at the time to answer them?

All of a sudden this little personal website had grown into quite a valuable tool, not my words, but from the Polyposis Registry at St Mark's Hospital in Harrow. I was invited to meet their staff to talk about both our websites and the possibility of newsletters and family days for FAP patients. What a day that was with a nervous factor way off the top of the scale. Turned out I need not have worried and to hear they thought the information I had put together was too important to lose stunned me. All right I was pretty chuffed with myself but to hear the academics saying that has again given me confidence to talk and share my opinions with anyone.

www.fapgene.org.uk

'The Visitor Training Course' and 'The Fashion Show'

I eventually found out about the Ileostomy and Internal Pouch Support Group in 2001 and joined the Leicestershire branch. The National and Regional Journals proved so valuable and still do. Sorry about that mouthful of text but in future will call it the 'ia'. It is important though to give the full title as otherwise it would seem to be for those only with an ileostomy not as well as any form of Internal Pouch. I have mentioned previously of how I had gained in confidence from taking the course and thought a little more about it would be appropriate as this confidence led me to a virtually different world to the one I had worked in for 40 years.

When I first thought about the course I did wonder if I was experienced enough with my stoma and also whether it was too soon after the finishing of my chemotherapy. One thing I hadn't thought about was my own credibility within the 'ia'. Rightly so the Leicestershire Branch, which I had recently joined, felt they didn't know enough about me to approve putting me forward for the course. Determined to push on I found it was possible for Sue my stoma nurse to do the necessary and weeks later I was accepted.



Then a rather daunting pile of paperwork arrived and I did have second thoughts for this time I couldn't use the colitis as an excuse to miss bits of the course- if needed that was. Another concern was two weekends at The Heathrow Marriott and coping with my stoma for the first time away from home. Luckily, for a small payment Ann could accompany me and this would also give her the chance of a trip into London on the Saturday's whilst I was slogging away.

Who were more nervous? The fifteen trainees or the tutors for whom this was the first visitor course the 'ia' had held. It was hard work for all of us but we were guided along even when some written work was required by the tutors. The second weekend was more relaxing as we knew each other and a little of what was expected of us. We all got through the course one way or another. And learned a lot about ourselves and also showed we could be relied on to provide the 'ia' with qualified visitors who understood all about confidentiality and help others through a difficult time both before and after their operations.

A more stressful time, if that was possible, came two years later when several of us met again on a follow up course to fine tune our Listening Skills. This time a bit further to travel and I used the train to Gatwick from Melton Mowbray which again was a first post-op for me. What amazed me was I never had to show a ticket on either journey. The end of that course saw several of us breaking a piece of wood with our fists! What confidence.

The Fashion Show



Who in their right mind at the age of 57 would even think of prancing along a catwalk as a male model? I think it would take a special reason and a certain amount of confidence and a lot of support from my wife, friends and family. A few years ago I probably had little of either, but times change and funny things, even pleasant things can happen. Let's start at the beginning quite a few years ago.

In a way the course was what eventually led me on to the catwalk. I realised I had actually taken part on the course with role play, which, whilst employed, any mention of I would miss by using my colitis as an excuse to disappear to the toilet until it was over. I am sure this covered my lack of self-confidence.

So after dropping some books off (for a charity stall) at the home of Mary Bell, the chairperson of the Leicestershire ia, she asked if I would consider being a model at a fashion show. In the past I would have run a mile. However as I mentioned, funny things can happen and without hesitation I found myself saying yes. Luckily, I found out later that although it was being held on a Saturday afternoon, Leicester City were playing away.

The fashion show was held at the Leicester Royal Infirmary and run by Helen Ghandi and her stoma department staff and I was quite confident and at ease on my two visits to pick items from 'Chums' catalogue and then to try them on later that week. The night before, I actually slept like a baby and, despite the heavy rain on the Saturday, arrived in a fairly decent state (with Ann for support and as a photographer).

Helen had organised quite a couple of hours. Besides the fashion show there were displays by around seven stoma care suppliers and the 'ia' and British Colostomy Association had their displays. Also, I am told, a very informative chat from the Red Cross on make up. There wasn't a lot of time for me to see those, as duty called. I resisted being made-up and about ten of us sorted out our clothes. For my first walk, I had chosen a pair of grey high-waisted trousers with a casual four-pocket shirt - unfortunately I never noticed it was a size too large - which I wore outside the trousers.

The music struck up and a member of the Hospital Radio Leicester Fox set the scene and off we went. Well, Eric did and the rest of us watched and tried to pick up a few useful tricks of the trade. The reception from around seventy people was fantastic. The cameras were flashing and even the Leicester Mercury newspaper cameraman was there. However he did seem to get side-tracked and wanted to photograph a rather stunning young lady who followed Eric (not that I can blame him).



My shirt was a little large, but the compere passed it off that I was a growing lad. Down the catwalk I strutted at a rather leisurely pace, turned at the end and did my best impression of a Chris Eubank pose before retreating to the start line only to be told to do another trip. All seemed to go well and I actually managed a hit of a smile and a few nods to the audience.

Then it was back into our little den (a rather large lecture theatre) to change into a pair of blue denim casual trouser with an elasticated waist and also a fleecy blue jacket. This time I really enjoyed it and walked along with the coat draped over my shoulder and struggled a bit getting it for the second walk but the compere managed to pull it over my arm and that was that.

I felt the ten of us had helped Helen to put on quite a reasonable display and when we all did a grand finale all together the applause was something special. Then it was time for mince pies, biscuits, wine, raffle tickets and a look at the various displays.

Several people passed comments about the clothes all of which were complimentary and after saying a 'Thank you' to all the organisers I was stunned to be given a flower arrangement, which Ann described as the largest she had seen, for my time and trouble. So that's how it all happened. I had quite a tingle when leaving and felt as if I had given something back, which, without the course might not have been possible for me.

The Future



I have often thought of what the future might hold for me. When first told I had cancer and the prognosis was pretty good I just assumed I would live to a ripe old age with only the usual threats that most people face in their lives. Even the mention of a five year period when I would be at an increased risk of cancer in the liver and lungs failed to alter this outlook.

This changed a bit when one of my chess playing friends eventually failed with his battle against the same cancer after five years. I realised then that nothing could really be taken for granted but tried to remain positive. This is something that sometimes gets me a bit agitated when those who have not had cancer say “You must be positive and you will beat it”. I just feel until you are in that position you just don’t know how you will react. Hopefully you can be positive and will fight and it will help.

I also assumed that having had surgery and my colon removed and providing the chemotherapy was successful, I would return to being a ‘normal’ person in the risk assessment stakes. The realisation of how wrong this was came slowly as my knowledge of The FAP Gene grew. It is as if there is almost always something waiting around the corner. To make it worse not everyone suffers from the same problems which can make you feel far lonelier again.

It seems my desire to help others find information of a non-medical nature has also had an effect on my future. This is down purely to the genetic nature of my cancer, something I am quite at ease to talk about and pass on the knowledge I have gained. In return there has often been a feeling of having found someone else who can help me to understand a little more which helps me cope.



I could never have imagined myself sitting on committees, attending workshops, doing video and narrative interviews in a million years. The pure thought would have seen me running to the toilet. I am also thankful for the support those concerned have given me. Finally there is the biggest thank you of all to my wife Ann and my family for looking after me and making sure I do not take on or do too much. They realise I do enjoy the work I am now doing and hopefully this booklet project will end up being useful to others facing similar problems. Even if it is just a few copies printed as and when people are interested, I will be happy but hope the future is rosier than that.

Update May 2006

FAP Gene is now gradually becoming a support group. With John Roberts the Chairman we held a successful Family/Information Day at Swarkestone Sailing Club near Derby in March 2006.

It was the largest gathering of patients with FAP and their relatives outside of London and has since attracted a great deal of interest. We felt afterwards that allowing ample time for general chat and getting to know each other was as important as the speakers. Kay Neale from the Polyposis Registry at St Mark’s Hospital in Harrow talked about the history of FAP and the Registry and Chris Jordan from SLA Pharma a very interesting talk on the new Alfa Capsules.

Already we have planned a similar event for March 31st 2007 at the same venue with a number of speakers already offering their support.

A newsletter is planned for Autumn 2006 and also an audio version of this booklet should be available during the summer.

Acknowledgements

I would like to thank Andrea, Charlotte, Daisy and Jill at CancerBacup for starting me out on writing my Genetic Journey in 2003. A chance reading of an article by Ann, my wife, in a woman's magazine about Genetic Cancer was responsible for my being invited with around 50 others to read through CancerBackup's (www.cancerbackup.org) new booklet Understanding Cancer Genetics.

Also to Kalbir Kaur-Mann at Glamorgan University for spending what must have been hours reading through that first draft and providing the ideas for expanding my feelings.

SLA Pharma (www.alfacapsules.com) for making the printing of this booklet possible.

Beating Bowel Cancer (www.beatingbowelcancer.org) is a leading UK charity for bowel cancer patients, working to raise awareness of symptoms, promote early diagnosis and encourage open access to treatment choice for those affected by bowel cancer.

The Ileostomy and Internal Pouch Support Group (www.the-ia.org.uk)

Macmillan Cancer Support (www.macmillan.org.uk)

This booklet is available for £4 including P & P Cheques Payable to FAP Gene

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