

Crohn's Disease

Wrestling the Octopus

Nigel Horwood

ZEBRA

LASER/BAND



Beginning

1977 was a year of transition. In the spring I had celebrated my 21st birthday, and was living at home with my mother and sister. My father had died tragically young of a massive, unexpected heart attack seven years previously. It was an event my mother never got over and one that I believe shaped my own attitude to life from then on.

The UK politician, Vince Cable, has described an event in his early life as having “cauterised” his emotions. This sums up, perfectly, the effect my father’s death had on me. I did not want sympathy. I would cope on my own so became very cold, detached and emotionless. This may just have helped me to manage all that Crohn’s disease has thrown my way.

Not wanting to leave my mother and sister on their own I had chosen to continue my education at a South London college as it was close enough for a daily commute. The four year course had the not very inspiring title of “*Batchelor of Science in Building*”. It wasn’t as bad as it sounded and the knowledge gained has been put to good use in the ensuing years, both professionally and personally.

A few weeks after my birthday I was introduced to a young lady outside my usual circle of friends. We had a mutual interest in music and were both avid record collectors. We quickly became an item and are still together today.

During the summer break from college I took a job at the local Coca-Cola bottling plant as they needed additional workers to cover their busiest period. It involved loading crates of newly filled glass bottles onto pallets, ready for collection by forklift. It was very physical work. By the time I returned to college in September, to start the third of the four years, I had developed quite a fine physique, though I say it myself.

The summer job paid well and the money earned was used to buy equipment for the band I played guitar with. The music I was playing and listening to was undergoing a significant transition as the influence of punk rock grew. Having very catholic musical tastes allowed me to embrace these new sounds without

abandoning the music I had been brought up on and that had inspired me to take up the guitar.

After a short while of being back at college I started to realise that something was wrong. I was suffering from an "*upset stomach*" and having to rush off to the bathroom many times a day. At first we blamed my condition on the fried food I used to eat every lunchtime at the Wandsworth Grill : greasy bacon; greasy sausage; greasy omelette - there was a common theme - or was it drinking too much ice cold Coke during the summer?

What was happening to me? In a matter of weeks I had gone from thoroughly fit to worryingly sick. Eventually I sought medical advice to try to sort out the diarrhoea* as it was getting worse. I should have gone sooner but felt embarrassed about the thought of discussing bodily functions. Any embarrassment I might have felt then has now, clearly, long disappeared.

** I was hoping not to have to mention diarrhoea so early in the text but needs must. I'd just like to assure readers that it doesn't run throughout the book.*

Initial diagnosis - it was October 1977 when I went to see my GP. At that time very few people had heard of Crohn's disease. I certainly hadn't and it wasn't on my doctor's radar either. He prescribed the obvious remedy for diarrhoea - Loperamide (Imodium) - those capsules you take when you've eaten something disagreeable on holiday. My long-term, on/off relationship with this drug had begun. Needless to say, it did not work effectively as it treats the symptoms and not the underlying causes. I felt extremely weak and was always very cold to the touch. Further investigation was required.

Another six months passed. By the time March 1978 arrived I had been booked in for a barium enema. You can imagine the dread I felt. If I was embarrassed at just talking about bodily functions how much worse would it be to have a tube stuck where the sun don't shine whilst a nurse poured in some form of liquid, presumably via a large funnel?

This was the first procedure I had to endure. As I suspected any semblance of dignity went out of the window. Firstly it was necessary to ensure that the bowel was completely clear of all contents. Not usually a problem for a Crohn's sufferer

but to be on the safe side I had been given preparation drinks to take the day before and told not to stray far from a bathroom.

At the hospital I changed into one of those hospital gowns that never meets at the back - the ones that are impossible to fasten as the ties have either been cut short or have dropped off. In the X-ray room I was asked to lie on my front as a rubber tube was inserted. The barium liquid, with the appearance and consistency of milk, was introduced and allowed to flow in with the aid of gravity. When it was all safely inside it was time to clench hard and roll onto my right-hand side to encourage it to move around the system.

Once sufficiently distributed I had to clench even harder and lay on my back for the images to be taken. So far so good. With the X-rays completed came the most worrying stage - having to get off the trolley, adopt an upright position and then hope I made it to the toilet without losing any of the liquid. Have you ever tried walking and clenching at the same time? Your answer to that one is probably “*Yes*” if you are an IBD sufferer.

The outcome of this procedure was a diagnosis of “*spastic colon*” which nowadays would be called Irritable Bowel Syndrome (IBS), that catch-all condition for describing any digestive disorder that is of indeterminate cause. There was still no mention of Crohn’s.


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Advert for Nacton from 1961

My GP put it all down to “*nerves*” and prescribed Nacton, a drug marketed for “*giving relief from the pain of peptic ulcers.*” It had no effect. In hindsight I should have questioned my GP's treatment or asked for a second opinion but I was still young and it wasn't the done thing to challenge members of the medical profession. They were god like.

Over the course of a year I had gone from eleven and a half stone (73kg) down to eight and a half stone (54 kg). I didn't really notice as the change was gradual and I wonder whether some form of mental defence mechanism kicked in, but anyone who hadn't seen me for a while was taken aback.

I became weaker and weaker and finally went to see my GP again. By now it was July 1978. Luckily he was on holiday so I saw a locum instead. He was shocked at my appearance and said that I needed to see a consultant immediately. If I was prepared to pay £25, the equivalent of £120 at 2016 values, I could see the consultant the next morning (Saturday) at his private practice in South Croydon. (I've since been told that my original GP had been censured for failing to diagnose another patient. Seeing his locum probably saved my life).

I'm not really in favour of jumping queues, just because you can afford to, but in this instance my mother paid the fee and I saw the consultant the next day.

We made our way to his surgery just outside Croydon in Coombe Hill and were shown into a rather gloomy room dominated by a large desk. Dr. Parrish, a tall, thin, distinguished looking man, was sitting behind it. He took one look, and said “*You need to be in hospital NOW! I will arrange for you to be admitted on Monday.*”



Dr. Parrish (centre) on his retirement from Mayday Hospital
in January 1988

My heart sank. Ever since I was a child my biggest fear was being admitted to hospital. I'm not sure where the fear came from. Maybe it was visiting my grandfather in our local, rather primitive, cottage hospital when he had undergone the removal of his gallbladder. I'm guessing that I must have rationalised my fears by saying to myself *"it's only for tests, not surgery"*.

There was something else on my mind. Croydon Council were organising an outdoor concert in a local park on Sunday 16th July. I had become involved in the organisation of the event and our band would be performing. We went over to the park on that Saturday afternoon after I had seen the doctor. The stage was set up but there was no roof - and rain was forecast. My girlfriend didn't want me to take part as she thought I was so weak that I would collapse on stage. I didn't want to pass up the chance to play as it would be our biggest gig yet.

On the day of the concert it rained and rained and then rained some more. The first act performed their set under a flimsy sheet of plastic. As they played it filled with water and leaks were appearing above their amplifiers. We decided it was too dangerous to go on. Water and electricity do not mix so we pulled out and in hindsight that was best all round. I probably would have collapsed.



• SQUELCH ON! The Mark Stevens Band playing in the rain. Photo: DEREK RILEY

Rain ruins rocking

A DECISION not to insure against the weather resulted in a loss of between £100 and £150 on the rock concert in Wandale Park, Waddon, on Saturday.

Organiser of the Croydon Youth Council concert, special events officer Steve Picco said: "Naturally we were very disappointed. "But we were pleased and surprised at the number who

did turn up — about 200."

Given the right weather, he had hoped for a crowd of up to 2,000.

But rain began deluging down at 6.55 pm, 35 minutes before the concert was due to start.

The concert started on time in the hope that the rain would stop, and the Mark Stevens Band took the platform.

Things had already begun to swing when the Mark Stevens Band, together with the other two groups who were due to

play, decided to pack up because they were worried about the danger of shocks from their musical instruments.

Mr Picco said that earlier they had discussed insurance against the weather, but decided against it because of the high premium.

"Had we had insurance there was sufficient rainfall for us to have claimed. We might well insure the next concert."

Any profits made at events

organised by the council during the year are donated to charity.

Last year it was the Croydon, Sutton and District Spastics Society which benefited. This year's good cause has yet to be nominated.

Undaunted by their misfortune on Saturday, the youth council are planning another event on September 2, but they have yet to decide whether it will be an open air disco, or another concert in Wandale Park.

Review: page 23.

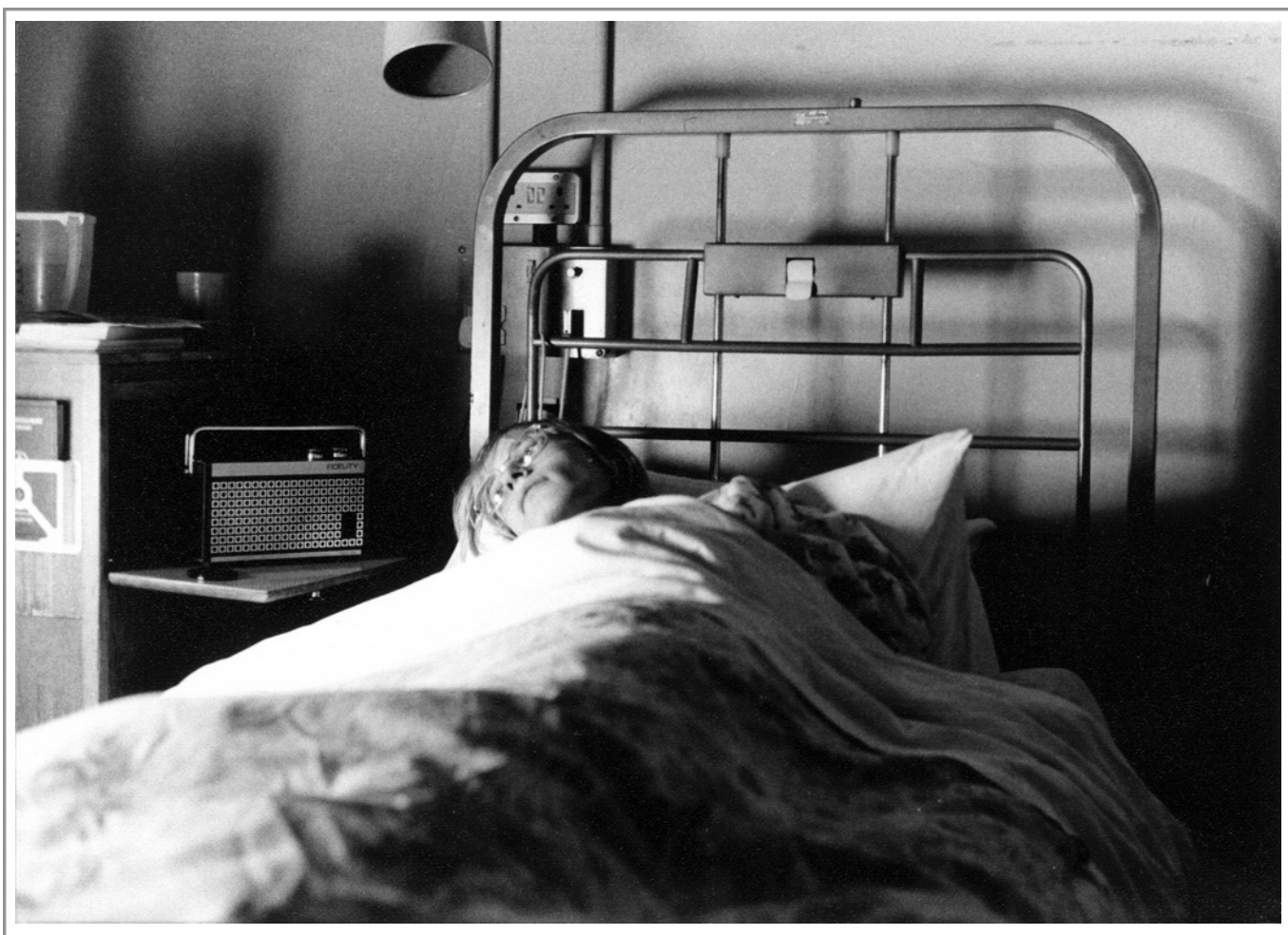
Concert report from a local paper

Tuesday 18th July 1978 - First Time in Hospital - I was admitted to the dreaded Croydon Mayday Hospital at 11am, three months after my 22nd birthday. I say “*dreaded*” as it did not have a good reputation. I know the precise details of my admission because they are recorded on the ward and doctor’s notes that I have subsequently obtained. The nurse’s first impression was “*looks pale and thin*”.

The ward sister must have taken pity on this “*young lad*”, only in there for tests, as instead of being put in a bed on the main ward I was given a side-room to myself. This was a great boost as I was allowed to have a television brought in and it was so much nicer when my girlfriend came in to visit.

The next three days were spent undergoing observations and giving samples.

It’s interesting to read the consultant’s thoughts from his first examination. A lot of them were written in medical shorthand or diagrams, which I have been unable to decipher, but on the fourth page there are the words “*probably Chron’s (sic) and U.C., exclude infections*”. I would need further tests before he could give me a diagnosis. I looked very anaemic and blood tests confirmed this.



A particularly pathetic sight

Friday 21st July 1978 - an X-ray followed by a sigmoidoscopy (a camera that only looks at the rectum and the lower large intestine). During the latter procedure a number of biopsies were taken from the walls of my intestine, then it was back to another few days of resting.

Monday 24th July 1978 - a busy day with various X-rays, including Chest, Abdomen and a Barium follow through. The conclusions were whilst my chest X-ray showed no abnormality, the one taken of my abdomen was showing tubular gas shadow in the R.I.F. (right iliac fossa - that includes the area where the appendix is), suggesting I had an abnormal bowel.

The Barium follow-through proved the most conclusive. The upper part of my small bowel was quite normal but working down towards the terminal ileum, where the small intestine joins the colon, less barium was showing up as the area was so inflamed it would not tolerate holding any liquid. There were also signs of a long stricture (narrowing) in the same location. It appeared that part of the colon was also abnormal.

I read this for the first time going through the records, nearly 35 years on from the event, and was surprised that they didn't decide to operate there and then to remove the narrowed section of the terminal ileum. They chose to try drugs instead. I know that surgery is usually treated as a last resort but in this instance I would have thought my condition was sufficiently advanced to make it worthwhile. Maybe I was just too underweight, under nourished and anaemic to take the risk.

Tuesday 25th July 1978 - It was decided I should be transfused with four units of blood to try to bring my haemoglobin (Hb) levels nearer to normal. It worked because the reading jumped from 9.5 to 13.3.

Wednesday 26th July 1978 - The results of the biopsies were back :

“Severe focal chronic inflammation with occasional multi-nucleated giant cells. This would do well for Crohn's disease”.

Thursday 27th July 1978 - Commenced treatment - salazopyrine, an anti-inflammatory drug, together with codeine phosphate, to slow my digestive system down, and iron tablets to boost my blood.

Friday 28th July 1978 - the consultant noted that the biopsy had confirmed “*Crohn's as well*” and that I had started to feel stronger after the transfusion.

They weren't in any hurry to discharge me from hospital so I stayed in Mayday until 3rd August, my mother's birthday. I guess they kept me in for this long to give my digestive system time to recuperate and monitor the start of treatment.

At some point I had asked one of the doctors what caused Crohn's disease. He had responded that nobody knew but he had heard some odd theories including cornflakes and stray bristles from toothbrushes. There was no cure.

You might have been expecting to read a few paragraphs expressing how I reacted to this diagnosis. The shock, total devastation, outright fear or maybe anger that I felt. These are some of the emotions other sufferers have written about. I don't recall any of those feelings. I never became angry at having been cursed with Crohn's. It must have been a case of “*ignorance is bliss*”. I simply did not understand the long term implications of what I had been told. There was no internet to consult and, potentially, scare myself witless. The overwhelming emotion was one of relief. I finally had a physical explanation and a name for my condition. It was not “nerves” after all. I wasn't going mad.

Whilst the internet was waiting to be invented there were, of course, books. My girlfriend was working at Medi-Cine, a company specialising in animated medical films. One of their team was a doctor and she mentioned my diagnosis to him. He found a section in one of his reference books that described Crohn's Disease. Being a medical tome it was written in fairly incomprehensible terms and concentrated on describing locations and symptoms rather than the likely affect on the patient's quality of life. Whilst it didn't make pleasant reading it wasn't unduly concerning. Maybe those details could have been surmised from the medical terms.

Back to being an Outpatient

In September I went to my first outpatients' clinic since discharge. After the appointment the consultant's registrar wrote to my GP. This extract sums up what they knew :

"On examination we thought he was pale and anaemic and felt the probable diagnosis was Crohn's disease. A rectal biopsy was performed and confirmed the diagnosis histologically. He was treated with a blood transfusion, Salazopyrine and Codeine Phosphate and appeared to make a reasonable recovery.

However, when I saw him in the clinic he was worse again and felt he had relapsed to his pre-admission state. His haemoglobin had dropped to 11.5".

As a result of this relapse the salazopyrine was stopped and my long relationship with steroids (prednisolone) began - 10mg three times a day. The letter ends with :

"He is aware of his diagnosis and appears to understand the disease". Really?

The new drug worked well. The general public had heard of steroids. They were those illegal drugs used by body builders and they had nasty side effects. One Friday night I was having a quiet drink in my local pub when one of our friends rushed up to me in an agitated state. She shouted: *"You fool. It's not worth it. Why are you doing this to your body?"* I was rather taken aback but then the penny dropped. Someone must have mentioned I was taking steroids. Not one to pass up the chance of a wind-up I explained that I wanted to change my physique and this seemed like a good way of doing it. (I did eventually put her out of her misery).

All seemed to be progressing well and I was able to start reducing them towards a target of 10mg a day. In March 1979 I completed my finals and during that period my digestive system behaved impeccably. It was once the exams were over that I noticed I was again having to rush off to the bathroom more frequently. I made an appointment to see my consultant but was seen by one of his registrars instead. That was in April 1979. He put me on loperamide instead of the codeine phosphate and said he would see me again in a month's time. I remember taking the prescription into the chemist's and the pharmacist saying *"Four weeks? You shouldn't take these for more than two days"*.

I saw the doctor again at the start of May and reported that I felt a little better. He told me to continue with the drugs I was already on and added a Predsol suppository to be *"taken"* (inserted) every night. He would see me in another four weeks. At that next appointment I was able to tell him that I had improved vastly over the last four or five days so the medication continued as prescribed.

I had started my first real job, since leaving college, working on a large construction site in King's Cross. In those days the area had not been gentrified and the walk between work and the Tube station was *"educational."* I couldn't work out why there was always a group of ladies waiting at the bus stop but they never boarded a bus. It wasn't until a colleague came in one morning and said that he'd been offered a *"quicky standup in a doorway for two quid"* that the penny dropped. I viewed them with renewed curiosity from then on.

I must have been feeling well enough to take the train to London everyday and then jump on the Tube to King's Cross. I don't remember much about the first couple of months on site or whether there were any warning signs as to what would happen next.

Tuesday 19th June 1979

I started getting terrible pains in my lower abdomen, right hand side. They became worse and worse until they were unbearable. I was still living at home at that time. By late morning the pain had reached such a level that my mother called an ambulance. I was rushed into Croydon General Hospital with suspected appendicitis. We sped down the main Brighton Road through Purley and on to West Croydon. I was expecting to go to Mayday again but this time it was Croydon General. My first trip in an ambulance and with the added bonus of *"blues and twos"*.

My biggest fear had been realised. I was heading to hospital, almost certainly to go under the knife. I thought about the alternative - refuse to have the operation, discharge myself and die. At that point I knew I really didn't have a choice and that I might as well accept my fate without trying to fight it - the first time I had been confronted by my own live or die situation. I decided that life would be easier if I made the experience as stress-free as possible. That was a turning point in my

life and has governed how I have since survived numerous visits to hospital, either for appointments, procedures or longer stays. Focus on a positive point in the future, beyond your current situation, then suspend normality and adjust your behaviour and attitudes to fit in with the regime you find yourself in.



The rather gloomy exterior of Croydon General Hospital (now a housing estate)

I was admitted to Princess Alexandra of Kent Ward at lunchtime but can recall little about the preparation for the operation other than one experience that sticks in my mind.

[Before we go any further I'd like to call a time-out whilst I work out how to explain it without straying into the realms of political incorrectness. It was the late 1970's. Attitudes were different in those days. Describing someone, of whichever sex, as young and pretty was perfectly acceptable. Continue.....]

An attractive (pretty), student (about my age) nurse appeared with a bowl of warm water, shaving foam and a razor. She (a female nurse in this instance) told me : *"You need to be shaved before your operation"*. I realised that being so unwell I looked a mess with quite a stubble growing but couldn't work out how smartening me up was going to help. Whatever. If they wanted me to look better then OK. Then it dawned on me that it wasn't my face she was going to shave. Suddenly I had something to take my mind off the pain and the imminent operation. I might have been feeling very poorly but I was sure something would start *"stirring in my loins."* I thought I'd better confront the situation head on, so to speak, and asked the

attractive, student nurse what would happen if something “*popped up.*” She produced a biro from her top pocket and said “*a short, sharp tap with this usually cures the problem.*” The threat was enough to ensure flaccidity.

At 6:15pm the pre-meds were administered and then an hour later I was put on a trolley ready to go down to theatre. My sister had rung my girlfriend to say that I had been admitted to hospital. Making her way to the ward she arrived to see me being wheeled past her on the trolley and genuinely thought that it would be the last time she saw me.

I was taken into the anaesthetic area. The anaesthetist introduced himself and explained what he was about to do. No doubt there was a consent form to sign. As he injected the first sedative he said : “*I want you to count to ten but you won't get past three!*” Yeah, right - “*One, two...*”

The surgeons prepared to do an appendectomy and made the first incision. I have a very neat appendix scar, about three inches long, to prove it. When they looked inside, however, they found that I had a hole in my bowel that had leaked into the abdominal cavity. The appendix was left in position as they didn't want to risk septicaemia. A new, much larger incision was made just to the right-hand side of my navel. They sewed up my bowel and cleaned out the cavity. The implications of that perforated bowel would come back to haunt me in the future.

I was returned to the ward at 9:30pm after this exploratory laparotomy. I had a “C” drain in place and a nasogastric tube on continuous drainage. What I didn't know, until recently, was whether my large or small bowel had burst and whether a section had been removed during the operation.

In the ensuing years I have often been asked by consultants and surgeons exactly what I had done in 1979. Having now obtained a copy of the discharge letter all the gory details are set out in black and white. It is reproduced towards the end of this chapter. I had always blamed the prolonged use of Imodium for causing a blockage and the subsequent perforation but with hindsight I think that is unlikely.

Wednesday 20th June 1979 - I must have been in a fair amount of pain after the operation as I was given shots of morphine. Amazing stuff and I could understand why it was taken as a recreational drug. At one point I could see a

circle of blue flames floating around the ward. I asked for some more, after all how often do you get a chance of taking Class 'A' drugs legally and for free? I should have kept my mouth shut about the hallucinations as that was the last shot I was allowed and that wasn't the only thing withheld.

I was to be "*Fluids Only*" for most of the next three weeks, fed intravenously through a tube (catheter) that entered at my wrist, travelled up my arm inside a vein and over my shoulder into my chest. Getting it into position was an experience. Just seeing the apparatus would be enough to make some patients faint. I like to think that I'm made of sterner stuff so the sight of a thin plastic tube, 800mm long, and knowing where it was due to go, was more a curiosity than a worry.

The installation process however did not go smoothly. The first attempt at insertion failed so the doctor tried the other arm. Still no luck. Go back to the original arm. Nope. By now I was surrounded by a small group of doctors and nurses. In all it took five attempts to get the tube into the correct position. I'm amazed I haven't been put off cannulas and needles for life but maybe once you've had one that long inserted the others pale into insignificance.



The daily nurses' meeting on Ward 15

Thursday 21st June 1979 - Day Two after the operation and no signs of nausea. The only significant change was being allowed to take small sips of water.

Saturday 23rd June 1979 - I was starting to turn the corner after the operation. Another bottle was added to my drip stand and an additional tube fed into the catheter. This new bottle contained an intravenous feed but looked rather like the contents of a catheter bag. The nurse noted that I had spent much of the day out of bed.

The first stand they gave me had no wheels and I probably wasn't up to getting around anyway, so my days consisted of moving between bed, bedside chair and back again. Anywhere within the radius of the drip tubes. Once I was fit enough to move around, the stationary stand was swapped for one with wheels on. I quickly learnt to propel myself across the ward for trips to the bathroom or the TV lounge, treating the stand as a skateboard.

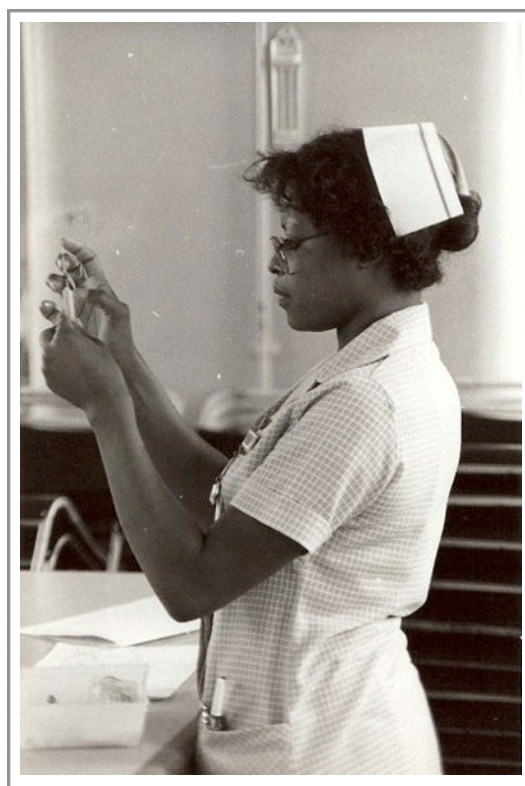
Saturday 30th June 1979 - The restriction on drinking had been lifted on the previous Wednesday and I was free to take in as much as I felt comfortable with. I was started on Vivonex, a powder mixed with water to provide nutritional support for those with severe gastro intestinal impairment. The downside was coming out in spots as my body reacted to the high protein content.



Tethered to my drips. The rosy cheeks suggest this was post-blood transfusion.

A routine I quickly became used to was the twice daily hydrocortisone injections. The chosen site for these jabs was my backside. The routine was : drop your pyjamas, roll on your side, jab. The day had come when the doctor, on his ward round, decided I didn't need any more as I was recovering well. Hurray. No more pin cushion bum.

That afternoon the rest of the band came to visit and spent most of the time eyeing up the nurses. There was a lot of good-hearted banter going on. A couple of nurses decided they would show just who called the shots, literally. Half way through visiting time they came over and said : *"Time for your injection."* I explained what the doctor had said but they were having none of it. They asked my friends to move away from the bed so they could pull the curtains around and then proceeded to give me instructions in very loud voices. *"Drop your pyjamas. No, lower. Right, roll over. Which cheek do you want it in? OK, you'll feel a little prick...."* You can imagine the effect this had. Lots of laughter and inappropriate remarks from outside the curtain. The nurse's ward notes called it a *"cheerful day"* and remarked that I was *"uncomplaining"*.



Nurse Hope in typical pose

Later in the evening, once visiting time had finished, I called over the lovely Nurse Hope and told her that I wasn't joking when I said that the hydrocortisone injections were no longer needed. She just replied *"we know"* and smiled broadly. I

later asked her to pose for her photo in her usual *"I'm about to stick this needle in your backside"* position. I wonder if she's still in nursing now?

Monday 2nd July 1979 - The lead consultant was on the ward round. He decided that the IV feeding could be stopped the following day and the Vivonex increased to six sachets daily.

Tuesday 3rd July 1979 - For the first time since 19th June I was going to be allowed a light meal that evening. My girlfriend was visiting when dinner was served, a bowl of chicken soup. Given how long it was since I had eaten I believe any food would have looked appetising but the smell coming up from the bowl was getting my tastebuds excited. As I lifted the spoon to take the first mouthful a nurse appeared and told me not to eat any. I was only allowed a liquid diet at this stage so she would have to take the soup away and strain out the pieces of chicken. I can laugh about it now.....

Friday 6th July 1979 - I was finally allowed to resume a normal diet. An appointment was arranged for me to see Dr. Parrish at Mayday Hospital the following Tuesday. As I was getting close to discharge it was decided that I could go home for the weekend. Quite a surprise.

Being the height of summer and with no air conditioning on the Ward the windows were often left open until the sun went down. That evening I could hear my name being called from outside the window, even though the Ward was on the third floor. Curiosity got the better of me. I poked my head out to see three of “my” nurses, all dressed up in their glad rags, heading off to go partying. They looked very elegant. *“Just wanted to see if you’d like to join us.”* The rapport built up with the nurses certainly helped me through my time in hospital. I wonder if it was easier as a young, male patient given that most of the time I was interacting with young, female nurses?

Weekend Leave - They weren’t in any hurry to discharge me from hospital. They knew that, providing I continued to make good progress, I would be going home the following week. The decision that I could have “weekend leave” was very welcome. When I returned to the Ward on the Monday morning the other patients said I had done well to be away. A guardsman from the local barracks had

been brought in complaining of a bite in a very delicate place. He claimed that the wound had been inflicted by a dog to which the doctors had replied that, looking at the shape of the teeth marks, the dog must have been wearing human dentures. The new patient had kept everyone up all Saturday night with his moaning and was discharged on the Sunday. I had a lucky escape.

Tuesday 10th July 1979 - Discharge day. I couldn't go straight home in the morning as I had an appointment to see Dr. Parrish, after lunch. Once I had seen him I was free to go and finally arrived home.

Croydon General Hospital	
LONDON ROAD, CROYDON, CR9 2JF	
Consultant Surgeon: M. L. Sutcliffe, F.R.C.S.	Telephone: 01-688 7755
File/SM/ /G772182	20th July, 1979
Admitted: 19.6.79	Discharged: 10.7.79
<p>He was admitted as an emergency with lower abdominal pain. He gave a history of being treated for <u>Crohn's disease</u> for the past year. The abdominal pain had got worse in the past 12 hours and also the diarrhoea. He was on Prednisolone 5mg. 5 times a day.</p> <p>On examination his temperature was 38.5°C. Clinically anaemic. There was no jaundice or lymphadenopathy. Heart sounds normal, no added sounds. Lungs clear. Abdomen soft but there was tenderness and some guarding of the lower abdomen maximum over the right iliac fossa. Bowel sounds were sluggish and P.R. examination showed he was tender and there was some soft faeces in the rectum.</p> <p>Hb. 12.4 g% and white count 10,300 with 84% neutrophils. Urea and electrolytes were in normal range. Chest x-ray nothing abnormal in the heart or lungs. Abdomen x-ray there were some distended loops of bowel seen mainly to the left of the spine and also within pelvis. Appearances of mucosal oedema seen in a segment of transverse colon to the right of L2, and the possibility of toxic mega-colon has to be considered.</p> <p>Clinically it was very difficult to exclude acute appendicitis in addition to Crohn's disease and there is a possibility that his physical signs may have been masked to some extent by the Steroids. Therefore, it was decided to operate on him and a lance incision was made over the right iliac fossa. The peritoneal cavity was entered and there was some turbid fluid which was sucked out. The appendix was slightly inflamed but the secum was more inflamed and the terminal ileum was idurated and oedematus. Crohn's disease was diagnosed and the large incision was closed and a right lower paramedial incision was made in the terminal area. About 2 ft. of it was inflamed and thickened and there were two early strictures in the terminal ileum. Part of the terminal ileum was in the pelvis and adherent to the pelvic peritoneum and this was cleared and found to be coated with fibrinous exudate. There may have been a small perforation in this area which was sealed off by fibrin now. The caecum was grossly oedematous and inflamed. There were skip lesions in the ascending colon and transverse colon. About 4 feet of small bowel proximal to the badly affected terminal ileum was also slightly inflamed and dilated. The rest of the intra-abdominal viscera appeared normal. As the appendix was only mildly inflamed as part of the Crohn's process and the caecum was grossly oedematous, it was decided not to perform an appendicectomy, especially as there is a high risk of formation of a faecal fistula.</p> <p>The peritoneum was washed with Noxiflex solution and the wound was closed in layers with corrugated rubber drain to the pelvis. The operation was covered with intramuscular Hydrocortisone and this was continued after the operation. He was given parenteral nutrition for the first six days post-op and then he was Vivonex orally.</p> <p>His recovery was remarkably uneventful. His steroids were gradually tapered to Prednisol 5 mg. three times a day orally and Codeine Phosphate 30 mg. twice a day p.r.n. His weight on the 7th July was 61 kilograms, haemoglobin 12.1 gm%. He was discharged home on the 10th July after seeing Dr. Parrish at Mayday Hospital. At the time of discharge he was on a normal diet with hardly any diarrhoea. He will be seen again in Out-patients in due course. I think Dr. Parrish will continue with his further medical management.</p> <p>Yours sincerely,</p> <p>P. L. Perera, F.R.C.S.E., Registrar to Mr. Sutcliffe</p>	

Discharge letter

The photographs - I asked my girlfriend to bring in my camera so that I could take some pictures of the Ward and nurses in action. We're not talking a small, compact camera but a full SLR. I did ask permission before snapping away. The nurses must have thought I was mad. I dug out the photos again to scan them for this chapter and it brought back a lot of memories; I can still remember the names of some of the nurses.



Making the beds

Hospital life - I lost any sense of embarrassment in hospital. Nowadays you would describe it as *“what happens in hospital stays in hospital”*. I found that by suspending my *“normal life”* mindset and replacing it with a *“hospital life”* mindset I could accept what was happening a lot more easily. (When you don't keep to the *“what happens in hospital”* principle it's a sure way of upsetting friends, colleagues and relatives with too much information.)

If you compare the very basic beds shown in the photographs with the hi-tech, all electric adjustable ones of today with their overhead telephones, TV and internet access you realise just how much we've moved on. The things that have not changed are the care and humour with which the nurses have treated me and the ritual of the daily ward round.

There is a well known clip from the 1954 film "Doctor in the House" that you can find on YouTube (just search for "Sir Lancelot Spratt"). If you haven't seen it before then please spend a couple of minutes watching. You will see that the ward environment in 1954 was very similar to the one I photographed in 1979. I refer to this clip in a later chapter as I won a bet with my wife that I would not ask a doctor what the "*bleeding time*" was. Unfortunately doctors nowadays either haven't seen this clip (which should be compulsory viewing) or have no sense of humour.

On 10th July I took a picture of, what I hoped would be, my last ever hospital meal.



The Last Supper. Lovely doily

The Drugs - When I was discharged from hospital I was still taking the prednisolone and codeine phosphate that I had been first prescribed in 1978. Prednisolone, a steroid, was the first choice for reducing inflammation. Unfortunately it has a number of potential side effects including weight gain, behavioural changes and osteoporosis. The approach is to hit the inflammation with a high dose and then progressively reduce to a safe level as soon as possible. Codeine phosphate is an opioid used in the treatment of Crohn's disease for its painkilling and anti-diarrhoeal actions. Being opium-based it can become physically and psychologically addictive.

The Memory Fades - I am struggling to remember the effect Crohn's had on my everyday life. As part of the research for this journal I looked through some old 35mm film slides. Many were labelled with the date taken and these have helped juxtapose some of my "*non-Crohn's*" activities with the ups and downs of my health.

For instance in May 1978 we went to see Queen at Wembley Arena and a month later were back there for The Electric Light Orchestra. I don't recall that my declining health or the possibility of having to find a bathroom quickly was ever a consideration in going or not going. A month further on and I had been admitted to Mayday Hospital for tests.

Similarly, on 17th June 1979, we had seen Manfred Mann's Earthband in concert at Fairfield Halls. Just two days later I was undergoing emergency surgery in Croydon General Hospital for a perforated bowel.

My own musical efforts had to take a back seat. The band had temporarily stopped gigging until I had regained my health. It was around a year later that we started playing again and had lined up such choice venues as the Thomas a Beckett in the Old Kent Road; The Castle in Tooting; the Walmer Castle in Peckham; and The Blue Anchor in South Croydon.

I have discussed with my wife the inability to remember many of the bad times. She then reeled off a number of occasions when I had had to rush to the bathroom or felt bad enough to consider A&E. I'm starting to wonder whether my subconscious is deliberately suppressing those bad memories.