

This is a retrospective journey through one of the most difficult times in my life. I want to see how I've changed and how the experience changed me.

Guillain-Barré Syndrome (GBS) is a rare, debilitating illness. Within a very short period of time the demyelination of the sufferers nerves can leave them completely paralyzed. Some 20% of sufferers will lose their ability to breath. They will need the assistance of a ventilator. There is no known cause and no known treatment or cure. Thankfully 80% will recover completely.

Some famous people whom have had GBS:

Tony Benn, British Politician

Joseph Heller, Author of Catch 22

Franklin D. Roosevelt, US President

Andy Griffith, American Actor

My memories of the events are roughly in chronological order but much of it returns to me through the haze of drugs I was given so it may read a little disjointedly.

I wrote the first draft of my experience one year after leaving hospital. The opening paragraph was:

"It has been almost a year since I left hospital. I go through feelings of depression mainly due to being robbed of a year from my career but I am about to start a new job that will hopefully be a new beginning for me. "

It was a new beginning but not in the way I intended. Within 18 months of leaving hospital my wife had left me and taken my son to live 250 miles away and I was living back with my Dad. But that's probably a whole new story...

...Back to the GBS story...

Every day I see things around me that remind me of what I've been through. When I see hospital documentaries on television and hospital based soaps I get the urge to do something with the knowledge that I have gained through my ordeal as if, in some way, what I've been through makes me special. I want to write a book about my time in hospital, I want to join the Guillain-Barré (GBS) support group and do some work with them. I also want to visit the people that I met whilst doing my time (like a prison sentence). I feel that after a year away from hospital I should be cutting my apron strings and getting on with my life but the attraction is strong. The fact that I'd fallen in love with my physiotherapist didn't help...

I never joined the GBS support group but I visit their Facebook page and forums from time-to-time. So here I'm trying to write about my GBS experience and how it has changed my life – or was it just a vivid snapshot of what my life is? What my life is already and what it is to stay? Now, all these years later, the thought of joining the GBS support group feels twee to me. I'd feel like I was trying to cling on to my past when there's nothing positive to be clinging on to. Obviously it was a huge part of my life but why is there the urge to constantly relive it? Is this what those with Munchausen's syndrome feel? Am I pathologically bound to this negative and traumatic experience purely because of the attention I received whilst going through it? Is this

something that was in me before I contracted GBS or is this some sort of addiction that came out of it?

We often hear a recurring theme when we hear such stories in that the people who experience them come out the other side with a new invigorated and energized view on life and they achieve amazing things. My life went back to being exactly the same. So what, if anything, did I learn from it? Or did the experience damage me in some way?

## **THE FIRST DAY**

Friday 26<sup>th</sup> November 1993

After suffering from flu-like symptoms for the past two or three weeks I took a turn for the worse. I didn't actually feel worse it's just that the new symptoms were interesting and intriguing. I now know that the bad headaches and pins and needles in my hands and feet were not really normal symptoms of the flu but I didn't have anything else to reference them against.

I awoke very early in the morning; in fact I don't think I slept at all. I remember that the only comfortable position in which I could sleep was completely straight; arms and hands down at my sides, flat on my back. I sat up on the edge of the bed not feeling as bad as I had the previous morning. The day before I remember also being awake very early and when I'd arrived at work, before anyone else, I put my hands on a hot radiator in order to get some feeling into them – in retrospect this would've been the nerve demyelination already starting from the ends of my finger-tips. I couldn't feel the heat from the radiator as the nerves were already incapable of sending signals to my brain.

I still felt tired and lethargic but as I tried to rise up from the bed I sank into a heap on the floor. I could not support myself. It actually seemed pretty comical and not at all scary. I considered myself to be invincible as most 23-year-olds do.

At the time I was a real gym freak – I wouldn't say 'fitness freak' because I did very little cardiovascular exercise – I went to the gym at least 5-times per week.

I pulled myself back up on the bed and assessed the situation. It didn't feel like my legs were weak or that I was attempting to lift a great weight. It felt more like the request to stand wasn't being received by my legs.

Outside it was quite bright but foggy. Mornings in November that are foggy today always bring the memories of this day flooding back. I climbed back into bed and asked my wife at the time, Alison, if she could get me a drink. She asked me why I wasn't capable of getting a drink for myself so I showed her that I couldn't stand. The demonstration shocked her and she was convinced that there was something very wrong. She insisted on calling out a doctor. Her initial thought of my having a brain tumor was assuaged by the locum that arrived. My own doctor was on vacation so I'd not met this doctor before. Before he arrived I had a small panic because I wasn't wearing any clothes; Alison helped me into a pair of boxer shorts. I wasn't to know but I was soon to give up on worrying about such small indignities. Anyone who's had to endure a prolonged stay in hospital knows that you leave your dignity and pride at the door when you enter.

The doctor spent less than ten minutes examining me and testing my reflexes and asking some quite strange questions. He then advised me to take a visit to see Doctor Bell at the Battle

Hospital in Reading. He asked me if I would like him to call me an ambulance and this was the first time I felt scared. I said no and that I would arrange my own transport. Alison didn't drive so she called my Dad to ask if he could drive me to the hospital. Dad arrived with my sister Jo, who was down visiting, as I was sliding myself down the stairs on my bum. The locum doctor had mentioned the mysterious illness Guillain-Barré Syndrome but I didn't take the words in. He wrote a note to be handed to Doctor Bell and sealed it in an envelope – this made me a little more anxious. To this day I'm still mightily impressed by this locum – he correctly diagnosed a pretty rare illness in less than ten minutes!

Alison was pregnant and couldn't give Dad and Jo a hand getting me into the car. She had packed me an overnight bag which I thought was odd because I hadn't contemplated the need to stay in overnight. How wrong I was.

On arrival at the hospital Dad went off to find me a wheelchair from the reception area. We then went off in search of Whitley Ward where Doctor Bell practiced. When we arrived the nurses were already expecting me which made me feel pretty special. I was given my own side room and told that the doctors would be along shortly to examine me. I was helped on to the bed and I got settled into flirting with and trying to build a rapport with the nurses. I was getting quite a buzz out of the situation and being the centre of attention.

As the day went on more and more doctors crammed into the room with each subsequent consulting session. There was obviously something interesting about my case. I've since learnt that GBS affects only 1 in 50,000 people so it's obviously quite special to see a case. In one of these sessions one of the junior doctors suggested a lumbar puncture so that my spinal fluid could be tested and the prognosis of GBS proved. They surreptitiously used the acronym L.P. I assume because it didn't sound so scary or I wouldn't know what it meant. From the hospital based soaps I'd watched I knew what it stood for and got really scared. The macho hard man image I put on for the nurses disappeared in an instant. I don't particularly like needles and the thought of having one inserted into the base of my spine to drain off my spinal fluid really didn't seem like fun. By this time my friend Jock had arrived. I'd known him for ten years at this point and it was the first time he'd ever seen me cry. Alison wasn't in the room at the time and I asked him not to say anything to her as I wanted to shield her from the reality of the situation as much as possible. This turned out to be a bad move because it made her feel even more alienated and out of touch with, or excluded from, what was happening. When I'd arrived at the hospital with Jo everyone had assumed she was my wife and they'd given her all the information on my prognosis.

During the Lumbar Puncture, which was given by a young houseman (intern), a student nurse was given the arduous task of holding my hand. I don't think I was starved of attention as a child but there really is something lovely about a pretty girl holding your hand. I tried to make light of the situation and attempted some poor attempt at flirting with her. Jock was having more success playing the fool wheeling up and down the corridor in a wheelchair outside my room. When the doctors' needle reached the correct spot the spinal fluid came spurting out rather more dramatically than he had anticipated but he managed to capture enough to be tested. After the results came back from the L.P., where they found the elevated protein level (without increased cell count pleocytosis), Mum phoned. Her call was transferred to a cordless phone so I could speak to her from my bed. I explained what was happening; including the scary details of the L.P. I probably shouldn't have given her these details but your Mum is the one person that you normally have to share these things with. I learnt throughout this

experience that although you're the one its happening too you have to be more thoughtful of the others close to you.

It started to become very uncomfortable in any position. Dad and Jo took on the task of keeping me comfy by constantly repositioning me. At this point I couldn't turn myself over. I wanted to write that I didn't have the strength to turn myself over but that's not how it was. For want of a better definition: I didn't have the signaling response mechanism to turn myself. Doctors still kept on coming in and out testing my reflexes, strength and range of movement. By this time I was unable to raise either leg from the bed. Young doctors would come in wanting to get first-hand experience of a GBS patient. I thought I was quite the celebrity.

The doctors became concerned about my breathing. About 20% of GBS sufferers need support in breathing via a ventilator. Throughout the day my lung capacity/strength was tested and I had reached a point where it was decided, as a precautionary measure, that I be moved to the Intensive Care Unit (ICU) at the Royal Berkshire Hospital across the other side of town. This all seemed quite surreal. Although I felt distinctly uncomfortable I did not feel ill. All the flu-like symptoms had gone but this may have been due to the adrenaline pumping through my system. The ambulance drivers that came to transfer me asked what me what my prognosis was but I still hadn't memorized the mysterious name. One of the nurses accompanying me came to my aid and said GBS but they were none the wiser. I asked if we were going to have the blue lights and sirens going for my trip and they gave me the choice – I decided to arrive quietly without the pomp and ceremony plus I didn't feel that I was a blue-light case. Upon arrival at the ICU I was put into a side room and connected to an arterial vein blood pressure sensing device. It's quite a bulky and invasive piece of equipment like a comedy needle you see in cartoons. I felt very sick and dizzy so they lowered the head end of my bed. The feelings didn't quickly subside so they lowered the bed some more. By the time the feelings eased I could see the wall behind me my head was so far back. ICUs are notoriously busy and noisy places so I didn't have a comfortable night.

The doctors said my condition hadn't deteriorated overnight and therefore sent me back to the High Dependency Unit (HDU) at Battle. It was here that I noticed the paralysis had spread across one side of my face. I attempted to clean my teeth but my hand completely missed my mouth and I almost took an eye out with the toothbrush instead.

Doctor Bell came in via his normal ward round and told me not to worry and that they'd have me fit and well by the middle of next year. It was November. He delivered this as though it was good news. I promptly started to cry and he left the room after a cursory pat on the shoulder in a weak attempt at reassurance. The two intensive care nurses, Lynn and Claire, hugged and reassured me. They assured me I'd be able to make my baby's birth in April; 5 months away.

My condition continued to get worse and I was moved back to the ICU across town. This time I was in the main part of the ward. I was told about the ventilator machine that was next to my bed but I couldn't see it as I couldn't turn my head. It was there 'just in case'. I didn't really know what that meant. Mum came to visit with Heidi – my little sister. Heidi was only in the room for a few seconds before she turned and left. It was quite a traumatic sight what with my lying flat and all the tubes leaving and entering my body. Every time I think of this I'm reminded of the song Wires by Athlete:

*"You got wires, going in*

*You got wires, coming out of your skin*

*You got tears, making tracks*

*I got tears, that are scared of the facts"*

I understand that they wrote this song about one of the bands daughters being very ill when she was born. Although I was in a scary place physically and emotionally I know that it was ten-times worse for those around me so I know how Heidi felt when she couldn't cope with seeing me this way. Dad pointed out to me that my mouth hung open and I quickly closed it. Heidi quickly composed herself and came back in to see me.

Mum and Heidi stayed with a friend as they lived 150 miles away. Mum couldn't sleep and spent the night pacing up and down. She was so upset she woke her friend in the middle of the night to check on my condition.

By this time I was completely paralyzed and my breathing weak. My body was finding it hard adjusting to being still and cramps set in. I was in constant pain. It was Monday 29<sup>th</sup> November 1993. Alison was due to attend an anti-natal appointment. Dr Waldman, the head of ICU, decided that it would be in my best interest to be ventilated via a tube down my throat. Unfortunately Alison missed the chance to wish me luck before I was put under for the procedure. She was so upset she called Dr Waldman an ass hole. She had given up her part-time job so that she could spend more time with me and she would spend many nights staying in the family rooms adjoining the ICU. Her sister was supposed to have gone home today but she decided to stay and offer moral support.

Tuesday 30<sup>th</sup> November 1993

Because one shouldn't stay ventilated via this method for sustained periods, because of the need to be sedated (without being sedated you would constantly gag on the tube), the doctors decided I should have a tracheotomy. I wasn't scared. Alison was phoned at home and asked to come in so that she could sign the consent forms. When she arrived at the hospital she was taken to the room our family named 'The Goldfish Bowl'. She apologized to Dr Waldman for calling him names but again there was a lack of communication and she didn't get a chance to see me before the operation.

I came around from the anesthetic rather sooner than everyone expected and it caused something of a panic. Alison and her sister Claire were by the side of the bed and they tried to hide their surprise at my being awake. Claire went off to get someone whilst Alison tried to keep me calm. It's odd because I don't remember being agitated but I must've been because of the reaction of those around me. The nurses fed more drugs into my arm but I wasn't having any of it and just wanted a hug with Ali – for my benefit or hers I'm not sure...

Dr Waldman explained to me that he'd had quite a tough job cutting open my throat because of the surrounding muscle. Apart from that the procedure had gone smoothly.

It felt strange to lose my voice but the tracheotomy was not painful. I had also been catheterized at the same time – I was very glad that I was out cold when they did that. Being rather spaced out by the drugs I kept trying to ask the time. I hoped that hours and days were passing rather than just the reality of seconds and minutes. Everyone was aware that I was extremely uncomfortable and that it could potentially be a very long stay. There is no known

cure or treatment for GBS but some evidence that an infusion of immunoglobulin can help so I was hooked up to 5 days worth of the treatment. The use of immunoglobulins is not without risk as it can occasionally cause hepatitis, or in rare cases, renal failure if used for longer than five days. To this day, some 18-years later, I'm unable to give blood because of this use of blood products. A special bed was bought in for me; it was inflatable with tiny holes all over that would create a cushion of air between me and it in an attempt to alleviate bed sores. When I was hoisted from the standard ICU bed I was drunk with relief. The release from pain and discomfort was immediate and beautiful. The new bed felt like I'd been wrapped in the most comfortable and comforting blanket ever made. It was the first time I'd smiled, albeit a lopsided half smile, in two days. The £800/day charge for the bed was well worth it in my mind.

I was being a little disruptive and constantly craving attention and reassurance from the nurses. I had realized that with the little movement I had left in my wrist I could wriggle it enough to set off the blood pressure sensor alarm and bring the nurses running. They soon got bored of this constant interruption and removed it from my arm. I would have to get used to the loneliness and isolation.

After my tracheotomy my throat and sinuses became congested with horrible green and red sludge. This required constant suctioning. Having a foreign body inserted causes an immune system reaction so all tracheotomy ventilated patients require some suctioning (a thin vacuum cleaner device that removes the fluid build-up in the tubes down to the lungs) Alison and Dad bravely took on this task to save the nurses from doing it. Because my body's reaction was severe Dr Waldman thought it would be useful to drain my sinuses. The nurse on-shift said I'd need extra anesthetic because I had 'the constitution of an Ox' which I was both pleased and perplexed by because if I had had the constitution of an Ox I wouldn't be in hospital with GBS in the first place! But I also felt oddly manly. Cocaine paste was put up my nose for the procedure and this put me in a good mood for the rest of the day. I blew my cheeks out whenever they tested my blood pressure and generally trying to have a bit of a laugh.

Some days weren't as much fun, particularly when Nurse Trevor was involved. Everyone else thought he was some kind of Super Nurse, they thought he was very knowledgeable and practical. But they never experienced his care first-hand. Every time there was a shift change I would dread him coming over to my bed.

Once when Andy was the nurse assigned to me (nurses are assigned one-on-one in ICU), I think it was a morning shift because he was giving me a bed bath - I was lying naked with my nether regions, catheter protruding, feeling pretty humiliated. Then along comes Trevor who starts chatting with Andy. I could tell that Andy saw it is an intrusion into my privacy and wasn't impressed. Andy was just finishing up when Trevor exclaimed, as if I wasn't there, "You haven't washed his glands!" Andy was embarrassed for both himself and me. I wanted to disappear into a hole but I did the only thing I could and closed my eyes and disappeared into my own head - something I've become too good at.

On another occasion Trevor had just come on shift and I was attempting to explain to Dad that the IV in my arm was hurting. Trevor took hold of the IV and ripped it out; at a forty-five degree angle to which it was inserted. Dad stood there, mouth agape and in shock. Tears streamed down by cheeks and beads of sweat broke out all over my body. I think that Trevor was used to working with patients that were unconscious and he'd become a little detached from the people he treated. Realizing what he'd done was wrong he wanted to make amends and he

suggested applying some sort of balm onto the still open hole. I shook my head as violently as I could to say no. Dad was on my side and said that I should be left alone but Trevor was having none of it. He wafted the balm under my nose in some way hoping that it would assuage my fears – but how could I smell anything when intubated? He then went and poured the entire contents down my neck and all over my bed. I think it was then that Dad saw Trevor as I saw him and he wasn't the Super Nurse everyone thought.

This wasn't the only time that Trevor proved himself to be over enthusiastic. One day when my friend Wayne was visiting, Alison and Jock were also at my bedside, the ice cream I'd recently eaten started to come out of my nose. I don't think my swallowing action was working correctly. So, with no sense of the occasion, Trevor launched at me with the largest suction catheter he could find and proceeded to ram it up my nostrils. Needless to say my visitors were shocked at the scene. Poor Wayne was very nearly sick but all credit to him he didn't run off and stayed with us.

The next few days were blurred. I became quite disorientated. My brain wanted to make sense of my surroundings and I began to imagine things that weren't there. I imagined that my bed was upright and that I was looking at everyone face-on when in reality I was still lying horizontal. I imagined that there were French doors leading to a patio area off to my right when in fact there was nothing outside the window apart from a large drop as the ICU was on the 3<sup>rd</sup> floor. I can still picture the slated roofs of the houses and tops of trees that were across the road. Today the reality and imaginings are still as clear to me as each other.

<tbid>smoke on the ceiling?

One doctor that we nick-named Doom-n-Gloom came round and pronounced that I was an accident victim that was obviously severely asthmatic. I tried to get the attention of those around me in an attempt to put him right but he continued to talk over me as if I was an inanimate object. Luckily Alison, who's never been one to keep quiet, came to my aid and put him straight. He was a little put out.

Claire had now gone home and this left Alison on her own. She would do chores at all hours just to keep her mind off the situation. Our friend Kerry stayed with her for a few nights to keep her company.

About a week later I was slid off of my nice comfortable bed onto a tilting table and was raised from the horizontal position. I felt like I was vertical but it was nearer 45 degrees. All my blood rushed to my feet. It felt like they were going to explode from the pressure. I became very giddy and my eyesight blurred. I remember the ventilator tube tugging at my neck as the distance between it and me was increased. I was very nervous that it would become disconnected and I'd suffocate.

Anyone who's spent time in hospital knows that everyone becomes obsessed with your bowel movements: "Have you been today?" was a common question. Because you're lying prone things don't work as they normally should. Various suppositories were already being inserted for pain relief which also didn't help. So, it was decided that I would receive daily enemas. The first few didn't work but as with waiting for a bus – three came along at once!

One day when Mum, Dad and everybody else seemed to be visiting Trevor came merrily along to 'install' my pain killers rectally. He didn't ask anyone to leave. He simply just turned me on my

side and got on with it. Dad was reading a Stephen King novel to me and holding my hand. I assume it was as embarrassing for him as it was for me. And then he came across a blockage that he said would have to be removed...

I thought this would mean another enema but it turned out to be the first of many manual evacuations. Just when you think a situation can't get any worse something like this happens. It was one of the most painful experiences of my life. I thought it would never end. It felt like his entire hand was inside me.

When it was over, when Andy convinced him that he had scooped enough into his washing-up bowl, I felt completely humiliated. Of course everyone was told about what I'd been through. Mum and Dad both came in with shocked expressions. I cried through embarrassment more than from the pain although that remained for the rest of the day. I managed to communicate to Mum that I was still in pain but this had the opposite effect to what I wanted: Trevor insisted on looking for damage. More humiliation.

The next time I was put on the tilt-table was Monday 13<sup>th</sup> December (18 years ago to the day at the time of writing). This time it was more scare than before and I didn't take to it very well and created quite a scene – which in itself is quite impressive as I couldn't talk; I just shook my head as violently as I could. The angle at which they had me was greater than before and therefore the ventilator tubing was put under more strain. The small balloon (a cuff) that stops air from escaping via the mouth and nose became deflated so small amounts of air was able to cross my vocal chords. I managed to squawk a few words, mostly in fear that I was going to suffocate from not being properly ventilated.

I had been moved to another bay to be by a window but there was not much to see; only the top of some old red-bricked buildings. Some days I was convinced that I was on the ground floor and that the windows next to me were French doors that opened out onto a patio. Some of my disorientation was due to the amount of drugs that I was consuming and some was due to the eye disorder papilledema. This is swelling of the optic disc caused by increased intracranial pressure. A very small percentage of GBS sufferers get this disorder as a side-effect. Some hallucinations were worse than others; one night I was woken by my ventilator alarm and I was convinced that I was wearing a white suit of clothes and that I was lying on a garden table – the type with a parasol. Two nurses came over, switched off the alarm, and suctioned my trachea tube. I was amazed they didn't comment on my new suit!

Another event was even more bizarre because I was convinced that I was able to move: I awoke in the middle of the night feeling particularly uncomfortable. The reason appeared to be many feet of plastic tubing that was wrapped around and under me. I could see my arms pulling at the tubing and throwing it to the floor. Although I knew these were phantom arms they looked and felt real. My real arms lay flaccid by my sides.

Yet another hallucination had me wearing lots of leather jackets. I was too hot and the phantom arms returned again to remove them. The only problem being every time I removed one jacket there was another underneath. A nurse noticed that I was becoming agitated and came over. I don't know how I managed it but I got her to give me a bed-bath at two-thirty in the morning!

Mum didn't know what to do with herself and was in a terrible state. She kept on at me to pull myself together and get better – like I had any control! She once brought me a self-esteem tape to listen to but it was all subliminal messages and all I could hear was waves crashing against a

shore. I would've preferred to have been listening to the local radio station. Actually I would've preferred to have been listening to the national radio station 'Radio 1' but the local one was all we could receive in the ICU. I like music and I have a short attention span so listening to the same records being played on an infinite loop was a little frustrating.

Jock was listening to the same station one afternoon and decided to phone in a dedication for me. I wasn't actually listening at the time but he had the sense to record it and bring it in for me to listen to. The ICU staff would often turn off the radio when someone in the ICU died. I remember a couple of occasions when someone died; one of them being a baby that had contracted meningitis. A vial of life saving medication had been flown by helicopter half-way across the country but it had arrived too late.

Listening to music and the radio went a little way to alleviating the boredom but having Dad read to me was real escapism. The whole ward would go quiet as everyone tuned in to his excellent reading voice. I was really into Stephen King at the time so the content probably wasn't appropriate for the environment! Trevor once scared Dad silly by creeping up behind him and whispering "You have a lovely voice" in his ear.

One particular doctor, who I think was Spanish, put me on a morphine drip. I believe his rationale was that it would ease my discomfort but it wasn't a long-term solution. It was an odd experience. I felt like I still had the pain but it was happening somewhere outside my body. After losing about three days to blissful ignorance my family asked for it to be withdrawn. I was completely out of it and uncommunicative. Although I was ventilated and mostly paralyzed I was still able to express myself and interact. This lack of communication was scary for Alison.

So, the morphine drip was withdrawn, but I was still given a small dosage every evening to help me get to sleep. When you're lying in bed 24-hours a day you drift in and out of sleep so you don't tend to sleep much at night. The morphine helped regulate my day-night pattern. Unfortunately morphine is incredibly addictive and I would clock watch waiting for my fix. I knew, and the nurses knew, that this couldn't continue. One of the nurses said she didn't want to see me coming back after recovering from GBS just to be treated for a drug addiction.

Bed baths took some getting used to. Waking at six thirty in the morning to find a six-foot nurse with huge hands and orange hair pushing and pulling me around scrubbing every inch was something that I just withdrew from. Lying there naked atop the bed brought home how dependent and useless I felt. It was pretty painful too but I couldn't tell them. A physiotherapist told me that I had very expressive eyes – they had to be because they were all I had to communicate. If the physio-terrorists (as we I came to call them) had to do something necessary, or painful, they would deliberately avoid making eye contact with me. A thrice-daily routine was to have them come and shake all fluid from my lungs. If you're ventilated and motionless then fluid and gunk builds up in your lungs and you're prone to infections. I used to look forward to these sessions as they broke up a very boring day but at the same time I also hated them as they were very painful. GBS makes skin and muscle very sensitive. I had managed to instruct the physio's to turn me by using the bony areas rather than those covered with muscle but they still had to pull me about and compress and shake my rib cage. During one of such sessions I was complaining bitterly by shaking my head and moving my shoulders. There was quite a gathering around the bed as I think it was during a ward round. One of the physio's spoke aloud to the crowd: "Stop making such a fuss! We have got other patients to visit Nigel!" A chuckle erupted around the bed. I have never felt so low.

Because I had been in the ICU for so long I didn't feel like the other patients. Most other patients had horrific injuries or had just had invasive surgery. I just couldn't move. I only thought I was going to die on a couple of occasions that turned out to be just panic attacks so I thought I was lucky compared to the others around me. This was especially true when the baby died of meningitis. I actually felt quite selfish after all of the fuss I made when that happened.

I was given beta-blockers to keep my blood pressure down and this didn't help me keep in a positive frame of mind. GBS alone has a depressive side effect so it was compounded by this medication. So, as is normal in these situations, they give you other drugs to counter the effects. I would still get quite anxious when someone meddled with the ventilator. Dad would often try to be encouraging by telling me when they'd lowered the pressure support and I was breathing more on my own but this would make me feel nervous. Several times the ventilator alarm going off would induce a panic attack. I had become emotionally attached to this machine that I still hadn't actually seen.

My nurse Andrea once had to remove a partial blockage in my trachea tube but she had some trouble and the alarm kept going off. My emotional state quickly escalated as she called for help from the other nurses. I was taken off the ventilator and put on to a bag pump. I could see that there was something wrong when the bag didn't inflate. I silently screamed for help although I knew that everything that could be done was being done. I started to shake my head violently which just made their jobs worse. The time was 9.07pm. I had consciously looked at the clock because I wanted to know exactly what time I was going to die. Then, suddenly, the ceiling shot upwards and away into a white dot surrounded by darkness. I had passed out.

I think the nurses would've been thankful. They then took charge of the situation and as the blockage was removed my breathing returned to normal. I was placed back on the ventilator.

In one of the morning physio sessions Trevor decided that it would be beneficial for me to sit in a head injury chair. A hoist was brought to my bedside and I was lifted onto the fabric sling without a problem. I worried, as normal, about the length of ventilator tubing being enough and the cuff deflating but I felt brave. But when they lifted me from the bed the shape of the sling forced me into a sitting position. The pain was unbelievable. The trip to the chair seemed endless. I wanted to die.

It took some time for me to calm down once seated. I was covered in sweat and exhausted. I managed to smile for Alison and eat some porridge although I found it difficult to swallow. I could feel the tube in my neck scraping inside and the tube tugging with each attempt.

After nearly an hour in the chair I wanted to go back to the safety of my bed. The trip back wasn't as smooth as the journey out. There was a problem getting the hoist wheels back under the bed which meant that I was suspended in the sitting position for what seemed like eternity. When I eventually got back into bed I slept solidly for two hours; utterly exhausted.

Staring at the ceiling was my biggest pastime when I wasn't trying to get the nurses attention. I used the tiles to count my prayers - each word of the prayer taking up one tile. I would try to bargain with God. I would try to make a deal and get time off for future promised good behavior. By the time I left ICU I was an atheist.

Some days were better than others. The best days were when Mum and Heidi would visit. They would mostly come at weekends and bring masses of food, magazines and other goodies.

Everyone had settled into routines and her visits would be weekly markers that would make me feel like I was making progress. One visit stuck in my mind as she was brought down by my uncle Roger. He said:

"I can't understand a word you're saying but I think you're being so strong and if you and Alison can make it through this you can make it through anything."

A lovely sentiment but he was wrong. We divorced less than two years later. But I don't know if it was he said or the way he said it but I cried. It meant so much to me because he'd been through so much himself.

He also brought me an electric toothbrush. Something that we all got a laugh out of as Mum didn't have a clue how to use it. It took her a while to realize that you shouldn't turn it on until it's in a mouth. I ended up with toothpaste all over me and the wall next to the bed.

### CHRISTMAS 1993

I had convinced myself that I would be out of hospital before Christmas but deep down I knew it wasn't going to happen. On Christmas Eve I was very lonely. All my visitors had left quite early. Trevor was on duty and I pleaded with him to give me my morphine and antidepressants early so that I could disappear into my dreams. But he insisted it was too early. The hours passed slowly. I eventually reached a fitful sleep. I awoke to find Trevor messing about by my bed. He was hanging a Christmas stocking from an IV stand. I smiled to myself and fell asleep till morning. I woke early to find Tina was my assigned nurse. She asked whether I'd like to take a look in my stocking or wait until Alison arrived. Before I could answer she took the contents out and looked them. She then hid everything away in a drawer. I was really upset. I didn't actually see any of the gifts before she'd scurried them away.

I'd already decided I didn't like Tina because of the way she'd handled a few previous incidents. On one occasion I'd coughed up the nasal gastric tube, by which I was fed, into my mouth. Alison noticed and asked Tina to remove it. She point-blank refused. She said that she was useless at putting them in so she didn't want to. Obviously this made me confident in her work! Meanwhile I continued to gag.

She eventually agreed to remove the tube and attempted to insert the new one. All the way through the procedure explaining how rubbish she was at the task.

She also had the odd habit of telling me about every single drug she gave me; every time she gave it. Even if I had visitors she would say: "This one is for your depression and this one is for your bowels; to keep your stools soft." An utterly horrible woman. I remember her wide and unforgiving horror smile to this day.

Most of the nurses were great. When you're in a hospital for a short period you only tend to see their professionalism and what a great job they do but after time you get to know their personalities. You soon realize they're just like everyone else. I even found the energy to have a crush on a few of them. One particular favorite was Carys. She could lip-read better than the others. I have a memory of trying to sneak a peek down her top as she bent down one day. Christine was also lovely. She was very pretty and had small hands – a great benefit if it was time for another manual evacuation!

My mood could often be attributed to the nurse that was on duty. If I was having a laugh you could bet that it was either Fiona or Andrea. If I was positive and calm it would be Evelyn and if I was feeling secure it would've been Claire, Lynn or Gaynel. I remember a lively northern nurse was the one with all the rude jokes.

Any man-chat would have come from Andy. He was always offering comforting advice. I remember his wife visited one day with their little baby. Andy brought him over to me and said this is what I needed to look forward to and get better for. A truly lovely guy. He once decided to try a new way of inserting my suppositories. Instead of turning me on to my side (which I found particularly painful) he placed a pillow under the small of my back and parted my legs. Not the most graceful of positions but indignity was outweighed by the lack of pain. Just as he was performing this procedure one of the physio's came barging through the curtains. He gave her a scowl that should've sent her running. He was always very conscious of my feelings.

Because I was not eating and drinking my urine flow was not always good. This became a popular topic especially when my catheter became blocked. The first time this happened I wasn't consulted and did not know what was going on until my nurse, Karen, unceremoniously deflated the cuff (inflated inside the bladder to stop it falling out) and pulled out the foot long tube. I wanted to arch my back and tense all my muscles but of course I couldn't I just silently screamed in pain instead. The insertion of the new tube was less painful. A syringe of local anesthetic was squirted up beforehand.

The second time I experienced a catheter blockage was in the middle of the night. I felt that my bladder was full. I tried to communicate this to my nurse who called the duty doctor to perform the replacement.

The catheter never bothered me normally except when someone sat on the bed and didn't see the tube under the sheets. At times I felt like a hooked fish. One evening just as Alison was about to leave she kissed me and told me how much she was missing me. I became aroused but the catheter cut that feeling off pretty quickly. It was nice to know that it still worked though.

My little sister was a huge Red Dwarf fan and I had taken her to see a couple of episodes being filmed. She had been in contact with the actor Danny John-Jules who played The Cat and told him about my situation. He wrote me sending his best wishes with a signed photo. Nurse Christine was impressed as she was also a big fan.

One evening when Dad was reading to me I felt calm and relaxed. I was happy to disappear into this fantasy land for a little escapism. But then I began to really disappear. Alarms started to sound and I became surrounded by a mass of blue-green. It wasn't another hallucination though: Dad had accidentally hit the emergency deflate button on my bed. The seven or eight nurses that had rushed to my side found it hilarious but Dad didn't really see the funny side.

Alison was sitting with me one afternoon when we were discussing child birth with Trevor. Rather they were discussing it and I just laid there listening – which is how most conversations happened around me. Trevor was studying so that he could specialize in infant car and he had his own baby monitor. He bought it over and let Alison and I listen to our babies heart beat. It was a really touching, emotional moment. He pulled the curtains around my bed and gave us some privacy. After a while we'd noticed that it had gone quiet in the ward and that everyone was listening in. I made a roaring sound through my trachea tube which made them all laugh.

One day I was transferred to a Parker-Knoll reclining chair just to get a different view of the world. To transfer me they had swapped the ventilator tube with a bag pump. We all noted with much pleasure that the bag inflated and deflated by itself: I was breathing on my own. The nurses had been reducing the pressure support on the ventilator for some time – without telling me as I'd requested. Over the next few days I was periodically taken off the ventilator. A piece of equipment blew dry and oxygenated air across the trachea tube. One of the doctors deflated the tubes cuff so I could speak. I had all these ideas as to what my first words would be but all I said was: "I don't know what to say!"

Detached from the ventilator I was able to move around a little. I was taken down to the visitors' room that I'd heard so much about. With the trachea tube still in place and blower attached, via an attachment they called a 'pig nose'; I was wheeled along in the Parker-Knoll chair almost fully reclined. I still couldn't face sitting up-right. When I arrived everyone went quiet. It was as though I had invaded their space. I had entered the place where they would talk about me and about things they didn't think I should hear. They didn't know what to say. The silence was broken by Trevor who said that he had a lot in common with my friend Jock. Jock was a little upset as Trevor was gay and he most definitely was not. A little defensively he put him straight saying they had nothing in common and everyone laughed.

Alison was going for her last ante-natal class one afternoon and nurses Moira and another big-n-bubbly nurse, whose name escapes me, thought it feasible for me to join her. I had pig nose attached and lifted into a much reclined wheelchair. With an oxygen bottle just-in-case and my catheter bag strapped to the side we set off across the hospital. Unfortunately we were too late as the class had finished a few minutes before. I was a little upset as it would've been nice to have been involved in at least one class. But I still enjoyed the scenery and the adventure.

Things seemed to go downhill for a while after this. I was having more problems with my bowels and hadn't passed anything for days. My abdomen was becoming very swollen and painful. All I wanted to do was roll up into a ball but of course this was impossible. Trevor came to the rescue by offering to rub some ointment into my belly and he pulled the curtains round before setting to work. One of the female nurses called over with a mischievous tone: "Would you like some help in there Trevor?" She said. With a wink and a smirk Trevor replied saying he was fine thank-you-very-much.

Mum decided not to tell me that my uncle Barry had died a few days earlier on the 4<sup>th</sup> January. Mum, Dad and Alison had a chat with Dr Waldman and he said that it was wrong to keep anything from me as I could interpret their subdued demeanor as to mean something was wrong with me. Mum was very brave when she told me and managed to keep composed. I'd known that Barry had been ill for a long time so I was more upset for my aunty and cousins he'd left behind. He was such a warm and generous man. I was very pleased that he'd made it to our wedding just six weeks prior to me falling ill. He had asked my aunty to visit me in ICU and to keep up on my progress. He was always thinking of others. The day of his funeral I was on the blower most of the day. It was dark day at the start but the sun came out in time for the funeral. I remember looking out of the window into the sky as the clouds cleared and the sun shone at two in the afternoon on the 13<sup>th</sup> January 1994.

22<sup>nd</sup> January 1994.

This is the day that my trachea tube was removed for the last time. I made sure that the nurses not tell any of my relatives should they phone in. I was informed that the procedure would take place whilst I was awake which frightened me a little. A pillow was placed under my neck to increase the space between my chin and chest. Andy and Fiona did the honors. They deflated the cuff and pulled the plastic tube from the hole in my neck. It wasn't painful but uncomfortable. I could feel my skin skipping over the bumps in the tube. I took in a long deep breath. The hole closed naturally and it was covered with some gauze. At first I didn't speak and then I didn't stop for hours! My voice was still slightly slurred because of the remaining paralysis in one side of my face but I could still recognize my own voice. I asked the nurses whether I could speak with my Mum and they managed to stretch a phone line across the ICU to the edge of my bed. My Mum worked at a craft center with Jo at the time. The nurse dialed their number and after my Mum's boss picked up the phone they explained who they were and that they shouldn't worry as it was good news.

They put the phone to my ear and I said: "Hello Mum!" ..There was a pause on the other end as Mum tried to take it what this meant. Mum, Jo and I talked for a few minutes and there were tears of joy. It was a bit overwhelming for all of us.

Next I asked to speak with my boss. The company I worked for had been brilliant. They'd been very supportive of both me and my wife during this difficult time. My manager Tony was unavailable but they got through to my supervisor Chris. When their receptionist said it was the Royal Berkshire ICU on the line he said he'd take the call in his office. He closed the door and pulled the blinds; expecting the worst. When I heard him say a worried "Hello?" I said "Hello Chris" back. There was a short pause before a mighty "NIGE!". We had a short conversation and he asked if he could visit. I hadn't wanted anyone apart from my immediate family up visiting up until this point but now I just wanted to talk and catch up. Chris and another colleague Gary came to visit that evening. They were shocked to see how much weight I'd lost. I had gone down from 13 stone (82kg) to around 9 stone in the eight weeks I'd been in hospital.

The same evening Gaynel arrived to do her night shift. She came over to the bed to say hello as usual but she hadn't expected me to say hello back. Tears welled up in her eyes and she gave me a big hug. I felt brilliant, on cloud nine. I thought the worst was over and it probably was but I was still going to spend another five months in hospital rehabilitating. Whenever I achieved one goal I would soon be faced with another.

My last week in ICU was a breeze. I was moved into a side room so Alison and I could have some privacy. I was found a reclining wheelchair with extending leg rests. I was still almost fully recumbent but it felt like I had a little freedom. Dr Collin from the Battle Hospital rehabilitation ward came to assess me for transfer and things generally seemed to be moving forward.

Garry and Alastair from work came at a time when everyone else seemed to be visiting. It was a little hectic and a bit overwhelming. Moira and some of the other nurses got me into my new wheelchair and they took me down to the canteen so that I could be with them all. They were always going beyond the call of duty.

In a quieter moment I was on my own in the side room when the fire alarm started blaring. For a few minutes nobody came in to tell me what was going on. I felt a little scared and abandoned. When Moira came in to see if I was OK she realized I was scared and apologized for

leaving me alone. She explained that the alarm had been tripped in another area of the building and that there was nothing to worry about. She asked if I would like her to sit with me but I was feeling reassured and declined her kind offer. I relaxed again and returned to staring at the familiar tiles on the roof. I began to think about fire and convinced myself that I could see a thin blanket of white smoke wafting around the ceiling. I recognized the same signs of an impending panic attack that I'd seen before. Luckily I managed to get a grip of myself and eventually fall asleep.

Everyone thought that it would be some time before a bed on the rehabilitation ward was found but on the 24<sup>th</sup> January 1994 I was transferred back to Battle Hospital. Castle ward was full of old people and it stank of piss. It was nice to be able to chat with people around me and to be in a different environment but it didn't take long for me to miss the one-on-one attention I'd received in the ICU. I also missed the staff on a personal level. I felt like we'd all got to know each other. These were the first signs of institutionalization. I had become used to being spoiled. I became depressed and spent all my time sleeping. Getting me out of my bed and into the wheelchair was taking five people and it was rare that it could be done without being very painful.

I awoke mid-morning from a doze to find around 20 doctors, nurses, physiotherapists and occupational therapists gathered around my bed. Dr Collin was describing my condition to the assembly and she asked me my age: "How old are you Nigel? 30?" Cuh! "23!" I replied. I'd been growing a beard ever since I'd had enough of letting nurses shave me so I put my old looks down to that. She also wanted to show them my legs and their lack of movement so she threw back the covers to reveal my naked body to all. She apologized and seemed a little embarrassed. I've always slept naked but the GBS made wearing clothes even more uncomfortable.

This meeting was also the first time that I met my physiotherapist Jo. It was love at first sight and the start of a full-on obsession for me. She was beautiful. I was always a little disappointed when she didn't arrive for my morning physio sessions. Instead these were delivered by Lorna who I'd already met in the ICU. She was a lovely person and great at her job but she had one down-side: she was always so damn positive! During my physio sessions I thought I was taking part in a Jane Fonda workout video! It all seemed surreal and ironic because I barely moved a muscle – that didn't dampen her enthusiasm though.

The nurses eventually refused to get me out of bed and in to my wheelchair because it was an awkward lift and very bad for their backs. This meant that Jo (Yay!) and Lorna had to come down from the physio gym to help move me. Jo didn't like doing this and decided to take drastic measures... They were going to make me sit up – no more reclining. I was taken to the gym for one normal afternoon session and slid across to a therapy plinth. Jo informed me, rather coldly, what she was going to do. I blankly refused. Her face tightened up and with vigor she grabbed my legs and told Lorna to get in to position behind me. Recognizing my anger Lorna suggested coyly that maybe we should put this off till tomorrow but Jo's face tightened up even more and she almost spat "No!" In one swift movement Jo swung my legs off the bed as Lorna lifted my upper body into a sitting position. I screamed and called them both "F\$%king Sl@gs". Jo didn't flinch. She said my bawling wouldn't make any difference and she was going to continue making me sit there. With my legs over the edge of the plinth I noticed it was too high for my feet to reach the floor. The pain caused in the backs of my legs because of the weight of their dangling was unbearable. I cursed even more. They eventually lowered the plinth and Lorna

leaned back a little. I was really angry and went into a big sulk. Jo didn't look me in the face for the rest of the session. She was embarrassed. I felt guilty for making such a fuss. Others in the gym tried to ignore the drama.

Jo learned from this episode that the best way to deal with me was to treat me like a spoiled child. Every time I was grumpy or difficult she would be little me like a primary school teacher would reprimand a young child. This would have the desired affect and I'd do as I was told. We still had moments where we'd get on well and I still had a major crush on her.

Nights on Castle ward were difficult as the noise level was intolerable. In the corner bed of our six-bed bay there was an old man that would constantly call out for "Mary". He would remove his clothes and attempt to remove his catheter. He would bring his leg up and wrap the tubing around his foot and then straighten his leg putting extreme pressure on the cuff inside his bladder. It must've been excruciatingly painful.

During one physio session Alison came in as I was strapped upright on a tilt table. She stood before me and hugged me. My arms were limp at my side so Jo took them and wrapped them around Alison. The closest I'd come to a proper hug in months.

I was assigned a social worker. She was very bubbly and full of life. She came bounding over and introduced herself. Her name was Sue. Alison and I had numerous concerns about money should I lose my job and how and if I could get to the impending birth of my child. She was there to help. She was amazingly supportive and helpful.

I noticed again one evening that my bladder was full. This meant that my catheter was blocked. It took me over an hour to pluck up the courage to tell anyone as I knew it was going to be a painful procedure to replace it. Damien was the only nurse on duty that had done the urology course and he tried to flush it through with a large syringe. This didn't work and as he discussed alternatives with another nurse he yanked and retrieved the 18inches of tubing. I yelled "Oooh Faarrk" but it was soon over. I was grateful for his little misdirection. I had explained beforehand that the next time it needed to be removed I would like to try going without. The nurses agreed. Unfortunately I'd lost bladder control and wet myself virtually as soon as I'd realized I'd needed to go. Accidents happened a few times before I regained control but eventually I was able to wait until a bottle was put in place.

I had a similar problem with my bowels. Every time I was stood up by the physio's I would feel movement. I would relay this information in a panicked way to Jo and Lorna but they would insist on my spending time on my feet. From previous experience I guessed they thought I was bluffing and just making a fuss. Nothing actually made its way out until one day when a student physio had come to watch me being strapped into the standing harness. Jo and Lorna were in their usual positions; Lorna sitting in front holding my knees and Jo (very close!) behind me holding me up under my arms. I complained about the pain, as usual, and about the feeling of my bowels about to open. The stand lasted for about 5-minutes before they let me sit down. Lorna's eyes widened in shock and I followed her gaze to the point on the floor where she was looking. Some poop had rolled down my trouser leg and out on to the floor. Jo noticed what had happened and pulled me away from the edge of the bed. The student was asked to leave and Lorna got rid of the evidence. I cried in shame. I wanted to hide my head in my hands but they wouldn't leave my lap. I was put back in my chair in silence. I didn't talk and just looked at the floor. Indignity was all part of a stay in hospital but I was so embarrassed by this I didn't

even tell Alison. She couldn't understand why I'd very specifically asked for some tight boxer-shorts.

Dad couldn't, and still can't, stand seeing anyone be sick. He couldn't even watch the famous Monty Python sketch with Mr. Creosote. So, when one night after eating a beef sandwich I told him and Alison I thought I was going to be sick; he made a hasty retreat. I don't know how she did it but Alison managed to make it to the bed with a bowl in time for me to be sick into it. Being sick was more scary than normal because I couldn't lift my head very easily and I thought I might choke on the vomit.

Getting me to the other block where the physio gym was becoming a fiasco. Hospital porters were now drafted in to help me get into my chair and I was routinely late for my appointments. So, when Dr Collin came on a ward round I put my case for a transfer to Caversham ward which was in the same block as the gym. I met Mike, a nurse from Caversham ward, later that evening and he asked if I'd like my own room. Of course I said yes.

I moved on to Caversham ward about 3-weeks after being discharged from the ICU. I really thought I'd be home by now and not just starting my rehabilitation. I was wheeled up with my special bed that had followed me from ICU. The porters went to find my room and I was introduced to my new nurse Mark. What a jerk. I almost laughed at the way he floated across to us. You could tell he was full of his own self-importance. He turned out to be very thoughtful of my privacy but useless at everything else. He was utterly patronizing.

My social worker Sue came to visit every Thursday morning. We had built up quite a rapport. She had become my confidant and sounding board. I could really let go and get everything off my chest with her. The subject of my fluid intake had come up and I knew she'd been briefed by the nursing staff to talk about it with me. I wasn't drinking enough but I didn't like to keep asking nurses to hold a drink up to my mouth every five minutes. Sue made me promise that I would ask but I didn't.

When feeding time came around a nurse would shovel food into my mouth so quickly that I'd sometimes not finished chewing the previous load. Whenever student nurses were around they would normally be assigned this simple task. They would be good company and often be willing to gossip. I got on with many of them and occasionally flirted. Not that they would find anything attractive about me but they played along which was great for my ego. During bed baths I would try and talk about anything else as a way to avoid embarrassment. One morning I noticed that a student nurse was taking rather longer than normal to wash my genitals. At the same moment 5 more student nurses walked in – they would often come to my room as it was a great place to hide out. The group were gossiping amongst themselves and not paying me any attention but it was a truly surreal experience.

Alison came in one evening crying and I attempted to reach out and hug her but my arms just fell to my sides. It turned out her uncle had died early that morning from a heart attack. It was all very sad and more stress that she didn't need. He was a lovely chap and a very talented guitarist. He had performed at our wedding.

I was still on various medications; Fibo-Gel drinks for my bowels, Fragmin to stop blot clots and my old friend amitriptyline – a tricyclic antidepressant (TCA). I found that it wasn't a very good antidepressant but it gave me some wild dreams. I would recall my dreams to Dad and anyone

else that would listen. They varied from short strange events to full length features. One of the long ones was an epic that loosely resembled Battlestar Galactica:

*I was in an open plan shower block with glass walls after having a grueling game of Squash (a game I've never actually played) when two huge alien creatures began to fight in an adjoining room. The fight became too much for the room that they were in and the walls collapsed and the fight spilt into the shower room. A man with whom I'd been playing squash escaped and tried to block my exit through the revolving doors. I don't know what I'd done to upset this man but he seemed desperate to get me killed. He didn't succeed as I was able to force the doors so that he was spun into my place. He was now trapped in the room and it wasn't long before the aliens picked him up and started throwing him at one another. Onlookers had gathered and were watching the battle (yes, as the shower block was all glass people could see everything...). Soldiers wearing the Battlestar Galactica uniform arrived and set up a perimeter. They were about to fire when I jumped in the line of fire, raising my arms and shouting "Stop!" I don't know why; it just seemed the right thing to do. One of the aliens then fell and morphed into a rock. It transpired that these aliens had been picked up by the intergalactic police for piracy and were waiting for trial by these planets courts. There was a hearing by some elders of different species that was held on the face of a huge cliff. Each of the elders materialized out of the rock face.*

*The death of the alien was considered an act of war and then the ground around us began to erupt into large mounds of rock. These mounds then morphed into more aliens. All hell broke loose with lights flashing and explosions. I was scared and ran away. I ran and ran wishing that I could fly. And then I flew. I flew away into a completely new dream... A new dream that had me flying over the wedding of Prince Charles and Diana...*

Strange, very strange.

One weekend when Jo and Mum were visiting I was excited to be able to show them that I could touch my thumb to my forefinger. I had been wearing special casts on my hands that straightened out my fingers as there was concern that my hands were becoming claw-shaped. It was about a week after this that I managed to pick my nose for the first time! I could also pull my knees together slightly. Jo had arranged for a bouquet of red roses to be delivered to Alison for Valentine's day – she dried and kept them until we eventually divorced. When flowers arrived in Thames block everyone was a-twitter wondering who they were for. There were a lot of disappointed faces when it turned out they were for me from Alison.

Lorna had asked whether I'd like to try hydrotherapy. She explained that they'd put me through so much against my will that they'd give me a choice on this one. At first I said no as I've never been a good swimmer or particularly fond of water (funny for someone with the name Pond). As I'd be completely in their hands the thought didn't appeal to me. A few days later it dawned on me that Jo and Lorna would both be in their swimming costumes! I informed Lorna that I'd changed my mind and would be willing to give it a go. In my first session I was accompanied by Jo, Lorna and Helen. I was in my element. I was hoisted into the pool and on to a sunken sun-lounger. Air became trapped in my trunks causing a comedy bulge. The girls had a giggle at my expense and Helen even gave the bulge a prod.

From my bed I could look out on to the path that led down to the Abbey building where I'd previously stayed. I spent many hours watching people walk by. The porters used to come past

with metal trolleys that contained cadavers. On the other side of the path was the canteen building and I could see into the manager's office. I got used to his daily ritual. He used to arrive at work on his dated push-bike, lock it securely to a post and then walk into his office and then remove all his cycling paraphernalia. First he would take off his bright yellow fluorescent band then his yellow windbreaker. Then he would very carefully remove his helmet so that it wouldn't disturb his comb-over. He would then spend ages making sure this little remaining flap of hair was perfectly in place. This is an example of how I spent the many boring hours when I wasn't in physio or occupational therapy.

Occupational therapy (OT) stopped me from going mad. Both Sally and Sue my OTs did as much as they could to help me fill my time constructively. When I'd regained some movement in my hands and fingers I would spend time on their computer (a classic BBC Model B). It wasn't the sort of machine I was used to and I think it gave the staff an insight into who I was as a person. I think I was able to show them I was more than the shell of a person that I currently was. It was Sue who'd spotted that the staff was just seeing me as a patient and not a person. I don't think it was their fault – I'd just become a part of the furniture. She went to my home to visit Alison who showed her our wedding photos and realized that maybe she had been guilty of the same. She came back to the hospital with some of these photos and put them up on the wall of my room. Everyone would ask who were in the pictures without realizing one of them was me. Even when I challenged them to pick me out of the line-up many couldn't.

I still had the beard and having seen the photos they all suggested I shave it off and cut my, now long, hair. I was even offered a bottle of Champagne to do it.

During one of my OT sessions I was having my hand casts refitted. There was a student therapist watching the procedure. I thought I recognized her so asked:

"Was your Dad in the army?" I said.

"Yes!" she replied obviously a little on edge. "Who told you?"

"You did." I replied. "Do you remember going to a gig in Bracknell a few years ago with your friend Emma?"

"Yes I do." She said. "Were you there?"

"I was your date." I replied.

You could see her mind working away; trying to piece together the events of that long ago evening. The band that were playing were friends of mine and I'd invited both Alison and this student therapist, Sarah. I fancied them both but decided to hedge my bets.

Sarah was a little shaken as I was obviously now a very different looking guy. She later came by my room and saw the wedding photos where she remembered what I'd previously looked like.

29<sup>th</sup> March 1994 – My first visit home.

I mentioned to Sue that I was worried I wasn't going to make it to my child's birth and that I'd really like to make it home, at least once, beforehand. Sue thought this was a great idea and a challenge. I cannot remember how many times we'd spoken about it and I was excited about the prospect but when it became a reality I was very nervous. I was going to be taken out of

my secluded and protective surroundings. I was in OT playing games when Sue came in and asked to speak privately with my therapist. They were outside for a few minutes before they both came back in grinning like Cheshire cats. Sue had borrowed a wheelchair adapted camper van from a friend that she knew from an old-peoples home. I phoned home and asked Alison if it was convenient for me to come home for a visit. She said yes.

I was made comfortable in my chair that had recently had a very expensive cushion fitted and I was lifted into the van. I watched and laughed as Sue struggled with the straps. We were both very excited and Sue was, quite rightly, very pleased with herself. I sat high in the van and took in everything we passed. Driving into the estate where I lived was very sad as many new houses had gone up. So much had changed in these past months. Both Dad and Alison gave me a big hug on my arrival and my neighbors came around and said it was nice to see me. I was parked between two chairs and Alison showed me all the clothes and paraphernalia that she'd brought in preparation for our new arrival. Mum had brought me a guitar for Christmas (In an act of denial with regard to my situation) and Alison placed it on my lap. I tried to put my arms around it but I couldn't manage. It made me little sad. I didn't feel at home in my own house. I felt as if I was intruding.

When it came time to leave there were a few tears. I think there were mixed feelings of joy that I'd made it home and of sadness that I still had a long recovery ahead. I was actually glad to be going back to the hospital as I felt safe there. Sue and I didn't talk much on the way. She admitted that she may have made a mistake in taking me home but she hadn't. It was dark when we got back and I tried to thank Sue for the effort she'd made. I was too drained to really express my gratitude. We hugged and she left. I sat alone in my room for some time feeling very small and inconsequential.

The day had arrived for me to chop off the beard. Jock had brought in the electric shaver as promised and he did the honors. It must've taken an hour to get it all off because we were laughing so hard as half-way through he'd informed me that the shaver had been used that morning on the owners girlfriend. Nice. Nurses came past and looked on in horror as hair went everywhere and we were cackling like drunken witches. Mum, Jo and Heidi came the next day but it was a good five minutes before Jo noticed the new look because she was so keen to tell me how badly Mum had driven. She eventually took a breath, paused, and then said that something about me was different!

We spent the day doing down to the Oxford road to look at the Ducati's in the bike shop and catching some sun. Anyone that came to visit got asked to take me on a trip to the bike shop as I had a real soft-spot for the 916 and Monster models on display. The owners must've seen me sitting outside in my wheelchair but they never came out to say hello. Though I'm not sure why I'd expect them to...

Dom once took me on the bike shop pilgrimage and went in to get me some brochures. I was made up. Already my OT Sue had garnered my room with various motorcycle posters that she'd got her boyfriend to get. So with the family pictures and posters my room was looking quite comfortable.

The next week physio Jo didn't get to see my freshly shaven face but Lorna did. She poked her head round the door to check I was awake for my morning session and her face dropped as she thought she'd walked into the wrong room. When she realized it was me she gave me a big

smile and said I looked a lot better. During my physio session the other therapists kept looking at me and saying how different I looked. It gave me quite an ego boost.

One evening that week I made another big move and had my hair cut. Again Jock did the honors and again it took forever because of all the laughing. Amazingly he did a pretty good job considering he's not a barber. Dr Collin didn't recognize me and went into a meeting to discuss the new patient she'd met in the corridor. All the other staff looked at her with blank expressions wondering who she was talking about.

The next week when Jo returned she walked into my room as I was reading a magazine. I lowered the magazine and her jaw dropped. She also thought I looked a lot better. I didn't get my bottle of Champagne though!

Everyone looked at and treated me differently from that point. It was though they could now see the person and not the patient. I looked like a normal person in a wheelchair rather than an ill person in a wheelchair.

20<sup>th</sup> April 1994 – The day of the birth.

The big day had arrived and all the arrangements made. Jock was to come and pick me up and take me to Alison. I had a big bag of supplies that included bottles for me to pee into should I require. I was wearing a modified pair of baggy trousers that had a Velcro fly so that I could open it easily.

I didn't know anything was afoot but I woke to find three nurses around my bed grinning widely. Two of the nurses were night staff and they'd refused to go home until they'd seen the expression on my face. They'd all known that Alison had been in labor since the previous evening but it didn't look like anything was going to happen quickly so they'd let me sleep. Early in the morning they'd been told that her contractions were getting closer and I'd better get over there. Jock was already on his way over – driving particularly fast, in my car, as I understand. I really wanted to tell Sue my social worker that all her planning was paying off but she was away on holiday.

I'd been in and out of a car a few times and Jock and I had the process streamlined and efficient. He loaded my chair and bags into the boot of the car and we set off. I remember the seats being very hard and it was quite painful but thankfully we didn't have a very long journey. On our arrival at the hospital Jock knew exactly where to go as he'd spent so much time here when I was in ICU. We wheeled into an elevator and headed up to the maternity ward. Unfortunately we'd chosen the only one that didn't want to stop on the correct floor. After a couple of passes we got out and tried another elevator. I was getting nervous. When we eventually got to the right ward and room Jock pushed open the door and pushed me in with one big shove, turned on his heel and departed. I don't think we wanted to be too close to the action.

Firstly I got positioned at the business end but thankfully managed to re-position myself a little closer to the head of the bed so I could hold Alison's hand. Alison was excited and also a little scared. The midwife was an obnoxious woman who declared that she'd never have kids. Alison's Mum was also there and about 6 other professionals. The obstetrician looked exactly like Marvin Gaye which I thought was pretty cool.

After some serious efforts on Alison's part my son Joshua was born with the help of some forceps and some extra snips. Initially he didn't move and our hearts sank. He was quickly taken to the corner of the room to have his airway cleared. Alison turned to the doctor and asked why her baby wasn't moving.

I thought that after everything we'd been through we couldn't deal with this too but then he started to cry. Alison had a cuddle and then I got to hold him. I was very nervous as my arms were still weak but it was so beautiful. Marvin congratulated us and then I left to tell everyone waiting outside the good news.

Unfortunately we'd been in the room for a very long time and when I wheeled to the waiting room with blood all over my hands and the wheels of the wheelchair they all looked a little horrified. That all changed when I told them everything was OK and then I invited them to come and meet my little boy.

Jock tried not to notice the blood on the floor and the placenta still sitting in a bowl. His face went quite pale.

After a while we made some phone calls to Mum, Dad, Nan & Pop and tell them the good news. It felt excellent to be able to finally tell some good news. Jock took me back to the ICU so I could tell everyone there. They were pleased to see me and made a note in their communications book so that everyone else could find out.

By the time I returned to my ward in Battle Hospital everyone already knew. Terry, a fellow patient, was sitting outside smoking and when I told him I was a dad he said "I know!" There was a great atmosphere about the place and a big sign had been put up sharing the news.

The next day I got loads of cards and some newspapers that Sue my OT brought. I was really touched. My other OT Sally had said it was like everyone had had the baby because so many had been involved in getting me there. All the planning had paid off. I owe them all so much for getting me to Josh's birth – it meant so much to me.

We all celebrated. Everyone was so happy for me as we'd been through so much over the past five months.

4<sup>th</sup> May 1995

Star Wars Day. May The 4<sup>th</sup> Be With You.

Everything had gotten back to normal after all the excitement and I concentrated on my physiotherapy sessions. I was spending my time in many different ways. I did some painting, wrote poetry and I even did some cooking. During one of my physio sessions I walked. Lorna had taken me to the parallel bars that were out in the corridor. I was scared until she let go but I found I was supporting myself. For a moment it felt great and then froze too scared to move. I implored Lorna to let me sit down but she insisted I was going to walk. I took two tentative steps. It made my day. Lorna said it made her career (she'd only graduated the previous year so I'm sure this is no longer the highlight). Some other physio's came to witness my second pass of the bars. I continue to make progress and was soon promoted to a Zimmer frame (AKA Guttural Rolator).

Sometime later when Lorna was away on vacation I was being led down a corridor with the frame by physios Fiona and Rachel. I wasn't paying enough attention to what I was doing (probably flirting again) and I fell. They didn't have a chance to catch me it all happened so fast. I screamed like a little girl. People came running from all directions. I felt like they left me on the floor for an age but it was probably only seconds. By the time the shock had subsided and I was back in bed I noticed a pain in my right ankle. Mark gave it a few prods to check the pain was real. He called Dr Collin to take a look and they both decided that it wasn't broken.

That night was agony. The nurses on the nightshift stripped me and pulled me about in all directions. They passed on fact that I was in a lot of pain through the night to the day staff and it was decided I should have a precautionary x-ray. I had to wait a day to get the results. Mike came by to tell me that I had a small fracture. I was more than a little pissed off that I hadn't been listened too before. Here was another hurdle for me to jump. I had a day out across town to have a cast made. Plenty of painkilling gas made the trip worthwhile.

When Jo came to see me I thought I was going to have to miss my hydrotherapy session but someone, Sue I think, managed to find a local company that made waterproof covers for casts.

The first pool session was with Lorna. We got into the water and made our way across to the other side. Lorna was standing in front of me and helping me stand. As I still didn't have much strength in my legs I lost control over my right leg. The air-filled bag that surrounded my cast made my leg elevate between Lorna's legs. We were both a little embarrassed as she struggled to get out of the way.

The broken ankle didn't put me back as much as I thought it would. Alison was very angry and said we should try and get compensation. This soon got around and caused a mild panic amongst the staff. All the paperwork was photocopied numerous times and there were meetings. I was never going to sue and it soon returned to normal.

Dr Collin was concerned as to why such a small fall had caused the fracture so sent me to a private hospital for a bone density scan. I was diagnosed with Osteoporosis. I had a 30% deficiency in bone density. Yet another hurdle to get over. Being immobile for so long causes bones to waste just has muscles do.

I started to spend more and more time at home - progressing from a few hours to a whole day. Alison's Mum and family stayed with her aunty whilst I visited. By the time I was allowed to stay for a whole weekend only her youngest sister remained. I still felt like I was intruding in someone else's home but it was nice to have Alison and Josh to myself and to have some privacy. The atmosphere on these trips was strange as we'd forgotten how to live like a married couple. We soon got over it.

27<sup>th</sup> June 1994

The day had come to go home. Alison's sister had moved to a local school down the road so would still be staying at our house during the week. This really annoyed me. Alison asked me if it was OK for her sister to stay even though I said no - it made no difference.

At the hospital I packed away my things in the morning as someone else was going to be moved into my room in the afternoon. I kept all the posters and the progress chart Lorna had made me. I said goodbye to everyone in turn. I asked OT Sally for a hug but she said she'd get

choked if she did. I got a hug from both Jo and Lorna before walking on crutches to the door. It was a very sad moment. I was leaving my surrogate family and home. I felt quite insecure. I climbed into the ambulance and looked back towards the hospital entrance. All the physio's had come out to wave me off. I waved back as I was driven from the grounds.

## Conclusion

My first impression of re-living this journey is that I think I knew things would never be the same again. As I left the hospital I didn't really know where I belonged. My own home had become someone else's and I felt I had to fight to regain my footing.

I continued to visit the hospital for out-patient therapy so the ties weren't cut as abruptly as they sounded. I soon went back to work, probably too soon, and I was determined to return to normality.

I had to briefly go back into hospital to have some bladder stones removed – a side effect of being catheterized for 13 weeks. I enjoyed being back which worried me.

Some parts have been left out from the story because they're too emotional to write about. There are brief flickers of incidents that my imagination doesn't want to re-visit.

So did the experience change me? Yes, very much so and probably not in a positive way. I'd been ill quite a bit as a child and have been in hospital a few times and I enjoyed the attention. I think I crave attention. I worry about wanting to be ill just to get attention although I don't think I'd go that far.

Has it been beneficial going through it all again? Yes, because it's a writing experience. I'm not a writer and I wish I could make it flow better but I don't know how to structure the text. Although the memories are disjointed and fragmented so this writing is an accurate reflection of how I remember it.