

The Invincible Journey



DIANE BOUSFIELD

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This book is dedicated to “70 Years of the NHS” with our heartfelt thanks to all the Health Professionals involved in Tony’s care

At

South Tees Hospitals NHS Foundation Trust

County Durham & Darlington NHS Foundation Trust

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Cover Photo by Marie Levy Internal Communications Manager South Tees Hospitals Foundation Trust

I would like to take you on “The Invincible Journey “following our experiences when my husband Tony acquired life changing brain injury in 2011, resulting in a 5 month hospital stay a challenging time in ICU and Neurosurgical HDU before starting rehabilitation. The journey continues with the ongoing co-morbidities and challenges we face on a daily basis 7 precious years on from his critical illness”.

I am the author of two collections of poetry “The Fight for Survival Volume 1” & “The Fight for Survival Volume 2”. My books are in hospitals, universities and outlets throughout the region and country raising awareness and hopefully helping others who have experienced critical illness.

In my previous life I worked for 30 years full time until undergoing extensive major surgery myself in 2009. I am now Tony’s full time Carer and the Secretary of ICUsteps Tees where I have the unique opportunity to support others who have experienced critical illness. “The excellent medical care and intervention we received and continue to receive is our reason for being alive”

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Times of Change

The journey started on the 1 January 2011 we had lunch at our friends café in Richmond followed by a walk by the river our usual start to the New Year, little did we know the trauma that would unfold in the months ahead. Tony drove home, he always loved to drive and I remember thinking I wonder what 2011 will have in store for us both as I was making a good recovery from major extensive surgery in July 2009. I'd been given another chance at life and we both wanted to make the most of every moment.

On arriving home we settled in for the last night of the holiday before work the following morning. Around 9 pm in the evening Tony started to complain of a pounding headache and flashing in the visual fields of his eyes, he said it was a migraine and he was going to lie down until it passed. Tony had suffered from severe migraines since childhood so at the time we thought no more about it. Later on I went to check on him and he told me he couldn't see the right side of my body. I remember being alarmed by this and asked Tony if he wanted me to ring for medical assistance however he reassured me this was a normal pattern for his migraines he took his medication and said it would pass.

The following morning Tony went to work his vision appeared to be normal although he did say he felt he had a cold coming on but as it was "that time of the year" and most people appeared to be coughing and spluttering he drove off as normal. I have known Tony over 30 years and you could count the number of days he had ever had off work on one hand.

As the days moved on his symptoms did not improve and he arranged an appointment at the doctors just to make sure. The GP confirmed there was a virus currently circulating and the flu symptoms he presented with were "doing the rounds" but if his condition worsened to come back down to the surgery. By this time Tony was still at work but experiencing dizziness vomiting and headaches accompanied by frequent migraines.

On 12 January Tony was due to go back to the Doctors in the afternoon by this time he had been off work for 2 days which was extremely unusual and I was growing more concerned by his symptoms and the lack of improvement in his condition. The night had been extremely un-nerving with vomiting and dizziness which seemed to have gone up a gear and he had started to walk into objects and could not turn on the bath taps or work out when to stop filling the bath. He then walked into the kitchen for a drink and couldn't remember why he was there. I telephoned the Doctor and asked if I could request a brain scan for my husband as at this point I had an instinctive feeling that he could have a brain tumour. When I talked to Tony's GP about the situation he said he would ring the hospital straight away and see if I could take Tony down. Within minutes his GP rang back and told me to take Tony down to Darlington Memorial Hospital and they would carry out investigations and a brain scan.

It was one of those moments where I was desperately hoping that my intuition was wrong and it really was just a bad case of flu but the symptoms and evidence of Tony's behaviour were so out of character I knew deep down we were in serious trouble. On the journey down Tony told me I was driving on the wrong side of the road and the hospital was not in that direction. I knew at this point he had lost his sense of orientation and part of his vision.

It was also very apparent to me that he couldn't see vehicles approaching from the left or pedestrians on that side of the road.

A comfortably numb sensation flowed through my body on the journey there at least we were going to find out once and for all what was going on. Part of me really was desperate to know so a solution could be found another part of me would have given anything to go back to a month prior when all was relatively normal.

We arrived at the hospital and Tony had his CT scan. The pointers on the clock in the waiting area appeared to be in slow motion 20 minutes seemed an eternity eventually Tony reappeared and we went onto an Acute ward to wait for the Consultant and the results. Tony was found to have a right homonymous hemianopia which accounted for the loss of vision of the left side and the CT brain scan showed changes which were suggestive of an intracranial brain tumour.

The news hit us both like a sledge hammer and the Consultant carefully explained that they would have to do an MRI scan of the brain to see whether there was a secondary source. It was agreed that Tony could go home that night as long as I stayed with him and brought him back the next day for his MRI scan. I was also told Tony could have epileptic seizures at any time and how to deal with these. He was referred to The James Cook University Hospital to Neuro oncology for brain surgery. He was also prescribed a high dose steroid treatment. It took some accepting that what had started off as a suspected flu virus "doing the rounds" had developed into a suspected brain tumour, at this point in time the truth was unbelievable. The reality was Tony was walking around with a ticking time bomb in his brain but on the positive side it had been identified and we were now receiving the right care for his medical condition.

On the way home I stopped at the local supermarket as Tony wanted to use the cash machine however the implications of the brain tumour were already starting to impact and he couldn't remember where the machine was or what to do with the card. On the way back to the car I needed to guide him as he started walking into parked cars his vision was severely restricted. The whole situation seemed surreal. On arriving back home everything was as it was when we left in the neighbourhood however our lives had changed so dramatically in a 5 hour segment of one day.

The night was restless Tony's sleep was agitated then the first seizure struck he fell to the floor, a taste of what was to be part of our lives from now on. In retrospect this was a manageable seizure for what the future had to hold.

The following morning I woke to the full impact and reality of our lives day by day was the only way to move forward. We arrived at Darlington Memorial Hospital and Tony went in for his MRI scan. I flicked through all the magazines on the table in the waiting area unable to concentrate on anything while I came to terms with the situation. In reality Tony may only have months to live. Tony eventually emerged from the MRI scanner room and I drove him home. At this point he seemed to have lost all awareness certainly of the seriousness of his situation, comfortably numb was the description which springs to mind and it was probably for the best in the circumstances.

We returned to Darlington Memorial Hospital the next day to see Tony's Heart consultant for his regular check-up it all seemed very surreal. We were reassured this was the only course of action we could follow to extend the time we had together.

We only had 6 days to wait to see Tony's Neurosurgeon which was very quick indeed but the days at this stage seemed to be never ending and the nights particularly un-nerving punctuated with seizures.

Eventually the 27 of January arrived and we travelled to The James Cook University Hospital. Tony insisted again I was going in the wrong direction and we would end up at Redcar for fish and chips if we followed this route. Although I must admit at this stage fish and chips at Redcar was definitely a more appealing option than the Neuro oncology clinic I chose to ignore my husband's normally excellent navigation skills and followed my own.

I guided Tony through the hospital car park navigating for us both it became very apparent to me the severity of Tony's visual deficits. I now had to be his eyes and direct him as he couldn't see stationary vehicles and when crossing the road appeared to have no sense of judgement regarding the speed of vehicles or awareness that they were even there. After a slightly hazardous trip across the car park we eventually reached the sanctuary of the hospital passing the James Cook World situated outside the entrance. How well I would become acquainted with that particular feature over the forthcoming months.

We waited in the Neuro oncology clinic and were called in to see Tony's Neurosurgeon who showed us the scans of Tony's brain which showed changes suggestive of a high grade primary brain tumour. He recommended a craniotomy and decompression of this which Tony agreed to without hesitation. I remember thinking how incredible it was that Tony was still functioning at all with the mass inside his brain. Twenty four hours previously I had not perceived viewing scans of my husband's brain but it enabled me to gain an insight into why Tony's sight had been so severely damaged by the location of the mass. Tony's Neuro surgeon was reassuringly confident he could remove the mass which we both found incredibly comforting.

To this day I can remember the layout of the small room we went into where we sat and the Macmillan nurse and students who were also part of the consultation. We were assigned a Macmillan nurse who would telephone me to see how things were going and answer any questions I may have. We were also informed the prognosis was not good only months after surgery and additional treatment. We had to stay strong and fight there wasn't really any other alternative.

We would receive a telephone call for the operation date and we needed to attend the Neurosurgical pre assessment clinic within the week with a view to admission for an operation soon after. A prescription for more steroids was issued for me to pick up from the James Cook pharmacy before we left.

Little be known to all of us in the room that day we were not going to follow that specific route instead an emergency admission, five month detour including an ICU and HDU

Neurosurgical stay and fight for survival would ensue. Sometimes it is better not to know what your future path entails.

We left the Neuro oncology clinic and sat in the James Cook atrium eating sandwiches. The world continued around us at its usual rate lots of patients and visiting families and friends medical staff and some interesting art work on the walls. This was a good place to sit and try to collect our thoughts. I remember looking upwards to where the Neuro ward was located and thinking that would be where I would be visiting Tony in the coming weeks. Tony had not retained any of the consultation and I found myself trying to explain what had been said whilst trying to absorb the enormity of the situation myself. In the back of my mind was the safety net that if the operation went well Tony could be home within a few days and would attend on a daily basis for further treatment.

Tony and I made our way down to the James Cook pharmacy to pick up his prescription and another bolt struck. Tony couldn't remember how to sign his name everyone at the pharmacy was very understanding and I was able to sign and collect the medication on his behalf. This was another significant deficit which had appeared since we left the house that morning. Tony's condition was definitely worsening but we only had 5 days to wait for his pre-operative assessment.

To our relief the days passed quickly to the 2 February and we attended for Tony's pre-op. His lack of awareness and memory were very apparent as he couldn't remember his past medical history or his parents. The nurse very patiently tried on numerous counts to extract blood from Tony's arms then his hands but he was not parting with any that day.

He was very much now in his own world as I drove back home he slept all the way and on entering our house started to complain of a thumping headache. Within half an hour after consuming a glass of water his headache had intensified and he started shouting in pain saying that his head felt like it was going to explode. Then he fell to the floor. I managed to get him back onto the chair where he laid down writhing in pain without hesitation I dialled 999 and the paramedic support team were with me in minutes. After stabilising Tony he was rushed to Darlington Memorial Hospital where time stood still in the resuscitation unit as the medics gallantly fought to control his pain levels and arranged for him to be transferred to The James Cook University Hospital for brain surgery.

The images of Tony in A &E that night will remain with me for the rest of my days. It was heart wrenching to see him so disorientated. I felt so desperate that I couldn't stop his pain he was so incredibly agitated and didn't know where to put himself. It took Mum and me all our time to keep him on the narrow bed in the cubicle and I knew then I was saying goodbye to the man I had known for 20 years of my life if he survived Tony would be different. In those brief moments our lives together rushed through my brain Tony had always been a very strong man and now I needed to draw on my inner strength and be there for him and face the hard fact that these may be the last moments we would have together.

I also took comfort that Tony was in the only place where he stood a chance. Although I was surrounded by medics I remember an overwhelming feeling of total isolation. Memories of the Consultants asking me a stream of questions about Tony's current medical condition and his medical history still haunt me today. I can picture the medics' station and the constant flow of paramedics bringing in seriously ill patients for medical attention.

I took a short walk to the hospital reception area to telephone Tony's mum to let her know what had happened. The outpatients' area was eerily quiet from its normal hectic hustle and bustle of patients and visitors coming in and out. The sandwich bar closed even the coffee machine was quiet. It was nearing midnight this had already been one of the longest days I had ever spent. Shortly after I returned to his bedside I was told he was due to be transferred very shortly and they were preparing him to go to The James Cook University Hospital as an emergency admission which would overtake plans we had for elective surgery. I was told to try and get some sleep and the Neurosurgical ward would ring me when he was stabilised so I could see him.

Somehow I managed some pockets of sleep and I drifted in and out for several hours before being woken by the distant tones of the telephone and the calm voice of a nurse from Neurosurgical HDU asking me if Tony was a violent man as he was lashing out. I couldn't actually believe what I was hearing as Tony was always in full control of his faculties. I was told to travel through as quick and safely as I could but they could not guarantee Tony would still be alive when I arrived.

Tony's condition had deteriorated with generalised seizures and repeated brain scans had raised suspicions that the suspected tumour was an abscess. Tony had been resuscitated intubated and ventilated and was now being prepared for theatre. In a state of shock I hastily left the house collecting my Mum on the way for support and sandwiches.

The journey along the A66 was never ending the lines of bollards and speed restrictions which seemed to pop up overnight I could have definitely done without. All the time my mind preoccupied with the unbearable thoughts throbbing through my brain that I may not make it to see Tony one last time and the overwhelming feeling of sickness that wouldn't leave me. I just prayed he would still be alive when I reached the hospital.

Life in the Balance

On arrival at Neurosurgical HDU I was greeted by a surgical team who took me into a private office and explained Tony was still fighting for his life and that repeat cranial imaging had raised concerns that the suspected tumour was an abscess. Following immediate resuscitation including intubation and ventilation Tony's Neurosurgeon was preparing to take him into theatre for a left occipital craniotomy and evacuation of brain abscess. In the meantime there were forms I needed to sign on Tony's behalf and I was also given access to a telephone to contact Tony's mum who needed to know Tony was in a life threatening situation.

The medical team explained to me clearly in layman's terms the gravity of the situation so as a non-medic it was very easy for me to grasp as at that time I was coping with a flood of overwhelming emotion and initial shock. The complications and severity of the surgery were very clearly explained to me and that if Tony survived he would be in ICU. I remember lots of questions flying round my head and medical staff reassuringly trying to answer them all.

I remember an intense feeling of relief knowing Tony was still alive coupled with an incredible feeling of anticipation and fear. He was the only person in the Neurosurgical HDU room with the curtains closed around him and numerous medical staff I wondered whether he would even know who I was. I was asked to give Tony's medical details to the theatre team and I clearly remember all the sounds coming from behind the curtains and medical staff stabilising him for theatre. I knew this was my one and only last chance to see Tony before he went for surgery.

I probably stood too close to Tony that day he was restrained for his own safety gasping for oxygen through a mask fighting for each breath he took the whites of his eyes rolling but he was still Tony to me. I was told not to touch him or go too close in case he lashed out but as I stood beside him he seemed to recognise my voice. His body was broken and he was with the only people who had the skill and expertise to help him. I remember seeing lots of puncture marks where the medical staff had tried to put in lines and take blood he was fighting with everything and everybody. I told Tony I would be waiting for him as he had been waiting for me when I underwent surgery 2 years earlier.

I am and always will be eternally grateful for the opportunity to talk and comfort Tony that day priceless precious moments essential to prepare me for what was ahead. If he hadn't survived I felt at least I had the opportunity to see and comfort him one last time.

I will never know whether Tony could see or hear me that day but he did calm down a little on hearing my voice. I can still visualise him laid in the bed and the sense of helplessness that I was powerless to help him, mixed with the comfort blanket of Tony's clinical team on whom his survival would depend along with whether his body was strong enough to survive. Only time would tell. We could not turn back the hands of time and our future was now in the balance.

A very kind nurse took my mum and me to the staff room where we ate our sandwiches and were offered some Thornton's chocolates. It all seemed very surreal as I was eating lunch Tony was being taken down for brain surgery which he may or may not survive. I was told the operation would be a lengthy one and that I would be able to visit him after if all went well. I really wanted to wait at the hospital but knew it was going to be a long wait and reluctantly with a little persuasion I agreed to go home and wait for the telephone call, hoping and praying that the operation would be a success.

I was also prepared for the fact that if Tony did survive he would be in ICU or Neurosurgical HDU but I would be able to see him whatever time he came out of theatre.

Eventually after an arduously long seven hour wait the telephone call came around 9.30pm. Tony had survived the surgery and made it to ICU. He was in intensive care ICU3 in an induced coma. The abscess had been evacuated. My initial reaction was total elation and amazement. Tony had survived the operation I knew deep down he had a chance now to fight for his survival.

My Dad accompanied me on the night shift travelling the same journey I had made only hours earlier that day thinking Tony may not be alive when I arrived. This time was different I knew he was on life support the machines would stop him from dying before I arrived. He was in a critical condition and the future was in the balance I could not afford to lose hope.

On arriving back at the James Cook University Hospital I had no problem parking it was after 10pm at night and the hustle bustle of the daily outpatients and visitors had substantially died down.

The hospital was calm the Neuroscience main entrance uncannily quiet the lull before the storm. My Dad and I climbed the stairs together. He always knew the right things to say at the right times but we both knew this situation was definitely going to be out of our comfort zone. As we walked along the corridor the calm and stillness lulled me into a false sense of security and I began to wonder what to expect when we entered the ICU. I had recently undergone major extensive surgery and was only too familiar with drips drains catheters ventilators and tubes but I was conscious and aware of my situation. I realised Tony would not respond to me at all when I saw him. He would be totally unaware in an induced coma and would be a situation of zero communication.

I opened the first door which led into the ICU3 waiting area and pressed the buzzer for the double doors to open and proceeded to ICU3. Outside we used sanitiser on our hands and put on aprons and I peered through the glass windows in the entrance door to see if I could see Tony's bed. I remember so eagerly wanting to go in but knowing that Tony was in a critical condition and if he did wake from his coma he would never be the same again.

I felt a combination of feelings on entering the unit anticipation fear relief and hope all rolled into one a mixture of emotions that would remain with me over the coming months ahead.

My heart was racing palms sweating adrenaline pumping I had to see him no matter how hard I needed to draw on all my strength to help him through. I clearly remember the anticipation as my Dad and I were led to the bed where Tony lay. My senses were in overdrive, my eyes registering all the other patients in the unit until I arrived at his bedside.

The bed where Tony lay was at the end of ICU3 on the right hand side as you enter. I can close my eyes to this day and still visualise the layout of the unit and the consultants and nursing staff constantly attending to the patients' needs. The windows seemed to be darkened so you were in a time warp as there was no clock visible. In a way this was strangely comforting it didn't matter what the time was or what the weather was doing I was now in the extraordinary world of ICU care a different world to the one I had left outside.

The patients were definitely outnumbered by the life-saving medical equipment keeping them alive. In a strange way when I saw Tony he was so peaceful since the last time he was resting not writhing in agony and distress. He was so silent just the beeping of the machines and his skin had more colour than prior to his admission his pale pallor had disappeared. He looked well cared for and extremely clean in fact everything was very white bright and light. It reminded me of looking at a new-born sleeping child who had no idea of the severity of the situation they were in.

Tony was in a suspended state of life neither in this one or the next. The life support machines taking the pressure of his body and the induced coma to help his brain heal. Within 24 hours he had journeyed from the extreme of being in tremendous pain to a peaceful almost transitional state and although totally shocking I couldn't help feeling relief that he had survived the surgery. Tony had actually made it to ICU he had a chance now to fight for his survival. He was safe the life support machines would keep him alive and although there were numerous tubes and wires they all had a specific function. These machines and wires were not to be feared but greatly respected and accepted as they were part of Tony's life support system and his wrap around care.

My emotions fluctuated the fear raged through my system like a torrent how did this happen and could we have prevented it? This particular mystery would never be solved but at that time I knew that the sooner I acknowledged life would from this day forth be different dispel the what if syndrome and focus on the present acceptance was without doubt the only way forward. Tony was relying on me to pull out all the stops to be there to support him.

I will never forget the ICU nurse who looked after Tony that night he was so dedicated constantly checking him and looking after his every need. I knew Tony was receiving excellent care and although his life was still very much in the balance he was in the best place possible for his fight for survival. I remember asking if the prognosis of a brain abscess was better than a tumour and the nurse was extremely truthful about the long term effects and disabilities Tony may have if he survived, which was information I needed to know at this stage. Knowing he was there for Tony made such a difference to me and he had informed and prepared me so I had the information to deal with the situation we were both in. I found myself clinging onto every word trying to absorb medical terminology and take in Tony's condition. Knowledge was power and it would help me prepare and cope with the months ahead. If there was anything I could do to help Tony I had to try no matter how much I was out of my own comfort zone.

My eyes were totally fixated by Tony's motionless state but I was determined to talk to him and hold his hand I wanted to believe that he may be subconsciously taking something in only time would tell. I just wanted him to know he was safe. He was in a world of his own, one where I couldn't reach him. I knew this was the start of a long road and every minute counted as his body fought with a complex raft of problems attacking his body's natural defence system. My heart strings were pulling me back to ICU I didn't want to leave Tony's side and go back to the outside world without my soulmate. Every moment being present at his bedside was so precious it may still be the last.

My imagination and senses were in permanent overdrive. I was visually trying to absorb and understand the readings on the life support machines. My ears trying to adjust to the constant noises from the machines and my smell receptors adjusting to the medicinal fragrances of ICU. Absorbing the situation the smells sights and sounds, the ties that would bind me to ICU along with a cauldron of emotions. A form of hypnotic vigil would ensue for the days and months ahead. We were all alone in our own time passages.

The wheels of the carousel would keep turning for the foreseeable future. I was in an alien world and I knew to survive and be able to support Tony I needed to accept and adapt like a chameleon to my circumstances. The past was gone and this was the here and now what the future held if in fact we would have a future together was uncertain. Tony's clinical team would become my colleagues and friends. I was an outsider and I had to find a way into the inner sanctum which I felt comfortable with find my feet quickly and learn to absorb my new world.

My Dad and I eventually left his bedside on the condition that I could ring ICU in the morning to see how Tony had managed the night. I travelled home reassured that at least for tonight he could not die the machines would keep him alive a very strange thought but incredibly reassuring.

I managed some sleep probably more from mental exhaustion accumulated over the past few days. Tony was by no means stable or out of danger but he had a chance and that feeling of hope and possibility for a future gave my inner strength and moral fibre a positive kick start.

The next morning I rang the unit after 10 am to see how Tony was and after hearing first-hand the night had been uneventful reassured I went for my usual morning walk. ICU visiting started from 2pm so going to the hospital before then was counterproductive. I had to get back into some form of routine as I needed to stay as strong and fit as I could to help Tony. It all seemed rather surreal everything going on around me as normal but I was in an ICU vacuum. Tony was there in body and soul his spirit had a tough road ahead and it was up to me to make sure I was there for him every step of the way.

On arriving at ICU accompanied by my Mum I had to wait to see Tony. I remember feelings of anticipation racing through my veins as I sat in the waiting area with families and relatives of ICU patients waiting for the green light to visit and hoping it would not have turned to red by the time we got to our loved ones bed. Empathy echoed around the waiting area no one had to say a word but the emotional turmoil was boiling within our very beings.

The minutes slowly ticked by and we were told Tony was ready for his visitors. I approached the door and gelled my hands put on a protective apron and peered through the door to see if I could see a glimpse of him before entering. The ICU medical team were very busy but very calm and on entering the unit looked even brighter by day. Tony was in his same motionless state as I expected him to be and I was informed that a repeat CT scan that morning showed hydrocephalus and there was concern of ventriculitis. Tony had therefore undergone an insertion of a right frontal external ventricular drain. His cerebral spinal fluid showed a mixed growth of bacteria consistent with ventriculitis. At this point in time my

mind was trying to juggle an image of bacteria invading Tony's brain via his spinal fluid while Tony was totally oblivious of his situation.

My brain was definitely in overdrive and I felt a compelling need to learn as much as possible about Tony's neurological condition. Increased complications and complexities were going to challenge his medical team and me over the months ahead. Tony on the other hand remained peacefully sleeping in his coma with a white bandaged head unaware of the severity of the situation he was in.

As the hours passed by that afternoon I sat by his bedside talking through our holidays and the places we had visited which now seemed a lifetime ago. It was a one way conversation with no feedback not a twitch of an eyelid or squeeze of a hand. Instead he lay there as the machines and medication continued to keep him alive a captive audience to my constant chatter.

I would have given anything for him to intervene but knew it was an impossibility at this stage this one way conversation was normal for the situation we were in. It was the hope that he would absorb some small part of my conversation subconsciously which kept me going. Whilst in his coma he looked very peaceful and I remember what the medical staff had told me that his brain was healing. Unknown to me at that time I would continue to reiterate our lives together for the foreseeable future.

Tony's body was broken his life was in the balance. I knew as a seashell offers protection for a mollusc to live in turbulent conditions I had to develop a hardened shell to protect myself against negative thoughts and fears racing through my brain. Then I could try to minimise the impacts of the initial shock and emotional injury so I could deal with the crisis situation Tony and I were in.

Tony's clinical team prepared and involved me in decisions every step of the way and this preparation and involvement were the keys to my survival when Tony was in ICU. This coping strategy became my invisible shell of protection giving me control both physically psychologically and emotionally whilst in a situation totally out of my comfort zone. There was going to be a long unpredictable journey ahead for Tony and I needed to remain strong to support him through his incredible and challenging fight.

I clearly remember waiting in the ICU lobby for Tony's Neurosurgeon to arrive wondering what the future had in store for Tony and talking to him in the relative's room. He explained very calmly and reassuringly that the evacuation of the brain abscess had gone well although the future was very uncertain. It was a case of waiting and that the ICU clinical team would look after Tony.

He would like to wake Tony from his coma in the next couple of days and I would be able to be present when the time was right. I would have loved to hear the words that Tony would survive and even maybe have a quality of life, but I knew surviving critical illness has no silver bullet. Every hour counts and survival of additional complications would be forthcoming obstacles to overcome. It was just a case of accepting the situation and remaining confident and positive for his survival.

After our conversation I remember feeling a sense of optimism and hope coupled with reality fear and suspense as to what our future would hold. I sat with Tony that afternoon as he lay in a motionless state with no response or feelings. I felt myself becoming entwined in the ICU world of infusions sedation intubation and ventilation. I became hypnotised by the machines continuously monitoring his basic bodily fluctuations and trying to visualise how things would be if and when Tony woke from his deep sleep. I continued to talk to him hoping he would be absorbing some of our conversation maybe reforming memories. It was comforting to think this could be the case.

I remember telling him that hopefully his coma would be reversed soon and we would be able to communicate with each other again. However deep down I had reservations as there was permanent damage to his vision and uncertainty over damage to the speech centre, not to mention cognitive and physical function so it was just a case of waiting and hoping. Tony was suffering with thrombocytopenia and had a platelet transfusion. I clearly remember sitting and watching the drips. He was trapped in his body so close to me but yet so far away.

Tony's clinical team were the last human barrier between here and now and the grave. His survival depended on the expertise and skill of his Neurosurgeon theatre teams ICU team physiotherapists dieticians and dedicated nursing staff all working together for total wrap around care. Tony's body had a large part to play as to whether it could sustain the barrage of medical intervention. For my part in all of this I needed to stay vertical and be there by his side on the off chance that one day he would recognise who I was and my barrage of constant chatter would have paid off.

The day finally arrived for his induced coma to be reversed at a time when I would be present. My primary emotions that day whilst waiting to go into ICU3 were a combined state of suspense, excitement, tension and obscurity about the future coupled with a degree of apprehension anxiety and uncertainty. To be there for Tony at key developmental stages and involved in the decision making process as he was unable to make decisions for himself were both crucial and essential for me. To be involved at this stage was a precious priceless experience for me.

I approached his bed Tony was in his motionless peaceful state attached to his drips and machines which became part of his care over the coming months. He was totally oblivious of the turbulence and suspense coursing through my veins. I stood on the left side of the bed where I had stood so many times before. My heart racing waiting for the consultant to reverse the coma.

I spoke to Tony holding his hand and waited. At first the silence was deafening the ICU team and consultants present decided to change positions with me as we knew Tony's sight was significantly damaged and there was a possibility I was out of his visual field. I started to move away from Tony to change places and let go of his hand at that point Tony spoke "Don't go lane". A flood of relief flowed through my body he could speak. Tony's first words will be forever imprinted in my brain as a parent remembers a child's first spoken words. I had been well prepared for his visual cognitive deficits and damage to the speech

centre the fact that he responded to my voice and knew who I was gave me tremendous hope fight and determination for the road ahead.

Tony was due to have a chest x-ray and I remember a member of the ICU nursing team passing me an x-ray protector to put on, which turned out to be considerably heavier than I was expecting so I could stay with him. A warm wave of hope and positivity washed over me as I stood beside him. Words will never be able to express the incredible roller coaster of emotions and feelings I experienced that day. Tony was starting to fight for his survival and we could communicate with touch and a few words, at least for that day Tony knew I was there for him and at that point in time I could want for nothing more.

I was very well aware Tony was far from stable and without his medical team he would cease to be. I was reassured they were with him every step of the way and he was in the best possible place for the intensive support he required. However unbeknown to me at that point in time multiple operations lie in wait for Tony. He was awake but far from out of the woods. We were now going to enter the hallucinogenic world of drips, drugs and delirium with occasional lucidity and infrequent speech as Tony battled with ongoing hydrocephalus and medical complications. Multiple operations would follow.

Tony constantly raised his hands upwards rotating them before trying to pull any wires he could reach totally unaware of the damage he would inflict on himself. Food tubes fell from grace on numerous occasions, and I would arrive at ICU3 to discover he was having another one fitted. My visiting times became very hands on literally. I had to continually distract him from pulling drips and wires desperately hoping he would not discover the fact that he had many staples in the back of his head. I think they only survived because he was oblivious to the fact they existed.

The safest place for wires and tubes were in the lower half of Tony's body although this was not always the most practical place to put them. At one point the oximeter was on his toe but he soon managed to shake it off. The ICU nursing staff came to the rescue with pillow cases on his hands to restrain his movement for his own protection. The nurses explained clearly to me that pulling wires was a positive sign in neurological cases, and although distressing to witness the underlying result was Tony was showing encouraging signs.

Although Tony was awake from his coma I found myself talking none stop as there was very little conversation taking place. Confusion hallucinations and delirium took centre stage. Every morning and evening I telephoned ICU and the nurses would always update me on his latest exploits. I clearly remember the feeling of tremendous optimism I felt when the nurses had told Tony I had telephoned and he had responded with "I love my wife".

My afternoon visits usually started with the latest instalment of Tony's wire pulling saga and the consequences. Tony spoke very little after the initial sentence apart from streams of binary data and he told me his deceased family members had been to see him. It was particularly hard as he kept asking when his Dad was going to visit and obviously had no recollection he had passed away many years ago. Tony's eyes would roll the whites would be visible and he would drift in and out of oblivion. He never wanted me to leave so I always used to say I would just be next door and this seemed to settle him.

He was convinced he was part of an experiment but it was top secret and I mustn't tell anyone. In hindsight this could have been his mind reverting back to when he used to volunteer at Darlington Memorial Hospital Cardio unit for the junior doctors to try and locate his heart murmur or it may have just been one of his many hallucinations. Tony's physio team were looking after his every need but as the days passed and he remained bedridden and attached to his many medical accessories I began to wonder whether in fact he would ever be able to mobilise again.

Tony's imagination was running wild. He was talking to the drips and machinery as though they were people. His brain malfunctioning creating people shapes and objects in his mind's eye a collage of external images he conjured up from deep within. Tony had always been a railway enthusiast whilst in ICU he managed to take this hobby a stage further by turning into a steam train driver on the North Yorkshire Moors railway. He told the man in the next bed he particularly loved driving the route from Grosmont to Pickering especially the Christmas lunch express which we had been on several years ago. Tony then proceeded to go through a raft of occupations from bank manager which delighted one of the nurses who wanted to know which branch he worked in to a race horse jockey training at Middleham racing stables.

He was also a Liverpool striker a recurrent theme throughout his delirium playing at all the different football stadiums in the country which he still appeared to remember. These hallucinations and delusions were a touch of reality intermingled with dreams uttered every so often in-between lapses of deep sleep. Every day was different but very real through Tony's mind. As a relative I had to take it all with a pinch of salt the barrage of hallucinations and delusions sometimes left me somewhat confused other times bewildered and amused. This was delirium visual apparitions and loss of control. Disorientation imbalances brain abscesses epilepsy drugs and bacterial bugs were all chief suspects. At this stage all I had to do was accept it was normal for Tony's condition and try to support him as well as I could through these kaleidoscopic surreal dreamlike images.

I can clearly remember the first time Tony asked me to take his legs off. Initially I was quite horrified by his request but realised he didn't think they were part of his body. I remember folding back the sheet to look at them in an attempt to reassure him, and he very calmly told me "that was rude". I therefore hastily covered him back up again. His modesty had to be maintained at all costs.

While in ICU Tony often accused my Mum of being a hot head and she needed to take her shopping trolley off to town to cool down. This statement was usually followed with an exasperated facial expression and panic that he had just squashed her under the bed, which he was always rather sorry about. It took me all my time to console and reassure him that he hadn't actually squashed her and she was very much alive and at his bedside to support him. At this point I had to accept pleasant confusion would continue to reign for the unforeseeable future. His previously logical brain was now in total disarray his occipital lobe malfunctioning resulting in reduced electrical signals fuelling the imagination.

I have vivid images of two physios trying to help Tony sit up unaided in his bed. I sat in front of him to encourage him to stay awake, but he kept slumping forward his upper body limp his lower body not moving. He looked totally exhausted just trying to keep his eyes focused on me. Tony really just wanted to sleep. At this point the nursing staff were turning him throughout the day and night as he was unable to do so himself.

Tony was transferred from ICU to Neurosurgical High Dependency Unit where he had a Hickman line inserted for antibiotic treatment and ongoing haematological support. Visiting continued being very hands on as his fascination for pulling wires did not diminish. I was involved in trying to occupy him when EEG's were taken as Tony was trying remove the wires as fast as the nursing staff were putting them on his head. Hospital volunteers would sit with Tony whilst he was in HDU and one afternoon he was enjoying a head massage when I arrived.

Tony's conversation remained limited and I clearly remember one afternoon a consultant and team of medical students surrounded Tony's bed as his history and medical conditions were explained. I squeezed Tony's hand and he said "Hello Diane". I remember the amazement on the consultants face as he was surprised he could speak and was keen to inform Tony's Neurosurgeon on his return to work. Tony maintained communication silence unless prompted or questioned however his responses ranged from fantasy to reality.

Snakes and Ladders

Tony reeled from one medical complexity to another. The following afternoon I was told he needed to undergo further surgery to remove his right frontal external ventricular drain and insert a left frontal external ventricular drain. Tony going down to theatre for operations was becoming a regular occurrence. His body was broken and his clinical team were trying to rebuild him in the best way they could. I remember walking round the hospital corridors waiting for the call to say Tony was back from surgery.

I sat outside the café watching the constant flow of ham and egg Paninis being served to hungry visitors. I was trying to act natural but totally in a world of my own. Text messages of support kept coming through my mobile phone and I remember reading them knowing that at this point in time Tony couldn't remember who any of his friends were. His world revolved around me when he knew I was there and my Mum and Dad plus his deceased relatives and his imaginary colleagues and friends along with the clinical team who were all "part of the experiment".

Eventually the call came he was back in HDU and I could go up. I found myself speed walking through the corridors I just had to know he was ok. What a relief to see him lying there another procedure successfully accomplished I could breathe a sigh of relief for today but Tony had more forthcoming attractions lined up for me in the course of events which were to follow.

Tony continued to remain unstable throughout February and March. I remember quite clearly going to pick up my Mum to take her through for our afternoon visit. I had just pulled up in the car on her drive and my mobile went asking for my permission to insert stents. Tony had developed a deep venous thrombosis of his right lower leg so we were off to the operating theatre again. This time on a local anaesthetic. On arriving at the hospital I wandered around those corridors again looking at all the artwork on the walls. Some of the pictures brought back some lovely memories of our walking days.

When I received the message he was out of theatre it was a case of speed walking once again up to Neurosurgical HDU. Tony had apparently been trying to help with the wires as they were inserting the stents. He was still very good and very quick at pulling wires and his fascination for this if anything had increased.

The lights were low when Tony returned from theatre and along with the heat from the machines after a while I could feel myself starting to feel drowsy. I couldn't help noticing how large his leg was with the thrombosis. Tony had obviously had a very busy time watching what was going on and had worn himself out so at this stage he was quite content to drift in and out of sleep with me sat at his bedside holding his hand. What was going on in the outside world was totally irrelevant. Time stood still the windows were darkened and Tony was still fighting, still hanging in there that was all that mattered. When I left Tony in the Neurosurgical High dependency unit that night I realised he had significant support with antibiotic haematological products and intravenous anticoagulation and they were keeping him alive.

When the time came to revise the external ventricular shunt the cerebral spinal fluid specimens showed Tony's ventriculitis was resolving and the CT scan showed involution of the abscess cavity. This was some positive news however it was to be short-lived as subsequent assessments showed Tony was dependent on his cerebral spinal fluid drainage. Therefore it was necessary for Tony to have another operation to remove the external ventricular drain and insert a right ventriculo-peritoneal shunt with a special antibiotic coating to help reduce infection. I remember the registrar explaining to me in great detail the procedure. He answered all my questions relating to the cerebral spinal fluid and how the shunt would act as a valve releasing the spinal fluid every 6 hours.

I could see Tony was fighting as hard as ever to stay in this world and as I was discussing the forthcoming surgery. Tony was laid there apparently listening but totally unaware of his next theatre trip which under the circumstances was probably for the best. He was certainly very drowsy at this stage and less aware than usual. I stayed with him until around 7pm that night as he was due to go into theatre later on. All I could do was hope and pray he would make it through the operation. I knew he had a dedicated team and could not be in better hands.

Relief all round when the telephone rang the operation had been a success and Tony was back in Neurosurgical HDU. When I went in to visit him he recognised me and squeezed my hand then started to pull wires again I knew he was still fighting.

Tony was starting by mid-March to stabilise and make slow but steady progress however on 20 March a routine follow up brain scan showed re-accumulation of the cerebral abscess. Tony would need further surgery to re-open the left occipital craniotomy and decompress the recurrent abscess. I remember that day very clearly Mum and I went into the neuro bay which Tony had been transferred into from Neurosurgical HDU a couple of days prior. Tony was sat up in bed looking brighter than usual. He was starting to string together more sentences and he recognised us as soon as we walked into the room. The HDU nurse who was looking after Tony on the bay as he had a Hickman line in for his treatments informed me Tony's Neurosurgeon needed to have a word with me and he wouldn't be long. It never crossed my mind at that point that he was going to tell me the abscess was back.

Tony's Neurosurgeon arrived with an entourage of medical students and senior nursing staff who all assembled round the bed with my Mum and me. It was like a scene out of a hospital TV drama but we were the players. We drew the curtains around Tony's bed and his Neurosurgeon explained to me the abscess had returned and we were basically back to square one where we had been on 3 Feb after Tony's first abscess was removed. Tony would require a further operation to re-open his left occipital craniotomy so the recurrent abscess could be decompressed. This would be followed by 6 weeks intravenous antibiotic medication. However there was a problem Tony had neutropenia his white cell count was low so they had some medication they could give to temporarily boost this in order to operate. If the surgery went well Tony would be back in Neurosurgical High Dependency Unit although there was a possibility he could be back in ICU it would be a waiting game. The drugs would take a while to work but as soon as he was able Tony's Neurosurgeon would be taking him back down to theatre for another craniotomy.

I was stood next to the wall at the time which was rather fortunate as I really felt like I needed propping up. The anaesthetist would be along shortly to go through the necessary details with us all. I really couldn't believe we were going to relive the experience again when we were all just trying to get over surviving it the first time, but I consoled myself with the fact that this time was different.

This was elective surgery planned with Tony's body as prepared as it could be. The team knew what they were dealing with and they were excellent they'd proved that the first time so I had to believe. I still remember feeling comfortably numb with the whole situation and a tremendous surge of suspense over how successful the operation would be and whether any other brain functions would be lost. Vibrant images of ICU and his raft of complications after Tony's last craniotomy impacted in my brain. I could not allow the past to taint the future. I must take control of my feelings of anticipation regulate the fear factor and not allow my facial expressions to show any concern to Tony.

Tony was the star player in this drama but was totally unaware of his forthcoming operation so I tried to explain it to him. Maybe again for the best he didn't really take it in just smiled and held my hand. The fight for survival was becoming the norm.

The anaesthetist arrived to go through the necessary protocol and paperwork prior to surgery. I found myself automatically answering all the questions however Tony did manage to add some confusion to the proceedings by uttering the words he was allergic to penicillin. Everyone around the bed at this point looked slightly shocked as he had been treated with it in the past and I reassured everyone that although it sounded very convincing Tony did not have an allergy to penicillin it was me. His dysphasia was evidently in overdrive.

Tony would be taken to theatre as soon as his white cell count was raised enough for the operation to proceed. Then it would be a case of me waiting for that telephone call again to find out whether he had survived was in ICU or Neurosurgical HDU.

I received a phone call the following morning saying Tony was ready for theatre and they would let me know when the operation was over. The hands of time continued to move but my life was on hold until I received news of Tony's survival. I was becoming case hardened to this way of life not a path I would have chosen. It was a heart rendering situation. Tony was so vulnerable there were no other options open to him and I couldn't help feeling he had been through enough. How much more could his body take? I consoled myself with the fact that his spirit and will to survive were very strong and I had to believe with excellent medical intervention Tony would live to see another day.

Eventually the phone rang to tell me Tony was out of surgery and to my relief he was in Neurosurgical HDU. At least this time he was not in ICU in a coma but I was still unaware of how he would be on my arrival at the hospital. The journey through to James Cook passed quickly and I found myself hurriedly racing through the car park desperate to see Tony.

On entering HDU there were 3 patients in the unit and Tony was near the window this time in the furthest bed from the door. Tony was motionless as I approached his bed I could see he was on oxygen with his usual accessories of wires and drips. My memory vaults were working overtime. An aura of apprehension washed over me as I waited for news. Relief came swiftly as I was informed the operation had gone well and the abscess had been decompressed. However Tony was suffering from neutropenia and would continue to require significant support with antibiotics haematological products and oxygen.

I sat by his bedside for a little while watching him peacefully sleeping and holding his hand and talking quietly to him. Then to my total surprise his eyes opened and he said "Hello Diane". Relief flooded through my body like an energising mountain stream at least this time he was back in the room with me within hours of his surgery and I found that very encouraging.

Those were the only words spoken that night but that was enough for me to feel reassured the fight would go on although I knew he was not out of the woods yet. Since his original brain injury Tony was not particularly talkative. There had been damage to his speech centre and his conversation was very limited usually only by prompt and just a few words at a time

not necessarily correct or in the right order then he would usually fall asleep. This was punctuated with delirium and hallucinations total normality for the situation Tony was in.

Without warning Tony's hand suddenly grabbed his oxygen mask which was in the main line of fire that night and I felt strangely relieved that he was still very handy at pulling wires. I kept telling him that it was Lake District fresh air and it would do him good to inhale it but he kept pulling off the mask and putting it on his head. Delirium hallucinations and confusion would continue to reign for the foreseeable future as he continued to drift in and out of sleep. It was impossible to know at this stage if there had been further damage to Tony's brain functions through the abscess. Only time would tell but again I knew I could rest easy in my bed as Tony was receiving the best possible care.

The following day when I visited HDU Tony seemed to be having his own very personal battle with his oxygen mask and wires. Drips were also perilously close to being pulled out not to mention his ongoing fight with his white blood cells. It was very apparent Tony was a long way from coming home in fact it seemed just like a distant dream but I was determined not to give up hope. Tony continued to see medical people in the corner of the room with flower pots on their heads. He would talk to people who weren't physically there in fact so convincing was his conversation one of the nurses actually turned round to see who he was talking to.

Visiting continued to be very hands on and thought provoking to say the least. Tony appeared to be more convinced the collage of external images he was experiencing were real and there was very little I could do to convince him otherwise. The controls on his bed had turned into biscuits and he wanted to pull them off and eat them. It didn't seem to matter how much I tried to tell him they were not edible Tony was unable through his delirium cognitive deficit sight problems and lack of awareness to make out what they really were.

The nurses kept asking him if he knew where he was. Tony's reply was always St James Park which for a lifelong Liverpool supporter was definitely a change of direction. He always managed to remember his age but I was looking good for 102. Visiting at this point was not for the faint hearted or the easily offended.

Tony's tastes for food and drink had definitely altered drastically since his brain injury he insisted he took 4 sugars in his tea and he must have a curry for his supper which was quite an achievement with a Hickman line. Tony also adamantly stated he was "Dying for a cigarette" which considering he'd never smoked in his life was a little disconcerting to say the least. However he also maintained he'd never drank didn't like the stuff. Now Tony always liked a pint or two his central processing unit was definitely in total disarray.

Although Tony and I were physically in the same room it seemed as though Tony spent most of his days in another dimension. We were two worlds rolled into one and every now and then he was "back in the room" with me. My memories of this time are vivid in my mind combining emotions mixed with information and situations context was everything to me.

On the other hand to Tony seeing was believing and dreams were chaotic as his brain continued to perceive experiences outside our everyday world.

When Tony was in his coma he was beyond the reach of sensation although I liked to think his brain was still listening to my constant chatter. In comparison Tony was now definitely living in the moment but his perception was distorted as he drifted between lucidity hallucinations and physical manifestations.

This was a new and challenging phase for us and the abnormal became normal for our situation. I have to confess sometimes it was very hard to keep a straight face with some of the comments and one line statements that Tony would utter. Then with the blink of an eye the conversation would be normal and extremely convincing before we returned to the hallucinogenic world with visual stimuli of every kind.

Tony remained “part of an experiment” throughout his hospital stay but not alarmed by this top secret plan he was involved in. I must not divulge this information to anyone as he was working undercover and he always spoke in a whisper.

Throughout his time in ICU and HDU dieticians catered for Tony’s every need through his drip feeds ensuring he had the correct balance of nutrients for his bodily needs.

The physiotherapists worked tirelessly with Tony to help him rebuild his strength trying to sit him up in bed moving his arms and legs. The day eventually arrived when I entered the HDU and he had been hoisted out of his bed and was sat in a large supportive blue chair. It took all the energy Tony could muster to stop his body from slumping forward but this was one great step which a few months ago would have seemed unimaginable. Over the coming days Tony was moved into a side room beside the consultant/nurses station with the best view in the hospital of Roseberry Topping although sadly Tony was unaware and unable to see it.

When I visited he would be sat in a chair beside his bed usually slumped forward with his feet up on a foot rest. I was always greeted with the same words “Can you take my legs off”. My Mum and I tried to manoeuvre the foot rest in a desperate attempt to ensure Tony would remain upright for a little longer as we knew the medical team were trying to build up his strength.

This however was a fight we were never going to win usually within 10 minutes he had slumped forward and needed to be hoisted by a team of nursing staff back into bed complete with his intravenous drips. Once safely back in bed the relief on his face was overwhelming then he usually fell asleep with total exhaustion.

Throughout Tony’s hospital admission I relived the first emotional reaction of “please let Tony live” and the second of relief that Tony had survived on a continual basis as he reeled from one life threatening complication to the next.

The sheer physical burden on Tony’s body trying to sit up was abundantly evident and clearly the acute rehabilitation road ahead of us was going to be long and winding. We were now starting to make very slow progress however I was under no illusion that things

would never be the same again. I had come to terms with realisation and acceptance of our situation within hours of his emergency admission. Eternal gratitude for Tony's survival overcame any ghosts from the past. We would have a new life a very different challenging one incorporating comorbidities hidden psychological social and emotional problems along with significant cognitive physical and visual deficits. Little did we both know at the time how much these deficits would strengthen us in ways we could never have imagined.

However for Tony's daily survival he was currently totally dependent on his ongoing medical support from his extensive clinical team coupled with my encouragement and positivity. Together we would ensure Tony would have a second chance of life.

The days slowly passed each with its own ups and downs until eventually I was told Tony would be moved into a bay which meant he was making progress. At this point Tony still had a Hickman line which required an HDU nurse to maintain the drips. I was asked to bring in different drinks in order to try to encourage Tony to increase his fluid intake. Tony showed no interest in drinking at all but I kept persisting and telling him it was doing him good.

I clearly remember the day Tony surprised me when with the help of two physio's I witnessed him take 4 small wobbly steps. Tony was starting to tackle the physical mobility mountain although he had a long way to climb he had started the journey. At this point he was still very much in his own world but there were glimpses of my soulmate starting to shine through.

Home on the Horizon

The next week I was told Tony was well enough to be moved to Darlington Memorial Hospital to continue his rehabilitation journey. My emotions were very mixed at this point James Cook had become part of my life at a very traumatic time and although I knew Tony was moving forward in the recovery process I was leaving behind many incredible people who had tirelessly helped and supported us both through this incredible phase in our lives. The rehabilitation chapter was about to begin.

At Darlington Memorial Hospital Tony was in a side room near the nurses station a room with a view over the nearby rooftops. I remember sitting with him for hours looking out of this window together wondering whether he would ever be well enough to come home. His bed was very low nearly floor level as a precaution as on his first day he had suffered a grand mal epileptic seizure. These would remain part of our daily lives for the years ahead.

Tony had managed to work out he had a hole in his head by feeling it with his hand. This was actually where the ventricular drain had been inserted and removed however he had not tumbled to the fact that he had actually undergone 2 craniotomies been in a coma and fought for his life. He still remained totally unaware of why he had been in hospital and in fact still was but said he had felt a little under the weather and his legs were causing problems.

At this point food remained an unknown quantity to Tony he never really wanted to eat couldn't really see what he was eating and had to be constantly encouraged to try. Visiting remained hands on regarding fluid and food. Prompting to eat and drink would always remain an issue.

The challenges of mobilisation would raise their heads over the forthcoming weeks months and in fact years as they still do today concerning visual deficit awareness dizziness and loss of orientation accompanied with breathlessness and total exhaustion.

Tony was still asking to see deceased people at this time and also waiting for an operation to remove his Hickman line which had been inserted several months earlier in James Cook. It was a considerable mystery to me how the Hickman line had survived the test of time. I put its survival down to the fact that it was hidden beneath his hospital gown and then his t shirt so it was not in the line of fire to be pulled out. Many other wires had come to a very sticky end.

The physio team in Darlington worked continually with Tony and a month later I was amazed to see Tony upright on a harness surrounded by 4 physios trying to walk a short distance. This was an incredible sight to see after 4 months of struggling to strengthen his severe muscle loss.

Tony would soon be on the move again this time to Bishop Auckland Hospital for a further month of acute rehabilitation.

Tony was on a ward with 3 men all on the rehabilitation journey. The physios had a comprehensive plan although Tony could never remember what he had been doing. They kept me constantly up to date with his progress on wobble boards to improve his balance and his mobility physio and tests for eyesight and cognitive ability.

As the days and weeks passed by Tony eventually uttered the words I was waiting for him to say "when will you take me home". This was the first time home had ever come into a conversation he had never questioned before why he was still in hospital.

Tony still had a raft of complex and significant deficits regarding visual cognitive and physical disabilities and would always require significant support from me. However it was agreed that Tony could have a home visit for an hour to see how he managed in the house. Adrenaline rushed through my body with a flood of relief that the end to his hospitalisation may be imminent.

As the car pulled up outside our home the physio got a wheelchair out of the boot and Tony out of the car. I had to pinch myself this was reality after 5 months Tony was making his first visit back home albeit only for an hour.

I remember hugging him as he sat in his chair which had been ordered for him by the home loan department especially for his visit. I made him a cup of tea and he ate a kit kat while the physio team looked round the house to see what aids and adjustments would have to be made for Tony's safety before he could come home.

After having his cup of tea Tony informed me that the house was similar to where he lived but I had moved the stairs and I looked like his wife but there was something a bit different about me but he still liked me. I tried to convince Tony that this was our home and we had lived there for a number of years. It was very clear to me as I saw him sitting in the chair that he was still my soulmate. He had survived life threatening critical illness and our lives together would be different. We still had a future and it was up to us to stay positive and tackle the challenges head on.

The physio team had made arrangements for alterations to the bedroom and bathroom and grab and handrails on stairs. They said Tony would make another home visit next week and they would see if he could manage our stairs or whether a stair lift would need to be installed. They would continue to work with him in relation to his leg strength and lifting them up steps as initially there were questions as to whether he would be in a wheelchair in the house. The hour passed by too quickly and I felt my heart wrenching as I had to say goodbye and the car pulled away with him staring at the house out of the car window.

Over the next few days I was assessed and asked if I would be able to manage or whether care support would be needed. I was also offered the opportunity to take Tony home for a night and bring him back in the next day for respite until he settled. However I have always believed that whatever the situation the sooner I adapted to it the better and when Tony came home that would be where he would stay. I knew it would be hard lots of sleepless nights as in fact there still are today, but we would be together and I needed to somehow adapt to our new routine.

I continued to visit Tony daily but couldn't wait for Tony's next home visit. Eventually the day arrived and the alterations had been made to the house everything was in place. Tony arrived the same as before in the car with his physio team. He needed to rest for a while before they showed me how he could climb the stairs. It took 4 stops with me going up behind him and coming down in front of him plus the use of grab rails. 7 years on we still use this strategy today.

Tony was more relaxed about his visit this time and actually said goodbye to the physio team when it was time to leave. It was very hard having to explain to him he had to leave again with them but he would really be coming home for good very soon.

Four days later on my usual visit I was called in by the ward sister who said they were happy for Tony to go home with me tomorrow. However if I found it too much I could bring him back for a few days and try again.

I was determined Tony was going to stay home with me no matter how hard the first few months and years were going to be. I was under no illusion Tony could not make decisions could not mobilise independently without guidance for his vision and orientation. He lacked awareness and needed prompting to eat drink and go to the toilet. I would be a full time carer day and night he would be totally reliant on me as he still is today. I would be his eyes and his memory but the reward would be immense my soulmate back home where he belonged. The feeling was overwhelming.

The next day I arrived to collect Tony he was sat in his chair on the ward and when I told him he was coming home he smiled. He had forgotten. To this day he cannot remember the journey home, any of his time in hospital or the incredibly dedicated clinical team of nurses health professionals and support workers who Tony had helping him throughout his fight for survival and rehabilitation.

My Mum helped me to get Tony out of the hospital with his walking frames and wheelchair. She has never been blessed with fantastic orienteering skills herself and went in the lift with Tony the plan being for her to take him to the main doors while I rushed ahead and pulled the car round.

Instead my Mum pressed the lift button and went up to the top floor with 2 nurses and a considerable amount of medical equipment. Then she went down to the basement before emerging with Tony who had no idea why he was in the carpark or where he was going.

This was it. This was the day I had been waiting and desperately hoping for after 5 months in hospital we were driving home together to start an incredible and challenging journey which would strengthen us both in ways we never thought possible. Our future was to fight for. There would be mountains to overcome and times when we would both feel totally out of our comfort zone but every day would be a bonus and we would never look at life in the same way again.

Welcome Home

Tony was quiet on the way home his exit from the hospital had left him totally exhausted. He drifted in and out of sleep clearly the energy he had exerted had taken its toll. I dropped my Mum back home and continued across town to our house. On arriving on the drive and turning off the car ignition Tony's body juddered and he opened his eyes wide blinking and trying to take in his new environment.

After sitting for several minutes for Tony to come back into my world we attempted to get out of the car with sticks frames and wheelchair. Eventually we crossed the threshold in an unstable way where Tony slumped into the first chair he could after we had navigated door posts and the door step without collision.

Our home which had previously seemed such a safe environment presented itself in a new light to my severely visually impaired and confused husband. I had already moved furniture back towards the walls making a clear path and knew it was essential that furniture must never be moved out of line as Tony would collide with it. Doors would always be propped open at the same angle. I had raised green buttons on the light switches although he did not know how to use a light switch. I was trying to prepare for every eventuality.

The first major obstacle had been overcome. Tony was safely back home it was now entirely up to me to ensure that safe would be how he remained.

I asked Tony what he would like for his dinner this would be our first meal together for 5 months. Food was a necessity to Tony's body but he really didn't feel the desire to eat. He

had been on drip feed for several months in hospital and his appetite had changed to say the least. Tony's tastes had also altered as in fact they still have today he now prefers strong tastes and foods which he would never have considered prior to his critical illness.

I decided possibly sausages would be the order of the day so went into the kitchen to prepare them with some vegetables. I kept checking on Tony. He remained asleep while I prepared the dinner but seemed relaxed in his own world.

I served dinner two sausages on each plate with vegetables being careful to use white plates as I was aware any patterns on the plates may look like edible items to Tony's eyes. Tony lifted his knife and fork he had been practicing in rehabilitation however those sausages obviously took some co-ordination and effort to cut and it was too much. I went into the kitchen to get a spoon for his vegetables and when I returned to chop his sausages he said "they've gone my sausages".

To my amazement and amusement I didn't have far to look they had relocated themselves on my plate. I now had 4 how they got there to this day will remain a mystery whether in fact they were catapulted or individually placed I will never know. Memory issues would become a normal part of our everyday living.

With a tremendous effort the sausages were eventually consumed vegetables were also subjected to relocation across the table floor and my plate. It was plainly obvious meal times would be different from now on but as long as Tony had eaten something that was the main thing.

Total exhaustion overcame him and he needed to go to bed. It was challenging to say the least navigating the stairs but we made it after considerable effort on both parts.

At the time we had a 36 inch TV set which Tony could not see a picture on at all. I thought putting photos of our past on the TV may start to jog some memories as Tony had lost 10 years of his life without prompt. I knew if I could find a TV Tony could actually see it may start stimulating memories so that was an item on my to do list for the future. In the present we had more pressing problems as Tony clearly could not remember the layout of our house and was feeling bewildered and confused.

I found myself constantly watching Tony to see if he was still breathing. As night approached I prepared for a long shift. It had already been an overwhelmingly draining day both emotionally and physically but it was only just beginning. Tony's speciality which I had been warned about from rehabilitation was his nocturnal wanderings. It had been suggested I had sensors on the bed which sounded each time he moved. However I was in the room next door as I had been throughout Tony's time in hospital or so he thought so I was determined to try without and see how we went. I had a mattress on the floor in case he fell out of bed through seizure or lack of awareness. Let the night shift begin.

On the plus side I was now definitely Tony's wife not someone who looked like her which was a positive move forward. I had a commode next to his bed and each time I heard him turn in the bed I jumped. The house had been so silent for 5 months I had to adjust to hearing his breathing and movement. Every night Tony was in hospital I would wake to the

deafening silence of not hearing his breathing beside me he was definitely now making up for it.

Nights in Tony's eyes were no different to days his circadian rhythm was in total disarray. His legs were extremely restless and he moved them constantly in the bed throughout the night. Then without warning he would try to wander but with his orientation dizziness balance and sight issues this was easier said than done.

Before Tony came home I had considered converting our integral garage into another bedroom/ en suite so Tony would be on ground level. However I was correctly advised that this would mean I would be up and downstairs all night checking him and unable to watch him as well as if I was just next door.

The first night was never ending Tony was adamant that he wanted to sleep the other way up in the bed with his head at the bottom and with all the tossing and turning punctuated with staggering and wandering if I managed 3 hours sleep I was lucky. He appeared at the end of my bed thinking he was in the bathroom clinging onto the door post and wondering why I was sleeping in the bathroom. We were definitely in the twilight zone this was not for the faint hearted and I knew getting through the first night would be the worst. In fact this pattern continued for the first few weeks before I found myself automatically waking up when Tony needed help and assistance.

I talked to Tony's GP the following day he was amazed and pleased Tony was home and came out to visit him in the afternoon to perform a general health check and see if there was anything we needed help with.

I explained we had been referred for a visual assessment with Tony's Ophthalmic Specialist and had repeat brain scan follow up appointments followed by appointments with his Neurosurgeon and Neuropsychologist. We had appointments at Orthotics for special footwear for Tony as he could no longer wear any of his existing shoes. Speech and language assessment and therapies were in the process of being set up to help with Tony's dysphasia and we were due to start attending day physio sessions at the Neuro stroke unit after Tony had been initially assessed at home. The low vision unit were also involved in making the house as safe as possible for Tony. District nurses were calling out to monitor bloods. Support surrounded us at all angles and I was asked how I was coping and whether or not I needed help with his care and support.

In my own mind I knew that Tony's condition was long term and I had to set up a coping strategy and ways to provide the care he needed whilst still retaining a level of fitness myself in order for us to function as a family unit. This strategy is still in place today. Constantly thinking for two people takes some adjusting to and also anticipating their every move to keep them safe as Tony needs assistance even to carry out a familiar journey due his visual and orientation deficits.

Tony's tablet situation required constant monitoring. The first day he was home I had a chart which I ticked for each tablet he took until I became familiar with his extensive medication routine.

Little did I know at this stage how much time I would always spend monitoring and managing Tony's raft of complex medical conditions and appointments between his specialists. I would also develop skills in relation to blood taking giving injections and monitoring blood pressures and oxygen levels not to mention distinguishing the difference between stroke transient ischemic attacks, epileptic grand mal seizures, absence seizures, confusion seizures, visual seizures, blocked shunts, diabetic hypos and hypers. These would all become forthcoming attractions woven into our everyday living.

The Neurosurgical Clinic Challenge

Twelve days after Tony's initial homecoming we faced our first outing together to James Cook to see Tony's Neurosurgeon. Fortunately this was an afternoon appointment as it turned out to be quite an epic journey for all concerned. My Mum offered to help which to this day she still does.

In order for Tony to attend any consultation or appointment he needs a backup team of 2 and we fit the criteria perfectly to assist with mobilisation navigation understanding and retention of information. We are his eyes ears memory and safety net for him to mobilise safely in his power chair without causing injury to himself or others.

The morning started late after the usual disrupted night of nocturnal wandering and I found myself in a somewhat dazed state trying to sort out medication which Tony really didn't want to take along with his breakfast. Washing and dressing were forthcoming attractions waiting in the wings.

Washing started in its usual format with the assistance of two bath seats a grab rail and bars. I managed to get him to sit on the top seat albeit the wrong way round to start with. After considerable manoeuvring of his lower limbs at least his feet and lower legs were in the water and he was the right way round while I washed him. The low seat was literally a step too far and had to make a hasty exit as Tony started to knock it with his feet his eyes could not make out its shape and he didn't know what it was.

Tony's balance had been and still is severely affected by his brain injury and as I was washing him he slumped forward and appeared to have fallen asleep. This did not bode well for the forthcoming appointment this afternoon so in an attempt to revive him I spoke and he grabbed my arm and I found myself in slow motion taking a head first dip in the bath which was not exactly the way I had intended to start the day. Tony did not make any attempt to stop me in fact I'm not sure whether or not he knew it had even happened his awareness levels are very restricted to say the least. This highlighted to me how basic everyday living was such a struggle and so fraught with hazards it was like a minefield trying keep Tony safe and in fact myself.

After struggling for what seemed like an eternity the bathing was over hair was washed now all I had to do was get him from the bathroom to the bedroom where he rolled on the bed and fell asleep.

At this point I decided I needed some sustenance to keep me going while he slept off the physical exertion of being bathed. Meanwhile the clock ticked and the countdown approached towards Tony's afternoon appointment.

Tony would have continued to sleep had I not woken him it would remain one of life's mysteries as to how Tony could drop off to sleep with physical exhaustion and fatigue in the strangest of settings yet no matter how tired he was at night he couldn't sleep. His circadian rhythms were in total disarray and to this day have not greatly improved.

After considerable bribery in the form that he could rest again in a few minutes I needed Tony to sit up with his grab rail on the bed so I could try and dress him. His limbs were so heavy for me to lift and his body was really not very co-operative. He tended to slump forward so dressing was quite an arduous process. To add into the confusion Tony would not lift his right arm when I asked or if he did it would be his left. Then all we needed to do was shave. Tony liked a wet shave the problem was he couldn't do it due to fatigue and lack of co-ordination. The fact that he suffered from visual neglect fuelled the situation so I found myself in the position of chief shaver which to this day I have never really quite got the hang of the shaving gel situation. However I have developed a more polished skill with the blades than initially for which I am sure Tony is very thankful.

All I can remember thinking at this stage was the tremendous effort involved in trying to get Tony ready for a certain time and wondered whether he would actually manage to stay awake for the appointment when we arrived.

My bribery eventually paid off and Tony was washed and dressed he had taken his medication which I handed him one by one the only safe way to know tablets had been swallowed and not removed. He had consumed a little food with a lot of coaxing it was very difficult to get Tony to eat and drink and he needed continual prompting as he still does to take fluid and nourishment to his body.

The doorbell rang and I was relieved to see the cavalry arrived in the form of my Mum who went straight into the kitchen and started making us a light lunch. Tony continued sleeping and I ensured the chair was ready and all the necessary documentation was in order for the appointment.

Tony ate a little lunch with considerable prompting and I gave him his tablets then he needed a fresh shirt before he fell asleep. At this stage Tony spent a considerable portion of his day drifting in and out of sleep and had no knowledge of day time hour or in fact where he was from hour to hour. Remaining conscious took all his energy. The forthcoming appointment would be interesting to say the least.

Using his wheeled frame I managed to get him into the car. We always keep one upstairs and one down they come in really handy for situations previously I would have never imagined.

Once Tony was settled we set off in the car Tony in the front seat and my Mum in the back. Within seconds Tony was “out of the room” back in the twilight zone as I drove along the road to James Cook. I had to keep checking his safety belt was not riding up round his neck as he slumped forward.

This was a very surreal experience for me I was revisiting for the very first time the hospital that had saved Tony’s life and seeing the Neurosurgeon who had performed his surgery and many of the clinical staff who had been instrumental in Tony’s survival. Memories of prior appointments and incidents came flooding through my brain as I waited at the traffic lights to turn into James Cook. This time it was different Tony was by my side he was not in ICU or HDU but very much trying to adapt to the outside world.

My emotions were mixed joy that he was still with me but sadness that he had endured so much and I knew the future was unbelievably uncertain. He truly was an incredibly strong and courageous man with a determination to fight and not give up in spite of all the obstacles thrown at him.

After driving round several car parks I eventually found a car parking space and managed to get Tony’s chair out and we set off towards what I liked to call “The James Cook World”. How well I knew that particular feature of the hospital grounds. Tony was very confused on arrival he had no idea where we were? or Why we were here? We sat in the Neurosurgical clinic reception and waited. Mum and I kept trying to keep Tony awake but it was an uphill struggle that we were not going to win.

Our appointment time came and we went in to see Tony’s Neurosurgeon who was amazed and delighted that Tony was out of the rehabilitation unit at Bishop Auckland. I explained they would have kept him in longer but I felt I was ready to have Tony home although it was certainly very challenging it was something I needed to become accustomed to.

In the room that day there were some medical students and the Macmillan nurse along with Tony’s Neurosurgeon who started the appointment by asking Tony how he was. Tony rolled his eyes the whites were still very predominant and his eyeballs were often raised from view at this point. Tony was silent so the question was asked again and to my surprise Tony said “Well” then paused. I couldn’t help noticing the students poised with pen and notepads in hand in anticipation as though Tony was going to utter some really thought provoking statement. No one could have been prepared for the next few words Tony spoke “My wife has nice legs”.

Everyone in the room including myself looked down at my legs and Tony fell asleep. Words of consolation offered to me at the appointment were “It could have been worse” which in hindsight I tended to agree with.

For the remainder of the consultation Tony remained in the twilight zone drifting in and out of the conversation while Tony's Neurosurgeon confirmed his latest CT scan showed progressive involution and resolution of the cerebral abscess which was good news. We then went on to discuss Tony's daily living restrictions and the significant input from me along with the hindrance of his significant disabilities in relation to ongoing problems with mobility restricted vision speech disturbance and cognitive deficit. A repeat CT scan of the brain would be taken in a couple of months a cognitive assessment was arranged with a Neuropsychologist for October and we would return to see Tony's Neurosurgeon at the Neurosurgical clinic in three months' time to monitor Tony's condition. An Ophthalmic assessment was also arranged to assess the limitations of Tony's vision.

Sitting in the same room with Tony's team who had been present at his original diagnosis prior to his emergency admission felt so strange to me. Tony's life had irreversibly changed in the following seven months and yet we were all back together for those moments in time and incredibly Tony was still with me maybe not really aware of what was going on but alive fighting and by my side. The clock was ticking hands of time moving on same place same people but now a completely different life for both of us.

Before ending the consultation Tony's Neurosurgeon asked us to confirm that Tony still had the same GP to which Tony suddenly answered "she's dead". After reassuring everyone concerned that I really didn't think this was the case the consultation ended.

On leaving the consultation room I was surprised Tony automatically shook his Neurosurgeon's hand which I found pleasantly reassuring. We left the neurosurgical clinic trying to leave other patients waiting in the corridor with all their toes keeping them well out of the way of Tony's wheels. Then it was the journey past the James Cook World and back to the car.

After considerable effort with frames and chair Tony was in the car time for the journey home and time to pat ourselves on the back our first hospital outing success mission well and truly accomplished.

Over the coming weeks Tony's Ophthalmic consultant registered him partially sighted with extensive loss of visual fields and we were referred to the low vision unit with immediate referral as potential risk factors were present. Tony's ongoing physio support continued with weekly sessions at the Neuro stroke unit. Tony had two further CT brain scans chest Xray ECHO heart scan spirometry further consultant appointments and orthotics punctuated with the usual bloodletting as we have come to call it by district nurses.

These mainly took place in Darlington with the exception of one scan in Bishop. Then it was time to revisit James Cook to see Tony's Neuropsychologist for the assessment of his cognitive abilities.

A Neuropsychological Twist

The day started with the usual 2 – 4 hours preparation of help and support needed before we could leave the house washing bathing medication eating and not forgetting to fit in a few snoozes. This is the same routine in place today. I always maintain Tony now has two speeds slow and stop and on a morning the latter is definitely more prevalent. Then it was a case of the cavalry arriving in the form of my Mum once again to assist us with the visit. This was a morning appointment as far as Tony was concerned mornings were and still are in a different time zone to the rest of the world. He takes a considerable amount of time to pull round and still spends most of them drifting in and out of oblivion.

As we set off on our journey I had put up some sandwiches in case we were there for longer than we anticipated and as the day's events rolled out I was very glad of being a brownie as a child. Being prepared was now starting to pay dividends.

I drove along the road with Tony in his usual morning state of slumber and arrived at the Disablement centre at the rear of James Cook Hospital. After the daily wrestle with Tony's chair and frame accompanied with fresh bruises due to colliding with his chair and frame we made our way to the unit with Mum and I acting as Tony's eyes and navigators. Tony is unable to interpret and read signs and symbols which in a hospital is a considerable disadvantage as all the corridors look very familiar and damage to his visual processing centre have left his navigational skills none existent in unfamiliar surroundings. I have to admit they are not much better in the familiar setting of his own home even after 7 years. On arrival I booked Tony in and waited for our appointment slot to be called.

A patient chatted to us in the neuro reception and asked if we were triplets as we were all wearing "hoopies" which we presumed were stripes. Whilst pondering on this thought Tony and I were called in to see his Neuropsychologist leaving my Mum to solve the mystery of the "hoopies" with my parting words of "we won't be too long."

We entered a small room and made introductions. Tony needed and to this day still needs significant input from me regarding communicating and engaging face to face and all seemed well for approximately 5 minutes as Tony remained vertical in his chair and remembered his name and after a good deal of contemplation his date of birth. Then came the hard one our address which as it turned out was never going to be uttered at this appointment as Tony started to shake with cold sweats feeling faint and pains in his arms. The only consolation I remember thinking at this stage was at least we were in a hospital.

Together Tony's Neuropsychologist and I managed to get him onto a bed in the adjacent room. While I tried to keep Tony on the bed which was easier said than done his Neuropsychologist contacted Tony's Neurosurgeon and went for medical assistance which arrived swiftly and Tony was transported to Accident and Emergency to be booked in. Once there he was assessed while my Mum was rescued from the ongoing "hoopies" conversation and followed on without the sandwiches.

Tony was drifting in and out and getting him to give a urine sample was proving extremely hard work. After a considerable amount of coaxing the task was complete and I took it straight out of cubicles to the consultants and nurses station where they sent it immediately for testing.

Tony's blood gas was 84 very low and his blood pressure was also causing concern and after numerous tests including a chest x-ray ECG and bloods it was suspected part of a blood clot had broken off and travelled to his lungs. He was admitted to the Acute ward for observation and given an injection of Enoxaparin. A course of 5 of these injections needed to be given daily and after watching the initial procedure it was agreed that if Tony was well enough after a period of observation I could take him home as long as I did the injections each day and then brought him back to the Acute ward five days later for a lung scan to see if we had "zapped it".

Meanwhile as they transferred Tony from cubicles to the Acute ward I went on the sandwich hunt and stocked up on supplies from the hospital shop as my original sandwiches had not caught up with me at this stage. This was all going swimmingly until on the way back I took a wrong turn and ended up in the maternity ward. A quick glance at the occupants of the beds quickly registered with me that I was definitely not in the Acute ward and I found myself reorienting and setting off in hopefully the right direction this time.

I knew today was going to be cognitively challenging for Tony I just hadn't foreseen it being as cognitively challenging for myself and my Mum but as the events unravelled we were all extremely grateful we were already in James Cook. This could have happened on our journey here. My Mum and those sandwiches had spent the majority of the day in transit from one end of the hospital to the other before we were all eventually reunited.

Around 7pm in the evening Tony was discharged from the acute ward and I was allowed to take him home complete with injections. On the journey home I talked to Tony in the car about today's events they were already history as far as he was concerned he couldn't remember a thing.

Tony's Neuropsychological assessment of his cognitive abilities was rescheduled for later on in the month hopefully it would not be quite as eventful as today's attempt and we would have in the meantime "zapped" that blood clot.

We returned to James Cook the following week for a lung scan and the results were clear blood clot well and truly "zapped". Success and apparently it turned out Tony thought I was very good at giving injections so that is another talent I appear to have developed since Tony's brain injury.

The following months were incredibly busy with the Neuropsychological assessment this time successfully completed. This confirmed Tony had very severe deficits in cognitive functioning particularly in relation to his memory slow information processing speed coupled with visuospatial and perceptual executive function which sadly remain today.

There then followed a catalyst of dopla's heart scans another appointment with Tony's Neurosurgeon and brain scans. Neuro physio recommenced for another year and an abnormal brain scan showing enlarged ventricles resulted in further neuro appointments. The ear nose and throat (ENT) became involved as both Tony's ears had been affected by his brain injury and two hearing aids were required.

We attended Carter Bequest Hospital for a speech and language assessment resulting in 2 years of speech and language therapy at Darlington Memorial Hospital for Tony's high level dysphasia complicated by visual and cognitive deficits. We were also given exercises for cognitive rehabilitation which we practised at length in-between snoozes. Tony had respiratory checks ophthalmic consultant appointments plus the usual "bloodletting" sessions. Meanwhile we managed to add in a congenital Gynaecomastia and mild antral gastritis to his medical history.

Not content with all the appointments Tony had an amaurosis fugax total loss of vision in both eyes in Tony's own words "the lights gone out everything is black". Investigations highlighted mild disease in the carotid artery build-up of plaque in the RCA bulb resulting in follow up appointments at the Stroke clinic at Darlington Memorial hospital. Diabetes came on the scene and then we had an emergency dash to A & E as Tony suffered a significant occipital lobe stroke which caused more damage to his visual fields. A specialist from Durham University Hospital Ophthalmic team confirmed further significant damage to the visual fields and that he was now also colour-blind.

We were referred to the Rapid Access TIA clinic at Darlington Memorial Hospital where I viewed the new right occipital infarct. There was now further permanent damage to visual fields only 25% vision in both eyes and cortex right side also showed a narrowing of the posterior cerebral artery. I was shown the previous scan showing the original damage to the occipital lobe. The shunt was fortunately working clearly no hydrocephalus just burr holes and infarctions visible.

The next few months were full of follow up appointments and scans until the epilepsy which had been lurking in the wings decided to give us a surprise none of us had been expecting.

Even with all the physiotherapy Tony was suffering from extreme lethargy dizziness breathlessness and fatigue coupled with lack of awareness and significant sight loss making mobilisation very difficult even with his chair and frame. The car was and still is the best way for Tony to see some of the countryside we both used to walk in our previous lives. Hence a change of scenery with a trip in the countryside appeared to be just what the Doctor ordered.

Unforgettable Sedbury Lane

I remember the events of the day incredibly clearly they are permanently etched in my memory banks. It was 21 December 2014. It was around 1pm in the afternoon and I decided to take Tony for a little run in the car to Richmond. I took the back road through the villages from Darlington crossing the A66 through Gilling West and then into Richmond.

I wanted to make the most of the light as it was the shortest day of the year but relatively mild.

As we approached Richmond I looked at Tony and noticed he was extremely drowsy but as we pulled into the market place he seemed to wake up a little. I dropped the windows for some fresh air and Tony would not let me take off his safety belt. He said he didn't understand what I was asking him to do and then started repeating "you worry too much" "you worry too much".

This immediately sounded alarm bells to me my first thoughts were a possible stroke hitting the speech centre then I thought it could be blocked shunt or the return of the brain abscess or a seizure but all I knew was Tony needed to be in a hospital and it was up to me whether or not I could get him there in time.

I quickly managed to get the safety belt round him while he continued to chant "you worry too much" "you worry too much" and set off as calmly as I could in the direction of Darlington. He seemed drowsy at this stage and my initial thoughts were if I could get to the Scotch Corner hotel I was on a main arterial road for paramedic back up. However it soon became apparently obvious this was not going to happen.

I drove through Skeeby village gently over the speed bumps and the bridge until I reached the first part of the z bend at the bottom of the bank ascending to Scotch Corner. At this point Tony tried to grab the steering wheel from me and started violently shaking and foaming at the mouth. All I could see was the safety belt tightening round his neck.

I managed to push him off the steering wheel and bring the car to a sudden stop near the second part of the z bend on the verge adjacent to Sedbury Lane. At this point Tony had started to try and put his legs through the windscreen. I had managed to get the safety belt off him but he was still foaming at the mouth shaking violently and only the whites of his eyes seemed visible. He was violently fitting and totally oblivious of what was happening.

I dialled 999 immediately hit the hazard warning lights on the car very aware that the light on the shortest day of the year was starting to rapidly fade and the nature of the road was such that I was still actually parked half on the road and half on the verge with a ditch at Tony's side of the car. My main priority was to get paramedic assistance as quickly as possible and keep Tony safely in the vehicle until help arrived although it seemed he subconsciously had other plans.

The lady who took my 999 call was very helpful and would send immediate blue light back up for me which was a great relief. She then asked the million dollar question "What is the postcode?" which she needed as the paramedic back up was coming from a central source. I hadn't a clue. I knew where I was on Sedbury Lane one mile approximately from Scotch Corner on the Richmond Road but no idea what the postcode was. I couldn't turn the ignition on the car to check the sat nav as Tony was fighting with everything and it took all my energy to keep him in the vehicle and from harming himself and me.

I therefore took extreme action and tried to flag down passing cars of which there really wasn't very many. The first one past without stopping on reflection probably thought I was acting highly suspiciously. However the second was the Good Samaritan who I will never forget to this day.

He pulled in with a passenger in the car. He helped me get the passenger seat into the reclining position as with Tony already in situ it was very hard to move. I would stay and make sure Tony's airways remained clear. He ran across the fields to the first available farm house with my phone to get the postcode and tell 999 immediately so the paramedic response unit could find us quickly. I still had Tony's phone as a backup and I tried to keep Tony as comfortable as I could until help arrived.

I really thought I was losing him all over again that day the generalised tonic-clonic seizure was not in the same as you see in TV hospital dramas and I hadn't medication to stop the violent fitting. Tony seizures were definitely in the premier league.

I very soon saw the blue light in the distance pulling up at the farm further down the road who obviously had the same postcode. They soon double backed and My Good Samaritan returned and paramedic back up arrived at the same time.

Fortunately I always carry my extensive list of Tony's up to date medication and his complex medical history with me which is invaluable in these situations. That day it was well and truly worth its weight in gold as the paramedics gratefully received it scanned it and started immediate treatment for Tony.

The paramedic got in the back of the car and tried to give Tony oxygen. He was still violently thrashing around and it was impossible to keep a mask on him or try to take his oxygen saturation levels. I remained in the front of the car trying to stop him harming himself telling him to "Stay with me" while outside the darkness started to creep in.

For well over 15 minutes Tony was unconscious. To this day I will never exactly know how long for I was definitely in fight mode that afternoon but eternally grateful for the excellent paramedic team who arrived and the Good Samaritan. I could not have managed without them.

The ambulance arrived with more paramedic back up and suddenly I felt an overwhelming sense of relief as they approached the car. The lady from the local farm tapped on the car window to ask if there was anything she could do and would we like a cup of tea. I never cease to be amazed in this crazy fast paced world we live in that there are so many caring people who often you find in the most unusual of circumstances.

At this point the Good Samaritan left I thanked him hugged him and inside knew that if he hadn't stopped that day the outcome for Tony and I may have been completely different. The kindness of a total stranger truly priceless.

Suddenly Tony sat up in the front seat his eyes staring wide and those unforgettable words "What's going on Diane?" Both the paramedic in the back of the car and myself were rather speechless at this sudden change in Tony's condition.

The paramedics after considerable amount of coaxing and lifting managed to get Tony out of the car avoiding the ditch and into the Ambulance. His cognitive deficit even more compromised by the confusion of the seizure. They then asked me if I was ok. Did I need medical assistance and was I ok to drive. I remember hugging them to thank them and reassuring them that I was ok to follow them to the hospital in my own car. The ambulance took Tony to Darlington Memorial Hospital as he was still suffering from loss of memory and cognitive function and I followed in the car. If I had not witnessed the sudden change in Tony's condition I wouldn't have believed it.

I drove back to Darlington along the back road trying to regain a little composure before arriving at the hospital. After extensive tests Tony's inflammation levels showed no sign of an additional stroke and ECG confirmed a Grand Mal tonic clonic seizure. After six hours of close monitoring in the A & E department I was allowed to take Tony home.

At this point he was still repeating words and sentences and unable to put on a safety belt. On returning home Tony was extremely confused communication was very difficult accompanied with cognitive deficit memory and physical problems but at least we were home. A scenario I could never have foreseen when I rang 999 only hours earlier on Sedbury Lane.

The following day Tony was seen by his GP who informed me he had an infection in his left lung pocket and prescribed antibiotics plus steroids. Tony's blood tests had also revealed a low white cell count. His GP would telephone me to tomorrow to see how Tony was progressing and whether there was any improvement since the seizure.

The following day his GP telephoned with confirmation that the bloods showed no inflammation no indication of another brain abscess forming but confirmed it had been a major seizure and we had to be prepared for another at any time. Meanwhile as we rapidly approached Christmas Day I was told to use A & E for Christmas Day and Boxing Day and an emergency doctor from the GP practice for the following days. Tony would be referred back to his Neurosurgeon at James Cook for a follow up.

Over the coming months we managed further Neuro appointments bronchial spasms ophthalmic appointments and Tony's diabetes was spiralling in all directions. Tony continued to have further seizures of the visual absence and confusion kind which I was able to manage on my own and his Neurologist at James Cook started to gradually increase his current epileptic medication to see if that would hold the seizures.

I was told I needed to be vigilant for excessive drowsiness or further lack of awareness as they had been seizure indicators in the past. Tony could have a grand mal seizure at any time always call 999 for paramedic back up if lack of consciousness keep airways clear. I asked whether carrying oxygen at this stage would be helpful but Tony's Neurologist correctly identified that if he needed oxygen I would also need the paramedics which I wholeheartedly agreed with. The more support when Tony had a grand mal seizure the better.

We continued to juggle audiology the rise and fall of Tony's blood glucose levels along with his low neutrophil and Lymphocyte levels over the coming weeks. At this time we were averaging a seizure a month but gradually increasing the epileptic medication as a cushion however Tony had other ideas.

The "Green People"

On 28 August at 11.05am Tony started with an absence seizure. He was sat in the front room staring into oblivion then he seemed to come "back into the room" before he started to chant the words "yes" "yes" "yes" "no" "no" "no" over and over again.

Images of the Sedbury Lane seizure as I now refer to it flooded back and I quickly took Tony's blood pressure, oxygen saturation and blood glucose levels. I knew I needed paramedic back up at this point in case it was going to develop into another grand mal seizure.

Time to dial 999 who as always were extremely helpful and said help would be with me very soon. They stayed on the line until I heard the siren of the ambulance on the main road. Reinforcements were on the way.

The paramedics arrived to Tony's greeting of "Hello Green people" followed by "yes" "yes" "yes". Meanwhile confusion continued to reign with Tony unable to carry out instructions mimicking a stroke although I felt sure again it was another seizure. Tony was swiftly taken to hospital where he underwent tests and brain scans to check for the usual suspects recurrent brain abscess tumour shunt blockage or stroke.

A complex partial seizure was diagnosed. Tony had high lactic levels in his body and we spent the day in cubicles as he slowly increased his vocabulary from yes and no to four or five word sentences much to the total amazement of the A & E Consultant looking after him. He was discharged to my care at 7.15pm. Relief all round for today it appeared that the increase in medication had prevented a generalised tonic clonic seizure.

Tony once home remained pleasantly confused he had regained around 85% of his speech and the Consultant felt he may regain more over the next 48 hours. I needed to observe Tony through the night and if I was worried I needed to dial 999 immediately.

The following morning Tony had an occipital lobe seizure and his GP telephoned to see if Tony's speech was improving which it had however he still had a high level of dysphasia and his short term memory which was already significantly impaired was worse. Extreme exhaustion was also added to the mix.

Over the coming days and weeks Tony suffered more visual absence and confusion seizures accompanied with dizziness and sickness until I was woken at 6.30 am on 29 October by a large thud. I sprung out of bed probably with shock to find Tony sitting on the floor at the side of the bed foaming at the mouth and shaking in an extremely confused state. He started to shuffle along the floor like a seal trying to hit his head on the walls. Without hesitation I dialled 999 and was told help was immediately on its way. At this point I could

not remain on the mobile phone I needed both hands free to try to prevent Tony from further harm.

Tony was on a mission to go headfirst down the stairs totally unaware of the danger he was in and not responding to any instructions. I had my work well and truly cut out trying to divert him into another room. The bathroom was not an option cast iron fittings and hard floor could only add insult to injury. The best option was to try and get him back into one of the bedrooms where at least the floors were carpeted.

I grabbed Tara the rather large cuddly tiger Tony had bought me many years ago and blocked her across the top of the stairs whilst trying to cushion Tony's head from the walls with pillows. Whilst waiting for the paramedics Tony certainly did not stay still instead he kept revolving his eyes and clashing his teeth of which he smashed and swallowed one whole. I actually managed to direct him away from the stairs but he became wedged in the little bedroom which I use as a study between the desk and the piano cutting his ankle very badly as he did so.

At this point it was all really blood sweat and tears accompanied with a considerable amount of confusion.

The paramedics arrived and as the front door was locked and it was impossible for me to leave Tony at this point I threw the keys out of the window. Now there was 4 of us in the smallest room in the house trying to stop Tony from causing himself any further harm. After an hour of the paramedics trying to help Tony up which was easier said than done as he could not understand or follow instructions and me crawling along the floor into the front bedroom in a desperate attempt that he would copy me we successfully got Tony back into the bedroom and onto the bed to recover in a postictal state. At this point Tony told me that I was annoying him but he loved me. After settling him on the bed I was advised by the paramedics to ring 999 immediately if Tony had another seizure in case it was status epilepticus.

Meanwhile I telephoned Tony's GP to inform him of events and he would visit this afternoon to check Tony's wounds. Tony's GP arrived in the afternoon to check Tony who was also now suffering pain in his right arm and his GP suspected a broken clavicle so he did an immediate referral to Darlington Memorial x-ray department and I took Tony to hospital fortunately there were no broken bones.

In the meantime Tony's epileptic medication continued to rise we had further Neurology appointments at James Cook and smaller manageable seizures plus a couple of urine infections requiring the urgent duty doctor. Spiralling diabetes and unusual blood results which were very much now becoming the norm added to the mix.

A New Language

It was 14 January 2016 around 11am when I noticed Tony was “out of the room” so to speak. I suspected one of his usual absence seizures so stayed with him and monitored him expecting him to resume awareness soon. He was sat in the chair staring but not taking anything in for around 5 minutes then he was “back in the room” not really totally with it but talking albeit a little confused.

I asked if he wanted the TV on to see if it would stimulate him into conversation but he just wanted to be quiet so I went into the kitchen to start preparing the vegetables for dinner.

When I returned to the room Tony seemed to be more coherent and I sat and talked with him however after a further half hour I noticed his vocabulary had reduced to just yes and no which he started repeating. He was displaying signs of dysphasia and his language was becoming incomprehensible. I also gave him a pen and soon realised he didn't know what it was or what it was used for. I instantly recognised the signs and asked if he could raise his hands or legs which was never a full proof test as with brain injury Tony often raises the opposite limb but then the chanting began. I realised it was time to call 999. The time was now 11.40am.

I had taken Tony's blood sugar blood pressure and oxygen saturation level as a gauge for when the paramedics arrived and at the moment he was in the chair and safe it was just a case of stopping him from moving although at this stage he had not displayed any signs of shaking. Instead he had started to speak fluently in what seemed like English backwards. I could only assume the seizure was hitting the speech centre.

The man at the end of the 999 call was again extremely helpful when I gave my address and postcode he said help would be with me very soon and to my amazement around 5 minutes later a Fire Engine and several Firemen came running down the drive. They were on first response. A paramedic support car arrived several minutes later followed by an ambulance.

I now had a 6 team back up in the house which was certainly reassuring. Tony continued to speak backwards at everyone and was unable to carry out any instructions. The paramedics carried out tests. Tony was displaying symptoms of possible stroke although I felt sure we were on the verge of another a major seizure unless the abscess had returned or the shunt had blocked.

One of the paramedics asked was my husband English and what actual language was he speaking Tony was so very convincing at this stage. I reassured them all he was English and a discussion ensued as to which hospital to take Tony to as if it was stroke it would be Durham. Darlington for Epilepsy. James Cook for Neurology. In the end Darlington was the order of the day.

Managing to get Tony into an ambulance was easier said than done as he wouldn't do what anyone asked so getting him out of the chair was quite an achievement. After considerable coaxing he was safely lifted into the ambulance and on his way to hospital.

Over the years I have developed a drill for hospital admissions. I usually let Tony go in the ambulance stock up with plenty of food and supplies and then make my way down in the car as sometimes if we are lucky he can be discharged six or seven hours later.

On arrival at Darlington Memorial I went into A & E cubicles where I was greeted by a Consultant who informed me that on arrival at the hospital Tony had suffered a generalised tonic-clonic seizure which was very severe and had required an Intensive Care Unit anaesthetist to sedate him. He was on oxygen and had been given medication to stop the seizure and was currently having a brain scan and they would let me know when I could see him.

I walked to the front of the hospital to collect my thoughts and get some much needed fresh air and some chocolate. Never underestimate the power of chocolate particularly in a crisis. I gathered supplies together and went back into the hospital to wait for Tony who had returned from his brain scan. He was on antibiotics and painkillers on a drip and in the resuscitation unit.

Tony was very difficult to control as he was postictal and kept trying to get off the bed and pull out his drips and wires memories of ICU came flooding back. Tony's speech remained backwards and it was extremely hard for everyone to understand what he was trying to say. At this stage I wondered if we would actually ever be able to communicate with each other in the same way again. I remained with him in the resuscitation unit and tried to stop him pulling wires which was easier said than done.

Around 6pm Tony was admitted to the Acute Medical Ward in a side room where I sat with him until around 10.30pm. The consultant who came to see Tony asked me if Tony spoke English and was his speech fluent. He confirmed Tony had unfortunately suffered two seizures but no stroke. They would run tests again tomorrow the brain was showing existing infarcts no new damage. Feedback to neuro team at James Cook tomorrow after tests in case spinal tap required to check for encephalitis which could be problematic as the presence of Tony's spina bifida occulta would mean a sample may have to come from the shunt.

Tony was still very confused at this point his speech was incoherent apart from an odd word he was unsure of his whereabouts and what was going on around him and I wasn't sure if he really knew who I was.

Before I left I tried to get Tony to speak and thought maybe if I said something that was familiar to him he may join in. I started with the Lord's Prayer I thought he may remember it and as I started to say it he joined in his voice rising and falling as if he was speaking the English language however it was still coming out backwards. Nursery rhymes had a similar effect so in the end I accepted that this was as far as Tony was going to progress tonight. He was still alive that was the main thing. He had further cognitive and physical deficit the battle scars of severe seizures but only time would tell whether he would ever speak coherently again.

I gave Tony a hug and said it really was getting late it had been a long day and I would be in the room next door resting. I always told Tony that when he was in hospital he seemed to understand that more than where home was. I kissed him and said "Goodnight Tony Love you" and to my amazement as I turned to go out of the door he said "Love you too Diane".

I was extremely shocked and tried to instigate more conversation from Tony but his language had gone backwards again but I had a really strong feeling he was going to speak again. I had been given tremendous hope before I left his bedside that night.

On my way out leaving the ward the Consultant looking after Tony talked to me. He seemed amazed that I managed Tony at home on my own without any additional caring support in view of Tony's complex disabilities and medical conditions. I told him we had our own routines and a new life since Tony's brain injury and we coped as well as we could under the circumstances. I left him with my parting words that I also thought Tony would speak tomorrow. From the look on his face I could see a little doubt creeping in but deep down Tony and I know you never say never.

The following morning I telephoned the hospital Tony had managed a relatively uneventful night considering although he had tried to wander which had caused problems as he was very unsteady and at high risk of falls. However he was safe and sound and he had regained some speech which was music to my ears. I was told to come down around 3pm as they were running more tests and scans and wait for Tony's neuro team at James Cook to see how they would proceed.

On arriving at the Acute Ward Tony was sat in a chair having some dinner and talking coherent English none stop to a nurse who was trying to assist him with his medication. An incredible transformation had taken place quite unbelievable but Tony could always surprise when you least expected it. As soon as he realised I was there it was a cheerful "Hello Diane the roast beef dinner is excellent here".

Relief flooded through me once again Tony had come back from the brink and although his conversation was confused it was definitely English. We were waiting for the green light from Tony's Neurologist at James Cook which came at 5pm as the inflammation markers were down and Tony was discharged to my care. I had to take Tony to James Cook in 5 days time to see his Consultant Neurologist. My Mum and I managed to get Tony out of the hospital as he shook hands with everyone who had looked after him.

On his arrival home Tony had dysphasia reduced memory and physical function some pleasant confusion and language deficit along with cuts to his mouth and pains in his limbs but together we were ready to tackle another day.

The following day started with a visual seizure which to be honest I was expecting as Tony usually follows a pattern of smaller seizures in the aftermath of a generalised tonic clonic seizure green and yellow flashing continued in his vision all day. His GP called out to see him to check how he was progressing and Tony although communicating in English was still convinced everyone was his mother and the neighbours were "Mr Coral and the emails". This was again perfectly normal for Tony at this stage after a seizure it usually took several

days for him to settle before people had their correct names. Each seizure takes its toll both cognitively visually and physically and Tony never regains the capacity he had prior to the grand mal seizure. It's a case of damage limitation and we can live with that.

Never Say Never

Over the following months Tony's Neurologist slowly weened Tony off his existing epileptic medication introducing a new medication at the same time. Meanwhile Tony continued to fit in a selection of absence confusion and visual seizures and the odd generalised tonic clonic seizure requiring the support of Tony's "Green People" the paramedics and further hospital admissions just to keep me on my toes.

We had an A & E admission when he swallowed his hearing aid battery which fortunately turned out to exit in a natural fashion which was a relief all round and the introduction of investigations surrounding high PSA readings and an enlarged prostate accompanied with repeated urine infections which may be also fuelling the epileptic seizure situation.

The diabetes which had been in remission suddenly burst into the forum along with ultra sounds of the abdomen and renal tract as Tony was retaining residual fluid in the bladder. I couldn't help feeling at this stage that we were actually very slowly working our way round all the departments in the Hospital and managing to turn into our own home pharmacy with the level of medication I was giving Tony.

Then on the 7 December 2017 Tony's Heart Consultant at Darlington Memorial Hospital confirmed our worst fears that Tony had severe irreversible heart failure. The heart muscle was severely damaged left ventricle pumping function was restricted and the course of action was to try to prolong life with medication which when taken previously Tony had suffered a severe reaction to. With a gradual increase we hoped and prayed he would tolerate it this time.

We would also have the involvement of the Cardio team who made home visits on a weekly basis to the house and monitored Tony's condition as his medication slowly increased. This prognosis was another hard hitting challenge we could have well and truly done without. However although bloodied we were determined with our usual unconquerable spirit of positivity to tackle this next chapter along Tony's journey with determination and resilience.

The diagnosis explained why further deficits had occurred in Tony's cognitive and physical function. He found it harder to breathe in the hotter weather without a fan his levels of fatigue had escalated and he drifted throughout the day from one power nap to another. Parts of the jigsaw were all starting to fit into place maybe not the place I would have liked but half the battle is finding out the cause the other half is learning to live with it. At least now we had the medical back up to ensure Tony's quality of life would be as good as possible under the circumstances.

Over the coming weeks the Cardio team visited the house taking bloods and increasing Tony's medication in line with his Heart Consultants recommendations.

True to form the Colorectal team then became involved with more scans to rule out internal bleeds and cancer in the colon as Tony had become extremely anaemic and his GP had correctly referred him for further investigations. This proved easier said than done as Tony's heart was too weak to undergo the conclusive procedures and a CAT scan with contrast was taken instead although this test would not be conclusive.

There was also the question of a cyst on the left kidney which had been quietly cited as not a cause for concern. However since the recent scan the Colorectal team were contacting Urology to rule out indications it could now be haemorrhagic. We currently await developments.

In the meantime Tony's most recent achievement was managing to swallow a whole wisdom tooth whilst leaving the roots in place. Fortunately this passed through without further injury. He confessed this on a recent trip to the dentist saying he thought it was something hard in his dinner although he couldn't remember when it happened.

Since Tony's hospital release in 2011 we have attended 541 medical appointments and still rolling. We will always be eternally grateful for the never ending dedication care and follow up from our incredible NHS health professionals involved in Tony's care. It has been and continues to be truly amazing.

Our courageous and inspirational friends from ICUsteps Tees support group continue to support us along our journey through the good times and the bad. They are travelling along the same journey not for the fainthearted with obstacles at every turn and have both empathy and understanding which is crucial when your world is turned upside down.

Tony's significant co-morbidities and hidden disabilities of visual cognitive and physical deficits are here to stay along with severe irreversible heart failure epileptic seizures diabetes and hearing difficulties but throughout it all we will energise our courage to fight another day with the revitalising stream of never ending care and support from our incredible family friends and NHS.

The invincible journey will go on.