

Heather's Story

I lived in Rugeley in Staffordshire, I retired early from the civil service job centre network but returned for temporary and short term contracts. Heather actually worked for the same organisation and we were working in the same office at one stage. I'd been to college to learn bookkeeping and accountancy with a view to going self-employed. I already had two clients with a number of other promises. Heather enjoyed gardening and socialising and we owned a mobile home in Somerset that we visited for holidays and weekends. We also holidayed regularly with our cousins in France, all over the place. Running was a big feature in our lives. For many years as competitors, coaches and race organisers. I competed in races up to marathon distance and also took on triathlon events involving swimming, cycling and running where I won a number of age group prizes. I even ran 101.5 miles in 24 hours to raise money for equipment for the local hospital. Heather and I started a senior women's section at our local athletic club as they only had one senior lady member when we began and we built up a quality team which went on to win a national cross country title at Sunderland. We also fostered a second group for beginners and social runners and we averaged about 45 or 50 members in total. Annually we also organised a running event for the British Lung Foundation, attracting several thousand runners and raised thousands of pounds for that charity.

In June 2001 Heather and I were on holiday with friends in Spain. When we got back, early one morning about two days after we returned, Heather complained of a pain in her left hamstring and I thought that might be a muscle pull because she'd been to aerobics the night before, a very get fit lady! The pain got worse so I had a look at it and I noticed immediately that the left leg was cold and discoloured so, after giving Heather an aspirin, I telephoned NHS Direct and following consultation with a doctor they arranged for immediate transfer to hospital. Following tests the doctor confirmed that there was a significant clot in the leg and she would have to be admitted. I remember the doctor describing this as 'fairly extensive'. I didn't realise, it certainly didn't register at the time that this was potentially a very, very serious situation. Two days after she was admitted, a catheter or filter was inserted in the main artery in the neck which would stop any pieces of the thrombosis breaking off and entering the heart or lungs or brain and potentially killing her. The filter would normally be inserted in the groin but this wasn't possible due to the position of the thrombosis because it extended from the upper thigh right into the lower stomach area. The surgeon had three attempts to insert the filter and a haematoma subsequently formed as blood leaked into the neck. Heather's neck became badly swollen and subsequently she found difficulty swallowing. She couldn't eat and held ice cubes in her mouth to let them melt and the water trickle down her throat and they put her on a drip to compensate for that and put her in a high dependency area. Mind you, she was still the life and soul of the ward and was trying to cheer other people up.

At seven o'clock the next morning, I had a phone call from the hospital saying Heather had taken a turn for the worse. When I arrived, I was told that she had suffered a respiratory and cardiac arrest after the haematoma had cut off her airway. Her heart took 20 minutes to restart and a tracheotomy was inserted to aid breathing and, following that, she was transferred to the critical care unit. For the next five days Heather remained very poorly and I stayed at her bedside 24/7 holding her hand; brain scans were taken which showed massive brain damage with very little brain activity and she was in a state of constant epileptic seizure. It was indicated by her consultant that she was unlikely to recover from

that position. Heather's elderly parents came to see her during this time and decided that they wouldn't visit again as it was too painful to see her as death was now inevitable. On the 6th July she was moved from the critical care unit to a side room on a ward, set aside for terminally ill patients. It was confirmed by the consultant that Heather had no hope of recovery and the best action would be to let her pass away in a dignified manner.

She was still fitting severely and the fits showed no sign of abating although controlled by drugs. It also seemed unlikely that there was any higher brain function. Following a meeting with the family, the decision was made to withdraw support and to allow her to pass away quietly. So antibiotic treatment and feeding by nasal gastric tube would be withdrawn and her file marked 'not for reventilation or resuscitation'. The following day Heather was anointed by the minister from the hospital chapel and this is a sort of 'saying goodbye' ceremony. For the next week, myself and the family sat vigil at the bedside holding her hand and talking to her and during this time we were asked if we wanted to take her home as she could be in this state for days or even weeks before she eventually got a lung infection and died. Also during this time Heather developed lots of eye flickering which was disconcerting. The doctor reviewed Heather and said there was nothing in it, but I was not convinced or didn't want to be convinced.

On the 13th July, I was sure that she squeezed my fingers. It happened again the day after and then she seemed to squeeze my fingers on demand and so we were quite pleased about that although obviously we didn't know what was causing it. But then she got her smile back, despite the fact that she was unconscious, she was smiling. We called the doctor and on request she gripped his hand and he immediately called for reintroduction of feed and antibiotics and agreed to review the situation after the weekend. After the weekend, we had two visitors. The doctor came and, seeing the improvement was still evident, ordered the introduction of an aggressive rehabilitation policy. The minister also dropped in and said it was the nearest thing to a miracle that she had ever experienced.

Only recently in a conversation with Alison, her senior carer, she said 'I died didn't I?' and after a pause and a thought she said 'I died, but I didn't like, it so I came back'.

From July 16th until September 3rd, Heather remained at the hospital where she continued to make progress and she was then transferred to a nearby rehabilitation unit where she remained until her final discharge on March 4th, 2002.

The experience had an adverse impact on my health. During the initial two months in hospital, I had lost two stone in weight and clearly not at my best. When Heather was moved from the critical care unit to the main ward, I would go home late in the evening after ensuring she'd received her last medication and return again the following morning. Because of staff problems, it was often well after midnight before she had the medication and I left for home. It was on this trip home in the evening that I planned my suicide when Heather eventually died. The road home took me through Forestry Commission land and this had many twists and turns and at one of these turns I would close my eyes, press hard on the accelerator and I couldn't fail to hit at least one of the trees. When I got home, I couldn't sleep, worrying about Heather. I felt so depressed that I took to alcohol in a heavy way which gave me a couple of hours' oblivion before I showered and dressed and returned to the hospital early the next morning.

One day while showering, I found a painful lump in the chest area and arranged to see my GP. He was sufficiently concerned about the lump to refer me to a breast cancer specialist. Unfortunately the specialist turned out to be the consultant in charge of Heather's care which left me with less than 100% confidence in his ability and, that apart, I think it was a very poor decision in itself. Eventually however, after mammograms and biopsies I was declared clear.

The news eventually that Heather could go home was great and to begin with we were offered daily home support and visits to hospital rehabilitation day units three times a week. However, when we got home, the hospital said that it could only provide two half days a week because Heather was no longer an in-patient and as a consequence many other facilities were no longer available to her, one of which was the therapy pool which was an experience that Heather really enjoyed. She would go to the rehab unit by ambulance bus along with other clients and, because she was one of the first on, it would take about 60 to 90 minutes to get to the hospital. The return trip was similar. So this became a very tiring and often traumatic experience and as a result she would invariably have epileptic seizures on her return. To make matters worse, she did very little while she was at the unit apart from occasional physiotherapy. I went in several times to find her sitting alone at a table with a magazine open in front of her and no ability to turn the pages. No home assistance could be provided at the weekends and only 45 minutes in the morning and 30 minutes in the evening during the week. So apart from washing and getting her up in the morning and putting her to bed at night, I had to look after her 24/7 myself. After a while, I even cancelled the evening input because Heather was invariably tired well before that and needed to go to bed. So I would do that myself and even when weekend support was added in, it was often late not by minutes but by hours or didn't turn up at all. A few days after discharge, we received a letter from Heather's social worker; it was actually her third social worker in the nine months she'd been in hospital saying that she had relinquished responsibility for Heather and that the local authority would take up the role. It never did. Nor was there any planned follow-up review with her consultant.

Home life as you can imagine, was very difficult. I had to convert our ground floor dining room into a bedroom; unfortunately this room was long and narrow and could only just house two single beds side by side. At night, I would have to bring this second bed down from upstairs for myself and put it next to Heather's. Heather was severely and doubly incontinent, a fact that the hospital had failed to inform myself and required hoisting on to a commode several times during the night. To do this, I needed to strip my bed off and remove it in to the next room, using the hoist, transfer her from bed to commode and complete the toileting (which was usually too late) and I had to do washing and cleaning before getting her back to bed again and then reinstating my bed. During this procedure she would often have epileptic seizures because the hoist was not her favourite mode of transport. Heather had virtually no use of her limbs; she couldn't bear weight and couldn't grasp anything. Her left arm was almost totally useless so everything had to be done for her including feeding and drink and all the usual domestic services. Obviously a stair lift would have been a tremendous help because we could have then got her into a proper bedroom with a bathroom and access to a double bed and showering etc. but no real home assessment was made and, in discussions with the occupational therapist, we were told that Heather would have to go on a waiting list if we needed a stair lift and it would be about six months before she could get on to the waiting list and from that point 12 months plus before they could provide a stair lift for her. Unfortunately we received no support during this time from being assessed as needing 24/7 care, brief daily input provided little respite for us. Simple operations like washing her hair I would have to carry out myself using the hoist. We would hoist her on to the edge of the bed, supported in the sling and put with her head just hanging over the edge of the bed, supported, put a bowl underneath and then wash her hair like that, you know. Obviously that was a traumatic experience in itself.

It all proved to be a horrendous experience, capped on March 14th when I went to our GP's surgery to get a repeat prescription for Heather's medications. In front of a busy surgery reception, I was told that they couldn't comply as the hospital had informed them on the 10th August in the previous year that Heather had died! As you can imagine, I almost collapsed on the spot.

We were getting desperate, as you can imagine, until one day we had an offer that we couldn't refuse. Heather's sister lived in Northumberland and she talked to the Northumberland Head Injury Service who said that they could provide a full rehabilitation package if we lived in their catchment area. So, with little thought, I took the immediate decision to move, even if we had to rent property. By August we'd moved to Northumberland having sold our previous home and bought a replacement albeit, unsuitable property in Bellingham, but it got us into the catchment area. The Northumberland Head Injury Service set up an extensive care regime for Heather and myself that included complete care package seven days a week as defined by Heather and myself; occupational therapy including access to necessary equipment for home and in fact we had two occupational therapists at that stage, one from the service and one from the local authority. She was provided with physiotherapy; she was provided with speech therapy, psychological therapy and rehabilitation group sessions where they actually got down to doing things. And obviously access to a consultant on a regular and on-demand basis. For someone who wouldn't survive, she now looks remarkably well. The effects of the brain injury are still evident: in the main, cognitive problems, difficulty with attention or concentration, memory problems, difficulties with problem solving - we don't give her a range of choices - it's often, at the most two or perhaps even one where she can say yes or no. Difficulties with problem solving and obviously taking longer to think about things, so you know, you don't rush her, just let the process work. Loud noises also upset her tremendously such as low flying jet fighters that we do have over this property from time to time and she gets easily fatigued. All symptoms of brain injury. She still suffers significantly with epilepsy but in the main that's controlled by drugs. However, now she can feed herself and particularly on the good days, she helps the carers to dress her and she can also put on a bit of makeup. She goes to the local gym twice a week and for someone who would never walk again, she does exceptionally well. She can now get about obviously with assistance, myself or a carer and she can even manage a few steps. Heather continues to improve and astound us all.

And how are things now? With Heather's improvement you would think we were absolutely delighted. However, since Heather left hospital friends and family assume that all is well and we no longer need their support. Nothing is further from the truth. We know lots of people in the area but we have no real friends apart from the carers and I must say that our team of carers are the most important people in our lives and we couldn't survive without them. All this has had a major impact on our lives. We have lost all the intimacy of marriage - I'm no longer a husband but a carer. Heather has lost all dignity with having people looking after her all the while and the presence of carers means that we have no privacy, although we wouldn't do without them. I take medication for depression, angina, high blood pressure, hiatus hernia, gout, high blood cholesterol and low bone density. I've had two minor strokes and recently had a replacement hip operation. I'm an alcoholic and have suffered a general loss of fitness and increase in weight. Oh yes, our problems are all over.