

The story of a Grade 3 Oligodendroglioma

Brain Tumour Survivor

It is not known when my brain tumour started, but I suspect it all started in 1975 when I was 13 years old and I was playing Hockey at school. I was the goal keeper and the opposing side's attacker was sprinting down the field with the ball, I ran out from my goal to minimise the angle and to encourage him to make an impulsive shot at the goal, it worked he flicked the ball up and went for the shot but missed the ball but I caught his hockey stick full on my forehead on the right hand side, I went down like a sack of wet spuds but was not knocked out. The teacher was getting very worried by the ever increasing size of the egg shaped bump coming up on my head so sent me to see the school medical nurse where I was given a witch hazel compress to hold over it and then sent to a quiet room for about half an hour, at this point I had no pain or headache. After my dinner break I went back into my class and soon I developed a raging headache so asked if I could see the school nurse again and she then gave me some paracetamol and told me to sit quietly in the quiet room, I was in there for about an hour this time before the nurse came in and asked how I was and I told her still a big headache so she then said she would have to take me home. The nurse told my mum that she should take me to see the doctor which we did the following morning as the surgery was on a half day closing but he said it looked ok and the swelling would go down in time and prescribed me with a strong pain killer and said don't read or watch telly for a couple of days and sit in a darkened room.

The egg shaped bump was to remain & sometimes it was a lot more noticeable than others. I had the rest of the week off school. I did not suffer any further problems until about a year later when I developed Bell's palsy where I could not open my right eye; I had to have a steroid injection in my backside every morning for 10 days at the doctors before I went to school. There was no more problems until I passed out when I was 16 inside West Ham football ground but this was put down to the heat wave we were having at that time and a maximum capacity crowd with the increased carbon dioxide level build up from the crowd, my brother was happy as he got to sit with me on the St John's ambulance bench for the remaining 15mins of the game. Then in 1981 my mother passed away a month before her 50th birthday after having a brain haemorrhage, I felt very guilty that I could not show any emotion at this time and since I followed my mum in most things she did, from that day I dreaded the thought of me never reaching my 50th birthday.

Then I passed out again a few years later when I jumped over a wall and tripped over then got up too quickly, I fell into a main road; luckily a passing motorist noticed and stopped by me to protect me from the traffic flow.

This was the same time I met my now wife Lynda in 1982 & we got married in 1985, I was very disappointed that my mum could not be at our big day but I have always known and will always know that she is up there keeping her beady eye on me & guiding me through life's troubled ways.

Then I had no real problems other than the occasional headache that only Nurofen Max could ease but this was put down to the stress from my work, also every time I picked up my 110 volt drill I used on building sites if it was raining I could feel a small tingle in my fingers but no one else could feel it. Then about 25 years later I picked up a very small empty cardboard box in the office and got a terrible shooting pain in my left shoulder which even very strong pain killers taken at 2 hourly intervals could not touch, I also coughed up blood one night after a Burger King meal and was sent to hospital for an endoscope to be put down my throat but this showed nothing. I went to a local chiropractor which had been recommended to me and started a course of treatment and after 4 sessions the pain had gone but I continued with the treatment (until I had the tumour removed as my consultant said that if he does any violent shaking of my head it may cause complications.) I had a feeling that there was still something wrong with me so booked myself a BUPA health check but this only showed I had a raised cholesterol level. I used to get a pressure pain in my head every time I or someone used a vacuum cleaner near me & this does not happen now.

I set up my own Electronic security company on 13th February 2012 after being made redundant. This is when it all kicked off, I got up from crouching down and went very light headed and thought I was going to pass out so I crouched back down again and put my head between my knees the symptoms went away. I went to see my GP the next morning and he diagnosed me with an inner ear infection and prescribed some tablets. 4 days later and still no improvement, this time my wife Lynda came with me as she wanted to ask the doctor some questions about me. After her questions I was sent for a neck x-ray which showed I had a very slight curvature of the spine in my neck so I continued with the tablets.

Still no improvement a week later so another trip to the GP's and this time my wife asked if we could have a CT scan. The doctor said he would send me to the hospital for the scan, this came through a month later for an evening appointment at Basildon Hospital and we went for the scan and we were told that the scan showed there was something that showed up and I needed an M.R.I. scan but the

department was now closed and they said I had to stay in overnight so I would be the first person down in the morning.

When I came out I was told that I had a brain tumour. I was sent home and when at home I developed hiccups, these lasted constantly for 5 days and occasionally I could not breathe when my diaphragm went into spasm. I cured this by hitting myself on the chest but it was getting worse and I thought I was losing control so I asked Lynda if she could come into the bedroom and sit with me. When I told her that if I blacked out she should hit me on the chest she said no and immediately called for an ambulance. A rapid response vehicle was on our driveway before she could tell me that they were coming. The ambulance was not far behind turning up. When there they put an echo cardiogram on me but this seemed to be ok. I was taken to A&E where they tried just about every drug available to cure my hiccups eventually a consultant came down and said try an epilepsy drug and this helped with the diaphragm spasm but did not cure the hiccups completely. They then said I could go home, but by this time I was way out of it and still could not stand up.

Lynda was in a terrible state by now and just let loose at the doctors screaming and shouting and they then admitted me in to the hospital. It was now 19th February, 2 days before my 50th birthday, Lynda must of scared the life out of my brother Ray that night when she phoned him as she told him I was in hospital and if he wanted to see me he had better get over here from Jersey fast, 10 days later I had the grapefruit sized tumour removed and on the morning of my operation the hiccups stopped. I stayed in hospital for 2 more nights before going home. On 2nd March 2012 I duly sent my driving licence up to the DVLA for the 1 year that I had been told. Every night for the first 10 days I had vivid dreams of all the bad things that had happened in the past and found myself waking up in the middle of the night in floods of tears.

A month later we then got a letter for a meeting with a consultant at Southend Hospital at this meeting we were told that the follow up treatment would start shortly and this would be chemotherapy then followed by radiotherapy if it was needed. With the thought of the hour plus drive to the hospital and the same back home again on a regular basis, we asked if we could have the treatment at Queens Hospital in Romford as this is only 10 minutes from Lyn's mum's and we are there most of the time as Lyn is a part time carer for her mother.

We were then told at Queens Hospital that the driving licence will not be returned until 2 years from the end of treatment. I am mad about cars and my brother had brought me a track day for my 50th which we swapped for a night away in a hotel because it was going to expire before I got my driving licence back.

- I am now recovering from the side effects of the operation and the radiotherapy. My energy & stamina levels have gone through the floor. I am now permanently tired and I am usually in bed between 18:00 & 19:00, my personality has changed for the worst Lyn says.

The operation has damaged the fourth nerve in my right eye and I cannot see clearly through it & have double vision, this has been rectified by a thin plastic prism stuck to the outside of the right side lens of my glasses, I have just been told that I have macular degeneration in my right eye and this will only get worse and could affect my left eye as well. I have also lost 20db of hearing in my right ear and now wear a hearing aid. I have short term memory loss which Lynda finds very frustrating that when she asks me to do a couple of jobs I only do half of them and forget the others. I get giddy and very light headed occasionally when I get out of bed & stand up and when I get up from sitting down, this has been said that my blood pressure is taking a short while to catch up so now I have to get up in stages and very slowly. I have developed a mild twitch / shudder occasionally, usually once or twice a day. I also get a very hot flush when I am out shopping with Lynda, this seems to be brought on by constantly walking then stopping, I also get it in the mornings when I come down for my coffee. I have had a blood test to check my cortisone levels as it was thought that this may be the problem, and yes they are low so I've now been prescribed fludrocortisone tablets. I feel these are not doing anything except giving me the shits & because it is a steroid I have put on a lot of weight. Emma my consultant has said that if I was a new patient and told her of these symptoms I am having she said the alarm bells would be ringing for a brain tumour but we know there is none as the M.R.I. scans are clear. But I am alive and the prognosis is good.

- The egg shaped bump has now disappeared completely. I now go out for a brisk walk most mornings which is between 1/2 & 3/4 of a mile; I do Sudoku in the newspaper every day and usually complete it, I have built a balsa wood model of an American motorbike, a motocross bike, a Formula 1 racing car & of course playing Candy Crush, Pepper Panic, Bejewelled, Solitaire & I have just started playing Bingo on Facebook to keep the little grey cells working.

I have bought myself a racing push bike to help with the energy and stamina levels, I usually do a mile circuit on this once a week with an occasional push to 6 miles and I feel this is helping. I also occasionally get a metallic taste in my mouth but have done nothing about this as yet. I now class myself as semi-retired as if a job comes along that I like & I know I can do I will go for it, but the days of full time work have gone as I know I would not be able to cope with it now. I am now trying to update the mum-in-law's bungalow, we have converted the father-in-law's loft hobby room

into a bedroom, but trying to get our 3 bed roomed house into 1 room of a bungalow is very difficult.

I have had to sell my beloved 1987 Harris Triumph Bonneville which I had always wanted but we had one very good year together. We sold Lynda's car as mine was more practical to keep, I have just applied for my driving licence back and hoping that I will be able to drive again after 30 months. The D.V.L.A. have sent back a letter and are asking for me now to have an eye test which I duly had and I think all went well as the optician would not say.

- I have just got my driving licence back after 2 years and 10 months, we have sold our house in Thurrock and now live with Lyn's mum in Hornchurch as it's much easier to get to Queens Hospital in Romford for my routine M.R.I. scans. I still have my good days and bad days but the bad are getting fewer. My brother is helping with my convalescence by getting us to cat sit their 2 cats in Jersey while they go on their 2 week holiday.

- We have decided that it is about time we saw some of this green and pleasant land we call Britain, Lyn & myself now go up town about once a month or we go down to the cliffs pavilion at Southend-on-Sea to see a show.

When you are told the bad news just remember that you cannot change the past, the future may never come so just live your life for today and have fun out there, remember life will always go on with or without you, but will always be a lot better with you in it, since I was diagnosed & until the current time 30 months later I have put on 2 and a half stone in weight as a result of the steroids and a more restful life style.

- We have convinced the Mum that the 20 year old shed and the 35 year old greenhouse are passed their use by dates and have replaced the shed and the greenhouse is now going to be a gazebo / summer house, I have started to build the gazebo by painting all the parts with a golden brown wood preservative, my hands look like they have a nice tropical tan but they are only stained from the preservative, we will drag mum into the 21st century but it is hard as her late husband built most of the items and she does not want to let go of them for sentimental reasons.

- I am going on a 30 minute walk in the local park with Macmillan Cancer to help with my energy and stamina levels, this will be a weekly event on a Monday at the local leisure centre and it is at the local hospitals oncology car park on Thursdays, this should not be too hard as I go for a walk around the block most mornings for

this amount of time which is usually approx 1.5 miles, so let's see how far and fast Macmillan's walk will be....

- This turned out to be a slow walk of approximately 1 mile, the following week I joined their normal walk which was a 2 mile walk at a slightly faster pace and this lasted for 1 hour. I have signed up for Cancer UK's Relay for life in Clacton and another Member of the Brain Tumour Group is also doing this.

- I have an appointment with a PIP medical Assessor for 18th December 2013 at 16:30, I had to cancel this as I was having one of my bad days and there was no way I could go so we called the appointment line to reschedule and was told an appointment will be put in the post the next day but when the letter came on 30th December 2014 it said I had been declined and scored 0's across the board. Lynda got straight on the phone and told the Atos operator and they said they could not believe the decision we received as they felt that a medical assessment had to be made as they thought I was boarder line for the basic award. Today 6th January 2015 we had a phone call from the Atos investigation team wanting to know the full details of what happened and they also said that was not acceptable and will launch an enquiry into it and we should hear from them within 5 working days

- I have just received my driving licence back on 23rd December 2014 and it is only valid for 1 year so I will have to go through the whole process again next year.

- I received a letter from PIP on 12th June 2015 and this time I scored 26 points which meant I was going to receive the enhanced rate of payment.

- Lynda & myself have decided to renew our wedding vows for our 30th wedding anniversary and then go to Rome for our second honeymoon. I have now developed tinnitus in my right ear which is annoying. I have just had my hearing checked and there is no change from when it was first done so at least it's not getting any worse.

- I am taking part in the Clacton Relay For Life on 4th & 5th of July 2015 to raise money for Cancer Research UK. I have also signed up for the 10km Twilight walk of Windsor in September.

Paul Ross

A member of the Romford Brain Tumour Charity Support Group