

## **Marian Dye**

In 1998 my symptoms first started – mainly headaches. But life was busy at the time, my husband had just been registered blind and I was working towards promotion, I assumed it was perhaps a migraine or stress related.



Things jogged on like this for the next nine to ten years. The headaches got worse and when I went to see the doctors they thought it was probably

because of a variety of reasons – my daily commute to London, studying for the promotion I had finally obtained and looking after my husband. Despite this I felt my GP was fabulous, I felt they really cared.

In 1997 I started dropping things, which on top of the headaches made me return to my GP. This time I was referred to a neurologist, in St.Albans, who organised an MRI scan for me. I remember asking her, ‘Do I really need one and would you have one if you were me?’ Her response “yes”

I had to go to Luton and Dunstable hospital for the MRI scan; I was petrified of going in to the scanner. I will never forget the faces of those radiologists as I left – they had obviously seen the tumour – it was pity, fear, sorrow.

A week or so later I had another appointment to see the neurologist – I remember it was 5.30pm at night, I had the last appointment – I left her at 7pm, she could not have been kinder to me. She explained it was a brain tumour but not only was it not malignant but it was also operable. I was not prescribed anything.

I remember feeling a sense of relief tinged with horror and fear. Relief because finally I knew what the problem was and I could make sense of the headaches. Horror and fear because of what the future would hold.

I took a cab home to my husband and told him, he was devastated, I remember thinking that I was the strong one until I got into bed that night and cried. I was training to be a tax inspector at the time within the civil service; I decided there and then to discontinue the training – the headaches and back ache was now so bad it was affecting everything I did. I had had back ache on and off since my daughter was five and despite going to the osteopath [who usually worked her magic] the pain continued.

In May 1998 while marking for a visually impaired bowling match whilst on a holiday in Western Super Mare, I suffered a seizure, a complete black out. Surprisingly I did not collapse and later I found out that these were classified as absences and are not fully blown seizures.

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I went to see my GP and she was brilliant and arranged for me to be referred, after consultation with the neurologist, to the Royal Free Hospital in London. My appointment came through for August. I continued working full time at that point.

In June I started to develop a sort of Bell's palsy on the right hand side of my face, so I went back to the GP. She still felt happy to leave the appointment for August.

One Friday in July, I was working at home; I received a letter from the hospital saying that due to holidays my appointment has been re-scheduled for November. For me this was the breaking point, I remember bursting in to tears and ringing the GP surgery and crying over the 'phone to the receptionist, Doctors' receptionists have a bad name, but I could not fault this lady, she arranged for me to get a call back from my doctor and a few minutes later my GP was on the phone. She had miraculously got me an appointment for that Sunday at the Royal Free. She also said she had spoken to the doctors at the Royal Free and they wanted me to go on a whole cocktail of drugs and asked me to come and see her immediately to pick up the prescription...

I had another MRI scan, the consultant radiologist, reviewed. He was my GPs husband, which may have accounted for the quick service. He was certainly one of the reasons why I was sent to The Royal Free. I look back and remember how incredibly calm I felt and I think that was because of the professionalism of the medical staff who dealt with me.

I remember that on that Sunday I met my surgeon who asked me if I would come into hospital on the 15<sup>th</sup> July (that Wednesday) for surgery. I said I could not do that because I had an important appointment at work. He very tactfully explained that I should have stopped work weeks ago and that I really should come into hospital on the Wednesday! I just don't think I realised how serious it was. The doctors went on to say that I should give up work immediately and to tell my boss that I was having surgery that Wednesday, July 15<sup>th</sup> 1999. I finally agreed to finish working by lunchtime on the 14<sup>th</sup> of July. The medical team went on to say that I would probably be off work for up to six months.

At that point I recall turning to the doctor and saying; "What are the chances of me coming through this?" I also remember telling them, that just in case anything went wrong, I had signed a donor card and that I wanted them to keep my body alive for as long as possible after my death so that they could harvest everything possible for medical purposes.

My surgeon laughed and said that I did not need to worry about anything like that.

On the Wednesday 15<sup>th</sup> July at 8am I was wheeled into surgery for what would be an eight hour operation.

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The night before the nurses had asked if I had any special requests for the operation – I named two. The first was that they would totally shave my head after I had been anaesthetised and the second was that they would not catheterise me.

My father, who loved medical programmes, asked my surgeon if he could watch the procedure, he said that would not be possible because there was no viewing gallery in the theatre!

Before the operation I was not allowed to eat anything after 8pm that night, so a friend came and picked me up early and we walked out to a local Italian Ice Cream parlour where we had the most fabulous ice-cream, me in my nightie, dressing gown and slippers!

The Registrar came to see me in ITU after the surgery just as I was coming round and asked me how I was feeling. I remember saying that my right leg had pins and needles in it but my right arm was fine.

The day after the operation I returned to the ward and the nurses came and apologised that they had after all had to catheterise me because the operation took longer than they had expected. I was later told that I had had to have over 8 units of blood also!

My husband was a great support throughout this although he did start smoking again. At one stage he thought that he was going to lose me, as the operation was taking so long.

My daughter, who had married the year before in 1998, came to visit me in the high dependency unit and she noticed that my right leg and right arm were really cold. I was not speaking properly and with the drugs I was pretty much all over the place.

On the 17<sup>th</sup> July, two days later, they moved me from the High Dependency Unit (HDU) to a four bed ward as I was no longer in danger and I was sitting up and taking notice of what was going on around me. That damned catheter came out, so I had to get out of bed and go to the toilet, even though I had to have help from a nurse or a walking stick.

I did ask the medical staff if I could take arnica for my bruises; they said it wouldn't do any harm and I was delighted to see that three days later my bruises had almost gone.

A friend suggested that I started to crochet to keep my right arm mobile and I continued to read newspapers. I recall that the hospital staff used to ask us silly questions every day to test our cognisance, e.g. "Where are we?" and "Who is the prime minister". All four of us were asked the same questions. I remember annoying them one day by asking whether they wanted me to give them the actual latitude and longitude of the Royal Free Hospital in Hampstead. I wasn't asked again! ☺

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I was glad they had shaved my head, it was easier to keep my wound clean, so it healed better. It also allowed the nurses to check the wound more easily. After all they had stapled me together with 22 steel staples. At this point, I still did not know how big the tumour had been.

After three weeks in The Royal Free, I was discharged into the care of Benenden hospital in Kent where I stayed for three weeks. How glad I was that I had joined Benenden, as the treatment I received was fantastic, I had my own private room, we had four nursing staff and a ward sister looking after just twelve of us.

The first few days I was placed in isolation in order to check that I was clear of MRSA. Then they organised my medications – at one point I had quite a scare with an allergic reaction, but working in conjunction with the Royal Free they were able to sort things out pretty quickly.

Then they started a gradual programme of specialist physiotherapy and occupational therapy, as I could not walk or talk properly. Much of the rehabilitation was organised in such a way, that I hardly realised what was happening. For instance each day they would send a porter to pick me up to take me to physiotherapy and each day he would get side-tracked at some point on his route and I would have to go out and meet him – by the end I was walking 10-15 minutes each way.

Staff and other patients would come to speak to me each day and gradually my speech improved. I was also encouraged to go into Tenterden, the local town, by bus on my own to help me gain independence; armed, of course, with a list of emergency numbers. I was so touched by the shop keepers in that town, they were so kind, they could tell I was at Benenden. I remember crying in Laura Ashley because a child had commented about my baldness and a sweet lady helped me choose a scarf to wear and made sure that it was bright and cheerful.

I had been seeing an osteopath since 1979 for my back troubles and after the operation I returned to the same lady because she was also a cranial osteopath, I had a couple of treatments for my back, which now, eleven years on, means I only need two/three precautionary treatments a year, I also had one or two cranial treatments.

On a post operative visit to my surgeon I explained that I was no longer having back pains since the brain tumour operation - he explained that my tumour had been the size of a man's fist and that it is called a meningioma it had been situated on top of my central nervous column, which would account for the back pains. In addition he explained that if I hadn't had the surgery when I did then I would have been dead within six weeks.

One of the GPs at the practice afterwards said how sorry she was for what I had been through and explained that there are 26 reasons for a headache and only three of these reasons are because of brain tumours. She went on to explain that when an individual who does not normally suffer with headaches starts to have really bad ones then this could be an indicator of a tumour. However, when

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somebody has a history of headaches then it becomes extremely difficult to diagnose a tumour.

After the operation I was put on epilim twice a day – they believed they had got the entire tumour. Of course, I can neither drive nor can I have a bath on my own or go swimming. My daughter says some things are worse and some are better, I am more short tempered and my memory is not as good, sometimes I say one thing and mean another. I used to do Scottish dancing but this has not been possible since the operation, due to the nerve damage in my right leg, in fact I can't even do a sedate waltz. I have also put on weight partly because of the drugs and partly because I couldn't do as much exercise. I did not continue to do the same level of technical work as I had been used to within the Civil Service; I reverted to my previous grade having decided not to work towards a more senior position. I then took early retirement from the Civil Service in 2007, this decision was not because of my surgery, however I did go back to work in 2008 and of course I continue to care for my husband and my mother who is now nearly eighty.

Six years ago we moved from St.Albans to a small town in Bedfordshire, in order to be near my daughter and her family. It was like moving to a third world country.

The GP surgery I joined decided to take me off epilim because of the cost – I lost 4.5 stones in weight but the headaches returned. My GP examined me and looked in my eyes but said he could not see the tumour, but that was not surprising because meningiomas do not exert any pressure on the eye.

I was referred to a neurologist who organised another MRI scan in November 2009, which showed no tumour, only bruising on the brain. It is now thought that as the tumour has not returned it never will.

I have had some really mixed experiences throughout this period of my life – meeting some amazing people who have helped me beyond the call of duty, but I have also met people who have treated me really badly. I broke my ankle and needed a wheelchair – it was a salutary experience – you become invisible.

Three months after the operation my husband and I went to Croatia on holiday. We had requested that a buggy should be available for the journey between the gate and the train station at Gatwick. When we arrived a woman was sitting in what we told was our buggy. We explained that we had booked it, however she insisted that she should have the buggy to herself because she had had her bunions done! My husband explained that I had just had brain surgery, but she insisted that her bunions had priority! I was very tired and distressed by this, however the airport staff rallied round and sorted everything out. They even made arrangements with Thameslink for staff to assist us on our railway journey home. What gems!

Most people don't understand, and what's more, don't want to understand how either living with a tumour or having had a tumour, affects you both emotionally

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and physically. It also impinges on your family and friends, without their help and support you can't continue.

Before the operation I only went to church occasionally, however this experience has made me realise that there had to be someone out there. I rediscovered my faith, was confirmed in St Albans Abbey, I received lots of help and support from some really special people at St Peters Church in St.Albans; I miss them more than words can say.

Through it all the things I have learned are that if you want to get better you will get better and that some doctors are great and some are not. The bad doctors are those who don't have the gumption to say, "I don't know!" but "I will find out". I have also learnt to live life to the full and enjoy myself. I would caution anyone reading this not to get into debt, however, as this will make them unhappy.

What it took me a long time to admit, and I still have problems saying this is that I had a benign cancer. However, I survived, thank you God, if I hadn't I wouldn't have seen my beautiful granddaughter.

I have had to keep going through all this. Who else would look after my husband?

Marian Dye – March 2010