

Melissa Huggins

I had always suffered with, what I thought were migraines since 2000. In September 2005 these became more frequent and intense. I have been to see my GP on numerous occasions between September and November 2005, but was continually told that they were migraines and all I needed were painkillers to control them. Quite rapidly, I deteriorated.



Along with constant headaches, I would get severe shooting pains up the back of my neck that would only last for seconds but they were very painful. The only way I could describe them was like a 'bolt of lightning' hitting me. On top of this, I would have bouts of numbness in my feet and face, was constantly being sick, felt dizzy (which we now know was due to the build up of pressure on my brain) and began to lose my memory. I suppose, to put it simply, I felt like I had a very bad case of the flu that I could not shake off.

By early December 2005, I had begun to sleep at every opportunity - and if you knew me before all of this, it was not like me at all as I was a very active lady! Unhappy with my condition, my family paid for me to have a private appointment with a Neurologist at St Margaret's Hospital in Windsor, Berkshire. I can safely say that this saved my life and I will be forever grateful for the doctor's quick diagnosis. The doctor looked in my eyes with some concern and asked for a second opinion from a colleague. They both agreed that they could see pressure behind my eyes. I still had absolutely no idea what they were looking for and almost felt a little silly for wasting their time (I was convinced I had damaged a nerve).

Within half an hour, I was having an MRI scan of my brain. Despite all the signs, I never thought it was a brain tumour. Things like that don't happen to a healthy 24 year old living her life to the full! But how wrong we all were and a lesson was learnt that day. These things can happen to you and you just have to deal with them the very best you can. I can remember the doctor showing us the scans of my brain and all I could think about was that my poor family were sitting behind me. What on earth must they be thinking? We were all in total shock, it was a very surreal situation. We all hoped it was a horrible dream.

I must admit, I did have a little feeling of relief that finally someone believed me and that there was a reason for why I was feeling so poorly. My partner James and I drove home, we were in total shock. He told me that I could have any dinner I wanted as I hadn't been eating properly in the months leading up to this day. Being typical Melissa, I chose a McDonalds with a chocolate milkshake. Just because I had a brain tumour, didn't mean I wanted special treatment!

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The next day, Friday 9 December 2005, The doctor phoned me at 8am sharp and told me to come straightaway to Charing Cross Hospital in Hammersmith, London. Of course, my family and I had been up for hours not being able to sleep and all pretending that everything was fine! It's funny how you deal with things in a crisis.

Although I had been diagnosed with a brain tumour, this was not the immediate danger. Due to the position of the tumour on my brain stem, it was preventing the brain fluid from draining down my spine which was causing a build up of pressure in my skull. Hence the intense headaches I had been suffering from. This was very dangerous as I could have suffered from a seizure or haemorrhage at any time. The doctors told me that I would have eventually gone into a coma if I had not received medical help.

Again, I had no idea what to expect and to be honest, I felt so poorly I didn't care what the doctors did as long as they could make me better. When we arrived at Charing Cross Hospital, they were ready to operate – but as no one had told me this, I had eaten breakfast that morning. Whoops! Therefore, I had to wait until a slot was available in the evening once my food had gone down and it was safe for me to have an anaesthetic.

That day was very long and tense. I sat with my Mum and James and we played lots of silly games to pass the time. I was so nervous. Every time a doctor or nurse walked past my heart sank. Were they ready for me? Suddenly the call came. I was going down to theatre and I was to have a 'shunt' inserted into my brain to relieve the build up of pressure in my brain. The shunt needed to drain the fluid into my stomach before they could even think about removing my brain tumour. This was it. This was real and this was really happening to me.

As they prepped me for surgery, I can remember thinking (being a typical girl) – I don't mind how much of my hair you shave, but please try not to go too far above my ears, then I can still wear my hair down. Looking back, how ridiculous is that? But, it's funny how silly little things like that bother you when you are faced with such a challenge. I know it was just my way of coping, trying to make a joke out of the situation, but of course this was serious and I was so very frightened. I didn't want to think about what was happening. I just needed to get better.

At 8pm I had emergency surgery to insert the shunt and I came round at about midnight. My first operation was a success and I was okay. A little groggy and sore, but I was on the road to recovery – with less hair! Apart from being very sick for those first few days, I began to feel 'normal'. The pressure had been drained and I was relieved from the pain for the first time in a very long time. Now I just had to wait for my second brain operation. The build up for this was much more intense and we knew (without being dramatic) that my life could be at stake. Our trust was firmly placed in the Neurology team and their expertise. There was nothing else we could do. We just hoped that they were good at their job.

This was the time I first met my Neurosurgeon, a man with great presence and knowledge. He was strict from the start. There was absolutely no way I was

about to get away with anything. What he says goes. From our first meeting, I had the greatest respect for him and he earned my trust. He made me feel safe and secure as he was so 'to the point' about what he was going to do. There was something about him that I liked. He didn't beat around the bush, but at the same time he made me feel comfortable. He never left the room without winking at me or giving me a little gentle squeeze on my leg. I think this was his way of reassuring me and letting me know that he cared. He'll never know what those tiny gestures meant to me and how full of admiration I was and always will be of him.

I was prepped for surgery on Tuesday 13 December 2005 (4 days after my first operation). We had to go through the usual paperwork where they make you sign your life away and that is when it hit me again. I remember asking my Mum if this operation was going to be like my first. She just looked at me and said 'No darling, it's not. It will be much harder, but you will be fine'. I cried. That night I couldn't sleep and my family and James arrived at the hospital at 7am. We sat in the waiting room and talked about anything and everything except what we were about to face. I opened some cards and presents from my friends, but I couldn't really concentrate and felt ungrateful. I thought I was nervous for my first operation, but this was a million times worse. I knew what this entailed and it was not going to be easy.

At 8.45am they came to get me. I refused to say goodbye to James and my family, just 'see you later' was all we said. Going down to theatre was eerie. The hospital had tried to make it look nice with paintings on the wall, but it was just like the 'Green Mile'. My destiny was in someone else's hands and I was scared. I cried again as I couldn't do that in front of James and my family. Weren't they going through enough already?

I was met by my anaesthetist who was the loveliest man. He was so kind and caring and made sure I knew what was happening and introduced me to his team. They stroked my head as I went to sleep and as for the operation itself, well you'll have to ask them exactly what they did. I'm afraid I was busy counting sheep.

I was woken 6 hours later in recovery by my anaesthetist and his team all cheering at me from the end of my bed. 'You've done it' they said and I thought 'you're all too energetic for me right now!' I remember placing my hand to my throat because they had warned me that if anything went wrong during the operation, they would have to put in a tracheotomy to help me breathe. Luckily, they hadn't and I think I knew at this point it was a success. I felt absolutely dreadful though. I was heavily medicated and sedated, but my neck was aching and I had a bad headache (funny that!). I kept asking for more drugs and they kept saying I'd had enough. I was lucky enough to have a student doctor sitting with me whilst I was in the recovery room and she reassured me and made me feel as comfortable as I could be. Having her there made a real difference because every time I woke up, it was nice to see a familiar face until I could be with my family and James.

Finally, I was taken up to the neurological High Dependency Ward where my family and James were only allowed to see me through a glass window. Every time I woke up, there was someone standing there for me and knowing that I was not alone, I could fall back to sleep. What was to follow was one of the hardest weeks of my life. Recovering from two brain operations is not easy. My actual wounds didn't really hurt that much, it was the sickness that was tough. I was being sick constantly and had tubes up my nose and down my throat, which didn't help. I also had a drain in my head, which made it very uncomfortable to sleep. The only time I managed to get some rest was when they gave me painkilling injections that sent me to sleep for two hours at a time.

I also sustained damage during surgery and this was discovered a few days later. Each time I tried to drink fluids I would choke. This is where they had damaged the part of my brain that tells me how to swallow. I had to re-train myself with the help of a specialist nurse. In the scheme of things this was minor and we had fun turning this into a fun 'drinking game' activity.

I was bedridden for a few days. The care I received from the nurses at Charing Cross Hospital was fantastic. They made me feel like a person without, at any point losing my dignity. They would always chat to me about holidays and Christmas. Early on, I tried to get up and out of bed, but each time I would black out and then I would be sick again. The nurses decided that I had to practise getting out of bed gradually each day. Firstly, rolling over then sitting up and then walking. One day, my Professor took me for a VERY slow walk around the ward and I felt like I was in an 80 year old body. Frustrating is an understatement! As I came back from my walk, my family and the nurses were waiting and clapping me. I remember getting really cross and saying 'I'm 24 and should be able to do this easily. Why are you clapping?' I know they all meant well, but I didn't want to be like this. I wanted to be better and back to my old self. I think secretly everyone was happy with this reaction as they knew I was on the mend and the old Melissa was coming back.

After some physiotherapy sessions on my legs (as my muscles had begun to waste a little) and investigation into the damage I had sustained during the operation to my throat, I was discharged from hospital on 23 December 2005. Now things were looking brighter and I could start trying to pick my life up where I had left off - but without this wretched tumour.

Being at home for Christmas was the best present I could have asked for. A bit clichéd I know, but absolutely true. If you learn anything from being so poorly, it's that nothing matters apart from your health and your family and friends. I have certainly learnt how to value mine. I am a true believer that everything happens for a reason. Being in the comfort of my family home was recovery in itself and along with a few short walks, medication and lots of rest - I was feeling better each day. I wasn't much company for the first few months as I would only need to walk down the stairs and I'd be shattered, so I would have to go back up to sleep it off. Whatever happened to me being the life and soul of the party? I was now old before my time! Not for long.

In the three years following my diagnosis I have enjoyed every moment of my life. It has been 3 years since my initial diagnosis. I have been on numerous holidays with family, James and my friends. James and I bought a house, got engaged and I also became a God-mum. There are lots of other things to mention too. I have been one lucky lady to come through something so serious the way I have.

Of course during these times I have had regular checkups at Charing Cross Hospital. These have included MRI scans and many consultations with my Professor. Each one brings with it different feelings. Sometimes I feel very positive and other times I have been extremely worried, although I never like to show it. Why worry people when there is nothing you can do about it? Sitting outside the Professors room is nerve racking and it doesn't really get any easier. For those few moments in the waiting room, my life is in someone else's hands once again and I just have to hope and pray I get some positive news. There have been a few scares along the way, but my Professor has always explained to me that they could only remove as much of the tumour as what the human eye could see. He also explained that he has been monitoring a 'shadow' from Day One hoping it was scar tissue from the operation.

During these last few years, living with a brain tumour is always at the back of my mind (literally!), but I have had to get on with my life and do the things I always wanted to do before diagnosis. There is absolutely no point going through something like this and not coming out with something positive at the end. For me, this is the appreciation I have for my life. I will never take it for granted again and also the love I have for James, my family and my friends. They will always be the centre of my world.

So, we carried on as normally as possible until Thursday 30 October 2008. In actual fact, I think we were all a little blasé about the results of this MRI scan and assumed that everything would be okay – after all it had been for the last 3 years. Why not now? I wasn't poorly anymore and I was just beginning to feel normal again in terms of my strength and stamina. But this was not meant to be.

I approached the Professor's room with some confidence. Big mistake. Huge. My family and I always bicker about who comes into the room with me for my results. They all want to be there and it's like an annual Huggins day out. As James and I were so sure I was going to be okay, we agreed that my Mum and Dad would come in with me on this occasion. James waited outside. I sat down with the Professor, who hit me with the news straight away. 'The shadow has started to change'. I knew exactly what he was saying. I will never forget those words. All I could think was 'Oh no, please, not again'. Total shock came over me as my worst fears were realised. My Dad quickly got James while the Professor carried on showing me the new MRI scans of the tumour. I knew this was not good. I remember feeling very hot and I started to breathe heavily. I think it was the shock and all I kept saying was 'okay' as information I did not want to hear was fired at me.

The tumour had returned and this time it was in three places growing up my brain stem. The Professor informed me that he was not willing to operate on me again

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as the risks of more surgery on my brain stem was too high. This was the second blow I felt that day. This was even worse than before because as far as I understood, they always operate on a brain tumour if they can and if they don't - it means it's inoperable. That was not what I wanted to hear. Rather than my Professor saying what he could do and us all looking ahead to the future, we were told that he couldn't help and I would have to be referred to an Oncologist, who would look into Radiotherapy for me. We left the Professor's room that day, totally stunned. It was worse this time round as we all knew what we were facing and it wasn't looking as hopeful as back in 2005. I needed a stiff drink and we headed to the pub to break the news to my sister and immediate family!

As a family, we began our own research into Radiotherapy and we have looked into how successful it would be. It was during these long hours on the internet that we also found that Proton Therapy offered more success than Radiotherapy. We decided that Proton Therapy was the best option for me, but there was a problem. It was not available in the U.K. There is only one machine in the UK and it is used for eye cancer. Unfortunately, the dosage is not strong enough for brain tumours, so that meant we would have to go abroad for treatment. Just typical! We then spoke with Dr Glaser and he has also had numerous meetings with the Professor about this therapy. They agreed that Proton Therapy was my best chance. I'll explain why:

As my tumour is positioned on my brain stem (which affects breathing, heartbeat etc) the radiotherapy that the NHS offers in the U.K may damage the surrounding tissue and cells. This could leave me with devastating long term affects. This is because the radiation hits the tumour and then spreads out into surrounding areas. Proton Therapy however, takes the shape of the tumour only and zaps it directly, without damaging other areas, surrounding tissue and cells. We have been told that as my tumour is a Grade III Ependymoma, it is likely to fight Radiotherapy. As a result, the dosage given needs to be as strong as it can be. If they give me conventional Radiotherapy, they cannot administer a high enough dose due to the damage it will do elsewhere in my brain, so the likelihood of the tumour coming back is higher. With Proton Therapy they can give me a higher dosage because they will be zapping the tumour alone.

We were also told by Dr Glaser and his team that I only have 1 shot at this treatment. Another shock to add to my pile! Again, this was due to the position of the tumour and they will only be able to give me one dose due to the damage it may do. This is why my one shot had to be the best possible shot if I was going to fight this. If my brain tumour comes back at a later date, they will not operate and I won't be able to have more radiation.

Dr Glaser is fighting for a Proton Therapy machine in the U.K, but these cost in the region of £100 million each (yes you did read that right.) This is why I needed to raise the funds to get me to America.

There was also a chance the hospital in Boston would not take me on and treat me. My case needed to be 'interesting' enough for them to treat me as demand outweighs supply for treatment out there. Luckily Dr Glaser had an association with a hospital in Boston who did accept me.

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Before going to the US I had another MRI scan that captured my whole body. Unfortunately, Dr Glaser confirmed that the tumour has spread to the base of my spine which meant Proton Therapy was even more vital than before.

I took two days off work, mainly to recover from the flu that I couldn't shake off, but also to get my head round my latest diagnosis. I am so pleased I did, as this is when the media attention really picked up. I needed all the energy I could muster if I was going to go public with my story. I had to be ready, have my wits about me and fight. This attention wasn't going to last for long and I needed to grab it with both hands and enjoy my 5 minutes of fame. I needed to make the most of the opportunity I had been given. I had to get my story across and raise awareness of my plight. I felt it was important to explain why I was doing all of this and how we do not have specialised proton therapy machines in the UK. I was lucky enough to know about the options available for treatment abroad, but others may not. I wanted to give other people battling cancer the chance to look into proton therapy too. Now that the tumour had spread to my spine, we needed the money for this treatment more than ever and I needed all the help I could get to raise the funds.

At this time my sister, Trina, partner James and best friend Lucy and I set up a website and a fund to raise the huge £250,000 for the trip to Boston see www.melissafightingfund.co.uk. My story was picked up by local and national papers including the Sun and various magazines. One of the children from school also wrote to GMTV and I was interviewed by Fiona Phillips – a truly awesome experience. After that I was also interviewed by Channel 5 and London Tonight.

My sister and I both had planned to be married in 2009 and instead donated all our wedding money to the trip – we both felt we could not ask others to give if we ourselves were not willing to give ourselves. We hope to get married in 2010 – smaller, more low key affairs.

The fundraising that we did and others did for us was amazing, one highlight for me was an auction night we had at a local golf club where we raised an amazing £50,000! We wanted the night to be such fun for everyone, as a family, this is something we have all agreed on. We want our fundraising events to be fun and for people to walk away and say 'I had a really good night and it was worth it'. It has and still is, very important for us to remain positive, strong and upbeat as we manage one of the most challenging episodes in our life. A smile and a laugh can go a long way.

We made it to Boston in January 2009 flying first class courtesy of British Airways and I was seen by a Dr. Shih at Massachusetts General Hospital. After another series of scans the news was not good. Dr Shih told me that my treatment was not going to be easy and once ependymoma tumours come back, they are hard to cure. Statistically, this type of tumour very rarely comes back, but if it does, it is not an easy one to fight. We also found out at the same meeting that there was now a 3rd tumour at the top of my spine and some 'spotting' in another place.

I thought 2 tumours were bad enough, but this wretched thing just keeps on multiplying! We focussed our discussion back to my treatment plans. I wanted to talk about what we could do rather than what we could not do. It doesn't matter how hard you try to protect yourself in these type of situations. I was knocked back again. I lost a little of my confidence and fighting spirit in that split second, but I soon picked myself back up.

Before we left the room, I told Dr Shih that whatever treatment they were considering, I wanted it to be as aggressive as possible. I had come here to fight and if that meant being extremely poorly for a while, then so be it. Anything is worth it to make me better. I love my life and I will do whatever it takes to keep it.

We waited for over a week while the surgeons reviewed my case and deliberated whether or not to operate on me. There was obviously a lot to decide and waiting to hear from them was one of the hardest parts of being in Boston. It was like torture not knowing and as much as I wanted that operation, I prayed very hard that whatever decision they made, it was the best one for me. Finally, Dr Carter called us back and told me there was nothing else they could do, no brain surgery, no spinal surgery and potentially no chemotherapy. I felt like I was grasping onto very little hope and it was back to square one again. My family and I began to focus on proton therapy once again. After all, this is what we had come out here for and this was the best form of treatment for me.

So after all the deliberations I had the proton therapy. The doctors there said that they did not believe they could cure the tumours but they did hope to arrest any change for at least five years – This took me completely by surprise, I never expected to hear that. I naively thought I had gone there to be cured. In September 2009 I was scanned again and the brain tumour had reduced by approx.75% and my spinal tumour by approx 70%. I was on cloud 9. There is a God and he was certainly looking over me.

I have had a dose of chemotherapy, 4 months worth from April – July 2009, but apart from that I am on no medication and am able to walk and even do three days teaching a week. To all intents and purposes, my life is back to normal, although I am left with double vision and tiredness still rules a lot of what I am able to do. I try to be normal, but living with a brain and spinal tumour never leaves you, you just have to learn how to manage it in the best way you can.

Melissa Huggins – March 2010