



Brainbow Service

Patrick's story by his mum, Sarah

Patrick was diagnosed following a routine eye examination. He had suffered the odd headache in the run up to Christmas but nothing that would concern us and we thought he just had a bit of a virus. It was such a surprise when the optician mentioned Patrick's optic nerves were swollen and she told me that it was normal practice to refer him into the eye clinic, and I would hear something about an appointment over the next week.

I of course googled what could cause swollen optic nerves and saw that Brain tumour was one cause but dismissed this because no one ever thinks worse case scenario, particularly when we are talking about our children. The more common cause would have been an infection somewhere, so this is what I had expected.

The next day when Patrick suffered a really bad headache I was worried his Infection was getting worse and I whisked him off to A & E. In A & E we were told that it was most likely an infection but an MRI was necessary to rule out anything else and that we should expect an appointment for an MRI in the next 7 to 10 days. The next day we received a call at 10am telling us they had a cancellation and could Patrick come along for 11.15am that day. We duly attended en masse: Patrick's father, me and his brother with no idea of how our lives were to change forever.

The MRI showed that Patrick had a 4.5cm tumour at the back of his brain and our simple ordinary lives changed forever.

We were told that we were being transferred to Addenbrookes that evening (Monday 6 January 2014) so that we could start treatment. It all happened very quickly; I think that the size of Patrick's tumour and the fact that he had started to suffer significant headaches meant that they were worried that things were progressing quite fast.

Once at Addenbrookes tests showed that Patrick had some weakness on his left side as a result of the tumour. Patrick was started on a course of steroids before his operation.

Suddenly we were introduced to a whole new vocabulary, and were talking about different types of tumours, benign and non-benign, hydrocephalus, rehabilitation and neurosurgery. It was absolutely terrifying.

It is the nature of the treatment of brain tumours that we fall within the care of a number of teams and in that first week before Patrick had his operation we were meeting so many different people: surgeons, neurologists, oncologists, different types of therapists; it was bewildering. We were warned of a wide range of problems that Patrick might have after his surgery such as difficulty swallowing or problems with his eyesight,

walking and talking. It was a parents living nightmare, our beautiful seemingly healthy little boy was facing an operation that could take his life and if not his life it could rob him of all that made him who he was.

It was during that first week that we started to meet members of the Brainbow team, who explained that they would be around to help Patrick to recover from his surgery. I confess during that first week there was so much to take in that you do not really start to process what people have told you until you have dealt with the immediate issue of will my son survive his surgery and how much of my little boy will I get back.

That first week we met with Dave who came over to assess Patrick before the operation so that he could see how Patrick was before the operation and I assume then he could see for himself any difference in Patrick following the operation. We also met with the Antonia, the Speech therapist and Ana the Brainbow psychologist who talked to us very generally about some of the issues Patrick might face following his surgery. Indeed Patrick did have some terrible nightmares following surgery about people drilling into his head and it was with the guidance of Ana that we were able to help him work through those nightmares.

Patrick had his surgery on Friday 10th January, five days after we were admitted to Addenbrookes. His surgery lasted for 9.5 hours and we were very lucky because the surgeon was able to remove Patrick's tumour.

Patrick was moved to high dependency and returned to the ward on Saturday 11 January 2014. Words cannot describe the elation. We were lucky Patrick could swallow and speak; his problems were with balance and co-ordination because the tumour had been located in the part of his brain that deals with balance and co-ordination. We were subsequently told that Patrick had a Pilocytic astrocytoma- a benign tumour at the back of his head.

We were so wrapped up in the success of the surgery that we had not thought about the process of rehabilitation.

It was on the Monday after surgery Katie and Dave (the occupational therapist and physiotherapist on the Brainbow service) came to see us, and they were like a breath of fresh air. They were the people from Brainbow that we worked most with, because this was where Patrick needed help.

I was helping Patrick to move in bed, as he had very little strength following his surgery and it simply didn't occur to me that he would be capable of anything for some time. It was Katie and Dave that showed both me and more importantly Patrick that he could now start to recover some of the balance and co ordination that had been impacted by the surgery.

I will never forget that first visit on the Monday when they said that Patrick could get himself out of bed; I had been all but lifting him in and out of bed. I had to take a step back and let Dave and Katie helps us start the process of rehabilitation. When I say I had to take a step back I literally moved to the other side of the room because the mum in me wanted to shout stop, no, wrap him up in cotton wool.

But Katie and Dave really engaged Patrick in the process and explained to him how he

could do this for himself, and he did. He followed their instructions and for the first time was able to move to the edge of the bed and stand up, albeit a bit wobbly.

That was a defining moment in Patrick's rehabilitation, for both Patrick and we as Patrick's family. For Patrick finally there were people there to help him achieve what he wanted which was to be physically able again, to help him have some control over his treatment and to give him something positive to work towards and achieve on a daily basis.

For us as parents we realised that the surgery was only half the story (albeit a very important part) and Patrick's quality of life was going to be directly impacted by how he recovered his balance and coordination.

So whilst the medical stuff continued on around us, something over which we had no control or really input into, the physical rehabilitation was something to which we were all able to engage with. Not only did this significantly improve Patrick's recovery outcome but it also impacted on his mental state; he could see for himself that he could get better and if he listened to what Katie and Dave told him then he could do this for himself.

There is no doubt it was incredibly difficult to see him being challenged and pushed in this way, but I knew it was needed and I trusted Katie and Dave. They gave Patrick permission to try and do things for himself, and to have goals and push himself- I really can't overstate how important this was. He trusted them and because he was lucky enough to see the same two amazing therapists every day it meant that he developed this trust and confidence in them and it emboldened him. He looked forward to their daily visits not only to show them what he could do but also so he could discuss with them what the next goal should be.

The daily visits meant that the goals could be achieved on a daily basis and this motivated Patrick even more because he could see his own improvement day by day.

Initially Patrick couldn't walk unassisted and when he was assessed about 2 weeks after surgery he could not catch or walk a straight line. That assessment was hard for all of us but again Katie and Dave were able to ensure that the outcome of the assessment was very constructive because they were able to work with Patrick to develop a scheme of exercises and activities that would help him recover those skills.

We saw a lot of Katie and Dave whilst Patrick was in hospital, and they were constantly asking him to set new goals for himself and think about what he'd like to try next. After leaving hospital we continued to have contact and update them on our progress.

He can now catch a ball and he rode a bike for the first time only 6 weeks after this operation (it was a bike ride round Rendlesham forest!)

It is only now some 8 weeks after Patrick's surgery that we can fully appreciate the very significant and indeed crucial part the Brainbow service played in Patrick's recovery. Patrick turned 9 at the weekend and he could not understand why I should be concerned by his wanting a tobogganing party!

The Brainbow service gave Patrick control over his recovery. The trust he had in the

Brainbow service and the confidence they gave him in his own ability to overcome the physical hurdles he faced in his recovery have meant that he is essentially already back to doing all the things he did before the surgery. Patrick is a very sporty boy, and so it was really important for him to get back to being physically active. Throughout this process we have left the medical and surgical treatment of Patrick's tumour to the doctors to take care of, which is how we wanted it, but the rehabilitation has been something that with the guidance of the Brainbow service we have all been able to engage with.

I can say without doubt or reservation that without the input of the Brainbow service Patrick would not have made the progress he has. The physical improvements have of course ensured that Patrick's state of mind has remained very positive, which again has assisted his recovery. Without the assistance of Brainbow I am sure that the physical limitations would have got on top of him. Instead Patrick has had the opportunity to access a service that allowed him to take control and drive forward his own recovery.

Eight weeks on from surgery, Patrick is now cycling, running and playing football. He is like any normal little boy. We know that the first three months after a brain injury and surgery are vital for getting back to normal, and we really do feel that if Brainbow hadn't been involved as closely as they were early on Patrick would not have been able to recover so quickly and absolutely. I know that he did a lot of the work for himself and I'm incredibly proud of him for that, but Brainbow gave him the time and resource to be able to do it. Knowing what Patrick is like, I cannot imagine the psychological effect it would have had on him if he hadn't had goals and seen such quick progress.

Now Patrick loves coming back to Addenbrookes for his follow up appointments- he's coming back in next week, and he can't wait to see the Brainbow service team to show them all the new things he can do. I didn't understand at the beginning how much difference a service like this could make, but I am so pleased that it was available and I feel strongly that without it Patrick would not be back doing the things that he is today.

Sarah- Patrick's mum.