

This article was written for the Childhood Brain Tumor Foundation, Germantown, MD.

My daughter is a true success story!



We took our daughter, Hayley, to the general practitioner on Wednesday as she complained of a headache. He told us that it probably was a virus but to bring her back in Friday. My last question was, "Could it be a brain tumour?" Was it mother's intuition?

She was fine on Tuesday and on the Friday we took her back expecting to be told she was fine. We had planned a day at Legoland. She had been a bit sick that morning, so our doctor referred us to the Paediatric Assessment unit at the hospital where she was assessed on her coordination. When she was finally seen by the Senior Doctor, she was so tired that she was quite clumsy. He referred her for an emergency MRI that evening, and an hour later we were rushed to Oxford about 35 miles away for the specialist department there and into the care of Dr. Peter Richards, the Paediatric Neurosurgeon.

Our four-year-old son was dropped off at friends by my husband and he met me at the hospital. Following an awful night, we saw the MRI scans and the size of the tumour. We met Dr. Richards the next morning. He was fantastic. He told us how awful it was, but gave us precious advice. "Don't let the family fall apart, look after your home life, your work, the extended family. and ask for help." This was as bad as life gets, but we needed to be strong for Hayley and each other.

Hayley was suffering from hydrocephalus which was causing the symptoms, so she was operated on that day. She would need to recover from that operation before he was prepared to operate on the tumour, which was scheduled for the following Monday. That first operation was bad, but we still had a whole nine days to wait. It was a bloody awful week. Dr. Richards advised us to keep busy during the operation, so we both had our hair cut. Hayley stayed in Intensive Care overnight after her six hour operation. Peter Richards was confident that he had removed all the tumour, and she had had a MRI straight after the operation. His initial thoughts were positive; he was confident it was benign.



Even though we thought the worst was over, the tough times had just began, with all the vomiting and a very stubborn two-year-old. We pleaded with her to use nappies, but she was adamant she needed the toilet although she couldn't sit up. We then went through wound leaks and vomiting, but she was signed out ten days after the operation. We were back in the hospital that next evening. Hayley had developed meningitis. The blows kept on coming when her wound leaked and she needed more drains and another operation to reseal her wound. We then started to see a huge difference. One day she was laying in bed when a nurse came in to give her IV antibiotics. The antibiotics were very painful and Hayley hated them. Hayley said, "Get that woman out of my room NOW!"

When she came home, Hayley had to build up her strength. She learned to walk again. It was mostly muscle weakness. Her balance is affected especially when she is tired. We have given up on ballet and rugby. She still does trampolining, swimming, and gymnastics--anything to build up her strength. Coaches

tell us that muscles will build up to compensate for problems in balance. She hates the beam, but we will give it a go at a low level.

We are part of the OSCAR support group which organizes events for children and families of children who have suffered from brain or spinal tumours. This year's event was at a Safari Park, and we have a Pantomime in January.

Hayley recently completed the Flora Fun Run in Hyde Park--a three mile circuit--and she raised 100 pounds. More importantly for Hayley, she got a medal. She is a very bright and assertive six-year-old. She is very smiley and well-liked by all. Are we proud of her or what!

Written by Nerys Wilkinson, parent of Hayley. In England, Hayley was treated at Oxford and the family has set up a support group for relatives and children with brain and spinal tumours.