



Personal Stories

OWEN'S STORY



My son Owen was diagnosed with an ependymoma brain tumour at the age of two and four months. He underwent nine hours of neurosurgery and sixteen months of intensive chemotherapy. When his tumour recurred and spread to his spine he had further chemotherapy and radiotherapy. Owen died at the age of six. His life although far too short, was full.

On the Monday morning of the week Owen was diagnosed he seemed extra tired and was reluctant to get out of bed. We had to take to take his sister, Kate, to school; a short ten minute walk which we undertook every week day with Owen in his pushchair. But every time I managed to take Owen out of bed and dress him he would try to crawl back up the stairs.

He was lethargic and out of sorts but by mid morning he was able to go to a soft play session with me. By Wednesday he had not improved so I took him to see the GP. He lay like a baby in my arms as the GP gave him a thorough examination. I could not give her specific symptoms, just a vague sense that something was wrong. I told her I felt he wasn't thriving. He was such a good child, almost too good.

Developmentally he was on target so I had no reason to suspect a brain tumour. My understanding of a brain tumour was that it would present with disability. But here was my two year son showing symptoms of nothing worse than a virus. Significantly though when the GP asked had Owen ran a fever, I said no. A sick child without a fever is not always a cause for concern but it should have alerted the GP that there was something more sinister going on. The GP was satisfied that Owen was well enough to go home. I had asked for a further referral to see

a consultant paediatrician. Owen had been referred to a paediatrician when he was just over a year old but they had found no problems. The GP didn't think it was necessary and asked why; my answer was simply "because he is too good." He wasn't climbing or playing with the same robustness as other two year olds. I couldn't explain my deepest fear that Owen wasn't going to be with me forever. Her reply was to come back in a couple of weeks if I was still concerned.

By the Friday morning Owen seemed to have improved and we visited my friends Zoe and Paul. While at Zoe and Paul's house Owen began to walk unsteadily and hold his head to the side. Zoe assumed it was an ear infection and called the GP's surgery for me to get an appointment for after lunch.

Owen and I went home and I phoned my mum. Her advice was to just go to the hospital. My neighbour was a nurse so I rang her. She didn't give me an option – within minutes she was at my front door with the car running. We rushed off with Owen's comforter, my old satin nightie and his bottle in case it was a long haul. It was three weeks before we were home again and in that time everything in our lives had changed beyond recognition.

At the hospital Owen cooperated with all the neurological tests, bemused to be entertained by a variety of medics. He didn't seem to be in any pain or discomfort, unless walking which became increasingly difficult for him as the day went on, but every so often he would say, "Mum, Mum, hug." He would fold into me and we would snuggle together, his soft curly blond hair just below my chin. I was asked about his medical history several times – he had been an overdue baby, his birth had been very long birth, and he was breastfed until 11 months, was hospitalised with breathing difficulties at four weeks; from a year old he had a pattern of repeated viruses and he was reluctant to try new foods. I had taken him to the GP frequently and at around sixteen months he had seen a hospital paediatrician who had tested him for every illness from Coeliac disease, which I have, to liver function and thyroid problems.



There was no reason to look for something neurological. He was a bright, affectionate child who had reached all his milestones on target.

I phoned my husband, Liam, at work and told him to meet me at the hospital and that so far all I had been told by a registrar was that there could be something seriously wrong with Owen's brain. Despite all our worrying this seemed far fetched.

Although Liam and I worried about him constantly it was out of a sense of unease rather than any specific or particular symptoms. Later that night Owen was sedated to enable a CT scan to take place. We watched as he was laid out on a trolley, still and deathly pale dressed in a hospital gown, waiting for the scanner to rotate around him. It was a foreboding image which stayed with us throughout the years.

We were told the devastating news, around nine o'clock on that Friday night in a room separate from our sleeping son. There were around five medics seated facing us while the consultant explained slowly and quietly what they had discovered. The scan revealed a mass at the back of Owen's head. We were so distraught that the consultant had to stop every now and again to allow us to regain some composure before he went on. He was visibly affected and I have always felt immense gratitude that he seemed to really care about us and more importantly about Owen.

I can clearly remember the consultant telling my husband and I that our son had a mass of tumour in the back of his head while he tried to control his own tears as he witnessed our devastation. I shall always be grateful that this consultant, who we had only met a couple of hours previously, treated us and more importantly Owen, with such compassion. It was easier to trust him knowing that he cared about our son and us.



Surgery followed on the Monday – which happened to be Valentine's Day and was as successful as could be hoped. We had been warned that the surgery was highly risky and that Owen could be left with disabilities. Importantly, Owen had not been 'damaged' during the surgery and for this we were grateful.

We were living in Cardiff, away from our home town of Belfast and our families, and we decided that we needed to return to have their support. Sixteen months of arduous chemotherapy followed.

While Owen endured the overwhelming nausea and tiredness induced by chemotherapy and was assaulted with repeated blood tests and scans, he managed to retain his sense of 'normality'. He was still a little boy who loved to play and learn. Through his example we learned as a family that the greatest gift we could give Owen was to be normal. While we were devastated by Owen's diagnosis we decided early on that we would do everything in our power to help him enjoy life. This included being upbeat and happy when we often felt the reverse. We believed that he shouldn't carry the burden of our grief. Our aim was to enable Owen to live the fullest life possible under the constraints of regular hospital stays and an impaired immune system due to the chemotherapy. We were paranoid about him catching infections and did everything we could to ensure he remained well enough to enjoy the days between cycles.

One of the best pieces of advice I was given at the beginning of my son's treatment was to keep a diary. The object of the diary was to record hospital appointment times, treatment periods and blood results. In keeping records I was able to anticipate the affect of certain drugs, to identify when Owen's blood counts were likely to be low and to have a clear overview of how he was coping with treatment. Being organised in this way gave me a sense of control and enabled me to be informed about Owen's wellbeing from one clinic appointment to the next. I needed to stay informed and to remember his reactions to each cycle of chemotherapy in order to provide the consultant with the information he needed about how Owen was responding and coping with treatment. Certain drug cocktails would make him extremely sick, others made his joints ache and caused headaches. Keeping records of how his blood count level responded to the chemotherapy enabled me to anticipate when his white cell count would be too low to risk catching infections and I could therefore avoid taking him into crowded areas.



Owen finished his chemotherapy in June of 2001 and began nursery school in September. He made many friends and loved being part of the school community. In June of 2002 he had routine follow up scan. We were devastated to learn that his tumour had grown and spread to his spine. We faced many decisions during this period. Owen was well, active and enjoying life. Radiotherapy and palliative chemo followed but thankfully Owen did not need to stay in hospital. He had experienced

enough of hospital stays and was determined to stay at home. Life continued as normally as possible. He was home tutored by a wonderful teacher, Margaret Rolston and was attended to by our Macmillian nurses; we also had great support from our family support worker Carol from Clic Sargent.

Despite knowing that Owen was not going to survive, and having to come to terms with the enormity of what this would mean for us all as a family, we managed for as long as possible to maintain that sense of normality. The last few months of Owen's life were far from easy – for him or for us. While the memories of those dark days are never far from us, they are too painful to write about. We try to focus on the positives, what a wonderful child Owen was, and how much joy he brought to us as a family, and all who knew him. We are, and always will be, immensely proud of the way he coped with his illness, almost helping us to do the same. His legacy lives on. Because of Owen I have come into contact with the CCLG, and through membership of the Publications Committee, and by contributing to *Contact* magazine, have found an outlet to allow me to channel some of my energies into helping other families.

Written by Sharon Dempsey

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