Holly's Story

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Holly is our middle child with an older brother Andrew, and a younger sister Delphi. In May 2003, Holly was diagnosed with neuroblastoma stage 4, a cancer of the specialised nerve cells, and our lives were turned upside down. It was the first of the three worst days of our lives. We were suddenly in a scary unfamiliar world and we had to do our best for our little girl. We were presented with her protocol and knew that it would be one day at a time. We were so scared and we had a very scared little girl to look after.

We all adapted to our new lives especially Holly who showed such bravery and lit up our lives and the lives of others with her wit, humour and strength! We went through a summer of chemo followed by surgery followed by a bone marrow transplant. During this treatment we managed to have her home for most of the time. She stayed in Our Lady's Children's Hospital, Crumlin on the days of her chemo but got home in between sessions. She spent a week in for surgery and was in HDU for 3 weeks after her transplant between May and November.

Normality was the crucial key for Holly. On her first day in hospital after being diagnosed, the thing she asked for was her Maths book. It wasn't that she had an amazing love of maths, but it represented normality for her. After that she had a course of radiotherapy in St. Luke's Hospital. She was in isolation after the transplant so her only visits out were to Crumlin and St. Luke's, with an odd visit to the park on good days when it was quiet and a cycle up the road. She only saw the family, her Nana and her teacher who came to do home tuition every day – everyone else was barred from the house. Holly made a little life for herself in the house every day – drawing, writing, playing with sylvanians, watching tv, listening to music. The one word we never heard was I'm bored. She was a busy little bee!

Her treatment finished in the summer of 2004 and at last she was allowed out and we were allowed to go places with her. Her hair had grown back in corkscrew curls, and she looked great and had energy. She went back to school in September and was so delighted to be back with her friends – more of that normality she loved. There were just a few lovely normal months where there was no treatment and she was well.

It wasn't to last unfortunately. In December, a week before her 8th birthday, when Holly was having a bath, I noticed one leg seemed bigger than the other. I measured it and yes it was a bit bigger. It never crossed my mind that it would be serious but when I took her into Crumlin and she had an ultrasound done, we found out that the tumour was back. This was the second of those three worst days. Now the hope that kept us going all along was gone. It was such an awful, awful day. This was a whole new story. How were we going to pick ourselves up this time? But there was no option. Our beautiful little girl was sick again and we were going to have to provide that normality that she craved in the midst of our despair.

Now we were on a different road – one that would be more difficult, and a whole new life again for all of us. A much more uncertain road – one where we didn't know how long Holly had left, how sick she would be and what she would be able for. Again we decided to take each day at a time.

Now we were back having tests done and new doctors and nurses to meet. We had more dealings with St. Luke's now as Holly was to have some more radiotherapy over Christmas. We remember on the day we took Holly there for measuring and scans etc. We were told we would be meeting a pain specialist who would look after her pain during her palliative care. We dreaded the meeting as it meant that if we were meeting someone specialising in pain, then pain was a big part of this time. No parent wants to know their child is going to be dealing with pain. However, one minute into our meeting with the Consultant in Palliative Medicine, Maeve, we knew it would be ok. Here was someone who we felt we could trust completely immediately and who was so easy to get on with and who was our saviour during this time. The homecare nurse, Kaye from Our Lady's Hospice and Care Service, Harold's Cross, came on board too and there was a team of 7 or 8 on the palliative care team from there. They didn't come too often at the beginning but we knew they were there when needed. Our palliative care liaison nurse from Crumlin, Imelda, became a regular visitor to our home as she came to take bloods.

Now it was time to make the most of the very precious time we had left. We didn't know how long we had and if the radiotherapy and tablet chemo would do any good. We celebrated her 8th birthday a week after getting the news of her relapse and it was wonderful. She enjoyed every minute. Then it was Christmas a week later – again very enjoyable but tinged with sadness. It was back to school for Holly after Christmas just as she wanted.

We were put in touch with Make a Wish and went to Disney in Florida for a week at the end of January. We had a wonderful week there. We met with the Maeve, before we left to learn what to do if anything went wrong or if pain became an issue. At that time her pain was being controlled with paracetamol and brufen. We went to Florida armed with strong pain relief and confident that if anything went wrong, Maeve was on the other end of a phone at any time. We had THE most relaxed week where we as a family could enjoy being together in a fun environment. It was hard on the other children too so the fact that Holly was with us as a family all the time and not away in hospital with controlled visiting times was very important.

Holly was in 2nd class – First Communion year. We were advised to bring it forward so Holly made First Communion in February surrounded by her family. She also made a second First Communion in May with her friends – she glowed that day and was so happy. We went to Westport at Easter, made numerous visits to Monaghan and Wicklow, did a LOT of shopping, and had a normal family life even though there was a very sick little girl in the house. She went to birthday parties and play dates like everyone else. We went to Lourdes and she went on her school tour with her school friends which was a highlight.

All the while, Holly had visits to Crumlin and St Luke's and her very special friend Imelda (our liaison nurse) came to visit regularly. A familiar face for both Holly and us. There were many laughs in the pink bedroom! The support was constantly there – Imelda, hospice nurses, Maeve in Luke's – we felt we and Holly were so well minded. Holly was very comfortable with the people who now surrounded her as we were. There was no air of gloom or negativity.

Holly's visits to Maeve were very funny – Holly was never slow at speaking her mind especially in the style department! There was always a joke and laughter and banter while at the same time the seriousness of what was going on was always dealt with. She enjoyed her visits. I remember one day being very worried because the pain wasn't responding to the medication so I texted Maeve to find out what to do. Immediately she phoned back and told me what to give Holly to help her.

The fact that Holly was at home all the time gave us control in looking after her. Every parent wants to look after their own child and do the best for them. There is a feeling of helplessness when someone else is doing everything. Children will naturally feel more comfortable and at ease when their Mum or Dad are looking after them. It's good for everyone in the house. It's good for the other children to see what's going on and not have their minds wandering to what might be happening in hospital. We were constantly monitored and trained in what to next if the next stage came. We felt totally secure with the support we were given. For everyone to be in the house together with everyday events going on as normal in the midst of having a very sick child there is a comfort to everyone.

We had access to a nurse who came to the house weekly to help Holly with relaxation and I got massage too. We only had to ask and this lovely lady was found who helped us all so much.

Holly had been asked to be a flower girl at her Uncle Enda's wedding in July 2005. She had been looking forward to it for a year and a half – the shopping for the dress, shoes and accessories had been done. In June, her tumour had grown and she had deteriorated. We feared that she might not make it till the wedding. We kept everything as normal as possible at home with the support of the team. She did make it and although she was a very sick and weak little girl, she made it up the aisle and looked beautiful. That was her last day out.

She got weaker after that and spent most of her time in her pink bedroom with her soft toys, notebooks, colours, music and her pink TV. She was surrounded by familiarity, by the things and people she loved best. The smells and sounds she knew. The hospice team were visiting more often now, and we were directed in what to do and what to expect. Holly slipped into a deep sleep and because she was with us and in her little bed that she loved, we were able to wander in and out of her room all the time. We all got special time with her when we could talk to her on our own and tell her how much we loved her. Her brother and sister were able to spend time with her and it was very natural for them. They knew exactly what was happening all the time and there was no fear for them. We knew that she could hear us even though her eyes were closed so we all chatted away to her. My friend and I even watched her favourite film 'Johnny English' in her room and discussed what was happening with her. She got weaker every day and on Wednesday, she was made comfortable and we knew she hadn't long. All the family came at different times and got to talk to her. At 5am that morning, we held her in our arms and she went to Heaven. She just slipped away. There it was, the third worst day. Our special little lady was gone.

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