

A little girl with a special heart

It is almost exactly seven years since the day we were told that Jessica's heart condition was so severe that she was unlikely to be suitable for surgery and would live a few days at best. Seven years since we sat in a hospital chapel and prayed desperately for a miracle. Our prayers were answered.

We were offered the chance for Jessica to have a hole in her heart enlarged while still in the womb.

It was risky and scary, but it gave us hope.

The moment she was born was one of the most joyous moments of our lives. To see her face and hear her cry was just amazing. We knew that there was quite a journey ahead, but we held on to hope and faith and walked it.

Over the next six and a half years, Jessica went through five surgeries – four of them in her first year of life and the last back in December. Throughout it all, she was the bravest, happiest little girl.

When she recovered well from her last surgery, we thought we could relax for a while and enjoy family life for a few years without the fear of surgery hanging over us. Sadly, it was not to be.

Seven years ago, if you had told us that we would be blessed with six and a half years with Jessica, we would have jumped at the chance. We are thankful for every day of those six and a half years whilst always wishing we could have had one more day, one more moment with our little girl. No amount of time really could ever have been enough.

Jessica brought so much joy into our lives from the moment she arrived. Her smile lit up our world; her laughter made our hearts sing. She might have only had half a working heart, but it carried a huge amount of love and she lived her life to the full.

To Jessica, having a special heart was just part of what made her special. The zip scar on her chest was a line of bravery – something that told the story of how the doctors had helped make her special heart work better. She didn't see it as something that held her back or stopped her doing the things she wanted to do – it was just part of who she was.

Only once did she express frustration over not being able to do something because of her special heart and that was the last time we took her swimming. She wasn't quite well and she got cold quickly so couldn't swim for as long as she wanted to. Other than that, she just accepted and embraced life as it was. She once turned around to Sophie and told her "you and Mummy and Daddy all have hearts, but only mine is special."

Jessica taught us to live in the moment and enjoy it. Every day was a gift because the future was uncertain and tomorrow never promised. She was a little girl with a huge amount of zest for life. She had the sunniest smile and an infectious little giggle. Her godmother Gillian once described her as a "joy carrier". If we had to sum up Jessica in two words, that would be it. She brought sunshine into the lives of all who knew her, and she touched the hearts of people who never met her.

She had so much strength and courage and took everything in her stride – even her last heart surgery. Right up to the moment she went off to sleep in the anaesthetic room, she was smiling away – excited about her "sleepover" at the doctors. Even when she had to undergo unpleasant procedures in intensive care, she accepted that the doctors and nurses were doing them to make her feel better and endured them bravely.

On her admission to A&E, four days before she died, she chatted away with the doctors, asking them about all the things they needed to do. As she went up to the ward, one of them told Louise that she was the politest little girl they had ever had. She was our little superstar and we were so proud to be her daddy and mummy.

She was the loveliest big sister to Sophie. The bond they shared was such a beautiful one. It was wonderful to watch them playing together – two little heads close together as they lost themselves in a world of their own imaginations. To see them cuddling up together over a book or the iPad; to listen to them giggle together; to watch them walking along hand-in-hand was beautiful.

Jessica was such a proud big sister. She was so excited when Sophie started Girls' Brigade with her – eager to show her what to do and look after her. There were times when the roles were reversed, and Sophie was protective of Jessica – aware of the times when Jessica needed a little extra help. One of the moments that sticks in my mind was on a day out last summer when Jessica was struggling to walk uphill. Sophie took her hand and said “come on Jessica, you can do it. I will help you.” The love they had for each other was wonderful.

When we told the girls that we were expecting another baby, Jessica was so excited. She was so looking forward to being a big sister to “Peanut”. She adored babies and was so gentle with them. It breaks our hearts that Peanut will never get to know what a wonderful big sister Jessica would have been, but we are sure that she will be looking over us all and we will keep her memory alive.

Thank you, Jessica, for six and a half amazing years. You taught us to be strong, to have faith, to love deeply and to live life to the full. We thank God for every single moment we had with you.

You brought us joy every single day of your life and we will miss you every day for the rest of ours. Although you are no longer here with us physically, we carry you in our hearts wherever we go and we have so many beautiful memories to look back on.

We will love you forever and one day we will be with you once more. Until then, goodnight darling girl and thank you for everything you brought to our lives.