

# Ross's Story



**I wrote an article for Heartline a few years ago, but now my story has a sad ending so just to warn you, as you may now decide not to read on any further as I know first hand how hard it can be to read these stories. As I used to be a parent who read the small memorials and similar stories with such emotion; registering the reality, fearing the worst may one day happen to us. Then in September 2005 our lives changed even more when it did!**

Ross was diagnosed with Hypoplastic Left Heart Syndrome (HLHS) when I was pregnant, during a scan at Kings College Hospital in May 2002. It was there we begun our Emotional Rollercoaster; our Journey into the CHD world. This devastating news rapidly put the previous problems in my life into perspective, a thought I am sure that you can each associate with.

HLHS was described to us as being one of the worst conditions as it was noncorrectable and a relatively new condition. This meant that there was little knowledge/evidence of the long-term life of children who had HLHS as a few had only reached the age of about 10.

We were told that we had 3 options, all of which would be life changing - to continue with the pregnancy and let our baby die in it's own time (palliative care), to continue with the pregnancy and consent to our baby having dangerous, open-heart surgery which carried various risks and uncertainties (there was also a chance that the condition could be even more complex than predicted) or to terminate the pregnancy.

## What Should We Do?

As each of you have experienced, this was all far too much to take in yet alone understand! My partner's immediate reaction to "terminate and not put a baby through surgery and pain" was what instantly

instigated my own thoughts of feeling that any chance would be better than no chance at all, knowing that I would subsequently live a life never knowing whether my baby would have lived a long happy life or not. My decision from that moment was to continue and this may be inappropriate to say but, I did this knowing that I would “do it alone” as the dad could not cope with this at all.

Ross was born on 20th June 2002 at Guy's. Being alone was what made it easier I think as I never had to carry everyone else's emotions on top of my own. Born on the Thursday night, Ross was taken to ITCU until he had his first surgery on the following Monday.

Ross sailed through the first 2 surgeries. Advised how we could be in hospital for 6 to 8 weeks we were home within days each time. Ross never seemed to follow any of the signs of a CHD child that we'd been told about at his initial fetal cardiology scan. Well... maybe mildly? He did get breathless with very little activity and was a terror for eating and like many, had to follow a high calorie diet. In the main I believed that he was a happy healthy little boy. Kidding myself... maybe?

He was just always so full of joy and smiles. A cheeky little monkey, with such a character of his own who brought such a pleasure to my life, even at ungodly hours of the morning, when we would often get up and go downstairs, and have a little dry cereal together. I truly enjoyed every minute with him knowing in the back of my mind that one day he may not be there.

Ross' had an MRI scan in August 2005 with a view to his 3rd and last stage of surgery. I did understand that this still wasn't it, that this was only until he may, one day, need a new heart.

I honestly thought the verdict would be to schedule his 3rd surgery in at least a years' time but, so sadly I was wrong! The cardiologist said how surgery would be before November.

I was with a new partner and expecting a baby in January, someone very different, I thought I'd met my match, the man of my dreams but, after Ross' MRI scan he did the usual disappearing act. Therefore, I faced the surgery with few options open to me, less people to take care of my other 2 boys and possibly new baby and so, all considered this was a better time than any, even though I would have much preferred to wait a good year. Guy's Hospital were also due to move their cardiac ward to St. Thomas' which was a slightly longer journey for my family, and further away from the Ronald McDonald House. I had tried to prepare myself this time for a much longer stay. I requested that, if possible, the surgery be before the hospital move. Like many I had an issue with choosing dates and then if that date then were cancelled .... typical, both things occurred! Like tempting fate, I had a choice of dates and then that date was changed to 21st September 2005.

*Realising first hand how so many of us take things for granted and how many families suffer in silence I began to want to raise awareness to help other families as well as my own, hence the beginning of “UD” which means exactly what it says.*

# City Hospital

A week before surgery I finally asked about being filmed, something I'd wanted to be involved in before but, never asked. By sheer chance, City Hospital were filming at that time and so I was put in touch with them. My correspondence with them was extremely blunt as I always knew that Ross could die. I paid much attention to them about filming as much as possible including surgery. I found it so clever and the only reason that my precious little boy was still alive, and I spoke of how it may be the last seen of him. So Ross's surgery was filmed for City Hospital, although after the tragic outcome it wasn't shown on TV until June 2006 (around the time of his birthday).

On the Sunday before, we went shopping, specifically to buy a special present for Ross to take with him to the hospital and a wooden puzzle - a ship from ELC. Ross chose teddies to give to James and Ben. I held a variety of teddies in front of him and both times he chose the same ones, the From Me To You bear clasping a scarf with the words "A Hug from Me To You". The same happened with keyrings - he chose the same set both times; the hearts broken into 2 pieces so that they could have one each. After Ross died and we had to let him go, James and Ben placed a half of the little keyrings he'd chosen for them in the coffin with him and had their teddies to remember him by that really were chosen by him.

We arrived at Guy's on 20th September to have all the usual tests prior to surgery. Ross was a little more aware now, after being a little treasure a month before after having bloods taken especially, and at the time of his MRI and laying still for Echo's. This time he was a little minx! Almost like he knew. I feared losing Ross so much. When I signed the consent form Mr Anderson quoted the 2% risk factor which will stick in my head as I suddenly felt such relief and even said about how much I'd worried!

At 5.20 am on the 22nd September he arrested twice in front of me. I was so angry with him, I knew exactly what was happening and I just wanted to pick him up and shout and shake him, to not do this; but, of course I didn't. I just had to stand back and watch. As awful as it all was, I am glad I was there with him every minute that I could be. My only regret is that I never held him during those 17 hours I sat and watched and felt his freezing cold body. I wonder if I had been able to hold him and warm him up whether he would still be here. I know there was a reason he was so cold, to keep his blood pressure stable but it all haunts me. I forgot I could hold him. It was only when I saw a photo in Heartline with a mummy holding her baby with a ventilator that I knew I could have done so.

# Telling Others the Dreadful News and How to Deal with My other Children

I had to phone my family and tell them the awful news. At the time I felt like a zombie, looking back I can't believe I did that - what had I ever done so wrong to have to put my boys through that? Before Ross was even born I attended a Child Bereavement course. Never would I have dreamt of young children seeing any dead person but eyes were opened after watching their video of children talking about how they felt after being left out. I learnt to be honest at an age appropriate level and to give the children choices about how far they felt they wanted to be involved. One part of the video stuck in my mind - a little girl who said, after her baby brother had died: "it wasn't fair, everybody saw my new baby

brother, the doctor's, nurses, my mum and dad but, not me".

## “Understanding Differences”

Ross was such a joy to have and this whole experience opened my eyes to many things that we would otherwise know nothing of. Realising first hand how so many of us take things for granted and how many families suffer in silence I began to want to raise awareness to help other families as well as my own, hence the beginning of “UD” which means exactly what it says. I know myself if we understood more it would be a little easier and others may be less judgmental.

The drive behind this is that everyone has different needs, but for me I wanted to be actively involved and to meet with other families.

“UD” was instigated with no disrespect to the charities I already was a member of but, to try to get local families to meet with and to offer something back to the community, putting in place the things that were still lacking in the system. I had to try to make something positive come from the dreadful journey put on my children and I, plus, I am that type of person, sort of a business entrepreneur, always coming up with bright ideas that I always put my ALL into. In October 2003 the internet Forums were new to me, a little outdated with far fewer contributors compared to what they are now and so I felt very alone with few communication channels and friends who understood. Having 2 other children made phone-calls difficult as the “world war 3 syndrome” hits our house too when I pick up the phone!

I also think that being a single parent was an additional issue - already comments had been made how I couldn't put this on my children on top of them not seeing their dads. I had to take on board those judgmental people and so speaking to others who were happily married left me feeling that they couldn't possibly understand what extra pressure I was under -even if that wasn't true. It wasn't doing it alone but the feeling I was being judged that was the issue.

As time has gone on the ideas I have had for “UD” have grown immensely as when I initially was awarded my first 2 grants I did not know that we needed a committee and all that stuff-even though they were approved on my own merit, when it came to banking the cheques a totally new door opened.

Understanding differences not only campaigns to raise awareness of Congenital Heart Disease, but also to educate schools and teachers on how to deal with issues such as disability, illness and bereavement, and also prejudice and bullying. It provides books and leaflets and has its own website:

[www.understandingdifferences.org.uk](http://www.understandingdifferences.org.uk). If you would like more information, or just a chat, please contact me, Donna Nevill, on 07832 245014.

I should end by telling you that since September 2005 I have had 2 new additions to my family. Kigh and Maiya; they have both been screened for CHD and were born with no problems at all; apart from their nutty mum! They have helped me to get through my days, as have the older 2 boys but Ross is forever in my thoughts as still I have lost a very big part of me. I haven't moved on but as someone said to me earlier, you move sideways. How you come across to people is all that changes and I can't imagine in a million years ever being able to accept what has happened.

Ross brought so much pleasure to my life and to his brother's that we would never have been without

him. I hope that my story has helped someone out there. If you would like to get in contact with me, please contact me on the number above or e-mail me through the UD Website.

**Donna Nevill**