

## JAN'S STORY

'We found something'... Three simple words that introduced me to the world of a children's hospital and the most terrifying months of my life. The conversation these words began crushed the hopes I had for my son and left me with one hope remaining: that he would live.

My baby had seemed perfectly healthy since his birth. His tests had been fine and he had taken to breastfeeding well. But the paediatrician doing discharge checks in Rotunda Hospital felt his hips repeatedly before saying he was taking him downstairs for a heart scan. Soon after, he returned alone, pulled the curtain around my bed, and told me if we had brought our son home that day as intended, he would not have survived past two weeks. His scan had shown three heart defects and he required emergency surgery in Crumlin Hospital. He was two days old.

The shock of my baby's sudden diagnosis made it difficult to process anything I saw or heard for days. It was like watching a movie of myself: a movie that made no sense and was full of scenes I wished to erase... rushing to ICU to find my son being wheeled off to an ambulance... then driving his empty car seat towards Crumlin Hospital... searching endless corridors for a 'Children's Heart Centre' and the pain of realising my son was there... wondering what nightmare this is... my tiny baby in a plastic box, covered in wires, stickers, beeping machines, staff prodding him with needles while saying 'congratulations'... a blur of surgeons, doctors, nurses, coming in and out keeping my son alive... hearing repeatedly of the risks of their surgical plan... then signing the consent form and wondering if it would set in motion the start or the end of my child's life... sitting in darkness in the hospital car park trying to empty my body of tears... finally getting home to see my toddler and turning my back on the bedroom ready for our baby... finding a bag labelled 'Baby's Going Home Clothes' in my case and the shock giving way to grief... hearing staff tell me that all going well, my son would be able to breastfeed after surgery and the realisation hitting me that they expected him to survive...

I truly thought all the hopes I had for my son were gone. But I was wrong. A turning point came for me when I saw posters in the corridors telling stories of mums breastfeeding their babies through horrendous illnesses, courses of chemotherapy, and year-long hospital stays. I stopped and read every story, and they left me in awe of these mums. They made me realize that it was possible to breastfeed a baby after a serious surgery. They reminded me that my breastmilk could just be the best thing for my son: a medicine of sorts for him, tailor-made by my body to suit his needs, and that it could help him fight infection and grow strong in the days after his surgery just like these babies had. I realised in those moments that although the list of what I could not do for my baby was long, there was one essential thing that only I could do for him.

My family sprang into action to help. They arrived at the hospital with bags of things I might need. They made meals for me I couldn't eat because I was nauseous with worry. They printed pictures for me of my baby: pictures I asked them to put away because they were taken before his diagnosis, and seeing them threatened to break a part of me I didn't know existed. They filled my house with biscuits: endless packets of biscuits. I'm still not sure why. Every time I opened the cupboards for weeks after my son's surgery, packets of biscuits would fall out. I think they ended up taking most of them back. But I understand now what the biscuits meant: support was there for me and my family wanted me to know it.

I called on help from specially trained nurses available in Crumlin Hospital called Breastfeeding Champions. They took the time to teach me how to use a breast pump and supplied me with the equipment I needed. They gently encouraged me to continue when I was exhausted. I could not have got through it without support and knowing the Breastfeeding Champions were close by to provide it was invaluable. A quote comes to mind when I think of the help we received: 'When you cannot look on the bright side, I will sit with you in the dark'. I learnt that it takes very special people to be strong enough and willing to support those who are in the darkness of a crisis. Those who cannot look on the bright side because there is no bright side to their child being seriously ill. Not only did I

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have a family full of these special people, but a hospital in Crumlin full of them too: a hospital full of staff and volunteers who make the decision to sit in the dark with people every day. And now that I am lucky enough to watch my son growing into a strong, healthy toddler, they are the reason I am inspired to help.

I created PumpPal to support mums in children's hospitals who are providing breastmilk for their babies. My family have suggested filling their cupboards with biscuits. I am going to pilot a Support Kit idea first. From June 2018, mums in Our Lady's Children's Hospital, Crumlin, who are providing breastmilk for their babies will be supplied with PumpPal support kits. Please follow the link for more details.

If you had told me a year ago that I would now enter a children's hospital voluntarily I would not have believed you. But the long corridors of Crumlin look different to me now. Now they are filled with parents, children, and staff fighting to help patients get better. They are filled with hope: with modern medicines, new research, progression in fields of medicine at a rate never seen before, and world-class surgeons. They are filled with the knowledge that a child in Ireland can survive heart surgery and thrive afterwards and the knowledge that my son is one of them. The people in these corridors saved my son's life and they continue to save lives every day. These people are everyday heroes. Unsung. Unseen. Unspoken. When I walk the corridors of Crumlin Hospital now, this is what I see.

But I will forever think of the parents who walk into a children's hospital for the first time as I did and don't yet feel hope in those corridors. I want them to know they are not alone. There are people thinking of them, willing them on, and supporting them from the side-lines: people they might not ever meet, but who have walked these corridors and understand the trauma they are experiencing. I want these parents to know we care. We see them. We are here to help. We have biscuits.

*Disclaimer: Apologies to the mums who receive a support kit from PumpPal and learn they do not in fact contain biscuits.*