

Messages of support and advice from Parents

Some messages of support and advice from parents in the ECHO heart community.



To any parents that are about to have a baby with a heart condition. I just want to let you know that you are strong enough to do this.

"If I was to give any advice on expressing and breast feeding- it would be to be kind to your body. You are under a lot of stress with having a heart baby and being in NICU with potentially the prospect of surgery and it takes a toll on your body. As time went on I found expressing more and more challenging but I tried to focus on every little bit helps (and they will freeze every little bit for you!) do as much skin-to-skin as you can and don't feel bad for using the donor milk or formula- our baby had a bit of everything whilst he was in hospital!"

I had to have an emergency c-section, this is probably, like me, not most women's first choice of delivery - however I tell everyone that it was, to my surprise, an incredibly calm and enjoyable experience. All the staff made me feel at ease and the anaesthetist played my choice of music on Spotify and talked to me throughout the whole thing!

We were in NICU and HDU for 5 days and then moved to the Evelina Savannah HDU for 6 days before our baby had his surgery. He was then on PICU for 6 days and back on Savannah for 4 days before going home. The move from NICU to the Evelina was a bit of a shock - when we moved to Savannah, I had forgotten that there would be lots of older children there and it felt a lot more noisy and busy! I cried a lot when we first moved over. However it only took a day to settle in and it was there that I really felt like he was my baby - almost like we had taken him home but had some nurses there to help us.

PICU was another different experience, it blew my mind how in a place that was so intense that everyone appeared so calm. Again, all the staff were amazing and every nurse and doctor that cared for our baby took time to speak to us and make sure we knew exactly how his recovery was progressing. All 3 wards are very different but the care for you as a family is consistent throughout.

My twin boys were both taken off to NICU straight away. Its one of the hardest things you'll go through, but you'll get through it. Even though they may have wires and tubes, you'll still be able to have cuddles. I'd recommend having a nighty or top with buttons at the front so you can put them on your chest easily. They have little woollen squares that you have on you (sleep with) so it has your smell, that you put next to the baby. You can talk, sing and read stories to bubba so they recognise your voice. I always expressed next to their bedside so I felt close and connected. We also printed photos and attached them to their incubators. The whole NICU team will support you, and they give you lots of hints and tips on how to be in NICU and how to bond with baby.