



## NEONATAL INTENSIVE CARE AND SPECIAL CARE

**Approximately half of twins and more than 90% of triplets require time in the Neonatal Intensive Care Unit (NICU) and/or the Special Care Baby Unit (SCBU). This presents an emotional and logistical challenge for multiples parents that is difficult to prepare for.**

Mothers are recovering from a pregnancy which was likely challenging, as well as a birth which is more likely to have been by c-section. Parents are navigating learning how to tend to the needs of two or more babies, and if one or more is medically fragile this is an even bigger learning curve.

A specific challenge that faces parents of multiples is the potential of a staggered discharge, in which one or more of their new infants is discharged from hospital days, weeks or even months before their siblings.

In addition to the advice and shared experiences of our members, the following links provide some useful resources

about preterm birth and neonatal care in New Zealand:

- **Premature multiples survey** by Multiples NZ - valuable insight into multiples families' experiences of NICU 
- **Wellington Regional Hospital's Neonatal intensive care unit**
- **Kangaroo care**
- **Car seat safety for NICU infants**
- **Expressing for premature infants**
- **Video tour** of Wellington Regional Hospital NICU
- **National NICU/SCBU units** - contact details for all neonatal care services in New Zealand

To support our whānau facing the possibility of time in neonatal care, Multiples Hutt Valley has interviewed some of our members to gain insight into their experiences and advice.



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## KRISSY'S STORY

We found out we were having a complicated twin pregnancy at 22 weeks. What was meant to be an extra scan to get a few more measurements on Baby A showed us that Baby B wasn't growing very well. She was diagnosed with IUGR (intrauterine growth restriction) and we had growth scans every two weeks to make sure she still had incremental growth.

I went into premature labour at 28 weeks but they were able to stop it and I was sent home on modified activity rest. My labour started again at 31 weeks and again they were able to control it, but I was then hospitalised on bedrest until the twins arrived.

At our growth scan at 34 weeks we found out our Twin B stopped growing and it was time to get her out. This coincided with me developing preeclampsia, so our twins were delivered by c-section at 34 weeks and 6 days. Our little boy weighed 5lb 4oz, and little girl weighed 3lb7oz.

We did two weeks in the Wellington NICU before being transferred to our regional hospital and did another two weeks in the SCBU in Masterton. The twins were in hospital for 28 days in total before we were discharged to come home; I was in hospital for 50 days.

Being completely honest, the NICU journey was one of the hardest things I have ever had to do. It is not normal, and goes against everything to walk away and leave your babies in the care of strangers (qualified and wonderful nurses and doctors but still strangers). Seeing your babies with tube and wires

and machines, the monitors and alarms - it's devastating. But it's also the absolute best possible place your babies could be, and we are so lucky to have such incredible teams trained to help our babies grow and develop until they are strong enough to come home.

Focusing on the fact that my babies needed me and I couldn't be there for them if I didn't look after myself was what got me through. I was pumping and knew that I needed to eat and drink lots of water in order to build up my supply, and this helped me to make sure I was keeping up my energy and staying hydrated.

I don't think anything could have prepared me for a NICU journey, but here are some things I wish I knew:

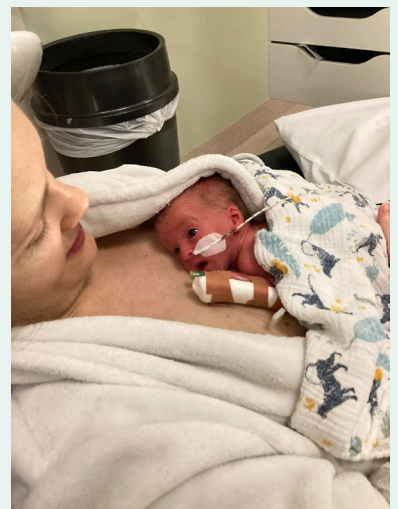
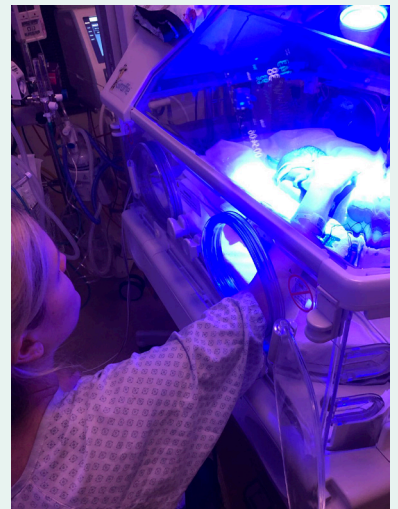
1. Advocate. Find your voice and use it. Ask questions. If you don't get an answer or don't like an answer, keep asking. Some nurses are absolutely incredible and really take into account what you want. Others just do what they need to, and it took me a while to advocate for what I wanted as their mum.
2. "Look at the baby. Not the machines." An amazing NICU nurse practitioner told me this. He said it was their job to watch the numbers on the machine, and my job to watch my baby. This helped when the alarms started blaring and I would get so caught up in the stats.
3. The UV lights for jaundice are a bit scary (for me it was the goggles), but I just thought of them as little lizards soaking up all the warmth and heat!



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4. Do as much of the “top to tail” personal care as you can. This is when you carefully wash your baby’s face, neck, hands then bottom. It’s a way to connect and care for your baby. The wires and cords are a bit scary at first, but you get used to them.
5. Tears are normal and healthy. Let them flow.
6. Breastmilk on heel pricks! We had a fantastic head midwife through MFM, and she told me to put breastmilk on any heel picks (or other test/IV sites, etc). This made a huge difference in them healing faster, and is something I did for any and all cuts/scraps the entire time I breastfed.
7. Tube to boob is hard, but doable! I firmly believe that any way a baby is fed, is the best way for that baby. I wanted to breastfeed, but I had to push to get support in this area. Talk to a lactation consultant - as many times as need to - and tell all the nurses you want the chance to breastfeed before bottle feeding.
8. Your babies will not remember this. The trauma is yours and it does fade in time.
9. @dearnicumama is an incredible instagram account that really helped me process the NICU experience while we were in it, and after. At the same time I unfollowed this when I felt as though I was ready to leave this in the past and not keep dwelling on it. Find things that serve you, and let them go when they don’t anymore.
10. You are not the only one going through this. Lean on your support network, but also try to connect with other people who have been there; they can provide a different level of solidarity and support.
11. You are incredible. You are powerful. You are exactly what your baby needs. You have got this. (I wish I could have told myself this; I wish I could have listened).

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## MEL'S STORY

I had one twin whisked quickly to SCBU after an elective cesarean - the other stayed with me.

My smaller twin ended up staying in there for 15 days with a nasogastric tube. And at one point she needed some antibiotics for her breathing

for a suspected respiratory infection. We were there during a really busy period; the unit can hold up to 12 babies, but there were 17, including my little Bella.

It was certainly difficult having the twins in different places and feeling



so torn. They run on pretty strict feeding schedules so when I was demand feeding Aria in my room, it didn't always match up and then, if I missed one of Bella's feeds, I'd feel incredibly guilty.

I found it hard to see my baby not being cared for to the level that I would be caring for her myself. For example, when I would visit her, she would often have dried sick down her face and on her bedding. Seeing her crying in her cot and not getting any attention from anyone was painful. The only contact she was having was with me, which didn't happen as often as I'd have liked due to me being very occupied by her sister.

Towards the end of Bella's stay, they allowed me to room in the ward. I had to have the other twin with me whilst rooming in, and didn't have any help with her. I was trying to navigate looking after one baby, whilst also trying to bond with a baby on the ward.

Doing it on my own meant that it was one parent to two babies, which was incredibly challenging whilst recovering from surgery physically, and adjusting to motherhood mentally. Eventually they eased off on the rules so I could have all the help I needed, until I was able to bring them both home.

The thought of taking Bella home was terrifying. When you see such a small, vulnerable baby it's hard to imagine being able to care for them by yourself at home when they have been cared for by many trained staff. Actually getting her home was much less scary, and far better than I could've imagined! Being in your own environment

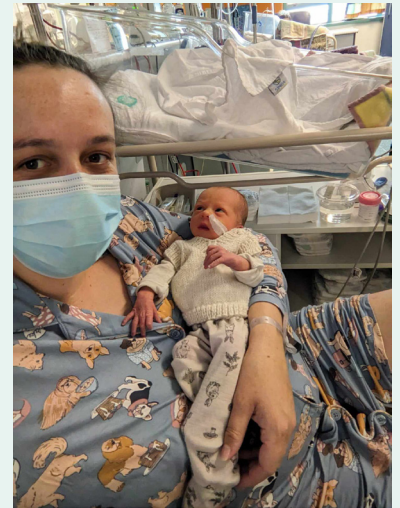
where you are relaxed makes a lot of difference.

Despite all these hurdles, my biggest challenge was taking care of myself. I look back now and get really emotional about how run down I became, and how little attention I gave myself and my needs. I was good at eating, but showers were rare - getting out of pyjamas was nonexistent, and sleep was dangerously neglected. But at least I ate!

I wish I could go back and take better care of myself, have dedicated time to shower and get dressed, and ask for help so I could get some rest. I was running on such an empty tank!

My advice:

- Prioritise YOU and your recovery. Don't put so much pressure on yourself to be there for them every second of the day. You'll be a better person once you're clean and rested
- There is SO much time to bond once you are at home in your own familiar, comfortable environment, so don't feel guilty for having that shower instead of that cuddle, or for getting someone else to hold them whilst you sleep
- It is YOUR baby. If certain rules don't align with how you wish to care for them, then question those rules. SCBU has so many rules, it can feel like you're walking on eggshells and going to get told off for doing anything slightly differently to them. Get as involved with your baby's care as you can, don't be afraid to upset staff by doing things your way.



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## JAIMIE'S STORY

We did IVF so found out at the 7-week scan that we had twins and there wasn't any obvious membrane between them. I eventually started looking into this when I got the letter from the fertility doctor to our obstetrician and first hear the term 'monochorionic monoamniotic'. Turns out it's really high risk and from that time on, pregnancy was pretty anxiety ridden.

From 17 weeks Twin B had intermittent blood flow through her umbilical tube. I started my prenatal hospital stay at 26 weeks with the intention of a c-section at 32 weeks. That quickly shifted to 30 weeks and then they came bang on 28 weeks. The c-section was fine, both babies cried when they came out, and then we had 5 weeks in NICU and must have been about 10 weeks in SCBU. All in all, they come home at 3 weeks corrected.

They had to have several blood transfusions, were on breathing support for a really long time, and developed severe reflux, one so bad that she kept stopping breathing. We had a couple of scares, but overall we probably got off relatively lightly. Getting them home, it was still COVID times so my planned support went out the window, and things were really really hard for a few months, then just really hard, then just hard. For me, things got better at about the 6-month mark; for my husband it took a lot longer. They are 2 now and things are good (but still hard, they are twin toddlers after all!)

The biggest challenge was wanting to be with them all the time - the travel to get to them and home,

and trying to share your time between the two of them while also pumping six times a day. What was less scary than my imagination? To be honest due to the really high risk of the pregnancy I had stopped imagining future stuff from about 7 weeks, so I didn't really have any preconceptions going in! But when it came down to actually having the c-section, it wasn't that scary to have them arrive and be whisked away immediately or to see them in the incubators. I was expecting it though, so it's not like I was taken by surprise.

I knew it was important to take care of myself so I made sure to eat, I had a routine with timers on my phone to tell me when to pump, and I didn't really do anything other than look after babies. Luckily my husband took care of all the house things including feeding me, and I made sure to be the most knowledgeable person about my babies. I read their charts and I knew what was happening with them, so my mind was as easy as possible, knowing I wasn't missing anything.

My most important piece of advice is to do some more research. I did none, as I was so concerned that they wouldn't survive, I didn't want to jinx it with planning. Even in NICU and SCBU, I wasn't reading parenting books, I was reading novels. I found a book, late in the journey, at the library called "Understanding the NICU: what parents of preemies and other hospitalized newborns need to know". It would have been good to have read that in advance or in the early days.



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## CHRISTINE'S STORY

When I was pregnant with di-di miracles, I experienced a small bleed at 10 weeks, but a scan confirmed both babies were OK.

I can't recall exactly when, but growth concerns were raised and fortnightly scans commenced - at 24 weeks I was hospitalised and on three times a day monitoring, with an urgent referral to Wellington.

This turned out to be an error in reading the singleton graph for a twin pregnancy, however it resulted in weekly monitoring and the growth concerns continued, with twin B having a damaged placenta (possibly related to the bleed at 10 weeks).

“It's a different kind of blessing and it's OK!”

I was really worried about my maternity leave dates initially, but found my way though that with open communication. My boss and team were amazing any time I had medical appointments, so I was able to work until late in my pregnancy (it was never recommended I go on bed rest).

The boys were born at 34+6 - Twin A was 2.1kg and twin B was 1.4kg.

I had a number of fears in the lead up to the birth. When it came to preparing for the idea of neonatal care, the thought of being at Wellington Hospital scared me, as it wasn't a hospital I knew - but by the time I gave birth it was my second home.

I was also worried about my midwife not being part of my journey as she was unable to operate in Wellington, BUT the hospital midwives and nurses were absolutely the best.

Another concern was around having a support person that wasn't my partner as he was working - I had to talk to the charge nurse to make that happen, but we got there.

Having a tour of NICU in advance took away my fear a little and helped me prepare - I am very grateful to the nurse who encouraged me to do it!

When the babies were admitted into NICU, I went into planning mode. I needed to get from Upper Hutt to Wellington daily, with a shift-working husband trying to save his leave for when the babies came home. It kept me focused. The hospital provided me with meals if I told them when I was visiting.

The babies came out of SCBU four days after their due date.

My advice to parents when their babies have been admitted into neonatal care is:

- It's a different kind of blessing and it's OK!
- Get expressing colostrum
- Just because they are professionals doesn't mean they are right. Ask ask ask and follow up
- Trust your Mum instinct
- Reach out the second you recognize you're not feeling yourself or your partner notices a change: PND stole so much of our early days



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