



# multiplesnz

*During the collation of the Multiples NZ 2011 Resource 'Precious Premies', a survey of parents was undertaken which was aimed at finding out about the experiences of Kiwi parents of premature multiples. These insights, suggestions and birth stories are collected here.*

## **Survey Snapshot—Being prepared**

We were prepared from 28 weeks, so every extra week was a blessing. Once admitted we were given a tour of NICU. We were informed of the most likely scenario that would happen once the babies were born. My husband and I discussed exactly what would happen when babies were born. In the theatre he bounced between looking at babies, and declaring their names, and reporting back to me, who was still be stitched up. He followed the babies to NICU and once they were settled he came back to me in recovery with the camera loaded with photos and video clips. I found having a second support person present invaluable (Midwife first and then she was relieved by a relative). That way, my husband was able to jump between NICU and recovery, and also make the relevant phone calls to family members. We were well prepared for our NICU experience. Because of this, my memories of our 10 day stay are very positive. The staff were brilliant and very supportive.

Advances in neonatal care mean the outlook is improving all the time. Stephanie and Berenice (L to R), were born at 33 weeks gestation, and are now happy, healthy 4 year olds.



## Survey Snapshot – Life in NICU

It's hard seeing your children for the first time in a plastic tub with wires and tubes, and is not the birthing and bonding experience you dream of. But you are still their mum and dad and have the chance to show this—as soon as it is safe you are allowed to touch your baby, first with a gentle hand to the tummy or the back or the head, depending on what skin is free of nappy and/or equipment. As they get better, you can carefully cradle them on your chest for 'kangaroo cuddles' which keeps them warm (mums and dads make the best newborn heaters), while you avoid pulling out their drip!

The first time you see your babies' faces without respiratory equipment is a major milestone (one twin eventually pulled his off, as he hated it so much). Enjoying a cuddle without wires and lines is another milestone. You don't get let off nappy duty either, and you can be shown the drill—which you do gingerly at first, worried this little bundle will snap in half, but with increasing confidence. As they move from incubator to open cot, you feel more and more like these little ones are really yours and slowly start making decisions, in consultation with nursing staff, about their feeding, sleeping and dressing. Once they have enough body weight, feed well, keep consistently warm themselves and can breathe easily, it's time to take them home!

A typical day started for us at about 7 am with the nursing shift changeover. The nurse would chat with us about a plan for the next twelve hours, and Mum or Dad (or both, in our case) might help with the feeding which may be at 2, 3 or 4 hourly intervals. To start with, all our boys' food was syringed in via a mouth tube, starting with colostrum, then breast milk, and glucose or formula. Our job was to hold the tube up as the feed was pushed into the tummy by gravity.

Breast feeding attempts were introduced when the babies showed sucking actions and the lactation consultant helped with getting started. Many of the nurses are former midwives, so they were constantly assisting with ensuring correct latching and stimulating the sucking reflex, which takes a while to develop in 35 weekers. As one mum put it, she's not had her boobs grabbed by so many people since she was a teen! If you can't feed your baby, you can go to the expressing machines and your expressed breast milk (EBM) is refrigerated for later use. I got hung up on the sucking reflex not developing until 36 weeks, and it was ages before I realised that, actually, that didn't matter as they learn it really fast.

Temperature check, eye cleansing and nappy changes usually preface the feeding, and if you were not expressing straight after the feed, then you might have tummy time for an hour or so before you expressed, and then it's all on again. Most importantly, always make sure you are there for morning doctors' rounds. Even though it meant I had to wake up at 6 am to beat the rush hour traffic, it was so important to be at the 9 am rounds. It was a chance to ask questions and learn things you may not otherwise be told.

## Survey Snapshots–Feeding premature multiples

Thank heavens for having twin Mums on staff at the hospital, who had been through the same experience. They were very kind, caring and helpful. I spent a lot of time with the "milking" machine called Murray and started producing small amounts of milk. It is such a bizarre experience watching your milk being delivered via a nasogastric feeding tube. I did find it a challenging process but was glad it worked until such time as the boys learned to suck and could do it by themselves. I know that breast feeding in tandem saves time, but if it is hard latching them on together, YOU CAN FEED ONE AT A TIME!! I wish someone had told me that it was OK. I felt so pressured to get them on at the same time that, at six weeks, I gave up breastfeeding and regretted the decision.

All the mums in the neonatal unit used to joke about the lactation consultants and nurses being battleaxes when it came to expressing milk. We were expected to do this every 2–3 hours and they would wake us during the night, too, which was pretty exhausting. I am so thankful to those nurses, as it meant that after 11 and a half weeks of the girls being in hospital, I had a great supply of milk and could still breast feed them. I would say it is definitely worth persevering with expressing, even though it seems like hard work to start off with, as research shows it is a great benefit to premature babies. However, I do realise that for some mothers, this just isn't possible but I'd say don't give up until you've talked to a lactation consultant and tried everything. Also make sure you start early, i.e. within a few hours of birth, as if you leave it too long it can be difficult to start producing milk.

To begin with, the feed times seemed to take forever as the girls were slow feeders with being premature. After feeding them, I would express milk afterwards, too, so by the time I did all of that, it felt like it was time for the next feed. My main advice would be to get a good twin feeding cushion and get the phone number of the hospital lactation consultant to give you advice. Also, if you are expressing milk for any length of time, a good investment is a dual electric breast pump - if possible hospital grade. The one I used was great. It was hospital grade, came in a rucksack and would even run on batteries, which was fantastic if you were out and about. These quality pumps are expensive to buy new but are money well spent. I managed to pick mine up on Trade Me second-hand. If you buy one new, you could always recoup some of your money by selling it later.

A few hours after the birth, I had midwives from the hospital coming in to show me how to express. I didn't realise the importance of this at the time and it's probably best that no one tried to explain it to me so early on as I still hadn't come to understand that I had just given birth to 2 babies. I cannot describe the pride I had when I took 0.1 ml of colostrum into the NICU room where my babies were staying. I handed it to the Paediatrician and he asked me who I would like to give it to – I told him both. Bless him, he looked at the syringe with 0.1 ml and said so kindly that he wasn't sure it was enough to split but he would see what he could do.

Continuing to express more and more for my babies over the next few days gave me purpose – I felt like I was doing something right after failing to carry them to full term... that I could now provide for them. I made it my mission to make sure that I expressed as much milk as humanly possible for my babies, so that they could get so strong and healthy that they would come home to me sooner. As time went on I began to help prepare the feeds for my girls. I would measure out the breast milk from the fridge, add the fortifier to help bump up the calories and then attach to the nasal gastric tube. We had to give Sofia thickener in her breast milk, too, as she wouldn't keep it down. I was very keen to introduce the babies to the breast as often as I could but it was a lot for them, so I couldn't do it for long.

The first time my babies actually fed from the breast, I didn't believe it, as I had become so dependent on feeding through the NG tube that I didn't think I was capable of feeding them directly. I started breast feeding them once a day. Any more would have tired them out too much. I would feed them in the rugby hold so that I was used to this position for when I tandem fed in the future. The day I fed them tandem was not planned, but I was feeding Sofia and Isabella woke, so the Lactation Consultant thought we may as well try. It worked straight away and was the most amazing feeling ever!

I looked forward to going to the hospital to feed my babies and would spend all day from morning to night at the hospital, then go home, express, go to bed, express in the night, get up, express and head back to the hospital. When I got to bring my babies home and they took the NG tube out, I was so reliant on this as my backup that I was so scared they weren't getting enough from me. Sofia was losing weight and I felt like I was failing her again. I wanted to put her on formula as I was adamant that it would fatten her up but I also wanted to keep breastfeeding as I knew it was the healthy choice that she needed.

I intended to breastfeed, but both girls had a nasogastric tube fitted in neonates, and one of them was given formula on day 3. Neither would latch on to the breast, I was tired, I didn't get support from most of the neonates nurses, who were keen to continue with the tubes to make sure the girls grew. They were both drinking 80% expressed breast milk, but I'm afraid the breast feeding just didn't happen. All just excuses - I could have made it happen if I'd been determined, but it just didn't happen. I expressed for 4 months, during which time I found it really hard to make time for expressing, especially with a 2 year old to look after as well. My milk supply fell off, and they were on formula only from 4 months old. I don't feel too bad about this, although I obviously have some regrets. Raising twins is challenging enough, without putting extra pressure on ourselves. Hats off to any mums that do breastfeed twins though!

Breastfeeding just didn't work for me. I had a lactation consultant but felt she didn't offer a balanced view – she was VERY one sided and formula was evil in her eyes. After I sacked her, I felt a whole lot better! Formula feeding worked well for us – we could share the night time feeds so I wasn't so sleep deprived, and my husband felt very involved.

I expressed and bottle fed, as I wanted to be out of hospital ASAP. They were topped up with formula if I hadn't managed to express enough milk. At eight weeks, we established breast feeding and I exclusively breastfed them both until 10 months. The hospital recommended supplementing with formula until my milk got up to speed. I didn't really like the idea at such a young age but as they were only 4 lb 6 oz and 4 lb 14 oz, it was more important that they started putting on weight. I was lucky enough to have my sister donate milk to provide top ups within a few days of their birth – she had a 3½ month old and excess milk, so dropped off daily bottles to help out the twins. Eventually, I had plenty of milk for them myself and took over. However, I stored any excess milk in the freezer and used this to top up one or both at the last night feed. This helped them sleep through the night at 9 weeks. If there wasn't enough expressed milk, I would top up one or both with formula at the last night feed. I almost gave up breastfeeding at about 5 weeks when the stress of having to wake sleepy premature babies wore me down, but stuck with it and ended up breastfeeding for nine months.

I put a huge amount of pressure on myself to breastfeed my twins and "get it right". It didn't work that well - the boys were premature and I was anaemic, sore and stressed. I wish someone had told me that 34 week old babies don't know how to suck very well! I blamed myself for the difficulties with breast feeding them. Expressing for my babies in NICU gave me a sense of purpose when I was on the maternity ward away from them. When in NICU, I expressed for every day feed, but I would skip one at night so I could get a good length of sleep. I found the progress with breast feeding strongly depended on the nursing staff on the NICU

unit. I was lucky to have a great nurse with my babies for 3 days in a row. She was the one who got me a room in NICU to sleep and would insist on getting both babies on the boob if they were both awake. For the first 4 weeks, the feeding schedule was like this: BF, nappy change, BF, EBM. Once we got to 4 weeks, we found we didn't need to do the EBM top up anymore.

The thing I found most difficult was trying to breastfeed - only one of the midwives could get my babies to latch on and I was desperate for her to come and see me the minute she came on shift! Some of the other midwives were very anti-formula and you virtually had to beg to get some to feed your babies. In the end, we took in our own bottles and formula and managed it ourselves - alleviated the pressure. I also found it quite hard being in hospital with high BP, as the midwives would often forget to give me my medication when it was scheduled to be given - I was sometimes given it 3 or 4 hours later. As you can imagine, this was VERY stressful, as pre-eclampsia can be quite serious. Best thing to do is get a script from your obgyn/midwife before being admitted and manage your own medication.

You may worry that you won't have enough milk for two, and that you're not producing enough milk quickly enough, but remember that premature babies have tiny tummies, and whatever they get from you is doing the most good for them. If your midwife or lactation consultant leaves you with feelings of inadequacy, ask for a different one! It seems that there are often a lot of difficulties in the early days with feeding premature babies, and not all midwives or lactation consultants have a lot of experience specifically with prems. Find someone who will encourage you to get through the difficulties and/or pain, because it will get better; don't let anyone make you feel inadequate for trying your hardest, in a very emotional time, to do the most important job in the world! My babies couldn't latch on. Totally not interested in breastfeeding at all, and this was my biggest challenge. That and NO milk, which can be associated with (a) pre-eclampsia/high BP and (b) having a c-section. We were really lucky and the boys didn't go into neonates despite being born at 36 weeks. Both boys had reflux. The smaller of the two vomited practically 100% of every meal until he was 18 months old, then every second meal until he was about two.

The worst thing about the babies coming early was being stuck in hospital for two weeks and the hard work of trying to teach the babies to suck so they could get feeding and we could go home. The SCBU staff were brilliant though, kind, caring and helpful and the lactation consultant at Whangarei Hospital had twins herself and was very helpful.

## **Survey Snapshot—Being separated from your babies**

I wasn't prepared for the fact that I wasn't going to be with my babies - I could hear every other baby on the ward (with their mothers) crying but mine were in the SCBU. I was in a lot of pain after my C-section but nurses were telling me I had to walk around to the SCBU, I felt alone and not supported at all. I didn't think the hospital was going to be as hard as it was.

## **Survey Snapshot—Dealing with tricky situations**

I think you just have to be so strong, and fight for what you want. Obviously, in some situations you won't get it - but being together as a family is so important in a time like that. One of my babies (the bigger one) is now a total daddy's girl, as her dad looked after her so much when she was tiny (which is nice for him). You will be closer than most families because of needing both of you to be fully involved.

Our babies, thankfully, went home together but there were a few occasions in the hospital when we weren't entirely happy with decisions made. It can be very easy not to raise your views when the doctors seem so busy, but it is important for you to speak up. We found in these situations that we would first of all speak to the head nurse in the unit (who was very approachable and understanding) and then ask for them to get the relevant doctor to speak to us when he had time. This resolved all of our problems, but if you are still not satisfied after this, most units have patient advocacy that you can contact.

Going home without the babies was a very hard experience. It didn't feel right being separated from them and no matter how many times people told me they were in the best place, it didn't help as in my head the best place was with me inside my tummy being nurtured and growing until they were full term. Focusing on getting them better and being there for them was what helped me get through this time.

Just ask lots of questions, put your foot down, don't let them do anything you don't like without lots of explanations. There are so many nurses in neonates, you might not see the same face twice, and they have different approaches. Some you will bond with, some you may see as a threat to your child's welfare (this also depends on how much sleep you get that day, too!). Just be honest and yourself - they are used to emotional mothers, and we have to protect our babies, right?

It was really tough leaving the boys in NICU and going home, I was physically fine (I only had a few internal stitches), so there was no real reason for me to be in there. I found a nurse I could really trust and felt comfortable talking to and she would voice my concerns or opinions. REMEMBER THEY ARE YOUR BABIES!!! Some of the older nurses made me feel like it was their way or no way. We had to be quite stern with regards to bathing them ourselves, changing them, etc. Make sure your presence is known.

Due to Maya's extra issues, my twins are developing and growing at different rates. This is very hard and sometimes makes me feel like I don't have twins at all. My main advice in this situation would be to try your best not to compare them. Prem babies are developmentally behind at the best of times, not taking into account all the extra stress little Maya went through with her heart surgeries. Embrace having a tiny baby a little bit longer than most people would have and celebrate all achievements for both twins. I think that's very important. Maya rolling over was celebrated just as much as Zoey rolling over two months before her.

(1). Don't argue with or confront staff. (2). Tell them you want time to make a decision. (3). Contact your most trusted person for support. (4). Explain to them the difficulty you are having and talk it through with them. (5). Decide on a plan of action. Work out who you need to approach at the hospital and what to say. (6). Get your friend to come in and support you - do NOT do it alone. (7). Ask to have time with the relevant decision maker or approach them. 8. Set out clearly, quietly and firmly what your decision is. (9). Listen to their response. (10). Go back to step one.

## **Survey Snapshots—Logistics and practical tips**

Fight to spend as long in the hospital as possible - if you have had a c-section and you cannot drive and you want to breastfeed, you have to be there or it is impossible. Organise a roster for people to cook you meals/deliver takeaways – seriously, you will need it! You need to have TONS of snacks - making milk for 2x babies (or more) takes energy.

If you don't have any other children, then staying in the unit is probably the most convenient option. Some units have facilities for both parents to stay, but more often it is just for the mum. However, speak to the social services department in the hospital, as there should be an allowance available for the father (or both parents) to stay in a motel nearby. There is also a travel allowance provided for parents who have to travel to and from a unit distant from their home. If you are staying at the hospital try and get out and about when you can, to give you a bit of a break from everything. Also, the nurses may offer for you to go home at times and this can be helpful for getting things ready for the babies' home-coming. If given the chance, you are better to do this early on though, as it will be more hands-on learning to breastfeed, etc. towards the end of your stay.

Tips for staying in NICU - have a book at hand. It takes your mind off being in such a weird environment, and take a bottle of water! It's hot in there.

Some hospitals may help with parking for parents with babies in NICU or SCBU, please ask.

Make sure you get outside for some sunshine/fresh air every day. Also getting out of the hospital grounds for lunch/coffee works wonders for your sanity.

## Survey Snapshots—How can others help?

I needed true friends, ones who weren't there to stop and chat but who would do the cares with me and let me get out for sunshine and a walk. I would have really appreciated contact with the Multiple Birth Club as it exists now, esp. from another mum who had been in NICU. I found it great to have friends visiting for support, however, it is really important to be strict about visiting times and taking phone calls because it can also become exhausting, on top of trying to keep up to date with your babies and expressing milk. Try and have set times for friends coming to visit and don't feel bad about turning your cell phone off, and asking the nurses to tell visitors or people phoning that you are not available or sleeping at certain times. If friends can be of help with anything going on at home, if you are in hospital, then don't be afraid to ask them, as they would probably be delighted to be able to help.

If you are staying at a hospital away from home and your partner has to leave to go back for work, then try and set aside a bit of time to chat to him each day - or even if he is staying with you, try to take a bit of time out together, as some of the stresses associated with prem babies can put a strain on relationships. When John was visiting us in the hospital, we would often go and sit with one of the girls on each of us (what is known as skin-to-skin contact) in the unit together. It was a nice escape from the busy world and was a good chance to spend time together.

Having the girls start their life in NICU is an experience I will never forget. The nurses really helped me through it, as they were there to look after the parents as well as the babies. Every morning on my drive to the hospital, I would have a good cry but I would be adamant that I was going to be strong in the hospital for my babies. I was there to do a job - to love them and look after them. My family is in the UK, so my friends were very important to me. Having friends visit throughout the days really helped me get through. I found that they made me feel like my babies were normal as even though they were tiny, and in incubators and covered in monitors, that people wanted to see them and me. I found it hard in the first couple of days to visit the girls on my own without crying - having friends visit, it was like they were doing the crying for me so I felt stronger. After 2 and a half weeks the girls were transferred to SCBU to a hospital closer to home. I hated it at first, as the rules were stricter and I could have no visitors. In the end, I appreciated it as it meant that I focused on my little girls getting stronger. It did however, shut me out from the outside world. I couldn't believe there was a world going on outside of the one I was experiencing. I didn't want to see anyone after that, as I wanted to spend all of my time at the hospital or asleep at home. Anything else and I felt guilty. Friends dropping off dinners and food was a great help. I received meals at the hospital as I was breastfeeding, but it was great for my husband. I knew my friends were there if I needed them, but there was no pressure for me to get in touch with them. To be honest the nurses became my friends as they had an idea of what I was going through and how hard it was.

Being in NICU - the nurses are fantastic, they tell you what to expect, and they show you how to do all the cares for your baby. You get to tube feed them, and kangaroo cuddle. We were lucky to have family support to look after our oldest whilst we were at the hospital most of the day. We would kangaroo cuddle and read books or sleep with the babies on us.

SLEEP SLEEP SLEEP as much as you can. Don't beat yourself up or worry about things - there is nothing you can do and your babies are in very good hands. Let go of the control you want - whether it is breast feeding/holding your babies/taking them home/seeing them tube/machine free - it will happen in good time, and neonates will be a distant memory when you have your babies well and happy at home.

The staff were very helpful and we can't thank them enough for their support and kindness. One night, a darling midwife bathed and fed the boys, so David and I went out for a hot chocolate (our last for a few months). Have some kind person to keep bringing you clean clothing and extra food. as once you start feeding you feel starving.

I was devastated that I wasn't offered a bed in Waikato Hospital after being transferred from Tauranga. I had only given birth the day prior and had to leave my twins in hospital and got told to go home. We spent most of our days in the unit with the twins, but it was nice to get rest at night - our last feed we helped with was midnight and were back at 8 am the next morning. Family were wonderful in bringing meals to us and supporting us through our 10 day stay in NICU.

I was in SCBU, rather than NICU, but the staff were fantastic and it was a matter of feeling my way as to what I was supposed to be doing. It was great to have my own room eventually, but it was hard being there for 2 weeks in beautiful summer weather. I just wanted to go home and start our new life. The biggest lesson was not to stress about every little detail and just trust that it will all work out in the end.

## **Survey Snapshots—Flying the coup, going home and doing it alone**

When we stayed overnight in the Parents Room before taking the girls home, we stayed for two nights to make sure we were confident. I would recommend comfy clothes and magazines. We couldn't get my computer to work with movies, but that would have been nice too, to relax and break up the day. As it felt a bit like 48 hours of 3 hourly feeds - not knowing what was night and day. Something we obviously had to get used to! I had mixed feelings about going home. I was excited to have my babies home with me, as it was positive as it meant they were ready and well. But I was nervous that it was all down to me as I had been able to rely so much on the nurses. When we first got them home, we called the hospital a few times to check things out but we also had homecare nurses who helped reassure us.

I pushed to go home on a daily basis - I was sure I could look after the girls myself, and wanted them out of neonates. I don't think they were sent home any earlier as a result, but it was good to get my frustrations off my chest. NICU was a great place in many ways - they do a fantastic job. I just didn't think we'd be there!

It's hard at first after having so much intervention - keep a log-book as you will seriously not remember who has or hasn't pooped, how much milk/formula they each had (etc), which side each child last fed from etc. I had a lovely male nurse who told me that it is really easy to get 'institutionalised' and that eventually you need to be able to relax and just be parents, like anyone else. You also need a mind-break from it all too - we had lots of people come over to bring us dinner and we would eat with them and chat - our babies slept in the lounge in the day and no-one was allowed to touch them in case they got sick, but we needed the contact with people, normal, laughing contact. One good trick is to put hot water bottles in their bed when you feed/change them and then when they go back to bed it is warm like you... Don't keep them up more than an hour - they are tiny and just need to sleep. We acted like they were still inside me until their due-date, feeding, sleeping, nothing else. We had to fight relatives who wanted to cuddle them (seriously. my mum was trying to read stories to them!) - they just needed sleep and food.

While I was in the hospital there was a lot of literature available about all baby issues and breastfeeding, etc. I tried to read as much of this as possible and ask questions to staff in the unit before I left the hospital. It is quite a daunting but also exciting prospect to be going home after weeks in NICU. If possible, try and get your husband to take a bit of time off work for some extra help. The first days can seem quite tough but once you are into a routine things become a lot easier. I was lucky and had my parents stay for 10 days when I was first home. Get in touch with Plunket early, so that if you have any problems you can speak to your Plunket nurse. Also if friends offer help, don't ever turn it down. My friends were great and brought me precooked meals when they came to visit, rather than flowers or chocolates. It was a real godsend, as it meant we could sit down to a decent meal at the end of the day without the pressure of having to find time to prepare it.

When we first got the babies home I felt so satisfied that I had my family with me. I was nervous that we didn't have the medical support on hand, if needed, but we called them often enough to reassure us that everything was ok. We also had Homecare nurses come and check on the babies, their weight etc. which helped reassure us that we hadn't been forgotten about. I think in some ways you are institutionalised a little bit, as all you know as a first time mother is hospitals and doctors. We had a few scares, one 4 am feed my Isabella had a slight apnoea, it reminded me how fragile they were (as if I needed reminding!) and so we promptly set up the apnoea sensor mattresses we had borrowed. We had concerns over Sofia's weight gain, as she lost it for quite a few weigh ins afterwards, but she began to pick it up and the nurses were comfortable, which reassured me. I can't rate the aftercare we received highly enough. I was certainly given enough support to build my confidence as a mum outside the hospital.

It is not as bad as you imagine. My girls thrived once they were home. It is initially worrying that they go from being weighed, examined, poos and wees assessed ad nauseum, etc to NOTHING, but life is much easier without all those daily scares, and after time in neonates you will be quite good at monitoring their progress naturally, anyway. Breathe a huge sigh of relief and enjoy - this is when family and friends are really needed! We didn't get much warning, the midwife said in the morning that you can go home today!! Panic, we didn't have the car seats and any premmie clothing organised. It was a rushed trip to Baby Factory to pick up the necessary gear. I remember looking at them in the car seats and thinking the straps would be too big, but we survived. When we arrived home it was kind of like "what do we do now?" Then it all started to fall into the feed, sleep, poop routine.

Make sure you have someone who can cook and clean for you in the first few weeks of being home. It will take all stress off you and gives you time to just be a mum and be with your babies. Make sure your partner, if you have one, takes time off work so he can bond with the babies as well. My husband took time off around the two month mark, when things had settled down and the babies weren't just sleeping and eating, so he felt like he could really help and bond with them a bit better.

We were stoked when the babies started feeding exclusively and put on weight so we could go home. Due to Maya's ongoing cardiac monitoring and feeding issues, we are visited on a weekly basis by a homecare nurse. We also have a speech language therapist and dietician visit us at home and numerous specialist appointments at Starship. I suppose at this stage I don't feel I have gone it alone yet, as doctors and specialists are still very much in control of Maya's wellbeing. It is nice, however, that first night at home knowing that no one will be telling you how to soothe your baby or look after it. I finally felt like a real mum.

## **Survey Snapshots—Going home with only one**

One of my twins had a bad heart and was required to stay in hospital until she reached 3 kg and could have her surgery. Taking one baby home was very odd but in some ways it was good, as we got to practise with one before coping with two! I was told I was ready to go straight home and didn't require the 'parents' room' (a room in NICU where parents would usually spend the night with their baby or babies to make sure it all works ok before being sent home). Big mistake. And my daughter Zoey paid the price. She went from one or two breast feeds in NICU to being expected to feed that way eight times a day, as the lactation consultant frowned on me using a bottle for her. She was virtually traumatised by the experience and stopped breastfeeding completely. If I tried to force her she would cry and shake. The Parent room would have picked up on this and perhaps I could have received a bit more help in transitioning her home.

Lucky for me, at three months she started breastfeeding out of the blue and now refuses a bottle. Put your foot down – even the most amazing mother requires parent room! Going back and forth to the hospital every day with my healthy twin in tow was very hard. NICU provided me with a cot for her, but by the time we got home at 8 pm she was very unsettled. She would cry every time I put her in her car seat. All she wanted to do was stay home and I couldn't give her that. It was torture. But knowing it wouldn't be forever and that I had to do my best for both of them made it a bit easier. Hang in there!

## **Survey Snapshots—Ongoing needs**

This is something we were worried about but our 21month old girls are great - their language is definitely slower than it should be and they only started walking recently, but we just have to keep an eye on it all. We have been incredibly lucky with our girls. Early on they both had problems with their eyes (retinopathy of prematurity) and hearing problems (recurrent ear infections and glue ear up to 21 months). However, now these problems have passed and they do not seem to have any adverse effects from being premature. We have been very impressed and reassured by the amount of medical follow-up they have received since being in hospital. They have had many paediatric appointments, as well as development, ear and eye appointments. If there is anything you are concerned about, just contact your doctor and ask for a referral appointment if you feel it needs to be taken further. One thing that gave us hope when we were in hospital, was the lovely poster displays made by other parents telling their stories and showing pictures of their premature babies at birth through to one or two years - they showed us that most of the babies turned into normal toddlers by the age of one or two.

As my girls were born at 30 weeks they needed to have iron and vitamin C for approx. 10 months, I gave it to them before their morning feeds. We also continued to have visits to the Paediatrician until about this time to watch their development. Other than this, and the funny looks I get from people when they ask me how old my girls are (as they are small for their age), I haven't experienced too many ongoing needs for them being prem. I'm conscious of their development, but at the same time understand that each child develops differently, regardless of whether they are prem or not. I'm told that at the age of two they should catch up size-wise and at five years old developmentally.

We had ongoing health issues with both girls: they had excellent follow up for development issues for a year after birth, and in the end, just turned two, neither has any lasting problems. After care was amazing. A really

good GP offered us great continuity - she knows the girls well and is the common link in appointments with various hospital departments.

The boys have now turned seven and have hit milestones around the right times. Our only long term problem has been intolerances to gluten and dairy. The symptoms started as soon as I stopped breastfeeding and were on full time formula. They were prone to stomach upsets, reflux and ear infections. They both had grommets put in at nine months and then again when they were two. Both had tonsils removed when they were four for ongoing problems. They have asthma, and a cold can become a chest infection/asthma attack very easily. This may all sound a bit negative, but I wish I had done more research on formula/breastfeeding together, rather than giving up.

For us, the only ongoing need was from a reflux point of view. I found having a multiple birth club fantastic - the previous group I went to had NO idea what it was like and were sending around emails congratulating themselves because their babies were sleeping through at 4 months, which made me feel like a total failure. Maya was classed as VLBW (very low birth weight) weighing just 1070 grams at birth - so we have appointments with a neurodevelopmental specialist and she has her eyes checked regularly. Despite being only 700 grams larger than Maya at birth, Zoey (classed LBW) is offered none of this follow-up care and makes do with paediatrician follow-up and Plunket visits. It can be strange when your twins are offered different care, just trust in those looking after you. Ensure all Plunket nurses and other professionals are aware of the issues. It helps to have a short summary written out and available to append to any relevant medical forms requesting information.

## They all catch up in the end ...

Felicity is mum to Alexander and Saskia, and a member of Multiples Auckland Central.

Our twins were born at 32 weeks, weighing 2.20 kg and 2.15 kg and were in NICU for 25 days before we were allowed to bring them home, weighing 2.76 kg and 2.63 kg. It was surreal being wheeled into their room in NICU, still in my hospital bed, to pay a visit to them. I was still pretty sick due to preeclampsia. I had listened to everything during my ante-natal classes, but nothing prepared me for seeing them for the first time. It was a pretty emotional moment, and I was so grateful for their safe arrival.

I could only stare in amazement at them in their enclosed incubators, lying on their backs with an enormous newborn-sized nappy on them. There were monitors on their toes and chests, but overall they looked pretty relaxed and laid back. Alexander was on CPAP (a breathing machine) for his first day, but generally, they were in excellent health, and great weights. They both had feeding tubes that went up their nose and into their stomachs. Initially, they were being fed 10 ml of formula milk every 2-3 hours, and this increased to 50 ml by the time we went home. Before they learnt to suck, feeds were administered through a syringe held aloft, as the milk drained away into their stomachs.

I was discharged and sent home after eight days, and had to leave the twins behind in NICU. I would go and visit them in hospital every single day, staying virtually all day. It was a pretty intense experience and the day passed incredibly fast, as I was so busy trying to express milk, feeding, changing, bathing, having visitors and snatching a few winks of sleep.

The nursing staff in NICU are amazing and they didn't mind me calling in the dead of night to check on their progress, or asking lots and lots of questions. I am grateful for the little shop run by the Neonatal Trust (previously known as Parentcare) at the entrance to NICU that sells premie-sized clothes, as it would be several months before they would fit newborn sized clothes. On the walls in the entrance to NICU there are some very inspiring and incredible stories about babies born weighing less than half-a-kilo, with photos of wedding rings up their arms and how they survived and thrived. It's very humbling, and I know of several ACMBC members with similar experiences.

I found it difficult to bond with the twins, and I think this was due to several factors. Firstly, being separated from them for so long, with them in NICU for 3½ weeks and not being home with them to cocoon and get to know each other. Secondly, I had virtually no milk supply, which meant that they were tube- and then bottle-fed since birth. Thirdly, just the fact that they were twins and my energies and time was shared between them. I did do kangaroo care when possible to try and help with the bonding.

Once we got them home it was pretty full-on and the tiredness was not conducive to bonding either. If I am honest, I have to say that I did not feel properly bonded with them for several months, which may alarm some people. I recall looking wistfully at mothers of singletons who had the luxury of being able to sit on a sofa and cuddle their only baby, gazing into their eyes for hours. I was just too busy to do that.

Due to their prematurity, it took a good few months for their weights to catch up with their peers on the weight graphs in their Well Child Books. I am aware that developmentally they have been slower than their peers when it comes to meeting their milestones, but hey, they all catch up in the end.



*One day old in NICU—Alexander (L) and Saskia ®*

## **Our NICU experience**

Nicci, mum to twins Archer and Toby.

My boys were born at 5.02 and 5.03 am on a Thursday, via an emergency c-section, after my waters 'broke' (i.e. flooded). Due to their prematurity (35 weeks), position (both transverse) and the speed with which they needed delivering (one had a cord around his neck), I was given a general anaesthetic so did not see the boys being born, and nor could my husband, as it was a sterile theatre. We never expected that neither of us would witness the birth, so that was a shock. When I came to, I found out about three hours after delivery that we had two sons!

Twin A was 2.688 kg (5 lb 9 oz) and Twin B was 2.530 kg (5 lb 6 oz), with Apgars of 9.5 and 8.5. Both were immediately transferred to the Neonatal Intensive Care Unit (NICU), Twin A needing just a feeding tube as he grew enough body fat to keep himself warm, and Twin B went onto, then off, respiratory support but was intensively monitored until he gained more weight.

It's hard seeing your children for the first time in a plastic tub with wires and tubes, and is not the birthing and bonding experience you dream of. But you are still their mum and dad and have the chance to show this—as soon as it is safe you are allowed to touch your baby, first with a gentle hand to the tummy or the back or the head, depending on what skin is free of nappy and/or equipment. As they get better you can carefully cradle them on your chest for 'kangaroo cuddles' which keeps them warm (mums and dads make the best newborn heaters), while you avoid pulling out their drip!

The first time you see your babies' faces without respiratory equipment is a major milestone (one twin eventually pulled his off as he hated it so much). Enjoying a cuddle without wires and lines is another

milestone. You don't get let off nappy duty either, and you can be shown the drill—which you do gingerly at first, worried this little bundle will snap in half, but with increasing confidence. As they move from incubator to open cot, you feel more and more like these little ones are really yours and slowly start making decisions, in consultation with nursing staff, about their feeding, sleeping and dressing. Once they have enough body weight, feed well, keep consistently warm themselves and can breath easily, it's time to take them home!

A typical day started for us at about 7am with the nursing shift changeover. The nurse would chat with us about a plan for the next twelve hours, and Mum or Dad (or both, in our case) might help with the feeding which may be at 2, 3 or 4 hourly intervals. To start with, all our boys' food was syringed in via a mouth tube, starting with colostrum, then breast milk, and glucose or formula. Our job was to hold the tube up as the feed was pushed into the tummy by gravity.

Breast feeding attempts were introduced when the babies showed sucking actions and the lactation consultant helped with getting started. Many of the nurses are former midwives, so they were constantly assisting with ensuring correct latching and stimulating the sucking reflex, which takes a while to develop in 35 weekers. As one mum put it, she's not had her boobs grabbed by so many people since she was a teen! If you can't feed your baby, you can go to the expressing machines and your expressed breast milk (EBM) is refrigerated for later use. I got hung up on the sucking reflex not developing until 36 weeks, and it was ages before I realised that, actually, that didn't matter as they learn it really fast.

Temperature check, eye cleansing and nappy changes usually preface the feeding, and if you were not expressing straight after the feed, then you might have tummy time for an hour or so before you expressed, and then it's all on again.

In Wellington, we had the option of staying in the parents' rooms (available for day or night stays) and we did this drillhours out of 24 (the nurses usually let us off one night feed so we could get some uninterrupted sleep). Otherwise, we could have spent the day at neonates and returned home in the evening, even though it is heartbreaking leaving your children behind. We decided that, although it was more exhausting staying in the unit, it was more satisfying—but we found, in the long run, it insulated us too much from preparing to take the babies home.

Whilst we acknowledge our children were safe, cared for and well-treated, overall my advice to parents would be to try and push for the shortest possible time in the NICU. We never felt as if we were fully listened to when we raised concerns, and I feel like it had a negative effect on our bonding and breast feeding with the children, which is possibly unavoidable, but leaving sooner would have helped minimise its extent.

We had no family who could help us in the unit, and because we weren't sure how long we would be there, it was difficult to plan for friends to come and help. My advice would be to actively plan that if you believe it is possible you will be in NICU for more than a couple of days, you have someone (who can be there with you for several days) already primed up to be your support and advocate for any issues you have.



*Toby (L) and Archer (R)—gorgeous, healthy 2 year-olds*

## **The hard part fades**

Carolyn, mum of Amy and Ruby and a member of the Whangarei Multiple Birth Club (now the Whangarei Satellite).

We were so excited to discover we were having twins at an eight week scan and then even more excited to discover we were having twin girls at our 20 week scan. I had been reading the multiple birth newsletters for a few months and figured out, looking at the birth notices that most people seemed to have their twins between 32-38 weeks. So, we planned on a December-January birth—first mistake!! Never plan for much when having twins!! The girls decided they wanted to come extra early and were born by emergency caesarean at 27 weeks, in November 2009.

I had had a great pregnancy, kept well and carried well. Then, on a Friday afternoon, I had some small spotting so was admitted to the Women's Assessment Unit and ended up staying two nights for observation. Luckily, my obstetrician decided to give me a course of steroids over two days—I think this probably saved the girls. I was discharged on the Sunday, despite me telling the hospital staff that I was having low belly pains. I took the Monday off work and did some gardening with my mum!! That night I went to go to bed and popped to the toilet, where my waters broke and five minute-apart contractions started!! We called an ambulance, as we got a bit concerned about the journey to hospital. My obstetrician met us at the hospital and explained I was fully dilated (after only half an hour of contractions) and the girls were both breech—good combination, eh! We had to make a very quick decision to have a c-section. From the time I had my first contraction to when the girls were born was only two hours.

The next four days in hospital were just a blur. I would get wheel-chaired up to the girls room in NICU every few hours to deliver any colostrum I had managed to express. I was then discharged and faced the horrible fact that I was leaving the hospital without my girls. It just felt so unnatural. We spent the next four months going to and from the hospital daily to visit the girls and be a part of their lives. It was a huge emotional rollercoaster and certainly not what I had envisaged or planned for the birth of my first children.

I think the biggest bridge I had to cross was getting over that fact and comparing my birth story, which was filled with fear, uncertainty and emotional hard work, with those of my antenatal class who had stories of elation, joy and happiness. The girls are now 17 months old (14 months adjusted age) and are the apples of my eye. They bring me joy every day, and the sadness of their early arrival has faded and been replaced with

a feeling of being blessed with such little delights. We really are lucky to be part of such a special club.

My advice to expectant multiple mums—be flexible about your birth plan—VERY flexible. The most important thing is that they are alive and part of your life. The ‘hard’ aspects of premature twins will fade, as do the memories of all the hard work. Take each day as it comes—don’t think too far ahead about all the what-ifs and the statistics of possible complications. Our girls have chronic lung disease, which they will grow out of. We are lucky. We have no other ongoing health issues and the girls are developmentally on track for their adjusted age. If only we’d had a crystal ball to know everything would turn out okay!



*(L to R) Ruby (15 months), Mike, Carolyn and Amy (15 months)*