MULTIPLE MATTERS

The official magazine of Multiples New Zealand

Winter Edition · July 2019

multiplesnz

RRP NZ$6.50

- **Premature Multiples**
- **National Training Forum**

Our Premature Multiples

Makenna & Quinn, New Plymouth, 34 weeks

Lara & Hazel, Taranaki, 35 weeks

Theo & Evie, Tauranga, 34 weeks

Olivia & Levi, Waitomo, 33 weeks

Forrest & Casey, Wellington, 31 weeks

Annaliese & Abby, Tauranga, 35 weeks

Charlie & Ben, Christchurch, 30 weeks

Dillion & Admaiah, Morrinsville, 32 weeks

Multiples NZ

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Magazine contributions

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Feature topic: International Multiples

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Cover photo

Our premature multiples: Twins Aspen and Atlas Madden were born at 36 weeks in Taranaki. Meet them on page 12.

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From your Editor

Time to snuggle up

Kirsty Saxon (Multiples NZ), Mummy to Xavier and Lilian (5), and Ruby (8).

Does anyone else feel like this year is flying by? It's nearly the end of June as I write this and it will be July when you read it. Sitting at the dinner table with my family this evening, I was reminded of that parenting quote: *"The days are long, but the years are short"*. It is hard to believe how fast those years really go. At one stage struggling with fertility issues, we were unsure if we would ever have a family. Now we have this crazy, loud, and busy whanau which I (lovingly) call the Saxa-tornado. Sometimes my husband and I sit here and question "will we miss this craziness when they've flown the nest?" It seems a long way away still, but the way the months and years are flying by, I bet it will come to pass faster than we are ready for and that kind of scares me. There's a line in my favourite song which goes: "I can't remember all the times I told myself to hold on to these moments as they pass." And I guess that's what we, as parents, are always trying to do.

This issue is dedicated to our super star families who welcomed their little multiples earlier than most. Our Multiples NZ Medical Advisor, Dr Emma Parry, defines preterm birth as: "when birth occurs after 20 weeks gestation and up to 36 weeks and 6 days." Babies born between 24 and 28 weeks are known as *extremely premature*. The average pregnancy length for twins is 37 weeks, with 34 weeks for triplets and 32 for quads—this means a lot of twins (40%) are premature, most triplets (90%) will be preterm, and all higher-order multiple gestations. Most parents expecting multiples will quickly learn that one of the main risks they face is having premature babies. We are so lucky that we have the support of our club specialist NICU support volunteers. We also work closely with the Neonatal Trust to support families who find themselves with prems. I hope you enjoy reading these amazing stories of hope and courage when faced with this challenge.

The programme for the National Training Forum 2019 has been published (see page 26 & 27). If you are considering attending, I would strongly recommend you give some thought to it for 2019. It's a great weekend in Wellington with like minded mums (and sometimes dads!) Plus a chance to celebrate the achievements of our clubs with the Volunteer Awards and Gala Dinner.

As usual, we welcome submissions on any topic related to multiples or anything relevant to our families. Send me an email if you have an idea for a story you would like to write or co-write with a friend. We are also always keen to get your pregnancy and birth stories, as I know we love reading about everyone's individual experiences. Next issue's theme is 'International Multiples' so if you have any thing to contribute, please get in touch!

For now, snuggle up with your kiddies and enjoy each moment.

Kirsty

Lilian, Ruby & Xavier, Ahipara, Far North

President’s Winter Report

Multiples NZ President **Ainslee Jacobson,** delivers her Winter report, and introduces our support partners for our premature multiples.

When my multiple pregnancy hit 30 weeks gestation, I was required to visit the hospital three times a week to measure the boys heart rates on a CTG machine. It was all terribly inconvenient and nerve wracking, but my boys decided they would stay warm inside until 37 weeks, and we were then just outside what is considered premature.

As our little family was leaving hospital, a close friend was arriving for her one month stay on the antenatal ward, followed by the early arrival of her little boy. I distinctly remember heading into the Neonatal Intensive Care Unit (NICU) and being surprised by how big her 32 weeker was. Turns out premmie singletons and term twins are very similar in size, and neither are what is considered big for a baby!

Supporting Service for our whanau with premature babies

There are two key organisations that provide invaluable support for our whanau and their premature babies and this is a great opportunity to say thank you:

The Neonatal Trust

Operating over 6 regions with nationwide support, the Neonatal Trust makes a huge difference to the journey of families through a Neonatal Intensive Care Unit (NICU). For us, The Neonatal Trust has been instrumental in getting the Purple Butterfly initiative off the ground and into the NICU’s.

Ronald McDonald House

Here in New Zealand we have three houses, three family rooms and a family retreat in Rotorua. The Ronald McDonald House charity is committed to keeping families together. Our families often have extended stays in hospital when babies are born early, and for some, these stays are a long way from home. The Ronald McDonald house gives our families a home away from home and eases the burdens of premature birth.

Best Start Payments and Multiple Births

Babies born on or after 1 July 2018 are entitled to weekly Best Start payments of $60 per child. All eligible families will receive $60 a week until their baby turns one, no matter how much they earn. In the case of multiple births, you would be entitled to $120, $180 or $240 per week, depending on the number of children you have had. You can apply for the Best Start payment, register your babies and apply for their IRD numbers via the SmartStart site:

www.smartstart.services.govt.nz

Multiples NZ has been in contact with Inland Revenue to address concerns raised by some parents, regarding Best Start payments for multiple births registered via Smart Start in August and September 2018. Inland Revenue has confirmed this issue was identified and corrective action was implemented.

Best Start payments begin once your Paid Parental leave has finished. If you have any concerns about the payments you are receiving from Inland Revenue, the first place to check is your Notice of Entitlement. If you are currently receiving Best Start payments please check the amount you're receiving is correct.

If you have a myIR account go to www.ird.govt.nz:

- Your My Family section will hold details of the children you are receiving payments for,
- My eDocuments section will hold your Notice of Entitlement,
- If any of the details are incorrect, you can either update these online, or by secure mail.

If for any reason a family has not received their full entitlement for Working for Families tax credits for the 2019 financial year (1 April 2018 to 31 March 2019), this will automatically be paid as a lump sum between June and July 2019 when the end of year calculations are completed. For more details on Working for Families tax credits including Best Start payments please visit www.ird.govt.nz and search keywords: Best Start.

Ainslee is mum to nine year old twin boys Cameron and Hunter, and lives in Wellington with her husband Craig. Ainslee juggles her president role with her work at AdviceFirst and Multiples Wellington.

Every journey is different

Kylie Burling (Alumni Member of Auckland Central) shares the story of her premature boys, born at 33 weeks.

You all know why we have multiples clubs, because there are so many things that we all experience and understand that those who do not have multiples just never understand. But despite our similar journeys, no two of us have precisely the same birth story. And for that reason no two of us have precisely the same experience with raising our children. A large proportion of us, though, find ourselves raising twins or triplets who were born prematurely - and almost none of us got much in the way of warning that this would be our journey.

My experience was a spontaneous natural delivery at 33 weeks, followed by 21 days for the twins in NICU/SCBU before we could take them home. The twins arrived very fast, and no amount of leg-crossing or steroid injections was going to slow them down. My pregnancy had been very 'normal', and there was nothing to make me suspect I would deliver them prematurely other than the usual risk associated with twin pregnancies.

Twin 1 was born pink and healthy, he cried well, had good Apgars, and he was perfectly happy to have a cuddle that was all too soon interrupted. I wasn't aware of any problems with Twin 2, but my obstetrician was. Twin 2 had got into distress, had spun around and was suddenly presenting footling breech, and when my obstetrician had reached in and pulled him out by his feet he was blue, did not cry, and had low Apgars. I didn't get a cuddle with him. There were eight minutes between them, but it felt like only one or two. It was two minutes before he cried, and that felt like so much more than the previous eight. I'm not certain I even breathed while those two minutes ticked by.

When the second baby was born it slowly dawned on me that I might lose one of them. I wasn't prepared for a premature birth, and in fact I hadn't taken a bag with me to hospital, because although I had one packed, when I left home that morning I was only going to get a steroid injection, not deliver twins. With the speed of the delivery I really had no choice but to just go with the flow and process everything later, but I realised that if I wasn't actually prepared for a premature birth (even though I knew the chance was high), I was totally and utterly unprepared for a stillbirth. Thankfully the staff were amazing and the obstetrician was absolutely brilliant, and I credit her completely for saving his life. I don't know how she knew he was in distress, but if she hadn't acted with instant reflexes there would have been nothing the other staff could have done to save him. They called it 'twin two syndrome', where the second twin becomes distressed during the delivery.

Post-delivery I developed a migraine, and was given Pethidine for it. But I got so spacey on it that I had to go to sleep, and so I didn't get to see my babies again until 8.00am the following day. It was nearly 16 hours after they had been born.

I found my way to the NICU area, with no idea of where to find my babies, or even if I still had two living. It was only just starting to hit me that one of them might not be alive, or might have problems to deal with if he was alive. I found their names on the first room I reached, but there were four incubators in the room and I didn't immediately know which one or two were mine. I felt uncertain of everything, and unsure of myself – like a visitor, not like a mother. I was relieved to find that both of my babies were alive.

I wondered whether I would be able to recognise my babies; one I had seen for a minute or two, and had a photograph taken with him, but the other one I had seen only on the digital camera as my family had taken a photograph of him through the incubator walls as he was being taken to NICU. There were so many tubes, which all looked huge against such a little baby, that I really didn't know if I had registered any specific features in my mind, or just the overall impression of tiny-baby-with-tubes-in-incubator.

Twin 1 was 5lb 1oz and had heart monitors on him, and Twin 2 was 4lb 9oz and had heart monitors, CPAP, and oxygen.

It was hard to see Twin 2 under all the tubes, so I still didn't really have a good idea of what he looked like. They both looked so tiny and fragile and not fitting their skin, and I just wanted to cuddle them but couldn't for a while.

They were lying naked but for nappies, on their backs, tucked around with a rolled-up towel, in their warm little incubator cocoons. The babies looked completely inaccessible to me, both because I dare not let them get cold by opening the incubator doors. They were covered with tubes so they couldn't be cuddled comfortably. They looked fragile, alone, and vulnerable - but also pink, healthy, and beautiful. I wondered how they felt being alone ... not only from being apart from me for the first time, but also apart from their womb-mate and therefore free of kicks and punches.

Seeing my tiny babies in incubators with tubes strapped to them was a time of very mixed emotions: happiness because they are here and alive; sadness because they are so tiny and helpless and the tubes and monitors look scary; uncertainty because I prepared for a 'normal' birth at full-term and didn't know what to do for little creatures dependent on medical equipment; guilt over delayed bonding; feelings of inadequacy over milk production etc.

There was an hilarious moment when the midwife on duty met me because Twin 1 had a green toenail and she was concerned it might have been something medical. It was nail-polish, in case we didn't know which one was which. After she had recovered from this shock, she showed me how to express to collect the colostrum, and how to do their cares. A few hours later I was able to give Twin 1 a skin-to-skin cuddle for the first time, and my husband was able to give Twin 2 a skin-to-skin cuddle. I still hadn't been able to do more than touch Twin 2 through the holes in the incubator, and I felt a bit upset by that. That first kangaroo care cuddle made a big difference for Twin 2 though, because within 24 hours he no longer needed oxygen. The next day I gave him another kangaroo care cuddle, and the following day he no longer needed CPAP. He had developed some jaundice though, which took a while to resolve. It was at about this time that the reality of having nearly lost him was really setting in for me because I hadn't been able to deal with it before that. But this realisation was timed with the removal of oxygen, then the removal of CPAP. It seemed to me that each morning I'd arrive to find something else had been removed without my knowledge. I suddenly felt anxious that it was all too much too soon, and I was not convinced that the right decisions had been made and perhaps something could still go wrong. I was distrustful and anxious, and really that feeling did not even start to go away until the boys reached their due date seven weeks later. The rest of the anxiety melted away by the time they were about six months.

Twin 1 with heart monitors; just 5lb 1oz

Twin 2 with heart monitors, oxygen, CPAP; just 4lb 9 oz

I felt so much like a visitor in NICU that I didn't want to do anything without permission. But I was told that not only was I allowed to touch them, I was encouraged to touch them, and do their care things like change nappies, and feed them, and cuddle them skin-to-skin. I felt reticent. I knew the medical staff were in charge, and the babies had CPAP and/or oxygen, and monitors everywhere, so I didn't want to just bowl on in and take over. I felt incompetent with the feeding and changing anyway, and I'm fairly sure I spent most of the first day looking at them through the plastic because I was scared to hold them or do the wrong thing.

If I was dealing with prems again, though, with the benefit of hindsight, I would pick them up and hold them and cuddle them every moment of the day if I could. I would recruit family to share that with me. When I look back, I can clearly see how much they benefited from touch. This could be seen by how quickly the oxygen and CPAP could be removed because Twin 2 started to thrive with the cuddles.

So my one piece of take-away advice that should fit for everyone who finds themselves on the prem journey is just that – there can never be too many cuddles for prems!

The midwives told me how to express milk, and gave me a machine to use. But it was so depressing that I couldn't seem to get even one full millilitre of colostrum initially. How was that ever supposed to feed two babies? Production slowly increased over the following days. But I always felt that I was 'behind', and their demand was greater than my supply. I was amazed that their appetites were satisfied by so little. I knew their hands and feet were tiny, I could see them, but it hadn't really occurred to me that their tummies were also tiny; much smaller than they would be in another seven weeks' time when they reached their due date.

The boys were relocated to SCBU at Waitakere on day three, and I was discharged. That was on my birthday, and it was the strangest birthday I have ever had. People wished me a happy birthday, but I felt like a different person, not myself. A birthday seemed irrelevant somehow.

The logistics of getting to and from hospital every day was a big challenge, as was getting through all the things I needed to do each day in the hospital. I had to express every three hours, feed each baby by tube, and do each baby's cares. I would take me an hour to deal with the first baby, another hour to deal with the second baby, and that would leave me another hour (or sometimes less) before I had to express again in which to eat and rest.

Continued over page...

I'd leave the hospital late at night, go home, and have to express throughout the night every three hours. It was a struggle.

It felt like I was feeding or expressing every single hour for 12 hours or so, and then still expressing during the night on a three hourly basis. I was starving, sleep-deprived, scared, and stressed. The last thing I wanted was some nurse or midwife to come along and tell me I was doing it all wrong (which they did!). But I soon realised that with each shift-change, the 'right' method would change too, because every nurse/midwife had their own 'right' way to do things, and they didn't always agree! Within a week, I had adopted the habit of listening to all the contradictory advice, but selecting only what worked for me and my babies, and standing up for myself to the staff if necessary.

I always felt that I was behind in the milk supply. When the boys were big enough to try feeding from me, I discovered an excruciating pain each time they fed, and no one could help me find out why. There was a nurse there who always came across as quite aggressive and judgmental, so there was that added stress for me to deal with too.

When the boys had gained enough weight we were able to room-in with the boys prior to taking them home, and it was the most hellish night of our lives. The feeding tubes were taken out and the only way to feed the babies was breast-feeding or with a bottle. They had not been getting enough milk from me to be solely breastfed, so we had no other option but to use bottles as well, and they screamed and screamed and screamed all night due to the air they had gulped in with the formula top-ups.

It is very easy to become institutionalised and over-rely on the medical staff, thinking that 'I cannot do anything without their knowledge, supervision, assistance,' etc. I found it very scary when machines were turned off (like CPAP) and monitors removed (like apnoea). Although one part of my brain accepted that these were signs of good progress and the staff knew what they were doing, the other part of my brain was terrified that it was too soon and my babies still needed it for survival. I felt that it was too soon to be considered for discharge too.

They were discharged 21 days after they were born, and passing their car-seat tests and everything else with flying colours. My husband and I, on the other hand, were emotional and physical wrecks after having almost no sleep that night. We were feeling certain that we were unprepared to have total responsibility for them because of the feeding problems. The staff at Auckland Hospital and NICU had been outstanding, and most of the staff at Waitakere SCBU had been great too, but because of the negative experience we had had with one nurse and the feeling of total abandonment during that hellish night of screaming babies we had very mixed feelings about taking the boys home. On the one hand we felt that they needed to stay in a day or two more getting used to bottle-feeding under supervision, and on the other hand we were happy to finally be getting them home to a stress-free environment.

We put the boys into the car and drove home. It was about a ten-minute drive, and probably the most nerve-wracking drive of our lives. Having subsequently had a full-term baby who left hospital within hours of birth, and was home from Birthcare three days later, I now realise just how much anxiety and stress I was dealing with at that time.

When we got them home they were still four weeks premature, and I had this horrible feeling that they shouldn't be out of hospital so soon. For the next four weeks I was tense and scared and overprotective until they reached their full-term date. Then suddenly their habits and behaviour changed as if to say, 'hey, I'm fully developed now, you can all relax.' So I did.

Medically we had few further problems after that. There was an x-ray for Twin 2 to ensure his hips were fine after his footling breech delivery, which he passed with flying colours. The biggest problems we had were the severe reflux which was triggered by the bottle-feeding, and me still having excruciating pain when breastfeeding. We found ways to manage these. I found there was less pain if I fed them singly instead of in tandem, and there was significantly less stress for me if I fed them singly too. By four months we switched them to only being bottle-fed, so that my milk could be thickened to help reduce their reflux.

We trialled all sorts of teats until we found some (Nuk) that had a good valve for air-flow and that did not make the boys gulp the milk too fast, and a lot of the anxiety about feeding times started to settle. Little by little their reflux settled; it improved a bit with thickened milk and anti-reflux formula; it improved a bit more with solids; and it improved a bit more with time.

I managed to keep expressing until their first birthday. I really pushed myself to achieve that, because my milk supply had never been abundant. In order to maintain a supply through all those months of expressing I had to take Domperidone three times a day, and I had to have a large breakfast and lunch and dinner with a drink each time, and a large morning and afternoon tea drink with some food each time. In order to achieve that level of food preparation on top of everything else I had to recruit my friends and family to spend specific days with me each week.

Throughout the first six months I really didn't realise how anxious I was that the babies would continue to breathe. They slept in a cot upstairs, and I lived my life upstairs for quite a few months. When I needed to be downstairs for any length of time, they would be in a double-pram in the lounge. They were never out of my sight or presence, and if I had to move them from upstairs to downstairs or vice versa I waited until someone was available to take the other baby when I took one, so neither of them was ever left alone. When I think about it now, it seems quite extreme and unnecessary, but my high levels of anxiety were ruling my life. I was scared they would stop breathing. I was scared that they would choke on their reflux. I was scared of the mess of reflux, if it meant waking the other baby in order to clean it up. I was scared of one crying himself sick with reflux while waiting for his meal if I was feeding the other one. I was scared of whether to wake the other one during the night if only one woke up. I was scared to make any noise because one twin took ages to get to sleep, and the other would fall asleep easily but wake after 45 minutes, and I was scared they would get out of routine with each other. I was just scared of everything.

By the time they were six months old they had put on enough weight to almost appear chubby. They no longer appeared fragile, and they were feeling more stable when carrying them because their neck strength had improved. Quite abruptly my anxiety started to settle. I was still with them 90% of the time by choice, but I had been with them 100% of the time for the first six months, and that little bit of relaxation felt like the greatest liberation I have ever experienced. I suddenly felt that they would be ok. I spent all my time with them from that time on because I wanted to, not because I felt their lives depended on it.

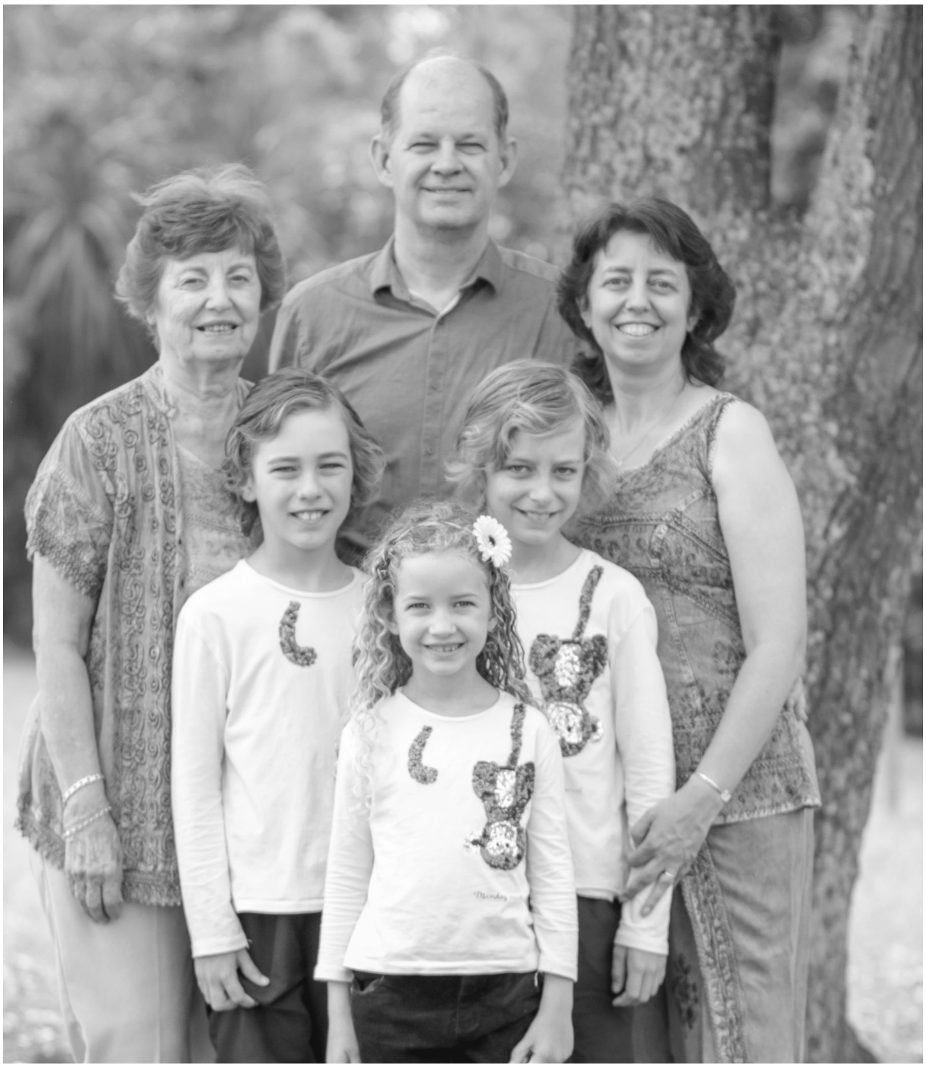
Most likely due to their prematurity they were slow to sit unaided, they were slow to crawl, and slow to walk. I felt like we had babies for a longer period of time than many people do. I get the impression that a lot of babies are only babies for a few months, and my third child was certainly like that, but my prem twins were babies for about 10 or 11 months. It was really only when they started to sit up by themselves that they lost that impression of being babies. One of them started to walk at 12 months, and the other at 15 months, and neither of them were talking anything other than single words until they were three years old.

By the time they were three and a half they were out of nappies day and night, and they were speaking in fairly full sentences (with a LOT of twin-speak though, haha), and that is about the stage when they really stopped showing signs of prematurity.

One thing that has been noticeable from birth, and is still noticeable to a lesser degree now, is that they are very sensory. As babies they would startle easily, and had strong 'hark!' reflexes, where they stopped whatever they were doing when they heard an unexpected or loud sound. They would appear to freeze for some moments until they had worked out what it was or had relaxed again.

As toddlers (between one and two years), they would cry and shake with tremors when the lawns were mowed or the rubbish truck came by. I did not know if that was because they did not expect the sound, or they did not understand what was happening, or if it was simply too loud for them. When they were two we moved to a bigger house, and neither the rubbish truck nor the lawn mower was as close to them as they had been in the previous house (where these things were only a few metres away from the windows), and so I do not know what age they would have been when this resolved if they had continued to be that close to these loud noises. When they were three they still did not cope well with unexpected or loud noises though. I remember taking them to a company Christmas party with about 40 people there all talking at once,. They had to be held and cuddled the entire time in order to stop them from shaking with fright. The sensory side of things has definitely settled over the years, but they remain with a more heightened sensory awareness than the general population, and that's their "normal".

They are 10 years old now, and they are fit and healthy and do not look like they were ever premature.



Kylie is an alumni member of the Auckland Central Club and lives in Glen Eden with her husband Fraser. They are the proud parents of Lennard and David, 11 years, and Rilla, 7 years.

Three Little Budds

Clara Budd (Multiples Auckland North) shares the story of her triplets born at 32 weeks.

We found out we were pregnant with triplets at nine weeks. We were told to 'just wait and see what happens' until we got to 12 weeks. Then, once we reached 12 weeks, it was confirmed as a viable triplet pregnancy.

We were looked after amazingly well by the team at the Auckland High Risk Fetal Medicine Unit. It was a very 'medicalised' pregnancy. My husband and I were ok with this but for some it may not be what they hoped for. During my pregnancy I presented to Auckland Hospital at least three times for either lack of movement of the babies or me feeling very unusual or unwell. It was never a problem to just show up at the hospital. The babies and I always received a full check-up and I was usually told to slow down.

At 28 weeks I started showing early signs of preeclampsia. Monitoring at this stage was almost weekly, with full scans, urine tests and sometimes blood tests. At just over 31 weeks I went for a scan and was admitted to hospital as there was concern about Triplet 2's growth and possible restricted blood flow (Triplet 1 and 2 are ID). I was immediately given a steroid injection in my thigh to help with the babies' lung development in case delivery was deemed necessary. After 48 hours of continually monitoring me and the babies I was sent home with two follow up appointments booked: one was two days later (the last appointment on New Year's Eve) and the other was three days later – the first appointment of the new year.

When we went to hospital at 12pm on New Year's Eve we never left. The specialist was very worried for Triplet 2 and said she needed to come out that day. I had just eaten (a huge bag of nuts!) so they decided to wait six hours. During that time I was nil by mouth. My husband and I spent the afternoon and early evening of New Year's Eve 2013 lying in a hospital bed talking about what the future might look like but also just enjoying the time alone together.

At about 6pm we were prepared for the surgery: my husband was in scrubs and I was being wheeled towards the operating theatre. Within 30m of the theatre we were turned around – there was an emergency c-section being rushed in. We spent another three hours in the hospital room napping and talking.

When I was finally wheeled into theatre around 9:30pm on New Year's Eve it was all quite overwhelming. At this point I broke down in tears. There were people everywhere and although I knew this would be the case it was still all a bit too much. The nurse dedicated to me was amazing as was the anaesthetist. They both talked me through what was happening. There were 12 people in the theatre, all with different roles. There was a neonatal team per baby. My team moved quickly to prepare me for the c-section.

Once the two surgeons started it only took about 90 seconds for all three babies to be delivered. Each one was briefly held up for me to see before being handed to their neonatal team. It was at this point Jason and I named each child – we had it all planned. Only one baby needed oxygen on arrival in theatre. Once Triplet 3 was delivered Jason was taken around to see them all. Our plan was for him to go with the babies in their incubators to NICU while I remained in theatre and post-op.

I have limited memory of my time in theatre and post-op. By this stage it was close to midnight and the hospital was very quiet. I didn't realise how much time had passed, but my husband came to look for me after about 90 minutes, when all the chaos of our three arriving in NICU and being 'set-up' in their incubators had calmed down. I hadn't been forgotten by the clinical team, there was just limited staff and they were waiting on an orderly to push my bed through to NICU. When I was wheeled into NICU I was able to see each baby. I do remember this happening, but at that point I don't recall too much emotion.

I was then taken to my room and my husband went back and forth between the NICU and me. In the lead up to the delivery I had only focused on the babies and ensuring (hoping) everything went well in delivery. What I hadn't prepared myself for was how having major surgery would affect me.

I was keen to start expressing so our premature babies got colostrum as early as possible. I had no idea how to start this – I'm not sure my body had even registered that I no longer had the babies inside me. I had an amazing nurse that evening who was happy to help and by about 2am that morning, through hand-milking, she was collecting colostrum in a syringe for the babies. My husband can clearly remember how proud he felt walking off down to NICU with about 5ml in a syringe! Seeing me being hand-milked by a stranger is something my husband says he was not prepared for – neither was I to be honest – but it happened.

By 6am I was awake again having had a few hours sleep. I knew I needed a shower to be 'ok' to be taken down to NICU. Although I found it incredibly hard to shower and ended up collapsing, I am pleased I did request the shower and I was with my three children by 7am that morning.

We were lucky that my sister, who is a paediatric consultant, was visiting from Canada at the time. She visited us at 8am on New Year's Day and through a combination of our three being stable enough and Juliet giving me the confidence to ask, all three babies came out of their incubators for Jason and me to have our first cuddles (about nine hours post-delivery at 32+2 weeks gestation). Our first family photo is a very special photo to us.

I personally struggled on the morphine post-op. It made me dizzy and dozy which was not helpful. After 24 hours I asked for the pump to be removed and controlled the pain with Panadol.

On day two I started expressing every three hours. My husband and I had decided I would give this a go in an attempt to breastfeed but had agreed that at any time, if needed, we would adjust our plan.

I started expressing one hour prior to the children's three hourly feed, delivering fresh breast milk to NICU for each feed. Until I was expressing enough for three babies this was mixed with formula.

On day three there was talk of discharging me (I was doing quite well). I was very strong, however, in requesting the full five days as I'd had a c-section, was a first time mum (of three!) and did not have any breast milk stored – if I was home overnight the babies would have no breast milk. In the end I stayed as an in-patient until day five and then the team found me a room on the Tamaki ward until day nine. This enabled me to continue to express three hourly and deliver milk through the day and night to NICU. My husband would go home each night and I would express and deliver the milk to NICU at 9pm, 12am and 3am. That amazing night-shift nurse would usually have a hot milo ready for me. My husband would arrive just before 6am, collect the milk to take to NICU and I would go back to sleep before my next express, knowing he was with the babies. This continued until day nine when we were shifted to North Shore Hospital.

Those first nine days were amazing but also a blur. The only thing I would do differently if I had my time again would be to have someone video my birth and then follow the babies for the 90 minutes that I wasn't with them. My husband has of course talked me through what happened, but I do feel I missed out on something. I would also have someone go with my husband and someone stay with me so that they could both communicate and provide me updates on the babies and Jason updates on me.

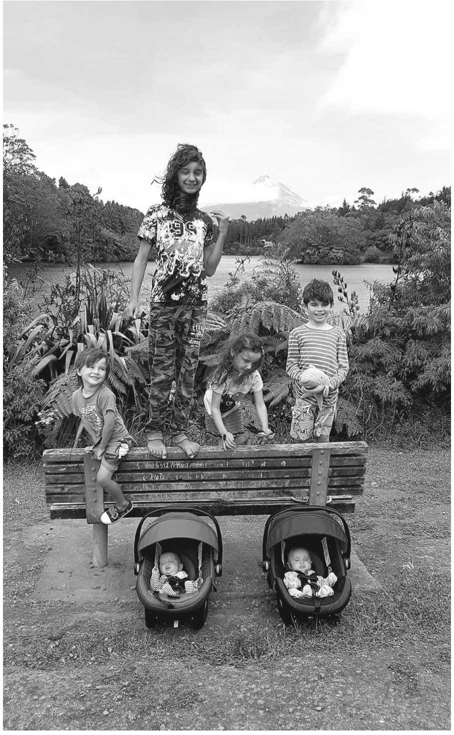
With everything that could have happened, might have happened or was possible in our triplet pregnancy, birth and the following six weeks in hospital, Jason and I know we were incredibly blessed to have three very healthy and happy babies – who are now five!!!

Clara and Jason are parents to five year old triplets Morgan, Isabel and Madeline .They are members of Multiples Auckland North. Clara says she is one very lucky mum and wife.

Pregnancy, Birth & Beyond

Stacey Madden (Multiples Taranaki) shares the roller coaster ride of when four children turn into six with twins Aspen and Atlas.

Before our multiple journey began we were already a big family of six living in New Plymouth. Richard (31), was a service locator and I (Stacey, 33) was a stay-at-home Mum to our three sons, Deacon (12), Kobe (7) and Noah (3) and our daughter, Blake (5). Then on 11th March 2018 Richard and I found out baby number five would be joining our family. 'What's one more?' we thought…



Over the next few weeks we processed the news and once the shock had settled, we decided to organise a midwife. We asked our last midwife to take us on and she agreed. At our first meet and greet we weren't too concerned about having a scan as we knew we were about four weeks along. The midwife noticed, however, that my uterus was higher than usual for my length of gestation and gave us a referral to get booked in for a scan. We didn't have to wait long, but by the time the scan was due my morning sickness had come in hard and fast. I've had morning sickness with moments of nausea before but this was next level.

Rich took the day of the scan off work so he could come with me. We had a babysitter at home with our other children who still didn't know what was going on. As the sonographer was performing the scan he asked if we had any children at home? 'Yes, we have four,' said Rich and then he said, 'Well you're having two more.' I asked if he could say that again, slowly. He did, while Rich yahooed excitedly beside me. He understood what had just happened but I still didn't. 'Nope,' I said, 'I don't think so!' Shocked was an understatement. He gave us a picture and sent us on our way. As we left I went to the bathroom and cried. When I came out Rich asked what was wrong. I said, 'I don't know how we are going to do this,' and he replied 'We got this together, it will be like having one baby but there's two.' We went straight to a baby shop. It was so overwhelming looking around and thinking we were going to need two of everything. It was just crazy! We were not really thinking straight so we went and sat in the car for a while. Rich was excited and couldn't contain it, which was just what I needed. In this moment we decided to embrace the adventure. I felt a huge pressure to protect myself and I ran with this urge right until the end.

After a couple of weeks, because I was so crook and wasn't doing the things I was usually able to, we decided to tell our children what was going on. I was a little nervous in case they didn't understand or didn't want to accept the news. We sat them down on our bed and explained as best we could and showed them a picture of our scan. They took the news well. They were very excited and told their entire school. News got out superfast as Rich couldn't keep it in either. He wanted to tell everyone because it was exciting news. As far as we knew there was no history of twins on either side of our families.

Over the next three to four months I was plagued with hyperemesis gravidarum (severe nausea and vomiting during pregnancy). Although I was prescribed medication I just wasn't able to keep it down. My new normal was taking spew bowls and towels with me to school and kindy drop offs, parks and doctor's appointments. Click and collect groceries was a huge help to me as I lost weight and was quite weak. Rich had to do all the cooking from about six weeks right up till 30 weeks. The vomiting slowed down but the nausea lasted every day all day until the birth. I was so crook I rarely went out. Then, at 28 weeks, gestational diabetes crept up on me. This meant a lot of pressure to actually eat and try to keep the food down. It was a slow process and I took it in my stride.

During these months I experienced a whole range of emotions including fear, excitement and anxiety. I developed a huge anxiety about even leaving the house. It was hard at times and a lot of these feeling came from hearing so many things from friends and strangers. I suppose in a way this created a kind of disconnect from my pregnancy because we had chosen not to find out the genders of the babies. We didn't know if they were identical or fraternal either. In some ways this was easier – to almost forget about being pregnant and carry on with everyday things. We wanted a complete surprise at the end.

People had lots of opinions about this. Even strangers really wanted to know about it all. I guess some people had been through it all so we had a lot of 'rather you than me, poor you guys, you'll need so much help, your husband will need a month off, it's going to be really hard.' This made me feel so sad and sorry to think people actually felt like that as we never did. We felt extremely lucky to be chosen to have twins. Although by nature Rich and I are really laid back people it definitely made me panic and feel like we weren't going to have enough help at home. There was also a fear of losing a baby or even both. I read so much information online and probably watched too many google videos. This fear never went away but I learnt to live with it by taking it one day at a time in the early stages then week by week. We had decided from day one we would go forward with our pregnancy in a positive way and the power of positive thinking continued right up to the birth and beyond.

For a long time, I had trouble trying to find two babies inside me. To me it just felt like one baby – it wasn't any different. At about 32 weeks I started to feel that there were two in there. They were in transverse position for the entire pregnancy and it was quite difficult to keep kick counts as they didn't move around much at all. It was like they were stuck but I had been up to the hospital for a couple of CTGs from about 32 to 34 weeks and everything was going well.

We were scheduled to have a caesarean section at 36 weeks and one day. One morning at nearly 36 weeks I woke up and just felt a little different. I took my children to school and kindy and then called my midwife. I mentioned it had been a few hours since I'd felt much movement. Being so close to my C-section with twins she didn't want to take any chances so up to the hospital I went for another CTG just in case something wasn't right. I thought ok, I'll go up there first and do my groceries and collect wood afterwards, so off I went.

I got on the CTG machine at around 10am. Rich came up at about 12pm and we thought afterwards we might go get lunch. We had some blood and urine tests done and my reflexes were tested and were a bit off. I had started to swell a little so they thought maybe I was heading towards preeclampsia, but my urine came back clear. At about 1pm I started having contractions. I downloaded an app on my phone and was able to track them. It was clear we weren't going anywhere for lunch; I wasn't leaving the hospital I was staying the night. Rich took the rest of the day off work, got the kids after school and was preparing to head back in to have one last dinner with the kids as a family of six.

Meanwhile my contractions weren't stopping. I'd never been in labour before. My previous births had all been caesarean sections, so this was new to me. At around 6pm there were whispers of taking the babies out as soon as possible, then the midwife on the ward came in and said, 'Where's your husband, they're taking your babies out now!' I was shocked. She gave me a gown to change into and I called my husband and said, 'Where are you?' he said they were just in the car park about to come in for dinner. I said 'Change of plans, go to my mums and drop the kids off and come back as soon as possible, they're taking the babies out now.' He was so shocked. I quickly called my mum to let her know Rich was on his way.

In the meantime a friend had randomly popped up to visit. She walked in to all this chaos. I filled her in and we had this emotional moment. I just cried – I think we both did – and I asked if she could let my father know as I didn't have any time to make more calls. We hugged and she left. Rich just made it back in time and it was all go.

I remember that moment being wheeled down the corridor. All these friends, family and colleagues were calling Rich. They had no idea what was going on. He had to politely explain 'having babies, call you back.' Before I knew it I was on the operating table. This was an incredible feeling awaiting the birth of the first baby Twin A. Our baby boy was first out at 9:20pm, completely perfect. Twin B, our baby girl, was born at 9:22pm. She needed a little help to breathe but was perfect too.

Once they were checked over and given the all clear they went straight to their Dad and our midwife as I had a wee complication. My bladder was accidently cut or 'nicked' as they say. A catheter was inserted (and stayed in for 10 days) and I was given antibiotics. About two hours later I was finally able to hold my babies for the first time. It was the most sublime feeling ever in the world. Whatever worries or fears and anxieties I had disappeared right at that moment.

It was after midnight when we were eventually taken to our room. We got to have about 20 minutes with the babies before they were taken to NICU.

Our babies weren't weighed until the next morning, coming in at five pounds each. They were so tiny to us but so healthy. My husband left that night to get some sleep as did I in my room. The next morning I got up, showered and found my way to NICU. Seeing them in the incubators was quite overwhelming. They looked helpless. It was amazing to know that they were ours. I had never had NICU babies before, so this was all new to me but they were

doing great. The next couple of days were filled with learning how to do their feeds.

Once the tubes came out, we could bottle feed them. On Saturday we asked, as they were only feeders and growers, could we go home on Monday? The kids had school and Rich had to pop into work on Wednesday. The babies got a check over and we had to do 24 hours of feeding and changing on our own. Rich went home and I did the feeding and changing by myself. It was a surreal feeling. Rich came in Monday morning after the kids were at school and we were given the all clear to go home. We left at 2:30pm which was great timing for school pick-up on the way home.

Once we were home things were a lot easier. Although we didn't have home help it was nice to figure things out on our own. We were figuring out our new normal as a family with six kids. Rich went back to work full time the following Monday and the kids were back at school and somehow the babies just fitted right in. We didn't bother with much of a routine the first month. Now I am up at 5am every morning. We have coffee together, Rich goes on his morning run and I get stuck into housework as this is the only time I get to do these things. We do homework with the kids every morning, as after school things are full on until bed.

Family time is really important to us. Every weekend, usually on Sundays, we have a family day. This is usually a nature-inspired walk dinosaur hunting and exploring down the coast. We only started doing this about two years ago. It's made us closer as a family unit. Our smaller two kids are about to start sport so winter this year will be full on. Having the twins hasn't stopped us doing anything. If anything it's made us live more and be more active as a family. We took this on with such optimism it has made our love and marriage so much stronger. We both grew during this part of our lives. I have such adoration for Rich. Watching him grow and learn has been incredible and we would do this again in a heartbeat.

We are excited about what the future holds for us as a family. We just wish for our children to be happy and healthy and enjoy being kids and to be there for each other always. All we can do is guide them in the right direction.

Stacey and Richard live in New Plymouth and are parents to Deacon (12), Kobe (7) and Noah (3), Blake (5) and twins Atlas and Aspen (6 months). Stacey is a super star stay at home mum and Richard works as a utility engineer.

The Purple Butterfly initiative

The Neonatal Trust & Multiples NZ are working together to establish the Purple Butterfly Initiative in New Zealand.

New Zealand is a world leader in neonatal care with babies born at 24 weeks gestation (16 weeks early) able to be saved and go on to have normal and fulfilling lives. However, in a very small number of cases, not all babies make it. For example, over 1,000 babies are cared for in the Wellington Neonatal Intensive Care Unit (NICU) each year. Of these, less than 20 pass away – an incredible statistic given the fact they are caring for the earliest and sickest babies.

It is more likely for a multiple pregnancy to result in premature birth. Carolyn Lister, Immediate Past President of Multiples NZ says "40% of twins are born early, as well as 90% of triplets. The gestational period is shorter than single births and as such they are subject to further risk".

The
Purple Butterfly
initiative

Millie, a neonatal mum in the United Kingdom, had a great idea for reducing the stress and anxiety involved in certain neonatal journeys. Millie sadly lost Skye, one of her twins. While still in the NICU there were a few emotional moments that Millie endured that she believed could have been avoided with the use of a consistent sticker. The Purple Butterfly initiative was born.

Read the full article about Millie here:
https://www.babble.com/parenting/butterfly-stickers-milli-smith/

In Millie's words:

We set up The Skye High Foundation in memory of our daughter. We have since created the Purple Butterfly sticker, which is meant to be placed on an incubator to let people know when a baby in a multiple pregnancy has passed away.

"None of the other parents knew what had happened or anything about Skye," Smith explains. "The comment was completely innocent and more out of humour. A parent of twins turned to me, when their babies were crying, and said, "You are so lucky you just have one". They weren't to know that I did at one point have two. But the comment nearly broke me. I ran out [of] the room in tears and they had no idea why. I didn't have the heart to tell them what had happened. A simple sticker would have avoided that entire situation."

Smith chose the purple butterfly as her symbol for a multiples loss because she saw the butterfly as a symbol of children who have "flown away" from this earth and purple was a colour that could be representative of both boy and girl babies.

Jessica Watson, a mother of two surviving triplets who blogs at Four Plus An Angel, explains that the butterfly stickers would have been very helpful for her. "When your baby is in the NICU so many medical professionals come and go and it's a heart-wrenching process to have to explain that they lost a sibling over and over again," she says.

Neil O'Styke, Executive Director of The Neonatal Trust, said that "the Purple Butterfly initiative is great and will assist families struggling with the process of mourning the loss of one child while also looking after and bonding with another".

PREGNANCY, BABY AND INFANT LOSS SUPPORT
Sands

In New Zealand, Baby Loss Awareness Week runs from 9th to 15th October each year. This is organised by SANDS, and includes the Global Wave of Light on the 15th of October. It provides an opportunity for parents, families and whanau around New Zealand to come together and remember the lives of their babies who have died. We acknowledge the lives and deaths of all babies, no matter what their gestation, length of life or how they died. It is also a chance to highlight the work done by Sands around the country. The global 'Wave of Light' is held in memory of all the babies who lit up our lives for such a short time. Sands New Zealand is a network of parent-run, non-profit groups supporting families who have experienced the death of a baby. SANDS have over 25 groups/contact people around the country. They promote awareness, understanding and support for those dealing with the death of a baby in pregnancy, birth or as a newborn, and due to medical termination or other forms of reproductive loss.

http://www.sands.org.nz

Introducing the Neonatal Trust

Neil O'Styke (Executive Director, The Neonatal Trust New Zealand) introduces the wonderful work the trust does for our premature babies in New Zealand.

Every year approximately 10% of all babies are born premature (before 37 weeks gestation) in New Zealand. That's one premature baby born every 90 minutes. There are also full-term babies whose condition or illness requires admission to a Neonatal Intensive Care Unit (NICU) or Special Care Baby Unit (SCBU) after they are born.

In all, over 5,000 babies have a difficult start to life in New Zealand each year. The average pregnancy length for twins is 37 weeks, with 34 weeks for triplets and 32 for quads—this means a lot of twins (40%) are premature, most triplets (90%) will be preterm, and all higher-order multiple gestations. So, most parents expecting multiples will quickly learn that one of the main risks they face is having premature babies. The good news is that the medical care preterm babies receive is constantly evolving and improving, which is resulting in high survival rates for these babies. Recent research indicates that there is very little difference in the survival rates of premature multiples, compared to singletons of the same gestational age.

Survival to discharge for premature babies is about 79% at 24 to 26 weeks, and 98% at 30 to 32 weeks—and these parameters are being constantly moved back, with the survival of extremely premature babies.

The Neonatal Trust works to provide and coordinate, support to families of neonatal (premature or sick full-term) babies as they make their journeys through neonatal intensive care, the transition home, and onwards.

We do not receive any Government funding and are entirely reliant on the generosity of individuals, companies and organisations in the form of donations, value-in-kind donations, grants, sponsorship and fundraising events to supplement operating costs and fund our services and initiatives.

How The Neonatal Trust helps

The Neonatal Trust exists to support families going through the stress and anxiety of a neonatal journey, and to support the enhanced care of their precious premature and/or sick babies.

Operating across New Zealand with a model light on paid staff but heavy on volunteer commitment and resources, the examples below fit with their objectives to:

1. Support neonatal families through the stress and anxiety of their journey
2. Fund neonatal research to increase understanding and enhance outcomes
3. Support the neonatal units and their staff so the babies receive the best care possible

Support examples:

Supporting research into enhanced care and understanding

We support research so that the care delivered is enhanced and the long term consequences of prematurity are better understood. This creates better outcomes for thousands of future neonatal babies.

For example, we support the research of Dr Max Berry and her team who are leading some wonderful research into the early care of neonatal babies and how these can impact their life beyond the neonatal unit. Specifically, this work includes:

- Looking into how blood transfusions are given and the potential to enhance their effectiveness
- The 'NIMO for Anaemic Infants ('NIMO-AI')' observational studies that are looking into how treating anaemia (a very common problem for preterm infants) with blood transfusions changes the oxygen levels in a baby's brain and other organs
- Researching the effect of nutrition in the first month of life and the long term effects
- The 'Unicorn babies' study to help understand the incidence of premature babies having some sort of brain injury. The impact of preterm associated brain injury varies enormously between children but we know that it increases their risk of going on to develop complications such as cerebral palsy or learning difficulties.

You can read more, and watch videos, on the great work of Dr Max Berry and her team at:

www.neonataltrust.org.nz/research


Supporting neonatal research

Support resources

A neonatal journey is often a time of great stress and anxiety. To help, we look to ensure that parents are enabled with information (in language they understand, free of clinical terms) to empower them and help them to be involved in the care of their baby/babies. This assists with bonding and the reduction of the risk of postnatal depression. Research proves that the assimilation of information is impacted when under stress. For the best results, information needs to be consciously developed with a particular tone and free of clinical terms.

Working with parents who have been on a neonatal journey, we're creating more resources to help reduce the stress of neonatal families through enhancing their understanding and empowering involvement in the care of their precious babies. Examples of the resources available include:

- **Reading to your baby—** created to encourage a practise that helps both parents and the baby
- **The Think REF –** Health and Wellbeing resource, to prompt parents to look after themselves
- **Kangaroo Cuddles—**which is great for both bonding and development

Purchasing furniture and equipment to enhance the experience of families

A great example of this is providing recliner chairs for parents to use - for both 'Kangaroo Cuddles' and also general comfort in the long hours next to an incubator or cot.


La Z Boys for parents to use for Kangaroo cuddles and general comfort.

Going home

While your baby is in a neonatal unit all you can think about is getting them home.

But for some parents, in particular those with a baby requiring ongoing special care, going home can be quite a stressful time. No longer do you have the immediate support of nursing staff and doctors. Your baby may be vulnerable to illness or have special requirements like medications or oxygen that you need to provide. Here are some ideas to help you with the transition:

- Accept that it might take time to feel 'under control' and to feel comfortable looking after your baby at home
- Try to let housework and other pressures go while you are getting used to caring for your baby
- Communicate your baby's needs to friends and family, this may include no visiting with colds
- Make sure everyone washes their hands regularly – this helps to stop the spread of infections
- Don't apologise for needing these things, your baby is precious and your goal is to care for him or her in the best possible way
- Your home is clean - you don't need to clean every surface and corner of your home to provide a healthy environment for your baby
- Take getting out and about in small steps, keep your baby in a pram or covered with a sun or rain cover if you want to avoid contact with people in the wider community
- Look after yourself. You might not feel the full effects of the experience you have been through until some weeks or even months after you get home
- Most important of all, enjoy your baby and celebrate that your baby is home!

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Premature Baby: Terminology in NICU

Becoming familiar with premature baby terminology that you may encounter.

It is very overwhelming for parents who find themselves in the Neonatal Intensive Care Unit (NICU) with their premature babies. Apart from learning to deal with the emotional aspect, they also have to learn very quickly all the terms used by the nursing staff in the NICU.

Samantha Lee Bingham having kangaroo cuddles with her precious premmies., Novem and Ryder born at 35 weeks.

Anemia - Too few red blood cells. Anemic babies may need blood transfusions.

Apnoea -A short period of time when the baby does not take a breath.

Aspiration -The drawing in of foreign matter or other material in the upper respiratory tract into the lungs. Aspiration also refers to a medical procedure in which fluids are sucked out of the lungs, nose, or mouth using a suction device.

Bagging - Helping the baby to breathe by connecting a special rubber bag either to a mask over the mouth or to a tube in the trachea and lung.

Bilirubin - A chemical created by the breakdown of the red blood cells. A large amount of this bilirubin in the body causes yellow coloring of the skin and eyes (jaundice). Nearly all babies have some jaundice, including healthy full-term babies.

Bilirubin lights (bili lights) - Fluorescent lights that reduce jaundice; help break down the bilirubin in the skin. Baby is undressed to expose as much skin surface as possible; the baby's eyes are covered with patches or a mask. Also called phototherapy.

Blood gas - A test using a small amount of blood to measure levels of oxygen and carbon dioxide in the blood.

Bradycardia - A slower than normal heartbeat; often occurs with apnoea.

Catheter - A tube which puts fluids into the body or drains fluids out.

Chest tube - A tube inserted through the chest wall; used to suction air and/or fluids from the chest.

Continuous Positive Airway Pressure (CPAP) - A continuous amount of air, sometimes with added oxygen, is delivered through tubes in the baby's nose to keep the airways of the lungs open as baby breathes.

Culture - Taking a sample of blood or body fluids to test for germs which may cause an infection.

Cyanosis - A bluish colouring of the skin and lips caused by a low level of oxygen in the blood.

Edema - The collection of extra fluid in body tissues, causing swelling or puffiness of skin.

Electrode - A sensor which sends heartbeat and breathing information to the monitor. They can be placed on the chest, arms, or legs. Also called leads.

Electrolytes - Sodium, potassium, and chloride levels in the blood. Correct levels of these chemicals must be present so that the body organs can function properly.

Endotracheal tube (ET tube) - A plastic tube inserted through the nose or mouth into the trachea (windpipe) to help breathing; usually connected to a breathing machine (ventilator).

Extubation - The process of removing an endotracheal tube.

Gavage feeding - Feeding a baby through a gastric tube inserted into the stomach.

Gestational age - The length of time from conception to birth (how long the baby stays in the womb). Full-term gestation is between 38 and 42 weeks.

High frequency ventilation (HFV) - A type of ventilator which gives very small breathes at a very fast rate; the baby's chest will actually vibrate. HFV works differently from "conventional" ventilation to treat specific breathing or lung problems.

Hyaline membrane disease (HMD) - A breathing problem that causes the tiny air sacs in the lungs to collapse; usually due to lung immaturity and lack of a natural lung chemical (surfactant). Also called respiratory distress syndrome (RDS).

Hydrocephalus - Excess spinal fluid causing enlargement of the ventricles in the brain.

Hypoxia - A low level of oxygen in the body tissue. If very low, tissue damage can occur.

Incubator / isolette / humidicrib - A small, heated bed enclosed in clear plastic. Keeps the baby warm, while allowing caregivers see the baby.

Intraventricular haemorrhage (IVH) - Bleeding within the brain's ventricles (spaces in the brain which contain spinal fluid). Also called intracranial haemorrhage (bleeding in or around the brain).

Intravenous line (IV) - A hollow needle or plastic tube inserted into a vein; used to give fluids, blood, and or medications.

Intubation - Placing a tube through the nose or mouth into the trachea (windpipe).

Jaundice - The yellow discoloration of a baby's skin and eyes caused by too much bilirubin in the blood.

Kangaroo Care - Skin-to-skin contact where baby is positioned on mum or dad's bare chest to promote bonding and healing.

Meconium - The first bowel movement/stool passed by a newborn, usually dark green and sticky.

Meconium aspiration syndrome - A type of pneumonia caused by stool being passed by the baby while still in the womb. The stool can be inhaled into the baby's lungs and can partially or completely block the baby's air passage. This makes it difficult for the baby to breathe.

Nasal Canula - A small plastic tube placed under the nose to provide oxygen.

Nasogastric tube (NG tube) - A tube inserted through the nose or mouth (orogastric or OG) and into the stomach. The tube delivers nutrients and medications, and removes undigested food and fluids from the stomach.

Necrotizing Enterocolitis (NEC) - A bowel condition caused by lack of blood supply. A section of the bowel may become severely inflamed or infected.

NICU - Neonatal Intensive Care Unit

Neonate - A newborn infant, less than 30 days old.

Neonatologist - A physician who specializes in the care of critically ill newborn infants.

Oscillator - type of high frequency ventilator.

Oxygen saturation - The level of oxygen in a baby's blood. Oxygen level is measured by a small probe on the baby's hand or foot, also by blood samples. This level tells at-a-glance how well oxygen is being carried through the body.

Patent Ductus Arteriosus (PDA) - A small vessel (ductus) between the major arteries of the heart and the lungs. Before birth, this vessel is open and allows blood to bypass the lungs (not yet in use). When this opening fails to close after birth, it can cause problems with oxygen rich blood getting to the body.

Peripherally Inserted Central Catheter (PICC) - A flexible, thin IV tube put into a vein in the arm, foot, or leg and then routed up into, or near, the heart.

Persistent Pulmonary Hypertension of Newborns (PPHN) - A serious condition that causes the baby to return to its prebirth route of blood circulation. The baby's blood is only partially oxygenated through the lungs. This results in very low oxygen levels, plus a higher blood pressure in the arteries of the lungs. Treatment includes, oxygen, ventilator therapy, medications and/or Extracorporeal membrane oxygenation (ECMO) . Also called persistent fetal circulation (PFC).

Phototherapy - See bilirubin lights.

Pneumothorax (pneumo) - Air escapes from the lung into the chest cavity, creating a pocket of air in the wrong place. This pocket of air then presses on the lungs or heart. A chest tube or catheter can be inserted to remove the pocket of air, which lets the lungs re-expand.

Pulse oximeter - An electronic monitor that detects oxygen saturation in the blood using a light sensor probe.

Respiratory Distress Syndrome (RDS) - See hyaline membrane disease (HMD).

Retinopathy Of Prematurity (ROP) - An eye disorder, involving the retina that can occur in premature infants.

Room air - The ordinary air we breathe which contains 21% oxygen. Oxygen therapy can deliver from 22 – 100% oxygen.

Sepsis - An infection caused by bacteria.

Spinal tap - The removal of a small amount of fluid from the spinal canal. The fluid is then analyzed for infection, bleeding, and other disorders.

Surfactant - A substance in the lungs that helps keep the tiny air sacs from collapsing and sticking together. A lack of this substance contributes to Respiratory Distress Syndrome (RDS).

Transient Tachypnea of the Newborn (TTN) - A condition when a baby breathes with quick, shallow breathes (usually over 80 breaths per minute). It is often caused by fluid in the lungs and will improve as this fluid is absorbed. Some babies need oxygen as this resolves. TTN is often associated with cesarean delivery.

Umbilical Catheter, Arterial or Venous (UAC, UVC) - A tube inserted through the belly button (umbilical cord) into the arterial or venous blood vessels. Either tube is used to give the baby fluids and to draw blood samples. The UAC is used to monitor the baby's blood pressure. If the baby requires oxygen therapy, the UAC will be used to draw blood gases and blood samples.

Ventilator - A machine which fills the baby's lungs with air and helps the baby breathe. Also called a respirator.

Ventricles of the brain - Spaces in the brain that contain spinal fluid to bathe and cushion the brain .

This information was previously published by The National Premmie Foundation, Australia.

http://prembaby.org.au/

Dayna and Mitchell

Cathy Johnston (Multiples Hutt-Valley) shares her story of the first few days after her twins arrived at 34 weeks.

It was the morning after my twins had arrived, and I was in a lot of pain from my caesarean section. I quickly realised that I was now a 'twin mum'. One of those revered titles I had secretly coveted for a long time. I gazed in wonder at the photographs which Matt had taken of our beautiful babies. They were in the neonatal unit where they would remain for a few weeks.

'Dainty Dayna' as we affectionately called her, looked bright eyed and alert in her first photos. Blue eyes, peering at the world around her. Lying underneath the warm glow of the UV (ultraviolet) phototherapy machine, her jaundiced skin resembled a recent vacation in the tropics. Despite her petite stature of 1500g/three pounds (the size of three blocks of New Zealand butter), her determined personality shone through.

I was so proud of Mitchell's photos. I was instantly drawn to his light blue knitted booties and matching blanket. Both items were draped across his incubator. (Volunteers had knitted his blanket, along with a pink one for Dayna). Mitchell weighed 2500g/five pounds, which was an excellent weight for a thirty-four-week old baby. We gave Mitchell the nickname of 'Mighty Mitch' simply because we saw him as an overcomer. He possessed an inner strength that only we would truly know and understand.

Mitchell's inner strength was the fighting ingredient for his first few days. His breathing was laboured and 'grunty' , requiring assistance in the form of CPAP (Continuous Positive Air Pressure). Initially, I was shocked to see him like this, until I realised there were plenty of other babies requiring the same treatment. Surely there was nothing to be concerned about.

Each day my babies were in the neonatal unit, I clung to every word of hope and advice that the doctors said.

Here are two Plunket book entries from Mitchell's first days:

26.06.07
Born via elective caesarean for poor growth of Dayna. Admitted to NICU for respiratory distress. Placed on WCPAP (Wellington Continuous Positive Airway Pressure) for grunting and subcostal indrawing. IV fluids started for hydration. Nursed in incubator for observation. Due to your breathing becoming faster, the respiratory support is changed to midline CPAP. Chest x-ray done. No abnormalities noted. IV antibiotics commenced.

27.06.07 Day 1:
Weight 2760g. Feeds started today via oral gastric tube (tube into stomach). Continues on midline CPAP in room air temperature.

Late that evening, I felt well enough to get out of bed. Matt pushed me in a wheelchair to the neonatal ward. In my hands were syringes of freshly expressed breast milk (colostrum). Our babies hadn't yet developed their sucking reflex (for breastfeeding), so I learned to feed them via a nasogastric tube.

Mitchell wasn't stable enough for me to hold him, so I nursed Dayna. Holding her tiny body against mine in a kangaroo hold brought tears of joy to my eyes. (A kangaroo hold is a method of holding a naked newborn baby which involves skin to skin contact). As I held her, she looked around, clutching me with her tiny hands. It was amazing. Through the bond of touch, I felt Dayna getting stronger by the day. Initially she felt like a tiny fragile doll wrapped in cotton wool. I wanted to protect her. I found it easy to fall in love with this beautiful little girl. For the first two days, I watched Dayna's jaundice gradually disappear.

For hours, she would lie happily. Her eyes were covered with a white eye patch. With her arms outstretched and legs kicking, she looked like a tiny sunbather. Right from the start, she was all about adventure. She also had an alert keenness to explore her surroundings.

Meanwhile her brother Mitchell still required CPAP. In my mind's eye, I imagined holding Mitchell for the first time. While holding Dayna, I would longingly gaze at Mitchell. I affectionately called Mitchell 'my little blue snuffly rabbit' because he was burrowed under tubes, wires and monitors. He looked as if he would snuggle up to anyone and sleep all day, cocooned in love. My heart ached for the want of holding him for the first time. If only I could hold both my twins simultaneously. Why did this waiting have to be so hard? Why was Mitchell so ill? It was hard seeing Mitchell struggling to breathe, trying to keep my expressed milk down without vomiting, and being pricked by countless needles on the sole of his foot, to draw blood. I felt helpless. All I could do was wait, and cry. And pray.

As yesterday melted into the shadows of evening twilight, nightfall brought welcome sleep. I woke at dawn, groggily awoken by a midwife informing me that my babies were hungry. I padded down the hallway, in a tired haze of exhaustion. The doors to the neonatal unit swung open as I identified myself to the security camera. I soon forgot my tiredness, as I was informed by the night staff that Mitchell was on the mend. This was welcome news! An neonatal nurse lifted Mitchell into my eager arms. This was our first opportunity to bond. After five long days, the moment had arrived. Big crocodile tears cascaded down my cheeks. They were tears of longing, joy, and relief; not sadness. I was overjoyed at finally being able to hold my precious son. My "snuffly blue rabbit" was safely tucked in my arms at last. Mitchell was perfect. I held Mitchell for a very long time. I did not care about the ache in my arms from holding him. It was almost as if time had slowed down just for myself and my precious baby boy. I knew without a doubt, that Mitchell had endured much pain and suffering over the last few days.

Plunket book entries showed that he was a strong boy. On day two, the Plunket book entry read:

28.06.07 Day 2: Weight 2542g. Feeds withheld today as you vomited and are having some difficulty feeding."

30.06.07 Day 4: Still nil by mouth. Have peripheral intravenous line giving you dextrose (glucose)."

It was a rollercoaster ride of emotions, especially in the first days following our twins' birth. Through the uncertainty of it all, I learned to count my blessings. I was thankful that my babies had arrived safely, and that they were in the capable hands of the NICU staff. A well known gospel song, "Count your blessings one by one, and you will be surprised at what the Lord has done", ran through my mind. I held on to anything to put myself in a positive frame of mind.

Five days after Mitchell and Dayna's birth, they were transferred by ambulance to Hutt hospital SCBU (Special Care Baby Unit). They were transported in a double incubator; Mitchell at the top end, Dayna at the tail end.

It didn't take long to get used to the routine at the SCBU. Our twins were fed on a four hourly feeding schedule (still on nasogastric tubes) until I was able to breastfeed them at three weeks of age. (Babies typically develop the sucking reflex at thirty-seven weeks gestational age). All they had to do now was to grow and gain sufficient weight to come home. "Dainty Dayna" (as we affectionately called her) was still very small and needed to reach her goal weight of two-and-a-half kilograms (five pounds) before she was on the home straight. Mitchell was already well enough to go home, but because they were twins, it made sense for them both to be discharged from hospital at the same time.

Finally that day arrived. On July 28th 2007, we brought our babies home. The 'firsts' such as artfully fitting them into the hospital elevator in their double pram; the challenge of buckling two babies into their car seats, and getting them home in one piece! Once home, Mitchell and Dayna slept peacefully in their cots, until they woke for a feed. There was just enough time to relax and take in the wonder of having them both home at last.

For the first three months, we lived in our bubble of contentment. Life with twins was amazing as expected, albeit broken sleep, numerous nappy changes, and round the clock feeds. The general public were like paparazzi to us, wherever we went. We felt really special. Often we heard them say typical comments like, "Are they all yours? Better you than me! Are they identical? I don't know how you do it!" As always, I grinned and thanked them for their comments, hiding the niggles which were starting to fill my thoughts.

Outwardly it was easy to put on a smile when we were out with our children. People cooed over the babies; inspecting them like royalty. But what people didn't see, was the worry behind our eyes. I worried constantly about Mitchell. He wasn't reaching the same milestones as his twin sister. No eye contact. He didn't react to loud noises. Inconsolable for hours on end; it wasn't colic. Frequent arching of his back. His neck and torso were floppy and he still wasn't sitting upright at nine months; nor was he crawling. He seemed distant most of the time, and uninterested in his surroundings. It pained us greatly, to see that he wasn't interacting with his twin sister Dayna. My concerns were real by now. I willed myself to believe my friends when they said things like, "Don't worry, he will catch up. Your babies were premature; that's the reason he's taking his time". Others said, "Boys take longer than girls to reach their milestones. He will grow out of it. It's just a phase".

Eventually my concerns were somewhat alleviated at our twins' four month check up with the paediatrician. Dayna was discharged from the paediatric department, as she was developing normally. We were informed that Mitchell had 'low muscle tone'. "I'd like to see Mitchell back in three months' time", she said. "If he hasn't improved, I will refer him to a specialist".

Dayna, 3 pounds

Mitchell, 5 pounds

Of course, I reasoned with myself that Mitchell would catch up in three months. Really, there was nothing wrong with him. That's what I wanted to believe. He looked 'normal' (just like any other kid) to myself and to everyone else. Surely everything was going to be okay. With his blue eyes and blond hair, Mitchell looked perfect to me. How could there possibly be anything wrong? Once again, I mentally shelved my worries into the back of my mind. It was easy, I reasoned to myself, to blend in at the kids' playgroups. I made up credible explanations as to why he appeared floppy. "He's tired", I would say, as if to shrug off any concern anyone else had. Eventually the truth came out. Time doesn't stop for anyone.

Weeks turned into months. Dayna reached one milestone to the next; from sitting to crawling, then walking. Meanwhile Mitchell remained lying down, seemingly oblivious to what his sister was achieving. By this time, we had received a visit from the VNT (Visiting Neurodevelopmental Therapist). She visited Mitchell in our home, quietly observing how he interacted with his siblings, toys, and the environment around him. Eventually, she conducted a developmental test on him, called, 'Bayleys'. This is a standard series of infant developmental tests. It takes approximately forty-five minutes to an hour to do the testing. It consists of several developmental play tasks. The scores are used for screening, helping to identify the need for further intervention, and identifying those at risk for developmental problems. Surely Mitchell was just lagging behind a little. That's all there is to it; see, nothing to worry about. Consoling myself always seemed to bring temporary relief.

A few weeks later, the test results came back. It was not the news I was hoping for. Then those dreaded words which no mother in the world wants to hear… "I am really sorry to say that Mitchell has low muscle tone. He has an intellectual disability as well." I was devastated. Receiving the news over a telephone conversation was one of the worst pieces of news. As I put down the telephone receiver, my world came crashing down around me. All the inner worries, concerns, and stress of 'not knowing why', needing answers…it just seemed so futile, like chasing after the wind. Hope seemed an intangible thing to grasp. It was like clutching at straws, while trying to climb out of a bad situation. My dreams for Mitchell attending university, learning to drive a car, going flatting, getting married, and having children…. The very things which most people take for granted. Would Mitchell be able to accomplish any of these things when he was older? And what about the 'here and now'? What was expected of him? It was hard to think about the future, and even harder to imagine what Mitchell might be like. A million questions ran through my head. Did I cause Mitchell's disability while he was in the womb? Was it something I ate? Did I not eat the right things? Naturally I blamed myself. How could this be?

Where did this come from? The VNT was understanding and sympathetic. She consoled me, saying she wished she could come over to our house to comfort us. I put the phone down, solemnly walked into our sunroom, and cried a river of tears. I seldom cried like this. The grief was overwhelming, like someone had died; raw and painful. It didn't make sense. Why would I be blessed with the miracle of twins, only to have one of them facing a lifelong disability? I really felt it was going to be a long road ahead. It would take its toll on us as a family. The emotional, physical, and financial toll was a major uphaul for all of us. Somehow I knew we would all pull together and get through this. It was a major bump in the road, yet I knew we would get through it somehow; most probably in our own strength. The best thing we could do at this point was to take it one day at a time.

And so began our journey of mass medical appointments, hydrotherapy (swimming), ENT (ear, Nose, and Throat) for regular eye and hearing check ups, neurologist appointments, and of course, finding babysitters. We were fortunate to receive 'Carer Support' forms from the MOH (Ministry of Health). This enabled us a certain number of days to hire a babysitter for Mitchell's preschool age siblings, so I could attend the appointments and therapies which Mitchell had. There were so many of them! We discovered having a good system in place worked best for us. We found a nanny who helped us for four hours per week. From 8.30am-12.30pm. At that stage in our busy lives, we had three children under the age of two. Our nanny would take the girls to playgroup, while I took Mitchell to an early intervention centre. Once back home, there was just enough time to feed the children lunch, then to drop our eldest child at afternoon kindergarten. Our twins would usually have an afternoon sleep. Before too long, it was time to collect Brianna from kindergarten.

They were indeed, busy years. Through the hectic schedules for all of our children, we developed systems, routines, and became well organised. There were days where we'd get by on next to no sleep. Freezer meals, quick to prepare meals, and everything in its place meant that we didn't need to think much on days when there was no energy to think. If we got through a day with the kids fed, clothed, bathed, and into bed on time, it was a good day.

A friend once said to me, "Take it one day at a time". Nothing could be closer to the truth!

Catherine is a member of Multiples Hutt Valley, who lives in Wainuiomata, Lower Hutt with husband Matt. They are parents of: Brianna (12), Mitchell (10), Dayna (10), Connor (6), Mackenzie (a girl, age 2). Mitchell has non-verbal autism and frequent epilepsy.


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triple the care.


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HUGGIES
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Selfcare isn't Selfish – it's Necessary

Leanne Mulcahy (Guest Contributor) shares five simple ways to take care of yourself. *(This article was previously published in Multiple Matters.)*

You're overwhelmed with work, your family needs you, you've got deadlines, and there's an ever-increasing list of things to do. You fall into bed each night exhausted only to wake in the morning with your first thought being about what you've got to get done today.

Imagine for a moment, waking up feeling more refreshed, more energised and instead of a get-things-done list running through your head, you take a few brief moments to revel in the beauty of your life. If this seems like a faraway fantasy I want to invite you to grab a cuppa and join me for a moment...maybe even put your feet up.

Women are experiencing more anxiety, stress, depression, burn out and physical illness than ever before and much of it is attributed to attempting to be everything to everyone else with little attention to our own needs and desires. Many still hold the belief that putting their needs before others (yes even their children) is a selfish act. And it's not surprising given the way many of us have been conditioned to think that self-care is only appropriate when everyone else's needs have been met first. I had this same belief until I realised that living this way was self-destructive for me and my family. My relationships suffered, my child suffered and my health suffered.

One question I always ask when speaking to a group of women is "When was the last time you did something on your own purely for your own pleasure?" Their answers tend to be some version of "I don't have time" or "I used to before I had children" and then there's the realisation that they've not ever given themselves time to think about what they want. They've spent their time and energy on everyone else and forgotten about themselves. They then connect the dots between how they feel (no energy, always tired, always busy, resentful, stressed etc), and things click into place.

When you learn to refuel yourself through love and nurturing, you have the opportunity to give with a full heart and you'll be happier, more satisfied, more energised and everyone and everything that matters to you will benefit.

Fitting it in

Fitting self-care into your life takes practice, so be gentle when you're starting out. By that I mean, start out slowly, just do one thing each day and remember when life happens (because it will) you get to start over the next day. You are creating a new habit, not another chore to add to your to-do list.

A great way to create time and space for self-care is to schedule it in your calendar and make it a non-negotiable commitment to show up, just like you would for a meeting with your boss, your board, or your best friend. That means that nobody gets to encroach on that time or space (real emergencies are an exception). This sends a powerful message out into the world that you matter and are worthy.

Here are five simple ways to help you start a daily self-care practice (and they don't cost a cent!):

1. Make a list of things that bring you joy

Write as many things as you can thing of and then put your list in a place where you see it each day. It'll act as a reminder when you're stuck for ideas of what to do.

2. Breathe in life

Notice how you are breathing. Is it up in your chest or down in your belly? Place your hands on your belly and breathe in deeply (so your belly expands), hold for three seconds, then exhale all the way up from your belly and out through your nose until there's no more air left. Repeat three times. This is an instant stress reliever and can help ground you when you're feeling overwhelmed.

3. Eat well

Our body and mind thrives when it receives nourishment. Eat slowly and enjoy meal time (it can become a ritual in itself) and feed yourself and your soul with real food.

4. Move your body

Our body is designed for movement so take any opportunity you can to get up, stretch, walk, run, dance or whatever feels good for you.

5. Ask for help

The goddess of all self-care practices is being able to ask for help. Help with the kids, help at work, help around the house or help from your partner, friends or family to hold that scared time and space to allow you to practice self-care.

Know that consistent practice creates new beliefs and that you are worthy of love, of receiving from others, of happiness and of living a life you love and fills you with joy. Above all, remember that you get to do this your way and in a way that feels right for you.

Imperfectly Perfect

Kate Clarke (Guest Contributor) reviews Leanne Mulcahy's book, 'Imperfectly Perfect—21 ways to love yourself more'.

Struggling to shut your inner critic up, feel comfortable in your own skin and exhausted from the expectations of being the perfect woman?

Prepare for laugh-out-loud moments as Leanne invites you to hitch up your bra straps, gather your girlfriends and get out of your own way as you discover what really matters … living a happy life … your way.

Leanne says the reason she wrote this book was with the hope that other women discover they too have choices, regardless of the roles they play or what society attempts to define them as. Her overall messages are that we are all unique. Our imperfections, or at least what we perceive as imperfections, are the very things that make us unique and perfectly us and with that in mind, Leanne encourages us all to move gently towards embracing the whole of who we are (bumps and all).

"In order to be truly loved by anyone else, I must first learn to love myself."

Read this book. Enjoy its simple and light hearted approach peppered with insights and a simple 21 tiny steps to encourage you to love the amazing woman you are. This is a small format book, perfect for busy mums of multiples. It focuses on such areas as: organisation, sleeping, dressing, exercise, nutrition, reigning in your inner critic, and much more. There is also a 21 step checklist to keep you on track at a glance.

Though this book was written in 2015, it has a very Marie Kondo vibe. Leanne advocates that the fundamentals of dressing are getting your clothes and underwear right. She suggests clearing out the old and the things that no longer represent the you, you are now; as well as having a professional bra fitting to ensure you are in the right size and style for your shape. Seems sensible to me!

"I deserve to have a sacred space that only plays host to things I love, that fit perfectly and reflect who I am."

This book is a timely reminder to put yourself first and start working to get out of that rut (if you're stuck in one).

This book is available in paperback from herstoryradio.com for $25.00 including postage.

Website Links:

https://oneidea.co.nz/
https://herstoryradio.com/
www.standoutwomen.me
www.facebook.com/StandOutWomen/

There will be a book giveaway of 'Imperfectly Perfect' coming up on our Multiples NZ Facebook group. Keep an eye out in July for your chance to win your own copy.

Leanne works alongside business owners who want to expand their reach, connect deeply with their audience and make a profound difference in the world. Her background as a mentor, business and marketing consultant, designer, stylist, copywriter, author, and podcaster. However, it is her intuitive observations of what makes people tick that allows her to cut through the BS and see what's preventing someone from being all they are destined to be…that's what lights her up.

Guest contributor and book reviewer, **Kate Clarke,** is a holistic health coach and mama to baby Fenix and rescue pups Zeus and Tui. Kate lives in Ahipara in the Far North and runs her business through her Facebook and Instagram pages: Empowered Health Coaching with Kate Clarke.

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National Training Forum

Saturday 19th and Sunday 20th October 2019
Brentwood Hotel, Kilbirnie, Wellington

PURPOSE: To strengthen Clubs, Club Committees and Club Volunteers so that they can better support our families in their local communities.

AUDIENCE: Club Committee members and Volunteers

Saturday
Facilitated by
Kerri Tilby-Price, Exult
Gala Dinner & Volunteer Awards

Sunday
Annual General Meeting
Networking

Registration Fee: $350

Information:
http://multiples.org.nz/index.php/news-events/conference

National Training Forum Programme

Multiples NZ Executive present the 2019 programme for the second annual national training forum.

The Multiples NZ Executive is looking forward to hosting you all at this year's National Training Forum. The value of meeting face to face, sharing struggles and celebrating successes is immeasurable. We have put together a simple programme that has space for learning, for networking, for idea sharing, for healthy debate about the future, and of course, the all important FUN!

Saturday

- Registrations
- Welcome, Introductions and Overview
- Morning Tea
- Roles and Responsibilities
- Lunch and room check in
- Sustainable Volunteering – growing great volunteer teams
- The Biggest Impact
- Wrap up
- Gala Dinner & Volunteer Awards

Sunday

- Breakfast & check out
- Trends in volunteering
- Sharing our successes
- AGM
- Fundraising & Grants: Strategies that work and the fundamentals to get right
- Lunch
- Break out groups on key topics
- Afternoon tea
- Sharing
- Wrap up & farewell
- Networking & Airport Transfers

We want people to stay onsite to maximise networking. This is a great opportunity to get some 'Me Time'. Our registration fee includes airport transfers, one night's accommodation (twin share at the Brentwood Hotel), a Gala dinner ticket, all meals including a cooked breakfast and, most importantly, a professional development opportunity for you personally and your Club.

Register here:
bit.ly/30o6Bc5

Cost: $350

This includes the cost of the workshop material for both days, meals (including the Gala Dinner on Saturday and a hot breakfast on Sunday morning), and shared accommodation for the Saturday evening (you can pay extra to have your own room).

Facilitated by Kerri Tilby Price

Comments from 2018 National Training Forum Attendees:

"I couldn't get enough of Kerri Tilby Price! More of her next year she was brilliant!"

"It was what we needed - for our club at this point in time. We are all on a high and we are now pulling lots of what we talked about into our club. We have lots of new fresh ideas."

"I liked the flow of the event, it was really well executed. Really valuable information was shared. I liked how the presentations were relevant. None of it felt like a waste of time or money. Meeting people that you liaise with frequently face to face. Was awesome, the sense of unity to know everyone has the same challenges and being able to learn from other clubs."

"I learned so much information about being on a committee as a relatively new committee member it really gave me so much knowledge. This has given me the confidence to make decisions in my role and as part of the committee to benefit the club."

"I'm a new volunteer and this conference has pretty much cemented the fact that I will be a volunteer in some capacity for life. Loved it!"

The Sixth Annual Multiples NZ Volunteer Awards &

Gala Dinner

A night of Celebration

Saturday 19 October 2019, 7 pm
Brentwood Hotel, Wellington

Tickets includes buffet dinner & complimentary drink
Register at: bit.ly/2GZJKvX

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6th Annual

Volunteer Awards 2019

Help us say thank you

Nominate a volunteer who has made a difference for our families

Categories

- Volunteer of the Year
- Community Dedication
- Emerging Volunteer of the Year
- Club of the Year
- Support Person of the Year

Nominations close
1st September 2019

WHIRIA TE TANGATA weaving the people together

NOW

Executive Support Volunteers

There are many volunteers who help keep Multiples NZ ticking over, and we would like to take a moment to introduce a few of them.

ICOMBO &
Immediate Past President
Carolyn Lister

Resources
Jane Rumyantseva

Resource Review/Development
Terri Lynn Mitchell

Magazine Support
Sarah Miller

Magazine Support
Claire Nevans

Magazine Distributor
Isabel Plieger

Triplets Plus
Stacey Morunga

Executive Support
Amy Dean

Higher Needs Support
Desiree Morgan

0800 Number—Jessica Zame

0800 Number—Fiona Purchas

0800 Number—Jacqui Newell

National Volunteer Week 2019

National Volunteer Week celebrates the collective contribution of the 1.2 million volunteers who enrich Aotearoa New Zealand.

National Volunteer Week 2019 ran from June 16-22. This year's theme was "Whiria te tangata – weaving the people together". Volunteering, Mahi Aroha and social action weave people and communities together. Volunteering is a powerful movement. When we volunteer our time we send a message about what is important in our communities.

Multiples NZ Volunteer Profile:

Kirsty Saxon

- National Executive
- Editor of Multiple Matters the national magazine of Multiples NZ
- Far North Contact

In 2013 my husband and I found out we were expecting multiples. Early on in the pregnancy we joined Multiples NZ. Multiples NZ is a nationwide parent-led support network supporting families in their journey from expecting to raising multiples. Multiples NZ is a completely volunteer-run organisation that seeks to address the diverse needs of families with multiples through networking, education, support and advocacy. We work in partnership with local Multiples Clubs, community groups, health care providers and educators to support our members. During pregnancy (and beyond) I was blessed to have a lovely buddy mum who answered all of my questions, a quarterly magazine all about multiples, and a huge village of multiple mums within an online support group. At every stage of my children's' development, there was a parent who was facing the same problems or milestones, or had been there!

If you or someone you know is expecting multiples, send them to www.multiples.org.nz to see where their nearest club is. This is the best thing you can do as it is all of their support, friendship, and knowledge in one spot. Then, treasure the new parents, just as you would a parent of one new baby ... make them meals; help with their laundry, cleaning or dishes; take the babies for a walk while mum has a decent shower; and most importantly keep asking if they are doing okay. Reinforce to mum that there is strength in asking for help. They may not admit it themselves, but do your best as a family member or friend to assess the situation, is this new mama coping? How can her village wrap it's support so tightly around her she will never be let down?

This year, we marked a special milestone in our family. At the beginning of December, our twinkles Xavier & Lilian, turned five. I didn't realise what an achievement that would feel like, having made it through those first hard and fast five years. This milestone also marked my five years as a volunteer for Multiples NZ. In the early days, we were members of the Nelson/ Marlborough satellite club of Multiples Canterbury. It was there I started volunteering and was the local contact for families in the top of the south, as well as writing for the club magazine. Fast forward five years, and I went from writing for and proofreading their magazine, to now heading into my second year as Editor, and a member of the National Executive of Multiples NZ. Along the way I have also used my day job skills as a photographer and graphic designer in my role. It is genuinely a lot of volunteer work, but somehow everything always falls into place. We have the help of our awesome exec and support team, and with everyone contributing we are able to provide an amazing service to our families. Now I have my national role on the exec, the editor role, as well as being the local contact for Northland families after moving to 90 Mile Beach in 2015. It really is weaving people together. We have families who genuinely want to help parents of new and older multiples. Through sharing stories, advice and support we are helping to make raising our families easier.

He waka eke noa

We are all in this together.

Promoting your organisation

Courtney Smith (Exult) explores methods for promoting your organisation in the community. *This article was previously published online February 2019.*

Sometimes standing out is hard to do, especially when there are so many great non-profit organisations out there, championing fantastic causes. So how do you rise above and make sure your voice is heard? Here are a few ideas that might get your promotional hat thinking.

Social Media

You have heard it before, but the social media train has well and truly left the station. If you don't have a seat, you are missing out. Facebook, Instagram, Twitter, Snapchat, YouTube are all hives of activity waiting to be tapped into. If you don't know where to start or need help improving the basics of what you have. If you don't know where to start or need help improving the basics of what you have, check out Wild Apricot's 'Beginner's Guide to Social Media': www.wildapricot.com/articles/bgsm-social-media-resources

Blogs

Blogs, just like this one, allow you to promote your organisation using a conversational tone. You can strip back all the jargon and be real with your audience. Discussing what is happening day to day in your organisation provides insight and understanding. There are plenty of platforms you can use, WordPress, Wix or Weebly. Check out this article for more info: www.wpbeginner.com/beginners-guide/how-to-choose-the-best-blogging-platform/

Newsletters

Simple but effective. Whether you are old school and circulate a paper copy or regularly send out an e-newsletter, this tried and true way of promotion is best served hot off the press. Keep your audience up to date, informed and interested in what you have to say. Include relative articles, images, videos, events that all link back to you and your cause. Mailchimp is an awesome online tool for creating and sending newsletters. Have a look at: www.mailchimp.com

Events

Local and national events are a great way to self-promote. Keep an eye out for events that are relevant to your cause and investigate how you can get involved. It may be as simple as popping your flyer into goodie bags at a triathlon event or having a stand at an arts festival. Be creative, you never know who will welcome you with open arms. For events right across the country, this website is the place to go: www.theweekend.co.nz

Paid Advertising

I know we love free stuff but hear me out. If you jump on board with an organisation or company with an already established audience, you are tapping into a well of keen ears without the hard work. This doesn't have to be a recurring thing, a simple one-off ad in a local mag may get you the momentum you need. You never know where it may lead.

The thing to remember, regardless of the avenue you take, is never stop promoting. Even age-old organisations need to keep climbing the ladder, otherwise they will get knocked off. Be passionate, be vocal, be present and you just might collect a few followers along the way.

What to include in your newsletter

Newsletters are still a thing! Whether you circulate old school hard copies or are up with the play on e-newsletters, this might help spark ideas on what to include in your next issue. *This graphic was previously published in the Exult Tonic Club E-Letter #277 March 11 2019.*

19 THINGS YOU MIGHT WANT TO INCLUDE IN YOUR NEWSLETTER

Profiles of volunteers, donors and supporters.

Upcoming programmes activities and events.

Information about making a financial donation or becoming a regular giver.

Photographs of your programme in action.

Testimonials from clients, supporters and volunteers.

Stories about how Bequest Giving has made a difference to your organisation. Provide contact details for accessing more information about leaving a legacy gift.

Stories from family or supporters of your clients – what differences have they seen?

Social Media information, so that people can follow your updates in other ways.

Client stories.

Upcoming opportunities to get involved.

Information about new initiatives… what are they, why are they necessary, what do you hope to achieve and how can people support them / get involved?

Infographics illustrating important, but potentially hard-to-digest, statistics.

Reader focussed articles with useful information (especially if you are a member-based organisation).

Your Vision and Mission statement. If people are reading your newsletter for the first time, this will help them get a big picture understanding of who you are.

A wish-list of specific ways people can help, (other than making a financial donation). The list could include bite-sized volunteer roles, as well as specific items that you would like donated.

Contact details including phone, email, website and social media.

Introductions to key staff, including their previous background / experience, their role, and what they enjoy about working for your organisation.

Key milestones or celebrations within your organsisation.

Thank-yous to a few key supporters. You don't need to thank everyone in the newsletter.

Tonic magazine fresh thinking for community groups

Newsletters, whether digital or hard-copy, have evolved considerably over the last ten years. While they are still a useful communication tool for many organisations, it is important to consider who you are sending it to, and what you are hoping the newsletter will achieve. Only then can you decide what is worth including, and the best way to include it.

exult HELPING NON-PROFITS GROW

ICOMBO Corner

Carolyn Lister from ICOMBO (icombo.org) & Multiples Canterbury shares an update on the 'Global Twins and Multiples Priority Setting Partnership'.

Global Twins and Multiples Priority Setting Partnership

ICOMBO stands for the International Council of Multiple Birth Organisations. We are a voluntary organisation whose aim is to raise awareness of the unique needs of multiple-birth infants, children, adults and their families promoting their health, education and welfare.

Online: www.icombo.org.nz

Facebook: International Council of Multiple Birth Organisations

The Global Twin and Multiple Priority Setting Partnership is a collaboration between Twins and Multiple Births Association (TAMBA) UK, St George's University of London, and Twins Research Australia. It is being led by Professor Asma Khalil, St George's Medical School, University of London. This partnership seeks to bring together multiples, parents, carers, clinicians, researchers, and scientists to improve the health of multiples. The aim is to answer:

What questions would you like future research to answer for the health of multiples?

This research is critical as multiples present many strengths, but also unique challenges, for families, health care professionals, and wider society. 'Multiples', includes twins, triplets, quadruplets and, higher order multiples.

In October 2018, the Priority Setting Partnership (PSP) launched its initial survey, asking multiples, parents, carers, clinicians, and scientists to suggest questions that could be used in future research to improve the health of multiples. Over 1,000 people submitted almost 3,000 questions (nearly 70 contributors were from New Zealand, mainly parents of multiples). Due to the overwhelming response, they have split the process into two parts: the first will focus on questions requiring statistical evidence (measurable information) and the second will focus on questions requiring qualitative evidence (exploring underlying reasons, opinions, and motivations). A second survey has just been undertaken which lists the remaining 89 questions requiring statistical evidence. From this they will be prioritising the top 10 questions at a workshop on Sunday 16th June at St George's University, London (I am hoping to attend by video link – it is going to be a long night!)

The questions requiring statistical evidence have been split into five categories. To give you an idea of the diverse questions that have been proposed here are just some examples from each category:

Antenatal Care (during pregnancy)

- What are the best management strategies for gestational diabetes (GDM) in multiple pregnancies, and what different dietary measures can be taken to reduce need for medication?
- What role does the mother's gut health have in multiple pregnancies and how do we optimise this to ensure a healthy pregnancy outcome?
- What effects do fertility drugs have on multiples' overall health and wellness, growth and development or their own fertility?
- How can the health of mothers pregnant with multiples be prevented from deteriorating during late pregnancy, onwards?
- What causes an embryo to split to produce identical twins?
- Would staff with specialist training in multiple pregnancies improve outcomes in these pregnancies?
- How are higher order multiple pregnancies best managed? And what are the long term effects to the mother and the babies?
- What treatment modalities can be used to manage and reduce pre-eclampsia in multiple pregnancies?

Intrapartum and Postpartum Care

- What supports and changes to the lifestyle of the mother carrying twins/ multiples have the most benefit on the birth and ongoing health outcomes?
- What is the optimal cord clamping time for monochorionic diamniotic (MCDA) twins?
- How can we reduce multiples' stay in the neonatal intensive care unit (NICU) during the postnatal period?
- What are the risks vs benefits of epidural in labour for multiples, and does this increase the risk for intervention?
- What health risks are the mother and babies at risk of following a multiple pregnancy?
- What interventions assist a mother in recovering from a multiple birth delivery?
- Are there lingering side effects from the hormone lift and drop post-partum with twins?
- What added complications are involved in the recovery following caesarean sections (c-sections) or vaginal deliveries in mothers of multiples?

Neonatal and Paediatric Health

- What are the long term health outcomes in preterm triplets?
- What medical conditions should be regularly screened for in multiples?
- What are the health benefits and disadvantages of being a twin?
- What is the average life expectancy of multiples compared to singletons?
- What are the long term outcomes in twin pregnancies, and how is this effected by early medical interventions and antenatal events?
- Does the smaller twin always have a greater chance of health issues?
- What nutritional support is best for preterm multiples, and how can their growth be best monitored (through customised growth charts)?
- Are multiples more likely to experience developmental delays, based on gestational age?

Child Psychiatry & Development

- Do interactions between twin and multiple babies help with early brain development (including mental/ motor skills) (during the first three years of life) in the same way that infant-parent interactions do?
- What are the long-term neurological outcomes for identical twins?
- What is the likelihood of all children in a multiple birth having special needs?
- What can be done to prevent ADHD/autism in twins?
- How does birth order correlate to developmental issues in multiples?
- What can parents do from day one to reduce the chances of language delays in twins/multiples?
- What parenting techniques are most effective for improving educational outcomes (for identical and non-identical twins)?
- What percentage of multiples experience speech delays?

Parental & Family Health

- How many people are involved in the upbringing of multiples in the first 5 years of life? What is their relationship with the multiples?
- How does long term lack of sleep/ continual sleep interruption impact the physical and mental health of parents or single parents with multiples?
- What interventions prevent or minimise the impact of postpartum depression in parents/ families of multiples (including twins)?
- Does attending multiple specific antenatal classes improve parenting resilience and reduce postnatal depression for families?
- What is the timing of the occurrence of postpartum depression in birth mothers of multiples?
- What interventions provide the best post-partum and mental health support for families of multiples?
- At what age do twins benefit from one-on-one time from the main caregiver and how much is adequate?
- What are the protective and risk factors for family unity in multiple birth families?

So as you can see there are some very interesting questions (and there are a whole lot more!). It will be interesting to see what makes up the top ten. Hopefully in the next edition I will be able to give you an update on the outcomes of the June workshop.

Carolyn is mum to Rose and Finn (14) and the immediate past president of MNZ and current research director for ICOMBO. She works at Plant & Food Research and lives in Christchurch.

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Club Member Discounters

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Find your discount code using your club or member login online in the member's area at

www.multiples.org.nz

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You can now subscribe for a printed copy delivered to you at multiples.org.nz

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'HOW TO' LOGIN TO THE MULTIPLES NZ WEBSITE

1 Open up the Multiples NZ website (**www.multiples.org.nz**), then click on the 'Contact us' tab (depending on your screen resolution, these tabs may appear on one row, or two as shown here). Select 'Login/Logout' from the drop down list. Or click the Login button on the front screen of the website

2 When you click on 'Login/Logout' you will come to this screen. Here enter in:
UserName: MultiplesNZ_member
Password: (provided by a Club)
Click the Log In button (if you tick the Remember Me you won't need to enter the login details again.

User Name
MultiplesNZ_member
Password
•••••••••••••
Remember Me ☐
Log in
- Forgot your password?
- Forgot your username?

3

There will now be two new tabs on the website menu, 'Members Area' and 'Multiples NZ Magazine'. Clicking on 'Members Area' takes you to Member Discount information while clicking on 'Multiples NZ Magazine' takes you to current and back issue copies of 'Multiple Matters'.

*Affiliated Club

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*Our free phone number **0800 4 TWINS ETC** (0800 489 467) is provided by Multiples NZ to assist people to contact their local multiples club. Manned by volunteers throughout the country, this number prevents clubs needing to reissue all their flyers when committee members move on. It is <u>your</u> number for <u>your</u> clubs, so please use it as often as you like!*

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Multiples New Zealand

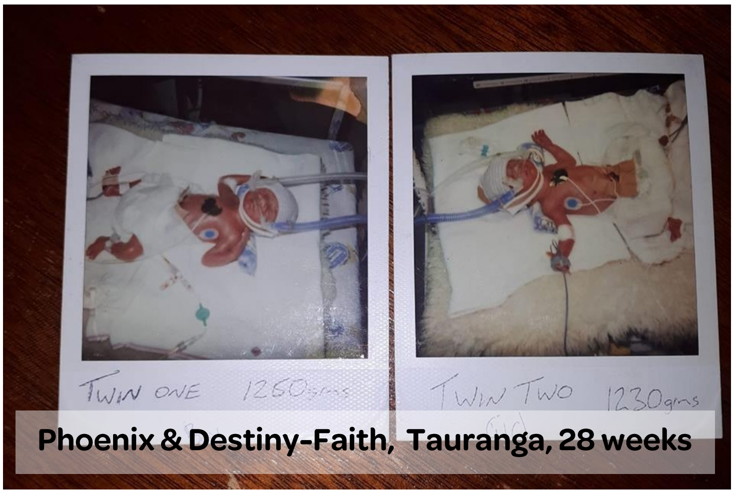
PO Box 1258, Wellington
0800 4 TWINS ETC (0800 489 467)
www.multiples.org.nz

Multiples NZ Mission Statement

To address the diverse needs of families with multiples through networking, education, support and advocacy. Working in partnership with local Multiple Clubs, community groups, health care providers and educators to ensure our values are upheld.

Our premature multiples


Brooklyn & Thomas, Tauranga, 33 weeks



Phoenix & Destiny-Faith, Tauranga, 28 weeks


Connor & Joel, Christchurch, 33 weeks


Dominik, Julian & Sebastian , Tauranga, 33 weeks

Jane & Shannon, Wellington, 29 weeks


Clara & Emily, Auckland, 35 weeks

Supporting families of multiples