



Episode 2: Premature Babies  
with Kylie Pussell, CEO and co-founder at Miracle Babies Foundation

## Premature Babies

**Tiffany:** Hi everyone. In this week's episode, we'll be discussing premie babies, some of their key developmental milestones, and the support that's out there for parents who are on this journey. Our guest today is Kylie Pussell. She's the CEO and co-founder for the Miracle Babies Foundation, and mum to three surviving babies herself. Thanks for joining me today Kylie, to discuss this important topic that's clearly close to your heart.

**Kylie:** Thanks so much for having me. In Australia, every year, there are more than 48,000 newborn babies that require specialized medical care, and 27,000 of those are born premature, so it's a lot of families that we're talking about today.

**Tiffany:** Wow, those stats are quite astounding. So glad that we're sort of delving into this topic a bit more today, Kylie. I think that there's so much information that we're just not aware of, and if we haven't been through it ourselves, we have no ideas. To kick things off today, could you start by telling us a little bit more about your background and why you started the Miracle Babies Foundation back in 2005?

**Kylie:** As you mentioned, I have three surviving children, but I've also had lots of heartache along the way with miscarriages and loss of babies at different gestations, so it's been a really traumatic time in having my family. When I heard about our founder, Melinda Cruz, wanting to bring some parents together to be able to support other families in the hospitals, it was something that I really wanted to be a part of, so I became one of the co-founders. Together as a group of mums from Sydney Southwest, all brought together by our own personal experiences, we gave birth to Miracle Babies, and here we are 15 years on supporting families.

**Tiffany:** Yeah, that's so wonderful, and it's so great to hear a bit more about your background. It's so interesting to find out where people start up these businesses, and foundations, and charities, because so often they are a result of these incredible personal experiences. Of course, yours is very sad, and I'm so sorry to hear about your loss, but obviously that creates a lot of passion, and drive, and dedication, and obviously that's been a huge part of the success of the Miracle Babies Foundation.



Episode 2: Premature Babies  
with Kylie Pussell, CEO and co-founder at Miracle Babies Foundation

**Tiffany:** (cont...) So thank you so much again. Kylie, could you tell us a little bit more about the definition of a premature baby, because I think that's something a lot of people maybe don't understand or don't really realize?

**Kylie:** A premature baby is when a baby is delivered before the 37th week of pregnancy, and we have babies surviving from as young as being born at 23 weeks gestation, which we call the extreme premature babies. There's definitely a long road ahead, and for families, a lot of the time it's unexpected. You think you'll have your baby at 37, 38, up to 40 weeks of pregnancy, and when that doesn't go to plan, it's really, really scary.

**Tiffany:** I mean, I haven't experienced it myself, but I have had some family members that have experienced having preemie babies, and I know it is very traumatic for the whole family. We're quite fortunate that we've had some babies that have made it through and survived today, so it is incredible what hospitals provide and the care that they offer. I guess though, there would be a lot of varying differences between hospitals. What type of care can people typically expect to receive today?

**Kylie:** In Australia, we have 23 neonatal intensive care units or NICU's, and they're in the tertiary hospitals. Then across Australia, there's numerous special care nurseries or SCNs, and it depends on where your baby goes to as to what level of care your baby might need. It's really, really hard on families if your baby needs that extra level of care and it's not close to home. That's a whole nother level of stress and anxiety, and a lot of isolation for families too, as they have to possibly travel to the city from the country for their baby to receive that specialized care.

**Tiffany:** That's quite incredible just to realize the difference in, I guess, the care that some babies will need to receive, and it's great to know there's so many incredible hospitals here in Australia that actually do have these incredible NICU units. Just amazing that they can help these little tiny babies survive and get home with their families. When preemie babies do go home, what type of care do they typically need, and when do they typically go home, because this must vary a lot between, of course, from one baby to another?



Episode 2: Premature Babies  
with Kylie Pussell, CEO and co-founder at Miracle Babies Foundation

**Kylie:** You're definitely right. It depends on the gestation or the week they were born, what kind of hospital journey they've had, if they've had any complications through their hospital time, but the majority of premature babies that have had a good experience in hospital will go home around their due date. Dependent on a few things such as weight, feeding, controlling their temperature, things like that. Then we do have the babies who do go home that still require a lot of help and they're ones that might have severe lung issues. Some of them can spend months after their due date in hospital before discharge, and some of them may even go home on oxygen or needing extra feeding support. It is really variable and each baby is so individual with that.

**Tiffany:** Mm-hmm. I guess it's like you said, it's very dependent on where they're at, at the time, when they're in hospital as to when they can go home and that sort of thing. Are there different types of things or considerations when it comes to caring for your baby when you do bring them home if they are still preemie?

**Kylie:** Depends on the level of care that baby needs after discharge, but definitely things can be quite different from baby to baby, but a lot of them will go home needing to be, I guess, that little bit extra protected. We come home as parents, really wanting to never have to go back or take our baby back to the hospital. It's a time that we don't want to revisit, so providing that extra level, I guess, of support for the family unit. Keeping everyone safe and together, and maybe that's minimizing your social time, and going out to the shops and things.

Some of these babies go home with a low immunity, so a cold to me or you, may not be that simple to a premature baby at home and could result in rehospitalization. It's definitely something that as parents, we all want to avoid, and the first 12 months at least is usually quite a lot of follow on appointments. You might be meeting with allied health, pediatrician, your GP, so there's a lot of things that we need to put into place. We have things that we need to do better in regards to that support once the baby is home. Around financial, practical, and the emotional support for families.



Episode 2: Premature Babies  
with Kylie Pussell, CEO and co-founder at Miracle Babies Foundation

**Tiffany:** Yeah, it must be so different when it comes to bringing babies home and being aware of what supports they might need, and then different follow-up appointments and that sort of thing, and of course, if there's certain issues that we need to be mindful of, particularly when it comes to their hygiene and looking after their low immunity, that must be really challenging, so it's great to know that there are those supports there. When it comes to dressing your preemie baby, this must be very different to dressing a full-term birth baby, I'm assuming.

**Kylie:** It is. I remember when my girls came home, they were still quite small, and some premature babies will be discharged a little bit smaller than usual. It's really quite scary to dress a really tiny baby and handling that baby, so we need, as parents, to get our confidence up in doing that. I remember really finding it hard to find clothes that would fit my girls. They were still quite small, and I know that that's certainly changing and Purebaby has a great range for that as well, but also families can be challenged if their baby's go home on oxygen or feeding tubes. Finding the right outfit and finding something that you can still access those oxygen tubes, and give the baby a comfortable way to be spending their days as well is really important.

**Tiffany:** Yeah, of course, and I know that seeing these tiny little babies brought in, I've seen a few that have been brought in to Purebaby, and they are just so tiny and they're so incredibly gorgeous, but you can imagine they're quite fragile. As a parent, it would take a bit of confidence to feel that you're able to do it safely, and be able to dress them and handle them, and that sort of thing would take, like you said, that confidence building. Are there extra day-to-day considerations when it comes to having a preemie baby at home, Kylie?

**Kylie:** We talked about the low immunity is one thing, but also these babies grow when they sleep, so that quiet environment with not too many distractions and really giving baby that chance to sleep and grow is really good. That once again, limits the parents a bit as to what they do, so supporting that whole family unit is really important during this time.

**Tiffany:** I think, like you mentioned, being aware that your routine might be different, and you might have to spend a bit more time at home, or being aware of the difference in having a preemie baby to having a full-term baby.



Episode 2: Premature Babies  
with Kylie Pussell, CEO and co-founder at Miracle Babies Foundation

**Tiffany:** (cont...) Just the family understanding that and friends being supportive there, I guess, would be helpful too. What kind of health risks are there for preemie babies typically? What are the main concerns there?

**Kylie:** There's different variants of health risks for premature babies. Just being born premature, and what gestation can put a baby at higher risk for some developmental concerns. Some of those can be lifelong and ongoing, so we definitely encourage parents here at Miracle Babies to talk about your child's birth story, and as they get older to encourage them to talk about it, because the more education and knowledge that we have around these risks, we can help to reduce those risk factors and help these children have longer, better outcomes.

**Tiffany:** Mm-hmm. Definitely. I think, like you said, talking about that experience gives people knowledge, and as we said, knowledge is power, as I always say. I think it is so important that people be more aware of some of the things that may not be in their realm of knowledge, because they've just never come across it in their life. It's great to know that that's something that you do encourage, and I think it is powerful to share birth stories regardless. What are some of the different developmental milestones for preemie babies as opposed to full-term babies there, Kylie?

**Kylie:** When a premature baby's in hospital, there's definitely a lot of different milestones than when you first take your baby home, and that's around sometimes breathing on your own, or some babies will be given caffeine to help with their breathing. Then they win, and they are off caffeine, so little different things like that. They might go into a hot cot and come out of the humidity crib, and they're really big things. Especially the breathing on your own, and as they progress through feeding and moving from a feeding tube onto a breastfeed or something like that. There's definitely some different milestones while you're in the hospital with your baby, and then when you are discharged home, it can be a little bit different. You have to readjust to those early childhood milestones being on your baby's corrected age, which can get really confusing, but you actually take those milestones from when the baby was meant to be due, not from the actual birth date, so it can get a little bit confusing for parents.

Episode 2: Premature Babies  
with Kylie Pussell, CEO and co-founder at Miracle Babies Foundation

**Tiffany:** I can imagine, I can imagine. Are there some things they need to be aware of when it comes to ongoing concerns with developmental milestones? As they grow different things that might be an issue that may not have been with a full-term baby?

**Kylie:** Definitely keeping an eye on when those milestones would have been due and put them onto the corrected age. Then if there is any delay, to definitely get some help. Reach out to your GP and your pediatrician. Some of these babies do require physio, and OT, and speech therapy to help get them back on track to those milestone pathways, but it's definitely worthwhile to keep an eye on it and get some help as needed, because there's great things around that can help your baby improve that development.

**Tiffany:** What are some of the milestones to look out for, for babies who are preemie, from sort of one to six months, because as we said, there's that corrective age? What are some of the things we need to be looking for there?

**Kylie:** The milestones that the baby's reach is still on the same skill level as other babies. It's just that time difference we need to be looking at. Those fun days when they find their feet or hands, they start rolling, looking for solids. Definitely speak to your pediatrician about solids and when to start that, because that can be a little bit different for premature babies as well. Sitting as well, they need a lot of that core strength to be able to do all of these things, so a lot of floor time, and being with them and playing with them on the floor is definitely going to help them reach those milestones better.

**Tiffany:** That's great to know. I think understanding a bit more about the different types of milestones that are going to come up and how they might be different. Like you said, talking to a pediatrician or talking to someone who can support you with understanding those, it'd be very useful to know. What type of emotional impacts does having a preemie baby have on the parent's mental health? What are the types of support that are out there, Kylie, because I think that, of course, there's so much focus on the baby, but like you've mentioned earlier, there's a lot of emotional impact that do obviously impact not only the parents, but the whole family who's going through this process of bringing a little preemie baby into the world.



Episode 2: Premature Babies  
with Kylie Pussell, CEO and co-founder at Miracle Babies Foundation

**Kylie:** What we know, and when we talk to parents, and what I've experienced as well, is that the emotional impact stays with the parents. That's something that can be from those really traumatic early days of when survival is really questionable, and watching your baby fight for life, you have no sense of control over anything. You've got your fear, you feel lonely, you're isolated. It's really hard to talk about, to bring all those emotions into words, so there's definitely a huge impact for families.

Then, as time goes on, especially the extended hospital stay, those feelings are still there, even though the baby may be doing better as the days and weeks go by. The exhaustion of going back and forth to the hospital, and maybe missing other children, doing that alone if your partner's back at work, there's so many challenges that come into play when we're talking about this. It's probably, for a lot of families, the most traumatic thing that they will actually go through, and it's something that can have that mental health impact for a long, long time, if not lifetime. It's something that we really need to look out for with these families in those really early vulnerable days, but also in the months and years ahead.

**Tiffany:** That's really interesting, Kylie, and I think, just knowing and understanding a bit more about those birth experiences and how it really does impact you. I think, talking to a lot of other women and going through birth myself, I know that having a positive birth experience really impacts you throughout the rest of your life in a positive way, but obviously not having a good birth experience, having something that's really challenging and traumatic, obviously would stay with you as well.

What are the different types of things that we can consider with making it as positive as possible? For instance, bonding after birth and that sort of thing. Are there some things that you can talk about there to help people understand that there's still ways in which you can create a positive experience, I guess, after birth?

**Kylie:** As you said, it's great to have a positive experience and have a plan, but when we have a premature baby, sometimes it just doesn't go to plan, and it's usually unexpected, and sometimes in really emergency situations, so it just is happening and as a mum, you've just kind of got to deal with that in the moment, and that's really hard, and then your baby's taken away. It's so much to deal with, and the best things that we can encourage is, as soon as you're able to, Mum and Dad go into the nursery and visit your baby, if your babies are healthy enough to have that bond and that interaction immediately after delivery.



Episode 2: Premature Babies  
with Kylie Pussell, CEO and co-founder at Miracle Babies Foundation

**Kylie:** (cont...) Also, in those first few hours, to get some help from the nurses, and start expressing your breast milk, because that's definitely one thing that we all know as mums that we can only do for our baby. That it's good mental health for us to feel that we're doing something, because as we said, the baby goes to the nursery and they're looking after your baby.

Being able to be part of that and do something such as expressing your breast milk for a baby, which we know has such a good, positive clinical outcome for babies is really good as well. Keep asking for your kangaroo cuddles as early as you can. The nurses will let you once the baby's stable enough, and keep trying to have that bonding and be part of your baby's care every day, as much as you can.

**Tiffany:** How many times a day, typically, would you get to spend with your baby if it's preemie, when it comes to the skin-on-skin that kangaroo care? How many times a day typically would you get to spend with your baby in a NICU unit, for example?

**Kylie:** In Australia, we usually have 24 hour access to our babies, for the parents, so you can usually be with them as often and as much as you like. Depending on how baby is coping that day with things, you can ask and have kangaroo care cuddles, which is really important for both baby and the parents. Unfortunately at this time in COVID, things are a little bit different, so check with your hospital what the situation is, and try and put a plan in place that allows you to have both parents with the baby and together as much as you can, and definitely keep talking to your nurses, and just gain access as much as you can.

**Tiffany:** I guess that time with a newborn baby is so important, whether it be a full-term baby or not, but like you said, with those little preemie babies, we do need to care for them as much as possible and in the best way that we can to provide that care. We're so dependent on the hospital at that time, but being able to think, "Okay, what can I do?" And like you said, being able to express some milk or have a bit of skin-on-skin time are the ways that you can try to support and help, so that's great advice. Before we finish up Kylie, what would be your top tips for soon to be parents or new parents with preemie babies?





Episode 2: Premature Babies  
with Kylie Pussell, CEO and co-founder at Miracle Babies Foundation

**Kylie:** Don't go through it alone. I think that's the biggest thing that we all need to remember. That we're not prepared for this. There's no lessons on how to deal with this, so reach out, and get support, and ask lots of questions from people who have been through that before. Miracle Babies offers a 24 hour support helpline, so you can call and speak to another parent who's walked in your shoes kind of thing. We also have in-hospital visits, so we can see you by the cot side, and then when you are discharged, we have nurture groups as well, so you can all the way through that journey, gain access and support from other parents who have been through the experience. They have wonderful tips. They're great at listening, and they are very empathetic and understanding, so you can definitely stay connected with people that really know what you're going through, and I think that's the biggest thing, is don't feel you have to do this alone. It takes courage to step up and go, "Okay, let me talk about this," and we hope that families can find that courage, and keep talking to us, and their family and friends as well.

**Tiffany:** Mm-hmm. Knowing that you've got someone there that you can just talk to who've been through the same experience, I think, would definitely be helpful. Like you said, knowing there's that ongoing support and that 24 hour family support line is just incredible, so doing incredible work there.

Thanks so much for your insight today, Kylie. It's been really interesting hearing about your journey, and perspective as a parent and co-founder. I've really enjoyed hearing all about your experiences and the incredible work that Miracle Babies do get involved with. I'm sure that all the listeners out there have also really enjoyed listening to what you've had to say today, so thank you so much for joining us.

**Kylie:** Thanks for having me, and to all the parents that are going through it or have been through it, reach out and get support if you can, and look after yourselves and be kind to each other as well.

**Tiffany:** Well, thanks so much, Kylie. Well, that wraps up our episode for today. For more information about preemie babies, what to expect and what support is out there, you can head to [www.miraclebabies.org.au](http://www.miraclebabies.org.au), or call the Miracle Babies Foundation 24 hour family support helpline on 1300 622 243, or 1300 MBABIES.