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16 September 2024

To the Select Committee on Reproductive, Maternal and Paediatric health services in Tasmania,

Miracle Babies Foundation is Australia's leading charity supporting premature and sick babies, their families and the hospitals that care for them.

Every year in Australia, more than 48,000 newborn babies require care in a neonatal unit. The need for care is either from being born premature or being critically ill. Up to one thousand of these babies are born in Tasmania.

Separation can exacerbate birth trauma as experienced by many parents who experience the emotional and stressful birth of a premature or sick baby. The early perinatal period for the parents can be filled with fear, guilt, stress, and grief. There is extensive research literature supporting that parents of preterm babies are at least two and a half times more likely to experience postnatal depression, and there is also a higher rate of post-traumatic stress disorder, in both parents, when baby is 12 months of age. There is also evidence that keeping mother and baby together reduces these adverse parental outcomes, these adverse outcomes will impact their baby's long-term development. Being together also improves the baby's chances of survival.

Zero Separation

We advocate and support the World Health Organisation's recommendation for Zero Separation; the keeping of mother and baby together from birth. Miracle Babies Foundation is a member of the Global Alliance for Newborn Care (GLANCE). A priority for the Alliance is to eliminate the systematic and often unnecessary separation of primary caregivers from their child.

Separation alone is traumatic. It also compounds any existing birth associated distress and the ensuing trauma.

The response from mothers when asked 'what was it like going home and leaving your baby in hospital?', even years later, often evokes a trauma response or; 'It was the hardest thing I have ever had to do!'

Across Australia, families have experienced the distress from being separated from their loved ones amid the COVID-19 pandemic. The pandemic exposed the inability of neonatal units to safely allow parents with airborne viral infections to visit their baby without the risk of infecting others.

Miracle Babies CEO and Co-Founder, Kylie Pussell, has many years' experience supporting families. She concludes; "Limiting the contact parents would otherwise have if the baby didn't need specialised care, causes unnecessary distress and trauma to the whole extended family. This results in other early challenges for the parents such as isolation and loneliness. Isolation and loneliness, results in the mother feeling unsupported. This situation is highly likely to evolve into postnatal depression. We support and encourage all hospitals to fully implement family-centred care and to support full and continuous access to their baby during the hospital stay. The experience of having a premature or sick baby is traumatic with a range of emotions including failure, guilt, fear, uncertainty and others. The family should be together wherever possible, for the long-term health and outcome of the baby, the parents and the whole family unit."

"About 9-10 days after her birth at 33 weeks' gestation, I finally went home which was bitter-sweet. I'll tell you this was by far the hardest journey. Every single time I left that hospital without my daughter it got harder and harder. I remember not being able to leave unless her eyes were closed and she was asleep. I would nurse her to sleep every night, giving her a kiss on the forehead and waiting for her to close her eyes. I hoped it would be easier leaving if she was asleep, but it never was. There is nothing normal or easy about having a baby in the NICU. I know people may think or say things like 'at least you get to go home and sleep" or "You have someone caring for your baby, you don't need to do anything" but you are up all hours of the night wondering if your baby is ok, or if your phone rings at any point, will it be the hospital calling to say something is wrong. The endless amount of sleep I got just wondering what she was doing and if that phone was going to ring was indescribable." Miracle Mum, Nikki

The World Health Organisation states 'Mother and infant should be enabled to remain together while rooming-in throughout the day and night and practice skin-to-skin contact, including kangaroo mother care, especially immediately after birth and during establishment of breastfeeding.'[1]

Clinical management of COVID-19: Living guideline 2023:
https://www.who.int/publications/i/item/WHO-2019-nCoV-clinical-2023.1

A 2020 Netherlands study found 'future intervention strategies should aim at reducing mother-newborn separation and intensifying active parent participation in neonatal care.'[2]

[1] World Health Organisation (2023) *Clinical Management of Covid-19 Living Guide* p. 100
[2] van Veenendaal et al (2022) *Association of a Zero-Separation Neonatal Care Model With Stress in Mothers of Preterm Infants,* JAMA Network Open

Well-designed neonatal units and best practice models of care will reduce the unnecessary separation of parents from their child. We know that these interventions will reduce adverse long-term outcomes, and not compound, what is often an already distressing period of maternal care.

Early Maternal Discharge

Often mothers are discharged home during their baby's admission, even when that admission is only for a few days. Many mothers describe the day they went home and left their baby in hospital was harder emotionally than the day they birthed. The trauma from 'the hardest thing I ever had to do' is re-lived each day parents attend hospital to see and care for their baby.

Many mothers have experienced a caesarean section and are still recovering physically when they are discharged. After discharge they are reliant on others to drive them to and from the hospital. Recovery from such a major procedure often precludes them from taking public transport. The need to visit their child impacts on their own recovery.

For many families, the impact of separation is further compounded by distance from the baby. The impact of distance is obvious for regional and rural families but is also present for metropolitan families whose travel times can be excessive. The mothers become isolated, initially from the baby then, unavoidably, from their partner and then their other children. The family unit is broken with guilt, fear, isolation and loneliness all triggering or aggravating difficulties experienced at the time of birth.

The impact of separation is compounded for vulnerable populations. Re-experiencing the powerlessness experienced by the removal of indigenous children from their families is triggering for some families, who now feel they are powerless to provide the support and maintain the physical and cultural contact their baby needs.

Other vulnerable groups are impacted. Families in low socio-economic brackets find it difficult to pay for petrol and hospital parking. Mothers with poor mental health find their mental health further deteriorates or is aggravated by the separation after birth. Conditions such as attention deficit hyperactivity disorder (ADHD), can be aggravated or even first exposed after birth, making the organisation required of visiting baby difficult. Mothers, who are at risk of their baby being taken into out-of-home care, are unable to attend to their baby's care and receive the support needed to keep their baby with them.

The health systems inability to keep mothers and their children together, we respectfully assert, is inhumane.

Breastmilk

Breastmilk is essential for babies born premature or unwell. Mothers are often discharged home from hospital before their milk supply is established. This stress is counterproductive to her establishing an adequate milk supply. Successful exclusive breastfeeding is reduced due to this separation.[3]

Human Milk: An Ideal Food for Nutrition of Preterm Newborn:
https://www.researchgate.net/publication/328312715_Human_Milk_An_Ideal_Food_for_Nutrition_of_Preterm_Newborn

Parental Leave for Parents of Preterm and Unwell Babies

Miracle Babies Foundation requests the Australia Government urgently change the Australian Paid Parental Leave Scheme to ensure parents can support each other and their baby while the baby is in hospital. We note the parental leave support for parents of premature babies is provided to the NSW Public Service. Though available for preterm birth, there is no provision for when the baby is admitted for other reasons. Other employers also provide some support for preterm birth, but this is uncommon. For other employees there is no provision for additional paid parental leave for families with a baby in neonatal care. Many use their parental leave before their baby is discharged from hospital. There is often no leave available for when the baby goes home, at a time that can be very demanding. Additional paid parental leave entitlement for babies in neonatal care for over 2 weeks, will ensure equitable and effective early home experience and support for families with a premature or unwell baby.

Maternity and Neonatal Unit Design and Models of Care

A systemic review with consumer consultation, is recommended to identify the barriers to Zero Separation. Evidence based models of care (including Family Intergrated Care (FiCare) and Kangaroo Mother Care) should be implemented. The recommendations of the Australian Health Facility Guidelines should be fully implemented and, when possible, be retrofitted to current neonatal units.
Australasian Health Facility Guidelines:
AusHFG | (healthfacilityguidelines.com.au)
Content Update: HPU 360 Intensive Care Unit | AusHFG (healthfacilityguidelines.com.au)
(SEE APPENDIX)

[3] Boquien CY (2018) *Human Milk: An Ideal Food for Nutrition of Preterm Newborn*. Front Pediatr.

Kangaroo care (skin-to-skin)

Kangaroo care or skin-to-skin contact are some of the terms used in Australia. Kangaroo care is a vital part of neonatal care for parents and baby.

Models of Care, equipment, training and infrastructure for immediate kangaroo care should be implemented universally. Every effort should be made so that, when clinically safe, neonatal care for premature or sick babies is provided while the baby remains with the mother. Similarly, Zero Separation, when clinically safe, should be implemented using a model of care that provides neonatal care in the maternity unit at the mother's bedside. Avoiding admission to the neonatal unit will reduce baby's length of stay and avoid separation.

Benefits to Baby:

- Maintain baby's body temperature
- Regulates baby's heart and breathing rate
- Encourages baby to spend more time in a deep sleep
- Increases baby's weight gain
- Improves oxygen saturation levels
- Can improve breast milk production and increases the chances of successful breastfeeding
- Longer periods of alertness
- Helps promote frequent breastfeeding

Benefits to Parents:

- Can build confidence
- Increases your bond with baby and can ease feelings of separation
- Can improve breast milk production and increases the chances of successful breastfeeding

"I visited my son an average of 12 hours every day and spent most hours next to his bedside. The time I treasured most was our daily Kangaroo cuddles; we would spend 2 hours snuggling together, often with the both of us drifting off to sleep. Though there were lots happening around us it often seemed that we were the only two people in the room." - Naomi, Miracle Mum to [redacted] born at 29 weeks.

Over the last few years an evidence base has developed that support continuous Kangaroo Care being provided by families. This development is called "Kangaroo Mother Care". The 2022 World Health Organisation Guidelines on immediate kangaroo mother care state; 'A review of 203 studies from low- middle- and high-income countries about "what matters" to families about the care of their preterm or LBW infant reported that families want a positive outcome for their baby, to be involved in delivering care and to take an active role in deciding what

interventions are given to their baby' 'Infants who need intensive care should be managed in special units, where mothers, fathers, partners and other family members can be with their preterm or LBW infants 24 hours a day'[4]

WHO immediate skin-to-skin recommendation:
WHO advises immediate skin to skin care for survival of small and preterm babies

Miracle Babies Foundation/Kangaroo Care:
https://www.miraclebabies.org.au/content/kangaroo-care-awareness-campaign/gjyjfc

Family Integrated Care

Family Integrated Care (FiCare) is widely researched and evidenced and should be at the forefront of all neonatal units design, implementation and staff training. Providing facilities, zero separation and FiCare all work together to improve optimal outcomes for premature and sick babies and their families, reducing trauma and risks of mental health concerns.

In the modern NICU, preterm babies are cared for by highly specialised staff. While parents are welcome in the NICU, they do not feel that they can care for their baby as much as they would like to. Separation of babies and parents in the NICU leads to feelings of disempowerment in the parents. As a result, parents may feel stressed and anxious, a loss of control and experience and they develop concerns around their ability to care for their baby after discharge.

Family Centred Care (FCC) or Family Integrated Care (FiCare) is an approach to planning and delivery of health care that encourages greater parent involvement in their baby's care. A Lancet article found that FiCare in the NICU, FiCare improved infant weight gain, decreased parent stress and anxiety, and increased high-frequency exclusive breastmilk feeding at discharge.

Internationally, clinicians caring for mothers and babies, conclude that Kangaroo Care, Kangaroo Mother Care FiCare are important advances in neonatal care.[5] These models of care all have evidence that they reduce mortality and morbidity.

Effectiveness of Family Integrated Care in the NICU:
Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial.

Miracle Babies Foundation/Family Integrated Care:

[4] World Health Organisation (2022) WHO *recommendations for care of the preterm or low birth weight infant.* Geneva: World Health Organization, Licence: CC BY-NC-SA 3.0 IGO
[5] O'Brien K, FRCPC, (2018), *Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial*, The Lancet Vol 2, Issue 4, pg 245-254

https://www.miraclebabies.org.au/content/family-integrated-care/gkb3l4

Research papers on Family Integrated Care:
https://familyintegratedcare.com/research/

Impact of Birth and Separation Trauma on Future Pregnancies

Many families experiencing post-natal birth trauma relate to the emotional, financial and mental health challenges of having another pregnancy subsequent to a traumatic birth, premature birth or having a critically ill newborn baby. The consequences include implications a fear of these events recurring. These concerns may result in a desire for another child being extinguished.

"Every future pregnancy following my first miscarriage was stressful. All my plans for future pregnancies or other children were very fearful. I didn't know if I could handle that level of stress through another pregnancy and the pain of worrying my husband and family was huge. After having 3 surviving children with losing 5 heartbeats along the way at different gestations I just couldn't do it anymore. Even though I longed for one more child, I eventually had to let this dream pass me by." Kylie [redacted] NICU Mother

Future Pregnancy Considerations after Premature Birth of an Infant Requiring Intensive Care:
https://pubmed.ncbi.nlm.nih.gov/35491347/

Findings from a study related to the fear of future childbirth following birth trauma and admission to a neonatal unit determined that that there is a need greater support for these mothers to help them process the trauma. The role of midwives and health professionals, and the delivery of empathetic care toward mothers and involvement in their own birth or baby's care experience, can play a significant role. Routines are needed for follow up with women who have experienced a traumatic birth and have a fear of childbirth (or pregnancy) as a result, along with greater service provision for these parents.

'Beck (2015) emphasizes that it is essential for healthcare professionals to prevent trauma whenever possible. She argues that women need to feel like they are being looked after, treated with respect, and communicated with in a way that makes them feel included in their own birthing process and able to maintain their dignity. The relational support and care women receive before, during and after childbirth could help prevent a traumatic birth experience (Dahlberg et al., 2016; Karlström et al., 2015; Lundgren & Berg, 2007; Lyberg & Severinsson, 2010; Nilsson et al., 2010).'

"I shut it out": expectant mothers' fear of childbirth after a traumatic birth: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9302015/

Going Home

Families who experience an early birth grieve the loss of those social experiences and events anticipated during their hoped-for experience of a good pregnancy. For example; the baby shower, gender/sex reveal, homecoming celebration and others. The weeks or months after birth are then a lonely and isolating experience. It is lived mostly without extended family and friends. Rather than the celebration of a healthy new life and a welcoming of a baby into the family this time is filled with fear, anxiety, isolation and a lack of parental confidence taking a new baby home without the support of medical professionals who have been a guidance and safety net since the birth.

Mental Health

Either parent of extreme preterm babies are two and a half times more likely to suffer post-natal depression.[6] Birthing a premature or sick baby places these parents with an existing mental health or neurodiversity at risk of exacerbating their condition.

The report, *Investing to Save – The Economic Benefits for Australia of Investment in Mental Health Reform* developed in association with Mental Health Australia, states that by intervening early, we can achieve positive health and social outcomes for people experiencing mental illness, while also delivering economic returns to the government and economy at the same time – avoiding significantly higher costs in the future.

They conclude that '(not only) will interventions save governments and their partners money in the long run…there is clear evidence to support the lives of people with mental health issues, their families, their friends and their communities will improve.'[7] This is exactly what we aim to achieve at Miracle Babies, improved outcomes and the opportunity to thrive for parents and families facing trauma associated with the birth of a premature or sick baby. Access to peer support from Miracle Babies Foundation in the critical care period will assist these families and can also assist the economy by providing a preventive solution for this community, potentially saving the government expenses of over $40million each year, if we were able to reach and support the 63,000 parents and 31,500 children at high-risk each year (based on $431 per person).

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[6] Pace CC, Spittle AJ, Molesworth CM, Lee KJ, Northam EA, Cheong JL, Davis PG, Doyle LW, Treyvaud K, Anderson PJ. (2016) *Evolution of Depression and Anxiety Symptoms in Parents of Very Preterm Infants During the Newborn Period.* JAMA Pediatr; Vol 170, Issue 9, p. 863-70.

[7] Belfield G, Rynne B (2018) Investing to Save The Economic Benefits for Australia of Investment in Mental Health Reform, Mental Health Australia and KPMG

Investing to Save also suggests that for every dollar invested by government in organisations like Miracle Babies, there could be '…longer term savings of up to $10 for every dollar invested. This highlights that there are significant gains to be made, particularly when targeted interventions are applied early…'[8]

The benefit of peer-to-support in the NICU environment is highlighted in this article from the Journal of Perinatology; 'There is now a growing body of evidence of the benefits that peer support provides to parents of NICU infants and special needs children. Parents who receive peer support have been found to have increased confidence and well-being, problem-solving capacity and adaptive coping, perception of social support, self-esteem and acceptance of their situation. Further, parents feel more empowered and interact with, nurture and care for their infants to a greater degree during more frequent visits to the hospital, leading to a shorter length of stay for their infants. Parental stress and anxiety, as well as depression, are all reduced. Peer support therefore offers a 'legitimate' and 'unique form of assistance that is not typically met by the formal service system' and one that cannot come from any other source.' [9]

Prevalence and risk factors for postpartum depression among women with preterm and low-birth-weight infants:
Prevalence and risk factors for postpartum depression among women with preterm and low-birth-weight infants: a systematic review - PubMed (nih.gov)

Evolution of Depression and Anxiety Symptoms in Parents of Very Preterm Infants During the Newborn Period:
Carmen C. Pace, PhD[1,2,3]; Alicia J. Spittle, PhD[1,2,4]; Charlotte M.-L. Molesworth, MBiostat[5]; et al
https://jamanetwork.com/journals/jamapediatrics/fullarticle/2532578

[8] Belfield G, Rynne B (2018) Investing to Save The Economic Benefits for Australia of Investment in Mental Health Reform, Mental Health Australia and KPMG
[9] Hall, S., Ryan, D., Beatty, J. et al (2015) *Recommendations for peer-to-peer support for NICU parents*. Journal of Perinatology 35 (Suppl 1), S9–S13

Post-Traumatic Stress Disorder (PTSD) Following Childbirth

The reported universal prevalence for Post-Traumatic Stress Disorder (PTSD) following childbirth ranges from 1.5% to 6%.[10]

Post-Traumatic Stress Disorder (PTSD) Following Childbirth: Prevalence and Contributing Factors:
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3745743/#:~:text=In%20various%20studies%2C%20childbirth%20has,childbirth%20(3%2D5).

Prevalence and Correlates of Posttraumatic Stress and Postpartum Depression in Parents of Infants in the Neonatal Intensive Care Unit (NICU):
https://link.springer.com/article/10.1007/s10880-010-9202-7

Post-Birth Practices for Mothers with a baby in Neonatal Care

A research study published in the *Journal of Clinical Nursing*, conducted in 2019, highlighted the lack of appropriate facilities and practices to cater for emotionally fragile mothers without their baby on the ward, these mothers described to have 'slipped through the cracks'.

'For most participants, being with mothers who had healthy full-term babies was confronting, as it heightened their awareness of what they were missing in the early months of motherhood. This was highlighted early for Mother 8 being in a postnatal ward after giving birth, surrounded by other mothers and their healthy babies. She described her emotional distress and the trauma she was experiencing as having *slipped through the cracks.'*

"They put us in a ward … everyone had their babies. No one told us what it meant to have an extremely premature baby. In my mind my baby was going to die … It was hard for me to hear their babies cry … I should never have gone to the postnatal ward … I don't think anyone with an extremely premature baby should ever go there. It was cruel and awful and even in that time in NICU I think I was … our child was quite a healthy baby … I think we slipped through the cracks and a lot of things. (M8)"

The forgotten mothers of extremely preterm babies:

[10] 3. 3. Andersen LB, Melvaer LB, Videbech P, Lamont RF, Joergensen JS (2012) *Risk factors for developing post-traumatic stress disorder following childbirth: a systematic review*. Acta Obstet Gynecol Scand. Vol 91, Issue 11, p. 1261–72.

The forgotten mothers of extremely preterm babies: A qualitative study - Fowler - 2019 - Journal of Clinical Nursing - Wiley Online Library

The relationship between prematurity and maternal mental health during the first postpartum year:
https://www.sciencedirect.com/science/article/pii/S135518412200206X

Factors health services delivering and families accessing maternity care that impact on the Trauma associated with admission to a Neonatal Unit

1.Regional, Rural and Remote Families

For families living in regional, rural and remote areas, the separation of not only mother, father/partner and baby causes concern, but also the separation from extended family, friends, colleagues and support of the whole community. As the ancient African proverb states 'It takes a village to raise a child'. Parenting is rewarding yet can also be challenging and difficult for many. With so much separation and trauma revolving around a baby's birth, which would usually be a joyful occasion, without a village, parenting can be a very isolating, lonely, stressful and traumatic experience. The financial burden of accommodation and public transport, petrol, parking to see and care for their baby in hospital each day is another layer of trauma which could be reduced by mother and baby units which would also reduce separation.

2. First Nations People

The word 'separation' can be very emotionally triggering for our First Nations people and being discharged or not provided the opportunity to be the primary caregiver of their baby can be extremely traumatizing. In addition to all the concerns raised above, our First Nations people are removed from Country and their Community to give birth or baby is transferred for care, away from Country and Community. This trauma can be significant and long term. Facilities and Unit Design and working toward Zero Separation can assist in reducing this level of trauma and keeping family together. According to the Australian Institute of Health and Welfare, *Australian Mothers and Babies Report* Aboriginal and Torres Strait Islanders are 75% more likely to have a preterm baby. [11]

3. People from CALD backgrounds

In addition to the concerns raised above, families from a CALD background often enter a clinical world they never knew existed and face at times, difficult language and culture obstacles and

[11] Hilder L, Zhichao Z, Parker M, Jahan S, Chambers GM (2014). Australian Institute of Health and Welfare (2012) *Australian Mother's and Babies Report*

barriers. Limited translation support and understanding such medical complexities in a second language or limited language can increase the birth trauma for these vulnerable families. They can feel uninformed and not confident in this environment.

4. LGBTQIA+ people

In addition to the concerns raised above LGBTQIA+ people can experience increased isolation, discrimination and judgment. According to COPE, although research into perinatal mental health conditions in same-sex parents is limited, one study found that lesbian and bisexual biological mothers were significantly more likely to experience symptoms of anxiety and depression when compared with heterosexual women.

5. Young Parent

In addition to the concerns raised above, young parents with a baby in neonatal care can experience severe isolation. At times due to being quite separate from their peers and friends their own age due to different life points and then being much younger than other parents in the unit. They can feel judged, watched, expected to fail which all leads to another layer of birth trauma along with the guilt, fear, isolation and loneliness that most parents feel.

Assocation of a Zero-Separation Neonatal Care Model:
Association of a Zero-Separation Neonatal Care Model With Stress in Mothers of Preterm Infants - PubMed (nih.gov)

WHO advises immediate skin-to-skin care:
WHO advises immediate skin to skin care for survival of small and preterm babies

Recommendations:

- The inquiry consults parent organisations, such as Miracle Babies Foundation https://www.miraclebabies.org.au/ and Australasian Birth Trauma Association https://birthtrauma.org.au/.
- The inquiry invites parent organisations, parents, consumers and clinicians to share their birth and postnatal lived experiences.
- These organisations are consulted to develop maternity and neonatal services that minimise trauma and ensure the psychological health of all family members.
- Policy, Investment and guidelines to implement neonatal unit design, development and retrofitting of family facilities.
- Develop maternity and neonatal models of care that support zero separation.
- Investment and recommendations to ensure, at birth, immediate and ongoing Kangaroo Mother Care and FiCare.
- Funding peer support services for families experiencing preterm birth or admission to a neonatal unit.
- Neonatal services provide both pre and post discharge transition to home support for preterm and unwell babies.

Thank you for the opportunity to provide this Submission to the **Select Committee on Reproductive, Maternal and Paediatric health services in Tasmania.** Please contact us should you require any further information or clarification.

Yours Sincerely,

[redacted]

Kylie Pussell
CEO & CoFounder
Founding & Chair Committee GLANCE
EFCNI Parent & Patient Board Member
Mum to 3 surviving miracle babies
Miracle Babies Foundation

FAMILY STORIES

Candace:

My name is Candace, and I gave birth to a beautiful son in [redacted] at 31 weeks and 2 days.

I live in regional NSW, and my prenatal care was average at best. At 28 weeks I found out my baby was measuring small and had extra scans and check-ups. One Monday, I went to my local hospital for a regular check-up where I found out I have extremely high blood pressure. After being coded, I was airlifted to a Sydney hospital to be monitored as my baby could not be cared for locally at his gestation and size.

After two days, my son went into distress early in the morning (after I mentioned I hadn't felt movements) and I had an emergency c-section under a general in the matter of minutes.

I did not get to experience any of the highs of giving birth or holding my son for the first time.

When I woke I was in a maternity room and wasn't able to see my son for hours until I was cleared to do so. The nursery was quite a walk from the ward which wasn't helpful for a post C-section mother and made bonding with a NICU baby extremely hard. Furthermore nurses in the maternity ward were less than understanding. I was moved out of maternity ward and into a prenatal share room on the count 'I had no baby with me'. I received next to no post-natal care. I struggled with expressing (a huge part of premature baby life).

This was all during Covid, meaning I could not have any family visit from regional NSW to Sydney or even the hospital due to the restrictions that were in place. My husband and I couldn't visit our son together as a couple (it was one or the other). And we didn't have the option to stay with our child, we left every day for 8 weeks without our son to our rented unit which had no comforts from home. Eventual we were transferred back to our local hospital, but by then the damage from the trauma of the experience was done. They did offer 'social workers' but that wasn't too helpful.

I eventually contacted PANDA, and they listened. But without seeing my GP for a mental health plan there wasn't much more to be done. This was not an option as I was 5 hours from my GP. There was so many flaws and problems with my birth experience, and I believe it could have gone differently.

I contacted the hospital about my poor care and it was dismissed.

I am happy to provide more details if it means this will happen to less expecting mothers. Still 2 years after, I am struggling with my birth, and the whole experience has meant I no longer want more children.

Candace [redacted]

Kalomira:

I suffered from severe hyperemesis from week 5-birth and was hospitalised several times. I was then hospitalised from 24 weeks as I had an open cervix at Mater Hospital in Brisbane. I suffered from extreme Symphysis Pubis Dysfunction and needed a walker to go to the bathroom and shower. At 32 weeks I was transferred to my private obstetrician's hospital and 2 weeks later I underwent an emergency c-section at 34 weeks with our son.

He spent 4 weeks in Special Care Nursery and the assistance offered was nil, no advice of where to seek help. Even when it came to car parking and the exorbitant costs involved with that. We had to travel an hour each day to and from the hospital, walking a ridiculous distance to get to the nursery each day. This constant movement caused my c-section wound to internally split open. I then had to wait 12 months to have it surgically repaired. 20 months later am still recovering and undergoing rehab work 2-3 times each week. I'm also seeing a colorectal surgeon and having to have a Urodynamic Assessment completed and this was a caesarean birth!

The 10 weeks in hospital during covid in the last half of [redacted] was isolating, stressful and scary. I only saw nurses twice a day, and my partner. We struggled financially, mentally and physically. There just was very little support. Because of the difficult pregnancy, I had to go back to work 3 weeks after taking our son home. There are so many aspects that could have been different if people that were in the know, would have shared resources and knowledge. Support was non-existent.

Kindest Regards,

Kalomira [redacted]

Alex:

I would like to share my birth story as it was definitely traumatic, that's for sure.

Our son [redacted] was born at 27 weeks gest in [redacted] at Nepean Hospital in Penrith, Sydney. His arrival was completely unexpected and my pregnancy was normal up until that time.

It all started at my best friends' wedding when I started to experience pains in my abdomen and back, 2 days later [redacted] was born. The pain increased and I lost my mucus plug the next day. I was scheduled to give birth at Norwest Private, so my husband and I rushed over there in the middle of the night, only to find that they could not look after us. So, we were transferred by ambulance to Westmead.

Upon arrival to Westmead, the nurses and doctors told me that my "Baby was coming". This was so completely shocking to me as I was not prepared in any way. I had not done any of the classes, read many books, set up a nursery, bought a pram etc. I remember screaming at them all to get out, that they were liars and didn't know what they were talking about.

Soon after, I was told that there were no beds for the baby in the NICU and we had to be moved again, this time to we were transported to Nepean Hospital, by this time it was well into the night and I was exhausted, emotional and a nervous wreck.

We arrived at Nepean and I was monitored closely throughout the night. During this time, my mind was "playing tricks" on me and I had many thoughts of losing the baby and even dying myself. My fear was so great, I barely slept a wink and was quite delusional.

The following morning our son was born weighing 1170gr and being a bit bigger than a can of coke. He was whisked away immediately and my husband and I saw him an hour or so later.

Our journey in the NICU started that day and we were there for 79 days in total until [redacted] was well enough to come home. I was lucky enough to live on-site at Nepean Hospital's Hope Cottage, a respite and accommodation centre for cancer carer's and NICU mum's. We were there for 3 weeks and then were transported by NETS to Westmead which was closer to home.

The days were long and filled with reports from doctors, expressing milk every 3-4 hours, care sessions, kangaroo care (skin-to-skin) contact for 1 hour and the ever-present beeping of the machines that were keeping him alive. All this time I was trying to figure out my role as a mother, looking at my child through the incubator, reading him stories, singing songs when I had him on my chest and then having to leave him and drive home.

I would often curl up into a ball and cry myself to sleep, wishing that my life would just be "normal and regular". The sight of mums with babies in prams at the local shops always made me cry too, as did the sound of the pedestrian crossing beeping at the lights. Then there was the constant smell of sanitiser and the resulting dry and flaky hands.

Soon, my behaviours changed and my thoughts became dark. I couldn't "do it". With the help of my GP I was referred to St John of God "Mother & Baby" unit in Burwood where [redacted] and I were admitted after he was discharged. We stayed there for 6 weeks (the first time)

During this first stay, I was diagnosed with BiPolar 1 disorder and placed on a strict program and medication. All the while, I had to be a mum and wife. I had to navigate this new life as it was unfolding before me. Suffice to say, there were 4 other hospital admissions over the next 5 years, by this stage [redacted] was ready for kindergarten.

I have been living with BiPolar 1 for 10 years now and have many mechanisms and supports in place that help me get through each day. I went on to have a second child, a daughter, 3 years later and she was born full term. In the meantime, my marriage broke down and life took yet another turn.

Today, I have 2 beautiful, healthy children that I am raising alone, whilst working full time, surrounded by loved ones and living life to the fullest. I am thankful that I am able to share my story and hope it brings light and inspiration to others.

Many thanks,
Alex

Dylan and Amy:

Amy and I were expecting our first child. No one truly warned us what an anxious time pregnancy could be. We sometimes questioned if we were ready to be parents, is anyone truly ready? Our family and friends would joke about the “late nights” and the dirty nappies. That didn’t deter us or worry us about the task and the journey ahead. We were excited and had overcome many obstacles, including miscarriage, just on the journey to conception.

Early in our pregnancy, we identified that Amy was carrying twins. This made sense as both of our Pops are twins! Unfortunately, early indications suggested that one was doing better than the other and at our second dating scan, it was confirmed that one was not developing any further. Amy struggled with this more than I did, not because I didn’t care but because I always believe things happen for reasons, good or bad.

This was our first child. We weren’t frequent visitors to Hospitals and there aren’t too many babies in either of our families. We trusted the entire time in the advice from health care professionals and people at ****** Hospital. We weren’t allocated a midwife or offered any classes, which we questioned at the time because of our history, but we were declared a low-risk pregnancy and our care transferred to our General Practitioner.

Amy’s pregnancy would be easy going until late second and early third trimester. Amy started to suffer with reflux and our little man was incredibly active inside the womb, particularly of a night. Amy was incredibly well informed and educated from her own research during her pregnancy and still is to this day. I will always admire just how much she learned independently in the lead up to having [redacted]

On [redacted], Amy woke up with a weird chest pain and nausea. The pain increased in severity throughout the day, and we visited ****** Hospital that afternoon to investigate. Amy was 35 weeks pregnant at that time. Unfortunately, we were there for a very long time trying to determine the cause of Amy’s discomfort. We were treated by multiple doctors until being sent home with the suggestion Amy was suffering from severe reflux. Amy knew her body and felt like it wasn’t reflux, but we trusted the advice from professionals. We went to the chemist and picked up standard reflux treatments, but they were to no avail.

Amy’s pain would continue over the next few days, fluctuating in intensity until it was again unbearable, and we presented back to ******* Emergency on [redacted] at 11pm. Emergency were unimpressed by our return, this time sending us to Birthing Unit, who sent us back to Emergency to be checked over once more.

We waited back at Emergency as Amy received pain relief and we prepared to go back home. We were then transferred back to Birthing Unit upon chance investigation from Dr *****, who spotted Amy struggling to walk from the Emergency department. Dr ****** and ***** at ****** Birthing Unit suggested something more sinister could be going on in the background, they inspected Amy’s blood results from Wednesday and conducted more tests and quickly

determined Amy was suffering from a severe case of HELLP Syndrome. Dr ******* contacted ****** Hospital and explained that due to the severity of Amy's condition, it was best she be transferred there.

Lights and sirens later, Amy arrived at ****** . *******was nice enough to come with us, and her calming presence was comforting the entire time. ****** Hospital quickly explained the severity of the situation and how critical it was that we acted quickly. By then, we were still trying to come to terms with the fact Amy was about to have our baby…

Amy's platelets had dropped at this point to below 20,000 and her liver, kidneys and the placenta were being drastically affected. Dr ****** advised us that the pain she had been experiencing since Wednesday was her liver swelling, and beginning to shut down, not reflux or GORD.

Amy's caesarean was a success and at 5:53am, our son [redacted] was born. Weighing 2.59kg at 49cm long and 5 weeks early. Amy remained in surgery until roughly 9am. Prior to her surgery Amy gave me her hair band as she couldn't have it on in theatre, I have worn it on my wrist every day since.

It wasn't until 3pm that day we were reunited, I managed to convince a nurse to give Amy her phone so we could text, I had some photos of our son on there as a surprise for when she opened it. Unfortunately though, it wasn't until 9:30pm did she meet [redacted]

Amy remained in hospital for 5 days in close care following [redacted] birth. We were fortunate to have amazing care at **** Birthing Unit the entire time. Amy's blood results and liver function were still of considerable concern as specialists visited and Amy received steroid injections. The specialists were always open, honest and communicated their concerns in easy-to-understand ways.

Following the surgery, Amy's platelets would not increase until Wednesday when they reached 47,000. An average adult should have above 150,000. By Wednesday, Amy started to look and feel better. Her liver function would also improve.

Late Thursday evening, Amy was discharged from Hospital. Amy's mum was waiting outside for us. They hadn't seen each other the entire time. Amy's platelets had exceeded 200,000. [redacted] remained at NICU until the 9th of September, when he was transferred to ***** Hospital's Special Care. Amy by this stage was recovering well from her operation but was unable to drive, walk for too long or lift anything heavy.

Our world would be flipped upside down once more when ****** Hospital decided to not allow Dads into the nursery. I did not see [redacted] again until he was discharged on the 19th of September. [redacted] spent 10 days in total at ***** Hospital.

Following his discharge on the 19th of September, we were finally able to spend time together as a family. By this stage and almost a month into his life, I don't believe we had spent any more than a few hours together.

Since then, [redacted] has grown quickly into a healthy and happy little boy. [redacted] loves to eat, clap his hands and can say 'Mum' and 'Dad'. He can stand up, crawl like a commando and is always laughing.

Amy and I have done our best to make up for lost time with him and will cherish this gift of parenthood forever. We both have significant mental trauma from our experience and will endeavour to ensure no one has to go through what we did, in our efforts to find closure.

Amy and I will have another child, not any time soon. We missed out on so many special moments at the beginning of [redacted] life that we couldn't bare miss again with another child.

We are disappointed in our treatment at **** Hospital and would like to highlight the importance of a human approach to things and a personable interest in someone's care, particularly when they are expecting a child.

We would like to sincerely thank Dr ***** and his team in BU, who essentially saved Amy and [redacted] life. We would also like to thank **** from the BU who went above and beyond with Amy at a very difficult time.

Dylan [redacted]

APPENDIX

Australasian Health Facility Guidelines:
AusHFG | (healthfacilityguidelines.com.au)
Content Update: HPU 360 Intensive Care Unit | AusHFG (healthfacilityguidelines.com.au)

2.4.4 Family Areas – General

Parents and siblings will spend significant periods of time visiting the unit. In order to improve their comfort and provide opportunities for them to care for their infant, a range of support space is required including the following:

- *family lounge / dining including a beverage bay for preparation of light meals and beverages and which also provides opportunity for families to congregate and engage with each other;*
- *play area for children;*
- *easily accessible toilets and showers;*
- *parent education facilities and access to educational and other support materials;*
- *hot desk space to enable parents to undertake some work or keep in contact with other family members;*
- *lactation support including quiet space for breastfeeding and expressing, and facilities for cleaning associated equipment;*
- *access to food and drinks out-of-hours, e.g. vending machines;*
- *access to a domestic laundry. Machines may be incorporated into the equipment cleaning room if accessed by staff only; and*
- *facilities to support early discharge programs including parent / newborn accommodation. The zone should have access to shared meeting and interview rooms on the unit.*
- *Overnight rooms to support early discharge programs should be provided within the unit to enable parents looking after their infant(s) to have direct access to staff support. A number of overnight rooms located in close proximity to the unit will also be required for mothers that are breastfeeding their child full time, parents that live a significant distance from the unit and to provide access for families to rest space away from the critical care environment. The number of overnight rooms provided will depend on access to other accommodation options on the site, e.g. Ronald McDonald House and the volume of families who live a significant distance away*