Stillbirth
CENTRE OF RESEARCH EXCELLENCE

# Submission to Select Committee into Stillbirth in Australia

Stillbirth CRE Bereaved Parent Advocacy Committee

*31st of January, 2025*

In April 2024, we established the Bereaved Parent Advocacy Committee, with support from the Stillbirth Centre of Research Excellence (CRE) and Stillbirth Foundation Australia. We are a national group of parents, researchers and health professionals, committed to increasing awareness, advocacy and research into pregnancy and baby loss through our lived experiences. We do this in honour of all our babies gone too soon, in the hope that fewer families experience this heartbreaking life sentence; and for those that sadly do, that they are cared for with understanding and compassion. We are passionate about creating equitable and accessible opportunities for parents and health care professionals to co-design improvements to perinatal care together. We make this submission to the Select Committee into Stillbirth in South Australia and thank you for acting on this important issue.

*Stillbirth CRE Bereaved Parent Advocacy Committee with Stillbirth CRE researchers and collaborators*

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*Our resounding voices are calling on you to commit to change. These are not just words. These are rallying cries that have followed gut-wrenching heartache, the gift of our shared grief, and immense strength through personal experiences that will live with us forever.*

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## Who are we?

- **Kirstin Tindal, Glass House Mountains, QLD –** Mum to ***Aurora***, stillborn at 22 weeks gestation in 2013. I was just 20 years old, and she was my first baby… I always wanted a little girl. Her death was due to a chromosomal abnormality and whilst her death was unpreventable, there were a lot of gaps in my care and stigma around being a young mum. I have had another three pregnancies since and am hoping to bring home my second baby earthside next month. The discrepancies in my care depending on which service I attend or which health professional I talk to has ranged from outstanding to abysmal. The out-of-pocket expenses incurred supersede thousands of dollars for mental health support, ultrasounds, genetic testing and more. Aurora has inspired me to undertake a PhD in the causes of stillbirth because every family deserves to bring home a healthy baby, no matter what their circumstances. Without government support and increased awareness, I fear we will fall short of this goal for future families.
- **Sarah Lawrence, Bendigo, VIC –** Mum to ***Harry*** who was stillborn in 2022. He was our first child, and it was the darkest time in our lives. I am passionate about research as a clear cause of Harry's death could not be determined – around a third of bereaved parents fail to get a specific answer for their babies heartbreaking death.
- **Jules Mallia, Jerrabomberra, NSW –** Mum to ***Willow*** who we devastatingly lost through termination for medical reasons at nearly 23 weeks gestation in 2021. Willow was my second born, after an early miscarriage and the healthy birth of my now 7-year-old son. Facing the complex emotions of pregnancy after loss with their little brother, who is now nearly 2years old, I am passionate about advocating for improvements to perinatal care at every stage. The support I received from Red Nose, and the stories shared lovingly and raw by other loss parents, both guide and inspire me to honour and share Willows life through volunteering and advocating for those impacted by baby loss.
- **Danielle Pollock, Adelaide, SA -** Mum to ***Sofia*** who was stillborn at 23 weeks. Her death left me seeking answers as to why we are still experiencing stillbirth, and why we do not adequately support bereaved parents. I started my PhD in 2016 (completed in 2020) where I developed the stillbirth stigma scale and explored the stigma experiences of bereaved parents. There has still not been a specific intervention aimed at reducing the stigma of stillbirth. The stigma of stillbirth continues to impact resourcing and the availability of services in the prevention of stillbirth and in the provision of bereavement care.
- **Emily Judd, Launceston TAS –** Mum to second child ***Jack*** who was stillborn at 38.6 weeks in 2021 after a very straightforward 'healthy' pregnancy. His death was sudden and unexpected. After tests including an autopsy, it was determined he had died due to an acute spontaneous

fetal maternal hemorrhage with the cause of that hemorrhage unknown. His death was not preventable, however, I feel strongly that conversations about stillbirth prevention including any changes in movement (slow or fast) should have been had with us despite this being a 'normal' second pregnancy, so we had the knowledge and could advocate for him and me. Our experience at, and leaving the hospital greatly impacted our time with our son, our trauma & grief (as a family and individually) to this day. We left not only without our baby but without referrals or access to support. As a result, we strongly advocate for better bereavement training for health professionals including trauma-informed care, better support, resources and continuity of care for bereaved families and their support networks.

- **Kylie Stewart, East Ryde, NSW -** Mum of ***Alexander*** who was stillborn at 35 weeks in June 2019. Alex was our first child, and I had a 'normal' and 'healthy' pregnancy. I had seen my obstetrician just two days prior to hearing those awful words 'we can't find your baby's heartbeat'. I had a placental abruption, the cause of which was never explained. While we had amazing support from the hospital nurses and midwives, my obstetrician, a social worker that was an angel sent to us, our ever-caring doctor and counsellor, and support groups (run by our social worker), we know that is not the case for everyone. It is devasting to leave hospital without your baby. It is devastating that not all families receive the appropriate and adequate support, compassion, understanding and medical care that is required both immediately and for as long as required thereafter. We advocate for parents to be partners in driving needed change in practices and education, as we sadly know from lived experience where we are failing families when they need support most.

- **Edith Drajkopyl, Melbourne, VIC –** Mum to our first-born son ***Daniel Junior (DJ)***, stillborn at 22 weeks' gestation on Christmas Day in 2022. It was the hardest, saddest but the most love filled day in our lives. DJ was small for his age, and when detected, his death was unpreventable. We later learned that DJs death was due to placental malperfusion and the journey to becoming a mum to our baby Cecilia Daisy, was not without stringent monitoring riddled with anxiety. I am passionate about honouring DJ through perinatal research initiatives that tie my passion for advocating for bereaved parents together with my own experiences as a researcher with a focus on creating improvements and outcomes for bereaved parents. I'm also passionate about educating researchers about the best ways to respectfully collaborate with bereaved parents with perinatal loss experiences.

- **Kiralee Innes, Perth, WA -** Mum to second child, ***James***, who was Stillborn at 30 weeks in 2021. All was very straightforward until 28 weeks at a routine antenatal appointment where they picked up a rare condition, which had evidently led to severe growth restriction. At the time of that ultrasound, James was still healthy and at that point there were no other signs that he was struggling, however, the severity of what was found meant that from that point forward he should have been closely monitored and delivered. I know this now, after the fact.

Unfortunately, I was someone who slipped through the cracks in the healthcare system and I did not receive the appropriate follow-up care. The protocols that should have been followed were not, leading to the death of my son just 10 days post-ultrasound. I am here to share my story in hopes that it can help prevent another death. I am passionate about research into preventative measures and truly hope that statistics improve soon. I hope that we can talk more openly about the reality that is stillbirth without feeling alienated by it. I now have the capacity that I did not have initially after James' death to look back on my experience and there are many things I wish I would have done differently. Things that at the time I did not think to do due to the shock and utter heartbreak of finding out that your baby has died.

- **Sarah Fogarty, Melbourne, VIC –** Mum of ***Jacob***, stillborn at 37 weeks' gestation in 2014. The acts of kindness and 'going above and beyond' received in our care made so much difference in our loss journey. We also received and experienced aspects of the journey that made it harder and more challenging. My experiences of loss inspired me to undertake research and to work with parents after a loss and when pregnant after a loss.
- **Till Heike, Perth, WA** – Mum to ***Claudia,*** who died suddenly as a result of unexplained stillbirth at 32 weeks gestation. Our third daughter was very wanted, loved and anticipated. Her sisters would attend ultrasounds with me, we had excellent care from our OBGYN and Midwife and it was in the offices that we had our last scan of Claudia alive, she was yawning and looking perfectly healthy. A few days later she was dead, suddenly, unexpectedly, no warming, no red flags. Claudia's life and death moved my career focus into Bereavement Care and Support for parents and siblings left to process this traumatic experience. My work with Sands and Red Nose has been a way to walk beside families in their grief, helping them navigate the immense feeling of isolation that accompanies this difficult type of loss. I have also used our story to inform my books on grief and loss and designed Commemorative Loss Certificates for the ACT and Victoria Governments respectfully.
- **Sophie Hickingbotham, Bendigo, VIC** –Sophie has been involved in the work of the Stillbirth CRE and her state-wide tertiary-level hospital as a bereaved parent representative following the neonatal death of her son, ***Reggie***, in 2022. Her willingness to be involved in research, advocacy and practice change comes from the intersections of her lived experience of early infant loss, a mother of three living in regional Australia, her understanding as a former nurse/midwife and current employment in public health evaluation. Sophie feels a keen sense of gratitude that her experience and opportunity to represent bereaved parents might ripple to inform others' experiences through improved practices, processes and projects.
- **Bruce McMillan, Geelong, VIC** - Bereaved dad to ***Liam Henry*** who was stillborn at 38.5 weeks after what my wife's kidney specialist had stated was a perfect pregnancy. My wife

had been diagnosed with chronic nephritis at the start of the pregnancy and as a result we were informed that the worst-case scenario was that we could lose either the baby or the baby and my wife. What followed was 38 weeks of seeing a specialist every week right up until three days before the loss of our son when he stated that he had "never seen a pregnant mum with her condition at this stage of pregnancy so healthy". Liam was stillborn on the 3rd of August 2012. As a result of our loss, I have been trying to highlight the lack of support for parents, not just mums but for dads who tend to get pushed to the background and are often asked how our partner is doing but rarely asked how we are doing after loss.

- **Sarah McIntyre, Sydney, NSW** - As someone who had multiple miscarriages, my husband and I received no offer of counselling or support. After three miscarriages I knew that our chances were getting less and less each time. But no one acknowledged that, nor did they offer support for what ended up being a massive shock for us (and our extended family) of no children. Everyone just kept telling me to keep trying – it was just chance and sooner or later it would happen. I knew that wasn't true, but we were never able to get to the bottom of why this happened. Eventually I found an exceptional counsellor at Sids and Kids and without her support, I am sure I would have been bitter, led a much sadder life and our marriage would not have survived. My husband developed clinical depression, but we found a wonderful psychiatrist to get him back on track. This shouldn't be up to the people grieving; we should have systems that connect directly to counsellors/social workers who have specific knowledge about this type of deep grief. I am also passionate about finding causes of stillbirth at all ages, to prevent where possible, so less families go through this.
- **Rachel Hill, Sydney, NSW** - Rachel is a bereaved mother to ***Tommy***, who died unexpectedly at 41 weeks from a true knot and tight cord wrapping. Since then, Rachel has also experienced unexplained secondary infertility requiring IVF, a miscarriage and an ectopic pregnancy. Rachel's lived experience drives her passion to change the narrative of infertility, pregnancy loss and stillbirth, by increasing awareness, open discussion, and improved research and clinical practice. Rachel is a Clinical Psychologist and is particularly interested in how to better support women and families who are touched by the grief of infertility, pregnancy loss and stillbirth. Rachel is grateful to be involved with the Stillbirth CRE and advocate for change in perinatal loss research and practice. Rachel is passionate in her desire to positively contribute to the improvement of services in honour of her lost little loves, and in the hopes that future families will have better outcomes.
- **Sarah Matheson, Gold Coast, QLD** - Mum to ***Aksel Jude*** who was Stillborn at 33+2 weeks after TFMR due to Intrauterine Growth Restriction (IUGR) and severe brain malformations after suspected brain damage/injury. He made me a mother for the 2nd time at the age of 33; navigating grief and loss all whilst having to parent a living child was just pure torture. I

became a functioning alcoholic for five months and didn't know how to handle my grief and outbursts. I have had two living children since and the pregnancy after loss was filled with anxiety and fear. I am a passionate advocate, speaker and writer within the baby loss community; no loss is too small and nothing/no one will ever replace them. Entering in only weeks away from Aksel's 7th birthday, he is the missing piece of our family puzzle we speak of everyday. Always included and forever loved.

- **Siobhan Loughnan-Henry, Sunshine Coast, QLD** – Mum to ***Ayla***, born in 2024. To discontinue a much-wanted pregnancy is a deeply traumatic experience marked by heartbreak, grief, isolation, and stigma. The pain can paralyse every aspect of life. While our family received good care, small moments of missed opportunities still linger. No parent should face the additional burden of deciding whether to endure a few more days or weeks of pregnancy to have their baby recognised with a birth and death certificate. This only deepens the trauma of TFMR. All loss is loss, and all loss matters. There is an urgent need for further research, funding, and better care to support families, guided by the voices of those who have lived this profound grief, in memory of all babies gone too soon.

- **Emma Porter, Brisbane, QLD** – Mum to ***Conor***, born still at 24 weeks. His brief life changed mine forever. While I received compassionate care, gaps in support left lasting scars—gaps no bereaved parent should endure. I left the hospital alone because staff were too busy to help me walk out the door. The image of him alone in that room will never leave me. I howled as I walked away, not knowing who would care for him in my absence. No grieving family should be left to navigate "what's next" alone. In my next pregnancy, I was labelled "severely anxious" and told my distress was excessive, I have now learned it was quite normal and to be expected as a bereaved Mum. A psychologist explained that I would think of Conor less over time, which terrified me. Not a day goes by that I don't think of him. Grief doesn't fade—it shifts. Pregnancy after loss is emotionally complex and must be recognised as such. Bereaved parents deserve seamless, compassionate, and informed care. Through my work leading a Perinatal Loss Team at the Mater Mothers Hospital and collaborating with the Stillbirth CRE, I am committed to making lasting change—so no family walks this path alone.

> *We never knew or expected it would be us. That it would be our babies who would die. We felt alone and isolated until we devastatingly found a whole community sharing a once silenced experience, with a desperate hope to support others facing the devastating deafness of loss.*

## Considerations throughout this submission

*Our committee met to discuss and reflect on this submission. This informed our collective response to each Term of Reference below and our subsequent recommendations.*
***Throughout this submission, we also emphasise the following:***

- Stillbirth lays on a spectrum of devastating pregnancy and newborn outcomes. These also include, but are not limited to ectopic pregnancy, miscarriage or early pregnancy loss, termination of pregnancy, newborn or infant loss. Though stillbirth is classified as the death of a baby from 20 weeks' gestation in Australia, loss is loss, no matter what. We urge this committee to consider implementing changes across the board, to benefit families affected by all forms of pregnancy and baby loss, and as such use this terminology throughout our submission.
- Pregnancy and baby loss affects expectant parents including mothers, fathers, and non-birthing partners, as well as the broader family unit, friendship networks and their community. It is essential to acknowledge and understand this.
- There are huge disparities in experiences of care and the rates of stillbirth for regional and remote communities, Aboriginal and Torres Strait Islander families, and migrant and refugee communities. All future initiatives must ensure that education and awareness is universally understandable or adapted to be culturally appropriate.
- Each individual experience of pregnancy and baby loss is unique. In sharing our individual stories throughout this submission, our committee highlights common experiences and also disparities experienced throughout the years and in different parts of the country in the lead up to, during and after our losses. The one thing we all have in common is that experiencing the death of our baby has impacted us irreversibly. Many of us have experienced multiple pregnancies and losses which shape the way we grieve, parent, and walk through life. A one-size-fits-all approach to reduce rates and improve care will never work. Personalised care based on best practice and evidence should be the main goal.
- This inquiry is the first step to creating real change, but requires a dedicated commitment to healthcare, research, public awareness and a huge influx of funds and resources to be effective.

## Response to Terms of Reference

### *a) Best practice stillbirth prevention education and awareness programs for expectant parents; including, but not exclusive to, the monitoring of babies in utero*

Devastatingly, there is an indication that many women are not guided through pregnancy with current preventative knowledge. Societally, we've grown comfortable having conversations about Sudden Infant Death Syndrome (SIDS)/ Sudden Unexpected Death in Infancy (SUDI) but when it comes to preventative measures during pregnancy, our own doctors, health professionals and community are not talking about the possibility of loss during pregnancy or birth. Despite 1 in 4 women reporting miscarriage, 6 babies being stillborn every day, 2 babies dying every day within 28 days of birth, and an estimated 3,000 babies lost to Terminations for Medical Reasons (TFMR) every year, which remains a silent issue. Without these necessary conversations contributing to education and awareness of pregnancy and baby loss prevention, we are failing prospective parents in many respects.

#### *Inadequate preconception planning and guidance*

The decision to start a family is far from simple, and yet there is very little public education about steps you might like to take before becoming pregnant, just how complicated conception can be, and little to no awareness that baby loss can occur at any stage of pregnancy. **There is no safe period, period.** There is currently little to no preconception planning and guidance for expectant parents, particularly around the risks of pregnancy. It has been encouraging to see more options for genetic testing in recent years, however, this is often dependent on access. A lot of education around planning pregnancy needs to happen with school aged young adults. We are taught so much about contraception and avoiding pregnancy during these formative years, but not about preserving fertility or responsibly planning pregnancy with full awareness of the risks of pregnancy.

#### *Inconsistent, contradictory and outdated information about stillbirth prevention*

There is a significant gap in continued professional development by under-resourced health care practitioners and a disconnect between primary and secondary care providers, resulting in a lack of clear responsibility or awareness around information gaps. This is evident amongst our committee where knowledge has been inconsistently delivered to expectant parents during pregnancy and postpartum. There is often differing guidance and dismissal of concerns relating to current evidence-based knowledge/awareness. Even for those who have continuity of care, this is not always the best option if that professional is not up to date with current evidence. There is also an inconsistency of information and resources provided between public and private hospitals.

> *"My midwife gave me all the info about risks of induction of labour, but no information on the risk of not inducing. I had no idea stillbirth was a risk."*

### *Families are expected to educate themselves but don't feel empowered to do so*

There seems to be an expectation that women are solely responsible for their health and that of their baby in utero. With a wealth of public information, the onus is on the parent to do their own education. Whilst this can be empowering, not everyone has the same access to information or tools to distinguish credible information from medical misinformation or unsolicited advice, which is rampant on the internet. Further efforts are required to adequately inform families about the risks during pregnancy, with fresh and innovative ideas on how to deliver this information. An overwhelming amount of pamphlets and resources are sometimes provided during antenatal care, many of which are confusing and end up in the bin. These should be clearly explained by healthcare professionals, with an opportunity to ask questions in a safe space.

Stillbirth also isn't talked about in pregnancy/antenatal classes because healthcare providers "don't want to scare parents". We need to get over the discomfort. For some reason, we're comfortable talking about smoking or drinking alcohol in pregnancy, but not stillbirth. The alternative to not discussing it is much worse than being a bit uncomfortable.

> *"I was prepared with a safe sleeping arrangement but no information to keep my baby safe before birth"*

### *Valid concerns are dismissed during pregnancy and access to care is limited*

Women are being denied additional monitoring when they express concern due to resourcing availability. Particularly those in rural areas do not have access to the same level of care and women with socioeconomic disadvantage or cultural differences are not having their concerns met or taken seriously. We continue to see Aboriginal and culturally diverse women disadvantaged, with limited access to timely, face-to-face, and culturally appropriate care. Women should be encouraged to trust their gut and seek help when needed, with zero concern of access, cultural barriers or 'being a bother'.

> *"The midwife over the phone did say to come in if I was concerned but I had to drive three hours for an ultrasound. First, I had to organise care for my other two children before I could hit the road. An hour or so into the drive, I felt my baby move and turned the car around. I felt silly for worrying and that I would be an inconvenience. The next day my baby died."*

### *Presumptions by healthcare providers about pregnancy care based on previous history*

Education is often lacking due to clinical history and healthcare professionals' presumptions about a woman's experience of pregnancy and/or birth, without consideration for her point of view. Women who have previously birthed without complications receive a reduction in information about risk due to their previous positive experience. Whereas women who have experienced an early pregnancy loss have this clinical information recorded and may not receive the necessary education or awareness because they have been pregnant before. Women who are pregnant for the first time follow the regular schedule of scans that involve a large break between the 12-week and 20-week morphology scans, even though growth and developmental abnormalities during this period can lead to pregnancy loss. There are other risks during pregnancy that are communicated relatively well, such as preeclampsia, gestational diabetes and birth preferences.

> *"My doctor let me know that placental malperfusion is so common in first time mothers, perhaps when their body isn't quite ready to deliver a child. If it's so common, why are we not educated on this front?"*

### *b) Public education programs/initiatives to increase community awareness of stillbirth and where people can access support in the community*

Previous successful community awareness campaigns demonstrate that progress can be achieved with the right approach. For instance, public education programs by Red Nose Australia have significantly reduced the number of SIDS related deaths, over 12,000 babies since 1987. Preventative stillbirth research exists, evidence continues to grow, and more needs to be done to consistently highlight preventable measures to reduce the rate of stillbirth. **Six babies every day is completely unacceptable.**

*Edith and DJ, Heartfelt photography*

> *"I wasn't told about stillbirth during my pregnancy and had no idea about the resources available via Still Aware, Red Nose etc"*

### *Workplace education and support should be a key initiative*

Campaigns such as the Pink Elephants *Leave for Loss* have helped raise awareness about support needed following miscarriage and has shown the successful impact of providing education and support through the workplace. All workplace parental leave policies should cover stillbirth adequately, with employers educated about entitlements and the best ways to support bereaved parents navigating this leave period. This includes respect and time, not pressuring them to return to work and allowing them to take their entitled parental leave without question, should they choose to. It should be standard practice for employees to feel comfortable to be upfront about their expectations and expanded recognition from workplaces through their policies and processes is still desperately needed. *One father on our committee was told:*

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*"You can't access parental leave because you don't have a baby anymore."*

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*All loss is loss.*

All pregnancy and baby loss has an everlasting effect on families and communities but there is still limited understanding around the loss of a baby before 20 weeks, which often require medical intervention and healthcare to support postpartum recovery. These losses can have significant long-term impacts and are associated with fertility issues and the risk of having a later gestation loss or complication also. Support at all gestations needs to be encouraged and valued. By reducing stigma and increasing empathy around all losses in healthcare and the community, we will see dramatic changes across the board.

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*"We need to stop the stigma of sharing news of a pregnancy before 12 weeks, and we need to recognise bereaved parents as parents, regardless of whether they are holding a living child."*

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*Awareness strategies should be informed by bereaved and expectant parents*

There needs to be a significant investment in public awareness campaigns, with co-design at its core to ensure campaigns capture everyone equitably and are informed by parent voices. Bereaved parents are unable to absorb important information in the acute period of loss due to shock and prioritising spending time with the baby and memory making. This is why education prior to and during pregnancy is so helpful and important. Time and time again we hear from bereaved parents, "I wish I had known" vital information, and only they can provide insight into how, when and where to deliver such information appropriately, whether it is preventative education or postnatal supports.

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*In order to make a difference, we need to get comfortable with the uncomfortable. We need to value, and validate, the lived experience of loss where families are given appropriate opportunities to co-design future care.*

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### *Address the education gap for fathers and non-birthing partners*

Often, fathers and non-birthing partners are barely considered during the pregnancy journey and even less-so when a loss occurs. There is a great opportunity to fill this gap by educating and empowering non-birthing partners to be actively involved in pregnancy and decision-making. A large proportion of responsibility is placed on the birthing parent. Whilst we acknowledge that this is appropriate when it comes to the woman's body, choices and healthcare, the current healthcare system is not inclusive of the non-birthing partner when it does not view them as the patient. They should equally be informed of the risks and particularly when there is a complication or pregnancy loss, the father or non-birthing partner should be empowered to advocate for their partner and baby. This only works when awareness and education is delivered to the family unit, not just the woman. Targeted approaches to encourage antenatal attendance and helpful steps that non-birthing partners can take during pregnancy should be implemented.

## ***c) Models of care in pregnancy that may contribute to a reduction in stillbirth (including for priority populations);***

Models of Care in pregnancy continue to expand and evolve to meet parent needs, values and experiences. This is excellent in practice when done right. A key to successfully expanding diverse models of care, is ensuring all care models meet regular reviews to ensure current safety standards are met.

### *Continuity of care*

Continuity of care is of huge benefit to families but is often not done well in Australia, particularly in the public system. Parents are often not aware that they can request a different professional if they are unhappy with the allocated one. Continuity of care though, has been shown to reduce many adverse outcomes, and is believed to contribute to reductions in stillbirth. Publicly accessible models of continuity of care should be prioritised to make progress not only in stillbirth rates, but to improve the birthing experience for families and reduce the chance of birth trauma. Particularly during pregnancy after loss, continuity of care can alleviate the burden for a parent having to repeat their story and history at every appointment, which is often a significant trigger.

### *Holistic care*

The current hospital systems and structures are centered around physical healthcare and outcomes. Pregnancy is a unique healthcare consideration, in that most patients are attending free of disease, illness or a healthcare concern and one body houses multiple patients. It is a time of transition for the family. As such, pregnancy should be managed holistically to support spiritual and emotional needs just as much. This is particularly poignant in the case of complications and pregnancy loss, when care very much does become treatment or management of the physical issues.

## *d) Models for follow-on care (including mental health support or care in subsequent pregnancies) for parents after stillbirth (and infant loss more generally)*

### *Follow-on and bereavement care has improved but there are still strides to be made*

Members of this committee have experienced pregnancy and infant loss over a range of time, some as recent as 2023, others, over 20 years ago. Upon reflection, it has been promising to hear positive stories of bereavement and follow-on care and it seems that overall support has improved in this area.

***Mother in the middle.*** *Kirstin and Aurora, Wander and Solas Photography*

Individuals accessed different support depending on the follow up care provided by the hospital (or lack thereof), personal preferences, and our means. *It was not uncommon to hear that many parents' needs were not fully met, and we highlight some of the gaps here:*

- No referral to access hospital to home services
- No referral for a 6-week postpartum checkup
- No resources provided whatsoever
- Psychology services encouraged but not Medicare funded to access
- No social worker available at the service

We could probably highlight hundreds of other examples but emphasise that the bare minimum care should include free and timely access to the above physical and emotional supports in the immediate weeks and months following a loss.

> *"It is unfathomable that some hospitals have dedicated bereavement midwives and teams, whilst others barely have a pamphlet to provide to parents after loss. These inequities in bereavement care must be addressed."*

### *Postpartum care*

Every previously pregnant parent deserves the right to equal postpartum care, regardless of if their baby is living or has died. Families are often discharged in a state of shock and trauma. Regardless of what information may have been provided in hospital, appropriate follow-up should not just be the responsibility of the family and their chosen GP. The idea of going anywhere after loss, being a 'bother', or the risk of being around other pregnant and breastfeeding women and their children out in the community, can prevent women seeking appropriate care for their concerns, many of which are heightened by associated trauma.

*The following relate to physical concerns that were not addressed in our follow-up care:*

- Our group were inconsistently informed about lactation after loss and safe options to express or suppress their milk supply.
    - Some facing earlier gestation losses were told they wouldn't lactate and did
    - Others weren't supplied suppression medication
- Information about normal bleeding after loss was not adequately provided. Women and their families need clear guidance on what's normal, and when to seek medical care.
    - Early inductions and D&Cs can result in retained placenta and/or babies remains even after medical intervention. Follow up care, including ultrasounds should be offered to help prevent further trauma, risks to fertility and avoidable complications to women's physical and mental health.

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> *"I wasn't aware that somewhere in my discharge, the midwife had noted possible retained placenta. It wasn't until I hemorrhaged three weeks after my birth that I became aware it had been noted."*

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### *Pregnancy after loss*

Parents on this committee have highlighted that often during pregnancy after loss, they receive better care than their first or previous pregnancy. Whilst we agree that EVERY pregnancy should be treated by gold-standard, evidence-based approaches we also realise that this is idealistic given the constraints of the current system. Therefore, we suggest that continuity of care programs and dedicated support groups should be prioritised for families facing pregnancy after loss to ensure that they are psychologically supported and take home a healthy baby.

## ***e) Support and training for healthcare professionals relating to stillbirth prevention and bereavement care***

### *All healthcare professionals working with pregnant patients require sensitivity training*

There is a prevailing hesitation and lack of confidence by healthcare professionals to have conversations about stillbirth due to a fear of creating anxiety during pregnancy for patients. When there is no standardised training to empower healthcare professionals to have these conversations, this then contributes to inconsistencies of approaches for both stillbirth prevention and in relation to bereavement care. We use the below examples to highlight minimum care compared to those that went “above and beyond” which can make all the difference to an experience, even if the outcome remained the same. Really though, the ‘above and beyond’ should be expected as usual care.

*These are some of the varied responses parents on our committee received when we called with concerns during pregnancy:*

- “Do you think you might have just been anxious when they did your blood pressure? …Because it’s normal now” – *Completely dismissed*
- “Call back in ten minutes” – *The onus put back on the parent*
- “My wife was told to come in immediately” – *Concern taken seriously*

*These are some of the options that were presented to some and not others in terms of memory making after birth. It can be especially hurtful to hear about these options from other parents who received them when it is too late:*

- Cuddle cots
- Taking baby home
- Heartfelt photography
- Handprints and footprints
- A lock of hair
- Taking baby for a walk around the hospital grounds in a pram
- Inviting family to meet the baby
- A small library to read children's books to the baby
- Small, portable speaker to play music while with baby
- Dressing baby and having onesies & baby clothing available
- Being presented with items such as a teddy bear to give to baby and/or hold on to in their memory
- A nursery at the hospital to return to after discharge to be with and hold baby prior to handover to funeral directors

> *"Something as simple as dressing him in a normal onesie, instead of the angel gown provided which I now look back thinking how much that made him appear less like a real-life baby that I had just given birth to. Not being made aware that we could stay for as long as we needed, that we could even stay overnight, and not rush the already little time we had to spend with him. This leads me to the conclusion that, even after the fact, there is not nearly enough information given to parents who at the time cannot properly function or think for themselves."*

### *Bereavement training*

Initial midwifery and obstetrics training should include specific bereavement education to empower professionals to provide best practice care when loss occurs. Bereavement training is currently not a standard requirement nationally. This can be detrimental to staff and parents, contributing to preventable trauma, high staff turnover and burnout.

> *“I think the fact there is no bereavement training standard impacts not only the staff but the bereaved family's grief and trauma. Bereavement care needs to be recognised as essential and mandatory.”*

Such training should also include a focus on compassionate care for pregnancy after loss.

### *Support for healthcare providers*

Health care professionals should be provided adequate debriefing after a loss has occurred. Depending on the circumstances, for parents and healthcare teams, there can be a benefit in reconnecting to provide feedback and discuss findings. This may be possible through post-mortem discussions with the support of a mental health provider.

## *f) Best practice regarding stillbirth investigations (including access, information for parents and case review), pathologist training and service provision*

### *Providing medical history and investigation results – the setting, processes and policies*

It should be the parents’ choice when, how, and if they receive investigation results. Given the busy setting of a hospital, often appointments are dictated to parents without consideration for their preferences, an option of timings should be provided to the parents in advance so that they can prepare emotionally and organise additional supports if needed, including an interpreter or mental health professional.

> *“I don’t want to face this, I don’t want to think about this right now”*

All parents should be given the option of hard and digital copies of their medical history and autopsy results without hesitation by medical staff. Results should be delivered in a private and calm setting, away from the maternity ward. At medical appointments and when delivering results, medical staff are encouraged to take the lead from parents regarding preferred language for their baby i.e. they may use the word ‘baby’ or ‘bub’ or refer to them by name[1].

Most hospitals do not have a clearly defined method for parents to provide feedback after a pregnancy loss and complaints process are notoriously difficult to safeguard the hospital system. Any follow-up, further investigation or feedback often requires the parent to instigate. User-friendly pathways should be implemented to be able to learn from patient experiences and make change. Parents should be involved in the audit process in a meaningful way and to the extent they wish[2].

### *Consent and potential biobanking*

A national biobank has been proposed with some controversy. Often, clinical samples are time sensitive and during the acute period of a stillbirth, it can be difficult for parents to process and provide consent. If such a biobank was established, retrospective consent would need to be sought. Research into the feasibility and acceptability of this should be conducted as a priority and the process of informed consent would need to be co-designed with bereaved parents to ensure the utmost sensitivity. Any remains, including blood work and swabs should not be disposed of without prior consent; however, if the parents request disposal, this should happen immediately. Storage and transfers should be clearly documented for families as this is still a piece of their baby and should they wish to know where samples are, this request should be accommodated as soon as possible.

### *Autopsy and other investigative considerations*

Autopsy is a choice, but not the only choice. Often this is not communicated well to parents, and many opt not to go down this path. Investigations can include any number of tests including maternal blood work, tissue samples, swabs, genetic testing, placental examination, x-rays, MRIs etc. The discussion on whether and how to investigate the cause of death should be based on informed decision-making with parents, with a robust discussion around the pros and cons of each method. It is important for parents to understand that the outcome of the investigations could still result in the cause of death remaining ‘unexplained’ and weighs heavily into decision making.

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[1] https://learn.stillbirthcre.org.au/learn/casand/approach-to-care-background-and-objective/approach-to-care/

[2] https://learn.stillbirthcre.org.au/learn/casand/perinatal-mortality-audit-and-classification/part-b-8-step-audit-cycle/

We support the widespread implementation of evidence-based training programs such as the Stillbirth CRE and PSANZ IMPROVE (IMproving Perinatal Mortality Review and Outcomes Via Education) national education program (available as eLearning and workshop) and South Australia's *Stillbirth Investigations and Bereavement Care* program to facilitate healthcare professionals' understanding and development regarding this.

### *g) Processes of data collection, reporting and monitoring;*

This is a significant area for improvement and should be included in national census collections (where families should have the choice to include all their losses if they wish), through compassionate collection of data through Births, Deaths and Marriages, and consistent reporting of loss through hospital records nationally. As every death deserves a death certificate, every birth deserves a birth certificate. Parents deserve recognition of their parenthood, and their bereavement needs validated.

*Every loss counts. Every loss matters. Every parent matters.*
*Miscarriage is not just a heavy period, period.*
*Stillbirth is still a birth.*

Through our committee alone, we have experienced miscarriage, stillbirth, terminations for medical reasons and infant loss. There is a lack of data supporting the experiences we have all faced. There is a disconnect in how data is collected at a state and territory, and even local level. When data is not collected and reported on all experiences, it minimises the lived experience and contributes to prevailing stigma that some types of loss are more significant than others. Furthermore, if our data is not correct, then research to prevent stillbirth and improve bereavement care is flawed. *We emphasise the following incongruences that are contributing to data inconsistencies that need to be amended:*

- Stillbirth is defined as the birth of a baby without signs of life, at 20 or more completed weeks of gestation or at a weight of 400 grams or more. Many deaths at ~19 weeks are misclassified as 'miscarriages' even if the birthweight was >400g.
- Terminations for medical reasons and psychosocial reasons after 20 weeks are classed as stillbirths, however, are often not delineated in state-wide data.

> *"Terminations for Medical and Maternal Health Reasons is a choiceless choice. Sometimes these losses are avoidable through preconception planning, preventative care during pregnancy, and parents' concerns being met with compassion."*

### *Birth and death certificates*

Many births after a loss are still not recognised with a birth certificate, despite a death certificate being required/issued. For parents who birthed their baby or required intervention, the recognition of their baby regardless of gestation is a right every parent deserves. The choice of naming, and honouring their baby, however they choose to, needs to be made available equally. This needs to be done compassionately and the processes put in place to support this.

Every parent deserves the right to include or refract the inclusion of their deceased babies on any future surviving babies birth certificate. They also deserve the right to change this in future, and the right to systems which can compassionately support these amendments. Staff managing call lines need to be trained to considerately manage or redirect calls regarding baby and child loss. Amongst our group, there were parents who prefer the inclusion of every child recorded on subsequent children's birth certificates, while for others this feels like a shadow of grief following future children around. Some had errors on the documents, i.e. the cause 'stillborn' looks like it was part of their baby's name, or "corrections" made to their baby's weight where loss occurred in an early gestation birth. Parents also shared stories about being hung up on, and discomfort of staff answering calls to amend subsequent children's birth certificates.

> *"It was super jarring when I received my living son's birth certificate with his brother (stillborn) on there... like this will now follow my son around every time he needs to use his birth certificate for the rest of his life"*

### *h) Allocation of research effort*

First and foremost, this committee was established as a group of bereaved parents to support the co-design, translation and implementation of perinatal research in partnership with the Stillbirth Centre of Research Excellence. Over the past year since establishment, we have become privy to the under-resourcing of research leading to poor implementation. There is quite a bit of evidence that is being neglected because it has not been prioritised into healthcare reform.

#### *Funding*

An analysis published in 2023 showed that of over half a billion dollars invested into newborn health research per year globally, only 2.5% of this is allocated to stillbirth research[3]. This analysis also showed that along the research pipeline, most funds are allocated to observational and epidemiological research, 30% to pre-clinical research and technology development, **and less than 15% of these funds are allocated to interventional and implementation research**. This means that the benefits of research are not being translated into meaningful clinical change. To significantly reduce stillbirth rates and improve newborn outcomes, significant investment must be made into implementing research into clinical practice.

#### *Prioritising the voices of bereaved parents to lead research ideas*

There is sometimes misalignment between the research conducted and the research bereaved, and expectant parents wish was being conducted. We highlight one particular research area that is being spoken about wildly within our community, but there is currently no research or information to support our anecdotal experiences.

Many of us report feeling ‘wild’ or ‘erratic’ movements in the days leading up to the death of our baby. We are often informed about decreased fetal movements, but not about increased movement. Upon reflection with many other bereaved parents, we feel as though this is our babies’ last signs of fighting for life, that they are struggling, but we are unaware that this is cause for concern. This is just one of many examples, where research has not caught up to lived experience and investment and initiatives to connect bereaved parents and researchers to partner together would improve future outcomes.

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[3] https://www.thelancet.com/journals/langlo/article/PIIS2214-109X(23)00379-0/fulltext

### i) *Any other related matters*

- More funding and resources are desperately required for regional areas to be supplied with ultrasound machines, new technologies and resources.
- There are proven long-lasting health effects of pregnancy loss on the mother i.e. a higher risk of cardiovascular disease and adverse mental health concerns which impacts not only them, but their family and the broader community. These long-term effects can be mitigated with proper care. A holistic approach is required where those that experience pregnancy loss are connected to the right services without having to legitimize their experience, with care extending to subsequent pregnancies and beyond. This will lead to clear health and economic benefits.
- In 2016, Stillbirth Foundation Australia published a report, prepared by PwC, regarding the economic impacts of stillbirth in Australia[4]. The direct costs such as investigations, hospital costs and counselling; indirect costs such as funeral expenses, absenteeism, government subsidies and other costs to the family; and intangible costs such as impact on mental well-being and flow-on effects on relationships, family and friends were all considered. The estimated economic impact over five years was >$680 million, however, the national investment into addressing stillbirth over this same period has been significantly disproportiante. Furthermore, the estimated loss of 'future productivity' to the economy for all stillborn babies lost is $7.5 billion nationally. No doubt, the impact of inflation will have seen this figure by 2025. By prioritising stillbirth prevention and investing in this issue NOW, the economic benefits will be profound in the decades to come.
- We strongly advocate that early birthing education should include empowering parents to think about their choices if given bad news or a diagnosis before birth (just like you would prepare for your own death with a will).

> *"There needs to be an introduction in early birthing classes, covering healthy pregnancy, prevention, and how to advocate as a parent throughout the perinatal period."*

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[4] https://stillbirthfoundation.org.au/wp-content/uploads/2020/08/Economic-Impacts-of-Stillbirth-2016-PwC.pdf

## Key recommendations:

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*The deafening silence of our babies after they were gone has connected us all. We hope our vulnerability and ever-growing love for our babies echoes within you to inspire profound change.*

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1. ***Prevention:*** Not all baby loss is preventable, but as parents with empty arms who have experienced loss, we know the value and importance of being able to create an environment where there is less loss. An increase in public awareness campaigns and significant research initiatives can lead to more babies that can be saved. It takes a whole community to support birthing parents and partners to ensure they are properly and consistently informed by current evidence.
    - **a.** Invest more funding into research, prioritising parent and health professional involvement.
    - **b.** Continual, mandatory education programs for active health professionals, beyond on-the-job experiences.
    - **c.** A clear line of responsibility for health teams and services.
    - **d.** Continued investment into improved medical resources and equipment.
    - **e.** Support a role within the South Australian Health Department to properly collect and report data related to pregnancy and baby loss in greater detail. This could become a national standard for other jurisdictions and the Federal Government to adopt.
2. ***Bereavement Support:*** As emphasized above, parents have experienced all different levels of care and support following a loss. The care and support that parents receive is crucial and has the potential to increase parents' capacity to cope with grief, adapt to their loss, and eventually find a way to move forward in life. Contrariwise, it can add to the burden of loss, decrease capacity, and delay or hinder parents to find a way to carry their loss. It is in peoples' darkest hours that they need the lights of others to shine through. All perinatal staff should have mandatory annual training on evidence-based bereavement care. Staff should seek out the lived experiences of families to understand where systems have either failed, met or exceeded care needs.

- **a.** In 2008, the Stillbirth CRE and Perinatal Society of Australia and New Zealand (PSANZ) released the first edition of Care Around Stillbirth and Neonatal Death (CASaND) Clinical Practice Guideline. The guidelines continue to expand and empower parent involvement and now include dedicated chapters for perinatal palliative care and subsequent pregnancy care. We emphasise that these guidelines be implemented in all healthcare services.
- **b.** Bereavement training to be added to the Nursing and Midwifery Skills and Training package provided by the South Australian Health Department[5]. This training should be extended to hospital social workers who have the power to be an integral part in making the bereavement care a positive and well-supported experience.
- **c.** Access to counselling after loss should be free for a substantive period to ensure appropriate and immediate access to support. The Medicare system currently requires a GP mental health plan. The fact that a mental health plan to access these supports is another sign that there is not appropriate recognition of the impact of stillbirth to families and society. When you lose a baby, that should be enough to access the necessary supports.
- **d.** Every hospital to have a dedicated bereavement room, with a CuddleCot, to hold the space for birth and spending time together.
- **e.** Every service should have social worker support for pregnancy loss. The social worker should be equipped to reach out to contacts to establish arrangements and provide culturally appropriate choices for the family. These arrangements include for example, access to Heartfelt photography, religious personnel (e.g. baptism), funeral directors that specialise in infant funerals, baby's resting place (e.g. baby urn if cremated), counselling. These are all arrangements that you don't want to think about after the loss of your baby – it is always too soon to let go.
- **f.** Models for follow-on care need to contain and be supported by the following:
    - **i.** Sensitivity and bereavement training for clinicians to provide personalised and trauma informed care.

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[5] https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/careers/i+am+a/nursing+and+midwifery+professional/nursing+and+midwifery+skills+and+training+package/nursing+and+midwifery+skills+and+training+package

   ii. Statewide review, agreement upon and provision in clinical care, referrals, death aftercare options and information provided in alignment with best practice guidelines (e.g. CASaND) for consistency in experience.
   iii. Ideally this is a seamless experience of continuity of care for those who experience pregnancy after loss.
   iv. A bare minimum of access to free and timely access to physical and emotional support.

3. ***Co-design research:*** Having bereaved parents co-design research will ensure that the research is relevant to bereaved parent's needs, experiences, and priorities, leading to more meaningful and impactful outcomes for those affected by pregnancy and baby loss. Bereaved parents bring a unique perspective and are passionate about making changes so that the experience, resources, and supports are better for those that come after them. Including bereaved parents in research design, conduct, reporting and implementation is paramount. Our committee is working to achieve the following, however, are only funded until the end of 2025. We require continued investment to:
   a. Facilitate an improved relationship with bereaved parents, clinicians and researchers. Funding bodies now mandate that 'consumer' involvement should be at the center of research efforts, however, there is very little support or guidance for this.
   b. Create frameworks and/or policies to ensure that engaging bereaved parents is not tokenistic and that collaboration is meaningful and multidisciplinary where individuals from diverse fields work together on a project. This ensures active contribution of their unique expertise to achieve a shared goal, rather than tokenistic engagement

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*We do this work, as we know what is like to go home without our baby. We have felt the immense pain and heartache knowing that our family will not be together. We never want anyone else to feel this pain, and because of that, we become your strongest advocates.*

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