Stillbirth
CENTRE OF RESEARCH EXCELLENCE

Submission to Victorian Maternity Taskforce

Stillbirth CRE Bereaved Parent Advocacy Committee

14th March 2025

Executive Summary

The Centre of Research Excellence in Stillbirth, Bereaved Parent Advocacy Committee (BPAC) thanks you for the opportunity to contribute our knowledge, perspectives, feedback, and expertise to the Victorian Maternity Taskforce (VMT). Our submission calls for urgent attention to the following areas:

- Continuity of care for every pregnancy after loss
- Standardisation of quality postnatal bereavement care
- Palliation for babies closer to their homes
- Enhancing antenatal education for all pregnant people
- Standardising stillbirth prevention education
- Mandatory professional development dedicated to bereavement care
- Partnerships for equitable access to memory-making services and support
- Creation of dedicated bereavement spaces within maternity services

Introduction

Established in April 2024, with support from the Centre of Research Excellence in Stillbirth (Stillbirth CRE) and Stillbirth Foundation Australia (SFA), BPAC represents a national group of bereaved parents, researchers and healthcare professionals committed to raising awareness, advocating for improved care, and advancing research on pregnancy and baby loss. We do this to honour 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.

Throughout this submission, we ask the VMT to consider the following critical factors:

- Stillbirth exists on a spectrum of devastating pregnancy and newborn outcomes. These include, but are not limited to ectopic pregnancy, miscarriage or early pregnancy loss, termination for medical reasons, newborn or infant loss. Loss is loss, and there is no hierarchy in the grief that follows. We urge the VMT to consider this when implementing changes for families affected by all forms of pregnancy and baby loss.
- Through our research and lived experiences there are huge disparities in experiences of care and the rates of stillbirth for regional, rural 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 and accessible and/or adapted to be culturally appropriate.
- Pregnancy and baby loss affects mothers, fathers, and non-birthing partners, siblings, as well as the broader family unit, friendship networks, workplaces and local community (SFA, 2016). It is essential the VMT acknowledges and understands this.
- Each individual experience of pregnancy and baby loss is unique.

Main Submission

Access to Service and Models of Care

Standardised Postnatal Bereavement Care: A National Imperative

Standardised, equitable access to timely, publicly funded physical and emotional support following stillbirth or neonatal loss, regardless of location. This includes:

- **Immediate Support**: Seamless referral to hospital-to-home services (e.g., Red Nose's Hospital to Home service in Victoria), and timely cancellation of any future scheduled antenatal appointments (e.g., midwife appointments or birthing classes). As well as prompt access to a trained hospital social worker and/or spiritual care.
- **Extended Postnatal Care**: Consistent, ongoing care with a designated hospital contact person for postpartum complications, proactive welfare check-ins (within 1-4 weeks), and scheduled debriefing sessions (6+ weeks). Private spaces should be designated for these sessions, with face-to-face pre-pregnancy planning consultations, as needed.
- **GP Integration**: Facilitated GP referrals for comprehensive postpartum check-ups, with clear guidance on physical recovery (e.g., lactation support, bleeding expectations, and contraception).
- **Mental Health Support**: Streamlined access to mental health services, including counselling and psychological support, through direct referrals or mental health care plans.

Continuity of Care: Essential for Pregnancy After Loss (PAL)

Continuity of care, centred on the woman or pregnant person, significantly improves outcomes and potentially reduces stillbirth rates. Universal access to publicly funded continuity of care models (e.g., midwifery-led care, obstetric, maternal-fetal medicine) is crucial. This continuity of care must be provided by trained healthcare professionals who are aware of trauma-informed practices, ensuring that care is delivered with sensitivity, respect, and empathy, addressing the unique emotional and psychological needs of individuals experiencing pregnancy after loss.

Palliative Care: Bringing Babies Home

Families facing end-of-life care for their babies must have the option to receive palliative care as close to home as practical. Just as transfer services exist for babies needing specialised care in metropolitan centres, reverse transfer options must also be available. In particular, the significant burden placed on families living in more remote or less accessible areas during metropolitan transfer must be acknowledged and mitigated.

Additionally, families in these areas should have direct access to teams of experts in paediatric palliative care, like the model provided by Queensland Children's Hospital's Paediatric Palliative Care Services. Such services not only provide immediate support to families but also empower healthcare providers in these locations by enhancing their knowledge and ensuring they have the security of expert guidance when needed.

Comprehensive Antenatal Education: Preparing for all Outcomes

Early antenatal education should empower parents to consider all potential outcomes, including adverse diagnoses or loss, and address the stigma surrounding perinatal death. Offering specific classes for parents

who have experienced pregnancy loss is crucial to support their emotional and psychological needs, helping them manage anxiety and feel more prepared in a subsequent pregnancy.

Quality and Safety

Standardised Stillbirth Prevention Education: Bridging the Gap

The current fragmented healthcare system, coupled with inconsistent professional development, leads to significant gaps in stillbirth prevention education. This results in unclear guidance and a lack of accountability across primary and secondary care providers.

To address this, we recommend:

- **Mandatory Training**: Implement mandatory, standardised training for all frontline perinatal care providers, comparable to the requirements for cardiotocography training in birth settings. This training should cover current best practices in stillbirth prevention.
- **System Integration**: Support efforts to improve healthcare system integration, fostering better risk management, communication, clinical care, and patient choice.
- **Consistent Clinical Information**: Ensure consistent provision of evidence-based information and advice on stillbirth prevention across all care settings.
- **Recording Pregnancy Loss**: Record all pregnancy losses when patients present in maternity settings, regardless of gestation.

By standardising training and improving system integration, we can ensure that all healthcare providers are equipped to deliver consistent, high-quality stillbirth prevention education.

Equitable Access to Pregnancy Care: Addressing Disparities

Significant disparities in access to pregnancy care persist, particularly in areas where geographic and socioeconomic challenges compound the quality of care received. The development of regional workforce pipelines and targeted solutions, including technology and telehealth options, are essential in addressing these inequities. Equitable access should be guaranteed, regardless of location or cultural background. We urgently call for:

- **Equal Access**: Guarantee equitable access to timely and individualised, face-to-face, and culturally appropriate pregnancy care, regardless of geographic location or socioeconomic status
- **Targeted Solutions**: Prioritise the development and implementation of technology and other solutions to address the specific needs of individuals in rural areas, as well as Aboriginal and Torres Strait Islander women and culturally diverse women
- **Addressing Disadvantage**: Acknowledge and address the systemic disadvantages that impact access to and quality of care.

It is imperative that the Victorian Maternity Taskforce prioritises these disparities and implements concrete solutions to ensure equitable and culturally safe care for all pregnant individuals.

Maternity Workforce

Mandatory Bereavement Training: A Critical Gap

The absence of mandatory bereavement training for all perinatal care providers is a critical failing. The profound impact of inconsistent care on bereaved families is unacceptable, especially given the availability of free,

evidence-based online and face-to-face bereavement training programs (Stillbirth CRE & PSANZ, 2025; Red Nose Australia, 2025).
Mandatory, dedicated time for bereavement professional development is essential to:

- **Empower Professionals**: Equip healthcare professionals with the skills and knowledge to provide best-practice bereavement care and support during pregnancy after loss.
- **Prevent Trauma**: Mitigate preventable trauma for both families and staff.
- **Improve Staff Retention**: Reduce staff turnover and burnout by providing adequate support and training.

Investing in comprehensive bereavement training is not only a matter of compassionate care but also a crucial step in ensuring a sustainable and supportive maternity workforce.

Consumer Experience

Co-design: Centering Lived Experience

Prioritising co-design with individuals who have lived experience of stillbirth and neonatal loss is paramount. We advocate for the collaborative development of best-practice perinatal care with diverse families and communities, alongside researchers and healthcare professionals. Lived experience provides invaluable insights that can drive meaningful improvements in research, clinical practice, and standards of care.
The current inconsistency and undervaluation of lived experiences by service providers must be addressed. We commend the Victorian Maternity Taskforce for seeking our input and urge you to embed co-design principles into all aspects of service development.

Equitable Access to Memory Making and Support

In a resource-constrained environment, strategic partnerships with bereavement services and funders are essential to ensure sustainable and equitable access to vital memory-making and support resources. These resources can significantly ease the burden of loss and create lasting positive impacts for bereaved families.
We strongly advocate for the following to be consistently available, regardless of location or background:

- Cuddle cots and/or the use of Techni Ice
- Photographs and memory items (e.g., Heartfelt photography, handprints and footprints, locks of hair, teddy bears)
- Opportunities to bathe and dress the baby, take the baby for walks in a pram, or enjoy time outside in nature
- Opportunities for family to meet the baby and, where possible, take the baby home
- Access to children's books and music
- A minimum period of stay in hospital, allowing families the option to stay as long as needed to spend meaningful time with the baby
- Access to religious or spiritual support for those who wish to have their baby baptised or blessed
- Dedicated nursery/memorial rooms for post-discharge visits

Standardising these options across all hospitals and services is critical. The inconsistency in access to these resources causes additional pain for families, and flexibility in length of stay and family preferences ensures dignity and comfort during an incredibly challenging time.

Dedicated Bereavement Spaces

Every birthing hospital must provide dedicated bereavement spaces. These spaces are essential for families experiencing loss and should be private, respectful, and provide comfort. In the absence of dedicated spaces, private birthing and recovery rooms should be made available.

References

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