The Secretary
Select Committee on Reproductive, Maternal and Paediatric Health Services in Tasmania
House of Assembly
Parliament House
Hobart TAS

By email: rmphs@parliament.tas.gov.au

Dear Secretary,

Please find attached my submission to the Select Committee on Reproductive, Maternal and Paediatric Health Services in Tasmania.

The submission addresses the following Terms of Reference:

(a)(ii) – maternal health services;
(a)(iii) – birth trauma;
(a)(iv) – workforce shortages;
(a)(vi) – perinatal mental health services; and
(c) – to make recommendations on actions that can be taken by the State Government to ensure reproductive, maternal and paediatric health and perinatal mental health services meet the needs of Tasmanian parents, families and children.

Although I am not a resident of Tasmania, the following experience gives me good standing to provide this submission to the Select Committee in order to assist Tasmanian citizens:

- Direct feedback I have received from Tasmanian families regarding their experiences of pregnancy loss within the Tasmanian health system;

- My Churchill Fellowship in 2023, identifying international best practice ways to improve both perinatal loss care and general maternity care in Australia;

- Effective advocacy within Australia since 2018 seeking improved care, particularly in hospitals, for families experiencing pregnancy complications and loss[1];

- The opening of a 3-bed, inpatient unit dedicated to caring for pregnancy complications and loss at the ACT's Centenary Hospital for Women and Children in 2023, as a direct result of my advocacy; and

- Lived experience of the maternity system (in another jurisdiction), including the loss of two babies in the second trimester of each pregnancy.

I give permission for the Select Committee to publish this submission. I am also prepared to give evidence at the hearing should it assist the Select Committee.

[1] See www.karenschlage.com

I commend the brave individuals who have made submissions to and appeared before this Inquiry to-date. It takes a lot of courage to share a very personal story in order to create meaningful change.

I also extend my heartfelt thanks to you and the Select Committee Chair, members and supporting staff for undertaking such an important Inquiry. I sincerely hope that you are all well supported personally and professionally as you work on this Inquiry, given the sensitive and often distressing material you are engaging with.

Yours faithfully,

Karen Schlage
14 September 2024

Response to the Terms of Reference

Churchill Fellowship

In 2023, I undertook a Churchill Fellowship and travelled to the United Kingdom, the United States of America and Canada. I set out to explore in-hospital companion programs for families experiencing pregnancy loss.

During my Fellowship, I engaged with:

- in-hospital and community doula and companion programs, including programs specializing in bereavement companion support;
- children's hospices and perinatal palliative care programs; and
- charities, advocacy programs, academics and government officials.

I returned to Australia having identified a number of best practice ways to support:

- pregnant people experiencing pregnancy complications;
- birthing people and families experiencing pregnancy loss; and
- health professionals providing relevant clinical care.

The breadth of my Churchill Fellowship experience also enabled me to identify a number of best practice ways to:

- improve support for all pregnant people, birthing people and health professionals in Australian hospital maternity units;
- positively impact clinical maternity outcomes; and
- improve the pregnant or birthing person's experience.

My report will be released in the near future at: https://www.churchilltrust.com.au/fellow/karen-schlage-act-2022/

The Tasmanian Department of Health should consider and apply the findings from the Churchill Fellowship report titled *The role of bereavement companions during pregnancy loss: Achieving better in-hospital support for birthing people, families and health professionals*, once it is published.

(a)(ii) – maternal health services

In-hospital companion programs

Overseas, in-hospital companion programs have proven to achieve increases in:

- satisfaction amongst pregnant and birthing people with their pregnancy and birth experience;
- non-instrumental, vaginal births;
- Vaginal Births After Caesarean (VBACs);
- Initiation of breastfeeding;

- Continuation of breastfeeding 6 weeks post-birth;
- Positive workplace experiences for clinicians; and
- Satisfaction and feelings of achievement amongst the companions themselves.

In-hospital companion programs have also proven to achieve decreases in:

- caesarean section births;
- instrumental births; and
- pre-term births.

These positive outcomes have particularly assisted people at risk of poorer birth outcomes overseas, such as black, indigenous and other people of colour, and other vulnerable cohorts.

In the United States, birth companions have proven so successful in supporting pregnant and birthing people and hospital care givers that, as at May 2024, 45 of the US states are either already reimbursing birth companion care through Medicaid, or are working towards doing so.

The initiatives identified during my Churchill Fellowship are evidenced-based examples from the United Kingdom, United States and Canada, supported by peer-reviewed academic papers. These countries have seen some remarkable results and there are important considerations for Australian maternity care, to make improvements for both pregnant and birthing people, and maternity care givers.

The Tasmanian Department of Health should introduce pilot programs for in-hospital companions to support pregnant and birthing people at Royal Hobart Hospital, with a particular focus on an in-hospital bereavement companion program to provide support during pregnancy complications and loss.

Subject to the outcomes of the pilot program, the Tasmanian Department of Health should introduce scaled, in-hospital companion programs for both perinatal bereavement and general maternity care, across Tasmania.

TeamBirth

Through my Fellowship engagements, I also identified a birth decisions program called TeamBirth, run by Ariadne Labs. Ariadne Labs is a health systems innovation centre, jointly run by the Brigham and Women's Hospital and the Harvard TH Chan School of Public Health in Boston, Massachusetts[2].

TeamBirth is an industry-standard process to improve communication, teamwork and shared decision-making throughout the birthing process. TeamBirth is designed to be used collaboratively between the birthing person and health professionals.

In a pilot trial of TeamBirth at four US hospitals, Ariadne Labs found that:

- 97% of birthing people had the role they wanted in making decisions about their childbirth experience
- 93% of clinicians felt that TeamBirth improved care

[2] www.araidnelabs.org/delivery-decisions-initative/teambirth/

- 90% of midwives, obstetricians and nurses would recommend TeamBirth for use in other birth units[3].

In the trials, TeamBirth also had a decrease in caesarean section numbers across all pilot sites, as well as increases in autonomy and trust and positive experiences for birthing people.

Consideration should be given to adoption of TeamBirth for use in Tasmanian maternity hospitals.

(a)(iii) – birth trauma and (a)(vi) – perinatal mental health services

Birth trauma and perinatal mental health in the context of pregnancy loss

Sadly, pregnancy loss (both early pregnancy loss and stillbirth) is very common in Australia. Miscarriage[4] is estimated to occur in at least one in every four known pregnancies, believed to be approximately 285 miscarriages every day[5], or one miscarriage every 5 minutes. Miscarriage numbers may be even higher, because miscarriage statistics are not specifically recorded in Australia. There are also 7.7 stillbirths[6] for every 1000 live births in Australia, or 6 stillbirths per day[7]. This equates to more than 106,000 pregnancy losses in Australia every year.

Pregnancy complications and loss are already a form of trauma for many birthing people and families, but it is often exacerbated by additional birth trauma.

A 2019 survey of Australian women found that 75% felt unsupported by their hospital care givers during their pregnancy loss[8]. International research indicates that up to 50% of women experience some form of psychological morbidity following miscarriage[9]. Recent Australian research shows that 60% of Australian women who have experienced pregnancy loss are living with depression and 31% of Australian women who have experienced pregnancy loss are currently dealing with Post Traumatic Stress Disorder (PTSD)[10]. One study shows that parents who experience a perinatal death have significantly worse quality of life than the general population[11]. Across the world, pregnancy loss has been linked to PTSD, depression, anxiety[12] , attempted suicide and completed suicide[13]. Pregnancy loss can also impact women's mental health during subsequent pregnancies[14].

Inappropriate or disrespectful language, and insensitive care

Families report birth trauma generated through the use of terminology that is deemed to be medically correct, but is often incredibly upsetting, such as "products of conception" or "spontaneous abortion".

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[3] www.ariadnelabs.org/2022/04/11/three-papers-detail-design-test-and-spread-of-teambirth/
[4] The loss of a pregnancy at less than 20 weeks' gestation.
[5] https://miscarriageaustralia.com.au/wp-content/uploads/2022/12/Understanding-Miscarriage.pdf
[6] The loss of a pregnancy at or beyond 20 weeks' gestation.
[7] https://www.aihw.gov.au/reports/mothers-babies/stillbirths-and-neonatal-deaths
[8] Berry, J. (2019)
[9] Lok & Neugebauer (2007)
[10] https://www.liptemberfoundation.org.au/2023-womens-mental-health-research
[11] Camacho et al (2024).
[12] Farren et al (2016); Westby et al (2021).
[13] Weng etc al (2018); Quenby et al (2021).
[14] Camacho et al (2024).

Insensitive interactions by medical care givers may create birth trauma during pregnancy loss that may endure for decades[15].

In addition to the use of inappropriate language, families report examples of insensitive care such as: care that was entirely clinical and not compassionate (and sometimes flippant or cruel); and care providers who were clearly uncomfortable and/or lacking training to provide appropriate care during pregnancy loss.

Care givers do not intentionally provide inappropriate or insensitive care to pregnant/birthing people and their families – the notion of causing these kinds of birth trauma is undoubtedly abhorrent to health professionals, who chose to enter caring professions. It is often a source of distress to hospital care givers that they are unable to provide the holistic and effective support families require[16].

However, people who are not trained in what to do or say at a time of pregnancy loss are more likely to either do or say the wrong thing, or to do or say nothing at all. Any of these possibilities are capable of causing birth trauma to grieving families. Tasmania must support its health care professionals to understand how to provide appropriate, family-led care during pregnancy loss.

This training is equally important in order to care for Tasmania's care givers as well as bereaved families; pregnancy loss is such a common occurrence that it is unfair to health professionals if they are not given adequate training to effectively support and holistically care for bereaved families. The risk of emotional and moral injury is great if insufficient training is provided to Tasmanian care givers in the pregnancy complication and loss space.

All Tasmanian health care professionals who are likely to provide care to people experiencing pregnancy loss must be required to undertake trauma-informed, bereavement-specific training, and to undertake regular refresher training.

Location of pregnancy loss care

I have heard from Tasmanian families about significant levels of birth trauma due to the location of their care during their pregnancy loss. Birth trauma has been caused for many families irrespective of whether they are cared for in hospital emergency departments (ED), early pregnancy assessment services (EPAS) or maternity units, including birth suites.

Hospital care pathways usually require that miscarriage is cared for in EDs or EPAS (depending on availability and opening hours). Stillbirth is typically cared for in birth suites.

Emergency Departments

From a clinical perspective, birthing people cared for in EDs are typically treated as non-urgent cases, because many are clinically stable when they present to ED.

[15] Ellis et al (2016).
[16] Ibid.

However, the birthing person and their family are often also experiencing significant distress, grief and anxiety. Birth trauma is often caused for bereaved families because care is delayed due to their allocated triage status. Once care is provided, it is often very clinical rather than compassionate.

Some birthing people miscarry in ED waiting room toilets and then face additional birth trauma when they need to decide whether to flush or retrieve their baby.

Early Pregnancy Assessment Services/Maternity Clinics

Pregnant people who are treated in EPAS or maternity clinics for pregnancy complications or loss report birth trauma from sitting in waiting areas alongside pregnant people who are not experiencing complications or loss. They report trauma from listening to everyday conversations that pregnant people have amongst themselves in such waiting areas: comments about feeling uncomfortable due to the baby's position or having swollen feet; grumbles about the delays; discussions about due dates and birthing choices. These are of course everyday chats that people are entitled to have. But they hurt incredibly deeply and cause trauma when you are sitting next to that person and you know your baby is experiencing complications or has already died.

This birth trauma is exacerbated when hospital staff engage with the birthing person presuming the baby is still alive or healthy, due to issues such as the pregnancy loss not being prominently identified in the medical file, or care givers not having time to read the notes.

Birth trauma is also caused when pregnant people are unable to access an EPAS due to limitations on opening hours or whether an EPAS is available at all, meaning they need to attend EDs or miscarry at home.

Maternity units/birth suites

Many birthing people describe the birth trauma caused when they were admitted to a maternity unit/birth suite for their pregnancy loss. Such trauma is caused when they see or hear other families on the unit, including the sights and sounds of foetal heartbeats, babies crying and the joy and happiness of families who have a living baby. A lot is done by health professionals to shield bereaved families from these sights and sounds, but they cannot be completely avoided when pregnancy loss care is provided in the same unit as live birth care.

Birthing persons experiencing pregnancy complications or pregnancy loss should be cared for in dedicated pregnancy complication/pregnancy loss units. Pregnancy loss care can then be diverted from EDs, EPAS and maternity units to the dedicated unit, ensuring a private and sacred space for families to worry or grieve.

The ACT recently opened such a unit[17], which has been very positively received across Australia and internationally, by both bereaved families and medical professionals. The unit is designed to be a therapeutic, healing space where pregnant and birthing people can receive the care they need from a multidisciplinary team. The unit supports overnight stays and incorporates three private-room beds with ensuites, a quiet room, a family room, an ultrasound room and consulting rooms. The unit is attached to the antenatal ward, but requires swipe access and ensures a private space for families.

[17] https://www.abc.net.au/news/2023-03-24/canberra-early-pregnancy-loss-unit-opens/102134498; https://www.cmtedd.act.gov.au/open_government/inform/act_government_media_releases/rachel-stephen-smith-mla-media-releases/2023/new-dedicated-unit-for-early-pregnancy-service

Bereaved families and their supporters are very strongly calling for this sort of care facility across Australia, with 31,161 Australians supporting a 2023 petition presented to Federal Parliament, calling for a dedicated bereavement suite or room in every Australian hospital[18].

The pregnant people, birthing people and families of Tasmania need to know that there will be somewhere they can go during pregnancy complications or pregnancy loss, where they will receive the care and support they require during a time that is emotionally, physically and mentally demanding. This care and support needs to be consistent in delivery, so that people can be assured of a dignified and comforting experience during pregnancy loss.

The Tasmanian Department of Health should open units dedicated to caring for people experiencing pregnancy complications and loss, which are co-designed and are physically separate to antenatal wards and clinics, birth suites and emergency departments, at the following hospitals:

- **Royal Hobart Hospital**
- **Launceston Hospital**
- **North West Regional Hospital**
- **Mersey Community Hospital**

A unit dedicated to caring for pregnancy complications and pregnancy loss should be provided in each hospital offering maternity services, particularly whenever any construction, renovation or relocation of maternity service facilities occurs in Tasmania.

Delays in treatment

Delays in treatment also cause birth trauma; some pregnant people have been required to continue carrying their deceased baby for many days beyond the diagnosis of their pregnancy loss. Where this is medically required, this needs to be very compassionately explained to the family and additional support must be given. Pregnant people should not be sent home with a perfunctory explanation and no support; walking around carrying a dead child inside you is incredibly devastating and traumatic. Surgical delays are similarly devastating and must be avoided wherever possible during pregnancy loss, in order to avoid additional birth trauma.

Once a pregnant person makes a decision regarding management of their pregnancy loss, the relevant medical care must be undertaken within a reasonable timeframe.

Diverse and marginalised communities

Additional birth trauma can be caused when the care provided during pregnancy loss focusses solely or largely on clinical care and not birthing person-led, psychosocial care.

Research evidences that non-pregnant/non-birthing parents experience significant grief[19], yet often feel excluded or unsupported during pregnancy complications and especially during pregnancy loss[20]. Birth partners often face different challenges to the birthing parent during loss, and their

[18] https://www.aph.gov.au/e-petitions/petition/EN4873
[19] Obst et al (2021).
[20] Watson et al (2019); Galeotti et al (2022); https://www.higa.ie/higa-news-updates/national-survey-maternity-bereavement-care-ireland-shows-most-parents-were

experiences need to be specifically recognised and supported[21]. This can be exacerbated when the birth partner already feels marginalised due to societal response to their identity.

Further issues can also be caused when information and resources do not reflect the identity or language of the birth partner and/or their family. Trauma can also ensue when no respect is paid to, nor allowance made for, the cultural or traditional beliefs and requirements of the birthing person and/or family. This denial of culture during pregnancy, birth and in memorialising the baby can cause significant distress.

Tasmanian resources and health professionals must:

- **use inclusive language and examples/case studies, particularly regarding those who identify as: First Nations, culturally and linguistically diverse, LGBTQIA+, and/or having a disability; and**
- **acknowledge, respect and incorporate different cultural and religious beliefs into Tasmanian health care for pregnancy complications and loss.**

Memory making and funerals

Birth trauma has been caused when bereaved families have been provided with incomplete or even no information about their options regarding memory-making and/or funeral arrangements, which prevents families from fully experiencing memory-making, bonding with and paying tribute to their baby.

Memory-making and funeral arrangements can be provided for any gestation of pregnancy loss, but the offering of such care is often for babies who die at a later gestation, leaving many families unaware of their options if they suffer early pregnancy loss.

The lack of information regarding these options has the potential to create further birth trauma by preventing families from following traditions that are culturally important to them.

Tasmanian resources and health professionals must ensure memory-making and funeral arrangement options are offered to families at the time of pregnancy loss within any Tasmanian health care setting.

Legislative settings

During my Churchill Fellowship, I became aware of relevant and important legislation introduced in Ontario, Canada in 2015.

The *Pregnancy and Infant Loss Awareness, Research and Care Act 2015* amended the *Ministry of Health and Long-Term Care Act 1990* to include the following function and duty of the Ontario Minister for Health: "to undertake research and analysis on pregnancy loss and infant death that assists those, including [parents] and families, who experience such loss and that informs the establishment or expansion of programs related to such loss".

[21] Obst et al (2020).

This legislation has allowed consistent focus and funding for pregnancy loss research, analysis and support within Ontario.

Legislative change such as this would enable Tasmania to lead the way in Australia by preventing birth trauma associated with pregnancy loss through the funding of research and analysis, and the provision of appropriate support for bereaved families.

Tasmania should introduce legislation requiring active research, analysis and support regarding pregnancy loss, with associated funding.

(a)(iv) – workforce shortages

The Tasmanian maternity workforce can be supported in providing both bereavement-specific and broader maternity care through the introduction of in-hospital companion programs. Overseas experience and best practice has shown these programs are full of potential to greatly assist obstetric health professionals, who are under incredible stress within health systems across Australia.

A recent survey of New South Wales nurses and midwives showed that 15% report high levels of symptoms that would meet the criteria for PTSD, and 58% of nurses and midwives surveyed planned to leave their role within the next five years, with 37% planning to leave within 12 months and 22% wishing to leave the health profession entirely[22]. While this clearly cannot be directly extrapolated to Tasmania, it is apparent from news coverage and anecdotal feedback that similar issues affect nurses and midwives in Tasmania and across Australia. As a society, we need to do everything we can to support our maternity care givers.

Internationally, appropriately trained companions who have clearly defined roles and scopes of practice have been proven to help ease clinicians' work and workloads. There is an opportunity for a shared emotional load between clinicians and companions, which may help to prevent stress and burnout for health professionals in the workplace. If support can be provided in these meaningful ways, it may assist in staff retention and the associated improvement of workforce shortages across the Tasmanian maternity system.

These overseas programs have become integral parts of the care provided by each relevant hospital. There is acknowledgement and gratitude amongst health professionals that companions are able to fill spaces and provide care that health professionals are unable to provide, due to workforce shortages, time constraints or workloads.

[22] https://www.nswnma.asn.au/wp-content/uploads/2023/02/Impacts-of-COVID-19-and-workloads-on-NSW-nurses-and-midwives-mental-health-and-wellbeing_final.pdf

(c) – to make recommendations on actions that can be taken by the State Government to ensure reproductive, maternal and paediatric health and perinatal mental health services meet the needs of Tasmanian parents, families and children

I make the following recommendations for consideration by the Select Committee:

1. The Tasmanian Department of Health should consider and apply the findings from the Churchill Fellowship report titled *The role of bereavement companions during pregnancy loss: Achieving better in-hospital support for birthing people, families and health professionals*, once it is published.

2. The Tasmanian Department of Health should introduce pilot programs for in-hospital companions to support pregnant and birthing people at Royal Hobart Hospital, with a particular focus on an in-hospital bereavement companion program to provide support during pregnancy complications and loss.

3. Subject to the outcomes of the pilot program, the Tasmanian Department of Health should introduce scaled, in-hospital companion programs for both perinatal bereavement and general maternity care, across Tasmania.

4. Consideration should be given to adoption of TeamBirth for use in Tasmanian maternity hospitals.

5. All Tasmanian health care professionals who are likely to provide care to people experiencing pregnancy loss must be required to undertake trauma-informed, bereavement-specific training, and to undertake regular refresher training.

6. The Tasmanian Department of Health should open units dedicated to caring for people experiencing pregnancy complications and loss, which are co-designed and are physically separate to antenatal wards and clinics, birth suites and emergency departments, at the following hospitals:

    - Royal Hobart Hospital
    - Launceston Hospital
    - North West Regional Hospital
    - Mersey Community Hospital

7. A unit dedicated to caring for pregnancy complications and pregnancy loss should be provided in each hospital offering maternity services, particularly whenever any construction, renovation or relocation of maternity service facilities occurs in Tasmania.

8. Once a pregnant person makes a decision regarding management of their pregnancy loss, the relevant medical care must be undertaken within a reasonable timeframe.

9. Tasmanian resources and health professionals must:

    - use inclusive language and examples/case studies, particularly regarding those who identify as: First Nations, culturally and linguistically diverse, LGBTQIA+, and/or having a disability; and

- acknowledge, respect and incorporate different cultural and religious beliefs into Tasmanian health care for pregnancy complications and loss.

10. Tasmanian resources and health professionals must ensure memory-making and funeral arrangement options are offered to families at the time of pregnancy loss within any Tasmanian health care setting.

11. Tasmania should introduce legislation requiring active research, analysis and support regarding pregnancy loss, with associated funding.

Karen Schlage
14 September 2024

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