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INQUIRY INTO BIRTH TRAUMA

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We are 3 counsellors who work, or have previously worked, with Red Nose in NSW. Red Nose provides bereavement counselling at no fee to individuals who have been impacted by the death of a baby or a child. This includes death of a baby during pregnancy due to ectopic pregnancy, miscarriage, termination for medical reasons, stillbirth, and neonatal death. Between the three of us we have qualifications in counselling, psychology and social work and have over 15 years experience of working with bereaved individuals and couples, many of whom have experienced birth trauma as a result of their pregnancy. This paper draws on the anecdotal evidence of working at Red Nose Australia, listening to parents share their experiences and other relevant research.

We wish to respond to specific items from the terms of reference: continuity of care, informed choices, and systemic barriers to trauma-informed care. We also wish to provide additional comments regarding trauma and perinatal loss whilst acknowledging that the gestation of a baby does not correlate with the level of grief or trauma a parent may experience.

We concur with the Australian Birth Trauma Association's definition of birth trauma: "Birth Trauma is a woman's experience of interactions and/or events related to childbirth that cause overwhelming distressing emotions and reactions, leading to short and/or long-term negative impacts on a woman's health and wellbeing (Leinweiber et al, 2022)." Please note we also include the woman's partner's experience within the scope of birth trauma.

Firstly, we want to acknowledge the many stories we have heard from our clients about the compassionate, respectful, collaborative, and wise care they received from healthcare professionals (including midwives, nurses, doctors, GPs, and paramedics) during their perinatal loss experience. Often several very specific moments in care continue to be appreciated as precious memories by parents.

Perinatal loss is often a traumatic event for women and their partner/support person. Recent studies confirm "women experience high levels of posttraumatic stress, anxiety, and depression after early pregnancy loss." (Farren et al., 2020). The loss of a baby is distressing, overwhelming, and often unexpected. "Emotional trauma is prevalent throughout the perinatal loss experience, with up to 60% of parents meeting the criteria for PTSD. Many parents continued to experience PTSD for years following their loss experience". (Berry, 2022). We have also worked with many individuals who have unfortunately experienced additional trauma through their perinatal loss related to the lack of continuity of care, lack of informed choice making, and interactions with healthcare professionals and institutions.

Insufficient informed choice

Assumptions may be made about the woman's knowledge. For example, some mothers when making the decision to terminate their pregnancy due to medical reasons are not aware this often means they will need to go through labour and delivery to terminate the pregnancy. Similarly some parents do not realise labour and delivery (as opposed to a caesarean section) is how their stillborn baby will be delivered. Some mothers in this situation are experiencing labour and delivery for the first time in order to deliver their baby who has died (or will die soon after birth). Fathers and birth partners can be left traumatised when there is a birth complication or emergency. Fathers/partners may be ushered out of the room and left alone elsewhere with insufficient information. They are left alone wondering if their partner is still alive and if their baby is alive. Compassionate provision of information is crucial to mitigate traumatic experiences.

Parents may be traumatised by their sense of powerlessness during their experience of perinatal loss. When mothers raise concerns that something is wrong with their baby/pregnancy they may not be treated like experts in their own body and pregnancy. Where a parent's concerns are not responded to with the perceived appropriate level of concern and their baby subsequently dies, parents can be left traumatised by a powerlessness to save their baby. Their failed attempts to advocate for their baby can haunt them. This can impact the parent's ability to trust the medical profession in the future to keep them and their baby safe.

Birth happens as part of miscarriage, termination for medical reasons, and stillbirth. As well as maternity wards, birth also happens in other settings including at home, in an emergency department, and in ambulances. Women may be traumatised by their experience of miscarriage at home after presenting to a hospital with concerns about their pregnancy and subsequently returning home. We know trauma can occur when a person feels overwhelmed and alone. Sending a parent home to await a natural miscarriage leaves them vulnerable to traumatisation. Some women are not given sufficient information about what to expect when miscarrying at home. Some women are only told to expect pain similar to period cramps however for some women their pain has been akin to labour contractions. Some women are traumatised after delivering their foetus alone at home into their hands or into the toilet. Some women are not prepared for and given options about what can be done with the remains of their baby. This means some women don't know if they are able to bury their baby in their backyard or a pot plant, if they can bring their baby's remains to a hospital or funeral home, or they may flush their baby's remains down the toilet because they are not prepared when this moment happens in their miscarriage. Sensitive and compassionate communication of choices, options, and information is urgently needed.

Parents experiencing miscarriage or threatened miscarriage may be traumatised by their experience of care in hospital emergency departments (ED). There are women who have been told to wait in EDs

while bleeding, terrified, and in pain. Some women have then miscarried their babies into a toilet in the ED. We understand Early Pregnancy Assessment Services (EPAS) were established after the NSW parliamentary inquiry following Jana Horska's 14 week miscarriage experience at hospital (Oderberg, 2021). Unfortunately EPAS clinics run during limited hours only (such as 8 am - 3 pm). Outside of these times, women may be directed to the ED. For parents in regional and rural areas, access is even more difficult.

Lack of continuity of care

The lack of continuity of care during a mother's or father's perinatal loss increases the risk of traumatisation. Often parents do not see the same healthcare providers throughout. This means stories may have to be repeated. Also different healthcare providers may have different opinions or different levels of concerns about the baby/pregnancy leaving parents feeling unsafe or confused during an already traumatic time.

Additional risks of traumatisation for regional and rural parents

Care available to parents experiencing perinatal loss is more limited in regional and rural areas. Parents may have to wait longer and/or travel hours for an ultrasound to check if their baby is still alive, or to have a termination for medical reasons, or to attend a suitable hospital to labour and deliver their baby who has died. This additional wait and time leaves parents more vulnerable to traumatisation.

Subsequent pregnancies after a previous perinatal loss

After a perinatal loss, some parents conceive again. Pregnancies subsequent to perinatal loss are often wrought with anxiety and PTSD (Berry, 2022). Participating in antenatal care can be triggering, for example being in a hospital room again or smelling the same smells again. Where parents in a subsequent pregnancy are treated no differently to any other pregnancy there is a risk of re-traumatisation.

Systemic barriers to trauma-informed care

Unfortunately interactions with healthcare professionals and institutions during perinatal loss can exacerbate trauma. There can be a lack of understanding that death of a baby (at any gestation!) is *a significant loss* and therefore appropriate bereavement care is not provided. Red Nose have been involved in the development of the revised NSW Health Guidelines for Perinatal Loss due to be released soon. We hope these guidelines are fully adopted and practised by all LHDs in NSW.

We have concerns about The NSW Health Integrated Trauma-Informed Care Framework. Our understanding of the framework recommends the approach of "presuming that every person — clients

and staff — may have experienced trauma" and that this trauma is historical "in the context of their past experiences" and has a particular focus on Adverse Childhood Experiences (ACEs). While these are all appropriate for the framework, we believe the framework needs to go further and acknowledge the potential for trauma to be *caused* by an individual's interaction with the NSW Health system. Specifically in relation to perinatal loss, it is critical to approach perinatal loss through a lens of trauma. Health care professionals have a key role in reducing risk of traumatisation and helping parents cope with posttraumatic stress. Berry (2022) suggests "the adoption of a Trauma-Informed Care framework specifically adapted to meet the needs of bereaved parents may improve patient outcomes following perinatal loss".

Conclusion

We have worked with many individuals who have unfortunately experienced additional trauma through their perinatal loss related to the lack of continuity of care, lack of informed choice making, and interactions with healthcare professionals and institutions.

Emotional trauma is prevalent throughout the perinatal loss experience, with up to 60% of parents meeting the criteria for PTSD. The gestation of a baby who dies does not correlate with the level of grief or trauma a parent may experience. Parents are vulnerable to traumatisation during a perinatal loss birth due to the lack of continuity of care, insufficient informed choices, and systemic barriers to trauma-informed.

Insufficient informed choice due to incorrect assumptions made about the parent's knowledge of birth and process of perinatal loss leaves parent's vulnerable to trauma. Parents may also be traumatised by their sense of powerlessness during their experience of perinatal loss. This can impact the parent's ability to trust the medical profession in the future to keep them and their baby safe. Fathers and birth partners can be left traumatised after being ushered out of the room and left alone to wonder if their partner and baby is still alive. Compassionate provision of information is crucial to mitigate traumatic experiences.

As well as maternity wards, birth also happens in other settings including at home, in an emergency department, and in ambulances. Women may be provided with insufficient informed choices regarding what to expect and how to prepare for miscarriage at home particularly in terms of pain, having a suitable support person present, and decisions regarding the remains of their baby. For miscarriages that occur in hospital settings but outside of maternity wards (for example, EPASs and EDs), a radical new approach is urgently needed. Due to current triage procedures and staff pressures we believe EDs are not able to provide appropriate miscarriage care.

Perinatal loss can be more traumatic for parents when they do not receive continuity of care due to needing to repeat stories, receiving differing opinions, and feelings of insecurity or confusion. Furthermore, parents who lose their baby in rural areas face more challenges and trauma due to limited and distant care options.

The lack of understanding that the death of a baby (at any gestation) represents *a significant loss* means appropriate bereavement care may not be provided. We hope healthcare facilities will be sufficiently resourced in order to thoroughly implement the revised NSW Health Perinatal Loss guidelines. Where parents in a subsequent pregnancy after perinatal loss are treated no differently to any other pregnancy there is a risk of re-traumatisation. Finally, we believe the NSW Health Integrated Trauma-Informed Care Framework needs to go further and acknowledge the potential for trauma to be *caused* by an individual's interaction with the NSW Health system. In relation to perinatal loss the adoption of a Trauma-Informed Care framework specifically adapted to meet the needs of bereaved parents is needed to reduce traumatisation and re-traumatisation.

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Jaclyn Rae, Social Worker
Kirsteen Moss, Psychologist.

We are all available to give evidence at a hearing.

References

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