



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

STANDING COMMITTEE ON HEALTH, AGEING AND COMMUNITY SERVICES
Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair)
Ms Caroline Le Couteur MLA

Submission Cover Sheet

Inquiry into Maternity Services in the ACT

Submission Number: 38 - Addendum

Date Authorised for Publication: 11.06.2019

**Addendum to Submission Number 38
Standing Committee on Health, Ageing and Community Services –
Inquiry into Maternity Services in the ACT**

The extension of time for the Inquiry into Maternity Services in the ACT has provided me with an opportunity to further refine my concept for the establishment of a perinatal hospice in the ACT.

I am grateful to the members of the ACT's medical and academic professions who have made themselves available to meet with me and to discuss ways in which the ACT's approach to perinatal and pregnancy loss can be strengthened.

I am also grateful to the ACT Minister for Health, for meeting with me in April 2019. The Minister undertook to put me in touch with the Chief Medical Officer and Chief Midwifery Officer for the ACT, with a view to the drafting of a relevant Model of Care. I hope to have this contact established and to meet with the Officers in the near future.

With the benefit of further research and consultation, the refined hospice concept is currently as follows:

Hospice concept

A facility:

- Providing perinatal hospice and pregnancy bereavement care services;
- Servicing women from the ACT and surrounding regions;
- Located within the Women, Youth and Children's Hospital (WYCH); close to, but not within, the Maternity ward;
 - I met with [REDACTED], then-Executive Director of WYCH, on 27 February 2019. [REDACTED] advised that WYCH will explore what options are available for a dedicated facility as part of the upcoming WYCH refurbishment.
 - WYCH undertook to come back to me by June 2019 to update me on progress in this regard.
 - I met with executive staff from Calvary Hospital, who indicated that they are supportive of my concept but that the Calvary Hospital footprint is too small to host a dedicated facility.
- That provides the highest standard of medical care, in a less-medicalised setting;
- That is solely dedicated to the purpose, unlike the TCH Angel Room which is used only when available (if a woman already occupies the room, she will not be moved in order to accommodate a woman who fits the criteria for the Angel Room);

- Where women who are experiencing miscarriage, stillbirth, labour and delivery following a medical termination, or delivery of a baby with a life limiting condition, are cared for;
 - This includes the provision of over-the-phone care for women experiencing miscarriage who do not wish to attend hospital. Clinical pathways must be created to specifically support this type of care.
 - This also includes the provision of over-the-phone care for women experiencing miscarriage who do wish to attend hospital; to ensure that clear, consistent information is provided to women so that they have certainty regarding when they should present to hospital.
- Where women who have given birth may transfer with their baby (including deceased babies), allowing them and their families and friends to spend quality time with their dying or deceased child. For deceased children, this would involve the use of Cuddle Cots or similar;
- Providing medical and ancillary care and/or referral for women and their babies, including but not limited to:
 - Obstetricians
 - Neonatologists
 - Geneticists
 - Sonographers
 - Midwives and nurses, including those specifically trained in perinatal loss and bereavement care
 - Lactation consultants specialising in lactation after grief
 - Bereavement and loss counsellors and doulas
 - Psychologists
 - Social workers
 - Social support services
 - Pastoral care support
 - Appropriately trained volunteers
- That allows women and their families to make meaningful plans to honour their baby's life, birth and death, no matter the baby's gestation. This includes but is not limited to:
 - Birth plans specific to their particular circumstances;
 - Ways of creating memories with their baby while the baby is still in utero;
 - Ways of creating memories with their baby after birth/death, such as the use of Cuddle Cots, taking photographs, making hand and footprints, the provision of Angel Gowns or similar, and the use of memory boxes; and

- Provision of information regarding options for funeral arrangements, and provision of assistance as appropriate (including baptism/blessing arrangements for a living baby).

Other requirements

- Education/information (a 'crash-course') must be provided to women and families presenting to hospital to labour & deliver when they have not yet been to childbirth education classes.
- Information regarding the option of a "palliative pregnancy"/perinatal palliative care must be presented to women whose baby has been diagnosed with a life limiting condition in utero.
- Information for women regarding what to do in the event of miscarriage is to be incorporated into community education provided by midwives
 - In my meeting with WYCH executive staff on 27 February 2019, this was undertaken to be introduced in the near future.
- Information regarding what to do in the event of miscarriage is to be incorporated into GP education sessions conducted by WYCH specialists.
 - In my meeting with WYCH executive staff on 27 February 2019, this was undertaken to be introduced in the near future.
- All medical staff engaging with women and families experiencing perinatal loss must be trained in identifying and using language appropriate to the woman/family, reflecting language used by the woman/family, such as "baby" rather than "products of conception" or similar medicalised terms.
- Perinatal bereavement care training must form part of the training for all those who are likely to professionally assist with perinatal loss. This must cover all forms of pregnancy loss and not just stillbirth/neonatal death.

I look forward to the opportunity to provide an update on further developments when I am called to appear before the Inquiry.

My recommendations for consideration by the Committee remain as per my initial submission.

Karen Schlage
2 June 2019