The Hon Roger Cook MLA  
Deputy Premier  
Minister for Health; Mental Health  

Our Ref: 60-09239

Hon Matthew Swinbourn MLC  
Chair  
Standing Committee On Environment and Public Affairs  
Parliament House  
4 Harvest Terrace  
WEST PERTH WA 6005

Dear Mr Swinbourn,

Thank you for your letter of 17 May 2018 requesting additional information regarding the Petition No 32 – Induced Premature Births, and advice to address specific concerns raised by the petitioners about the management of live births following late term abortion.

As requested by the Standing Committee on Environment and Public Affairs, please find attached advice responding to each of the additional issues raised. This is located in Attachment 1.

All responses for ‘late term abortions,’ in attachment 1 have been interpreted as meaning post 20 weeks gestation abortions for the purposes of this reply.

As you will see from this response, the service for post 20 week abortions is provided in accordance with the relevant procedures and policies within the WA legislative framework, as well as the guidelines from the World Health Organisation.

Further to my letter of 9 April 2018, I confirm my position that I will not be recommending a review on the process or an inquiry into individual cases. This topic is extremely sensitive and it is necessary to respect the privacy and confidentiality of the grieving families.

Thank you for writing to me on this important matter.

Yours sincerely,

[Signature]

HON ROGER COOK MLA  
DEPUTY PREMIER  
MINISTER FOR HEALTH; MENTAL HEALTH

Att:

20 JUL 2018

13th Floor, Dumas House, 2 Havelock Street, WEST PERTH WA 6005  
Telephone: +61 8 6552 6500 Facsimile: +61 8 6552 6501 Email:Minister.Cook@dpc.wa.gov.au
1. **What is accepted as the borderline age for gestational viability?**
   The accepted borderline age is 23-25 weeks gestation.

2. **It is the Committee's understanding that the concept of 'intolerability' is generally applied in determining a baby's best interests in regard to treatment.**
   Given that all severe fetal abnormalities that may justify a late term abortion in accordance with s334(7) of the Health Act 1911 (the Health Act) will not inevitably result in death, but may impose an intolerable burden upon a baby, what are the most common types of:
   - **lethal abnormalities where neonatal death is inevitable**
     The common types of lethal abnormalities where neonatal death is inevitable include: Anencephaly, Bilateral Renal Agenesis, Thanatophoric dysplasia.
   - **non-lethal abnormalities?**
     The common types of abnormalities, which may be but are not necessarily lethal, include: Neural Tube Defects, Hydrocephalus, Severe Complex Cardiac Anomalies and Chromosomal Anomalies.

3. **How many late term abortions resulted in a live birth since 2013?**
   'Late term abortion' has been interpreted as abortions undertaken at 20 weeks gestation or greater. From 2013 to 2017 (inclusive) there were 8 abortions at 20 weeks gestation or greater that resulted in a live birth.

4. **How many live births since 2013 involved:**
   - **babies born beyond the clinical limit of viability?**
     Less than 5
   - **babies with a lethal abnormality**
     To identify this number would allow the calculation of the answer to the next dot point due to the answer at question 3. In the circumstances, it is not appropriate to identify the number.
   - **babies with a non-lethal abnormality**
     Less than 5

   *NOTE: The answer to this question has been given presuming the question relates to post 20 week gestation abortions and NOT all registered live births. Due to the potential of disclosure of this sensitive information to cause further distress to the grieving families, the Department of Health suppresses information in accordance with the Department of Health's Guidelines for the Release of Data where there are 5 or less cases to avoid any inadvertent breach of confidentiality.*

5. **How many babies born after late term abortion died from "reasons other than the severe abnormality for which the abortion was performed" (such as prematurity), unless the abnormality is such that early neonatal death is inevitable irrespective of gestational age?**
   The babies (number less than five) who were born alive with a non-lethal abnormality died at gestations considered to be either pre-viable or at borderline viability.
6. Please provide current clinical guidelines for late term abortion.
All post 20 week abortions performed at King Edward Memorial Hospital (KEMH) are managed as a perinatal loss through the Perinatal Loss Service, recognising that these are wanted pregnancies where parents have made the difficult decision to interrupt the pregnancy due to a serious maternal and/or fetal medical disorder.

7. Is intracardiac potassium or other methods used for non-lethal abnormalities to ensure that late term abortion does not result in a live birth?
Yes

   - In what circumstances is feticide not part of the termination procedure?
     Feticide is not part of the termination procedure if the gestation is less than 22 weeks, unless the mother requests it or when the termination is for severe maternal disease with risk to the mother’s life and there is no time to wait for the expertise of trained personnel to undertake a feticide procedure. The chance of the fetus surviving labour in these circumstances is very low.

   - Are there situations where a live birth has occurred following late term abortion for a non-lethal fetal abnormality? Why?
     Yes, these births occurred at gestations considered to be below the limit of viability.

8. What is the range of survival duration for live births following late term abortion since 2013?
The range of survival duration is 9 minutes to 2 hours 10 minutes.

9. What care is provided to a baby following live birth after a late term abortion?
Sensitive comfort care is provided in a similar manner to care provided to babies born at pre-viable gestations following spontaneous premature labour with the baby being wrapped in blankets and the parents offered the chance to hold their baby for the short time that their baby is alive.

   - What considerations are involved in the decision-making process about appropriate care? Please provide relevant clinical guidelines.

     Clinical Guideline - Perinatal Palliative Care Model of Care (Attachment 2)
     The Perinatal Palliative Care Model of Care (the Model) provides pathways for the referral and entry of the fetus/newborn and their family into a palliative care approach. In addition the model assists health care professionals planning and providing this care, and the wider community of service providers involved.

     Generally three circumstances exist where perinatal palliative care may be considered:

     1. Prenatally diagnosed fetal anomalies or life-limiting conditions.
     2. Pre-viable preterm fetus where birth is imminent.
The goals of care may differ for the fetus and newborn compared with other babies, however, the standard and quality of care is the same. The goals of care for the fetus/newborn and family are that they will:

- receive best practice perinatal palliative care according to their needs;
- participate in decision making and care planning throughout their care with the focus being on the 'best interests' of the baby;
- have ready access to specialist palliative care services;
- receive coordinated care across all sectors of health and community agencies;
- receive care and support in their chosen place of care; and
- be supported in their bereavement.

**When is palliative care provided and what does it involve?**

Palliative care following near-term delivery is often offered as an alternative to termination. This is an active process of care but with a focus on providing support and comfort for the child and family. For some families this a preferred option.

When offered the family meet with the perinatal loss midwifery consultant and a neonatologist who are involved in this care. Over the course of one to several meetings a care plan is jointly constructed that covers labour, birth and subsequent care of the child and family. While the details are specific to the family the following is an outline of what is covered:

- List of all involved -- contacts
- Care during labour -- monitoring etc
- Mode of birth
- Details of resuscitation to be offered
- Whether care is with parents or in nursery
- Feeding
- Pain relief if required
- Likely mode of death
- Possibility of discharge home and supports likely to be required.
- What will happen after death, funeral arrangements, possible PM etc.

**When is intensive care provided and what does it involve?**

Neonatal intensive care is the provision of appropriate intervention to infants with a focus on survival. Active resuscitation is undertaken with transfer to an appropriate level of neonatal nursery for ongoing management as required.

**When is it not in the baby's best interest to be provided with intensive care treatment?**

There are circumstances when the burdens and harms of neonatal intensive care may outweigh the potential benefits. For infants with some conditions this may be ascertained antenatally.

Anencephaly (failure of formation of the higher brain and skull vault), trisomy 18, trisomy 13 and inoperable congenital heart disease are examples of conditions where a palliative approach is offered.
10. What are the legal implications for health workers when intensive care is not provided to a baby born alive with a non-lethal condition following an abortion? Has the Health Department sought legal advice in relation to this issue? Legal advice has not been sought on this question.

11. Has the medical/legal environment changed since current abortion legislation was introduced in Western Australia?

The ministerially appointed panel consists of experts in the clinical areas of Maternal Fetal Medicine, Neonatology and Genetics as well as other medical clinicians. Additional external expertise via report is obtained as required.

Advances in prenatal diagnosis and paediatric management have resulted in a change to those conditions which were previously considered to have a severe medical condition as reason to justify an abortion under Section 334(7) of the Health Act. These include advances in prenatal diagnosis with improved ultrasound and imaging technology and genetic testing with the advent of microarray techniques and detection of single gene disorders for example as well as advances in paediatric medical and surgical techniques.

Similarly these new diagnostic techniques mean that such severe conditions may now be diagnosed before birth, enabling parents to request termination of pregnancy under Section 334(7) of the Health Act. Such severe conditions may not necessarily be able to be diagnosed prior to 20 weeks gestation.

- Has current practice been reviewed in the last ten years in relation to clinical practice, ethics and the law in relation to the management of late term abortion?

In June 2017 KEMH introduced the practice of feticide for terminations of pregnancy after 22 weeks, including those for lethal abnormalities.

The exception is when the termination is for severe maternal disease with risk to the mother's life and there is no time to wait for the expertise of trained personnel to undertake a feticide procedure. The chance of the fetus surviving labour in these circumstances is very low. This is consistent with practice in the UK and also in Victoria, Australia.

There are occasions where women, seeking abortion and where panel approval has been given under Section 334(7) of the Health Act, choose to continue their pregnancy knowing their child has a lethal condition, rather than having the invasive procedure of feticide. In these circumstances, their live born child would be offered perinatal palliative care rather than active or intensive care.
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Endorsed by SHEF September 2014. Revised August 2015 with minor edits. For details of the edits, please contact palliativecare.cpcn@health.wa.gov.au.

A steering group (as detailed in Acknowledgements) developed this document with support from the WA Cancer and Palliative Care Network and Women’s and Newborns’ Health Network.

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Important disclaimer

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Contact information

For further information, contact the WA Cancer and Palliative Care Network, WA Department of Health on (08) 9222 0202 or contact palliativecare.cpcn@health.wa.gov.au.
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**Acknowledgements**

Members of a Core Steering Group developed the *Perinatal Palliative Care Model of Care* (Model). The members included:

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<th>Area</th>
<th>Dates</th>
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Additionally, a diverse range of stakeholders contributed to the development of the Model through a consultation process undertaken in early 2014.
Executive summary

Perinatal palliative care is a holistic approach to supportive and end-of-life care. The aim of the Perinatal Palliative Care Model of Care (Model) is to ensure provision of best care during pregnancy, childbirth and the newborn period when a fetus has an identified fetal anomaly or a newborn has an identified life-limiting condition.

This Model provides pathways for the referral and entry of the fetus/newborn and their family into a palliative care approach. In addition the model will assist health care professionals planning and providing this care, and the wider community of service providers involved.

Generally three circumstances exist where perinatal palliative care may be considered:

1. Prenatally diagnosed fetal anomalies or life-limiting conditions.
2. Pre-viable preterm fetus where birth is imminent.

The goals of care may differ for the fetus and newborn compared with other babies, however, the standard and quality of care is the same. The goals of care for the fetus/newborn and family are that they will:

- receive best practice perinatal palliative care according to their needs
- participate in decision making and care planning throughout their care with the focus being on the ‘best interests’ of the baby
- have ready access to specialist palliative care services
- receive coordinated care across all sectors of health and community agencies
- receive care and support in their chosen place of care
- be supported in their bereavement,

Three stages are outlined that reflect best practice perinatal palliative care in WA:

1. Entry into a palliative care pathway.
2. Living with the condition.
3. End-of-life and bereavement care.
Recommendations

The recommendations for the implementation of the *Perinatal Palliative Care Model of Care* (Model) are:

1. The *Perinatal Palliative Care Model of Care* is endorsed for use by the Department of Health, Western Australia.

2. Health care providers have access to education and training to enable them to provide quality palliative care to families facing a perinatal loss.

3. An audit of satisfaction with, and effectiveness of, the Model be considered in consultation with King Edward Memorial Hospital (KEMH) and Princess Margaret Hospital (PMH) and other service providers as appropriate.

4. Outcomes from the audit inform the development of statewide evidence based policies and protocols and clinical guidelines for best practice palliative care in the perinatal period.

5. Services are informed of the referral pathways described in the Model to promote appropriate referrals.

6. Strategies are developed to provide culturally appropriate perinatal palliative care for Aboriginal and Culturally and Linguistically Diverse (CaLD) infants, and their families, in partnership with Aboriginal Health Services and other appropriate stakeholders.

7. The *Perinatal Palliative Care Model of Care* is regularly reviewed by the Women’s and Newborns Health Network and WA Cancer and Palliative Care Network (Palliative Care Program) to ensure it reflects best practice.
1. **Overview of the *Perinatal Palliative Care Model of Care***

The *Perinatal Palliative Care Model of Care* (Model) outlines best practice palliative care for the fetus/newborn and their family during pregnancy, childbirth and in the newborn period. The Model sits under the overarching *WA Palliative Care Model of Care*, the *Improving Maternity Services Framework* and the *Framework for the Care of Neonates in Western Australia*. It aligns with the *Paediatric and Adolescent Palliative Care Model of Care*.

**Figure 1:** The *Perinatal Palliative Care Model of Care* in relation to other WA Models of Care

![Diagram showing the relationships between WA Palliative Care Model of Care, Framework for the Care of Neonates in Western Australia, Improving Maternity Services Framework, Rural Palliative Care, Paediatric & Adolescent Palliative Care Model of Care, and Perinatal Palliative Care Model of Care.](image)
2. Overview of perinatal palliative care

The perinatal period is considered to commence at 20 completed weeks of gestation and ends 28 days after birth.

Perinatal palliative care is a holistic approach to supportive and end-of-life care for fetuses/newborns and their families. It follows an agreement between the family and the multidisciplinary care team on a palliative care approach for a fetus/newborn and their family. This holistic approach is patient and family-centred and “…embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the [neonate/infant] and support for the family. It includes the management of distressing symptoms…and care through death and bereavement.”

Perinatal palliative care can be planned and initiated early where the condition of the fetus/newborn is known prior to birth. This may occur when a fetus is diagnosed with a lethal fetal anomaly or where there is an imminent birth at a pre-viable gestation. Palliative care can be initiated for newborns/infants in the postnatal period when the condition is diagnosed after birth. It can be integrative with curative treatment where appropriate and there may be a period of transition from active to palliative care with symptom management only when it is recognised that the baby will not benefit from life-sustaining interventions.

Maternal health and wellbeing during pregnancy, childbirth and the postnatal period remain a component of maternity care, including when there is a palliative approach to the care of the baby.

2.1 Background of perinatal palliative care in WA

There were 1326 perinatal deaths comprising stillbirths and neonatal deaths in Western Australia (WA) between 2004 and 2008. Birth defects are a major cause of perinatal death. The WA Register of Developmental Anomalies from 1980-2010 reported that 3.8% of all births had a congenital anomaly. The most common congenital anomalies were musculoskeletal, cardiovascular and neural tube defects.

Where a prenatal diagnosis of a fetal anomaly is made, management options include continuing or terminating the pregnancy. The subject of termination of pregnancy is a complex issue, which is not discussed in this Model of Care. In WA, an increasing number of families choose a palliative approach in the presence of a fetal anomaly as an alternative to termination. This trend has also been noted internationally, possibly in response to improved palliative care options.
3. **Model of Care**

The aim of the *Perinatal Palliative Care Model of Care* (Model) is to improve care provision during pregnancy, childbirth and the newborn period where there is an identified fetal anomaly or life-limiting condition. It aims to support families by incorporating a palliative approach into perinatal care. This Model provides pathways for the referral of, and entry of, the fetus/newborn and their family into palliative care. In addition, the Model will assist health care professionals in planning and providing this care and the wider community of service providers involved in care.

### 3.1 Principles of the Model

The principles underpinning the Model are adapted from the *Paediatric and Adolescent Palliative Care Model of Care*. The goals of care may differ for the fetus and newborn in perinatal palliative care compared with other babies and their families, however, the standard and quality of care remains the same.

<table>
<thead>
<tr>
<th><strong>Right Care</strong></th>
<th>The fetus/newborn, mother and family form the focus of care. Physical, spiritual, psychosocial and cultural needs direct the care to be provided.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Right Time</strong></td>
<td>Palliative care is accessible at any stage in the fetus/newborn and mother’s journey; this may be antepartum, intrapartum, at birth or in the postnatal or neonatal period.</td>
</tr>
<tr>
<td><strong>Right Team</strong></td>
<td>A specialist Multidisciplinary Team (MDT) with expertise in maternal and newborn care and palliative care continues to manage care with support from specialist palliative care services. Primary, secondary, tertiary and community professionals work collaboratively to provide care, promoting continuity of care and caregiver. The Model recognises the need for a case manager and care coordination (local to the fetus/newborn and mother if possible).</td>
</tr>
<tr>
<td><strong>Right Place</strong></td>
<td>Care is provided in any setting that is considered appropriate to the circumstances, with priority given to safe care of the mother and fetus/newborn. These settings may include clinics, birthing units and wards, nursery areas and home/community.</td>
</tr>
</tbody>
</table>
3.2 Goals of care
The goals of care are that the fetus/newborn and family will:

- receive best practice perinatal palliative care according to their needs
- participate in decision making and care planning throughout their care with the focus being on the ‘best interests’ of the baby
- have ready access to specialist palliative care services
- receive coordinated care across all sectors of health and community agencies
- receive care and support in their chosen place of care
- be supported in their bereavement.

3.3 Entry into perinatal palliative care (referral pathways)
The time of referral to palliative care is often complex requiring considered decision-making between family members and health care professionals.

Generally three circumstances exist where perinatal palliative care may be considered (refer to Figure 2). For each circumstance, the entry points into a palliative care service are based on the timing of diagnosis and decision making for palliative care.

1. Prenatally diagnosed anomalies or life-limiting conditions
These anomalies may be life-limiting with death expected prior to or soon after birth. These conditions are not considered curable, although length of life may vary for each fetus/newborn. Conditions include Trisomy 13 & 18, severe cardiac anomaly and severe neural tube defects.

Referrals:
- Where there is a prenatal diagnosis (or investigation) of fetal anomaly, a referral should be made to Maternal Fetal Medicine (MFM) at KEMH.
- Once a palliative care approach is chosen, a referral will be made to a palliative care services team coordinated through KEMH.
- With the baby’s survival, referral to a primary care provider with consultancy from a specialist palliative care service provider may be considered on a case-by-case basis as part of discharge planning.
2. Pre-viable preterm fetus where birth is imminent
This typically includes babies born at pre-viable gestations where survival is not possible unaided, yet the baby may be born alive. In these circumstances it may be decided that intensive resuscitation would not be in the best interests of the baby.

Referrals:
- Preterm birth at peri-viable gestations of 23-24 weeks should always be discussed with KEMH Obstetrics and Neonatology or Newborn Emergency Transport Service (NETS WA) if the likelihood of a neonatal transport is needed. Ideally, all women in threatened preterm labour at this gestation will be transferred to KEMH. Resuscitation prior to 23 weeks gestation is not advised due to the extremely poor prognosis for these babies.
- Obstetric or Neonatal Paediatric services will refer to the Perinatal Loss Service at KEMH. This may include local maternity unit case management if transfer to KEMH does not occur.

3. Newborns with postnatally diagnosed anomalies or life-limiting conditions
These conditions are usually diagnosed within a neonatal unit and will involve a Neonatologist or Paediatrician and other specialists (e.g. Neurologist, Cardiologist). Conditions include hypoxic ischaemic encephalopathy (HIE) and congenital anomalies (e.g. cardiac defects or neuromuscular conditions). The length of life for newborns with these conditions can be unpredictable.

Referrals:
- Referral pathways for these newborns are directed by Neonatologists or Paediatricians on a case-by-case basis.
- With the baby’s survival, referral to a primary care provider with consultancy from the non-oncology Paediatric Palliative Care Service may be considered on a case-by-case basis as part of discharge planning.

3.4 Discharge from perinatal palliative care services
Discharge from perinatal palliative care services may include reasons other than the baby’s death. Discharge may be due to continued survival of the baby, or if the family moves out of Western Australia.

The Paediatric and Adolescent Palliative Care Model of Care may inform patient and family care considerations with continued survival of the baby. A strong link with a primary care team is integral to the baby transitioning across these Models of Care.
Figure 2: Entry points into perinatal palliative care

1. **Prenatally diagnosed anomalies or life-limiting conditions**
   - life-limiting
   - not curable
   - death expected soon after birth
   - death eventual outcome

2. **Pre-viable preterm where birth is imminent**
   - intensive resuscitation not in the best interests of the fetus
   - includes fetus at pre-viable gestation
   - survival not possible unaided
   - may be born alive

3. **Newborns with postnatally diagnosed anomalies or life-limiting conditions**
   - may not be determined prenatally
   - may be unexpected
   - usually determined in a neonatal unit.
   - Multidisciplinary team diagnosis

- Referral by practitioner to specialty palliative care service
  *Entry point to perinatal palliative care*

- Referral to Perinatal Loss Service at KEMH
  Case managed
  Individualised care plan developed (Perinatal Palliative Care Plan)

- Local area coordination, consultation and collaboration

**Maternal Fetal Medicine, Obstetrician, Neonatal Paediatrician, Specialty units, other**

**KEMH Obstetrics and Neonatology, Newborn Emergency Transport Service (NETS WA)**

**(Neonatal) Paediatric Consultant**

**Maternity Obstetrics/Midwifery Paediatric Primary care**

**Maternity care unit**

**Paediatric services Primary care**
(consultancy from non-oncology Paediatric Palliative Care)
4. Stages of perinatal palliative care

The following three stages outline best practice perinatal palliative care in WA, based on the principles outlined by ACT in *A Neonatal Pathway for Babies with Palliative Care Needs*.11

**Stage one: Entry to the Perinatal Loss Service**

**Communication**
Discussion about diagnosis and prognosis:
- Initiated early
- Inclusive of all options and potential outcomes
- Full, open, transparent and honest
- Held often and willingly
- Clearly documented

Offer psycho-social support.

**Appoint a case manager with contact details made available to all involved, including the family.**

**Care planning**
Care plans should consider right care, right place, right team, right time:

**Maternal:**
Antenatal planning:
Includes antenatal, labour and birth, resuscitation extent and immediate postpartum care.

Postnatal planning:
Includes place of care and length of stay with a planned non-urgent discharge process.

**Newborn:**
Examination, investigation and care of the newborn by a neonatologist/paediatrician.
Discharge planning to involve primary care and palliative care teams as appropriate.

**Stage two: Living with the condition**

**Assessment and care plans**
- A multidisciplinary assessment of baby and family’s needs.
- A clearly written care plan for:
  - Clinical care
  - Religious, spiritual and psychological support
  - Primary health and community supports
  - Consultancy from the non-oncology Paediatric Palliative Care Service and options for secondary or tertiary re-entry as required on a case-by-case basis.
- A copy of the care plan for parents, key clinicians and community staff.
- Care coordination model with a key person identified as the lead.
- Collaborative and ongoing communication.
- Some babies survive longer than expected. Care plans are continuously reviewed with the best interests of the baby identified.
- Parallel planning in case of long-term survival of the baby.
- Ongoing staff education and peer support.
- Case Manager to provide professional and peer support as required.
Stage three: End-of-life and bereavement care

End of life plan

- A written plan to guide end-of-life care.
- Discuss with family and support staff:
  - Place of care
  - Practicalities of care e.g. feeding, respiratory support, monitoring
  - Signs of discomfort/distress
  - Plans to alleviate distress (including medication)
  - What to expect at the time of death
  - The practicalities of care after death, legal requirements, care of the body, funeral arrangements.

Staff involved with end-of-life care should be constant and supported.

Mother/Family ongoing bereavement support

- Offer comprehensive support: psychological, social, spiritual, cultural and religious aspects.
- Perinatal Loss Service (KEMH) offers a comprehensive service, offering counselling and advice for all perinatal deaths, to parents and health care providers.
- SIDS and Kids WA provide bereavement support to the family. They can also provide preparatory counselling.
- Community health providers should be aware of their local resources for mental health assessment and management (e.g. community and child health nurses offer mental health assessment and referral).

A summary of key service providers (Appendix 1) and contact details for referral (Appendix 2) for perinatal palliative care is provided at the end of the document.
4.1 Example of perinatal palliative care

This is an example of how the Model may look when a baby is diagnosed antenatally. The example demonstrates Multidisciplinary Team (MDT) planning, satellite and outsourced care and coordination to the local area.

Right care

The fetus/newborn, mother and family form the focus of care. Physical, spiritual, psychosocial and cultural needs direct the care to be provided.

A fetal anomaly is noted on an anatomy scan by an external health care provider. The mother is referred to Maternal Fetal Medicine (MFM) at King Edward Memorial Hospital (KEMH) for review and investigations. After considered discussions with the family, it is determined that palliative care is appropriate. The palliative care team review the family at KEMH and discuss options for care. The family choose to have care provided by health professionals in their local area who consult with perinatal palliative care health professionals when required. An individualised care plan is developed by the MDT case manager in liaison with local area practitioners and the family.

Right time

Palliative care is accessible at any stage in the fetus/newborn and mother’s journey; this may be antepartum, intrapartum, at birth or in the postnatal or neonatal period.

The palliative care plan is inclusive of the mother’s antenatal care and progress, including options related to labour and birth. Consultation between local area practitioners and KEMH services is available at any time in the mother’s journey.

Right team

A specialist Multidisciplinary Team (MDT) with expertise in maternal and newborn care and palliative care continues to manage care with support from specialist palliative care services. Primary, secondary, tertiary and community professionals work collaboratively to provide care, promoting continuity of care and caregiver. The Model recognises the need for a case manager and care coordination (local to the fetus/newborn and mother if possible).

A local area clinical lead is identified by the family and KEMH MDT (this is likely to be an Obstetrician or GP Obstetrician). A case conference is held between local health care providers, in particular the maternity unit manager, local paediatrician and community health care professionals. The local area case manager coordinates care and consults with perinatal palliative care health professionals when required.

Right place

Care is provided in any setting that is considered appropriate to the circumstances, with priority given to safe care of the mother and fetus/newborn. These settings may include clinics, birthing units and wards, nursery areas and home/community.

Care in a local area may be considered when the local area practitioners are confident of providing safe clinical care and have supportive networks in place and readily available. This may include primary/community health and bereavement support. Telehealth can be considered for face-to-face communication during the care of the mother and family.
### Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antenatal (also prenatal)</td>
<td>Existing or occurring before birth.</td>
</tr>
<tr>
<td>Antepartum</td>
<td>The period from confirmation of pregnancy to before birth.</td>
</tr>
<tr>
<td>Community care</td>
<td>Care provided by health professionals in the community rather than in hospital e.g. Child Health Nurse.</td>
</tr>
<tr>
<td>Fetal and/or congenital anomaly</td>
<td>Also known as birth defects, congenital disorders or congenital malformations. Congenital anomalies can be defined as structural or functional anomalies (e.g. metabolic disorders) that occur during intrauterine life and can be identified prenatally, at birth or later in life.</td>
</tr>
<tr>
<td>Fetus</td>
<td>The unborn baby in the period after the seventh or eighth week of pregnancy.</td>
</tr>
<tr>
<td>Intrapartum</td>
<td>During labour.</td>
</tr>
<tr>
<td>Life-limiting condition</td>
<td>Condition that can be reasonably expected to cause the death of the patient within the foreseeable future. This definition is inclusive of both malignant and non-malignant illness.</td>
</tr>
<tr>
<td>Maternal</td>
<td>Relates to the mother.</td>
</tr>
<tr>
<td>Model of Care</td>
<td>A multifaceted concept based on best practice principles which broadly define the way health services are delivered. It outlines best-practice patient-care delivery through the application of a set of service principles across identified clinical streams and patient-flow continuums.</td>
</tr>
<tr>
<td>Multidisciplinary Team (MDT)</td>
<td>An integrated team approach to health care in which medical, nursing and allied health care professionals consider all relevant treatment options and collaboratively develop a treatment plan for each patient.</td>
</tr>
<tr>
<td>Neonatal</td>
<td>Relating to the baby from birth until 28 days of life.</td>
</tr>
<tr>
<td>Newborn</td>
<td>Relating to the baby in the hours immediately following birth.</td>
</tr>
<tr>
<td>Palliative care</td>
<td>An approach that aims to improve the quality of life of patients and their families facing problems associated with life-threatening illness. This is achieved through the prevention and relief of suffering by means of the early identification, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.</td>
</tr>
<tr>
<td>Perinatal</td>
<td>The perinatal period is considered to commence at 20 completed weeks of gestation and ends 28 days after birth.</td>
</tr>
<tr>
<td>Peri-viable</td>
<td>From 23-24 weeks gestation.</td>
</tr>
<tr>
<td>Postnatal (also postpartum)</td>
<td>From the birth of the placenta to six weeks after birth.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Preterm</td>
<td>Occurring before 37 completed weeks of pregnancy.</td>
</tr>
<tr>
<td>Pre-viable</td>
<td>Below 23 weeks gestation.</td>
</tr>
<tr>
<td>Primary care</td>
<td>The care the patient receives at first contact with the health care system, usually involving coordination of care and continuity of care over time.</td>
</tr>
<tr>
<td>Secondary care</td>
<td>Care provided by a specialist or facility upon referral by a primary care physician.</td>
</tr>
<tr>
<td>Tertiary care</td>
<td>Care provided by a facility that includes highly trained specialists and often advanced technology.</td>
</tr>
</tbody>
</table>
References


3. Department of Health Western Australia. Framework for the care of neonates in Western Australia. Perth: Health Networks Branch, Department of Health Western Australia; 2009.

4. Department of Health Western Australia. Paediatric and Adolescent Palliative Care Model of Care. Perth: WA Cancer and Palliative Care Network, Department of Health Western Australia; 2009.


11. ACT. A neonatal pathway for babies with palliative care needs. Bristol: ACT (Association for Children’s Palliative Care); 2009.
Appendices

Appendix 1: Right team, right care, right time, right place matrix

The goals of care may differ for the fetus and newborn compared with other babies and their families, however, the standard and quality of care remains the same. Maternal health and wellbeing during pregnancy, childbirth and the postnatal period remain a component of maternity care, including when there is a palliative approach to the care of the baby.

<table>
<thead>
<tr>
<th>Right team</th>
<th>Prenatal diagnosis</th>
<th>Pre-viable preterm</th>
<th>Postnatal diagnosis</th>
<th>Continuing care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Maternal Fetal Medicine (MFM) - KEMH</strong></td>
<td>Screening, diagnosis, care planning</td>
<td></td>
<td>Screening, diagnosis, decision making, planning</td>
<td>Continued planning</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Right care</td>
<td>Right care</td>
<td>Right care</td>
</tr>
<tr>
<td><strong>Perinatal Loss Service - KEMH</strong></td>
<td>Case managed/coordinated care, health provider support, education, consultancy, parent support</td>
<td>Health provider support, education and consultancy. Planning for care</td>
<td>Consultation, health provider support, education and consultancy, parent support</td>
<td>Care coordination, health provider support, education and consultancy, parent support</td>
</tr>
<tr>
<td>Neonatologist / Paediatrician (Neonatal Unit) – KEMH, NETS WA</td>
<td>Antenatal advice/planning, at birth, newborn/infancy</td>
<td>Antenatal advice/planning, at birth, newborn/infancy</td>
<td>Case coordination, hospital care, outpatient follow-up</td>
<td>Outpatient care</td>
</tr>
<tr>
<td><em><em>Paediatrician</em> - PMH</em>*</td>
<td>With the baby’s survival, referral on a case-by-case basis with consultancy from the non-oncology Paediatric Palliative Care Service</td>
<td>Referral on a case-by-case basis with consultancy from the non-oncology Paediatric Palliative Care Service</td>
<td>Outpatient care</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maternity Services Obsteric services Midwifery services</td>
<td>Supportive planning, Case coordination</td>
<td>Supportive planning</td>
<td>Supportive planning</td>
<td>Maternal after-care</td>
</tr>
<tr>
<td>General Practitioner*</td>
<td>Family health Primary care team where appropriate</td>
<td>Family health Primary care team where appropriate</td>
<td>Family health</td>
<td>Family health</td>
</tr>
<tr>
<td>Specialty medical teams* e.g. Cardiology, Genetic Services WA</td>
<td>Screening, diagnosis, planning, primary care team where appropriate</td>
<td>Screening, diagnosis, planning, primary care team where appropriate</td>
<td>Follow-up, pre-conception counselling</td>
<td></td>
</tr>
<tr>
<td>Primary Care Services Child/Community Health Nurse</td>
<td>Pre-birth contact Enhanced home visits</td>
<td>Maternal health and support</td>
<td>Home/community care Family support</td>
<td>Home/community care Family support</td>
</tr>
<tr>
<td><strong>WA non-oncology Paediatric Palliative Care Service - PMH</strong></td>
<td>With the baby’s survival, referral to provide consultancy to a primary care team Consultancy</td>
<td>Referral with discharge planning to provide consultancy to primary care team Consultancy</td>
<td>Referral with discharge planning to provide consultancy to primary care team Consultancy</td>
<td></td>
</tr>
<tr>
<td>Psychosocial support / Social Work / Counselling</td>
<td>Ongoing parent and family support</td>
<td>Postnatal, ongoing parent and family support</td>
<td>Postnatal, ongoing parent and family support</td>
<td>Ongoing parent/family support. Community referrals</td>
</tr>
<tr>
<td>Community palliative care</td>
<td>Referral with the baby's survival, consultancy, ongoing care</td>
<td>Referral with discharge planning, consultancy, ongoing care</td>
<td>Referral with discharge planning, consultancy, ongoing care</td>
<td></td>
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<td>----------------------------------------------------------</td>
<td>----------------------------------------------------------</td>
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</tr>
<tr>
<td>e.g. Silver Chain</td>
<td>Advice, transport, clinical care</td>
<td>Advice, transport, clinical care</td>
<td>Advice</td>
<td></td>
</tr>
<tr>
<td>Ambulance / Royal Flying Doctor Service / NETS WA</td>
<td>Support decision making, shared care</td>
<td>Maternal health, support family health, follow-up</td>
<td>Support decision making, shared care, practicalities</td>
<td></td>
</tr>
<tr>
<td>Aboriginal Medical Services</td>
<td>Maternal health, support family health, follow-up</td>
<td>Support decision making, shared care, practicalities</td>
<td>Support decision making, shared care, practicalities</td>
<td></td>
</tr>
<tr>
<td>Bereavement services e.g. SIDS and Kids</td>
<td>Parent/family support</td>
<td>Parent/family support</td>
<td>Parent/family support</td>
<td></td>
</tr>
<tr>
<td>Right place</td>
<td>MFM, Obstetrics, Midwifery Maternity Services</td>
<td>Maternity Unit</td>
<td>Maternity unit</td>
<td></td>
</tr>
<tr>
<td>Right time</td>
<td>Pregnancy, birth, post birth Continuing</td>
<td>Intrapartum Continuing</td>
<td>Neonatal Unit</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

*Can be the primary care team with the baby’s survival – referral on a case-by-case basis with consultancy from the non-oncology Paediatric Palliative Care Service.*
## Appendix 2: Contact details for referral

<table>
<thead>
<tr>
<th>Contact</th>
<th>Role / Responsibility</th>
<th>Contact details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Maternal Fetal Medicine (MFM) KEMH</strong></td>
<td>Assessment of fetal condition, options, management and plan e.g. continue active management of pregnancy, termination of pregnancy, palliative care</td>
<td>08 9340 2700 OR Clinical Midwife Consultant 08 9340 2222 pager 2705 OR Consultant MFM 08 9340 2222</td>
</tr>
<tr>
<td><strong>Perinatal Loss Service KEMH</strong></td>
<td>Planning and documentation of management plan and clinical pathway for families where there is a palliative approach to care of the fetus/newborn</td>
<td>Clinical Midwife Consultant 08 9340 2222 pager 3430 OR Clinical Midwife Consultant Perinatal Loss Service 0416 019 020</td>
</tr>
<tr>
<td><strong>Obstetric Consultant KEMH</strong></td>
<td>Advice and triage on management of the pregnancy, planning, transfer if required</td>
<td>08 9340 2222 Ask switchboard to transfer to the Obstetric Consultant on duty for the day</td>
</tr>
<tr>
<td><strong>Neonatal Consultant KEMH</strong></td>
<td>Advice and triage on management of the newborn, planning, transfer if required</td>
<td>08 9340 2222 Ask switchboard to transfer to the Neonatal Consultant on duty for the day</td>
</tr>
<tr>
<td><strong>Newborn Emergency Transport Service (NETS WA)</strong></td>
<td>Advice about newborn management and retrieval if required</td>
<td>NETS emergency 1300 NETS WA (1300 6387 92)</td>
</tr>
<tr>
<td><strong>Non-oncology Paediatric Palliative Care Service, PMH</strong></td>
<td>Advice to a primary care team about babies with continued survival.</td>
<td>Mon-Fri 8.30-4 0429 687 698 Other times: 08 9340 8222</td>
</tr>
</tbody>
</table>
This document can be made available in alternative formats on request for a person with disability.