WA Cancer and Palliative Care Network

Perinatal Palliative Care Model of Care

Revised August 2015

Government of **Western Australia**
Department of **Health**

Endorsed by SHEF September 2014. Revised August 2015 with minor edits. For details of the edits, please contact palliativecare.cpcn@health.wa.gov.au.

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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.
3. Newborn with postnatally diagnosed life-limiting condition.

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

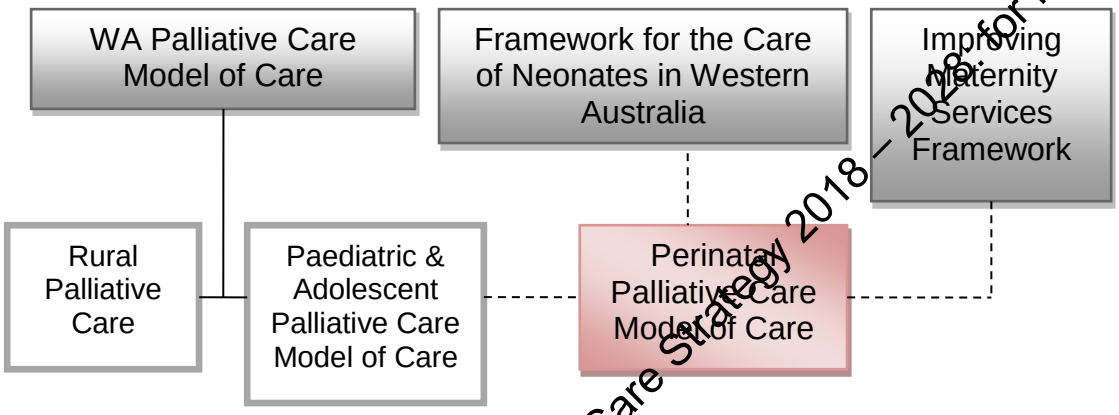
The recommendations for the implementation of the *Perinatal Palliative Care Model of Care* (Model) are:

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*[1], the *Improving Maternity Services Framework*[2] and the *Framework for the Care of Neonates in Western Australia*[3]. It aligns with the *Paediatric and Adolescent Palliative Care Model of Care*[4].

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



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[5]. It follows an agreement between the family and the multidisciplinary care team on a palliative care approach for a fetus/newborn and their family[5]. 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." [6].

Perinatal palliative care can be planned and initiated early where the condition of the fetus/newborn is known prior to birth[7]. 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[7].

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[8]. Birth defects are a major cause of perinatal death. The WA Register of Developmental Anomalies from 1980-2010[8] 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[9].

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*[4]. 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.

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.**
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.**
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).**
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.**

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:

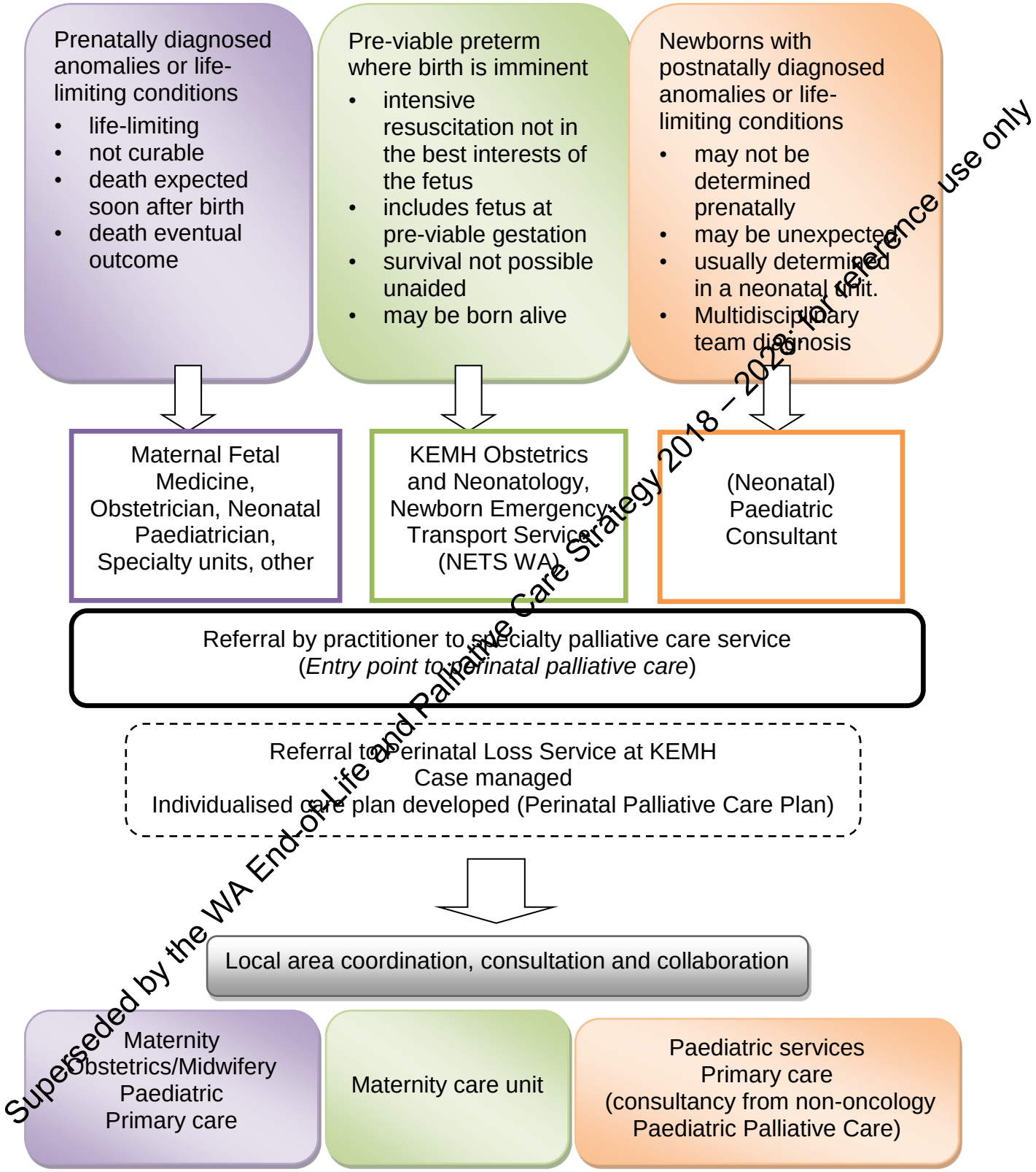
- Referral pathways for these newborns are directed by Neonatologists or Paediatricians on a case-by-case basis.
- With the baby's survival, referral to a primary care provider with consultancy from the non-oncology Paediatric Palliative Care Service may be considered on a case-by-case basis as part 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*[4] 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



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

Antenatal (also prenatal)	Existing or occurring before birth.
Antepartum	The period from confirmation of pregnancy to before birth.
Community care	Care provided by health professionals in the community rather than in hospital e.g. Child Health Nurse.
Fetal and/or congenital anomaly	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.
Fetus	The unborn baby in the period after the seventh or eighth week of pregnancy.
Intrapartum	During labour.
Life-limiting condition	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.
Maternal	Relates to the mother.
Model of Care	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.
Multidisciplinary Team (MDT)	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.
Neonatal	Relating to the baby from birth until 28 days of life.
Newborn	Relating to the baby in the hours immediately following birth.
Palliative care	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.
Perinatal	The perinatal period is considered to commence at 20 completed weeks of gestation and ends 28 days after birth.
Peri-viable	From 23-24 weeks gestation.
Postnatal (also postpartum)	From the birth of the placenta to six weeks after birth.

Preterm	Occurring before 37 completed weeks of pregnancy.
Pre-viable	Below 23 weeks gestation.
Primary care	The care the patient receives at first contact with the health care system, usually involving coordination of care and continuity of care over time.
Secondary care	Care provided by a specialist or facility upon referral by a primary care physician.
Tertiary care	Care provided by a facility that includes highly trained specialists and often advanced technology.

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Appendices

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

Key stakeholders noted in red/bolded/italics

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.

	Prenatal diagnosis	Pre-viable preterm	Postnatal diagnosis	Continuing care
Right team	**Right care**	**Right care**	**Right care**	**Right care**
Maternal Fetal Medicine (MFM) - KEMH	Screening, diagnosis, care planning		Screening, diagnosis, decision making, planning	Continued planning Pre-conception counselling
Perinatal Loss Service - KEMH ***Neonatologist / Paediatrician (Neonatal Unit) – KEMH, NETS WA***	Case managed/coordinated care, health provider support, education, consultancy, parent support Antenatal advice/planning, at birth, newborn/infancy	Health provider support, education and consultancy. Planning for care Antenatal advice/planning, at birth, newborn/infancy	Consultation, health provider support, education and consultancy, parent support Case coordination, hospital care, outpatient follow-up	Care coordination, health provider support, education and consultancy, parent support Outpatient care
Paediatrician* - PMH	With the baby' survival, referral on a case-by-case basis with consultancy from the non-oncology Paediatric Palliative Care Service		Referral on a case-by-case basis with consultancy from the non-oncology Paediatric Palliative Care Service	Outpatient care Referral on a case-by-case basis with consultancy from the non-oncology Paediatric Palliative Care Service
Maternity Services Obstetric services Midwifery services	Supportive planning, Case coordination	Supportive planning	Supportive planning	Maternal after-care
General Practitioner*	Family health Primary care team where appropriate		Family health Primary care team where appropriate	Family health
Specialty medical teams* e.g. Cardiology, Genetic Services WA	Screening, diagnosis, planning, primary care team where appropriate		Screening, diagnosis, planning, primary care team where appropriate	Follow-up, pre-conception counselling
Primary Care Services Child/Community Health Nurse	Pre-birth contact Enhanced home visits	Maternal health and support	Home/community care Family support	Home/community care Family support
WA non-oncology Paediatric Palliative Care Service - PMH	With the baby's survival, referral to provide consultancy to a primary care team Consultancy		Referral with discharge planning to provide consultancy to primary care team Consultancy	Referral with discharge planning to provide consultancy to primary care team Consultancy
Psychosocial support / Social Work / Counselling	Ongoing parent and family support	Postnatal, ongoing parent and family support	Postnatal, ongoing parent and family support	Ongoing parent/family support. Community referrals

Community palliative care e.g. Silver Chain	Referral with the baby's survival, consultancy, ongoing care		Referral with discharge planning, consultancy, ongoing care	Referral with discharge planning, consultancy, ongoing care
Ambulance / Royal Flying Doctor Service / NETS WA		Advice, transport, clinical care	Advice, transport, clinical care	Advice
Aboriginal Medical Services	Support decision making, shared care	Maternal health, support family health, follow-up	Support decision making, shared care, practicalities	Support decision making, shared care, practicalities
Bereavement services e.g. SIDS and Kids	Parent/family support	Parent/family support	Parent/family support	Parent/family support
Right place	MFM, Obstetrics, Midwifery Maternity Services	Maternity Unit	Maternity unit Neonatal Unit	Community
Right time	Pregnancy, birth, post birth Continuing	Intrapartum Continuing	Postnatal Newborn Discharge	Diagnosis Pre-discharge

*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

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

This document can be made available in alternative formats on request for a person with disability.