

<b>Title</b>	<b>Thames Valley Network Perinatal Palliative Care Framework</b>
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## **Executive summary**

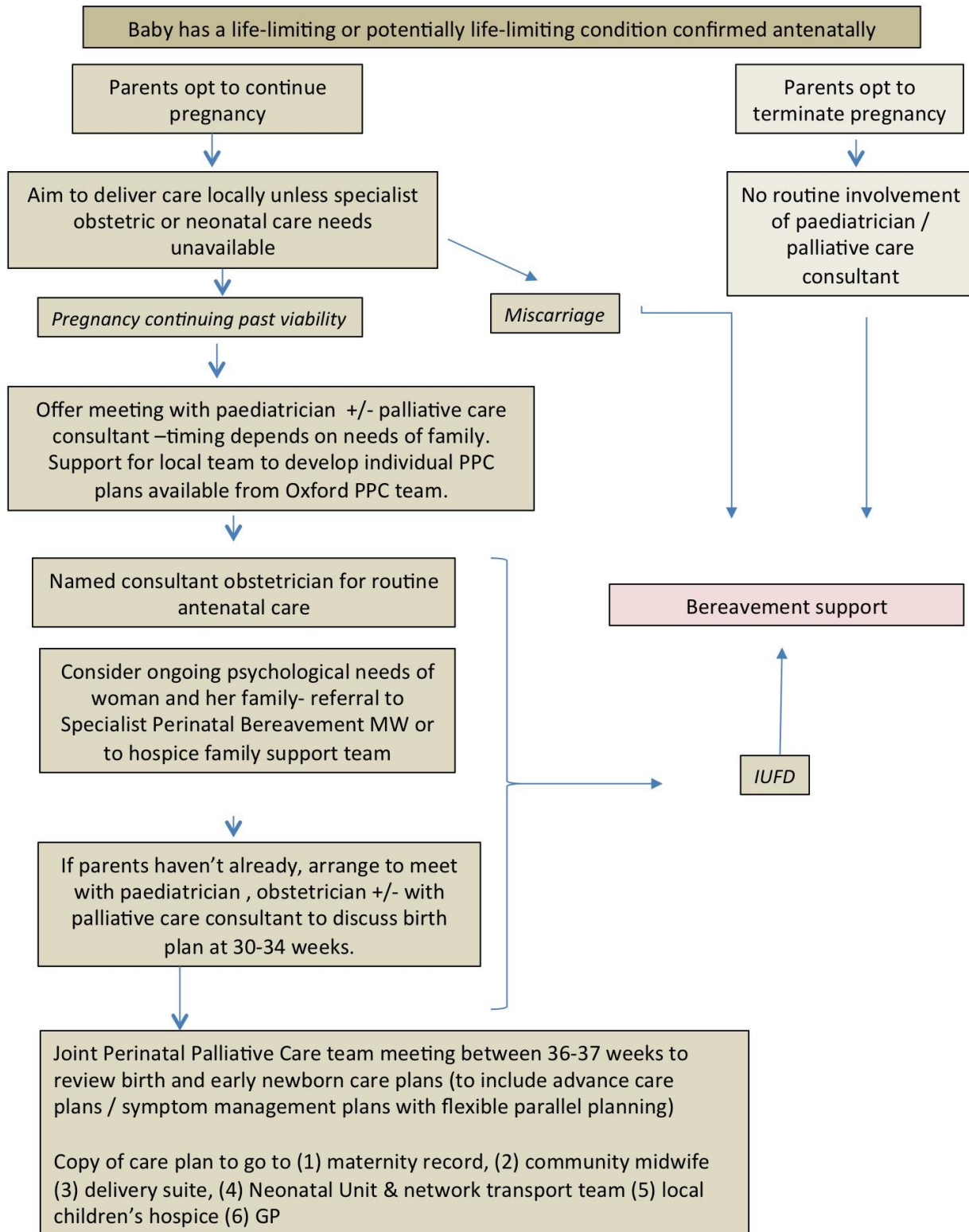
<b>1</b>	Perinatal Palliative Care (PPC) describes a philosophy of care for women and families following antenatal diagnosis and expected delivery of a fetus/infant with a life-limiting condition. PPC focuses on the prevention of pain and distress of the infant, and on the psychological, social and emotional support of the family.
<b>2</b>	The purpose of developing a PPC framework within the Thames Valley is to enable clinical staff to deliver consistent, high quality ongoing care for families electing to continue pregnancy with a fetus with a life-limiting condition, to develop and communicate advance care plans and to help ensure uniform standards of care wherever families are cared for in the region.
<p><b>Aims:</b></p> <ol style="list-style-type: none"> <li>1. Implementation of a PPC framework within Thames Valley network</li> <li>2. Increase awareness of the concept of PPC amongst healthcare professionals in the region</li> <li>3. Develop education resources to support training of staff involved in caring for families whose child is on the PPC pathway</li> <li>4. Increase awareness of PPC as an option for parents with a fetus with an anticipated life-limiting condition</li> </ol>	

## **Abbreviations and definitions**

PPC	Perinatal palliative care
LLC	Life-limiting condition
PLLC	Potential life-limiting condition
BAPM	British Association of Perinatal Medicine
FMU	Fetal Medicine Unit (Oxford)
SONeT	Southampton Oxford Neonatal Transport -provides neonatal transport services for the Thames Valley and Wessex region

**PPC Framework for Thames Valley clinical network - summary**

**Perinatal palliative care pathway- Thames Valley Network**



## **Background**

### ***What is perinatal palliative care?***

Perinatal palliative care provides holistic multidisciplinary support for families facing the death or potential death of their newborn infant.

PPC provides integrated ongoing support through pregnancy, delivery and the postnatal period as well as, where appropriate, bereavement care.

(For further specific guidance on neonatal palliative care see [Thames Valley and Wessex Neonatal Operational Delivery Network's Neonatal Palliative Care Guideline](#))

### ***Who would be eligible for consideration of perinatal palliative care?***

Women and families who have had an antenatal diagnosis of a confirmed or potentially life-limiting condition, and who are continuing their pregnancy would be considered eligible for PPC.

#### ***Confirmed life-limiting conditions (LLC):***

Confirmed Life-limiting conditions include diagnoses that are highly likely to lead to death in utero or in infancy. For these conditions, the diagnosis and prognosis are unequivocal. LLC would include:

- Trisomy 13, 18
- Anencephaly
- Bilateral Renal agenesis
- Severe skeletal dysplasia
- Severe osteogenesis imperfecta
- Hydranencephaly
- Holoprosencephaly

#### ***Potentially life-limiting conditions (PLLC):***

Potentially life-limiting conditions include diagnoses where there is a significant chance of death in utero, in the newborn period, or early infancy. Prognosis may not always be clear at time of diagnosis. For PLLC, assessment may be necessary after birth to determine if PPC is appropriate or whether active intervention is indicated. PLLC would include:

- Severe multicystic dysplastic kidneys and oligohydramnios
- Severe hydrocephalus
- Severe congenital cardiac conditions that may not be amenable to surgery, or only with severe morbidity
- Severe Fetal cardiomyopathy
- Hydrops fetalis

### ***Rationale for developing PPC framework in Thames Valley***

Around 5% of pregnancies are complicated by congenital structural abnormalities, 15% of which are life-limiting or potentially life-limiting. Hospitals within the Thames Valley network continue to support pregnant women and families in this situation.

The aims of the Thames Valley PPC framework include facilitation of perinatal palliative care and delivery close to the family's home and provision of specialist input, advice and training to support local teams within the region.

## Thames Valley Network Perinatal Palliative Care Framework

Such a framework aligns with the “Five Priorities” articulated by the NHS Leadership Alliance for the Care of Dying People

- Recognition
- Sensitive Communication
- Involving family in decisions
- Support needs of family
- Planning care

It is also compliant with the models of service delivery recommended in NICE Guidance for end of life care in infants, children and young people

### ***Framework for PPC in Thames Valley***

#### **Guiding principles**

1. To provide timely support tailored to the needs of families
2. To provide multidisciplinary support for patient choice and values.
3. To facilitate delivery close to the family’s home
4. To provide specialist input and advice to support local teams within the region to provide PPC to families delivering in local unit
5. To provide training and support for staff locally and in regional units providing PPC to enable confidence to care for the baby at birth to engage in parallel planning and to deliver a supportive end-of-life care plan.

#### **Determining eligibility for PPC: diagnosis of a life-limiting or potentially life-limiting condition**

There are currently three pathways to diagnosis/initial care in relation to LLC/PLLC in the network:

1. Antenatal diagnosis of a major structural abnormality may be made at the 11-13 week scan or midtrimester anomaly scan and is ordinarily confirmed by a fetal medicine consultant with recourse to specialist fetal echocardiography for cardiac anomalies. The majority of pregnant women in this situation will be referred to Oxford Fetal Medicine Unit for tertiary review and assessment which may include additional investigations (invasive testing, MRI). These cases are subsequently discussed at the weekly FMU multidisciplinary team meeting (MDT) with regards to diagnosis and prognosis and to consider any implications for maternal health where pregnancy is ongoing. Palliative care would be an option when there is multidisciplinary agreement and certainty regarding diagnoses and prognosis.
2. Some fetal conditions for which there is simple definitive diagnostic tests and an unequivocal prognosis e.g. T13, T18, anencephaly, may be diagnosed and managed entirely at local hospital level where fetal medicine expertise exists.
3. In other cases, invasive testing may occur in Oxford but results are communicated to local units and ongoing care is managed locally.

#### **Pregnancy options after diagnosis of LLC or PLLC**

Following diagnosis of LLC or PLLC, parents should be counselled about all available pregnancy options, this includes termination of pregnancy, continuation of pregnancy with palliative care plan, or (in some cases) continuation of pregnancy with active post-natal care plan. Initial counselling is usually delivered by the

Thames Valley Network Perinatal Palliative Care Framework

fetal medicine consultant/obstetrician with fetal medicine training with input from a specialist midwife. In some cases, additional counselling may be provided from a neonatologist/paediatrician.

If after this initial counselling, a pregnant woman opts to continue pregnancy, referral to PPC would be offered.

The flowchart above provides an overview of the proposed PPC framework for the network.

**When should women be referred?**

Referral can be made at any point from viability (23+/40). Some parents-to-be may seek consultation earlier than this in order to understand care planning for pregnancy and after birth.

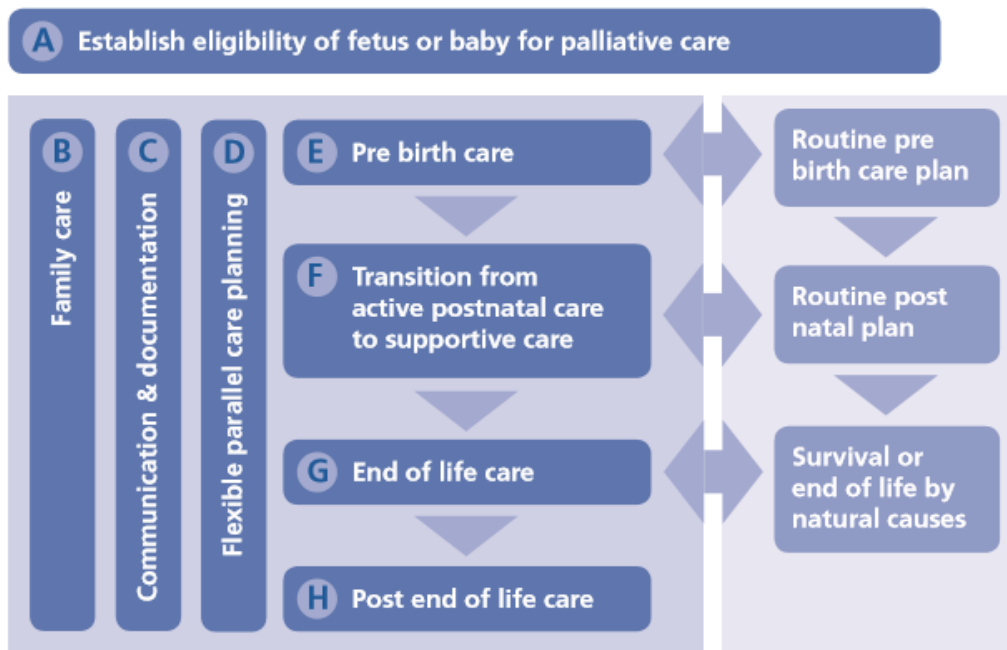
**Who should the referral for PPC be made to?**

This would depend on where diagnosis of LLC/PLLC was made and/or where ongoing care is planned. If initial counselling following diagnosis takes place in a local hospital, referral would usually be to the local paediatric/PPC team. Where women have been seen by the Fetal Medicine team in Oxford, referrals should be discussed in weekly FMU MDT to allow triaging/gathering of information.

**Key components of palliative care planning**

The figure below provides a structured approach to care after diagnosis. This framework should be adapted to the individual needs of a family.

Stages of palliative care planning



(BAPM, 2010)

**Advance care planning**

This would be appropriate for ongoing pregnancy where newborn has anticipated LLC.

## Thames Valley Network Perinatal Palliative Care Framework

- The process of Advance Care Planning involves discussions with parents about the goals and desired direction of their baby's management, particularly with regard to end of life care. This comprises personalised as well as parallel planning.
- Typically covers parents' concerns and wishes about care, including what should be done, where, how, when and by whom. Importantly, Advance Care Plans also consider what should not be done. An effective care plan allows care to be delivered according to the wishes of the family allowing them to retain autonomy, to influence how they are looked after and what is done to their baby. The discussion around an Advance Care Plan provides a forum for honest and direct communication between members of the multidisciplinary team, and the family. People can talk about their fears and uncertainties, ask questions and regain some control over what happens to them.
- Family-centred care, including psychological, spiritual and social support should be available throughout.
- Formal care plans should be communicated to all involved in the pregnancy.
- Planning obstetric and neonatal management around birth is important to ensure that the care reflects the wishes of parents and the best interests of the baby
- Palliative care input may be appropriate even if full resuscitation and active management is contemplated in the newborn period.
- Generic palliative care skills are found within most children's community nursing teams; district general hospitals, and general practice surgeries. It is important to establish contact as early as possible with local services in order to ensure smooth delivery of care.

### **Parallel planning**

For conditions with uncertain prognosis, or where longer-term survival is possible, planning needs to encompass a range of possible outcomes, and can involve elements of active medical management and palliative care

- Parallel planning includes
  - consideration of end of life care and early death
  - ongoing care needs in the event of survival
  - transition from active routine care to palliative care, (or vice versa).

### **Care planning and support for local centres in the network**

For infants with confirmed LLC, the aim is to facilitate delivery in the local obstetric centre. Some parents may wish to go to a paediatric hospice with their baby after delivery (see below).

For women booked to deliver in their local unit, telephone advice from Oxford PPC team is available to support care planning/palliative care management. Review in Oxford by PPC team to assist development of plan for local delivery and postnatal care would also be possible where this is felt to be of benefit.

Delivery in the tertiary centre may be appropriate (as would be the case for any pregnancy), where there are anticipated specialist obstetric or paediatric care needs that cannot be provided in local hospital. Potential life-limiting conditions (with uncertain prognosis) would often require delivery in the tertiary centre. Such cases would be discussed at the weekly Oxford FMU MDT.

### **Inpatient palliative care and transport following delivery**

A summary of additional, third sector palliative care services available across Thames Valley is outlined in Appendix 1.



For live-born infants, transfer to hospice should be arranged with the Neonatal transport service – SONeT. Transfer after death to hospice would usually be in parents' car.

### **Training and support of staff and multidisciplinary teams**

Successful implementation of a PPC pathway in network units will require appropriate training and support for staff to enable confidence to care for the baby at birth and to deliver the supportive and end-of-life care plan. For deliveries where infants are anticipated to die soon after birth, consideration should be given to briefing and debriefing staff on delivery suite caring for the family

### **Overview of delivery of care**

#### **PPC team consultation**

Joint consultation with obstetrics/paediatrics/palliative care potentially serves to ensure efficient review within the shortest time, reducing unnecessary overlap in counselling, and improve communication between teams. Further opportunities for PPC consultation might include a visit to the hospice to meet some of the care team.

#### **Antenatal care**

In most cases, the mother would continue to receive routine antenatal care. If fetal diagnosis increases risk to maternal health, additional appropriate antenatal care would be arranged (e.g. fetal hydrops). Given existing data, it is envisaged that only a very small number of cases would require fetal medicine assessment alongside antenatal care.

#### **Intrapartum care**

In general, unless there is a specific maternal health issue, the aim would be to wait for spontaneous labour. Caesarean section would be considered if labour would increase risk for the mother.

#### **Postpartum care**

If after delivery, the woman elects to stay in hospital, care would be as per usual local pathway following in utero fetal demise.

#### **Care after discharge from hospital**

Where available and desired by families, transfer of the infant/mother to a paediatric hospice when the woman is medically fit for discharge may be appropriate. Early support from hospices within the Thames Valley has been associated with reduced psychological morbidity and distress, shorter length of stay in hospital and fewer NICU admissions.

For families opting to take their baby home for end of life care; domiciliary support is likely to come from children's community nursing services, often supported by third sector organisations specialising in palliative care for babies and children. It is important for the family's GP and local paediatric services to be informed as soon as possible, so as to ensure medical support out of hours. Specialist medical telephone support to the family or those caring for them is likely to be available from a paediatric palliative care consultant if needed.

## **Appendix 1: Thames Valley Palliative Care services**

A summary of non-statutory, third sector (charitable) palliative care services available across Thames Valley is outlined below.

*Please note that there will be some expertise in planning and delivery of palliative care for babies within local District General Hospitals and Children's community nursing teams, and that the best care often involves statutory and third sector organisations working in partnership.*

### **Inpatient palliative care**

#### **Helen and Douglas House**

Oxford): 01865 794749 [www.helenanddouglas.org.uk](http://www.helenanddouglas.org.uk)

- Service: Able to provide admission for end of life care, as well as admission in transition to discharge home for infants with confirmed or potential life-limiting conditions. Also potential for admission after neonatal death – for acute bereavement care. Consultant-led specialist palliative care support and nursing outreach care available by phone for babies being cared for in the region.
- Catchment area: Oxfordshire and surrounding counties (approximately 90 minute radius by road)

#### **Keech Cottage (Luton)**

01582 492339; [www.keech.org.uk](http://www.keech.org.uk)

- Offer dedicated paediatric in-patient services and outreach nursing (24/7 support), delivered by medical team supported at Consultant level by a service level agreement with Great Ormond Street hospital for phone support. Able to accommodate babies.
- Catchment area: Bedfordshire, Hertfordshire (covering Stoke Mandeville, Luton & Dunstable, Lister, Bedford, QEII as well as Milton Keynes hospitals).

#### **Naomi House (near Winchester)**

01962 760 060 [www.naomihouse.org.uk](http://www.naomihouse.org.uk)

- Able to provide admission for palliative care / end of life care for babies. Catchment area: Central South (potential for families living south of Reading)
- Catchment: Hampshire, Wiltshire, Dorset, Berkshire, West Sussex, Surrey and the Isle of Wight.

#### **Alexander Devine Children's Hospice Services (Berkshire)**

01628 822777 [www.alexanderdevine.org.uk](http://www.alexanderdevine.org.uk)

- Currently developing an inpatient unit (due to open 2017).
- Able to offer some home nursing / respite support in Berkshire, as well as support within RBH including advance care planning.

#### **London Neonatal network hospices**

[www.londonneonatalnetwork.org.uk/neonatal-complex-and-palliative-care/guidance/](http://www.londonneonatalnetwork.org.uk/neonatal-complex-and-palliative-care/guidance/)

#### **Outreach palliative care**

Ian Rennie Grove House (Pepper Nurses) 01442 507 324 [www.pepper.org.uk](http://www.pepper.org.uk)

- Offering specialist PPC nursing care in the home. They have a service level arrangement with HDH for medical back up, including Consultant support where needed. They could support a family who opted to be at home. Catchment: Chiltern area of Buckinghamshire and Hertfordshire,

**Appendix 2:References and further information**

British Association of Perinatal Medicine: Palliative care (supportive and end of life care) A framework for clinical practice in Perinatal medicine (2010)

[http://bapm.org/publications/documents/guidelines/Palliative\\_Care\\_Report\\_final\\_%20Aug10.pdf](http://bapm.org/publications/documents/guidelines/Palliative_Care_Report_final_%20Aug10.pdf)

Association for Children’s Palliative Care: A Neonatal Pathway for Babies with Palliative Care Needs (2009)

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Critical care decisions in fetal and neonatal medicine: ethical issues. Nuffield Council on Bioethics 2006

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Kilby MD et al., Multidisciplinary palliative care in unborn and newborn babies. BMJ 2011;342:d1808. doi: 10.1136/bmj.d1808

Thames Valley and Wessex Neonatal Operational Delivery Network’s Neonatal Palliative Care Guideline

<https://www.networks.nhs.uk/nhs-networks/thames-valley-wessex-neonatal-network/documents/Neonatal%20Palliative%20care%20guideline.FINAL.pdf>