# WESSEX FRAMEWORK FOR PERINATAL PALLIATIVE CARE

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**Distribution**
- Thames Valley & Wessex Network Governance
- Thames Valley & Wessex Neonatal Clinical Forums
- Thames Valley & Wessex Neonatal ODN E-Bulletin
- SHIP - LMS

**Related documents**
- Association for Children’s Palliative Care: A Neonatal Pathway for Babies with Palliative Care Needs (2009) [www.act.org.uk](http://www.act.org.uk)
Implications of race, equality & other diversity duties for this document

This guideline must be implemented fairly and without prejudice whether on the grounds of race, gender, sexual orientation or religion.

Wessex Framework for Perinatal Palliative Care

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1.0 **Aim of Framework**

This framework aims to provide practical guidance for the planning and delivery of perinatal palliative care for infants diagnosed with a life-limiting or potentially life-limiting condition antenatally, for all sick and preterm infants. In particular, this framework also aims to:

1. Aid implementation of a PPC framework within Wessex network
2. Increase awareness of the concept of PPC amongst healthcare professionals in the region
3. Develop education resources to support training of staff involved in caring for families whose child is on the PPC pathway
4. Increase awareness of PPC as an option for parents with a fetus with an anticipated life-limiting condition

2.0 **Scope of Framework**

This framework applies to all Neonatal Units within Wessex Neonatal Operational Delivery Network. This includes the following hospitals:

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<td>Dorset County Hospital NHS Foundation Trust</td>
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<td>Hampshire Hospitals NHS Foundation Trust</td>
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<td>Hampshire Hospitals NHS Foundation Trust</td>
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<td>Isle of Wight NHS Trust</td>
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<td>Poole Hospital NHS Foundation Trust</td>
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<td>Salisbury NHS Foundation Trust</td>
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<tr>
<td>University Hospital Southampton NHS Foundation Trust</td>
<td>- Princess Anne Hospital</td>
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<tr>
<td>Western Sussex Hospitals NHS Foundation Trust</td>
<td>- St Richard's Hospital, Chichester</td>
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3.0 **Executive Summary**

1. 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.

2. The purpose of developing a PPC framework within the Wessex Neonatal Network 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.

4.0 **Definitions**

<table>
<thead>
<tr>
<th>ACP</th>
<th>Advance Care Plan</th>
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<tr>
<td>PPC</td>
<td>Perinatal palliative care</td>
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<td>LLC</td>
<td>Life-limiting condition</td>
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<tr>
<td>PLLC</td>
<td>Potential life-limiting condition</td>
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<tr>
<td>BAPM</td>
<td>British Association of Perinatal Medicine</td>
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<tr>
<td>FMU</td>
<td>Fetal Medicine Unit (Southampton)</td>
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<tr>
<td>SOnET</td>
<td>Southampton Oxford Neonatal Transport - provides neonatal transport services for the Thames Valley and Wessex region</td>
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<td>SMP</td>
<td>Symptom Management Plan</td>
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5.0 Details of Procedure to be followed

5.1 PPC Framework for Wessex clinical network – summary

Perinatal Palliative Care Pathway - Wessex

- Baby has a life limiting or potentially life limiting condition confirmed antenatally
- Discussion with fetal medicine consultants, relevant tertiary specialists and neonatologist/paediatrician

- Parents opt to continue pregnancy
  - Aim to deliver locally unless specialist obstetric or neonatal care needs unavailable
  - Offer meeting with local paediatrician +/- paediatric palliative care team.
    - Timing depends on needs of family
    - Support for local team from paediatric palliative care team to develop individual PPC plan including ACP and SMP
    - Needs named local Named Consultant Obstetrician, Midwife and Paediatrician
  - Consider ongoing psychological needs of woman and her family
    - Consider referral to local bereavement midwife or nurse, and/or hospice family support team
  - If parents haven’t already, arrange to meet with paediatrician, obstetrician +/- palliative care team to discuss birth plan at 30-34 weeks

- Parents opt to terminate pregnancy
  - No routine involvement of paediatrician or paediatric palliative care team
  - Miscarriage
  - Local Bereavement Support (usually Midwifery led)

- In-utero fetal death

- Consider or discuss Children’s Hospice referral (e.g. Naomi House)

Agree ACP, SMP and overall PPC plan for use at and after delivery (Paediatric Palliative care team can review these if needed)
Copy of the plan to go to maternity record, community midwife, delivery suite, local neonatal unit, SOnET, local children’s hospice
5.2 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 Wessex

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

The aims of the Wessex 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.

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

5.3 Framework for PPC in Wessex

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 Southampton 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. Cases are then discussed at the joint neonatal and fetal medicine perinatal liaison meeting each week. 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 Southampton 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 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 diagnosis. 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/PLL 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 team and/or the paediatric palliative care team and/or the Naomi house team as appropriate/available. Where women have been seen by the Fetal Medicine team in Southampton, referrals should be discussed in weekly FMU MDT meetings and perinatal liaison meetings 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

Advance care planning
This would be appropriate for ongoing pregnancy where newborn has anticipated LLC.
- 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.
- Development of an individualised symptom management plan (SMP) is also important to facilitate management of symptoms by local teams and/or parents after birth. This can be done by or with help from the paediatric palliative care team based at UHS and Naomi House.
- 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. This can be accessed via local children’s hospices.
- 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 children’s hospice with their baby after delivery (see below).

For women booked to deliver in their local unit, telephone advice from Southampton PPC team is available to support care planning/palliative care management. Review in Southampton 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 Southampton FMU MDT.

Inpatient palliative care and transport following delivery
A summary of additional, third sector palliative care services available across Wessex 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 Wessex 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 team if needed.
6.0 Implementation

Information for all staff on induction and regular updates as necessary

7.0 Process for Monitoring Compliance/Effectiveness

Key aspects of the procedural document that will be monitored:

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<th>What will be reviewed to evidence this</th>
<th>How and how often will this be done</th>
<th>Detail sample size (if applicable)</th>
<th>Who will coordinate and report findings</th>
<th>Which group or report will receive findings</th>
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| 1 DRAFT | July 2017| Work began on adapting Thames Valley Neonatal Network Perinatal Palliative Care Framework for use in Wessex Network | M Johnson
L Leppard
L Imber
S Boxall
L Bengree
C Cochran
C Forster |          |

1 Final | April 2019 | Modified in response to comments from network consultation | M Johnson
L Leppard
L Imber
S Boxall
L Bengree
C Cochran
C Forster |          |

Review Date: April 2022
Appendix A

Appendix A: Wessex Palliative Care services
A summary of non-statutory, third sector (charitable) palliative care services available across Wessex 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
Naomi House (near Winchester)
01962 760 060 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.

Helen and Douglas House
Oxford: 01865 794749 www.helenanddouglas.org.uk
- 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)

Chestnut Tree House (West Sussex)
01903 871800; http://www.chestnut-tree-house.org.uk/
- Chestnut Tree House is a children’s charity providing hospice care services and community support for children and young people with progressive life-shortening conditions throughout East and West Sussex, Brighton and Hove and South East Hampshire.

Julia’s House (Dorset)
01202 644220 https://www.juliashouse.org/
- Julia’s House is a children’s hospice charity dedicated to bringing comfort and care to families across Dorset and Wiltshire.
Appendix B: Local Contacts with an interest in Paediatric Palliative Care

Southampton
Paediatric Palliative Care Team:
Dr Michelle Koh, Consultant in Paediatric Palliative Care
Colette Cochran, Children’s Cardiac Nurse Specialist

Dorchester
Dr Penny Mancais, Consultant Paediatrician

Basingstoke
Julia Shaw, Consultant Paediatrician

Winchester
Ollie Bevington, Consultant Paediatrician

Portsmouth
Dr Louise Millard, Consultant Paediatrician

Poole
Dr Martin Hussey, Consultant Paediatrician

Salisbury
Dr Rowena Staples, Consultant Paediatrician

Isle of Wight
Dr Bettina Harms, Consultant Paediatrician

Chichester
Dr Nick Brennan, Consultant Paediatrician