Perinatal Palliative Care (GL1135)

Approval

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<th>Approval Group</th>
<th>Job Title, Chair of Committee</th>
<th>Date</th>
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<tr>
<td>Maternity Clinical Governance Committee</td>
<td>Chair, Maternity Clinical Governance Committee</td>
<td>1st March 2019</td>
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Change History

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<tr>
<th>Version</th>
<th>Date</th>
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<tr>
<td>1.0</td>
<td>Feb 2019</td>
<td>Surabhi Bisht, Consultant Obstetrician</td>
<td>Trust requirement</td>
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1. Introduction

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.

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

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

2. 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.

2.1 Confirmed life-limiting conditions (LLC):  

Confirmed Life-limiting conditions include diagnoses that are highly likely to lead to death in utero or in infancy. LLC would include:

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

2.2 Potentially life-limiting conditions (PLLC):

Potentially life-limiting conditions include diagnoses where there is a significant chance of death in utero, in the new-born 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
3. Guiding principles

1. Refer to fetal Medicine JRH, Oxford (only where required)
2. Provide timely support tailored to the needs of families
3. To provide multidisciplinary support for patient choice and values.
4. To facilitate delivery in willow/ patient’s home (only if safe to do so)
5. To provide specialist input and advice to support and provide PPC to families

4. 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.

4.1 Key components of palliative care planning (from AHSN)

Stages of palliative care planning

- Establish eligibility of fetus or baby for palliative care
- Family care
- Communication & documentation
- Flexible parallel care planning
- Pre birth care
- Transition from active postnatal care to supportive care
- End of life care
- Post end of life care
- Routine pre birth care plan
- Routine post natal plan
- Survival or end of life by natural causes

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5. Advance care planning

This would be appropriate for on-going 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. 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 to 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, it is important to establish contact as early as possible with them in order to ensure smooth delivery of care.

6. 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
- on-going care needs in the event of survival
- transition from active routine care to palliative care, (or vice versa).
7. Overview Delivery of care

7.1 Combined Clinic (Fetal Medicine/ MDT) meeting - This clinic appointment is arranged once diagnosis of Fetal anomaly (LLC/PLLC) is confirmed, mainly to discuss prognosis of baby after birth.

7.2 MDT/ Perinatal Palliative Care- team consultation ( SB/SA; JY/AS - Fetal medicine team, AG - Neonatal team, AM- Palliative consultant, AW/SG - Bereavement team, TC- Children Community service) (all contacts- see appendix 1)

Joint consultation with obstetrics/paediatrics/palliative/ bereavement and hospice team to discuss care of patient and her fetus during labour/ delivery and after birth.- This is to ensure efficient review of patient occurs within the shortest time, reducing unnecessary overlap in counselling, and improve communication between teams.

7.3 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 (consultant led). Transfer to SB care where appropriate

7.4 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.

7.5 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.

7.6 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.

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. 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.
Perinatal Palliative Care Pathway for RBH (see AHSN pathway appendix 2)

Fetus has a life limiting condition or a potentially life limiting condition confirmed antenatally

- Refer to JRH, Oxford (only where required)
- Parents opt to continue pregnancy

Parents opt to terminate pregnancy

- No routine involvement of Paediatric/ palliative team
- Miscarriage/ IUD at any stage

Once pregnancy reaches viability- Offer MDT discussion with FM team, Neonatal consultant and Palliative Consultant + hospice +children’s community nurse + Bereavement midwives- to discuss care during pregnancy; place of delivery, labour; and for mum and baby after birth

Named Consultant for routine Ante Natal Care (If not booked with any consultant then SB to be the named consultant)

Copy of care plan to go to
  a. Maternity record/ Hospital file
  b. Community midwife
  c. Delivery suite
  d. Neonatal unit
  e. Ambulance service/ Transport team
  f. Local Children’s hospice
  g. GP
## Appendix 1 - Contacts

<table>
<thead>
<tr>
<th>Name</th>
<th>Email</th>
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Appendix 2 – Perinatal palliative care pathway TVN

Perinatal palliative care pathway- Thames Valley Network

Baby has a life-limiting or potentially life-limiting condition confirmed antenatally

Parents opt to continue pregnancy

Aim to deliver care locally unless specialist obstetric or neonatal care needs unavailable

Pregnancy continuing past viability

Offer meeting with paediatrician +/- palliative care consultant – timing depends on needs of family. Support for local team to develop individual PPC plans available from Oxford PPC team.

Named consultant obstetrician for routine antenatal care

Consider ongoing psychological needs of woman and her family- referral to Specialist Perinatal Bereavement MW or to hospice family support team

If parents haven’t already, arrange to meet with paediatrician, obstetrician +/- with palliative care consultant to discuss birth plan at 30-34 weeks.

Joint Perinatal Palliative Care team meeting between 36-37 weeks to review birth and early newborn care plans (to include advance care plans / symptom management plans with flexible parallel planning)

Copy of care plan to go to (1) maternity record, (2) community midwife (3) delivery suite, (4) Neonatal Unit & network transport team (5) local children’s hospice (6) GP

Parents opt to terminate pregnancy

No routine involvement of paediatrician / palliative care consultant

Miscarriage

Bereavement support

IUFD
8. References


