



Establishing a care pathway for Perinatal Palliative Care

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Introduction

Around 2-3% of pregnancies are complicated by congenital structural abnormalities, 15% of which are life-limiting or potentially life-limiting. Over recent years it has become apparent that there is a need for clearer pathways for palliative care for this group of infants that can begin prior to delivery. This includes consideration of location and timing of delivery, where care will be provided after birth, clear advanced care plans (ACPs) and symptom management plans (SMPs), education and support for staff in local hospitals, and bereavement support for parents.

Aim

- To establish seamless links between fetal medicine, paediatric palliative care, neonatal team, children's hospices and specialist services such as cardiology to develop plans for infants requiring perinatal palliative care, and work with local paediatric and obstetric teams to deliver this care.
- The aims of the Wessex Perinatal Palliative Care (PPC) framework includes 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.
- Increase awareness of PPC as an option for parents with a fetus with an anticipated life-limiting condition ensuring informed choice.

This 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

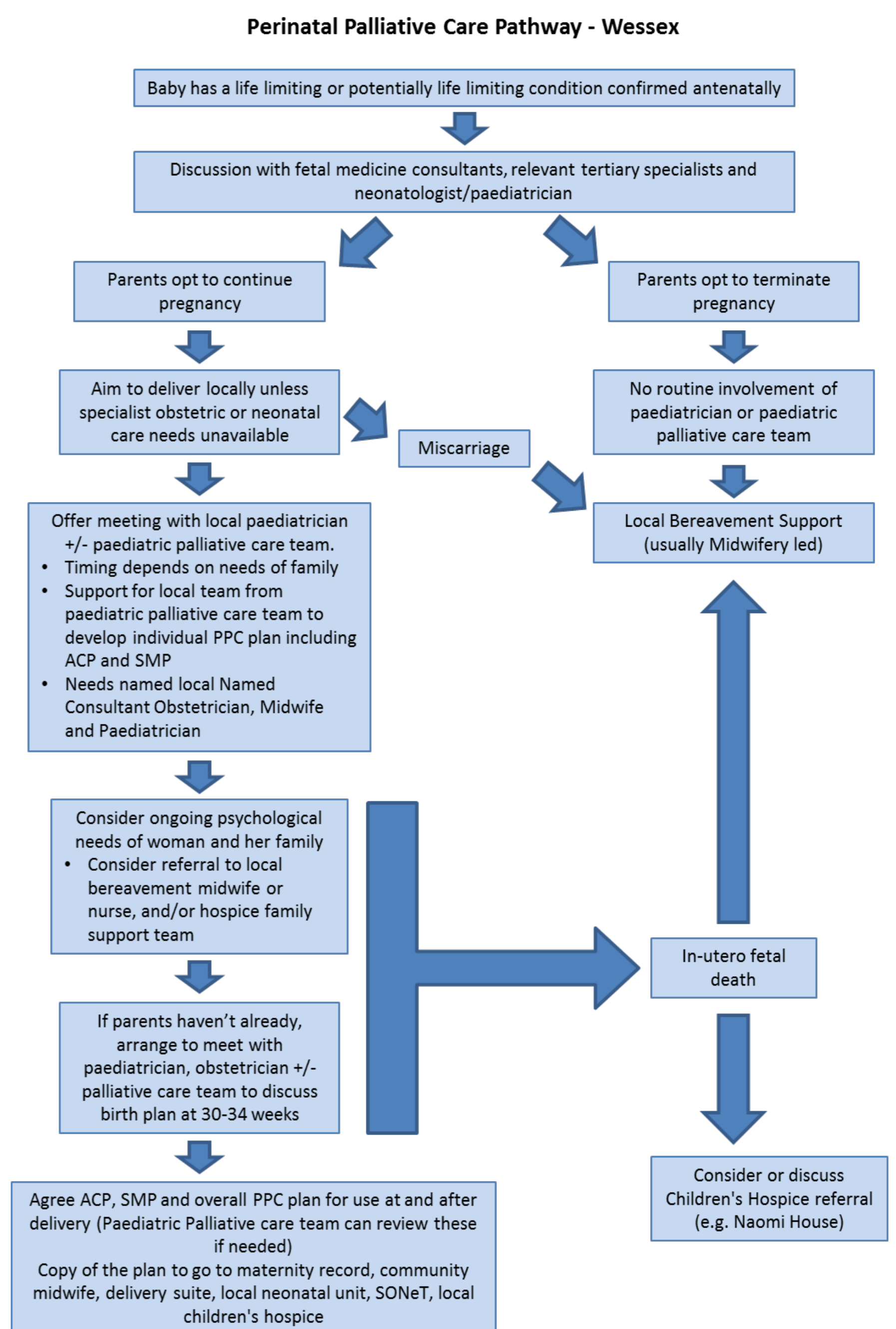


Figure 1: A proposed perinatal palliative care pathway for Wessex (adapted from Thames Valley Pathway with permission)

Outcome

- Two perinatal cases have been supported locally with palliative care following delivery. The regional teams were able to support the local MDT with education, advanced care planning and symptom management.
- In one case the baby had antenatally diagnosed Hypoplastic Left Heart Syndrome (HLHS) which carries a poor long term prognosis.
- The second case had significant renal dysplasia with oligohydramnios and pulmonary hypoplasia with extremely poor prognosis and was unlikely to survive longer than a few days.

Conclusion

PPC focuses on the prevention of pain and distress of the infant, and on the psychological, social and emotional support of the family. The purpose of developing a PPC framework within the Wessex 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.