Palliative Care Pathway for neonates - Full Clinical Guideline

Reference no.: UHDB/NEONATE/11:21/N9

Contents

1. Introduction

This guideline supports staff to plan and help families through the palliative care pathways available, for babies diagnosed with an ante-natal or postnatal life-limiting condition, at UHDB.

2. Purpose and Outcomes

- Keep the family central to the care, aiming to keep mother and baby together.
- Involve local teams and facilities such as Hospice Care and community teams as early as possible, to ensure the family is supported by a skilled multi-disciplinary team of their choice (MDT).
- Ensure plans are made and agreed by the family and MDT.
- Have an identified Lead for each family at diagnosis. This could be the Fetal Medicine Consultant, Fetal medicine Midwife or Bereavement Midwife.

3. Key Responsibilities and Duties

To ensure:

- Families' wishes are central, with the need of the baby remaining the highest priority
- Early involvement of palliative care teams to:
  - ensure consistent and supportive shared care for families
  - assist staff when a baby's condition changes or deteriorates
- Sharing of information and agreed management plans, between parents hospital and community settings. The lead HCP responsible for dissemination of agreed plan, ensuring consistent family centred care for the family.
- Opportunity for a follow up meeting after death or discharge to be offered by the Lead, Obstetrician and Neonatologist, with the appropriate staff as requested by the family.
- Identification, documentation and handover of palliative care lead responsibility to local neonatal or community team, if the baby is to need on going prolonged palliative care management in the hospital, hospice or home

4. Abbreviations and Definitions

CMW	-	Community Midwife
GP	-	General Practitioner
HCP	-	Health Care Professional
MDT	-	Multidisciplinary Team
MW	-	Midwife
NICU	-	Neonatal Intensive Care Unit

Palliative Care - planning and provision of supportive care during life and end of life care for a fetus, new-born infant and their family …(BAPM, 2010)

Lead HCP - lead health care professional for the baby and family, who will coordinate the care and share information with the MDT.

5. Antenatal Care

5.1. Create a team

- Fetal medicine Consultant ideally to be identified as the MDT Lead, for consistency of information and management of care of mother and baby, from diagnosis to birth.
- Fetal Medicine MW, CMW, and Bereavement Midwife to form **a 'team around the family'**, and obtain emails and contact numbers of all agreed practitioners to update and communicate on going plans.
- **Consider other professionals**– NICU Consultant, CMW, Bereavement Midwife, NICU Family Care Sisters, Kite Team, GP, Health Visitor and Hospice staff.
- Gain consent from the family if they wish to be referred for hospice support, alternatively they can refer themselves.

5.2. Arrange a MDT team meeting with the family

- Arrange aMulti-disciplinary team meeting with the family to explore family's needs and wishes regarding care planning during their ante natal, intra partum and post natal period
- Commence the care pathway document/ Advance Care Plan (appendix's).
- Agreed Advance Care Plan to be held in the mother's notes

5.3. Continuing care

Fetal Medicine Midwife, or Bereavement Midwife to update care plan and MDT as pregnancy progresses.

6. Intrapartum care (labour and baby born in hospital)

- NICU in charge Nurse and on call Consultant Neonatologist should be informed by admitting midwife and Consultant Obstetrician repectively regarding:
  - Admission of expectant mother
  - Agreed advance care plan.
  - Revisit agreed resuscitation and advance care plan, if time permits
  - Requirements for a Neonatologist / Paediatrician to attend the birth.

7. Postnatal

After birth:

- Care for mum provided by midwives either on LW, or the postnatal wards
- Midwife to inform NICU staff, Hospice Staff, Family Care Sisters, Bereavement Midwife (as per contacts below)
- Avoid separating mother and baby where possible. This should be agreed between Labour Ward, PN ward and NICU, taking into account family wishes.
- NICU nurses can support care of the baby in some circumstances such as NG tube feeds and pain management. This should be agreed with the NICU Matron or Lead Nurse.
- The Advance Care Plan should be followed and the Midwife / Nurse caring for the baby to update the MDT (NICU staff, Hospice staff, Family Care Sisters/ Bereavement Midwife)
- NICU consultant on take, to be named consultant for the baby.

Postnatal care plan:

- To be revisited with the parents in an MDT meeting, if end of life management is expected to be longer than 6-8 hours
- Postnatal MDT meetings should be led by the Neonatologist, to explore parents and family wishes with regards to location of on-going care, feeding options and pain relief if needed
- Confirm with community services and transport team, prior to any arrangements with the family
- Advanced Care plan to be filed in the baby notes and disseminated to the involved team

7.1. Site specific operational guidance RDH site

7.1.1. PN discharge to Home

- Labour Ward Midwife to complete Birth Notification
- Discharge as normal with information to GP, CMW, Health Visitor via Lorenzo.
- Inform NICU Outreach team on nicuoutreach@nhs.net and leave a message at reception to say contact has been made- 01332 785644.
- Inform the Kite team via dhftkiteteam@nhs.net
- Inform the Bereavement Midwifery team uhdbperinatalmortalityteam@nhs.net

7.1.2. PN discharge to Rainbows Hospice (See section 9 for referral form)

- Labour Ward Midwife to complete birth notification.
- If baby is discharged to Rainbows, transport must be arranged by RDH staff, either by ambulance transfer or family car with appropriate safe equipment (*see below)

- Call Rainbows prior to ensure they are expecting the baby. 01509 638 000
- Neonatologist to write a handover letter to receiving doctor, and Midwife to write a handover letter to the nursing staff, with a background of the diagnosis, birth and care after birth.
- Discharge as usual on Lorenzo to GP, CMW and HV, ensuring details of place on on-going care are clear.
- If NICU Outreach Team, Kite Team has been involved, update them by email. nicuoutreach@nhs.net, and inform Derby Bereavement Midwifery team

* Gov.uk child car seats: the law states:

0-10kg: lie-flat or lateral baby carrier, rear-facing carrier, or rear-facing baby seat using a harness

0-13kg: rear-facing baby carrier or rear-facing baby seat using a harness

7.1.3. Hospital

- If baby needs to remain in hospital for more than 6-8 hours, the best place to care for the baby and family can be discussed during the postnatal MDT's and will also be dependent on the mother's clinical condition.
- Labour Ward Midwife to complete birth notification

7.2. Site specific operational guidance QHB site

Discharge home: Baby discharged to care of GP, with support from CMW, Children's Community Team East , Health Visitors and if referred Hospice at Home team at Rainbows, Donna Louise Hospice or Acorns.

- Rainbows Hospice. If baby is discharged to Rainbows, transport must be arranged by QHB staff, either by ambulance transfer or family car with appropriate safe equipment * see above 7.1.2
- Call Rainbows prior to ensure they are expecting the baby. 01509 638 000
- Inform GP, CMW , HV and Children's Community Nursing East if referred.
- Hospital: If baby needs to remain in hospital, NICU Consultant to liase with Children's Ward to ascertain the most suitable place of care for baby. Inform CMW,GP, HV.

8. End of life (only applicable if baby dies in hospital)

- After he baby has died, follow all usual procedures to support the family with memory making, use of cold cots.
- The family might want to consider the option of taking their baby home, or to their local hospice. Follow the 'Taking baby home' guideline

8.1. Home or Hospice

- Midwife ensures birth is registered
- NICU consultant to complete medical certificate and cremation form.
- Complete NND checklist.
- Transfer baby to mortuary for funeral director or family to transfer baby to on-going place of care.
- If parents wish to take baby home directly from the labour ward, please liaise with mortuary technicians to discuss completion of mortuary records and refer to the 'Taking your baby home' guideline.
- Parents are offered opportunity to meet with Lead HCP and senior clinical staff for debrief appointment.

8.2. Staff support

Staff involved in bereavement care should be offered support from their line manager, PMA, if midwifery, colleagues and in some instances through an organised debrief.

9. Forms/templates to be used

Neonatal Palliative Care Plan (direct download from KOHA)

Click here for Rainbows Referral Form

10. Monitoring Compliance and Effectiveness

As per agreed business unit audit forward programme

11. References

Together for Short Lives

East Midlands Neonatal Operational Delivery Network

Appendix A

Contacts

Acorns Hospice Walsall 01922 422500

Ambulance transfer – Burton

Ambulance transfer – Derby 01159 675 099

Bereavement Office Derby 01332 785557

Bereavement Midwife Burton 01283 511511 ext: 4383

Bereavement Midwife Derby 01332 789791

Community Children's Nursing East 01283 504 867/ on call 07817756336

Coroners office Derby 01629 535050

Coroners office South Staffs 01785 276126

Donna Louise Hospice Stoke 01782 654440

Derby NICU Outreach team 01332 785462 nicuoutreach@nhs.net

Fetal Medicine Derby 01332 785409

Kite team Derby dhftkiteteam@nhs.net

Mortuary Burton 01283 511511 ext: 4086

Mortuary Derby 01332 785013

NICU Burton 01283 511511 ext: 4346

NICU Derby 01332 785040

Rainbows Hospice 01509 638 000

Appendix B

Candidate conditions for perinatal palliative care

These can be considered in five broad Categories.

Category 1. An antenatal or postnatal diagnosis of a condition which is not compatible with long term survival, e.g. bilateral renal agenesis or anencephaly.

Category 2. An antenatal or postnatal diagnosis of a condition which carries a high risk of significant morbidity or death, e.g. severe bilateral hydronephrosis and impaired renal function.

Category 3. Babies born at the margins of viability, where intensive care has been deemed inappropriate.

Category 4. Postnatal clinical conditions with a high risk of severe impairment of quality of life and when the baby is receiving life support or may at some point require life support, e.g. severe hypoxic ischemic encephalopathy.

Category 5. Postnatal conditions which result in the baby experiencing "unbearable suffering" in the course of their illness or treatment, e.g. severe necrotizing enterocolitis, where palliative care is in the baby's best interests.

Taken from:

Palliative Care (Supportive and End of Life Care)
A Framework for Clinical Practice
in Perinatal Medicine.

Report of the Working Group August 2010

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