University Hospitals of Derby and Burton NHS Foundation Trust

Palliative Care Pathway for Neonates
Full Clinical Guideline

Reference no.: UHDB/NEONATE/09:24/N9

Contents

1. Introduction

This guideline is for all staff in perinatal services who are caring for babies and their families facing an uncertain prognosis and outcome, to promote a palliative care approach, parallel care planning and the integration of specialist palliative care services.

Where there may be a diagnosis of a life-limiting or life threatening condition, it is recognised that there is uncertainty around whether the baby can or will survive but early implementation of the palliative care pathway should provide the significant benefits of palliative care for those babies who die in infancy or early childhood and help to plan and prepare families for the loss of their child, enabling families to have no regrets about how they spend this time.

2. Best interest

The overriding legal and ethical principle is that all treatment decisions must be taken in the child's best interest.

3. Purpose and Outcomes

- To recognise the uncertainty around life limiting/life threatening conditions and that staring a palliative care pathway for a baby does not automatically require an end of life pathway.
- To ensure that an MDT is created around the family who will provide personalised, parent led care ensuring that parents can change their mind at any time.
- Every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity.
- To ensure that infants are afforded the utmost dignity and respect in all aspects of their care.
- The MDT will support informed decision making, ensuring that parents are put at the heart of their baby's care, aiming to keep parent and baby together.
- To help families decide on an end of life care plan which should be provided with sensitive care and support to help them achieve this.
- To work collaboratively with other disciplines including community teams, Hospice's (with consent) and tertiary centres to ensure the family is supported by a skilled multi-disciplinary team of their choice (MDT).
- To have an identified lead for each family at diagnosis. This could be the Fetal Medicine Consultant, Fetal medicine Midwife, Bereavement Midwife or Neonatal Palliative and Bereavement Care Specialist Nurse
- To provide emotional support for parents that is empathetic, honest and straight forward.
- The time that parents spend with their baby may be short and therefore very precious. Consider the parents' own health needs and help to facilitate this time effectively.
- Ensure partners needs are met and support them to support them in caring for the needs of their baby as well as their partner.
- Bereavement support should be provided along the care pathway and continue throughout the baby's death and beyond.

4. Key Responsibilities and Duties

- Once a baby has been identified as having the potential to benefit from palliative care it is important that this is communicated with family members and with other health care professionals in a way that effectively communicates prognostic information but that also responds to the emotions generated by the conversation.
- It is the responsibility of the lead HCP to enable the early involvement of the MDT to ensure consistent and supportive collaborative care, improving communication and allowing for a positive care experience.
- The care provision should be parent led using a family integrated approach ensuring the best interests of the baby are met.
- The lead HCP will support continuity of communication and care planning through the baby's neonatal stay
- Promote good communication and ensure that information and agreed management plans are shared appropriately between potential multiple teams and services and the parents
- An end of life care plan should be easily accessible to the MDT to ensure a smooth plan should the baby's condition change.

5. Abbreviations and Definitions

ACP	-	Advanced Care Plan
CMW	-	Community Midwife
GP	-	General Practitioner
HCP	-	Health Care Professional - lead health care professional for the baby and family, who will coordinate the care and share information with the MDT.
MDT	-	Multidisciplinary Team
MW	-	Midwife
NICU	-	Neonatal Intensive Care Unit
NND	-	Neonatal Death

'**Palliative care'** refers to an active approach to the care of children with life-limiting conditions from the time of diagnosis through to death and bereavement. It embraces physical, emotional, social and spiritual needs and focuses on the enhancement of quality of life and support for the child's family(12). Palliative care is not the same as end-of-life care (the care of a baby in the dying phase), though it includes end-of-life care as and when that is appropriate.

6. Antenatal Care

6.1. 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, Neonatal Specialist Nurse, Community Nursing teams, GP, Health Visitor and Hospice's.
- Early, honest conversations should commence with the family to allow for parallel planning, if the parents' wish.
- Gain consent from the family if they wish to be referred for hospice support, alternatively they can refer themselves.

6.2. Arrange a MDT team meeting with the family

- Arrange a Multi-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 and enabling informed decision making.
- Commence the care pathway document/ Advance Care Plan (appendix's).
- Agreed Advance Care Plan to be held in the mother's notes

6.3. Continuing care

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

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

NICU Nurse co-ordinator and on call Consultant Neonatologist should be informed by admitting midwife and Consultant Obstetrician respectively regarding:

- Admission of expectant mother
- Agreed advance care plan.
- Revisit agreed resuscitation and advance care plan, if time permits
- Neonatologist/Paediatrician should attend the birth

8. Postnatal

After birth

- Care for mum provided by midwives either on LW, or the postnatal wards
- Midwife to inform NICU staff, Hospice Staff (if consented to), Bereavement Midwife and Neonatal Specialist Nurse (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.
- If Neonatal Specialist Nurse is unavailable, NICU nurses can assist in the support care of the baby requiring NG tube feeds and/or pain management. This should be agreed with the NICU Matron, Neonatal Unit manager or Clinical Coordinator.
- The Advance Care Plan should be followed and the Midwife / Nurse caring for the baby to update the MDT. NB the ACP is not a legally binding document and can be reviewed at any time.
- NICU consultant on call, 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

8.1. Site specific operational guidance RDH site

8.1.1 PN discharge to Home

- Labour Ward Midwife to complete Birth Notification
- Discharge as normal with information to GP, CMW, Health Visitor via Lorenzo.
- Inform the Kite team via dhftkiteteam@nhs.net
- Inform the Bereavement Midwifery team uhdb.matbereavementteam@nhs.net
- Inform neonatal nurse specialist kate.jackson3@nhs.net

PN discharge to Hospice

- Families booked in to RDH and those with a Staffordshire address will be referred to Dougie Mac Hospice, Stoke and those with a Derbyshire address will be referred to Rainbows, Loughborough.
- Labour Ward Midwife to complete birth notification.
- If baby is discharged to a hospice, transport must be arranged by RDH staff, either by ambulance transfer or family car with appropriate safe equipment (*see below)
- Call hospice 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/Badger to GP, CMW and HV, ensuring details of place on on-going care are clear.
- If Neonatal Specialist Nurse or Kite Team have been involved, update them by email 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

8.1.3 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

8.2 Site specific operational guidance QHB site

8.2.1 Discharge home

- Baby discharged to care of GP, with support from CMW, Children's Community Team East , Health Visitors and if referred Hospice at Rainbows, Donna Louise Hospice or Acorns.
- If baby is discharged to a hospice, transport must be arranged by QHB staff, either by ambulance transfer or family car with appropriate safe equipment * see above 7.1.2
- Call the hospice prior to ensure they are expecting the baby.
- 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 or NICU/SCBU to ascertain the most suitable place of care for baby. Inform CMW, GP, HV.

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

- After the baby has died, follow all usual procedures to support the family with memory making, use of cold cots.
- The family should be offered the opportunity to take their baby home, or to their local hospice. Follow the 'Taking baby home' guideline

9.1. 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.

9.2. Staff support

A staff debrief should be offered and staff to be supported practically and emotionally using the support structures and systems in place if needed.

10. Forms/templates to be used

Neonatal Palliative Care Plan (direct download from KOHA)

End of Life Care plan

11. Monitoring Compliance and Effectiveness

As per agreed business unit audit forward programme

12. References

Together for Short Lives: 2017, A Perinatal Pathway for Babies with Palliative Care Needs Second Edition

East Midlands Neonatal Operational Delivery Network

BAPM: April 2024, Recognising uncertainty: an integrated framework for palliative care in perinatal medicine - A draft Framework for Practice

Appendix A

Contacts

Acorns Hospice Walsall

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

Coroners office Derby 01629 535050

Coroners office South Staffs 01785 276126

Donna Louise Hospice Stoke 01782 654440

Fetal Medicine Derby 01332 785409

Kite team Derby 01332 786807 dhftkiteteam@nhs.net

Mortuary Burton 01283 511511 ext: 4086

Mortuary Derby 01332 785013

Neonatal Complex, Paediatirc and Bereavement Specialist Nurse 07385 954840 ext: 01332 787412

SCBU 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

Documentation Control

Reference Number: UHDB/NEONATE/09:24/N9	**Version:** **UHDB Version 2**		**Status:** **FINAL**	
Version / Amendment	Version	Date	Author	Reason
	1	Sept 2021	Angela Thompson – Specialist Midwife Bereavement Support - RDH Samantha Evans – Bereavement Midwife QHB	New
	2	June 2024	Kate Jackson - Neonatal Complex, Palliative and Bereavement Care Specialist Nurse Maternity Bereavement Team	Review
Intended Recipients:				
Training and Dissemination: Cascaded electronically through lead sisters/midwives/doctors via NHS.net, Published on Intranet, Article in Business unit newsletter;				
To be read in conjunction with:				
Keywords:				
Consultation with:	Neonatal Team			
Business Unit sign off:	02/09/2024: Maternity Guidelines Group: Miss A Banerjee – Chair 10/09/2024: Tier 4 Maternity Quality & Safety Assurance - Miss J Heslop Exceptional Ratification			
Notification Overview sent to TIER 3 Divisional Quality Governance Operations & Performance: 17/09/2024				
Implementation date:	25/09/2024			
Review Date:	September 2027			
Key Contact:	Joanna Harrison-Engwell			