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Neonatal Palliative Care Plan

For babies and their families with an antenatal diagnosis, on the Neonatal Intensive Care Unit, or being discharged home or to a hospice.

Aug 2015 AM/JH

Acknowledgement

NICU CARE PATHWAY by Norfolk and Norwich University Hospitals NHS Foundation Trust, Norfolk Community Heath Care and East Anglia's Children's Hospice, Written by Julia Shirtliffe, Charlotte Devereux, Amy Brown, Amanda Williamson.

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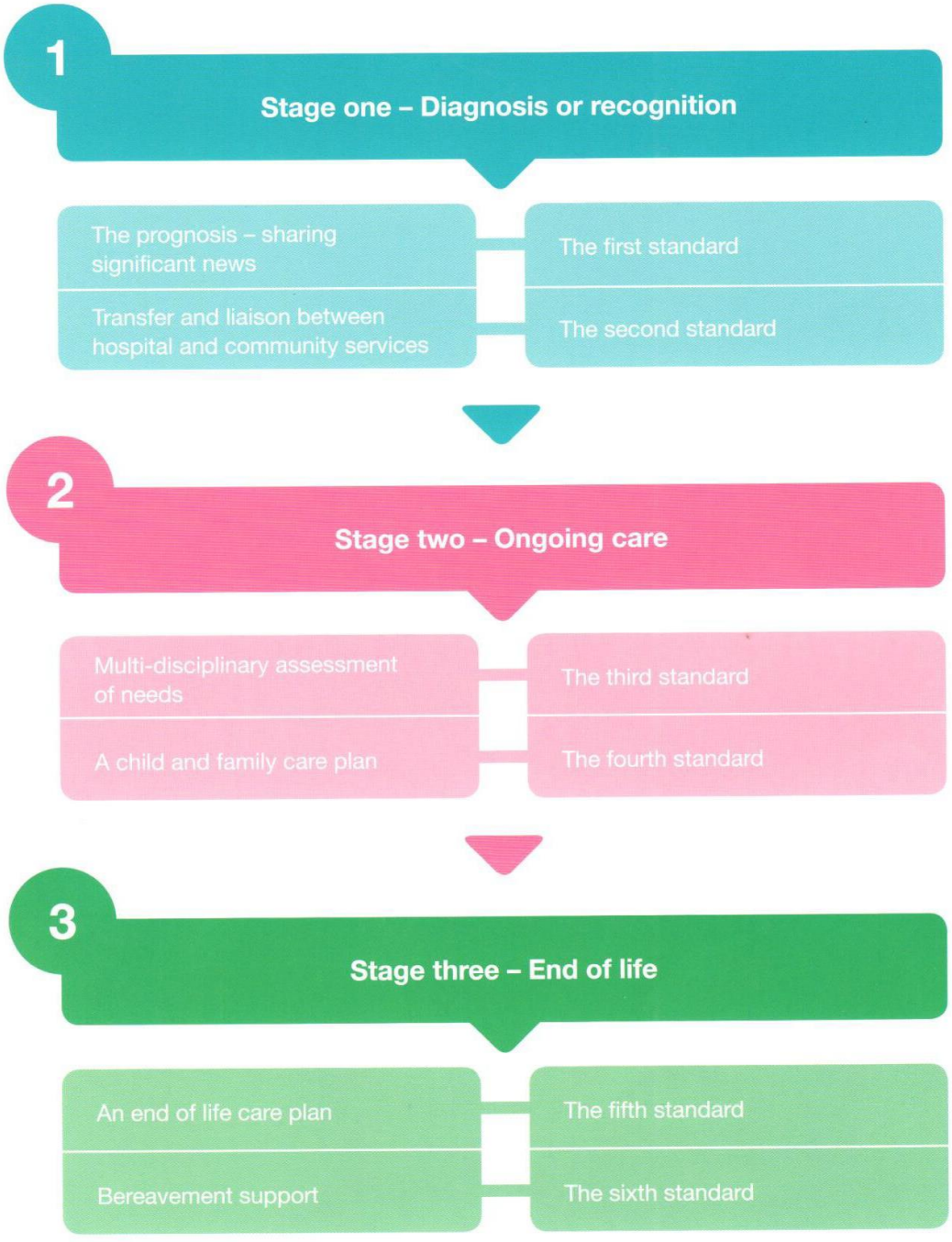
Figure 1: Pathway summary diagram: A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions



This care plan should be commenced when:

The neonatal medical and nursing team, in collaboration with the family and members of the Multi-Disciplinary Team (MDT) have agreed in partnership that the baby is requiring palliative or end of life care.

Date Care Pathway Initiated:			
Baby's Name: Mother's Name:	Date of Birth:		
Hospital Number: Mother's Hospital Number:	NHS Number:		
Antenatal diagnosis: Diagnosis; Current problems:			
Mother: Contact Number:	Father: Contact Number:		
Other contacts:			
Family Address;			
Lead Consultant:			
Lead Nurse:			
GP Name: Address: Telephone:	HV Name: HV Contact:		
Ventilatory support required; Nursing support required;			
Preferred place of care:	Hospital	Home	Hospice

CONTACT NUMBERS

Children's Community Nursing Team 0207 349 3258
for Kensington & Chelsea

Kaleidoscope
Paediatric Palliative Care Nursing Team 0207 266 8840/8713
K&C, H&F and Westminster

Paediatric Palliative Care Team (London) 0207 829 8678
Great Ormond Street Hospital Aircall 0207 405 9200

Shooting Star Chase Children's Hospice 0208 783 2000
(includes all North West London ODN)
www.shootingstarchase.org.uk

The Children's Trust 01737 365080
www.thechildrenstrust.org.uk

ARC – Antenatal results & choices 020 76310285
http://www.arc-uk.org/

BLISS 020 7378 1122
www.bliss.org.uk/

Child Bereavement UK 01494 446648
www.childbereavementuk.org

London Organ Donation Services Team 0207 301 6922
LODSTMAN@nhsbt.nhs.uk

Rainbow Trust Surrey: 01372 363438
www.rainbowtrust.org.uk/ West London: 01895 448378
Central London:0207 324 4620

SANDS – Stillbirth and neonatal death charity 020 74365881
www.uk-sands.org/

Together for Short Lives 0117 989 7820
www.togetherforshortlives.org.uk

Planning Meeting for the family

Date & Time:

Date of discharge:
(if known)

Professionals	Name & Details	Date of Involvement		Contact Number
NICU Lead Consultant				
NICU Named Nurse				
GP				
HV				
Midwife Community				
Obstetrician				
Community Nursing Team				
Kaleidoscope Nursing team				
Paediatric Palliative care team				
Community Paediatrician				
Rainbow Trust				
Hospice contact				
Spiritual Support				
Local hospital				
Ambulance directive				
Physio				
SALT				
Dietician				
Surgeon				
Gastro Support				
SNOD				

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Goals for Care

Patient Focus	
1. *Pain* **Goal: Baby is pain free** • Neonatal assessment of pain. • Pain free on movement. Medication • Appears peaceful.	
2. *Feeding* **Goal: Baby tolerating milk** • TPN – line care • Absorption	
3. V*omiting* **Goal: Baby is not vomiting** • Anti-reflux meds. • Baby comfortable.	
4. *Elimination* **Goal: No abdominal distension** • Normal bowel motion in last 3 days and passing urine	
5. *Agitation/restless/distress* **Goal: No sign of agitation** • Parents/nurse report that baby is settled, restful and sleeping for normal periods.	

Goals of Care continued…….

6. *Mouth Care* **Goal: Mouth and lips appear moist** • Regular mouth care	
7. *Respiratory tract secretions* **Goal: No audible secretions in baby** • No excessive dribbling or cough	
8. *Medication* **Goal: Being administered by a safe and appropriate route** • Absorption • Symptom control	
9. *Mobility and pressure area care* **Goal: Baby cared for in a safe environment** • Baby comfortable and has appropriate pressure relieving aids • Regular positioning •	
10. *Care of the Family* / Privacy & Dignity **Goal: Up to date information** • Baby and family treated with respect • Psychological support • Practical support . • Spiritual support. • Bereavement support • Health needs	

Multidisciplinary Care Plan

Time/Date	Care Plan Comments	Print name and sign

Multidisciplinary care plan continued…

Time/Date	Care Plan Comments	Print name and sign

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End-of-Life Care Plan

Family's request for preferred place of death discussed (Hospital/Hospice/Home)
Family's hopes and wishes at end-of-life (siblings/music/cuddles/photos)
Discussion about what physical changes will occur at time of death;
Parents aware of who to contact if baby dies at home: Name: Contact Number:
Discussion about care of baby after death (Where will the baby go/what needs to be done)
Family/Friends to be involved after the baby dies (grandparents/siblings)
Hand/foot prints, photographs, keepsakes, lock of hair taken? Photographer?
Memory boxes for siblings/family?
Name and Signature:…… Designation:…… Date:…….

Transition Care Plan-Goals

Goal 1: Discharge planning discussed with Hospice and parents			
Please tick boxes when interventions and goals are achieved – if not achieved please document in variance box.			
Goal achieved		Date:	Initials:
Liaison with HOSPICE Date: Time: Person contacted: Initials:			
Consultant liaison with GP: Date: Time: Person contacted: Initials:			
Discussed with parents: Date: Time: Initials			
Any variance:			

Goal 2: Resuscitation discussed and documented			
Goal achieved		Date:	Initials:
Not for resuscitation		Date:	Initials:
For suction and oxygen only		Date:	Initials:
Letters for paramedics written		Date:	Initials:
Any variance:			

Transition Care Plan-Goals continued…

Goal 3: Family aware of possible complications of illness and potential mode of death			
Goal achieved		Date:	Initials:
Discussion with consultant and hospice staff		Date:	Initials:
Family have access to telephone and transport in an emergency:		Date:	Initials
Plan of action and support in case of death in transit or immediately after discharge discussed with family (Appendix 1		Date:	Initials:
Name and Contact Details of hospital doctor to complete death certificate if death occurs in transit		Date:	Initials:
Post mortem examination requested?		Yes	No
Plan for organising post mortem agreed with family		Yes	No
Any variance:			

Goal 4: Medication, nutrition and equipment needs			
Goal achieved		Date:	Initials:
Non essential medication discontinued		Date:	Initials:
Route, timing and mode of administration of essential medication appropriate for Discharge		Date:	Initials:
Non essential tubes/lines removed		Date:	Initials:
Any other invasive interventions Discontinued		Date:	Initials:
Monitoring Discontinued		Date:	Initials:
Any variance:			

Transition Care Plan-Goals continued…

Goal 5: Medical needs for transfer to HOSPICE or HOME			
Goal achieved		Date:	Initials:
No specific needs for journey		Date:	Initials:
Oxygen required for journey		Date:	Initials:
Ventilation required for journey and arranged		Date:	Initials:
Suction required for journey		Date:	Initials:
Medical or nursing staff to accompany baby on journey		Yes	No
Any variance:			

Goal 6: Suitable transport for baby's transfer			
Goal achieved		Date:	Initials:
Paramedic Ambulance		Date:	Initials:
Transport Incubator prepared?		Yes	No
Hospital Taxi			
Family Transport			
Other (please specify)			
Suitable transport arranged for family (if different to baby)			
Any variance:			

Transition Care Plan-Goals continued…

Goal 7: Medical needs for HOSPICE or HOME			
Goal achieved		Date:	Initials:
Medication/ TTO's prescribed and ready for transfer?		Yes	No
Any variance:			

Goal 8: Religious, cultural, spiritual, communication support needs discussed			
Goal achieved		Date:	Initials:
Family's insight into the condition assessed:			
<u>Awareness of diagnosis:</u>			
Parents:	Yes	No	Initials:
Siblings:	Yes	No	Initials:
<u>Recognition of end of life:</u>			
Parents:	Yes	No	Initials:
Siblings:	Yes	No	Initials:
Formal Religion identified as……			
Special needs now and end of life plans made (see section 5)	Yes	No	Initials:
Any variance:			

Transition Care Plan-Goals continued…

Goal 9: Discharge Plan communicated				
Discharge Check list completed (see section 4)	Yes	No	Date	Initials
The following people informed of discharge:				
NICU Lead Consultant			Yes	No
Neonatal Community Team			Yes	No
General Practitioner			Yes	No
Spiritual Support			Yes	No
Hospice			Yes	No
Social Worker			Yes	No
Health Visitor			Yes	No
			Yes	No
Dietician			Yes	No
Midwife			Yes	No
Coroner's Office			Yes	No
Any variance:				

Transition Care Plan-Goals continued…

Goal 10: Equipment				
Goal achieved			Date:	Initials:
Equipment required for care at Home or Hospice arranged and available?	Yes	No	Date	Initials
Oxygen required	Yes	No		
Oxygen Prescribed	Yes	No		
Nasal Cannula/adhesive dressings	Yes	No	Date:	Initials:
Oxygen checklist completed	Yes	No	Date:	Initials:
Training for parents	Yes	No	Date:	Initials:
Home suction	Yes	No		
Suction machine arranged	Yes	No	Date:	Initials:
Suction equipment	Yes	No	Date:	Initials:
Training for parents	Yes	No	Date:	Initials:
Home tracheostomy care	Yes	No		
Equipment for Tracheostomy care arranged?	Yes	No	Date:	Initials:
Discussion with family about Tracheostomy care?	Yes	No	Date:	Initials:
Parents able to perform emergency tube change?	Yes	No	Date:	Initials:
Ongoing equipment supplies arranged?	Yes	No	Date:	Initials:
Any variance:				

Transition Care Plan-Goals continued…

Goal 11: Nutritional needs				
Goal achieved			Date:	Initials:
Naso gastric tube	Yes	No		
Gastrostomy tube	Yes	No		
Supplies of appropriate naso gastric tubes, adhesive dressings, syringes, pH indicator papers given to parents or Hospice	Yes	No	Date:	Initials:
Training for parents given	Yes	No	Date:	Initials:
Supply of Feeds Required	Yes	No		
Dietician Informed	Yes	No	Date:	Initials:
Supply of feeds to take home or to hospice	Yes	No	Date:	Initials:
Prescription for feeds arranged with GP	Yes	No	Date:	Initials:
Any Variance:				

Goal 12: Elimination Needs				
Goal achieved			Date:	Initials:
Stoma Care required	Yes	No		
Stoma Nurses aware of discharge	Yes	No	Date:	Initials:
Stoma equipment arranged for Home or hospice	Yes	No	Date:	Initials:
Any variance:				

Goal 13: Risk assessment for NICU/COMMUNITY Staff				
Goal achieved			Date:	Initials:
NICU/COMMUNITY have undertaken a risk assessment of home if baby is to return home	Yes	No	Date:	Initials:
Any variance:				

Transfer:
HOME or to HOSPICE for End of Life care Discharge

Check list	Initials
End of life Care Pathway commenced.	
Follow up appointment with Lead Consultant arranged.	
Transfer letter outlining what to do in case of cardio pulmonary arrest written by Consultant ready for transfer. Emergency Care Plan.	
Discharge Check undertaken by Doctor and appropriate page completed in medical notes and SEND.	
Doctor to complete SEND summary / Nurses ensure that parents have a copy prior to discharge (advise that this may contain confidential information).	
Check that TTO's have been prescribed and ordered.	
Any medication given to parents to take home needs to be checked by 2 trained members of nursing staff and documented in medical notes.	
Fill in discharge sheet.	
1. On day of discharge complete discharge page in nursing notes. 2. Document if Community support to be given.	
Discuss with Community Nurses re discharge: Arrange appointment time for visit by • Community Nurses to home or hospice • Obtain a map of location of house • Take contact telephone number • Parents first names	
Name and Signature:…… Designation:…… Date:…….	

Assessment at Discharge

Diagnosis:	Please briefly summarise current care of any symptoms below or say if not a current problem
Symptoms :	
Tolerating feeds	
Vomiting	
Constipated	
Pain	
Agitated / restless / distressed	
Seizures	
Conscious	
Urinary difficulties	
Respiratory problems, secretions/ dyspnoea	
Skin condition	
Any known infections	
Current comfort measures	
Other relevant information	
Current comfort/ Management measures - Analgesics - Anti-emetics - Sedatives - Anti-cholinergic - Anti-convulsants	
Any syringe drivers?	

Assessment continued:		
Communication with Multi-disciplinary team:		
NICU Lead Consultant	Yes	No
Neonatal Community Team	Yes	No
GP	Yes	No
Spiritual Supporter	Yes	No
Hospice	Yes	No
Social Worker	Yes	No
HV	Yes	No
Gastro Specialist Nurse	Yes	No
Neonatal Surgical Nurse Specialist	Yes	No
Dietician	Yes	No
Midwife	Yes	No
Name and Signature:…… Designation:…… Date:…….		

Transfer Outcome Summary

To be completed either by transport team or by receiving community or hospice team.		
Baby died in transit	Yes	No
If yes, time of death…….. Place of Death……. Death verified by (print name and sign)…… Designation……. Death certified by (print name and sign)…… Designation……. Time of arrival at transfer destination…….….		
Transfer documentation received	Yes	No
Any significant events during transfer:		
Is there anything that may have been useful for the baby's transfer?		
Completed by (print name and sign)……. Time and Date……... Contact Details……..		

Transition to Home Care from Hospice

If baby's life is prolonged, HOSPICE will initiate Transition to Home Care Plan, and will communicate with all professionals on contact details sheet.		
1. HOSPICE Team to complete home assessment	Date:	Initials:
2. Review Goal 10 – Equipment (complete checklist)	Date:	Initials:
Any other goals for care:		
Name and Signature:…… Designation:…… Date:…….		

Review after the death of a baby
(please refer to NICU bereavement folder)

Baby's Name:	Gender:	
Date of Birth:	Date & time of Death:	
Address:		
Telephone:	Mobile:	
GP: HV:		
Diagnosis:		
Family details:		
Parent's together:	Yes	No
Mother's Full Name:		
Address and contact number if different to the baby:		
Father's Full Name:		
Address and contact number if different to the baby:		
Details of – Other parents / partners / significant other family members:		
Siblings:		

Care of the Family	Yes	No	N/A
Parents present at time of death?			
Did they spend time with their baby according to their wishes?			
Siblings / other family members present or visited?			
Did a healthcare professional visit as requested?			
Have religious / cultural beliefs been considered according to family's wishes?			

Keepsakes	Yes	No
Were photos offered and taken if requested		
Hand/foot prints and cast taken/ lock of hair		
Precious Memories given		

Information / Practicalities	Yes	No	N/A	Print name and sign
Coroner's office informed?				
Bereavement information given to parents?				
Arrangements made to register death?				
Medical certificate for cause of death completed?				
Funeral Directors informed?				
Records completed?				
Siblings admitted to service for support if required and record prepared?				
Bereavement visits arranged?				
Child Death Review Panel informed of death? MBRRACE completed?				

Professional / Services Involved

Consultants involved (Hospital & Community)

Please record all Consultants below	Yes	No	N/A	Date	Print name and sign

Professionals involved (Hospital & Community)	Yes	No	N/A	Date	Print name and sign
Neonatal Community Team NICU Lead Consultant					
HOSPICE					
GP HV					
Referring Hospital					
Dietician					
Social Worker					
Spiritual Support					
Other Specialities involved					
Surgeons					

Collection of Equipment Arranged	Yes	No	N/A	Date	Print name and sign
Neonatal Community Equipment					
HOSPICE equipment					

Debrief of Staff arranged	Yes	No	N/A	Date	Print name and sign

Copy of completed Care plan sent to NICU C&W	Date:	Print name and sign

Key Documents

- **Practical guidance for the management of palliative care on neonatal units (2014)**
- **A Neonatal Pathway for Babies with Palliative Care Needs (2009)**
- **The management of babies born extremely preterm at less than 26 weeks of gestation (2008)**
- **Palliative Care (supportive and end of life care) A framework for clinical practice in perinatal medicine – the report of a working party in draft at present (2010)**
- **Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice (2015**
- **Bliss: Making Critical Care Decisions (2011)**

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Blood and Transplant

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(NHSBT)

24 HR
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When using the pager please ALWAYS state

- Your name
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- Telephone number with STD code
- Any bleep or extension number

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