North West Neonatal Palliative Care Plan for Babies Cared for on a Neonatal Unit

January 2020

"There is no footprint so small, that it does not leave an imprint on this world"

This care plan has been produced in partnership with the Northwest Paediatric Palliative Care Network

Instructions for use

- If you are unfamiliar with this plan please refer to the NWNODN palliative care guideline
- The purpose of this care plan is to provide a standardised model of care. However **it is not a rigid document** and professional judgment must be used as appropriate.
- You must sign for all care that **you** have provided. Do not sign for care that you have not undertaken yourself. If no signature is present it is assumed that the care has not been provided.
- This plan is laid out chronologically so please complete the care record for the relevant day
- When the care plan ends, please **cross out the next page and sign** to indicate no further pages are relevant to this episode.
- Record time in **24 hour** format (ie HH:MM), and the date must be in **DD/MM/YYYY** format. Use **black ink only** (legal requirement).

Plan starts:

- When the Multidisciplinary Team (MDT) has agreed, in partnership with the family, that a ventilated baby is or will be requiring end-of-life care on the neonatal unit and a compassionate extubation has been decided upon

- When the MDT has agreed, in partnership with the family, that a non-ventilated baby with an antenatally detected anomaly will require end-of-life care on the neonatal unit

Plan ends:

- Baby dies in the Neonatal Unit and bereavement care at a Hospice is declined
- Baby dies in the Neonatal Unit and the family transfer to a Hospice
- If the intention is for the baby to die at a hospice or at home then 'North West neonatal palliative care plan for babies who will be cared for in a hospice' or at home should be used

If you are unsure how to complete any part of this form, please discuss with:

- The Neonatal Senior nurse or the Neonatal/Paediatric consultant

Section 1: Patient details

Ward/Location: _____

For staff use only:
Hospital no:
Surname:
First names:
Date of birth:
NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

Section 1 – Patient Details	
Date care plan initiated:	DD / MM / YYYY
Baby's name:	Gender: male ☐ female ☐
Diagnosis:	
Lead Consultant:	
Obstetric Lead:	
Hospice contact if transferring after death:	Name: Tel No:
Preferred place of care after death:	Home ☐ Hospice ☐ Hospital ☐
Family Details:	
Mother's full name:	Parental responsibility: Yes ☐ No ☐
Mothers' address and contact number (if different to addressograph)	
Mother's main contact number:	
Father's full name:	Parental responsibility: Yes ☐ No ☐
Fathers' address and contact number: (if different to addressograph)	
Father's main contact number:	
Details of: other parents / partners / significant other family members:	Parental responsibility: Yes ☐ No ☐
Siblings:	
Other contact numbers for family:	

Page Completed By:
Print Name: _____ Designation: _____ Ext: _____

Signature: _____ Date: DD / MM / YYYY Time: __ __ : __ __

Section 2: End of Life Care Plan
Ward/Location: _____

Hospital no:
Surname:
First names:
Date of birth:
NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

	Section 2 – End of Life (EoL) Care Plan		Date & Time completed	Signature, Print Name, Designation
Objective 1: Commencing EoL discussions				
MDT	Agreement achieved between MDT and family, that end-of-life care is appropriate for their baby		DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Family's insight into condition assessed:			
	Awareness of diagnosis Parents Yes ☐ No ☐ Siblings Yes ☐ No ☐ Other significant family members Yes ☐ No ☐	**Recognition of end of life** Parents Yes ☐ No ☐ Siblings Yes ☐ No ☐ Other significant family members Yes ☐ No ☐	DD / / YYY __ __ : __ __	Signature, Print Name, Designation
	Free Text …… …… …… …… …… …… ……			
Dr	Discussion of exact EoL care process with Consultant		DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Nursing staff present during EoL discussion with Consultant		DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Organ donation offered if applicable *See resource folder for guidance and Organ Donation Guideline*			Signature, Print Name, Designation
MDT	Place of EoL care discussed with parents		DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Commence memory making if not done so already (e.g. religious/naming ceremony, hand and foot prints, keepsakes)			Sign Print Name, Designation

Section 2: End of Life Care Plan

Ward/Location: _____

Hospital no:
Surname:
First names:
Date of birth:
NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

Nurse	**Objective 1 achieved**	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
Objective 2: Resuscitation Discussed and Documented - in accordance with local trust policy and documents			
Dr	No form of resuscitation decided	DD/MM/YYYY __ __ : __ __	
	No form of resuscitation <u>documented</u>	DD/MM/YYYY __ __ : __ __	
	Limited resuscitation plan decided	DD/MM/YYYY __ __ : __ __	
	Limited resuscitation plan <u>documented</u> **<u>Details</u>**: …… …… …… …… …… …… ……..	DD/MM/YYYY __ __ : __ __	
	Non-escalation of treatment decided	DD/MM/YYYY __ __ : __ __	
	Objective 2 achieved	DD/MM/YYYY __ __ : __ __	

Section 2: End of Life Care Plan
Ward/Location: _____

Hospital no:
Surname:
First names:
Date of birth:
NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

Objective 3: Compassionate extubation - see appendix for compassionate extubation checklist			
MDT	Exact process of compassionate extubation discussed with family	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Options for location of compassionate extubation offered	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Changes in how a baby looks when they die discussed with family	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Ensure family can be left in privacy but are aware of where and how to get support from staff	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Option of transfer to a hospice or home **after** death offered	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Offer of family/friends to be involved/present during EoL care	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Offer option of dressing baby in own clothes/blanket that parents may have or alternatives (e.g. clothing held on unit)	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Continue discussing memory making	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
Nurse	**Objective 3 achieved**	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation

Section 2: End of Life Care Plan
Ward/Location: _____

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NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

Objective 4: Medication, nutrition and equipment needs rationalised			
Dr	Non-essential medication discontinued	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Route, timing and mode of administration of essential medication appropriate for EoL care prescribed *Refer to NW ODN Palliative Care Pain and Symptom Control Document or Association of Paediatric Palliative Medicine (APPM) Master Formulary if needed*	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
Nurse	Non-essential tubes / lines removed if no post mortem is needed	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Any other invasive interventions discontinued	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Monitoring discontinued	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Objective 4 achieved	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
Objective 5: Transfer to place of EoL care <u>within</u> neonatal unit			
Nurse	Location of compassionate extubation process decided by family ☐ Cotside ☐ Place of privacy	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
	Requirements for transfer to place of extubation ☐ No specific needs for journey ☐ Oxygen required ☐ Ventilation required ☐ Suction required	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation

Section 2: End of Life Care Plan
Ward/Location: _____

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First names:
Date of birth:
NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

Objective 5: Transfer to place of EoL care <u>within</u> neonatal unit (continued)		
Mode of transport ☐ Transport incubator ☐ Incubator only ☐ Incubator and portable transport ventilator ☐ Transport ventilator only ☐ Parents arms ☐ Hot cot ☐ Cot ☐ Pram	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
Nursing staff to accompany baby Staff name(s):	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
Objective 5 achieved	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation

Section 2: End of Life Care Plan
Ward/Location: _____

Hospital no:
Surname:
First names:
Date of birth:
NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

Objective 6: Religious, cultural and spiritual support needs		
Formal religion identified as:	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
Religious/naming ceremony offered	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
Spiritual or personal wishes:		Signature, Print Name, Designation
Pastoral support offered	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
Formal representative identified as:	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
Are there any specific requirements at or after the death of the baby (*e.g. burial needed within 24 hours, fast registration of death – Refer to 'Religious Practices' document within resource folder if needed)* Document: …… …… …… …… …… ……	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation
Objective 6 achieved	DD/MM/YYYY __ __ : __ __	Signature, Print Name, Designation

Objective 7: Memory Making	
To be completed by nurse at place of death	
Date and Time of Death: Date: DD/MM/YYYY Time: __ __ : __ __	
Care of Family	
Parents present at time of death?	Yes ☐ No ☐
Did they spend time with their baby according to their wishes?	Yes ☐ No ☐
Siblings / other family members present or visited?	Yes ☐ No ☐
Did the bereavement team visit prior to death if requested by the parents?	Yes ☐ No ☐
Have religious / cultural / spiritual beliefs been considered according to family's wishes?	Yes ☐ No ☐
Keepsakes – refer to memory making checklist in resource folders if needed	
Have photographs been offered and taken if requested?	Yes ☐ No ☐

Section 3: Care after Death – Memory Making

Ward/Location: _____

Hospital no:
Surname:
First names:
Date of birth:
NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

Has option of professional photos taken by Medical photography/Remember My Baby/other options been offered?	Yes ☐ No ☐
Has option of bathing baby been offered?	Yes ☐ No ☐
Did medical photography/Remember My Baby/other attend?	Yes ☐ No ☐
Has a lock of hair been taken?	Yes ☐ No ☐
Have hand and foot prints been taken?	Yes ☐ No ☐
Have clinical items belonging to baby been collected together? e.g. BP cuff, ECG leads, cot cards, dummy etc.	Yes ☐ No ☐
Have any towels/clothing baby has worn/used been collected together?	Yes ☐ No ☐
If there an option for 3D hand/foot casts or clay casts have these been taken	Yes ☐ No ☐
Has a Journey/Memory box been updated and taken home?	Yes ☐ No ☐

Print Name: _____Designation: _____

Signature : _____Date: DD/ MM /YYY

Information / Practicalities	Date & Time completed	Signature, Print Name, Designation
Parents		
Bereavement information given to parents (SANDS folder) Yes ☐ No ☐	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
Arrangements made/information given about registering birth / death Yes ☐ No ☐	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
Siblings support arranged if possible/required Yes ☐ No ☐	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
Bereavement visits arranged if possible Yes ☐ No ☐	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
Objective 7 achieved	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation

Section 3: Care after Death - Documentation

Ward/Location: _____

Hospital no:
Surname:
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NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

Objective 8: Post death care and communication			
Dr	Doctor to certify death of the baby Staff name:	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
	Medical certificate for cause of death completed Yes ☐ No ☐	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
	Has the first part of the Cremation form been completed by the doctor issuing the Medical certificate for cause of death ***THIS SHOULD BE DONE IN ALL CASES*** Yes ☐ No ☐	DD/ MM /YYYY __ __ : __ __	
	If death certificate cannot be completed has there been a referral to the coroner Yes ☐ No ☐	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
	Coroner's office informed if needed Yes ☐ No ☐	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
	Non coroners post mortem examination offered Yes ☐ No ☐	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
	Non coroners post mortem examination consent form signed by parent Yes ☐ No ☐	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
	Post mortem examination requested to local pathology department Yes ☐ No ☐	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
	Is the baby to be transferred directly to a hospice following death? Yes ☐ No ☐	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
Nurse	Family given details about Funeral directors Yes ☐ No ☐	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
	Has the family decided upon burial or cremation Yes ☐ No ☐	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
	Offer Cabergoline to mother to suppress milk production Yes ☐ No ☐ ***Can usually be done by contacting delivery suite, even if the mother is no longer an in patient***	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
	Lactation after loss leaflet given to mother (see resources on website)	DD/ MM /YYYY __ __ : __ __	
	Expressed breast milk discarded ☐ or donated with consent ☐	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation

Section 3: Care after Death - Documentation

Ward/Location: _____

Hospital no:
Surname:
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Date of birth:
NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

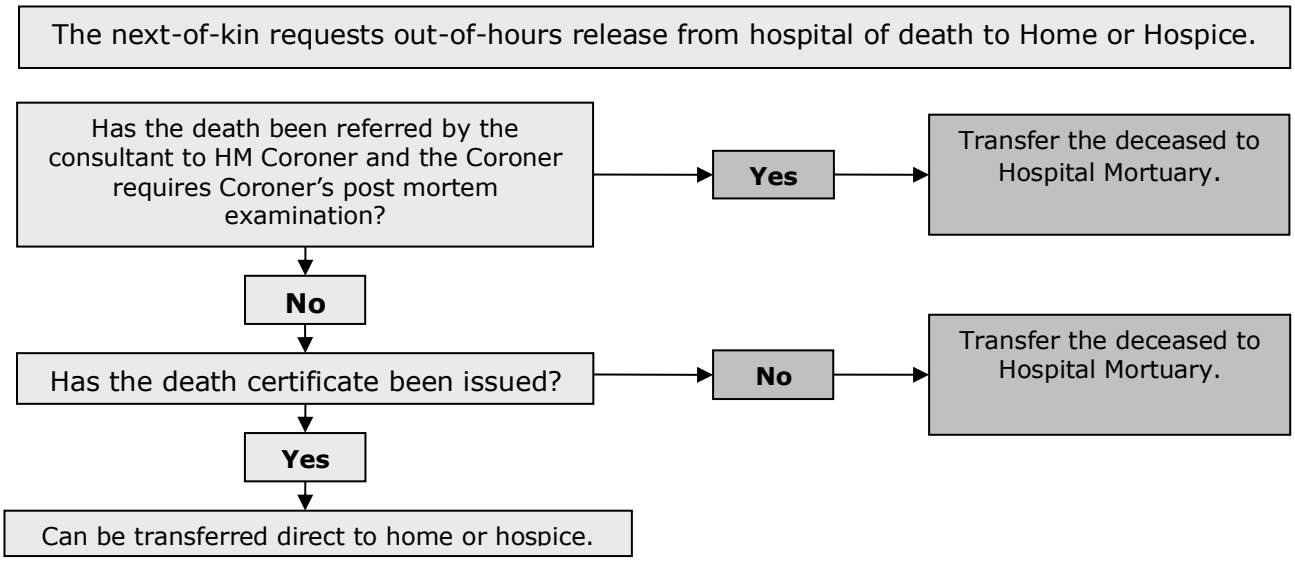
People to be informed of death: ☐ NICU Lead Consultant ☐ General Practitioner (both mother's and father's if different) ☐ Community Midwife ☐ Spiritual Supporter ☐ Health Visitor ☐ Midwife/obstetrician ☐ Social worker ☐ Neonatal Community Team ☐ Safeguarding Team if appropriate ☐ Hospice Team if involved ☐ Bounty ☐ NICU counsellor ☐ Child Health Surveillance ☐ Child Death Overview Panel ☐ Specialist paediatric consultants if appropriate	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation
Objective 8 achieved	DD/ MM /YYYY __ __ : __ __	Signature, Print Name, Designation

Section 3: Care after Death - Documentation

Ward/Location: _____

Hospital no:
Surname:
First names:
Date of birth:
NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

To be completed by NICU Nurse



PLEASE NOTE:

- The deceased may be transferred to a hospice if a **hospital** post mortem is requested but **not** if a coroners post mortem is requested.
- The deceased can be transferred to the location of the hospital post mortem from the hospice and then return there afterwards.
- The family must be counselled on the implications of transfer to a hospice prior to post mortem.
- Hospices can arrange their own transport vehicles to take the baby and family to the hospice (contact individual hospice to confirm).

Print Name: _____ Designation: _____ Ext: _____

Signature: Date: DD / MM / YYYY Time: __ __ : __ __

Section 3: Care after Death - Documentation

Hospital no:
Surname:
First names:
Date of birth:
NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

If parents would like to transfer their baby home after death **To be completed by NICU Nurse**
It is mandatory to complete ALL sections of this form **The original must be retained in the medical notes**
Section 1 (for completion by ward staff)
Name of infant / baby: *Ensure identification bands are on the baby* Date of birth: DD / MM / YYYY Date of Death: DD / MM / YYYY Name of Consultant:
Section 2 (for completion by ward staff)
Please list all items of property transferred with infant / baby:

1.	2.
3.	4.
5.	6.
7.	8.
9.	10.

Section 3 (for completion by family member with parental responsibility)
I, _____ (name of family member) _____ (relationship to infant / baby) give permission for _____ (name of infant / baby) to be transferred from _____ to _____ Signature: _____ Date: DD / MM / YYYY
Section 4 (for completion by ward staff)
Signature witnessed by: Print Name: _____ Designation: _____ Ext: _____ Signature: Date: DD / MM / YYYY Time: __ __ : __ __
Section 5 (for completion by ward staff)

A copy of this form MUST be given/sent to the following	
Parents/family	Funeral director
Hospital mortuary	Hospice (if relevant)

Section 3: Care after Death - Documentation

Hospital no:
Surname:
First names:
Date of birth:
NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

End of Life Management Plan

THIS DOES NOT HAVE TO BE FILLED IN FOR EVERY BABY

The aim of this plan is to ensure that ……. is settled, pain free and not distressed or agitated. Consider stopping non-essential drugs. Essential medications include: anticonvulsants, analgesics, sedation and laxatives.

Include specific details of management in the '**MANAGEMENT'** column, information within the '**POTENTIAL PROBLEMS'** column if for guidance only

Potential condition(s) to be treated:

DATE	POTENTIAL PROBLEMS	MANAGEMENT
	Feeding issues / vomiting Include current feeding regime and an alternative if vomiting Options for alternative: 1. Reduce feed volume 2. Increase time in between feeds Consider: 1. Anti-reflux medication	…name…… is demand breast fed …name…… is currently being fed on ……..mLs/kg/day, every……hours of…….milk. Route of feeding is orally/via OGT/NGT/PEG If symptoms arise the following should be done: …… …… …… …… …… ……
	Constipation Introduce laxative therapy especially if opiates are commenced.	If …name……. is constipated commence lactulose at …..mLs, ……times a day. If it continues: …… …… …… …… ……

Section 3: Care after Death - Documentation

Hospital no:
Surname:
First names:
Date of birth:
NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

	Increased secretions / noisy breathing If breathing becomes noisy and distressing consider: 1. Suction 2. Hyoscine patch	**Free text**
DATE	**POTENTIAL PROBLEMS**	**MANAGEMENT**
	Agitation and restlessness Consider simple management including position change, reassurance including skin to skin/cuddles, Consider using buccal midazolam or alternative routes i.e. intranasal	**Free text**
	Pain Please be aware of the WHO analgesia ladder Consider, sucrose, paracetamol, oral morphine	**Free text** If …name…… is in pain commence
	Breakthrough / incident pain If not absorbing administer the breakthrough dose via a SC/IV route.	**Free text**

Section 3: Care after Death - Documentation

Hospital no:
Surname:
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NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

	Seizure activity Ensure buccal midazolam is prescribed for seizure activity. This should be prescribed even if a child does not have a history of seizures, as this is a potential problem for end of life care.	**Free text** If …name……. is having seizures commence
	Any other symptoms	**Free text**

Section 3: Care after Death - Documentation

Hospital no:
Surname:
First names:
Date of birth:
NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

COMPASSIONATE EXTUBATION (CE) CHECKLIST *To be carried out in partnership with parents*
Religious/naming ceremony offered
Ask about other family members visiting before CE
Options for location of CE offered (cotside/private room)
If cotside chosen advise other parents to leave the family in privacy
Ensure Quiet room or Parent room is free if this is chosen
Discuss changes in appearance of their baby as they die
Discuss the length of time it might take for their baby to die
Exact process of CE discussed
Staff to be present during CE decided upon
Transfer options evaluated and best option selected (transport incubator/incubator/transport ventilator/parents arms)
Check any extra equipment that is needed is working
Remove all ECG leads and saturation probes after discussion with parents to ensure they agree with this – do not just disconnect them if the decision is for them to be removed
Remove gastric tube and any Duoderm if possible without causing distress
Clean face
Dress in own clothes/blanket that parents have
Discontinue all IV medication apart from midazolam and morphine
If agitation present give morphine or midazolam bolus
If no IV access consider nasal fentanyl or midazolam
Ensure corridor is clear
If the baby is to be moved – move at this point
Ensure family is left in privacy but are aware of where to get support
Ensure that family have method of contacting help (own mobile phone/landline with contact number for supporting staff)
Offer to take a lock of hair
Offer to bath baby with parents
Offer to take photographs with unit camera and/or contact hospital medical photography service
'Remember My Baby' [free professional photography service] to be offered to parents and contacted on their behalf. www.remembermybaby.org.uk
Make ink prints or plaster/clay casts of baby's hands and feet
Update journey box to convert into memory box or provide memory box
Contact delivery suite to offer Cabergoline to mother to suppress milk production if applicable
Ensure referral to local bereavement team made and local documentation completed
Consider offering transfer of baby to a hospice after death to enable family to spend more time together

Hospital no:
Surname:
First names:
Date of birth:
NHS No: _ _ _ /_ _ _ / _ _ _ _
(Use hospital identification label)

North West Neonatal Palliative Care plan for Babies Cared for on a Neonatal Unit

Feedback to ODN Palliative Care Group

We would appreciate your feedback; any member of the MDT can complete the below form.

Please return your completed form to: Caroline Travers, NWN ODN, C/O Alder Hey Children's NHS Foundation Trust, Neonatal Network Office, Eaton Road, Liverpool L12 2AP

No	Question	Yes	No	Comment
1	Did you find this document useful?			
2	Did you find this document easy to use?			
3	Do you think this document takes too long to fill out?			
4	Does this document reflect the patient's journey?			
5	Does this document outline the anticipated process of care?			
6	Does this document reflect the input of all those who contribute to care/treatment (i.e. the multidisciplinary team)			
7	Did you find this document led to a lot of duplication with local checklists/policies?			
8	Is there anything you would like added to this document?			
9	Is there anything you would like removed from this document?			
10	Please add any further comments (e.g. comments about the **North West Perinatal Palliative Care Guideline** if used)			