



North West Perinatal/Neonatal Palliative Care Guideline

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

**This guideline has been produced in partnership with
the Northwest Paediatric Palliative Care Network**



Document Control Page

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Communication

With Parents

- Answer questions openly and honestly
- If you do not know the answer, say so and find someone who can
- Use empathetic but unambiguous language

With Colleagues

- Support all colleagues through the process
- Arrange regular debriefs for staff

Principles

Family Centred Care
Ensure Privacy
Respect Religious and Cultural Beliefs
Provide written information where possible
Allow time for decision making
Use active listening
Repeat information
Promote continuity of care
Involve experienced staff
Inform relevant Care Providers (e.g.G.P)
Complete Documentation

Resource Folders

1. Antenatal Care
2. Care Plans
3. Pain and Comfort Measures
4. Family Support
5. Care after Death
6. Staff Education and Support
7. Hospice Care
8. Resources

Introduction

Perinatal palliative care is the holistic management of supportive and end of life care for a fetus, neonate or infant and their family in the situation where a life limiting condition has been identified. It starts from the point of diagnosis or recognition (including antenatal), and continues throughout the infant's life, death, bereavement and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the baby and support for the family.

This guideline for perinatal/neonatal palliative care has been developed by the North West Neonatal Operational Delivery Network (NWNODN) in collaboration with multi-disciplinarily and cross-organisational providers and stakeholders.

The purpose of this guideline and accompanying suite of documents is to assist health care professionals with their care provision, trying to ensure the right conversations take place at the right time, in the right place and with the right people. It is aiming to standardise best practice in order to provide the highest standard of family centred care at this painful time.

Selecting **HIGHLIGHTED TEXT** will take you to the relevant documentation needed for that step of the palliative care journey

Diagnosis

Babies who may require palliative care can be considered in 5 broad categories [Table 1]. Decisions about perinatal end of life care planning should be based on the best possible information on the diagnosis and prognosis of the underlying condition. Palliative care should only be considered if the fetus or baby has a candidate condition.

Clinical situation	Example
Antenatal or postnatal diagnosis of a condition that is not compatible with long-term survival	Bilateral renal agenesis, anencephaly, chromosomal abnormality
Antenatal or postnatal diagnosis of a condition which carries a high risk of significant morbidity or death	Severe bilateral hydronephrosis, severe spina bifida
Babies born at the margins of viability where intensive care has been deemed inappropriate	22 to 24 weeks gestation
Postnatal conditions with a high likelihood of severe impairment of quality of life	Severe hypoxic ischaemic encephalopathy
Postnatal conditions which result in the baby experiencing 'unbearable suffering'	Severe necrotising enterocolitis, refractory seizures from intraventricular haemorrhage

Table 1

- A Consultant in Obstetrics and Fetal medicine, Neonatology or Paediatrics should confirm and document the information on diagnosis and prognosis of a baby's condition including palliative care starting in the antenatal period. [ANTENATAL HYPERLINK](#)
- Ideally antenatal discussions and postnatal care planning should be documented on the **Multidisciplinary antenatal assessment of infants with significant, complex, life-threatening or life-limiting, congenital anomalies** [ANTENATAL HYPERLINK form](#) and filed in the maternal hand held notes
- Based on this information the Consultant responsible for care should make a decision about whether the baby has, or may develop, a palliative care need. Multidisciplinary discussion including a second consultant should ideally be part of this decision making process
- This should be done at the earliest opportunity during the antenatal or postnatal period. [ANTENATAL HYPERLINK](#)
- Every family should receive the news of their baby's diagnosis and prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity***
- These discussion are best led by the most senior clinician available
- Information should be provided for the family using language that they can understand, ideally backed up with written information
- A plan of care should be made in partnership with the family, including early memory making, keeping the process of parallel planning in mind at all times
- The information on diagnosis and prognosis should also be communicated to:
 - lead clinicians at both specialist and local referring units
 - GP
 - community midwifery team

The Neonatal Palliative Care Process Overview

	Antenatal	Postnatal				After death
Clinical situation	Congenital malformation	High likelihood of not surviving current illness or need for imminent end of life care		Diagnosed life limiting illness but not dying Ongoing care is focused on comfort and quality of life, not invasive treatment		Any
Setting	Fetal Medicine Services	NICU <i>Acutely</i> deteriorating infant	NICU <i>Gradually</i> deteriorating infant	Hospital	Hospice or Community	
Purpose	Documentation of information sharing with parents when a life limiting condition is diagnosed antenatally	Documentation of parallel palliative care planning as intensive care becomes less appropriate	Documentation of parallel palliative care planning as intensive care becomes less appropriate	Documentation of diagnosis and information sharing with parents which is available to all members of the hospital MDT	Documentation of diagnosis and information sharing with parents which is available to all members of the hospital and wider MDT (hospice, GP, community nursing, paediatric palliative care)	Notification to relevant services (GP, HV etc.)
	Involvement of Neonatal/Paediatric consultant to begin discussions or other MDT members (hospices, bereavement teams)					Assistance of funeral planning
	Transmission of information between professionals in different settings by utilising maternal hand held notes	Allow limitation of treatment options as appropriate and ensure its documentation	End of life planning to be documented including any future wishes	To provide a place for end of life planning to be documented including future wishes	Guidance regarding post-mortem wishes	
	Allow staged planning about place of delivery and actions around the time of				Documentation of follow-up appointments	
	To ensure that comfort and end of life issues are addressed in advance of dying				Guidance on filling out correct medical certificate of cause of death	
						Information regarding national bereavement services/support

	delivery	To ensure no futile interventions are inappropriately attempted e.g. Cardiopulmonary resuscitation	
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Commencing a Care Plan

Two care plans have been developed for use:

North West Neonatal Palliative Care plan for babies cared for on a neonatal unit	This care plan should be used for babies where death is expected to occur on the neonatal unit	Example: compassionate extubation process
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North West Neonatal Palliative Care plan for babies who will be cared for in a hospice or at home	This care plan should be used for babies where a life threatening condition has been diagnosed but death is NOT expected to occur on the neonatal unit	Example: antenatal detection of Edwards syndrome
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The care plan should intend to cover all foreseeable outcomes but be flexible enough to allow for changes in the condition of the baby or in the parent's views and wishes.

The use of the care plan should be considered

- As soon as it is clear that an infant is moving towards imminent end of life care
- If it is recognised that the infant has a life threatening condition but could be transferred home or to a hospice

This plan should only be commenced when the Multi-Disciplinary Team (MDT) has agreed in partnership with the family that the infant

- Is requiring end-of-life care on a neonatal unit
- Has a life threatening condition and transfer to home or hospice is appropriate

Ideally the concept of "rapid discharge" should be introduced to the family by the Lead Consultant. Hospices should be contacted prior to discussions with the family to ensure end of life care at home or at hospice is a viable option.

Guidance for the use of the Care Plan

- It is the responsibility of the nurse caring for the infant on any particular shift to coordinate and document the rapid discharge process as indicated on this care plan, this responsibility should then be handed over to the nurse taking over the infant's care on the next shift. Other members of the MDT may also complete sections as required.
- The medical discharge summary must be completed and accompany the infant on discharge.
- Consider a MDT meeting if circumstances change, as it may be necessary to reassess the appropriateness of the plan.
- The original care plan should go with the infant.

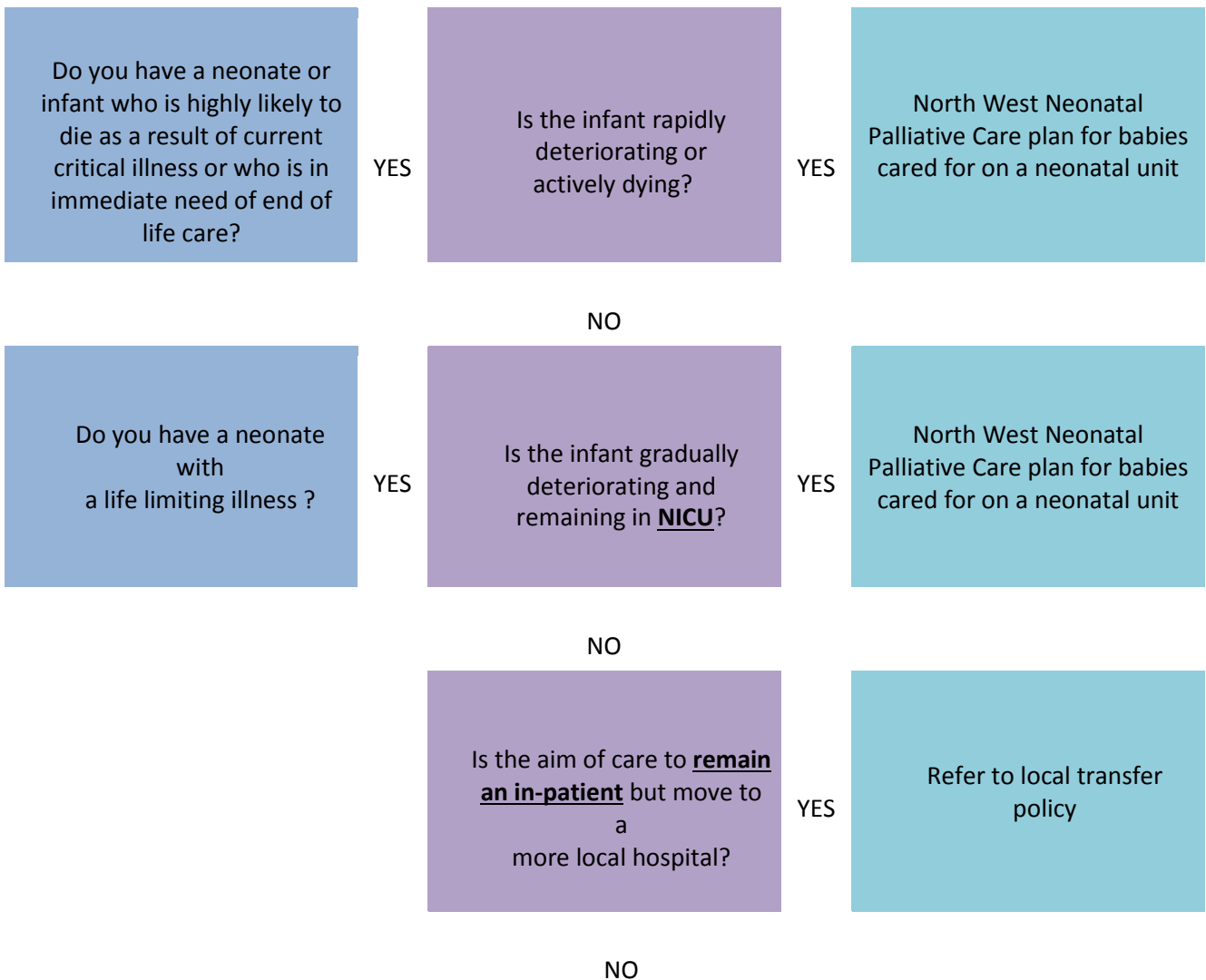
□ A copy of the care plan should go in the infant’s medical notes

[CARE PLAN HYPERLINK](#)

Neonatal Palliative Care Flowchart

This flowchart is designed to make the use of the care plans simple. The documents are to be used as and when appropriate, depending on the clinical circumstances.

[CARE PLAN HYPERLINK](#)



Is the aim of care to move the infant to a **hospice or to their own home** for on-going care?

YES

North West Neonatal Palliative Care plan for babies who will be cared for in a hospice or at home

Key Components of Care Planning

Flexible Parallel Care Planning

Whilst there are many situations where there is a reasonable certainty of death during fetal and neonatal life, there are babies who survive longer than expected during supportive and end of life care. It is vital that care planning is continuously reviewed in the best interests of the baby. There should be parallel planning for transition periods into and out of active, supportive and end of life care. Any changes should be well documented and communicated.

Antenatal Care Planning

When a diagnosis of a life-limiting condition is made antenatally it may be appropriate for palliative care planning to begin prior to the birth of the baby. A senior clinician and nursing/midwifery staff should be involved in creating a palliative care plan for the baby with the family. This should include an approach and limitations to resuscitation at birth and location of ongoing care.

[ANTENATAL HYPERLINK](#)

Planning Care of the Baby While Alive with Parents

This period of time can range from hours, days or weeks and in certain circumstances be much longer than expected. A baby with a serious or life limiting abnormality diagnosed during pregnancy may die at any time during pregnancy and through to infancy. For some babies it can be very difficult to predict a time of death. The multidisciplinary team should discuss the possible or likely timing of death and any uncertainties with both parents and staff. Parents and staff should be informed as soon as possible of any change

Care of the baby needs to be planned including the approach to resuscitation, nutrition, pain relief and comfort care. The appropriate place for this care should be discussed and what support the family will need. It is important that the wishes and needs of the family are respected.

- Give the parents choices of how they would like to spend time with their baby as they will rarely have any idea of what they can or want to do and will often look to staff for advice.
- Ask if they wish to be with their baby, some don't but may find this difficult to verbalise. Parents should be offered a copy of the BLISS leaflet 'Making critical care decisions for your baby'.

- Manage parent's expectations and assure facilities are available before offered.

Location of Care and Death

Depending on the situation and the level of support required the baby might die on the delivery suite, on a postnatal ward, in the neonatal unit at the cot side or in a quiet room, at home, in a children's hospice or other place of choice.

The lead clinician should discuss with the parents where the baby will be cared for, explain what is likely to happen and take their wishes into account as far as possible. The mother's health must also be considered and planned for. Where possible transport should be arranged to allow time at the place of choice prior to the period of end of life care. It is vital you are confident any choices offered can be delivered. This should all be documented in the care plan.

Organ Donation

Organ and tissue donation can be considered for term or near term babies and conversations can be started in the antenatal period with families. Kidneys, hearts or heart valves, hepatocytes and possibly other tissues can be considered. There are no set criteria for the acceptance of organs, it is judged on an individual basis in terms of the baby's condition and the potential recipient of the organ by the transplant surgeon. All term or near term babies where a decision has been made to re-orientate active treatment, should be referred to the Specialist Nurse for Organ Donation (SNOD). The referral should take place as soon as this decision is made. The family ideally should not be approached about organ donation until a discussion has taken place with the SNOD by the lead consultant. Treatment should not be altered, withdrawn or limited until the child has been referred to the SNOD.

Where appropriate, the SNOD will endeavour to offer all families the option of organ donation as a normal part of end of life care. The SNOD will work alongside the neonatal staff to support a family through this process. **The embedded SNOD for the locality covered by the NW ODN can be contacted on 07590 353138. There is also an on-call co-ordinator available via long-range pager on 07659 184748.**

[CARE AFTER DEATH HYPERLINK](#)

Physical Comfort Care

Continue to give care to minimise distress including positioning, skin care, mouth care, human contact including breast feeding (if appropriate), and skin-to-skin contact. Ensure baby is warm and comfortable and developmental needs should not be forgotten. Addressing specific needs such as pain, distress and agitation, nutrition and feeding are vital.

[PAIN AND COMFORT HYPERLINK](#)

Monitoring and Investigations

Monitoring is not necessary during end of life care. Investigations should only be performed if the results might lead to treatment that will improve the baby's quality of life or help with the diagnosis and management of subsequent pregnancies.

Changes in Appearance of the Dying Baby

Staff should explain to parents the physical changes that are likely to occur as their baby dies and should discuss with them whether they want to see and hold their baby whilst dying or after death. Terminal gasping should

be explained in order to reassure parents that this is a natural part of death. If becoming distressing consider treating with an opiate [PAIN AND COMFORT HYPERLINK](#). Parents should be made aware that the time until death can vary from minutes to hours and sometimes days or longer. It is important to make clear that parents can revisit the decision to have palliative care at any time.

Referral for Hospice Care

Children’s’ Hospices are all independently run and funded and are not part of the NHS. They are funded by charities. This leads to each hospice having their own admission criteria. They are mainly run by nursing staff with medical support from GPs who have contracted hours to the hospice. Hospices accept the following for on-going care. However, as they are independently run, not every hospice will offer all of these services

- End of life care
- Compassionate extubation
- Care of a family where their baby has already died in order to support them spending time together in a ‘cold room’
- Care of a family where their baby was still born in order to support them spending time together in a ‘cold room’
- On-going counselling and support services for families including siblings and wider family members such as grandparents

Initial referrals can be made by telephone and your local hospice will inform you of the referral process and whether they are able to accept the baby for on-going care. Check with the hospice what exactly they require in terms of discharge documentation as this varies between hospices. For a list of Children’s hospices within the NWNODN [HOSPICE HYPERLINK](#)

It is important to not offer hospice care to families prior to contacting a hospice to see if transfer is possible in order to provide realistic expectations

Contact Information for Hospices	
HOSPICE	CATCHMENT AREA
Claire House	Wirral, West Cheshire and Merseyside, North Wales* 0151 334 4626
Zoe’s Place	Liverpool and North West 0151 228 0353

Derian House	Sefton Borough and West Lancashire 01257 233300
Francis House	Greater Manchester, Central and East Cheshire 0161 443 2200
Brian House	Blackpool, Fylde and Wyre Districts 01253 358 881
Hope House	North Wales, Wirral, Cheshire, Shropshire 01691 671 999
Ty Gobaith	North Wales, Wirral, Cheshire, Shropshire 01492 651 900
Eden Valley	Cumbria 01228 810801
Donna Louise	Staffordshire and South Cheshire 01782 654 440
Rebecca House	Isle of Man 01624 647 400

Table 2

Transport from a Neonatal Unit to Care at Home or Hospice

Ambulance Transfer

- A letter detailing actions to be undertaken in the event of cardiopulmonary arrest must be completed and accompany the infant on discharge. Ambulance transfer staff must be aware of the plan and agree to follow it prior to transit.
- If an infant dies in transit the transfer staff will proceed to the discharge destination rather than commencing cardiopulmonary resuscitation and/or diverting to the nearest Accident and Emergency Department.
- Parents must be included in the decision making
- Medical personnel are able to confirm death and will document accordingly in their own records. The arrangements made prior to discharge for completion of the death certificate should be followed.
- If the chosen mode of transfer is an ambulance then earliest referral to Ambulance services will enable this to be carried out as a semi-planned transfer, at the most appropriate time

Transfer in Family's own Transport

- If the infant dies in the family's own transport the infant should be transported to the planned destination.
- The GP should then be contacted to confirm death.
- The arrangements made prior to discharge for the completion of the death certificate should be followed.

Transfer in Hospice Transport

If the infant dies in hospice transport the infant will be transported to the planned destination.

The Advanced Care Plan

Any baby being discharged home or to a hospice for palliative care must have the [North West Ambulance Service \(NWAS\) agreed Child & Young Person's Advance Care Plan](#) completed and agreed. Guidance about completing the form can be found in the [CARE PLAN HYPERLINK](#)

Advance Care Plans:

- Include resuscitation guidance
- Include what to do in the event of an acute deterioration
- Document the wishes of the family
- Include contact details of key members of staff
- Should be printed and disseminated to the appropriate people
- Should be copied and given to the family

If the baby is to receive care at another centre, then the outcome of these discussions must be communicated as soon as possible to the local team who will be caring for the family. It is vital to involve or inform members of the primary care or hospice team about palliative care planning as soon as possible as they may be part of the team delivering palliative care, and will provide ongoing support to the family.

[CARE PLAN HYPERLINK](#)

Communication

Discussions and decision-making can take place during the antenatal period, at birth or at any time after birth. Families will require support at many levels. Parents may be shocked, frightened and stressed by the knowledge that their baby has a life limiting condition or abnormality not compatible with life. They may also be grieving for the loss of a normal pregnancy and birth and a planned for and dreamed of future. Parents of twins and other multiples may have to cope with additional complex and conflicting emotions, for example dealing simultaneously with end of life care for one baby whilst remaining hopeful and optimistic for another. Parents in these situations are likely to be both emotionally and physically exhausted. They may have other children to care for and may be travelling long distances to visit their baby. All of the above make it difficult for parents to understand and take in complex and distressing information. Ideally parents should have the name and contact details of a key member of staff and staff covering them when on leave.

Discussions should be conducted in a place of the parents choosing, this may be in a quiet and private setting or at the baby's cot side in privacy. The family should be offered the opportunity of others to be present in order to support them. Consideration should be given to the location of meetings between parents and professionals and, in particular, the area in which parents will have to wait beforehand. Parents should have a choice whether to wait in antenatal clinics or paediatric clinics with families who are experiencing uncomplicated pregnancies or have children with them, or have more privacy.

Parents should be given time to assimilate information and time to discuss it with their wider family or friends if they wish to. Further discussion should be offered. The phrase 'withdrawal of care' should be avoided and

'palliative care', 'comfort care' or 'allowing a natural death' should be offered. An interpreter should be available if required.

All information must be clearly documented and handed over between shift changes. It is vital to involve or inform members of the primary care and wider multidisciplinary team about palliative care planning as soon as possible, especially if the baby is being transferred into the community. This includes GP, children's community nursing team, health visitor, paediatric palliative care team and children's hospice, if appropriate, as they may be part of the team delivering palliative care.

Family Support

Psychological Support

Many parents will be grateful if staff suggests that they start to create and collect mementoes. These will provide valuable memories of their baby's life and their time together and can be very important in the months and years to come.

[FAMILY SUPPORT HYPERLINK](#)

Sibling Support

As soon as end of life discussions are taking place with parents enquire as to whether there are any siblings that will need support and provide this support if possible. Charities such as the Rainbow Trust and Child Bereavement UK can be contacted to see if they can offer any immediate support on the unit.

[FAMILY SUPPORT HYPERLINK](#)

Offering Choices and Creating Memories

It is very important for parents to think very carefully about how they would like to spend time with their baby. Parents may have no idea about how they would like to spend that time or what may be possible. As staff we need to guide them and know about what choices can be offered whilst respecting their wishes and decisions.

[FAMILY SUPPORT HYPERLINK](#)

Spiritual Support

Care should reflect personal, cultural, spiritual and religious wishes. Parents should be offered a choice of whether they would like to have a religious or spiritual ceremony. Staff should ask parents sensitively what they would like and, where appropriate, help to organise this.

[FAMILY SUPPORT HYPERLINK](#)

Social Support

Parking and restaurant discounts are available at some hospitals. Parents should be signposted to information about benefits and maternity and paternity rights. Staff should ensure that mothers know that they must apply for benefits within three months of the baby's birth. Information about obtaining help with funding a funeral should be given to parents, as certain charities will help with this. Specific needs for social support should be discussed at each stage

[FAMILY SUPPORT HYPERLINK](#)

Care after Death

Actions to be taken after an infant's death

- Medical certification of the cause of death (death certificate) to be completed
- The death should be notified to the Registrar in the district where the infant died
- The death should be notified to the Child Death Overview Panel
- The Coroner for the district where the infant died to be informed if necessary for your region or a cause of death cannot be documented on the death certificate
- The doctor issuing the death certificate should complete the first part of the cremation form **in all cases** unless it is clear that the baby is not for cremation (e.g. Muslim or Jewish families). This is to ensure that there is no delay in funeral arrangements for the family if the doctor issuing the death certificate it not going to be at work for some time
- The second part of the cremation form must be completed by a second doctor from a different department
- Post mortem examination should be offered to parents so that maximum information can be obtained and results fed back at a follow up meeting with parents
- Signposting for funeral arrangements
- Signposting for on-going bereavement support for family including siblings and wider family members
- Local guidelines and paperwork should be completed

- SANDS bereavement pack to be given to all parents in its entirety. Staff should explain that there is a lot of information within it, some of which is useful now but that they may want to 'dip' into some of the other leaflets as and when they feel is necessary in the future

Further Information about each of the above actions can be found in the [CARE AFTER DEATH HYPERLINK](#)

Funeral Arrangements

Most parents would not have arranged a funeral before so will need information on how to arrange their baby's funeral. Neonatal staff, hospital bereavement services, family members or pastoral care workers can assist with arrangements. The timing of this information will vary from family to family. Some people will want to know before the baby dies and others will not want to discuss it until after death. It is important to remember that there is no rush to organise the funeral and sometimes if it is culturally appropriate, it may be better to wait in certain circumstances e.g. if the mother is unwell. Further information about funerals can be found in the [CARE AFTER DEATH HYPERLINK](#)

Taking a Deceased Baby Home

There is no legal reason why parents may not take their baby out of the hospital at any gestation. The baby must be taken home in an appropriate casket or Moses basket. The parents then have legal responsibility for arranging baby's funeral. However, for the protection of the parents and to avoid misunderstandings, staff should give parents documentation to take with them. The means of transport home must be appropriate i.e. private and not public transport. [CARE AFTER DEATH HYPERLINK](#)

Staff Support

The work of providing end-of-life care for infants and their families is very intense. It is essential that all staff participating in this form of care have both on-going support and debriefings. Staff needing support must not be limited to the nursing staff; it must include all health care and ancillary personnel who have interacted with the infant or family. If further support is required for members of staff then they should be referred to occupation health in order to obtain this. [STAFF SUPPORT AND EDUCATION HYPERLINK](#)

References and Consultation Documents

- Practical guidance for the management of palliative care on neonatal units. RCPCH 2014
http://www.ehospice.com/internationalchildrens/ArticleView/tabid/10670/ArticleId/9532/language/en-GB/View.aspx#.Uylx7fl_tjQ

- A Core Care Pathway for Children with Life-limiting and Life-threatening conditions
http://www.togetherforshortlives.org.uk/assets/0000/4121/TfSL_A_Core_Care_Pathway_ONLINE.pdf.

- A Framework for Clinical Practice at the time of Birth. Arch Dis Child FNN Online October 6, 2008 as 10.1136/adc.2008.143321.

- A Neonatal Pathway for Babies with Palliative Care Needs (TsSL 2009)
http://www.togetherforshortlives.org.uk/professionals/care_provision/care_pathways/neonatal_care_pathway.

- Critical care decisions in fetal and neonatal medicine: ethical issues. Nuffield Council on Bioethics 2006
[.www.nuffieldbioethics.org](http://www.nuffieldbioethics.org).

- Management of babies born extremely preterm at less than 26 weeks of gestation: a framework for clinical practice at the time of birth. Wilkinson et al. Arch Dis Child Fetal Neonatal Ed 2009; **94**:2-5. (BAPM2008
http://www.bapm.org/publications/documents/guidelines/Approved_manuscript_preterm_nal.pdf)

- Palliative Care (supportive and end of life care) A Framework for Clinical Practice in Perinatal Medicine (August 2010) British Association of Perinatal Medicine.

- Pregnancy Loss and the Death of a Baby: Sands Guidelines for Professionals. J Schott, A Henley, N Kohner, .Sands, 2007.

- Withholding or Withdrawing Life Sustaining Treatment in Children – A Framework for Practice. Royal College of Paediatrics and Child Health, 2nd Ed. May 2004.

Appendix 1- Project Group

Angela Andrews	(Chair) Volunteer	Hope House Hospice
Belal Abuzgia	Consultant (LSC LNU rep)	University Hospitals of Morecambe Bay NHS Foundation Trust
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Flo Bergquist	Manager	Zoe's Place
Jackie Birch	Consultant (GM LNU rep)	Tameside Hospital NHS foundation Trust
Linda Brook	Consultant Paediatric Palliative Care	Alder Hey Children's NHS Foundation Trust
Carrick Brown		New Life Charity
Neil Caldwell	Consultant Neonatal Pharmacist	Wirral University Teaching Hospital NHS Foundation Trust
Diane Corrin	Manager	Isle of Mann Hospice
Clare Doig	Manager	Claire House Hospice
Penny Davis	Neonatal Nurse (LSC LNU rep)	Lancashire Teaching Hospitals NHS Foundation Trust
Karen Hughes	Neonatal Nurse	Hope House Hospice
Julie Johnson	Neonatal Nurse (GM NICU rep)	Bolton NHS Foundation Trust
Julie Kearney	Educator	Blackpool Teaching Hospitals NHS Foundation Trust
Ian Kilroy	Consultant Paediatrician	Warrington & Halton Hospitals NHS Foundation Trust
Debbie Massey	Transport Nurse (Transport rep)	CMNNTS
Liz Meates	Neonatal Nurse	Central Manchester University Hospitals NHS Foundation Trust
Julie Maddocks	Neonatal Network Director	North West Neonatal Operational Delivery Network
Jacqui Morgan	Matron	Wirral University Teaching Hospital NHS Foundation Trust
Chris Navin	Specialist Midwife	University Hospital of South Manchester NHS Foundation Trust
Jan Sutherland Oakes	Director of Clinical Services	Claire House Hospice
Anna Oddy	Children's Complex Care Coordinator and Palliative Care Specialist Nurse.	Pennine care NHS FT
Shirley Potts	North Development Lead	Child Bereavement UK

Clare Robinson	Senior Neonatal Sister/Bereavement Team Lead	Central Manchester University Hospitals NHS Foundation Trust
Iram Siddiqui	Consultant obstetrician	The Pennine Acute Hospitals NHS Foundation Trust
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Kat Williams	Neonatal Nurse	Claire House Hospice
Debbie Yates	Neonatal Nurse	Warrington & Halton Hospitals NHS Foundation Trust

Appendix 2 – Contents of Folders

Folder	Contents
1. Antenatal Care	<ul style="list-style-type: none"> <input type="checkbox"/> Antenatal Paediatric Referral Form <input type="checkbox"/> Antenatal Discussion Form for Congenital Anomaly Form <input type="checkbox"/> Parent Information Leaflet Congenital Anomaly <input type="checkbox"/> NWNODN Guideline- Non-viable or pre-viable births, including live birth following termination <input type="checkbox"/> Maternity Care Guideline <input type="checkbox"/> Suppression of Lactation <input type="checkbox"/> Certificates for Parents

2. Care Plans	<input type="checkbox"/> NWNODN Palliative Care Plan for babies cared for on the Neonatal Unit <input type="checkbox"/> NWNODN Palliative Care Plan for babies who will be cared for in a hospice or at home <input type="checkbox"/> NWNODN Compassionate Extubation Checklist <input type="checkbox"/> Children and Young Peoples Advanced Care Plan <input type="checkbox"/> Rapid Discharge Plan for End of Life Care <input type="checkbox"/> Clinicians Guide for Advanced Care Plan
3. Pain and Comfort Measures	<input type="checkbox"/> NWNODN Guideline Pain and Comfort Measures <input type="checkbox"/> APPM Master Formulary 2015
4. Family Support	<p>Psychological Support</p> <input type="checkbox"/> Support Organisations <input type="checkbox"/> NWNODN Guideline Family Support <input type="checkbox"/> Rainbow Trust- Parent Support Leaflet <p>Social Support</p> <input type="checkbox"/> Financial Advice <input type="checkbox"/> Money Advice Leaflet <p>Spiritual Support</p> <input type="checkbox"/> NWNODN Guideline Religious Practices <input type="checkbox"/> Information Sheets- all religions <p>Sibling Support</p> <input type="checkbox"/> Book Resources for Parents and Families <p>Making Memories</p> <input type="checkbox"/> NWNODN Guideline Making Memories
5. Care after Death	<input type="checkbox"/> CDOP Form
6. Staff Education and Support	<input type="checkbox"/> NWNODN Guideline Psychological Support for Staff <input type="checkbox"/> Debrief following significant event <input type="checkbox"/> Palliative Care Education Framework
7. Hospice Care	<input type="checkbox"/> NWNODN Guideline Hospice Care <input type="checkbox"/> NWNODN Transport Guideline <input type="checkbox"/> CBUK Transport Leaflet

8. Resources

- ACT Pathway for Babies (2009)
- Practical Guidance for the Management of palliative care on the neonatal unit (RCPCH 2014)
- North West Children's Palliative Care Service Directory

Appendix 3 - Pain and Comfort Measure Guideline

North West Neonatal Operational Delivery Neonatal Network Palliative Care Pain and Symptom Control

There are three main categories of babies that potentially require end of life care either on the neonatal unit or in the community

1. The ventilator dependent infant where death is expected to occur soon after withdrawal of respiratory support [extreme preterm population]
2. The seriously ill term infant for whom a catastrophic event has happened antenatally who is 'actively dying' and for whom survival is anticipated to be hours, days or at best a few weeks [e.g. hypoxic ischaemic encephalopathy]
3. The infant with a congenital non-reversible condition that is incompatible with long-term survival, but who may survive several months or longer and may have significant complex care needs [e.g. Edwards/Patau syndrome T18, congenital cardiac condition]

Location of Palliative/End of life Care

Depending on the clinical situation and the level of support required the baby might die on the delivery suite, on a postnatal ward, in the neonatal unit, at their local hospital, at home or in a children's hospice. The lead clinician should discuss and decide with the parents where the baby will be cared for, explain what is likely to happen and take their wishes into account as far as possible. If a baby is being transferred home or to a children's hospice, the mother's health must also be considered and planned for with the local community midwifery service; where possible transport should be arranged to allow time at home or at the hospice prior to the period of end of life care. The parents' wishes should be listened to and all options of choice of place of death discussed

Prescription for 'Out of Hospital' Palliative care

If transferring to a community setting anticipatory prescribing should occur with medicines dispensed and supplied from the referring hospital.

The drugs to prescribe are a one week course of:

Paracetamol 10 mg/kg/dose PRN oral/ OG/NG (6-8 hourly/max 4 doses in 24hours)
Morphine Sulphate 50 microgram/kg/dose PRN oral/OG/NG (4 hourly/max hourly)
Buccal midazolam 100 microgram/kg/dose PRN (4 hourly/max hourly)

Further prescribing advice is available from the BNFC, and the Association of Paediatric Palliative Care Medicine Formulary and Northern Neonatal Formulary

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Nausea / vomiting

Constipation

Seizures

End of life Management Plan

An end of life management plan aims to ensure that the baby is comfortable at all times. Any distress or symptoms are minimised and well managed. Any reversible conditions and end of life care symptoms (as documented below) are to be treated

Management of Agitation and restlessness – Comfort Measures, Oral Morphine, Buccal Midazolam

The clear goal is to ensure that baby is settled, pain free and not distressed or agitated.

This may present as being unsettled and not handling as usual. Consider comfort measures as you would any other baby e.g. changing of nappy, gentle rocking, hunger, ensure adequate warmth and not over heated.

Simple management includes, position change, comfort and reassurance. If the baby is comfortable temperature does not need to be monitored

Also consider analgesia if pain is the possible cause of the restlessness/agitation.

Start with simple agents such as **Paracetamol** or **sucrose**.

If no effect start **choral hydrate** 25-50mg/kg 4-6 hourly

If this is not effective move onto **morphine or midazolam**

- Initial dose of 50 microgram/kg/dose of **oral morphine**
- Can be increased to 65 microgram/kg/dose or 85microgram/kg/dose to ensure the baby is comfortable.
- Oral morphine dose can be repeated after one hour.
- There is no limit to the dose of morphine for relief of pain or distress even in the knowledge that this may cause respiratory depression (doctrine of double effect).

If they remain agitated/restless:

- Consider using buccal **midazolam** 50-100 microgram/kg/dose PRN (4 hourly/max hourly)
- Preparation: Midazolam injection is 5mg/5mL. 5mL ampoule, licensed product readily available (administration via buccal or nasal route is off-label). This is the most appropriate formulation to use to accurately measure doses of less than 1mg.
- No reconstitution needed, simply draw up required dose
- If a dose of more than 0.1mL (1mg) is required use Midazolam buccal liquid (Epistatus®)10mg/mL
- This can be repeated after one hour, but please consult with senior clinical team prior to giving second dose.
- If 2 or more doses are required in a 24 hour period consider commencing a subcutaneous continuous infusion of midazolam

Management of Pain – Comfort Measures, Paracetamol, Morphine preparations

The following are the most reliable indicators of pain:

- Persistent crying
- Furrowing or bulging of the brow
- Furrowing of nasolabial folds (between lips and nose)
- Tight squeezing of the eyes

Consider comfort measures as you would any other baby e.g. change of nappy, gentle rocking, not hungry, ensure adequate warmth and not over heated.

If unresolved with comfort measures:

- Try sucrose, this can be used intermittently alongside all other analgesics
- Commence paracetamol 10-15 mg/kg/dose PRN oral/ OG/NG (6-8 hourly/max 4 doses in 24hours)
- If regular paracetamol is not effective or pain is assessed to be more severe give oral morphine as detailed in **“Management of Agitation and restlessness – Comfort Measures, Oral Morphine, Buccal Midazolam” above.**
- Oral morphine dose can be repeated after one hour.
- There is no limit to the dose of morphine for relief of pain or distress even in the knowledge that this may cause respiratory depression (doctrine of double effect). Pain assessment and regular evaluation of analgesia is essential
- If it is felt that the baby is needing escalating doses of morphine to remain pain free discuss with palliative care team for the consideration of a sustained release preparation of morphine

Further prescribing advice is available from the BNFC, and the Association of Paediatric Palliative Care Medicine Formulary and Northern Neonatal Formulary

End of life Management Plan

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
	<p><u>Feeding issues / vomiting</u></p> <p>Include current feeding regime and an alternative if vomiting</p> <p>Options for alternative:</p> <ol style="list-style-type: none"> 1. Reduce feed volume 2. Increase time in between feeds <p>Consider:</p> <ol style="list-style-type: none"> 1. Anti-reflux medication 	<p>...name..... is demand breast fed</p> <p>...name..... is currently being fed onmLs/kg/day, every.....hours of.....milk. Route of feeding is orally/via OGT/NGT/PEG</p> <p>If symptoms arise the following should be done:</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>
	<p><u>Constipation</u></p> <p>Introduce laxative therapy especially if opiates are commenced.</p>	<p>If ...name..... is constipated commence lactulose atmLs,times a day. If it continues:</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>

	<p><u>Increased secretions / noisy breathing</u></p> <p>If breathing becomes noisy and distressing consider:</p> <ol style="list-style-type: none"> 1. Suction 2. Hyoscine patch 	<p>Free text</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>
DATE	POTENTIAL PROBLEMS	MANAGEMENT
	<p><u>Agitation and restlessness</u></p> <p>Consider simple management including position change, reassurance including skin to skin/cuddles,</p> <p>Consider using buccal midazolam or alternative routes i.e. intranasal</p>	<p>Free text</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>
	<p><u>Pain</u></p> <p>Please be aware of the WHO analgesia ladder</p> <p>Consider, sucrose, paracetamol, oral morphine</p>	<p>Free text</p> <p>If ... <u>name</u> is in pain commence</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>
	<p><u>Breakthrough / incident pain</u></p> <p>If not absorbing administer the breakthrough dose via a SC/IV route.</p>	<p>Free text</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>
	<p><u>Seizure activity</u></p> <p>Ensure buccal midazolam is prescribed for seizure activity.</p> <p>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.</p>	<p>Free text</p> <p>If ... <u>name</u> is having seizures commence</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>

	Any other symptoms	Free text
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Drug	Use	Dosage	Frequency	Route
Atropine sulphate	Antisecretory	20-40microgram/kg/dose	PRN – 2-3 times a day	Oral
Chloral hydrate	Sedation	20–30mg/kg up to 50mg/kg	PRN – 4 times a day	Oral/rectal
Hyoscine hydrobromide	Antisecretory antiemetic	Quarter to a half of a 250micrograms patch to skin	Every three days	Transdermal patch applied to hairless area of skin behind ear
Lactulose	Constipation	2.5 – 10 mL	Twice daily Adjusted according to response	Oral
Lansoprazole	Gastro-oesophageal reflux	0.5-1mg/kg (a quarter of a 15mg Zoton FasTab)	Once a day	Oral (melt)
Midazolam	Respiratory distress Sedation	50-100 microgram/kg/dose	PRN – maximum 6 times a day	Buccal/oral
	Seizure	300 micrograms/kg	Repeated once after 10 minutes if necessary	Buccal
		150 -200 microgram/kg/min	Bolus	Intravenous
		60 -300 microgram/kg/min	Continuous infusion	Intravenous
Morphine	Pain	50-100 microgram/kg/dose	PRN	Oral
		100 microgram/kg/dose	PRN - Bolus	Intravenous
		10-300 microgram/kg/hour	Continuous infusions	Intravenous

	Respiratory distress	25 microgram/kg/dose	PRN	Oral
Omeprazole	Gastro-oesophageal reflux	700mcg/kg/dose increased if necessary after 7–14 days to 1.4mg/kg	Once a day	Oral
Paracetamol	Analgesia Pyrexia	28 -32 weeks postmenstrual age 15mg/kg as a single dose then 10-15mg/kg	PRN – 2-3 times a day Maximum dose 30mg/kg/24hours	Oral/rectal
		> 32 weeks postmenstrual age 15mg/kg as a single dose then 15mg/kg	PRN – 3-4 times a day Maximum dose 60mg/kg/24hours	
Phenobarbitone	Seizures	20mg/kg	Bolus	Slow intravenous injection
		Then: 2.5–5 mg/kg Dose and frequency adjusted according to response	Once a day	Oral/slow intravenous injection
Ranitidine	Gastro-oesophageal reflux	3mg/kg	3 times a day	Oral
Sucrose solution 24%	Analgesia	32-36 weeks gestation: 0.5-1mL (regardless of weight) Term babies: 2mL (regardless of weight)	PRN - maximum 4 doses in 24hours	Oral