



North West Perinatal/Neonatal Palliative Care Guideline

December 2020



"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**



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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 Centered 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

- Antenatal Care
- Care Plans
- Pain and Comfort Measures
- Family Support
- Care after Death
- Staff Education and Support
- Hospice Care
- 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.

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 Please refer to the 'Diagnosis and Management of Preterm Guideline which can be accessed at: https://www.neonatalnetwork.co.uk/nwnodn/network-guidelines/
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

- 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.
- 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 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.
- 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

Relevant documents can be accessed on the NWNODN website at <https://www.neonatalnetwork.co.uk/nwnodn/palliative-care/#1501244917744-1f6d6a33-7c9b>

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 On-going care is focused on comfort & 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 delivery				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
		To ensure no futile interventions are inappropriately attempted e.g. Cardiopulmonary resuscitation				

Commencing a Care Plan

Two care plans have been developed for use:

<p>North West Neonatal Palliative Care plan for babies cared for on a neonatal unit https://www.neonatalnetwork.co.uk/nwnodn/wp-content/uploads/2020/11/NWODN-Palliative-Care-plan-for-babies-cared-for-on-a-neonatal-unit_2020-1.pdf</p>	<p>This care plan should be used for babies where death is expected to occur on the neonatal unit</p>	<p>Example: compassionate extubation process</p>
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<p>North West Neonatal Palliative Care plan for babies who will be cared for in a hospice or at home https://www.neonatalnetwork.co.uk/nwnodn/wp-content/uploads/2020/11/NWNODN-Palliative-Care-Plan-for-Hospice-or-Home-2020.pdf</p>	<p>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</p>	<p>Example: antenatal detection of Edwards syndrome</p>
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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 recognized 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

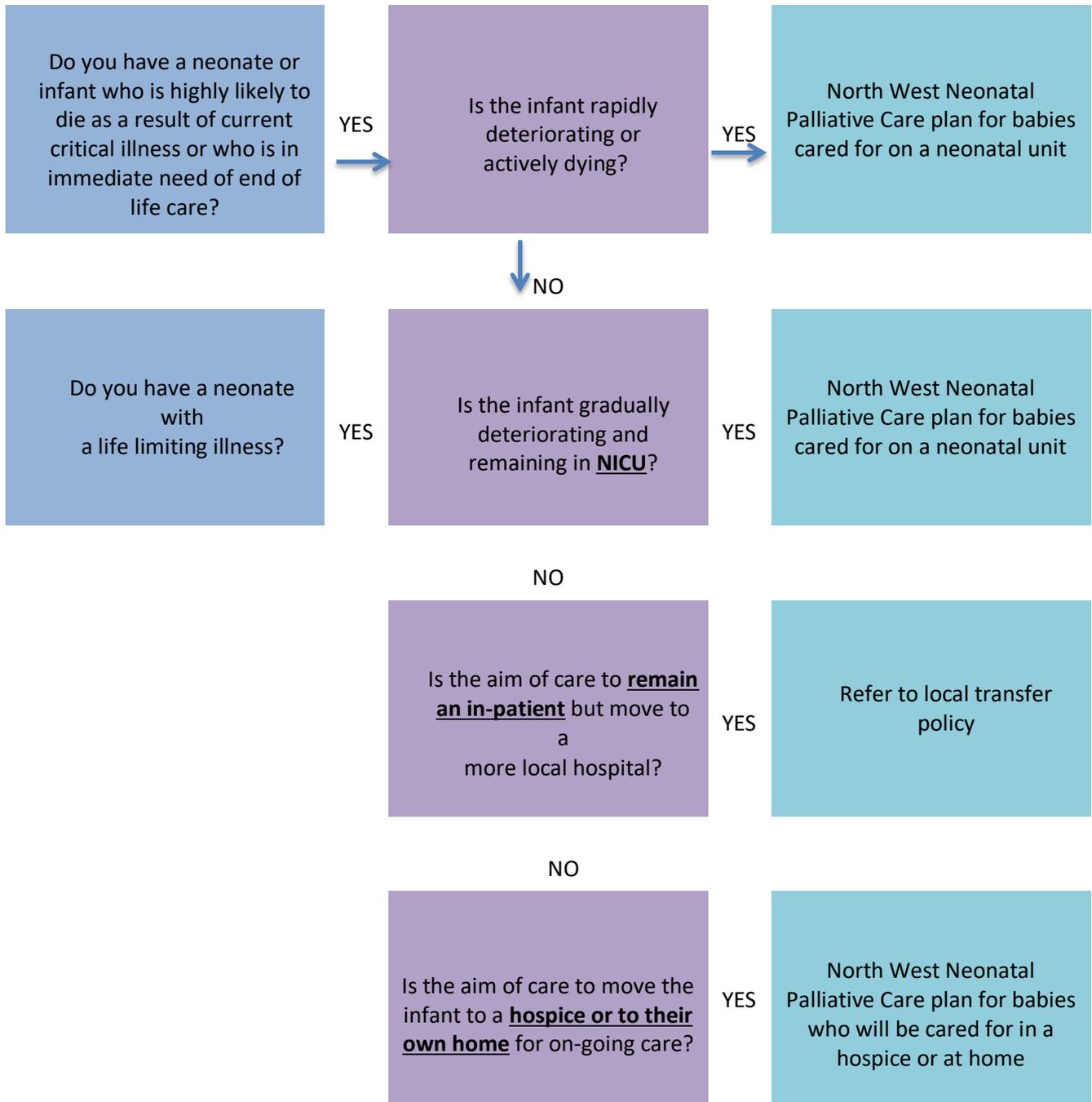
Ideally the concept of "rapid discharge" should be introduced to the family by the Lead Consultant. Hospices should be contacted prior to discussions with the family to ensure end of life care at home or at hospice is a viable option.

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

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.



Key Components of Care Planning

Flexible Parallel Care Planning

Whilst there are many situations where there is a reasonable certainty of death during foetal 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.

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 to settle 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. Hepatocytes, hearts or heart valves 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 SNOD for the locality covered by the NWNODN can be contacted on 0151 268 7210. There is also an Organ Donor Referral Line - 03000 20 30 40 and it is recommended this is the first point of call as accessible 24 hours a day.**

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.

Guidance notes and template can be accessed at:

https://www.neonatalnetwork.co.uk/nwnodn/wp-content/uploads/2020/11/Northwest-Operation-Delivery-Neonatal-Network-Palliative-Care-Pain-and-Symptom-Control_2020.pdf

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 this becomes distressing consider treating with an opiate. 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

Childrens' 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 individual 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 stillborn 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. A list of Children's hospices within the NWNODN can be accessed at <https://www.neonatalnetwork.co.uk/nwnodn/palliative-care/#1502187566921-08af292d-e1b8>

It is important not to 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 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

Transport from a Neonatal Unit to Care at Home or Hospice

The NWNODN Guidance on the referral and transportation of palliative care babies can be accessed at: <https://www.neonatalnetwork.co.uk/nwnodn/wp-content/uploads/2020/06/PW-ODN-03-Palliative-Care-Transport.pdf>

Ambulance Transfer

It is recommended units' contact ConnectNW if an ambulance transfer is required who will then advise on the most appropriate course of action. Please note if the transfer is carried out directly via NWS then the referring unit may need to provide a member of staff during the 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 (NWS) agreed Child & Young Person's Advance Care Plan (RESPECT) completed and agreed. Guidance about completing the form can be found at: https://www.neonatalnetwork.co.uk/nwnodn/wp-content/uploads/2017/06/clinicians_guide_for_using_cypacp_paperwork.pdf

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.

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

Further information and useful resources can be accessed on the NWNODN website at <https://www.neonatalnetwork.co.uk/nwnodn/palliative-care/#1501245355602-079c34b5-024e>

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.

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.

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.

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.

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.

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
Note – if a death is anticipated over the weekend and rapid burial is requested by the family in accordance with faith / cultural requirements, then discussions with the Registrar in advance is advisable to facilitate an out of hours death registration and avoid delay.
- 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 is 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 who has seen the body (as per usual legal processes).
- 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 packs 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 necessary in the future. The packs are available directly from SANDS and can be ordered or downloaded from <https://shop-sands.org.uk/en/products/bereavement-support/sands-bereavement-support-book>

Further Information about each of the above actions can be found at: <https://www.neonatalnetwork.co.uk/nwnodn/palliative-care/#1501245430690-e4e428c1-ae8d>

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.

Taking a Deceased Baby Home

There is no legal reason why parents may not take their baby out of the hospital at any gestation, however the registration of death must be completed and the body released by the hospital morgue. 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, i.e. death certificate and release of body statement. The means of transport home must be appropriate i.e. private and not public transport.

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; support should 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. More information on supporting staff can be found at <https://www.neonatalnetwork.co.uk/nwnodn/palliative-care/#1501245474889-d97ec12d-5ac2>

References and Consultation Documents

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- The Perinatal Pathway for Babies with Palliative Care Needs (2017)
- www.togetherforshortlives.org.uk/resource/perinatal-pathway-babies-palliative-care-needs/.
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