Guideline framework for Neonatal Palliative (Supportive and End of Life) Care

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1.0 Introduction
This guideline sets out best practice in planning palliative and end of life care for a neonate. Decisions about end of life care planning should be made using the best possible information about the diagnosis and prognosis of the underlying condition. Palliative care should only be considered if the baby has a life limiting condition. Joint decision making with parents, open communication and clear documentation are essential. An individualised care plan should be drawn up as soon as possible after multidisciplinary discussions take place between the neonatal team and the parents. Subsequent discussions with other professionals who will be involved in providing palliative care should then be added to the care plan. The care plan should cover all foreseeable outcomes and should be flexible enough to allow for changes in the condition of the baby or in the parent’s views and wishes.

1.1 Scope:
This guideline applies to all neonates cared for within Ashford and St. Peter’s Hospitals who qualify for palliative care.

1.2 Purpose:
To provide guidance for clinical staff on decision making and developing integrated care pathways across Ashford and St. Peter’s Hospitals for neonatal palliative care.

1.3 Definitions:
“Palliative care for the neonate with a life limiting condition is an active and total approach to care from the point of diagnosis or recognition, throughout the child’s life, death 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. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.” ACT 2009.

2.0 Background
Advances in antenatal diagnosis, obstetric and neonatal care and care at the margins of viability have all increased the need for decision making about end of life care for the neonate. Antenatal diagnoses of abnormalities not compatible with life are being confirmed earlier in pregnancy and a plan for palliative care may be needed at any stage, particularly when the diagnosis is made beyond 20-22 weeks
gestation. Palliative care may also be needed in the perinatal period for example because of extreme prematurity or following the diagnosis of a condition with a very poor long-term prognosis.

The Nuffield Council of Bioethics (Nuffield 2006) and the British Association of Perinatal Medicine guidance support the decisions of clinical staff and parents not to resuscitate or institute intensive care when this would not be in the baby's best interests. The Royal College of Paediatrics and Child Health (RCPCH) provides guidance on withholding and withdrawing life sustaining treatment in children, and the GMC document ‘Treatment and Care Towards the End of Life: Good Practice in Decision Making’ includes a specific section for neonates, children and young people.

Palliative care planning involves multidisciplinary team planning. Choices in care may vary up until the end of life and there may be a transition into and out of active, supportive and end of life care.

3.0 Aspects of neonatal palliative care to consider:

- Establish eligibility of baby for palliative care
- Family care
- Communication and documentation
- Flexible parallel care planning
- Pre-birth care
- Transition from active postnatal to supportive care
- End of life care
- Post end of life care

3.1 Establish eligibility of baby for palliative care:

These can be considered in 5 broad categories:

1. Antenatal/ postnatal diagnosis of a condition that is not compatible with long-term survival e.g. bilateral renal agenesis, anencephaly.

2. Antenatal/ postnatal diagnosis of a condition which carries a high risk of significant morbidity or death e.g. severe bilateral hydronephrosis and impaired renal function, severe spina bifida.

3. Babies born at the margins of viability where intensive care has been deemed inappropriate.
4. Postnatal conditions with a high likelihood of severe impairment of quality of life either when receiving life support or that may at some point require life support e.g. severe hypoxic ischaemic encephalopathy.

5. Postnatal conditions which result in the baby experiencing ‘unbearable suffering’ e.g. severe necrotising enterocolitis, where palliative care may be in the baby’s best interests.

The prognosis for all babies should be agreed by at least 2 senior clinicians (neonatologist/ surgeon/ cardiologist/ neurologist/ geneticist etc as appropriate). The prognosis should then be explained and discussed with the family. If either the parents or staff members are still uncertain about the diagnosis or prognosis a second opinion, either internal or external, should be sought.

3.2 Planning palliative care with families:

3.2.1 Communication:

- 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.

- When planning palliative care, it is essential that there should be multidisciplinary discussions involving the parents, a senior clinician and a neonatal nurse involved with the care of the baby (minimum). The discussion 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, and the family should be offered the opportunity of others being present to support them.
• The 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, as it is essential that the parents have a full understanding of what is being discussed. Prior to discussions the interpreter must be made aware of the nature of the conversation to ensure that they are prepared. The interpreter should then gain the families consent for the discussion to go ahead. Family members, friends and siblings should not normally be used unless no alternative is available. If families insist on a relative translating then the difficulties with using family members must be explained and documented in the patient notes.

3.2.2 Psychological Support:
Many parents will be grateful if staff suggest 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. The General Practitioners, the primary care team, or hospice service may be helpful in providing support and access to specialist counselling. Alternatively information can be found via NHS Choices www.nhs.uk or access to counselling via British Association of Counselling/Psychotherapy www.BACP.co.uk.

3.2.3 Spiritual Support:
Parents should be offered a choice of whether they would like to have a religious or spiritual ceremony. Ensure clear handover of information with shift changes. Care should reflect personal, cultural, spiritual and religious wishes.

3.2.4 Social Support:
Written information should be made available for parents informing them of what benefits and support they are entitled to. Parents need to be informed that they are entitled to discounted parking. SANDS Guidelines for Professionals www.uk-sands.org has information for staff regarding these benefits.
3.3 Communications and Documentation:

3.3.1 Planning Care of the Baby While Alive With Parents

- This period of time can range from hours or days to weeks (typically but may be longer). 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.
- 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. It is important their wishes and needs are respected.
- 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.

3.3.2 Advance Care Plan:

- All babies must have an Advance Care Plan completed and agreed. This includes resuscitation guidance, what to do in the event of an acute deterioration, wishes of the family and contact details of key members of staff. At a minimum this should be a consultant and one named nurse. It must be printed and disseminated to the appropriate people. Parents should always keep a copy.
- If the team making these decisions with the family are not local to where the baby will receive care then the outcome of these discussions must be communicated as soon as possible to the local team who will be caring for the family. Parental consent should be obtained for this.
- It is vital to involve or inform members of the Primary Care team/hospice service 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.
- Ensure all therapists involved are aware of the plan to move to palliative care.
3.4 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.

3.5 Pre-Birth Care:
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 (neonatal/ surgical/ cardiologist etc) 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.

3.6 Transition from Active Postnatal to Supportive Care:
In some situations a rapid assessment by a senior clinician may be needed to confirm a candidate condition for palliative care. Occasionally specific tests may be helpful e.g. rapid karyotype of cord blood in the case of anomalies suggestive of life limiting chromosomal abnormality.

3.7 End of Life Care:

3.7.1 Predicting the time of death:
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 changes.

3.7.2 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 their local hospital, 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.

3.7.3 Physical comfort care:
Continue to give care to minimise distress; 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.

3.7.4 Pain, distress and agitation:
Assess and treat any underlying causes of pain. Consider paracetamol and ibuprofen, if not sufficient, use morphine by the route best tolerated by the baby (oral, buccal, intravenous or subcutaneous). Increase doses by 30-50% to ensure the baby is comfortable. Discuss with the Consultant and refer to suggested dosages on page 11 when prescribing morphine for relief of pain or distress even in the knowledge that this may cause respiratory depression. However it is illegal to give any medication with the intent of hastening death. Midazolam may also be used and is particularly helpful if seizures are a feature or agitation is prominent. Be aware that there may be risk of respiratory depression with the use of opioids and benzodiazepines.
### 3.7.5 Suggested Drug Dosages & Infusion Instructions:

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<th>Dose</th>
<th>Comments</th>
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<tr>
<td>Morphine IV</td>
<td>25 microgram/kg bolus starting dose, May increase to 50-100 microgram/kg bolus</td>
<td>For acute pain, repeat as needed.</td>
</tr>
<tr>
<td></td>
<td>5-20 microgram/kg/hour infusion</td>
<td>Use starting dose in non-ventilated babies. Titrate according to response.</td>
</tr>
<tr>
<td>Morphine subcutaneous</td>
<td>100 microgram/kg for acute pain</td>
<td>Diamorphine may be preferable if using subcutaneously as smaller volumes are required.</td>
</tr>
<tr>
<td>Morphine sulphate orally</td>
<td>25-100 microgram/kg 4 hourly starting dose</td>
<td>To convert IV to oral: multiply total daily dose by 2 and give in 6 divided doses.</td>
</tr>
<tr>
<td>(orally (oramorph))</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Morphine (buccal)</td>
<td>1/3rd-1/2 oral dosage</td>
<td>Use IV solution. Rapid absorption, useful 1st line if no IV access available/appropriate.</td>
</tr>
<tr>
<td>Diamorphine subcutaneous</td>
<td>See BNFc for morphine equivalence chart</td>
<td></td>
</tr>
<tr>
<td>Midazolam</td>
<td>50-200 microgram/kg bolus</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20-30 microgram/kg/hour infusion for anxiety</td>
<td>Titrate according to response.</td>
</tr>
<tr>
<td></td>
<td>60 microgram/kg/hr starting dose for seizures</td>
<td></td>
</tr>
<tr>
<td>Midazolam (buccal)</td>
<td>100 microgram/kg for agitation</td>
<td>Can use IV solution. Rapid absorption, useful 1st line if no IV access available/appropriate.</td>
</tr>
<tr>
<td></td>
<td>300 microgram/kg for seizures</td>
<td></td>
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<tr>
<td>Paracetamol oral</td>
<td>28-32 weeks: 20 mg/kg single dose then 10-15 mg/kg every 8-12 hours</td>
<td>28-32 weeks Maximum 30 mg/kg/day in divided doses</td>
</tr>
<tr>
<td></td>
<td>Over 32 weeks: 20 mg/kg single dose then 10-15 mg/kg every 6-8 hours</td>
<td>Over 32 weeks: maximum 60 mg/kg in divided doses</td>
</tr>
<tr>
<td>Paracetamol rectal</td>
<td>28-32 weeks: 20 mg/kg single dose then 15 mg/kg every 12 hours</td>
<td>28-32 weeks Maximum 30 mg/kg/day in divided doses</td>
</tr>
<tr>
<td></td>
<td>Over 32 weeks: 30 mg/kg single dose then 20 mg/kg every 8 hours</td>
<td>Over 32 weeks: maximum 60 mg/kg in divided doses</td>
</tr>
<tr>
<td>Paracetamol IV</td>
<td>Preterm over 32 weeks: 7.5 mg/kg every 8 hours</td>
<td>Preterm over 32 weeks: maximum 25 mg/kg/day</td>
</tr>
<tr>
<td></td>
<td>Neonate: 10 mg/kg every 4-6 hours</td>
<td>Neonate: maximum 30 mg/kg/day</td>
</tr>
<tr>
<td>Hyoscine Patch</td>
<td>250 microgram (1/4 patch) every 72 hours</td>
<td>Cover rest of patch – do not cut</td>
</tr>
<tr>
<td>Lactulose</td>
<td>2.5ml bd</td>
<td>Adjust according to response</td>
</tr>
<tr>
<td>Glycopyrronium oral</td>
<td>40-100 microgram/kg tds-qds</td>
<td>Maximum single dose 2mg Use crushed tablets suspended in water or injection solution for oral administration</td>
</tr>
<tr>
<td>Sweeteeze (Sucrose 24% solution)</td>
<td>Infant under 1000g: up to 0.5ml Infants 1001g-2000g: up to 1ml Infant 2001g and over: up to 2ml</td>
<td>See Trust guidelines</td>
</tr>
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For local specialist symptom management advice see Appendix A.

3.7.6 Nutrition, Feeding and GI Symptoms:
The goal of feeding is to provide comfort and reduce distress from hunger with growth as a secondary outcome. The route of feeding should be what is most suitable for the baby. Breast-feeding may be comforting for the baby and mother.

- Vomiting: Consider reducing feed volume and the use of anti-reflux treatment if symptomatic.
- Respiratory secretions: Should only be treated if causing distress to the baby. Consider hyoscine patches.
- Constipation: May be caused by opiates. If causing distress use lactulose or glycerine suppositories.
- Urinary retention: May be caused by opiates. Consider bladder expression and catheterisation if necessary.

3.7.7 Monitoring, investigations, and treatment:
Monitoring is not necessary but may be used in negotiation with the family if helpful. 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. Treatments such as oxygen, antibiotics, anticonvulsants, and anti-reflux medication may all have a role in symptom control. Immunisations may be given as per national immunisation programme unless contra-indicated.

3.7.8 Resuscitation plans:
Limitations to resuscitation should be discussed, documented and regularly reviewed. Comfort and dignity of the baby should be maintained.

3.7.9 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 not an indication of suffering. (Refer back to 3.7.4)
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.

3.7.10 Post mortem examination:
Discussions about post mortem examination can begin prior to a baby’s death if felt appropriate. A senior member of staff should sensitively discuss post mortem examination so that maximum information can be obtained. This may confirm the diagnosis and provide information, which may help the parents to come to terms with their loss. Information gained may also be important when the parents think about another pregnancy. The coroner should be informed about any death where the cause is unknown or uncertain. The coroner’s officers are happy to discuss cases and give advice. The Consultant will arrange to meet parents once the post mortem results are available, normally 6 – 10 weeks.

3.7.11 Tissue donation:
It may be possible for parents to donate baby’s heart valves for transplantation. If baby is eligible ensure parents are given this choice. Donation can be seen as a positive event following the tragedy of their baby’s death and therefore should be offered to them if deemed appropriate and if baby meets the criteria for donation. See: Neonatal Heart Valve Donation Policy & Procedures.

3.8 Post End of Life Care:
- Local guidelines and paperwork should be completed
- Inform families about registering the birth and death, funeral arrangements and sources of ongoing support.
- Child Death Overview panel (CDOP) paperwork will also need to be completed.
See: Guidelines to Follow in the Event of a Death Occurring on the Neonatal Intensive Care Unit

3.8.1 Certification and registering of death:
If a baby is born with signs of life before 24 weeks, is stillborn at or after 24 weeks, or is born alive and subsequently dies, the parents must register the stillbirth or birth and death. They should be given verbal and written information about how and
where to do this, together with information about arranging a funeral. A doctor who has seen the baby within the past 14 days and is certain about the cause of death can sign the death certificate. Death certificates are usually signed by the Consultant but a Registrar may complete following discussion with the Consultant. When an expected death occurs at home there is no urgency for the family to call a doctor. The Advance Care Plan (ACP) should indicate who and when to inform when a baby dies at home. If a family calls an ambulance when a baby dies, the police are automatically informed unless they have an ACP. The ACP is particularly important at this point and parents should keep a readily available copy at their home.

In the case of a Coroner’s Post Mortem, medical staff cannot issue a medical certificate of death, it will need to come from the coroner. The Coroner’s Office will contact the family directly to inform them of the process that will take place. i.e. with regards to the baby’s registration of death and the need for an inquest if a cause of death cannot be found at post mortem.

3.8.2 Muslim funerals:
Generally following the registration of birth/death, the Mosque funeral director will accompany the family to the Bereavement Office (ASPH: 01932 722319). Here the necessary paper work is completed to allow the funeral to happen that day if possible.
See also: Guidelines in the Event of Parents Requesting to Take Their Deceased Baby Home (post 24 weeks).

- Baby graves are pre dug and locked so they are easily available.
- Muslim babies are usually buried in designated areas.
- Muslim babies cannot be buried at a weekend or on Bank Holidays, as generally Bereavement Offices are not open. Therefore, this would be organised for the next available working day. Other Register Offices may work differently. If babies need to go out of area for burial, the baby still has to be registered in the normal way and can be done by contacting the out of hours Registrars Number if needed out of office hours.
- Parents may wish to contact the Mosque and Imam themselves. Please ask what their wishes are.
• If this is the case the Imam will organise everything including the registration, as long as the parents have a Cause of Death Certificate.

Local Funeral Directors who arrange Muslim funerals for ASPH:
The Ribat Institute
Woking
Tel: 07595 479581
Or 07779 253507

3.8.3 Alternative Religions
A reference file is available on the bereavement trolley listing procedural variances required for specific religious groups. This will help ensure the individual spiritual needs are met for all families.

3.8.4 Communication and Follow-Up:
Staff should ensure the mother’s GP and the local primary care team/hospice service are informed about the baby’s death so that they can offer ongoing care and support. Staff should check they have contact details of the relevant charities that offer care and support to bereaved parents such as SANDS, BLISS and the Child Bereavement Trust.

Support websites:
www.uk-sands.org
www.childbereavement.org.uk
www.simonsays.org.uk
www.tcf.org.uk
www.crusebereavementcare.org.uk

Parents should be offered a follow up appointment with the Consultant to have the chance to discuss their baby. The timing of this may vary depending upon the availability of outstanding investigations including the post mortem, or the parent’s needs and wishes. More than one follow up contact may be appropriate.

3.8.5 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, for the protection of the parents and to avoid
misunderstandings, staff should give parents documentation to take with them, such as a Cause of Death Certificate.
See: Guidelines in the Event of Parents Requesting to Take Their Deceased Baby Home (post 24 weeks).

4.0 Referral for Hospice care:

4.1 Referrals:
Hospices accept referrals for infants’ who have a life limiting or life threatening condition and require palliative care, symptom management and support. These can be made antenatally.
Planned/Routine referrals can be made for babies expected to live for a while. The hospice may be able to offer a ‘stepped discharge’ and ongoing respite and support. Each baby is assessed and medical information gained from the baby’s consultant. Usually this information is then discussed at clinical committee – this can take a few weeks.
Urgent referrals are accepted for end of life care for babies who have not been previously known to them. Hospices are able to ‘fast track’ these referrals to ensure families can visit as soon as possible. Some hospices can visit the unit to meet the parents and offer symptom management support to the team.
Cold Room: Some Hospices are able to offer the use of a cold room/chilled bedroom facility. This is a place where babies can lay at rest after their death until the day of their funeral. This allows the family to stay with their baby and say goodbye in a supportive environment. To use this facility a referral must be made whilst the baby is still alive.
Initial referrals can be made by telephone and your local hospice will inform you of the referral process.

4.2 Points to remember:
- Some of the hospices like to visit/meet the parents prior to the transfer agreement, facilitate this if required.
- All current & possible medication/dressings including Controlled Drugs & Anti convulsants must be provided (they may not stock all medication).
When writing controlled drugs on TTO forms all requirements including name and address of patient, the form and strength of preparation, the dose and total quantity in both words and figures must be written

- Any enteral feeding? If so do they have a supply?
- Detailed summary of stay to date (BadgerNet) & Advanced Care Plan (ACP) - including any special requirement/wishes from the parents, to accompany baby.
- ACP should include a clear plan from lead consultant.
- Who will be staying with the baby?
- Has the baby been registered? If not then the father will not be able to complete the paperwork on his own following the infant’s death if parents are not married.
- Document whether post mortem has been discussed with the family.

4.3 Children’s hospices within the Kent, Surrey and Sussex Network:

A list of all children’s hospices can be located on the ‘Together for short lives’ website: [http://www.childhospice.org.uk/home.aspx](http://www.childhospice.org.uk/home.aspx)

See Appendix B for a list of your local children’s hospices.

5.0 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 how they would like to spend that time or what may be possible, therefore as staff we need to guide them and offer choices but also respect their wishes and decisions.

Things they may like to consider:

- Spending time with their baby before and after death, as a family and in privacy. They may wish to bring their own home comforts to have around them. Ambience is an important thing to consider.
- Choosing clothes for a religious service if there is to be one. Taking photographs/video of that service.
- Parents may like to sit and read, play music or sing to their baby.
- Involve other family members if parents wish.
• Photographs with siblings, family and friends. With a twin if possible. Encourage parents to capture all the moments in the time they have together, i.e. washing, dressing the baby.
• It may be appropriate to have discussions regarding funerals or post mortems before or after death. The importance of allowing parents to take time with their decision making cannot be emphasised enough.
• They may like to take their baby for a walk or spend some time out of the Neonatal unit environment.
• Remember it may be appropriate to offer the parents the choice of transferring their baby to a place of their choice to die. This would need to be discussed on an individual basis before facilities are offered.
• Consider the use of the transport team if available.
• They may have a special place they wish to share with their baby.
• Gather mementos they may like to keep or things they wish to stay with their baby. Encourage siblings, where appropriate, to draw pictures for the baby.
• Create a memory box/journey for the siblings if that’s appropriate.
• Ask what they would like to keep. Don’t assume.
• Offer hand and foot prints and moulds (leaflets are available). Parents may wish to help with the footprints. Carefully explain that the moulds are tiny hands and feet, not just impressions. These may be taken before or after death.
• Following the death of their baby, they should be given time and not feel rushed.
• They may wish to spend the night with their baby.
• We have the use of the Daffodil Room fridge on labour ward if parents wish.
• They may like to take their baby home after death, for a short time or until the funeral director collects the baby.
• They may wish to see their baby again. Choices should be offered and requests facilitated whenever possible.
• Transfer to hospice following death may be a possibility for the use of a cold room if this facility is available.
• They may wish to discuss decisions with their extended family.
• Parents may have wishes of their own and they should be encouraged not to be afraid to ask staff and for staff to help them achieve this, if at all possible.
5.1 Guidance for peri-mortem photography:

- Any photography should be undertaken with parents verbal consent.
- When taking photos avoid being too intrusive.
- Consider using black and white images and switch off the flash.
- Suggest take images of hands and feet (perhaps holding a parent’s finger or soft toy).

Remember this is all the time parents have. They will not have this time again. These are all the memories of their baby they will ever have.

TIME, CHOICE and RESPECT are key words to remember.

6.0 Key Points to remember when moving to palliative/comfort care:

6.1 Prior to meeting family:

- It must be made clear who is taking the lead role.
- The needs of the baby and family should be assessed as soon after diagnosis as possible.
- Explore, before meeting with the family, all local options available.
- Information should be gathered and recorded systematically, to ensure consistency.

6.2 Discussions with family:

- Ensure that information gathered about the baby is shared about with the family.
- Straightforward language should be used. Avoid medical jargon.
- Confidentiality and consent should be addressed.
- Professionals need to be open and honest with families.
- Explore the concerns and feelings of all family members, including extended family, if appropriate.
- Assessments need to be made in partnership with the family.
• Joint planning between families and professionals should start as soon as possible.
• Commence ACP to document families' wishes and discussions around limitations to resuscitation.
• Make an assessment of all medical, nursing, practical, social, psychological and spiritual needs.
• Aim to reach an understanding of the individual situation and the impact that situation has on the family.
• Ensure an agreed and documented plan for care/intervention.
• The baby must be kept as central in the process however care should be taken to include the needs of the whole family.
• The family’s religious, cultural and personal beliefs should be respected.
• It may be appropriate to introduce the subject of Post Mortem examination at this point if felt appropriate. Staff with appropriate skills and local knowledge must make assessments and take consent. Generally this would be the Consultant lead. Give relevant written information as required.
• The ACP communication checklist should be completed and signed as soon as possible to ensure all appropriate persons are notified.

6.3 Follow up:
• Information sharing is important and full and frank handover of care is essential.
• Staff involved in the care of the families should have their own access to support and supervision.
• Ensure families are offered verbal and written advice and information about contact details of support available to them after they have left the neonatal unit.
• Ensure that follow up is offered.

7.0 Key Points for Palliative Care/comfort care at home:
• All babies receiving palliative/ comfort care at home should have an agreed ACP, with verbal communication and copies sent to the relevant people.
• Every family should have a key worker to co-ordinate their plan. This may be the named nurse/Neonatal Outreach Sister/ Community Nursing Team/ Hospice team.

• Community Children’s Nurses/Hospice outreach team should be involved to support the family.

• The plan should include the whole family and take account of the baby’s symptoms and personal care. It must include psychological care of the family, siblings and baby.

• A 24-hour plan must be put in place and agreed to by the senior clinicians and nursing teams. This should include drug dosages, prescribing and obtaining medications, all contact details, transport arrangements and support available. There must be 24-hour access to pain and symptom control, and a written symptom control care plan.

Also include:

Feeding Documentation regarding comfort or demand feeding

NGT Feeding with full plan and management of tube if appropriate

Suction

Monitoring Sats/ apnoea etc if appropriate

• If the baby is alive after 2 weeks at home, consider the offer of a senior clinician visit at home.

• The family should be able to request a review at any time and the baby and family needs will require ongoing assessment. This should be clear in the pathway.

• The multi-disciplinary team must assess their effectiveness and coordination daily when delivering care.

• Ensure the family are given extra support at the time of baby’s death or if there is crisis.

• Ensure discussions with family have taken place and have been documented around their wishes following the death of their baby. BE AWARE families may change their minds and this should, as far as possible be accommodated.

• If there are any changes to be made to the care, a new care plan (ACP) must be agreed and documented.
References


A Neonatal Pathway for Babies with Palliative Care Needs. ACT (Association for Children’s Palliative Care). http://www.act.org.uk/


A care pathway to support extubation within a children’s palliative care framework http://www.act.org.uk/page.asp?section=406&sectionTitle=A+care+pathway+to+support+extubation+within+a+children’s+palliative+care+framework
Appendix A: Local Symptom Management Advice

Great Ormond Street (London)
The Louis Dundas Centre
Oncology Outreach & Palliative Care Team
Level 4, Main Nurses Home
Great Ormond Street Hospital for Children
Great Ormond Street
London
WC1N 3JH
Telephone number: 020 7829 8678
Fax number: 020 7829 7983
Team email: louisundugas_centre@nhs.net

Team Administrators:
Petra Michalcova
Email: Petra.Michalcova@gosh.nhs.uk
Maria Nguyen
Email: Maria.Nguyen@gosh.nhs.uk

Helen and Douglas House (Thames Valley)
Dr Emily Harrop, Paediatric Palliative Care Consultant
eharrop@helenanddougla.us.org.uk
Dr Susie Lapwood, Senior Speciality Doctor Slapwood@helenanddougla.us.org.uk
Karen Brombley, Nurse Consultant kbrambley@helenanddougla.us.org.uk

Naomi House and Jack’s Place (Hampshire)
Dr Ian Rodd, Consultant Paediatrician ian.rodd@hhft.nhs.uk

Royal Berkshire Hospital (Reading)
Dr Abigail McLeod, Lead for Paediatric Palliative Care
Abigail.macleod@royalberkshire.nhs.uk
Appendix B: Network Children’s Hospices

KENT

Demelza Kent
Demelza House, Rook Lane, Bobbing, Sittingbourne, Kent ME9 8DZ
Age 0-19 years
Telephone: 01795 845200
Email: info@demelza.org.uk
www.demelza.org.uk

EllenorLions Hospices Children and Young People’s Services
EllenorLions Centre, St Ronan’s View, East Hill Drive, Dartford, Kent DA1 1SA
Age 0-19
Telephone: 01322 221351
Email: info@chyps.org
www.ellenorlions.org

Demelza South East London
5 Wensley Close, Eltham, SE9 5AB
Age 0-18
Telephone: 0208 859 9800
Email: info@demelza.org.uk
www.demelza.org.uk

Richards House Children’s Hospice
Richard House Drive, Beckton, London E16 3RG
Age 0-19
Telephone: 0207 540 0200
Email: info@richardhouse.org.uk
www.richardhouse.org.uk
**SURREY**

Shooting Star CHASE – Christopher’s Children’s Hospice
Old Portsmouth Road, Artington, Guildford, Surrey GU3 1LP
Age 0-19
Telephone: 01483 230960
Email: info@shootingstarchase.org.uk
www.shootingstarchase.org.uk

Shooting Star CHASE – Shooting Star House
The Avenue, Hampton, Middlesex TW12 3RA
Age 0-19
Telephone: 0208 783 2000
Email: info@shootingstarchase.org.uk
www.shootingstarchase.org.uk

Alexander Devine Children’s Hospice Service
113 Whitby Road, Slough, Berkshire SL1 3DR
Telephone: 0845 055 8276
Email: fundraising@alexanderdevine.org
www.alexanderdevine.org

The Children’s Trust
Tadworth Court, Tadworth, Surrey KT20 5RU
Age 0-19
Telephone: 01737 365000
Email: enquiries@thechildrenstrust.org.uk
www.thechildrenstrust.org.uk

Rainbow Trust Children’s Charity
Practical and Emotional Support UK Wide
6 Cleeve Court, Cleeve Road, Leatherhead, Surrey KT22 7UD
Age 0-18
Telephone: 01372 363438
Email: enquiries@rainbowtrust.org.uk
SUSSEX

Chestnut Tree House Children's Hospice
Dover Lane, Poling, West Sussex, BN18 9PX
Age 0-19
Telephone: 0845 450 5820
Email: info@chestnut-tree-house.org.uk
www.chestnut-tree-house.org.uk

Demelza Community
Red Lion House, Magham Down, Hailsham, East Sussex BN27
Age 0-19
Telephone: 01323 446461
Email: info@demelza.org.uk
www.demelza.org.uk

HAMPShIRE

Naomi House
Stockbridge Road, Sutton Scotney, Winchester, Hampshire. SO21 3JE
Telephone: 01962 760555
www.naomihouse.org.uk
**Pathway 1: Recognition of Poor Prognosis**

**ACT First Standard**
Every family should receive the disclosure of their baby’s prognosis in a face to face discussion, in private and should be treated with respect, honesty and sensitivity. Information should be provided for the family using language they can understand.

**ACT Second Standard**
Every baby and family should have an agreed transfer plan involving carers, hospital, community and hospice service (if appropriate). The family should be provided with the resources they need.
Pathway 2: Planning for Withdrawal of Active Treatment

**ACT Third Standard**

Every family should receive an assessment of their needs as soon as possible after the life limiting/life threatening diagnosis has been made. They should have their needs reviewed at regular intervals.

If appropriate discussion around the need/desirability of Post Mortem Examination/Organ Donation

Pathway 1: ‘Recognition of Poor Prognosis’ Completed

Discuss with the family their needs and wishes

- Physical
- Emotional
- Spiritual

Discuss resuscitation status

Commence Advanced Care Plan with the Family

**ACT Fourth Standard**

Every family should have a care plan agreed with them to coordinate care and support their needs. A key worker should be identified and agreed with the family.

Family
- Emotional
- Physical
- Financial
- Informed choice
- Interpreters
- Spiritual needs
- P/N Care of Mum
- Bereavement Care

Baby
- Physical care needs
- Symptom & pain control
- Spiritual needs

Environment
- Place of Care
- Time
- Privacy
- Support
- Create memories
- Ceremonies
- Friends & Family

If the decision is made to transfer the baby Home or to a Hospice or other place of choice then move to ‘Pathway 3: Transfer to Chosen Place for End of Life Care’

If the decision is made to allow a natural death on NICU then move to ‘Pathway 4: End of Life Care’
Pathway 3: Transfer to Chosen Place for End of Life Care

**ACT Standard**
Every baby and family should have an agreed transfer plan involving the family, carers, hospital, community and hospice service if appropriate. The family should be provided with the resources they require before leaving hospital.

**Completed pathways 1 & 2**
‘Recognition of Poor Prognosis’ and ‘Planning for Withdrawal of Active Treatment’

**Planning for Home/Hospice/Repatriation or other place.**

**ACT Standard**
Every family should have an agreed multi-agency care plan for the delivery of coordinated care and support to meet their individual needs. A key worker to assist with this should be identified and agreed with the family.

**Family**
- Team meeting
- Care choices
- Support in caring
- Training
- Sibling well being
- Family well being
- Postnatal care of mother
- Equipment
- Plan for resuscitation (ACP)
- Emergency contact numbers for support team
- Emotional support
- Interpreters
- Financial/Benefits
- Meet with the team who will be caring for them in the community.

**Baby**
- Symptom control
- Equipment
- Baby care needs
- Medication

**Advance Care Plan**

**Baby care needs**
- Nursing supplies
- Therapies

**Move to 'Pathway 4: End of Life Care'**

**Environment**
- Family
- Liaison between health care professionals (i.e. GP, HV, CCN, NICU, Outreach Sister)
- Social Services
- Midwifery Team
- Home visit by multiple agency team
- Funeral directors

**Access to:**
- Training
- Psychological support
- Spiritual needs
- Pharmacy needs
- Equipment supplies
- Access to team
- Weekend & night time plan
- Advice for after death

- Identification of lead consultant
- 24 hour contingency plans documented & liaised
- Drug dosages, how these are obtained and by whom
- Documented and agreed ACP
- Support for family
- Contact details
- Transport arrangements
- Parallel planning: O2, nasogastric tube, suction, monitoring.
Pathway 4: End of Life Care+

Family
- Communication
- Time
- What to expect when baby is dying, colour, breathing, etc.
- Informed choices about spending time with their baby
- Contact details of professionals
- Liaise with the referring unit if applicable
- Spiritual and emotional support
- Practical arrangements (including registration of birth/death & transport)
- Cultural and religious needs
- Funeral planning
- Post natal care for mother
- Care of the extended family
- Creating memories (involve the family in this)

Baby
- Symptom control
- Pain control
- Dignity
- Time with family
- Spiritual needs

Continued bereavement support (after death)

At Home
- Practical advice on how to contact the funeral director
- Length of time to keep baby at home
- Community teams (GP, HV, MW, CCN)
- Support groups

Environment
- Place of death
- Transfer arrangements
- Ambience
- Place after death
- Nursing and medical documentation
- Multidisciplinary communication throughout (GP, Health Visitor, Mortuary, Chaplaincy, Porters, Funeral Directors, Wards, etc)
- Use of cold room at local hospice
- Transport

Funeral
- Burial or cremation
- Private of Hospital
- Ensure correct documentation completed

Follow Up Support
- Continued emotional support
- Refer as appropriate, i.e. counselling or support groups
- Practical advice
- Information for extended family and siblings
- Follow up arrangements, appointments with consultants

Completed pathways 1, 2 & 3 ‘Planning for Withdrawal of Active Treatment’ and ‘Transfer to Chosen Place for End of Life Care’

ACT Fifth Standard
Every family should be helped to prepare an end of life care plan for their baby and should be provided with care and support to achieve this.