

NNeTS Guidance for Palliative Care Transfers (including for end of life care and compassionate extubation)

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1 HOW TO USE THIS GUIDELINE

This guideline outlines the steps required to conduct a NNeTS transfer for a baby with palliative or end of life needs. It includes information about:

- Pre-referral planning
- (mandatory) Paperwork required
- What is expected of the referring *and* receiving units
- What can be expected from NNeTS
- Medication (ongoing and for symptom relief)
- Parallel planning
- Planning for events after death/liaison with other agencies

The guidance is written in detail so that those units faced with this situation infrequently have that which they need to complete a successful process.

Those from other units which deal with these situations more frequently may wish simply to access the referral form which is found in Appendix 1 at the end of this document, and complete it with reference as required to Section 5 of this document (below).

Once completed, the referral form should be send by secure (nhs.net) email after telephoning the NNeTS hotline (0191 2303020) to make the referral. At the time of telephoning, a secure recipient email address will be provided.

The referral form can either be completed as an electronic document, or printed/completed/scanned, then sent via email.

2 Introduction

Choice of place of care when appropriate, and possible to offer it, should be available to parents of babies with life limiting illness including those whose babies are having end of life care ^{1,2}.

In neonatal medicine, the commonest 'palliative' situation faced is likely to be the need for end-of-life (EoL) care in critically unwell babies. Here, death usually occurs after withdrawal of life-sustaining treatment, particularly invasive respiratory support. Examples might include babies with unsurvivable lung disease of prematurity or severe hypoxic ischaemic encephalopathy. In this situation, a proportion of babies may be clinically stable enough to be moved closer to home into another neonatal/paediatric unit, hospice or home itself, before withdrawing life-sustaining treatment. Where this is wanted by the family, they should be moved with a defined plan, which may include 'compassionate extubation' and planning for death or survival thereafter. It is acknowledged that there is often only a short time between a decision to move between 'intensive care' and 'supportive/comfort' treatment. In some instances, parallel planning conversations to ascertain the families wishes in the event that the baby dies may need to be started prior to a final decision to discontinue intensive care treatment. Transfer of babies requiring highly technological life-sustaining treatments should be carried out by NNeTS.

Babies may also be born with life-limiting illnesses due to genetic, cardiac, or other anomalies which may necessitate palliative care during later stages of the disease process but which, early on, require no specific 'medical' management. Trisomy 18 is an example in which cardiac defects may exist and central apnoea is the mode of death later in life, but where little symptom control is needed early in the course. Often these babies go home from hospital after a short period of time in the delivery suite, postnatal ward or NICU, but depending on their place of delivery and antenatally discussed plans, they may require transport by NNeTS to another location.

For those with palliative care needs alone, ensuring symptom control is in place by routes and methods appropriate to non-hospital settings, plans are in place for escalation of the symptom control and crisis/readmission management, and inclusion of the teams who are receiving the baby into their care is complete is essential, to ensure continuity of care.

For all babies with end-of-life care needs, who may be moving care settings, there needs to be robust parallel planning in place with contingency planning for if death occurs sooner, or later, than expected.

3 Guideline scope

This guideline is intended to guide the Northern Neonatal Transport Service (NNeTS) team and teams across the Northern Neonatal Network (NNN) to provide safe and seamless care for babies with palliative and/or EoL care needs, thus facilitating choice for families about place of care or death, in line with the NNN ethos of providing the right care at the right time as close to home as possible. It is also intended to be a resource complimenting the Neonatal Comfort Care Bundle (appendix 2), which is the Northern Neonatal Network resource available online (www.nornet.org.uk) that should be used in planning transfer of babies with palliative and/or EoL care needs out of hospital to other places of care.

4 Evidence Review and Evaluation

There is little quantitative evidence published about specialist transport for neonatal palliative or end of life care. What is clear is that unexpected death during transport is very different from transporting babies with palliative or EoL care needs who are at risk of dying. Different transport teams around the country use their own guidelines, tailored to the availability of local services such as hospices, the pathways which exist for involving community services, and the requirements of coroners and other services in their own areas of responsibility. The use of such guidelines is to allow alignment between referring, transporting and receiving teams so that the process is transparent and all parties are invested in focusing care on the baby at hand.

5 Guideline

This guidance is for use in conjunction with Neonatal Comfort Care Bundle³ – ‘Transfer Checklist’. It is anticipated that information in the Neonatal Comfort Care Bundle (see www.nornet.org.uk) will have been referred to and all sections of the checklist will have been considered and addressed as appropriate. Where transport is across healthcare boundaries for end of life care, a Neonatal Comfort Care Plan should be used³.

The referral form (appendix 1) will need to be completed in full at the time a referral to NNeTS is made and emailed to NNeTS with other supporting clinical information (e.g. EHCP, discharge letter). A suitable nhs.net email address will be provided during the referral telephone call.

What needs to be done prior to referral to NNeTS?

Communication with family

- Benefits and disadvantages of transfer to other locations should have been discussed. For advice on practicalities of moving to another location local hospices or consultants with expertise in palliative care can be involved and early conversations are encouraged.
- Family should understand the baby's expected poor prognosis and that giving accurate prognostic information is challenging.
- For compassionate extubation the family should be aware of the expectation that the baby will die but have been counselled that this may not occur immediately after removal of respiratory support and that, in some cases, babies can survive.
- Families must understand that NNeTS will not re-intubate the baby once planned extubation has occurred at the destination.
- Parallel planning for the possibility of survival must be discussed with the family, including eventual discharge to home if appropriate where initial step down is to another hospital or hospice. The family must understand what medical interventions are planned to continue and which will be discontinued both prior to transfer and by the NNeTS team at arrival at chosen destination.
- The family should understand that the baby could die en-route to the chosen location and their wishes for this eventuality should be known and recorded within the EHCP and DNACPR documents.
- Although it may not be possible for many babies (due to weight, gestation, illness), there should have been prior discussion of tissue (and rarely organ) donation and the family should know if this is an option for their baby.
 - **Organ donation** is likely to preclude a move to a community or lower dependency setting at the end of life. If the family wish to pursue this, feasibility must be explored with the specialist nurse in organ donation (SNOD) team who should meet to speak to the family prior to transfer. Transfer is only likely to continue if organ donation is *not* possible
 - **Tissue donation** may be carried out up to 48 hours after death but specialist nurses in tissue donation should be contacted as early as possible and prior to discharge from the hospital in order appropriate arrangements (such as cooling the body in the required time) can be made. If a family wish to donate

tissue the need to cool the body within a specified time may preclude transfer to a home setting but this should be possible within a lower dependency hospital or hospice setting with appropriate planning and monitoring.

- The family should understand who members of the receiving team are and what their individual roles will be.

Communication between professionals

- In the case of compassionate extubation, all members of the MDT and the patient's family must be in agreement with the decision for compassionate extubation.
- For families with a clear wish to be transferred out of NICU, where possible, early liaison with NNeTS as well as receiving teams (e.g. palliative care, hospice, local paediatrician and community teams including the relevant community nursing team and the GP) is beneficial. It is accepted that there are some cases for whom this will not be possible and this is *not* a barrier to transfer out of NICU for end of life care.
- It is important that the receiving team know in advance exactly what has been discussed with the family in terms of parallel planning for the possibility of survival and what medical interventions are planned to continue and which will be discontinued.
- Where time allows familiarisation visits with hospice should be considered prior to transfer of the infant to a hospice setting. Early contact with hospices should enable this to take place.

Paperwork

- DNACPR⁴ and EHCP⁵ forms should be completed and an original colour copy of each should accompany the patient at all times.
- The EHCP should be written as usual but **MUST** include
 - clear plans actions for the occasion that death occurs during transfer
 - Up to date list of professionals involved with the case in order that they can subsequently be contacted and informed of the child's progress/death as appropriate
 - Up to date list of medications *including* anticipatory medications and a plan for control of anticipated symptoms both during transfer and on arrival at planned destination.

- An up to date, thorough discharge letter/summary should be completed. A copy should have been seen by the family and accompany the patient, and copies should be sent in advance to all relevant professionals.
- The Neonatal Comfort Care Plan paperwork should be completed, and this will serve as a parent held multidisciplinary record for all carers to use as a means of record and communication.
- A North East Ambulance Service (NEAS) Special Patient Note (SPN) Form [Version 2 (August 2018)] should also be filled out and sent to NEAS and sent via email to special.patient.notes@nhs.net .

Note: the ECHP, DNACPR and SPN forms are all available at:

<https://www.northerncanceralliance.nhs.uk/deciding-right/deciding-right-regional-forms/>

Plans for after death

- The final page of the Neonatal Comfort Care Plan – Plans for after death should be completed with the family.
- For babies being transferred home the family must be aware of what actions to take following death including who to contact and over what time frame (usually not required urgently for expected deaths). For babies planned to stay at home after death the family will need a plan in place to be able to keep the body cold. The family's chosen funeral director should be able to assist with this.

It should be clear to the receiving team(s):

- Who will verify and certify the death? If a local physician is to complete the medical certificate of cause of death (MCCD) they must have seen the child in the 14 days before death.
- Whether a neonatal (<28 days old) MCCD will be required and where the local team can obtain this if needed (for community teams who would not usually complete this paperwork)
- It may be helpful to discuss what the cause of death is expected to be. Following death, it may be helpful for the local team to discuss with referring NICU/SCU centre.

- Whether a Coroner's referral is expected to be required and whether any prior discussions with the Coroner have taken place. Note: The Coroner who has responsibility for a given case is the one in whose jurisdiction the child dies and where, subsequently, the body lies. Therefore, advance discussions must take the likely place of death into account in order to have the appropriate discussions with the correct coroner, if that coroner will require a discussion after what will be classified as an 'expected death'. Wide variation in practice is seen between Coroners within the Northern region. It is notable that if a patient is admitted to a new setting and dies within 24 hours this usually requires a discussion with a Coroner's discussion as best practice, though it is not legally required.

In some areas of the north east (for example in Newcastle) **all** child deaths are expected to be discussed with the local Coroner. If referral to the Coroner is anticipated this should, in the majority of cases, be highlighted to the family prior to transfer. The relevant police forces should also know about the transfer before it happens, to prevent them treating subsequent death as 'unexplained/unexpected'.

- If a post-mortem examination is required, whether a hospital post-mortem should be offered to the family and if this has been discussed prior to death. Generally, the tertiary unit will be best placed to discuss this with the family prior to discharge from the NICU if this is likely to be required.
- If post-mortem is planned and the patient dies outside of a hospital setting consideration should be given to arrangements and feasibility for the body to be moved back to hospital, and the time period during which this should occur. If a Coroners post-mortem is expected to be required, this will require liaison with the appropriate coroner prior to transfer of the child. The family's chosen funeral director is likely to be the most appropriate method of transport after the child has died. **NNeTS are unable to facilitate the transfer of babies to further destinations beyond that planned, after death has occurred.**
- If the families have any specific requirements after death, including spiritual/religious requirements (e.g. do the family wish for a rapid funeral?).

Parallel Planning:

It is important to give consideration to, and document agreed plans on an EHCP for, when the baby may survive longer than expected after cessation of life sustaining treatment. This will include information for the NNeTS and receiving team on:

- Feeds/fluids – whether planned to continue and if stopped when and if they should be restarted and in what manner. Whether hydration therapy be escalated (e.g. should the baby receive IV fluids if readmitted to hospital).
- Medications – if medications have been rationalised whether there are regular medications which should be restarted, and if so, when and in what manner.
- Readmission to hospital/escalation of care – what circumstances this should occur in (e.g. if a reversible problem/acute illness occurs), where should the baby be admitted to and who is the local consultant responsible for care of the baby.

If there is a possibility the baby will survive any length of time after the transport team have left a home/hospice setting, open access to the local paediatric ward should be arranged before transport. **Note:** NNeTS are not able to transport babies from the community back to hospital and this would need to be done via the usual emergency '999' ambulance if required.

Medications

For all patients

- Consider discussing requirements as early as possible with the pharmacy team, NNeTS and the receiving unit/team.
- Consider rationalisation of unnecessary medications.
- Check whether medications need to be prescribed on the appropriate community drug kardex (for home/hospice settings).
- For home/hospice settings consider what other equipment is required to ensure medications can be given (e.g. enteral syringes, sterile water, water for injection, spare NG tube.)
- The amount of discharge medication should be agreed with the receiving team but should generally be at least 72 hours of medication.

The specific medication requirements of the two subgroups of babies (see below) being discharged home from the NICU with palliative care/end of life needs differ

greatly. Where necessary, consider the benefits of teaching parents to administer medication prior to transport home.

1. Babies for whom death is expected rapidly following discontinuation of life-sustaining treatments (e.g. compassionate extubation).

- IV access should be retained if possible. Any infusions with a potential to maintain comfort (e.g. Morphine, Midazolam) should be continued.
- If death occurs rapidly and prior to departure of the transport team symptom control is likely to be well maintained with any continuous infusions and/or IV bolus of medication already being used.
- IV infusions are unable to continue for babies transferring to lower dependency settings (home, hospice) after NNeTS depart. There must be a contingency symptom control plan for all infants in case of survival longer than expected taking into account the likelihood of survival, underlying condition, anticipated symptoms and most appropriate route for medication. This should be documented in the EHCP and appropriate discharge medications supplied.
- If stridor is likely to occur following removal of ET tube referring team should consider commencing IV dexamethasone 24 hours prior to time of proposed transfer.

2. Babies with life-limiting conditions not requiring technological life-sustaining treatments.

- IV access is unlikely to be required for symptom control. IV access is not necessarily required for transfer. Alternative routes of medications are more appropriate for lower dependency settings.
- First consider Oral/NG/PR routes. In some instances, topical, buccal and intranasal routes may be more appropriate. Delivery of subcutaneous infusions is theoretically possible but requires very close liaison with receiving teams and colleagues experienced in symptom control. The size of some preterm/growth restricted babies may preclude subcutaneous delivery of medication due to absence of subcutaneous fat.
- A robust plan detailing anticipated symptoms and symptom control management plan must be included in the EHCP/Neonatal comfort care bundle documentation. This should be agreed with the receiving team prior to

discharge from the NICU. Medications detailed in this plan must be discharged with the patient.

- For discharge to the home setting **the family must understand how to use the medication** and know what action to take if the route fails (e.g. NG tube dislodged).
- For further specific advice contact hospital pharmacist/palliative care specialist /APPM formulary.

What can be expected of the NNeTS transport team?

- For families being transferred home consideration should be given to any risks in the property. This should include discussion with family and consideration of:
 - access to house/environment
 - sources of combustion (oxygen being carried into home environment)
 - pets or other sources of risk to the NNeTS team
- If there is a concern or questions regarding a home property, and time allows, a local children's community nurse may be asked to perform a preliminary home visit and liaise with the NNeTS team.
- A consultant, HST trainee or equivalent, plus specialist transport nurse will be involved in all palliative care transfers.
- Palliative care/end of life transfers will be carried out Monday-Friday during working hours unless exceptional circumstances.
- One family member will be able to accompany the baby during transfer. This parent will need to be fit and well as per NNeTS 'parents travelling' guideline.
- All babies will be transferred in the transport incubator as per standard NNeTS practice.
- Unless otherwise specified prior to arrival of the NNeTS team at referring centre, medical monitoring will not be carried out during transfer.

For referrals for 'compassionate extubation'

- The majority of babies being transferred to a home location will require hand ventilation (with a t-piece circuit and portable oxygen cylinder) into the property and the expectation is that the ET tube will be removed very soon after arrival at the property. If the transport trolley can safely access the

property (e.g. other hospital, hospice), the transport ventilator may be used in place of hand-ventilation until moment of extubation.

- The transport team will be responsible for extubating the baby.
- Reintubation will NOT be offered
- The transport team will leave within one hour after removal of ET tube, and may be called away sooner if there is an emergency.
- For home and hospice transfers all IV access will be removed by the NNeTS team prior to departure from destination (unless otherwise arranged and agreed).
- If the baby is alive at the time of NNeTS team departure, any NG tube may be left in situ. Removal of this will become the responsibility of the receiving team.
- If the baby has died prior to NNeTS team leaving all invasive lines and tubes will be removed by the transport team prior to departure.
- If the baby dies while a NNeTS doctor is present, they are able to verify death, but the GP must also be present (unless death occurs during transit). Certification of death and completion of the cremation form will be the responsibility of the receiving team but support and advice from the referring team may be required. This can be supported via the NNeTS hotline.

If death occurs during transit

- Patient death during transport guideline does not apply to expected deaths.
- Complete journey to destination (unless alternative prior arrangement).
- Where possible inform those at receiving unit (hospital/hospice) and those meeting team at home setting (GP, CCN) prior to arrival.
- Verification of death can take place on arrival at destination.
- Verification and certification will need to be completed by NNeTS team (receiving team will not have seen the baby alive). In this instance arrangements may be needed for completion of cremation form by NNeTS or referring team (if required).
- All invasive tubes/lines can be removed by the NNeTS team following arrival at destination.

- NNeTS team should consider whether staff involved in compassionate extubation or where death occurs during transit require a debrief.

What is expected from the receiving team?

- The receiving team including local named consultant, children's community nursing team and GP should all be aware of the transfer and happy for the transfer to go ahead as planned.
- For transfer home the local GP and a member of the local children's community nursing service should meet the patient, family and NNeTS team on arrival at the property. This allows an appropriate handover and ensures that a local doctor has seen the patient alive in order to support verification and certification of death and completion of cremation form if required.
- The receiving team should check symptom control plans and medications following arrival of the patient.
- For those patients in home settings the receiving team should ensure that parents have appropriate emergency contact names and numbers and know who to ring in what situation (e.g. escalation of symptoms, onset of new symptoms, unanticipated emergency). The receiving team should be certain that the family are aware of required actions following the death of the child.

6 Training, Implementation, Resource Implications

The implementation of this guideline at, and by, NNeTS will not require any increased resources. The guideline reflects a process based on best practice and therefore it is anticipated that units which request NNeTS assistance with a palliative or EoL transfer to a different location will have worked through the process before contacting NNeTS. The delivery of a palliative transport is not a frequently occurring event with around 50 being reported as completed by neonatal transport teams nationally each year. It is not, therefore anticipated that providing this service within the bounds specified in this guidance will have unmanageable resource implications for the NNeTS team.

This guideline will be highlighted to the NNeTS team when published. The team will be expected to be familiar with its content and if required, additional training will be made available during the bi-monthly governance sessions. It will also be made available for all provider units to refer to on the Northern Neonatal Network Website.

If service user units request additional training this will be considered on a case by case basis.

7 Guideline Monitoring

The rarity of palliative transports means that audit per se is not a helpful way to review these transports in any meaningful way. Therefore, it will be standard practice to:

1. Review these transports against the guideline in the normal review process (daily review), where possible with those who completed the transport present.
2. Where step 1 raises questions, concerns or identifies need for staff debriefing, the NNeTS medical and nursing leads will review the case independently (with statements from staff as required) and the findings presented to the bi-monthly governance meeting for discussion.
3. If required, the case may be taken to the Quarterly Northern Neonatal Network meeting for discussion.
4. Palliative care transport numbers are reported annually to the NTG for benchmarking purposes and will continue to do so while they remain an NTG dataset item.
5. The NNeTS medical lead (or equivalent) will be available for local reviews/CDOP processes as necessary if requested by service user colleagues.

8 References

1. **Together for short lives, 2017: A Perinatal Pathway for Babies with Palliative Care Needs.**
<https://www.togetherforshortlives.org.uk/resource/perinatal-pathway-babies-palliative-care-needs/>

2. **Mancini A., Uthaya S, Beardsley C et al “Practical guidance for the managements of palliative care on neonatal units” Feb 2014.**
<http://www.chelwest.nhs.uk/services/childrens-services/neonatal-services/links/Practical-guidance-for-the-management-of-palliative-care-on-neonatal-units-Feb-2014.pdf>

3. **Northern Neonatal Network website:**

<https://nornet.org.uk/professionals>

This includes links to a wealth of neonatal palliative care resources including the Comfort Care Bundle checklist 2 – transfer checklist, regional nSTEP (neonatal stratified escalation plan) form, comfort care plan documents.

4. **Deciding right, DNACPR form**

<http://www.northerncanceralliance.nhs.uk/wp-content/uploads/2018/11/DNACPR-NHS-Fillable-form-v17.pdf>

5. **Deciding right, Emergency Health Care Plan (EHCP) form**

<http://www.northerncanceralliance.nhs.uk/wp-content/uploads/2018/11/EHCP-NHS-Fillable-form-v14-April-2013.pdf>

Appendix 1: Neonatal Palliative Care Transfer Referral Form



Please thoroughly read the accompanying guideline and transfer checklist of the neonatal comfort care bundle prior to completion of this form.

Patient Name: <i>Affix addressograph if available</i>	DOB:
Address:	NHS Number:
	Hospital Number:
Parents Names: Names of other key family members:	
Transfer for <i>(delete those not applicable)</i> Compassionate extubation / end of life care / other palliative care need	
Contact details for lead clinician: Contact details for referring unit:	
Transfer Destination (including phone number & full address with postcode):	
Urgency of transfer:	
Name of receiving consultant:	
Contact Details for receiving consultant (including place of work) <i>to be available for discussion at the time of transport and arrival at destination:</i>	
Please confirm who will meet transport team at destination (e.g. GP, CCN, Neonatal community nurse) and give contact details:	
Are there any infection control problems? Yes <input type="checkbox"/> No <input type="checkbox"/> If yes, please give details:	
Is the patient intubated? Yes <input type="checkbox"/> No <input type="checkbox"/>	
Will the transport team be responsible for withdrawal of respiratory support: Yes <input type="checkbox"/> No <input type="checkbox"/>	

Does the patient have IV access? Yes No
(not compulsory for palliative care transfers, see guideline,)

Will the transport team be responsible for discontinuation of infusions (e.g. sedation, analgesia, inotropic support): Yes No
Please give details:

Does the patient have other lines/feeding tubes/catheters in place which will be required to be removed by the transport team? Yes No
If yes, please give details:

*Consider discussion with transport & receiving teams and removal of non-essential lines.
NG tubes should usually be left in situ*

Who wishes to accompany the patient during transfer? (e.g. a parent)

Please confirm EHCP and DNACRP forms have been completed: Yes

Please confirm there is a symptom control plan detailed in EHCP and appropriate anticipatory medications available if symptoms occur during transfer or following arrival at destination: Yes

Please confirm plans for verification and certification of death are in place: Yes

Please give details of any other information the transport team need to be aware of:
(e.g. consider including if the family require an interpreter, if children are subject to child protection plan)

Please ensure copies of EHCP, discharge letter and DNACPR forms are included with this form as appropriate.

Appendix 2: Transfer Checklist (NCCB)

NICU Comfort Care Bundle: TRANSFER Checklist

This checklist is for an infant who has been diagnosed with a life-limiting illness but is not necessarily dying. Use this if preparing to transfer an infant to a different setting; a more local hospital, paediatric ward, home, a community setting or children's hospice

In most cases this will be AFTER plans for transfer have been shared with parents.

Not all areas need to be addressed simultaneously, but the status of all parts should be reviewed daily where appropriate.	Any actions commenced, plans to address areas of need, or appropriate omissions should be briefly documented in the patient notes at ward rounds or review.
Comfort Consideration Category	Key considerations:
1) Discussion with parents	<p>Document that a Senior doctor has spoken to parents: Cover working diagnosis, parental and medical team concerns. Prepare parents for short term expectations of transfer. Longer term prognosis may be more difficult to be specific about.</p> <p>Discuss and document reason for transfer: Consider whether this is the most appropriate setting for the infant, depending on parents' wishes, social circumstances, medical complexity and prognosis. Consider and discuss if death is a possibility en-route as this may influence their decision making.</p> <p>Document discussion of the use of the Neonatal comfort care plan (NCCP) parent-held multidisciplinary documentation.</p>
2) Supporting parents and their wishes	<p>If transfer is for planned cessation of respiratory support: DECIDE and DOCUMENT: <i>Where</i> and <i>When</i> in advance if possible; <i>Parental wishes</i> (e.g. side-room, holding child, who present) Discuss plans for survival being longer than expectations - does the receiving team have capacity?</p> <p>Even in uncertain prognosis, consider discussing with parents: Their priorities for their baby before death:</p> <ul style="list-style-type: none"> • Blessing or equivalent (including non-religious) • Meeting family and friends • Making memories with siblings <p>Preferred place at the time of death</p> <ul style="list-style-type: none"> • Religious rituals: would they like a faith leader present? • Preferred place after death <p>If parents' preference is for death at home, consider: Do social circumstances support this? If the family is known to Social Services, discuss the appropriateness of the setting of transfer with them. Inform receiving local police prior to transfer</p>

NICU Comfort Care Bundle: TRANSFER Checklist

	<p>Inform the local Coroner prior to transfer</p> <p>Document support offered to parents: Psychologist support (especially if one of a multiple pregnancy where other child(ren) surviving) Breastfeeding cessation advice if required Sibling Support: school, pre-bereavement support Financial Support: travel, impact on income</p>
3) Treatment Ceiling decisions	<p>Does the baby have a complex medical diagnosis or difficult family situation where it would be appropriate to fill in a best-interests form? The best interest forms is called 'MCA2 v15'⁶</p> <p>Where particular escalation of treatment is not thought to be appropriate, document: Which treatments are not to be commenced Reasons for ceiling of treatment Date for review of decision Consider completing a STEP (Stratified Treatment Escalation Plan) or EHCP (Emergency Health Care Plan)</p> <p>Discuss whether intensification of care would be appropriate e.g. return to NICU, admission to PICU or local paediatric unit In particular - in the event of deterioration (e.g. developing heart failure) or acute illness (e.g. bronchiolitis)</p>
4) Resuscitation Status	<p>Ensure Regional documentation is completed prior to transfer as appropriate⁵. DNACPR or EHCP following discussion with family² DNACPR order only applies to resuscitation; all other treatment and care that is appropriate will be given. The baby's comfort and dignity are paramount concerns. Complete if the baby is not to be resuscitated in the event of a sudden life-threatening deterioration or cardio-respiratory arrest. In the event of this form not being completed, full resuscitation measures will be initiated.</p> <p>EHCP (Emergency Health Care Plan) may be more appropriate if prognosis is uncertain or where certain specific interventions may be of benefit.</p> <p>If infant may die en route, discuss whether travel should continue to destination, local hospital or return to NICU.</p> <p>Ensure DNACPR or EHCP are completed as necessary.</p> <ul style="list-style-type: none"> • Original colour copy to travel with infant • Fax copy to Ambulance control with NEAS notification form • File copy in medical notes (state 'copy') <p>Check there are no earlier plans that need to be moved and filed.</p>
5) Comfort Care	<p><u>Anticipatory planning is vital</u> Anticipate and prescribe for a range of possible symptoms on a community prescription chart.</p> <p>Discuss medication needs with hospital Pharmacy who will fast track the order. Remember sterile water for making up syringe pumps, infusions, giving sets, syringe pumps and sharps box as appropriate</p> <p>Parents should have access to 'just in case medications' with a</p>

NICU Comfort Care Bundle: TRANSFER Checklist

<p>5) Comfort Care (continued)</p>	<p>clear management plan and/or access to review</p> <p>Basic symptom control in paediatric palliative care manual is available on-line⁴</p> <p>Comfort considerations:</p> <ul style="list-style-type: none"> • Environment: quiet, calm, family-orientated • Non-pharmacological intervention: suckling (pacifier or breast), positioning/swaddling, positive touch/massage/parental hold • Consider if skin integrity requires extra care measures • Rationalise medications <p>if oxygen is needed at home, complete and fax HOOF form http://www.hscbusiness.hscni.net/pdf/hoof_v2_3_final.pdf</p>
<p>6) Specific Symptom control</p>	<p>SPECIFIC management plans (if appropriate):</p> <ul style="list-style-type: none"> • Pain: Sources of PAIN and scoring measures <ul style="list-style-type: none"> ◦ Analgesia: Dose, Route, Escalation • Seizures: Anticonvulsants <ul style="list-style-type: none"> ◦ Rescue medications? • Respiratory tract secretion: antimuscarinics, possibly gentle suctioning • Vomiting: alter feed volumes, cease feeds, NG drainage • Agitation • Consider discussing options if increasing symptoms are anticipated, e.g. large VSD <p>Ensure local community pharmacy can supply ongoing medication needs, particularly customised formulations</p>
<p>7) Monitoring</p>	<p>If and as appropriate, consider and document reasons to:</p> <p><u>Remove</u>: Invasive and/or electronic monitoring</p> <p><u>Replace</u>: continuous monitoring with intermittent assessment of (a) Medical parameters (e.g. HR) (b) Comfort</p> <p><u>Rescind</u>: any unnecessary tests (OR document why they are being continued)</p>
<p>8) Fluids & Nutrition</p>	<p>Document feeding decisions and background rationale</p> <p>Accurate prognostication is difficult</p> <p>Optimise what can be tolerated: volume of feed, calorie concentration, mode of delivery.</p> <p>Ensure availability of feed type</p> <p>Consider potential options if enteral feeding fails: Does this warrant an increase in invasiveness of hydration delivery (SC/IV) or should comfort and symptom control take priority?</p>
<p>9) Completion of diagnostics</p>	<p>In infants without a definitive diagnosis: DECIDE, DISCUSS WITH FAMILY and DOCUMENT where possible:</p> <ul style="list-style-type: none"> • Whether peri-mortem samples are needed for diagnosis (e.g. muscle or skin biopsy). Ideally take skin or muscle biopsies prior to discharge from level 3 unit. • Whether post-mortem examination or imaging will be needed (full/limited)

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<p>10) Longer term planning</p>	<p>One local practitioner (key worker) should be identified to take the lead, to act as the family's first point of contact for communication, and to ensure information flows to all services.</p> <p>End of life is difficult to predict in all babies with complex needs: teams need to be available to sustain many weeks of care at end of life, and have contingencies for support if a baby's end of life phase is prolonged.</p> <p>Options to consider:</p> <ul style="list-style-type: none"> • Applying for Fast track Continuing Health Care provision (via CCG) to support care at home (or hospice) • Referral to Hospice for respite or palliative support • Referral to Social Services (for children with disabilities)
<p>11) Practicalities for transfer</p>	<p>1) Close liaison with GP is VITAL to support care at home</p> <ul style="list-style-type: none"> • Ideally a home visit by the GP should occur on the day of transfer • The infant should be added to the primary care palliative register • The infant should be medically reviewed fortnightly to aid certification <p>2) Complete the NCCP to aid communication between agencies. File a copy on discharge in the medical notes. Complete the final page of the NCCP: 'Summary of plans when death occurs'</p> <ul style="list-style-type: none"> • Who will be able to verify death in and out of hours and how should parents make contact? • Who will certify death? <p>3) Inform NORTHERN DOCTORS (or other locally covering out of hours services) that a dying patient is being discharged (fax form to Northern Doctors using 0300 123 1852)</p> <p>4) Careful detailed handover between clinicians is imperative for facilitating transfer. If acute hospital admission is needed:</p> <ul style="list-style-type: none"> • Where will this be? • How and Who should the family contact? • Identify a named receiving Consultant and ensure he is up to date with discharge plans and clinical situation <p>Ensure local paediatric team are aware of additional treatment and equipment needs - in particular check compatibility of systems and Children's community nurses are able to supply disposables</p> <p>4) Consider whether local paediatric palliative expertise would be helpful and refer as necessary</p> <p>5) Book ambulance 0191 4143144: there is currently an extended hours end of life service. If transfer is less urgent, state DNAR category 1 or 2 (as below) Fax 0191 4302080 NEAS flagging form and copy of EHCP/DNACPR</p> <p><u>Categories of transfer:</u></p>

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<p>11) Practicalities for transfer (continued)</p>	<p>Category 1: patients are being transported to a location where death is imminent and may occur during transport</p> <p>Category 2: Patients are clearly ill and need a high level of care en route (accompanied by a nurse). Whilst these babies have a DNAR order, their death may not be imminent.</p> <p>If parents wish to transport their baby:</p> <ul style="list-style-type: none"> • Inform local police • Inform parents' car insurance company if oxygen is carried <p>Consider involving local professionals (especially if they already have family involvement): Health Visitor, School nurse</p> <p>A discharge summary detailing all areas of the checklist is imperative.</p>
<p>12) Care after death</p>	<p>1) Complete the final page of the NCCP: 'Summary of plans when death occurs'</p> <p>2) Provide the opportunity to discuss parents' plans for after death care. Include information about who to call, what needs to be done immediately and what can wait. Help the family to think in advance about support systems available after their child has died.</p> <p>3) Sensitive communication and good information and advice for the family are essential in cases where post-mortems are required.</p> <p>4) Parents may like to consider the option of tissue (rarely organ) donation. This is possible up to 48 hours after death (see additional information)</p> <p>5) Parents should be aware of the Child death overview process.</p> <p><u>Families may want to start thinking about organising a ceremony prior to the death of their child.</u></p>

References:

1. Palliative Care (Supportive and End-of-Life Care): A Framework for Clinical Practice in Perinatal Medicine (BAPM, 2010):
2. Decisions relating to cardiopulmonary resuscitation (BMA, RC(UK) and RCN, 2014)
3. A guide to end of life care: care of children and young people before death, at the time of death, and after death (Together for Short Lives, 2012)
4. http://www.togetherforshortlives.org.uk/professionals/resources/2434_basic_symptom_control_in_paediatric_palliative_care_free_download
5. <http://www.nescn.nhs.uk/common-themes/end-of-life-care/deciding-right/regional-forms/>
6. <http://www.nescn.nhs.uk/deciding-right/regional-forms/>