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	**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. **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. Document discussion of the use of the **Neonatal comfort care plan** (NCCP) parent-held multidisciplinary documentation.
2) Supporting parents and their wishes	**If transfer is for planned cessation of respiratory support:** DECIDE and DOCUMENT: *Where* and *When* in advance if possible; *Parental wishes* (e.g. side-room, holding child, who present) Discuss plans for survival being longer than expectations - does the receiving team have capacity? **Even in uncertain prognosis, consider discussing with parents:** Their priorities for their baby before death: • Blessing or equivalent (including non-religious) • Meeting family and friends • Making memories with siblings Preferred place at the time of death • Religious rituals: would they like a faith leader present? • Preferred place after death **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

	Inform the local Coroner prior to transfer **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
3) Treatment Ceiling decisions	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 'MCA**2** v15'[6] **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) **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)
4) Resuscitation Status	**Ensure Regional documentation is completed prior to transfer as appropriate[5]. DNACPR or EHCP following discussion with family[2]** **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. **EHCP (Emergency Health Care Plan)** may be more appropriate if prognosis is uncertain or where certain specific interventions may be of benefit. If infant may die en route, discuss whether travel should continue to destination, local hospital or return to NICU. **Ensure DNACPR or EHCP are completed as necessary.** • Original colour copy to travel with infant • Fax copy to Ambulance control with NEAS notification form • File copy in medical notes (state 'copy') **Check there are no earlier plans that need to be moved and filed.**
5) Comfort Care	**Anticipatory planning is vital** Anticipate and prescribe for a range of possible symptoms on a community prescription chart. 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 Parents should have access to 'just in case medications' with a

5) Comfort Care (continued)	clear management plan and/or access to review Basic symptom control in paediatric palliative care manual is available on-line[4] **Comfort considerations:** • 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 If **oxygen** is needed at home, complete and fax HOOF form http://www.hscbusiness.hscni.net/pdf/hoof_v2_3_final.pdf

6) Specific Symptom control	**SPECIFIC management plans (if appropriate):**
	• **Pain**: Sources of PAIN and scoring measures
	  ○ *Analgesia: Dose, Route, Escalation*
	• **Seizures**: Anticonvulsants
	  ○ *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
	
	Ensure local community **pharmacy** can supply ongoing medication needs, particularly customised formulations

7) Monitoring	**If and as appropriate, consider and document reasons to:** *Remove*: Invasive and/or electronic monitoring *Replace*: continuous monitoring with intermittent assessment of (a) Medical parameters (e.g. HR) (b) Comfort *Rescind*: any unnecessary tests (OR document why they are being continued)
8) Fluids & Nutrition	**Document feeding decisions and background rationale** **Accurate prognostication is difficult** Optimise what can be tolerated: volume of feed, calorie concentration, mode of delivery. Ensure availability of feed type **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?
9) Completion of diagnostics	**In infants without a definitive diagnosis:** DECIDE, DISCUSS WITH FAMILY and DOCUMENT where possible: • 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)

10) Longer term planning	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. 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. **Options to consider:** • 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)
11) Practicalities for transfer	**1) Close liaison with GP is VITAL to support care at home** • 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 **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'** • Who will be able to verify death in and out of hours and how should parents make contact? • Who will certify death? **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) **4) Careful detailed handover between clinicians is imperative for facilitating transfer.** If acute hospital admission is needed: • 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 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 **4) Consider whether local paediatric palliative expertise would be helpful and refer as necessary** **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 Categories of transfer:

11) Practicalities for transfer (continued)	**Category 1**: patients are being transported to a location where death is imminent and may occur during transport **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. If parents wish to **transport** their baby: • Inform local police • Inform parents' car insurance company if oxygen is carried **Consider involving local professionals** (especially if they already have family involvement): Health Visitor, School nurse A **discharge summary** detailing all areas of the checklist is imperative.
12) Care after death	1) Complete the final page of the NCCP: **'Summary of plans when death occurs'** 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. 3) Sensitive communication and good information and advice for the family are essential in cases where post-mortems are required. 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) 5) Parents should be aware of the Child death overview process. **Families may want to start thinking about organising a ceremony prior to the death of their child.**

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/