This checklist is for an infant who is either: acutely unwell and at high risk of dying; or in the process of dying; or who has an unsurvivable illness and/or who has a gradually deteriorating clinical status[1].

In *most* cases use of this checklist will *usually* be AFTER concern has been shared with parents. Exceptions *may* occur in rapid deterioration of clinical status

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:** conversation including team and parent worries, working diagnosis, expected prognosis even if not certain. Where time is limited, discuss any **priorities** parents may have regarding: • Religious requirements or rituals • Blessing or equivalent (including non-religious) • Enabling extended family to meet the baby before death if wished
2) Pain Relief and Comfort Care[3]	**SPECIFIC documentation of (if appropriate):** 1) Sources of PAIN and scoring measures 2) Analgesia: Dose, Route, Escalation 3) Synergistic/Non-Narcotic medicines: Paracetamol 4) Environment: quiet, calm, family-orientated 5) Non-pharmacological intervention: suckling (pacifier or breast), Positioning/swaddling, positive touch/massage/parental hold, buccal expressed breast milk or sucrose
3) Other Symptom control[3]	**SPECIFIC documentation of (if appropriate):** 1) Seizures: continue anticonvulsants 2) Secretions: Antimuscarinics, possibly gentle suctioning 3) Skin integrity 4) Vomiting: alter feed volumes, cease feeds, NG drainage 5) Muscle spasms: consider midazolam, baclofen, gabapentin For advice about medical symptom control refer to TFSL formulary: **http://www.togetherforshortlives.org.uk/professionals/resources/2434_basic_symptom_control_in_paediatric_palliative_care_free_download** **OR** During Normal weekday working hours there is a children's palliative care advice line contacted via St Oswalds Hospice, Newcastle upon Tyne **OR** There will always be a neonatal consultant on call for each of the level 3 NICUs who might provide some advice by telephone

4) 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)
5) Fluids & Nutrition	**Document feeding decisions/rationale with COMFORT as key aim:** 1) *IF short duration anticipated*, stop feeds and institute good symptom control 2) *IF stopping nutrition will be primary mode of death* ensure hunger does NOT cause distress 3) Where *oral* feeding is established it can usually be continued PRN for comfort (unless causing vomiting, discomfort: see category '3' above) NOTE: if milk is not tolerated but thirst/starvation distress is a symptom that requires treating, consider trying oral rehydration solution (ORS) **IF nutrition/hydration is CONTINUED document:** 1) Assessment of balance of *need* vs. *invasiveness of delivery* (SC, IV) 2) Plan of action if the delivery mode fails.
6) Ventilation and Oxygen	**For planned cessation of respiratory support:** DECIDE and DOCUMENT: *Where* and *When* in advance if possible; *Parental wishes* (e.g. side-room, home, hospice, holding child)
7) Completion of diagnostics	**In infants without a definitive diagnosis:** DECIDE, DISCUSS WITH FAMILY and DOCUMENT where possible: • Whether perimortem samples are needed for diagnosis (e.g. muscle or skin biopsy) • Whether post-mortem examination or imaging will be needed (full/limited)
8) Treatment Ceiling decisions	**Where particular escalation of treatment is not thought to be appropriate, discuss:** • Which treatments are ***not*** to be commenced • Reasons for ceiling of treatment • Date for review of decision **DOCUMENT THESE DECISIONS:** **Use of an EHCP[4] is advised (editable & printable PDF) but a suitable alternative e.g. Stratified Treatment Escalation Plan (STEP) form may be a more easily used alternative in time-limited situations** If the baby has a **complex medical diagnosis or difficult family situation consider completing a best-interests form.** The best interest forms is called 'MCA**2** v15'[4]
9) Resuscitation Status	**When appropriate ensure DNACPR[4]/allow natural death order (regional document) is completed and discussed with family especially if transferring infant[2]** **CONSIDER PLACE OF CARE: Does this baby need to be in a NICU?** Could it be elsewhere? Is it safe/practical to move them?

10) Support for parents	**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 **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

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:http://www.togetherforshortlives.org.uk/professionals/resources/2434_basic_symptom_control_in_paediatric_palliative_care_free_download

4: http://www.nescn.nhs.uk/deciding-right/regional-forms/