GUIDANCE TO SUPPORT NEONATAL CARE IN THE LAST DAYS OF LIFE

## Commonly used PRN medicines and infusion doses for end of life care:

The drug doses below are for neonates unless otherwise indicated in the comments column. Refer to the APPM Master formulary for infants older than 1 month of age.

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| Indication | Drug | Dose | Frequency | Route |
| Pain | **Morphine**  | 25-50 micrograms/kg if opiod naïve120 micrograms/kg/24hr  | every 6-8 hours adjusted to response Over 24 hours adjusted to response | Oral/ Sub cut or IV (over at least 5 minutes)Continuous subcutaneous or IV infusion |
| Respiratory secretions | **Glycopyronium bromide****Hyoscine Hydrobromide** |

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| 40–100mcg/kg  |

250mcg ( quarter of a patch) | 6-8 hourlyEvery 72 hrs | OralTransdermal |
| Seizures | **Midazolam** | 0.5-1 mg/kg/24 hours increasing up to 7 mg/kg/24 hours (maximum 60 mg/24)300microgramms/kg | Over 24hrs.Single dose repeated once if necessary | Sub cut or IV infusionBuccal or intranasal |
|  | **Phenobarbital** | 20mg/kg Then2.5-5mg/kg once daily | Single dosePer 24 hours | Slow IV /Sub cut or oralOral/slow intravenous injection or infusion |
| Anxiety / distress | **Midazolam** | 25micrograms/kg50 micrograms/kg25 micrograms/kg0.5-1kmg /24hrs | Repeated hourly as necessaryOver 24 hours | Buccal or intranasalOral Sub cut or ivSub cut or iv infusion |
| Dyspnoea | **Morphine****Midazolam** | 10-20 micrograms/kg if opiod naïve40-60 micrograms / kg/24hrs25micrograms/kg50 micrograms/kg25 micrograms/kg0.5-1kmg /24hrs | every 6-8 hours adjusted to response Over 24 hours adjusted to response  Repeated hourly as  necessaryOver 24 hours | Oral/ Sub cut or IV (over at least 5 minutes)Continuous SC or IV infusionBuccal or intranasalOral Sub cut or ivSub cut or iv infusion |

**Additional notes:**

(Ref Practical guidance for the management of palliative care on neonatal units – Chelsea and Westminster)

**Pain relief**

• All infants receiving palliative care must have consideration given to relief of pain and discomfort. This includes the type of medication, the dose, route of administration and the likely duration of need—consideration should be given to the use of formal tools to assess pain.

• Should the infant have intravenous access in place, this route is preferable in the immediate period after discontinuation of life-sustaining care.

• If an infant is already receiving analgesic medication this should be continued—if opiates are to be initiated, an initial bolus dose should be given before commencing an infusion so that adequate analgesia is achieved promptly. The dose may be increased or reduced depending on ongoing assessment of distress and development of tolerance—if relevant, parents should be made aware that opiates while relieving pain and distress also suppress respiratory drive and may hasten death.

• If the intravenous route is not available and adequate analgesia cannot be achieved through oral medication, a subcutaneous infusion may be necessary. Intramuscular medication is never appropriate. For rapid symptom management, buccal medication can be considered, usually in addition to longer acting medication via the enteral route or subcutaneous infusion.

• Non-narcotic analgesia such as paracetamol and oral sucrose may be used for less severe pain or in combination with narcotic analgesics.

• Non pharmacological interventions to reduce pain and discomfort should be used in conjunction with analgesic medications—these include a calm environment with minimal noise and light stimuli, non-nutritive sucking with a pacifier, music and positioning with arms and legs flexed close to the trunk using a blanket or rolls and massage.

• Assist the parents to hold their baby.

• Support continued suckling at the breast if the mother wishes.

 **Fluids and nutrition**

• The goal of treatment is comfort, not the provision of nutrition.

• In those infants able to tolerate milk feeds their ongoing provision should be determined by their clinical condition and the cues that the infant demonstrates.

• Oral nutrition should only be withheld if it is felt that providing it will cause pain or discomfort.

• If vomiting is a problem, the volume of enteral feeds should be reduced appropriately.

• It may be appropriate to allow the infant to suckle at the breast if able to do so.

• In those infants in whom the duration between the withdrawal of life-sustaining care and death is expected to be short, it is reasonable to cease all feeds if it is felt feeding could cause distress, and to discontinue intravenous hydration an