



# North West Neonatal Operational Delivery Network Palliative Care Pain and Symptom Control Document 2020



*"There is no footprint so small, that it does not leave an imprint on this world"*

**This guideline has been produced in partnership with  
the Northwest Paediatric Palliative Care Network**



# Northwest Operation Delivery Neonatal Network Palliative Care Pain and Symptom Control Document

There are three main categories of babies that potentially require end of life care either on the neonatal unit or in the community

1. The ventilator dependent infant where death is expected to occur soon after withdrawal of respiratory support [extreme preterm population]
2. The seriously ill term infant for whom a catastrophic event has happened antenatally who is 'actively dying' and for whom survival is anticipated to be hours, days or at best a few weeks [e.g. hypoxic ischaemic encephalopathy]
3. The infant with a congenital non-reversible condition that is incompatible with long-term survival, but who may survive several months or longer and may have significant complex care needs [e.g. Edwards/Patau syndrome T18, congenital cardiac condition]

## **Location of Palliative/End of life Care**

Depending on the clinical 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 or in a children's hospice. The lead clinician should discuss and decide 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. If a baby is being transferred home or to a children's hospice, the mother's health must also be considered and planned for with the local community midwifery service; where possible transport should be arranged to allow time at home or at the hospice prior to the period of end of life care. The parents' wishes should be listened to and all options of choice of place of death discussed

## **Prescription for 'Out of Hospital' Palliative care**

If transferring to a community setting anticipatory prescribing should occur with medicines dispensed and supplied from the referring hospital.

The drugs to prescribe are a one week course of:

Paracetamol oral suspension 120mg/5ml (see cBNF for dosing schedule) Morphine Sulphate oral solution 100 micrograms/ml (see The Association of Pediatric Palliative Medicine master formulary [www.APPM.org.uk](http://www.APPM.org.uk) for dosing schedule)

Buccal midazolam 2.5mg/0.5ml (see The Association of Pediatric Palliative Medicine master formulary [www.APPM.org.uk](http://www.APPM.org.uk) for dosing schedule) **NB – the dose is often too small to draw up, in such cases dilute 2.5mg/0.5ml with 4.5ml of water to give strength of 2.5mg/5ml.**

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## End of life management plan

An end of life management plan aims to ensure that the baby is comfortable at all times. Any distress or symptoms are minimised and well managed. Any reversible conditions and end of life care symptoms (as documented below) are to be treated

### Management of Agitation and restlessness – Comfort Measures, Oral Morphine, Buccal Midazolam

The clear goal is to ensure that baby is settled, pain free and not distressed or agitated.

This may present as being unsettled and not handling as usual. Consider comfort measures as you would any other baby e.g. changing of nappy, gentle rocking, hunger, ensure adequate warmth and not over heated.

Simple management includes, position change, comfort and reassurance. If the baby is comfortable temperature does not need to be monitored

**Also consider analgesia if pain is the possible cause of the restlessness/agitation.**

Start with simple agents such as **Paracetamol** or **sucrose**.

If the baby remains agitated/restless:

- Consider using buccal midazolam 4 hourly PRN but can be used hourly if symptoms persist.

Dose as per APPM Master Formulary - [www.APPM.org.uk](http://www.APPM.org.uk)

*NB: Midazolam solution may require further dilution to give strength where dose can be accurately drawn up. Advise to use strength of 2.5mg/0.5ml and then dilute with 4.5mls water to give a strength of 2.5mg/5mls.*

Assessment of pain can be very difficult in young babies. The following are the most reliable indicators of pain:

- Persistent crying
- Furrowing or bulging of the brow
- Furrowing of nasolabial folds (between lips and nose)
- Tight squeezing of the eyes

Consider comfort measures as you would any other baby e.g. change of nappy, gentle rocking, not hungry, ensure adequate warmth and not over heated.

If unresolved with comfort measures:

- Try sucrose, this can be used intermittently alongside all other analgesics
- Consider Paracetamol 8 hourly (dose as per cBNF)
- If regular paracetamol is not effective or pain is assessed to be more severe consider oral morphine 6-8 hourly (max hourly at EOL) Dose as per APPM Master Formulary [www.APPM.org.uk](http://www.APPM.org.uk)  
If this is not effective repeat 1 hour after administration. Dose can be adjusted according to effect: suggested increase of 30%-50% depending on the frequency of the doses and severity of the symptoms.
- There is no limit to the dose of morphine for relief of pain or distress even in the knowledge that this may cause respiratory depression (doctrine of double effect). Pain assessment and regular evaluation of analgesia is essential.
- If requiring regular doses of morphine to remain pain free discuss with palliative care team for the consideration of a sustained release preparation of morphine

## Dyspnoea

This is the subjective sensation that breathing has become unpleasant, rather than an objective observation that it has become fast or difficult. It may be very frightening for the baby and family. Babies will be most comfortable sitting/propped up with moving air (e.g. fan) or oxygen in a calm atmosphere. Be guided by their appearance and comfort.

Possible treatment:

- Consider **low flow oxygen** if deemed beneficial but do not let this interfere with contact with family or be escalated to a level that is uncomfortable for the baby

- Consider oral morphine at a dose of 30% of the analgesic dose of morphine.

This reduces anxiety and pain, settles the respiratory centres and reduces pulmonary artery pressure (more marked in diamorphine). Usual dosing schedule is 4 hourly, but it may be repeated hourly if the baby remains unsettled.

Dose can be adjusted according to effect: suggested increase of 30%-50% depending the frequency of dosing and severity of symptoms.

- Consider anxiety dose of **buccal midazolam**
- Oxygen is not contraindicated at the end of life in patients with congenital heart disease. It must be considered though that in the setting of a duct dependent circulation the administration of oxygen although valuable for symptomatic relief may hasten death by closing the duct
- In babies with congenital heart disease, although Prostaglandin E2 (Prostin) is probably not appropriate (needs discussion with parents) **diuretics** should be considered to counteract any cardiac failure that may be contributing to dyspnoea e.g. **furosemide** 1mg/kg 12 hourly

## Increased secretions / noisy breathing

This can be a common problem at the end of life. The family should be warned to expect it and reassured that it is not a direct cause of distress to their baby. It occurs when the baby's level of consciousness has decreased such that they are unable to cough up or swallow secretions within the large airways.

If the symptoms are mild and not troubling, no medication may be required, but if they increase and breathing becomes noisy and distressing, consider:

- Positioning the baby's head to allow secretions to drain
- Consider gentle oral suction if appropriate – if no benefit, do not continue
- If secretions become more troublesome apply **hyoscine hydrobromide transdermal** patch 250micrograms (quarter of a 1.5 mg patch to skin) every 72 hours.
- Hyoscine hydrobromide** patch can be increased to half of a patch if secretions are not controlled on a quarter of a patch
- If not controlling secretions use subcutaneous or intravenous bolus of **Hyoscine hydrobromide** (as per APPM) or start a continuous infusion
- Consider **atropine sulphate** 20-40microgram/kg/dose 2 or 3 times a day PRN. Use atropine injection solution and give orally

## Feeding/Loss of enteral route

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. Parenteral fluids and nutrition are rarely indicated. Breast-feeding may be comforting for the baby and mother. The goal of treatment at end of life is comfort, not the provision of nutrition.

If *baby* develops symptoms of not absorbing feeds:

- Consider decreasing the feed volume. Feeds can be reduced down to 50-100mL/kg/day for hydration and comfort.
- Give feed 1-2 hourly to maintain smaller volumes
- Feeds can be omitted if the baby is clearly not absorbing feeds and this can be discussed with the family that it is ok as long as the baby is not distressed
- If baby is receiving oral medication consider alternative routes e.g. nasal/buccal/SC
- If a gastric tube came out and end of life was deemed imminent, consideration should be taken regarding the appropriateness of re-passing the tube at this time.
- Ensure adequate mouth hygiene (wetting lips and cleaning mouth for comfort).

## Nausea / vomiting

Vomiting can be a common symptom in babies:

Useful advice:

- Manage correctable causes e.g. pain
- Certain smells may antagonise
- Avoid strong odours
- Feeding at this stage is for comfort and not nutrition

Also:

- Aspirate any wind from the baby's stomach via the oro-/naso-gastric tube prior to administration of a feed
- Consider decreasing the feed volume. Feeds can be reduced down to 100mL/kg/day for hydration and feeds given hourly to maintain smaller volumes to reduce vomiting
- It is reasonable to omit a feed and reassure the family that their baby will not feel hunger when condition deteriorates overall. Reassess prior to each feed
- Consider use of erythromycin (dose as per BNF for gastro-intestinal stasis)

## Constipation

Monitor bowel motions. If constipation becomes a problem, consider introducing a laxative like **lactulose** and increasing fluids if possible.

Commence a regular laxative (e.g. **lactulose**) if opiates are commenced regularly

## Seizures

### Management of seizures:

- If the baby has evidence of seizure activity, ensure appropriate positioning to protect the airway and ensure that they do not sustain injury.
- **Buccal midazolam** (seizure dose as per APPM master Formulary) can be administered to stop generalised tonic clonic seizures lasting more than 5 minutes or clusters of generalised tonic clonic or focal seizures lasting more than 20 minutes.
- The APPM master Formulary dose for status epilepticus is 300microgram/kg. However, experience has led us to prescribing a half dose for neonatal patients as this is usually effective. Therefore, the initial dose is half the recommended dose as a test dose - **150microgram/kg**. Should seizure activity continue, this could be repeated after 15 mins.
- If both doses required, all subsequent doses would be at the higher dose (300 microgram/kg).

## END OF LIFE MANAGEMENT PLAN

The aim of this plan is to ensure that ..... is settled, pain free and not distressed or agitated. Consider stopping non-essential drugs. Essential medications include: anticonvulsants, analgesics, sedation and laxatives.

Include specific details of management in the '**MANAGEMENT**' column, information within the '**POTENTIAL PROBLEMS**' column if for guidance only

Potential condition(s) to be treated:

DATE	POTENTIAL PROBLEMS	MANAGEMENT
	<p><b><u>Feeding issues / vomiting</u></b></p> <p>Include current feeding regime and an alternative if vomiting</p> <p>Options for alternative:</p> <ol style="list-style-type: none"> <li>1. Reduce feed volume</li> <li>2. Increase time in between feeds</li> </ol> <p>Consider:</p> <ol style="list-style-type: none"> <li>1. Prokinetic medication</li> </ol>	<p>...name..... is demand breast fed</p> <p>...name..... is currently being fed on .....mLs/kg/day, every.....hours of.....milk. Route of feeding is orally/via OGT/NGT/PEG</p> <p>If symptoms arise the following should be done:</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>

	<p><b><u>Constipation</u></b>          Introduce laxative therapy especially if opiates are commenced.</p>	<p>If ...name..... is constipated commence lactulose at .....mLs, .....times a day. If it continues:</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>
	<p><b><u>Increased secretions / noisy breathing</u></b>          If breathing becomes noisy and distressing consider:</p> <ol style="list-style-type: none"> <li>1. Suction</li> <li>2. Hyoscine patch</li> </ol>	<p><b>Free text</b> .....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>
<b>DATE</b>	<b>POTENTIAL PROBLEMS</b>	<b>MANAGEMENT</b>
	<p><b><u>Agitation and restlessness</u></b>          Consider simple management including position change, reassurance including skin to skin/cuddles,          Consider using buccal midazolam or alternative routes i.e. intranasal</p>	<p><b>Free text</b></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>

	<p><b><u>Pain</u></b></p> <p>Please be aware of the WHO analgesia ladder</p> <p>Consider, sucrose, paracetamol, oral morphine</p>	<p><b>Free text</b></p> <p>If ...name..... is in pain commence .....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>
	<p><b>Breakthrough / incident pain</b></p> <p>If not absorbing administer the breakthrough dose via a SC/IV route.</p>	<p><b>Free text</b></p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>
	<p><b>Seizure activity</b></p> <p>Ensure buccal midazolam is prescribed for seizure activity.</p> <p>This should be prescribed even if a child does not have a history of seizures, as this is a potential problem for end of life care.</p>	<p><b>Free text</b></p> <p>If ...name..... is having seizures commence .....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>

	<b>Any other symptoms</b>	<b>Free text</b> ..... ..... ..... ..... ..... .....
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Drug	Use	Dosage	Frequency	Route
Atropine sulphate	Antisecretory	20-40microgram/kg/dose	PRN – 2-3 times a day	Oral
Chloral hydrate	Sedation	20–30mg/kg up to 50mg/kg	PRN – 4 times a day	Oral/rectal
Hyoscine hydrobromide	Antisecretory antiemetic	Quarter to a half of a 250micrograms patch to hairless area of skin behind ear	Every three days	Transdermal patch applied
Lactulose	Constipation	2.5 – 10 mL Adjusted according to response	Twice daily	Oral
Lansoprazole	GORD	0.5-1mg/kg (a quarter of a 15mg Zoton FasTab)	Once a day	Oral (melt)
Midazolam	Respiratory distress Sedation	50-100 microgram/kg/dose	PRN – maximum 6 times a day	Buccal/oral
	Seizure	300 micrograms/kg	Repeated once after 10 minutes if necessary	Buccal
		150 -200 microgram/kg/min	Bolus	Intravenous
		60 -300 microgram/kg/min	Continuous infusion	Intravenous
Morphine	Pain	50-100 microgram/kg/dose	PRN	Oral
		100 microgram/kg/dose	PRN - Bolus	Intravenous
		10-300 microgram/kg/hour	Continuous infusions	Intravenous
	Respiratory distress	25 microgram/kg/dose	PRN	Oral
Omeprazole	GORD	700mcg/kg/dose increased if necessary after 7–14 days to 1.4mg/kg	Once a day	Oral
Paracetamol	Analgesia Pyrexia	28 -32 weeks postmenstrual age 15mg/kg as a single dose then 10-15mg/kg	PRN – 2-3 times a day Maximum dose 30mg/kg/24hours	Oral/rectal
		> 32 weeks postmenstrual age 15mg/kg as a single dose then 15mg/kg	PRN – 3-4 times a day Maximum dose 60mg/kg/24hours	
Phenobarbitone	Seizures	20mg/kg	Bolus	Slow intravenous injection
		Then: 2.5–5 mg/kg Dose and frequency adjusted according to response	Once a day	Oral/slow intravenous injection
Sucrose solution 24%	Analgesia	32-36 weeks gestation: 0.5-1mL (regardless of weight)  Term babies: 2mL ( regardless of weight)	PRN - maximum 4 doses in 24hours	Oral