

# A Brief Guide to Symptom Management and End of Life Care for Children During Pandemic Influenza

## Background

- This guidance is intended **ONLY** for use in situations where health services are overwhelmed and larger numbers of children require symptom management and end of life care than can be fully supported by the usual resources. It is **NOT** intended as a substitute for specialist palliative care advice and support from consultant led specialist palliative care teams, children's hospice or other services.
- The guidance forms part of overarching guidance on capacity planning for the management of children with palliative care needs and those receiving end of life care in the event of an influenza pandemic [Alder Hey Children's Hospital: Influenza Pandemic Guidance for Palliative Care Sept 09]. It is **ESSENTIAL** that workforce and resource planning for symptom management and end of life care are incorporated into overarching Pandemic Flu plans in all localities. Paediatric medical and nursing staff need to be identified to take a lead on symptom management and end of life care. Redeployment of these staff to provide acute technological care must be a last resort. This will require robust management.

## ETHICAL CONTEXT

The aim is to provide the "most for the most" in situations where resources are scarce [1, 2]. Thus:

- Every human life, regardless of age, gender, disability is considered equal
- There is an ethical duty to allocate limited resources where they can be of greatest benefit. This means that resources are allocated to ensure the greatest number of lives can be saved.
- Where it is decided that resources are allocated to individuals with lower levels of pre-existing healthcare need this is because these individuals have a greater chance of recovering from the illness and benefitting from the allocation of available resources.
- It is unethical to allocate limited healthcare resources to those who cannot realistically be expected to benefit from them. For instance: where, due to an underlying condition, it is unlikely that escalation of treatment to intensive care will change the outcome for the individual patient.
- It is the overarching duty of all healthcare professionals to ensure maximum quality of life and minimize pain and suffering. This duty of care applies regardless of any decision regarding allocation of limited healthcare resources.

## ADDITIONAL RESOURCES

Rainbow's Symptom Control Manual 2008 download from

<http://www.act.org.uk/index.php/other-resources/view-category.html>

[http://www.gosh.nhs.uk/clinical\\_information/](http://www.gosh.nhs.uk/clinical_information/)

<http://www.rcpch.ac.uk>

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<sup>1</sup> NHS emergency planning guidance 2005: underpinning guidance gateway reference 8442;  
<http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH-081282>

<sup>2</sup> Department of Health. Responding to Paedemic influenza: the ethical framework for policy and planning.  
<http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH-080751>

**Steps to ensure comfort and reduce unnecessary suffering:**

ADVANCE CARE PLANNING<sup>3</sup>

- Advance care planning involves a series of discussions between parents or carers, professionals and where appropriate children or young people themselves, with the aim of identifying the child or young person's future needs and considering how they may best be met. Advance care planning may include discussions around withholding or withdrawing life sustaining treatment. These will be based on the child's quality of life, best interests, the likely nature of future deterioration in the child's condition and whether such deterioration is likely to be reversible. However the most important outcome of discussions is to put in place a plan for appropriate management of the child's condition in the event of sudden or unexpected deterioration in their condition.
- Where locally developed emergency care plans are not available, collation of the following information, ideally in a parent or patient held format is recommended

- Basic demographic details of child/young person
  - Name
  - Date of birth
  - Address
  - Hospital reference/NHS Numbers
  - Current weight
- Details of parent/carers
  - Names
  - Contact numbers (mobiles)
  - Who has parental responsibility
- Contact details for key professionals, including identification of keyworker or lead professional role
  - GP
  - Lead Clinician
  - Community Children's Nurse
  - Other specialist Clinicians
  - Social worker
- Diagnoses
- Active health problems
- Current medication
  - Including emergency treatment
  - Allergies or previous adverse reactions
- Thumbnail sketch of child/young person at their best, to give indication of quality of life when well
- Advice given to family about what to do if child/young person becomes unwell, specifying emergency actions for any issues that might arise for the individual child/young person
- Details of any discussions regarding limitation of treatment and outcomes of these discussions e.g DNAR order
- Details of any discussions regarding preferred setting for end of life care
- Any other specific issues that might impact on triage decision
- State who is best to contact if triage team want further information to inform decision making in an emergency
- Consultant signature and date

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<sup>3</sup> Reference: Jones N, Fetherston A, Horridge K 'User views of Emergency health Care Plans for Disabled Children and Young People' Dev Med Child Neurol 2009 51 7 570-571

## Five step management plan for symptom management and end of life care

- The guidance below provides an appropriate plan of ongoing care when a child's condition continues to deteriorate despite provision of maximum appropriate, available, treatment.
- The plan is NOT intended to hasten death or to compromise chances of recovery but to ensure that unnecessary pain and distress for child and family is avoided.
- In a pandemic situation the most appropriate setting for end of life care is likely to be the setting where it is recognised that the child is likely to be at the end of life. Although transfer of dying patients to home or hospice may be appropriate in normal circumstances, in a pandemic situation, when services are overwhelmed, efforts to facilitate transfer home or hospice for end of life care may not be best use of resources e.g. diverting ambulances from bringing patients to hospital.
- Where a prior decision has been made not to admit a child to hospital if their condition deteriorates, end of life care should be provided at home or hospice as appropriate. However if no such decision has been made deterioration to possible end of life should not otherwise preclude consideration of transfer to hospital for assessment and treatment as appropriate.
- Specialist paediatric palliative care advice and support, where this is available, will be most effectively utilised by empowering others (particularly family members and other professionals providing direct care) to deliver hands on care wherever possible. Depending on availability of resources. ward/home visits can then be provided as required for difficult symptoms that cannot be managed remotely.

### 1. REVIEW AND SIMPLIFY

Discontinue inappropriate medical and nursing interventions:

- Blood tests; the results of these will not alter medical management at this stage.
- Discontinue routine observations.
- Oxygen saturation measurement does not correlate with breathlessness and can therefore be discontinued. Breathlessness best correlates with work of breathing.
- Turn for comfort and skin care only and find which position works best for comfort and ease of breathing.
- Discontinue all non-essential medications:
  - Consider whether antibacterials and antivirals are still of benefit.
  - Continue regular anticonvulsants even if there is concern regarding absorption

### 2. ANTICIPATORY PRESCRIBING

- Prescribe and ensure 'as required' medications for symptom management are available in advance (see below), to avoid delay in treatment.
- Doses should be rounded down to sensible amounts that can safely be drawn up and administered by families, with least potential for drug errors.
- Medication should ONLY be administered when symptoms are present in the individual patient. Not all patients will experience symptoms and suggested drugs should NOT be given unless a symptom is troublesome.
- It is important to note that some patients may remain comfortable without any additional medication.
- STOP any drugs that prove ineffective and keep drug regime as simple as possible.
- Empower family/carers to give medication where possible, including medication administered via buccal or rectal routes. It may also be necessary to train family members to administer subcutaneous injections, where nurse staffing levels are critically low.

**Anticipatory prescribing for all patients:**

Symptom	Drug	Route (aim to avoid intravenous route where possible)
Pyrexia	Paracetamol or Ibuprofen or Diclofenac	Oral or rectal Oral Oral or rectal
<b>Respiratory symptoms:</b>		
Wheeze	Salbutamol or Ipratropium bromide	Spacer device (avoid nebulisation if possible due to risk of aerosol generation)
Excess respiratory tract secretions	Hyoscine hydrobromide	Transdermal patch or subcutaneous bolus/infusion (Enteral absorption is unlikely to be effective at end of life)
Cough	Dihydrocodeine	Oral or subcutaneous
Breathlessness	Morphine (remember doses are 1/3 of those used for severe pain)	Oral or concentrated solution sublingually or subcutaneous bolus
<b>Other patients in addition:</b>		
Pain	Morphine	Oral or use concentrated solution sublingually or subcutaneous bolus
Nausea and vomiting	1 <sup>st</sup> line domperidone or 2 <sup>nd</sup> line levomepromazine	Oral or rectal Subcutaneous (or intravenous)
Anxiety/agitation	1 <sup>st</sup> line midazolam or 2 <sup>nd</sup> line levomepromazine	Buccal or subcutaneous Subcutaneous (or intravenous)
Seizures	1 <sup>st</sup> line midazolam 2 <sup>nd</sup> line paraldehyde	Buccal or subcutaneous (or intravenous) Rectal

## 3. BASIC SYMPTOM MANAGEMENT (SEE TABLES P 6)

- The subcutaneous route should be used in preference to the intravenous route when resources for siting an intravenous line and administering intravenous medication are limited (unless the child already has permanent central venous access).
- Where symptoms difficult to control with 'as required' medications, a continuous subcutaneous infusion should be commenced.
- Remember non pharmacological measures
  - Comfort, reassurance and explanation
  - Excess respiratory tract secretions
    - Repositioning so that excess respiratory tract secretions can drain
    - Consider suction
  - Breathlessness
    - Calm reassurance
    - Repositioning,
    - Gentle physiotherapy

## 4. COMMUNICATION AND EXPLANATION

- Ask family about specific religious spiritual cultural needs
  - respect these wherever possible
  - provide simple explanation when not possible to fully meet these e.g. no chaplain available
- Inform other relevant teams and services
  - GP practice
  - Infection control (as appropriate)
- Discuss with child/young person/family
  - Rationale for decision-making
  - Prognosis
  - Plan of care
  - Necessary infection control measures
  - Discuss whether cardiopulmonary resuscitation is appropriate and document the outcome including "permit natural death" or "do not attempt resuscitation" if appropriate
  - Calm, honest and supportive answers to questions and concerns

5. CARE AFTER DEATH

- Fact of death confirmed by doctor or other authorised healthcare professional
- Inform infection control (if applicable) and GP
- Family have option to take mementoes (lock of hair, photograph) and “say goodbye” to their child
- Laying out as per local policy
- Complete death certificate
- Inform Coroner (if applicable)
- Inform local lead paediatrician for child death overview panel/child death coordinator (procedures may need modification if services overwhelmed)
- Family have necessary information to register death (may need modification if services overwhelmed)
- Family are asked regarding wishes for ongoing support, resources permitting, after the death. In practical terms this may mean keeping a register of deaths and wishes for contact until such resources are available.

This guidance has been developed based on consensus.

No systematic search of the literature has been specifically done on this topic (H1N1 Pandemic Flu has not been previously described).

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## Symptom Management and End of Life Care in Pandemic Influenza

### Alder Hey Children's NHS Foundation Trust Palliative Care Dose Guidelines

- Practitioners should refer to local policy guidance where available
- Alder Hey Children's NHS Foundation Trust Palliative care dose recommendations are provided for circumstances where overarching local guidance is unavailable.
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Drug	Indication	Route	Recommended dose by age				Times per day	Notes
			Birth – 1 month	1 month – 2 years	2-12 years	12 years and over		
<b>Diclofenac</b>	Resistant pyrexia Moderate pain not responding to paracetamol/ibuprofen	Oral, rectal		>6 months 300microgram - 1mg/kg/dose [a]		25 - 50mg/dose (maximum 150mg/24 hours) [a]	2 - 3	Do not use if Gastrointestinal irritation/inflammation /bleeding known/suspected
<b>Dihydrocodeine</b>	Weak opioid analgesic moderate pain Cough	Oral or subcutaneous injection		1 month - 4 years 500 microgram/kg/dose; 4 - 12 years 500 microgram - 1mg/kg/dose (maximum 30mg/dose) [a]		30mg/dose [a]	4 - 6	If inadequate response to maximum dose change to strong opioid; prescribe prophylactic laxatives if given regularly. Injection not to be used intravenously.
<b>Domperidone</b>	Nausea & vomiting; Prokinetic antiemetic	Oral	100 - 300 microgram/kg /dose [a]	250 - 500 microgram/kg/dose (maximum 20mg/dose) [a]		10 - 20mg/dose [a]	3 or 4 times a day; Neonate up to 6	
		Per rectum			15 - 35kg - 30mg/dose; >35kg - 60mg/dose [a]		60mg [a]	2
<b>Hyoscine hydrobromide</b>	Distressing noise from excess respiratory tract secretions	Intravenous or subcutaneous injection		10 microgram/kg/dose (maximum 400 microgram DOSE) [a]		400 - 600 microgram/dose [b]	As required. maximum hourly or 6 doses in 24 hours	
		Transdermal			< 3 years 1/4 patch; 3 - 9 years 1/2 patch; >9 years 1 patch [a]		Change patch every 48 - 72 hours	
		Intravenous or subcutaneous continuous infusion		40 - 60 microgram/kg/24 hours (maximum 2.4mg/24 hours) [a]		1.2 - 2.4 mg/24 hours [b]	Continuous over 24 hours	
<b>Ibuprofen</b>	Pyrexia or mild to moderate pain	Oral		5-10mg/kg/dose. (Maximum 30mg/kg/24hrs or 2.4g/24hrs) [a]		200 - 400mg/dose; (Maximum 2.4g/24hrs) [a]	3 or 4	
<b>Ipratropium bromide</b>	Wheeze	Inhaled		1 month – 6 years: 20 microgram 6 – 12 years 20 – 40 microgram [a]		20 – 40 microgram [a]	3 or 4	
<b>Levomepromazine</b>	Nausea and vomiting	Oral		100 - 400 microgram/kg/dose [a]		6.25 – 25mg/dose [a, b]	Nocte or 2	Antiemetic doses are lower than antipsychotic doses
		Intravenous or subcutaneous continuous infusion		100 - 400 microgram/kg/24 hours [a]		5 - 25mg/24 hours [a, b]	Continuous over 24 hours	
	Agitation and delirium in palliative care	Intravenous or subcutaneous continuous infusion		350 microgram - 3mg/kg/24 hours [a]		50 - 75mg/24 hours (maximum 300mg/24 hours) [a, b]	Continuous over 24 hours	

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Drug	Indication	Route	Recommended dose by age				Times per day	Notes
			Birth – 1 month	1 month – 2 years	2-12 years	12 years and over		
<b>Loperamide</b>	Chronic diarrhoea	Oral		100 - 200 microgram/kg/dose; (max 2mg/dose) [a]		2 - 4mg/dose [a]	3 - 4	
<b>Midazolam</b>	Agitation or anxiety in end of life care	Buccal or sublingual		100 - 150 microgram/kg/dose [c] or: <u>6 - 12 months</u> 1.25mg/dose; <u>1 - 5 years</u> 2.5mg/dose; <u>5 - 10 years</u> 3.5mg/dose; <u>Over 10 years</u> 5mg/dose [c]		5mg/dose [c]	As required max 6 - 8 hourly	
	Status epilepticus	Buccal or sublingual		200 - 300 microgram/kg/dose [a] or: <u>6 - 12 months</u> 2.5mg/dose; <u>1 - 5 years</u> 5mg/dose; <u>5 - 10 years</u> 7.5mg/dose; <u>Over 10 years</u> 10mg/dose [a]		10mg/dose [a]	As required max 6 - 8 hourly	If need to repeat after 10 minutes because seizures ongoing, set up continuous infusion/try alternative
	Agitation or anxiety in end of life care	Intravenous or subcutaneous injection		50 - 100 microgram/kg/dose (maximum 5mg) [a]		5mg/dose [b]	As required repeat up to hourly	If more than 2 doses required in 24 hours consider continuous infusion
	Agitation or anxiety in end of life care	Intravenous or subcutaneous continuous infusion		240 - 420 microgram/kg/24hrs [d, e]		25 - 60mg/24 hrs [b]	Continuous over 24 hours	If patient does not settle on 30mg/24 hours or 420 microgram/kg/24 hours add in antipsychotic before increasing dose further
	Status epilepticus	Intravenous or subcutaneous continuous infusion		500 microgram - 5 mg/kg/24hrs [c]		500 microgram – 5 mg/kg/24hrs [c, f]	Continuous over 24 hours	If no significant response to increasing dose of midazolam or midazolam for breakthrough seizures consider changing to Phenobarbital
<b>Morphine</b>		Oral or rectal	<u>1 - 3 months</u> 50 - 100 microgram/kg/dose <u>3 - 6 months</u> 100 - 150 microgram/kg/dose <u>6 - 12 months</u> 200 microgram/kg/dose <u>1 - 12 years</u> 200 - 300 microgram/kg/dose maximum 15mg [g]			10 - 15mg/dose [b]	As required. Usual frequency 4-6 hourly; maximum hourly	Always prescribe regular stimulant laxatives. For dyspnoea or intractable cough doses of approximately 30% analgesic doses are effective
<b>Morphine modified release</b>	Severe pain; Breathlessness (30% pain doses) Strong opioid analgesic	Oral		Commence on immediate release morphine as above. After 48 hours dose is 25% of total morphine required over 48 hours including breakthrough doses [b]		2	Always prescribe regular stimulant laxative. Starting doses; increase in increments of 30 - 50%. Increase dose no more than every 24 hours [b] according to requirement for breakthrough doses; appropriate breakthrough dose is 1/6 24 hour dose given as immediate release preparation	

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Drug	Indication	Route	Recommended dose by age				Times per day	Notes
			Birth – 1 month	1 month – 2 years	2-12 years	12 years and over		
<b>Morphine injection</b>	Severe pain; Breathlessness (30% pain doses) Strong opioid analgesic	Intravenous or subcutaneous injection	<u>Birth - 3 months</u> 50 - 75 microgram/kg/dose; <u>3 - 6 months</u> 75 microgram/kg/dose; <u>6 - 12 months</u> 100 microgram/kg/dose <u>Over 12 months</u> 100 – 150 microgram/kg/dose [g]			5 - 7.5 mg/dose [b, f]	As required. Usual frequency 4-6 hourly; maximum hourly in titration of analgesia.	
		Intravenous or subcutaneous infusion	<u>Birth - 3 months</u> 100 - 200 microgram/kg/24 hrs; <u>3 - 6 months</u> 200 - 300 microgram/kg/24 hrs; <u>6 - 12 months</u> 400 - 600 microgram/kg/24 hrs; <u>over 12 months</u> 400 - 900 microgram/kg/24 hrs [g]			20 - 50mg/24 hrs [b]	Continuous over 24 hours	Starting doses; increase in increments of 30 - 50%. Increase no more often than every 12 hours [b] according to requirement for breakthrough doses; appropriate breakthrough dose is 1/6 24 hour dose given as intravenous or subcutaneous bolus
<b>Macrogols (Movicol paediatric plain or Movicol half)</b>	Osmotic laxative; chronic constipation	Oral		<u>1-6 yrs</u> 1 – 8 sachets/24 hours; <u>6-12 yrs</u> 2-12 sachets/24 hours daily. Adjust to produce soft stool (not runny) most days Mix each sachet in 60-65ml water [a]	2 – 16 sachets/24 hours[a]	Total dose over 24 hour period	<u>Constipation including opioid-induced.</u> Start at low dose and increase according to response.  <u>Faecal impaction</u> Start at low dose and increase by 2 sachets per 24 hours until bowels open. Then halve dose and continue as maintenance.	
<b>Paracetamol</b>	Mild to moderate pain; pyrexia	Oral, rectal or intravenous	<u>&lt; 3 months</u> 10 - 15mg/kg/dose; maximum 60mg/kg/24 hours[a]	10 - 20mg/kg/dose, OR <u>3 months - 1 year</u> ; 60 - 120mg/dose; <u>1 - 5 years</u> ; 120 - 250mg/dose; <u>6 - 12 years</u> ; 250 - 500mg/dose;  <u>&lt; 6 months</u> ; maximum 60mg/kg/24hrs <u>&gt; 6 months</u> maximum 90mg/kg/24hrs [a]	500mg - 1g/dose; maximum 4g/24hrs [a]	4 - 6		
<b>Paraldehyde (prepared enema)</b>	Status epilepticus resistant to two doses midazolam	Rectal via syringe and quill/cut off feeding tube	0.8ml/kg/dose prepared enema [a]; Or <u>1-3 months</u> 1ml/dose; <u>3 - 6 months</u> 2ml/dose; <u>6 months - 1 year</u> 3ml/dose; <u>1 - 2 years</u> 4ml/dose; <u>2 - 5 years</u> 6-8ml/dose; <u>5 - 12 years</u> 10-20ml/dose;			10 - 20ml/dose [a]	As required up to 2 hourly	Care in handling – dispose of syringe immediately and wash hands
<b>Phenobarbital</b>	Control of seizures not responding to midazolam infusion	Oral, intravenous or subcutaneous injection;	20mg/kg/dose max 1g [a]				Single loading dose	

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			Birth – 1 month	1 month – 2 years	2-12 years	12 years and over		
<b>Phenobarbital</b>	Control of seizures	Subcutaneous or intravenous injection or infusion	5 - 10mg/kg/24 hours [a]			600mg/24 hours [a]	Continuous or 2 divided doses	For patients already on phenobarbital doses equivalent to the patient's usual total daily dose of enteral phenobarbitone have been used. Doses up to 20mg/kg maximum 1200mg/24hrs [b]
<b>Salbutamol</b>	Wheeze	Inhaled		100 – 200 microgram via spacing device [a]	100 – 200 microgram via spacing device [a]	4 – 6		
<b>Senna (7.5mg/5ml or 7.5mg tablets)</b>	Stimulant laxative	Oral		0.5ml/kg/dose (max 2.5ml) [a]	<u>2 - 6 years</u> 2.5 - 5ml/dose; <u>6 -12 years</u> 5 - 10ml/dose or 1 - 2 tablets/dose [a]	10 - 20ml or 2 - 4 tablets/dose [a]	Nocte	
<b>Sodium Picosulfate</b>	Constipation (Stronger stimulant laxative)	Oral		<u>1 month–4years</u> 250 microgram/kg (max 5mg) at night <u>4-10 years</u> 2.5 – 5mg at night <u>10 yrs and over</u> 5-10mg at night [a]		Once at night	Onset of action 6-12 hrs. Higher doses may be used on specialist advice	

### References

- a BNFC
- a BNFC2
- b PCF
- c Does extrapolated from BNFC
- d Dose extrapolated from BNF
- e Doses extrapolated from PCF2
- f BNF
- g Doses rationalized from known potency ratios, doses of IV diamorphine and oral morphine in MFC2, BNFC and ABCD