
PAEDIATRIC PALLIATIVE CARE GUIDELINES (2006)

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INTRODUCTION

These guidelines have been written to help doctors and nurses looking after children with terminal illnesses and their families.

Management of the terminally ill child

Medical Assessment

- Make sure you are armed with as much information about the child and his family as possible.
- Make sure you involve all the right people: this might include parents, siblings, other carers. Whether you involve the child him/herself will depend on the child's age, understanding and state of health and the parents' wishes. It is often helpful to have another involved professional present, for example the district nurse in the community setting, so that someone else is fully aware of the discussion and can answer any questions the family might have after you have left.
- Try and arrange things so you are not in a hurry and you are unlikely to be disturbed.
- Be methodical: take a thorough History, and perform a full examination. Explore other issues as appropriate. Allow the child and parents time to voice their concerns as fully as possible.

Explanations

- Explain symptoms and management as far as you can and as far as you feel is appropriate.
- You may not have all the answers: if not, say so.

Plans

- Formulate a plan of action in consultation with the parents and/or child. Listen to any concerns that arise from this and be prepared to compromise on a management plan if the parents/child want something different.
- Run over the plan at the end of the consultation in a language the parents and/or the child can understand.

Review

- Make a time/date when the management plan will be reviewed, and by whom.
- Make sure carers are aware of whom they can access in the meantime and how they can contact this person/service, particularly out of normal working hours.

Communication

- Liaise with relevant professionals and carers- leave clear written instructions in medical records or contact the community team to discuss directly- many different health care professionals may be involved particularly in the community, and it is important that everyone is aware of any changes in management.

Summary:

Explanation
Informed Choice
Compromise
Communication
Regular review
Access to service

Routes for drug administration

According to the bioavailability of the drug, medical condition or an individuals' preference, different routes of administration should be considered for each drug prescribed. These include:

Oral/Gastrostomy
Sublingual
Buccal
Nasal
Intravenous/Hickman Line
Subcutaneous
Transdermal
Rectal
Epidural

The syringe driver

A syringe driver is a small portable battery driven infusion pump used to give continuous medication parenterally, usually over a 24hr period. Syringe drivers can deliver medication intravenously (e.g. via central venous catheter) or subcutaneously. It is particularly suitable for children who are unable to tolerate oral medication or who require immediate control of difficult symptoms, which are resistant to oral medication. Although it is a common route to administer medication at the end of life it can also be used for short periods prior to this to gain control of difficult symptoms or when the oral route is temporarily impractical (e.g. persistent vomiting).

Indications for using a syringe driver

Unable to absorb oral medication
Difficulty swallowing
Persistent vomiting
Bowel obstruction
Not fully conscious
Unsatisfactory response to oral medication

Advantages of using this delivery system are

- continuous blood levels of medication,
- less requirement for needles,
- maintenance of mobility and independence
- the ability to deliver complex drug combinations safely in the community.

Certain common combinations of drugs can be mixed together and given in the same syringe driver. Some drugs such as dexamethasone and other drugs in high concentrations will require the use of a separate syringe driver.

As a general rule it is advisable not to mix more than 3 drugs in any one driver - check compatibility first.

A continuous infusion delivered via patient controlled analgesia (PCA) is an alternative to the syringe driver and has been used effectively in the post-operative setting by children as young as 7yrs. This device provides a background continuous infusion and allows the patient to administer bolus p.r.n. doses of analgesia by pressing a 'boost' button. The dose and number of p.r.n. doses available is pre-set and the device has a 'lock-out' facility which prevents overdose.

However, if using a Graseby pump be aware that the boost button may have to be pressed many times to establish a p.r.n. dosage.

Setting up a Syringe Driver : See Adult Section

Drug information

This document was written in April 2003. Whilst every effort has been made to ensure all information is accurate it remains the responsibility of the prescriber to check this information against the most current available before administering any of the drugs in this document.

It is important to note that the doses of the same medication may vary for different indications and this document should be consulted by symptom section rather than drug name.

Due to limitations of space, information regarding all side-effects and interactions for each drug is not included; further information regarding this should be sought from more detailed texts such as RCPCH Medicines for Children and the British National Formulary. Many drugs used in the palliative care setting are used for indications or by routes not licensed by the manufacturer, and some information regarding this is included in this document. In the U.K., unlicensed use is permitted at the discretion of the prescriber, and is the prescriber's responsibility.

Abbreviations used

CAPD	continuous ambulatory peritoneal dialysis
CNS	central nervous system
PCA	patient controlled analgesia
i/v	intravenous route
SC	subcutaneous route
SL	sublingual route
i/m	intramuscular route
p.o	oral route
PR	rectal route
o.d.	once daily
b.d.	twice daily
t.d.s.	three times daily
q.d.s.	four times daily
nocte	at night
p.r.n.	when required
SPC	Specialist palliative care

AGITATION

Consider the following causes:

- Gastro-oesophageal reflux
- Urinary retention
- Constipation
- Medication
- Epileptic seizures
- Muscle spasm
- Unidentified injury or fracture
- Sepsis
- Cerebral causes: raised intracranial pressure, intracranial bleed
- Hypoxia
- Environmental irritation: too hot/ cold/ bright light
- Fear/ anxiety
- Uncontrolled pain
- Nausea
- Positioning

Management:

General measures

- Treat specific causes, see below
- In addition and if the measures below are unsuccessful, medical intervention may be necessary
- Benzodiazepines are the most commonly used medication in this setting; Haloperidol may also be helpful

Causes of Agitation:

- Cerebral causes: raised intracranial pressure (rare except in children with space occupying lesions), intracranial bleeds, subclinical or clinical fitting.
History and careful neurological examination may help with this diagnosis. Consider whether investigation is in the best interests of the child and whether it will influence management before instigating.
Optomise treatments for epilepsy or myoclonus.
- Constipation
Common causes include analgesia (particularly opioids), dehydration and immobility. Poor diet may be contributing but may not be rectifiable. See section on constipation.
- Environmental irritation
Too hot/ cold, bright light, noise, lack of comforting, stimuli, eg. touch, music
- Fear/ anxiety
Discuss directly with the child if possible/ appropriate. Explanations and reassurance are the most helpful if feasible. Anxiolytics may also be useful but are not always necessary.
- Gastro-oesophageal reflux/ indigestion
Common in multiply disabled children. Also a possibility in children

taking steroids or undergoing chemotherapy/radiotherapy that may make them susceptible to oesophageal candidiasis. See section on reflux.

- **Hypoxia**
Invasive tests should be avoided. A pulse oximeter may confirm the diagnosis but is only helpful if you know what the child's usual reading is and should not be interpreted in isolation. A trial of low dose oxygen may be the most helpful diagnostic tool.
- **Medication**
Check drug chart for medication which may increase agitation.
- **Nausea**
Check history and drug chart for likely causes and treat/ adjust medication as appropriate.
- **Positioning**
The child may simply not be comfortable, and this may be frustrating for a child unable to turn himself. It may be worth adjusting position/ turning if you suspect this may be a problem.
- **Sepsis**
Check temperature and examine for source of infection: upper and lower respiratory tract, ears, wounds, Hickman lines and bladder are possible sites to consider. Swab/ send samples as appropriate but first consider whether doing so will affect your management. Discuss whether treatment is appropriate/desirable with the child, parents and other professional involved. Sometimes treatment may be appropriate even in the terminal phase to control unpleasant symptoms. See section on infection.
- **Uncontrolled pain**
Check history and fully examine before excluding pain. In children unable to communicate ask parents and carers how their child expresses pain. Look for facial expression, frowning and grimacing, during examination and turning/ mobilising.
- **Urinary retention**
Children with neurodegenerative disease often have ongoing problems with retention of urine. Constipation may cause or exacerbate retention. Retention predisposes to urinary tract infection which will add to the discomfort, so consider 'dipsticking' urine or sending a midstream specimen (M.S.U) sample for analysis. Retention may be relieved by gentle bladder massage or a warm bath; catheterisation may also be necessary but need not necessarily be permanent. Opioids may also cause urinary retention in children.

Medication

- Lorazepam

Form:

Tablets: 1mg (scored), 2.5mg

Oral suspension: only available as 'special'

Injection: 4mg in 1ml, 1ml ampoule

Dose (sublingual, oral):

All ages: 25-50 micrograms/kg single dose

Most children will not need more than 0.5-1mg for a trial dose

Well absorbed sublingually (good for panic attacks - fast action) and parent/child has control

Injection can also be given sublingually.

Contraindications and warnings: severe pulmonary disease, sleep apnoea, coma, and CNS depression. Caution in hepatic and renal failure.

Licence: tablets are licensed in children >5yrs as premedication. Injection not licensed in children <12yr except for treatment of status epilepticus.

- Midazolam

Form:

Injection: 10mg in 2ml; 10mg in 5ml.

Injection may be diluted if required, in sodium chloride 0.9% or glucose 5%. Injection can be used for buccal, intranasal, oral or rectal administration.

Oral syrup and buccal liquid only available as 'special'.

Single doses

Intravenous/subcutaneous:

>1month -18yr: 100micrograms/kg

Buccal:

>1month -18yr: 500micrograms/kg (max. 10mg)

Tastes bitter when given orally but can be mixed with juice or chocolate sauce.

Intranasal:

>1month -18yr: 200-300micrograms/kg

Intranasal route may be unpleasant but has a fast onset of action (5-15 minutes).

Rectal:

>1month -18yr: 500-750 micrograms/kg

Continuous intravenous/subcutaneous infusion:

>1month -18yr: 10-200micrograms/kg/hr.

Contraindications and warnings: caution with pulmonary disease, hepatic and renal dysfunction (reduce dose), severe fluid /electrolyte imbalance and congestive cardiac failure. Avoid rapid withdrawal after prolonged treatment.

Licence: licensed for sedation in intensive care and for induction of

anaesthesia in children > 7 yr. Other routes and indications not licensed.

- Diazepam

Form:

Tablets: 2mg, 5mg, 10mg.

Oral solution: 2mg in 5ml and 5mg in 5ml.

Injection (solution and emulsion): 5mg in 1ml.

Suppositories: 10mg.

Rectal tubes: 2mg in 1ml: 2.5mg tube, 5mg tube, 10mg tube.

Dose (oral):

1 month -1yr: 50micrograms/kg b.d.

1-4yr: 500micrograms-3mg b.d.

5-12yr: 1.5-10mg b.d.

>12yr: 2-10mg b.d.

Licence: rectal preparation is licensed for use in children >1yr with severe agitation. Other forms not licensed for agitation per se.

- Haloperidol

Form:

Tablets: 0.5mg, 1.5mg, 5mg, 10mg, 20mg.

Capsules: 500micrograms.

Oral liquid: 1mg in 1ml, 2mg in 1ml, 1mg in 5ml (special)

Injection: 5mg in 1ml, 1ml ampoule; 10mg in 1ml and 2ml ampoules.

Dose (oral):

2-12 yr: 12.5-25micrograms/kg b.d. (max. 10mg/24h)

>12 yr: 250micrograms-15mg b.d. (max 30mg/24h)

Contraindications and warnings: bone marrow suppression, phaeochromocytoma.

Licence: licensed for use in children.

ANOREXIA

- Poor appetite and weight loss are common in children with terminal illness, particularly towards the end of life.
- This causes a great deal of anxiety amongst many parents and carers because:
 - They may consider one of their main caring roles is to keep their child well-fed
 - They often perceive eating as a road to recovery
 - Acceptance that their child doesn't want to eat may go hand in hand with acceptance that the terminal phase is approaching

Consider reversible causes:

- Oral candidiasis
- Pain (in mouth: check for ulcers and dental caries)
- Pain (elsewhere)
- Nausea/vomiting (see appropriate section)
- Constipation
- Medication
- Anxiety
- Depression

Management:

General measures

- Explanations and discussion with family/carers may be helpful. Listen to parents concerns and reassure/ discuss as appropriate.

Other advice includes:

- Providing small meals on small plates
- Making food less effort to eat: providing mashed meals or wholesome soups; offering ice cream and rice pudding etc.
- Offering favourite meals such as MacDonalds
- Offering supplement high calorie/ high protein drinks (more palatable if served chilled)
- Not making an issue out of meal times
- Low dose steroids will stimulate the appetite, and may occasionally be appropriate, but will not change the course of the disease and may have harmful side-effects, and so should only be used for short periods

BLEEDING

Management:

General measures

- If bleeding is likely, explain this to the parents
- If a significant bleed is a possibility benzodiazepines +/- opioids should be readily available (see below) and the use of red towels and blankets may be helpful in these circumstances
- If a tendency to bleed occurs in a girl who has started menstruating consider the continual use of the oral contraceptive pill to prevent menstruation occurring.
- If coagulation is abnormal secondary to liver dysfunction, consider Vitamin K either orally (propylaxis) or intravenously (acute treatment).

Medication

Bleeding gums

- Use soft toothbrush and consider gentle regular antibacterial mouthwash to prevent secondary infection
- If low platelets are a contributory factor and the symptom is very distressing consider platelet transfusion

- Tranexamic acid

Form:

Tablets: 500mg

Injection: 100mg in 1ml, 5ml ampoules.

Oral suspension only available as 'special'

Dose (mouthwash): Use undiluted preparation for injection to apply directly to bleeding point or dilute 1:1 for use as mouthwash/oral use.

Dose (oral):

1month - 18yr: 25mg/kg t.d.s.

Caution: reduce dose in renal failure; caution in haematuria because of the risk of clot retention.

Licence: licensed for use in children.

Small bleeds:

- Tranexamic acid

Form: Tablets 500mg

Injection: 100mg in 1ml, 5ml ampoules.

Oral suspension only available as 'special'

Dose (oral):

1month -18yr: 25mg/kg t.d.s.

- Topical Adrenaline

Form: 1:1000 solution

Small external bleeds: soak gauze, apply directly to bleeding point.

- Sorbsan dressing

Haemostatic dressing: apply directly to bleeding point.

- Platelet transfusion

Consider if bleeding is problematical and related to low platelet count in a child with a reasonable prognosis where transfusion would improve quality of life.

Catastrophic haemorrhage

Some units recommend the use of i/v /SC diamorphine and midazolam. An anxiolytic such as diazepam/midazolam is useful as a large haemorrhage is likely to be very frightening if the patient is conscious. If haemorrhage is likely an anxiolytic in a suitable form should be readily available and carers/staff should be aware of how to administer it.

- Midazolam

Form:

Injection: 10mg in 2ml

Dose (sc/i/v stat):

All ages: 100micrograms/kg

Haemorrhage is unlikely to be painful and the use of diamorphine in this instance may not be appropriate.

BREATHLESSNESS

Consider reversible causes and treat as appropriate:

- Anaemia
- Anxiety
- Ascites
- Cerebral tumours
- Congenital heart disease
- Cystic fibrosis
- Pneumonia
- Raised intracranial pressure
- Respiratory muscle dysfunction e.g. neurodegenerative disorders.
- Primary or secondary lung tumours
- Uraemia
- Pleural effusion/Pneumothorax
- Pulmonary fibrosis
- Superior vena cava obstruction
- Increased secretions
- Pain
- Pulmonary embolism
- Pericardial effusion
- Mechanical restriction

Management:

General measures

- Anxiety is likely to be a feature associated with breathlessness; therefore reassure parents and child
- Cool draught - fan/window
- Breathing exercises: older children can be shown how to control their breathing
- Positioning the child as upright as possible or leaning over a table or pillow may help
- Poor respiratory effort or excess secretions may respond to gentle physiotherapy +/- suction
- Consider play therapy/ distraction

Medication

- Oxygen

May be helpful, consider nasal specs if mask raises anxiety.

Consider humidifying oxygen, which will dry mouth less.

Oximetry is of limited value. Some children with normal oximetry will find oxygen beneficial.

- Ipratropium

May be helpful if bronchospasm is present.

14 SYMPTOM CONTROL PAEDIATRIC PALLIATIVE CARE - BREATHLESSNESS

Form:

Nebulised solution: 250micrograms in 1ml, 500 micrograms in 2ml

Dose (nebulised):

<1yr: 125micrograms t.d.s.- q.d.s.

1-5yr: 250micrograms t.d.s.- q.d.s.

5-12 yr: 500micrograms t.d.s.- q.d.s.

>12yr: 500micrograms t.d.s. - q.d.s.

- Salbutamol

May be helpful if bronchospasm is present.

Form:

Nebulised solution 2.5mg in 2.5ml, 5mg in 2.5ml, 5mg in 1ml

Dose (nebulised):

Birth- 1 month: 1.25-2.5mg t.d.s. /q.d.s.

> 1 month-18 years: 2.5-5mg t.d.s. /q.d.s.

N.B. Salbutamol may not be effective in very young children due to immaturity of the receptors; ipratropium may be more helpful in those <1yr. Salbutamol may make anxiety/agitation worse, and cause a tremor if over-used.

- Morphine

Reduces anxiety, pain, and pulmonary artery pressure.

Begin with half the analgesic dose, and titrate to effect (see section on pain).

- Midazolam

Form:

Injection: 10mg in 2ml; 10mg in 5ml.

Injection may be diluted if required, in sodium chloride 0.9% or glucose 5%. Injection can be used for buccal, intranasal, oral or rectal administration.

Oral syrup and buccal liquid only available as 'special'.

Single doses

Intravenous/subcutaneous:

>1month -18yr: 100micrograms/kg

Licence: licensed for sedation in intensive care and for induction of anaesthesia in children > 7 yr. Other routes and indications not licensed.

- Lorazepam

Form:

Tablets: 1mg (scored), 2.5mg.

Oral suspension only available as 'special'

Injection: 4mg in 1ml, 1ml ampoule

Dose (sublingual, oral):

All ages: 25-50micrograms/kg single dose.

Most children will not need more than 0.5-1mg for trial dose. Well absorbed sublingually (good for panic attacks) and child has control.

Injection can also be given sublingually.

Contraindications and warnings: severe pulmonary disease, sleep apnea, coma, CNS depression. Caution in hepatic and renal failure.

Licence: tablets licensed in children >5yr as premedication. Injection not licensed in children <12yr except for treatment of status epilepticus.

- **Dexamethasone**

May be helpful in some very rare circumstances such as bronchial obstruction, lymphangitis carcinomatosa, superior vena cava (SVCO) also in obstruction, and raised intracranial pressure.

To avoid potentially distressing side effects prescribe a short course (3-5 days) only. This may be repeated if beneficial.

Form:

Tablets: 500micrograms; 2mg.

Oral solution: 2mg in 5ml; other strengths available as 'specials'

Injection: 4mg in 1ml, can be given orally.

Dose (oral/ i/v over 3-5 minutes):

1 month -18yr: 100micrograms/kg b.d.

Dose (sc/ i.v.):

Can be given in equivalent doses as single doses or as continuous infusion.

Prescribing regimen:

Give 3-5 day trial and then aim to stop - whether effective or not (no need to tail off dose).

If a prolonged course is necessary (>2 weeks): start at 0.1mg/kg b.d. and reduce by 25% every 4 days to the lowest dose that controls symptoms.

Do not give after midday as can affect night time sleep.

Co-prescribing: consider antacids and anti-thrush treatment.

Contraindications and warnings: caution in renal disease, cardiac disease or cystic fibrosis. Avoid in cardiac insufficiency.

Licence: not licensed for this indication in children.

CONSENT

Treatment should be discussed with parents and the child if appropriate, and ideally both will have an understanding of what is involved and agree to consent. Where this is not the case, providing more time for families to think about things may help. In extreme circumstances a court can be asked to decide what is best.

Providing consent

- A person with parental responsibility for the child (mother, father if married to mother), father if unmarried but named on birth certificate can give consent on behalf of the child up to the age of 18yrs.
- A child over 16yr can give consent to treatment or examination; the health care professionals do not have to ask the parents as well.
- Sometimes a child under 16yrs can give consent provided they are deemed mature enough to fully understand what is involved.

Refusing consent

- If the child is under 16yrs the parents have the right to refuse treatment on the child's behalf, however if the child wants treatment and is deemed mature enough to understand what is involved the law does allow health care professionals to provide treatment or care they believe is appropriate.
- Children between 16 and 18yrs can give consent in the same way an adult can. However if a child decides to refuse treatment, sometimes the parents can consent on their behalf, up to the age of 18yrs, and can overrule a child's decision not to have treatment.

CONSTIPATION

Consider cause:

- Inactivity
- Metabolic: dehydration; hypercalcaemia; hypokalaemia
- Cystic fibrosis
- Reduced oral intake
- Spinal cord/cauda equina compression
- Bowel obstruction
- Fear of pain on defaecation: secondary to hard stools, rectal/anal grazes and tears
- Drugs: opioids; anticholinergics; anticonvulsants; 5HT3 antagonists; vincristine chemotherapy
- Social: shy about using toilets away from home. Not knowing where the toilets are etc.

Liaise with parents:

What are child's usual bowel habits? - children vary a lot; what is constipation for one may be normal pattern for another.

Has there been a change in the usual pattern?

Management:

General measures

- Check for bowel obstruction, faecal impaction and rectal/anal grazes/tears
- Treat underlying cause if appropriate/possible
- Co-prescribe prophylactic laxatives with drugs that commonly cause constipation
- Try oral medication first, then proceed to rectal preparations
- A plain abdominal x ray may be helpful if the clinical picture is unclear. Explain cause and discuss treatment options with parents. They are often anxious and want immediate results, which may not be realistic; their co-operation is essential in successful management.

Medication

- Bisacodyl

Form:

Tablet 5mg

Suppository: 5mg, 10mg.

Dose (oral/rectal):

give tablets at night, suppositories in the morning.

1month-10yr: 5mg o.d.

>10yr: 5-10mg o.d.

Acts in 12h orally, 20-60 minutes rectally.

Stimulant laxative.

- Senna

Form:

Syrup: 7.5mg in 5ml

Tablets: 7.5mg.

Dose (oral):

>2yr: Syrup 0.5ml/kg o.d.

2-6yr: Syrup 2.5-5ml o.d.

6-12yr: Syrup 5-10ml or 1-2 tablets o.d.

>12yr: Syrup 10-20ml or 2-4 tablets o.d.

Stimulant laxative.

Acts in 8-12h

Licence: Syrup licensed in children >2yr, tablet not recommended in children <6yr.

- Movicol Paediatric

Form:

Sachet: oral powder (paediatric plain)

Starting Dose (oral):

2-6yr: 1 sachet o.d.

7-11yr: 2 sachets o.d.

>12yr: 2-4 sachets o.d. (or 1-2 adult sachets)

Increase as needed; usual maintenance is 1-4 sachets daily

Faecal impaction regimen

Number of movicol paediatric plain sachets							
Age	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
2-4 yrs	2	4	4	6	6	8	8
5-11 yrs	4	6	8	10	12	12	12

- Dantron (Co-danthramer)

Form:

Suspension: dantron 25mg/poloxamer 200mg in 5 ml; dantron 75mg/poloxamer 1g in 5 ml (Forte).

Capsule: dantron 25mg/poloxamer 200mg; dantron 37.5mg/poloxamer 500mg (Forte).

Dose (oral):

N.B. Only use in terminally ill children.

<12yr: 2.5-5ml suspension or 1 capsule o.d.-b.d.

>12yr: 5-10ml suspension or 1-2 capsules o.d.-b.d., titrate as needed.

Combined softener and stimulant laxative

Acts in 8-12h

Makes urine red (inform child and carers)

Can cause superficial burns in children who are incontinent/in nappies - use alternative laxative.

Licence: only licensed for use in terminally ill children.

- Docusate sodium

Form:

Elixir: 12.5mg in 5ml; 50mg in 5ml. Dilute with milk or orange juice.

Capsule: 100mg.

Enema: Fletcher's Enemette: 90mg in 5ml

Norgalax micro enema: 120mg in 10g.

Dose (oral):

6 months -12yr: 2.5mg/kg t.d.s.

>12yr: 100mg t.d.s.

Dose (rectal):

<3yr: 2.5ml Fletcher's enemette

>3yr: 5ml Fletcher's enemette

Acts in 24-48h.

Softener and stimulant.

Licence: capsule not licensed for children. Norgalax microenema licensed for children >12yr. Fletcher's Enemette licensed for children >3yr.

- Lactulose

Form:

Solution 3.1 - 3.7g in 5ml with other ketoses

Dose (oral):

<1yr: 2.5ml b.d.

1-5yr: 5ml b.d.

5-10yr: 10ml b.d.

>10yr: 15ml b.d.

Mild osmotic laxative

Acts in 48h

Titrate up as required. May cause bloating/flatulence.

- Arachis oil enema

Form: Enema 130ml arachis oil BP

Dose (rectal):

3-7yr: 1/3-1/2 enema

7-12yr: 1/2-3/4 enema

>12yr: 3/4-1 enema

Use as required.

Faecal softener.

Contraindications and warnings: hypersensitivity to arachis oil or peanuts.

- Sodium Citrate enema

Form: Micro-enema 450mg sodium citrate/75mg sodium laurylsulphate/5mg sorbic acid in 5ml (Relaxit). Other combinations available, but not licensed for children under 3yr.

Use as required.

Dose (rectal):

1 enema (when using in children <3yr insert only half nozzle length).

Osmotic laxative.

- Phosphate enema

Form: Enema sodium acid phosphate 21.4g/ sodium phosphate 9.4g in 118ml.

Dose (rectal):

3-7yr: 1/3-1/2 enema.

7-12yr: 1/2-3/4 enema.

>12yr: 3/4-1 enema.

Not more than 1 in 24rs.

Osmotic laxative.

COUGH

Consider reversible causes and treat if appropriate:

- Infection
- Asthma
- Gastro-oesophageal reflux
- Aspiration
- Drug induced (e.g. ACE inhibitors)/ treatment related (e.g total body irradiation)
- Malignant bronchial obstruction
- Heart failure
- Epileptic seizure activity
- Neuro-degenerative disorders

Management:

General measures

- Keep child as upright as possible
- Raise head of bed: Use blocks under head end of cot/bed or pillows
- Consider Physiotherapy +/- suction
- Consider trial of Humidified air/oxygen

Medication

Cough suppressants

- Simple linctus

Form:

Linctus : paediatric preparation (0.625% citric acid monohydrate); adult preparation (2.5% citric acid monohydrate)

Dose (oral):

1 month -12yr: paediatric preparation 5-10ml t.d.s.- q.d.s.

>12yr: adult preparation 5-10ml t.d.s.-q.d.s.

Licence: licensed for children and adults (appropriate preparation).

- Codeine linctus

Form:

Linctus: paediatric preparation: codeine phosphate 3mg in 5ml; adult preparation: 15mg in 5ml.

Dose (oral):

1-5yr: 5ml paediatric preparation t.d.s. -q.d.s.

5-12 yr: 2.5-5ml adult preparation t.d.s. -q.d.s.

Licence: not licensed for use in children under 1 yr.

- Morphine linctus:

Form:

Solution: 10mg in 5ml

Dose (oral):

<1yr: 12.5 microgram/kg 4 hrly

1-12yr: 30-60 microgram/kg 4 hrly

>12yr: 5-15mg 4 hrly

Bronchodilators

Cough can be a manifestation of hyper-reactive airways/ asthma and a trial of nebulised salbutamol/ ipratropium may be helpful

- Salbutamol

Form:

Nebuliser solution: 2.5mg in 2.5ml, 5mg in 2.5ml, 5mg in 1ml. (other preparations available, see appropriate text)

Dose (nebulised):

Birth- 1 month: 1.25-2.5mg t.d.s.- q.d.s.

1 month-18 years: 2.5-5mg t.d.s.- q.d.s.

May induce mild tachycardia, nervousness, tremor or hypokalaemia.

Interactions: see appropriate text.

Licence: licensed for use in children.

N.B. May not be effective in very young children due to immaturity of the receptors; ipratropium may be more helpful in those <1yr. May make anxiety/agitation worse.

- Ipratropium

Form:

Nebuliser solution: 250 micrograms in 1ml, 500 microgram in 2ml

Dose (nebulised):

<1yr: 125micrograms t.d.s.- q.d.s.

1-5yr: 250micrograms t.d.s.- q.d.s.

5-12yr: 500micrograms t.d.s.- q.d.s..

>12yr: 500micrograms t.d.s.- q.d.s.

Mucolytics

May be helpful if secretions are thick.

- Normal saline

Dose (nebulised):

2.5-5ml

May induce cough reflex in some cases.

- Carbocisteine

Form:

Liquid 125mg in 5ml

Dose (oral):

2-5yr: 62.5-125mg q.d.s.

6-12 yr: 250mg t.d.s.

>12 yr: 750mg t.d.s. initially, reducing to 1.5g/day in divided doses.

Use primarily in children with Cystic Fibrosis.

- Acetylcysteine

Form:

Granules 100mg, 200mg sachets. Named patient basis only.

Dose (oral):

1 month - 2yr: 100-200mg t.d.s.

2-12yr: 200mg t.d.s.

12-18 yr: 200-400mg t.d.s.

Used primarily in children with Cystic Fibrosis.

Licence: not licensed in children for this use.

- Dornase alfa

Form:

Nebuliser solution: 1,000 units in 1ml as 2.5ml vial

Dose (nebulised):

Not for children < 5yr.

>5yr: 2.5ml o.d., or b.d. in infective exacerbations

Used primarily in children with Cystic Fibrosis.

Licence: licensed for use in children >5yr.

Excessive secretions:

See section on noisy breathing.

FITTING

- Most commonly seen in the palliative care setting in children with neurodegenerative disorders or intracranial malignancy.
- Children with neurodegenerative disorders will often already be on multiple anticonvulsant medications and their parents/carers will be knowledgeable about recognising and treating fits. For these children fits are often variable in type and may become frequent and severe and more difficult to control towards the end of life.
- Children with intracranial malignancy will not necessarily develop fits. However, for those who do, it is a frightening new symptom for the child and carers to learn how to manage. If fits are likely, children should be considered for prophylactic anticonvulsants; parents should be warned what to expect, have diazepam available at home, and know how to administer it.
- Not all fits are grand mal, more subtle characteristic behaviours may also represent seizure activity.
- Investigation and treatment of persistent fitting should be tailored to the child's stage of illness and will require discussion with senior doctors and family.

Consider causes and treat as appropriate:

The emergence of, or increasing frequency/severity of fits may be caused by worsening disease but other potentially reversible factors should be considered:

- Hypoglycaemia
- Electrolyte imbalance
- Sub-therapeutic anticonvulsant medication
- Infection e.g. UTI
- Raised intracranial pressure/ other intracranial pathology

Management:

- Choice of baseline anticonvulsant depends on the type of fit and is beyond the remit of this text
- Currently it is thought that most seizures can be controlled with a maximum of two agents.
- Withdrawal or addition of anticonvulsants should be cautious as most agents need to be tailed off or titrated (see appropriate text)
- Higher doses of anticonvulsants are required for children <3yr because of a higher metabolic rate and more efficient drug clearance. Have a low threshold for consulting your local paediatric neurologist for advice on seizure control.
- Not all fits require treatment.
- The burdens and benefits of treatment should be carefully considered before embarking on treatment.

Persistent fits/ status epilepticus:

- Aim to secure airway, give high flow O2 and stop fit
- Exclude hypoglycaemia, particularly in the very young
- If fits last >15minutes, consider checking U&E, glucose, calcium, drug levels and sending urine +/- blood for culture (if service available).

Step 1:

Diazepam: give rectally as a solution via rectal tubes (suppositories take longer to work) or deliver via NG/ gastrostomy if in situ

Dose (rectal) :

<1 month : 1.25 - 2.5mg

1 month - 2yr : 5mg

2 - 12yr : 5 -10mg

>12yr : 10mg

Wait 5 minutes

Step 2:

REPEAT STEP 1

Wait 5 minutes

Step 3:

Paraldehyde

Form: Injection 5ml ampoules

Dose (rectal):

<12yr : 0.4ml/kg (max 10ml) PR in arachis or olive oil diluted 1:1.

>12yr : 5-10 ml PR in arachis or olive oil diluted 1:1. Avoid arachis oil in children with peanut allergy.

Licence: unlicensed.

If fitting remains uncontrolled, and i/v access, consider also:

Phenytoin

Dose (i/v):

>1 month : 18mg/kg over 35-45 mins

or if already on phenytoin:

Phenobarbital

Dose (i/v):

>1 month : 15mg/kg

No faster than 1mg/kg/min

If the above unavailable or no i/v access, use Midazolam (see over)

Wait 20 minutes

Step 4:

Repeat paraldehyde 1-2 hourly if required

Consider also:

Clonazepam infusion

Dose (i/v/SC):

> 1 month: 10micrograms/kg/hr (up to 60micrograms/hr has been given)

Consider hospitalisation if appropriate to paralyse and ventilate. Otherwise persist with measures in step 4, or see below

Fitting in the terminal stages

- Tends to be more frequent and more difficult to control
- Children at this stage are also likely to have stopped taking regular anti convulsants orally

Medication

- Midazolam

Can be used intravenously, buccally, intranasally or as a continuous subcutaneous infusion.

Form:

Injection: 10mg in 2ml; 10mg in 5ml.

Injection may be used for buccal and intranasal routes.

Oral syrup and buccal liquid only available as 'special'.

Dose for initial control:

Intravenous: 100-200micrograms/kg single dose

Intranasal: 200micrograms/kg (max. 10mg)

Buccal: 500micrograms/kg (max. dose 10mg)

Dose (SC continuous infusion):

All ages: 10-100micrograms/kg/h, titrate up as required.

Dose very variable between centres, some recommend up to 300 micrograms/kg/h : use clinical judgement. Adult starting dose is 10-30mg/24h.

If dose reaches >150mg/24hrs with inadequate control consider changing to phenobarbital. As Midazolam is only available in 10mg/2ml for injection, volume may become an issue when used in Graseby syringe drivers - in this case split the dose into 12 hourly drivers to phenobarbital.

- Phenobarbital

Can be given as a continuous subcutaneous or intravenous infusion and has anticonvulsant and anxiolytic properties

Form: Injection: 200mg in 1ml

Dose (i/v stat):

>1 month: 15mg/kg I/V. Single dose or loading dose

No faster than 1mg/kg/min

Dose (i/v continuous infusion)

Birth-12yr: 5-10mg/kg/24h

>12yr: 600mg/24h

Dose (SC continuous infusion):

Birth-12yr: 5-10mg/kg/24h

>12yr: 600mg/24h titrate up as required

Review dose after 1 week as drug induces its own metabolism.

Requires separate syringe driver (does not mix)

GASTRO-OESOPHAGEAL REFLUX

- Many of neurologically impaired children suffer with gastro-oesophageal reflux (15-75%)
- Consider reflux if child refuses food, vomits, has dysphagia, or is particularly irritable when lying flat. Also if there is unexplained weight loss, failure to thrive, or respiratory symptoms such as recurrent respiratory tract infections, cough, wheeze or excessive respiratory secretions.

Management:

General measures

- Check for overfeeding
- If NG/ gastrostomy fed consider changing regimen from large bolus to more frequent small volumes
- Thicken feeds
- Check optimal posture for feeds
- Adjust posture overnight to keep child more upright: use blocks under cot/bed, or pillows

Surgery can be considered in children with a longer prognosis.

Fundoplication +/- pyloroplasty is effective in 80%, but has a high rate of post-operative complications and recurrent symptoms are relatively common. Gastrostomy may also be an option.

Medication

- Gaviscon

Form:

Tablets: alginic acid 500mg, anhydrous aluminium hydroxide 100mg, magnesium trisilicate 25mg, sodium bicarbonate 170mg.

Liquid: sodium alginate 250mg, sodium bicarbonate 133.5mg, calcium carbonate 80mg in 5ml.

Infant sachets: sodium alginate 225mg, magnesium alginate 87.5mg with colloidal silical and mannitol / dose (Half dual sachet).

Dose (oral):

Birth - 2yr: 1/2-1 dual infant sachet.

2-12yr: 5-10ml liquid or 1 tablet after meals and at bedtime.

>12yr: 10-20ml or 1-2 tablets after meals and at bedtime.

Licence: liquid and tablets licensed for use in children over 2yr, for children 2-6yr on medical advice only. Infant sachets licensed for infants and young children but for children under 1yr only under medical supervision.

- **Lansopranzole**

Form:

Capsule: 15mg.

Orodispersable tablet (Fast tab): 15mg

Sachets (suspension): 30mg/sachet

Dose (oral):

>12yr: 15-30mg o.m.

Licence: not licensed for use in children under 12 years of age.

- **Omeprazole**

Form:

Capsule: 10mg, 20mg, 40mg.

MUPS dispersible tablets: 10mg, 20mg, 40mg

Tablets: 10mg, 20mg, 40mg

Intravenous infusion: 40mg vial

Intravenous injection: 40mg vial

Dose (oral):

1 month -12yr: 700micrograms-3mg/kg o.d.- round up to nearest capsule size.

>12yr: 20-40mg o.d. or divide dose to give b.d.

Capsules can be opened and the granules mixed in acidic drink, e.g. orange juice.

Tablets can be dispersed in water or mixed with fruit juice or yogurt.

Contraindications and warnings: caution in patients with hepatic impairment.

Interactions: see appropriate text.

Licence: licensed for use in children >2yr with severe ulcerating reflux oesophagitis.

- **Ranitidine**

Form:

Tablet: 150mg, 300mg.

Effervescent tablet: 150mg, 300mg.

Syrup: 75mg in 5ml

Oral solution: 75mg in 5ml.

Injection: 25mg in 1ml, 2ml ampoule.

Dose (oral):

Birth - 6months: 1mg/kg t.d.s.

6 months -12yr: 2-4mg/kg (max 150mg) b.d.

>12-18 yr: 150mg b.d.

Dose (i/v):

Birth - 6months: 1mg/kg t.d.s.

6 months -12yr: 1mg/kg q.d.s.

>12-18 yr: 50mg t.d.s.

Licence: The parenteral route is unlicensed for children. oral treatment licensed in peptic ulceration only.

- Domperidone

Form:

Tablet: 10mg.

Suspension: 5mg in 5ml.

Suppositories: 30mg

Dose (oral):

1 month -12yr: 200-400micrograms/kg q.d.s.

>12yr: 10-20mg q.d.s.

Dose (rectal):

2-12yr: 15-30mg b.d. if <25kg, t.d.s. if 25-35kg, q.d.s. if >35kg.

>12yr: 30-60mg b.d.-q.d.s.

Acute dystonic reactions less common than with metoclopramide.

Licence: not licensed for gastro-oesophageal reflux in children.

- Metoclopramide

Form:

Tablets: 5mg, 10mg.

Syrup/oral solution: 5mg in 5ml.

Paediatric liquid: 1mg in 1ml.

Injection: 5mg in 1ml, 2ml ampoule.

Dose (oral):

Birth -12yr: 100micrograms/kg b.d.- t.d.s.

>12yr (under 60kg) 5mg t.d.s.

>12yr (over 60kg): 10mg t.d.s.

Dystonic reactions which are reversible with benztropine or procyclidine can occur with any dose.

Cautions: in mild/moderate renal failure use 75% dose, in severe renal impairment use 25-50% dose. Reduce dose in severe liver disease.

Licence: licensed for use in children, tablets licensed only in children >15yr.

INFECTION

- Infection, particularly pneumonia is often the event leading to death in children with terminal illnesses
- Discuss and record a course of action with the parents +/- child in advance of the terminal phase if possible, making it clear that any decisions can be revised as time goes on
- Sometimes antibiotics will improve a symptom and improve quality of life in which case they may be appropriate in the terminal phase
- Treatment of infection may not change the outcome but may allow parents to feel they did everything possible for their child. Whatever the decision ensure the parents are as comfortable as possible with it as it may seriously affect the grieving process if this is not the case.

MOUTH CARE

- Good mouth care can enhance the quality of life for children in the palliative care setting
- Full examination should always include inspection of the mouth as oral problems are easily overlooked, but can usually be easily managed

Consider cause and treat as appropriate:

- Oral candidiasis
- Dry mouth: mouth breathing, oxygen
- Ulcers: traumatic, aphthous, infectious
- Bleeding gums
- Dental caries
- Gum hyperplasia
- Medication e.g. morphine, anti depressants, antihistamines, anticholinergics; Radiotherapy

Management:

General measures

- Keep mouth clean and moist. Clear a coated tongue by gently brushing with a soft tooth brush, or by using effervescent vitamin C
- Regularly clean mouth and teeth with gauze dipped in water or mouthwash, particularly after eating/drinking
- Refer to dentist if appropriate

Medication

Oral candidiasis

May present as the classic white plaques or less commonly as atrophic candidiasis with a red glossy tongue. Remember that candidiasis may extend beyond your line of vision to the oesophagus.

- Nystatin

Form:

Pastilles: 100,000 units

Oral solution: 100,000 units in 1ml

Dose (oral):

1 month -18yr: 1ml or 1 pastille 6 hrly

For oesophageal candida in the immunocompromised: 5ml 4-6hrly

Continue 48h after clinical cure to prevent relapse.

Licence: licensed for children.

- Miconazole oral gel

Form:

Oral gel: 24mg in 1ml

Dose (topical to inside of mouth, then swallow or apply directly to affected area for localised infections):

Birth-1month: 1-2ml b.d.

1 month-2yr: 2.5ml b.d.

2-6yr: 5ml b.d.

>6yr: 5ml q.d.s.

- Fluconazole

Form:

Capsules: 50mg, 150mg, 200mg

Oral suspension: 50mg in 5ml; 200mg in 5ml

(Also available i/v)

Dose (oral):

< 2weeks: 3mg/kg every 72h

2 weeks-1 month: 3mg/kg every 48h

1 month -18yr: 3mg/kg daily for 14 days

Contraindications and warnings: reduce dose in renal impairment, monitor liver function. Co-administration of terfenadine contraindicated. Interacts with several drugs: see other texts. May cause haematological and biochemical abnormalities particularly in children with HIV or malignancies.

Licence: licensed for use in children.

Dry mouth

- If using oxygen, consider humidifying
- Some medication will cause a dry mouth as a side effect e.g. morphine, anti-spasmodics, tricyclic anti-depressants and antipsychotics: consider changing or reducing dose if possible

- Artificial saliva

There are several preparations available in various forms including Glandosane spray

- KY jelly

Is well tolerated and can be used around the inside of the mouth

- Pineapple chunks

Sucking fresh pineapple may help with dryness and also help to prevent candidiasis

- Vaseline

Applying Vaseline or a similar product regularly to lips will help prevent cracking

Ulcers/Mucocitis

- Often related to high dose chemotherapy or total body irradiation with bone marrow transplantation
- Can be extremely painful
- Opioid analgesia is usually given s/c continuous infusion +/- PCA prophylactically

Apthous ulcers:

- Adcortyl in Orabase

Form:

Oral paste

Dose (topical):

Apply thin layer of paste b.d. - q.d.s.

- Choline Salicylate (Bonjela)

Form:

Clear gel

Dose (topical directly to ulcers):

>4 months: 0.5cm of gel up to 6 times daily
may sting initially

Bleeding gums

See section on bleeding

MUSCLE SPASM

Management:

General measures

- Muscle spasm is commonly associated with neurodegenerative disorders, and also with prolonged periods of bed-rest or inactivity
- Early involvement of a physiotherapist is invaluable for advice on moving, handling, positioning and seating, and is essential to prevent the problem worsening
- Massage may be useful and also allows the family to join in care in a practical way, and to have 'hands on' time with their child.
- Discussion with a paediatric neurologist may be helpful
- Long standing contractures in a child with a relatively long prognosis can inhibit daily caring and may be managed surgically or with botulinum toxin injection. This should be assessed by an orthopedic surgeon.
- It is important to distinguish between muscle spasm and spasticity, both of which would require specialist neurological management.

Medication

- Baclofen

Form:

Tablet: 10mg.

Liquid: 5mg in 5ml

(Also available as intrathecal injection for specialist use see below)

Starting dose (oral):

>1yr-12yr: 2.5mg t.d.s.

>12yr: 5mg t.d.s.

Increase dose every 3 days to maintenance dose.

Maintenance dose (oral): - NB Total daily dose can be given as divided doses according to preference - two, three or four times daily.

1yr-2yr: 5-10mg b.d.

2-6yr: 10-15mg b.d.

6-10yr: 15-30mg b.d.

>12yr: 10-20mg t.d.s.

Baclofen can also be used intrathecally as a continuous infusion into the lumbar intrathecal space via an indwelling catheter and infusion pump. The rate of infusion can be altered according to the child's clinical needs at different times of day and is controlled by a computer. This is available at a limited number of centres some of which will provide an outreach service to other areas.

Contraindications and warnings: May cause drowsiness and increased hypotonia. Avoid rapid withdrawal. Use with caution in epilepsy. See other texts for interactions.

Licence: licensed for oral use in children >1year.

- Diazepam

Form:

Tablets: 2mg, 5mg, 10mg.

Oral solution: 2mg in 5ml and 5mg in 5ml.

Injection (solution and emulsion): 5mg in 1ml; suppositories: 10mg; and rectal tubes: 2mg in 1ml: 2.5mg tube, 5mg tube, 10mg tube.

Dose (oral):

1 month - 2 yr: 250micrograms/kg b.d.

2-5yr: 500micrograms-2.5mg b.d.

5-12yr: 5mg b.d.

12-18yr: 3-15mg b.d.

May cause sedation.

Licence: tablets and liquid licensed for use in cerebral spasticity and control of muscle spasm in tetanus.

- Ibuprofen

Form:

Tablet (immediate release): 200mg, 400mg, 600mg.

Tablet (slow release): 800mg.

Capsule (modified release): 300mg.

Liquid: 100mg/5ml. Granules: 600mg/sachet.

Dose (oral):

1 month -12yr: 5-10mg/kg t.d.s.-q.d.s. (max. 2.4g/24h)

>12yr: 200-600mg t.d.s.-q.d.s. (max. 2.4g/24h)

Ibuprofen decreases pain but does not reduce spasm.

Cautions: avoid if peptic ulcer or history of; risk of gastrointestinal bleeding (ibuprofen is considered safer than other NSAIDS); avoid if hypersensitivity to other NSAIDS or aspirin. Caution in renal, cardiac or hepatic impairment and asthma.

Licence: Granules and 800mg tablet not licensed for children. Liquid and immediate release tablets not licensed for children <7kg/<1 year.

- Dantrolene

Form:

Capsules: 25mg, 100mg.

Dose (Oral):

Starting dose:

1 month -12 yr: 500micrograms/kg o.m.

>12yr: 25mg o.m.

Titration: Increase dose frequency to t.d.s. then q.d.s. at 4-7 day intervals. If response unsatisfactory continue increasing dose in increments of 500micrograms/kg in children <12 years, and 25mg in those > 12yr until maximum dose reached.

Maximum dose:

1 month -12 yr: 2mg/kg (or 100mg total) q.d.s.

>12yr: 100mg q.d.s.

Contraindications and warnings: Hepatic impairment.

Caution with cardiovascular/respiratory disease. Monitor liver function tests.

Licence: not licensed for this indication in children.

- Tizanidine

Form:

Tablets: 2mg, 4mg.

Dose (oral):

<12yrs: seek specialist opinion

>12yr: Initially 2mg daily as a single dose increased according to response at intervals of 3-4 days in steps of 2mg, up to 24mg daily in 3-4 doses. (max 36mg/24hr).

Licence: not licensed for use in children.

- Chloral Hydrate

Is not a specific treatment for spasm but may be helpful in breaking the spasm-pain-anxiety cycle.

Form:

Oral Solution: chloral mixture BP; 500mg in 5ml; chloral elixir paediatric BP 200mg in 5ml, extemporaneously prepared.

Syrup: 500mg in 5ml available as 'special'

Suppositories; 25mg, 50mg, 100mg, 250mg, 750mg.

Dose (oral/rectal):

1 month-12yr: 30-50mg/kg (max 1g) nocte

Contraindications and warnings: Avoid in liver disease and severe renal failure. Caution in cardiac disease, respiratory insufficiency, porphyria and gastritis, Avoid prolonged course and abrupt withdrawal.

Licence: unlicensed in children.

NAUSEA AND VOMITING

Consider cause:

- Obstruction: Gastric outflow/ bowel
- Constipation
- Uraemia/ Deranged electrolytes/ Hypercalcaemia
- Raised intracranial pressure
- Upper gastrointestinal tract irritation
- Anxiety
- Cough
- Pain
- Drugs: opioids, chemotherapy, carbamazepine, NSAIDS.
- Intercurrent illness: e.g. otitis media, gastroenteritis, urinary tract infection, epilepsy

Management:

General measures

- Treat/remove underlying cause if possible.
- Avoid strong food smells and perfumes which may antagonise nausea.
- Keep meals small and remove left over food quickly
- Nausea and vomiting can become associated with a wide range of situations that provoke anxiety, and non-drug interventions such as playtherapy and psychotherapy may be helpful.

Give an appropriate antiemetic according to cause (see below), +/- H² receptor antagonist/ proton pump inhibitor if gastric irritation is thought to be a contributory factor.

Use SC/ SC continuous infusion/ rectal routes until symptoms are under control then consider oral route.

- Metoclopramide

Form:

Tablet: 5mg, 10mg.

Syrup/oral solution: 5mg in 5ml.

Paediatric liquid: 1mg in 1ml.

Injection: 5mg in 1ml, 2ml ampoule.

Dose (oral /slow i/v):

All ages: 100-170 micrograms/kg t.d.s.

Dystonic reactions can occur with any dose: reverse with benztropine or procyclidine

Use with caution if intestinal obstruction suspected: if colic develops, reduce dose or stop altogether.

Cautions: in mild to moderate renal failure use 75% dose, in severe renal impairment use 25-50% dose. Reduce dose in severe liver disease.

Licence: tablets only licensed in children >15yr.

38 SYMPTOM CONTROL PAEDIATRIC PALLIATIVE CARE - NAUSEA & VOMITING

- Domperidone

Form:

Tablet: 10mg.

Suspension: 5mg in 5ml.

Suppositories: 30mg

Dose (oral):

1 month -12yr: 200-400micrograms/kg q.d.s.

>12yr: 10-20mg q.d.s.

Dose (rectal):

2-12yr: 15-30mg <25kg: b.d.; 25-35kg t.d.s.; >35kg:q.d.s.

>12yr: 30-60mg b.d.-q.d.s.

Acute dystonic reactions less common than with metoclopramide.

Use with caution if intestinal obstruction suspected: if colic develops, reduce dose or stop altogether.

Licence: only licensed for use in children in nausea and vomiting secondary to radiotherapy/ chemotherapy.

- Cyclizine

Form:

Tablet: 50mg.

Injection: 50mg in 1ml.

Suppositories: available as 'specials' 12.5mg, 25mg, 50mg, 100mg.

Dose (oral, rectal):

<1yr: 1mg/kg t.d.s.

1-4yr: 12.5mg t.d.s.

5-12yr: 25mg t.d.s.

>12yr: 50mg t.d.s.

Maximum dose in adults 150mg/24h

Dose (i/v stat):

<2yr: 1mg/kg

2-5yr: 20mg

6-12yr: 25mg

>12yr: 50mg

Dose (sc/i/v continuous infusion):

<2yr: 3mg/kg/24h

2-5yr: 60mg/24h

6-12yr: 75mg/24h

>12yr: 150mg/24h

Cyclizine is compatible with drugs most commonly used subcutaneously including diamorphine.

Licence: Licensed in children >6yrs

- Haloperidol

Form:

Tablet: 0.5mg, 1.5mg, 5mg, 10mg, 20mg.

Capsule: 500micrograms.

Oral liquid: 1mg in 1ml, 2mg in 1ml, 1mg in 5ml as special

Injection: 5mg in 1ml, 1ml ampoules; 10mg in 1ml, 2ml ampoules.

Dose (oral):

1 month -12 yr: 12.5-25micrograms/kg b.d. (max. 5mg/24h)

>12 yr: 500micrograms-2mg b.d.-t.d.s.

Dose (SC/ i/v continuous infusion):

All ages: 50micrograms/kg/24h.

licensed: licensed for use in children except 1mg in 5ml liquid.

- Levomepromazine

Form:

Tablet: 25mg, 6mg available as 'special'

Injection: 25mg in 1ml, 1ml ampoule.

Dose: (oral):

2-12yr: 0.25-1mg/kg o.d. - b.d.(maximum 25mg/24h)

>12yr: 6.25-25mg o.d. - b.d. (maximum 50mg/24h)

Dose: (SC/ i/v continuous infusion):

All ages: 0.1-0.25mg/kg/24h (max 25mg/24h).

Sedative. No experience in very small children.

- Dexamethasone

Form:

Tablet: 500micrograms; 2mg.

Oral solution: 2mg in 5ml. Other strengths available as 'special'

Injection: 4mg in 1ml can be given orally.

Dose (oral/ i/v):

1 month -1yr: 250micrograms-1mg t.d.s.

1-5yr: 1-2mg t.d.s.

6-12yr: 2-4mg t.d.s.

>12yr: 4mg t.d.s.

Co-prescribing: consider antacids and anti-thrush treatment. Use in short courses to limit unwanted side effects.

Caution: renal disease, cardiac disease or cystic fibrosis. Avoid in cardiac insufficiency.

40 SYMPTOM CONTROL PAEDIATRIC PALLIATIVE CARE - NAUSEA & VOMITING

- Ondansetron

Form:

Tablet: 4mg, 8mg.

Tablet (melt): 4mg, 8mg.

Oral solution: 4mg in 5ml.

Injection: 2mg in 1ml, 2ml and 4ml ampoules.

Dose (i/v over 2-5 minutes):

1 month -12yr: 5mg/m² (max. 8mg) b.d.

>12 yr: 8mg b.d.

Dose (oral):

1 month -12yr: 4mg b.d.

>12yr: 8mg b.d.

Can increase to t.d.s. if necessary

Consider co-prescribing laxative (ondansetron is constipating)

Licence: licensed for post chemotherapy nausea and vomiting.

- Octetide

Form:

Injection: 50micrograms in 1ml, 100micrograms in 1ml,

500micrograms in 1ml, 1ml ampoules; 1mg in 5ml multidose vial

Dose for intractable vomiting (continuous SC infusion):

25micrograms/kg/24hrs

Licence: not licensed for use in children for nausea and vomiting.

See section on raised intracranial pressure

NOISY BREATHING

- Excessive respiratory secretions can often cause distress to the child and carers in the terminal phase.
- Drug treatment is more effective if started before or immediately the secretions are evident.
- Anti-secretory agents may cause drowsiness and anti-cholinergic side-effects: glycopyrronium has less CNS side effects than hyoscine hydrobromide because it does not cross the blood brain barrier

Management:

Medication

- Atropine

Form:

Injection: 600micrograms in 1ml.

Injection (Prefilled disposable syringes); 100micrograms in 1ml, 5ml, 10ml, 30ml; 200 micrograms in 1ml, 5ml; 300micrograms in 1ml, 10ml; 600 micrograms in 1ml, 1ml only.

Eye Drops: 1% atropine.

Dose (sublingual):

All ages: 1-2 drops, eye drops or use injection 500micrograms 4-6 hourly.

Licence: Injection is licensed for use in children. Oral/Sublingual administration of the injection, eye drops or 'specials' are not licensed.

- Glycopyrronium Bromide

Form:

Injection: 200micrograms in 1ml, 1ml amps

(Also available as tablets: 1mg, 2mg; named patient basis only)

Dose (i/v/ SC):

1 month -18yr: 4-8 micrograms/kg (max. 200micrograms) t.d.s.-q.d.s.

Dose (continuous SC infusion):

1 month -18yr: 10-40micrograms/kg/24hr (max. dose in adults is 1200micrograms/24h).

Dose (oral):

1 month -18yr: 40-100micrograms/kg t.d.s.-q.d.s.

Contraindications and warnings and warning: see appropriate text.

Licence: not licensed for this indication in children.

- Hyoscine hydrobromide

Form:

1.5mg Self adhesive patch, drug released at rate of 1mg over 72h.

Injection: 400micrograms in 1ml, 1ml ampoule. 600microgram in 1ml, 1ml ampoule.

Dose (topical):

In some centres not used in <5yrs.

Caution in children with intracranial malignancy, may cause agitation.

<3yr: A quarter of a patch over 3 days.

3-9yr: Half a patch over 3 days.

>10yr: One patch over 3 days.

Dose (SC):

Single dose:

1-12yr: 10micrograms/kg

>12 yr (40kg): 400micrograms

Subcutaneous continuous infusion:

All ages: 20-60micrograms/kg/24h (max. dose 2400micrograms/24h)

Licence: transdermal preparation licensed for use in children >10yrs for motion sickness.

PAIN

(see also 'Other pain syndromes')

- Assessment should include a careful history and examination to elucidate the exact nature and likely cause(s) of pain so that the most effective management can be initiated.
- Assessment should include discussion with parents/carers and staff as well as the child if possible.
- There are a number of pain assessment tools available to aid diagnosis, monitoring, and analgesic effect. These tools should be used as scores can be invaluable means of measuring progress in situations that are often complex.
- Assessment of pain in children particularly young infants and non-verbal children may be difficult.
- Pain may be under-diagnosed and therefore inadequately treated in children, particularly those unable to communicate readily.
- Pain is closely associated with fear and anxiety.
- Carefully record all information in medical records on a regular basis to enable anyone who consults the records to easily recognise changes.

Recognising pain in children with communication difficulties:

- Discuss with family/carers who know the child well.
- Look for signs including: crying, becoming withdrawn, increased flexion or extension, hypersensitivity, frowning/grimacing on passive movement, increasing numbers of fits.

Management:

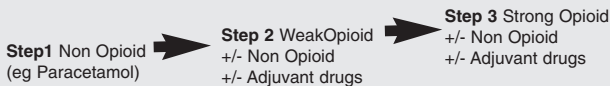
General measures

- Management should include reducing stress/anxiety as far as possible as well as analgesic measures if appropriate.
- Explanations and discussion often help to reduce anxiety.
- A calm, quiet environment may help to reduce anxiety.

Principles of medication in the management of pain:

- Use the ladder (see below).
- Administer regularly, by the clock.
- Use the least invasive route of administration (usually oral).
- Don't forget to prescribe breakthrough doses.
- Filtrate to effect: aim to relieve symptoms with minimal side effects.
- Once requirement is stable, minimise the number of doses per day: convert to a sustained release preparation.
- Remember non-opioids, weak opioids and adjuncts all have a role to play.
- Seek further advice if pain is not controlled swiftly.

World Health Organisation Three step analgesic ladder



Medication

Choosing an analgesic:

- For most types of pain, it is usual to start non-opioid analgesic on a p.r.n. basis, progressing to regular use.
- Some non-opioid analgesics may be used in conjunction with one another (e.g. paracetamol and NSAIDS) or in conjunction with opioids for added analgesic effect (see below).
- If non-opioid analgesics do not control pain effectively opioid analgesics may be helpful. Opioid analgesics can be given p.r.n. or regularly. Weak opioids have a dose limitation, strong opioids do not and the dose should be titrated until effective analgesia is achieved or side effects prevent further escalation. If side effects are problematic these can be treated with other medication, or the opioid can be changed to a different preparation with a different side-effect profile; likewise, if analgesia is sub-optimal changing the opioid may help.
- If a patient is prescribed regular opioids it is important to prescribe additional p.r.n. analgesia in a suitable form and dose, for breakthrough analgesia.
- All analgesic regimens should be regularly reviewed, particularly during titration.

Non-opioid analgesics for mild/moderate pain

- Paracetamol

Form:

Tablet: 500mg; dispersible tablet: 120mg, 500mg.

Oral solution: 120mg in 5ml.

Oral suspension: 120mg in 5ml; 250mg in 5ml.

Suppositories: 60mg, 120mg, 125mg, 240mg, 250mg, 500mg, 30mg as special.

Dose (Oral):

Birth -3 months: 10-15mg/kg 4-6hrly (max. 60mg/kg/24h)

3 months -1yr: 60-120mg 4-6hrly (max. 90mg/kg/24h)

1-5yr: 120-250mg 4-6hrly (max. 90mg/kg/24h)

6 -12yr: 250-500mg 4-6hrly (max. 90mg/kg/24h or 4g/24h)

>12yr: 500mg-1g 4-6hrly (max. 90mg/kg/24h or 4g/24h)

Dose (rectal):

Birth -1 month: 20mg/kg max. 8hrly. (max. 60mg/kg/24h)

1 month -12yr: 20mg/kg 4-6hrly (max. 90mg/kg/24h or 4g/24h)

>12yr: 500mg-1g 4-6hrly (max. 90mg/kg/24h or 4g/24h)

Contraindications and warnings: dose related toxicity in hepatic failure; in moderate renal failure (creatinine clearance 10-50ml/min/1.73m²) the minimum interval between doses is 6 hours. In severe renal failure (creatinine clearance <10ml/min/1.73m²) the minimum interval is 8 h. Significantly removed by haemodialysis but not by CAPD.

May provide additional analgesia in combination with opioids.

Licence: licensed for analgesic use in children >3months, except 30mg suppository.

Non-steroidal anti-inflammatory drugs

- Can combine with paracetamol or opioids for additive analgesia.

For example:

- Ibuprofen

Form:

Tablet: 200mg, 400mg, 600mg.

Tablet: (slow release): 800mg.

Capsule (modified release): 300mg.

Liquid: 100mg/5ml.

Granules: 600mg/sachet.

Dose (oral):

1 month -12yr: 5-10mg/kg t.d.s.-q.d.s. (max. 2.4g/24h)

>12yr: 200-600mg t.d.s.-q.d.s. (max. 2.4g/24h)

Cautions: avoid if peptic ulcer or history of; risk of gastrointestinal bleeding if coagulation defects (ibuprofen considered safer than other NSAIDS); avoid if hypersensitivity to other NSAIDS or aspirin. Caution in renal, cardiac or hepatic impairment and asthma.

Licence: Granules and 800mg slow release tablet not licensed for children. Liquid and immediate release tablets not licensed for children <7kg/<1year.

- Diclofenac

Form:

Tablet: (enteric coated) 25mg, 50mg; (dispersible) 50mg; (modified release) 75mg, 100mg.

Capsules: (modified release) 75mg, 100mg.

Suppositories: 12.5mg, 25mg, 50mg, 100mg.

Injection: 25mg in 1ml as 3ml ampoule.

Dose (oral/ rectal):

6 months-18yr: 300micrograms-1mg/kg t.d.s. (max. 150mg/24h)

Dose (i/v dose must be further diluted and given over 30-120 minutes):

>6 months: 300micrograms-1mg/kg o.d. b.d. (max. 150mg/24h)

Cautions and contraindications and warnings: avoid if peptic ulcer or history of; avoid if hypersensitivity to other NSAIDS or aspirin. Caution in renal, cardiac or hepatic impairment and asthma. Avoid suppositories if ulceration of lower bowel/anus. Avoid i/v use if concurrent NSAID or anticoagulant therapy.

Licence: 25mg and 50mg tablets and 12.5mg and 25mg suppositories licensed for chronic arthritis in children>1yr. Other preparations not licensed for use in children.

Opioid analgesics for moderate/severe pain

- These are usually only tried when non-opioid analgesics have been tried and have not been fully effective.
- Always co-prescribe a regular laxative: opioids usually cause constipation and it is better to prevent this from the outset.

Other side effects which should be anticipated and promptly managed are:

- Nausea and vomiting: normally settles within 5-7 days, but if treatment is required, use cyclizine first-line; otherwise prochlorperazine (may produce unwanted side effects) or ondansetron.
- Pruritus: maintain skin hydration carefully; topical agents such as Eurax may be helpful; systemic agents such as ondansetron have shown some mixed results in adults but may be worth trying. Opioid rotation is another option - less pruritogenic opioids are hydromorphone and oxycodone. Chlorpheniramine or other non-sedating anti-histamine may be helpful.
- Urinary retention: occasionally catheterization may be required. Check that constipation is not a contributory factor. Carbachol or Bethanecol may also help.
- Respiratory depression: is very very rare, and can be avoided with steady dose titration. Naloxone will reverse respiratory depression at the cost of analgesic effect, and should be used with caution as it can also cause rebound agitation.
- Drowsiness: usually wears off after 3-5 days.
 - Nightmares are occasionally reported. These may settle with time, but if troublesome opioid rotation may be helpful.
 - Physical dependence: is not usually a problem in this setting, but if planning to stop opiates always do it slowly to avoid the unwanted effects of withdrawal.

- Tolerance: may occur as opiates are often used over prolonged periods. Doses should be titrated up carefully in the usual fashion, or if side effects preclude this, opioid rotation should be considered.

Weak opioids:

- Codeine phosphate

Form:

Tablet: 15mg, 30mg, 60mg.

Syrup: 25mg in 5ml.

Linctus: 15mg in 5ml; 3mg in 5ml.

Injection: 60mg in 1ml, 1ml ampoule (for i/m use, never give i/v).

Suppositories (specials) : 1mg, 2mg, 3mg, 6mg.

Dose (oral/rectal/i/m):

Birth -12yr: 500micrograms-1mg/kg 4-6hrly

>12yr: 30-60mg 4-6hrly (max. 240mg/24h)

Cautions and contraindications and warnings: little experience in young children, avoid in children <3months. Avoid in renal impairment. Use with caution in hepatic impairment.

- Dihydrocodeine tartrate

Form:

Tablet: 30mg.

Liquid: 10mg in 5ml.

Injection: 50mg in 1ml.

Dose (oral /deep SC):

1-4yr: 500micrograms/kg 4-6hrly

4-12yr: 500micrograms-1mg/kg 4-6hrly

>12yr: 30mg 4-6hrly

Cautions and contraindications and warnings: avoid or reduce dose in moderate/severe renal failure, chronic liver disease and hypothyroidism. Avoid in respiratory depression, cystic fibrosis, head injury and raised intracranial pressure.

Licence: Licensed for children >4yrs.

Strong Opioids

- Morphine Sulphate

Form:

Tablets 10mg, 20mg, 50mg.

Tablets/capsules (modified release): 5mg, 10mg, 15mg, 20mg, 30mg, 50mg, 60mg, 90mg, 100mg, 120mg, 150mg, 200mg.

Granules for suspension (modified release): 20mg, 30mg, 60mg, 100mg, 200mg sachets.

Oral solution: 10mg in 5ml; 100mg in 5ml; 20mg in 1ml.

Injection also available but diamorphine is preferable for this purpose (see below).

Suppositories: 10mg, 15mg, 20mg, 30mg. (5mg available as special).

Dose for opioid - naive children (oral/rectal):

1 month -1yr: 100micrograms/kg 4hrly

1-12yr: 200-500micrograms/kg 4hrly

>12yr: 10-15mg 4hrly

Dose - For children who are on opioids already : see appropriate conversion chart below.

N.B. In children from 6 months - 5 yr morphine is metabolized more rapidly than in adults, in infants less rapidly.

Prescribing regimen:

- Always prescribe breakthrough dose (total dose/24h divided by 6) in addition to regular dose.
- If pain not controlled increase dose according to amount of breakthrough used in previous 24 hours.
- Use 4hrly dosing until pain well controlled, then convert to modified release preparation and prescribe 12hrly (total dose/24hr divided by 2).
- Keep required dose under constant review and adjust to give optimum pain control.

Contraindications and warnings: avoid in paralytic ileus, acute respiratory depression and liver disease. Caution in raised intracranial pressure, head injury, biliary colic, hypothyroidism. Reduce dose in renal failure: use 75% in moderate renal failure (creatinine clearance 10-50ml/min/1.73m²) and 50% in severe renal failure (creatinine clearance <10ml/min/1.73m²)

Licence: Sevredol licensed in children >3yr. Oral solution licensed in children >1yr. MST licensed for children with severe cancer pain.

Oramorph SR tablets and Morcap SR capsules are unlicensed for use in children. Suppositories are not licensed.

- Diamorphine Hydrochloride

Form:

Injection: 5mg, 10mg, 30mg, 100mg, 500mg.

(Tablets: 10mg but no advantage over morphine sulphate and less doses available).

Diamorphine is more potent than morphine. Diamorphine is metabolized to morphine but is more water-soluble and therefore considered more convenient for SC and i/v injection.

Dose: (continuous i/v infusion):

All ages: 12.5-25micrograms/kg/hr.

Dose: (continuous SC infusion):

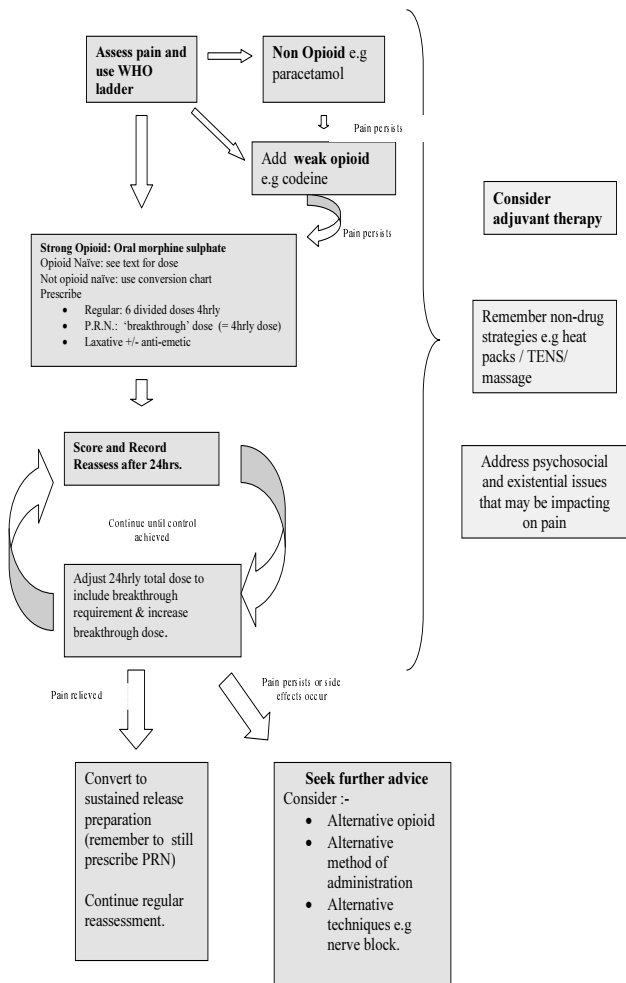
All ages 20-100micrograms/kg/hr.

If converting directly from oral dose to SC dose: total SC dose morphine sulphate over 24h is total oral dose divided by 3.

Contraindications and warnings: paralytic ileus, pheochromocytoma. Avoid in head injury or raised intracranial pressure. Caution in acute respiratory failure and biliary colic. Reduce dose by 25-50% in severe renal impairment.

Licence: injection form licensed for children with terminal illness.

PAIN FLOW CHART



- Fentanyl Citrate

Form:

Patches: for transdermal absorption over 72 hours: 25micrograms/hr, 50micrograms/hr, 75micrograms/hr, 100micrograms/hr.

Lozenge: for buccal use: 200micrograms, 400micrograms, 600micrograms, 800micrograms, 1200micrograms, 1600micrograms.

(Injection form available but not used in the palliative care setting).

Dose (transdermal):

Start at 25micrograms/hr and monitor closely or

Convert from oral morphine Sulphate:

Oral morphine (mg/24h)	<135mg	135-224mg	225-314mg	315-404mg	405-494mg
Fentanyl patch (micrograms/hr)	25	50	75	100	125

Converting from oral morphine sulphate to transdermal fentanyl:

- Continue oral preparation for up to 12h after start of first fentanyl patch as fentanyl patch will take 6-12h to reach therapeutic levels. Wait 24-48h before evaluating analgesic effect or changing dose.
- Always provide p.r.n doses of oral morphine for breakthrough pain.
- Use new area of skin with each patch change.
- Avoid exposure of patch to excessive heat (sun bathing, fever, hot water bottle etc) as heat will increase absorption.

Dose (buccal):

Useful for incident and breakthrough pain.

Dose not related to background analgesic dose, therefore start with 200microgram lozenge and adjust dose according to response.

Contraindications and warnings: see diamorphine. Fentanyl is less problematic in renal failure than diamorphine.

Licence: Lozenges and transdermal preparation unlicensed in children.

- Oxycodone

Can be used in patients intolerant of morphine

Form:

Capsules: (immediate release) 5mg, 10mg, 20mg

Liquid: 5mg in 5ml

Concentrate: 10mg in 1 ml

Tablets, modified release: 5mg, 10mg, 20mg, 40mg, 80mg

Dose (oral).

For opioid naive patients:

2-12yr: 0.2mg/kg immediate release preparation 4hrly

>12yr: 5-10mg immediate release preparation 4hrly

For patients already on opioids:

>2yr: (Total oral morphine dose divided by 12) 4hrly

Convert to long acting preparation when dose stable

Contraindications and warnings: contraindicated in acute respiratory depression. Avoid in paralytic ileus and liver disease. Avoid in moderate/severe renal failure.

Licence: not licensed for use in children.

- Hydromorphone

Can be used in patients intolerant of morphine.

Form:

Fast acting Capsules (Palladone): 1.3mg and 2.6mg

Controlled release (Palladone SR): 2mg, 4mg, 8mg, 16mg, 24mg

Can be swallowed whole or opened and sprinkled into soft food.

Avoid administration via PEG or NGT as hydromorphone will cause blockage

Dose

Starting dose (for opioid naïve patients)

Oral: 0.06mg/kg every 3-4hrs

Controlled release : 0.18mg /kg every 12 hrs

If switching from another opioid start on equianalgesic dose of the modified release form of hydromorphone supplemented with appropriate rescue doses of the fast acting capsule

Dose conversion:

4 hrly oral morphine equivalent	Hydromorphone palladone capsules 4 hrly	Hydromorphone palladone SR capsules twice daily
10mg	1.3mg	4mg
20mg	2.6mg	8mg
30mg	3.9mg	12mg
40mg	5.2mg	16mg
50mg	6.5mg	20mg
60mg	7.8mg	24mg

Contraindications and warnings: contraindicated in acute respiratory depression. Avoid or reduce dose in hepatic and renal impairment.

Licence: Not licensed for use in children.

- **Buprenorphine**

Alternative to transdermal fentanyl. Particularly useful in infants and when smaller doses are required as the patch can be cut to help adjust doses up or down.

Form:

Transtec patch: for transdermal absorption over 72hrs: 35 micrograms/hr, 52.5 micrograms/hr, 70 micrograms/hr

Tablets (sublingual), 200 micrograms, 400 micrograms,

Injection 300 micrograms/ml

Dose:

Transdermal: Convert from oral morphine sulphate

Oral morphine (mg/24hr)	50mg	75mg	100mg	
Buprenorphine patch (micrograms/hr)	35	52.5	70	

Sublingual: child over 6 years, 16–25 kg, 100 micrograms every 6–8 hours; 25–37.5 kg, 100–200 micrograms every 6–8 hours; 37.5–50 kg, 200–300 micrograms every 6–8 hours

Converting from oral morphate solution

- Continue oral morphine for 12 – 24 hrs after start of buprenorphine patch until therapeutic levels are reached.
- Evaluate analgesic dose after 24 – 72hrs
- Provide PRN doses of either oral morphine or sublingual buprenorphine for breakthrough.
- It may take approx 30 hrs for the plasma concentration to decrease by 50% after patch is removed.

License: Licensed for use in children over the age of 6 years.
Cutting the patches is not recommended by manufacturers.
Using in this way is therefore off license.

- Tramadol

Form:

Capsule: 50mg, 100mg, 150mg, 200mg

Tablet modified release: 100mg, 150mg, 200mg, 300mg, 400mg

Orodispersable tablet (to be sucked & then swallowed): 50mg

Sachets (effervescent powder): 50mg, 100mg

Injection: 100mg

Dose: 50mg 6hrly In children over the age of 12 yrs

Licence: Not licensed for use in children under 12 years of age

OPIOID POTENCY RATIOS

	Route	Relative potency to oral morphine
Codeine	Oral	0.1
Dihydrocodeine	Oral	0.1
Buprenorphine	Sublingual	60
Pethidine	Oral	0.125
	IM	0.375
Tramadol	Oral	0.2
Morphine	SC infusion	2
Diamorphine	SC infusion	3
Oxycodone	Oral	2
	SC infusion	3
Fentanyl	Patch	150
	SC infusion	150
Alfentanil	SC infusion	30
Hydromorphone	Oral	5-10

OTHER PAIN SYNDROMES

Bone pain

Radiotherapy

- Useful for discrete bone metastases, may be a short course or single dose.
- Effective
- Generally a traumatic treatment.
- May require anaesthesia in very young children.

NSAIDS

- Useful analgesia.
Used in combination with opioids lowers dose of opioid required for effective analgesia. A common choice is:
- Ibuprofen

Form: Tablets: (immediate release) 200mg, 400mg, 600mg.

Tablets (slow release): 800mg

Capsule (modified release) 300mg.

Liquid: 100mg/5ml.

Granules: 600mg/sachet.

Dose (oral):

1 month -12yr: 5mg/kg t.d.s.-q.d.s. (max. 2.4g/24h)

>12yr: 200-600mg t.d.s.-q.d.s. (max. 2.4g/24h)

Cautions: avoid if peptic ulcer or history of; risk of gastrointestinal bleeding if coagulation defects (ibuprofen considered safer than other NSAIDS); avoid if hypersensitivity to other NSAIDS or aspirin. Caution in renal, cardiac or hepatic impairment and asthma.

Licence: licensed for use in children

Steroids

Useful for bone pain and pain secondary to raised intracranial pressure or nerve damage.

- Avoid if possible or consider short courses
- Short courses can be very effective
- Side effects include:
 - Loss of blood sugar control especially in diabetic children
 - Mood and behaviour problems
 - Weight gain and body image change
 - Reduced mobility - proximal myopathy
 - Insomnia (give entire dose before midday)
 - Dyspepsia
 - Oral/Oesophageal candidiasis

- Dexamethasone

Is the steroid of choice

Form:

Tablet: 500micrograms; 2mg.

Oral solution: 2mg in 5ml. Other strengths available as 'specials'.

Injection: 4mg in 1ml can be given orally.

Dose (oral/ S/C / i/v over 3-5 minutes):

Birth-18yr: 125-500microgram/kg b.d.

Do not give after midday as can affect night time sleep.

Contraindications and warnings: caution if renal disease, cardiac disease or cystic fibrosis. Avoid in cardiac insufficiency.

Licence: licensed for use in children for symptoms associated with brain tumours but not specifically for nerve pain

Raised intracranial pressure

See section on raised intracranial pressure.

Nerve infiltration/ compression

Steroids

- Dexamethasone

As above

Anti-depressants

- Amitriptyline

Form:

Tablet: 10mg, 25mg, 50mg.

Oral solution: 25mg in 5ml; 50mg in 5ml.

Dose (oral):

1-18yr: 0.5-1mg/kg nocte.

Contraindications and warnings: acute porphyria impairment.

Caution with cardiac disease (monitor ECG over 150mg/day).

Interactions and side-effects: see other texts for full information. Note causes antimuscarinic effects, sedation, cardiac arrhythmias, and lowers seizure threshold.

Licence: not licensed for neuropathic pain in children.

Anticonvulsants

- Gabapentin

Form:

Capsules: 100mg, 300mg, 400mg.

Tablets: 600mg, 800mg.

Dose (oral):

Starting dose: 10mg/kg: once daily for 4 days, then b.d. for 4 days, then t.d.s. Adjust dose according to response. Maximum dose in adults is 1.8g/24h.

Contraindications and warnings: avoid abrupt withdrawal. Caution in renal failure: reduce frequency of doses.

Capsules can be opened and contents added to small volumes of fluid or food, the contents of the capsules are very bitter.

Licence: not licensed for children <12yr.

- Carbamazepine

Form:

Tablet (immediate release): 100mg, 200mg, 400mg.

Tablet (modified release): 200mg, 400mg.

Chewable Tablets: 100mg, 200mg.

Oral liquid: 100mg in 5ml.

Suppositories: 125mg, 250mg.

Dose (oral):

1 month -12yr: 2.5-10mg/kg b.d.

>12yr: 200-400mg b.d.-t.d.s.

Start with low dose and increase by up to 5mg/kg at weekly intervals

Contraindications and warnings: A-V conduction abnormalities, history of bone marrow depression, intermittent porphyria, MAOIs within previous 2 weeks, sensitivity to tricyclics. Dose reduce in advanced liver disease. Numerous drug interactions.

Licence: licensed for use in children

Other medication for Nerve Pain

- Ketamine

Seek specialist advice.

Can be useful i/v , S/C or orally for resistant nerve pain.

- Nitrous oxide (Entonox)

Child uses via face mask (children under 5 yr do not usually have sufficient respiratory power or co-ordination to operate).

- Nerve block or epidural

May be helpful and can give lasting pain relief; consult local anaesthetic team.

Epidurals can be managed in the community if the professional support is available.

Mucositis

- See section on mouth care

Tumour pain

- Treatment directed at the tumour (chemotherapy, radiotherapy) may relieve pain in the longer term, but there may be a time delay before pain reduces: it is therefore important to treat the pain in the meantime.
- See main pain section.

Painful procedures

- If a procedure is likely to cause discomfort take preventative action!
- Explain all procedures to parents and children as appropriate to reduce anxiety.
- Undertake procedures in friendly if not familiar surroundings.
- Have parents/carers or the nurse who knows the child best present.
- Use anaesthetic creams and distraction techniques as appropriate to the age of the child. Consider local or general anaesthetic where appropriate.
- Benzodiazepines are often employed in small doses in conjunction with analgesia for more difficult procedures e.g midazolam given buccally, i/v, or intranasally gives light sedation and some amnesia- see section on agitation for doses. Inhaled nitrous oxide has analgesic and amnesic properties (not sedating), and is useful in co-operative children over 5 yrs.

PSYCHOLOGICAL

- The psychological issues surrounding a dying child and their family are far reaching and complex.
- Professionals caring for these families need to consider these issues to help their understanding of what the families may be feeling and enable appropriate support to be given.
- Problems and priorities will vary from family to family but a broad outline of some of these issues is given below:

What happens when a child becomes ill?

Possible Issues for parents

- Dealing with the news
- Parent takes on new role: now responsible for sick child
- Getting on with other aspects of life
- Explaining to siblings
- Giving other siblings attention
- Giving partner support and attention
- Financial implications of not working

Concerns re: responsibility for illness?

- problem during pregnancy
- problem during birth
- problem with genes

Taking care of child

- short term/ long term
- knowledge of illness
- recognising important symptoms, ignoring others

Leaving child in care of others

- will anyone take child on
- will parent feel able to leave child
- will schooling be possible

Possible Issues for Child

- symptoms
- restricted lifestyle
- feeling abnormal
- cause of worry to others
- guilt
- relationship with other children different
- facing prognosis
- educational concerns

Possible Issues for Siblings

- jealousy/ resentment
- guilt re: above
- guilt re: responsibility for sibling's illness
- concern re: own health
- responsibility for care of sick sibling and supporting parents

Providing support

- Give the family time and be ready to listen when they are ready to talk.
- Supporters will be chosen by the family not by the professionals- some families will talk to nurses, teachers, clergy, other parents, or domestic staff.
- Professionals should offer help on a regular basis.
- Honesty is usually helpful if it is offered gently and you are sure of the question being asked.
- If you do not know the answer it is better to explain this.
- Do not be afraid to allow the child to talk but check with parents that they are aware and comfortable with this.

Anxiety and depression

- May be present in the terminally ill child and should not be ignored.
- The clinical picture will depend on the age and development of the child.
- Diagnosis may be difficult: trust the instincts of parents and carers and consult a child psychologist at an early stage.

Management:

General measures

- Provide support as above.
- Provide an environment and the opportunity for the child to raise their concerns and fears.
- Consider complementary therapies for parents and children. May be particularly beneficial for non-verbal children.
- Offer counselling and complementary therapies to parents if possible.

Medication**Anxiety**

- Midazolam

Form:

Injection: 10mg in 2ml; 10mg in 5ml. Injection may be diluted in Sodium chloride 0.9% or glucose 5%. Injection can be used for oral, buccal, intranasal and rectal administration.

Oral syrup and buccal liquid: only available as 'special'.

Dose: single doses:

Intravenous/subcutaneous:

>1month -18yr: 100micrograms/kg

Buccal:

>1month -18yr: 500micrograms/kg (max. 10mg)

Tastes bitter when given orally but can be mixed with juice or chocolate sauce.

Intranasal:

>1month -18yr: 200-300micrograms/kg

Intranasal route may be unpleasant but has a fast onset of action (5-15 minutes).

Rectal:

>1month -18yr: 500-750 micrograms/kg

Continuous intravenous/subcutaneous infusion:

>1month -18yr: 10-200micrograms/kg/hr.

Contraindications and warnings: caution with pulmonary disease, hepatic and renal dysfunction (reduce dose), severe fluid /electrolyte imbalance and congestive cardiac failure. Avoid rapid withdrawal after prolonged treatment.

Licence: licensed for sedation in intensive care and for induction of anaesthesia in children > 7 yr. Other routes and indications not licensed.

- **Lorazepam**

Form:

Tablet: 1mg (scored), 2.5mg.

Suspension: only available as 'special'

Injection: 4mg in 1ml

Dose (sublingual, oral):

All ages: 25-50micrograms/kg single dose, repeat as required.

Most children will not need more than 0.5-1mg for trial dose

Well absorbed sublingually (good for panic attacks) and child has control.

Injection can also be given sublingually.

Contraindications and warnings: severe pulmonary disease, sleep apnoea, coma, CNS depression. Caution in hepatic and renal failure.

Licence: tablets licensed in children >5yrs as premedication. Injection not licensed in children <12yr except for treatment of status epilepticus.

- **Diazepam**

Form:

Tablets: 2mg, 5mg, 10mg.

Oral solution: 2mg in 5ml and 5mg in 5ml.

Injection (solution and emulsion): 5mg in 1ml.

Suppositories: 10mg.

Rectal tubes: 2mg in 1ml: 2.5mg tube, 5mg tube, 10mg tube.

Dose (oral):

1 month -1 yr: 50micrograms/kg b.d.

1-4yr: 500micrograms-3mg b.d.

5-12yr: 1.5-10mg b.d.

>12yr: 2-10mg b.d.

Potential for dependency in prolonged courses.

Licence: rectal preparation is licensed for use in children >1yr with severe anxiety. Tablets and liquid licensed for night terrors and sleep-walking

- Levomepromazine

Form:

Tablets 25mg, 6mg tablets available as 'special'.

Injection: 25mg in 1ml, 1ml ampoule.

Dose (oral):

>12yr: 6.25- 12.5mg b.d.-q.d.s. (maximum 50mg/24h)

Dose ((SC continuous infusion):

350micrograms-3mg/kg/24h. (max adult dose 300mg/24h)

- Haloperidol

Form:

Tablets: 0.5mg, 1.5mg, 5mg, 10mg, 20mg.

Capsules: 500micrograms.

Oral liquid: 1mg in 1ml, 2mg in 1ml, 1mg in 5ml (special)

Injection: 5mg in 1ml, 1ml ampoule; 10mg in 1ml, 2ml ampoule.

Dose (oral):

1 month-12 yr: 12.5-25micrograms/kg b.d. (max. 10mg/24h)

>12 yr: 250micrograms - 15mg b.d. (max. 60mg/24h)

Licence: licensed for use in children.

Depression

- Fluoxetine

Form:

Capsules: 20mg, 60mg.

Liquid: 20mg in 5ml

Dose (oral):

12-18yr: 20mg o.d.

Contraindications and warnings: avoid in hepatic or renal insufficiency.

Caution in poorly controlled epilepsy: Lowers seizure threshold. Do not use with, or within 2 weeks of taking MAOIs.

Interactions: see appropriate text.

Licence: not licensed for use in children.

- Imipramine

Form:

Tablets: 10mg, 25mg.

Syrup: 25mg in 5ml.

Initial dose (oral):

6-7yr: 25mg nocte.

8-11yr: 25-50mg nocte.

12-18yr: 25mg t.d.s. or 75mg nocte.

Maintenance dose (oral):

12-18yr only: Increase stepwise to 150-200mg daily in divided doses in first seven days. Continue until definite improvement then gradually reduce dose to long-term maintenance dose of 50-100mg daily.

Contraindications and warnings: acute porphyria; hepatic impairment.

Caution in cardiac disease. Do not use with, or within 2 weeks of taking MAOIs. Lowers seizure threshold.

Interactions: see appropriate text.

Licence: not licensed for this indication in children.

Difficulty sleeping

Management:

General measures

- Address the child's fears/concerns if possible.
- Consider sleep pattern: the child may be sleeping a lot in the day and may be reversing day/night pattern. It may be appropriate to keep the child awake more in the day or to provide extra stimulation during the day- this will depend on the child's stage of illness. The child may not be aware of when he is expected to sleep if a lot of intervention is given around the clock.
- Optimise bedtime routine: bath if possible, story if appropriate, hot drink if appropriate, lights low.
- Consider complementary therapies to aid relaxation.
- Over night try and disturb as little as possible, this may mean re-scheduling medications.

Medication

- Temazepam

Form:

Tablet: 10mg, 20mg.

Capsules: 10mg, 15mg, 20mg, 30mg.

Oral solution: 10mg in 5ml.

Dose (oral):

1 month -12yr: 1mg/kg nocte.

>12yr: 20mg nocte.

Contraindications and warnings: caution in severe liver disease. Avoid in CNS depression and acute pulmonary insufficiency.

Interactions: see appropriate text.

Licence: not licensed for use in children.

- Melatonin

Form:

Capsule (immediate release): 1mg, 2mg, 2.5mg, 3mg, 5mg and 10mg - named patient.

Capsule (sustained release): 3mg - named patient.

Dose (oral):

Starting dose: All ages 2-3mg nocte, 30-60 minutes before bed.

Dose may be increased to 4-6mg if insufficient benefit after 1-2 weeks.

Dose increase to 9-10mg may be suggested under specialist care. If no benefit after 2 weeks on the higher dose then melatonin should be stopped.

Licence: Unlicensed. Available on named patient basis.

- Triclofos

Form:

Oral liquid: 500mg in 5ml.

Dose (oral):

1 month -12yr: 30-50mg/kg. nocte.

>12yr: chloral hydrate is generally used.

Less gastric irritation than chloral hydrate.

Contraindications and warnings: avoid in liver disease and severe renal failure. Caution in cardiac disease, respiratory insufficiency, porphyria and gastritis. Avoid prolonged administration and abrupt withdrawal.

Licence: unlicensed for this indication in children.

- Promethazine hydrochloride

Form:

Tablet: 10mg, 25mg.

Elixir: 5mg in 5ml.

Injection: 25mg in 1ml as 1 ml ampoule.

Dose (oral):

<1yr: 5-10mg nocte.

1-5yr: 10-20mg nocte.

5-12yr: 20-25mg nocte.

>12yr: 25-50mg nocte.

May be useful in mild cases.

Contraindications and warnings: Porphyria; CNS depression; hypersensitivity to phenothiazines. Do not use with, or within 2 weeks of taking MAOIs.

Licence: Licensed for use in children >2yr.

- Amitriptyline

Form:

Tablet: 10mg, 25mg, 50mg.

Oral solution: 25mg in 5ml; 50mg in 5ml.

Injection: 10mg in 1 ml as 10ml vial

Dose (oral):

1-18yr: 0.5-1mg/kg nocte.

Contraindications and warnings: acute porphyria impairment.

Caution with cardiac disease (monitor ECG over 150mg/day).

Interactions and side-effects: see other texts for full information. Note causes antimuscarinic effects, sedation, cardiac arrhythmias, and lowers seizure threshold.

Licence: not licensed for neuropathic pain in children.

RAISED INTRACRANIAL PRESSURE

Consider raised intracranial pressure if the child shows evidence of:

- Confusion
- Drowsiness
- Vomiting
- Headache (especially on waking)
- Focal neurology
- Personality change

Management:

General measures

- Investigation should be considered only if it will contribute to management decisions.
- Reduction of tumour bulk may improve symptoms e.g. cranial irradiation and chemotherapy. Occasionally a ventricular shunt may be appropriate and this should be discussed with a neurologist or neurosurgeon.
- Symptomatic management may include analgesia (see pain section), antiemetics and steroids. The antiemetic of choice is cyclizine.

Medication

- Dexamethasone

Form:

Tablet: 500micrograms; 2mg.

Oral solution: 2mg in 5ml. Other strengths available as 'specials'.

Injection: 4mg in 1ml can be given orally.

Dose (oral/ i/v over 3-5 minutes):

For headache:

1 month -12yr: 250micrograms/kg b.d.

12-18yr: 4mg b.d.

For 5 days then stop or reduce to 1/2 dose or 1/4 dose.

For other symptoms associated with brain tumour:

1 month -12yr : 125-500micrograms/kg b.d.

12-18yr: 4mg b.d.

Do not give after midday as can affect night time sleep.

Dose (SC):

Can also be given in equivalent doses SC as single doses or as continuous infusion.

Dosing regimen:

Definitive procedures: use high dose prior to treatment and reduce rapidly to zero after procedure.

Symptom control: If no effect after 3-5 days stop steroids (no need to tail off)

Prolonged course: start at 0.1mg/kg b.d. and reduce by 25% every 4 days to the lowest dose that controls symptoms.

Co-prescribing: consider antacids and anti-thrush treatment.

Contraindications and warnings: caution if renal disease, cardiac disease or cystic fibrosis. Avoid in cardiac insufficiency.

Licence: licensed for use in children but not as antiemetic.

- Cyclizine

Form:

Tablet: 50mg.

Injection: 50mg in 1ml.

Suppositories: available as 'specials' 12.5mg, 25mg, 50mg, 100mg.

Dose (oral, rectal):

<1yr: 1mg/kg t.d.s.

1-4yr: 12.5mg t.d.s.

5-12yr: 25mg t.d.s.

>12yr: 50mg t.d.s.

Maximum dose in adults 150mg/24h

Dose (i/v stat):

<2yr: 1mg/kg

2-5yr: 20mg

6-12yr: 25mg

>12yr: 50mg

Dose (sc/i/v continuous infusion):

<2yr: 3mg/kg/24h

2-5yr: 60mg/24h

6-12yr: 75mg/24h

>12yr: 150mg/24h

Cyclizine is compatible with drugs most commonly used subcutaneously including diamorphine.

Licence: Licensed in children >6yrs

SKIN

Management:

General measures

- Children with terminal illnesses have skin that is susceptible to breakdown and has poor healing abilities.
- Prevention is better than cure.
- Good nursing care is required to foresee and prevent problems.
- Frequent and appropriate turning is essential to avoid pressure areas breaking down.
- Suitable mattresses and mobility aids should be employed.

Medication

At risk areas

- Protect with OpSite, Tegaderm or Cutifilm

Broken areas

- Use DuoDerm, Spyrosorb.

Infection

- Send swab for growth. Use IntraSite gel, Iodosorb paste covered with OpSite, or Tegaderm+/- antibiotics.

Cavities

- Pack with Kaltostat or Sorbsan.

Fungating tumours and odour

- Use topical metronidazole gel, charcoal dressings or honey and sugar.

Painful ulcers

- Consider anaesthetic preparations e.g. Emla cream or a topical morphine gel such as Lutrol gel. (Lutrol gel is available on request from St. Thomas' Hospital, London and other hospital pharmacies may make this up specially).

SWEATING

Consider cause:

- Disease e.g. malignant pyrexia, lymphoma, neuroblastoma.
- Drugs e.g. opioids, amitriptyline, chemotherapy.
- Infection

Management:

General measures

- Anti-cancer limiting treatment may improve sweating if it is part of a malignant syndrome.
- Fan, cotton clothing, skin care.
- Encourage plenty of fluids to avoid dehydration.

Medication

- Paracetamol (indicated if child is pyrexial)

Form:

Tablet: 500mg; dispersible tablet. Indicated if child is pyrexial 120mg, 500mg.

Oral solution: 120mg in 5ml.

Oral suspension: 120mg in 5ml; 250mg in 5ml.

Suppositories: 60mg, 120mg, 125mg, 240mg, 250mg, 500mg. 30mg as special.

Dose (oral):

Birth - 3 months: 10-15mg t.d.s. - q.d.s. (max. 60mg/kg/24h)

3months-1yr: 60-120mg t.d.s. - q.d.s. (max. 90mg/kg/24h)

1-5yr: 120-250mg t.d.s. - q.d.s. (max. 90mg/kg/24h)

6-12yr: 250-500mg t.d.s. - q.d.s. (max. 90mg/kg/24h or 4g/24h)

>12yr: 500mg-1g t.d.s. - q.d.s. (max. 90mg/kg/24h or 4g/24h)

Dose (rectal):

Do not use rectal route if child is neutropaenic.

Birth -1 month: 20mg/kg max. t.d.s. (max. 60mg/24h)

1 month -12yr: 20mg/kg t.d.s. - q.d.s. (max. 90mg/kg/24h or 4g/24h)

>12yr: 500mg-1g t.d.s. - q.d.s. (max. 90mg/kg/24h or 4g/24h)

Contraindications and warnings: dose related toxicity in hepatic failure; in moderate renal failure (creatinine clearance 10-50ml/min/1.73m²) minimum interval between doses should be 6 hours. In severe renal failure (creatinine clearance <10ml/min/1.73m²) the minimum interval is 8 h. Paracetamol is significantly removed by haemodialysis but not by CAPD.

Licence: licensed for antipyretic and analgesic use in children >3months.

- Naproxen

Form:

Tablets: 250mg, 375mg, 500mg.

Dose (oral):

>1 month: 5-10mg/kg b.d. (max. 1g/24h)

Contraindications and warnings: Contraindicated in children who have shown hypersensitivity to aspirin or other NSAIDS. Caution in asthma and cardiac, hepatic or renal failure; avoid if creatinine clearance < 20ml/min/1.73m². Extreme caution if current or previous history of peptic ulceration.

Licence: not licensed for use in children for this indication.

- Cimetidine

Form:

Tablet: 200mg, 400mg, 800mg.

Effervescent tablet: 400mg.

Syrup: 200 mg in 5ml.

Dose (oral):

1 month-12yr: 5-10mg/kg q.d.s.

>12yr: 400mg b.d. - q.d.s.

Licence: Not licensed for this indication in children.

TERMINAL RESTLESSNESS

Restlessness and agitation are not uncommon during the terminal phase. Nursing the child in a calm, peaceful, and preferably familiar environment is helpful, as is having a parent or other trusted adult present, many children settle when held by parents or family. It is important to exclude pain or inadequate positioning as a cause of distress. Hypoxia may also be a factor.

Management:

Medication

- Midazolam

Form:

Injection: 10mg in 2ml; 10mg in 5ml.

Injection may be diluted in Sodium chloride 0.9% or glucose 5%. Injection can be used for oral, buccal, intranasal and rectal administration.

Oral syrup and buccal liquid only available as 'special'.

Single doses

Intravenous/subcutaneous:

>1month -18yr: 100micrograms/kg

Buccal:

>1month -18yr: 500micrograms/kg (max. 10mg)

Tastes bitter when given orally but can be mixed with juice or chocolate sauce.

Intranasal:

>1month -18yr: 200-300micrograms/kg

Intranasal route may be unpleasant but has a fast onset of action (5-15 minutes).

Rectal:

>1month -18yr: 500-750 micrograms/kg

Continuous intravenous/subcutaneous infusion:

Dosing policies vary considerably between centres.(see below) If in doubt start at a lower dose and be prepared to titrate up over a short period until symptoms are controlled:

>1month -18yr: 300-700micrograms/kg/24h

1200-7200micrograms/kg/24h

250micrograms-1000micrograms/kg/24h

Well absorbed subcutaneously.

Titrate dose up according to need.

Midazolam is compatible in a syringe driver with diamorphine, cyclizine and other commonly used drugs.

Contraindications and warnings: caution with pulmonary disease, hepatic and renal dysfunction (reduce dose), severe fluid /electrolyte imbalance

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and congestive cardiac failure. Avoid rapid withdrawal after prolonged treatment.

Raises seizure threshold therefore a good choice for children likely to fit.

Licence: licensed for sedation in intensive care and for induction of anaesthesia in children > 7 yr. Other routes and indications not licensed.

- Levomepromazine

Form:

Tablets: 25mg (6mg available on named patient basis)

Injection: 25mg in 1ml, 1ml ampoule

Dose (SC/ i/v):

All ages: 0.5-1mg/kg/24h. (max adult dose 300mg/24h)

Titrate according to need

Also acts as antiemetic.

May lower seizure threshold.

Can be used in conjunction with midazolam.

Licence: not licensed for use as an antiemetic in children.

- See also section on noisy breathing.

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