BASIC SYMPTOM CONTROL IN PAEDIATRIC PALLIATIVE CARE

THE RAINBOWS CHILDREN'S HOSPICE GUIDELINES

7th Edition 2008

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The authors have made every effort to check current data sheets and literature up to Oct 2007, but the dosages, indications, contraindications and adverse effects of drugs change over time as new information is obtained. It is the responsibility of the prescriber to check this information with the manufacturer's current data sheet and we strongly urge the reader to do this before administering any of the drugs in this document. In addition, palliative care uses a number of drugs for indications or by

routes that are not licensed by the manufacturer. In the UK such unlicensed use is allowed, but at the discretion and with the responsibility of the prescriber.

SYMPTOM CONTROL IN PAEDIATRIC PALLIATIVE CARE

FOREWORD

Welcome to the 7th Edition of the Rainbows Symptom Control Manual. It is very pleasing to hear of its use around the world. This edition, following feedback, has new chapters on neonatology, paediatric palliative care emergencies, fluid and electrolyte balance and where to get help. Please let me know if you would like additional chapters on particular themes or if you have any comments on the work by e-mailing me sat@jassal.f9.co.uk.

This manual is provided free of charge and all the contributors work to improve paediatric palliative care around the world. Feel free to make as many copies as you like but please do not alter, plagiarise or try to copy any of the work into your own name. If you wish to use the work in a specific way then contact me for approval, I rarely say no.

We now give all the parents of our children who are receiving end of life care a copy to keep at home, to help visiting health professionals. We hope you find it useful.

INTRODUCTION

This protocol has been written to allow doctors (both GPs and Paediatricians) and nursing staff in specialised units and in the community, an understanding of the basis of symptom control in paediatric palliative care. This topic normally instills tremendous anxiety in professional people. Quite rightly if we think that the average GP will have to look after only one or two children with life limiting disorders in their entire working life. Fortunately, provided we remember the basic skills we were all taught, care of a child follows a very similar pathway to that used in adult palliative care. This protocol assumes a narrative style deliberately, as distinct from a textbook, as it is designed to provide more practical support and hands on clinical information in the acute setting. There is much more to supporting the terminal child and family than just the symptom control outlined in this paper: we must also remember the important emotional, social and spiritual needs of the child, siblings, parents, grandparents, family and society around the child.

Unless the child is older and can describe their symptoms, we need to glean an understanding of how the illness is affecting the child from all possible sources. Remember to read the notes from hospital consultants, ward nursing notes, question any specialist community health visitors and ask the opinion of the nursing staff supporting you. Doctors will spend on average 5 to 30 minutes a day looking at a child. It therefore follows that palliative care can only be done as a team approach.

The first rule is don't panic, do not dive in blindly, keep your hands tucked behind your back, your mouth shut and listen to the parents. In terminal care the parents assume a pivotal role in the care for their child. They have often experienced a variety of levels of medical and nursing care ranging from excellent to pathetic and have a much deeper understanding of their child's medical, nursing and social needs then we give them credit for. Only once you have obtained a good history from all sources should you start an examination. Remember the laying on of hands is as important as anything you may discover on your examination. Be methodical, logical and above all professional: the parents have allowed you into their lives because they perceive that you may be able to help them. Once you have formulated a plan of action go through it with the parents in language that they understand. Parents may well feel that they want more or even less than has been recommended to them. Explanation, compromise and the knowledge that decisions can be amended as the child's condition changes, allows the parents to feel that they have informed choice in the care of their dying child. This particular point is also very important in post bereavement support.

The second rule is to document and disseminate information to all your care team. Check that they are happy about the care plan and that everyone is clear about their role. Unfortunately, care at the terminal phase cannot be conducted by numerous junior doctors, deputising services or half a dozen different key workers. We as health care professionals have to make ourselves available even at short notice.

The third rule is beware that you do not fall into the same trap as Icarus (who flew too close to the sun). The intensity of emotion surrounding a dying child would make even the sun pale. Many nurses and doctors get so personally attached that they burn out emotionally. This unfortunately will be of little or no benefit for the next family they have to look after. Remember to retain a sensitive professional distance.

ANOREXIA

One of the primeval instincts all parents have is to feed their children. So when children, particularly those with malignancy, stop eating it generates considerable anxiety in their parents. Anorexia can be caused by:

- Pain
- Anxiety
- Nausea or vomiting
- Thrush in the mouth or oesophagus
- Drugs
- Depression

It is always worth hunting out and treating these conditions. Otherwise it is important to reassure the parents that the inactive child may need less food and will not be feeling hungry. There are other common-sense approaches, such as presenting small meals on a small plate, spending some time on the presentation and remembering that many of children's favourite meals, such as Macdonald's, are in fact very high in calories. The only therapeutic approach is small dose steroids used in 5 to 7 day courses. However the side effect profile is often so profound that it is normally difficult to justify.

BLADDER

Although one need not get too concerned about falling urinary output in the terminal phase of illness one should remember two special cases.

Firstly, a number of children with neurodegenerative disorders may have problems with emptying their bladder.

Secondly, children on opiates may go into retention.

Urinary retention due to opioids may improve with bethanechol or carbachol. Fentanyl causes less urinary retention than other opiates and a change to Fentanyl may be helpful. In these children gentle bladder massage, warm baths or catheterisation can easily alleviate the obstruction. Catheterisation of children is similar to adults with due regard to catheter size and depth of insertion. The loss of bladder function in a child who has previously been continent can often be a source of great distress to parents – another 'loss' that needs to be mourned, another indignity the child must suffer. The use of pads is non-invasive and simple, although may require a careful approach of tact and sensitivity to introduce.

Table 1: Drugs to treat opioid induced urinary retention

DRUG	ROUTE	SINGLE DOSE			FREQUENCY (TIMES DAILY)
		2 to 5 years	6 to 12 years	Over 12 years	
Bethanechol	Oral	0.2-0.5mg/kg/dose		10-25mg	Repeat up to 3 times daily
Carbachol	Subcutaneously	75 mcg	150mcg	250mcg	Repeat up to 3 times daily

BLEEDING

The sight of blood is very distressing to patient, parent and carer alike. If bleeding is likely, or if it has already started, gentle warning of the possibility that it could happen, or get worse, may help to reduce the distress and shock the parents' experience. Bleeding can be a major problem in a number of malignancies and liver diseases. Although it is a subject that should normally be dealt with in specialist units, in the terminal phase heroics are often inappropriate.

- Small bleeds can often be dealt with by using oral tranexamic acid or topical Adrenaline 1:1000 on a gauze and applied directly to the wound
- Bleeding gums can be helped with tranexamic acid mouthwashes or absorbable haemostatic agents such as Gelfoam or Gelfilm.
- Liver dysfunction with coagulation abnormalities can be helped with Vitamin K both orally (prevention) or by injection (acute bleed)
- Vaginal bleeding can respond to oral progestogen.

To minimise the shock of seeing their child's blood, the use of red towels and blankets may be tried.

In the face of a catastrophic haemorrhage, some authors recommend the use of intravenous diamorphine and diazepam or midazolam. If no intravenous route is available then subcutaneous diamorphine with rectal diazepam can be given. However it is important to recognise that haemorrhage of this type is normally painless and that the principle of double intent for the use of diamorphine may apply in this situation.

Table 2: Drugs to treat bleeding

DRUG	ROUTE	TOTAL DAILY DOSE (T.D.D.)		TIMES DAILY (Divide T.D.D. by this figure)
		1 month to 12 years	Over 12 years	
TRANEXAMIC ACID	ORAL	75mg/kg	2-6g	3
VITAMIN K Konakion tablets 10mg. Oral solution. Injection 1mg/0.5ml ampoules, Konakion MM 10mg/ml	ORAL, IM, IV BOLUS OVER 15-30MINS	300mcg/kg	10mg	ONCE (1mg/0.5ml injection may be used i.m. but Konakion MM must not be used i.m.)

CONSTIPATION

The management of constipation in paediatrics follows many of the same principles as in adult care, but there are certain important differences.

- The definition of constipation in paediatrics can be difficult. A newborn baby may not open its bowels for 3 days. A breast-fed baby may not open its bowels for seven days. However they would not be thought of as being constipated. It is better perhaps in paediatrics to think of alteration in bowel habits as a way of detecting constipation.
- The ability of a medication to relieve constipation is often linked less to pathophysiology than to the flavour. If it tastes bad then it's not going to go down that child's mouth without a fight. After a week of fighting, the parents will be knocking on the doctor's door.
- Oral preparations are generally preferable to rectal. Because of the number of medications that can be given to children rectally, some nurses and parents are often keen to jump into using rectal treatment very early. One should try to resist this pressure, trying to remember that this may not be in the best interests of the child.
- It is important in paediatrics to recognise the specific sensitivities of the child. Rectal examination in adults is fairly straightforward. In children it should be done only when absolutely necessary and then only by experienced physicians or nurses. The little finger should be used in most cases. A child with an anal tear may well have anal spasm of a level that makes it impossible to insert a finger without causing significant pain. Children who have had repeated rectal examinations in the past may become very distressed if they need to be re-examined. This can make the examination technically very difficult and emotionally traumatic for both the child and doctor. It is important to explain the reasons for a rectal examination to the parents, especially from a medico-legal position.
- Although much is made of diet in the management of constipation, many of the children that we see in paediatric palliative care fall under the heading of special needs. These children will have disorders that limit their ability to chew food or even swallow their food easily. The food often has to be puréed and it can take up to an hour to feed that child a single meal. Many of the children will have gastrostomies and feeds specially designed and calculated for them by dietitians.

Before rushing in to prescribe, one should consider the possible causes of constipation in children.

- Inactivity – some children with neurodegenerative or genetic disorders can find themselves becoming wheelchair bound e.g. the muscular dystrophy boys.
- Neurological – as some of the neurodegenerative disorders progress they can affect the nerve pathways and musculature required for defecation e.g. myotonic dystrophy. Due to the rarity of many of these conditions we are often unaware of the actual mechanism involved.

- Metabolic – dehydration can affect all children very quickly. Cystic fibrosis (meconium ileus equivalent) can cause constipation. Hypercalcaemia and hypokalaemia can cause problems in paediatric oncology.
- Decreased food intake – as any parent will know, any child who feels unwell may go off their food. Children in the paediatric oncology field are particularly susceptible as they are affected both by the disease process and the treatment modalities.
- Fears of opening bowels – a child who is constipated may well get significant pain when he does actually defecate. For the child the best way not to have pain is to hold back the urge to empty his bowels for as long as possible.
- Rectal tears - when children pass hard, large stools, these stools can through stretching cause superficial rectal tears. This results in two problems. The tears are very painful when the child tries to empty its bowels. The tears produce anal spasm and so emptying the bowels require the child to exert even greater pressure and strain than normal.
- Social –many children are shy or nervous about using toilets outside the home or away from their parents. They may not know where the toilets are, or may be too shy to ask a nurse to help them.
- Drugs –one of the major causes of constipation in the hospice is iatrogenic. Doctors continue to fail to appreciate the side effect profiles of the drugs that they use. Although the constipation side effects of the opioids are well recognised many physicians fail to remember that anticholinergics (hyoscine etc) and anticonvulsants can also induce constipation.
- Liase with parents –they know their child and his/her habits, also they may have misconceptions about defecation and use of laxatives, cooperation is needed for treatment to be successful.

Types of laxatives.

The types of laxatives used in paediatrics are often limited by special factors such as taste. Laxatives can be divided into predominantly softening or peristalsis stimulating, also whether they are used orally or rectally.

Table 3: Softening Laxatives Given Rectally

Type	Mechanism	Notes
Lubricant e.g. *Arachis oil, olive oil*	Penetrates stools and softens.	Used as retention enemas overnight to soften stool. Be careful of nut allergy as arachis oil is made from peanuts.
Surfactant e.g. *sodium docusate*	Act like detergents and increase water penetration into stool.	Can be used by itself. Other similar compounds found in mini-enemas.
Osmotic e.g. *glycerine*	Soften stool by osmosis and act as a lubricant.	Very useful as they come in various sizes.

Saline e.g., *sodium phosphate*	Release bound water from faeces and may stimulate peristalsis.	Very effective in difficult cases. Also has an osmotic mechanism of action. Repeated use is inappropriate and can cause biochemical imbalance.

Table 4: Softening Laxatives Given Orally

Type	Speed of onset	Mechanism	Notes
Lubricant e.g. *Paraffin*	1 to 3 days	Penetrates stools and softens	Taste and risk of inhalation particularly in children with gastro-oesophageal reflux limits use. No longer recommended for internal use
Surfactant e.g. *docusate or poloxamer*	1 to 3 days	Act like detergents and increase water penetration into stool.	Docusate can be used by itself. Poloxamer is combined to make co-danthramer.
Bulk forming e.g. *Fybogel*	2 to 4 days	Act as stool normalisers.	Very limited use in paediatric palliative care.
Osmotic e.g. *lactulose*	1 to 2 days	Exert an osmotic influence in the small bowel and so retain water in lumen.	First line treatment. Sickly taste can be overcome by using granules.
Saline e.g. *Magnesium hydroxide or sulphate, sodium sulphate*	1 to 6 hours	Osmotic effect in all of gut. Increase water secretion and stimulate peristalsis.	Not used very much in ill children because of their strong purgative action.

Table 5: Peristalsis Stimulating

Type	Speed of onset	Mechanism	Notes
Anthracene e.g. *senna and danthron* Polyphenolics e.g. *bisacodyl and sodium picosulphate*	Orally 6 to 12 hours or rectally 15 to 60 minutes	Directly stimulate the myenteric plexus	Senna is very commonly used as the liquid. It combines well with lactulose. Danthron is used in combinations e.g. co-danthramer. Bisacodyl can be given orally or rectally. It is particularly useful in its suppository form. Sodium picosulphate should be reserved for the most difficult cases.

Having developed an understanding of the special needs of children with constipation and the types and mode of action of the medication we can now outline a simple strategy.

Step 1 –take a history and examine the child. Abdominal examination may reveal a sausage shaped mass in the left iliac fossa. Rectal examination may reveal a rectum that is full of hard stools, soft stools or empty. Assess possibility of impaction and overflow presenting as diarrhoea or faecal soiling.

Step 2 –start with lactulose, building up the dose over a week.

Step 3 –if no improvement add senna or change to co-danthramer.

Special Step 4 –if the child is on an opioid then ignore step 2 and start on co-danthramer straight away.

Step 5 –if the child is distressed with the constipation, then from the rectal examination:-

If stool hard – use glycerine suppository.
If stool soft – use bisacodyl suppository.
If rectum empty –use bisacodyl suppository to *bring stool down* or high phosphate enema.

Step 6-if severely constipated use MiraLax or phosphate enema or if you have time movicol (see table 6)

Movicol is an iso-osmotic laxative only licensed for children over the age of 2 years. It is flavour and sweetener free but most importantly it is highly effective

Table 6: Number of sachets of Movicol to use in Severe Constipation

Number of Sachet of Movicol							
Age	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
2-4yrs	2	4	4	6	6	8	8
5-11yrs	4	6	8	10	12	12	12

Step 7 –if manual removal is necessary then use a topical anaesthetic gel or discuss the possibility of a general anaesthetic with the local hospital.

As with so many conditions in medicine, prevention is better than cure. The physician should attempt to predict the possibility of constipation and treat it prophylactically.

Novel approaches

It is helpful to know about a number of alternative approaches to constipation, although all of these are unlicensed uses of these agents. The use of prokinetic drugs such as metoclopramide or domperidone (less effective but less dystonic) have been shown to be helpful. The side effects of increased bowel motility with erythromycin

can be effective. Oral naloxone can help with opioid induced constipation, whilst its poor absorption from the gut limits its effects systemically.

Table 7: Drugs used to treat constipation

DRUG	ROUTE	TOTAL DAILY DOSE (T.D.D.)		TIMES DAILY (Divide T.D.D. by this figure)	SPEED OF ONSET	NOTES
		1 month to 12yrs	Over 12yrs			
LACTULOSE	Oral	1ml/kg	45mls	1 to 3	36-48hrs	Tastes sickly. Often use more
SENNA	Oral	0.5ml/kg syrup	15-30mg	1 to 2	8-12hrs	Syrup7.5 mg/5ml
BISACODYL	Oral or Rectal	5mg	10mg	1	Tabs 10-12 hrs Sup 20-60 mins	
DOCUSATE	Oral	**Over 6 months** 5mg/kg	Up to 300mg	3	24-48hrs	
	Rectal	1mg/kg		1	20-60 mins	
CODANTHRAMER 25/200	Oral	2.5-10mls	10-20mls	1 or 2	8-12hrs	
CODANTHRUSATE	Oral	2.5-10mls	10-20mls	1 or 2	8-12hrs	
SODIUM PICOSULPHATE	Oral	**2-5 years**: 2.5 mls **5-10 years**: 2.5-5mls	5-15ml	1		At night
GLYCERIN	Rectal	**<1 year**: 1g **1-12 years**: 2g	4g	1		Moisten with water before insertion
MICRALAX enema	Rectal	**Over 3 years** 1 dose (5ml)	5ml	1	15-30 mins	
PHOSPHATE enema	Rectal	**3-7 year**: 1/3 to ½ enema **7-12 year**: ½ to ¾ enema	¾ to 1 enema	1		Risk of electrolyte imbalance
METOCLOPRAMIDE	Oral	300 micrograms/kg	**Under 60kg** 15mg **Over 60 kg** 30mg	3		
NALOXONE	IV Bolus	10 microgram/kg Then 100 microgram/kg (maximum 2mg)	10 microgram/kg (Max. 800 microgram) then 2mg	Single dose		

	IV Infusion	5-20 microgram/kg/hr	Infuse a solution of 4 microgram/ml at a rate adjusted according to response	Continuous		

COUGH

The management of cough involves accurate diagnosis of the various causes of cough. Often the underlying illness will give clues to the cause but be wary of dual pathology.

Causes.

- Cystic Fibrosis
- Heart Failure
- Lung Metastases
- Infections
- Neurodegenerative Disorders
- Gastro-oesophageal Reflux
- Seizure activity

Initial treatment consists of treating the underlying cause i.e. diuretics for heart failure, antibiotics for infections etc. Clues to coughing being driven by subclinical seizure activity are its paroxysmal and episodic clustering, its association with retching and/or screaming together with a background of poorly controlled epilepsy. Oral chlormethiazole (although recognised to have poor efficacy in epilepsy) can be effective for this and is less likely to increase respiratory secretions than benzodiazepines. Hyoscine patches can help dry excessive secretion particularly in the neurodegenerative disorders.

However, we are often confronted with situations when symptomatic treatment is required. Humidified air or oxygen can help in a number of cases. It is often worth trying nebulised salbutamol or Atrovent although sometimes nebulised normal saline works just as well. Sometimes a child unaccustomed to masks and nebulizers may become distressed with this treatment, and staff along with parents may have to judge whether the efficacy of this treatment is worth the distress caused to the child.

Physiotherapy with or without suction can often settle a child down. One of the most effective treatments is to hold the child propped up: parents and carers are very good at this and it may help them to feel involved in the care of the child. Cough suppressants can also be used starting with simple linctus or pholcodine (often not very effective at this level), then codeine linctus and if necessary morphine or diamorphine linctus. Coughing can be very exhausting for the child and family and warrants aggressive management from the care team. An adult approach is to use nebulised local anaesthetics such as lignocaine or bupivacaine. However, this is much less appropriate in children both because of the unpleasant taste and numbness that it leaves in the mouth and because in the presence of neurological compromise, there is risk of aspiration when the gag reflex is anaesthetised.

Table 8: Drugs used to treat cough

DRUG	ROUTE	TOTAL DAILY DOSE (T.D.D.)		TIMES DAILY (Divide T.D.D. by this figure)
		1 month to 12 years	Over 12 years	
Morphine Linctus	Oral	**<1 year** 80 microgram/kg **1-12 years** 200-400 microgram/kg	30-90mg	6
Codeine Linctus	Oral	1mg/kg	60-240mg	4
Chlormethiazole	Oral	1.5-3mg/kg	-	6 (higher doses may be required)
Hyoscine hydrobromide	Transdermal patch	**2-3 years** ¼ patch **3-9 years** ½ patch **10-12 years** 1 patch	1 patch	Behind ear, or other hairless area, every 72 hrs. Patches can be cut but masking a proportion of the patch is better practice
	SC or IV infusion	60-100 microgram/kg/day		Continuous over 24 hours

DIARRHOEA

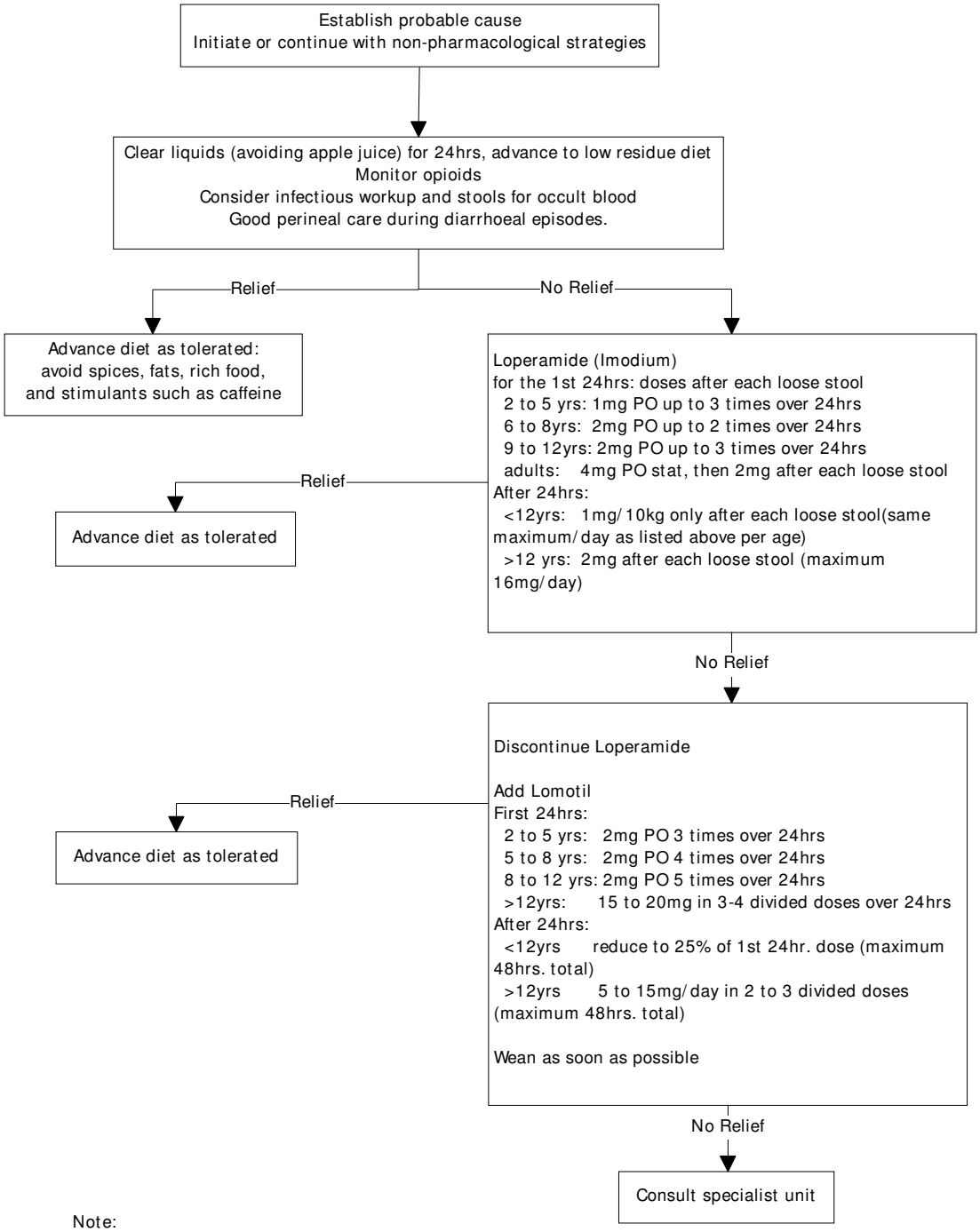
Diarrhoea in children can occur for various reasons and requires a detailed history of past illness, diet, medication and treatments.

Causes

- Gastroenteritis
- Faecal impaction
- Malabsorption / diet
- Drug induced e.g. antibiotics
- Post radiation / chemotherapy
- Concurrent illness e.g. colitis

Simple reassurance, and clear fluids, can deal with most cases. Dioralyte can be helpful to replace sugar and salts in the short term. Faecal loading and impaction would need appropriate treatment. Nappy rashes are common and barrier creams should be used early to prevent rashes. Subsequent rashes can be treated with exposure of the skin to air and Daktacort cream. Stool cultures and reducing substance screens are sometimes needed to make an appropriate diagnosis. The use of live yoghurt or soya milk can sometimes help with malabsorption. If however simple methods fail, then a pharmacological approach is needed.

Diarrhoea Treatment Algorithm



Note:
For AIDS patients, consider metronidazole; if malabsorption is contributing to diarrhoea

Adapted from and used by permission: Mo Pomietto Pediatric Pain and Symptom Algorithms for Palliative Care.

DYSPNOEA

Dyspnoea refers to a subjective sensation that breathing has become unpleasant, rather than an objective observation that it has become fast or difficult. This is an important distinction as it underlines the importance of discrimination in investigating and treating.

Dyspnoea can be a frightening symptom; the idea that their child is suffocating to death would terrify any parent. Correct early treatment can be very rewarding and helps parents to develop confidence in the care team. As in all symptoms a good understanding of pathology and physiology makes management a simple and logical process.

Causes include:

- Anaemia
- Anxiety
- Ascites
- Cerebral tumours
- Congenital heart disease
- Cystic fibrosis
- Hepatic or renal impairment
- Infection
- Metabolic
- Mechanical
- Pleural effusion, left ventricular failure or pneumothorax
- Raised intracranial pressure
- Respiratory muscle dysfunction e.g. neurodegenerative disorders
- Secondary tumours i.e. lymphoma

Anaemia is often seen in the haematological malignancies, and towards the terminal phase can cause mild to moderate dyspnoea. The decision to give blood transfusions is often difficult. Transfusion is an invasive process, which limits parent child contact and is not without a degree of discomfort for the child. Transfused blood itself, for various reasons of storage, is not always as successful as expected at reducing dyspnoea. Communication between hospital specialist unit, the care team and parents is therefore essential in making the appropriate decision.

Anxiety and dyspnoea is the proverbial chicken and egg. Anyone who cannot breathe will feel anxious. The process of anxiety itself will lead to hyperventilation. This in itself will make the dyspnoea feel worse. It is therefore important that initial management should be to calm the situation down and reassure both the child and parents. Small dose diazepam, midazolam or chloral hydrate can be helpful without necessarily suppressing respiration.

Cerebral tumours can affect the respiratory centres either directly through local invasion or indirectly by raising intracranial pressure. Dexamethasone is helpful in the

short term, but eventually the progression of the disease or side effects from the steroids reduce their benefit.
A child propped up by a calm parent or carer with oxygen via a nasal tube will help most cases of dyspnoea. In palliative care higher than normal flow rates are perfectly acceptable. However we will often see children on heroic doses of oxygen (10-14L/min). This is very rarely necessary for the child and appears to be more for the doctors and parents. It is often helpful to measure oxygen saturation (pulse oximeter) but probably better to look at the child and their condition in the context of their illness.
The oxygen cylinders used in the community are smaller than those in hospitals so with higher rates of flow it is always worth ordering more cylinders than normal

1360L cylinder lasts 11 hrs @ 2L/min

Nasal cannulae	1L/min	24% delivered
	2L/min	28% delivered
Ventimask	2L/min	24% delivered

Oxygen concentrator x1 = 2-4L/min
X2 = 4-8L/min

Dyspnoea is commonly seen in the neurodegenerative disorders due to weakened respiratory muscles and inability to clear secretions. Physiotherapy should be done very gently in these often fragile children. Suction can cause more distress than benefit and should in such cases be undertaken by experienced staff or not at all. Thick secretions can be managed with mucolytics such as n-acetyl cysteine. The use of nebulised normal saline can also be helpful in difficult cases (be aware that some children can have reflex bronchospasm).
Pleural effusions are thankfully rare, tending to occur in lymphoma and other malignancies. Pleural taps are invasive, can be distressing for the child and may only give temporary relief.
Two other empirical treatments that should be considered are nebulised bronchodilators and analgesia. Even without the presence of wheeze, nebulised salbutamol or ipratropium can produce symptomatic benefit. Remember Atrovent at this stage need not be limited to the under ones. The use of oral morphine or subcutaneous diamorphine (in half-analgesic doses) can help settle dyspnoea. They reduce anxiety and pain, settle down the respiratory centres and reduce pulmonary artery pressure, which is the cause of a lot of breathlessness (this effect is more marked with diamorphine).

Table 9: Drugs used to treat dyspnoea

DRUG	ROUTE	Individual Single DOSE		TIMES DAILY
		1 month to 12 years	Over 12 years	
Salbutamol nebulizer soln 2.5mg/2.5ml	Nebulizer	**6 months-5yrs** 2.5mg **Over 5 yrs** 5mg	5-10mg	Up to 6-8
Ipratropium nebulizer soln 250mcg/ml	Nebulizer	**Under 1 yr** 125mcg **1-5years** 250mcg **Over 5 yrs** 500mcg	500mcg	Up to 4
Acetylcysteine (Use is controversial)	Nebulizer	8mls 10%	8mls 10%	Use up to 4 times a day (Avoid contact with metal or rubber Dilute 20% neb soln with equal volume of NaCl 0.9%)
	Oral	100-200mg	200-400mg	3
DRUG	**ROUTE**	**TOTAL DAILY DOSE (T.D.D.)**		**TIMES DAILY (Divide T.D.D. by this figure)**
		1 month to 12 years	Over 12 years	
Dexamethasone 2mg/5ml	Oral	1-6mg		2
Diazepam	Oral	**2-12 years** 5-10mg	5-30mg	3

EMERGENCIES IN PAEDIATRIC PALLIATIVE CARE

Uncontrolled and distressing symptoms are a medical emergency and need to be actively treated.

Types of emergency in paediatric palliative care:

- Severe pain.
- Difficulty breathing and airway obstruction.
- SVC obstruction.
- Spinal cord compression.
- Agitation.
- Haemorrhage.
- Seizures.
- Urinary retention.

Most emergencies can be anticipated by knowing the natural history of a disease (for example, anticipate breathlessness in disease that metastasises to lungs) and from a knowledge of the individual child (eg anticipate haemoptysis in a child with pulmonary Aspergillus).

Proactive planning and preparation for medical emergencies is essential

- Discuss possible events with the family.
- Discuss how events could be managed at home, in hospital or in a hospice. Management can sometimes vary according to location (eg a chest drain would not be inserted at home to manage a pneumothorax, but could be done in hospital).
- Find out where the child and family want to be in an emergency situation eg move to hospice, stay at home.
- Have a management plan which parents can initiate.
- Appropriate drugs available and usable.
- Make sure parents have professional they can contact.
- Make sure the professional they will contact has a plan.

Investigation, management and treatment of palliative care emergencies

With all emergencies it is important to consider:

- Do I need to know the underlying cause or can I manage the symptom effectively without confirming the cause?
- Is the underlying cause likely to be treatable?
- Are investigations of the underlying cause appropriate (for example, are they invasive, do they require being in hospital etc).
- Will treating the underlying cause improve prognosis or quality of remaining life?
- How effective could any potential treatment be?
- How toxic could any potential treatment be?

- Will the child have to move to another location for the investigation and/or treatment? Will this be possible, will they be willing to do this?
- Wishes of child & family.

It is essential to adopt a holistic approach to symptom management, as medication alone is rarely sufficient.

Uncontrolled or poorly controlled pain

Good early pain control is the best way to avoid severe uncontrolled pain at the end of life. It is essential that drug doses are increased quickly enough to manage rapidly escalating pain, and that the right analgesic is used. Inadequately treated neuropathic pain is perhaps one of the hardest to manage emergencies, yet one that is potentially preventable when tackled early.

Sudden onset rapidly escalating opiate-sensitive pain

This type of pain is often seen in children with cardiac disease associated with pulmonary constriction. It is also seen in children with malignant disease who have rapid onset of break-through pain that is opiate responsive, but where oral opiates take too long to be effective.

Intranasal or buccal morphine

- Use the i.v. solution.
- Start with a dose of 0.05 mg/kg if the child is opiate naïve, 0.1mg/kg if the child is already on opiates.
- Make sure the parents are able to draw up and administer the medication – it is useful to mark the syringe clearly with the volume of morphine they will need to give.
- Advise the parents to repeat the dose every 10-15 minutes up to a maximum of the dose you would give if you were giving an i.v. breakthrough dose. It is unusual for a child to need as much as this.
- If a child needs 2-3 doses, increase the starting dose for the next episode to the total dose that was needed in the previous episode.
- If you do not get good pain relief, despite titrating the dose up, then this is unlikely to be purely opiate sensitive pain.

Neuropathic pain

Neuropathic pain should always be considered in the following groups of children:

- Any solid tumour
- Epidermolysis bullosa
- Rapidly progressive spinal curvature
- Dislocated/displaced hip

We also suspect that some children with encephalocoele and hypoxic ischaemic encephalopathy experience neuropathic pain.

It is absolutely essential that neuropathic pain is treated early, particularly in children with malignant disease, before a crisis situation arises.

For children with severe neuropathic pain that needs emergency treatment the following options should be considered:

- For solid tumours: high dose dexamethasone and radiotherapy.
- Methadone: either added in as an additional analgesic or by converting all opiates to methadone.
- Ketamine: sublingual or by continuous subcutaneous infusion.
- Lidocaine: by continuous subcutaneous infusion.
- Regional nerve block.
- Intrathecal and epidural analgesia: this is best considered ahead of a crisis situation. In the right situations it can be extremely effective and children with severe uncontrolled neuropathic pain can become completely pain free.

We strongly advise that methadone, ketamine and lidocaine are only considered with the support of a specialist palliative care or pain team.

Breathlessness

Breathlessness should be anticipated in the following situations:

- Reduced lung volume eg tumour growth, chronic lung disease.
- Upper airway obstruction eg from tumour.
- Pneumothorax eg in children with lung metastases.
- Superior vena cava obstruction.
- Pulmonary oedema eg in children with cardiac failure.
- Chest infection.
- Anaemia.

Treatment of the underlying cause should always be considered, but may not be appropriate or possible

- Steroids and radiotherapy or chemotherapy for malignant disease.
- Chest drain for pneumothorax.
- Diuretics in pulmonary oedema.
- Antibiotics for chest infection.

Severe sudden onset breathlessness:
When this occurs, it is often a terminal event. The goal of care is to get the child settled and comfortable as quickly as possible

- Give buccal midazolam 0.5mg/kg and buccal morphine 0.1 mg/kg.
- Repeat every 10 minutes until the child is settled.
- As soon as possible, set up a continuous subcutaneous or intravenous infusion of midazolam 0.3mg/kg/24hrs and morphine or diamorphine at a dose that is at least the equivalent of an intravenous breakthrough pain dose. If pulmonary oedema is likely to be a contributing factor to the breathlessness, consider

adding furosemide, either 0.5mg/kg (od-qds) stat or into the continuous infusion (NB at high opiate doses, furosemide may precipitate out).

Superior Vena Cava (SVC) Obstruction

SVC obstruction is most likely to occur in children with mediastinal tumours.
Typical signs of SVC obstruction are:

- Breathlessness.
- Headache.
- Visual changes.
- Dizziness.
- Swelling of face, neck, arms.

Emergency treatment is usually with steroids, usually dexamethasone (1-2 mg/kg/day up to 16mg maximum)
Radiotherapy and/or chemotherapy may then be considered
Symptomatic management of breathlessness before the tumour shrinks is essential

Spinal Cord Compression

This is a real medical emergency and prompt appropriate treatment is essential. By the time clinical signs are classic, treatment is unlikely to reverse the disability

Most usually seen in children with intramedullary metastases, intradural metastases or extradural compression (vertebral body metastases, vertebral collapse, interruption of vascular supply)

Early signs of spinal cord compression

- Back pain.
- Leg weakness.
- Vague sensory disturbance in legs.

Late signs of spinal cord compression

- Profound weakness.
- Sensory level.
- Sphincter disturbance.
- Emergency treatment is with steroids, usually dexamethasone (1-2 mg/kg/day up to 16mg maximum).
- Radiotherapy and/or chemotherapy may then be considered.
- Spinal surgery may also be an option.

Agitation

Consider and treat underlying causes where appropriate, eg

- Fear, anxiety, bad dreams
- Pain
- Medication
- Constipation
- Dehydration
- Hypoxia

- Anaemia

Sudden onset severe agitation can be relieved with intranasal or buccal midazolam 0.2-0.5mg/kg. The buccal preparation is not always easy to get hold of quickly, so the i.v. solution can be used instead (given intranasally or buccally at the same dose).

Cerebral irritability

This is not always easy to diagnose and is often a diagnosis of exclusion. It is most frequently a problem in children with severe birth asphyxia. Whilst not strictly something that occurs acutely, these children can cry for hours, without any response to comfort or analgesia.
Medication that can be helpful includes:

- Phenobarbital (1-4mg/kg once to twice daily)
- Levomepromazine (0.25 – 1 mg/kg up to 4x day)
- Buccal midazolam (0.5mg/kg as needed). Midazolam can be used in a crisis situation when the baby needs something to break the cycle of crying and help him relax and go to sleep. It should not be considered as 'treatment' for the irritability, but as an essential drug for crisis management.

Acute pulmonary haemorrhage

Children most at risk from this are those with pulmonary Aspergillus, often following bone marrow transplant. It can be a dramatic and catastrophic terminal event. Families must be warned if this is a risk.

- Use coloured towels to soak up blood, so the visual bleeding is less dramatic
- Give buccal or intranasal midazolam 0.5mg/kg and buccal or intranasal morphine 0.1mg/kg. Repeat these every 10 minutes until the child is settled. Giving buccal drugs can be very difficult during an acute haemorrhage, so if in hospital give stat i.v. or s.c. doses.
- As soon as possible, start a continuous subcutaneous or intravenous infusion of midazolam 0.3mg/kg and morphine at a dose that is at least the equivalent of an i.v. breakthrough dose. In an acute severe haemorrhage, the child is likely to die before this is possible.

Seizures

Seizures should be treated according to local seizure management protocols eg using PR diazepam, buccal midazolam, paraldehyde and/or i.v. lorazepam.

Resistant seizures can become a medical emergency.

- First line treatment should be with a continuous infusion of midazolam 0.25-3mg/kg/24hrs. We would recommend starting at a low dose and incrementing every 4-6 hours as necessary.
- If seizures continue, add in s.c. phenobarbital. If the child has not recently been on similar drugs, give a loading dose of 15mg/kg over 30-60 mins, then start a continuous infusion at 500mcg/kg/hr. Increment by 20% increases every 6 hours until seizures stop.

- For children with severe neurological disorders who have been on multiple anticonvulsants, we have found midazolam is not always helpful and tend to omit this step.

Urine retention

The most usual causes of urine retention are:

- Side effect of morphine.
- Constipation.
- Spinal cord compression.
- Solid tumours.

Treating the underlying cause can be effective, such as switching to an alternative opiate or using dexamethasone and/or radiotherapy to shrink a solid tumour.

Having a warm bath and encouraging the child to pass urine in the bath is often the most effective crisis management for children with opioid-induced retention. Creating a relaxed atmosphere and gentle bladder massage are also helpful.

Catheterisation may be necessary to relieve the discomfort of a full bladder. This will usually only be needed for a short time in opioid-induced retention. Be very cautious if considering catheterisation in a child with a solid tumour obstructing urinary outflow – it is likely they will need a suprapubic catheter.

NOISY BREATHING

Noisy breathing from excessive secretions or a death rattle in an unconscious child is very distressing. Excessive respiratory secretions are a dose-related side effect of all the benzodiazepines.
Hyoscine hydrobromide can be used to dry secretions and its sedative effects can be helpful. It can be given as patches (some centres use 3 days on, 1 day off) or by subcutaneous infusion. It has a tendency to inflame subcutaneous sites after 24-48hrs and so the site should be moved regularly. Officially the patches should not be cut but instead occluded to produce the half and quarter patch, in reality most users tend to cut the patches.
The anticholinergic drug Glycopyrronium has been used in children with chronic handicap to reduce hypersalivation.
The death rattle can be treated with diamorphine, midazolam subcutaneously or diazepam rectally.

Table 10: Drugs used to treat noisy breathing

DRUG	**ROUTE**	**TOTAL DAILY DOSE (T.D.D.)**		**TIMES DAILY (Divide T.D.D. by this figure)**
		1 month to 12 years	Over 12 years	
Midazolam	S.C or I.V. infusion	25-150microgram/kg/hour		Continuous over 24 hours
Hyoscine hydrobromide	Transdermal Patch	**2-3 years** ¼ patch **3-9 years** ½ patch **10-12 years** 1 patch	1 patch	Behind ear, or other hairless area, every 72 hrs. Patches can be cut
	SC or IV infusion	40-60 microgram/kg/day		Continuous over 24 hours
Glycopyrronium	Oral	120-400 microgram/kg/day		3-4
Diazepam	Rectal soln	**2-12 years** 5-10mg	10-30mg	3

FLUID AND ELECTROLYTES MANAGEMENT

Patient weight and blood pressure are useful parameters in assisting with fluid balance interpretation, but it should be borne in mind that BP may be elevated due to causes other than fluid overload. Also, insensible losses need to be considered, so a positive balance on a chart is usually not strictly accurate as it does not account for this loss.

For practical purposes, 1kg of weight = 1 litre of fluid.

No action should usually be taken on the basis of a single parameter (eg fluid balance alone). The child should be fully assessed, including BP, heart rate, respiratory rate, capillary refill time, temperature, weight and general condition.

Remember, older children can tolerate a larger positive fluid balance than younger ones.

Normal Fluid Requirements

Blood volume is about 100ml/kg at birth, falling to about 80ml/kg at 1 year of age. Total body water varies from about 800ml/kg in the neonate to about 600ml/kg at 1 year, and subsequently varies very little. Of this, approximately 2/3 (or 400ml/kg) is intracellular fluid, the rest is extracellular fluid.

Normal daily fluid maintenance requirement is calculated on the basis of the amount of fluid required to keep a patient well hydrated and passing reasonable amounts of urine. The standard calculation (based on APLS recommendations) includes the following considerations:

1. Baseline maintenance requirements.
2. Replacement of insensible losses through sweating, respiration, normal stool loss (usually 10ml/kg in an adult, 20ml/kg in a child & 30ml/kg in a baby <1 year).
3. Replacement of essential urine output (= minimal urine output required for waste excretion).
4. Some extra fluid to maintain a modest amount of diuresis.

The calculation is by weight and thus applies to all age ranges.

Total daily fluid requirement consists of:

Maintenance + Replacement of Deficit (existing/ongoing loss) + Resuscitation (if required).

Calculation of Maintenance Fluid Requirement
(Includes 1+2+3+4 above)

Body Weight	Fluid Requirement per 24 hours	Fluid Requirement per hour
First 10 kg	100ml/kg/24 hrs	4ml/kg/hr
Second 10 kg	50ml/kg/24 hrs	2ml/kg/hr
Each subsequent 1 kg	20ml/kg/24 hrs	1ml/kg/hr

e.g., 24kg: = (100x10kg) + (50x10kg) + (20x4kg) OR (4x10kg) + (2x10kg) + (1x4kg)
= 1000 + 500 + 80 = 40 + 20 + 4
= 64ml per hour x 24
=1580ml per 24 hours **= 1536ml per 24 hours**

This shows that either method of calculating fluids is acceptable, giving reasonably close answers for fluids for a 24 kg child over a 24 hour period. (Indeed, the difference between the 2 methods is less than 2ml/hr).

In addition to the above, maintenance fluid requirements, ongoing losses (eg due to significant gastrointestinal losses i.e. diarrhoea or vomiting, polyuria) need to be considered and replaced. In febrile patients, insensible losses through sweating and respiration will be higher than usual; add approximately 13% extra fluid for each 1 degree C > 37.5 degrees C.

Replacement Fluid (Deficit = existing + ongoing losses)

Ongoing losses, e.g., due to significant diarrhoea or vomiting, may be replaced intravenously on an ml-for-ml basis or as part-replacement if the patient is also tolerating some oral fluids.

Existing losses (i.e., dehydration)

Percentage dehydration can be estimated clinically using the following parameters: (APLS guidelines)

Signs and Symptoms of Dehydration

Sign/Symptom	Mild (<5%)	Moderate (5-10%)	Severe >10%
Decreased urine output	+	+	+

Dry mouth	+/-	+	+
Decreased skin turgor	-	+/-	+
Tachypnoea	-	+/-	+
Tachycardia	-	+/-	+

NB Tachypnoea may be due to, or worsened by, metabolic acidosis & pyrexia.
Tachycardia may be due to hypovolaemia, but also due to other causes e.g. pyrexia, pain or irritability.

A low blood pressure is a serious sign in a child: it may be due to hydration / hypovolaemia or due to other causes e.g. septic shock. It is a late/peri-arrest sign, and preventative action should be taken prior to the child reaching this stage.

To Calculate Replacement Fluids (according to % dehydration):

Fluid deficit (ml) = Percentage dehydration x Weight (kg) x 10
e.g., A 24 kg child is 7.5% dehydrated, calculated fluid requirement.
(Assuming no resuscitation required)

Fluid deficit = 7.5 x 24 x 10
= 1800ml

Maintenance = (100 x 10kg) + (50 x 10kg) + (20 x 5kg)
= 1000 + 500 + 80
= 1580ml

Thus Total fluid requirement = Maintenance + Deficit + Resuscitation fluids
= 1580ml + 1800ml + 0
= 3380ml over 24 hours
(+ addition for ongoing losses on a ml-for-ml basis)

Normal Daily Electrolyte Requirements

Sodium	2-4mmol/kg/day
Potassium	2 mmol/kg/day
Calcium	3 mmol/kg/day
Magnesium	0.75mmol/kg/day

To calculate electrolyte deficit:

Deficit (mmol) = (Normal level – actual level) x weight (in kg) x 0.7

e.g., 24kg child with serum potassium of 2.5mmol/l

Deficit = (4-2.5) x 24 x 0.7
= 25.2mmol

Maintenance = 2mmol/kg/day
= 2 x 24

= 48mmol

Thus, total requirement = Deficit + Maintenance
= 25 + 48
= 73mmol

If not taking oral fluids will need maintenance hydration containing 73mmol over next 24 hours.
If taking diet, and hence maintenance electrolytes, needs 25 mmol extra potassium over next 24 hours.

GASTRO-OESOPHAGEAL REFLUX

GOR is a very common and probably under recognised problem in neurologically impaired children, perhaps around 50% (15-75%) in this group. The commonest GOR-associated symptoms are shown in bold type. The symptoms are particularly significant if multiple, and if during or after feeds.

Gastro-intestinal:
Food refusal
Vomiting (especially during /after feeds and supine at night)
Dysphagia / difficulty swallowing
Weight loss / failure to thrive
Haematemesis / melaena

Respiratory:
Troublesome secretions
Aspiration pneumonia
Recurrent RTIs / bronchitis
Cough
Wheezing
Choking / gagging

Other symptoms, especially with temporal relation to feeding:
Irritability (especially when supine)
Pain
Hyperextensive posturing
Sandifer's syndrome (neck extension and head rotation during / after meals in infant / young child, associated with iron deficiency anaemia and severe oesophagitis)

Non-drug treatments

- Adjust posture.
- Alter feeding regime from large bolus to frequent small volume, or if nasogastric/gastrostomy fed, overnight feeding / continuous feeding (sometime this may aggravate symptoms: try it and see).
- Check for overfeeding, especially if nasogastric/gastrostomy fed.
- Thicken feed with gum or starch. However, this may aggravate symptoms by osmotic effect.

Drug treatments

- Antacids, especially Gaviscon for its raft as well as antacid effects
- Omeprazole reduces noxious effects of reflux via its actions as a proton pump inhibitor.
- Ranitidine can be used as second line, but can give problems with rebound nocturnal acid secretion.
- Prokinetic e.g. domperidone or metoclopramide.

If, despite maximal medical therapy, vomiting, weight loss or distress continues then surgery needs to be considered. Fundoplication with or without pyloroplasty is effective in over 80% of cases, but has a high morbidity (26-59% post-operative complications, 6-70% get recurrent GOR and 5-15% need repeat surgery). If the child has severely compromised nutrition, inefficient feeding, NGT dependency or swallowing problems then gastrostomy should be considered simultaneously.

Table 11: Drugs used to treat gastro-oesophageal reflux

DRUG	ROUTE	TOTAL DAILY DOSE (T.D.D.)		TIMES DAILY (Divide T.D.D. by this figure)
		1 month to 12 years	Over 12 years	
Gaviscon	Oral liquid	**Over 2 years** 5-10mls	10-20ml	Single dose after meals
	Infant sachet 1 dose = half a dual sachet	**Under 2 years** < 4.5 kg = 1 dose > 4.5kg = 2 doses		Single dose with each feed
Omeprazole	Oral	700 microgram/kg up to 3mg/kg/day	20-40mg	Once
Ranitidine	Oral	4-8mg/kg (maximum 300mg)		Twice
Domperidone	Oral	200-400mcg/kg (Up to 1.6mg/kg/24hrs)	10-20mg	Single dose (May be repeated up to 4 times. Watch for extrapyramidal effects)
Metoclopramide	Oral	200-300mcg/kg	**Under 60kg** 15mg **Over 60kg** 30mg	Three

Omeprazole

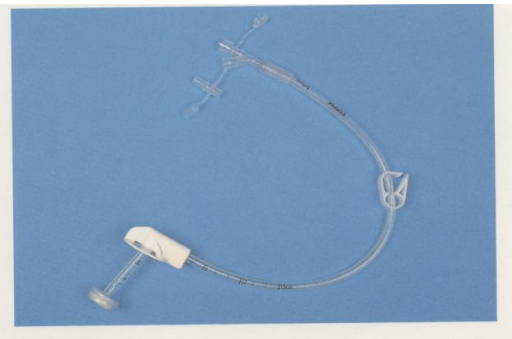
For children who can not swallow tablets or capsules then the following can be tried

Open capsule and mix granules with acidic drink (orange or apple juice) and swallow without chewing
MUPS tablets can be dispersed in water, fruit juice or yogurt
For PEG and NG tubes the MUPS tablets can be dispersed in a large volume of water
For PEG and NG tubes the granules can be mixed with 10mL of sodium bicarbonate 8.4% and left to stand for 10 minutes until a turbid suspension is formed. The suspension is given immediately then flushed with water
For older children Lansoprazole fastabs dissolve very well in water and do not block the tubes as badly as omeprazole.

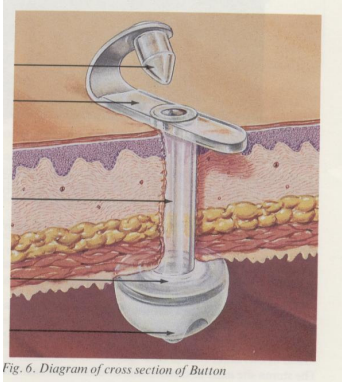
GASTROSTOMY CARE

Many of the children requiring palliative care will have a gastrostomy in situ, often for feeding requirements or for medication to be administered where the oral route is either inappropriate or holds the potential risk of aspiration/choking for the child.

The two main types of gastrostomy tubes are PEG (Percutaneous Endoscopic Gastrostomy) and balloon type , usually a MIC–KEY. There are various reasons why some children have one type and some have another. Such reasons could be the length of time the device is in situ, the surgeon's preference and the appropriateness of the device for the child and family.



PEG tube



MIC-KEY Button

DAILY CARE

- Clean the skin around the stoma site and under the external fixation device or Mic–key head with warm water daily. Normal bath or shower routine can be followed, but the new stoma site should not be submerged in water for 3 weeks post-operatively. Ensure area thoroughly dried. Do not use talcum powder around stoma area.
- To prevent blockage, the gastrostomy tube should be flushed with water before and after all feeds and medication. Usually a minimum of 10mls of water unless the child is fluid restricted or a small infant.
- Rotate gastrostomy tube 360 degrees every day to help avoid the formation of granulation tissue.

- Check any external fixation device, (present on all PEG's & some balloon tubes), is comfortably positioned approximately 2mm from the skin surface, and adjust according to manufacturer's instructions.
- THE RETENTION DEVICE SHOULD NOT BE MOVED FOR TWO WEEKS POST OPERATIVELY , TO ALLOW TRACT TO BECOME ESTABLISHED. IF TIGHTNESS OR DISCOMFORT IS NOTED DURING THIS TIME, CONTACT APPROPRIATE MEDICAL STAFF.
- Avoid the use of occlusive dressings over the gastrostomy as these may encourage skin maceration and bacterial growth.
- Check stoma site for signs of irritation, redness or swelling. Contact appropriate medical / nursing staff for advice.

ORAL HYGIENE

- If a child has reduced or no oral feeds, plaque can build up on their teeth rapidly. Poor oral hygiene will cause soreness and pain.
- Teeth need to be cleaned twice daily, and artificial saliva or mouthwash can be used where appropriate.

WEEKLY CARE OF BALLOON GASTROSTOMY

- If gastrostomy is newly formed, do not deflate the balloon until 2 WEEKS post-operatively to ensure stomach firmly adhered to the abdominal wall.
- Once established, change water in balloon weekly using sterile water if in hospital, or cooled boiled water in the home. (Usually 5mls).
- A balloon gastrostomy will require replacing every 4 – 6 months according to the manufacturers' instructions.

TUBE BLOCKAGE

It is important that the gastrostomy tube is only used for administering specific enteral feed, water or medication in an appropriate form i.e. liquid, unless specified by a pharmacist.
In the event of a blockage the following tactics can be tried:-
Using a 50ml syringe the following fluid (25-30mls) can be used (as age appropriate) to try to unblock the tube, usually a minimum of 10mls.

- Flush with warm water.
- Flush with soda water.
- Flush with cola.
- Flush with pineapple juice (contains an enzyme that helps to dissolve the blockage).
- If blockage persists, gently draw back on the syringe and flush as before.
- Gently squeeze the tube between your fingers along its length to 'milk' the tubing.

If blockage persists:-

- PEG - a pancreatic enzyme (Pancrex V) may be obtained from a dietitian / doctor which is instilled and left in the tube for approximately 30 minutes , then retry the above.
  If remains blocked, contact appropriate medical staff.

- Mic–Key / Balloon gastrostomy - consider a change of tube by an appropriately trained individual deemed competent to do so.

LEAKAGE AROUND THE STOMA SITE

- A newly formed gastrostomy may experience slight seepage around tube until the tract is established.
- If established balloon gastrostomy, check sufficient water in balloon.
- If established PEG, check external fixation device has not slipped by pulling gently on gastrostomy tube until resistance is met and positioning fixation device 2mm from skin surface.
- Aspirate tube prior to feeding to remove excessive air from stomach:-
  PEG - use 50ml syringe ensuring Luer port is closed.
  MIC–KEY - as above or use decompression tube provided with the kit.
- If child inactive, encourage sitting upright following feed or position on right side with head elevated, to promote gastric emptying.
- Discuss with Dietitian the possibility of reducing rate of feed, or giving smaller, more frequent feeds.
- Gastric contents will quickly cause excoriation and soreness. Protect the skin with water proofing product such as stoma care skin wipes or Cavilon, whilst establishing and correcting cause.
- If leakage persists, contact appropriate medical staff.

Ensure leakage not due to:-

1. Granulation tissue.
Looks like a raised red lip or cauliflower type growth(s) around the stoma site.
Will produce a copious, sticky, mucus type discharge - often mistaken for infection.
Treatment = Topical steroid based, antifungal cream i.e. Tri–Adcortyl.
Apply twice daily for maximum of 10 days then review.
May need 2nd course of treatment but advise parent / carer against prolonged use.
If in doubt swab before starting treatment.

2. Infection.
Inspect for signs of redness, swelling or tenderness around gastrostomy site.
Note colour and consistency of leakage.
If infection suspected swab before starting treatment.
Consider Fucidin cream for topical application or systemic antibiotics.
(Caution with erythromycin with children who have epilepsy).

IF GASTROSTOMY TUBE PULLED OUT

- Appropriate action needs to be taken as soon as possible as the stoma will begin to close after 4 – 6 hours.
- Leakage may occur from the stoma site – use skin protective wipe or Cavilon if available, and cover with dry dressing.

Mic–key or balloon gastrostomy.
Child should have spare tube with them which can be replaced by appropriately trained nursing / medical staff or carers. Or contact hospital ward or Children's Community Nurses.

PEG gastrostomy.
Contact hospital surgical team as soon as possible.
A size 12g Foley catheter can be used to keep the stoma patent until PEG is replaced. If this is to be used for feeds / medication - ensure tip of catheter has not migrated into small bowel – inflate balloon and pull back gently until resistance felt, secure to skin with tape, note length of external catheter from stoma site.

HICCOUGHS

Hiccough is a common occurrence in normal individuals, and only becomes a symptom when it becomes troublesome, severe or intractable, which can occur in palliative care situations.

In terminal care the most common cause of hiccough is gastric distension. The first line of treatment is often a defoaming antiflatulent containing Simeticone (active dimeticone such as Asilone or Maalox Plus). If this fails to settle the hiccough a prokinetic drug such as Metoclopramide can be added to tighten the lower oesophageal sphincter and promote gastric emptying. Sometimes peppermint water is helpful, by relaxing the lower oesophageal sphincter to facilitate belching, but as this works in opposition to the action of Metoclopramide these two should not be given together.

Gastrointestinal reflux can sometimes cause hiccough, and this can be reduced by the use of prokinetics such as Metoclopramide, or by H2 antagonists or proton pump inhibitors.

Diaphragmatic irritation is another cause of hiccough seen in palliative care. Baclofen is seen as the drug of choice with its muscle relaxant properties.
There are also single case reports in adults for the use of Gabapentin, Nifedipine and Haloperidol supporting their potential benefit for intractable hiccough.

Stimulation of the pharynx may help with the management of hiccough, and this is the basis for how a lot of the traditional "folk" remedies for hiccough may work. Such advice includes swallowing crushed ice, a cold key down the back of the neck, and drinking from the wrong side of the cup.

More medically based treatments that stimulate the pharynx include normal saline 2mls nebulized over 5 minutes, and oro-pharyngeal stimulation with an NG tube, both of which suggested a reduction in hiccough. A similar method is by massaging the junction between the hard and soft palate with a cotton bud. Forced traction of the tongue to stimulate a gag reflex is also thought to potentially work by pharyngeal stimulation.

Central suppression of the hiccough reflux can be achieved in several ways. Re-breathing air out of a paper bag and breath holding are both thought to inhibit processing of the hiccough reflex in the brain stem by elevating $PaCO_2$
Dopamine antagonists such as Metoclopramide may help by both their central action and if there is associated gastric distension.
Other drugs to centrally suppress hiccough include Haloperidol, or Chlorpromazine. GABA agonists such as Sodium Valproate 200 to 500mg daily are also potentially effective by central suppression.

Potential biochemical causes of hiccough should be sought and corrected appropriately if possible, including hyponatraemia, hypocalcaemia (e.g. after bisphosphonate treatment), and in renal failure.

If hiccoughs persist, the possibility of infection or a brain stem lesion / intra-cranial lesion should be considered.

In summary, if hiccoughs become a persistent and distressing symptom, effort should be made to relieve treatable causes such as gastric distension and reflux or correct biochemical causes, whilst considering infection and neurological causes. Simple "folk" remedies and attempts at other methods of pharyngeal stimulation should then be tried, followed by specific drug treatment if the above remedies have proved ineffective.

Table 12: Drugs used to treat hiccoughs

DRUG	ROUTE	TOTAL DAILY DOSE (T.D.D.)		TIMES DAILY (Divide T.D.D. by this figure)
		1 month to 12 years	Over 12 years	
Omeprazole	Oral	700 microgram/kg up to 3mg/kg/day	20-40mg	Once
Asilone	Oral		5-10mls	After meals and bedtime
Maalox Plus	Oral	**Under 5 years** 5mls	**Over 5 years** 5-10mls	After meals and bedtime
Haloperidol	Oral		4.5mg	Three Start with lower dose and increase as required
Chlorpromazine	Oral	**Over 6 years** 10-30mg		One to Three
			100-200mg	Three to Four
Metoclopramide	Oral	200-300 micrograms/kg	**Under 60kg** 15mg **Over 60kg** 30mg	Three

INFECTIONS

Any infection causing symptoms and affecting quality of life should be treated. Antibiotic resistance and allergies are a common problem. In the palliative care setting rules may be bent; hence antibiotics not normally recommended for children e.g. tetracycline could be given. Other antibiotics not normally available in liquid form for children can be given. Hospital pharmacies and traditional retail pharmacies can be very helpful in providing such information. Remember to record in the notes and discuss with the parents what you are doing to protect yourselves medico-legally.

Pneumonia is sometimes called the old man's friend. It is also the commonest cause of the terminal event in many children with life threatening conditions. The use of antibiotics can present the parents and care team with an ethical dilemma. It is best to sit down and discuss the pros and cons of treatment together. Oral treatment in the terminal phase does not extend the life expectancy of the child but can allow the parents to feel that they tried their best to the last. Most parents will accept that intravenous antibiotics are normally inappropriate at this stage.

It is worth remembering that while we cannot insist on treating an infection if the parents refuse, neither are we forced to give treatment that we consider is inappropriate. This type of dilemma is best resolved by negotiation with parents and, where appropriate, the child.

Sometimes antibiotics are necessary e.g. pain relief in acute ear infections or severe tonsillitis, even when the parents of the child have decided on no more active treatment.

MOUTHCARE

This is an overlooked aspect of palliative care but correct management can easily enhance the quality of life for a dying child. As in all cases take a good history and look inside the mouth. Establishing the cause of the mouth problem helps to direct the correct treatment.

Causes	Oral candidiasis	
	Poor oral hygiene	
	Dry mouth from	a) Mouth breathing
		b) Oxygen that has not been humidified
		c) Drugs i.e. morphine, hyoscine or amitriptyline
		d) Radiotherapy
	Mouth ulcer	a) Traumatic
		b) Aphthous
	Bleeding gums from	a) Haematological cancers
		b) Liver disease
		c) Clotting disorders

Oral hygiene can be maintained by careful and gentle cleaning of teeth and gums. This is a task that the parents may like to carry out as part of the child's daily routine.

- Pink sponges dipped in mouthwash can be applied to the gums and teeth to keep the mouth moist and cream applied to the lips to prevent dryness and cracking. This attention to mouth care will go a long way to maintaining hygiene, preventing some of the complications and aiding the child's comfort.
- Oral thrush can be cleared using various anti-fungal agents. Nystatin drops are really not very effective in these cases and miconazole oral gel applied gently around the mouth is better. Fluconazole, which is a once daily oral anti-candidal agent, is often more effective than topical agents.
- Artificial saliva e.g. Glandosane comes in various forms and the spray is particularly effective. KY Jelly is very effective for dry mouths and is well tolerated.
- Community dentists can advise regarding traumatic ulcers.
- Aphthous ulcers can be treated with Adcortyl in Orabase applied locally.
- Bleeding gums can be helped with tranexamic acid mouthwashes or haemostatic agents such as Gelfoam or Gelfilm. Bleeding from blood malignancies may require platelet transfusions even in the palliative setting. Oral ethamsylate decreases capillary bleeding and has been used in adults at a dose of 500mg qds in a palliative care setting.

Table 13: Drugs used to treat mouth problems

DRUG	ROUTE	TOTAL DAILY DOSE (T.D.D.)		TIMES DAILY (Divide T.D.D. by this figure)
		1 month to 12 years	Over 12 years	
Miconazole oral gel	Oral	**Under 2 years** 5ml		2
		2-6 years 10ml		2
		Over 6 years 20ml		4
Tranexamic Acid	Oral	75mg/kg	2-6g	3
Fluconazole	Oral	**Over 4 weeks** 3mg/kg	50-100mg	1

MUSCLE SPASM.

Muscle spasm is a common problem in the neurodegenerative disorders. They may be due to pain: look for other clues to this, such as response to handling. Alternatively they may be epileptic tonic spasms. There is sometimes no substitute for sitting down, listening to the story carefully and watching the spasms.

Anyone who has had muscle cramps will appreciate the level of pain that can be experienced. Children who have repeated muscle spasms are often very distressed. The early involvement of a physiotherapist may be useful and advice on seating, positioning, moving and handling may assist in preventing positioning that can cause muscle spasm.

Unfortunately the treatment for the spasms can have some detrimental side effects. Increased muscle tone and spasm may be the only thing that allows the child to sit or stand up. Thus treatment may decrease the child's mobility. The medications can also cause unnecessary sedation. The two drugs worth trying are baclofen and diazepam. Baclofen may make epilepsy worse. Diazepam may be sedating and/or dulling. Dantrolene and tizanidine, although not licensed for children are both useful. A phone call to the local paediatric neurologist can be very helpful in difficult cases.

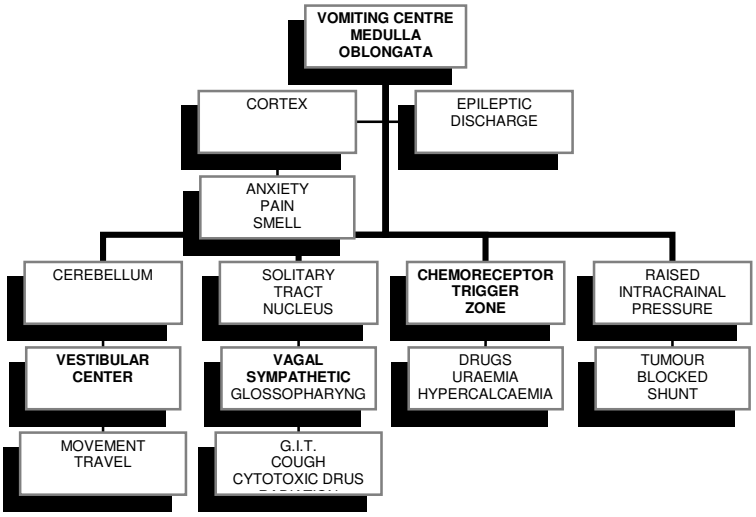
Table 14: Drugs used to treat muscle spasm

DRUG	ROUTE	TOTAL DAILY DOSE (T.D.D.)		TIMES DAILY (Divide T.D.D. by this figure)
		1 month to 12 years	Over 12 years	
Baclofen	Oral	**1-2 years** 10-20mg	100mg maximum	3-4
		2-6 years 20-30mg		
		6-10years 30-60mg		
Diazepam	Oral	**1 month-1 yr.** 500mcg/kg **1-4 years** 5mg **5-12 years** 10mg	6-30mg	2-3
Dantrolene	Oral	1mg/kg		2 (Initial dose)

			25mg	1 (Initial dose)
		12mg/kg (Maximum 400mg)	400mg	4 (maximum dose)

NAUSEA AND VOMITING

The management of nausea and vomiting highlights the importance of understanding the cause of a symptom to determine the appropriate therapeutic course.



Whilst nausea and vomiting can be effectively managed with medication, common sense principles must not be forgotten.

- Identify and manage the correctable causes e.g. pain, infection, drugs, biochemical, etc
- Certain smells may antagonise the nausea.
- Left over food must be removed immediately.
- Staff and parents advised against the use of strong perfumes.
- Strong odours avoided.
- Meals kept small but often, if the child's appetite allows.

Once we have an understanding of the cause we can then target anti-emetics according to their mode of action. It may be necessary to use a number of different anti-emetics and logic dictates that we use medications from different groups. Many of the drugs used will overlap in their site of action.

There is no evidence to support any particular dosage of dexamethasone when used as an anti-emetic. Another rule of thumb is 8mg/m^2/day. Remember not for long-term use because of side effects and altered body image.

Octreotide has been used in adults for vomiting secondary to obstruction but its benefits in children is unknown.

If you need to use more than one anti-emetic then make sure they are complementary e.g. cyclizine and haloperidol and not antagonist e.g. cyclizine and domperidone.

Table 15: Site of action of anti-emetic drugs

DRUG	SITE OF ACTION	NOTES
Haloperidol	Chemoreceptor trigger zone	Anxiolytic benefits
Thioridazine	Chemoreceptor trigger zone	May have some benefits in epilepsy, although generally phenothiazine can exacerbate epilepsy
Chlorpromazine	Chemoreceptor trigger zone	Sedation benefits. Contra-indicated in epilepsy
Prochlorperazine	Vestibular centre and Chemoreceptor trigger zone	Side effects in children limit use
Ondansetron	Chemoreceptor trigger zone Medulla Oblongata Also may work at vagal level	Side effects of flushing, headaches and constipation More effective combined with corticosteroids (dexamethasone) Onset of action 30mins, peak 1-2hrs, duration 12hrs
Cyclizine	Medulla Oblongata	Commonly used and highly effective Sedating antihistamine with antimuscarinic properties May crystallise with diamorphine in s/c infusion Side effects drowsiness, dry mouth, blurred vision, urinary retention Onset 30mins, peak 2hrs, duration 4-6hrs
Levomepromazine	Effects at all levels	Phenothiazine Broad spectrum Use when there is failure of specific anti-emetic Stable with diamorphine in s/c infusion Side effects sedative and postural hypotension
Domperidone	Vagal sympathetic	Prokinetic in upper gut Good for dysmotility in neurological conditions
Metoclopramide	Vagal sympathetic	Crosses blood brain barrier Causes extrapyramidal side effects in children limit use
Dexamethasone	Intracranial pressure	Use in short bursts due to side effects Reduces permeability of chemoreceptor trigger zone and blood brain barrier to emetogenic substances and reduce GABA in brainstem

Table 16: Drugs used to treat nausea and vomiting

DRUG	ROUTE	TOTAL DAILY DOSE (T.D.D.)		TIMES DAILY (Divide T.D.D. by this figure)
		1 month to 12 years	Over 12 years	
Haloperidol	Oral		1-4mg	2-3
	SC infusion	25-50 mcg/kg/24hrs		Continuous
Chlorpromazine	Oral	**2-5years** 1.5mg/kg **6-12 years** 30mg	75-150mg	3
Cyclizine	Oral	**5-12 years** 75mg	150mg	3
	SC infusion	**1month-1yr** 1mg/kg/24hrs **1-4 years** 25mg **5-12 years** 50-100mg	50-100mg	Continuous
Domperidone	Oral	200-400mcg/kg (up to 1.6mg/kg/24hrs)	10-20mg	Single dose
	Rectal	**0ver 2 years** 15-30mg	30-60mg	Single dose
Dexamethasone 2mg/5ml	Oral	1-6mg		2
Levomepromazine	Oral	**1-18 yrs** 0.25-1mg/kg 3-6 times/day		
	SC infusion	**1-18 yrs** 0.5-3mg/kg/day		
Metoclopramide	Oral	300mcg/kg	**Under 60kg** 15mg **Over 60kg** 30mg	3
Octreotide	SC infusion	25 micrograms/kg/24hrs		Continuous
Thioridazine 25mg/5ml	Oral	0.5-1.3mg/kg	1-2.5mg/kg	2
Ondansetron	Oral	**Under 0.3m2** 1mg **0.3-0.6m2** 2mg **0.6-1.2m2** 4mg **0ver 1.2m2** 8mg	8mg	Single dose every 8-12hrs

NEONATAL PALLIATIVE CARE

Introduction

There have been many advances both in antenatal diagnosis and neonatal intensive care over recent times. However there still remain a number of babies where full intensive care is not indicated, or is futile.

There are a number of common reasons that neonatal intensive care may be withheld or withdrawn after discussion with the family including:

- Genetic problems with a limited life expectancy- for example Trisomy 18.
- Severe congenital abnormalities- for example spina bifida or cardiac problems that are not amenable to surgery.
- Complications of extreme prematurity- for example, low blood pressure that fails to respond to inotropic medication, or extensive bowel damage that is incompatible with life following necrotizing enterocolitis.
- Perinatal hypoxic brain injury with a poor prognosis.

Some babies, particularly preterm babies, will already be receiving intensive care support when the decision is made to withdraw or withhold intensive care.

The intensive care support received may include:

- Support of the respiratory system, either via an endotracheal tube, or via nasal continuous positive airway pressure (CPAP).
- Support of the blood pressure with inotropic medication.
- Infusion of opiate medications or muscle relaxants to facilitate artificial ventilation.
- Organ support (renal replacement therapy etc).

Following discussion with the family, there may be a decision made, not to escalate the intensive care support further, or more commonly, to withdraw support, keep the baby comfortable and allow the baby to die with their family.

Many parents will have built up a relationship with the team on the neonatal unit, and will choose to spend time with their baby on the intensive care unit, supported by the staff that they know. Some families may prefer for the baby to die at home, or in the hospice setting.
It is usual practice on the intensive care unit to discontinue muscle relaxant medications, and allow these to 'wear off,' but to continue any other sedative or analgesic medications after removing the baby from the ventilator. Intravenous access is often left in place to allow for the administration of palliative medications, but oral and subcutaneous medications can be given, even to the smallest of infants.

There are a number of issues that need to be thought about when caring for the dying baby, and the principles of care are similar to those for an older child. It is important to remember that simple comfort measures, such as positioning the baby with suitable boundaries, gentle rocking and swaddling, can be very effective.

Feeds

Most full term babies will feed around 120ml per kilogram per day of breast or formula milk if left to their own devices. Most babies feed 6-7 times per day, but many breast fed infants feed more frequently than this.
Preterm babies start to learn to suck and swallow at around 33-34 weeks gestation, and babies younger than this are usually fed via a nasogastric tube.
Babies who are receiving palliative care should be allowed to feed orally if they wish to do so. They are likely to find breast feeding comforting even if they are not able to take much milk. If a baby is unable to take oral feeds, it is usually appropriate to offer feeds via a nasogastric tube. Providing around 50ml/kg/day of milk, split into 6-8 feeds, will keep the baby hydrated, and may produce less vomiting and feed intolerance than using higher volumes. The aim of this approach is to reduce distress from hunger, rather than to provide calories for growth.

Gastro-oesophageal reflux

A small amount of vomiting or posseting following feeds is normal for babies. Antiemetics are not often required or used in small babies because of the significant side effect profile.

Gastro-oesophageal reflux is fairly common, particularly in babies with neurological problems.
This can be distressing for the infant and can be dealt with by:

- Feeding with the head of the cot slightly elevated, and the baby lying with the left side down.
- Giving nasogastric feeds slowly (sometimes it is best to remove the plunger from the syringe and allow the milk to flow in 'by gravity.').
- Giving smaller volume feeds more regularly (2 hourly instead of 4 hourly for instance).
- Considering anti-reflux medications:

Table 17: Drugs commonly used as anti-reflux medications in neonates:

Drug	Use	Dose
Gaviscon Infant	'feed thickener'/ alginate	Half a dual sachet mixed with feeds (100ml of milk). If breast fed mix with a little water and give after the feed
Ranitidine oral solution	H_2 antagonist	1-2mg/kg up to three times daily
Domperidone	prokinetic	100-300 microgram/kg four to six times daily before feeds

Constipation

Constipation can be a problem, particularly for babies taking long term opioids. Lactulose syrup 2.5ml twice daily titrated to response can be helpful, and ensuring adequate hydration is important. Lactulose may take 36-48 hours to act.
Distressing constipation in babies can be relieved by administering the 'tip' of a glycerine suppository rectally (it is easiest to slice a small chip off a 1 gram suppository with a blade)

Pain

It is imperative that all babies receiving palliative care have close attention paid to their analgesia. The assessment of pain in babies is very difficult.
There are many pain 'scoring systems' that have been widely used for neonates, but the scores given are often subjective and not always clinically useful.

The following features are the most reliable indicators of pain in small babies:

- Persistent crying (although remember that a silent baby may be suffering from severe pain).
- Furrowing or bulging of the brow.
- Furrowing of the nasolabial folds (the folds between the lips and nose).
- Tight squeezing of the eyes.

Simple environmental methods may be very effective for relieving pain in babies
Babies (particularly preterm babies) will often settle simply with a dark, quiet, warm environment. Other methods include swaddling of the baby in a blanket, allowing the baby to suck at the breast or on a dummy (see below), gentle rocking, stroking and massage of the baby.
There is good evidence that sucking on a syringe or dummy containing glucose or sucrose provides short term pain relief. This is particularly useful for procedural pain,

including dressing/ stoma changes for example. Glucose 30% solution 1ml orally as required can be used.

***Non-opioid analgesia*:**

Paracetamol:

Paracetamol can be given orally, or PR if needed by cutting up suppositories.

Paracetamol suspension, orally, 20mg/kg as a 'loading dose' followed by 10-15mg every 6-8 hours (max 60mg/kg/day)**.**

Paracetamol suppository, rectally, 30mg/kg as a 'loading dose' then 20mg/kg every 8 hours (maximum 60mg/kg/day).

Non steroidal anti-inflammatory drugs:

Ibuprofen suspension 5mg/kg 3-4 times per day, after feeds.

Diclofenac is not usually recommended below 6 months of age because of the significant side effects. However, if the oral route is unavailable, rectal diclofenac may be useful in neonates weighing 3.125kg or greater. The dose is 0.3-1mg/kg tds. The smallest dose that can practically be given is 3.125mg (by cutting a 12.5mg suppository into quarters).

Opioids

Morphine remains the most commonly used medication for neonatal analgesia. Morphine can be given intravenously for acute pain, using a dose of 40 to 100 micrograms per kg as needed.

Intravenous morphine infusions are used, even in the smallest preterm infants, and doses of 10-40 micrograms/kg/hour are often used. In unventilated babies the initial dose is 10-20 micrograms/kg/hour and is then titrated to response. High doses of morphine can lead to a change in the respiratory pattern, and occasionally respiratory depression.

Subcutaneous infusions of morphine can be used in small babies, but are often problematic in small preterm infants, because of a lack of subcutaneous tissue.

Diamorphine is useful for subcutaneous use as it is more water soluble than morphine so smaller infusion volumes can be achieved, and is the preferred opioid for subcutaneous use. Intravenous diamorphine has been extensively used in ventilated neonates, a dose of 100 micrograms/kg is useful for acute pain, and an initial infusion of 2.5 to 7 micrograms / kg / hour can be used safely in non-ventilated babies and then titrated to response.

Morphine sulphate oral solution is the most common oral opioid used. The total daily intravenous opioid requirements can be calculated and converted to an oral regime, giving the morphine every 4 hours initially. Breakthrough analgesia (PRN doses) should also be prescribed and given in-between the regular doses if required. The dose is then adjusted to response - there is no maximum dose of morphine for neonatal palliative care- high doses of morphine will often change the breathing pattern, and may cause respiratory suppression.

Codeine phosphate is occasionally used. It is not as effective as oral morphine and often causes problematic constipation.

Opioids may also help to relieve breathlessness at rest.

Fentanyl has been associated with chest wall muscle spasm in neonates, and is not often used. It is difficult to cut fentanyl patches into small enough pieces for use with small babies.

Table 18: Drugs used to treat pain in neonates

Drug	Dose	Comments
Morphine IV	40 to 100 micrograms/kg	For acute pain- can be repeated as needed
	10-20 microgram/kg/hour continuous infusion	Usual starting dose for infusions in non ventilated babies- can be titrated according to response
Morphine Subcutaneous	150 microgram/kg for acute pain	Diamorphine is preferable for using subcutaneously (see text)
Morphine Sulphate Orally	Double the total daily IV morphine requirements can be titrated and given 4 hourly	Morphine requirements are very variable- see text
Diamorphine IV	100 microgram/kg	For acute pain
	2.5-7 microgram/kg/ hour	Continuous infusion in non ventilated babies- can be adjusted to response
Diamorphine Subcutaneous	Total daily oral morphine dose : subcutaneous diamorphine dose = 1:0.33	See text

Seizures

Seizures are a common problem encountered in neonatal palliative care. These are often secondary to a perinatal hypoxic insult to the brain or a primary brain problem and can be distressing for the family to see. Seizures can manifest in subtle ways in babies, common features are cycling movements of the arms and legs, unusual mouth movements or lip smacking.

There are a number of medications used for seizures in neonates- most neonatologists start with phenobarbital.

Table19: Drugs used to treat seizures in neonates

Drug	Dose	Comments
Phenobarbital (phenobarbitone)	Initially 10-20mg/kg loading dose often followed by a maintenance dose of 2.5-5mg/kg once daily	Most commonly used first line medication in neonates- causes sedation and may suppress respiration in high doses Can be given iv or orally
Phenytoin	Initially 20mg/kg loading followed by 2.5-5mg/kg twice daily	Commonly used as a second line agent in neonates- can be given iv or orally. May cause blood and skin disorders with long term use
Clonazepam	For status epilepticus: 100 microgram/kg IV single dose- repeated after 24 hours if needed	Very effective anticonvulsant- significant sedation which can be useful in palliative care. Can be given orally or iv- iv dose associated with respiratory depression Can be used to ameliorate distressing gasping
Midazolam	*Seizures* 300 microgram/kg buccal single dose	Midazolam is not often used for iv or subcut infusions in neonates as it tends to accumulate, and can cause

	150 microgram/kg IV loading dose followed by 1 microgram /kg/minute IV infusion to control seizures if needed. Dose can be increased by 1microgram/kg/min every 15 minutes until seizure controlled (max dose 5 microgram /kg/min) For sedation a dose of 50-100microgram/ kg IV or subcut can be used	respiratory depression. It is not licensed for sedation below 6 months but is still occasionally used, with good effect Can be used to ameliorate distressing gasping

Sedation

It is important to ensure that babies who are 'unsettled' are not in pain.
Occasionally babies benefit from oral sedative drugs to help them sleep.
The most commonly used sedatives in babies are:

- Chloral hydrate 30-50mg/kg orally or rectally at night / as required. May be used up to QDS for continuing sedation.

The oral solution can be given rectally if suitably sized suppositories are unavailable. (Chloral can accumulate if used regularly in babies. It is also irritant to the stomach if given orally so should ideally be given with or after milk feeds).

- Alimemazine (trimeprazine) 2-4mg/kg orally as required (max four times daily).

Excessive Secretions

Many babies with neurological problems have difficulties clearing secretions from their mouth and pharynx.
Some babies are managed at home, or in the hospice setting with oral suction.
Hyoscine patches (quarter of a patch, applied behind the ear, every 72 hours) are often useful for excessive respiratory secretions.

Mouth Care

Opioids and hyoscine may cause dry mouth – regular mouth care should be performed.

Syringe Drivers

In palliative care, when the parenteral route becomes necessary for symptom control, the use of syringe drivers to administer continuous subcutaneous infusions can be useful to reduce the discomfort of repeated injections. Commonly used drugs given via continuous subcutaneous infusion include opioid analgesics, antiemetics, sedatives and anti-secretory agents. Most drugs can be diluted with water for injection for continuous subcutaneous infusion. Luer-Lok syringes should be used.

When given subcutaneously, diamorphine is preferred over morphine because it is more soluble so can be made up in smaller volumes which are suitable for subcutaneous use.

Daily oral or IV morphine requirements can be used to calculate equivalent daily subcutaneous diamorphine doses;

Total daily dose of oral morphine: total daily dose of subcutaneous diamorphine
= 1: 0.33

Total daily dose of IV morphine: total daily dose of subcutaneous diamorphine
= 1: 0.66

Caution must be used when using Graseby pumps to administer subcutaneous infusions to ensure the correct rate of administration, because the rate of delivery is set in either mm per hour (MS16A device) or mm per 24 hours (MS26 device). The rate of delivery is calculated by measuring the "length of infusion fluid" in the syringe.

Once the drug to be administered as a continuous infusion over 24hours is diluted to the volume required the "length of infusion fluid" in mm can be determined by measuring the length in mm from the top of the syringe barrel to the top of the plunger.

Graseby MS16A

Rate (mm/hr) = measured "length of infusion fluid" in mm ÷ delivery time in hours.

Graseby MS26

Rate (mm/24hours) = measured "length of infusion fluid" in mm ÷ delivery time in days.

If a patient is receiving several subcutaneous infusions, it may be possible to mix both drugs in one syringe to avoid multiple infusion sites – check the compatibility of the combination with a Pharmacist before proceeding.

The site of subcutaneous infusion should be monitored to check for precipitation of drug, local reactions, fluid accumulation and inflammation.

Summary

The palliative care of infants is important, and follows the same principles as in older children. There should be a focus on relieving pain and distress, and opioids remain the most commonly used medication. Unfortunately, many of the other medications used in older children, accumulate in babies and this can cause problems if these medications are used in the longer term.

The treatments discussed are by no means comprehensive- in difficult cases it would be advisable to seek the advice of a Neonatologist or a neonatal pharmacist.

References

BNF for children, 2006. BMJ Publishing Group Ltd, London.

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Dickman, Schneider & Varga. The syringe driver, 2nd edition, 2005. Oxford University Press.

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PAIN ASSESSMENT

Assessing pain in children with life-limiting illness can be complex but is assisted by
- building a relationship with the child and family,
- understanding the context in which pain occurs and
- being familiar with the child's medical condition.

The object of pain assessment is to capture the various dimensions of the pain, including:-
- location,
- intensity,
- character (for instance is it burning or sharp?),
- the significance or meaning of the pain for the child and family.

Pain Measurement
The main purposes of pain measurement are to
- quantify the experience,
- monitor the effects of treatment,
- provide a shared medium through which the child can communicate the experience to others.

Children's self-report of pain
Children are less able than adults to quantify and qualify abstract phenomena so any measures of pain need to be appropriate to the child's cognitive and developmental level. It should be born in mind that during illness children may be less able to use tools designed for their age and cognitive ability.

There are several tools that can help the child to communicate their pain to others. It is sensible to have a few that are well known to your practice.

Pain Location

Body map
The child can be asked to indicate on a body outline (or themselves) where the pain is. Children could also be asked to choose colours which signify different levels of pain and use these to colour in the painful areas.

Pain intensity

Faces pain rating scales
Faces scales consist of a number of cartoon type faces in which the facial expression varies on one end with either a smiling face or a neutral (no pain) face to an expression which signifies extreme pain. The child is asked to identify their own pain intensity from the faces offered. Faces pain scales are suitable for children who are at a developmental age of five or above. Adolescents may find the tool tiresome if used over the longer term and may prefer a straightforward Numerical Rating Scale (NRS).

The Wong-Baker Faces Pain Rating Scale is probably the most commonly used. Copies can be downloaded from the web for clinical use. Web page listed at end.

Numerical rating scales
Children must have a sound understanding of language, order and number to be able to use either the verbal or the numerical scales, probably 7-8 years upwards. Ask the child how bad their pain is on a 0 to 10 scale, with 0 being no pain and 10 being as much pain as you can imagine.

Verbal pain rating scales
Four to five point categorical scale with pain ratings from no pain to severe, or very severe pain i.e. pain is … none, mild, moderate, severe, very severe.

Parents as proxy reporters of their child's pain.
When children are unable to rate their pain, parents or clinicians can provide a proxy rating. The source of these ratings is usually the child's behaviour in relation to their non-pain behaviour, the context in which the behaviour is taking place, and the provider of the ratings own attitude towards pain. As with the children themselves, parents may place particular meaning on a change in the child's behaviour and this can be explored. Assessments can sometimes vary between proxy raters of the child's pain, and it is helpful to discuss and explore the reasons for any differences.

Behaviours that signal pain

There are categories of pain cues that, whilst the emphasis may change with age, are common across all ages, these include changes in

- facial expression
- vocal sounds
- bodily posture
- movements
- mood

Facial expression and cry are widely discussed in the literature on neonatal and infant pain, but their importance as indicators of pain appears to decrease with age. This

downward trend is associated with, in normal circumstances, the development of a wider repertoire of behaviour which includes language. Consequently, older children are normally less likely to emit behaviours with high 'signal value' such as crying and grimacing. In addition, as children mature they learn to moderate their behaviour in line with the expectations of the culture within which they live.

Children who are unable to communicate verbally or by augmentative means are wholly dependant upon their carers correctly interpreting their behavioural cues of pain The Paediatric Pain Profile (PPP) has been developed for children with severe neurological impairments. The 20-item behaviour rating scale is incorporated into a parent-held document which can be downloaded. See below for link.

Pain diaries and flow sheets

Ask parents, children or carers to keep a pain diary or a flow sheet, where space is provided to write the time, duration, context in which pain has occurred, pain measurement on one of the above tools or suitable alternative, the intervention and the outcome of the intervention using the same pain measure. The use of a standard pain measure will help to evaluate the effectiveness of different interventions.

Some useful web resources

International Association for the Study of Pain. Pain assessment in children
http://www.iasp-pain.org/PCU95b.html

Cancer Page. Pain relief for children.
http://www.cancerpage.com/centers/pain/pediatrics_p.asp

Wong Baker Faces Pain Rating Scale
http://www3.us.elsevierhealth.com/WOW/fyi03.html

Paediatric Pain Profile, a behaviour rating scale for children with severe to profound neurological impairments http://www.ppprofile.org.uk

Institute of Child Health, Children's pain assessment project
http://www.ich.ucl.ac.uk/cpap/

Eland colour tool and other faces scales
http://www.stat.washington.edu/TALARIA/attachment.html

A pain flow sheet. http://www3.us.elsevierhealth.com/WOW/op020.html

To purchase the World Health Organisation book - Cancer Pain in Children
http://www.tso.co.uk/bookshop/bookstore.asp?FO=1160671&DI=352971

PAIN

The commonest expressed fear in paediatric palliative care by parents is that their child may experience pain. Fortunately in the majority of cases, pain control is relatively straightforward and easier to manage than some of the other symptoms. The whole topic of pain is so vast that this section can only represent a synopsis of the basics of cause and management. In more complex cases it is worth consulting with local hospices, pain clinics and paediatric consultants.

Determining whether a child is in pain, or the level of that pain is not easy. Various pain-scoring techniques have been developed and if one has knowledge of these, they are worth trying. However in most cases, parents and experienced nurses can provide invaluable information from their knowledge of the child's behaviour. Older children can often describe pain but only in the context of their experience related to their age. A good history and knowledge of pathogenesis of the disease will help to direct one to the underlying cause of pain.

Causes

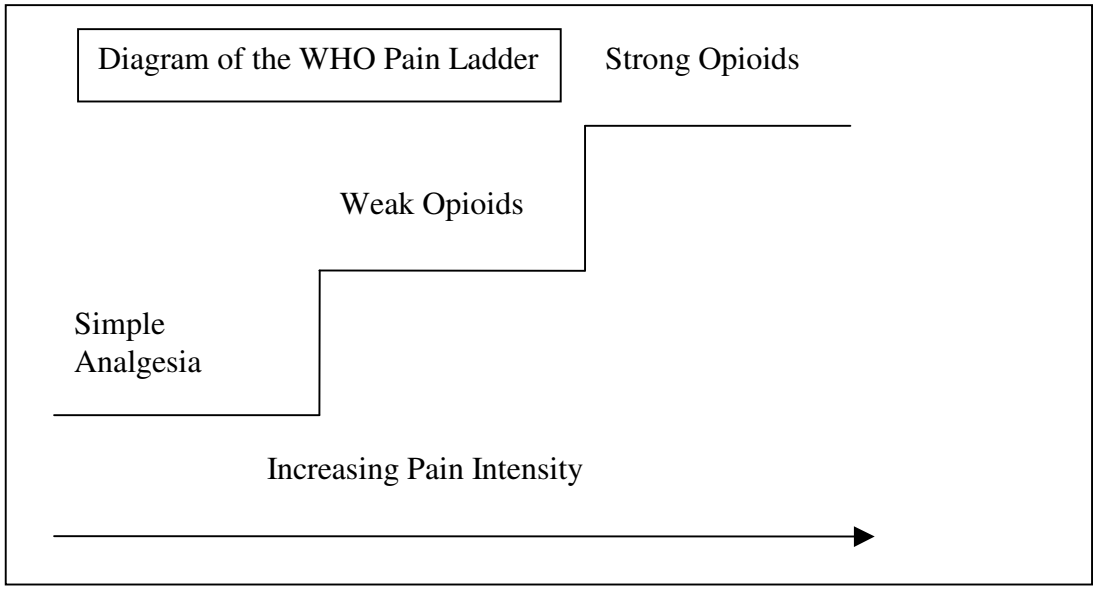
- Direct visceral involvement
- Bone involvement
- Soft tissue infiltration
- Nerve compression
- Nerve destruction
- Raised intracranial pressure
- Muscle spasm
- Colic / constipation
- Gastritis
- Retention of urine
- Psychological

As with all the other symptoms it is worth remembering to 'listen, look and examine' before rushing in with medication. Not all pain can or needs to be controlled with opiates. It is relatively easy to feel or percuss a child's bladder. Pain from direct tumour spread will often improve by reducing inflammation around the tumour with non-steroidal anti-inflammatory drugs or steroids.
Good nursing and social support can help the child and family cope with pain. Religion and/or strong faith can modify perceptions of pain. Alternative medical practises such as herbal, reflexology etc. may be of help in the future as we learn more about them. The only rule in pain control is that there are no rules; you need do whatever it takes to help the child out of their pain.

Treatments

There are numerous drugs on the market for pain control. It is always best to get to know one or two drugs from each group well. Using the ladder system of increasingly stronger drugs within each group is a useful tool in general medicine. In paediatric palliative care however it is best to change to a stronger group if one medication does not work.

WHO Pain Ladder
Pain control should follow the rules laid down by the WHO pain ladder, i.e. start at the bottom of the ladder and work your way up depending on the severity of the pain and the control achieved. If treatment at one level does not work then do not try other drugs of the same level, but go up the ladder. **Use adjuvant therapy at any level of the ladder.**



Non-opioids
Paracetamol is the drug of choice in mild pain. Its antipyretic effects are also very helpful with concurrent infections. Administration is aided by the fact that it comes in so many strengths and forms. Ibuprofen is often used specifically by families, as it is available over the counter. Ibuprofen has a mild antiplatelet effect and should be used with caution in patients with a bleeding tendency.

Weak opioids

Codeine Phosphate or Dihydrocodeine are the drugs of choice in moderate pain. Both drugs suppress the cough reflex and cause constipation. They also both have a maximum dose limitation above which they do not provide any increase in benefit.

Strong opioids

There is often great hesitancy shown from parents and carers about initiating morphine. There are a great many fears and myths surrounding its use. It is very important that before starting any treatment these issues are addressed and the parents and child are aware of the truth.

Myth: It will shorten the child's life.
Truth: Pain control does not shorten a child's life; it only brings comfort to a child's death. It can even extend a child's life because they are not exhausted from fighting pain.

Myth: It will suppress a child's breathing.
Truth: Respiratory depression can be avoided by steady increases of dose.

Myth: It will give the child nausea.
Truth: Nausea may occur in 25% of cases but will normally settle in 5-7 days.

Myth: It will make the child even more constipated.
Truth: Constipation must be prevented by the early use of prophylactic laxatives.

Myth: They will develop addiction to it.
Truth: Addiction is not a problem encountered in paediatric palliative care.

Myth: Sedation will affect the quality of the child's life in the final days.
Truth: Sedation will normally improve within a few days of taking morphine.

Myth: It is the beginning of the end.
Truth: Our experience is that children will often live longer than we expect. Also dosage can be reduced or increased depending on the child's state.

Also

- It is not a problem to wean children off morphine should they improve for a while.
- Children metabolise opiates very well: their excretion through the kidneys is, if anything, better than adults.
- There is no evidence to suggest that morphine gets into the CSF of children any more than it does in adults.

The opioids have no upper limit effect. Incremental increases in dose should be of the level of 30-50% or based on previous days breakthrough pain dose.

The morphine based products come in numerous types and forms. It is best to get to know a few well and keep the rest for specific uses. Liquid morphine is often the best way to start, using it on an as required bases (clinical skill, judgement and knowledge of the child should be used in children unable to communicate). After a few days the child can be converted over to slow release morphine with additional liquid morphine for breakthrough pain. The conversion factor is one to one. Slow release morphine is available in tablet and granular forms. Once a child is unable to take preparations orally then it is worth thinking of either fentanyl patches or diamorphine infusion.

Fentanyl patches come in various strengths. A few key points need to be observed when using them.

- Unfortunately the size of the stronger patches can be a problem in the smaller child,
- The old reservoir patch cannot be cut. The new patches are matrix based and in theory may be cut but this is not advised by the manufacturer.
- The strength of patch to use is dependent on the morphine dose and conversion has to be done correctly.
- They take 12 hours to reach therapeutic plasma levels. If converting from 4 hourly oral morphine, then continue to use morphine for 12 hours.
- If converting from slow release morphine, then apply patch at same time as last oral dose.
- Fentanyl patches have the advantage of lasting 72 hours each and provide a level release of opiate.
- They also cause less sedation, less respiratory depression and less constipation than morphine.
- Fever and external heat (from hot baths, hot water bottles, radiators etc.) increase the rate of absorption and can cause toxic effects.
- Because they do not involve using needles and can be administered by a competent parent, they tend to be fairly well received by the families.

Diamorphine infusions can be given via a central line or subcutaneously. Diamorphine has the advantage of being highly soluble and can be mixed with other drugs. This mode of administration allows constant levels of analgesics with the benefit of greater dose variations and the ability for parents to give boost doses via syringe drivers. Dose conversion is based on one third of the total oral dose of morphine over 24 hours.

- Maximum solubility of diamorphine is 400mg/ml.
- Oral diamorphine and morphine are equipotent.
- Peak blood levels of intravenous diamorphine are approximately double that of a s.c. or i.m. dose.
- Peak plasma levels of morphine / diamorphine occur approximately 30mins after i.m. or s.c. injection, but 2-3 hours after setting up a continuous s.c. infusion.

- Subcutaneous injection or infusion of diamorphine is 1.5 times as potent as morphine (e.g. 15mg morphine s.c. = 10mg diamorphine s.c.).
- Oral morphine is only half as potent as by injection.
- Thus oral morphine dose conversion to diamorphine subcutaneously or by infusion is one third (e.g. 30mg morphine p.o. = 10mg diamorphine s.c.).
- For **breakthrough pain** give a dose of oral morphine 50-100% of the 4 hourly equivalent dose.
- Buccal or intranasal diamorphine may be useful for rapid pain control.

Two side effects of opioids that appear to be more common in children are urinary retention and pruritus.

- Urinary retention may improve with carbachol or bethanechol
- Pruritus can be treated with topical treatments (calamine lotion, Eurax, hydrocortisone creams) or oral antihistamines. Ondansetron and oral naloxone have also been used. Reducing the dose of opioid or changing to an alternative such as fentanyl can also help.

Oxycodone is an alternative opioid analgesic used as second or third line treatment in patients who are unable to tolerate morphine. It is not licensed for use in children under the age of 18 years. It comes in 3 forms

1. OxyContin prolonged release tablets (every 12 hours)
    - The tablet is biphasic with initial fast release providing early onset analgesia followed by controlled release over 12 hours.
    - Morphine equivalence is 2:1 (20mg oral morphine = 10mg oral Oxycodone).
    - The tablets can not be crushed, broken, chewed or halved.
    - The tablet matrix is insoluble and may be passed in stools (the drug will have been absorbed in the GI tract).
    - Breakthrough pain dosage is $1/6^{th}$ total 24 hour dose.

2. OxyNorm immediate release liquid or capsules (every 4-6 hours)
    - The capsules can not be opened
    - The liquid can be mixed with soft drinks and contains no sugar
    - There is no data on administration down an NG tube.

3. OxyNorm 10mg/ml, solution for injection or infusion
    - Can be given i.v. or s.c. by injection or infusion
    - Can be diluted in 0.9% saline, 5% dextrose or water for injection
    - Conversion ratio for oral to parenteral Oxycodone = 2:1
    - Conversion ratio for parenteral morphine to parenteral Oxycodone = 1:1
    - Conversion ratio for parenteral diamorphine to parenteral Oxycodone = 1:1
    - OxyNorm injection is stable for 24 hours at room temperature and need not be protected from sunlight.

- See appendix for compatibility with other drugs

Hydromorphone use in the paediatric setting is currently unclear. It is an alternative opioid analgesic used as second or third line treatment in patients who are unable to tolerate morphine.

- It is licensed for use in children from age 12 years.
- It comes in 2 forms a slow release capsule and standard release capsule for breakthrough and incident pain.
- It can be used if there is renal impairment.
- The capsules can be opened and sprinkled onto cold soft food (swallow without chewing: chewing SR formulations can lead to over dose).
- Morphine equivalence is 7.5:1 (30mg oral morphine = 4mg oral hydromorphone).

NSAID

Inflammation can cause pain either directly or by adding to pressure e.g. tumours in bones. Anti-inflammatories such as diclofenac, naproxen or indomethacin can be very effective in these cases. Piroxicam is available as oral 'melts'. Be watchful for dyspeptic symptoms, which are a common side effect and can be reduced by concurrent use of prophylactic omeprazole or misoprostol. The new Cox-2 selective NSAID e.g. celecoxib may be helpful although many of these types of NSAID have been withdrawn due to cardiac side effects. Oral ketorolac is very effective for short-term postoperative pain relief and the intravenous form can help with severe pain from soft tissue or bony metastases, if this has been poorly responsive to other NSAID.

Steroids

Steroids particularly dexamethasone, can help reduce pain from raised intracranial pressure, bone pain and pain from nerve infiltration. Used in short courses they can be very effective.
Unfortunately long-term use can cause problems including: -

a) Mood and behaviour problems
b) Weight gain and changes of appearance
c) Reduced mobility
d) Insomnia
e) Dyspepsia
f) Peptic ulceration
g) Oral or oesophageal candidiasis
h) Psychosis

Antidepressants

Pain due to nerve compression or destruction (often described as burning pain) can be modified with the use of certain tricyclic antidepressants e.g. imipramine, amitriptyline or doxepin. Benefit should be seen within 3-4 weeks. If the is no response then it is worth changing to an anticonvulsant.

Anticonvulsants

Stabbing pain from nerve damage can be modified with the use of certain anticonvulsants e.g. carbamazepine or phenytoin. Gabapentin is now also being used with good effect. Benefit should be seen within 3-4 weeks. If the is no response then it is worth changing to an antidepressant.

Other drugs

Methadone is used in parts of the world although experience in the UK is limited. Difficulties with its long plasma half life and broad-spectrum receptor affinity limit its uses to specialist units

The intravenous preparation of ketamine given orally can be useful for resistant neurogenic pain. However it is not always well tolerated and bioavailability is unpredictable, as such its use should be limited to specialist units.

Nitrous oxide given by facemask can be useful in the older child.

Bisphosphonates have been used for bone pain in children.

Hyoscine butylbromide is the initial treatment of choice for colicky abdominal pain. Beware the use of opioids with this type of pain.

Radiotherapy

Even in cases where therapeutic radiotherapy is no longer appropriate, pain from bone or soft tissue malignant deposits can be treated with palliative local radiotherapy.

Nerve blocks

This form of treatment is best left to specialist pain clinics. Our experience in paediatric palliative care of this is limited.

Nursing and Supportive Care

Good nursing care is beyond value. A child who is in pain or distress can be seen visibly to improve and settle just by being held and hugged. The reassurance of physical contact and affection can and does modify perceptions of pain.

Spirituality / Religion

Whether the carers concerned believe that religion modifies perceptions of pain is irrelevant. What matters is what the child and family believe. Our job is to use all the means available to aid the child, and to that end religion and faith is a most powerful tool in appropriate cases.

Other

There appears to be an emergence of a number of alternative medical practises, acupuncture, reflexology, aromatherapy, herbal medicine etc. Just because we do not necessarily understand how these work does not mean we should ignore them. Some may in the future become useful additions to our armoury against pain.

Table 20: Oral analgesic equivalence to morphine

Multiply drug dose with potency ratio to obtain equivalent dose of morphine	
Analgesic	**Potency ratio with morphine**
Codeine / Dihydrocodeine	1/10
Oxycodone	1.5-2
Methadone	5-10
Hydromorphone	7.5
Fentanyl (transdermal)	150

Adapted from Symptom Management in Advanced Cancer by Robert Trycross

Table 21a: Drugs used to treat pain

DRUG	ROUTE	TOTAL DAILY DOSE (T.D.D.)		TIMES DAILY (Divide T.D.D. by this figure)
		1 month to 12 years	Over 12 years	
Paracetamol	Oral or rectal	**Under one year** 10-15mg/kg (Single dose) **1-5 years** 120-250mg (Single dose) **6-12 years** 250-500mg (Single dose)	0.5-1g (Single dose)	**Single dose,** may repeat every 4-6hrly. Max 4 doses in 24hrs
Codeine Phosphate	Oral	**Over 1 year** 3-6mg/kg	180mg	4 –6
Dihydrocodeine	Oral	**1-4 years** 2-3mg/kg **4-12 years** 2-6mg/kg (Maximum 1mg/kg/dose)	120-180mg	4 –6
Morphine	Oral or rectal	**Under one year** 80microgram/kg (Single dose) **1-12 years** 200-400 microgram/kg (Single dose)	10-15mg (Single dose)	**Single dose,** may repeat up to 6 times in 24hrs
Diamorphine	IV infusion	12.5-25 microgram/kg/hour		Continuous
	SC infusion	20-100 microgram/kg/hour		
Oxycodone	Oral (in opioid naïve)	0.2mg/kg (Single dose)	5-10mg (Single dose)	Up to 6 times in 24 hours Convert to modified release preparation once optimal doses are achieved
	Oral (patients already on opioids)	1/12 times total equivalent daily dose of morphine (Single dose)		
Diclofenac	Oral	**Over 1 year** 3mg/kg	75-150mg	2-3
Naproxen	Oral	10-15mg/kg	500-1000mg	2-3
Ibuprofen	Oral	20mg/kg	0.6-1.8g	3-4
Ketorolac (Maximum duration 48 hours)	Oral	**2-12years** 1-4mg/kg		4
	IV bolus	0.5mg/kg bolus followed by EITHER 1mg/kg every SIX hours		
	IV infusion	OR 0.17mg/kg/hour		Continuous
Omeprazole	Oral	0.7-3 mg/kg		1-2
Misoprostol	Oral	No dose recommendation if required estimate by age or body surface area	800microgram	4

Table 21b: Drugs used to treat pain

DRUG	ROUTE	TOTAL DAILY DOSE (T.D.D.)		TIMES DAILY (Divide T.D.D. by this figure)
		1 month to 12 years	Over 12 years	
Dexamethasone 2mg/5ml	Oral	1-6mg		2
Imipramine	Oral	200-400 microgram/kg Increasing by 50% every 2-3 days To 1-3mg/kg		At night. Start at lower dose and titrate against pain / side effects
Amitriptyline	Oral	-	30-150mg	At night
Carbamazepine	Oral	5-20mg/kg	800-1200mg	2-3 Start at lower dose and titrate against pain / side effects
Phenytoin	Oral	5mg/kg Then 5-15mg/kg (Maximum 300mg per day)	150-300mg Then 300-400mg (Maximum 600mg)	2
Ketamine (Only for specialised units)	Oral	0.1-0.3mg/kg/hr		Maximum 1.5mg/kg/hr
Methadone (Only for specialised units)	Oral starting dose	**2-12years** 0.2mg/kg as a single dose	5-10mg as a single dose	Give single doses every 4-12 hours PRN After 48 hours calculate total dose of methadone given over 48hours. Divide this figure by four to give 12 hourly dose
	IV or SC starting dose	0.1mg/kg as a single dose	5-10mg as a single dose	
Hyoscine butylbromide	Oral IV bolus IM SC 24hrly infusion	**1month-2years** 1.5mg/kg **2-5 years** 15mg **6-12 years** 30mg	80mg	3-4

Table 22: Dose conversion of morphine to Fentanyl patches

DOSE CONVERSION OF FENTANYL PATCHES							
4 HOURLY ORAL MORPHINE (mg)	<20	25-35	40-50	55-65	70-80	85-95	100-110
FENTANYL PATCH STRENGH	25	50	75	100	125	150	175

24 HOUR ORAL MORPHINE DOSE (mg)	<135	135-224	225-314	315-404	405-494	495-584	585-674

SPIRITUAL PAIN

> "Suffering is not a question that demands an answer; it is not a problem that demands a solution; it is a mystery that demands a presence." (Source unknown).

INTRODUCTION.

Spirituality and spiritual care are the proper concern of all who work with you as a family. It should be recognised that the issues of spirituality and religion are very important. However, they are two different aspects of care. It has been suggested that we all have a spiritual dimension and needs, and some people also have religious needs. It is possible to have spiritual needs independently of religious needs. Religious needs are to do with a shared faith, beliefs, practices and rituals that help a person make a connection with their 'God'. Spiritual needs are to do with our search for meaning and purpose and a sense of well-being and wholeness. Somebody once said that it puts us 'in touch with both our freedom and our destiny, enabling us to find our "selves" and find our way with others'.

These next few pages are not about answering all the questions you may now have about 'Why my child' or 'Why our family' or 'What is the meaning of life' and all those very difficult questions you now face with your child and family. Nobody can give you the answers to these profound questions you, your family or your child now ask.

Within this section no answers are given, but it is suggested that you do something that is far from easy for anyone to do. That is to sit with your child and try and stay in that difficult place and listen to your children's questions and hear their fears. You will not be failing your children by not knowing the answers to some of the questions they may now have. Not knowing can be a place of strength and maybe even reassuring for your child.

I once read a book which that was called, "*Failure, the gate way to hope"*', which I found very reassuring in itself. We won't always get it right, so don't expect to. Don't go looking for perfection. You will struggle with your own doubts as well as those of your child and family, but the struggle will be worth it.

The next few pages focus on the needs of your child who is ill, but they are just as applicable to you as parents or to your other children. I would suggest that we all have spiritual needs to which we must attend. Our spirituality is something that cannot be

turned on and off at will, it is a part of us and is always present. Your spirituality cannot be isolated from all that makes you who you are, or your family who they are.

All sick children will at some time think about what is going on, not only in their bodies, but also in their inner worlds. On this journey they need you to sit with them, in effect to watch with them, wait with them and let them wonder. They need you to be their companion, their guide and their advocate. However, the most you can do is to prepare and hold that space where they can start to do the work they need to do for the next stage of their journey, where they can explore their inner-world and where the miraculous may happen.

You now find yourself on a journey, a journey that you have had very little choice about making, and would have preferred not to have started.

I have suggested that this is about a 'journey' to the centre, to the heart of the matter, to our 'deep centre', where sometimes we meet our pain and have to name it. Children do come ready equipped for their spiritual journey, in so far as they have an openness and awareness, which in a way is unique to a child's early years. As we get older this openness and awareness gets pushed to one side.

DEFINITION:

Spirituality is what gives a person's life meaning. It is about how people view the world they find themselves in and this may or may not include a God figure or a religious faith. Spirituality is about how we view the world and how we react within it.

In talking about spirituality we need to bear in mind that we all come from different social and cultural contexts, that we each have a past and some of us have a future; and it is out of this setting that our spiritually will manifest itself. It is from this background or setting that your child's questions will flow. Therefore, you may well be the best person to offer this aspect of care, with help and support from others around you.

I have found that children with a life-limiting or threatening illness have a highly developed sense of their own spirituality, though they may not say or show it directly. It may well be deeper and more mature, than other children of their age and development. However, they may not always have the words or means of expressing it. Therefore, you as parents are very important, because you will be able to understand your child's language and play far better than anyone else.

PRACTICALITIES:

If we are to understand our children, their spirituality and their needs, we must first reflect on our own spirituality and be prepared to question our own assumptions about spirituality and religion. How do we see spirituality in our own lives and the psychological influence it may have had on us coming from some distant place in our past? The current situation in which you find yourself will challenge your value systems and notions of spirituality and cause you to reflect deeply. This process of

questioning often happens and you need to know that it is not unusual and you should not be wracked with guilt for questioning.

Spiritual care is about responding to the uniqueness of your children and accepting their range of doubts, beliefs and values just as they arise. It means responding to the spoken or unspoken statements from the very core of your children's being as valid expressions of where they are and who they are. It means being their friend, companion and their advocate in their search for identity on their longest journey and in the particular situation in which they now find themselves. It is to respond to them without being prescriptive, judgemental or dogmatic and without preconditions, acknowledging that your child and other members of the family will be at different stages on this very painful spiritual journey.

In order to be able to respond to this call, you need to try and create a safe and secure place, which I have come to call a 'sacred space', where your children can express their inner suffering and know that it is alright to do so, that they will be heard and taken seriously. You can help them best by just sitting with them, watching with them, waiting with them and just wondering. Take your lead from them, go with them, do not try to direct them, and use the language and imagery they use.

We need to be open to what our children have to teach us. We need to be prepared to learn from them. The skill here, as in other aspects of your children's care, is to be able to understand or 'crack' their code. We can start to do this, if we just sit with them, if we learn to watch, wait and wonder with them, if we take our lead from them, and be responsive to their needs and not the needs we think they may have or our own needs.

Never underestimate your child's understanding of what is going on. You do so at your peril. You may be surprised at how your child has an unclouded, clear way of thinking and their "take" on abstract ideas is often quirky, but relentlessly practical. This is the way in which they can help us with our struggle in trying to understand their suffering.

You may have discovered for yourself by now that you cannot fill the hole in a doughnut as much as you try to fill it, it just keeps disappearing out the back into some black hole. What you need to remember is that when you are with your child, the spaces or the gaps in the conversation do not need to be filled. This may be the centre of their journey and you just need to hold that space with your child and be present with them. "Suffering is not a question that demands an answer; it is not a problem that demands a solution; it is a mystery that demands a presence." (Source unknown).

PSYCHOLOGICAL

The whole subject of child psychiatry in paediatric palliative care is vast and complex. The symptoms that present are more often a reflection of the internal stresses and strains within a family. Helping the parents cope with a particular illness is as important as helping the child itself. All parents with healthy children who have been up with them a few nights during a trivial illness will have a brief understanding of the tiredness, fatigue, frustration and worry that is constantly felt by the parents of children in the hospice. The children themselves can also be left feeling frightened and guilty about their illness. There is no magical secret in helping these children and families. It requires good old-fashioned care and compassion. We need to give the family our time and we need to be prepared to listen. Giving honest answers to straight questions can allay fears and anxieties. A doctor or specialist counsellor is not necessarily the best or only person to tackle these issues. Our experience is that children and their families often prefer to talk to the nurses, teachers or priests. All these carers will, however, need support to cope themselves with the issues.

When, however, despite our best efforts, a child is manifesting clinical symptoms of anxiety or depression, then we must not be afraid of using medication as an adjuvant to our counselling and support. Symptoms manifested by children are not the same as those manifested by adults. They are also very dependent on the age and development of the child. Younger children tend to regress and develop behavioural problems; older children may have nightmares, insomnia or become introspective. It is very difficult without experience to diagnose many of the psychological problems that these children can get. Fortunately a child psychiatrist can be very helpful and supportive. Also it is worth trusting the natural instincts of the parents and nurses who often know the children better than we do.

Anxiety, particularly in the terminal stages can be helped with a number of drugs each of which can have different benefits. Midazolam and methotrimeprazine are two of the first line drugs for treating anxiety (although midazolam can cause paradoxical agitation). Chlorpromazine works well and its sedating effects can be helpful in certain cases. Diazepam also has sedative effects and its rectal form can be used in urgent cases when agitation is a major problem. Haloperidol has an important role in treating confusion.

Insomnia is a problem not only for the child but also for the parents. Parents may benefit from the use of complimentary therapies, particularly aromatherapy and massage, which can help to reduce tension and anxiety and promote relaxation and hopefully sleep. Temazepam can be used for the older child. Triclofos is useful in the younger child. The antihistamine promethazine can be used in the milder cases.

Melatonin can help in managing insomnia and appears to be used increasing in children with special needs. However it is unlicensed in the UK for this and so many general practitioners may feel unhappy about prescribing it.

Depression treatment has the disadvantage of taking 2-3 weeks to work. The older child may benefit from serotonin re-uptake inhibitors such as fluoxetine. Paroxetine has been used in the past but is now no longer licensed for use in children due to its side effects. There is currently a lot of controversy about the other forms of serotonin re-uptake inhibitors (except for fluoxetine) and in view of this it is probably best to avoid them unless there is no other option. The young child can be treated with tricyclics such as imipramine.

Parents and other family members may also require medical treatment.

Table 23: Drugs used to treat psychological problems

DRUG	ROUTE	TOTAL DAILY DOSE (T.D.D.)		TIMES DAILY (Divide T.D.D. by this figure)
		1 month to 12 years	Over 12 years	
Haloperidol	Oral	50microgram/kg (maximum 10mg)	1.5-20mg (maximum 60mg)	2
Levomepromazine	Oral	N/A	50-100mg	4
	SC infusion	0.35-3mg/kg		Continuous
Chlorpromazine	Oral	**1-5 years** 500microgram/kg Single dose given every 4-6hr (maximum 40mg/day) **6-12 years** 30-75mg/day	75-300mg	3 Adjust dose according to response
Diazepam	Oral	**1 month-1 yr.** 500mcg/kg **1-4 years** 5mg **5-12 years** 10mg	6-30mg	2-3
Temazepam	Oral	1mg/kg	20mg	Single dose
Triclofos	Oral	30-50mg/kg		Single dose at night
Promethazine	Oral	**Under 1 year** 5-10mg **1-5 years** 10-20mg **5-12 years** 20-25mg	25-50mg	Single dose at night
Imipramine	Oral	**6-7 years** 25mg **8-11 years** 25-50mg **Over 11 years** 50-75mg	75mg	At night
Fluoxetine	Oral		20mg	Single dose

SEIZURES

The child who has seizures falls into one of two categories.
1. The child with a neurodegenerative disorder who has had multiple seizures and is on a multitude of anti-epileptics. The parents are normally relaxed and knowledgeable about the seizures and how to treat them.
2. The second case is linked to malignant disorders and here seizures are a new and frightening complication of the illness for the parents. A calm and gentle warning to the parents of what can happen; with a positive explanation of what can be done to reduce the child's distress may help to reduce the parent's shock. Equally, the care team members who are not experienced with a fitting child may find the experience distressing. It is however important that seizures are managed in a calm and logical manner.

Rule one is that not all seizures are grand-mal epileptic seizures; they come in many forms and it is important to recognise the different types.

Rule two is that not all seizures require immediate administration of diazepam. The majority of seizures will settle given a bit of time. Simple seizures can be left 10-15minutes, particularly in the neurodegenerative disorders before administering diazepam.

Rule three look for reversible causes of increased seizures and try to correct them e.g infection, biochemical imbalance, hypoglycaemia, raised intracranial pressure and inappropriate epilepsy management (see intractable epilepsy)

The first line of treatment for persistent seizures is diazepam. Although it can be given intravenously, obtaining a new access site is difficult. It should be given rectally as a solution because suppositories take too long to work (there is no justification for rectally administered medication if the child already has a gastrostomy or naso-gastric tube).If given intravenously its has an onset of action in 1-3 minutes but a short duration of action of 15-20 minutes. It is effective in 80% of cases with control in 5 minutes. Intra-muscular injections should not be used in palliative care. The dose can be repeated once 5-10 minutes later.
If there is still no response then rectal paraldehyde should be administered. Paraldehyde should be given mixed in an equal volume of arachis oil (or olive oil if there is any nut allergy), drawn up into a glass syringe and given via a quill (if urgent a plastic syringe can be used provided it is drawn up and given immediately).

In the terminal stages seizures tend to become more severe and frequent. The child at this stage is normally not able to take or absorb oral anti-epileptics and in such cases continuous subcutaneous midazolam or phenobarbitone can be used. Both drugs are also good anxiolytics. Clonazepam is an alternative to midazolam.

Midazolam can be mixed with diamorphine in a syringe driver. It has an onset of action of 1-5minutes and duration of action of 1-5 hours. The main problem with midazolam is that it comes only in one strength, as a result the volume in a Graseby syringe driver can become a problem. In such cases it is best to split the dose over 12 hours rather than 24 hours. Anecdotal evidence suggests that a small dose of diamorphine added to the syringe driver can help with seizure that are requiring increasing doses of midazolam. Buccal midazolam can be used instead of subcutaneous or intravenous infusion, the intravenous formulation of 10mg in 2mls given in the appropriate dose buccally.

Phenobarbitone has a slower onset of action but a much longer duration of action 24-72 hours.

Intractable Epilepsy

The management of intractable epilepsy is beyond the scope of this manual. But it is worth remembering a few basic points

40% of children with epilepsy are misdiagnosed. This can be due to

- Underlying aetiology overlooked
- Misdiagnosis of syndrome and seizure type
- Poor EEG recording and interpretation
- Non epileptic disorders that mimic epileptic disorders

There are often errors in therapy due to

- Inappropriate choice of drugs
- Inappropriate dose and dosing interval.
- Inappropriate polytherapy

In all cases of children with intractable epilepsy check that

1. The child has actually seen a Paediatric Neurologist and has had a formal diagnosis of type of epilepsy made.
2. Regular re calculation of drug dosages are made as the child grows and put on weight
3. If the child is on polytherapy has this decision been made by a Paediatric Neurologist and if not what is the rational for the polytherapy.

Table 24: Drugs used to treat seizures

DRUG	ROUTE	TOTAL DAILY DOSE (T.D.D.)		TIMES DAILY (Divide T.D.D. by this figure)
		1 month to 12 years	Over 12 years	
Midazolam	SC or IV infusion	Loading dose 0.15mg/kg Maintenance dose 50-300 microgram/kg/hour		Over 150mg consider changing to phenobarbitone
	Intranasal	200-300microgram/kg/single dose		Unpleasant taste and irritating to nasal passages
	Buccal	500microgram/kg/single dose		Up to 10mg
Diazepam	Rectal solution	**Under 1 yrs** 2.5mg **1-3 years** 5mg **4-12 years** 5-10 mg	10mg	Single dose. Repeat after 5 minutes if necessary
Paraldehyde special enema 50%in arachis or olive oil	Rectal	0.8ml/kg of prepared enema	10-20ml of prepared enema	Single dose
Phenobarbitone	SC or IV infusion	Loading dose 15mg/kg		Then maintenance dose over 24 hours
		5-10mg/kg	600mg	
Clonazepam	IV bolus over 30 seconds	50micrograms/kg (Maximum 1mg)	1mg	Single dose. Can be repeated
	IV infusion	10 microgram/kg/hr		Continuous. Up to 60 microgram/kg/hr have been given
Lorazepam	IV slowly Rectal Sublingual	50-100 microgram/kg	4mg	Single dose, repeated once 24 hours later if necessary. IV injection can be given rectally or sublingual

SKIN

Management of skin problems is often challenging. This is one subject where prevention is better than cure. Our children are often wasted and immobile. Because the metabolism of the body enters a catabolic phase during severe illness the skin becomes very vulnerable to breakdown and subsequent poor healing. Good nursing care is required to predict where potential problems may occur. Special mattresses, aids and appliances can be organised. Turning of the child needs to be frequent and regular. Skill is also required in knowing how to move the child. Hoists and harnesses may be needed.

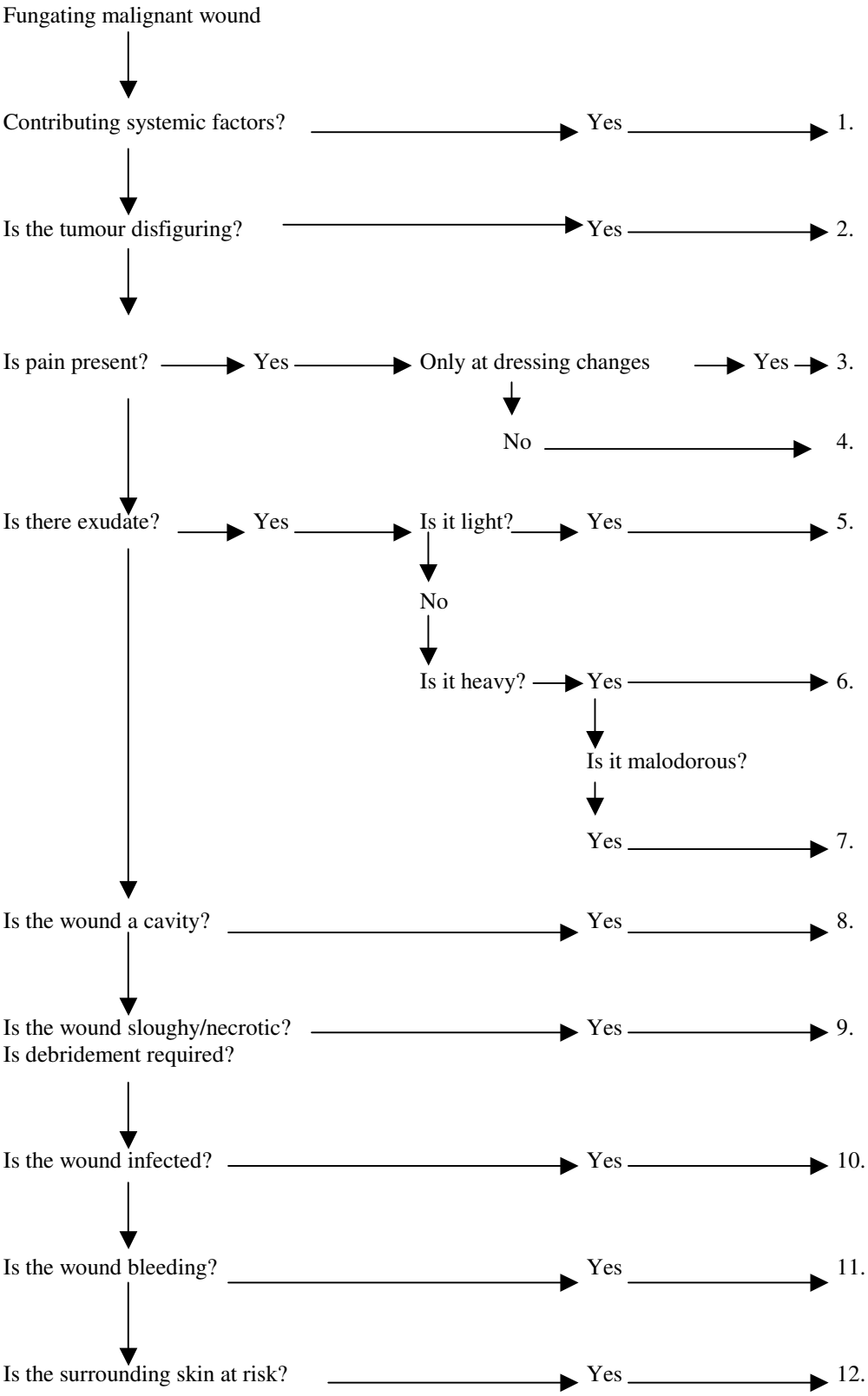
- Initial problems tend to start from pressure sores or friction burns.
- The skin at this stage can be protected with OpSite, Tegaderm or Cutifilm.
- Care must be taken when removing these dressings so as not to further damage the skin.
- Once it breaks down then DuoDerm or Spyrosorb can be used.
- Infected skin ulceration will require IntraSite gel or Iodosorb paste to remove discharge or necrotic tissue (top dressings can be OpSite or Tegaderm).
- Cavities can be packed with Kaltostat or Sorbsan. Re-dressings are done as required depending on the amount of exudate.
- Oral antibiotics may be necessary if cellulitis or discharging pus is present. Because many of the children may be on anti-epileptic drugs, erythromycin must be used with caution.
- Fungating tumours when infected can be very smelly. This causes great distress to the child and family. Metronidazole orally or topically is very effective and a deodoriser can help. The skin can also be dressed with Actisorb (charcoal dressing) to help reduce the smell. Honey and sugar can be used topically to reduce the smell of ulcers and they are also bacteriostatic.

Table 25: Types of dressings and their use

Type	Example	Benefit	Notes
Films	OpSite, Tegaderm, Cutifilm	Semipermeable, totally occlusive, allow observation	Cannot absorb exudates
Hydrocolloids	Granuflex, Comfeel, DuoDerm, Spyrosorb	Occlusive but absorb exudates	Facilitate autolysis of slough and eschar
Hydrogels	IntraSite gel, Iodosorb	Absorb large amounts of exudates	Useful for cavities. Can damage healing tissue if allowed to dry
Alginates	Kaltostat, Sorbsan	Highly absorbent, Haemostatic	
Foams	Lyofoam, Silastic	Highly absorbent, Good for deep cavities	Not for wounds with sinuses
Low adherent	Release, Mepore	Protects wound surface, absorb some exudates	If dried out then wet to remove

(Table adapted from commonly used dressing Symptom Management in Advanced Cancer by Robert Twycross)

Flow chart of management of fungating tumours



1. Consider potentially treatable factors
   - Reducing or stopping steroids
   - Improving nutrition

2. Modify the size and appearance of the tumour
   - Surgery by debulking or excision
   - Radiotherapy
   - Chemotherapy

3. If pain present at dressing changes
   - Short acting analgesic e.g. buccal diamorphine
   - Topical anaesthetic agents e.g. lignocaine
   - Entonox

4. If pain present all the time
   - Review analgesia
   - Consider topical diamorphine in dressing

5. For light exudates
   - Semi-permeable film dressing
   - Hydrocolloid interactive dressing
   - Low adherent dressing
   - Alginate dressing
   - Hydrophilic foam dressing

6. For heavy exudates
   - Hydrocolloid interactive dressing
   - Hydrogel with secondary dressing
   - Alginate dressing
   - Hydrophilic foam dressing
   - Use of paediatric stoma bags

7. For malodour consider
- A counter odour e.g. household air freshener, ostomy agents, aromatherapy oils.
- A deodorant e.g. Naturcare or electric deodoriser
- Metronidazole either topically or systemically
- Live yoghurt
- Charcoal impregnated alginate or foam dressing
- Totally occlusive dressing e.g. OpSite or almost totally occlusive dressing e.g. Granuflex

8. If a cavity is present consider
- Cavity dressing e.g. alginate
- Silastic foam if wound is clean
- Foam dressing

9. If debridement is required consider
    - Surgery
    - Enzymes e.g. Varidase
    - Hydrocolloid paste with dressing
    - Hydrogel

10. If the wound is infected
    - Topical metronidazole e.g. Anabact or Metrotop
    - Irrigate with IV metronidazole solution
    - Systemic antibiotics
    - Honey and icing sugar dressing

11. If the wound is bleeding
    - Calcium alginate dressing (haemostatic properties)
    - Topical adrenaline 1 in 1000 solution
    - Radiotherapy
    - Use non-adherent dressings and soak dressings off with normal saline

12. If the surrounding skin at risk
    - Protect surrounding skin with barrier ointment

Care must be taken with dressing to

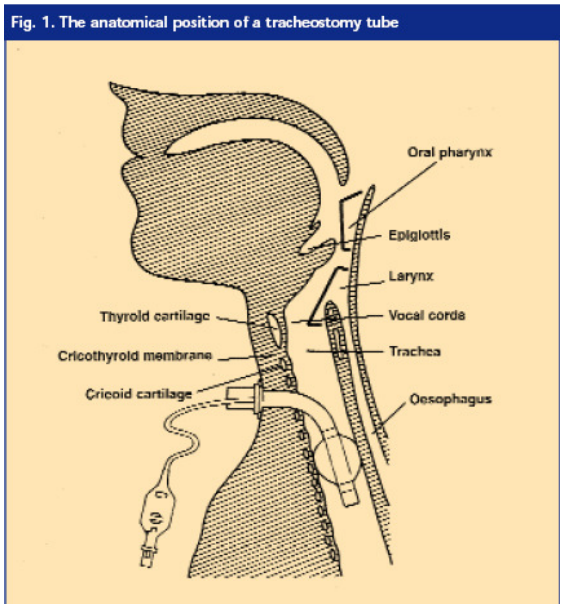
- Remove dressings without pain
- To make dressings cosmetically acceptable to the child
- To lengthen the time required between dressing changes
- To understand the cost effectiveness in terms of time and money for all the different types of dressings

TRACHEOSTOMY CARE

What is a Tracheostomy? This is an artificial opening into the windpipe (trachea) which is held open by a tracheostomy tube. This helps the child to breathe easily; air now goes in and out through the tracheostomy bypassing the mouth.

Indications for a tracheostomy

1) a narrow upper airway
2) the need for long term ventilation
3) bronchial toilet



There are several types of tracheostomies. They can be made of plastic or metal, may be cuffed (avoided in children), uncuffed, or fenestrated (with a hole in the canula to facilitate speech). The child will be given the one most suitable for his / her needs.

All children that have a tracheostomy must at all times have with them the following:

- Suction machine and charger.
- Appropriate size suction catheters.
- Change of tracheostomy tube - same size and one size down.
- Change of ties / tapes.
- Scissors.
- Water based lubricant.
- Normal saline and gauze.
- Water to clear tubing.
- Gloves.
- Change of Swedish nose.
- Most importantly, a capable adult to change a tracheostomy in the event of an emergency.

Prior to any procedure in relation to the tracheostomy it is important to reassure the child and explain as much as possible about the procedure to be performed.

Daily Care

The tracheostomy stoma needs cleaning daily as tracheal secretions can infect the stoma site. Cleaning may need to be increased if child unwell or there are a lot of secretions. The stoma site is cleaned with normal saline and a cotton wool applicator. This is a time to inspect the stoma for any signs of redness or the presence of granulation tissue (excess new skin). If there is redness / irritation a sterile keyhole dressing can be applied between the skin and the flanges, taking care not to cover the tracheostomy tube. The dressing should be changed regularly as wet dressings can cause irritation and infection. BARRIER CREAM SHOULD NOT BE APPLIED.
If there is granulation tissue present discuss with Tracheostomy Nurse Specialist as this will need to be cauterised or removed.

Tape Changes

The tracheostomy tube is held in place by either cotton ties or Velcro tapes. These need to be changed daily or more frequently if soiled.
This is a two person procedure; one person secures tracheostomy in place, while the other person changes the ties or tapes.

Prior to any procedure ensure that all the necessary equipment is at hand:

- Two lengths of ¼ inch cotton tape or Velcro ties.
- Normal saline and gauze to clean the skin.
- Tracheostomy tubes.
- Suction if necessary.

1. Position child on his / her back with the neck extended over a rolled towel.
2. One person secures tube in place, the other cuts and removes the soiled tapes.
3. Thread the end of one of the tapes through the tracheostomy tube flange on the far side and tie it to the other with three knots.
4. Repeat the procedure on the other side but instead of securing the tapes with a knot, just tie in a bow. Keep the tapes as unwrinkled as possible and try to achieve the correct tension before tying the bow.
5. Continuing to hold the tube, sit the child forward and with child's head bent forward it should be possible to place one finger between the ties and the skin. This is the safest recommended tension.
6. If tension is correct then change the bow to three knots securely.
7. If Velcro tapes used, remove soiled tapes, position new tapes, thread the Velcro part through the flange of tracheostomy, fasten and repeat on the other side, ensuring that the safe tension is maintained at all times.

Suctioning

Why suction?

- If secretions are allowed to accumulate they will block the tube.
- Secretions left in the tube could lead to infection.

When to suction?

- Noisy breathing (sound of air bubbling through secretions).
- Visible secretions.
- A cough that sounds like secretions are in the tube.
- Restlessness/crying.
- Increased respiratory rate.

Suctioning Instructions

Make sure you have at hand all the equipment you need.

- Suction unit.
- Catheter (correct size) - new one for each suction.
- Connecting tubes if needed.
- Syringe of saline
- Bowl or bottle of water to clean the catheter.

1. Turn on suction pump and check pressure is correct as instructed.
2. Gently insert catheter into tracheostomy, Ensure thumb is off port of suction catheter.
3. Apply suction, by covering the port with thumb and withdraw catheter. This should only take 5 or 6 seconds.
4. Repeat if necessary but allow child time to settle in-between.
5. Disconnect the catheter from the tubing and dispose of safely. Clear the tubing with the water provided.
6. Attach a new catheter to be ready for next time.

Each time you suction it is important to observe the secretions.

- Have they changed colour?
- Are they thicker than usual?
- Are you suctioning more frequently?
- Unpleasant smell?
- Tinged with blood?

Child may have infection. GP needs to be informed in case child needs antibiotics. Be aware that when a child has a chest infection he / she will require more frequent suctioning.

Changing tracheostomy tube

In a non-emergency situation leave tube change for 1 ½ hrs after feed as child may vomit when upset. Tracheostomy tubes are usually changed weekly.

Prepare equipment

- Round ended scissors.
- Two lengths of ¼ inch cotton tapes or Velcro tapes.
- New tube, check correct size and that the tube is intact.
- A smaller sized tube in case the correct size does not go in.
- Water based lubricant.
- Prepare tube, insert introducer, apply a small amount of lubricant on the outer tubing away from end of tube, place tube ready to use.

1. Position child as for tape change, older child can sit up.
2. Hold the tube (one person).
3. Second person cut and remove the dirty tapes and place clean tapes behind child's head.
4. First person holds tube; second person holds the new tube by flanges and positions the tip near the child's neck.
5. Gently remove the old tube following the curve of the tube. Same person firmly and gently slide in the new tube following the curve of the tube so as not to damage the trachea. Remove introducer if used.
6. Hold new tube securely.
7. If child is coughing allow to settle.
8. Check air flow through tube, child's breathing pattern and colour, suction if necessary.
9. Clean the skin around the tube. Tie the tapes.

10. Do not let go of the tube until the tapes are securely tied.

Humidification

The normal mechanism of warming and humidifying air is removed with a tracheostomy. Therefore most children have a Swedish nose applied to the tracheostomy to give dry humidification. Wet humidification may also be given by using nebulised saline.

Nebulising with a tracheostomy?

Medication checked and instilled into nebuliser as prescribed. The most important thing to remember is to stand next to the child with the nebuliser near the tracheostomy, to allow the nebulised medication to be given, but NOT to attach the nebuliser to the tracheostomy as this will cause major damage and restrict breathing.

How to recognise blocked tube?

- Childs may be coughing vigorously.
- Difficulty breathing.
- Change in colour leading to unconsciousness.

Immediate action is required.

1. **Try suctioning**. *If no better.*
2. **Cut tapes and remove tracheostomy tube**. In long standing tracheostomies the tract will be well developed and no immediate action is required. *If still no better.*
3. **Insert new tube same size or if necessary a smaller size.** *If still no better.*
4. **Insert a cut off piece of suction catheter to allow some air to pass through**, *call for help and phone 999.*

If changing tube has resolved the problem hold tracheostomy tube in place until another person arrives to help. Reassure child and allow to settle.
Suction only if necessary.

Child stops Breathing

1. Call for help if someone within earshot.
2. Check if child responsive.
3. Turn child onto back on firm flat surface.
4. Tilt head back slightly to expose tracheostomy.
5. Is tracheostomy blocked? Attempt suction.
6. Still seems blocked? Attempt to change tube.
7. Look listen feel for breathing.
8. If not breathing, shout for help get someone to dial 999.
9. Commence basic life support immediately.

DO NOT LEAVE CHILD ALONE, EVEN IF BREATHING RETURNS TO NORMAL

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TRAVEL ABROAD

Many of our patients will have a desire to travel abroad during their limited life span. This can present particular problems in terms of carrying medication across borders. There are strict rules laid down by the UK Home Office in relation to which medication can be carried and which requires a special Home Office personal export license. These restrictions not only concern controlled drugs but can affect other types as well. There are also rules in terms of the limit of quantity. Each country visited will also have their own rules and the family must contact the appropriate embassy to find out exactly what these are. The Home Office license is for crossing UK borders only; many countries prohibit the import of diamorphine, morphine or methadone for personal use.

It is important to check all these details. To find out more information then contact the Home Office on.

DLEU
6th Floor
Peel Building
Home Office
2 Marsham Street
London SW1P 4DF
Telephone: 0207 217 8446
Fax: 0207 035 6161
Web: www.drugs.homeoffice.gov.uk

HOME VENTILATION

Children require long-term non-invasive ventilation for a number of reasons;
*Neuro-muscular disease - Duchenne Muscular Dystrophy
*Ondine curse - Where the child requires ventilation when asleep
*Broncho-pulmonary Dysplasia
*Cranio-facial abnormalities
*Spinal injuries

Levels of ventilatory support required will vary among children. For most children nocturnal ventilation of between 8-10 hours is sufficient. The duration and level of ventilatory support required will be dependent on the child's medical condition.

Some may have Continuous Positive Airway Pressure (**C.P.A.P**) via a facemask or nasal mask whilst asleep, while others may require Positive Pressure Ventilation (**P.P.V**) with the use of facemask, nasal mask or even tracheostomy over 24 hours. Most of the patients are able to come off ventilation for short periods of time. This should be encouraged as this will help to wean the patient off ventilation for periods of time, this will also help with feeding, communication etc.

There are various types of home ventilation support devices and these include the following:-

The Breas ventilator
The Nippead Ventilator

Not all children will require additional oxygen through their ventilator unless they become ill or as a result of disease progression. If additional oxygen is required then this is normally achieved by attaching the oxygen supply directly to the mask or a connector close to the mask.

Common Problems;

- **The child may become hot/sticky/sweaty beneath the silicone mask.** This can also be due to the humidification requirements. If there is excessive moisture then the humidifier heat can be turned down to reduce moisture. Ensure the child's environment is adequately ventilated and appropriate clothing and bed linen are applied.

- **Pressure marks often appear around the ears as a result of the head harness straps, which** need to be tightly tied in order that the mask does not slip, as well as reducing air leaks. It is absolutely vital that the head harness is **NOT** over tightened. Place some gauze over the child's ears prior to fixing the straps. This will prevent the tapes from moving and will provide more comfort around the ears.

- **The facial mask also has the potential to create pressure sores around the mouth and the bridge of the nose**. A DuoDerm dressing placed under the edges of the mask where it appears to be tight will minimise this risk. Pressure sores can also be avoided if the mask is **NOT** over tightened. Most of the machines are designed to cope with small leaks.

- **The ventilator continues to alarm.** If the settings are appropriate and it is correctly connected to the child, there may be water in the patient tubing. Disconnect the small tubing from the ventilator and apply suction to the openings on the ventilator. This will remove any excess water within the system. Reconnect the tubing to the appropriate ventilator openings. Consider changing the whole circuit. If not successful, seek further advice.

- **If ventilator connection becomes unattached, ventilator will alarm.** Establish if air leak is due to break in circuit. This needs to be resolved, as ventilator pressures will drop, causing machine to alarm. Replacing the whole circuit usually resolves this problem.

- **The child experiences elements of claustrophobia when the facemask is applied.** Consider use of different interface such as a nasal mask if appropriate with the type of ventilation required.

All alterations to the ventilator settings must be undertaken by an appropriately trained and qualified professional, i.e. Respiratory Consultant, Respiratory Service Lead Professional, in collaboration with the multi-disciplinary team. Any changes made to the ventilator prescription must be documented.

In the event of a power cut, establish whether your ventilator has an inbuilt battery back up or whether it requires a separate battery pack. This should always be fully charged. This battery back up will have **approximately 2 hours or longer up to 8 hours** of usage, this will depend on the capacity of the battery and the power consumption of the ventilator. For long term power failure alternative arrangements will need to be established – e.g. Respiratory services supplying a back up ventilator, informing the Electricity Board to ensure the child's needs become priority, and in the event of the child having Ondine Curse, wake the child up and keep him/her awake until alternative arrangements are in place.

In some instances it may be necessary to continue with the manual ventilation of the child via a 'bag and mask' device until alternative arrangements are established. Someone who has been trained and deemed as competent in this task must undertake this. These people will be evident within the child's care package or will be established within the environment in which the child is residing.

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APPENDIX 1: DON'T PANIC, WHERE TO GET HELP

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Royal Liverpool Children's Hospital - Alder Hey
Eaton Road
Liverpool L12 2AP
0151 252 5187
07881 788903
Long range bleep via switchboard (0151 228 4811)
Lynda.Brook@RLC.NHS.UK

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Canal Court
42 Craiglockhart Avenue
Edinburgh
EH14 1LT
Tel: 0131 444 1900
Tel: 0131 444 4015 DDL
F: 0131 444 4001
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Organisations

ACT: The Association of Children's Palliative Care
Orchard House, Orchard Lane
Bristol, BS1 5DT
United Kingdom
Tel +44(0)117 922 1556
Fax +44(0)117 930 4707
http://www.act.org.uk

The Association of Children's Hospices
First Floor
Canningford House
38 Victoria Street
Bristol
BS1 6BY
Tel: 0117 989 7820
Fax: 0117 929 1999
http://www.childhospice.org.uk

BSPPM: British Society of Paediatric Palliative Medicine
Chairman – Dr Richard Hain
Secretary – Dr Finella Craig

Association of Children's Hospice Doctors
Chairman – Dr Mike Miller
Secretary – Dr Pat Carragher

Diploma in Paediatric Palliative Medicine
Dippallmed@velindre-tr.wales.nhs.uk

Palliative Drugs.Com
(Website hosts the latest version of the Palliative Care Formulary, as well as an active bulletin board for drug-related questions).
www.palliativedrugs.com

Medical resources: paper-based

- Care of the Dying Child (2nd edition): Ann Goldman

- A Guide to Symptom Relief in Palliative Care (5th edition): Claud Regnard 2003 (includes a bit of paediatric content from Justin and Susie). User friendly and practical.
- Oxford Handbook of Palliative Care: Max Watson et al (2005): a wealth of resources in a small space, including a useful paediatric section.
- Medicines for Children: 3rd edition RCPCH 2006
- BNF for Children 2007 (and of course the standard BNF).
- Palliative Care Guidelines 2006: Max Watson et al. This was the precursor to the Oxford Handbook. It was produced for the SW London Cancer network, has both adult and paediatric sections, and copies are available very cheaply from Princess Alice Hospice, Esher, Surrey, and from the handbook website (www.greenbox.net/palliative; 0870 163 0073)
- Oxford Textbook of Palliative Medicine (3nd edition) Doyle et al 2005
- Oxford Textbook of Palliative Care for Children: Goldman, Hain, Liben (Jan 06)
- Symptom Management in Advanced Cancer: Twycross.
- Palliative Care Formulary: Twycross (same as is available on line through Palliative Drugs site): 3rd edition Oct 07.

Medical resources on line

a) child-specific:

http://www.act.org.uk/ - Association for Children with Life Threatening Conditions. Go to the 'downloads' and 'other resources' option for the useful *Rainbows Symptom Control Manual (2006).*

This site also hosts PaedPalCare (an electronic listserve to post and respond to queries on line) and PaedPalLit (free electronic access to a quarterly-ish roundup of relevant journal abstracts).

http://www.childhospice.org.uk/ - Association of Children's Hospices (UK).

http://www.cnpcc.ca/ : Canadian paediatric palliative care, with useful links and resources.

http://www.gosh.nhs.uk/clinical_information/ Great Ormond Street Hospital website: useful for clinical guidelines and patient information.

b) other sites relevant for palliative care:

http://www.palliativedrugs.com/ Excellent Palliative drugs website and bulletin board. Very active and helpful international palliative medicine community: post a query here and you should get a useful answer within the day. Also hosts the electronic version of Palliative Care Formulary (Palliative version of the BNF, which includes syringe driver compatibility charts etc), and a 'RAG' section with lots of useful guidelines and protocols from elsewhere.

http://book.pallcare.info/ : A useful UK site, including the 'Palliative Care Matters' handbook.

http://www.palliative.info/ : Canadian palliative care website with a lot of useful links and protocols.

http://www.palliative-medicine.org/ Association for Palliative Medicine

http://www.helpthehospices.org.uk/education/index.asp Help the Hospices site is useful – in particular the 'education' section has a very full listing of courses

available, and the 'e-learning' section has helpful (if basic) brief modules based on the CLIP programme.

For information regarding specific diseases:
http://www.rarediseases.org/search/rdblist.html Rare diseases database - great for looking up rare syndromes.
http://www.ninds.nih.gov/disorders/disorder_index.htm#F National Institute for Neurological diseases and Stroke – again a good disease database for medical information (US site).
http://www.cafamily.org.uk/home.html 'Contact a Family' site – useful disease information for families etc and disease-based self help groups.

APPENDIX 2: Protocol for Subcutaneous Drug Administration

Aim

Safe, effective administration of drugs for palliative care via subcutaneous route.

Checking procedure – prior to setting up pump

General points:

1). Ensure that the child and parents/carers have been prepared. The aims of the syringe driver, the drugs to be administered, the siting of the butterfly, appearance and 'sounds' from the driver should all be explained to the child and carers by the doctor, with the nurse present if possible. The child and carers should be given the opportunity to ask any questions, anxieties should be acknowledged and reassurance given where appropriate.

2). The drugs to be administered, including the Diluent, should be checked by two nurses of RSCN or RNCB level who have successfully completed an assessment in the use of Graseby Pumps No. MS16 and MS26 (or other models as appropriate) with attendance at annual mandatory Graseby Pump training sessions.

3). Check that the following details on the drug chart are correct prior to setting up equipment and check against child's records:

-Date
-Time
-Child's name
-Child's date of birth
-Weight in kg

4). Check that the prescription is rewritten every 24 hours by the doctor and signed.

Drugs:

1). Check that the dosage is appropriate by comparison with previous levels of oral medication or by comparison with the preceding 24 hours dosage administered via the syringe driver. Refer to pharmacy literature and check with prescribing doctor if in doubt.

As a general rule, on commencement of the syringe driver, the dosage of diamorphine over the first 24 hours equates to one third of the previously required total daily dosage of oral morphine, e.g. 20mg diamorphine is equivalent to 60mg oral morphine in the preceding 24 hour period.

The maximum recommended dose of diamorphine when used as the sole agent in a syringe driver should not exceed 400mg/ml although such levels are unlikely to be used in a paediatric setting.

2). If more than one drug is to be used check compatibility by reference to Table 20. Where possible, the number of drugs used should be kept to a minimum, usually no more than two or three.

3). Check Diluent suitability.

Water for injection is the preferred Diluent for most drugs except non-steroidal anti-inflammatory drugs, which mix better with 0.9% saline.

Dilute diamorphine prior to mixing with other drugs.

Do not use 0.9% saline to dilute cyclizine because of the high risk of precipitation.

Instructions for use of Graseby Syringe Drivers

1). Assemble equipment:

Syringe driver
Battery
Luer-Lok syringe – usually 10 or 20ml
Giving set
Fine-gauge butterfly
Clean dressing – OpSite/Tegaderm

Diluent
Drugs prescribed

2). Insert correct sized battery – alarm will sound for a few seconds.

3). Press start/boost button. Motor will run for a short while as safety circuits are checked.

4). Release start button.

5). Set the rate of delivery. This is calculated as:

$$\frac{\text{Length of infusion volume}}{\text{Delivery time}}$$

For the MS16 pump, the setting is in mm/hour. Therefore, if the infusion volume is 48mm, over 24 hours the rate will be 48mm / 24 hours = 2mm/hour.

Rate dial set at **0 2**

For the MS26 pump the setting is in mm/day. Therefore, if the infusion volume is 48mm, over 24hours the rate will be 48mm/day.

Rate dial set at **4 8**

6). Draw up prescribed amount of medication in a 10ml Luer-Lok syringe and dilute with sterile water for injection. If using diamorphine, draw this up first by dissolving the contents of the vial in a known amount of sterile water for injection and discarding any excess amount of drug if necessary, i.e. calculate the correct volume of dissolved diamorphine required to obtain the dose required. (Diamorphine is available in 5, 10, 30 and 100mg vials).

Once all of the required drugs have been drawn up, make the volume up to the correct amount with sterile water for injection. The total volume in the syringe is usually 8-9ml which gives a volume infusion length of 48mm. In calculating the total volume, sufficient water needs to be drawn up to allow for priming of the giving set i.e. filling the whole line including Luer connectors. For most sets this 'dead space' accounts for 0.5-1ml.

7). Site butterfly - the reader should refer to the protocol for insertion of subcutaneous butterfly needle.

8). Start driver by pressing start/boost button. The light will flash every 20-25 seconds. Note that the driver can only be switched off by removing the battery.

9). Protect mixture from light and apparatus from accidental damage by using a holster or carry case.

Care of the infusion

1). Check at intervals that the device is functioning correctly, i.e. the light flashes at regular intervals and those connections have not come loose.

2). Check that the child remains comfortable and has an adequate degree of symptom control and an acceptable level of side effects.

For breakthrough symptoms the following rules should apply:

For breakthrough pain the stat dose of diamorphine is the equivalent 4 hourly dose i.e. 1/6th the total diamorphine dose over 24hours.

Do not alter the rate of the syringe driver once set up. This makes it difficult to calculate the dose of drug that has been administered and can potentially lead to excessive doses of one or more of the syringe driver constituents being given.

Either: administer additional drugs orally or via bolus subcutaneous, intramuscular or other appropriate route,

Or: set up a new syringe driver containing an adjusted dose of drugs.

Similarly, use of the boost button is not recommended on more than an 'occasional' basis.

3). Check the butterfly site for signs of infection or inflammation. Change the position of the butterfly each time the butterfly is replaced.

4). Check for cloudiness or discolouration of the infusion at regular intervals (indication of degradation of the drug or precipitation). If this occurs, discard and replace the infusion immediately.

Table 26: The compatibility of drugs with OxyNorm injection

Drug	Compatible with OxyNorm injection
Dexamethasone	Yes
Haloperidol	Yes
Hyoscine butylbromide	Yes
Hyoscine hydrobromide	Yes
Levomepromazine	Yes
Metoclopramide	Yes
Midazolam	Yes
Cyclizine	Incompatible in concentrations >3mg/ml of cyclizine (i.e. 30mg in standard 10ml syringe). Use water for injection as diluent.
Prochlorperazine	NO

Table 27: The compatibility of drugs combined in a syringe for s.c. infusion

	Diamorphine	Metoclopramide	Haloperidol	Cyclizine	Methotrimeprazine	Midazolam	Hyoscine Hydrobr.	Hyoscine Butylbr.	Dexamethasone
Diamorphine		c3 ++	c2 ++	c1 ++	++stable at any concentration of either drug	++stable at any concen-tration of either drug	++stable at any conc. of either drug	++stable at any conc. of either drug	c
Metoclopramide	c3 ++		n	p	n	+	++	n	++
Haloperidol	c2 ++	n		+	n	++	+	+	p
Cyclizine	c1 ++	p	+		+	c	+	++	p
Methotrimeprazine	++	n	n	+		++	+	+	p
Midazolam	++	+	++	c	++		+	+	p
Hyoscine Hydrobromide	++	++	+	+	+	+		n	
Hyoscine Butylbromide	++	n	+	++	+	+	n		
Dexamethasone	c	++	p	p	p	p			

++ compatible at therapeutic concentrations-some published evidence
+ compatible at therapeutic concentrations-common usage but no published evidence
c=caution at higher concentrations
p=likely to precipitate
n=generally not a clinically useful combination (same group of drug or counteracting effects)
1=stable up to diamorphine up to 20mg/ml + cyclizine up to 20mg/ml
2=stable up to diamorphine up to 10mg/ml + haloperidol up to 1mg/ml
3=stable up to diamorphine up to 25mg/ml + metoclopramide up to 5mg/ml

(Adapted from Faull, Carter and Woof, Handbook of Palliative Care, Blackwell Science, 1998).

GRASEBY M26 SUBCUTANEOUS INFUSION CHART

NAME **AGE** **D.O.B.** **WT**

SYRINGE SIZE BD- **TOTAL VOLUME IN SYRINGE** **DILUTENT**

DATE	TIME STARTED	DRUG-PRESCRIPTION	TOTAL DOSE IN SYRINGE	RATE MM/24HR	RATE VARIATIONS ALLOWED	DR SIGN	CHECKED	

TIME																								
RATE: MM/24HR																								
HOURLY INFUSION MM/HR COMPLETED																								
SITE CHECK																								
RESPIRATION RATE																								
PAIN ASSESSMENT																								
SEDATIVE EFFECT																								
SUCTIONING																								
POSITION CHANGE																								
BOOSTS GIVEN																								

PAIN

 = 0  = 3

 = 1  = 4

 = 2  = 5

SEDATIVE EFFECTS

- UNCONSCIOUS = 1
- ASLEEP/ROUSABLE = 2
- AWAKE/COMFORTABLE = 3
- UPSET = 4

SITE CHECK

- CLEAN/ NO REDNESS = 1
- TRACKING/ WARM = 2
- BLOOD/ INFLAMMATION = 3
- INFILTRATION = 4

RESPIRATORY PATTERN

TACHYPNOEA = T
WHEEZING = W
DYSPNOEA = D
CHEYNE STOKES = C