Palliative care for children in resource-limited countries

Introduction
Most children who need palliative care in resource-limited countries will require identification and treatment in the community rather than in hospital. Moreover, in the presence of effective care and support networks, home has frequently been demonstrated to be the best setting for palliative care for both the child and the family.

A high proportion of children do not reach hospitals in Africa. This percentage ranges from approximately 57% in Uganda to 85% in Ethiopia. Also, hospitals need to be aware that most families would wish for their child to die at home, where they can look after them and they can be buried with their ancestors near to the home. The cost of transporting a body is very high, so economic factors also play a part.

Therefore any treatment that is given in the hospital must be of a kind that can be continued at home, otherwise the child will never be able to leave the hospital. Healthcare workers in hospital, with the support of Ministries of Health and community leaders, must set up systems to help community health workers to provide care in the community, including the safe management of morphine treatment when it is required.

Allowing the family and child to choose the setting for palliative care is of great importance. However, it is recognised that the necessary resources may be minimal or absent in many locations, and local conditions will determine what options are available.

This section describes the use of affordable medications that have been proven to work in resource poor settings. In resource limited situations, it is vital that government funds are spent carefully on measures which work and are not too expensive thus ensuring that the poorest families can also receive their right to palliative care for their children.

Although palliative care actually means relief of symptoms in all care, the term is usually associated with relieving symptoms when the emphasis is no longer on curative treatment. The decision to stop or withdraw curative treatment will never be easy for parents or healthcare professionals, and may evolve over a period of time. It is important, however, to state that even when we cannot cure the body, it is never true that nothing more can be done.

Like all of us, children have personal needs, and careful attention must be given to the physical, social, emotional and spiritual needs of the child and their family. Staff, too, should be receiving support through what can be a distressing time.

Essential healthcare for the dying child

- Include parents or familiar caregivers.
  - This matters at all times.
  - Their familiar presence will comfort the child.
  - Even apparently unconscious children may still know their parents’ or caregivers’ voices.
  - Parents invariably want to be able to provide care for their child. This is a natural wish and can aid their own coping strategies.

- Set realistic goals.
  - The art of terminal care is to know when both goal and treatment must change.
  - The goal is to help the child to enjoy and cope with what is left of their life.
  - It should be clearly and well communicated that resuscitation measures are not to be a feature of terminal care.

BOX 1.16.1 WHO definition of palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:
- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor to postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient’s illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO definition of palliative care for children

Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves giving support to the family.

- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child’s physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children’s homes.
— Our aim is now not to cure, and never to kill, but always to comfort.
— The social needs and goals of a dying child include access to siblings and friends to play with and talk to. They should be made welcome.

- Listen and explain.
— It should be clear from the child’s deteriorating condition that the goals are changing and death is imminent. This must be gently explained and the parents’ and child’s questions answered. It is wise, especially with children, to clarify the real question that is being asked. Replies must be honest, but the truth should be shared sensitively, a little at a time.
— Explanations are very important for both parents and children, and appropriate, understandable terms should be used.
— Forewarning of procedures, with hugs and praise afterwards, will reduce fears and fantasies.
— Honesty results in greater trust and cooperation than saying something won’t hurt when it will.
— All of those involved, from a young child to an elderly grandparent, will harbour fears and anxieties. Active listening is a major part of caring for a dying child and their family. Great comfort can be derived from the acknowledgement and expression of anxiety, and this helps to dissipate the feelings of isolation that are frequently experienced.
— Adolescents will also have particular concerns and worries, and often have spiritual needs as well.
— Principles of pain control

Pain

Principles of pain control

Pain is probably the most common symptom in palliative care, and is frequently seen in both malignant and non-malignant disease. It is a complex sensation related to the physiological insult to the tissues, but is also influenced by psychological, social and cultural factors.

It is helpful to think of severe pain in terms of response to opioids.
— Opioid-responsive pain is relieved by opioids.
— Opioid-semi-responsive pain is relieved by the concurrent use of an opioid and an adjuvant drug.
— Opioid-resistant pain is not relieved by opioids.

Neuropathic or nerve pain is more likely to fall into the semi-responsive or unresponsive groups. Bone pain falls into the semi-responsive group.

Analgesic approaches to pain relief

The optimal approach to pain management in children includes drug therapy, with analgesics usually being the mainstay of treatment. Correct use of analgesic drugs

<table>
<thead>
<tr>
<th>Medicine</th>
<th>Reason</th>
<th>Morning</th>
<th>Afternoon</th>
<th>Evening</th>
<th>Night</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morphone</td>
<td>Pain</td>
<td>2.5 mL</td>
<td>2.5 mL</td>
<td>2.5 mL</td>
<td>2.5 mL</td>
</tr>
<tr>
<td>Senna</td>
<td>Constipation</td>
<td></td>
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<td></td>
<td>2</td>
</tr>
<tr>
<td>Ibuprofen</td>
<td>Pain</td>
<td>2</td>
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<td>2</td>
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</tbody>
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Medication chart for………………………………………………… Date………………………………..

FIGURE 1.16.1 Example of treatment chart for family use in the community.
will relieve pain in most children, and should be based on the four key concepts recommended by the WHO:

- by the ladder
- by the clock (or by the sun if there is no clock!)
- by mouth. Injections are not given at home because there are too few community health workers. Subcutaneous infusion pumps are not always acceptable, and also need close monitoring, which is often not possible
- by the child or carer.

By the ladder

Use the ‘two-step’ approach to analgesia, non-opioids and opioids. The second step in the three-step ladder that was proposed in 1986 by the WHO is now widely being omitted, and a two-step ladder is used instead (see Figure 1.16.2). This is because the middle step, namely codeine, is expensive and causes severe constipation, and if the child has cancer they will need morphine, so can commence with a small dose that can then be titrated to the pain. Pain is classified as mild, moderate or severe, and the analgesic choices are adjusted accordingly. The ladder approach is based on drugs that are widely available in most countries. The sequential use of analgesic drugs is based on the child’s level of pain, with a non-opioid analgesic usually being the first step.

Importantly, however, assessment of a child’s pain may indicate the need for immediate use of a strong opioid. Morphine is the safest and most effective opioid, and the only affordable one in resource-limited settings.

There should be no hesitation in moving on to Step 2 of the analgesic ladder if pain control is inadequate.

Only one drug from each pharmacological group should be used at the same time but remember that paracetamol plus a non-steroidal drug can be used together if there is no contraindication. Strong opioids can be increased until pain is relieved. Occasionally an alternative strong opioid (rarely affordable in resource-limited countries) may be substituted if side effects from the first opioid tried are intolerable.

The aim is for the child to be:

- pain free on movement
- pain free at rest
- pain free at night.

By the clock (or by sunrise/sunset)

Analgesia should be given regularly (e.g. every 4 hours or according to the half-life).

There is no place for ‘when-requested’ prescribing of analgesics in palliative care. The dose must be titrated against that needed to control the pain of the individual patient.

Paracetamol and ibuprofen should be given at the recommended doses (see Section 1.15), but the dose of morphine needed must be titrated against that needed to control the pain.

The dosing interval should be determined according to the severity of the child’s pain and the duration of action of the drug being used. Additional ‘rescue’ doses for intermittent and breakthrough pain should be prescribed and explained to the family, so that these can be given as soon as breakthrough pain occurs.

The effectiveness of analgesia should be regularly reviewed, so that it can be titrated effectively against pain.

By the appropriate route

Children should receive drugs by the simplest, most effective and least painful route. For this reason the oral route is the preferred route.

IM injections should not be used. They are painful, and there is a risk of abscess and/or haematoma formation, particularly in children who may have low platelet counts or other blood-clotting problems. Also, use of the parental route means that the patient must be in hospital or a clinic and cannot go home. Children who are afraid of injections may deny that they are in pain and therefore suffer unnecessarily.

When selecting the best route of analgesic administration it is important to consider the nature and severity of the pain, the potency of the drug, the required dosing interval and the compliance of the child.

By the child

The doses of any analgesic must be based on the individual child’s symptoms and circumstances. There is no single dose that will be appropriate for all children.

Regular reassessment of the child’s pain and of the effectiveness of the analgesia is essential, so that the drug doses can be adjusted accordingly to keep the child pain free.

For some children, particularly those with cancer-induced pain, very large doses of opioids may be required in order to achieve satisfactory pain control.

Therefore it should be noted that some of the suggested dosage recommendations included in this section differ from those specified elsewhere in the manual. This is appropriate in palliative care, and it reflects the differences in goals and priorities between the acute setting and the palliative setting.

CASE EXAMPLE: Haji, aged 3 years, presented with a clinical diagnosis of retinoblastoma. He was in severe pain. The lesion was too friable for a biopsy. Morphine was commenced immediately, based on weight, according to the WHO recommendation for children. This was titrated against the pain, and Haji’s pain was controlled on 100 mg 4-hourly and 100 mg at night. The radiologists allowed him to receive radiotherapy without a biopsy. The tumour disappeared. The morphine was reduced until he was pain free and well.

Today Haji is well, aged 9 years, and is attending school.
Analgesics

Non-opioid analgesics
Non-opioid analgesics are used to relieve mild pain or, in combination with opioids, to relieve moderate and severe pain. Paracetamol is the drug of choice because it has a very high therapeutic ratio for children and can be given orally or rectally. It is available in an elixir, tablet and suppository form, and can be given 4- to 6-hourly. Non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen and diclofenac are also helpful (for doses, see Section 1.15).

It is now recommended that one should progress straight from paracetamol and NSAIDs to morphine.

Strong opioid analgesics (morphine)
Morphine is required either alone, or in combination with non-opioid analgesics and/or adjuvant drugs, to provide effective pain relief. Morphine does not have an analgesic "ceiling effect" (i.e., there is no maximum dose), and children may require extremely large doses to obtain pain relief, but start at the recommended dose for severe pain (as described in Section 1.15).

The strong opioid of choice internationally is oral morphine.

The oral route is preferred for morphine, but if the subcutaneous or IV route is required, it can be given by a slow continuous infusion, which will give a steady level of analgesia and is preferred to intermittent subcutaneous or IV administration. Although a continuous infusion is commonly used in well-resourced countries, it is possible to achieve complete pain control with oral or rectal paracetamol or morphine in the palliative care setting. In resource-limited settings, children and their families may be alarmed by infusions.

Children have been found to rapidly eliminate morphine metabolites, and this is most marked in younger children (under 9 years). This group of children may require more frequent dosing and relatively higher doses to achieve pain relief. However, if oral doses are given at regular intervals, the most potent metabolite of morphine, M6G, accumulates and leads to smooth pain control.

Morphine must be available in all countries. However, this is not the case at present. In Africa, only 15 out of 56 countries have oral morphine available for use at home, which is where most terminally ill patients want to die. Oral morphine that is made up in the country or within a district is where most terminally ill patients want to die. Oral morphine that is made up in the country or within a district is the affordable ideal. The drug is then immediately available, so pain can easily be controlled with it.

More complicated formulae and preparations may be available as immediate- or sustained-release preparations, including immediate-release suppositories. Once-daily preparations are commercially available, but there is little experience of their use in children, and they are too expensive for most resource-limited countries. Ideally, morphine should be free to all in need, and prescribed by a recognised prescriber. Usually only doctors can prescribe. However, in Uganda, nurses can now prescribe after completing a Diploma in Palliative Care and clinical officers after a 9 week special training that emphasises prescribing methods and controls. Clinical officers have been trained for 4 years and can do more than nurses in most countries. In some African countries they are allowed to prescribe class A drugs after qualification.

Immediate-release morphine (from the list of essential medicines for children published by the WHO in 2010)
- Morphine tablets (Sevedol): 10 mg, 20 mg and 50 mg.
- Morphine sulphate mixture (Oramorph): 10 mg/5 mL.
- Morphine sulphate mixture (Oramorph concentrate): 100 mg/5 mL.

The most affordable preparation is a morphine solution made from morphine powder in a pharmacy without the exorbitant profit taken by the ‘middle man’ (see Section 1.15).

The oral morphine starting dose is 150–300 microgram/kg every 4 hours.

Immediate-release morphine should be given regularly every 4 hours. It may be useful to increase the nighttime dose by 50–100% to eliminate night-time waking. Immediate-release oral morphine is the best choice in children because it is easier to titrate exactly against the pain.

Sustained-release morphine tablets (MST Continus) (5 mg, 10 mg, 15 mg, 30 mg, 60 mg, 100 mg and 200 mg) and morphine granules for suspension (MST Continus) (20 mg, 30 mg, 60 mg, 100 mg and 200 mg), although available, are very expensive and therefore inappropriate for most situations in resource-limited countries. Those planning for a service must keep in mind the needs of the poor and spend the money available for morphine wisely so that there is enough for all in need.

Breakthrough pain
Immediate-release morphine should be prescribed at a dose equivalent to the 4-hourly doses as soon as pain breaks through (i.e. 16–17% of the total daily dose). The WHO recommends that it should be 5–10% of the total daily dose. This can be given up to hourly for breakthrough pain, and the parents should be advised to keep a record of all extra doses given so that the regular dose of morphine can be titrated accurately, and more supplied as necessary.

Titration of the morphine dose
Pain relief should be reviewed regularly. The morphine dose should be titrated against the level of pain. If frequent breakthrough analgesia is required, the total dose of morphine taken during the day (regular doses plus ‘breakthrough’ doses) must be assessed. Usually increments of 20–50% of the previous total daily dose are required. Regular review allows the regular dose of morphine to be adjusted according to the level of breakthrough pain. Remember to

FIGURE 1.16.3 ‘As needed’ (PRN) versus ‘by the clock’ versus ‘high dose’. Initially, to the left, the PRN dosage regime results in episodes of unrelieved pain. In the middle, too high a dose produces drowsiness. To the right, the by-the-clock dosage regime results in constant relief of pain without drowsiness. (Diagram supplied by Dr Anne Merriman.)
increase the dose of breakthrough morphine accordingly, when the regular dose is increased.

Alternatives to oral route of administration
Indications for these include:
- persistent vomiting
- non-compliance with oral medication
- dysphagia
- bowel obstruction
- physical deterioration that prevents oral intake
- unsatisfactory response to oral medication.

Rectal route
This route may be acceptable for some children who are unable to take oral medication. Any oral preparation can be given rectally with similar effects:
- Paracetamol can be given as a suppository.
- Morphine solution (see above) can be easily given rectally and is very effective.
- Morphine suppositories (10 mg, 15 mg, 20 mg or 30 mg) can be given if available.

Although one can use the same dose and interval as for the oral route (i.e., 4-hourly), this is traumatic for the child, and generally a larger dose given in tablet suppository form as half the daily dose 12-hourly is more acceptable.

Subcutaneous route
Many drugs are well absorbed subcutaneously and can be easily established in those children who do not have established venous access. However, many resource-limited countries will not be able to use syringe drivers, and buccal and rectal administration may be just as effective, especially if human resources for managing the syringe driver/infusion pumps safely are not available, although some parents may be able to manage them.

Changing from oral morphine to subcutaneous morphine
The potency of morphine administered by injection is approximately twice that of oral morphine. Therefore use half of the total daily oral morphine dose as the equivalent 24-hour morphine dose for subcutaneous infusion.

If syringe drivers are not available, parents can be trained to give regular boluses of morphine subcutaneously or IV at home. The total daily dose of either morphine or diamorphine is divided by a practical number that coincides with the number of individual doses to be given (usually 1- to 2-hourly during the day, and 4-hourly at night).

Intravenous route
- This will usually only be indicated where a child has an established venous access, such as a Hickman line (unlikely to be available in most resource-limited countries), or when death is likely to occur within 7 days, when community health workers may place a peripheral venous cannula.
- Divide the total daily dose of oral morphine by two to obtain the equivalent daily dose of morphine given IV or subcutaneously.

As approximately 80% of children will die at home in resource-limited countries, oral or rectal morphine is likely to be the mainstay of treatment, with IV morphine only available to a small proportion of these patients.

Although diamorphine is the drug of choice for subcutaneous infusion, because it is more soluble, it is not available in most countries of the world. Divide the total daily dose of oral morphine by 3 to obtain the equivalent daily dose of diamorphine given IV or subcutaneously. The starting dose in opioid-naive patients is 12.5–25 micrograms/kg/hour by continuous infusion. For both subcutaneous and IV routes, the diamorphine should be titrated according to breakthrough pain in increments of 20–50%.

Side effects of opioids
All opioid drugs cause similar side effects. These problems are well known, and should be anticipated and treated whenever children are given opioids, so that pain control is not accompanied by unacceptable side effects. When appropriate, parents and children should be informed about the possible side effects and their management. Children on strong opioids should be assessed regularly.

Constipation
This is a common side effect, and laxatives such as bisacodyl (dulcolax) or senna or sodium docusate must always be prescribed with strong opioids (see below). Advice should be given to increase intake of fluids and fibre (vegetables, fruit and cereals) in the child’s diet where appropriate.

Nausea and vomiting
Routine anti-emetics are not commonly needed, but should be prescribed if required in case of opioid-induced nausea and vomiting. When such symptoms do occur, they normally resolve within 3 to 4 days.

Drowsiness and confusion
Daytime drowsiness, dizziness and mental clouding can occur at the start of treatment and sometimes following a dose increase. They almost always resolve within a few days. Cognitive and psychomotor disturbances are minimal once the patient is receiving a stable dose of opioid.

Pruritus
Itching is a not uncommon side effect of opioid treatment in children. Simple skin care alone may be effective. Also consider the following:
- Avoid hot baths
- Avoid using soap. Add Oilatum to the bath water and use aqueous cream as a soap substitute.
- Pat the skin dry rather than rubbing it.
- Avoid overheating and sweating.
- Use cool cotton clothing and bedding.
- Keep the fingernails short to reduce damage caused by scratching.

If itching is persistent, review the medication. If itching is opioid related and the drug cannot be changed, the addition of a systemic antihistamine such as chlorpheniramine may be beneficial.

Pruritus associated with obstructive jaundice will require good skin care plus systemic medication such as stanzozolol, ondansetron or levomepromazine, if available.

Respiratory depression
Respiratory depression is uncommon in the conscious patient with severe pain. If it does occur, management will
be dictated by the child’s overall condition and the place of care.

**Nightmares and hallucinations**
Both can occur. If they are distressing and not resolved by reassurance or resolution of other anxieties, try giving haloperidol at night (50–100 micrograms/kg).

**Urinary retention**
Urine retention may be a problem, particularly after rapid dose escalation. Most children respond to simple measures such as a warm bath, warm packs or relief of constipation. Catheterisation may be required, but is usually only needed for a short period.

**Morphine toxicity**
This can occur as a result of:
- too high a dose
- too rapid dose escalation
- pain that is not morphine responsive
- renal impairment
- previous therapeutic intervention to relieve pain (e.g. radiotherapy or nerve block).

Warning signs include:
- drowsiness
- confusion
- pinpoint pupils
- myoclonic jerks
- hallucinations (auditory and visual)
- vomiting
- nightmares.

If toxicity occurs, consider reducing the morphine dose (several doses may need to be missed), then restart at a lower dose or stop morphine altogether.

Toxicity is rare when morphine is titrated against the pain. Constipation is the worst complication, and can be prevented by introducing a laxative when morphine is started, unless the child has diarrhoea already, in which case the constipation would be beneficial for a few days, but the laxative needs to be introduced as soon as it ceases.

**Watch carefully for breakthrough pain.** Address any side effects as discussed above. Escalating doses of opioids and metabolic disorders can exacerbate myoclonic jerks. Oral diazepam can be useful, if the child is unable to swallow, rectal diazepam or subcutaneous midazolam are effective.

Consultation with healthcare professionals who are experienced in palliative care is recommended.

**Addiction and tolerance**
Fear of addiction is not relevant when using opiates in palliative care, provided that a permanent source of opiates is available, which must be the case. In Uganda, in 2012, around 20,000 patients had been treated with affordable oral liquid morphine, without any abuse or addiction. Approximately 30% of these cases were children.

**Prescribing opioids in patients with renal impairment**
The active morphine metabolites are excreted by the kidney and accumulate in renal impairment, causing toxicity. When prescribing any opioid analgesics in children with renal failure, caution must be exercised, as patients with renal failure are extremely sensitive to opioids. Renal failure is part of the dying process, and the team must be aware of this and reduce doses or increase time intervals as the child approaches death.

Suggested management strategies are as follows:
- Prescribe smaller doses of opioid analgesic.
- If problems with toxicity continue, consider giving smaller doses less frequently (i.e. 6- to 8-hourly).

**Alternatives to oral morphine for severe pain**
For information on approaches that can be used in well-resourced settings, see the Further reading section on p. 91.

**Adjuvant therapy**
Few children are truly morphine intolerant, and if the pain is not responding to morphine, always consider the aetiology of the pain and review the use of adjuvant therapy.

**Neuropathic pain**
Co-analgesics such as an anticonvulsant or tricyclic antidepressants are essential, because this pain is only semi-responsive to opioids. The possibility of neuropathic pain should be considered if the pain has a burning or stabbing/shooting component. According to the WHO, there is no evidence on which to make recommendations for or against antidepressants and anticonvulsants. However, the WHO does agree that there is wide experience of the use of amitriptyline in children, and doctors are familiar with the use of the carbamazepine in children who have seizures. However phenoxyin is more available, affordable and therefore of choice in less resourced countries. However some anti-retroviral drugs (ARVs) may interact with phenoxyin so there is a need to check this out for children with HIV on ARVs.

**Nerve compression pain**
This may arise from compression of a nerve root, and morphine plus a trial of oral steroids should be tried. The steroid should relieve pain within 48 hours, probably by reducing oedema around the tumour. If there is no improvement, steroid treatment should be discontinued.

**Nerve injury pain**
This may arise from tumour invasion of a nerve or as a side effect of radiotherapy.

**Anticonvulsants**
These drugs are useful for pain that is shooting or stabbing. Carbamazepine and sodium valproate are commonly used. Clonazepam and gabapentin are more recent additions that are not widely available in resource-limited countries. The cheapest, most effective drug with the fewest side effects is phenoxyin.

Start at a low dose and gradually increase the dose to avoid sedation and toxicity. Low doses are usually the most effective, and this therapy should stop if the pain does not respond to low doses.

**Carbamazepine**
This drug is expensive, has side effects, and needs to be monitored, so is not so useful in the community setting.
- Starting dose: 2.5 mg/kg twice daily, increasing by 2.5–5 mg/kg/day at weekly intervals.
● Maintenance dose: 10–20 mg/kg/day in two to three divided doses, increasing gradually as above.

This corresponds to the British National Formulary for Children (BNFC) dose for epilepsy and trigeminal neuralgia.

Sodium valproate (often not available)
● Starting dose: 20 mg/day in two divided doses, increasing if required by increments of 5 mg/kg at weekly intervals.
● Maintenance dose: 20–30 mg/kg/24 hours in divided doses.

The BNFC doses for epilepsy are:
● Age < 12 years: initially 10–15 mg/kg/day in one to two divided doses, increasing to 25–30 mg/kg/day in two divided doses.
● Age ≥ 12 years: initially 600 mg/day in one to two divided doses, increasing by 150–300 mg every 3 days to 1–2 g/day (maximum of 2.5 g/day) in two divided doses.

Phenytoin
● Age < 12 years: (1.5–2.5 mg/kg starting dose to target) and then 2.5–5 mg/kg twice daily (maximum 7.5 mg/kg twice daily or 300 mg once daily).
● Age 12–18 years: 75–150 mg adjusted according to response up to 150–200 mg twice daily (maximum 300 mg twice daily).

The BNFC doses for epilepsy are:
● Age < 12 years: 1.5–2.5 mg/kg twice daily, increasing to 2.5–5 mg/kg twice daily (usual maximum 7.5 mg/kg twice daily).
● Age ≥ 12 years: 75–150 mg twice daily, increasing to 150–200 mg twice daily (maximum 300 mg twice daily).

Tricyclic antidepressants
● These drugs are useful for pain that is burning in nature.
● Give at night to avoid excessive sedation during the day. They can cause constipation.
● The analgesic effect begins after about 3–7 days of treatment, but may take longer than this.
● Starting dose: amitriptyline 0.5 mg/kg at night increasing, if needed, to 1 mg/kg/day. Increase carefully to avoid excessive drowsiness. Lower doses are the most effective.

The BNFC doses for neuropathic pain are:
● Age 2–12 years: 0.2–0.5 mg/kg (maximum 10 mg), increasing gradually to a maximum of 1 mg/kg twice daily.
● Age > 12 years: 10 mg at night, increasing gradually up to 75 mg at night if needed.

For difficult cases, consider referral to or discussion with a pain control team if one is available.

Bone pain
Non-steroidal anti-inflammatory drugs (NSAIDs)
● NSAIDs have analgesic, anti-pyretic and anti-inflammatory properties. They are often effective in relieving musculoskeletal pain that is associated with bone metastases or soft tissue inflammation.

● Regular dosing is required for their full effect, but the maximum effect is usually seen within 2 weeks.
● It is worth trying another NSAID if there is no response to the first type.
● Damage to the gastrointestinal mucosa is the most frequent side effect. Gastric erosion and bleeding can be severe and difficult to control. If possible, ensure that NSAIDs are taken after food.
● NSAIDs are not usually appropriate for children with thrombocytopenia, because of their potential to cause gastric erosions and so increased tendency to bleed.
● According to the WHO there is no evidence for recommending the use of bisphosphonates in children. In adults, modest improvements in pain have been observed, but also serious side effects such as osteonecrosis of the jaw.

For common dosages of NSAIDs, see Section 1.15.

Steroids
Steroids have specific benefits in palliative care because of their ability to produce euphoria, improve appetite and increase weight gain. They also have an anti-inflammatory effect, which may be helpful in patients with nerve compression and raised intracranial pressure.

However, steroids should be used with caution in children, as the side effects of long-term steroid treatment can far outweigh its benefits. They include rapid weight gain, change in appearance, mood swings, behaviour changes and insomnia, which can be distressing for both the child and the parents, and the risk of gastric erosions. Most children experience symptom relief after short intensive courses, and if the prognosis is long, steroids should be withdrawn. If there is no improvement in symptoms within a short period of time (e.g. 5–7 days), steroids should be discontinued. If the initial symptom relief is not maintained, long-term use of these drugs should be avoided.

Dexamethasone
Dexamethasone should be taken before 6 pm, and ideally in the morning, in order to minimise insomnia.

High-dose dexamethasone is normally used to relieve pain associated with raised intracranial pressure, or spinal cord or nerve compression. Give steroids in the morning to avoid sleepless nights and to copy the normal diurnal rhythm of cortisol.

The initial dose is given in the morning as 25 mg for patients over 35 kg and 20 mg for patients less than 35 kg, followed by a sliding scale of reducing by 4 mg every 3 days until down to 10 mg per day, then continuing to decrease by 1–2 mg per day.

IM or IV in an emergency or until can swallow (usually once only):
● Age 1 month to 12 years: 100–400 micrograms/kg, once daily in the morning.
● Age 12–18 years: 8–24 mg daily.

Low-dose dexamethasone is normally used to improve appetite and well-being.
● Age 2–8 years: 0.5–1 mg, once daily in the morning.
● Age > 8 years: 1–2 mg, once daily in the morning.
● Radiotherapy.
This therapy is only available in just over half the countries in Africa.

Radiotherapy can be particularly useful for treating isolated sites of a disease if a tumour is radiosensitive. This may include bony metastases, spinal cord compression, and relief of nerve compression from a solid tumour and isolated cerebral metastases. Radiotherapy can also be used in the management of fungating tumours. Single treatments or short courses are often appropriate and effective in palliative care, if radiotherapy is available.

Non-pharmacological approaches
Non-drug therapies must be an integral part of the management of children's pain, complementing but not replacing appropriate drug therapy.

A combination of non-pharmacological approaches, used in conjunction with analgesics, may be extremely effective. These approaches include:
- progressive relaxation
- diversional therapy with music, art or traditional games, according to the age of the child
- hypnosis and guided imagery
- massage and reflexology
- heat pads or cold packs
- transcutaneous electrical nerve stimulation (TENS).

Management of other symptoms
Nausea and vomiting
These are common symptoms in palliative care. The causes may be multifactorial, and it is important to try to determine the cause(s) in order to implement an effective treatment plan.

Common causes
Cancer-related causes include:
- raised intracranial pressure
- the presence of an abdominal mass
- irritation of the upper gastrointestinal tract
- gastric outflow obstruction
- anxiety
- uraemia
- pain
- blood in the stomach.

Treatment-related causes mainly involve the side effects of drugs, especially:
- opioids
- chemotherapy
- NSAIDs
- carbamazepine
- antibiotics.

Management
- Identify the cause(s) as described above (e.g. constipation, raised intracranial pressure) and implement appropriate management.
- Consider stopping gastric irritants such as antibiotics, NSAIDs and steroids if possible.
- Prescribe an H$_2$-receptor antagonist (ranitidine, 2–4 mg/kg 12-hourly, or cimetidine, 5–10 mg/kg 6-hourly).
- Or the proton pump inhibitor omeprazole (age < 2 years, 700 micrograms/kg once daily increased to 3 mg/kg once daily, maximum dose of 20 mg once daily; body weight 10-20kg, 10 mg once daily, increased to 20 mg if needed; body weight over 20 kg, 20 mg daily increased to 40 mg once daily if needed. Give the higher dose for 12 weeks only).
- Prescribe an appropriate anti-emetic according to cause.
- Review the therapy regularly and adjust it as required.
- IV fluids may be needed to counteract dehydration, but nasogastric tube insertion should be avoided where possible.
- If treatment is unsuccessful, consider the following:
  - Was the cause of the vomiting correctly identified and the appropriate anti-emetic prescribed?
  - Has the anti-emetic had time to work at maximum dose?
  - Is the route of administration appropriate for the child?

Anti-emetic therapy
Severe nausea and vomiting may require initial management by subcutaneous or IV infusion and then switching to oral medication when control is gained. The choice of anti-emetic depends on the cause of vomiting and the site of the anti-emetic action, so combinations of drugs with different sites of action are sometimes required, but to avoid side effects, avoid combining drugs of the same class. Extra-pyramidal side effects can occur with cyclizine, metoclopramide and domperidone (see Section 1.15).

**Haloperidol** is the anti-emetic of choice for opioid-induced vomiting. It acts on the chemoreceptor trigger zone.

Dosage: 12.5–25 micrograms/kg twice daily by mouth, subcutaneously or IV. Haloperidol can be given orally at night.

**Cyclizine** is used for nausea and vomiting caused by raised intracranial pressure or intestinal obstruction.

Dosage: all ages, by mouth, 1 mg/kg three times daily up to a maximum of 50 mg per dose.

The BNFC doses are as follows:
- Oral or rectal route:
  - Age < 6 years: 500 microgram–1 mg/kg (rectal 12.5 mg) up to three times daily
  - Age 6–12 years: 25 mg up to three times daily
  - Age > 12 years: 50 mg up to three times daily.

IV or subcutaneous route:
- All ages, 1 mg/kg 8-hourly or

Continuous IV/subcutaneous infusion:
- Age < 2 years: 3 mg/kg over 24 hours
- Age 2–5 years: 50 mg over 24 hours
- Age 6–12 years: 75 mg over 24 hours
- Age > 12 years: 150 mg over 24 hours.

**Dexamethasone**
Dosage: use moderate doses (e.g. 100 micrograms/kg 12-hourly).

**Metoclopramide**
This acts on both the upper gastrointestinal tract and the chemoreceptor trigger zone, and speeds up gastric emptying. The extrapyramidal side effects are more common in children. It is useful for oesophageal reflux, gastric stasis, gastric irritation, gastric outflow and high bowel obstruction.
Its use should be avoided in patients where there is complete bowel obstruction.

**Dosage:**
- Oral route:
  - Age 1–12 years: 100 micrograms/kg, two to three times a day
  - Age > 12 years: 5–10 mg, two to three times a day.

**Subcutaneous/IV route:**
- Age 1–12 years: 500 micrograms/kg over 24 hours
- Age > 12 years: 15–30 mg over 24 hours.

**Domperidone** acts on both the upper gastrointestinal tract and the chemoreceptor trigger zone, and speeds up gastric emptying.

**Dosage:**
- Oral route:
  - Age 1–12 years: 200–400 micrograms/kg, three to four times a day
  - Age > 12 years: 10–20 mg, three to four times a day.

**Rectal route:**
- Age 1–12 years: 15–30 mg, two to three times a day
- Age > 12 years: 30–60 mg, two to three times a day.

**Constipation**

Constipation is common in paediatric palliative care, and the causes may be multi-factorial. The prevention and relief of constipation in the terminally ill child is very important, as if left unresolved it can cause abdominal pain and discomfort, and nausea and vomiting.

Consider the following causes:
- drug induced (e.g. opioids, anticholinergics, antidepressants)
- reduced physical activity
- poor oral intake and general debility
- dehydration
- bowel obstruction
- spinal cord compression.

**Management**

- Treat the underlying cause where this is appropriate and possible.
- Constipation should be anticipated when opioid, anticholinergic or antidepressant drugs are being used, and laxatives should be prescribed prophylactically.
- Use laxatives appropriately and at the right doses, and avoid mixing two drugs from the same group (e.g. two stimulants).
- A good first choice is the combination of a stimulant laxative and a softening agent (e.g. senna plus sodium docusate).
- Titrate doses up as required, rather than adding a new laxative.
- If oral therapy fails, consider rectal measures such as suppositories/enemas.

**Bowel obstruction**

Bowel obstruction may be mechanical or functional, or both. The aim is to control pain and nausea. In children with advanced disease, surgical management is not usually indicated. The aim of treatment is the palliation of symptoms. Nasogastric tubes and IV fluids are rarely appropriate, although for persistent vomiting due to obstruction a nasogastric tube may be helpful.

**Management**

**Elimination of pain and colic:**

- For constant background pain, administer buccal morphine solution or morphine by continuous IV or subcutaneous infusion, using a portable syringe driver.
- If colic is present, avoid prokinetic anti-emetics (e.g. metoclopramide, domperidone).
- Discontinue bulk-forming, osmotic and stimulant laxatives.
- Relieve associated constipation, continue to use softening agents if possible, and use rectal measures to relieve faecal impaction.
- If colic persists, add hyoscine butylbromide (Buscopan), 10–20 mg orally 8-hourly or give IV as a single dose over at least 1 minute (age 2–6 years, 5 mg IV; 6–10 years, 10 mg IV; 11–15 years, 15 mg IV; 15–18 years, 20 mg IV). Repeat 8-hourly as required.

**Elimination of nausea and reduction of vomiting**

- The choice of anti-emetic depends on whether colic is present.
- If colic is present, cyclizine is the first-line drug. Add haloperidol if nausea persists.
- If colic is absent and flatus is present, a trial of subcutaneous or IV metoclopramide is indicated. If this is ineffective, instigate management as described above.
- Dexamethasone may be of benefit in second-line management.

**Dyspnoea**

Shortness of breath associated with pulmonary complications in advanced paediatric cancer can be very distressing for both the child and the parents, and requires effective management. The underlying pathophysiology needs to be considered when deciding on the management.

Common causes of dyspnoea include:
- metastases
- effusions
- pulmonary fibrosis
- anaemia
- infection
- superior vena cava (SVC) obstruction
- anxiety/fear
- increased secretions
- cardiac failure
- chest wall pain or constriction
- pulmonary embolus
- gross ascites.

**Management**

- Identify the cause.
- Give a clear explanation to the parents and the child.
- Treat the specific cause(s) or modify the pathological process (e.g. high-dose steroids and radiotherapy for superior vena caval obstruction).
- Non-drug measures are also important and include:
  - a calm approach
  - breathing exercises
  - an appropriate position
  - providing cool air (e.g. with a fan)
  - play therapy.
Drug treatment
Morphine has a complex effect on respiration, which is not fully understood. It can reduce the respiratory rate to a more comfortable level. This drug should be prescribed regularly in children with continuous breathlessness at standard analgesic starting doses. If the child is already on morphine, increase the dose by 30–50%.

The anxiolytic and sedative effects of benzodiazepines also cause relaxation of the respiratory muscles. This may be helpful if the child or teenager is very anxious, and these drugs should be administered as a single dose and then at night or twice daily. The long half-life of benzodiazepines (around 36 hours) means that they should be avoided if possible.

Diazepam (oral route):
- Age 4 weeks to 1 year: 200 micrograms/kg, two to three times daily
- Age 1–12 years: 2 mg, two to three times daily
- Age > 12 years: 5–10 mg, two to three times daily

Lorazepam is not always available, but is well absorbed sublingually (so is useful for panic attacks), short acting, with a rapid onset of relief and a shorter half-life.

Dosage:
- Age 1–12 years: 50–100 micrograms/kg (maximum of 4 mg per dose) (BNFC).
- Age > 12 years: 1–4 mg per dose. The dose may be repeated after 12 hours.

Corticosteroids may be useful, particularly in patients with superior vena caval obstruction and multiple lung metastases. Moderate doses of dexamethasone should be used and the benefit should be apparent within 5 days. The dose should then be reduced to the lowest effective dose.

Oxygen will be of benefit for hypoxic patients, but is rarely available for home use. It may also be helpful if a child is very anxious.

Nebulised saline or salbutamol may provide subjective relief, especially if wheezing is present.

Cough
Consider the following causes:
- respiratory infection
- airways disease
- malignant obstruction
- drug induced
- oesophageal reflux
- aspiration of saliva.

Wherever possible, the cause of the cough should be treated. Symptomatic management should follow the guidelines for the management of dyspnoea.

Drug management may include the following:
- simple linctus
- codeine linctus (this will cause constipation, so add a stool softener)
- opioids (as above)
- nebulised saline
- oral antibiotics (these are indicated if symptomatic chest infection with a productive cough is affecting quality of life).

Anxiety
Anxiety is not uncommon in palliative care. Talk to the child and give enough time to both the child and the parents or carers to discover the cause, and give reassurance. Try to identify the cause of the child’s anxiety (e.g. whether it is related to symptoms or fears about what is happening). Simple explanations, reassurance and a calm environment are important. Physical therapies such as relaxation and massage may be helpful, or anxiolytics such as diazepam or lorazepam as required or regularly may be of benefit if other measures fail.

Anxiety and discomfort go together, so reassess the child’s pain.

Bleeding
Massive external bleeding
Death from massive external bleeding is uncommon in children, but the risk of this is frightening and distressing for both the child and the parents, and prevention of such bleeding should be the aim of management, although this may not always be possible.

Causes of external bleeding include the following:
- a low platelet count
- clotting deficiencies
- primary or secondary liver disease
- disease progression
- initial treatment (e.g. radiotherapy, chemotherapy).

Management
If there is a risk of massive haemorrhage, it is extremely valuable to have IV or subcutaneous morphine and an appropriate sedative (e.g. rectal diazepam, buccal midazolam) readily available at home.

Persistent surface bleeding
This is not uncommon in children with leukaemia, and can be alarming to both the child and their family, but can be managed in the home environment.

Management
- Topical treatment soaking gauze in adrenaline 1 in 1000 solution and applying it directly to the bleeding point.
- Other haemostatic dressings can be used for persistent surface bleeding (e.g. in fungating tumours). These include crushed metronidazole sprinkled on to the area, or an alginate dressing such as Kaltostat if this is available.
- Tranexamic acid can be useful if it is available, and can be used topically undiluted, applied directly to bleeding gums or nostrils, or used as a mouthwash. It can also be given systemically or parenterally as prophylaxis.
- The use of a dark-coloured handkerchief or towel at home to mop up the blood may help to reduce anxiety.

Spinal cord compression
Consider spinal cord compression if the following signs and symptoms are present:
- localised pain in the spine, radiating around the chest
- sudden onset of weakness (e.g. of the legs)
- sensory disturbance
- sphincter dysfunction.

This is usually a clinical diagnosis, and action needs to be taken immediately.
Investigations such as computerised tomography (CT) and magnetic resonance imaging (MRI) are not usually available.

**Management**
- Patients with paraparesis have a better prognosis than those who are totally paraplegic.
- Loss of sphincter function is a poor prognostic sign.
- Rapid onset of complete paraplegia has a poor prognosis.
- The main therapeutic options are:
  - corticosteroids that can shrink the tumour and relieve spinal cord compression
  - radiotherapy.
- Steroids should be given in high doses initially and then reduced according to the response. These drugs often bring about an early improvement and relief of pain by reducing the peri-tumour inflammation. Give steroids in the morning to avoid insomnia and to copy the normal diurnal rhythm of cortisol.
- High-dose dexamethasone: The initial dose is given in the morning as 25 mg for patients over 35 kg and 20 mg for patients less than 35 kg, followed by a sliding scale of reducing by 4 mg every 3 days until down to 10 mg per day, then continuing to decrease by 1–2 mg per day. The initial dose can be given IV if urgency required but oral doses should then follow. However, if symptoms recur revert to a higher maintenance dose.
- Referral for concurrent radiotherapy should be considered if the prognosis is not very poor. This therapy is not available in around 30% of African countries, and unless the parents have enough financial resources to take their child to another country, palliative support is the best option.
- Surgery, such as laminectomy, is only rarely indicated.
- Consider using a pressure-relieving mattress, and give pressure area care.
- Pay attention to bowel function.
- Start physiotherapy to prevent contractures.
- Perform catheterisation.
- Avoid danthron-containing laxatives if the child is catheterised or incontinent, because of the risk of danthron burns.

**Psychological support**
Children experience significant psychological suffering as a result of loss of their ability to walk or run, as well as their inability to play and go to school. They therefore need understanding and sympathetic advice from their healthcare provider and carer at this time.

**Convolusions**
Convolusions may be a potential or existing problem for children with brain tumours or other neurological and metabolic disorders.

For emergency management of seizures in palliative and terminal care, **diazepam** given rectally is the drug of choice.

**Dosage:**
- Age < 1 year: 2.5 mg (half of a 5 mg rectal tube/rectal solution)
- Age 1–4 years: one 5 mg rectal tube/rectal solution
- Age 5–12 years: 5 mg or 10 mg rectal tube/rectal solution
- Age > 12 years: 10 mg rectal tube/rectal solution.

For continuing severe seizures, consider giving midazolam by the buccal route, subcutaneously or by IV infusion if the child is in hospital (see Section 5.16.E). Care is required with midazolam as it may give permanent anaesthesia so that communication becomes impossible.

**Muscle spasm**
Muscle spasm can be severe in children with neurological and neurodegenerative disorders. It may occur alone or be triggered by pain elsewhere (e.g. due to constipation).

**Useful drugs for muscle spasm**
**Diazepam** orally (initial doses are shown):
- Age 1 month to 1 year: 250 microgram/kg twice daily
- Age 1–5 years: 2.5 mg twice daily
- Age 5–12 years: 5 mg twice daily
- Age > 12 years: 10 mg twice daily up to a maximum dose of 40 mg/day (BNFC).

**Baclofen** orally
- Age 1–10 years: initial dose 300 microgram/kg/day in four divided doses, increasing to usual dose of 0.75–2 mg/kg/day in divided doses
- Age > 10 years: 5 mg three times daily, increasing to 20 mg three times daily (up to a maximum dose of 100 mg/day).

**Incontinence**
Incontinence can be the source of much discomfort and anxiety for both children and their families, as well as presenting difficulties in keeping the child clean and protecting their skin.

Children with some degenerative conditions may have had faecal or urinary incontinence for a long time, whereas for others this may become a feature during the end stage of their disease (e.g. due to local tumour, neurological/spinal cord damage to bladder control, laxative imbalance).

For children with long-standing difficulties, intermittent catheterisation or the use of an indwelling catheter may be a well-established, successful and accepted method (see Section 4.2.D).

Some useful suggestions include the following:
- Review laxatives where appropriate.
- Consider giving intranasal **desmopressin**, 20–40 micrograms at bedtime, if nights are disturbed by urinary incontinence. Alternatively, desmopressin tablets, 200–400 micrograms, or sublingual tablets, 120–240 micrograms, can be used (BNFC doses for enuresis). Care is needed as desmopressin can cause water retention and hyponatraemia, so start with lower doses.
- Keep a urinal or bedpan close to the bedside.
- Use cotton pads or towels (with plastic underneath) on top of the bed sheet. This will avoid the need to change all the sheets, and thus minimise disturbance to the child.
- Keep the area well ventilated (or keep a window open if appropriate).
- Try to ensure that the skin is kept clean, and use dimethicone, zinc and castor oil or other barrier creams if these are available.
- Help the child to wash regularly.
- Try to preserve and maintain the child’s dignity at all times. Give reassurance and support to both the child and the parents.
**Fungating wounds**

Fungating wounds are rare in paediatric palliative care, but in resource-limited settings they are not infrequently encountered. They may occur with soft tissue sarcomas, often of the head and neck, which can be very distressing for the child and their family.

Useful tips for management (where available) include the following:

- Soak any dressings with saline or Ringer-lactate or Hartmann’s solution to ease removal, as these tumours may be friable and prone to bleeding.
- If possible, have available topical adrenaline 1 in 1000, or an alginate dressing (e.g. Kaltostat, or tranexamic acid), to apply topically to the tumour if it bleeds profusely (e.g. during a dressing change).

These tumours can cause offensive smells due to anaerobic microorganisms, which can be distressing to the child and their family. Sprinkle crushed metronidazole tablets on the fungating area. Oral metronidazole does not penetrate the fungating area, as the blood supply to it is poor. Metronidazole is cheap and readily available in all resource-limited countries, and it is very effective. **Charcoal dressings, if available, may help to absorb the odour.** The use of honey for dressings is also of benefit in controlling bacteria and odour. Simple measures such as the use of aromatherapy oils around the home may be helpful, too.

**The final days and hours of life**

**Terminal restlessness and agitation**

These symptoms are not uncommon in the final stages of life. Useful drugs include buccal midazolam, and oral or rectal diazepam.

**Midazolam** is the sedative of choice, as it can be given via the buccal mucosa.

**Dosage:**

The initial regime is 30–100 micrograms/kg given as required. Titrate upwards as required (the upper dose may be limited by volume).

**Rectal diazepam** may also be useful.

**Dosage:**

5–10mg rectal tube as required. The dose may be repeated if child remains very agitated and restless.

**Increased secretions**

- Increased secretions (the ‘death rattle’) can be more distressing for the parents and carers than for the child. It is important to explain this to those caring for the child.
- Good mouth care is essential.
- Anti-secretory agents are useful, but can cause drowsiness and anti-cholinergic side effects.
- Start drug treatment early in order to avoid build-up of excessive secretions.

**Hyoscine hydrobromide (scopolamine)**

- This drug is anticholinergic.
- It reduces pharyngeal secretions.
- It should be used prophylactically at the first sign of excess secretions.
- It mixes with other commonly used drugs.
- Potential routes for administration: oral, as a sublingual tablet, IV or subcutaneous.

**Dosage:**

**Oral/sublingual route:**

- Age 1–12 years: 10 micrograms/kg/dose, four times a day.
- Age > 12 years: 300 micrograms/dose, four times a day.

**Subcutaneous or IV infusion:**

- All ages: 10–50 micrograms/kg/24 hours.

**Loss of the oral route for food and medication**

As a child’s condition deteriorates it may become difficult to use the oral route for medication. Buccal and rectal routes are the best options in this situation, and work well. As discussed earlier, other routes that can be used at this point are the rectal, subcutaneous and (where already established) IV routes. Children who have been treated for cancer in well-resourced hospitals may have central IV access, which can be used effectively in palliative care, but usually only in hospital.

Drugs that can be given via the subcutaneous or IV route include analgesics, anti-emetics, sedatives, anxiolytics and anticholinergic drugs. These can be combined together in an infusion, provided that they are compatible with each other.

If they are available, it is possible to use small portable infusion pumps (e.g. Graseby MS 26, WalkMed) to deliver combinations of medication over 24 hours. However, these devices are unlikely to be available for home use in most resource-limited countries, and home palliative care teams would not generally be able to provide this form of treatment. Sometimes individual carers may be able to manage this form of treatment.

**Additional notes**

- Avoid administering high concentrations of drugs in combination, especially when using cyclizine.
- Avoid mixing dexamethasone with other drugs if possible.
- Never give chlorpromazine, prochlorperazine or diazepam subcutaneously.
- More than two drugs can be combined in portable syringe drivers, although there is little supporting evidence in the form of clinical data. Always consult your local pharmacist before using any unusual combinations.

**Psychological support for the child, parents and siblings**

Care that is child and family centred is an essential principle of palliative care. The availability of an experienced key worker to coordinate the child’s care with community healthcare professionals is essential, with good communication both between professionals and between professionals and the family being of paramount importance.

Initially, parents may need a lot of support when deciding whether to withdraw curative treatment and where to care for their child. Whether the care setting is in hospital or at home, the parents will have many questions, fears and anxieties at this time, and if possible the opportunity to discuss their worries, changes in the child’s condition and symptom management should be available 24 hours a day. Commonly asked questions include “How long will it be?” and “How will my child die?” These questions are not easy to answer, and will also depend on the nature of...
the child’s illness. For example, a child with leukaemia may have a very short period of palliative care, whereas a child with a brain tumour or neurodegenerative disease may live for several months. It is probably best to give an indication of time span, but to emphasise that every child is different, and to guide the parents as the disease progresses. ‘Days or weeks’, ‘weeks or months’ or even ‘hours rather than days’ give adequate warning without being too precise.

Parents may worry about their child being in pain, but also have anxieties about the use of strong medication such as morphine. A clear explanation of the use of analgesics is essential in this situation.

Many parents will want advice on talking to the dying child and their siblings. How to prepare the child’s brothers and sisters will depend very much on their age and level of understanding, and on parental beliefs. For older children and teenagers it is probably best to be honest, to prepare them gradually for what is happening and allow them to ask questions and participate in their sibling’s care if appropriate. With younger children, the language used must be very simple and clear. For example, it is important to avoid using the phrase ‘going to sleep’ as the analogy for death. It is probably more appropriate to prepare younger children for a sibling’s death when the end is obviously very close. Cultural preferences also need to be taken into account.

Talking to the child who is dying is a very personal matter for parents, and will also be influenced by the child’s age and understanding of the illness. For example, a teenager with cystic fibrosis may have anticipated death in adolescence or young adulthood, and a teenager who has had multiple relapses of cancer for many years may now realise that the treatment is no longer working. Where possible and appropriate, it is important that children and teenagers are given the opportunity to express their wishes and anxieties. When children are not allowed to express themselves they can become very anxious and agitated, or even withdrawn. Healthcare professionals can only try to encourage the parents to have an open and honest approach to their child’s questions and wishes at this time.

**Preparation for death**

Parents commonly have many questions about the time and nature of death, and what happens afterwards. It can be very helpful to try to prepare them for what may happen at the time of death if they wish to have this information. Changes in breathing are commonly distressing, and simple explanations of, for example, Cheyne–Stokes respiration or the ‘death rattle’ can avoid unnecessary distress. A single expiratory breath after death if the child is moved is not the ‘death rattle’ can avoid unnecessary distress. A single expiratory breath after death if the child is moved is not

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1.17 Hospital issues regarding immunisation

Introduction

Immunisation is one of the most effective disease prevention strategies in children. In this process, an antigen is introduced into the body, where it stimulates immunity against the specific antigen by priming the specific memory cells. Subsequent natural infection produces an effective and vigorous response by the body, and the patient is thus protected from the disease and its effects and complications.

In 1974, the World Health Organization (WHO) initiated the Expanded Programme on Immunisation (EPI). This aims to develop widespread national commitment to achieve high vaccination coverage in mostly low-income countries. The choice of the original six EPI vaccines was based on the importance of the disease and the availability of safe, efficacious and low-cost vaccines.

The WHO recommended vaccination schedule is widely used in almost all countries, with newer vaccines being added as some programmes evolved (see Table 1.17.1).

### TABLE 1.17.1 Current EPI vaccination schedule recommended by the WHO, May 2014

<table>
<thead>
<tr>
<th>Age</th>
<th>Vaccine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth</td>
<td>BCG*, OPV#0, HBV#1</td>
</tr>
<tr>
<td>6 weeks</td>
<td>DTP#1, Hib#1, OPV#1, HBV# 2 PCV#1</td>
</tr>
<tr>
<td>10 weeks</td>
<td>DTP#2, Hib#2, OPV#2, HBV#3 IPV#1 PCV#2</td>
</tr>
<tr>
<td>14 weeks</td>
<td>DTP#3, Hib#3, OPV#3, IPV#2 PCV#3</td>
</tr>
<tr>
<td>9 months</td>
<td>MCV/RCV #1 Yellow fever (in countries where it poses a risk)</td>
</tr>
<tr>
<td>12–15 months</td>
<td>MCV/RCV#2</td>
</tr>
<tr>
<td>9 years girls</td>
<td>HPV#1 plus HPV# 2 after at least 6/12</td>
</tr>
</tbody>
</table>

BCG, bacillus Calmette-Guérin; OPV, oral poliovirus vaccine; IPV, inactivated polio vaccine HBV, hepatitis B vaccine; DTP, diphtheria, tetanus and pertussis; Hib, Haemophilus influenzae type B; Pneumococcus PCV; Rotavirus RV; Measles/Rubella MCV/RCV; Human papilloma virus HPV

*BCG must not be given if HIV infection is present or clinically suspected

See these links for further information:

- [www.who.int/immunization/policy/Immunization_routine_table2.pdf?ua=1](http://www.who.int/immunization/policy/Immunization_routine_table2.pdf?ua=1)

Vaccine schedules are a continuously changing phenomenon. It is recommended that regional variations on programmes are followed.

Polio

Live oral poliovirus vaccine (OPV) and inactivated poliovirus vaccine (IPV) are the two effective vaccines that are available, but there are important differences between them.

- WHO no longer recommends an OPV only vaccination schedule, at least 1 dose of IPV should be added to the schedule.
- In polio-endemic countries and in countries at high risk for importation and subsequent spread, WHO recommends an OPV birth dose (a zero dose) followed by a primary series of 3 OPV and at least 1 IPV doses.
- The WHO target to eradicate poliomyelitis within the next 10 years is dependent on high infant immunisation coverage and national immunisation days (NIDs), which aim to eradicate the circulation of wild virus. NIDs are designed to complement routine immunisation by targeting the most vulnerable individuals in as short a time period as possible. OPV is given over a 2-day period, 1 month apart, and the NIDs are repeated annually for at least 3 years.

Pertussis

Fever and mild local reactions are common. Consider a two-dose schedule for those areas where services can be provided only twice a year.

Measles

Accelerated implementation of strategies to reduce the burden of measles is required. Targeting children under 5 years of age in major cities is a priority. Strategies to reduce the impact of infant measles include:

- increasing coverage to the 9–23 months age group
- a two-dose schedule at 6 months and 15 months is most appropriate for epidemic situations, and a two-dose