Yorkshire and Humber Children and Young People’s Cancer Network

End of Life Care and Symptom Control Guidelines for Children and Young People with Cancer Requiring Palliative Care

February 2016
## Document Control

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### Version Control

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## ii. Information Reader Box

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CNS teams in Paediatric & TYA Oncology and Haematology  
Paediatric Oncology Shared Care units  
Children’s Community Nursing Teams |
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Scope
This guideline aims to provide guidance for symptom control in children and young people with progressive malignant disease who require palliative care. This guidance applies to patients in all settings across the Yorkshire and Humber Children’s and Young People’s Cancer Network (YHCYPCN).

This includes:-

- Children and young people under the care of the Principal Treatment Centre (PTC) in Leeds.
- Children and young people in Paediatric Oncology Shared Care Units (POSCU’s).
- Children and young people receiving care through any of the regions children’s hospices.
- Children and young people being cared for by community nursing teams at home.
- Children and young people for the purpose of this guideline are those under the care of a paediatric Oncologist or Haematologist aged 0-18yrs.

Guideline Background
Palliative Care is:-

“an active and total approach to care, from the point of diagnosis or recognition throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on enhancement of quality of life for the child/young person and support for the family. It includes the management of distressing symptoms, provision of short breaks and care through death and bereavement” (ACT)¹

“the active, holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of an illness in conjunction with other treatments.” (WHO)²

These guidelines are being developed to allow doctors (both GPs and Paediatricians) and nursing staff in the PTC, POSCU’s, hospices and in the community to have an understanding of the problems and symptoms that are likely to be encountered by children and young people with progressive malignant disease and the interventions they may require to try and manage these problems.

This document, whilst not exhaustive, will address most of the common symptom management problems encountered by children and young people with cancer including:

- Pain
- Respiratory problems - breathlessness, cough, secretions, hiccups, haemoptysis, pleural effusions
- Gastrointestinal problems - nausea and vomiting, constipation, diarrhoea, obstruction, anorexia, ascites, mouth care
- Neurological problems - seizures, agitation, delirium, raised intracranial pressure, spinal cord compression, muscle spasm
- Urinary and biochemical problems
- Skin problems - pruritis, lymphoedema, malignant wound care
- Haematological problems - anaemia, thrombocytopenia, bleeding, thrombosis
- End of life care
- Psychological problems - anxiety, depression

Individual advance care and symptom management plans will be written for each child requiring by the Child’s Nurse Specialist Key Worker in consultation with either their Oncologist or Haematologist and if necessary the Consultant in Paediatric Palliative care. These plans will follow the draft outline as identified by the Yorkshire and Humber Children’s Palliative Care Network and include documentation of resuscitation status (Appendix1).
Principles of Symptom Management

1. **Remember to consider the ‘whole patient’**.
   Symptoms are never purely physical or purely psychological, and all symptoms and treatments will have an impact on the children or young person and their families.

2. **Evaluate symptoms thoroughly**.
   Consider potential causes and remember to consider causes other than cancer. Consider the impact of the symptom on the child or young person’s quality of life.

3. **Find out what has been tried previously and whether it was used optimally**.

4. **Effective communication with patient and family is essential**.
   Explain the reasons for symptoms and management strategies in simple terms and avoid medical jargon. Discuss treatment options with the child or young person and their family, and involve them in the management plan.

5. **Correct the correctable**.
   As long as the treatment is practical, not overly burdensome and in the child or young person’s best interests.

6. **Consider non-pharmacological treatments**
   e.g. palliative radiotherapy for metastatic bone pain, simple repositioning, or the use of a TENS machine. Complementary therapies may also help psychological distress.

7. **Keep treatment simple and prescribe prophylactically**.
   When using drug treatments for persistent symptoms keep drug treatment as simple as possible. Remember to prescribe and administer regular and also “as required” medications. Pre-empt possible side effects of treatments e.g. laxatives for patients on opiates.

8. **Review interventions regularly and adjust treatment accordingly**.

9. **Plan in advance**
   Ensure the child or young person has a written symptom management plan. Ensure that anticipatory or emergency drugs are prescribed and available.

10. **Establish a child, young person or parent’s wishes for their future care**.
    They may want to document their wishes as part of the care and symptom management plan. Keep staff and other professionals involved in the care of the child or young person informed.

11. **Ask for help**.
    The child will have a named nurse specialist responsible for their symptom management plan. There will always be a nurse specialist on call to advise, assess and to support other professionals as well as the child/young person and family. The child/young person will be under the care of a Consultant Paediatric Oncologist or Haematologist who can be called upon for advice. There is always a consultant on call. Specialist palliative care advice is also available from the children’s hospices.
End of Life Care

Key Elements of Care for the Dying Child:

1. Recognition that the child is dying.

2. Clear, compassionate communication with patient (where possible and appropriate), and always with the parents, family and loved ones.

3. Provision of spiritual care to patient and family.

4. Development of an individual care plan with full discussion with patient (where possible and appropriate), and always with the parents, family and loved ones including discussions regarding place of care. This should be shared with the family and appropriate professionals including GP, ambulance service and children’s community nurses if the child is being discharged to home/hospice.

5. Clear documentation of resuscitation status should be made (LOTA) and agreed with patient (where possible and appropriate), and always with the parents, family and loved ones.

6. Anticipatory prescribing for symptoms including pain, respiratory tract secretions and shortness of breath, agitation, nausea and vomiting and seizures as per the Together for Short Lives Basic Symptom Control in Paediatric Palliative Care Guideline, and if appropriate, the Yorkshire and Humber Children and Young Peoples Cancer Network (YHCYPCN) individual symptom guidelines.

7. The focus of care should be on promoting comfort, and minimising distress and painful interventions including discontinuation of non-essential medication.

8. An MDT review of hydration and nutritional needs should occur in conjunction with patient (where possible and appropriate), and always with the parents, family and loved ones.

9. Regular reassessment of the patient should occur.

10. Parents and carers should have an up to date list of emergency numbers for staff and agencies they may need to contact including access to a key worker if they are being discharged to home/hospice.

11. There should be an opportunity for the family to discuss their wishes for care after death.

12. Dignified and respectful care for patient and family should occur after death and bereavement support should be offered.
End of life care (EOL) in Children and Young people
Together for Short lives defines ‘end of life’ as the phase of life which begins when a judgement is made that death is approaching. Whether this occurs suddenly or gradually over time careful planning in conjunction with the family is needed to help children and young people live as well as possible until they die.

Principles
Good EOL care should:
- Enable the child/young person and family to exercise choice
- Prepare the child/young person and family for an anticipated death in the place of their choosing (where possible)
- Enable management of the end stage of a terminal medical condition including care at the time of death and immediately afterwards. This should include the management of symptoms and the holistic care of the child and family

Management

1) Recognition that the child is dying
Recognising that a child or young person is entering the last days of life is difficult. Advanced care planning prior to this stage ensures that children and young people have plans in place in order to manage the terminal stages of their illness. The child’s main consultant, Nurse Specialist key worker and the family, along with the wider MDT should be involved in discussions to help recognise and plan for end of life from the earliest appropriate opportunity. The following documents may be helpful in recognising EOL:


2) Communication
Communication with the child/young person and family regarding EOL care should be performed by appropriately trained senior staff. It should be undertaken by the child’s named consultant and key worker or another designated medical or nursing professional who knows the family well. It should be in an appropriate environment with the child/young person, if appropriate, and family members. The fact that the child/young person is entering the terminal stages of their illness should be clearly and compassionately communicated. The family should be informed of what to expect over the coming days in terms of symptoms and their management. An advanced care plan should be discussed and initiated. Opportunity should be given for the patient’s and families wishes regarding place of care, management of symptoms, appropriateness of interventions, and care and support after death to be incorporated into the care plan. Written information should be offered if appropriate and interpreting services utilised if needed. Booklets available include:

Discussions should be documented carefully and disseminated to the family and appropriate professionals along with the completed care plan and any limitation of treatment agreement (LOTA).

3) Provision of Spiritual care
An assessment of the patient and family’s spiritual needs should be made.

Spirituality has been described as “what it is to be human – to the things that give life meaning and value, and as such is a deeply personal and subjective thing. It can involve questions and concerns about life, meaning, morals and values, and can encompass our relationship with ourselves, other people, the world around us, and sometimes but by no means always, a god or deity.”

http://www.togetherforshortlives.org.uk/assets/0000/4085/TfSL_Spiritual_wishes_family_factsheet_Nov_12.pdf

Parents should be offered support, which may be a visit from the appropriate hospital chaplain, or their own religious or spiritual leader, or an opportunity to discuss such issues with a health care professional or Social Worker. Religious and cultural ceremonies should be offered and supported. Together for short lives has developed a factsheet for families which may be appropriate

http://www.togetherforshortlives.org.uk/assets/0000/4085/TfSL_Spiritual_wishes_family_factsheet_Nov_12.pdf

4) Development of an individualised end of life care plan
The patient’s consultant and key worker will develop an individualised care plan for the patient in consultation with the family. A template is available for this if the child is going to home or hospice (Appendix 1) and this should include a list of key contacts, details of diagnosis and management to date, current clinical status, current medications, plans for management of individual symptoms, details of anticipatory medication provided in the palliative care drug box, and documentation of discussions re place of care and any limitations of treatment (LOTA). If the child or young person is to remain in hospital a separate care plan for the dying infant, child or young person is available.

Symptom Management
Guidance regarding the management of individual symptoms can be found in this document. Additional symptom management guidance can be obtained from Basic Symptom Control in Paediatric Palliative Care produced by Together for Short Lives and drug doses from the Association of Paediatric Palliative Medicine Master Formulary.

The patient’s Consultant, the Children’s Haematology and Oncology Outreach Team or a Paediatric Palliative Care Consultant can also be consulted for advice.

The process of completing the advance care and symptom management plan should be used as an opportunity to discuss with families what to expect when their child dies including possible changes in appearance e.g. cyanosis, pallor. Possible symptoms such as pain, agitation, gasping should be explained sensitively in order to reassure parents of what is expected and that each symptom will be treated proactively. Parents should be made aware that the time until death after withdrawal of life sustaining treatments or a decision to offer palliative care can vary greatly and this should be clearly documented in the notes.

Tissue Donation
Discussion should also include the possibility of tissue donation and how this may influence care before and after death. If a family in partnership with the child’s Physician has requested organ donation; Rapid Discharge for EOL care cannot occur. For some children organ and tissue donation may not be possible because of a child’s underlying diagnosis. Advice and support can be sought from the Organ Donation Service 0117 975 7575

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If a family in partnership with the child’s Physician wishes to request tissue donation; a discussion with The National Blood Service (NBS) on call Tissue Donation Nurse on 0800 432 0559 is essential in assessing if Tissue Donation is an appropriate option after death. The assessment will identify medical suitability as well as determine the logistical arrangements that will need to be made in order to retrieve donated tissues after the child has died. It will be the responsibility of the NBS Tissue Donation Service to gain consent for tissue donation and to coordinate all aspects of the Tissue retrieval following the Child's death.

Post Mortem
If there is any concern expressed around the cause of death from either medical staff or the child’s family, the coroner must be informed as soon as possible in order to identify the type of post mortem and any specific requirements. This may be a limiting factor for rapid discharge for end of life care to occur.
If a family or the child’s physician in partnership with the family has identified the need or request for a post mortem following a child’s death, this will normally be a hospital post mortem and the coroner does not need to be informed. The arrangements for PM and consent need to be obtained and organised prior to discharge. It will also be necessary to organise transportation back to the hospital.

Place of care
All families should be offered a choice of place of care for delivery of palliative care and this should include transfer to home or hospice for continuing care if local services are available. “The Children and Young People’s Palliative Care Rapid Discharge Guideline” available on Leeds Health Pathways exists in order to facilitate rapid discharge to home or hospice if the family wishes.

If care is to be undertaken in hospital, every effort should be made to care for the child in a private room, where the parents can sleep, away from the intensive care environment. Families should be given as much space and privacy as possible. Where this is not possible, a side room should be used or the bed space screened.

Children can be discharged home under the care of the Children’s Haematology and Oncology Outreach team and/or where available local hospice outreach services. Transfer home or to the hospice should be discussed and a plan should be agreed. If the child is thought to be within the last 48hrs of life the Children and Young People’s Palliative Care Rapid Discharge Guideline should be used. The patient can be discussed with the EMBRACE team if an ambulance or car transfer is not felt appropriate. Parents should be informed if there is a risk of the patient dying in transit, and the care plan should cover this occurrence. A Limitation of Treatment Agreement (LOTA) form (Appendix 2) should also be completed and should accompany the patient on discharge. Drug charts should be photocopied and amended to the care plan, so that medication can be continued easily after leaving hospital. The GP should be informed of any discharge home for palliative care prior to the child leaving the hospital.

Local hospices include:

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<th>Website</th>
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<tr>
<td>Martin House Children’s Hospice</td>
<td>Grove Road, Boston Spa Wetherby, LS23 6TX</td>
<td>01937 845045</td>
<td><a href="http://www.martinhouse.org.uk/">http://www.martinhouse.org.uk/</a></td>
</tr>
<tr>
<td>Bluebell Wood Children’s Hospice</td>
<td>Cramfit Road, North Anston Sheffield S25 4AJ</td>
<td>01909 517 369</td>
<td><a href="http://www.bluebellwood.org/">http://www.bluebellwood.org/</a></td>
</tr>
<tr>
<td>Forget me not Children’s Hospice</td>
<td>Russell House, Fell Greave Road Huddersfield HD2 1NH</td>
<td>01484 411 040</td>
<td><a href="http://www.forgetmenotchild.co.uk/">http://www.forgetmenotchild.co.uk/</a></td>
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Dissemination of the care plan
If the patient is going to home or hospice the plan should be distributed to the family and all appropriate professionals including the GP, Patient’s consultant, keyworker, community nursing teams, the ambulance service, hospice (if appropriate), school (if appropriate) and a copy should be filed in the patient’s notes and put on ppm.

5) Limitation of treatment agreements (LOTA)
The aim of any treatment at end of life when no further curative treatment is available should be to ensure comfort and to avoid unnecessary and distressing interventions. This should be discussed with the patient (if appropriate)
and the family and any limitations of treatment including resuscitation should be formalised and documented using the LOTA form (Appendix2). Copies should be filed in the patient’s notes, uploaded to ppm and distributed to the family and appropriate professionals. The patient (if appropriate) and family should be made aware that this agreement may change in response to the patient’s improving or deteriorating condition in consultation with them. The agreement is valid for 6 months in the community. It should be reviewed at least weekly while the child is in hospital and more frequently if the child’s condition improves. Supporting documentation including an accompanying guideline “A guideline for initiation, implementation and documentation of ‘Limitation of Treatment Agreement’ (LOTA) in End of Life Care for Children and Young People (incorporating Cardiopulmonary Resuscitation (CPR) Decisions)”, a parent’s guide, staff information and a summary flowsheet are available on Leeds Health Pathways.

6) Anticipatory prescribing
Anticipatory prescribing for symptoms including pain, respiratory tract secretions and shortness of breath, agitation, nausea and vomiting and seizures as per Basic Symptom Control in Paediatric Palliative Care\(^3\) and/or the YHCYPCN individual symptom guidelines should be undertaken and documented in the appropriate individualised care plan. Flow sheets are available within the Children’s Hospital end of Life Care Guideline (available on Leeds health Pathways) (Appendix3) to help with this. Guidance re dosing is also available in the APPM Master Formulary\(^4\). If the child is going to home or hospice a palliative care drug box containing this medication will be prescribed and will reside in the patient’s home in case required. This is prescribed by the child’s consultant using the proforma in Appendix4. This can be delegated to an appropriately trained senior doctor or independent nurse prescriber if the patient’s consultant is not available. A drug chart is also completed so that drugs can be administered by community and/or Children’s Haematology and Oncology Outreach team nursing staff. Appropriate dose ranges should be documented on the prescription so that treatment can be escalated or reduced. Both of these prescriptions will be checked by either the appropriate departmental pharmacist or the pharmacist on call if out of hours. Copies of this documentation are included in the palliative care drug box, filed in the patient notes and distributed to all on contacts on the individualised end of life care plan. If the child is remaining in hospital an inpatient paediatric palliative care syringe driver prescription chart is available (Appendix5). The same principles of anticipatory prescribing, dose ranges and ensuring adequate ward stock of prescribed medicines apply.

7) Minimising painful interventions and review of medication
At this stage of treatment the focus of care should be on promoting comfort and minimising distress. Investigations and procedures should be kept to an absolute minimum and only performed in the child’s best interests. Routine observations and blood tests should be discontinued whether the child is at home/hospice or in the hospital. A review of the patient’s medication should occur and all non-essential medication should be discontinued.

8) Review of fluid and dietary needs
An assessment of the patient’s fluid and dietary needs should be made. The goal of feeding and hydration in palliative care is to provide comfort and reduce distress from hunger and thirst. If the patient is less active their feeding and fluid requirements will be less than normal and this should be explained to the patient and family. The route of feeding should be that which is most suitable for the child or young person. A patient who is able to feed orally should be encouraged to do so. Nasogastric feeding can be considered in a child who is not able to feed orally, but who is hungry. It may not be possible to maintain hydration, and this is acceptable. Parenteral fluids are rarely indicated in palliative care. A patient who is unable to tolerate enteral fluids should be treated symptomatically for distress if required. Where death is predicted to be imminent, or where the provision of fluids is merely prolonging death fluids can and should be withheld in consultation with the patient (if appropriate) and family. If a patient is receiving TPN or IV fluids at the time when it is recognized that the child is dying, withdrawing the TPN/fluids should be considered, after discussion by the consultant with the patient (if appropriate) and family.

9) Regular review
At end of life symptoms can change on a minute to minute and hour to hour basis. It is important that careful plans are in place and that regular reassessment is undertaken in case these plans need to change or new symptoms develop. Regular planned review by appropriately trained staff should be undertaken and provision should be made
to in case review is required as an emergency. Any changes in management should be documented and disseminated.

10) **Emergency Contacts**
An up to date list of emergency contacts should be detailed on the individualised care plan and distributed to the family and relevant professionals in case an emergency review is required or advice needed. This should include out of hours cover and it should be clear to the family who they should contact when.

11) **Planning for care after death**
As part of the individualised care plan the patient and families wishes for care after death should be discussed and documented. Provision should be made for any religious or cultural observances to be undertaken. Staff should explain and facilitate the option to create and collect mementoes. A memory box can be provided for this purpose. If families do not wish to take photos and foot and hand prints, consider offering to arrange for these to be done and kept, in case the family changes their mind at a later date. The taking of photographs should be encouraged. Parents may wish to spend time with their child after death, and if in hospital this should be accommodated in a private room. Other options for place of care after death are available including transfer home, to a children’s hospice, to a local chapel of rest and transfer to the hospital mortuary and these should be discussed with the family. If the patient is an inpatient in LTHT there is a Standard Operating Procedure (SOP) for taking a Baby, Child or Young Person from Hospital after Death which is available on Leeds Health Pathways. Parents may wish to bathe and dress their child themselves after death, and staff should not do this without asking the parents first. Families should be provided with appropriate written information as appropriate as detailed above.

12) **Bereavement support**
All families will be offered bereavement support as detailed in the Children and Young People’s Cancer Network bereavement support guidelines. All families should be offered a follow up appointment with the Child or Young Person’s named consultant approximately 4-6 weeks after death to address any questions that the family may have. Practical and financial advice and support should be offered by the patient’s social worker and Nurse Specialist Key Worker.
Managing Pain Symptoms

Quick reference guide

Pain Assessment

1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. If mild pain consider paracetamol or ibruprofen if not contraindicated
4. If moderate to severe pain consider an opiate. The first line is oral morphine.
5. Advise regular use then convert to long acting preparations if appropriate
6. Always prescribe breakthrough doses with long acting preparations
7. Treat opiate side effects prophylactically
8. If the oral route is not available consider transdermal, subcutaneous infusion or IV (if central line)
9. Consider Co-analgesia and adjuncts at every step especially if neuropathic or bone pain
10. Reassess and plan in case of deterioration/no response
Managing pain

Pain is a common symptom experienced in children and young people with advanced cancer and can be difficult to manage. It is a total, personal experience with physical, psychological, social and spiritual dimensions. To achieve optimal control all of these potential contributory factors must be taken in to consideration.

Acute cancer pain can be caused by direct invasion of anatomical structures by a tumour, resulting in pain through pressure, distension, inflammation, obstruction and nervous tissue compression. Treatment can also cause pain as can general debility. Not all pain experienced by a child or young person with advanced cancer is caused by the cancer itself and it may be due to another concurrent disorder. Often several pains coexist, and an accurate diagnosis of the cause or mechanism of each pain must precede effective treatment.

Classification of pain (WHO 2012)

There are two major types of pain, nociceptive and neuropathic. It is important to make a distinction between nociceptive and neuropathic pain because the treatment approaches are different. Pain can also be mixed.

“Nociceptive pain” arises when tissue injury stimulates pain receptors called nociceptors. Nociceptors are sensitive to noxious stimuli and can respond to heat, cold, vibration, stretch stimuli and chemical substances released from tissues in response to oxygen deprivation, tissue disruption or inflammation. This type of pain can be subdivided into somatic and visceral pain depending on the location of activated nociceptors.

- **Somatic pain** is caused by the stimulation of nociceptors in either surface tissues (skin, mucosa of mouth, nose, urethra, anus, etc.) or deep tissues such as bone, joint, muscle or connective tissue. For example, cuts and sprains causing tissue disruption produce surface somatic pain while muscle cramps due to poor oxygen supply produce deep somatic pain.

- **Visceral pain** is caused by the stimulation of nociceptors located in the viscera (the internal organs of the body that are enclosed within a cavity, such as thoracic and abdominal organs). It can occur due to infection, distension from fluid or gas, stretching or compression, usually from solid tumours.

“Neuropathic pain” is caused by structural damage and nerve cell dysfunction in the peripheral or central nervous system (CNS). Any process that causes damage to the nerves, such as metabolic, traumatic, infectious, ischaemic, toxic or immune-mediated pathological conditions, can result in neuropathic pain. In addition, neuropathic pain can be caused by nerve compression or the abnormal processing of pain signals by the brain and spinal cord. It can be peripheral i.e. arising from a lesion in a peripheral nerve or central(arising from a lesion affecting the CNS).

“Mixed pain”- Neuropathic pain may occur alongside nociceptive pain.

Other pain types:

**Breakthrough pain** is classified as a “temporary increase in the severity of pain over and above the pre-existing baseline pain level”. It is usually occurs suddenly and is of short duration and can be severe. It often occurs in cancer pain.

**Incident pain** or pain due to movement has an identifiable cause. The pain is triggered by simple movements, such as walking, weight bearing, coughing or urination.

**End of dose pain** occurs just before the next dose of medicine may be due and is caused by the blood level of the drug falling below the minimum effective analgesic level.
## Characteristics of the different pain types which may help in diagnosis (Taken from WHO guidelines)

<table>
<thead>
<tr>
<th>Type of pain</th>
<th>Origin of stimulus</th>
<th>Localization</th>
<th>Character</th>
<th>Referral and radiation of pain/sensory dysfunction</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nociceptive Pain</strong></td>
<td>Arises from nociceptors in skin, mucosa of mouth, nose, urethra, anus, etc. Nociceptive stimulus is evident.</td>
<td>Well localized</td>
<td>Usually sharp and may have a burning or pricking quality</td>
<td>None</td>
<td>Abscesses Postsurgical pain from a surgical incision Superficial trauma Superficial burn</td>
</tr>
<tr>
<td>Superficial somatic pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Bone pain due to metastasis Fractures Muscle cramps Sickle cell Vasoocclusive episodes</td>
</tr>
<tr>
<td><strong>Nociceptive Pain</strong></td>
<td>Arises from nociceptors in bone, joint, muscle and connective tissue. Nociceptive stimulus is evident.</td>
<td>Usually well localized with tenderness to palpation.</td>
<td>Usually dull or aching or throbbing in quality.</td>
<td>In some instances, pain is referred to the overlying skin. No associated sensory dysfunction.</td>
<td>Pain from acid indigestion or constipation Pain due to stretching from liver metastasis, pleura stretching due to pleuritis, as in pneumonia or tuberculosis</td>
</tr>
<tr>
<td>Deep somatic pain</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Nociceptive Pain</strong></td>
<td>Arises from nociceptors in internal organs such as the liver, pancreas, pleura and peritoneum.</td>
<td>Poorly localized, diffused. Palpation over the site may elicit an accompanying somatic pain.</td>
<td>Usually vague, dull, aching, cramping or tightness, deep pressure, spasms, or squeezing or colicky in nature. Nausea, diaphoresis and emesis are frequently present.</td>
<td>In some instances, pain referred to skin supplied by same sensory roots that supply the diseased organ. There may be radiation of the visceral pain, but it will not be in a direct nerve distribution. No associated sensory dysfunction.</td>
<td></td>
</tr>
<tr>
<td>Visceral pain</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Neuropathic pain</strong></td>
<td>Is generated at various sites, and is not always stimulus dependent.</td>
<td>Poorly localized, diffuse pain in an area of sensory dysfunction in the area of anatomical distribution of nerve supply.</td>
<td>Difficult to describe and different words may be used in different populations: burning, pricking or needle like pain; sharp or shooting. The pain may be persisting or recurrent.</td>
<td>Neuropathic pain is perceived within the innervation territory of the damaged nerve. There may be abnormal radiation. The pain is associated with sensory dysfunction</td>
<td>Central neuropathic pain due to spinal cord injury from trauma or tumour Painful peripheral neuropathies, due to HIV/AIDS, cancer or anticancer treatment pain (e.g. vincristine) Phantom limb pain</td>
</tr>
</tbody>
</table>
Assessment of Pain

Optimal pain management begins with a pain assessment. Assessment should occur at regular intervals to evaluate the effectiveness of treatment strategies and to assess how pain changes over time in response to the disease process and other factors.

Pain assessment should involve the child, parents / family and health care professionals. It should also take account of the psychosocial, social, cultural and spiritual factors, all of which can influence how a child and family perceive pain. There are multiple tools available for assessment of pain at different ages e.g. smiley faces, paediatric pain assessment tool and these can be used.

Diagnosis and assessment

The assessment of pain should include a detailed history

- Previous pain experiences
- Previous analgesia
- Current pain experience

- Helpful questions to consider in the assessment of pain²
  - What words do the child and family use for pain?
  - What verbal and behavioural cues does the child use to express pain?
  - What do the parents and/or caregivers do when the child has pain?
  - What do the parents and/or caregivers not do when the child has pain?
  - What works best in relieving the pain?
  - Where is the pain and what are the characteristics (site, severity, character of pain as described by the child/parent, e.g. sharp, burning, aching, stabbing, shooting, throbbing)?
  - How did the present pain start (was it sudden/gradual)?
  - How long has the pain been present (duration since onset)?
  - Where is the pain (single/multiple sites)?
  - Is the pain disturbing the child’s sleep/emotional state?
  - Is the pain restricting the child’s ability to perform normal physical activities (sit, stand, walk, run)?
  - Is the pain restricting the child’s ability/willingness to interact with others, and ability to play?
  - Are there any potentially reversible causes of pain?

- Developmental level
- Non verbal expressions of pain

- Behavioural indicators of acute pain²:
  - facial expression
  - body movement and body posture
  - inability to be consoled
  - crying
  - groaning.

These behavioural responses may be reduced in persisting pain, except during acute exacerbation.
Behaviours in children with chronic pain can include:
- abnormal posturing
- fear of being moved
- lack of facial expression
- lack of interest in surroundings
- undue quietness
- increased irritability
- low mood
- sleep disruption
- anger
- changes in appetite
- poor school performance.

Level of activity

Physical Examination

Principles of managing pain in CYP with advanced cancer
- Where possible the child, young person and / or their family should be involved in the assessment of their individual pain experience.
- The focus of care should be on promoting quality of life and comfort and minimising distressing and painful interventions
- Recognise and treat potentially reversible causes of pain.
- Interventions must be tailored to each child or young person. Use a logical stepwise approach.
- In general, successful relief of pain in palliative care patients requires:
  a) Regular, as well as p.r.n. (as required) dosing
  b) Titration of dosage against effect with no rigid upper limit for most opiates except buprenorphine and dihydrocodeine
  c) Appropriate time interval between doses
  d) Sufficient dose to prevent return of pain before next dose is due
  e) Willingness to give strong opiates early when other analgesics fail
  f) Early consideration of co-analgesics and nonpharmacological approaches
  g) Regular review and assessment
  h) Explanation and information regarding pain and medications
  i) Referral for anaesthetic analgesic interventions as necessary
  j) Ensure antiemetics and laxatives are prescribed to counteract opiate side effects

Management

<table>
<thead>
<tr>
<th>Potential reversible causes of pain</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infection</td>
<td>Consider antibiotics if appropriate for symptom control e.g. Dysuria and UTI, Chest infection and chest pain</td>
</tr>
<tr>
<td>Constipation/anal fissure</td>
<td>Laxatives, review of medications, local anaesthetic cream</td>
</tr>
<tr>
<td>Mucositis</td>
<td>Check for HSV and consider aciclovir, review medications, consider mouthwashes and local anaesthetic sprays</td>
</tr>
<tr>
<td>Fracture</td>
<td>POP and/or fixation if appropriate</td>
</tr>
<tr>
<td>Raised ICP</td>
<td>Steroids, shunt if appropriate</td>
</tr>
<tr>
<td>PE/DVT</td>
<td>Consider anticoagulation</td>
</tr>
<tr>
<td>Ascites</td>
<td>Consider drainage if appropriate but likely to re-accumulate</td>
</tr>
</tbody>
</table>
Pharmacological Management
Medicines should be administered to children by the simplest, most effective, and least painful route, ideally orally. The choice of alternative routes of administration, such as transdermal, intravenous (IV), subcutaneous (SC), rectal, or buccal when the oral route is not available should be based on clinical judgement, availability and patient preference. The intramuscular (IM) route of administration is painful and is to be avoided. The rectal route has an unreliable bioavailability, both for paracetamol and morphine, which limits its applicability and carries the risk of infection for immunocompromised patients.

WHO (2012)\(^2\) recommend that a two-step approach to pain management is adopted for all children requiring pain management.

- **Step 1** Mild pain - Paracetamol and/or ibuprofen if appropriate
- **Step 2** Moderate to severe pain - Opiate

Some pains are only partially opiate-responsive. These include tension headache, post-herpetic pain, muscle spasms, nerve damage/compression, bone pain, visceral distension, and activity provoked pain. These may require co-analgesics, nerve block or specific oncological treatments. Co-analgesics include non-steroidal anti-inflammatory drugs (NSAIDs), anti-convulsants, anti-depressants, benzodiazepines and corticosteroids. Such co-analgesics and adjuvant therapies should be considered alongside both steps of the analgesic ladder.

**Step one – First line analgesia**
Paracetamol and ibuprofen are the medicines of choice in the first step (mild pain) in the absence of any contraindication e.g. bleeding, low platelets. For children below three months of age, the only option is paracetamol. If paracetamol or ibuprofen are contraindicated dihydrocodeine could be considered as a first step. Please refer to the BNF or APPM formulary for appropriate doses.

**Step two – Opiate analgesia**
If pain is moderate or severe, the administration of a strong opiate is necessary. Morphine is the medicine of choice for the second step, although other strong opiates should be considered in case of intolerable side-effects such as nausea, vomiting, sedation and confusion or contraindications such as renal impairment. Some opiates can also be helpful for neuropathic pain e.g. oxycodone, tramadol. Please refer to the APPM formulary for appropriate starting doses.

Switching opiates and/or route of administration in children is recommended in the presence of inadequate analgesic effect with intolerable side-effects.

If children are requiring several p.r.n. doses a day, assess whether this is due to inadequately controlled background pain or the presence of episodic pain. Consider whether such break-through pain is predictable (incident pain) e.g. on movement, or unpredictable (spontaneous) and how long the break-through pain lasts. Such assessment will determine how p.r.n. analgesics are tailored for the individual child, specifically in terms of dose and duration of action. Inadequately controlled background pain usually requires the background dose to be titrated, whereas planned use of p.r.n. medication may be acceptable for incident or spontaneous pain.

**Opiate side effects include:**
- Constipation (very common) – consider the prescribing laxatives to prevent constipation.
- Nausea and vomiting (a common but controllable and transient side effect that usually improves after approximately 5 days) – Consider the use of anti-emetics.
- Drowsiness (often dose-related and temporary) – provide appropriate explanation and reassurance
- Respiratory depression (clinically rarely a problem if dose is titrated correctly).
- Tolerance and addiction are not significant problems in children requiring palliative care.
Morphine sulphate
Give orally if the child can swallow and absorb the drug.

Review the dose after 24 hours to assess effectiveness. If the dose is not adequate it should be increased by 30 – 50%.

Once an effective dose has been established, convert to sustained release oral morphine (MST). The starting dose depends on their previous 24 hours dosing requirements:
e.g. Child needed 10mg oromorph 4hrly for last 24 hours. Total 60mg morphine in 24hrs. Give MST 30mg bd.

Prescribe short acting morphine in addition for breakthrough pain at a dose that is one tenth to one sixth of their 24 hour requirement. This can be given 2-4hrly if needed.

If the background dose of sustained release morphine is increased the breakthrough dose of oral morphine should also be reviewed.

If parenteral morphine is required, a continuous infusion by portable syringe pump should be used. This can be administered as a continuous subcutaneous infusion or if the child has a central line as a continuous intravenous infusion. Diamorphine is the first line drug of choice because its high solubility allows larger doses to be given in small volumes.

To determine the starting dose of diamorphine the child’s previous requirements for oral morphine must be considered and converted to a parental dose. Generally the starting dose of diamorphine is one third of the oral dose.
e.g. child needing MST 30mg bd plus 3 doses of 10mg oromorph in 24 hours. Total morphine is 90mg in 24 hours. Prescribe Diamorphine 30mg infusion over 24 hours.

Oxycodone
Oxycodone is a strong opiate with pharmacological properties similar to morphine. It is a useful second line strong opiate for children who have not tolerated morphine and for those who have an element of neuropathic pain. Oral oxycodone is 1.5 to 2 times more potent than oral morphine. Consult a dose conversion chart (Appendix 6) when starting oxycodone or ask advice from the Children’s Haematology & Oncology Outreach Team or pharmacist.

On commencing oral oxycodone the dose should be reviewed after 24 hours to assess effectiveness. If the dose is not adequately relieving the child’s pain it should be increased by 30 – 50%.

Once an effective dose has been established the child should be converted to sustained release oxycodone (Oxynorm). The dosage of Oxynorm will be dependent on their previous dosing requirements over a 24 hour period.

Additional oral oxycodone should also be prescribed to manage any breakthrough pain. This should be at a dose that is one sixth of their 24 hour requirement. Breakthrough oral oxycodone can be given 4hrly.

As with morphine sulphate the need for breakthrough medication (p.r.n.) should be regularly reviewed and dosages titrated in accordance with requirements.

If parenteral oxycodone is required, a continuous infusion by portable syringe pump should be used. This can be administered as a continuous subcutaneous infusion or if the child has a central line as a continuous intravenous infusion.
To determine the starting dose of oxycodone the child’s previous requirements for oral oxycodone and oxynorm must be considered and converted to a parental dose. To convert from oral oxycodone to IV divide the oral dose by 1.5.

**Fentanyl**
Fentanyl (and alfentanyl) can be more appropriate for patients with renal impairment or those with poor compliance with oral opiates or swallowing/absorption problems. It is available as transdermal (patch), buccal or IV preparations.

Patches are only suitable for children with chronic pain already stabilised on other opiates as they have a 72 hour duration of action.

Consult dose conversion chart (Appendix 6) when starting transdermal opiates or ask for advice from the Children’s Haematology & Oncology Outreach Team or a pharmacist.

All children using transdermal patches should also be prescribed an immediate release preparation for breakthrough pain which can either be as buccal fentanyl or oral morphine, the dose is dependent on the patch strength being used.

**Buprenorphine**
This drug is available as a patch and may be more appropriate for patients with renal impairment. Transdermal buprenorphine patches are available as:

- Low dose patches (BuTrans®) which have a duration of action of 7 days. These may be helpful in children with poor compliance who require a low dose opiate.
- Higher strength patches (Transtec®), which have a duration of action of 96 hours but are designed to be replaced twice a week.

**Methadone**
Methadone is a very long acting opiate which is available in oral and IV preparations and may be useful in neuropathic pain. It should only be commenced by practitioners experienced in its use and therefore should only be used in consultation with a consultant paediatric palliative care specialist.

**Neuropathic pain**
Neuropathic pain often requires co-analgesics such as anticonvulsants, antidepressants, ketamine to be added in to a child’s first or second step analgesia. Some strong opiates e.g. oxycodone have some effect in neuropathic pain. Children may develop adverse effects before benefit, and effective analgesia may take up to a week to be achieved for some medications.

**Anti-convulsants e.g. gabapentin, carbamazepine, sodium valproate, phenytoin**
Gabapentin or carbamazepine are useful first line oral medications in neuropathic pain. They can cause drowsiness and constipation.

**Anti-depressants e.g. amitriptyline**
May be helpful if mood issues and to help with sleep, however may have unacceptable side effects e.g. dry mouth, urinary hesitancy, postural hypotension and constipation.

**Ketamine**
This is an anaesthetic induction agent and is available in oral and IV preparations. It may produce dysphoria and haloperidol may be needed to counteract this. This should only be started in consultation with a paediatric palliative care specialist or anaesthetist.
Other adjuncts
Epidurals and nerve blocks should be considered early and in some cases prophylactically in consultation with a paediatric anaesthetist. In extreme cases nerve ligation may be required. Steroids such as dexamethasone can be considered if there may be any element of nerve compression by the tumour. These should be given as short 5 day courses to avoid unacceptable side effects. Radiotherapy can be useful and should be given as an emergency if spinal cord compression is suspected and the tumour may be radioresponsive.

Bone Pain
Consider:

NSAIDs
Ibuprofen, diclofenac and Cox 2 inhibitors can be considered if there are no contraindications e.g. gastric ulceration, asthma, bleeding and low platelets, and renal failure. They have important side effects and risk benefits should be assessed.

Bisphosphonates
Such as Pamidronate are osteoclast inhibitors and are useful for metastatic bone pain. Their effect can last many months but sometimes two doses are required to obtain benefit.

Corticosteroids
Steroids such as dexamethasone can be considered. These should be given as short 5 day courses to avoid unacceptable side effects.

Other adjuncts
Radiotherapy can be considered and be a very useful adjunct in relieving bone pain.

Spasmodic pain
Spasmodic abdominal pain can be relieved by antimuscarinics such as hyoscine butylbromide. In bowel obstruction octreotide and or dexamethasone may be useful adjuncts. Muscle spasm may be relieved by benzodiazepines such as diazepam or by baclofen.

Non-Pharmacological Management of pain
These should be considered in addition to analgesia.
- Reassurance and explanation
- Distraction and relaxation techniques
- Positioning of the child or young person to aid relief of pain
- Establish the meaning and impact of pain for the child, young person and family and explore fears
- Psychological support – to reduce the distress of anxiety for the child, young person and family.
- Consider physiotherapy if appropriate
- Planning and modification of activities of daily living including aids and adaptations
- Warm/cold packs - always ensure these are reviewed regularly especially if there is an element of loss of sensation as may cause burns. Never use directly on skin.
- TENS machines
Managing Respiratory Symptoms

Quick reference guide

Breathlessness
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Consider oxygen
4. Consider opiates and/or benzodiazepines
5. Consider non pharmacological measures e.g. positioning, psychological support
6. Reassess and plan in case of deterioration
7. If acute tracheal compression sedate until unconscious with midazolam

Cough
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Wet cough consider hyoscine hydrobromide
4. Dry cough consider linctus, opiates and/or nebulisers
5. Consider non pharmacological measures e.g. positioning, psychological support
6. Reassess and plan in case of deterioration

Haemoptysis
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Consider antifibrinolytics e.g. tranexamic acid
4. Consider non pharmacological measures e.g. positioning, psychological support
5. Reassess and plan in case of deterioration
6. If catastrophic haemorrhage sedate until unconscious with midazolam

Hiccup
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Try non pharmacological interventions e.g. startle reflex, breath holding and rebreathing
4. To reduce gastric distension consider prokinetics, peppermint water or dimeticone.
5. To relax smooth muscle consider nifedipine, baclofen or midazolam
6. If central cause suspected consider haloperidol, chlorpromazine or sodium valproate
7. Reassess and plan in case of deterioration
Respiratory Symptoms
Respiratory symptoms are frequent in children and young people with terminal cancer, and tend to become more common and severe in the last few weeks of life. For dosages of all medications please see APPM Master Formulary or BNFC.

♦ Breathlessness
Breathlessness is the subjective experience of breathing discomfort. It is present in many children and young people with cancer in the last few weeks before death and can be severe for a proportion.

Principles
• The focus of care should be on promoting quality of life and comfort and minimising distressing and painful interventions
• It is important to recognise and treat potentially reversible causes of breathlessness.

Clinical features
The causes of breathlessness are usually multi-factorial: physical, psychological, social and spiritual factors all contribute to this subjective sensation.
Breathlessness is generally associated with an increase in respiratory rate. It is often intermittent, occurring in episodes, exacerbated by physical exertion, bending over or even just talking, and is associated with feelings of exhaustion.
Breathlessness can result in a restriction in physical activity, and increase in dependence, frustration and anger and induces feelings of anxiety, fear or panic.

Diagnosis and assessment
• History and clinical examination
  – Assessment of the impact of breathlessness on normal activity
  – Features of any expectorant
  – Situations that make it worse
  – What helps
• Investigations
  – Chest x-ray
  – Chest CT / MRI if indicated
  – Full blood count if indicated
  – U&E if indicated
• Assess for potentially reversible causes of breathlessness

Management
Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Potential causes of breathlessness</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pneumonia / infection</td>
<td>Consider antibiotics where appropriate</td>
</tr>
<tr>
<td>Anaemia</td>
<td>Treat symptoms rather than Haemoglobin level</td>
</tr>
<tr>
<td>Bronchospasm/asthma</td>
<td>Consider bronchodilators or steroids</td>
</tr>
<tr>
<td>Anxiety/depression</td>
<td>Psychological support, anxiolytics</td>
</tr>
<tr>
<td>Tracheal/ bronchial obstruction from malignancy</td>
<td>Consider radiotherapy or steroids</td>
</tr>
<tr>
<td>Pleural effusion / Pericardial effusion</td>
<td>Consider drainage procedures</td>
</tr>
<tr>
<td>Pneumothorax</td>
<td>Consider drainage procedures</td>
</tr>
<tr>
<td>Pulmonary Embolism</td>
<td>Consider anticoagulation but only if appropriate</td>
</tr>
<tr>
<td>Superior vena cava (SVC) obstruction</td>
<td>Consider steroids</td>
</tr>
<tr>
<td>Ascites</td>
<td>Consider drainage or diuretics depending on cause and if felt appropriate</td>
</tr>
<tr>
<td>Hypoxia</td>
<td>Consider oxygen therapy</td>
</tr>
<tr>
<td>Acidosis</td>
<td>Consider treating metabolic disturbance</td>
</tr>
<tr>
<td>Cachexia and muscle weakness</td>
<td>Consider nutritional support and physiotherapy if appropriate</td>
</tr>
</tbody>
</table>
Pharmacological Management

**Oxygen therapy**
- Oxygen therapy may help children and young people who are breathless at rest or who become so on exertion. It may also help due to facial or nasal cooling effect.
- Consider a trial of oxygen for any child or young person who is hypoxic. If this not tolerated or of no benefit then discontinue.
- Oxygen therapy can limit mobility, be a barrier to communication, or be inconvenient to the child or young person.
- Domiciliary oxygen for continuous or p.r.n use should be prescribed according to local guidelines using a home oxygen order form (HOOF) Appendix 7.

**Corticosteroids**
May reduce inflammatory oedema. Indications include SVC obstruction, airway obstruction and bronchospasm.
Drug choice:
- Dexamethasone. May help reduce oedema, and the impact of SVC obstruction
- Prednisolone. May be indicated to help alleviate bronchospasm and wheeze.

Treatment with corticosteroids should be reviewed after 5 days.
If symptoms have improved, reduce dose gradually to the lowest effective dose.
If no improvement in symptoms, steroid should be stopped or reduced to previous maintenance dose.

**Opiates**
Opiates can decrease perception and experience of breathlessness, decrease anxiety and decrease pain
Drug choice:
- If a child or young person is opiate naïve:
  - Oral short acting morphine should be prescribed and titrate according to response in a dose of 30-50% of that used for pain¹.
  - If a child or young person needs more than 2 doses in 24hr, consider long-acting opiate
- If a child or young person is already taking a regular strong opiate for pain: for breathlessness use an additional p.r.n. dose of strong opiate which is in the range of 30-50% of the 4 hourly strong opiate dose depending on severity of breathlessness
- Consider increasing the regular dose by 30-50% to achieve a response and titrate according to response

**Benzodiazepines**
Benzodiazepines can be effective in reducing anxiety and distress. They act as a muscle relaxant and can reduce the potential for anxiety and panic attacks
Drug choice:
- Midazolam sublingually (short acting half life = 2.5hrs).
- Diazepam orally (long acting half life = 20-100hrs)
- Midazolam continuous infusion subcutaneously or intravenously for intractable breathlessness, distress and or an inability to tolerate oral or sublingual preparations.

Review the treatment with benzodiazepines on an ongoing basis and reduce if accumulating and causing drowsiness.

**Nebulised medications**
Nebulisers can be useful to hydrate secretions and for bronchospasm.
Drug choice:
- Sodium chloride 0.9%. Hydrating may help viscous secretions
- Salbutamol Bronchodilator for bronchospasm or wheeze.

Monitor for adverse effects and effectiveness, stop if no response
Antimuscarinics
Antimuscarinics can be useful to manage the pooling of saliva in the pharynx and the rattling noise this produces. Drug choice:
- Hyoscine hydrobromide patch or continuous SC / IV infusion

Diuretics
Ascites can make breathing difficult due to the splinting effect on the diaphragm. Drug choice:
- Spironolactone may help to reduce fluid volume in the abdomen.

Treatment with diuretics should be reviewed after 5 days and if no improvement in symptoms should be stopped.

Non-Pharmacological Management
- Reassurance and explanation
- Distraction and relaxation techniques
- Positioning of the child or young person patient to aid breathing
- Increase air movement – fan/ open window
- Consider humidification
- Establish the meaning and impact of breathlessness for the child, young person and family and explore fears
- Psychological support – to reduce the distress of anxiety for the child, young person and family.
- Consider physiotherapy if appropriate
- Planning and modification of activities of daily living including aids and adaptations

Acute tracheal compression
This is a rare palliative care emergency
Drug choice
- IV Midazolam until the child or young person is unconscious
- Consider a continuous background IV / SC infusion
- Buccal Midazolam if IV administration is not possible. Doses can be repeated every 10 mins if needed.

♦ Cough
The presence of cough in children or young people requiring palliative care for cancer is most likely to occur because of disease, it can also be treatment related or due to other diseases. Prolonged bouts of coughing can be exhausting and frightening, especially if associated with breathlessness and haemoptysis, and can lead to vomiting.

Principles
- The focus of care should be on promoting quality of life, comfort and minimising distress.
- It is important to assess the likely causes(s) and purpose of the cough and to treat reversible causes.
- Cough may serve a physiological purpose and where possible expectoration should be encouraged.

Clinical features
Cough can be productive and wet, or dry, with causes similar to those that result in breathlessness. It can also cause pain and lead to vomiting.

Diagnosis and assessment
- History and clinical examination
  - Nature of expectorant
  - Presence of blood
  - Impact of cough on daily life
  - What makes it worse/better
- Investigations
  - Chest x-ray if indicated
  - Chest CT / MRI if indicated
Management
Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Potential causes of cough</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pneumonia / infection</td>
<td>Consider antibiotics where appropriate and/or Nebulised saline 0.9%</td>
</tr>
<tr>
<td>Bronchospasm</td>
<td>Consider bronchodilators or steroids</td>
</tr>
<tr>
<td>Pleural effusion</td>
<td>Consider drainage techniques</td>
</tr>
<tr>
<td>Cardiac failure / pulmonary oedema</td>
<td>Consider diuretics</td>
</tr>
<tr>
<td>Gastro-oesophageal reflux</td>
<td>Consider antacids, proton pump inhibitors and feed thickeners plus positional measures</td>
</tr>
<tr>
<td>Tracheal/ bronchial obstruction from malignancy</td>
<td>Consider radiotherapy or steroids</td>
</tr>
</tbody>
</table>

Pharmacological Management

**Wet Cough**
Drug choice:
- Sodium chloride 0.9% nebulised can help reduce irritation and reduce sputum viscosity.
- Salbutamol can help manage bronchospasm
- Hyoscine hydrobromide patch or continuous SC / IV infusion. Be aware that thick secretions can make expectoration more difficult

**Dry Cough**
Drug choice:
- Simple linctus - locally soothing demulcent action with some anti-tussive effect
- Codeine linctus - If already taking a strong opiate for pain there is no rationale for using codeine linctus.
- Strong opiates can ease coughing. If established on opiates consider increasing dose. Methadone could be considered in consultation with the palliative care service.
- Sodium chloride 0.9% nebulised can help reduce irritation.
- Gabapentin can also be used for refractory chronic cough

Non-Pharmacological Management
- Reassurance and explanation
- Distraction and relaxation
- Positioning of the child or young person patient to aid breathing
- Increase air movement – fan/ open window
- Humidification may help

**Haemoptysis**
Haemoptysis in children and young people may be directly related to the underlying tumour or related to treatments or infection. A clotting disorder or thrombocytopenia may also be a contributory factor.

**Principles**
- The focus of care should be on promoting quality of life, comfort and minimising distress
- It is important to assess the likely causes(s) and treat any reversible ones if appropriate

**Clinical features**
Haemoptysis is characterised by the coughing up of blood stained sputum, blood clots or fresh blood and can be classified into acute and non-acute haemorrhage. This can be a catastrophic terminal event.
Diagnosis and assessment

- History and clinical examination
  - Nature of expectorant
  - Frequency and amount of blood present
  - Daily pattern of haemoptysis
  - What makes it worse/better

- Investigations
  - Chest x-ray if indicated
  - Clotting screen/FBC if indicated

Management

It is essential to anticipate and explain and prepare the child, young person and family for the possibility of haemoptysis. Consider whether there is a treatable cause:

<table>
<thead>
<tr>
<th>Potential causes of haemoptysis</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pneumonia / infection</td>
<td>Consider antibiotics where appropriate</td>
</tr>
<tr>
<td>Pulmonary Embolus</td>
<td>Consider anticoagulation if appropriate</td>
</tr>
<tr>
<td>Tumour bleeding erosion into vessel</td>
<td>Consider radiotherapy</td>
</tr>
<tr>
<td></td>
<td>Consider antifibrinolytics e.g. tranexamic acid</td>
</tr>
<tr>
<td>Thrombocytopenia</td>
<td>Consider platelet support</td>
</tr>
<tr>
<td>Clotting disorder</td>
<td>Consider correction</td>
</tr>
</tbody>
</table>

Pharmacological Management

Haemostatic and antifibrinolytic agents may help control bleeding and reduce the potential for major haemorrhage. Drug choice:
- Tranexamic acid to reduce the breakdown of clots
Discontinue if symptoms do not respond after 1 week and continue for 1 week post cessation of haemoptysis. Consider longer term prophylaxis if haemoptysis recurs.

Non-Pharmacological Management

- Reassurance and explanation
- Distraction and relaxation
- Positioning of the child or young person patient to aid breathing
- Psychological support – to reduce the distress of anxiety for the child, young person and family.

Major life-threatening haemorrhage

Ensure the child or young person patient is not left alone and provide reassurance and explanation to the child/family.

Have dark towels/bedding available

Drug choice
- IV Midazolam until the child or young person is unconscious
- Consider a continuous background IV / SC infusion
- Consider buccal, PR or SC sedation if IV administration is not possible.

Non-Pharmacological Management

- Positioning of the child or young person appropriate to condition

Hiccups

The presence of hiccup in children or young people requiring palliative care for cancer can be because of disease, treatment related or due to other diseases. Hiccups are a consequence of diaphragmatic irritation and are often associated with liver enlargement or gastric irritation.

Principles

- The focus of care should be on promoting quality of life, comfort and minimising distress
- Consider treating any reversible causes
- Consider non-pharmacological measures first
Clinical features
It is characterised by sudden inspiration followed by an abrupt closure of the glottis. It can be continuous or intermittent in presentation.

Diagnosis and assessment
- History and clinical examination
  - Establish pattern of hiccups
  - Impact on daily life
  - Situations that make it worse
  - What helps
- Investigations
  - Chest x-ray if indicated
  - CT / MRI if indicated
  - U&E if indicated

Management
Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Potential causes of hiccups</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pneumonia / infection</td>
<td>Consider antibiotics where appropriate and/or Nebulised saline 0.9%</td>
</tr>
<tr>
<td>Gastro-oesophageal reflux</td>
<td>Consider antacids, proton pump inhibitors and feed thickeners plus positional measures</td>
</tr>
</tbody>
</table>

Other causes include gastric/abdominal distension, diaphragmatic irritation, phrenic nerve irritation, uraemia, CNS tumour, steroids.

Non-Pharmacological Management
- Reassurance and explanation
- Distraction and relaxation
- Breath holding and rebreathing from a paper bag increases pCO2
- Startle reflex (causes hyperextension of the neck)
- Small frequent meals rather than large meals

Pharmacological Management

Reduce gastric distension
Drug choice:
- Prokinetics e.g. metoclopramide/domperidone
- Peppermint water
- Dimeticone contained in some antacids e.g. Asilone, Maalox Plus, Infacol

Relax smooth muscle
Drug choice:
- Nifedipine
- Baclofen
- Midazolam

Suppress central hiccups reflex
Drug choice:
- Haloperidol
- Chlorpromazine
- Sodium valproate
Managing Gastrointestinal Symptoms

Quick reference guide

Constipation
1. Reassure and explain
2. Consider prophylactic laxatives if on opiates
3. Consider the cause and treat the treatable if appropriate
4. Ensure adequate hydration and dietary fibre if appropriate
5. Tailor laxative to acceptability to patient, oral route preferable
6. Start with oral macrogol or lactulose
7. Reassess and plan in case of deterioration/no response

Diarrhoea
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Ensure hydration for comfort
4. If no infective cause consider anti-diarrhoeal agents
5. Reassess and plan in case of deterioration/no response

Ascites
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Ensure adequate analgesia and control of breathlessness
4. Consider diuretics first line
5. Drainage will lead to eventual re-accumulation but can be considered for short term relief
6. Reassess and plan in case of deterioration

Malignant bowel obstruction
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Can often be improved with a combination of corticosteroids, antiemetic and anti-secretory drugs.
4. IV/SC hydration and NGT insertion may be appropriate but only in selected cases
5. Surgery and/or radiotherapy may be appropriate in selected cases
6. Reassess and plan in case of deterioration
Managing gastrointestinal symptoms

GI tract symptoms are frequent in children and young people with terminal cancer, and tend to become more common and severe in the last few weeks of life. For dosages of all medications please see APPM Master Formulary or BNFC.

♦ Constipation

There can be many reasons for terminally ill children to develop constipation including inactivity, altered diet, reduced intake of fluid/food, metabolic disturbance (hypercalcaemia/hypokalaemia), and medication. Constipation is a common opiate side effect and a prophylactic laxative should be started to avoid this.

Principles

- The focus of care should be on promoting quality of life and comfort and minimising distressing and painful interventions.
- It is important to recognise and minimise potential causes of constipation e.g. opiates, ondansetron, amitriptyline.
- It is important to consider the most appropriate route and type of laxative use which is tolerable for the patient and their carer/s (e.g. oral/rectal, small/large volumes, flavour).
- Use oral medication unless there is severe nausea and vomiting, dysphagia, weakness, or coma, when other routes may be necessary.
- Keep the number of drugs to a minimum.

Clinical features

Constipation is not easy to define. It is normal to pass more frequent stools as an infant and young child (e.g. a few times per day) with less frequent passage as a school aged child (e.g. once daily).

The Paris Consensus on Childhood Constipation Terminology (PACCT) Group in 2005 define Chronic Constipation as 2 or more of the following in the preceding 8 weeks:

- Fewer than 3 bowel movements per week.
- More than one episode of faecal incontinence per week.
- Either palpable stools in the abdomen, or large stools palpable rectally.
- Passing stools so large they block the toilet.
- Retentive posturing and withholding behaviours.
- Painful defecation.

In general the passage of painful, infrequent, difficult to pass or large stools can be considered to be constipation.

Diagnosis and assessment

- History and clinical examination
  - Frequency of stool passage
  - Stool type (Bristol Stool Chart)
  - Distress or difficulty on passage of stool
  - Fluid, food intake and vomiting
  - Opiate use and other constipating drugs (e.g. ondansetron, amitriptyline)
  - Check for abdominal mass (particularly left iliac fossa) and ascites
  - Examine anal area (external) for fissure
- Investigations
  - Consider checking serum electrolytes if imbalance possible and deemed appropriate
  - Consider checking for serum acidosis if appropriate
Management
Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Potential causes of Constipation</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opiate use</td>
<td>Consider prescribing alternative pain relief if appropriate. If using opiate prescribe prophylactic laxatives</td>
</tr>
<tr>
<td>Ondansetron</td>
<td>Consider alternative anti-emetic prescribing</td>
</tr>
<tr>
<td>Hypercalcaemia</td>
<td>Consider correction</td>
</tr>
<tr>
<td>Hypokalaemia</td>
<td>Consider oral or intravenous correction</td>
</tr>
<tr>
<td>Ascites</td>
<td>Consider drainage or diuretics depending on cause if felt appropriate</td>
</tr>
<tr>
<td>Acidosis</td>
<td>Consider treating metabolic disturbance</td>
</tr>
<tr>
<td>Cachexia and muscle weakness</td>
<td>Consider nutritional support and physiotherapy if appropriate</td>
</tr>
<tr>
<td>Anal fissure</td>
<td>Consider laxative and topical analgesia</td>
</tr>
<tr>
<td>Malignant bowel obstruction</td>
<td>See separate section</td>
</tr>
</tbody>
</table>

Pharmacological Management

For most causes of constipation, including opiate-induced, start with the use of an osmotic laxative such as macrogol orally. If the child is unable to tolerate large oral volumes consider starting with lactulose (as this is a small volume). If there is no response after a few days add in a stimulant e.g. senna. Where the oral route is not tolerated consider using glycerin suppositories, bisacodyl suppositories or micro/phosphate enemas. If the child has no response to the above a macrogol faecal impaction dose regime can be used if felt appropriate. If this will not be tolerated then consider micro or phosphate enemas.

The anus should be examined visually for anal fissures. Local anaesthetic gel or topical GTN may be used in conjunction with laxatives. Rectal examination should be avoided in children.

Osmotic laxatives

- Macrogol (oral)
  - used in faecal impaction, constipation and opiate-induced constipation
  - need to maintain hydration to be effective
- Lactulose (oral)
  - caution/contraindication in galactosaemia, intestinal obstruction, lactose intolerance
  - relatively ineffective in opiate induced constipation
- Glycerol (rectal)
- Micro-enema (sodium citrate) (rectal)
- Phosphate enema (rectal)

Stool softeners

- Docusate (oral/rectal)
Stimulant laxatives
- Senna (oral)
- Sodium picosulphate (oral)
  - may have reduced activity during antibiotic treatment as depends on breakdown of gut flora
- Bisacodyl (oral/rectal)
- Co-danthramer (oral)
  - for use in terminal illness only (potential carcinogen), turns urine red/brown
- Co-danthrusate (oral)
  - for use in terminal illness only (potential carcinogen), turns urine red/brown

Opiate-induced constipation not responsive to other laxative therapy
- Methylnaltrexone (subcutaneous injection) (licenced in adults)

Non-Pharmacological Management
- Reassurance and explanation
- Try to improve mobility and consider changes in posture
- Increased oral fluid intake (if previously suboptimal and appropriate)
- Increased dietary fibre intake (if previously suboptimal and appropriate) e.g. change in NG feed type
- Ensure adequate privacy and regular toileting after meals if appropriate
- Consider abdominal massage in the direction of stool passage

♦ Diarrhoea\(^3,4,5\)

Principles
- The focus of care should be on promoting quality of life, comfort and minimising distress.
- It is important to assess the likely causes(s) of the diarrhoea and to treat reversible causes.
- Consider simple reassurance and clear fluids as adequate management in most cases
- Rehydration salts such as Dioralyte can help replace salt and sugar in short term as supportive therapy
- Consider investigation for potential infective causes, and in the absence of these other treatments such as anti-diarrhoeal agents (e.g. Loperamide) may be employed.

Clinical features
Increased frequency of stools and/or loose/watery stool. Assess hydration status.

Diagnosis and assessment
- History and clinical examination
  - History of recent travel, contact with illness
  - History of recent antibiotic use
  - Frequency and volume of diarrhoea
  - Impact of diarrhoea (distress, skin breakdown)
  - Drug history for any laxative or pro-motility agents

- Investigations
  - Stool sample for infective causes (viral, microbiology, ova/cysts and parasites)
  - Consider serum electrolytes and urea if appropriate

Management
Potentially reversible causes should be investigated and treated. Address hydration status and rehydrate as appropriate. Monitoring and supplementation of electrolyte disturbance may be appropriate.
Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Potential causes of Diarrhoea</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infection - viral</td>
<td>Supportive therapy</td>
</tr>
<tr>
<td>Infection – bacterial (food poisoning/C. difficile)</td>
<td>Targeted antibiotic therapy if appropriate</td>
</tr>
<tr>
<td>Infection – parasites (e.g. from foreign travel)</td>
<td>Targeted anti-parasitic medication if appropriate</td>
</tr>
<tr>
<td>Post radiation and chemotherapy</td>
<td>Supportive therapy</td>
</tr>
<tr>
<td>Iatrogenic from pro-motility agents (Domperidone, Erythromycin) or medications containing laxative properties (e.g. Baclofen which contains Isosorbide)</td>
<td>Avoidance or reduction of such medications</td>
</tr>
<tr>
<td>Overflow diarrhoea in severe constipation</td>
<td>Treatment of constipation</td>
</tr>
<tr>
<td>Malabsorption (e.g. post infection) or diet</td>
<td>Avoidance of lactose in short term</td>
</tr>
</tbody>
</table>

Pharmacological Management

**Non-infectious diarrhoea**

Drug choice:
- Anti-diarrhoeal agent such as Loperamide (tablet or liquid) or Co-phenotrope (tablet, can be crushed)
- Dihydocodeine and other opiate can be considered
- In intractable diarrhoea an intravenous/subcutaneous infusion of Octreotide can be considered

**Infective diarrhoea**

Drug choice:
- Discuss with microbiology with regards to the most appropriate antibacterial or anti-parasitic agent to use and preferred administration route
- Avoid anti-diarrhoeal agents

**Non-Pharmacological Management**

- Reassurance and explanation
- Ensure frequent toileting and changing to avoid skin breakdown
- Consider using protective barrier cream in nappy area
- Keep well hydrated and modify feeds/diet if felt appropriate
- General infection prevention measures

♦ Ascites

Ascites in children and young people may be directly related to the underlying tumour or related to treatment or infection.

**Principles**

- The focus of care should be on promoting quality of life, comfort and minimising distress
- Assess the likely causes(s) and treat reversible ones if appropriate
- Pharmacological treatments and drainage can reduce ascites though if stopped it is likely to recur in time
- More invasive surgical treatments are possible and should be considered on a case by case basis
Clinical features
Ascites is characterised by increased abdominal circumference with flank dullness, shifting dullness and fluid thrill on examination. It is caused by increased intra-abdominal fluid and is only detectable clinically when a large amount of fluid has accumulated. Ascites can cause increased abdominal pressure, discomfort and pressure on organs such as the bowel leading to constipation. Additionally it can cause splinting of the diaphragm and make respiration more difficult, particularly when lying flat. Spontaneous bacterial peritonitis can occur in the presence of ascites and can be relatively asymptomatic with mild abdominal pain, vomiting, confusion and fever.

Diagnosis and assessment
- History and clinical examination
  - Examine the abdomen looking for the presence of distension, abdominal mass (alternative cause of increased abdominal girth) and shifting dullness
  - Look for signs of liver, heart disease and fluid overload
- Investigations
  - Consider checking serum albumin, electrolyte and urea and liver function tests if appropriate
  - Consider cardiac echo/blood pressure measurement if cardiac failure is possible and appropriate

Management
Consider whether there is a treatable cause:

<table>
<thead>
<tr>
<th>Potential causes of Ascites</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdominal or pelvic tumour</td>
<td>Consider dexamethasone to reduce tumour oedema</td>
</tr>
<tr>
<td>Reduced serum albumin (contributing factors can be protein losing enteropathy, impaired liver function, poor nutrition)</td>
<td>Optimise nutrition as tolerated. Consider supplements if appropriate.</td>
</tr>
<tr>
<td>Intra-abdominal infection</td>
<td>Antibiotic therapy (targeted to any culture results from aspirated ascitic fluid if appropriate)</td>
</tr>
<tr>
<td>Cardiac failure</td>
<td>Diuretic therapy</td>
</tr>
<tr>
<td>Liver failure and portal hypertension</td>
<td>Consider cause of liver failure and if treatable treat</td>
</tr>
<tr>
<td>Pancreatitis (secondary to chemotherapy)</td>
<td>Consider nil by mouth until pancreatitis resolves if appropriate</td>
</tr>
<tr>
<td>Inferior vena cava or hepatic vein occlusion</td>
<td>If tumour related consider dexamethasone to reduce tumour oedema. If clot related consider anticoagulation if felt appropriate.</td>
</tr>
<tr>
<td>Blockage/leakage of the lymphatic drainage of the abdomen (producing chyle)</td>
<td>Consider changes in feed/diet to low fat. Consider drainage/gluing (if leak)/shunt if felt appropriate</td>
</tr>
</tbody>
</table>

Pharmacological Management
Consider using diuretic therapy to reduce ascites
- Spironolactone as an initial therapy with Furosemide added in if required
- Ensure adequate analgesia to relieve any pain (see pain guideline)
- Treat any breathlessness secondary to ascites appropriately (see respiratory guideline)
- Treat any constipation secondary to ascites appropriately (see above)
Non-Pharmacological Management
- Reassurance and explanation
- Positional measures e.g. sitting up to relieve breathlessness
- Sensible fluid restriction but comfort should be considered at all times
  - Therapeutic paracentesis of ascitic fluid with replacement of intravenous fluid/albumin can be considered to relieve large or refractory ascites. This is a sterile procedure and potential symptom control benefits should be weighed up against the discomfort and distress that can be caused undertaking the procedure. It should be noted that ascites is likely to re-accumulate depending on cause.
- If ascites is due to chylous leak, gluing may be considered but this would require a general anaesthetic and may not be deemed appropriate.
- A transjugular intrahepatic portosystemic shunt (TIPS) can be used in patients with refractory ascites needing frequent paracentesis (>3/month). It can be a local anaesthetic procedure (with sedation) and has generally replaced surgically created portocaval shunts. Shunts block in about a quarter of cases. Again potential symptom control benefits and the length of time these will be provided should be weighed up against the discomfort and distress that can be caused undertaking the procedure.

♦ Malignant bowel obstruction
Malignant bowel obstruction is more common in adults with in advanced cancer though can occur in children and young people. It is particularly associated with ovarian or bowel cancer but can be associated with any abdominal tumour.

In children non malignant and possibly treatable causes of abdominal pain/distension and vomiting such as volvulus or intussusception should be kept in mind as the presentation is the same.
Aggressive pharmacological management can be very effective in reversing obstruction and reducing gastrointestinal symptoms in inoperable bowel obstruction. A combination of drugs is usually necessary and treatment should be initiated early.

Principles
- Focus of care should be on promoting quality of life, comfort and minimising distress
- Assess the affect the symptoms are having on the young person and treat to improve quality of life without prolonging distress
- Unlikely that oral drug therapy will be tolerated and subcutaneous/intravenous drug administration is usually required.
- Pharmacological treatments can reduce or reverse malignant bowel obstruction, though if reversed it is likely that it will recur in time
- More invasive surgical treatments are possible, but should be assessed on a case by case basis.

Clinical features
Malignant bowel obstruction may cause pain, nausea, vomiting, abdominal distension and reduced or absent passing of faeces or flatus.

Diagnosis and assessment
- History and clinical examination
  - Have a higher suspicion in ovarian, bowel cancer for the occurrence of MBO
  - Abdominal pain and distension
  - Associated vomiting
  - Reduced passage of flatus/absent
  - Absent or tinkling bowel sounds
- Investigations
  - Abdominal x-rays to demonstrate fluid levels (if absent does not exclude MBO) if appropriate
Management

Pharmacological Management
In many cases reduction in symptoms may be possible by using a combination of corticosteroids, prokinetic, antiemetic and antisecretory drugs. Consider:

1. **Dexamethasone** to reduce tumour oedema and as an antiemetic. Consider a 5 day trial and stop if ineffective.

2. **Metoclopramide or other prokinetic** but only if without colic and if still passing flatus. If severe colic these are contraindicated. This should be discontinued if the patient experiences increased pain.

3. **Ondansetron** may be helpful as increased intraluminal pressure leads to 5HT release.

4. **Other anti-emetics** such as haloperidol, cyclizine or levomepromazine should be considered to control vomiting if the above ineffective (see nausea and vomiting guideline).

5. **Octreotide** may be added to reduce production of secretions and is particularly effective in high obstruction with large volume emesis.

6. **Hyoscine butylbromide or glycopyrrolate** can also reduce colic and secretions but is less effective.

7. **Ensure adequate analgesia by the non-oral route**.

8. **Stool softening laxatives (e.g. docusate)** can be considered if partial obstruction. Stimulants and bulk forming laxatives should be avoided. Suppositories can also be considered.

Non-Pharmacological Management
At all stages give reassurance and explanation.

**Hydration**
Artificial hydration may cause symptoms to worsen due to increased third spacing and oedema and the risk/benefits must be carefully considered before starting. Most patients can be managed with careful mouthcare plus small amounts of fluid little and often. Ice cubes and lollies may be useful for this.

**Nasogastric tube placement**
Most patients can be managed without a nasogastric tube. It is usually reserved for patients with frequent or severe symptoms and for short term use while waiting to see if pharmacological management is effective. If necessary for control of symptoms, conversion to a venting gastrostomy tube may be useful in those patients for which it may be appropriate.

**By-pass surgeries and stenting**
Can be considered in selected patients depending on the nature of the obstruction, condition of the patient, prognosis and likely benefit – this is a particularly invasive management strategy and must be carefully weighed against degree and length of symptom benefit.

**Radiotherapy**
Radiotherapy may be effective in selected cases and should be considered.
Managing Nausea and Vomiting

Quick reference guide

Nausea and Vomiting

1. Reassure and explain
2. Treat reversible causes
3. Prescribe the most appropriate antiemetic given the cause regularly by the most appropriate route
4. If not effective consider changing the antiemetic or adding in another
Nausea and vomiting can be a common symptom experienced with many children and young people with progressive cancer. Around 40% will experience nausea and 30% vomiting. Nausea frequently occurs without vomiting.

Principles
- The focus of care should be on promoting quality of life and comfort and minimising distressing and painful interventions
- It is important to recognise and treat potentially reversible causes of nausea and vomiting.

Clinical features
The causes of nausea and vomiting can be multi-factorial: physical, psychological, and pharmacological factors can all contribute to this problem.

Nausea - an unpleasant feeling of the need to vomit.
Vomiting - the forceful expulsion of gastric contents through the mouth. This is not regurgitation or expectoration.

Nausea and vomiting is generally associated with an increase in the experience of feeling or actually being sick. It is often intermittent, occurring in episodes, and can be exacerbated by smells and strong odours.

Nausea and vomiting can result in a restriction in physical activity and an increase in fatigue, dependence, frustration and anger inducing feelings of anxiety, fear or panic.

Diagnosis and assessment
- History and clinical examination
  - Assessment of the impact of nausea and or vomiting on normal activity
  - Features of any vomit
  - Situations that make it worse
  - What helps
  - Investigations
    - Abdominal examination
    - Abdominal X-ray if indicated
    - U&E and glucose if indicated
    - CT/MRI if indicated for raised intracranial pressure
  - Assess for potentially reversible causes of nausea and vomiting

Management
It is important to understand the cause of nausea and vomiting to determine the appropriate therapeutic interventions. It is possible that there may be more than one cause for nausea and vomiting.

- Remove reversible causes if identified and possible
- Treat according to the likely pathophysiological mechanism
- If vomiting or severe nausea precludes the use of the oral route, consider alternate routes of drug administration until symptoms are controlled
- Avoid triggers (e.g. food smells and strong odours); aim for small frequent meals
- Try to maintain hydration with small, frequent amounts of oral fluid if tolerated.
Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Potential causes of nausea and vomiting</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drug therapy</td>
<td>Stop or find alternatives unless essential</td>
</tr>
<tr>
<td>Constipation</td>
<td>Laxatives, bowel intervention</td>
</tr>
<tr>
<td>Urinary retention</td>
<td>Consider catheterisation</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Psychological support; determine fears; provide explanations; consider anxiolytics</td>
</tr>
<tr>
<td>Infection (UTI, URTI, oral candidiasis)</td>
<td>Consider antibiotics or antifungals</td>
</tr>
<tr>
<td>Gastritis</td>
<td>Stop irritant drugs unless essential; consider PPI</td>
</tr>
<tr>
<td>Raised intracranial pressure</td>
<td>Consider corticosteroids; consider assessment and revision of shunt if indicated</td>
</tr>
<tr>
<td>Electrolyte disturbance</td>
<td>Correct if possible and appropriate</td>
</tr>
<tr>
<td>Bowel obstruction</td>
<td>Consider radiotherapy, chemotherapy, octreotide, dexamethasone to reduce tumour oedema, NGT if appropriate</td>
</tr>
<tr>
<td>Uncontrolled pain</td>
<td>Appropriate analgesia via tolerated route</td>
</tr>
<tr>
<td>Uncontrolled cough</td>
<td>Cough suppression (See respiratory section)</td>
</tr>
</tbody>
</table>

Pharmacological Management

**Anti-emetics**

Once an understanding of the cause is known it is possible to target anti-emetics according to their mode of action. It may be necessary to use a number of different anti-emetics from different groups. Many drugs used will overlap in their site of action it is therefore essential to ensure that their use is complimentary. Please see Figure 1 to help decide on the best receptors to target given the most likely cause then use Table 1 to look at which anti-emetics target which receptors.

- Decide on the most likely cause and select an appropriate first line treatment
- Give medication regularly until symptoms are controlled
- Select the best route
  - SC or IV infusion may be needed initially then return to oral route if possible
  - Consider alternative preparations such as melts if available
- Reassess daily and increase the dose as needed until at a maximum
- If no response, reassess the cause
  - If the cause changes then use the most appropriate medication
  - If the cause is the same then consider an alternative anti-emetic. Combinations of anti-emetics may be needed but limit this to the minimum.
- If sedation is also required consider levomepromazine

**Non-Pharmacological Management**

- Reassurance and explanation
- Distraction and relaxation techniques
- Establish the meaning and impact of nausea and vomiting for the child, young person and family and explore fears
- Psychological support – to reduce the distress of anxiety for the child, young person and family.
- Planning and modification of activities of daily living.
- Consider NGT in the context of bowel obstruction but only if tolerable, acceptable and less invasive interventions failed.
Figure 1: Vomiting control pathway and receptors involved

CTZ = Chemotrigger zone
<table>
<thead>
<tr>
<th>Drug</th>
<th>D2 CTZ</th>
<th>5HT2 VC</th>
<th>Ach VC</th>
<th>H1 VC</th>
<th>5HT3 CTZ/ gut</th>
<th>Recommended uses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Haloperidol</td>
<td>+++</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Biochemical disturbance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Anxiolytic benefits</td>
</tr>
<tr>
<td>Metoclopramide</td>
<td>++</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>(+)</td>
<td>Gastric stasis, compressed stomach</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Avoid in complete bowel obstruction</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Can cause extrapyramidal effects</td>
</tr>
<tr>
<td>Cyclizine</td>
<td>-</td>
<td>-</td>
<td>(+)</td>
<td>+++</td>
<td>-</td>
<td>Cerebral irritation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Vertigo</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Obstruction</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Can be added to haloperidol</td>
</tr>
<tr>
<td>Domperidone</td>
<td>+</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Gastric stasis</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Dysmotility</td>
</tr>
<tr>
<td>Hyocine hydrobromide</td>
<td>-</td>
<td>-</td>
<td>+++</td>
<td>-</td>
<td>-</td>
<td>Reduces secretions</td>
</tr>
<tr>
<td>Levomepromazine</td>
<td>+</td>
<td>+++</td>
<td>+</td>
<td>+</td>
<td>-</td>
<td>Covers many receptor groups</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Sedative and anxiolytic</td>
</tr>
<tr>
<td>Ondansetron etc</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>+++</td>
<td>Chemotherapy related N+V</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Adjuvant in renal failure, biochemical disturbance</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>gastric irritation</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Can cause constipation</td>
</tr>
<tr>
<td>Dexamethasone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Cerebral oedema</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Liver metastases</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Bowel obstruction</td>
</tr>
<tr>
<td></td>
<td>Reduces inflammatory response, may have a central effect</td>
<td></td>
<td></td>
<td>Use as a short course to limit side effects</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 1: Common antiemetics and receptors they antagonise
CTZ = chemotriggr zone, VC = vomiting centre, D2 = dopamine receptor, Ach = acetylcholine, H1 = histamine receptor 1
Managing Neurological Symptoms

Quick reference guide

Seizures
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Consider oxygen
4. Consider buccal midazolam for acute seizure management if >5-10 mins
5. Consider non pharmacological measures e.g. positioning
6. Reassess and plan in case of deterioration
7. Consider commencing/optimising regular anticonvulsant treatment
8. Terminal/intractable seizures may require midazolam infusion in consultation with palliative care team

Raised Intracranial Pressure
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate particularly VP shunt blockage
3. Consider dexamethasone
4. Treat pain, nausea and vomiting, agitation and secretions symptomatically
5. Consider non pharmacological measures e.g. positioning
6. Reassess and plan in case of deterioration

Spinal Cord compression
1. Reassure and explain
2. Consider formal investigation with MRI
3. Consider dexamethasone
4. In rare cases consider chemotherapy, radiotherapy or surgery
5. Ensure excellent support with positioning, toileting and pain relief

Muscle spasm
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Give appropriate opiate analgesia and consider benzodiazepines or antispasmodics

Agitation, Delirium and Terminal Restlessness
1. Reassure and explain
2. Actively looking for and treating reversible causes such as pain is essential
3. Consider buccal midazolam in the acute setting followed by infusion if needed

Anxiety and depression
1. Reassure and explain
2. Actively looking for and treating reversible causes such as pain is essential
3. Psychological assessment
4. For anxiety consider buccal midazolam in the acute setting followed by infusion if needed
5. For depression consider antidepressants in consultation with CAMHS/psychology
Neurological Symptoms

Neurological symptoms are frequent in children and young people with terminal central nervous system (CNS) cancers, but can also occur in CNS relapse of solid and haematological malignancies. They can also occur as a result of electrolyte imbalance or metabolic disturbance due to renal or liver failure. They tend to become more common and severe in the last few weeks of life. For dosages of all medications please see APPM Master Formulary\(^4\) or BNFC\(^5\).

Seizures

Seizures are a sudden disruption of the brain's normal electrical activity accompanied by altered consciousness and/or other neurological and behavioural manifestations that may or may not include repetitive muscle jerking called convulsions. Epilepsy is a condition characterized by recurrent seizures and may be present prior to diagnosis or entry into the palliative phase of treatment.

Principles

- The focus of care should be on promoting quality of life and comfort and minimising distressing and painful interventions
- It is important to recognise and treat potentially reversible causes of seizures

Clinical features

Seizures can include generalised tonic-clonic convulsions which can be preceded by non-specific symptoms such as dizziness, visual disturbance or abdominal discomfort known as an aura. They can also be focal in nature and can affect sensory as well as motor pathways. They may be precipitated by intercurrent illness, temperature or metabolic disturbance. They can be particularly distressing for family members and may restrict normal activities.

Diagnosis and assessment

- History and clinical examination
  - Assessment of the impact of seizures on normal activity
  - Features of any seizures
  - Precipitating factors
  - Current medication and previous treatments for acute events
- Investigations
  - CT / MRI if indicated
  - Full blood count if indicated
  - U&E, Calcium, Magnesium, BM if indicated
  - Anticonvulsant drug levels if indicated

Management

Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Potential causes of seizures</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>CNS infection</td>
<td>Consider antibiotics where appropriate</td>
</tr>
<tr>
<td>Electrolyte disturbance</td>
<td>Correct imbalance if indicated</td>
</tr>
<tr>
<td>Hypoglycaemia</td>
<td>Consider Glucogel, glucagon or dextrose IV</td>
</tr>
<tr>
<td>Under treatment of epilepsy</td>
<td>Optimise anticonvulsants to achieve effect</td>
</tr>
<tr>
<td>Raised intracranial pressure</td>
<td>Consider steroids</td>
</tr>
<tr>
<td>Hypoxia</td>
<td>Consider oxygen therapy</td>
</tr>
<tr>
<td>Acidosis</td>
<td>Consider treating metabolic disturbance</td>
</tr>
</tbody>
</table>
Non-Pharmacological Management
- Reassurance and explanation
- Positioning of the child or young person patient in the recovery position
- Consider oxygen
- Not all seizures require medication and may be self-limiting. The majority will resolve within 5-10mins with the supportive measures above. If not consider pharmacological interventions.

Pharmacological Management

**Anticonvulsants**
Benzodiazepines can be effective for acute seizure management.
Drug choice:
- Midazolam buccally
- Diazepam rectally
- Midazolam continuous infusion subcutaneously or intravenously for intractable or terminal seizures, distress and or an inability to tolerate oral preparations. Rapid incrementation can be employed to achieve effect.
- Paraldehyde rectally can be considered if indicated

Review the treatment with benzodiazepines on an ongoing basis and reduce if accumulating and causing respiratory depression.
If the child is having recurrent seizures then consider regular anticonvulsant therapy in consultation with a paediatric neurologist. If they already have a history of epilepsy and are already on anticonvulsants optimise regular treatment.

**Corticosteroids**
May reduce oedema. Indications include raised ICP or spinal cord compression which may be concurrent.
Drug choice:
- Dexamethasone.

Treatment with corticosteroids should be reviewed regularly.
If symptoms have improved, reduce dose gradually to the lowest effective dose.
If no improvement in symptoms, steroid should be stopped or reduced to previous maintenance dose.

♦ **Raised Intracranial pressure**
The presence of raised intracranial pressure (ICP) in children or young people requiring palliative care for cancer is most likely to occur because of disease. Importantly it can also be related to a potentially treatable blocked VP shunt.

**Principles**
- The focus of care should be on promoting quality of life, comfort and minimising distress.
- It is important to assess the likely causes(s) to treat reversible causes.

**Clinical features**
The signs and symptoms of raised ICP vary with age. Classical symptoms include:
- Headache - Classically morning headache present on waking. Headache that wakes patient from sleep is also very suspicious.
- Vomiting
- Visual disturbance
- Change in behaviour or mood
- Fluctuating level of consciousness
- Ataxia or other motor disturbance
- Abnormal pupils (may be noted by relatives)
- Seizures
However as mild or chronically raised ICP may produce subtle signs it is important to have a high index of suspicion and take a thorough history in children at risk.

Severely raised ICP is indicated by the following signs and symptoms
- Cushing’s response (bradycardia and hypertension). This is a pre-terminal sign due to impending herniation of the brainstem.
- Papilloedema (late sign) in the presence of any decrease in conscious level
- Sunsetting – eyes deviated medially and inferiorly

**Diagnosis and assessment**
- History and clinical examination
- Consider treatable causes
- Impact of symptoms on daily life
- Investigations
  - CT / MRI if indicated
  - Depending on clinical context if shunt present consider shunt series/discussion with neurosurgeon
  - FBC if indicated and at risk of low platelets
  - BP if indicated

**Management**
**Treatment for potentially reversible causes:**

<table>
<thead>
<tr>
<th>Potential causes of raised ICP</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intracranial infection</td>
<td>Consider antibiotics where appropriate</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>Consider shunt assessment and revision/tap if present and clinically indicated</td>
</tr>
<tr>
<td>Intracranial haemorrhage</td>
<td>If indicated consider the use of prophylactic platelets if low and/or correction of coagulopathy</td>
</tr>
<tr>
<td>Venous sinus thrombosis</td>
<td>If indicated consider heparin</td>
</tr>
<tr>
<td>Hypertension</td>
<td>Consider antihypertensives if hypertension causing raised ICP</td>
</tr>
<tr>
<td>Prolonged seizure</td>
<td>Treat seizure - consider anticonvulsants as above</td>
</tr>
</tbody>
</table>

**Pharmacological Management**

**Corticosteroids**
May reduce oedema and improve headache, nausea and vomiting and/or neurological signs

**Drug choice:**
- Dexamethasone.

Treatment with corticosteroids should be reviewed regularly.
If symptoms have improved, reduce dose gradually to the lowest effective dose.
If no improvement in symptoms, steroid should be stopped or reduced to previous maintenance dose.

**Analgesia**
This should be implemented if in pain concurrently to other management strategies. Please refer to Pain Pathway.

**Antiemetics**
These should be implemented if nausea and vomiting present concurrently to other management strategies. Please refer to Nausea and Vomiting Pathway.
**Benzodiazepines**
These should be implemented if agitation, distress or seizures present concurrently to other management strategies. Please refer to Seizure and/or Agitation and Terminal Restlessness Pathway.

**Antimuscarinics**
Patients with reduced conscious level secondary to raised ICP or inability to swallow effectively due to concurrent cranial nerve palsies may be unable to clear secretions. Antimuscarinics such as Hyocine hydrobromide should be implemented if this is causing distress to patient or family concurrently to other management strategies.
- Hyoscine hydrobromide patch or continuous SC / IV infusion. Be aware that thick secretions can make expectoration more difficult.

**Non-Pharmacological Management**
- Reassurance and explanation
- Distraction and relaxation
- Positional measures e.g. semi-recumbent
- Suction and postural drainage if appropriate for build up of secretions

♦ **Spinal cord compression**
Spinal cord compression is a palliative emergency where tumour, either directly, by leptomeningeal spread or via metastatic vebral collapse or haematoma, compresses the spinal cord or cauda equina causing pain, paraesthesia and paralysis.

**Principles**
- The focus of care should be on promoting quality of life and comfort and minimising distressing and painful interventions
- It is important to recognise and treat potentially reversible causes of spinal cord compression.

**Clinical features**
Back pain with abnormal bladder or bowel function is common in lower lumbar spinal cord / corda equina compression. Pain with altered upper limb pain, power and sensation should also have the diagnosis considered. Any patient with this combination of symptoms needs consideration of investigation to rule out compression. Sensory abnormalities are less common, but need to be taken seriously when they occur.

**Diagnosis and assessment**
- History and clinical examination
  - Assessment of speed and nature of any pain, altered sensation and altered power
  - Assessment of bladder/bowel function
  - Examination of the bony spine
  - Current medication and general health and disease trajectory
- Investigations
  - MRI if indicated
  - Full blood count & clotting if indicated

**Management**
Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Potential causes of seizures</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>New tumour mass</td>
<td>Chemotherapy, radiotherapy or surgery</td>
</tr>
<tr>
<td>Clotting abnormalities</td>
<td>Correct clotting abnormalities</td>
</tr>
<tr>
<td>Vertebral collapse</td>
<td>Consider vertebroplasty</td>
</tr>
</tbody>
</table>
Non-Pharmacological Management

- Reassurance and explanation
- Positioning of the child or young person with frequent changes of position to relieve pressure areas.
- Assistance with toileting and mobility. Consider urinary catheterisation.
- Depending on the nature of the disease and its trajectory, treatment with palliative radiotherapy, decompressive surgery or palliative chemotherapy may be appropriate. Multi-disciplinary discussion is advised.

Pharmacological Management

Corticosteroids
May reduce oedema. Indications include raised ICP or spinal cord compression which may be concurrent.
Drug choice:
- Dexamethasone.

Treatment with corticosteroids should be reviewed regularly.
If symptoms have improved, reduce dose gradually to the lowest effective dose.
If no improvement in symptoms, steroid should be stopped or reduced to previous maintenance dose.

Chemotherapy
In very specific circumstances, a limited chemotherapy approach may be warranted.

Drug choice:
- Depends upon disease and patient factors. Please discuss with Paediatric Oncology/Haematology Consultant on call urgently.

Analgesia
The use of opiate and anti-neuropathic analgesia is frequently required. Please refer to APPM Master Formulary and YHCYP CN Pain Control Guidelines for Children and Young People Requiring Palliative Care.
Drug choice:
- Morphine is first line for opiate analgesia although ketamine is very useful for neuropathic pain and may be considered in consultation with a palliative care or paediatric pain team consultant.
- For neuropathic pain consider amitryptilline or gabapentin. Amitryptilline may also be useful to help improve mood and to help with difficulty sleeping.

Muscle Spasm
Episodic pain can occur due to muscle spasm.

Principles
- The focus of care should be on promoting quality of life and comfort and minimising distressing and painful interventions
- It is important to recognise and treat potentially reversible causes of muscle spasm

Clinical Features
Skeletal muscle spasm: acute onset of pain as the muscle contracts. A bulging muscle may be seen or felt underneath the skin where the muscle is located. The spasm may resolve spontaneously after a few seconds though it may last many minutes. The patient may feel the need to stretch the muscle involved which may relieve the spasm. Smooth muscle spasm: colicky pain. Exact symptoms depend on organ involved.
Diagnosis and assessment

- History and clinical examination
  - Assessment of the child’s baseline tone
  - Assessment of possible triggers
  - Current medication and relieving factors

- Investigations
  - MRI if indicated
  - Orthotics review

- Assess for potentially reversible causes e.g. constipation, seizures, gastro-oesophageal reflux and discomfort from orthotic supports

Management
Look for triggers and treat the treatable.

Non-Pharmacological Management

- Reassurance and explanation
- Avoidance of triggers if possible
- Positioning of the child or young person and consideration of physiotherapy, stretches and splinting

Pharmacological Management

Benzodiazepines
Diazepam may be useful in the treatment of muscle spasm and also has an anxiolytic effect.

Antispasmodics
Baclofen and dantrolene can be considered but may have detrimental effects including sedation and hypersalivation.

Opiates
Opiate analgesia may be needed. Please refer to the APPM Master formulary and the YHCPCN Pain Control Guidelines for Children and Young People Requiring Palliative Care.

Targeted therapies
Botulinum toxin, intrathecal drug delivery and surgical intervention can be useful in selected cases.

♦ Agitation, Delirium and Terminal restlessness
Agitation, delirium and terminal restlessness are a palliative care emergency and are distressing both for the child or young person and their families.

Principles

- The focus of care should be on promoting quality of life and comfort and minimising distressing and painful interventions
- It is important to recognise and treat potentially reversible causes of agitation, confusion and restlessness

Clinical Features
Impaired conscious level, poor concentration and short term memory, disorientation, hallucinations, paranoid delusions, misinterpretations, incoherent rambling speech, crying and shouting, aggressive behaviour, sweating and restlessness, difficulty sleeping.
Diagnosis and assessment

- History and clinical examination
  - Features and timing of any episodes
  - Precipitating and relieving factors
  - Current medication and previous treatments for acute events
- Investigations
  - CT / MRI head if indicated
  - U&E, Calcium, Magnesium, BM if indicated
  - Oxygen saturations if indicated
  - Basic infection screen if indicated and appropriate e.g. urine dipstick, CXR

- Assess for potentially reversible causes

Management

Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Potential causes of Agitation, delirium and terminal restlessness</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Adequate analgesia</td>
</tr>
<tr>
<td>Medication especially opiates, antimuscarinics, steroids</td>
<td>Consider changing or withdrawing medication thought to be responsible</td>
</tr>
<tr>
<td>Infection</td>
<td>Consider antibiotics where appropriate</td>
</tr>
<tr>
<td>Electrolyte disturbance</td>
<td>Correct imbalance if indicated</td>
</tr>
<tr>
<td>Hypoglycaemia</td>
<td>Consider Glucogel or glucagon</td>
</tr>
<tr>
<td>Raised intracranial pressure</td>
<td>Consider steroids, palliative radiotherapy</td>
</tr>
<tr>
<td>Hypoxia</td>
<td>Consider oxygen therapy</td>
</tr>
<tr>
<td>Acidoasis</td>
<td>Consider treating metabolic disturbance</td>
</tr>
<tr>
<td>Fear, anxiety, bad dreams</td>
<td>Reassurance and consider psychology referral/medication</td>
</tr>
<tr>
<td>Depression</td>
<td>Consider antidepressants and psychiatry referral</td>
</tr>
<tr>
<td>Urinary retention</td>
<td>Consider bethanechol if secondary to opiates or catheterisation</td>
</tr>
<tr>
<td>Constipation</td>
<td>Consider laxatives</td>
</tr>
</tbody>
</table>

Non-Pharmacological Management

- Reassurance and explanation
- Keep calm, avoid confrontation and respond to patient’s comments
- Allay fear and suspicion and reduce misinterpretations by e.g. use of a night light, reassuring presence of a carer, minimise changes to environment, keeping things quiet, explaining procedures in detail and clarifying perceptions

Pharmacological Management

- Buccal midazolam can be used to quickly alleviate distress and can be followed by an IV or SC infusion if required
- If nausea and vomiting is also a problem levomepromazine or haloperidol may be useful

Anxiety and depression

Anxiety and depression are common in patients and families in palliative care situations.

Principles

- The focus of care should be on promoting quality of life and comfort and minimising distressing and painful interventions
- It is important to recognise and treat potentially reversible causes of anxiety and depression
Clinical features
Depression can be difficult to diagnose in the palliative setting as many of the physical manifestations may be present anyway in the dying child. These include depressed mood, diminished pleasure in most activities, weight loss and decreased appetite, not sleeping or hypersomnia, fatigue, feelings of worthlessness, suicidal ideation. Anxiety can manifest in many different forms and may include separation anxiety, procedure related anxiety, fear of abandonment, fear of death, nightmares and agitation.

Diagnosis and assessment
- History and clinical examination
  - Assessment of the child’s mood
  - Assessment of possible triggers
  - Current medication and relieving factors
- Assess for potentially reversible causes e.g. anxiety always related to a particular procedure - can this be stopped? See list of reversible causes in agitation, delirium and terminal restlessness section

Management
Look for triggers and treat the treatable.

Non-Pharmacological Management
- Reassurance and explanation
- Avoidance of triggers if possible
- Keep calm, avoid confrontation and respond to patient’s comments
- Allay fear and suspicion
- Distraction
- Family support and advice
- Referral to psychology for assessment and possible therapy

Pharmacological Management

Anxiety
See section on agitation, delirium and terminal restlessness section above
If longstanding consider SSRI’s in consultation with CAMHS/psychology

Depression
Consider SSRI’s in consultation with CAMHS/psychology
Managing Urinary and Biochemical Symptoms

Quick reference guide

Urinary frequency, urgency, incontinence
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate especially UTI
3. Bladder drill
4. Catheterisation can be considered if sleep disturbance or risk to skin integrity

Urinary hesitancy, retention
1. Reassure and explain
2. Consider the cause and treat the treatable
3. Try running water, passing urine in bath, gentle suprapubic pressure
4. Consider bethanechol if related to opiates
5. Catheterisation can be considered if appropriate

Bladder spasms, dysuria
1. Reassure and explain
2. Consider the cause and treat the treatable
3. Analgesia
4. Consider oxybutynin

Biochemical disturbance
1. Routine blood tests should not be performed
2. Only do tests if having symptoms and will help guide treatment
3. Treatment should be adjusted according to symptoms not blood tests
Urinary and biochemical symptoms

Urinary symptoms can occur in paediatric oncology patients due to the effect of their disease and treatment. They can also occur due to medications being used to control other symptoms. Routine blood tests should not be performed in palliative care patients but may be helpful to determine the cause of symptoms and treat them. The guiding principal should always be control of symptoms not normalisation of blood tests. For dosages of all medications please see APPM Master Formulary\(^4\) or BNFC\(^5\).

◊ Urinary symptoms

These can occur individually and in combination. There is often a reversible cause which may have exacerbated a longstanding irreversible cause of the symptom and this should be investigated and treated appropriately.

Principles

- The focus of care should be on promoting quality of life and comfort and minimising distressing and painful interventions
- It is important to recognise and treat potentially reversible causes of urinary symptoms

Clinical features

Urinary symptoms include:

- Frequency: The passage of urine 7 or more times during the day or more than twice at night
- Urgency: A strong and sudden desire to void urine
- Urge incontinence: Involuntary loss of urine associated with a strong and sudden desire to void urine
- Stress incontinence: Involuntary loss of urine associated with laughing, coughing, lifting, sneezing
- Dysuria: Pain on or after passing urine
- Bladder spasms: Suprapubic colicky pain often associated with passing urine
- Hesitancy: Delay between attempting and achieving micturition
- Retention: Inability to void urine

Diagnosis and assessment

- History and clinical examination
  - Assessment of the impact of symptom on normal activity
  - Precipitating factors
  - Current medication and previous treatments for acute events

- Investigations
  - Urine dipstick for MC and S and glucose
  - Biochemistry if appropriate

- Assess for potentially reversible causes of symptom
# Management

Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Urinary symptom</th>
<th>Potential causes</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency/urgency/incontinence</td>
<td>UTI</td>
<td>Consider antibiotics where appropriate</td>
</tr>
<tr>
<td></td>
<td>IDDM</td>
<td>Control of blood sugar if appropriate</td>
</tr>
<tr>
<td></td>
<td>DI</td>
<td>DDAVP if appropriate</td>
</tr>
<tr>
<td></td>
<td>Diuretics</td>
<td>Stop/reduce drug</td>
</tr>
<tr>
<td></td>
<td>Hypercalcaemia/uraemia</td>
<td>Treat hypercalcaemia/uraemia if appropriate</td>
</tr>
<tr>
<td>Dysuria</td>
<td>UTI</td>
<td>Consider antibiotics if appropriate</td>
</tr>
<tr>
<td>Bladder spasms</td>
<td>UTI</td>
<td>Consider antibiotics if appropriate</td>
</tr>
<tr>
<td>Hesitancy/retention</td>
<td>Opiates</td>
<td>Switch opiate, bethanechol, catheter if appropriate</td>
</tr>
<tr>
<td></td>
<td>Constipation</td>
<td>Laxatives</td>
</tr>
<tr>
<td></td>
<td>Antimuscarinics</td>
<td>Discontinue drug if possible</td>
</tr>
<tr>
<td></td>
<td>Spinal cord compression</td>
<td>See spinal cord compression guideline</td>
</tr>
<tr>
<td></td>
<td>Clots</td>
<td>See bleeding guideline</td>
</tr>
<tr>
<td></td>
<td>Tumour blocking part of renal tract</td>
<td>Steroids, radiotherapy, palliative chemotherapy, catheter if appropriate</td>
</tr>
</tbody>
</table>

### Non-Pharmacological Management
- Reassurance and explanation
- Good hygiene and skin care
- Fluids as appropriate, cranberry juice
- Bladder drill - regular voiding
- Running water, passing urine in bath
- Hot water bottle
- Catheterisation if appropriate for hesitancy, retention, frequency not due to infection

### Pharmacological Management
- Analgesia - opiates. Consider NSAIDs and/or buscopan.
- Appropriate antibiotics for infection
- Urgency - oxybutynin
- Hesitancy/retention due to opiates - bethanechol
- Bladder spasms - oxybutynin and other antimuscarinics

### Biochemical disturbances
Routine blood tests cause distress to patients and should not be performed. If symptoms of a particular biochemical disturbance manifest, biochemical tests could be undertaken if appropriate to guide treatment. Treatment should be guided by symptoms and tolerance of medications NOT blood test results.

### Principles
- The focus of care should be on promoting quality of life, comfort and minimising distress.
- It is important to assess the likely causes(s) to treat reversible causes.
- The aim should be relief of symptoms not perfect biochemistry

### Clinical features
- Hypercalcaemia: Thirst, nausea and vomiting, constipation, polyuria, lethargy, depression
- Uraemia: itching, gout
- Hyponatraemia, hypocalcaemia, hypoglycaemia should be considered if seizures occur as supplementation may help reduce/prevent further seizures
Diagnosis and assessment

- History and clinical examination
- Consider treatable causes
- Impact of symptoms on daily life
- Tolerability of any medications to treat

- Investigations
  - Urine electrolytes, dipstick
  - Electrolyte tests if appropriate

Management

Treatment for potentially reversible causes:
Check medications such as diuretics
Check for DI, IDDM and treat if appropriate

Pharmacological Management

If symptomatic of an electrolyte deficiency e.g. seizures and affecting quality of life and patient can tolerate a supplement this could be considered.

**Hypercalcaemia:**
Adequate fluids and/or bisphosphonates can be considered to relieve symptoms.
Treat pain with analgesia, nausea and vomiting with antiemetics

**Uraemia:**
Analgesia and consider allopurinol for gout
See skin guideline for management of pruritis

**Analgesia**
This should be implemented if in pain concurrently to other management strategies. Please refer to Pain Pathway.

**Antiemetics**
These should be implemented if nausea and vomiting present concurrently to other management strategies. Please refer to Nausea and Vomiting Pathway.

Non-Pharmacological Management

- Reassurance and explanation
Managing Skin Symptoms

Quick reference guide

Lymphoedema
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Consider non pharmacological measures
4. Reassess and plan in case of deterioration

Pruritus
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Consider non pharmacological measures
4. Consider pharmacological interventions depending on cause of itch

Sweating
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Consider non pharmacological measures
4. Consider pharmacological interventions depending on cause of sweating

Fungating Tumours
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Treatment depends on nature of wound
Introduction
The management of skin problems in children and young people with progressive malignant disease can be challenging. Children with a terminal illness are prone to skin breakdown and have poor healing abilities. Good nursing care is needed to predict and prevent problems, which once established may be difficult to treat.

♦ Lymphoedema
Lymphoedema is chronic swelling, generally of the extremities, resulting from a failure of the lymphatic system to drain fluid from the interstitial spaces. Although rare in children and young people it can occur secondary to the underlying cancer or previous cancer treatment (radiotherapy, surgery). It is usually a progressive condition that can be very debilitating.

Principles
In advanced cancer it is generally not possible to reduce the size of a lymphoedematous limb.

- The focus of care should be on promoting quality of life and comfort and minimising distressing and painful interventions
- Emphasis should be placed on preventing deterioration and relieving discomfort.
- Try to prevent complications
- Preparation and advice to the child and family on how to manage the condition should be given

Clinical features
Oedema, tightness of the skin and heaviness
Chronic inflammation
Skin changes - dry skin, thickened tissues, infection, erythema, blistering and or weeping skin
Temperature
Pitting of the skin in the early stages
Pain or achiness
Impaired function or mobility

Diagnosis and assessment
- History and clinical examination
  - Site / sites of lymphoedema
  - Assessment of the impact of lymphoedema on normal activity
  - Situations that make it worse
  - What helps
  - Drug history
- Investigations
  - Swabs for microbiology if indicated
- Assess for any potentially reversible causes of lymphoedema

Management
The focus of care is on trying to reduce the potential for deterioration, promote comfort and to maximise mobility

- Treat reversible causes if identified and possible
- Ensure the family are fully informed of care and management requirements

Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Potential causes of lymphoedema</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Retroperitoneal or pelvic tumour</td>
<td>Consider radiotherapy or steroids</td>
</tr>
</tbody>
</table>
Pharmacological Management

- Consider the use of analgesics to relieve discomfort.
- Consider the need for antibiotics to manage any acute inflammatory episodes.
- Consider the use of NSAIDs in acute inflammatory episodes to relieve discomfort and swelling.
- Consider prophylactic antibiotics following an acute inflammatory episode.

Non-Pharmacological Management

- Skin care
  - Wash and moisturise daily with aqueous cream.
  - Dry the skin well following bathing.
  - Avoid trauma - protect hands when carrying out tasks, avoid being bare foot.
  - Treat any cuts or grazes with prompt washing and the application of antiseptics.
  - Daily skin checks for acute inflammation.
  - Avoid sun exposure.
  - Avoid injection, venepuncture and blood pressure measurement in affected limb.

- Massage
  - Consider referral to lymphoedema nurse specialist.

- Compression / support
  - Use of compression garments.
  - Application of tubigrip or light support bandages with padding.

- Exercise
  - Encourage gentle active exercise and mobility.
  - Physiotherapy assessment, support and advice.
  - Support the affected limb when at rest.

- Psychological support to reduce the distress of anxiety for the child, young person and family.
- Planning and modification of activities of daily living.

Pruritus (itch)

Pruritus is a symptom of skin disease and also occurs in some systemic diseases, notably cholestasis, chronic renal failure (uraemia) and malignant disease. It is described as an "unpleasant sensation that provokes the desire to scratch". Whilst a rare symptom in children and young people with cancer it is seen in those progressive Hodgkin’s disease, liver and renal malignancies.

Principles:

- It is likely that the underlying cause of pruritus cannot be rectified.
  - The focus of care should be on comfort and minimising distress and pain for child and family.
  - Preparation and advice to the child and family on the possibility of itch and its management.
  - It is important to assess the likely causes(s) and if possible to treat reversible causes.

Clinical Features:

The cause of pruritus is complex and not fully understood, but it is known that both central and peripheral mechanisms are involved.

Uncontrollable itch
Sleep disturbance secondary to itch
Diagnosis and assessment
- History and clinical examination
  - Time of day that itch occurs
  - Site / sites of itch
  - Assessment of the impact of itch on normal activity
  - Sleep disturbance
  - Situations that make it worse
  - What helps
  - Drug history

- Investigations
  - Liver function tests / urea and electrolytes

  - Assess for any potentially reversible causes of itch

Management
The focus of care is on trying to reduce the potential for deterioration, promote comfort and to maximise mobility

- Treat reversible causes if identified and possible
- Ensure the family are fully informed of care and management requirements

Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Potential causes of Pruritus</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication</td>
<td>Discontinue any non-essential medication and any likely to be causing itch e.g. aspirin; erythromycin; opiates</td>
</tr>
<tr>
<td>Infection</td>
<td>Treat with appropriate antibiotics</td>
</tr>
<tr>
<td>Consider non cancer causes of itch</td>
<td>Iron deficiency - supplement iron</td>
</tr>
<tr>
<td></td>
<td>Skin rash / insect bite - consider aqueous cream, antihistamine cream</td>
</tr>
<tr>
<td></td>
<td>Thyrotoxicosis</td>
</tr>
</tbody>
</table>

Pharmacological Management
- Hodgkin’s disease / Lymphoma
  - 1st line consider steroids
  - 2nd line substitute steroids with cimetidine
  - 3rd line substitute cimetidine with mirtazapine

- Cholestasis
  - 1st line consider naltrexone
  - 2nd line substitute naltrexone with rifampicin
  - 3rd line substitute rifampicin with cholestyramine

- Paraneoplastic itch
  - 1st line consider paroxetine
  - 2nd line substitute paroxetine with mirtazapine
  - 3rd line combine paroxetine and mirtazapine
  - 4th line substitute paroxetine and mirtazapine with thalidomide

- Opiate induced
  - 1st line consider switching to an alternative opiate
  - 2nd line consider ondansetron
  - 3rd line substitute ondansetron with paroxetine
  - 4th line substitute paroxetine with anti-histamines

- Consider sedatives
- Consider night sedation
Non-Pharmacological Management

- Radiotherapy intervention
  - Consider in the presence of Hodgkin’s disease / lymphoma
- Surgical intervention
  - Consider stenting of common bile duct if indicated
- Skin care
  - Discontinue the use of soap for washing
  - Wash with emulsifying ointment or aqueous cream as a soap substitute
  - Add Oilatum to bath water
  - Dry the skin gently but well following bathing
  - Moisturise daily with emollient following bathing
  - Consider TENS machine
- Lifestyle
  - Avoid spicy food
  - Avoid alcohol
- Complimentary therapies
  - Consider acupuncture
  - Consider aromatherapy
- Psychological support – to reduce the distress of anxiety for the child, young person and family.
- Planning and modification of activities of daily living

♦ Sweating

Sweating is a normal part of the temperature control of the body. Profuse sweating (hyperhidrosis) occurs in approximately 16% of patients with advanced cancer and is often worse at night (nocturnal diaphoresis). Fluid loss may be significant. Sweating can be viewed as severe when a patient needs to change clothing and / or bed linen on a regular basis.

Principles:
- The focus of care should be on comfort and minimising distress and pain for child and family
- Preparation and advice to the child and family on the possibility of sweating and it’s management
- It is important to assess the likely causes(s) and if possible to treat reversible causes.

Clinical Features:
Pyrexia
Uncontrolled sweating
The need to frequently change clothing and or bedding

Diagnosis and assessment

- History and clinical examination
  - Time of day that sweating occurs
  - Site / sites of sweating
  - Assessment of the impact of sweating on normal activity
  - Sleep disturbance
  - Situations that make it worse
  - What helps
  - Drug history
- Investigations
  - Infection screen if indicated
- Assess for any potentially reversible causes of sweating
Management
The focus of care is on trying to reduce the potential for deterioration, promote comfort and to maximise mobility

- Treat reversible causes if identified and possible
- Ensure the family are fully informed of care and management requirements

Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Potential causes of sweating</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medication</td>
<td>Discontinue any non-essential medication and any likely to be causing sweating e.g. hormone mediation, SSRI antidepressants</td>
</tr>
<tr>
<td>Infection</td>
<td>Treat with appropriate antibiotics</td>
</tr>
<tr>
<td>Cardiac failure</td>
<td>Consider diuretics</td>
</tr>
</tbody>
</table>

Pharmacological Management
- Sweating with pyrexia
  - Consider paracetamol
- Sweating – associated with tumour – apyrexial
  - Consider non-steroidal anti-inflammatory or dexamethasone
  - Consider cimetidine
  - Consider venlafaxine for hormone related sweats

Non-Pharmacological Management
- Skin cooling using fans
- Opening windows
- Using cotton bed linen
- Loose cotton clothing
- Oral fluids
- Tepid Sponging
- Reassurance

♦ Fungating Tumours
A fungating tumour is a primary or secondary cancer that has ulcerated the skin. Typically these tumours can be disfiguring and frightening to the child and family. It is not unusual for fungating tumours to become infected and or bleed.

The consequences of having a fungating tumour secondary to cancer can be far reaching for the child and family and encompass physical, psychological, social, sexual and spiritual dimensions.

Principles:
The management of fungating tumours focuses on alleviating the distressing symptoms associated with the wound and providing emotional support to the child, young person and family. Treatment is directed towards, control of bleeding, odour restriction, absorption of exudates, control of pain associated with the lesion and comfort / cosmetic appearance

- The focus of care should be on comfort and minimising distress and pain for child and family
- Preparation and advice to the child and family on the possibility of itch and it’s management
- It is important to assess the likely causes(s) and if possible to treat reversible causes.

Clinical Features:
Skin changes above site of known tumour
Odour or skin weeping
Pain
Diagnosis and assessment

- History and clinical examination
  - Site / sites of the wound / wounds
  - Assessment of the impact on normal activity
  - Situations that make it worse
  - What helps
  - Drug history
- Investigations
  - Liver function tests / urea and electrolytes
  - Swabs for microbiology
  - Clotting screen
- Assess for any potentially reversible causes ie infection, abnormal clotting

Management

The focus of care is on trying to reduce the potential for deterioration, promote comfort and to maximise mobility

- Treat reversible causes if identified and possible
- Ensure the family are fully informed of care and management requirements
- Provide the child and family with emotional and psychological support

Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Potential reversible causes</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease progression</td>
<td>Consider local palliative radiotherapy</td>
</tr>
<tr>
<td>Deranged clotting</td>
<td>Correct clotting factors</td>
</tr>
<tr>
<td>Infection</td>
<td>Treat with appropriate antibiotics</td>
</tr>
<tr>
<td>Poor nutrition</td>
<td>Consider interventions to improve nutritional status if indicated</td>
</tr>
</tbody>
</table>

Pharmacological Management

- Palliative chemotherapy
  - Consider in an attempt to halt or reduce tumour progression if indicated
- Pain relief
  - Ensure adequate analgesia is prescribed with breakthrough prescribed to cover dressing changes - buccal diamorphine; topical lignocaine; entonox
  - Consider the use of topical diamorphine in the dressing
- Infection and or malodour
  - Consider systemic or topical metronidazole - irrigate wound with IV metronidazole solution
- Bleeding
  - Consider the use of topical adrenalin, tranexamic acid and correcting low platelets/deranged clotting
  - Form a management plan if catastrophic bleeding a possibility (see guideline)

Non-Pharmacological Management

- Radiotherapy intervention
  - Consider if the tumour is disfiguring or in the presence of difficult symptoms - bleeding, malodour
- Surgical intervention
  - Consider debulking or excision if indicated
- Psychological support – to reduce the distress of anxiety for the child, young person and family.
- Planning and modification of activities of daily living

Wound management

- Light exudate - consider the following
  1. Semi-permeable film dressing
  2. Hydrocolloid interactive dressing
  3. Low adherent dressing
  4. Alginate dressing
  5. Hydrophilic foam dressing
• Heavy exudate - consider the following
  1. Hydrocolloid interactive dressing
  2. Hydrogel with secondary dressing
  3. Alginate dressing
  4. Hydrophilic foam dressing
  5. Use of paediatric stoma bags

• For malodour consider the following
  1. A counter odour e.g. household air freshener, ostomy agents, aromatherapy oils
  2. A deodorant or electric deodoriser
  3. Metronidazole either topically or systemically
  4. Live yoghurt applied to the wound
  5. Charcoal impregnated alginate or foam dressings
  6. Totally occlusive dressing e.g. opsite / granuflex

• If a cavity is present consider the following
  1. Cavity dressing eg alginate
  2. Silastic foam if the wound is clean
  3. Foam dressing

• If debridement is needed consider the following
  1. Surgery
  2. Enzymes eg varidase
  3. Hydrocolloid paste with dressing
  4. Hydrogel

• If the wound is infected consider the following
  1. Topical metronidazole
  2. Irrigation with IV metronidazole solution
  3. Systemic antibiotics
  4. Honey and icing sugar dressing

• If the wound is bleeding consider the following
  1. Calcium alginate dressing
  2. Topical adrenaline
  3. Radiotherapy
  4. Use of non-adherent dressing and soak dressing with normal saline

• If the surrounding skin is at risk consider the following
  1. Protect the surrounding skin with barrier ointment
Managing Haematological Symptoms

Quick reference guide

Bleeding
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Consider non pharmacological measures e.g. positioning, psychological support, pressure
4. Treat any abnormalities of coagulation and/or FBC if appropriate
5. Consider antifibrinolytics
6. Reassess and plan in case of deterioration

Catastrophic haemorrhage
1. Remain calm
2. Reassure and explain
3. Ensure patient and family are not left alone
4. Manage as per plan with early use of sedation and analgesia as appropriate
5. If at home and no doctor or nurse available, family can be instructed to give sublingual sedation.
6. Keep patient warm
7. Use dark towels to absorb haemorrhage
8. If haemorrhage affecting airway use positional measures and suction if available

Anaemia
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Transfusion can be considered if felt appropriate and will improve quality of life

Thrombocytopenia
1. Reassure and explain
2. Consider the cause and treat the treatable if appropriate
3. Transfusion can be considered if felt appropriate and will improve quality of life
Bleeding

Haemorrhage occurs in approximately 6%–10% of patients with advanced cancer. When visible it can be a distressing symptom for both children and their parents.

Principles

- The focus of care should be on promoting quality of life and comfort and minimising distressing and painful interventions
- It is important to recognise and treat potentially reversible causes of bleeding.
- Preparation and advice to the child and family on how to recognise and manage bleeding.

Clinical features

Bleeding may result from local vessel damage and invasion by tumour or from systemic processes such as disseminated intravascular coagulopathy (DIC) or abnormalities in platelet functioning and number. The underlying causes of these abnormalities are varied and include liver or renal failure, medications such as anticoagulants, chemotherapy, radiotherapy, surgery, and the cancer itself. Occasionally, concurrent diseases, such as idiopathic thrombocytopenia, may be responsible. Haemorrhaging can manifest in a number of ways, including haematemesis, passage of fresh blood in stools, melaena, haemoptysis, haematuria, epistaxis, vaginal bleeding, or from ulcerated skin lesions. It may also present as petechiae, or bruising. Haemorrhage may occur as an acute catastrophic event, episodic major bleeds, or on-going low-volume oozing. These characteristics can provide clues as to the underlying cause and guide management.

Diagnosis and assessment

- History and clinical examination
  - Site / sites of bleeding
  - Assessment of the impact of bleeding on normal activity
  - If haemoptysis, features of any expectorant
  - Situations that make it worse
  - What helps
  - Drug history

- Assess for potentially reversible causes of bleeding

Investigations

- Full blood count
- Clotting screen (may be insensitive to some causes of acquired haemostatic dysfunction)
- Swabs for microbiology if indicated
- Imaging/endoscopy depending on site of bleeding and appropriateness of investigation

Management

It is important to understand the cause of bleeding to determine the appropriate therapeutic interventions. It is possible that there may be more than one cause for bleeding.

- Consider application of pressure depending on site
- Treat reversible causes if identified and possible
- Treat according to the likely pathophysiological mechanism
- Correct any abnormalities of clotting or FBC if appropriate
- Consider antifibrinolytics (unless macroscopic or heavy microscopic haematuria present)
- If bleeding precludes the use of the oral route, consider alternate routes of drug administration until symptoms are controlled e.g. topical
## Treatment for potentially reversible causes:

<table>
<thead>
<tr>
<th>Potential causes of bleeding</th>
<th>Possible interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drug therapy e.g. anticoagulants, steroids</td>
<td>Check drug levels and treat if abnormal. Stop or find alternatives unless essential</td>
</tr>
<tr>
<td>Thrombocytopenia</td>
<td>Consider platelet support and or anti-fibrinolytic agents</td>
</tr>
<tr>
<td>Epistaxis</td>
<td>Consider ENT assessment re cautery/packing and or anti-fibrinolytic agents or naseptin applied to nostrils</td>
</tr>
<tr>
<td>Malignant wounds</td>
<td>Refer to skin management guidelines</td>
</tr>
<tr>
<td>Tumour erosion</td>
<td>Consider palliative radiotherapy and or surgery if appropriate. See section on catastrophic haemorrhage.</td>
</tr>
<tr>
<td>Infection (UTI, URTI, oral candidiasis)</td>
<td>Consider antibiotics or antifungals</td>
</tr>
<tr>
<td>Gastritis/ulcers</td>
<td>Stop irritant drugs unless essential; consider PPI</td>
</tr>
<tr>
<td>Oesophageal varices</td>
<td>Consider gastroenterology review and banding/injection if appropriate or drug therapy e.g. octreotide /vasopressin</td>
</tr>
<tr>
<td>Abnormal clotting factors</td>
<td>Consider correction if appropriate.</td>
</tr>
<tr>
<td>Mucositis</td>
<td>Anti-fibrinolytic agents and analgesia</td>
</tr>
<tr>
<td>Intracranial haemorrhage</td>
<td>Consider neurosurgical opinion if appropriate. If surgery not appropriate consider treatment of symptoms according to raised ICP pathway</td>
</tr>
<tr>
<td>Bleeding from renal tract/bladder</td>
<td>If haematuria do not give tranexamic acid</td>
</tr>
<tr>
<td>Bleeding from vagina</td>
<td>Oral progestogens or tranexamic acid can be considered</td>
</tr>
</tbody>
</table>

### Pharmacological Management
- Anti-fibrinolytic agents e.g. tranexamic acid either as tablets, solution or injection which can be used topically (unless macroscopic or heavy microscopic haematuria present)
- Consider the use of topical haemostatic agents, astringents and or vasoconstrictors to manage bleeding malignant wounds (see skin guidelines)

### Non-Pharmacological Management
- Reassurance and explanation
- Distraction and relaxation techniques
- Establish the meaning and impact of any bleeding for the child, young person and family and explore fears
- Psychological support – to reduce the distress of anxiety for the child, young person and family.
- Planning and modification of activities of daily living
- Compression dressings if appropriate
- Ice, cautery and/or nasal packing if epistaxis and appropriate
- Dark towels to absorb bleeding
- Positional measure and suction if appropriate

### Catastrophic Haemorrhage
This is a frightening experience for both patients and carers. It may be a terminal event in both advanced cancer and non-malignant disease.

### Principles:
- The focus of care should be on comfort and minimising distress and pain for child and family
- Preparation and advice to the child and family on the possibility of catastrophic bleeding and its management
Clinical Features:
Significant bleeding may occur from:
- Tumour invasion of blood vessels
- Bleeding of oesophageal varices
- Stomach: may be associated with use of non-steroidal drugs, especially if steroids are used concomitantly
- Lower GI tract
- Haemoptysis (see respiratory guideline)
- Epistaxis

Pre-emptive Management:
- To plan ahead where possible
- If there are warning signs or high anticipated risk of bleeding have a management plan in place ideally which has been discussed with family and staff and if appropriate the patient
- Record management plan in case notes and communicate this to all team members
- Pre-prescribe sedation and analgesia in case needed urgently (Both buccal and intravenous) which can be repeated as required
- Recommend use of dark bedding
- Provide dark coloured towel to disguise blood loss.

In the event of catastrophic bleed:
- Remain calm
- Give explanation and reassurance to child and family throughout
- Ensure patient and family are not left alone
- Manage as per plan with early use of sedation and analgesia as appropriate
- If at home and no doctor or nurse available, family can be instructed to give sublingual sedation
- Keep patient warm
- Use dark towels to absorb haemorrhage
- If haemorrhage affecting airway use positional measures and suction if available

Pharmacological management for distress, agitation and/or pain:
- Midazolam either buccal, subcutaneous or IV loading dose as per advanced care plan/APPM formulary. Can be repeated after 10mins and decide if infusion necessary
- Diamorphine either subcutaneous, IV or buccal. Doses as per plan/APPM formulary. Follow with infusion if necessary

Further care:
If bleeding temporarily stops further management will depend on overall clinical status and discussion with family and consultant on call re appropriateness of any other interventions

♦ Anaemia
Symptoms of anaemia are common in advanced cancer and haematological malignancies. Treatment of anaemia in palliative care should be undertaken based on symptoms and quality of life not blood results.

Principles:
- The focus of care should be on comfort and minimising distress and pain for child and family
- Regular transfusion to improve quality of life is sometimes appropriate however, continual assessment needs to be made and there may come a point where transfusion is no longer appropriate
Clinical Features:
- Tiredness
- Pallor
- Dizziness
- Headache
- Shortness of breath

Management
Treat reversible causes such as bleeding, vitamin, and mineral deficiencies if possible and appropriate. The need to transfuse should be based on symptoms rather than blood values and regular monitoring is not usually appropriate. Transfusions if appropriate should be undertaken according to the Yorkshire blood and bone marrow transplant programme clinical policy “Guideline for blood component support in paediatric and adolescent oncology and haematology”. Transfusions can sometimes be undertaken at home or in the local hospice.

Thrombocytopenia
Symptoms of thrombocytopenia are common in advanced cancer and haematological malignancies. Treatment of thrombocytopenia in palliative care should be undertaken based on symptoms and quality of life not blood results.

Principles:
- The focus of care should be on comfort and minimising distress and pain for child and family
- Preparation and advice to the child and family on the impact of thrombocytopenia and its management. This should include advice on the avoidance of activities likely to increase the risk of bleeding.
- Regular transfusion to improve quality of life and prevent bleeding is often appropriate however, continual assessment needs to be made and there may come a point where transfusion is no longer appropriate

Clinical Features:
- Bleeding
- Petechiae
- Easy bruising

Management
Treat reversible causes such as medications which may be contributing. Consider alternative ways of controlling bleeding as above. The need to transfuse should be based on symptoms rather than blood values and regular monitoring is not usually appropriate. Transfusions if appropriate should be undertaken according to the Yorkshire blood and bone marrow transplant programme clinical policy “Guideline for blood component support in paediatric and adolescent oncology and haematology”. Transfusions can sometimes be undertaken at home or in the local hospice.
Further Advice

Children, young people and their families under the care of the Principal Treatment Centre (PTC) in Leeds will have a nurse specialist key worker who will be responsible for their palliative care and symptom management. With the child, young person and their family they will devise an individualised symptom management plan to help anticipate symptoms and the likely interventions required to address symptoms as they arise and develop.

The nurse specialist is available to support and facilitate clinical assessment and decision making. Outside of normal working hours a 24 hour on call service is provided to support this and is for children, young people and their families and those professionals in primary / secondary care and children’ s hospices. Outside of normal working hours the Nurse Specialist on call can be contacted as detailed on the Paediatric Oncology and Haematology Palliative Care On Call Rota or by contacting Ward L31 at Leeds Children’s Hospital.

Each child or young person will remain under the care of a consultant paediatric oncologist / haematologist who is also available for advice and support to address patients’ symptom management needs.

Additional advice can also be sought from Martin House Children’s Hospice and Forget Me Not Children’s Hospice.

Useful Telephone Numbers

<table>
<thead>
<tr>
<th>Service</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children’s Haematology and Oncology Outreach Team</td>
<td>0113 3922323</td>
</tr>
<tr>
<td>Ward L31</td>
<td>0113 3927431</td>
</tr>
<tr>
<td>Ward L33</td>
<td>0113 3927433</td>
</tr>
<tr>
<td>Children’s Haematology and Oncology Day Care Unit</td>
<td>0113 3927179</td>
</tr>
<tr>
<td>Martin House Children’s Hospice</td>
<td>01937 845045</td>
</tr>
<tr>
<td>Forget Me Not Children’s Hospice</td>
<td>01484 411040</td>
</tr>
</tbody>
</table>
References / Evidence base


(6) Constipation in children and young people, NICE Clinical Guideline (May 2010); Diagnosis and management of idiopathic childhood constipation in primary and secondary care


(9) Malignant bowel obstruction: Individualized treatment near the end of life, Soriano and Mellar, Cleveland Clinic Journal of Medicine March 2011 vol. 78 3 197-206


Yorkshire Cancer Network and North East Yorkshire and Humber Clinical Alliance, A Guide to Symptom Management in Palliative Care, 2012 (Version 5.1)
Appendix 1 - Advance Care and Symptom Management Plan Template

This care plan has been developed to guide treatment provided to xxxx. It aims to ensure that any treatment given is in their best interest, keeps them comfortable, and free of distress. It may need to be changed according to the exact circumstances, and xxxx and his Parents have the right to change their minds about any aspect of this care plan at any time. This document is also tool for discussing and communicating the wishes of a child / parent(s) or young person.

### Dedicated Care Plan for

<table>
<thead>
<tr>
<th>Name</th>
<th>Likes to be called</th>
<th>NHS</th>
</tr>
</thead>
<tbody>
<tr>
<td>D.O.B</td>
<td>Allergies</td>
<td>No</td>
</tr>
<tr>
<td>Address</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight KG</td>
<td>Requires 2 weekly Medical review</td>
<td></td>
</tr>
</tbody>
</table>

### This care plan covers:

1. Contact list
2. Diagnosis and management to date
3. Present condition
4. Current medications
5. Child/young person and Family Wishes
6. Management of symptoms
7. Anticipatory medication provided if needed
8. Decision Making
9. Consideration of limitations of treatment

### Contact

<table>
<thead>
<tr>
<th>Family</th>
<th>Telephone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
<td>Home</td>
</tr>
<tr>
<td>Relation</td>
<td>Mobile</td>
</tr>
<tr>
<td>Name</td>
<td>Home</td>
</tr>
<tr>
<td>Relation</td>
<td>Mobile</td>
</tr>
</tbody>
</table>

### Health Care Professionals

<table>
<thead>
<tr>
<th>Health Care Professionals</th>
<th>Mobile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key Worker</td>
<td></td>
</tr>
<tr>
<td>Macmillan/Liaison Nurse</td>
<td></td>
</tr>
<tr>
<td>General Practitioner</td>
<td></td>
</tr>
<tr>
<td>Inpatients</td>
<td>Ward 33 LGI</td>
</tr>
<tr>
<td>Outpatients and Day Care</td>
<td>Ward 79 LGI</td>
</tr>
<tr>
<td>Paediatric Oncology Consultant:</td>
<td>Dr</td>
</tr>
<tr>
<td>Palliative Care Consultant</td>
<td></td>
</tr>
<tr>
<td>Community Nursing Team</td>
<td></td>
</tr>
<tr>
<td>Hospice</td>
<td></td>
</tr>
</tbody>
</table>
### Diagnosis and management to date

### Present condition

<table>
<thead>
<tr>
<th>Current Medications</th>
<th>Indication</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Wishes during life</strong></td>
<td></td>
</tr>
<tr>
<td>-----------------------</td>
<td></td>
</tr>
<tr>
<td><strong>Child’s / Young Person’s wishes</strong></td>
<td></td>
</tr>
<tr>
<td>Preferred place of care</td>
<td></td>
</tr>
<tr>
<td>People to be involved</td>
<td></td>
</tr>
<tr>
<td>Activities to be continued</td>
<td></td>
</tr>
<tr>
<td><strong>Family Wishes</strong></td>
<td></td>
</tr>
<tr>
<td>Where you want to be as a family</td>
<td></td>
</tr>
<tr>
<td>Who you would like to be involved</td>
<td></td>
</tr>
<tr>
<td><strong>Other wishes</strong></td>
<td></td>
</tr>
<tr>
<td>School friends, siblings etc</td>
<td></td>
</tr>
<tr>
<td>Discussed with</td>
<td></td>
</tr>
<tr>
<td>Discussed by</td>
<td></td>
</tr>
<tr>
<td>Wishes Around End of Life</td>
<td></td>
</tr>
<tr>
<td>----------------------------------</td>
<td></td>
</tr>
<tr>
<td>Preferred place of death</td>
<td></td>
</tr>
<tr>
<td>Funeral preferences</td>
<td></td>
</tr>
<tr>
<td>Spiritual and cultural wishes</td>
<td></td>
</tr>
<tr>
<td>Other wishes</td>
<td></td>
</tr>
<tr>
<td>Organ and tissue donation</td>
<td></td>
</tr>
<tr>
<td>Discussed with</td>
<td></td>
</tr>
<tr>
<td>Discussed by</td>
<td></td>
</tr>
</tbody>
</table>
Symptom Management

Pain.

Current Symptoms and management

Non Pharmacological management:

<table>
<thead>
<tr>
<th>Medicine Management (Drug name, Dose and Route and Frequency)</th>
<th>Date commenced</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st line Drug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2nd line Drug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3rd line Drug</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If xxxx is receiving prolonged release analgesia, breakthrough doses should be calculated at 1/6 of the morphine equivalent.

If xxxx is requiring regular breakthrough opiates, his/her previous daily requirements should be used to titrate his / her prolonged release analgesia.

If xxxx is unable to tolerate pain relief orally, then an IV or SC continuous infusion should be considered. Dosage and conversion advice can be obtained from the on call Macmillan Nurse. Breakthrough doses of analgesia should also be prescribed. Escalating pain and or the need for breakthrough analgesia is an indication to review parenteral analgesia dose.

Further doses of either oral or IV opiates will be determined by response and in consultation with xxxx xxxx / or the on call Macmillan Nurse

Evaluation
**Constipation**

If xxxx has commenced on opiate analgesia remember to ensure laxatives are prescribed.

Non Pharmacological management:

<table>
<thead>
<tr>
<th>Drug name, Dose and Route and Frequency</th>
<th>Date commenced</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>1&lt;sup&gt;st&lt;/sup&gt; line Drug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2&lt;sup&gt;nd&lt;/sup&gt; line Drug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3&lt;sup&gt;rd&lt;/sup&gt; line Drug</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Evaluation

**Seizures**

Description of usual seizures:

Rescue medication

<table>
<thead>
<tr>
<th>Drug name, Dose and Route and Frequency</th>
<th>Date commenced</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>1&lt;sup&gt;st&lt;/sup&gt; line Drug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2&lt;sup&gt;nd&lt;/sup&gt; line Drug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3&lt;sup&gt;rd&lt;/sup&gt; line Drug</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other instructions for seizures.

If xxxx continues to fit after two doses of buccal midazolam then xxxx xxxx / or the on call Macmillan Nurse should be contacted for advice

Evaluation
**Raised Intracranial Pressure**

<table>
<thead>
<tr>
<th>Drug name, Dose and Route and Frequency</th>
<th>Date Commenced</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>1(^{st}) line Drug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2(^{nd}) line Drug</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Other instructions.</strong></td>
<td></td>
<td></td>
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</tbody>
</table>

**Evaluation**

---

**For Distress or Agitation**

<table>
<thead>
<tr>
<th>Drug name, Dose and Route and Frequency</th>
<th>Date Commenced</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>1(^{st}) line Drug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2(^{nd}) line Drug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3(^{rd}) line Drug</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If xxxx's restlessness / agitation does not settle, IV drug dosages can be escalated to achieve a response. XXXX XXXX/ or the on call Macmillan Nurse should be contacted for advice.

**Evaluation**
For Nausea / Vomiting

<table>
<thead>
<tr>
<th>Drug name, Dose and Route</th>
<th>Date Commenced</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>1&lt;sup&gt;st&lt;/sup&gt; line Drug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2&lt;sup&gt;nd&lt;/sup&gt; line Drug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3&lt;sup&gt;rd&lt;/sup&gt; line Drug</td>
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</tbody>
</table>

Evaluation

Management of bleeding

Non Pharmacological measures:

The management of bleeding will depend on the site, severity and duration of the bleed. Application of pressure and the use of ice.

Medicine management

<table>
<thead>
<tr>
<th>Drug name, Dose and Route and Frequency</th>
<th>Date Commenced</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>1&lt;sup&gt;st&lt;/sup&gt; line Drug</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2&lt;sup&gt;nd&lt;/sup&gt; line Drug</td>
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</tr>
</tbody>
</table>

Consider platelet transfusion as indicated. If xxxx is unable to travel to hospital consider transfusion at home with appropriate cover.

Evaluation
**Management of Spinal cord compression**

Consider symptoms (Pain, Weakness, bladder and bowel changes):
- Contact their consultant/Consultant on call.
- Consider urgent steroids.
- Consider surgical decompression.
- Consider urgent radiotherapy.

**Medicine management**

<table>
<thead>
<tr>
<th>Drug name, Dose and Route and Frequency</th>
<th>Date Commenced</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st line Drug</td>
<td></td>
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<tr>
<td>2nd line Drug</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Evaluation**

---

**Management of bowel obstruction**

Consider symptoms associated with obstruction (Nausea and vomiting, Pain, distension):
- Discuss with Consultant/Consultant on call.
- Consider insertion of naso gastric tube to relieve vomiting and fluid replacement.
- Stop Laxatives and any prokinetic drugs (e.g Metoclopramide)
- Consider dexamethasone.
- Consider antispasmodics
- Consider octreotide

**Medicine management**

<table>
<thead>
<tr>
<th>Drug name, Dose and Route and Frequency</th>
<th>Date Commenced</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st line Drug</td>
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<tr>
<td>2nd line Drug</td>
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</tbody>
</table>

**Evaluation**

---
Management of Anaemia

Consider Symptoms associated with anaemia and refer to care plan

Consider blood transfusion if indicated.
Blood transfusions are an invasive procedure and not without risk.
Consider the benefit that xxxx would gain from receiving a transfusion.
Transfusion should normally be given in hospital, so xxxx should be able to comfortably make the journey
If xxxx is unable to travel to hospital consider transfusion at home with appropriate cover.

<table>
<thead>
<tr>
<th>Medicine management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Premedication required prior to transfusion</td>
</tr>
<tr>
<td>Drug name, Dose and Route and Frequency</td>
</tr>
<tr>
<td>1st line Drug</td>
</tr>
<tr>
<td>2nd line Drug</td>
</tr>
</tbody>
</table>

Evaluation

Excessive Secretions and cough

Non Pharmacological measures:

Simple changes in position or postural drainage can often help to clear secretions.
If secretions are in the back of the throat then some simple suction, if xxxx is able to tolerate it, can be considered.

<table>
<thead>
<tr>
<th>Medicine management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drug name, Dose and Route and Frequency</td>
</tr>
<tr>
<td>1st line Drug</td>
</tr>
<tr>
<td>2nd line Drug</td>
</tr>
</tbody>
</table>

Evaluation
General deterioration in conscious level, restlessness and agitation

<table>
<thead>
<tr>
<th>Drug name, Dose and Route and Frequency</th>
<th>Date Commenced</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1st line Drug</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>2nd line Drug</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Evaluation</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Breathlessness**

- Non Pharmacological measures:
  - Position xxxx in most comfortable position, which is.....

- Consider causes of breathlessness (anaemia, pain, anxiety ...)
- Consider pharmaceutical management (see below)

<table>
<thead>
<tr>
<th>Dose and frequency</th>
<th>Date Commenced</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oxygen therapy.</td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Drug name, Dose and Route and Frequency</th>
<th>Date Commenced</th>
<th>Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1st line Drug</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Diazepam</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>2nd line Drug</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Evaluation</strong></td>
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</tbody>
</table>
2. Anticipatory medication available in the home if needed

<table>
<thead>
<tr>
<th>Drug</th>
<th>Presentation</th>
<th>Route</th>
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</thead>
<tbody>
<tr>
<td>Diamorphine</td>
<td>10mg vials</td>
<td>IV</td>
</tr>
<tr>
<td>Midazolam</td>
<td>10mg/2ml vials</td>
<td>IV</td>
</tr>
<tr>
<td>Midazolam buccal suspension</td>
<td>10mg/ml</td>
<td>Buccal</td>
</tr>
<tr>
<td>Levomepromazine</td>
<td>25mg/ml vials</td>
<td>IV</td>
</tr>
<tr>
<td>Hyoscine hydrobromide patches</td>
<td>1mg/72hours</td>
<td>Transdermal patches</td>
</tr>
<tr>
<td>Cyclizine</td>
<td>50mg/ml vials</td>
<td>IV</td>
</tr>
<tr>
<td>Tranexamic acid injection.</td>
<td>100mg/ml</td>
<td>IV</td>
</tr>
<tr>
<td>Tranexamic acid syrup</td>
<td>500mg/5mls</td>
<td>Oral</td>
</tr>
</tbody>
</table>
Advanced care Plan - Decision Making.

Consider the following

- What does the child/young person know about their condition, recent changes and prognosis?
- What do siblings understand about the condition and prognosis?
- What involvement is appropriate and possible for the child/young person in the decision making progress.
- To what extent is the child/young person been involved in the decision making progress.
- What does the child/young person know about the decisions that have been made

Communications and discussion

xxx has xxxxxxxx for which there is no curative treatment available. The aim of all interventions and management should be for xxx's comfort. It would seem inappropriate to perform treatments or interventions which may cause distress or loss of dignity to xxx, or which are very unlikely to be of benefit.

In the event of xxx deteriorating with a respiratory or cardiac arrest it would be futile to attempt resuscitation. This has been fully discussed with his parents who are in agreement that they do not want resuscitation attempted in the event of respiratory or cardiac arrest.

The aim of any treatment would be to keep Xxx as comfortable as possible, surrounded by familiar people, and to manage his symptoms as well as possible. Xxx Xxxx - Macmillan Nurse or Dr xxxxx can be contacted if necessary.

When a child with a life limiting condition dies of an expected cause, there is no need for urgent action or immediate involvement of medical or nursing services. If they die at home they can continue to be held and touched by their family. However when parents are ready, the Macmillan and Community nursing teams, and the doctor who last saw the child should be contacted.

Consultant’s Agreement
I support this dedicated care plan

<table>
<thead>
<tr>
<th>Name</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

Consultant

Children's Macmillan Liaison Nurse
I support this dedicated care plan and have discussed it with the parents and young person

<table>
<thead>
<tr>
<th>Name</th>
<th>Signature</th>
<th>Date</th>
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</thead>
<tbody>
<tr>
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</tbody>
</table>

Macmillan Nurse
<table>
<thead>
<tr>
<th>Copies of this plan to be held by</th>
<th>Name</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Notes</td>
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<td></td>
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</tr>
<tr>
<td>Macmillan team notes</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Children’s Community Nursing team</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP</td>
<td></td>
<td></td>
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<tr>
<td>Hospice</td>
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</tr>
</tbody>
</table>
# Appendix 2 - Limitation of Treatment Agreement (LOTA) PDF file

## Limitation of Treatment Agreement (LOTA): for use in all locations

Management of acute paediatric/neonatal deterioration and cardio – respiratory arrest

<table>
<thead>
<tr>
<th>Name:</th>
<th>Address:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth:</td>
<td>Address:</td>
</tr>
<tr>
<td>NHS number:</td>
<td>Postcode:</td>
</tr>
<tr>
<td>Hospital number:</td>
<td></td>
</tr>
<tr>
<td>Religion:</td>
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</tr>
<tr>
<td>Parent/Carer Home phone no:</td>
<td></td>
</tr>
<tr>
<td>Parent/Carer Mobile phone no:</td>
<td></td>
</tr>
</tbody>
</table>

Regardless of the patient’s resuscitation status, immediately reversible causes should be treated: choking, anaphylaxis, blocked tracheostomy tube, other (please state): ..........................................................

This LOTA applies to anyone providing care to the child named on this form. Clearly cross out the column below that DOES NOT apply:

<table>
<thead>
<tr>
<th>Attempt resuscitation with modifications below</th>
<th>Do not attempt cardiopulmonary resuscitation (DNACPR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-specific modifications to standard resuscitation guidelines e.g. Airway, Breathing, Circulation, Drugs, Seizure, Escalation to ICU</td>
<td>In the event of the child’s death please contact:</td>
</tr>
<tr>
<td>OR</td>
<td>GP or OOH GP service □ OR</td>
</tr>
<tr>
<td>OR</td>
<td>Local Hospice □ OR</td>
</tr>
<tr>
<td>OR</td>
<td>24 hour community paediatric team (where available) □</td>
</tr>
<tr>
<td>Contact names and phone numbers on back page.</td>
<td></td>
</tr>
</tbody>
</table>

**Diagnosis and Rationale for decision**

<table>
<thead>
<tr>
<th>Senior Clinician* Signature</th>
<th>Name</th>
<th>GMC No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>* as defined by local policy</td>
<td>Institution/Hospital/Hospital/Community setting</td>
<td></td>
</tr>
</tbody>
</table>

Lead clinician responsible for reviewing this form is ..........................................................

<table>
<thead>
<tr>
<th>Date Initiated</th>
<th>First Date Review* Due</th>
<th>Length of time</th>
<th>Senior Clinician* Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date reviewed*</td>
<td>Name &amp; title of lead reviewer</td>
<td>Next review* due</td>
<td></td>
</tr>
</tbody>
</table>

\* Review date frequency as defined by local policy - recommended maximum: 1 week (in patient) and 6 months (outpatient)

If the child or young person becomes unwell and needs an Ambulance, inform Ambulance Control that the child has a Limitation of Treatment Agreement (LOTA).

Please follow the instructions above, however if the family request treatment including cardiopulmonary resuscitation then follow their request.

Any other specific instructions during patient transport: ..........................................................

Final Version 1: July 2013: Review Date July 2016
Appendix 3 - End of Life Care Symptom Management Flow Sheets

Pain management

Assess the patient
- Assess the cause of the pain and look for non-verbal cues
- Involve the child (where appropriate) and family.
- Manage reversible cause’s e.g. re-positioning, catheter for urinary retention, constipation.
- Discuss any concerns about the use of opiates (e.g. drowsiness)
- If pain remains uncontrolled, first check analgesia is appropriate. Check that any infusion is running correctly. Then consider increasing total analgesia and/or adding in adjuvant agents e.g for neuropathic pain
- If on a transdermal opiate e.g. fentanyl patch continue. Ensure suitable morphine p.r.n. is prescribed.
- For patients with renal impairment (eGFR < 50) avoid morphine & consider oxycodone. Discuss with a paediatric pharmacist if advice needed
- Naloxone is very rarely appropriate in a dying patient and is not routinely prescribed
- Always prescribe laxatives and antiemetics prophylactically to prevent opiate side effects
- For children not in pain at the time of assessment, prescribe an anticipatory (‘ahead of time’) opiate for if pain should develop.
- Seek advice if concerned about side effects; rapidly escalating pain; persistent pain; suspected opiate toxicity; opiate conversion; unsure what to do.

Opiate prescribing guide
- If able to tolerate oral/peg route Morphine 0.2mg/kg po p.r.n. 2 hourly ‘for pain’. Maximum starting dose 10mg 4hrly
- If unable to tolerate oral/peg route If > 1yr Diamorphine 75-100micrograms 4hrly prn If < 1yr see APPM formulary for diamorphine doses
- If 4 x p.r.n. doses in 24 hours then a medical review is required regarding regular analgesia.
- If morphine contraindicated consider oxycodone
- Review after 24 hours. If two or more p.r.n. doses are used with good effect then consider diamorphine infusion over 24 hours.

If the child is able to tolerate the oral route increase dose according to number of breakthrough doses needed in last 24 hours.
E.g. PO morphine sulphate modified release (MST®) 30mg b.d. (60mg) + 3 x morphine sulphate immediate release (Oramorph®) 10mg p.r.n. (i.e. 3x10mg = 30mg)
Thus total of 60mg + 30mg = 90mg PO morphine in 24 hours
Increase MST to 45mg bd with 10mg 4hrly prn Oramorph
Switch to subcutaneous route or IV route if central line in situ (24hour infusion plus breakthrough) when oral route no longer available or pain not controlled by oral route. Consider adjuvant treatments.

MAINTENANCE DOSE
- If converting from PO morphine to 24 hour infusion of diamorphine divide TOTAL dose of PO morphine used in previous 24 hours by 3
E.g. PO morphine sulphate modified release (MST®) 30mg b.d. (60mg) + 3 x morphine sulphate immediate release (Oramorph®) 10mg p.r.n. (i.e. 3x10mg = 30mg)
Thus total of 60mg + 30mg = 90mg PO morphine in 24 hours
90mg ÷ 3 = 30mg diamorphine in CSCI over 24 hours.
- To convert from tramadol, codeine, oxycodone or other analgesia seek Specialist Palliative Care advice.
- Give a p.r.n. dose at same time as commencing infusion.

‘WHEN REQUIRED’ p.r.n SC DOSE
- Always prescribe p.r.n analgesia for breakthrough pain
- Calculate by dividing previous 24 hour opioid dose by 6

Is the child currently in pain?

YES AND PRESCRIBED AN OPIATE

YES AND NOT PRESCRIBED AN OPIATE

NO: ANTICIPATORY PRESCRIBING
Terminal Restlessness

Assess the patient

- Agitation and delirium contribute to condition known as terminal restlessness.
- Treatment is defined by the signs and symptoms. Consider signs of terminal restlessness. Cues are often non-verbal e.g. agitation, anxiety, moaning or calling out, twitching, pulling at bedclothes, aggression, purposeless but coordinated movements or trying to get out of bed. These can be transient and intermittent. If delirium is present: paranoia, plucking, hallucinations and altered cognition are often displayed.

Assess cause(s) of terminal restlessness and treat reversible causes if appropriate:

- Common causes: urinary retention, constipation, pain, breathlessness, retained secretions, infection, adverse effects to medication (e.g. opiates, steroids), biochemical abnormalities (e.g. hypercalcaemia, hypoglycaemia, uraemia), brain tumour/ metastases, spiritual & emotional distress, nicotine/alcohol withdrawal.

Management plan for terminal restlessness

- **Involve the child (where appropriate) and family in the management plan.** Explain clearly the likely causes and indications for any medication and the likely side effects e.g. sedation.

- **Non pharmacological management**
  - Emotional distress may be helped by a quiet room, reassurance or the presence of loved ones.
  - Spiritual distress may be helped by appropriate support mechanisms e.g. spiritual advisor, establishing any wishes/preferences.

- **Pharmacological management**
  - Midazolam – anxiolytic (sedating) drug of choice if agitation predominates. Benzodiazepines can exacerbate symptoms associated with delirium
  - Occasionally haloperidol or the combined administration of haloperidol and midazolam is required in consultation with a palliative care specialist

- For children not restless at time of assessment **prescribe anticipatory (ahead of time) p.r.n. anxiolytic** should symptoms develop and clearly discuss and document a management plan.

- **Seek advice if symptoms persist or if doses are rapidly escalating or you are concerned about side effects or unsure what to do.**

Is the child showing signs of agitation or restlessness?

**YES**

- Give buccal midazolam 100 microgrammes/kg p.r.n.
- If ineffective, after 20 minutes repeat the dose
- If second dose ineffective, after a further 20 mins seek medical review or specialist advice.
- For restlessness recurring within 4 hours consider an infusion. Usual starting dose is 2x the prn dose given midazolam SC or IV (only if line in situ) over 24 hours.

Further p.r.n. doses may be required if effective. Titrate infusion if appropriate as per the APPM formulary. If unsure of dosages or if more than 60mg midazolam

**NO: ANTICIPATORY PRESCRIBING**

Options:

- Midazolam buccal 100 microgrammes/kg p.r.n. ‘for terminal restlessness’
  
  Maximum starting dose 10mg

- Do not repeat within 20 minutes.

- Review after 24 hours. If two or more p.r.n. doses are used with good effect then consider infusion over 24 hours.
Nausea and Vomiting

Assess the patient

Assess cause(s) of nausea and vomiting and treat reversible causes if appropriate:
- Common causes: drugs, constipation, gastric stasis/obstruction, coughing, hypercalcaemia, uraemia.

Management plan for nausea & vomiting
- Involve the child (where appropriate) and family.
- In malignant bowel obstruction explain that complete symptom control is difficult as the cause is mechanical. Aim is to reduce symptoms. Seek specialist advice or see the YHCYPN oncology guidelines available http://www.yorkshire-cancer-net.org.uk/html/publications/guidelines_cyp_clinical.php
- Non-pharmacological (good mouth care, avoid strong smells)
- Pharmacological management: Choice depends on cause of nausea & vomiting.

Individual considerations
- Choice of antiemetic depends on cause but Cyclizine is a good first line option if an infusion is required due to syringe driver compatibilities
- Levomepromazine is a broad spectrum anti-emetic and can be useful when the cause is not clear and is a good second line option.
- AVOID haloperidol, levomepromazine and metoclopramide in patients with previous dystonic reactions.
- AVOID cyclizine in congestive heart failure.
- If patient does not have nausea/vomiting at time of assessment, discuss a management plan and prescribe anticipatory (ahead of time) p.r.n. antiemetic should symptoms develop.
- Seek advice if symptoms persist, antiemetic doses are rapidly escalating, you are concerned about side effects or unsure what to do.

---

Does the child have nausea or vomiting?

- **YES** - CONTROLLED WITH CURRENT ANTI-EMETIC BUT ORAL ROUTE NOT AVAILABLE
  - Switch to subcutaneous route (or IV if central line in situ) when oral route no longer available.
    - 1st line Cyclizine 3mg/kg over 24hours (max 150mg in 24hrs)
    - 2nd line Levomepromazine 0.1mg/kg over 24 hours. Can be titrated up to 0.4mg/kg over 24hours if needed. May also cause sedation.
    - If unsure seek advice.

- **YES AND NOT CONTROLLED WITH CURRENT ANTI-EMETIC**
  - Review the cause of nausea and vomiting.
  - Seek specialist advice if needed.
  - Consider changing anti-emetic to levomepromazine - see anticipatory prescribing box.

- **NO: ANTICIPATORY PRESCRIBING**
  - Options
    - If oral/peg route available/tolerated treat based on most likely cause. If unsure:
      - 1st line Cyclizine 1mg/kg tds (max 50mg tds) po
      - 2nd line Levomepromazine 0.1mg/kg bd (max 6.25mg bd)
    - If oral/peg route not available:
      - 1st line Cyclizine 3mg/kg over 24hours (max 150mg in 24hrs)
      - 2nd line Levomepromazine 0.1mg/kg over 24 hours. Can be titrated up to 0.4mg/kg over 24hours if needed. May also cause sedation.
      - Review after 24hours
      - If unsure/ineffective seek advice.
Retained Secretions

Assess the patient

Patients in the last days or hours of life may not be able to clear secretions by coughing or swallowing.

Assess the source of the secretions:
- Sources can be salivary, bronchial or from gastric reflux.
- Increased bronchial secretions are less likely to respond to anti-secretory drugs, consider specific management if appropriate.
- Exclude fluid overload. Review clinically assisted hydration/nutrition and adjust as necessary.

Management plan for retained secretions
- **Involve the child (if appropriate) and family in the management plan.**
- **Explain probable cause of the problem and the likely efficacy of any treatment.**
- If the patient is unconscious emphasise that patient is unlikely to be aware of the problem.
- Consider **non-pharmacological management**: re-positioning, suctioning if appropriate and tolerated.
- Consider **Pharmacological management (anti-secretory)**: see below.
- Ensure good mouth care, dry mouth is a side effect of the medication.
- For patients with no retained secretions at time of assessment, discuss a management plan and **prescribe anticipatory (ahead of time) p.r.n. anti-secretory**, should symptoms develop.
- **Seek advice if symptoms persist, concern about side effects or unsure what to do.**

Does the child have noisy or troublesome respiratory tract secretions?

**YES**

Consider non-pharmacological management

If symptoms persist:
- **Hyosine hydrobromide**
  1month-3years ¼ patch
  3-10years ½ patch
  >10years 1 patch every 72hours.
  For persistent symptoms consider other causes (see above)
- AVOID metoclopramide.

Alternative to hyosine butylbromide
- **Glycopyronium** (non-sedative)
  - 1month-12years 10microgrammes per kg over 24hours (max 1.2mg/24hrs)
  - >12years 600microgrammes per 24hours
  - Can be titrated upwards as per APPM formulary

Consider **midazolam** if the patient is distressed by retained secretions. Follow ‘Terminal Restlessness Symptom Management’ guidance.

Provide explanation and appropriate reassurance.

**NO: ANTICIPATORY PRESCRIBING**

- **Hyosine hydrobromide**
  1month-3years ¼ patch
  3-10years ½ patch
  >10years 1 patch every 72hours.
  ‘for retained secretions’
- Alternatively **Glycopyronium bromide S/C**
  1month-12years 10microgrammes per kg over 24hours (max 1.2mg/24hrs)
  >12years 600microgrammes per 24hours
  Can be titrated upwards as per APPM formulary
- Review after 24 hours.
Breathlessness

Assess the patient

- For many patients the fear of dying in a state of marked breathlessness with acute anxiety / panic is their biggest, if unspoken, fear. Address breathlessness as soon as distress becomes apparent.

Assess the cause(s) of breathlessness and treat reversible causes if appropriate:

- Common causes: infection, anaemia, arrhythmia, pulmonary embolism, bronchospasm, heart failure, pleural effusion, stridor, anxiety.

- Consider fluid overload. Assess any artificial hydration/nutrition and if appropriate consider adjusting rate.

Management plan for breathlessness

- Involve the child (where appropriate) and family in the management plan.

- **Non-pharmacological management** e.g. positioning, facial cooling e.g. fan, opening windows, reassurance and calming presence, relaxation and meeting spiritual needs.

Pharmacological management

- **Opiate therapy**
  - Morphine - used to relieve sensation of breathlessness
  - Monitor for signs of opiate toxicity, particularly if poor renal function. Naloxone is very rarely appropriate in a dying patient.

- **Midazolam** - used for persistent distress /anxiety associated with breathlessness.

- **Oxygen therapy** may be beneficial even if patient is not hypoxic. Rate should be adjusted with symptoms and oxygen saturations should not be monitored

- For patients not breathless at time of assessment prescribe **anticipatory (‘ahead of time’) p.r.n. opiate for breathlessness** should symptoms develop (taking into consideration opiate prescribed for pain management).

Is the child breathless?

YES AND PRESCRIBED OPIATES FOR PAIN OR BREATHLESSNESS

Consider non-pharmacological management.

- Usual p.r.n. opiate dose can also be used to treat breathlessness.

- **Switch to subcutaneous route (or IV if central line in situ) when oral route no longer available.** See Pain Symptom Management guidance or seek advice. Buccal preparations could also be used.

YES AND OPIATE NAIVE

- If oral/peg route available Prescribe morphine sulphate 0.2mg/kg p.r.n. 2 hourly, ‘for breathlessness’. Maximum 10mg 4hourly.

- If oral/peg route not available and >1yr prescribe diamorphine 75-100microgrammes/kg 4hrly p.r.n ‘for breathlessness’. Maximum starting dose 2.5mg 4hrly. Maximum 10mg SC in 24 hours then medical review required. If <1year see APPM formulary for doses.

- Review after 24 hours. If two or more p.r.n. doses are used with good effect then consider infusion over 24

NO: ANTICIPATORY PRESCRIBING

If persistently distressed with breathlessness consider addition of midazolam. See Symptom Management for Terminal Restlessness or seek advice.
Seizures

Assess the patient

Assess cause(s) of seizures and treat reversible causes if appropriate:
- Common causes: infection, adverse effects to medication (e.g. opioids, steroids), biochemical abnormalities (e.g. hypercalcaemia, hypoglycaemia, uraemia), brain tumour/ metastases, hydrocephalus, venous sinus thrombosis, hypertension, fever, low anticonvulsant levels

Management plan for terminal restlessness
- Involve the child (if appropriate) and family in the management plan. Explain clearly the likely causes and indications for any medication and the likely side effects e.g. sedation.
- Non pharmacological management
  - Reassurance to patient and family members, positional measures
- Pharmacological management
  - Midazolam – first line drug of choice in palliative care setting
  - Occasionally other medications may be more appropriate for patients with complex seizure disorders and a plan from their consultant paediatric neurologist should be actively sought in advance
- For patients not having seizures at the time of assessment prescribe anticipatory (ahead of time) p.r.n. seizure medication should symptoms develop and clearly discuss and document a management plan.
- Seek advice if symptoms persist or if doses are rapidly escalating or you are concerned about side effects or unsure what to do.

Is the child having a seizure?

YES
- Give buccal midazolam
  <3 months 300microgramme/kg max 2.5mg
  3-12 months 2.5mg
  1-5 years 5mg
  5-10 years 7.5mg
  >10 years 10mg
- If ineffective, after 10 minutes repeat the dose
- If second dose ineffective, after a further 10 mins seek medical review or specialist advice.
- For recurring seizures. Usual starting dose is 2x the prn dose given midazolam SC or IV (only if line in situ) over 24 hours.
Further p.r.n. doses may be required if effective. Titrate infusion if appropriate as per the APPM formulary. If unsure of dosages or if more than 60mg midazolam in 24 hours is required seek advice.

NO: ANTICIPATORY PRESCRIBING

Options:
- Midazolam buccal p.r.n. ‘for terminal restlessness’
  <3 months 300microgramme/kg max 2.5mg
  3-12 months 2.5mg
  1-5 years 5mg
  5-10 years 7.5mg
  >10 years 10mg
- Do not repeat within 10 minutes.
- Review after 24 hours. If two or more p.r.n. doses are used with good effect then consider infusion over 24 hours.
- Seek advice if midazolam is not effective
The drugs and quantities listed below are kept in this palliative care drug box. The medication in this box is solely for the use of the above patient and MUST NOT be used for any other patient. This palliative care box should be used in conjunction with the community drug administration chart written specifically for this patient. There is space for another item or controlled drug item at the bottom of the table. This can be added by the doctor if he/she feels that the individual patient is likely to suffer from symptoms that are not managed by the drugs listed below. For legal purposes, any controlled drug prescribed must be in the doctors own handwriting with full directions.

<table>
<thead>
<tr>
<th>DRUG</th>
<th>FORM</th>
<th>STRENGTH</th>
<th>QUANTITY</th>
<th>DIRECTIONS</th>
<th>INITIAL IF REQUIRED (Doctor)</th>
<th>PHARMACY DISP</th>
<th>CHECK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cyclazine</td>
<td>INJ</td>
<td>50mg/mL</td>
<td>10 x 1mL</td>
<td>To be used as directed</td>
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<tr>
<td>Chlorpheniramine</td>
<td>INJ</td>
<td>10mg/mL</td>
<td>2 x 1mL</td>
<td>To be used as directed</td>
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<tr>
<td>Hydrocortisone</td>
<td>INJ</td>
<td>100mg</td>
<td>2 x 1mL</td>
<td>To be used as directed</td>
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<tr>
<td>Hyoscine</td>
<td>INJ</td>
<td>400 microgram/mL</td>
<td>10 x 1mL</td>
<td>To be used as directed</td>
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<tr>
<td>Hyoscine patch</td>
<td>Topical</td>
<td>1mg/72 hours</td>
<td>1 patch</td>
<td>To be used as directed</td>
<td></td>
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<tr>
<td>Hyoscine Butylbromide</td>
<td>INJ</td>
<td>20mg/mL</td>
<td>5 x 1mL</td>
<td>To be used as directed</td>
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<tr>
<td>Levomepromazine</td>
<td>INJ</td>
<td>25mg/mL</td>
<td>5 x 1 mL</td>
<td>To be used as directed</td>
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<tr>
<td>Sodium Chloride 0.9%</td>
<td>INJ</td>
<td>10mL</td>
<td>5 x 10mL</td>
<td>To be used as directed</td>
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<tr>
<td>Tramadol</td>
<td>INJ</td>
<td>100mg/mL</td>
<td>5 x 5 mL</td>
<td>To be used as directed</td>
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<tr>
<td>Water for Injection</td>
<td>INJ</td>
<td>10mL</td>
<td>1 x 10mL</td>
<td>To be used as directed</td>
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Controlled drugs should be prescribed below as in the example

Example: Benztrapine | INJ | 10mg immediate | FIVE &.Imps | Max 10mg every 2 hours |

Prescribers signature: .......................................................... PRINT name: .......................................................... Date: ..........................................................

Pharmacist check: .......................................................... PRINT name: .......................................................... Date: ..........................................................

Macmillan Nurse collecting: .......................................................... PRINT name: .......................................................... Date: ..........................................................

Completed prescriptions should be filed in the notes and a copy placed in the palliative drug box.
Appendix 5 - Paediatric Palliative Care Syringe Driver Prescription Chart PDF

The Leeds Teaching Hospitals

**PAEDIATRIC McKINLEY T34 CONTINUOUS INFUSION PUMP PRESCRIPTION CHART**
for Intravenous or Subcutaneous use in Paediatric Patients only

**THIS PRESCRIPTION IS VALID FOR 2 DAYS IF UNCHANGED**

<table>
<thead>
<tr>
<th>Start date</th>
<th>Drugs</th>
<th>Dose in 24hours</th>
<th>Actual dose given Day 1</th>
<th>Actual dose given Day 2</th>
<th>Diluent</th>
<th>Volume (a)</th>
<th>Water for injection</th>
<th>Infusion duration (b) (Hour)</th>
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<tbody>
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**ADMINISTRATION RECORD**

<table>
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<th>Day 1</th>
<th>Drug</th>
<th>Batch no</th>
<th>Strength</th>
<th>Quantity</th>
<th>Expiry</th>
<th>Day 2</th>
<th>Drug</th>
<th>Batch no</th>
<th>Strength</th>
<th>Quantity</th>
<th>Expiry</th>
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</tbody>
</table>

(a + b) Rate set (mLs per hour): Site of needle:

Water for Injection
Batch no and Expiry date:

Given by:
Signature:
PRINT name & Contact details:

Witness:
Signature:
PRINT name & Contact details:

Date & Start time:
Date:
Start time:

Amount wasted:
Signature:

Syringe Driver Number:

PLEASE COMPLETE CHECKLIST OVERLEAF

Approved by Medicine Risk Management Group

Signed:

Next Review Due:

Pharmacy reference no:

For further supplies please contact your Ward Pharmacist

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Appendix 6 - Opiate conversion and titration

The following guidance on titration and conversion is adapted from the British National Formulary for Children

**Oral route**
Where possible morphine should be given by mouth or enteral route as immediate-release or modified-release preparation. During the titration phase the initial dose is based on the previous medication used, the severity of the pain, and other factors such as presence of renal impairment or frailty. The dose is given either as an immediate-release preparation 4-hourly Morphine, or as a 12-hourly modified-release preparation, in addition to rescue doses. The starting dose of 12-hourly modified-release preparations is usually 200–800 micrograms/kg every 12 hours. If replacing a weaker opiate analgesic (such as codeine), starting doses are usually higher.

If pain occurs between regular doses of morphine ('breakthrough pain'), an additional dose ('rescue dose') of immediate-release morphine should be given. An additional dose should also be given 30 minutes before an activity that causes pain, such as wound dressing. The standard dose of a strong opiate for breakthrough pain is usually one-tenth to one-sixth of the regular 24-hour dose, repeated every 2–4 hours as required (up to hourly may be needed if pain is severe or in the last days of life). Review pain management if rescue analgesic is required frequently (twice daily or more). Each child should be assessed on an individual basis.

Children often require a higher dose of morphine in proportion to their body-weight compared to adults. Children are more susceptible to certain adverse effects of opiates such as urinary retention (which can be eased by bethanechol), and opiate-induced pruritus.

When adjusting the dose of morphine, the number of rescue doses required and the response to them should be taken into account; increments of morphine should not exceed one-third to one-half of the total daily dose every 24 hours. Thereafter, the dose should be adjusted with careful assessment of the pain, and the use of adjuvant analgesics should also be considered. Upward titration of the dose of morphine stops when either the pain is relieved or unacceptable adverse effects occur, after which it is necessary to consider alternative measures.

Once their pain is controlled, children started on 4-hourly immediate-release morphine can be transferred to the same total 24-hour dose of morphine given as the modified-release preparation for 12-hourly administration. The first dose of the modified-release preparation is given with, or within 4 hours of the last dose of the immediate-release preparation. Increments should be made to the dose, not to the frequency of administration. A suitable laxative should be prescribed routinely.

Oxycodone can be used in children who require an opiate but cannot tolerate morphine. If the child is already receiving an opiate, oxycodone should be started at a dose equivalent to the current analgesic (see below). Oxycodone immediate-release preparations can be given for breakthrough pain.

**Equivalent doses of opiate analgesics**

The table below is details the equivalent doses of 10mg of oral morphine. It is only an approximate guide (doses may not correspond with those given in clinical practice); children should be carefully monitored after any change in medication and dose titration may be required.

<table>
<thead>
<tr>
<th>Analgesic</th>
<th>Route</th>
<th>Dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diamorphine</td>
<td>IM,IV,SC</td>
<td>3mg</td>
</tr>
<tr>
<td>Hydromorphone</td>
<td>PO</td>
<td>2mg</td>
</tr>
<tr>
<td>Morphine</td>
<td>PO</td>
<td>10mg</td>
</tr>
<tr>
<td>Morphine</td>
<td>IM,IV,SC</td>
<td>5mg</td>
</tr>
<tr>
<td>Oxycodone</td>
<td>PO</td>
<td>6.6mg</td>
</tr>
</tbody>
</table>
Parenteral route
Diamorphine is preferred for injection because, being more soluble, it can be given in a smaller volume. The equivalent subcutaneous dose is approximately a third of the oral dose of morphine. Subcutaneous infusion of diamorphine via a continuous infusion device can be useful. If the child can resume taking medicines by mouth, then oral morphine may be substituted for subcutaneous infusion of diamorphine. See table below of Approximate Equivalent doses of Morphine and Diamorphine.

<table>
<thead>
<tr>
<th>Oral morphine sulphate</th>
<th>Subcutaneous infusion of morphine sulphate</th>
<th>Subcutaneous infusion of diamorphine hydrochloride</th>
</tr>
</thead>
<tbody>
<tr>
<td>Over 24 hours</td>
<td>Over 24 hours</td>
<td>Over 24 hours</td>
</tr>
<tr>
<td>30 mg</td>
<td>15 mg</td>
<td>10 mg</td>
</tr>
<tr>
<td>60 mg</td>
<td>30 mg</td>
<td>20 mg</td>
</tr>
<tr>
<td>90 mg</td>
<td>45 mg</td>
<td>30 mg</td>
</tr>
<tr>
<td>120 mg</td>
<td>60 mg</td>
<td>40 mg</td>
</tr>
<tr>
<td>180 mg</td>
<td>90 mg</td>
<td>60 mg</td>
</tr>
<tr>
<td>240 mg</td>
<td>120 mg</td>
<td>80 mg</td>
</tr>
<tr>
<td>360 mg</td>
<td>180 mg</td>
<td>120 mg</td>
</tr>
<tr>
<td>480 mg</td>
<td>240 mg</td>
<td>160 mg</td>
</tr>
<tr>
<td>600 mg</td>
<td>300 mg</td>
<td>200 mg</td>
</tr>
<tr>
<td>780 mg</td>
<td>390 mg</td>
<td>260 mg</td>
</tr>
<tr>
<td>960 mg</td>
<td>480 mg</td>
<td>320 mg</td>
</tr>
<tr>
<td>1200 mg</td>
<td>600 mg</td>
<td>400 mg</td>
</tr>
</tbody>
</table>

Transdermal route
Transdermal preparations of fentanyl and buprenorphine [not licensed for use in children] are available; they are not suitable for acute pain or in those children whose analgesic requirements are changing rapidly because the long time to steady state prevents rapid titration of the dose. Prescribers should ensure that they are familiar with the correct use of transdermal preparations (see under fentanyl) because inappropriate use has caused fatalities.

The following 24-hour oral doses of morphine are considered to be approximately equivalent to the buprenorphine and fentanyl patches shown, however when switching due to possible opiate-induced hyperalgesia, reduce the calculated equivalent dose of the new opiate by one-quarter to one-half.

Buprenorphine patches are approximately equivalent to the following 24-hour doses of oral morphine

<table>
<thead>
<tr>
<th>Morphine salt 12 mg daily</th>
<th>=</th>
<th>BuTrans 5 patch</th>
<th>7 day patches</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morphine salt 24 mg daily</td>
<td>=</td>
<td>BuTrans 10 patch</td>
<td>7 day patches</td>
</tr>
<tr>
<td>Morphine salt 48 mg daily</td>
<td>=</td>
<td>BuTrans 20 patch</td>
<td>7 day patches</td>
</tr>
<tr>
<td>Morphine salt 84 mg daily</td>
<td>=</td>
<td>BuTrans 35 patch</td>
<td>4 day patches</td>
</tr>
<tr>
<td>Morphine salt 126 mg daily</td>
<td>=</td>
<td>BuTrans 52.5 patch</td>
<td>4 day patches</td>
</tr>
<tr>
<td>Morphine salt 168 mg daily</td>
<td>=</td>
<td>BuTrans 70 patch</td>
<td>4 day patches</td>
</tr>
</tbody>
</table>

72-hour Fentanyl patches are approximately equivalent to the following 24-hour doses of oral morphine

<table>
<thead>
<tr>
<th>Morphine salt 30 mg daily</th>
<th>=</th>
<th>Fentanyl 12 patch</th>
</tr>
</thead>
<tbody>
<tr>
<td>Morphine salt 60 mg daily</td>
<td>=</td>
<td>Fentanyl 25 patch</td>
</tr>
<tr>
<td>Morphine salt 120 mg daily</td>
<td>=</td>
<td>Fentanyl 50 patch</td>
</tr>
<tr>
<td>Morphine salt 180 mg daily</td>
<td>=</td>
<td>Fentanyl 75 patch</td>
</tr>
<tr>
<td>Morphine salt 240 mg daily</td>
<td>=</td>
<td>Fentanyl 100 patch</td>
</tr>
</tbody>
</table>
## Appendix 7 - Home Oxygen Order Form

Home Oxygen Order Form (HOOF)

### Part A (Before Oxygen Assessment – Non-Specialist or Temporary Order)

All fields marked with an ‘*’ are mandatory and the HOOF will be rejected if not completed.

### 1. Patient Details

<table>
<thead>
<tr>
<th>1.1 NHS Number*</th>
<th>1.7 Permanent address*</th>
<th>1.9 Tel no.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.2 Title</td>
<td></td>
<td>1.10 Mobile no.</td>
</tr>
<tr>
<td>1.3 Surname*</td>
<td></td>
<td>2.1 Name</td>
</tr>
<tr>
<td>1.4 First name*</td>
<td></td>
<td>2.2 Tel no.</td>
</tr>
<tr>
<td>1.5 DoB*</td>
<td></td>
<td>2.3 Mobile no.</td>
</tr>
</tbody>
</table>

#### 1.6 Gender

- □ Male
- □ Female

<table>
<thead>
<tr>
<th>1.8 Postcode*</th>
</tr>
</thead>
</table>

### 2. Care Details (if applicable)

<table>
<thead>
<tr>
<th>2.1 Name</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>2.2 Tel no.</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>2.3 Mobile no.</th>
</tr>
</thead>
</table>

### 3. Clinical Details

#### 3.1 Clinical Code(s)

<table>
<thead>
<tr>
<th>4.1 Main Practice name:*</th>
</tr>
</thead>
</table>

#### 3.2 Patient on NIV/CPAP

- □ Yes
- □ No

#### 3.3 Paediatric Order

- □ Yes
- □ No

| 4.2 Practice address: |

<table>
<thead>
<tr>
<th>4.3 Postcode*</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>4.4 Telephone no.</th>
</tr>
</thead>
</table>

### 5. Assessment Service (Hospital or Clinical Service)

| 5.1 Hospital or Clinic Name: |

| 6.1 Name: |

| 5.2 Address |

| 6.2 Tel no.: |

| 5.3 Postcode: |

| 6.3 Discharge date: / / |

| 6.4 Tel no: |

### 6. Ward Details (if applicable)

| 7. Order*

| 8. Equipment*

#### 8.1 Static Concentrator

| Back up static cylinder(s) will be supplied as appropriate |

#### 8.2 Static Cylinder(s)

| A single cylinder will last for approximately 8hrs at 4l/min |

### 9. Consumables*

| Type |

| Litres / Min |

| Hours / Day |

| Quantity |

| Nasal Canulae |

| Mask % and Type |

### 10. Delivery Details*

| 10.1 Standard (3 Business Days) |

| 10.2 Next (Calendar) Day |

| 10.3 Urgent (4 Hours) |

### 11. Additional Patient Information

| 11.2 Tel no. |

| 12.1 Name: |

| 12.3 Mobile no. |

### 12. Clinical Contact (if applicable)

| 12.2 Tel no. |

| 12.3 Mobile no. |

### 13. Declaration*

I declare that the information given on this form for NHS treatment is correct and complete. I understand that if I knowingly provide false information, I may be liable to prosecution or civil proceedings. I confirm that I am the registered healthcare professional responsible for the information provided. I also confirm that the patient has read and signed the Home Oxygen Consent Form.

Name: 

Profession: 

Signature: 

Date: 

Referred for assessment: □ Yes □ No

Fax back no. or NHS email address for confirmation / corrections:

### 14. Clinical Code

<table>
<thead>
<tr>
<th>CODE</th>
<th>Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Chronic obstructive pulmonary disease (COPD)</td>
</tr>
<tr>
<td>2</td>
<td>Pulmonary vascular disease</td>
</tr>
<tr>
<td>3</td>
<td>Severe chronic asthma</td>
</tr>
<tr>
<td>4</td>
<td>Interstitial lung disease</td>
</tr>
<tr>
<td>5</td>
<td>Cystic fibrosis</td>
</tr>
<tr>
<td>6</td>
<td>Bronchiectasis (not cystic fibrosis)</td>
</tr>
<tr>
<td>7</td>
<td>Pulmonary malignancy</td>
</tr>
<tr>
<td>8</td>
<td>Palliative care</td>
</tr>
<tr>
<td>9</td>
<td>Non-pulmonary palliative care</td>
</tr>
<tr>
<td>10</td>
<td>Chest wall disease</td>
</tr>
<tr>
<td>11</td>
<td>Neuromuscular disease</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CODE</th>
<th>Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>Neurodisability</td>
</tr>
<tr>
<td>13</td>
<td>Obstructive sleep apnoea syndrome</td>
</tr>
<tr>
<td>14</td>
<td>Chronic heart failure</td>
</tr>
<tr>
<td>15</td>
<td>Paediatric interstitial lung disease</td>
</tr>
<tr>
<td>16</td>
<td>Chronic neonatal lung disease</td>
</tr>
<tr>
<td>17</td>
<td>Paediatric cardiac disease</td>
</tr>
<tr>
<td>18</td>
<td>Cluster headache</td>
</tr>
<tr>
<td>19</td>
<td>Other primary respiratory disorder</td>
</tr>
<tr>
<td>20</td>
<td>Other</td>
</tr>
<tr>
<td>21</td>
<td>Not known</td>
</tr>
</tbody>
</table>
Patient agreement to sharing information
(as part of the supply of Oxygen by the Home Oxygen Service)

My doctor or a member of my care team has explained the arrangements for supplying Oxygen at my premises, that my information will be stored in line with the Data Protection Act 1998, and I understand these arrangements, such that:

1. information about my condition/condition of the patient named above* will be transmitted to the Home Oxygen Service (HOS) Supplier to enable them to deliver the Oxygen treatment as per the Home Oxygen Order Form (HOOF),

2. information will be exchanged between my hospital care team, my doctor, the home care team and such other teams as necessary related to the provision, and review, of my Oxygen treatment and safety,

3. the HOS Supplier will be granted reasonable access to my premises, so that the Oxygen equipment can be installed, serviced, refilled and removed (as appropriate),

4. information will also be shared with the local Fire Rescue Services team to allow them to offer safety advice at my premises and where appropriate install/deliver suitable equipment for safety, and

5. information will also be shared with my electricity supplier/distributor where electrical devices have been installed.

6. From time to time, I may be contacted to participate in a patient satisfaction survey/audit.
   (should you wish not to participate please inform your HOS supplier)

7. I understand that I may withdraw my consent at any time (at which point my HOS equipment will be removed)

* Delete as applicable

Patient’s signature Date
(see note 3 where signed and witnessed on patient’s behalf)

I confirm that I have responsibility for the above-named patient.

Carer’s signature Name
Relationship to patient Date

I confirm that I am the healthcare professional responsible for the care of this patient and I have completed this form on his/her behalf as s/he is unable to provide/withhold consent. The patient has been given a copy of this form.

Clinician’s signature Date

Name