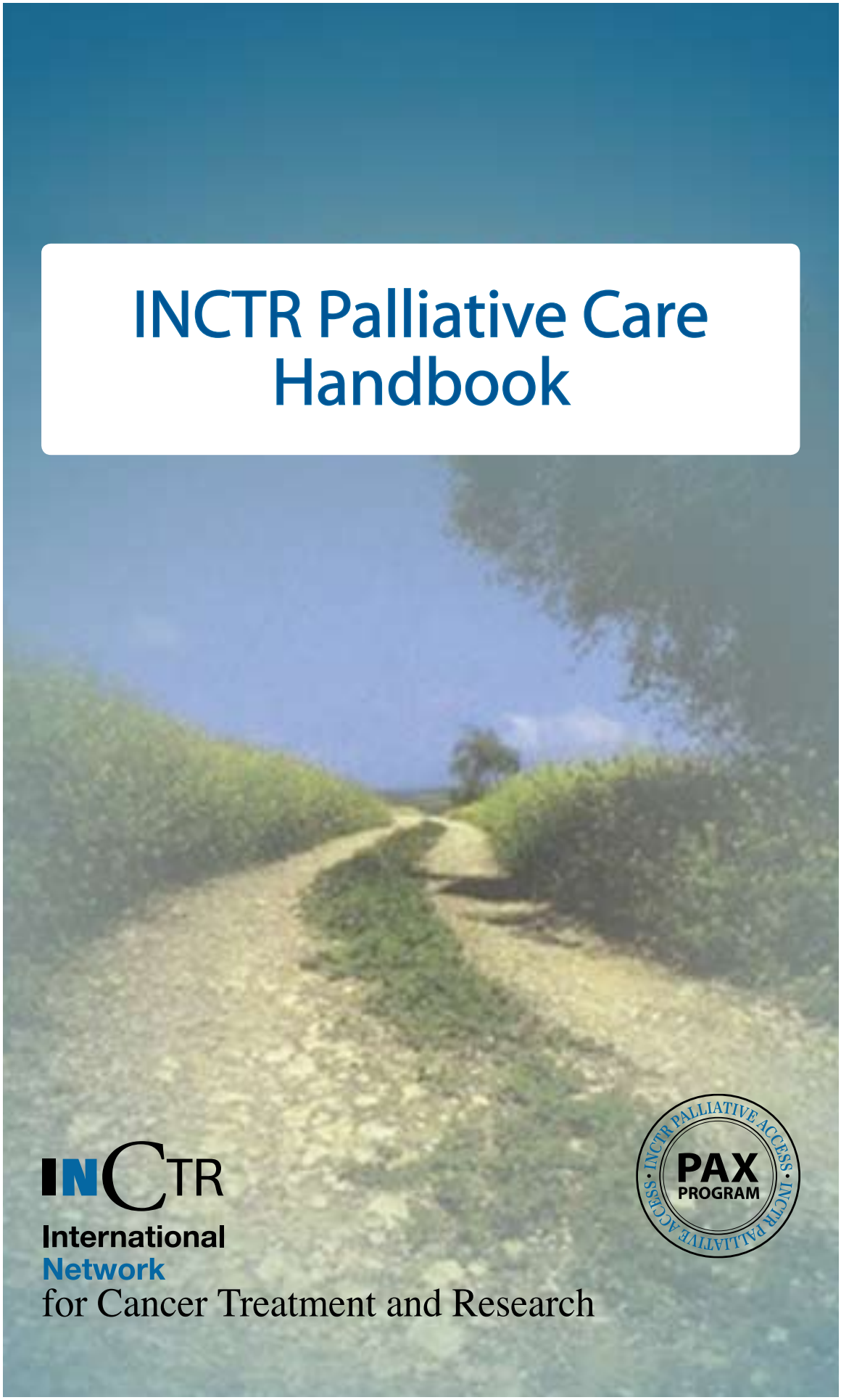
INCTR Palliative Care Handbook



INCTR
International
Network
for Cancer Treatment and Research

INCTR PALLIATIVE ACCESS · INCTR PALLIATIVE ACCESS ·
PAX
PROGRAM

INCTR

INCTR is a non-profit organization whose founder members are the International Union against Cancer and the Institut Pasteur, Brussels. The goals of the organization are to assist in controlling cancer in developing countries through the development of infrastructure for cancer treatment and research. INCTR emphasizes international collaboration and works to improve communication among the wide range of professionals and volunteers working to control cancer throughout the world.

PAX (Palliative Access) PROGRAM

The aim of the PAX Program is to help improve the delivery of good quality palliative care in resource poor areas. Our strategies are threefold: collaborative efforts to develop Regional Palliative Care Centres at various key institutions who work with INCTR, the provision of expert consulting and advisory services to national and regional governments, and the promotion of good generalist palliative care practice amongst oncology and other professionals through clinical guidelines, workshops and other means.

Endorsing Agencies

PALLIUM INDIA
CARE BEYOND CURE

BC Cancer Agency
CARE & RESEARCH
An agency of the Provincial Health Services Authority

African Palliative Care Association
APCA
Ensuring Quality - Extending Coverage

AORTIC OAREC

European School of Oncology
Learning to care

VANCOUVER ISLAND health authority

APPNA MERIT

MIDDLE EAST CANCER CONSORTIUM
MECC

Victoria Hospice

SLACOM
Sociedad Latinoamericana y del Caribe de Oncología Médica
Latin American and Caribbean Society of Medical Oncology

Division of International Health
UBC Department of Family Practice

IAEA | Programme of Action for Cancer Therapy PACT

This program was funded in part through an educational grant from Lilly Oncology. Lilly had no input into the content.

Lilly Oncology

Lilly

ISBN 978-2-9600839

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We would also like to thank our Nepali, Indian and Tanzanian colleagues as well as Dr. Ian Magrath, Benedicte Chaidron and Sophie Lebedoff for all their efforts and support.

October 2008 **INCTR Publication No. 3**

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Definition adapted from World Health Organization (WHO):
http://www.who.int/cancer/palliative/definition/en/

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FOREWORD

This handbook was created at the request of oncologists, cancer nurses, social workers and others who collaborate with the International Network for Cancer Treatment and Research (INCTR). Our hope is that this user-friendly guide will help in the management of common palliative care problems encountered in their daily work. It is, therefore, primarily aimed at those who have completed some basic training in palliative care but are not specialists in the field. We also hope that the handbook will be of benefit to people living with life limiting illnesses, other than cancer, such as HIV/AIDS. Although we have aimed at brevity there are four topics that we thought deserved special mention in this foreword. These are the philosophy of palliative care, the need for good assessment, the importance of pediatric palliative care and 'balanced care'.

The Philosophy of Palliative Care has been defined by the World Health Organization and other health care organizations in a variety of ways. In essence, it should be viewed as a holistic and interdisciplinary approach that aims to improve the quality of life of people of all ages - and their care givers - who live with life-limiting health conditions.

In general terms, palliative care:

- is both a philosophy and a clinical approach to care
- responds to physical, psychosocial, and spiritual dimensions of suffering - both of the patients and of their caregivers
- responds to people's beliefs and practices as well as their social and cultural values
- is applicable throughout the illness continuum, including bereavement
- can be applied in combination with other therapies, or may be the sole focus of care

• responds to the unique needs of children and their families

Assessment is the process of gathering information to help guide patient care. Thoughtful and thorough assessments are the foundation of good palliative care, requiring the practitioner to listen well, ask relevant questions and understand physical evaluation. However, the physical, emotional and spiritual dimensions of an illness that affect quality of life can also be further evaluated using appropriate tools. The patient is at the centre of this process, but it should also include the family and other caregivers. An on-going cycle of assessment and reassessment is vital in the management of palliative care patients who often have rapidly changing symptoms from multiple causes. Investigations, particularly those which carry a physical or psychological burden, require a balanced consideration of the patient's prognosis, his or her wishes, and any likely benefit.

Palliative Care for Children Caring for seriously ill children requires particular attention, and sensitivity to the developmental stage and cognitive abilities of the child. It is extremely important to recognize the distress parents and siblings may experience when a young child is ill, and to provide additional family support. Children often understand more about their illness than we realize or acknowledge, and it is best to answer their questions as honestly as possible. Children may also use art, drawings, or play as a way to express what they are feeling inside, and this can be a helpful way to explore a child's fears, sadness, and hopes. The management of physical symptoms in pediatric palliative care has much in common with that of adults. However, there are some differences both in medication choice and dosage. We should ensure that children

with life threatening and serious illness remain foremost in our minds and are not abandoned when cure is no longer possible. They and their parents need to be supported with compassion and understanding combined with expert symptom assessment and management.

Balanced Care Within the context of patient's wishes and prognosis it is important to balance the benefits of investigation and treatment against the burdens and possible harm. Perhaps more than any other area of medicine a balanced approach is needed in palliative care to achieve the best quality of life for our patients. Trying to decide whether or not to carry out any particular intervention (such as an investigation or a treatment) often creates a complex clinical dilemma - and sometimes an ethical one. It may be helpful to reflect on the following questions:

Is there a reasonable chance of benefit to the patient?
Is the intervention likely to improve symptoms for the patient and enhance quality of life? Is the improvement likely to be maintained? For instance a transfusion of blood may help a feeling of fatigue or breathlessness in a patient with anemia who has months of life ahead but for a patient close to death it is much less likely to make a positive contribution.

Will the intervention likely cause harm to the patient?
Most interventions will have drawbacks either in terms of physical suffering, wasting of valuable time or sometimes in raising "false hope" with either the patient or the family.
For instance, carrying out a CT scan when the result will not change the treatment but may exacerbate pain as well as create a possible expectation for disease modifying treatment (when none is planned) should be avoided.

Is the intervention a proper use of available resources (justice)?
In most situations medical resources are limited and have to be used in a fair manner. For instance, in a situation where there is a shortage of platelets for transfusion these may to have be reserved for patients who are having curative treatment rather than those with terminal illness.

Having tried to find a balance between these elements one should ask: *What are the patient's wishes?*
When appropriate, the patient should be informed of the possible benefits and drawbacks of the intervention and his or her wishes identified. Their beliefs, developmental stage, cognitive abilities and life experiences (especially that of their illness) will influence their decision making and should be taken into consideration. The family or other caregivers are often a part of this process.

Caring for children creates an added complexity. Sometimes children's wishes may differ from their adult caregivers. Special effort should be made to try and understand the needs and wishes of all concerned.

Since the material in this handbook is summarized it should be interpreted in the context of other materials and textbooks.

Anorexia and Cachexia

KEYPOINTS

- Cancer and other diseases, such as HIV/AIDS, can often cause a lack of appetite (anorexia) and weight loss with muscle wasting (cachexia)
- These are often accompanied by fatigue
- The process of anorexia/cachexia is complex and involves numerous metabolic changes
- Anorexia/cachexia is present in up to 80% of patients with cancer
- Children with solid tumours are more likely to develop cachexia than with haematological malignancies
- Seeing a child not eating may be very distressing for family

ASSESSMENT

see comment on page 13

- A good history and clinical assessment is important to try and identify any reversible cause of the anorexia/cachexia
  - Assess appetite
  - Assess ability/difficulty in swallowing and chewing
  - Identify any other symptoms such as pain, constipation, depression, or nausea and vomiting that may be causing decreased appetite
  - Examine the mouth for any sores, lesions or infection
- Treatable causes of anorexia/cachexia include:
  - Ongoing pain
  - Nausea and vomiting
  - Depression
  - Oral problems
    - Dry mouth

- Mucositis secondary to chemotherapy
- Thrush/candidiasis
- Oral herpes

- Gastrointestinal motility problems
  - Reflux oesophagitis
  - Gastric stasis
  - Constipation

❍ As in adults: evaluate possible correctable conditions that affect appetite and feeding such as nausea, pain, oral conditions, constipation and depression

MANAGEMENT

Consider treatment of the underlying cause if one is identifiable ***Consider if patient is well enough to benefit***

NONPHARMACOLOGIC APPROACHES

- Patient and family education
- Eliminate dietary restrictions
- Encourage patient to eat their favourite foods

PHARMACOLOGIC APPROACHES

- Ensure good pain and nausea/vomiting control, treat constipation
- Stimulate appetite
  - **Megestrol acetate 40-240 mg up to four times a day PO or 800 mg once daily PO**
  - **Dexamethasone 4-8 mg qAM PO**

❍ As in adults: Corticosteroids may help appetite. However, because of potential significant adverse side effects they should probably not be used if anorexia/cachexia is the only symptom they might benefit

PITFALLS/CONCERNS

❍ Increasing calorie intake is unlikely to increase body weight and quality of life in advanced cancer cachexia

PALLIATIVE TIPS

❍ Despite the appearance of malnutrition, anorexia/cachexia is usually NOT simply reversed with improved nutrition

❍ Aggressive feeding can often make symptoms such as nausea, vomiting and pain worse

❍ Educating the family that wasting is a part of the disease process and not the result of the family not providing enough nutrition for the patient is important

❍ Anorexia can cause significant anxiety and distress for family members and caregivers who may not understand that loss of appetite is a common symptom of dying

❍ There is no evidence that providing nutritional support either enterally or parenterally improves morbidity or mortality in terminally ill patients

❍ Smaller, more frequent meals of the child's favourite foods may help

❍ Small plates and using straws may also may help

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Ascites

KEYPOINTS

- Ascites is reported in 15-50% of patients with malignancy
- 10% of all cases of ascites are from malignancy. Non-malignant ascites may also be seen in cancer patients (from other causes), and non-cancer palliative patients may have ascites (cirrhosis, CHF, tuberculosis etc)
- Ascites is common in ovarian, breast and GI malignancies (30% of ovarian cancer patients develop ascites)
- The prognosis is poor so the goal is usually comfort with minimal disturbance (exception is ovarian cancer which may still have a moderate prognosis)
- Paracentesis is safe in children
- Children may fear invasive procedures such as paracentesis. It is important to explain what will happen and gain the child's consent, depending on his or her ability to understand

Consider if patient is well enough to benefit

ASSESSMENT

see comment on page 13

- Clinical features include abdominal swelling, bloating, weight gain, reflux, and dyspnea
- Exam may reveal increased abdominal girth, bulging flanks, shifting dullness
- Investigations to consider are ultrasound, diagnostic paracentesis (cytology, albumin, bacterial culture), serum electrolytes and albumin
- Malignant ascites may be caused by liver disease/ metastases leading to portal hypertension, intra-abdominal metastases/peritoneal seeding, lymphatic obstruction and leakage (chylous ascites), or a combination of these

MANAGEMENT

- Consider treatment of the primary tumour (particularly with ovarian cancer), but usually the cancer is advanced and the prognosis is poor
- Diuretics can be helpful in some patients with ascites. Serum electrolytes (Na, K) may need to be followed. Diuretics are unlikely to be helpful in chylous ascites (accumulation of lymph in the peritoneal cavity characterized by increased triglyceride concentrations)
- Paracentesis is best for immediate symptom relief, if the ascites does not respond to diuretics and for chylous ascites

- Pharmacologic Management
  - **Spironolactone** starting with 50 mg/day and increasing up to 400 mg/day if required
  - **Furosemide** starting at 40 mg/day and increasing up to 160 mg/day if required

- Paracentesis
  - This is a simple procedure that can be done at the bedside or with ultrasound guidance (recommended if there is diagnostic uncertainty, possible loculations or uncertainty about catheter placement due to tumor masses)
  - Remove the drain after 6 hours, after 5 liters have drained or when the drainage has stopped
  - A small number of patients (<5%) may deteriorate rapidly after paracentesis. Sepsis and catheter blockage are other complications
- Intravenous fluids and albumin infusions are not routinely required (unless hypotensive, dehydrated, or severe renal impairment)

- During paracentesis; check vital signs
- Remove the quantity of fluid that gives optimum symptomatic relief
- Not more than 10% of body fluid by volume/24hrs

PITFALLS/CONCERNS

In patients in the final terminal phase – ie. hours to days, it would be normally inappropriate to drain the ascites (treatment should be as least invasive as possible)

In patients in the final terminal phase – ie. hours to days symptomatic relief through pharmacologic and other means would be preferred

PALLIATIVE TIPS

- Drain for symptomatic relief, not just because the fluid is there
- If the drain site keeps leaking afterwards, an ostomy bag over the site is helpful in containing the fluid
- Some patients who rapidly re-accumulate fluid despite high dose diuretics may benefit from an indwelling catheter. If the prognosis is many weeks, consider a tunneled catheter to reduce infection risk
- Patients with ascites from cirrhosis may benefit from sodium restriction. The benefit of this must be weighed against unnecessary discomfort from dietary restriction
- **Octreotide** may be useful in controlling ascites

METHOD OF PARACENTESIS

- If there is substantial ascites (tense abdomen), it is probably safe to proceed without ultrasound
- With patient semi-recumbent and with an empty bladder, choose a puncture site below the umbilicus in the midline

or the LLQ at the anterior axillary line below the level of percussible dullness

- ❍ Using sterile technique, prep the skin with antiseptic and infiltrate local anaesthetic
- ❍ Retract the skin inferiorly; insert a 14-16 g needle or catheter that is attached to a drainage tube (IV extension tube)
- ❍ Gravity drain to dryness or a total of 5-6 liters into a container
- ❍ Withdraw the needle allowing the skin to return to the original position (creates a Z-track and lowers the post procedure leakage)

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Bleeding

KEYPOINTS

- ❍ Bleeding can sometimes occur in cancer especially as the disease progresses
- ❍ Patients and families can be very distressed by even small amounts of visible bleeding

ASSESSMENT

see comment on page 13

- ❍ It is important to make an assessment of the cause, the severity, and the prognosis of the patient when assessing bleeding
- ❍ When appropriate carry out relevant tests including a coagulation screen

MANAGEMENT

- ❍ Treatment of bleeding in palliative patients depends on the patient's prognosis and whether the treatment is likely to be effective ***Consider if patient is well enough to benefit***

General Measures

- ❍ Reassure and explain the situation to patient and family
- ❍ General supportive measures including fluid replacement if the bleeding is severe
- ❍ Stop medications such as NSAIDs or anticoagulants that may be causing or exacerbating the bleeding
- ❍ Consider correcting any abnormal clotting ie. with Vit K or fresh frozen plasma if available

Transfusion when appropriate (see appendix 6)

- ❍ Packed red cells
- ❍ Platelets

Other

- **Tranexamic acid**, adult: 1G tid PO or IV,
  10-20 mg/kg/dose bid to tid IV;
  25 mg/kg/dose tid to qid PO
- Consider haemostatic radiation or embolisation

Bleeding from a wound/ulcer

- Apply steady pressure
- **Adrenaline/epinephrine** (1;1000) impregnated dressings

Bleeding from GI Tract

- Stop NSAIDS and reduce and discontinue steroids if possible
- Start **omeprazole**, **ranitidine** or similar medication
- Endoscopy if possible and if warranted

Bleeding from Bladder

- May benefit from continuous bladder irrigation and instillation of haemostatic agents
- If well enough consider cystoscopy/diathermy
- **Tranexamic acid** should be used with caution in genitourinary bleeding as clot formation may be problematic

Bleeding from mouth/gums

- Cautious cleaning of the mouth
- **Tranexamic acid** IV liquid (50% diluted with water) as mouthwash may be useful

Bleeding from nose

- Can be stopped by continuous pressure
- Use silver **nitrate sticks**
- Packing for 15 minutes with gauze soaked in 1;1000 **adrenaline/epinephrine**

Massive Haemorrhage in Terminal Phase

- Stay with patient
- Reassure family
- If appropriate sedate patient with **midazolam** 5 mg-10 mg SC/IV stat
- Use red, green or blue towels to disguise blood

PITFALLS/CONCERNS

- If a massive haemorrhage is likely at some stage the family and patient should be prepared for this as far as is possible
- Do not use **tranexamic acid** when disseminated intravascular coagulation (DIC) is suspected

PALLIATIVE TIPS

- Patients with advanced liver disease or renal failure may develop abnormal clotting complicating this problem. (In addition, they may have been started previously on anti-coagulants for another problem)

Constipation

KEYPOINTS

- Prevention is the most important part of treatment
- Constipation is defined as the infrequent and difficult passage of hard stools
- Constipation may be related to the disease, the treatment or may be unrelated
- The prevalence of constipation in palliative care patients is 29-86%
- Constipation can be a distressing symptom for patients and cause other problems such as nausea and vomiting, abdominal pain, or if left untreated, bowel obstruction
- Preventing and relieving constipation can improve quality of life
- Normal frequency of bowel movements varies between individual children
- Painful dry stools should be taken to indicate constipation

ASSESSMENT

see comment on page 13

- Taking a thorough history and performing a good clinical assessment (including rectal exam to assess for the presence of hard stool in the vault and rule out impaction) is important to try and identify the underlying cause(s) of the constipation
- Causes of constipation can include: opioids or other medications, dehydration, mechanical obstruction, immobility, emotional stress, decreased oral intake, and electrolyte imbalances
- Investigations to consider may include: abdominal x-ray to assess bowel gas pattern and rule out ileus or bowel obstruction
- Mass in (L) lower quadrant may be present
- Rectal exam may show impacted faeces, fissure or tumour

MANAGEMENT

- Mild constipation
  - ***If possible***
    - Increase fluids
    - Increase fibre ***(if not accompanied by increase in fluids may make constipation worse)***
    - Increase activity
- Mild or moderate or <u>when initiating opioids</u>
  - As above + stool softener, i.e.
    - **Docusate 100-200 mg bid PO** <u>as well as</u> a peristaltic agent:
    - **Bisacodyl 5-15 mg bid PO or**
    - **Senna two tabs PO at HS, increase to bid if necessary PO**
- No stool for 3 days and stool in rectum
  - As above +
  - **Lactulose or sorbitol 70% 15-30-cc PO/BID,**
  - **<u>Glycerine</u>** and **<u>dulcolax</u>** <u>suppositories</u>
  - <u>Fleet or **saline enema**</u> if suppositories not effective
- Constipated stool in rectum
  - Disimpaction if indicated
- As with adults, try to prevent constipation by adding laxatives when starting opioids:

  Docusate
  - <3 years: 10-40 mg/24hrs bid PO
  - 3-6 years: 20-60 mg/24hrs bid PO
  - 6-12 years: 40-120 mg/24hrs bid PO

  Bisacodyl
  - 6-12 years: 5-10 mg once daily PO

Senna

- 2-6 years: one half daily to one tab bid PO
- 6-12 years: one tab daily to two tabs bid PO

Lactulose

- 1month-1 year: 2.5 mls BID PO
- 1 year-5 years: 5 mls BID PO
- 5-10 years: 10 mls BID PO
- 10-18 years: 15 mls BID PO

… and adjust according to response

PITFALLS/CONCERNS

In patients in the final terminal phase, ie. hours to days, it may be inappropriate to treat obstruction or constipation

- Do not use enemas or suppositories in children with neutropenia and thrombocytopenia
- Children with constipation may have developed rectal tears complicating the problem

PALLIATIVE TIPS

- Bowel regimens should be individualized and titrated to patient response
- A bowel regimen should be initiated at the time opioids are started and should be continued for as long as the patient takes opioids
- Urinary retention, nausea and vomiting, terminal restlessness, and other symptoms can sometimes be relieved by treating constipation
- As with adults, encourage increased fluid intake and exercise when appropriate

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Cough

KEYPOINTS

- Cough may be related to the disease, the treatment or may be unrelated
- Cough can be a distressing symptom for the patient and interfere with sleep
- Using cough suppressants (e.g. **codeine, morphine**) can bring symptomatic relief and improve quality of life
- Coughing can be very exhausting for both the child and the family

ASSESSMENT

see comment on page 13

- A good clinical assessment is important to try and identify the underlying cause of the cough (e.g. pneumonia, CHF, pleural effusion, asthma, etc)
- Investigations to consider may include:
  - Chest x-ray to assess possible cause

MANAGEMENT

- Consider treatment of the underlying cause (e.g. oncological treatment of tumour, draining of pleural effusion, treatment of infection, gastroreflux disease)
  Consider if patient is well enough to benefit
- Simple measures such as moist inhalations or **nebulized 0.9% saline** can be helpful
- Simple cough suppressant may be tried
- A weak opioid such as **codeine 15-30 mg q4h PO** or **dextromethorphan 30 mg (or higher doses) q4h PO** can be used to suppress cough
- **Morphine** should be used if the cough is not suppressed by **codeine** or other means

The initial starting dose will depend on the patient's previous exposure to opioids

- A dose of **morphine 2.5 mg regularly q4h PO (or 1 to 2 mg SC/IV)** and a breakthrough or rescue dose every hour, as required (see Appendix 1) is suitable for an opioid-naive patient
- A dose of **morphine 5-10 mg regularly q4h PO (or 2.5 - 5 mg q4h SC/IV)** and a breakthrough or rescue dose every hour, as required (see Appendix 1) should be used for patients who have already been on **codeine**
- For a patient already on **morphine** an increase in the dose by 20% may improve the cough

- Also consider a trial of **dexamethasone 8 mg qAM PO**
- Inhaled corticosteroids or **sodium cromoglycate** may be helpful
- For refractory symptoms consider nebulized local anaesthetics such as **lignocaine/lidocaine 5 ml of 2% solution (without adrenaline) prn**
- If tenacious secretions are difficult to clear with coughing:
  - Consider using **moist inhalations**
  - **Nebulized hypertonic saline** can be effective
  - Try **normal saline** if this is not available
- Children with persistent non productive cough (like adults) will benefit from opioids

Codeine

- Children more than 6 months: 0.5-1.0 mg/kg q4h PO (max 60 mg/dose)

Morphine

- Starting doses for opioid naïve infants less than 6 months: 0.01 mg/kg q4h SC/IV, or 0.02 mg/kg q4h PO

- Starting dose for opioid naïve infants/children more than 6 months:
  0.02 mg/kg q4h SC/IV, or 0.04 mg/kg q4h PO

PITFALLS/CONCERNS

In patients in the final terminal phase – ie. hours to days, antibiotics will make little difference to the course of events

PALLIATIVE TIPS

- A bedtime dose of **codeine or morphine** can help suppress the cough and allow for an undisturbed sleep

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Delirium

KEYPOINTS

- Delirium (with or without hallucinations) is commonly experienced by patients with advanced illnesses
- Possible causes are many, may be multifactorial and difficult to determine in about 50% of cases
- Delirium or confusion can be caused by the opioids themselves, and/or the accumulation of opioid neurotoxic metabolites
- There are many causes of delirium and hallucinations in children
- May be due to fatigue only

ASSESSMENT

see comment on page 13

Non opioid causes include:

- Dehydration*
- Hepatic and renal failure*
- Urinary retention
- Infection e.g. urine infection
- Constipation
- Brain metastasis
- Biochemical imbalances, i.e. hypercalcemia, hyponatremia
- Medications, i.e. tricyclics, **corticosteroids**, **benzodiazepines**
- Hypoxia

** delirium possibly caused by accumulation of opioids and their metabolites*

MANAGEMENT

Consider if cause of delirium identifiable and if patient well enough for intervention

- Discontinue drugs that may be causing the delirium (such as anticholinergics, etc)

- A trial of hydration if the patient's condition would tolerate this. (May help correct electrolyte disturbances and may diminish opioid toxic metabolite accumulation)
- Correct electrolyte imbalance; hypercalcemia may respond to hydration and/or to biphosphonates such as **pamidronate 60-90 mg (single dose) IV**

PHARMACOLOGIC MANAGEMENT

If symptoms persist, pharmacological management includes:

1) Neuroleptics
   - **Haloperidol** is commonly used.
   - **Chlorpromazine** may be more effective in cases of severe agitation

NEUROLEPTICS		via
Haloperidol	0.5-5 mg bid + q4h	PO/SC/IV
Chlorpromazine	15-50 mg bid	PO/IV
Risperidone	0.5-4 mg bid	PO
Olanzepine	2.5 mg qhs-10 mg od to bid	PO

2) Benzodiazepines
   - **Lorazepam** or **midazolam** can also be used in situations where there is considerable agitation. It should be noted however that benzodiazepines can sometimes make confusion worse and should not be used alone for the treatment of delirium

BENZODIAZEPINES		via
Lorazepam	0.5-2 mg bid to qid + q1h prn	PO/SC/IV/PR
Midazolam	5-60 mg/24h via infusion	SC/IV

3) Opioid rotation (if alternative opioids available)
   - ***Opioid rotation (switching from one opioid to another) can be helpful for some patients who do not respond to the addition of neuroleptics or benzodiazepines. This is especially so in patients who may have renal failure in whom metabolites from morphine can accumulate. If an opioid rotation is done, establish the equianalgesic dose from an equianalgesic table, and start the new opioid at 25-50% of the equianalgesic dose. (See Appendix 3). This is to take into account that there is a large variability between individuals in response to various opioids***

- Try to prevent delirium by ensuring regular sleep
- Use familiar stories and music etc.

Haloperidol
- 0.05-0.15 mg/kg/24hrs as continuos infusion or in divided doses bid or tid PO/SC/IV

If agitated delirium consider addition of:

Lorazepam
- 25-50 mcg/kg (max 1 mg) as single dose or q4-8h PO/SL

Midazolam
- 500 mcg/kg (max 10 mg) SL as single dose
- 100 mcg/kg SC as a single dose
- 300-700 mcg/kg over 24 hours as continuous infusion

PITFALLS/CONCERNS

- Antihistamines may cause paradoxical agitation and confusion
- Benzodiazepines can be useful in children in controlling agitation but at higher doses may worsen delirium in some children

PALLIATIVE TIPS

- If opioids are suspected as the cause of delirium, it is important to realize the symptoms may disappear after a few days of stable dosing of the opioid. Thus, unless the symptoms are severe, it is recommended to treat them pharmacologically (e.g. as with a neuroleptic) initially, prior to deciding on changing the opioid
- The newer atypical antipsychotics such as **risperidone** and **olanzapine** can also be used effectively and offer the advantage of less antiparkinsonian/anticholinergic side effects
- Adequate lighting, keep noise to low level and keep family present

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Dyspnea

KEYPOINTS

- Dyspnea has a prevalence of 50% in people with any type of cancer (not just lung cancer)
- Dyspnea is moderate to severe in more than 28% of terminally ill cancer patients
- Opioids (e.g. **morphine**) play an important and effective part in the management of dyspnea
- Dyspnea (like pain) is a subjective symptom and therefore it is important to ask the patient about their feelings of dyspnea rather than rely on clinical exam findings
- Breathlessness is common in children in the terminal stages of life

ASSESSMENT

see comment on page 13

- A good clinical assessment is important to try and identify the underlying cause of the dyspnea (e.g. pneumonia, CHF, pleural effusion, etc)
- Investigations to consider may include:
  - Chest x-ray to assess possible chest disease
  - CBC to rule out anaemia or infection
  - Oxygen saturation (not necessarily arterial blood gases) can sometimes be helpful
- Dyspnea (like pain) is a subjective experience, so simply asking a child 'is your breathing troubling you?' can be very helpful in assessment. However, tests such as carbon dioxide/oxygen saturation or spirometry have not been shown to relate closely to the actual experience of dyspnea.
- Validated assessment tools for children suffering from dyspnea are available e.g. the Dalhousie Dyspnea Scale

MANAGEMENT

- Consider treatment of the underlying cause (e.g. oncological treatment of tumour, draining of pleural effusion, treatment of infection, COPD, CHF, etc.)
  Consider if patient is well enough to benefit
- Simple measures such as repositioning, opening a window or providing a fan and relaxation techniques can be very helpful
- Ensure patients do "not feel trapped" by being crowded by people and equipment
- Oxygen may or may not be helpful for dyspnea and is not necessary for all patients. For some patients it may make their feeling of dyspnea worse to have their face covered by an oxygen mask or nasal prongs.
  Treat the patient's symptoms, not the lab test (i.e. the oxygen saturation)
- Fresh air may be as helpful as oxygen for many patients
- **Morphine and other opioids** are an effective treatment for dyspnea. The initial starting dose will depend on the patient's previous exposure to opioids
  - A dose of **morphine 2.5 mg regularly q4h PO (or 1 to 2 mg SC/IV)** and a breakthrough or rescue dose as required (see Appendix 1) is suitable for an opioid-naive patient
  - A dose of **morphine 5-10 mg regularly q4h PO (or 2.5–5 mg q4h SC/IV)** and a breakthrough or rescue dose as required (see Appendix 1) should be used for patients who have already been on **codeine**
  - Patients who are already on strong opioids for pain will usually benefit from an increase in their regular dose
  - Titrate **morphine** in the same way as for pain management - see guideline on pain (some patients may require high doses for dyspnea)

Benzodiazepines, corticosteroids and bronchodilators may also be helpful

- Correctable causes of dyspnea in children such as anemia, infection and effusion can be treated
  Consider if patient is well enough to benefit
- As with adults, opioids such as **morphine** are accepted as an important and effective treatment for dyspnea in advanced cancer and other diseases;

Morphine

- Starting doses for opioid naïve infants less than 6 months:
  0.01 mg/kg q4h SC/IV, or 0.02 mg/kg q4h PO
- Starting dose for opioid naïve infants/children more than 6 months:
  0.02 mg/kg q4h SC/IV, or 0.04 mg/kg q4h PO

- Benzodiazepines, corticosteroids and bronchodilators are also useful.

Lorazepam

- 25-50 mcg/kg (max 1 mg) as single dose or q4-8h PO/SL

Midazolam

- 500 mcg/kg (max 10 mg) SL as single dose
- 100 mcg/kg SC as a single dose
- 300-700 mcg/kg over 24 hours as continuous SC infusion

Dexamethasone

- 2-5 years: 0.5-1 mg bid PO/IV (if IV give over 3-5 minutes);
- 5-12 years: 1-2 mg bid PO/IV (if IV give over 3-5 minutes)

Salbutamol (Ventolin) nebulizer solution

- 6 months - 5 years: 2.5 mg prn/q4h;
- 5-12 years: 5 mg prn/q4h via nebulizer

Ipratropium (Atrovent) nebulizer solution

- 1-5 years: 125 mcg prn/q6h;
- 5-12 years: 250 mcg prn/q6h via nebulizer

PITFALLS/CONCERNS

In patients in the final terminal phase – ie. hours to days, antibiotics will make little difference to the course of events even if infection is suspected

Intubation is not appropriate for palliative care patients

- Fear of using opioids in children can result in unnecessary suffering at the end of life

PALLIATIVE TIPS

- Remember to ask the patient about their feelings of dyspnea – physical examination findings and medical staff's observations of tachypnea or perceived difficulty in breathing do not always correlate with the level of distress
- Educating the patient about dyspnea can reduce the anxiety that patients feel when short of breath
- Sedation may be needed in severe cases
- Psychological treatment such as reassurance by adults and calm surroundings are helpful
- As with adults supplemental oxygen titrated to comfort can be helpful

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Hiccups

KEYPOINTS

- Hiccups (singultus) are repeated involuntary contractions of the diaphragm and respiratory muscles
- There are close to 100 different causes of hiccups - causes may be natural or drug-induced
- Gastrointestinal causes are the most common cause of hiccups
- Hiccups can be extremely distressing and can lead to fatigue and sleep disturbance
- Treatment options include both pharmacologic and non-pharmacologic approaches

ASSESSMENT

see comment on page 13

- A good clinical assessment is important to try and identify the underlying cause of the hiccups. Finding the cause (if possible) can often help direct treatment

Causes of hiccups include:

1. (Most common) gastric distension or gastro-oesophageal reflux disease
   - Overload
   - Obstruction
   - Gastritis or oesophagitis
2. Irritation of the diaphragm
   - Hepatic and other tumours
   - Infection or inflammation
   - Ascites
3. Other problems involving the thorax or abdomen
   - Pneumonia
   - Pericarditis
4. Pancreatitis
5. Medications
   - e.g. corticosteroids
6. Metabolic problems
   - Renal failure/uraemia
   - Hyponatremia
7. Intracranial disease
   - Tumours - especially brain stem lesions
8. Infection
9. Idiopathic (unknown cause)

MANAGEMENT

- Consider treatment of the underlying cause if one is identifiable
  Consider if patient is well enough to benefit
  - Remove offending pharmacologic agents
  - Correct imbalances/infections if possible
- If due to gastric distension
  - Decrease gastric distension by encouraging smaller more frequent meals
  - Use a prokinetic drug such as **metoclopramide 10 mg qid PO or domperidone 10 mg qid PO**
  - **Simethicone/dimethicone containing agents 5 mls qid PO and prn** may help to decrease gas and distension
- If due to gastro-oesophageal reflux provide treatment such as **omeprazole 20 mg once a day PO**
- If a cause can not be identified or corrected then general measures should be used
- General non-pharmacologic measures (many different measures have been suggested):
  - Pharyngeal stimulation
    - Eating 1-2 teaspoons of sugar or crushed ice

- Lightly rubbing the midline of the soft palate for 1 minute
- Long slow slips of water

- Breath holding or rebreathing into a bag
- Passage of a naso-gastric tube
- Massage of external auditory canal

❍ General pharmacologic measures
(many have been tried – little evidence of efficacy exists):

- **Baclofen 5-10 mg tid PO** has been shown to be effective in intractable hiccups
- **Chlorpromazine 10-25-50 mg qid PO**
- **Nifedipine 10-20 mg bid to tid PO**
- **Haloperidol 1-5 mg every 4-12 hours PO/SC/IV**
- Anticonvulsants (starting doses)
  - **Phenytoin 200-300 mg HS PO**
  - **Gabapentin 300 mg HS PO**
  - **Carbamazepine 100-200 mg bid PO**
  - **Clonazepam 0.5-1 mg bid PO**
- Consider SSRI's

Metoclopramide
- 0.1 to 0.2 mg/kg/dose q6h PO/SC/IV

Chlorpromazine
- 0.5-1 mg kg/dose every 4-6 hrs PO or every 6-8 hrs IV

Haloperidol
- 0.05-0.15 mg/kg/24hrs in divided doses BID or TID PO/SC/IV

Phenytoin
- 4-8 mg/kg/24hrs in divided doses bid or tid PO

Gabapentin
- 10-30 mg/kg/24hrs in divided doses tid PO

Carbamazepine
- Less than 6 years: 10-20 mg/kg/24hrs in divided doses bid or tid PO
- Over 6 years: 100 mg bid PO

PITFALLS/CONCERNS

❍ ***The same agents that are used to treat hiccups may also cause them !***

❍ Although sometimes used to treat hiccups some reports suggest that benzodiazepines may cause or exacerbate hiccups

❍ **Metoclopramide** and **haloperidol** (and other neuroleptics) can cause extra pyramidal reactions in children and can be used in combination with **diphenhydramine** to reduce likelihood of this

PALLIATIVE TIPS

❍ Gastric distension and gastro-oesophageal reflux disease are the most common cause of hiccups and a trial of treatments as outlined above should be considered

❍ Combinations of agents is sometimes required for intractable hiccups

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Malignant Bowel Obstruction

KEYPOINTS

- Has been reported in 5-15% of cases of advanced cancer
- 5-40% of ovarian cancer and 5-24% of bowel cancer
- Signs and symptoms of bowel obstruction may not be 'classic' in advanced malignant disease
- May resolve spontaneously especially in early stages
- Oral administration of medications is unreliable
- The "goals of care" must be clear: *"is this a patient that we would consider for surgery, oncological treaments or comfort only?"*
- In children non malignant causes such as volvulus or intususception should be kept in mind

ASSESSMENT

see comment on page 13

- Clinical features may include pain, nausea, vomiting, abdominal distension and reduced or absent passing of faeces or flatus
- Investigations to consider for diagnosis may include:
  - Abdominal x-rays to demonstrate fluid levels
- If surgical intervention is a possibility, consider imaging (CT or contrast plain films) to help define level of obstruction (gastrograffin is preferable as may be useful in restoring bowel function in some cases)

MANAGEMENT

PHARMACOLOGICAL TREATMENT

- **SYMPTOM MANAGEMENT OR POSSIBLE REVERSAL OF BOWEL OBSTRUCTION**
  - In many cases, reversal of the bowel obstruction or marked reduction in symptoms may be possible by using a combination of corticosteroids, prokinetic, antiemetic and antisecretory drugs.
    A trial of **dexamethasone 16 mg/day SC/IV, metoclopramide 10-30 mg qid SC/IV and haloperidol 1-2 mg/24 SC/IV** is used for 3 to 5 days. **Octreotide** may be added or substituted for the **metoclopramide**
  - **Hyoscine butylbromide** can also reduce colic and secretions but is less effective

- **PAIN CONTROL**
  - Use of appropriate opioid analgesics such as **morphine SC/IV** as outlined in the section on pain is the mainstay of treatment
  - For colic add: **hyoscine butylbromide 20 mg q6h/prn SC or hyoscine hydrobromide 0.4 mg sc q4h prn**

- **NAUSEA AND VOMITING**
  - **Haloperidol 2-4 mg/24hrs PO/SC/IV in divided doses**
  - **Metoclopramide 10-30 mg qid SC/IV or as infusion** ***(Metoclopramide may increase colic as it is a prokinetic agent and therefore should be monitored closely and discontinued if the patient experiences more pain)***
  - **Dexamethasone 16 mg/day SC/IV:** can be helpful to reduce nausea and vomiting, increase water and salt absorption form G.I. tract, reduce peritumoral oedema and alleviate obstruction. Give for a 5-day trial, reduce dose as tolerated or discontinue if not helpful
  - **Octreotide 200 mcg-500 mcg in divided doses (bid or tid) SC or 300-1200 mcg/24hrs by SC infusion:** can be useful especially in cases where there is high volume emesis

NON-PHARMACOLOGICAL TREATMENT

- **NASOGASTRIC TUBE** will relieve some patients especially with high level obstruction

  This is usually reserved for patients with frequent or severe symptoms. Usually short term use only while waiting to see if pharmacological management is effective.

  If necessary for control of symptoms, conversion to a venting gastrostomy tube is beneficial

- **BY-PASS SURGERIES AND STENTING** may be considered in selected patients depending on the nature of the obstruction, condition of the patient, prognosis and likely benefit

HYDRATION

- Administration daily of 1-1.5 L solution containing electrolytes (+/- glucose) IV or SC may be useful in maintaining electrolyte balance and preventing adverse effects such as opioid toxicity and delirium.
- Hydration may also cause some symptoms to worsen due to increased third spacing and oedema

Metoclopramide
- 0.1 to 0.2 mg/kg/dose q6h PO/SC/IV

Haloperidol
- 0.05-0.15 mg/kg/day bid/tid PO/SC/IV

Dexamethasone
- 2-5 years; 0.5-1 mg bid PO/IV (if IV give over 3-5 minutes);
- 5-12 years: 1-2 mg bid PO/IV (if IV give over 3-5 minutes)

Octreotide
- 1-10 mcg/kg/24h SC/IV

PITFALLS/CONCERNS

- ***In patients in the final terminal phase – ie. hours to days, invasive treatments should be minimized***
  - ***Prolonged use of nasogastric tubes can cause considerable distress as well as medical complications***
  - ***Hydration should be tailored to individual needs; beware of over-hydration***
  - ***If the bowel obstruction does reverse it may recurr at some point in the future***
- **Metoclopramide** and **haloperidol** (and other neuroleptics) can cause extra pyramidal reactions in children and can be used in combination with **diphenhydramine** to reduce likelihood of this

PALLIATIVE TIPS

- 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
- Treatment should be initiated early
- Hydration may be given by SC infusion (hypodermolysis) up to 80 cc/h
- In cases of partial obstruction with constipation; continue stool softeners (**docusate**) but stop stimulants (**senna and bisacodyl**) if colic is a problem. Try rectal measures such as suppositories

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Malignant Spinal Cord Compression

KEYPOINTS

- A palliative care emergency
- Common in multiple myeloma, prostatic, renal and breast cancer
- Can occur with sarcoma (Ewings especially), but also neuroblastomas, germ call tumours, lymphomas and primary CNS tumours

- Many patients can live a relatively long time with added burden of paralysis

ASSESSMENT

see comment on page 13

- A high level of suspicion is required. Increasing back pain is often the earliest sign, with sensory, motor and neurological symptoms occurring later on

MANAGEMENT

- While awaiting confirmation by imaging; initiation of high doses of steroids (**dexamethasone** 20 mg od or more in adults)

Dexamethasone
- 1-2 mg /kg/PO/IV

- Once confirmed; emergency referral for radiation therapy or sometimes for surgical decompression ***Consider if patient is well enough to benefit from investigation or treatment***

PITFALLS/CONCERNS

- Delay in diagnosis or treatment may result in preventable paralysis

PALLIATIVE TIPS

- Back pain exacerbated by the Valsalva manoeuvre should increase suspicion for developing cord compression

Malignant Ulcers or Wounds

KEYPOINTS

- Malignant ulcers or wounds can be caused by direct invasion of the skin by a primary tumour or by metastasis to the skin
- These wounds can have both ulcerative and fungating features
- Odour and discharge are common problems with malignant wounds
- Pain, infection and bleeding can also occur
- The psychological distress to the patient or caregivers caused by these wounds should also be addressed
- These wounds rarely heal but the symptoms can usually be controlled with good assessment and management
- Malignant wounds occur in 5-10% of patient with metastatic disease, most commonly in breast cancer and melanoma
- Rare in children; can occur with rhabdomyosarcomas

ASSESSMENT

see comment on page 13

- A clinical assessment is usually all that is required
- It is important to review the symptoms of odour, discharge, pain, bleeding and psychological impact when assessing the wound
- Swab cultures can sometimes be helpful to determine the need for antimicrobial treatment.
  Local bacterial colonization of the wound is expected and should be treated with topical cleansing, debridement as appropriate, and antimicrobial creams.
  If there are signs of systemic infection, the use of oral or intravenous antibiotics may be considered
- Wound location, size, appearance, exudate, odour, condition of surrounding skin, and pain should all be assessed
- The potential for serious complications, such as hemorrhage, vessel compression, or airway obstruction should be evaluated and a plan developed for management

MANAGEMENT

- **Cleaning the wound**
  - Wound cleansing reduces odour by removing necrotic tissue and decreasing bacterial counts
  - Gentle irrigation of the wound with normal saline is helpful and can be done as often as needed
  - Good handwashing is very important in caring for malignant wounds
  - Local debridement can be performed by *very gently* scrubbing the necrotic areas with gauze saturated with saline or wound cleanser. This must be done carefully and gently to avoid bleeding or pain
  - Topical antimicrobial ointments or creams can be helpful

- **Exudate/Discharge**
  - The inflammation and oedema of malignant wounds can cause significant exudate (drainage)
  - Dressings should be selected that can best conceal the wound, absorb exudate and reduce odour
  - Dressings are generally changed 1-2 times per day based on the amount of exudates and odour
  - Menstrual pads can be especially effective because of their good absorption and availability

- **Odor control**
  - Wound odour is caused from bacterial overgrowth and necrotic tissue

- Managing odour is extremely important for the well-being of the patient and family
- Wound cleaning and dressings for exudates/ discharge (as mentioned above) is important to reduce odour
- **Metronidazole** (orally or topically) can be very helpful
  - **Metronidazole 500 mg bid or tid PO/IV**
  - **Metronidazole gel** or **injectable metronidazole** can be apllied (not injected!) on the wound with each dressing change
  - **Metronidazole capsules/tablets** can also be broken and the powder contents sprinkled onto the wound with each dressing change
- Activated-charcoal dressings or a basket of charcoal placed under the bed or table can help absorb and reduce odour
- Peppermint or other oils placed in the room can be helpful. Incense may be helpful but strong scents can sometimes cause difficulties in breathing for patients or may induce nausea

❍ **Pain**

- It is important to help control pain by using **morphine** and other medications as mentioned in the section on pain (some malignant wounds can cause neuropathic pain)
- Topical **morphine** can be helpful for the wound for some patients. Injectable **morphine** (e.g. 1 ampoule of 10 mg/ml can be mixed in most gels that may be applied over the wound)
- Dressing changes can be particularly painful Giving a breakthrough or rescue dose of **morphine** prior to the dressing change can often be helpful

❍ **Control of bleeding**

- The viable tissue in a malignant wound may be very friable and bleed with minimal manipulation
- Prevention is the best method to avoid bleeding. Care must be taken when removing dressings to avoid bleeding. Use warmed normal saline irrigation to moisten the dressing and prevent trauma during dressing changes. Use non-adherent dressings and moist wound products when possible
- If bleeding does occur, apply direct pressure for 10-15 minutes. Local ice packs can also assist in controlling bleeding
- Radiotherapy can be considered if appropriate for the patient and the tumour is thought to be radiosensitive
- Haemostatic dressings or pressure dressings are sometimes required if the bleeding is severe
- If a patient is at the end of life and having uncontrolled bleeding from a large wound, using dark towels/ blankets to mask the blood can decrease anxiety for the patient and family. Pain control and sedation with a benzodiazepine would be important considerations in this situation

Metronidazole

- 15-35 mg/kg/24h in divided doses q8h PO or 30 mg/kg/24h in divided doses q8h IV

PITFALLS/CONCERNS

❍ ***Ensure that the dressing used is not "too dry" and therefore causes more pain and bleeding at the time of dressing changes***

❍ **Perfumes used sometimes become associated with the unpleasant odour rather than "hide" the smell and do not necessarily help**

- **Healthcare providers can become "desensitized" to the smell and so must listen to the patient or family if they complain about the smell from the wound rather than rely on their own observations**

PALLIATIVE TIPS

- It is very important to pay particular attention to the emotional impact of these wounds on the patient and family. Medical staff can help reduce social isolation that can often occur

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Nausea and Vomiting

KEYPOINTS

- A distressing symptom present in over 50% of patients with advanced cancer
- There are multiple receptors in the central nervous system, which are involved in the development of nausea. Blocking of these receptors forms the basis of antiemetic medications.
  These receptors are: dopaminergic, muscarinic, cholinergic, histaminic, and serotonergic
- The choice of antiemetic therapy should be based on what is the presumed underlying cause of the nausea
- Often multiple, concurrent medications from different classes may be required for effective control (e.g. **metoclopramide** and **haloperidol**, or **prochlorperazine** and **dexamethasone**, etc)
- In children with life limiting diseases benign causes such as gastroenteritis, reflux and infections such as otitis media should still be ruled out
- Nausea and vomiting may also occur in children due to emotional distress

ASSESSMENT

see comment on page 13

- Examination and investigation can be helpful in determining the underlying cause of the nausea/vomiting
- In addition to a (normally transient) side effect of initiating opioids, other causes of nausea/vomiting include severe constipation and impaction, bowel obstruction (malignant and non-malignant), chemotherapy, radiotherapy, metabolic abnormalities (e.g. hypercalcaemia), infection and other medications

MANAGEMENT

- Management should be "mechanism based" and reflect the most likely underlying cause of the nausea and vomiting
  - For gastric stasis consider a prokinetic such as **metoclopramide 10-20 mg q4-6h PO/SC/IV**
  - For opioid-induced nausea consider a prokinetic (see above) or a neuroleptic (see below)
  - For metabolic abnormalities or uremia consider a neuroleptic such as **haloperidol 0.5-2 mg q6-12h PO/SC/IV, metoclopramide 10-20 mg q4-6h PO/SC/IV** or **prochlorperazine 10-20 mg q6h PO/IV** or **25 mg q6h PR.**
    These act as dopamine receptor antagonists at the chemoreceptor trigger zone (CTZ).
    Olanzapine 1.25-2.5 mg OD PO is a atypical neuroleptic which is both a dopamine and 5HT receptor antagonist
  - For gastric irriation consider stopping offending agent and adding an H2 blocker such as **ranitidine 150 mg bid PO** or a proton pump inhibitor such as **omeprazole 20 mg once a day PO**
  - For chemotherapy or radiation-induced nausea consider 5HT3 receptor antagonists such as **ondansetron 4-8 mg q8-12h PO/IV** and/or **dexamethasone 4-20 mg qAM PO/IV/SC**
  - For motion-induced nausea consider an anti-histamine such as **dimenhydrinate 50-100 mg q4-6h PO/IV**
  - For infection consider treatment with antibiotics
  - For raised ICP (intracranial pressure) consider **dexamethasone 4-20 mg qAM PO/IV/SC**
  - For hypercalcemia consider treatment with hydration and bisphosphonates such as **pamidronate 60-90 mg (single dose) IV**
  - For constipation see section on constipation
  - For bowel obstruction see section on bowel obstruction
  - For over eating re-educate patient and family to reduce intake
- If no resolution then consider an additional antiemetic agent that targets different receptors (prokinetic, neuroleptic, anti-histamine, 5HT3 receptor antagonist)
- If anxiety is thought to be a contributing factor to the nausea or vomiting then **lorazepam 0.5-2 mg q4-6h PO/SC/PR** can be effective in control of nausea and vomiting in addition to other medications such as those mentioned above
- If no resolution then consider corticosteroids i.e. **dexamethasone 4-20 mg qAM PO/IV/SC**
- Medications should be dosed **regularly** if nausea and vomiting are ongoing symptoms

Metoclopramide 0.1 to 0.2 mg/kg/dose q6h PO/SC/IV
Haloperidol 0.05-0.15 mg/kg/day bid/tid PO/SC/IV
Ranitidine (if gastritis) dose 2-4 mg/kg BID PO
Ondansetron 0.15 mg/kg/dose q8h IV (max 8mg/dose)
Dexamethasone
- 2-5 years: 0.5-1 mg bid PO/SC/IV:
- 6-12 years: 1-2 mg bid PO/SC/IV;
- 12 (plus): 2-4 mg bid PO/SC/IV

PITFALLS/CONCERNS

- In the setting of complete bowel obstruction the use of prokinetic agents such as **metoclopramide** may result in increased pain and cramping and should be discontinued
- **Metoclopramide** and **haloperidol** (and other neuroleptics) can cause extra pyramidal reactions in children (as well as adults) and can be used in combination with **diphenhydramine** which will reduce likelihood of this

PALLIATIVE TIPS

- For intractable nausea and vomiting, a multimodal approach combining antiemetics targeting different receptors is recommended (eg. **haloperidol** + **dimenhydrinate** + **dexamethasone**)
- Similar to the setting of ongoing pain, ongoing nausea requires regular dosing of antiemetics rather than just prn!
- Distraction, and the avoidance of the smell of food and unpleasant odours may be helpful with children

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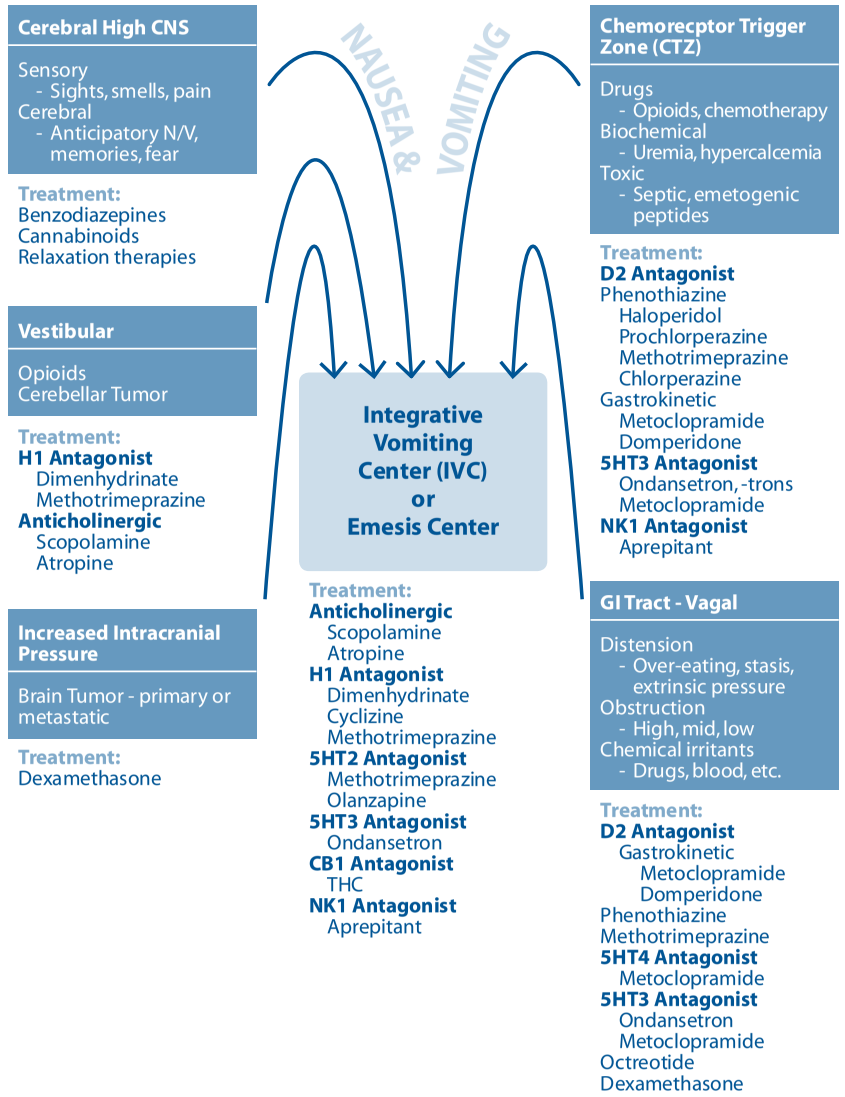
Nausea and Vomiting



Pain

KEYPOINTS

- Pain in advanced cancer occurs about 70-90% of the time
- Almost all pain can be satisfactorily controlled using simple medication combinations
- The use of the World Health Organization (WHO) analgesic ladder (Appendix 2) is a helpful tool in treating pain
- The WHO method can be summarized in five phrases: "by mouth", "by the clock", "by the ladder", "for the individual" and "attention to detail"
- **Acetaminophen/paracetamol** and NSAIDs can be used for mild pain
- Opioids such as **morphine** should be used in moderate to severe pain
- Remember to prevent or treat the side effects of **morphine** such as constipation and nausea/vomiting
- There is no "upper ceiling" dose to the amount of **morphine** that can be used. The right dose is the dose that works
- Neuropathic pain is common and is pain which is transmitted by a damaged nervous system (Appendix 5)
- Consider the use of adjuvant medications at all levels of the analgesic ladder (especially with neuropathic pain)
- Infants and children experience pain as much as adults and it is common in advanced cancer and in other severe life threatening diseases
- Pain receptors are mature (and inhibitory systems are immature) at birth therefore infants and new borns **do** feel pain (perhaps even more so than adults)
- Pain that is poorly managed initially can lead to difficult-to-treat neuropathic pain syndromes and other symptoms
- Pain suffered by children with life limiting disease may have considerable effects on both the child and others

ASSESSMENT

see comment on page 13

- A good clinical assessment is important to try and identify the underlying cause of the pain (e.g. tumour involvement, bone metastases, liver enlargement, etc)
- Listening to the patient describe their pain location, intensity, quality, "what makes it worse", "what makes it better", etc can tell a lot about what might be causing the pain and how best it might be treated
- The use of pain measurement scales such as the Visual Analogue Scale (VAS) or a "0-10" scale are important tools to use in assessing a patient's pain and the response to treatment
- The impact of pain on things such as function and sleep is important to ask about
- Investigations to consider may include
  - Radiologic investigations (e.g. x-ray) to determine if there is bony metastasis or tumour involvement
- Assess for the presence of neuropathic pain (Appendix 5)
  - Pain or discomfort resulting from injury to the peripheral or central nervous system
  - Pain is often described as "burning, stabbing or shooting"
  - Allodynia or hyperalgesia may be found on exam and suggests the presence of neuropathic pain
    - Allodynia – something that is usually not painful is now experienced as painful
    - Hyperalgesia – something that is a usually a little painful is now experienced as more painful
- A quiet sleeping child may be exhausted and withdrawn but may still be in pain
- Children may fail to report pain because they do not want to be thought of as 'bad' or because they fear what might happen next (eg. they will receive a painful injection)

- Children are good at self distraction and may still be in pain at play or watching TV etc.
- Even small children can "self report" pain
- A number of tools based on age, development and ability to communicate have been developed

MANAGEMENT

- Consider treatment of the underlying cause (e.g. oncological treatment of tumour, radiation for bone metastasis etc.)

  Consider if patient is well enough to benefit
- **See Appendix 2 for the use of the WHO analgesic ladder**
- The WHO method can be summarized in five phrases: "by mouth", "by the clock", "by the ladder", "for the individual" and "attention to detail"

For mild pain

- **Acetaminophen/paracetamol 650 mg-1 gm every 4h or 1 gm every 6h** (daily maximum 4 g/d)
  - Hepatotoxicity can occur at doses higher than this
  - **Acetaminophen/paracetamol** can also be combined with NSAIDs
- NonSteroidal Anti-inflammatory Drugs (NSAIDs)
  - Produce an analgesic effect within 1 to 2 hours
  - Serious side-effects can occur with NSAIDS including:
    - Gastrointestinal (GI bleed)
    - Renal toxicity
    - Congestive heart failure
  - They should therefore be used with caution especially in patients at risk for GI or renal toxicities
  - If GI symptoms occur, the NSAID can be discontinued or the risk of GI toxicity can be reduced by the addition of a protective agent such as an H2 receptor antagonist **(eg. ranitidine), misoprostol** or **omeprazole**
  - Evidence to support efficacy or safety of one NSAID over another is currently lacking
  - Examples of NSAIDs include:
    - **Ibuprofen 200-400 mg PO tid**
    - **Diclofenac 50 mg PO/SC tid**
    - **Naproxen 250-500 mg PO/PR bid**
    - **Ketorolac 10 mg PO qid or 10-30 mg SC tid**
    - Multiple other NSAIDs exist

For moderate pain

- A "weak" opioid such as **codeine 30-60 mg q4h PO** or **tramadol 50 mg PO qid** can be tried. **Codeine** is often combined with other agents such as **acetaminophen/paracetamol** and thus maximum doses may be limited by the amount of **acetaminophen/paracetamol**
- **Morphine** can also be used at this point and should definitely be used if the pain is not controlled by **codeine** or other means
- Remember to consider the use of adjuvants along with the opioid

For severe pain

- **Morphine** or another opioid should be started
- The initial starting dose will depend on the patient's previous exposure to opioids:
  - A dose of **morphine 2.5 mg regularly q4h PO (or 1 to 2 mg SC/IV)** and a breakthrough or rescue dose every hour, as required (see Appendix 1) is suitable for an opioid-naive patient
  - A dose of **morphine 5-10 mg regularly q4h PO (or 2.5-5 mg q4h SC/IV)** and a breakthrough or rescue dose every hour, as required (see Appendix 1) should

be used for patients who have already been on **codeine**
- It is necessary over the next days to titrate the regular dose to achieve good control (more than 3 BTDs/day often means that the baseline **morphine** is not enough)
- To determine the new dose, add the number of breakthroughs being used in a 24h period to the regular total daily dose. Then divide by 6 to determine the new q4h dose. Alternatively, you can also increase the total daily opioid dose by 25% to 50% depending on the severity of the patient's pain
- Remember that there is no "upper ceiling" dose to the amount of **morphine** that can be used. The right dose is the dose that works

❍ Alternative routes for **morphine** include:
rectal, subcutaneous, buccal, intravenous and via a gastrostomy tube – **the oral route** for **morphine** should be **the route of choice** in most cases.
The PO: SC **morphine** ratio is 2:1
The PO: IV **morphine** ratio is 2-3:1
e.g. 10 mg oral **morphine** = 5 mg SC **morphine**

❍ Be aware, educate patients/families about, prevent and treat the common side effects of **morphine**:
- Constipation (prescribe laxatives/stool softeners when starting someone on **morphine**, see section on constipation)
- Nausea (usually only temporary - ensure an antiemetic is available especially if just starting someone on **morphine**)
- Excessive sedation or drowsiness (usually only temporary)

Adjuvants

❍ Adjuvants are medications or measures that provide relief to the patient in addition to the analgesic medications themselves

❍ They are often used in pain due to bone metastases PO and in neuropathic pain

❍ For bone pain consider:
- NSAIDs, corticosteroids, radiotherapy

❍ For neuropathic pain consider (Appendix 5):
- Trial of antidepressant: start with low dose and increase every 3-5 days if tolerated (eg, **nortriptyline**, **amitriptyline** or **desipramine 10-150 mg PO od**) and/or
- Trial of anticonvulsant: start with low dose and increase every 3-5 days if (eg, **gapabentin 100-200 mg tid PO; carbamazepine100-400 mg bid PO**)
over 6 years: 100 mg bid PO

❍ Opioids are the main analgesics for children with severe life threatening disease

❍ Use WHO ladder (including the use of adjuvants) as in adults (Appendix 2)

Acetaminophen/paracetamol
- Under 1 year: 10-15 mg/kg q4h/prn PO;
- 1-5 years: 120-250 mg q4h PO;
- 5-12 years: 250-500 mg q4h PO (maximum of 75 mg/kg/day)

Diclofenac
- 6 months to 12 years:
- 2-3 mg/kg/24h in divided doses bid or tid PO

Naproxen
- 5-7 mg/kg q 12h PO

Ibuprofen
- 5-10 mg/kg q 8-12h PO

Ketorolac
- 0.2 mg/kg q4-6h PO, 0.2-0.5 mg/kg q 6h IV prn

Amitriptyline
- 500 mcg/kg HS

Gabapentin

- Starting at 10-15 mg/kg/24 hrs in divided doses bid or tid (max of 60 mg/kg/24hrs)

Codeine

- Children more than 6 months: 0.5-1.0 mg/kg q4h PO (max 60 mg/dose)

Morphine

- Starting doses for opioid naïve infants less than 6 months: 0.01 mg/kg q4h SC/IV, or 0.02 mg/kg q4h PO
- Starting dose for opioid naïve infants/children more than 6 months: 0.02 mg/kg q4h SC/IV, or 0.04 mg/kg q4h PO

PITFALLS/CONCERNS

- ***Pethidine/meperidine if used on an ongoing basis will cause a build up of the metabolite (normeperidine) and may cause delirium and seizures – it should be avoided in the treatment of cancer pain***
- ***Never ever use a slow-release opioid as the breakthrough or rescue medication (use regular short-acting instead)***
- ***Serious side-effects can occur with NSAIDs – they should be used cautiously. An opioid such as morphine may be a more effective and safer option***
- Children less than 6 months are more sensitive to possible opioid induced respiratory depression and therefore need lower **initial** doses with subsequent normal titration
- Because of some immature metabolic processes codeine may not be appropriate in younger children and infants
- About 10-15% of adults and up to 35% of children may not be able to metabolize codeine and therefore it may not be an effective analgesic

- Urinary retention and pruritus (as a side effect of opioids) are more commonly seen in children compared to adults

PALLIATIVE TIPS

- Treat pain promptly and aggressively!!!
- The WHO guidelines remind us that the "relief of psychological, social and spiritual problems is paramount. Attempting to relieve pain without addressing the patient's non-physical concerns is likely to lead to frustration and failure
- Constant pain requires regular analgesia. Use "around-the-clock" dosing to treat and prevent pain
- Make sure to provide a breakthrough or rescue dose (BTD) in addition to the regular dose of **morphine**
- Optimize the opioid by titrating up until pain improved
- The PO **morphine** to SC/IV **morphine** ratio is 2:1 e.g. 10 mg oral = 5 mg SC
- **Morphine** 10 mg PO = **codeine** 100 mg PO
- Remember the use of adjuvants in the treament of pain (eg. neuropathic pain - Appendix 5)
- Children have less distress when they can understand what is happening and are involved in their symptom management
- Play, music and games can be very helpful in association with the pharmacological methods as described above

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Pleural Effusion

KEYPOINTS

- Approximately half of all patients with metastatic cancer will develop a pleural effusion
- Lung and breast cancer are the most common causes of a malignant pleural effusion although it can occur in almost any type of cancer
- Patients may experience dyspnea, dull aching chest pain, or dry cough due to this fluid accumulation
- Thoracentesis (removal of the fluid) can be helpful in relieving dyspnea in some patients
- Pleurodesis (after thoracentesis and drainage) is sometimes used to try and prevent re-accumulation of the fluid
- Pleural effusion may be the first presenting sign of cancer, or suggestive of recurrent or advanced disease
- Children may fear invasive procedures such as thoracocentesis. It is important to explain what will happen and gain the child's consent depending on his or her ability to understand

ASSESSMENT

see comment on page 13

- A moderate to large pleural effusion can most often be diagnosed by clinical exam alone (decreased breath sounds and dullness to percussion)
- A good clinical assessment can also help to identify the underlying cause of the pleural effusion
- Pleural effusions can be caused by malignant or non-malignant processes
- Non-malignant processes include:
  - Congestive heart failure
  - Pneumonia

- Low albumin (hypoalbuminemia)
- Pulmonary embolus
- Pancreatic disease
- Interstitial lung disease
- Ascites

❍ Investigations to consider may include:
- Chest X-ray to assess extent of effusion and evidence of other diagnoses (eg. pneumonia)
  - If the fluid amount is > 200 to 300 ml it can usually be detected by chest X-ray
  - Smaller amounts of fluid can sometimes be detected using ultrasound or a CT scan

❍ Analysis of the pleural fluid (if removed) may help in diagnosing the underlying cause of the effusion. Malignant pleural effusions are typically exudative but on rare occasion can be transudative

MANAGEMENT

❍ The management of dyspnea and cough are covered in other areas of this handbook and should be followed if these symptoms are present

❍ A small effusion that is not causing the patient any distress does not normally need to be drained

❍ Pleural effusions can sometimes resolve on their own with effective treatment of the underlying disease, such as congestive heart failure

❍ Consider drainage of the pleural fluid (thoracentesis) if the patient is highly symptomatic

⚖ ***Consider only if patient is well enough to benefit***

- Risks and benefits of a thoracentesis should be explained to the patient before proceeding. These would include hemothorax, pneumothorax and infection

❍ **Thoracocentesis** procedure (adapted from *Oxford Handbook of Palliative Care*):
- The patient should be sitting, leaning forward on a bedside table
- Choose a point in the posterior chest wall, medial to the angle of the scapula, one intercostal space below the upper limit of dullness to percussion
- On insertion, be careful to avoid the inferior border of the rib
- Inject local anaesthetic. Wait for the area to be anaesthetized then advance the needle until pleural fluid is obtained
- Introduce a large bore IV cannula with a syringe attached until fluid is just obtained, then advance a further 0.5-1 cm to ensure that the cannula is in the pleural space
- Ask the patient to exhale against pursed lips (this will increase the intrathoracic pressure) and remove the metal trochar or needle and then attach a large syringe with a three-way tap
- Aspirate 50 ml at a time until:
  - Drainage complete or
  - Patient starts to cough or
  - Light-headedness or chest discomfort occurs
- Remove the cannula, having asked the patient to take a breath, and immediately seal with an appropriate dressing

❍ Sometimes a chest tube is left in place while the fluid continues to drain

❍ Pleurodesis is sometimes carried out following thoracentesis and drainage.
- It occurs by inducing inflammation of the pleura by the introduction of a sclerosing agent administered

by a chest tube or indwelling catheter into the chest cavity
  - Talc is the most effective sclerosing agent used for pleurodesis
  - Pleurodesis is not always effective and does have procedure-related side-effects including increased pain
  - Patients should be evaluated on an individual basis when deciding whether or not to undergo pleurodesis. It should only be done if the patient has an expected survival of at least several months and is not debilitated
- During thoracocentesis; check vital signs.
  Remove the quantity of fluid that gives optimum symptomatic relief. Not more than 10% of body fluid by volume/24hrs

PITFALLS/CONCERNS

- ***In patients in the final terminal phase – ie. hours to days, it would be normally inappropriate to drain a pleural effusion (treatment should be as least invasive as possible)***

- ***In patients in the final terminal phase – ie. hours to days, symptomatic relief through pharmacologic and other means would be preferred***

PALLIATIVE TIPS

- The decision whether to repeatedly perform thoracentesis must be carefully weighed against the patient's wishes, available resources, the patient's ability to tolerate the procedure, the risks involved with repeated thoracentesis, the knowledge that the fluid will likely reaccumulate and the ability to symptomatically control dyspnea by other non-invasive means
- It is important to remember that malignant effusions usually recur and the fluid can re-accumulate in as little as a few days. Serial thoracentesis may result in loculated fluid and worsening of symptoms
- Repeated thoracentesis, especially if the fluid rapidly reaccumulates, is usually not indicated

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Pruritus

KEYPOINTS

- Pruritus can be described as an unpleasant cutaneous sensation which produces the desire to scratch
- Pruritus is relatively uncommon in advanced disease but can be very unpleasant and difficult to treat
- General non-pharmacologic treatment can be very helpful
- Generalised itching (often the child repeatedly rubbing the nose-tip) due to opioids is more common in children than adults.

ASSESSMENT

see comment on page 13

- History should include the times at which the itching occurs (whether continuous and whether at night or day) its nature (burning, itching, etc), location and relevant medication history
- Examination should include review of dryness of skin, possible presence of scabies, possible presence of jaundice

MANAGEMENT

General Measures

- Pruritus is often caused by dry skin, so a good first measure is a simple moisturiser cream
- Keep patient cool and use cool clothing
- Tepid (around 37 C) baths and showers (avoiding detergents), followed by gentle drying and application of moisturiser cream
- Keep nails short (filed not cut)
- Avoidance of alcohol and spicy foods

Topical Agents

- **Menthol** 1% and **camphor** 1% compounded in aqueous cream can be used several times a day as needed

Cause Specific Therapy

- Cholestasis
  - Use general measures (see above)
  - HI and H2 receptor blockers likely to be ineffective
  - Place biliary stent (if possible and if patient's general condition warrants this)

    The burden of investigation and treatment should always be weighed against the prognosis, the likely benefit of treatment and the patient's wishes.
  - **Cholestyramine** 4 g 1-6 times/day PO to a maximum of 36 g/day
- Uraemia
  - Use general measures (see above)
  - HI and H2 receptor blockers likely to be ineffective
  - **Capcaisin** 0.025% or 0.075% cream applied 3-5 times daily is useful where there is localised pruritus. Do not apply to large body areas
- Hodgkins Lymphoma
  - Use general measures (see above)
  - HI and H2 receptor blockers likely to be ineffective
  - Radiation or chemotherapy where appropriate
  - Corticosteroids e.g **dexamethasone** 4-8 mg daily If ineffective, substitute:
  - **Cimetidine** 400 mg bid PO or **ranitidine** 150 mg bid PO
- Itch due to an opioid
  - Use general measures (see above)
  - HI and H2 receptorblockers likely to be ineffective
  - May be transitory lasting a few days

- May be relieved by 'switching opioids'
- **Paroxetine** 5 mg/day PO to 20 mg/day can be helpful

PITFALLS/CONCERNS

- Potential side effects of antihistamines may be agitation or confusion

PALLIATIVE TIPS

- Itching of the skin is present without obvious cause in over 50% of patients over 70 years
- Itching associated with cholestasis often starts on palms and soles and the severity is unrelated to the level of bile acids in skin
- H1 recepeptor blockers are useful in histamine based itch such as a drug reaction or urticaria
- **Ondansetron** is helpful when spinal opioids cause itching
- **Antihistamine** creams may cause a contact dermatitis
- **Lidocaine** cream may cause a contact dermatitis and worsening of itching
- **Calamine** cream may cause drying of the skin and worsening of the itching

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Respiratory Secretions at the End of Life

KEYPOINTS

- Noises caused by upper airways secretions are heard in approximately 50% of dying patients
- Caused by air passing through airways with secretions present (as the patient is unable to swallow or clear them)
- The presence of respiratory secretions is a strong predictor of death (76% die within 48 hours from onset of this symptom)
- Repositioning the patient is often helpful and all that is necessary
- Anticholinergic medications (e.g. **atropine**) can be helpful in many cases to reduce the secretions and noise
- Children like adults, may be unaware of this symptom but it can be very distressing for family members
- Ongoing support and education of family around this symptom is very important to minimize the distress of the family witnessing this in their dying child

ASSESSMENT

see comment on page 13

- A clinical assessment is all that is required
- Other investigations would not be appropriate at this stage as the patient's condition is very poor and death can be expected in the near future

MANAGEMENT

- Much of the management focuses on teaching and support of the family who may find this symptom difficult to watch or hear
- Repositioning the patient is often helpful in decreasing the noise

- Place the patient on their side with upper body elevated

❍ Good mouth-care can also be helpful

❍ Administering anticholinergic medications can sometimes be helpful for upper airway secretions:
- **Hyoscine hydrobromide 0.4 mg as a single dose SC.**
  Several doses q 30 minutes may be required
  If effective, continue using 0.3-0.6 mg q4h SC.
- **Atropine 0.6-0.8 mg SC.**
  If effective, continue, using q4h and prn.
- **Glycopyrronium/glycopyrrolate bromide 0.2 mg as a single dose SC.**
  If effective, continue using 0.2 mg q4h and prn SC.
- **Hyoscine butyl bromide 20 mg as a single dose SC.**
  If effective, continue, using **20 mg q4h SC.**

❍ Suctioning is usually not necessary (or helpful) and may be distressing to the patient
- Consider suctioning if thick mucous, blood or other fluid is in the mouth/throat and can be easily removed with a soft catheter (i.e. no deep suctioning or rigid suctioning)

Glycopyrronium/glycopyrrolate
- 4-10 mcg/kg q6h IV/SC (max of 200 mcg/dose)

Hyoscine hydrobromide
- 1 year-12 years: 10 mcg/kg SC/IV as single dose;
- 20-60 mcg/kg over 24hours in SC or IV infusion

Hyoscine butylbromide
- Less than 6 years: 0.3 mg/kg/dose tid PO/SC/IV;
- 6-12 years: 5-10 mg up to tid PO/SC/IV

PITFALLS/CONCERNS

❍ ***Anticholinergic drugs as mentioned above should be used cautiously in patients who are still responsive as they can cause agitation. They generally are used in patients close to death.***

❍ ***Glycopyrronium/glycopyrrolate bromide and hyoscine butyl bromide (as compared to atropine and hyoscine hydrobromide) do not cross the blood brain barrier and may therefore cause less CNS effects***

❍ ***Treatment with these agents is not always successful in reducing the secretions so it is important to support family***

❍ Parenteral **glycopyrronium/glycopyrrolate** can be given PO (at same dose) and is usually well tolerated by children

PALLIATIVE TIPS

❍ Explaining to the family that the noisy respiratory secretions are unlikely to be distressing for the patient who is unconscious is an important part of helping to support the family

❍ The drug treatments are quite effective for upper airway secretions, but will not work for secretions deep in the lungs, pulmonary oedema, pneumonia etc.

❍ Hydration with IV fluids may increase the severity of this symptom – use fluids cautiously in the dying

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Seizures

KEYPOINTS

- Seizures are relatively common in the palliative care population, occurring in up to 10% of patients
- Most seizures are brief, self-limited and rarely harmful themselves
- **Pethidine/meperidine**, if used on an ongoing basis, can cause seizures due to an accumulation of **normeperidine**, a neurotoxic metabolite. **Pethidine/meperidine** should therefore be avoided in palliative care patients
- Can be extremely frightening to family
- Quite common at the end of life in children

ASSESSMENT

see comment on page 13

Treatment is usually symptomatic and a full seizure workup is, in most cases, not necessary

- Causes of seizures include:
  - Brain tumours
  - Drug toxicity (eg. **pethidine/meperidine**)
  - Metabolic or electrolyte abnormality
    - Hypoglycemia
    - Hyponatremia
    - Hypercalcemia
  - Hypoxia
  - Severe hepatic failure
  - Infections of the central nervous system
  - Epilepsy
- Cancers most likely to metastasize to the brain are: lung, breast and malignant melanoma
- Where appropriate treat correctable causes of seizures
- In children with a longer prognosis a review by a neurologist to optimise prophylactic treatment might be appropriate

MANAGEMENT

- Most seizures are brief, self-limited and rarely harmful in themselves

ACUTE TREATMENT OF SEIZURES (STATUS EPILEPTICUS)

- Clear airway
- **Diazepam 10 mg PR.**
  Repeat after 15 and 30 minutes if needed
  or
- **Lorazepam 2-4 mg SL, SC or IV.**
  Repeat after 15 and 30 minutes if needed
  or
- **Midazolam 5-10 mg SC or IV.**
  Repeat after 15 minutes if needed
  If no response:
- Consider doubling the dose of **diazepam** or **midazolam**
  or
- **Phenobarbital 100-200 mg SC or IV (slowly by IV over 30 minutes with 100 cc of saline).**
  May repeat if necessary.
  Follow this with 100 mg tid SC

PROPHYLACTIC MANAGEMENT OF SEIZURES

Seizure prophylaxis with anticonvulsants has only been proven useful in patients with brain metastasis due to malignant melanoma and patients with brain metastasis from other cancers who have already had a seizure

- **Anticonvulsant medication**
  - **Phenytoin** 300 mg PO followed by 100-200 mg PO tid
  - **Carbamazepine** 100 mg PO bid
  - **Valproate** 200 mg PO tid
  - Others options exist (**lamotrigine, gabapentin, toprimate**)
- **Corticosteroids**
  Are helpful in the prevention and management of seizures which are secondary to brain metastasis, by decreasing the oedema surrounding a tumour mass
- **Radiation**
  Can be helpful in preventing seizures in patients with metastatic brain disease
- **Opioid rotation**
  Opioids very rarely cause seizures. (Except **pethidine/ meperidine** which can cause cerebral excitation and seizures). Switching to another opioid can be helpful in this situation
- **Acute Treatment**

  Diazepam
  - 0.3-0.5 mg/kg/dose PR SC IV or

  Lorazepam
  - 0.06-0.1 mg/kg/dose PR SC SL IV or

  Midazolam
  - 100 mcg/kg SC over one minute, then if necessary 300-700 mcg/kg over 24hours by continuous SC infusion or

  Phenobarbital
  - 10-20 mg/kg IV or PO; followed by 3-5 mg/kg/day IV SC or PO

- **Prophylactic Treatment**

  Phenytoin
  - 4-8 mg/kg/24hrs PO in divided doses bid or tid

Carbamazepine
- Less than 6 years: 10-20 mg/kg/24hrs PO in divided doses bid or tid
- Over 6 years: 100 mg bid PO

Valproate
- Initial: 10 mg/kg/24hrs PO in divided doses tid
- Increment: 5-10 mg/kg/24hrs at weekly intervals
- Maintenance: 20 mg/kg/24hrs in divided doses tid (monotherapy). Higher doses (30-60 mg/kg/24hr) are often required in patients on polytherapy.

PITFALLS/CONCERNS

- ***There are many drug-drug interactions that occur with anticonvulsant medications***
- ***It is important to monitor the dose and duration of treatment with corticosteroids frequently especially when used for more than 4 weeks, to prevent long-term side effects such as steroid myopathy, hyperglycemia and gastrointestinal bleeding among others***
- ***Pethidine/meperidine can cause cerebral excitation and seizures***
- Parents should be trained in use of SL and PR if there is a likelihood of child having prolonged seizures at home

PALLIATIVE TIPS

- Prophylactic anticonvulsant therapy for all patients with cerebral metastases is unnecessary as most patients are unlikely to seize due to their metastases. If they do indeed seize, anticonvulsant therapy should then be started
- If seizures last longer than 5 minutes, or if they occur at frequent intervals and the patient does not recover fully between intervals, the patient is considered to be in status epilepticus (see acute management of seizures)

- Rectal administration can be given by syringe with a small feeding tube cut at 5 cm to deliver medication up to 4 to 5 cms beyond the anal margin for an older child and less for an infant

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Superior Vena Cave Syndrome Adults and Children

KEYPOINTS

- A syndrome of dyspnea, headache, swelling of the face, neck and upper limbs should alert to this possible diagnosis. Occurs as a result of compression or obstruction of the superior vena cave
- Can sometimes be life threatening but usually occurs with a gradual increase in signs and symptoms

ASSESSMENT

see comment on page 13

- Chest X Ray or CT Scan will aid diagnosis

MANAGEMENT

- **Dexamethasone** should be used in the short term
- Radiotherapy may help with tumour causing external compression

Consider if patient is well enough to benefit

PITFALLS/CONCERNS

- Tends to occur late in the disease trajectory of children

PALLIATIVE TIPS

- May also be caused by thrombus around a subclavian arterial catheter

PSYCHOSOCIAL CARE

"People come to palliative care not as a disease… but as complex human beings, with hopes and fears, needs, history and expectations based on the context and experiences of their lives, their families, and their culture" *

Psychosocial care is an essential component of palliative care. There are a complex range of experiences and issues (psychological, spiritual, cultural, emotional, physical, socio-economic and practical) that may impact patients and family/caregivers**, and health care teams.

This section provides information and tools to assist health care professionals in providing psychosocial support to patients and family/caregivers from point of contact and throughout the care continuum, including bereavement.

Psychosocial care is an expanding field within palliative care, and literature supports a range of theories, models, and practice approaches. Cultural and social diversity reminds us there are no universal methods for providing psychosocial care. Therefore, it is important that information provided in this section is utilized and adapted to suit the individual and collective needs of people within each community and health care setting.

** The concept of family can have many meanings. The term 'family/caregivers' are the people that the patient identifies as their source of support.

References * Cairns M., Thompson M., Wainwright W. *Transitions in Dying and Bereavement: A Psychosocial Guide for Hospice and Palliative Care.* Victoria Hospice Society 2003.

Communication

KEYPOINTS

- Communication is a cornerstone of palliative care, affecting both quality of care and quality of life
- Communication affects the interpersonal relationships within and between health care teams, patients, and family/caregivers
- Communication can influence: symptom control, understanding of information, decision-making, abilities to cope
- Effective communication reduces uncertainty, helps people feel understood, helps people maintain a sense of control, gives people a direction in which to move, gives people sense of hope
- Specific communication skills can facilitate supportive conversations and help people get their needs met
- Communication of information, difficult or otherwise, is an ongoing process
- Personal beliefs, values and assumptions impact the way we relate to and understand the experiences and needs of patients and family/caregivers

CONSIDERATIONS

COMMUNICATION: PATIENTS AND FAMILY/CAREGIVERS

- What information about the patient and their family/caregivers would be helpful?
- How do patients and family/caregivers want to be involved in information sharing and decision-making?
- How does the patient understand their situation? What information is known and what do they want to know or not know?

- How does the family/caregiver understand the situation? What information is known and what is being shared or not shared between patient and family/caregivers?
- What opportunities and challenges exist within the patient and family relationship?
- What tools or resources may be helpful when sharing information? eg.: visual aids, written information, interpreters, presence of a loved one

COMMUNICATION: HEALTH CARE TEAM

- What information gets shared between the team and how is this communicated and/or documented?
- What information do patients and family/caregivers want people to know or not know?
- Good communication within a team can improve patient care and satisfaction
- Dealing with conflict and differences in a team can often be challenging and requires time and commitment to developing a process
- How do teams approach conflict or differences with patients and family/caregivers?

STRATEGIES

EFFECTIVE COMMUNICATION

- **ACTIVE LISTENING**

  Active listening is a powerful therapeutic intervention. It involves ways of listening, giving full attention, expressing empathy, and responding to another person that improves mutual understanding. People's ways of thinking, seeing, hearing, and interpreting the world is influenced by their beliefs, values, fears, and social and cultural backgrounds. Active listening is best done without interpretation or evaluation.

Facilitating Conversation

- Open-ended Questions

  Open-ended questions allow people the opportunity to describe and express their feelings, thoughts, and concerns more fully.

  Examples: *"How are you feeling today?"*
  "What has been worrying you most?"
  "How have you been coping with these experiences?"
  "I understand that you have some questions and concerns about your care. Can you tell me more about that?"
  "How do you see things going from here?"

- Clarifying Responses

  Clarifying responses help to understand the facts and people's feelings, attitudes, beliefs and values.

  Examples:
  "Can you give me an example of what you are talking about?"
  "Tell me more about_____"
  "As you were talking I noticed _____ in your body language. I am wondering if you are feeling / experiencing _____?"

- Paraphrasing and Summarizing

  Paraphrasing and summarizing let's people know that they are being listened to and their experiences are understood. It also provides an opportunity to get further clarification.

  Examples:
  "What I hear you saying is that you have been experiencing _____ which has been making you feel _____. Have I understood that correctly?"
  "What would be most helpful? Is there anything else you need?"

- **Non verbal communication**
  How people communicate is rooted in cultural and social traditions, values and beliefs. Observing people's body language, posture, gestures, and facial expressions can provide clues to people's feelings, emotions, and capacities for coping. It is important to attend to the complex ways people communicate non-verbally and carefully and respectfully explore with the individual what information they may be communicating and are unable to verbalize. It is equally important to attend to our own non-verbal communication and how this may impact our attempts to convey respect, compassion, and understanding.

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Breaking Bad News

KEY POINTS

- Entering difficult conversations can be challenging and stressful for all involved
- Bad news can include any information that may seriously affect a person's perception and experience of their future
- How information is delivered has tremendous impact on how patients and family/caregivers hear the news, how they cope, and how they make decisions
- Everyone is unique in how they would like to be given information, what information they want to know, and whom they want to know
- Bad news is always "in the eye of the beholder"
- It is difficult to estimate the impact of the bad news until one has learned the recipient's expectations and understanding of the situation
- Speaking openly and with compassion and empathy shows patients and family/caregivers you care

CONSIDERATIONS

BARRIERS TO BREAKING BAD NEWS

Information sharing can be a complex communication skill. The following are examples of experiences that may occur in the process of breaking bad news:

Health care professionals giving bad news

- Fear of their own emotions
- Fear of patient and family/caregiver emotions and reactions
- Uncertainty in how to support these responses
- Communicating information in technical language that is not easily understood

- Avoiding discussion of distressing information
- Giving false hope – telling patients and family/caregivers what they think they want to hear

PATIENTS AND FAMILY CAREGIVERS RECEIVING BAD NEWS

- Fear of what might be said
- Not feeling prepared
- Feeling that people are not being truthful or honest
- Feeling that their decisions and hopes are not being respected
- May only be able to take in information a little bit at a time
- May have differences in what information they want each other to know
- May have a need to seek a second opinion
- May have limited understanding of medical/physical processes
- May be embarrassed by own lack of knowledge

STRATEGIES

There are no universal approaches that will work in all situations when communicating bad news. When faced with the task, the following considerations may be helpful:

PREPARATION

- Take time to reflect on your own feelings, emotions, and concerns of the situation
- Be familiar with background and details of participants (see Assessment)
- Write down important points to be discussed and bring relevant health records
- Come prepared to talk about possible next steps
- Determine with the patient and family/caregivers who will be present

- Choose a space that is private, comfortable, and limits opportunities for distractions and interruptions

ENGAGING IN CONVERSATION

- Sit in a place that is most comfortable and supportive to the patient
- Ask open-ended questions about: what is currently known and understood about the situation (see Communication Strategies)
- Provide honest and direct information in words that are easily understood
- Pace the information and give time for silence – everyone processes information at different rates
- Anticipate a range of feelings and emotions – patients and family/caregivers may have very different ways of responding to the news
- Ask open-ended questions about how this new information has been understood
- Discuss and address the immediate physical and/or psychosocial/spiritual needs
- Discuss strategies and next steps - explore the hopes patients and family/caregivers may have at this time and for the future
- Offer an opportunity for a follow-up meeting to address and clarify any concerns or new questions

DEBRIEFING (Reflecting after the meeting)

- It is important that health care professionals pay attention to the range of feelings, responses, and concerns they may experience after meeting with patients and family/caregivers
  (eg.: sadness, frustration, anger, guilt, relief, uncertainty, helplessness, disagreement)

- Discussing the meeting with team members is helpful because:
  - Perceptions and concerns of the event can be discussed
  - Support and suggestions from the team can be provided
  - New skills and awareness can be gained for future patient interactions
  - Debriefing helps build good team communication

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Psychosocial Assessment

KEY POINTS

- Illness affects and impacts people differently and there is no set "formula" for assessment
- A holistic approach to assessment includes attending to the range of biological, psychological, social, cultural, and spiritual aspects of a person
- Assessment begins with knowledge of the issues that may influence the well-being of the patient and family/ caregivers
- Assessment involves collecting information and identifying strengths, resources and needs
- Assessment and the gathering of information is an ongoing process - The psychosocial needs of patients and family/caregivers often change over the course of illness

CONSIDERATIONS

INITIAL ASSESSMENT

The Initial Assessment provides an opportunity to gather as much information as possible about the context of the patient and the family/caregivers and the impacts illness is having in various areas of their lives.

All relevant assessment information may not be gathered in the first meeting. The following are examples of areas of assessment that may be helpful:

Areas of Assessment

<u>Bio-Medical Considerations</u>

- Diagnosis
- Previous / concurrent health issues – medications
- Traditional and non-traditional health practices

Psychosocial Considerations

- Demographic information
- Social support system
- Impacts of illness on daily living and relationships
- Work/education history, skills and interests
- Strengths and coping strategies
- Self-care activities, eg.: meditation, exercise, prayer, etc.
- Understanding of diagnosis and prognosis
- Experience and comfort level with health care system
- Goals/hopes/expectations
- Fears/concerns
- Previous and/or anticipated losses
- Communication and Information needs
- Psychological issues and support needs

Spiritual / Cultural Considerations

- Spiritual beliefs and connections
- Patient's description of their spirituality
- Spiritual needs/requests/rituals
- Beliefs and values around health/illness/death
- Beliefs and values around pain and pain management

Practical Considerations

- Financial needs
- Transportation
- Housing/living arrangements/child care needs
- Burial/funeral planning

STRATEGIES

The following are examples of questions that may help facilitate discussion during the initial assessment process and on-going assessment:

General Questions

- What are people's family and community of origin?
- What role/responsibilities does this person have in the family and community?
- How is this illness impacting daily living? Relationships?
- What are people's beliefs and fears about illness, death, dying, and bereavement
- What do people know, want to know, and want others to know about their current health status?

Strengths-Focused Questions

- What do patients and family/caregiver identify as their internal and external strengths and abilities?
- In the past, what has given people strength to cope with difficult situations?
- What makes people feel connected to their spirituality? What spiritual beliefs may influence decision-making?
- What are people's illness beliefs?
- Family dynamics – What is working? What is challenging?
- What is most helpful and supportive at this time?
- What meanings and hopes do people attach to their lives? (eg.: Spiritual, social, emotional connection to self and others)

Risk-Focused Questions

- What is currently worrying or distressing?
- What prior loss experiences and concurrent life issues exist?
- What social and cultural factors may impact people's experiences? (eg.: gender/family/social roles, issues, pressures, expectations)
- Is there history of family conflict, complex relationships, recent losses?
- Is there history of addiction, abuse or mental health issues?

Practical Needs Questions

- What practical assistance is needed now and in the future? (eg.: around finances, housing, transportation, food, child care, advocacy, decision-making, care planning, burials and funerals, etc.)
- What connections exist with other helping professionals?
- What other community resources may be helpful?
- What assistance is necessary to access other supports?

References Psychosocial Assessment: Cairns M., Thompson M., Wainwright W., editors. *Transitions in Dying & Bereavement: A Psychosocial Guide to Hospice and Palliative Care.* Victoria Hospice Society. Baltimore: Health Professions Press, Inc.; 2003

ON-GOING ASSESSMENT

The psychosocial/spiritual needs and experiences of patients and family/caregivers often change over the course of illness. The following psychosocial/spiritual considerations for the *Palliative Performance Scale* (see Appendix 7) are meant to serve as a general guide, to be individually adapted and adjusted to suit the uniqueness of each person's experiences and transitions.

PPS 60-50%

Communication Issues

Psychosocial Considerations

- Feelings of shock, uncertainty, hope, despair
- Patients and families may make different choices about what and with whom to communicate
- Patients, families, and team may be in different places regarding prognosis and expectations

Helpful Strategies

- Daily life routines increasingly impacted - support adjustments from familiar to new routines

- Normalizing differences in coping and communication styles
- Suggest ways to broach difficult topics
- Discuss people's needs and feelings
- Model words/language that facilitate ways to approach delicate conversations *(see Communication)*

Family Issues

Psychosocial Considerations

- Strategies for coping, adjusting, and relating will be tested
- Pre-existing conflicts and tensions may resurface
- People's capabilities and decisions may be doubted and questioned

Helpful Strategies

- Acknowledge conflict - opportunity for dialogue
- Facilitate discussion - offer opportunities for people to come together to discuss and explore concerns and strategies

PPS 40-30%

Dependence and Withdrawal

Psychosocial Considerations

- Increased reliance and dependence on family/caregivers
- Struggles in adjusting with the practical, social, and emotional implications
- Changes in roles and relationships between patients and families

Helpful Strategies

- Support independence and help people recognize their choices and aspects of situation that they can control
- Identify alternative sources of support - exploring ways to preserve familiar roles and ways of relating to each other
- Help people find meaning

Family Stress

Psychosocial Considerations

- As care needs increase families may feel overwhelmed and inexperienced in meeting these new demands
- Growing reality of death

Helpful Strategies

- Assess coping
- Explore people's feelings, abilities to manage, and available or needed resources
- Explore and encourage strategies for self-care

PPS 20-10%

Communication

Psychosocial Considerations

- Dialogue between patients and families may change dramatically
- Dying people may only speak a few words, use metaphorical language, or not have the capacity to speak
- Families may struggle to comprehend what is said, know how to communicate, or conclude the person is 'already gone'

Helpful Strategies

- Normalize changes in communication
- Support continued communication – give people ideas about how to elicit a response from and how to respond to the dying person
- Encourage gentle touch / use of words
- Encourage self care for caregivers

Expectations about dying

Psychosocial Considerations

- Prior experiences and/or perceptions about death and dying will influence how people cope during this time

Helpful Strategies

- Explore people's expectations or hopes
- Ask about prior experiences with dying and death
- Ask about people's hopes and fears about the time of death – e.g.: do they hope to be present or do they anticipate any fears?

PPS 0%

Nature of Death

Psychosocial Considerations

- Moment of death is unique for every dying person - contextual
- Though death is expected, families may have questions about causation or things that may have been observed / experienced during dying process

Helpful Strategies

- When possible, review events prior to death
- Give families chance to describe what happened and how they responded
- People may need reassurance for the care they provided
- Explain and explore perspectives on any unsettling or frightening events or experiences
- Encourage people to articulate their own perspectives of experience

Family Reactions

Psychosocial Considerations

- Wide range of human responses, emotions, needs, and rituals at time of death and afterwards

Helpful Strategies

- Normalize different responses within the family

- Be aware of signs of shock and/or trauma after the death
- Identify support systems and plan of support and follow-up

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Distress

KEY POINTS

- Distress is a common occurrence throughout the illness continuum from diagnosis, treatment, to palliative care
- Experiences of distress are related to the physical, psychosocial, cultural and spiritual contexts that impact a person's ability to cope
- Distress is also influenced by type, stage and site of disease
- Distress can occur along a continuum of severity and range from common, normal feelings to problems that become disabling
- Anxiety and depression are common forms of distress and may benefit from pharmacological and non-pharmacological approaches *(see below)*
- Hope is a powerful coping mechanism and tool of support for some people
- Distress rating scales (verbal, numerical, and visual) are simple and efficient
- The use of relaxation, breathing exercises and other therapeutic techniques are helpful interventions that can be easily taught to patients and family/caregivers *(see Therapeutic Interventions)*
- Effective communication and on-going assessment are key to knowing how to support people in their experiences of distress

CONSIDERATIONS

DISTRESS: CONTRIBUTING FACTORS

PHYSICAL

- Loss/change of bodily functions and body image

- Unrelieved pain or fear of pain
- Unrelieved/persistent/re-occurring symptoms

PSYCHOSOCIAL

- Understanding of disease, treatment and symptom management options
- Loss/change in control, independence, dignity, sense of belonging, hope, empowerment, future
- Loss/change in relationships and social connections
- Isolation, stigmatization, abandonment from loved ones and community
- Poverty and financial hardship
- Loss/change of job, social position, family role
- Feelings of being a burden on family/caregivers
- Fears and concerns for surviving family/caregivers
- Pre-existing mental health issues

CULTURAL

- Differences in beliefs/attitudes around illness, suffering, loss, death
- Language barriers (eg.: information is not understood) *(See Communication)*
- Influence of gender and social roles/expectations

SPIRITUAL

- Loss of participation in spiritual practices and rituals
- Changes in relationship to higher power
- Absence of spiritual mentor or community
- Self-blame - suffering as punishment
- Existential questioning - meaning of life and death

Feelings and emotions that may be associated with Distress

Anxiety	Depression	Sadness	Hopelessness
Guilt	Withdrawal	Anger	Frustration
Fear	Grief	Pain	Helplessness
Powerlessness	Panic	Abandonment	Isolation
Nervousness	Worry	Loss of interest	Worthlessness

Physiological factors that may be associated with Distress

Pain	Nausea	Fatigue	Insomnia
↓Mobility	↓Ability for self care	Dyspnea	Mouth sores
Appetite	Indigestion	Constipation	Diarrhoea
Fevers	Skin irritation	Congestion	Swelling
↓Sexual Desire	Appearance	Memory loss	↓Concentration

STRATEGIES

Assessing the severity of distress and the range of biopsychosocial/spiritual issues that may be contributing factors can be challenging. Assessment of distress is an on-going process throughout the care continuum. Everything that is expressed and experienced is important to listen to, support, and help alleviate if desired.

DISTRESS TOOL

A helpful tool for assessing a person's experiences of distress is the use of a numerical scale (0-10 with 10 being the highest and 0 being the lowest) or some other scale that makes sense to the person, such as colors, symbols etc. Invite the patient to indicate on the scale the level of distress they have been experiencing that day and over the past week within the various

areas of their life (eg.: physical, psychological, spiritual, etc). A response of 5 or more is an indication to the health care team that further investigation and support may be needed. It is also beneficial to reassess levels of distress after meeting with the patient, as the patient may feel better just for talking with you. This might help them identify their own strengths and coping mechanisms. This will also help identify what further support may be helpful. *(see Therapeutic Interventions)*

Questions to facilitate investigation of Distress

- *"On a scale of 0-10, with 10 being the highest, how would you rate your level of distress at this moment? Over the past week?"*
- *"What areas of your life are you finding most distressing?" (eg.: personal, physiological, psychological, social, spiritual domains)*
- *"Tell me about how you have been experiencing distress?" (eg.: physical sensations, emotions, changes in sleep)*
- *"How do you cope with this distress? What are your strengths/find helpful? What do you find challenging?"*
- *"At the beginning of our conversation you had said that your level of distress in this area was rated at _____. How has that changed for you during this conversation?*
- *"What would be helpful in supporting you with your distress now? In the future?"*

- *"What are the most important things (people, conditions, etc.) that are currently helping your quality of life?"*
- *"What are the most important things (people, conditions, etc.) that are currently impacting on your quality of life?"*

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Anxiety

KEY POINTS

- Anxiety is fear that doesn't have a recognizable source
- Anxiety is a common experience for both patients and family/caregivers
- Prevalence of anxiety is influenced by type, stage and site of disease, coping mechanisms, and access to social and emotional support
- Unrelieved symptoms such as pain or dyspnea may create or worsen anxiety. Good symptom management of these and other symptoms is important
- Psychological, social, and spiritual distress are equally important contributing factors
- Anxiety can be reduced using both pharmacological and non-pharmacological interventions

CONSIDERATIONS

The following are some important factors to consider when assessing and managing anxiety:

ANXIETY

- The person's expressed experiences of their distress, including characteristics, severity and duration
- Assessment of the sources and causes for anxiety
- Previous experiences with anxiety
- Family/caregiver reactions and concerns to the patient's distress
- Resources available to the patient, family/caregivers and team
- Weighing the benefits and pitfalls of treatment options
- On-going assessment and evaluation of patient's responses to interventions

STRATEGIES

Anxiety can occur along a continuum of duration and intensity. Both pharmacological and non-pharmacological interventions may be of help:

NON-PHARMACOLOGICAL

- Interdisciplinary assessment (identifying and attending to range of physical/psychological/social/spiritual factors)
- Counselling support
- Therapeutic interventions:
  - Relaxation techniques
  - Guided imagery
  - Breathing exercises
  - Meditation
  - Coping skills (strengths-focused)
  - Cognitive behavioral approaches
  - Music/rituals

(See Therapeutic Interventions)

PHARMACOLOGICAL

- Low dose benzodiazepines (eg. **lorazepam**, **clonazepam**, **diazepam**) may be helpful
- See section on agitation in delirium for dosing and treatment options
  - Treatment with antidepressants (eg. SSRIs) may also be of benefit to some individuals

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Depression

KEY POINTS

- Every individual's experiences with depression are different
- Depression can occur in both patients and caregivers
- Depression often goes under-recognized
- Depression is sometimes difficult to diagnose given the changes of the disease process which may mimic signs and symptoms of depression (loss of appetite, energy, etc)
- Important to ask about history and current experiences of depression for patients and family/caregivers
- Depression screening and assessment tools exist but often are not specific to a palliative care population
- Non-pharmacological and pharmacological approaches exist – every individual is different
- Choosing an approach may vary depending on the time and resources available, the patient's prognosis, and the patient's desire for support
- Side effects of medication may limit treatment options

CONSIDERATIONS

Signs and symptoms of depression can be difficult to diagnose. The following provides examples of psychological, social, and spiritual factors that may be indicators of depression. A thorough assessment of all factors is important when evaluating for depression.

POSSIBLE RISK FACTORS

- Prolonged grief
- Un-controlled pain
- Unrelieved emotional and spiritual distress

- Overwhelming financial distress
- Overwhelming family distress
- Isolation and abandonment from family, community, and spiritual connections
- Pre-existing mental health issues in patient and/or family/caregivers

POSSIBLE INDICATORS

- Excessive feelings of worthlessness, guilt, shame, hopelessness, helplessness
- Recurrent thoughts of death and suicide
- Loss of interest/pleasure in almost all activities

- **NOTE:** Physiological symptoms such as fatigue, loss of energy, anorexia, or insomnia are not as reliable since the illness itself can produce these

STRATEGIES

NON-PHARMACOLOGICAL

- Interdisciplinary assessment (identifying and attending to range of physical/psychological/social/spiritual factors)
- Counselling support (social worker, psychologist, psychiatrist, spiritual advisor etc.)
  - Cognitive Behavioural Therapy (CBT)

PHARMACOLOGICAL

- Tricyclic antidepressants
  - More side effects, especially in higher doses
  - Starting dose should be low and increase slowly
  - If anxiety or insomnia present may choose a sedating TCA at bedtime

  - May also help with neuropathic pain
  - Often less expensive
- SSRIs
  - Less side effects
  - Temporary nausea and anxiety common as side effects
  - May be more expensive
- Psychostimulants (eg. **methylphenidate**)
  - Often a rapid onset of action
  - Potential side effects include agitation, anxiety and insomnia

Questions to facilitate investigation of Depression

- *"Tell me about how your mood has been recently?"*
- *"How often have you been experiencing these feelings and emotions?"*
  (eg.: how many times per week, at what times of the day, under what circumstances etc.)
- *"Do you think you are depressed? How do you know when you are depressed?"*
  (eg.: physiological and emotional symptoms)
- *"Have you ever been depressed? What did you do in those situations? Was it helpful?"*
- *"What do you notice about the situations and moments that you are not depressed? "What is helping in these times?"*
- *"What would be helpful now in supporting you with how you are feeling?"*

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Hope

KEY POINTS

- It is important to identify and understand the hopes of patients and family/caregivers
- Hope is about possibility and is a common coping mechanism
- Hope builds strength, and is critical to the psychosocial well-being of patients and family/caregivers
- Feelings of hope and hopelessness may occur at the same time
- People's hopes may change throughout the course of their illness
- Patients and family/caregivers may be hoping for different things and at different points throughout the illness continuum
- Health care professionals have influence on the hopes of patients and family/caregivers
- To foster hope, it is important to set goals and encourage patients and family/caregivers to participate in decision making

CONSIDERATIONS

This table illustrates examples of some of the hopes patients and family/caregivers may experience.

WHAT MIGHT PATIENTS AND FAMILY/ CAREGIVERS HOPE FOR?

Hope:

- for a cure
- for control and management of pain and symptoms associated with the disease

- for continued quality of life as defined by the individual
- for continued connections to important social relationships
- for resolving interpersonal conflicts or issues
- that they are not a burden on family/caregivers
- that the experience of dying will not be painful
- that family/caregivers will be okay after they die
- for spiritual connection

STRATEGIES

People's hopes may change over time and circumstance. Hopes expressed by patients and family/caregivers may be very different than that of the health care team.

It is important to find balance between being honest and providing hope.

Communication and on-going assessment throughout the care continuum is important for understanding and supporting people's hopes.

Questions to facilitate investigation of Hope

- *"Is hope important to you?*
  What do you hope for at this time? In the future?"
- *"How have these hopes changed for you over the course of your illness?"*
- *"Tell me about what gives you hope during this time?*
  How do you maintain hope?"
- *"How can I support you in your hopes at this time?"*

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Loss, grief and bereavement

"…restoring the fit between the world that is and the world that should be…"
from Parkes, Colin M. Bereavement. Mortality: Virtual Themed Issue 2003.

KEY POINTS

- Loss is a common human experience. How people experience loss varies tremendously.
- Grief is a natural response to loss and there are no right or wrong ways for expressing grief
- Grief can be experienced psychologically, behaviorally, socially, and/or physically
- Grief can be experienced in losses that are not always associated with death
- Grief involves people finding ways to adapt and cope with change, explore meaning in their loss, and find ways to have a continued bond with the deceased
- Emotions, expressions, and understandings of grief are specific to the person and their relationship to their social, cultural, and spiritual world
- Rituals, customs and mourning practices have enormous spiritual, social, and personal significance for the dying and the survivors
- Secondary stressors and life circumstances are risk factors that impact processing and adjustment to loss and death
- Distress and positive emotions are possible at the same time
- Stressful and difficult caregiving situations can impact grief and bereavement

CONSIDERATIONS

Supporting people through their losses, grief, and bereavement involves attending to a wide range of possible experiences and contributing factors.

LANGUAGE OF LOSS

Grief

- Personal feelings, emotions and reactions to loss

Bereavement

- The state of having experienced a death and the process of integrating the death into one's life

Mourning

- The private and public rituals, customs, practices and processes to loss

Anticipated Grief

- Grief or distressing experiences that may occur when a patient or family/caregiver is expecting a future change, loss, or death

Difficult Grief

- May be influenced when there are multiple and/or concurrent losses and deaths – survival issues take priority
- May occur when the loss or death is not recognized, valued or accepted in the family and/or community of the bereaved
- May occur when specific social and cultural responses to grief are either intensified or suppressed
- Sudden or unexpected death of patient or other person

Secondary Losses

- Other past, present, or future losses and experiences that have happened or may happen as a result of illness and death (eg.: loss of income, faith, support, identity and roles, social connections, personal relationships intimacy, home and other material resources)

LANGUAGE OF GRIEF

Grief can involve a combination of feelings, emotions, reactions and behaviours. Sometimes, these may seem to conflict with one another.
This is a natural and normal part of processing, adjusting, and making meaning to the loss or anticipated losses.
They are culturally and socially influenced.

Some examples include:

Common Grief Responses

Physical Symptoms of shock, tightness in chest, shortness of breath, weakness, restlessness, lack of energy, disruption to sleeping and eating patterns, emptiness

Emotional Numb, empty, anger, sadness, crying or wailing, helplessness, hopelessness, fear, guilt, relief, despair, feeling lost, calm, overwhelmed, abandoned, freedom, anxious, frustration, powerlessness, conflicting emotions

Cognitive Confusion, poor concentration, self-blame, disbelief, forgetfulness, problems with short term memory, pre-occupation with thoughts of the deceased, acceptance, lost sense of purpose, shift in perspectives

Behavioural Isolation, embarrassment, social withdrawal, need for information or understanding from different sources, pre-occupation with other tasks and responsibilities, verbal expression of anger, silence, dissociation

Spiritual Blame, exploring hope and purpose, wanting to die or join the deceased, loss or strengthening of beliefs, explore continuing relationship with the deceased

FACTORS IMPACTING GRIEF AND BEREAVEMENT

Personal

- Coping skills
- Circumstances of the illness and death
- Involvement in the care of the deceased
- Illness beliefs
- Unresolved/concurrent losses
- Addiction or mental health issues

Interpersonal

- Relationship with person who died
- Family dynamics
- Gender, social, and cultural expectations
- Roles and responsibilities within family and community systems
- Availability of cultural and/or language support
- Competing and/or current stressors (Eg.: other caregiving responsibilities, own illness, etc.)

Socio-economic

- Access to immediate and on-going social support
- Access to financial resources, stable living arrangements, employment

Cultural and Spiritual

- Access and availability of spiritual and cultural support systems
- Access to traditional healing practices
- Ability to conduct/participate in rituals, customs and mourning practices
- Loss of meaning or faith

STRATEGIES

Grief and loss is experienced not only after the death of a loved one (bereavement) but can occur throughout the illness continuum. The following questions may be helpful during conversations with patients and family/caregivers to better understand and support their grief, loss, and bereavement experiences:

- *"What stresses or changes are you experiencing at this time?" (eg.: illness changes, difficulties coping, other life stresses)*
- *"How are you feeling physically? What are you noticing?"*
- *"What kinds of thoughts and feelings have you been experiencing recently?"*
- *"How are you coping with your thoughts and feelings? Is there anything about your thoughts and feelings that you are concerned or worried about? What do you find helpful?"*
- *"Who do you share your thoughts and feelings with? How do you share your thoughts and feelings with _____? How do you support each other?*
- *"Tell me about how you are managing with all of your other responsibilities, aside from caregiving for your loved one? (eg.: family, employment, community responsibilities)*
- *"Tell me about any important decisions that you are making, or are finding challenging to make?"*
- *"What are your family, spiritual, and/or cultural traditions that are important for the health care team to know?"*
- *"How are you finding ways to take care of your self (physically, emotionally, spiritually) during this time?"*
- *"How can we support you? What would be most helpful during this time"*
- *What other types of support might you find helpful?" (eg.: spiritual support, community organizations, mental health professional, volunteer etc.)*

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Self Care

KEY POINTS

- Caring for someone at the end of life can be a tremendous challenge and will have different impacts on people
- Family/caregivers and health care professionals caring for those with cancer, AIDS, and other illnesses may experience burnout, compassion fatigue, and vicarious trauma
- People may encounter a range of physiological and psycho-spiritual experiences associated with stress and burnout
- Personal strategies and work environments impact the stress experiences of health care professionals and teams
- While caring for others, taking time for self-care is vital for our own well-being
- Self-care involves paying attention to how we are impacted by the work and responsibilities, and accessing the resources that are helpful
- Everyone has different emotional, physical, social and spiritual ways for caring for themselves

CONSIDERATIONS

FAMILY/CAREGIVERS

Family/caregivers often play a primary and critical caregiving role. A variety of factors may impact people's capacities and experiences in providing care. Some examples include:

Personal and Psychological Domain

Factors that Impact Caregiving

- Coping mechanisms
- Relationship to patient
- Type and stage of illness/disease
- Family conflict
- Comfort/skills/knowledge in providing different levels of care
- Previous caregiving experiences
- Age and physical ability
- Pre-existing mental health conditions

Socio-economic Domain

Factors that Impact Caregiving

- Social/cultural practices and expectations of caregiving
- Isolation from social support system
- Dislocation from home and community
- Poverty and financial strain
- Access and affordability of medications and medical supplies

Spiritual Domain

Factors that Impact Caregiving

- Ability to maintain and participate in spiritual practices
- Access to spiritual supports

Practical Domain

Factors that Impact Caregiving

- Access to health care professionals for support
- Availability of medications and medical supplies

Family/caregivers and health care professionals are vulnerable to stress and burnout. The following are examples of physiological and psychosocial/spiritual experiences that people may encounter. It is important to monitor the frequency, intensity, and duration and their impacts in order to implement helpful strategies.

Physiological Experiences

- ❍ Stress and chronic fatigue
- ❍ Headaches
- ❍ Body pain
- ❍ Changes in sleep
- ❍ Stomach disorders
- ❍ Numbness
- ❍ Poor concentration
- ❍ Changes in appetite
- ❍ Muscle aches
- ❍ Difficulty breathing

Psychosocial/spiritual Experiences

- ❍ Feelings of powerlessness
- ❍ Helplessness
- ❍ Loss of hope
- ❍ Withdrawal from family and social system
- ❍ Survivor guilt
- ❍ Fears about the future
- ❍ Resentment for the demands and responsibilities of caregiving
- ❍ Guilt around care provided
- ❍ Unresolved and/or difficult grief
- ❍ Spiritual/religious concerns
- ❍ Distress, depression and anxiety
- ❍ Drug and alcohol use

STRATEGIES

The following questions may be helpful in assessing the experiences of family/caregivers and our own experiences:

- *"How are you doing with caregiving for _____?"*
- *"In caring for _____, what do you feel you are doing well? What are you finding challenging?"*
- *"How are you feeling physically? Have you been experiencing any problems such as _____? How often and for how long"?*
- *"How have you been feeling emotionally? How have you been coping with the range of feelings and emotions?*
- *"How are you caring for your self?" What do you find helpful in giving you the strength to do what you do?"*
- *"What does your personal support system look like? What support do you find most helpful?"*

Everyone is different in how they experience and cope with stress, burnout, and compassion fatigue. It is important that people access the resources and tools that are most beneficial to their own well-being. Caring for ourselves gives us the strength to care for others.

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Therapeutic Interventions

When we are anxious, in distress, in pain, worried, or feeling burned out, we often don't realize the changes and impact it is having on our mind and body.

The following methods and approaches may be helpful in reducing distressing experiences and bringing about the relaxation response, awareness, and self-regulation in stressful situations. They can be easily taught to patients, and family/caregivers. For some, bringing awareness and connection to the body may not be/feel safe or comfortable. It is important to ask permission of the person prior to engaging with any of these approaches.

People may already have techniques that are part of their spiritual or cultural practice and it is important to identify and encourage these as early as possible.

GROUNDING

- Take a moment to bring awareness of how your body is making connection to the ground/chair/bed etc. Notice your feet and how they feel as they connect with the ground. Notice your sitting bones and how they feel as they make connection with the chair/bed/floor. If you are standing, notice other parts of your body - legs, arms, head etc. - and how in this moment they are all interconnected and making connection with the ground/earth/chair/bed etc. As you bring awareness to these connections notice the sensations that may be present for you - heat, coolness, tingling, tightness, numbness etc. - and make any adjustments you need to in order to make yourself comfortable as you ground yourself in the present moment.

BREATHING

Example 1

- Place one hand on abdomen and one hand on chest
- Inhale slowly and deeply through nose, breathing all the way down to your belly, (this allows more airflow into the lungs)
- Notice how your abdomen rises and the chest follows
- Exhale slowly out your nose or mouth, whichever is most comfortable
- Take a moment to pause between each inhalation and exhalation
- Count to 3 as you breath in, pause, and count to 3 as you breath out
- Notice the nice, slow rhythm of your breath
- Notice any changes that may be happening in your body
- This exercise may last for a only a few minutes or longer. Each person will be different

Quick Tools:

** These exercises may be helpful in distressing situations where there is little time to prepare*

1)
- Breath in deeply and clench your fists
- Breath out slowly and let yourself go as limp and loose as possible
- Start yawning
- Repeat these 3 steps as often as necessary

2)
- Breathe slowly through your nose to the count of 4
- Breathe slowly out of your mouth for a count of 6

- As you are exhaling, imagine that you are blowing bubbles and your mouth is in a circular shape

RELAXATION

Focus Word

- ❍ Pick a focus word, short phrase, or prayer that is firmly rooted in your belief system
- ❍ Sit or lie quietly in a comfortable position and close your eyes
- ❍ Relax your muscles, starting at your head and neck, your shoulders, moving to your chest, abdomen, and down your legs to your thighs, down to your calves, to your feet and all the way through to your toes (If this feels uncomfortable, start from your feet and work up to the head). This may take several minutes, or as long as the individual needs
- ❍ Breath slowly and naturally, and as you do, say your focus word, sound, phrase, or prayer silently to yourself as you exhale
- ❍ If other thoughts come to your mind, don't worry. Gently return to your focus word
- ❍ Slowly open your eyes. Continue where you are for a minute or two before moving around.

Example:

Breathing in – "I breath in calmness and peacefulness"

Breathing out – "I breathe out distress and worry"

BODY SCAN

Take a moment to sit or lie down. Scan through your body from the top of your head to the tips of your toes.
Notice any areas of tension or relaxation, your heartbeat,

your breath, the temperature of your hands and feet.
Imagine any tension or discomfort gently flowing downward through your body, through the legs, and out through the soles of the feet into the ground.

Quick Tools:

** These exercises may be helpful in distressing situations where there is little time to prepare*

1) Sitting down, gently place one hand on the forehead and the other hand on the back of the neck.
This quick, yet effective tool naturally calms the mind and helps induce the relaxation response.

2) While you are (sitting, lying down, standing etc.) take a moment to notice your breathing and where you feel the breath going in your body.
As you breathe in, imagine that your breath is filling you wherever your attention to your body goes.
As you breath out, notice any changes that may be happening in your body

IMAGERY AND VISUALIZATION

Imagery and visualization are ways of daydreaming or creating an inner picture that you find peaceful at that moment. It often uses all your senses. These approaches for reducing stress combine deep breathing and meditation.
Your mind imagines a peaceful scene, setting, or experience often from a memory, as you practice deep breathing.
In this place of calm relaxation, you may imagine pain, tension, or discomfort washing away, your body becoming relaxed, or making spiritual connections. Some may find the use of soft gentle music helpful during this process.

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Appendix

Appendix 1

BREAKTHROUGH OR RESCUE DOSES OF MORPHINE

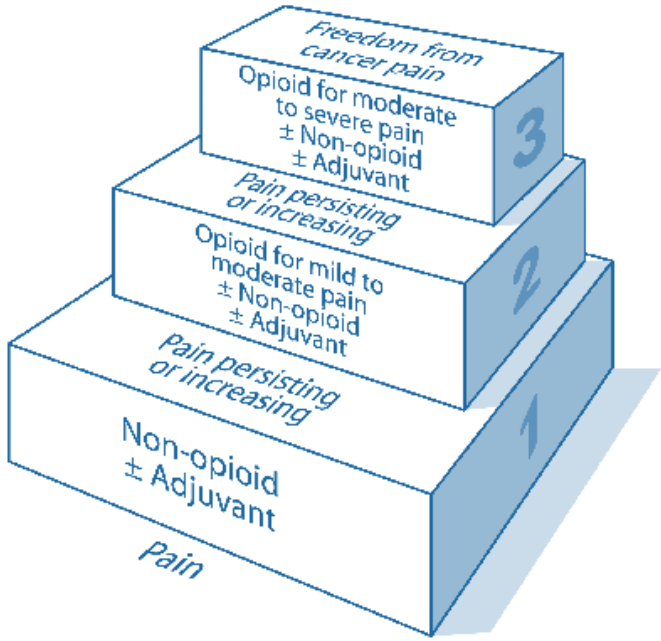
- A breakthrough or rescue dose (used interchangeably in the literature) of **morphine** is one that is given when the patient requires **morphine** for symptoms in addition to the regularly prescribed dose
- It is used to treat episodic or breakthrough pain which has several types:
  - Spontaneous pain (unrelated to movement or other incident)
  - Incident pain (related to an activity, action or event)
  - End-of-dose pain (occurring just prior to the next scheduled dose)
- It is made available on a prn basis **in addition** to their regular dose
- Providing a breakthrough or rescue dose of **morphine** is an important part of managing pain, dyspnea and cough
- ***Breakthrough or rescuedoses are generally approximately 10% of the total 24 hour dose and should be ordered q1h prn (on an as needed basis)***

  Example 1: *A patient receives 10 mg q4h SC of **morphine** = 60 mg in 24h SC. Therefore, appropriate breakthrough or rescue dose is 5 mg q1h prn SC*

  Example 2: *A patient receives 5 mg q4h PO of **morphine** = 30 mg in 24h PO. Therefore, appropriate breakthrough or rescue dose is 2.5 mg q1h prn PO*

Appendix 2

WORLD HEALTH ORGANIZATION PAIN LADDER



This diagram shows the step-wise approach to cancer pain management recommended by the World Health Organization (WHO).

Note: pain control should be based on the level indicated by the patient. For example, it may be clinically indicated to start at "Level 3" on the analgesic ladder for patients who present with severe, difficult pain.

World Health Organization. Cancer Pain Relief. 2nd Edition. Geneva: WHO; 1996

Appendix 3

*** RECOMMENDED INITIAL DOSE FOR OPIOID CONVERSION TO DURAGESIC® (FENTANYL) PATCH

Oral 24-hour morphine equivalent daily dose (MEDD mg/day)	Duragesic® dose equivalent (ug/hour)
60-134	25
135-224	50
225-314	75
315-404	100
405-494	125
495-584	150
585-674	175
675-764	200
785-854	225
855-944	250
945-1034	275

*** JANSSEN-ORTHO 2006

EQUIANALGESIC TABLE FOR CHRONIC OPIOID DOSING

DRUG	ORAL (PO)	PARENTERAL (SC, IV)
Morphine	10 mg	5 mg*
Codeine	100 mg	65 mg
Hydromorphone	2 mg	1 mg*
Oxycodone	5.0-7.5 mg	-
Methadone	1 mg but highly variable ratio & complex**	Not readily available
Fentanyl patch	25 ug patch ≅ 60-134 mg oral morphine daily dose MEDD***	

* Common ratio PO:SC is 2:1, but may be 3:1

** Rotation is complex, with delayed accumulation. Ratio varies from MOR:METH 5:1 at low doses to 10:1 or up to 20:1. Must be individualized

*** A range of fentanyl doses - see Table

NOTE: Due to incomplete cross-tolerance, may reduce equivalent dose of new drug by 25% to 50% & titrate.

Appendix 4

THE USE OF NALOXONE IN RESPIRATORY DEPRESSION DUE TO OPIOID OVERDOSE

- The fear of respiratory depression is sometimes a reason why physicians are reluctant to use opioids
- The risk of respiratory depression in a patient who has already been on a regular opioid dose (for even a few days) is very small
- Even if there is a slowing in the respiratory rate (eg. 6-8/min) this is usually not a cause for alarm as the patient can often simply be monitored. Sometimes it is appropriate for the next dose of opioid to be omitted or reduced.
- Take care to distinguish this from respiratory changes at the very end of life which are to be expected and need no intervention
- It is very rare therefore that an opioid antagonist such as **naloxone** needs to be used
- However, if a significant respiratory depression does occur (perhaps if the patient mistakenly receives an overdose) and if it is deemed absolutely necessary to give an opioid antagonist, the following approach should be used:

- Dilute 1 ml ampule of **naloxone** (eg. 0.4 mg/ml) with 9 ml of saline
- Give small amounts of the diluted mixture (eg. 1 ml) either IV or SC every minute until the respiratory rate increases
- The aim is for partial opioid reversal but not a complete reversal
- Additional small amounts can be given at appropriate intervals to maintain an adequate respiratory rate

NOTE: Giving the complete ampule instead will result in an acute withdrawal from the opioid and cause immediate extreme pain or dyspnea

Appendix 5

AN APPROACH TO NEUROPATHIC PAIN

- Patients with neuropathic pain should have a trial of a tricyclic antidepressant and/or an anticonvulsant (Evidence Grade A, Level 1a and 1b)
- The effectiveness of opioids (especially **methadone**) must not be forgotten when treating neuropathic pain
- Combination therapy with two or more drugs should be considered in the event of partial response to a single medication
- Other options such as NMDA receptor antagonists (e.g. **ketamine**) and antiarrhythmic agents (e.g. **lidocaine**) are not routinely used as first-line but are sometimes tried by clinicians with experience/skill in the use of these agents
- An analgesic ladder for neuropathic pain such as that shown on the following page has been suggested as an approach to neuropathic pain

Adapted from Medical Care of the Dying, 4th ed. (2006) p. 264, Victoria BC with permission, Victoria Hospice Society

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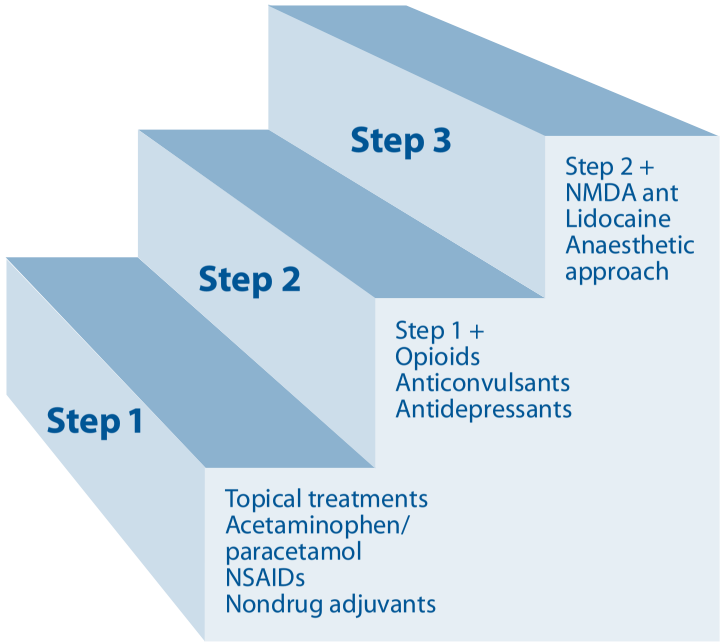
Analgesic Ladder for Neuropathic Pain



Appendix 6

TRANSFUSION OF BLOOD PRODUCTS IN PALLIATIVE CARE

Transfusion of blood products in patients with advanced and life threatening disease can be a lead to difficult ethical and clinical situations.

There are perhaps two basic scenarios encountered:

1. A new situation that has arisen which giving a transfusion may alleviate to some extent (for instance, a bleeding from a tumor which has caused the patient to become anemic and have symptoms of fatigue and breathlessness)

2. An ongoing disease process in which transfusion of blood products has been part of normal supportive care. As the disease progresses the question arises whether these should be continued (for instance, with a child with relapsed leukemia for whom there is no further curative therapy)

In both situations within the context of patient's wishes and prognosis there should be balance between the benefits of transfusion and the burdens and possible harm (see comments regarding 'Balanced Care' on page 13).

At all times the patient and family/caregivers should be part of the process of deciding whether a transfusion should take place or regular transfusions should be ceased

Red Blood Cells

- If the patient is found to be anemic transfusion may help symptoms of weakness, fatigue, breathlessness and headache. If the life expectancy of the patient allows, a trial of transfusion of red cells may be warranted. If the patient continues to be anemic further transfusions may be warranted
- If the patient deteriorates then continued transfusion may become futile or increasingly burdensome
- Adverse effects such as fluid overload and transfusion reactions should be monitored in the usual manner

Platelet transfusion

It should be remembered that transfused platelets remain viable for around 2 days

May be considered if spontaneous bleeding is occurring

- and is distressing
- and if patient's prognosis makes the transfusion worthwhile

Or may be considered to prevent possible bleeding

- if there is a specific reason to prevent spontaneous bleeding (i.e. during travel)

Fresh Frozen Plasma

May be considered in special circumstances in palliative care when coagulation affected by:

- warfarin overdose
- liver disease
- DIC

Appendix 7

PPS LEVEL	AMBULATION	ACTIVITY & EVIDENCE OF DISEASE	SELF-CARE	INTAKE	CONSCIOUS LEVEL
100%	full	Normal activity & work No evidence of disease	full	normal	full
90%	full	Normal activity & work Some evidence of disease	full	normal	full
80%	full	Normal activity *with* Effort Some evidence of disease	full	normal or reduced	full
70%	Reduced	Unable Normal Job/Work Significant disease	full	normal or reduced	full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assis-tance necessary	normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death Bound	-	-	-	-

PALLIATIVE PERFORMANCE SCALE (PPSV2)

Victoria Hospice

INSTRUCTIONS FOR USE OF PPS *(see also definition of terms)*

1. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score.

2. Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located.
   These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

   Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise at a fully conscious level with good intake would be scored at PPS 50%.

   Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'

3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.

4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

DEFINITION OF TERMS FOR PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

1. **Ambulation**
   The items '**mainly sit/lie**,' '**mainly in bed**,' and '**totally bed bound**' are clearly similar. The subtle differences are related to items in the self-care column. For example, 'totally bed bound' at PPS 30% is due to either profound weakness or paralysis such that the patient not only can't get out of bed but is also unable to do any self-care. The difference between 'sit/lie' and 'bed' is proportionate to the amount of time the patient is able to sit up vs. need to lie down.

   '**Reduced ambulation**' is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer on their own but at PPS 60% needs occasional assistance.

2. **Activity and Extent of disease**
   'Some', **'significant'**, and **'extensive'** disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply 'some' disease, one or two metastases in the lung or bone would imply 'significant' disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be 'extensive' disease.
   The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, 'some' may mean the shift from HIV to AIDS, 'significant' implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. 'Extensive' refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc.
   The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or

activities. Decline in activity may mean the person still plays golf but reduces from playing 18 holes to 9 holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (eg. trying to walk the halls).

3. **Self-Care**
   '**Occasional assistance**' means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

   '**Considerable assistance**' means that regularly every day the patient needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat of his or her own accord.

   '**Mainly assistance**' is a further extension of 'considerable.' Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

   '**Total care**' means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

4. **Intake**
   Changes in intake are quite obvious with '**normal intake**' referring to the person's usual eating habits while healthy.

   '**Reduced**' means any reduction from that and is highly variable according to the unique individual circumstances.

   '**Minimal**' refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

5. **Conscious Level**
   '**Full consciousness**' implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc.

   '**Confusion**' is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies.

   '**Drowsiness**' implies either fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor.

   '**Coma**' in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

Q&A REGARDING PPSV2

Examples on the PPSv2 Instruction Sheet

1. Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

2. Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

3. Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'

Additional Examples

4. *What are the definitions of 'some evidence' of disease, 'significant' and 'extensive' disease? Is this measured purely in terms of pathology or are psychological impact etc. considered?*
   - 'Some,' 'significant,' and 'extensive' disease refer to both physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply 'some' disease, one or two metastases in the lung or bone would imply 'significant' disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be 'extensive' disease.
   - As this is a physical functional scale, psychological impact is not considered in the determination. It is what a person is capable of doing, not what they choose to do. For example, anxiety, sadness or demoralization may result in the patient sitting at home a lot, but unless they actually require some assistance to get up (PPS 50% or 60%), the PPS would be higher.

5. *Often we see people at diagnosis who are fully ambulatory, normal activity and work but have extensive disease where do they fit in?*
   - PPS is determined by a "best fit" recognizing, as noted here, that some categories do not line up well. This necessitates a clinical judgment decision. In this case, the aspect of full ambulatory and normal activity indicates quite a high PPS and the 'extensive disease' is clinically less relevant, at least for the moment. A PPS 80% would be appropriate designation.

6. *People who are unable to work because chemotherapy is demanding, but only have some evidence of disease, how do I score them?*
   - PPS should be determined by the actual ability to do something, not by desire, or lack of. In this case, it is not clear what 'demanding' means. If the patient is so physically sick or fatigued that they cannot work, then the PPS is rated accordingly - PPS 70% would be appropriate if can do some work at home, but could be reduced to PPS 50% if they were so sick that they required actual assistance at home.

7. *People who are unable to do most activities due to poor family support or depression but have only some evidence of disease, where do they fit in?*
   - PPS should be determined by the actual ability to do something, not by desire, or lack of. If the patient is clinically depressed and thus not getting up much, but is in fact able to do so, then the PPS level would be higher at 70% or 80% since in this case there is little evident primary disease impact.
   - The same would apply to family support. Little or no assistance by family or friends to get dressed or out of bed will clearly impact quality of care, and may eventually add to physical decline, but if the patient could be up with adequate assistance, then PPS would be accordingly higher.

8. *Can PPSv2 be used with dementia patients?*
   - In general, the answer is yes. PPSv2 is a functional performance scale which primarily focuses on ambulation, activity and self-care. Particularly in advanced stages of Alzheimer's disease, the patient fits quite well into such levels as PPS 50% through PPS 10%.
   - The cognitive aspects of 'dementia' are not well differentiated with PPSv2 in that cognitive decline may occur while 'ambulation' is still quite good. However, in terms of activity and evidence of disease in the second column, PPS 70% and PPS 80% indicate difficulty with normal work or job function which in the case of Alzheimer's is attributed to mental status challenges from the disease rather than actual physical capacity.
   - The fifth column 'Conscious Level' was mainly intended to separate full 'alertness' from reduced levels such as drowsiness, obtundation and coma. It does recognize confusion but primarily as it relates to these factors and possible delirium rather than dementia where full consciousness is present, at least at higher PPS levels.
   - As with all diseases, PPS is a horizontal 'best fit' and judgment is always required.
   - Case example:
     a) Ms. Jones is a 75 year old woman who has had increasing forgetfulness over the last 3 years. She does self-care with her husband observing her. Sometimes he has to help her. She no longer drives but can walk to the grocery store 3 blocks away in a straight line by herself. She requires a list, however, of what she is to purchase and carries a label with her name, address and her husband's name to give to someone if she gets lost which has not happened so far. She generally is up during the day and sleeps most of the night. She used to read and knit at night but no longer does so, and will watch television, although she does not always remember what the content is. Meal preparation is done by her husband preparing the ingredients and her cooking the meal. She generally will eat a full meal but recently requires coaxing on occasion. [PPS is 60% in each of the five categories]

9. *What level of staff are using this tool - nurses, occupational therapists, pastoral workers?*
   - PPSv2 can be used by many palliative workers - nurses, physicians, RT, PT, OT, dieticians, pastoral, volunteers, etc.

10. *Have family members who are caring for their loved ones at home ever been educated on the use of the PPS or in your opinion would it even be useful?*

- PPS is used mainly by professional staff. However, there are some patients or family members who are very involved and meticulous in their care and what is being assessed and planned. For these occasional times, sharing PPS has been helpful and appreciated.

11. *How often do you recommend the use of this tool in a home care palliative care setting where there is possibly various levels of caregivers in the home? Daily visits?*
    - In general, PPS should be rated on each home nursing visit which of course may vary from daily to weekly or less. In our Palliative Care Unit, it is done each day or at anytime the patients' condition changes.

12. *When a patient's mobility is limited because she/he has a fracture in a weight bearing bone, will it translate into the same score as if the inactivity was due to extreme weakness and fatigue?*
    - Yes, the PPS will be lower as the patient functionally is less able to activate. If in full traction, PPS would likely be PPS 40% since he or she is bed-bound but can do some self-care. If in a cast and using a walker or crutches, PPS might be 50%. It would also be expected that, all things being the same, the PPS will increase shortly as mobilization improves.

13. *How is the "Intake" domain scored for patients whose primary or total intake is via feeding tube?*
    - PPSv2 is used by a 'best horizontal fit' of the 5 domains. As such, there are times where one domain such as intake is difficult to interpret and a G-tube or JPEG makes this challenging. Two suggestions may assist in decision making.

- The primary process is that if the other 4 domains seem clear at one PPS level, then that is likely the best-fit irregardless of intake. This is logical since the provision of some nutrition at any level becomes a non-distinguishing factor.
- The second consideration is the somewhat common observation that the tolerability and the volume of fluid given via parenteral tubes usually decreases with overall decline and closeness to death. For example, an ALS patient earlier in disease may tolerate 500-1,000 ml at one time but later in the course can only tolerate 300 ml or 100 ml. This is also seen in advanced cancer patients.

14. *Can PPS be used in the pediatric population?*
    - There is no solid data regarding PPS and children. Clinically, we have used this in some children who are a little older and previously ambulatory, but it is not likely of value for infants.
    - One would need to substitute "job/work" for school or usual activities, but otherwise most other factors are anecdotally reasonable.

Appendix 8

SIGNS AND SYMPTOMS AT THE END OF LIFE

KEYPOINTS

- Unless properly treated severe symptoms at the end of life are common for many children [1]
- Even quite young children can have an understanding of death

CONFUSION / DISORIENTATION / DELIRIUM

- Confusion/delirium is very common at the end of life
- It is the result of multiple, nonreversible factors, such as: hypoxemia, metabolic and electrolyte imbalances, toxin accumulation due to liver and renal failure, adverse effects of medications, infection, and the underlying disease process
- Patients will demonstrate increased drowsiness, a need for more sleep, and decreased responsiveness
- Some patients may experience an "agitated" delirium due to central nervous system excitation. The risk of agitated delirium is increased if the patient has cerebral metastases.
  Refer to the Delirium Guidelines
- Since reversing the cause of the delirium is often not possible at the end of life, the focus should be on managing the symptoms associated with the delirium, keeping the patient safe, and reassuring the patient and family.
  Refer to the Delirium Guidelines
- Evidence suggests that unconscious patients may still be able to hear conversations, and family members can be encouraged to speak to their loved one as though they were conscious

WEAKNESS/FATIGUE

- Weakness and fatigue increase as the patient gets closer to death
- It is NOT appropriate to give stimulants (**methylphenidate**, steroids) to try to "wake the patient up" at this stage of the illness
- Patients may need gentle passive movement to minimize risk of pressure ulcer formation if they are too weak to turn in bed. (However, this must be done cautiously since turning and repositioning may cause pain. If death is imminent, the risk of pressure ulcer formation is not relevant)
- It is important to allow the patient to rest and to help family members understand that this weakness and fatigue is a normal part of the dying process
- Patients will have a limited amount of energy, and we can help the patient prioritize how they want to use this energy. For example, inserting a foley catheter may allow the patient to use energy talking and visiting with family that he would otherwise use moving to the toilet

DECREASED ORAL INTAKE

- Loss of oral intake (both food and fluids) is a normal part of the dying process.
  Refer to the Anorexia/Cachexia Guideline
- Actively dying patients are not hungry or thirsty, and oral intake may actually be dangerous as the risk of aspiration increases as the patient becomes weaker
- Parenteral or enteral feeding at the end-of-life has not

been shown to improve symptom control or lengthen life
- Excessive parenteral fluids, especially in the setting of hypoalbuminemia, can cause fluid overload and significantly increase patient's distress by exacerbating peripheral oedema, ascites, pulmonary oedema and dyspnea
- Frequent oral care (swabbing the mouth with water, keeping lips moist with vasoline/balm) is generally more important for patient comfort than giving fluids

DECREASED BLOOD PERFUSION/RENAL FAILURE

- As cardiac output and intravascular volume decrease there will be evidence of diminished blood perfusion
- Tachycardia, hypotension, cool extremities, cyanosis and mottling of skin are common at the end of life
- Urine output is reduced as perfusion of the kidneys fails. Oliguria/anuria are expected signs
- Parenteral fluids will not reverse this circulatory failure

VITAL SIGN CHANGES

RESPIRATION

- Changes in the dying patient's breathing pattern typically indicate significant neurological compromise
- Breaths may become shallow and frequent, or shallow and slow
- Periods of apnea and increased use of accessory respiratory muscles is common
- It is important to control the symptom of dyspnea, not only for the patient's comfort, but also because family members often view this as the most distressing sign at the end of life. *Refer to Dyspnea Guideline*

TEMPERATURE

- Elevated temperature is common at the end-of-life.

It can be due to infection, dehydration and/or the underlying disease (i.e."tumor fevers")
- Reversing the fever at the end of life is generally not possible
- The most effective treatment is **acetaminophen/paracetamol** rectal suppositories, 650 mg given q4-6 hours either around the clock or prn
- Diaphoresis can be managed with frequent linen changes and cool sponge baths/soaks

HEART RATE/PULSE

- Heart rate may increase with an irregular rhythm
- Cyanosis can be seen as cardiac output falls, and is often first noted in the tip of the nose, nail beds and knees
- Extremities will become mottled and cooler. Progressive mottling indicates death within a few days; absence of a radial pulse may indicate death in a few hours

DECREASED OR DIMINISHED SWALLOW REFLEX

- Weakness and decreased neurologic function impair the patient's ability to swallow at the end of life
- The patient loses the ability to clear secretions from their oropharynx
- This accumulation of saliva and oropharyngeal secretions may lead to gurgling or rattling sounds with each breath, sometimes called "death rattle"
- This sound can be very distressing to family members, as it may sound as though the patient is choking. Family education is critical
- Medications such as atropine or **glycopyrronium/glycopyrrolate** can help reduce this symptom. Repositioning the patient in a lateral recumbent position can facilitate the clearing of secretions. Gentle

oropharyngeal suction can sometimes be helpful.
Refer to the Respiratory Secretions at End of Life Guideline

SURGES OF ENERGY

- Patients may experience a period of increased energy and mental alertness prior to their death
- This can be a time for quality interaction between family members and the patient

INCONTINENCE/URINARY RETENTION

- Fatigue and loss of sphincter control can lead to incontinence of urine and/or stool at the end of life
- Family members should be educated that this is a common occurrence
- Special attention should be paid to keeping the patient clean and dry. A foley catheter may be helpful, but may not be necessary if urine output is minimal and can be controlled with absorbent pads
- Urinary retention can occur. If a patient is restless and has a distended bladder it may indicate the bladder needs to be emptied and insertion of a foley catheter may bring relief

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Appendix 9

ABBREVIATIONS

Abbreviation	Meaning
bid	twice daily
BTD	breakthrough dose
g	gram
h	hour
HS	bedtime
IV	intravenous
kg	kilogram
L	litre
mcg	microgram
mg	milligram
min	minute
mL	millilitre
PO	by mouth
PR	rectally
prn	as needed
qAM	every morning
q1h	every hour
q4h	every 4 hours
q6h	every 6 hours
qid	4 times a day
SC	subcutaneous
SL	sublingual
tab	tablet
tid	3 times a day

Prescribed Drugs / Medications

IAHPC* List of Essential Drugs for Palliative Care

MEDICATION	FORMULATION
Acetaminophen/paracetamol	100 - 500 mg tablets 500 mg rectal suppositories
Amitriptyline**	50 - 150 mg tablets
Bisacodyl	10 mg tablets 10 mg rectal suppositories
Carbamazepine***	100 - 200 mg tablet
Citalopram (or any other equivalent generic SSRI except paroxetine and fluvoxamine)	20 mg tablets 10 mg/5 ml oral solution 20 - 40 mg injectable
Codeine	30 mg tablets
Dexamethasone	0.5 - 4 mg tablets 4 mg/ml injectable
Diazepam	2.5 - 10 mg tablets 5 mg/ml injectable 10 mg rectal suppository
Diclofenac	25 - 50 mg tablets 50 and 75 mg/3 ml injectable
Diphenhydramine	25 mg tablets 50 mg/ml injectable
Fentanyl (transdermal patch)	25 micrograms/hr 50 micrograms/hr
Gabapentin	tablets 300 mg or 400 mg
Haloperidol	0.5 - 5 mg tablets 0.5 - 5 mg drops 0.5 - 5 mg/ml injectable
Hyoscine butylbromide	20 mg/1ml oral solution 10 mg tablets 10 mg/ml injectable
Ibuprofen	200 mg tablets 400 mg tablets

MEDICATION	FORMULATION
Levomepromazine	5 - 50 mg tablets 25 mg/ml injectable
Loperamide	2 mg tablets
Lorazepam****	0.5 - 1 - 2 mg tablets 2 mg/ml liquid/drops 2 - 4 ml injectable
Megestrol Acetate	160 mg tablets 40 mg/ml solution
Methadone (immediate release)	5 mg tablets 1 mg/ml oral solution
Metoclopramide	10 mg tablets 5 mg/ml injectable
Midazolam	1 - 5 mg/ml injectable
Mineral oil enema	
Mirtazapine (or any other dual action NassA or SNRI)	15 - 30 mg tablets 7.5 - 15 mg injectable
Morphine	Immediate release: 10 - 60 mg tablets Immediate release: 10 mg/5 ml oral solution Immediate release: 10 mg/ml injectable Sustained release: 10 mg tablets Sustained release: 30 mg tablets
Octreotide	100 mcg/ml injectable
Oral rehydration salts	
Oxycodone	5 mg tablet
Prednisolone (as an alt to Dexamethasone)	5 mg tablet
Senna	8.6 mg tablets
Tramadol	50 mg immediate release tablets/capsules 100 mg/1 ml oral solution 50 mg/ml injectable
Trazodone	25 - 75 mg tablets 50 mg injectable
Zolpidem (still patented)	5 - 10 mg tablets

*
IAHPC = International Association for Hospice and Palliative Care

**
Side-effects limit dose

***
Alternatives to amitriptyline and tricyclic antidepressants
(should have at least one drug other than dexamethasone)

****
For short term use in insomnia

NOTE: In the section Prescribed Drugs / Medications, some basic information on number of the medications mentioned in the guidelines is given. This information is drawn from a number of sources listed on page 225 and the reader is encouraged to access these and other relevant literature for more detail. As always, sound clinical judgment should used in individual clinical cases. In particular, it should be remembered that there can be significant variation in the pharmokinetics of a drug based on a number of factors (including the individual patient's metabolism/disease status and how the medication has been formulated).

Acetaminophen/paracetamol

PHARMACOLOGY

It most probably acts by inhibiting prostaglandin synthesis in the CNS and perhaps also by blocking pain-impulse generation peripherally. In addition, it acts centrally on the hypothalamus to produce peripheral vasodilatation resulting in an anti-pyretic effect.

Onset of action: 15-30 minutes
Time to peak: 40-60 minutes
Duration of action: 4-6 hrs
Plasma ½ life: 2-4 hrs

DOSING

650-1000 mg q4-6h to a maximum of 4 g per day PO

Acetaminophen/paracetamol

- under 1 year: 10-15 mg/kg q4h/prn PO;
- 1-5 years: 120-250 mg q4h PO;
- 5-12 years: 250-500 mg q4h PO
  (maximum of 75 mg/kg/day)

UNWANTED EFFECTS

Rash, GI upset, rarely hepatotoxicity and nephrotoxicity

Amitriptyline

PHARMACOLOGY

Tricyclic antidepressant that blocks the pre-synaptic uptake of serotonin and norepinephrine

- ❍ Onset of action: analgesic effect after 3-7 days; up to 30 days for depression

- Time to peak plasma concentration: 4 h PO
- Plasma 1/2 life: 9-25 h PO;

DOSING

Starting dose 10-25 mg PO hs titrating upward as required to 150 mg (higher doses rarely required in palliative care)

500 mcg/kg at night PO

UNWANTED EFFECTS

Sedation, dry mouth, delirium, postural hypotension, fatigue, hyponatremia, headache, urinary retention

PITFALLS/CONCERNS

- Low doses should be used initially in the elderly
- Sedation may affect performance of some tasks
- Avoid abrupt withdrawal after discontinuation
- Should not be used with an MAOI, recent myocardial infarction, arrythmias, mania or severe hepatic impairment

Atropine

PHARMACOLOGY

Antimuscarinics/anticholinergics such as **hyoscine hydrobromide**, **atropine**, **glycopyrronium/glycopyrrolate**, **hyoscine butyl bromide** are used primarily as smooth muscle antispasmodics and antisecretory agents. They are used in palliative care for intestinal colic, genitor-urinary colic, inoperable bowel obstruction with colic and respiratory secretions at end of life.

Hyoscine hydrobromide and **glycopyrronium/glycopyrrolate** are less likely to cross the blood-brain barrier as they are less lipid-soluble thereby causing less central side-effects (eg. delirium). Overall efficacy in reducing respiratory secretions at end of life is seen in about 1/2 to 1/3 of patients

Onset of action: < 10 minutes SC/IM/IV
Plasma 1/2 life: 5-6 hrs

DOSING

0.6-0.8 mg SC. If effective, continue, using q4h and prn.

UNWANTED EFFECTS

Blurred vision, cardiovascular effects, dry mouth, constipation, heartburn, urinary retention, delirium

PITFALLS/CONCERNS

- Avoid concurrent use with prokinetics as **atropine** may block the action of agents such as **metoclopramide**
- Glaucoma may be precipitated in patients at risk

Bisacodyl

PHARMACOLOGY

Increases bowel motor activity

Onset of action: tablets 10-12 hours;
suppositories 20-60 minutes

DOSING

5-15 mg od to bid

6-12 years: 5-10 mg once daily PO

UNWANTED EFFECTS

Intestinal colic (cramping), diarrhoea

Carbamazepine

PHARMACOLOGY

Time to peak: 4-8 hours
Plasma 1/2 life: 8-24 hours

DOSING

100-200 mg od-bid, increase by 100-200 every 2 weeks, (usual maximum dose 800-1200 mg in divided doses)

- Less than 6 years: 10-20 mg/kg/24hrs in divided doses bid or tid PO
- Over 6 years: 100 mg od PO

UNWANTED EFFECTS

Drowsiness, headache, unsteadiness on feet, dizziness, headache, nausea and vomiting

- There are many drug-drug interactions with anti-epileptics

Carbocisteine

PHARMACOLOGY

Carbocisteine decreases the viscosity of sputum secretions

DOSING

750 mg tid

UNWANTED EFFECTS

Occasional gastro-intestinal irritation

PITFALLS/CONCERNS

Can rarely cause gastro-intestinal bleeding

Chlorpromazine

PHARMACOLOGY

Chlorpromazine is a phenothiazine antipsychotic which selectively antagonizes dopamine D2 receptors in the brain

Onset of action: I.M.: 15 minutes; Oral: 30-60 minutes
Plasma 1/2 life: 23-37 hours

DOSING

Oral, I.M: 15-50 mg 2-4 times/day

Children more than 6 months: 0.5-1 mg kg/dose every 4 to 6 hours PO or every 6 to 8 hours IV or in divided doses q6-q8h IV

UNWANTED EFFECTS

Anticholinergic effects: (constipation, dry mouth, blurred vision, urinary retention).
Extrapyramidal symptoms: (pseudoparkinsonism, akathisia, dystonias, tardive dyskinesia)
Sedation, orthostatic hypotension, paradoxical agitation/ excitement, restlessness, rash, photosensitivity

Citalopram

PHARMACOLOGY

It is a highly selective serotonin reuptake inhibitor (SSRI) with minimal effects on neuronal reuptake of **norepinephrine**

(NE) and dopamine (DA). It acts as an antidepressant by potentiating the serotonergic activity in the CNS

DOSING

Initial 20 mg/day PO as a single dose in the morning or evening;
dose increases should usually occur in increments of 20 mg at intervals of no less than one week;
maintenance, 40 mg/day PO; MAX dose 60 mg/day

UNWANTED EFFECTS

lightheadedness, syncope, nausea, xerostomia, confusion, dizziness, somnolence

Clonazepam

PHARMACOLOGY

Benzodiazepines have GABA-potentiating actions in the CNS (spinal cord, hippocampus, cerebellum, cerebrum) thereby reducing neuronal activity

Onset of action: 20-60 min PO
Time to peak: 1-3 hours
Duration of action: Children 6-8 hours, adults less than 12 hours
Plasma 1/2 life: 20-60 hours

DOSING

Anxiety and neuropathic pain: 0.25-2 mg OD or BID

- Less than 30 kg or less than 10 years old:
  0.01-0.05 mg/kg/24 hr in divided doses tid PO;
- More than 30 kg:
  0.5 mg/24 hr in divided doses tid PO

UNWANTED EFFECTS

Sedation, fatigue, decreased co-ordination, blurred vision, memory impairment, hypotension, anxiety, decreased libido, depression, headaches, insomnia, oedema

PITFALLS/CONCERNS

- Benzodiazepines used alone in delirium will likely exacerbate the condition
- There are some drug-drug interactions with benzodiazepines
- Abrupt cessation of long-term benzodiazepine therapy can cause withdrawal symptoms
- May cause hypotension
- Use with caution in severe hepatic disease

Codeine

PHARMACOLOGY

Codeine is a pro-drug of **morphine**. Its metabolites bind to the u-opioid receptor providing analgesia. It is about 1/10 as potent as **morphine**.
Codeine may not provide analgesia if the patient is a poor CYP2D6 metaboliser or if another drug such as paroxetine is acting as a CYP2D6 inhibitor.
Codeine also has antitussive properties and will slow gastro-intestinal motility and is sometimes used in diarrohea

Onset of action:
- 0.5 to 1 hour for analgesia;
- 1-2 hours for antitussive effect

Time to peak effect: 1-2 hours
Duration of action: 4-6 hours
Plasma 1/2 life: 2.5-3.5 hours

DOSING

Commonly it is given in a compounded preparation with **acetaminophen/paracetamol** or another agent which may limit its use based on "ceiling dose"

Analgesia: 30-60 mg PO q 4h
Antitussive: 15-30 mg PO q 4h prn
Diarrhoea: 30-60 mg PO q 4h prn

- Children more than 6 months:
  0.5-1.0 mg/kg q4h PO (max 60 mg/dose)

UNWANTED EFFECTS

- Common initial: nausea and vomiting, drowsiness, unsteadiness, delirium (transient)
- Common ongoing: constipation, nausea and vomiting
- Occasional: dry mouth, sweating, pruritis, hallucinations, myoclonus
- Rare: respiratory depression, dependence

PITFALLS/CONCERNS

- Causes constipation
- Some individuals (about 7% of Caucasians) are poor metabolisers of codeine and therefore are unable to achieve a significant analgesic benefit from **codeine**
- Because of some immature metabolic processes **codeine** may not be appropriate in younger children and infants

Desipramine

PHARMACOLOGY

Tricyclic antidepressant that blocks the pre-synaptic uptake of serotonin and norepinephrine

Onset of action: analgesic effect after 3-7 days; up to 30 days for depression
Time to peak plasma concentration: 4 h PO
Plasma 1/2 life: 9-25 h PO

DOSING

Starting dose 10-25 mg PO hs titrating upward as required to 150 mg (higher doses rarely required in palliative care)

UNWANTED EFFECTS

Dry mouth, sedation, delirium, postural hypotension, hyponatremia, headache, urinary retention

PITFALLS/CONCERNS

- Low doses should be used initially in the elderly
- Sedation may affect performance of some tasks
- Avoid abrupt withdrawal after discontinuation
- Should not be used with an MAOI, recent myocardial infarction, arrythmias, mania or severe hepatic impairment

Dexamethasone

PHARMACOLOGY

Dexamethasone decreases inflammation by changing the permeability of capillaries and by decreasing neutrophil migration
In comparison to many other corticosteroids, **dexamethasone** has high glucorticoid activity but insignificant mineralocorticoid effect

Duration of action: 36-54 hours
Time to peak plasma: 1-2 hours PO, 8 hours SC

DOSING

Anorexia: 2-4 mg PO OD
Anti-emetic: 2-4-8 mg PO OD to BID
Raised intracranial pressure: 8-20 mg PO OD
Spinal cord compression: 16 mg PO daily

- 2-5 years: 0.5-1 mg bid PO/SC/IV
- 6-12 years: 1-2 mg bid PO/SC/IV
- 12 (plus): 2-4 mg bid PO/SC/IV

UNWANTED EFFECTS

Short term: hyperglycemia and diabetes mellitus, increased susceptibility to infection (eg. thrush), mental disturbances (insomnia, depression, euphoria, paranoid psychosis), peptic ulceration (especially if given with an NSAID)
Longer term: muscles wasting and weakness, osteoporosis, cushing's syndrome (moonface, striae, acne), avascular bone necrosis

PITFALLS/CONCERNS

- May exacerbate or precipitate diabetes mellitus
- Abrupt cessation of corticosteroids can precipitate an adrenal crisis
- If used with NSAIDs there is a high risk of peptic ulceration

Dextromethorpan

PHARMACOLOGY

Controls cough by depressing the medullary cough center

Onset of action: 15-30 minutes
Duration of action: Approximately 6 hours
Plasma 1/2 life: 11 hours

DOSING

Oral: 10-20 mg every 4 hours or 30 mg every 6-8 hours
1-2 mg/kg/24 hr in divided doses tid or bid PO

UNWANTED EFFECTS

Constipation, sedation, nausea, dizziness, respiratory depression

Diazepam

PHARMACOLOGY

Benzodiazepines have GABA-potentiating actions in the CNS (spinal cord, hippocampus, cerebellum, cerebrum) thereby reducing neuronal activity

Onset of action: 15 min PO; immediate IV
Time to peak: 30-90 min PO
Duration of action: 3-30 hours
Plasma 1/2 life: parent drug 20-50 hours; active metabolite 50-100 hours

DOSING

Anxiety: 2-10 mg PO OD to QID
Muscle spasm/myoclonus: 5-10 mg PO OD
Anti-epileptic: 10 mg PR/IV
0.3-0.5 mg/kg/dose PR SC IV

UNWANTED EFFECTS

Sedation, fatigue, decreased co-ordination, blurred vision, dizziness, hypotension, anxiety, decreased libido, depression,

headaches, insomnia

PITFALLS/CONCERNS

- Benzodiazepines used alone in delirium will likely exacerbate the condition
- There are some drug-drug interactions with benzodiazepines
- Abrupt cessation of long-term benzodiazepine therapy can cause withdrawal symptoms
- May cause hypotension
- Use with caution in severe hepatic disease

Diclofenac

PHARMACOLOGY

NSAIDs block the synthesis of prostaglandins by inhibiting the enzyme cyclooxgenase. Through this mechanism, NSAIDs decrease inflammation and pain

Onset of action: 30-60 minutes
Time to peak: 1-2 hours
Plasma 1/2 life: 2 hours

DOSING

Analgesia:
50 mg 3 times/day, maximum dose: 150 mg/day
Rheumatoid/osteoarthritis:
150-200 mg/day in 2-4 divided doses
2-3 mg/kg/24 hr in divided doses bid or tid PO

NOTE: *Have patient take with food if possible to decrease GI upset*

UNWANTED EFFECTS

Headache, dizziness, itching/rash, fluid retention, abdominal cramps/pain, constipation or diarrhoea, flatulence, indigestion, nausea, peptic ulcer/GI bleed, tinnitus, acute renal failure

PITFALLS/CONCERNS

- Many of the toxic effects of NSAIDs are related to their primary mechanism of action (the inhibition of prostaglandin synthesis)
- Common adverse effects:
  - Gastrointestinal complications:
    - Dyspepsia
    - Peptic ulcer disease
    - Gastrointestinal bleeding
  - Renal toxicities:
    - Acute renal failure due to renal vasoconstriction
  - Cardiovascular:
    - Possible increased risk of myocardial infarction, stroke, and new onset or worsening of hypertension
  - Tinnitus:
    - Typically reversible after stopping NSAIDs
  - Antiplatelet effects:
    - Inhibit platelet aggregation
    - Can increase risk of significant bleeding for patients undergoing surgery, thrombocytopenic patients (platelet count < 50,000), or patients on anticoagulant therapy such as **warfarin**
  - Respiratory:
    - Can precipitate bronchospasm or worsen asthma in small percentage of individuals
- NSAIDs should generally be avoided in pediatric patients with fever due to risk of Reye Syndrome. **Acetaminophen**/**paracetamol** should be used instead

Bottom Line: NSAIDs are effective, inexpensive, anti-inflammatory drugs that are well tolerated in most people and can provide significant pain relief. However, patients with significant gastrointestinal problems, bleeding risks, or renal or cardiac compromise should be carefully evaluated before beginning therapy with NSAIDs. May need to adjust dose and monitor renal function for patients with renal compromise

Dimenhydrinate

PHARMACOLOGY

Competes with histamine for H1-receptor sites on effector cells in the gastrointestinal tract, blood vessels, and respiratory tract; blocks chemoreceptor trigger zone, diminishes vestibular stimulation, and depresses labyrinthine function through its central anticholinergic activity

Onset of action: 15-30 minutes
Plasma 1/2 life: 3.5 hours

DOSING

50-100 mg every 4-6 hours PO/IV, maximum 400 mg/day
5 mg/kg/24 hr divided into q4h or q6h PO/IV

UNWANTED EFFECTS

- Slight to moderate drowsiness/sedation, headache, dizziness.
- Anticholinergic effects: (constipation, dry mouth, blurred vision, urinary retention)
- Paradoxical CNS stimulation

Diphenhydramine

PHARMACOLOGY

Acts as an antihistamine by competing with histamine for receptor sites (also has antiemetic and antispasmotic properties)

Time to peak: 1-3 hours
Duration of action: 4-7 hours
Plasma ½ life: 5 hours

DOSING

25-50 mg bid to qid PO
1 mg/kg/dose Q6H PO/IV (max 300 mg/day)

UNWANTED EFFECTS

Drowsiness, dizziness, dryness of the mouth, nausea, nervousness. Rare: blurred vision, vertigo, palpitations, thickening of bronchial secretions

Docusate

PHARMACOLOGY

An emulsifying and wetting laxative with relatively weak effect on bowel transit
Onset of action: 12-72 hours

DOSING

Starting dose 100 mg bid, increasing to 200 mg bid-tid

- Less than 3 years: 10-40 mg/24hrs bid PO
- 3-6 years: 20-60 mg/24hrs in divided doses bid PO
- 6-12 years: 40-120 mg/24hrs in divided doses bid PO

UNWANTED EFFECTS

Diarrhoea, unpleasant aftertaste

Fentanyl transdermal patch

PHARMACOLOGY

Fentanyl is a strong opioid analgesic which produces its effects predominantly via agonist actions at the mu opioid receptor. The transdermal patches deliver a steady hourly dose of **fentanyl** by utilizing a rate-limiting membrane and the 'time to peak plasma concentration' can be up to 48hrs when first applied. Therefore they should only be used in the management of chronic, moderate to severe pain requiring around-the-clock opioid therapy after the patient's opioid requirements have been ascertained. They can be particularly useful in situations where the patient cannot swallow.
They are thought to be less constipating than **morphine**.
Fentanyl is less likely than morphine to cause adverse effects in renal impairment.

DOSING

The patient's opioid requirements should have been previously stabilized by titrating a shorter acting opioid formulation. The strength of the patch to be used should be then be determined on this basis of an equianalgesic chart specifically for **fentanyl transdermal patch** (see example of one in Appendix 3). A minority of patients may need to change the patch every 48hrs.

PITFALLS/CONCERNS

It is not recommended to attempt treat uncontrolled or acute pain with **fentanyl transdermal patches**.

The patches, when removed, still contain active medication and should be disposed of as per manufacturers instruction. If left lying around they may be a danger to children
*See manufacturer's recommendation or appendix 3 for conversion to and from **morphine***

UNWANTED EFFECTS

Pruritus, sweating symptom, nausea, vomiting, xerostomia, confusion, dizziness, sedated, urinary retention, constipation

Gabapentin

PHARMACOLOGY

Increases GABA synthesis but exact mechanism of action not fully understood

Onset of action: 1-3 hours
Time to peak: 2-3 hours PO
Plasma 1/2 life: 5-7 hours, (increases with renal failure)
Duration of action: 8-12 hours

DOSING

300 mg od PO increasing to 600-1200 mg tid
10-30 mg/kg/24hrs in divided doses tid PO

UNWANTED EFFECTS

- Common: Drowsiness, dizziness, fatigue, ataxia, tremor, nystagmus
- Other: Headache, weight gain, nervousness, dysarthria, rhinitis, diplopia, peripheral oedema, constipation

Glycopyrronium/glycopyrrolate

PHARMACOLOGY

Antimuscarinics/anticholinergics such as **hyoscine hydrobromide**, **atropine**, **glycopyrronium/glycopyrrolate**, **hyoscine butyl bromide** are used primarily as smooth muscle antispasmodics and antisecretory agents.
They are used in palliative care for intestinal colic, genitor-urinary colic, inoperable bowel obstruction with colic and respiratory secretions at end of life.

Hyoscine hydrobromide and **glycopyrronium/glycopyrrolate** are less likely to cross the blood-brain barrier as they are less lipid-soluble thereby causing less central side-effects (eg. delirium). Overall efficacy in reducing respiratory secretions at end of life is seen in about 1/2 to 1/3 of patients

Onset of action: < 30 minutes SC/IM/IV; 50 min PO
Duration of inhibition of salivation: 7 hours

DOSING

0.4 mg as a single dose SC.
Then effective, continue using 0.2 mg q4h and prn SC
4-10 mcg/kg q6h (max of 200 mcg/dose) IV/SC

UNWANTED EFFECTS

Blurred vision, cardiovascular effects, dry mouth, constipation, heartburn, urinary retention, delirium

PITFALLS/CONCERNS

- Avoid concurrent use with prokinetics as antimuscarinics will block the action of agents such as **metoclopramide**

- Glaucoma may be precipitated in patients at risk

Haloperidol

PHARMACOLOGY

Dopamine-receptor antagonist. Inhibitory effect on the area postrema (chemoreceptor trigger zone).

In palliative care **haloperidol** has been used for nausea, vomiting, delirium and intractable hiccup.

Can be given PO, SC, IV

Onset of action: 10-15 min SC; >1h PO
Duration of action: Usually 24 hours
Plasma 1/2 life: 13-35 hours

DOSING

Antiemetic: 0.5-2 mg od at HS (usual dose 3-5 mg; maximum 10-20 mg od HS or in divided doses/day
Antipsychotic/anxiolytic: 0.5-5 mg bid PO or SC
0.05-0.15 mg/kg/24hrs in divided doses bid or tid PO/SC/IV

UNWANTED EFFECTS

Extrapyramidal effects (acute dystonias, pseudoparkinsonism, and akathisia), hypotension, sedation

PITFALLS/CONCERNS

- Should not be used in Parkinson's disease
- Watch for extrapyramidal effects – if present decrease or discontinue **haloperidol** and treat symptoms using

anticholinergics (benztropine), beta-blockers or benzodiazepines if necessary

Hyoscine butyl bromide

PHARMACOLOGY

Antimuscarinics/anticholinergics such as **hyoscine hydrobromide**, **atropine**, **glycopyrronium/glycopyrrolate**, **hyoscine butyl bromide** are used primarily as smooth muscle antispasmodics and antisecretory agents. They are used in palliative care for intestinal colic, genitor-urinary colic, inoperable bowel obstruction with colic and respiratory secretions at end of life. **Hyoscine hydrobromide** and **glycopyrronium/glycopyrrolate** are less likely to cross the blood-brain barrier as they are less lipid-soluble thereby causing less central side-effects (eg. delirium)

Overall efficacy in reducing respiratory secretions at end of life is seen in about 1/2 to 1/3 of patients

Onset of action: 10 minutes SC/IM/IV
Time to peak plasma concentration: 1-2 h PO
Plasma 1/2 life: 5-6 h

DOSING

20 mg as a single dose SC
If effective, continue, using 20 mg q4h SC

- Less than 6 years: 0.3 mg/kg/dose tid PO/SC/IV;
- 6-12 years: 5-10 mg up to tid PO/SC/IV

UNWANTED EFFECTS

Blurred vision, cardiovascular effects, dry mouth, constipation, heartburn, urinary retention, delirium

PITFALLS/CONCERNS

- Avoid concurrent use with prokinetics as antimuscarinics will block the action of agents such as **metoclopramide**
- Glaucoma may be precipitated in patients at risk

Hyoscine hydrobromide

PHARMACOLOGY

Antimuscarinics/anticholinergics such as **hyoscine hydrobromide**, **atropine**, **glycopyrronium/glycopyrrolate**, **hyoscine butyl bromide** are used primarily as smooth muscle antispasmodics and antisecretory agents.
They are used in palliative care for intestinal colic, genitor-urinary colic, inoperable bowel obstruction with colic and respiratory secretions at end of life. **Hyoscine hydrobromide** and **glycopyrronium/glycopyrrolate** are less likely to cross the blood-brain barrier as they are less lipid-soluble thereby causing less central side-effects (eg. delirium).

Overall efficacy in reducing respiratory secretions at end of life is seen in about 1/2 to 1/3 of patients.

Onset of action: < 10 minutes SC/IM/IV
Plasma 1/2 life: 5-6 h

DOSING

0.4 mg as a single dose SC
If effective, continue using 0.3-0.6 mg q4h SC

- 1 year-12 years: 10 mcg/kg SC/IV as single dose;
- 20-60 mcg/kg over 24 hours in SC or IV infusion

UNWANTED EFFECTS

Blurred vision, cardiovascular effects, dry mouth, constipation, heartburn, urinary retention, delirium

PITFALLS/CONCERNS

- Avoid concurrent use with prokinetics as antimuscarinics will block the action of agents such as **metoclopramide**
- Glaucoma may be precipitated in patients at risk

Ibuprofen

PHARMACOLOGY

NSAIDs block the synthesis of prostaglandins by inhibiting the enzyme cyclooxgenase. Through this mechanism, NSAIDs decrease inflammation and pain

Onset of action: Analgesic: 30-60 minutes
Anti-inflammatory < 7 days
Time to peak: 1-2 hours
Plasma 1/2 life: 2-4 hours
Absorption: Oral: rapid (85%)

DOSING

Inflammatory disease: Oral: 400-800 mg/dose 3-4 times/day (maximum: 3.2 g/day)
Analgesia/pain: Oral: 200-400 mg/dose every 4-6 hours (maximum 2.4 g/day)
5-10 mg/kg q 8-q12h PO

***Have patient take with food if possible to decrease GI upset*

UNWANTED EFFECTS

Dizziness, headache, fluid retention, nervousness, itching/rash, dyspepsia, nausea, vomiting, heartburn, tinnitus, abdominal pain

PITFALLS/CONCERNS

- Many of the toxic effects of NSAIDs are related to their primary mechanism of action (the inhibition of prostaglandin synthesis)
- Common adverse effects:
  - Gastrointestinal complications:
    - Dyspepsia
    - Peptic ulcer disease
    - Gastrointestinal bleeding
  - Renal toxicities:
    - Acute renal failure due to renal vasoconstriction
  - Cardiovascular:
    - Possible increased risk of myocardial infarction, stroke, and new onset or worsening of hypertension
  - Tinnitus:
    - Typically reversible after stopping NSAIDs
  - Antiplatelet effects:
    - Inhibit platelet aggregation
    - Can increase risk of significant bleeding for patients undergoing surgery, thrombocytopenic patients (platelet count < 50,000), or patients on anticoagulant therapy such as **warfarin**
  - Respiratory:
    - Can precipitate bronchospasm or worsen asthma in small percentage of individuals

- NSAIDs should generally be avoided in pediatric patients with fever due to risk of Reye Syndrome. **Acetaminophen/paracetamol** should be used instead

Bottom Line: NSAIDs are effective, inexpensive, anti-inflammatory drugs that are well tolerated in most people and can provide significant pain relief. However, patients with significant gastrointestinal problems, bleeding risks, or renal or cardiac compromise should be carefully evaluated before beginning therapy with NSAIDs.
May need to adjust dose and monitor renal function for patients with renal compromise.

Imipramine

PHARMACOLOGY

Blocks the pre-synaptic uptake of **serotonin** and **norepinephrine**

Onset of action: analgesic effect after 3-7 days; up to 30 days for depression
Time to peak plasma concentration: 4 h PO
Plasma 1/2 life: 9-25 h PO;
active metabolite nortripyline 13-93 hours
Duration of action: 24 h

DOSING

Starting dose 10-25 mg PO hs titrating upward as required to 150 mg (higher doses rarely required in palliative care)
0.2-0.4 mg/kg/dose HS PO

UNWANTED EFFECTS

Antimuscarinic effects, sedation, delirium, postural hypotension, hyponatremia

PITFALLS/CONCERNS

- Low doses should be used initially in the elderly
- Sedation may affect performance of some tasks
- Avoid abrupt withdrawal after discontinuation
- Should not be used with an MAOI, recent myocardial infarction, arrythmias, mania or severe hepatic impairment

Levomepromazine (Methotrimeprazine)

PHARMACOLOGY

A neuroleptic phenothiazine which possesses a broad anti-emetic effect as well as antipsychotic, anxiolytic, sedative and analgesic properties

Onset of action: 30 minutes
Time to peak: 1-3 hrs PO, 30-90 minutes SC
Duration of action: 12-24 hours
Plasma ½ life: 15-30 hours

DOSING

2.5-10 mg tid (maximum 200 mg/24 hours)
0.1-04 mg/kg over 24hrs by SC infusion

UNWANTED EFFECTS

Drowsiness, orthostatic hypotension, extrapyramidal effects, dryness of the mouth, urinary retention in elderly

Loperamide

PHARMACOLOGY

This is primarily a mu opioid receptor agonist which acts locally to reduce intestinal motility but does not cross blood/brain barrier. Used to treat diarrhoea, to reduce fecal output and to relieve symptoms of abdominal cramping

Time to peak: up to 24 hrs
Plasma ½ life: 11 hrs

DOSING

4 mg initially followed by 2 mg after each loose stool PO (max 16 mg/day); in cases of ongoing diarrhoea (and where overflow diarrhoea and other treatable conditions have been ruled out) a regular dose may be needed bid

- 10-20 kg: 1 mg tid,
- 20-30 kg: 2 mg bid,
- More than 30 kg: 2 mg tid

UNWANTED EFFECTS

may cause constipation and overflow diarrhoea, drowsiness, dry mouth, nausea and vomiting, and rarely hyperglycemia

Lorazepam

PHARMACOLOGY

Benzodiazepines have GABA-potentiating actions in the CNS (spinal cord, hippocampus, cerebellum, cerebrum) thereby reducing neuronal activity

Onset of action: 5 min SL; 10-15 min PO

Time to peak: 1-1.5 h SL/SC, 1-6 h PO
Duration of action: 6-72 h
Plasma 1/2 life: 12-15 h

DOSING

Insomnia: 0.5 to 2 mg HS
Anxiety: 1 mg SL/PO bid - increase to 6 mg/24hrs in divided doses
Agitation: 0.5-2 mg bid + q1h prn PO/SC/IV/PR
Status epilepticus: 2-4 mg SL, SC or IV. Repeat after 15 and 30 minutes if needed
25-50 mcg/kg (max 1 mg) as single dose PO/SL

UNWANTED EFFECTS

Sedation, fatigue, decreased co-ordination, blurred vision, memory impairment, hypotension, anxiety, decreased libido, depression, headaches, insomnia

PITFALLS/CONCERNS

- Benzodiazepines used alone in delirium will likely exacerbate the condition
- There are some drug-drug interactions with benzodiazepines
- Abrupt cessation of long-term benzodiazepine therapy can cause withdrawal symptoms
- May cause hypotension
- Use with caution in severe hepatic disease

Megestrol Acetate

PHARMACOLOGY

It is a synthetic derivative of progesterone, is used to increase appetite in selected patients. The exact mechanism of action

in cachexia remains unknown

DOSING

40-240 mg up to four times a day PO or 800 mg once daily PO

UNWANTED EFFECTS

hypertension , rash, sweating symptom, hot sweats, weight gain, diarrhoea, flatulence, indigestion, nausea, vomiting, insomnia, mood swings
Rarely: DVT, pulmonary embolism, adrenal insufficiency

Methadone

PHARMACOLOGY

It is a synthetic opioid and is an agonist at the mu and delta receptors. It is also an NMDA antagonist and therefore can be a useful opioid to rotate to in cases of neuropathic pain.
Onset of action: 30 minutes
Time to peak: 90 minutes
Plasma ½ life: 15 -75 hrs

DOSING

(see below)

UNWANTED EFFECTS

Cardiac dysrhythmia, hypotension, sweating, constipation, nausea, vomiting, (rarely: prolonged QT interval, torsades de pointes)

PITFALLS/CONCERNS

The use of **methadone** in the palliative care setting can be challenging because of its long half life and subsequent

accumulation. The appropriate determination of the correct conversion ratios from other opioids can also be problematic. We would advise that its use should only be undertaken with advice from a practitioner with experience in its use. There are also many more drug-drug interactions with **methadone** compared to other opioids. Caution must be used when adding or stopping other medications.

Metoclopramide

PHARMACOLOGY

Metoclopramide acts as a combined dopamine-receptor antagonist and 5HT4-receptor agonist.
It has prokinetic properties.
It is used for nausea and vomiting.
It can be given PO, SC or IV

Onset of action: 10-15 min SC; 15-60 min PO
Duration of action: 1 to 2 hours (sometimes longer)
Plasma 1/2 life: 2.5-5 hours

DOSING

5-10-20 mg PO/SC tid-qid ac meals
0.1 to 0.2 mg/kg/dose q6h PO/SC/IV

UNWANTED EFFECTS

Extrapyramidal side effects (acute dystonias, pseudoparkinsonism, and akathisia), drowsiness, akesthesia (restlessness), depression and diarrhoea.

PITFALLS/CONCERNS

- Serious drug interactions exist
- Avoid concurrent use with antimuscarinics which block the action of prokinetics such as **metoclopramide**
- Used most commonly for nausea and vomiting due to gastric stasis due to its prokinetic properties.

Midazolam

PHARMACOLOGY

Benzodiazepines have GABA-potentiating actions in the CNS (spinal cord, hippocampus, cerebellum, cerebrum) thereby reducing neuronal activity

Onset of action: 5-10 min SC; 2-3 min IV; 15 min sublingual
Time to peak: 30 min SC; 60 min PO
Duration of action: 4 hours
Plasma 1/2 life: 2-5 hours

DOSING

2.5-5 mg PO/SC STAT and prn
Infusional rate: 10-60 mg/24 hrs
Anti-epileptic: 10 mg SC
100 mcg/kg SC over one minute, then if necessary
300-700 mcg/kg over 24 hours by continuous SC infusion

UNWANTED EFFECTS

Sedation, fatigue, decreased co-ordination, blurred vision, memory impairment, hypotension, anxiety, decreased libido, depression, headaches, insomnia

PITFALLS/CONCERNS

- Benzodiazepines used alone in delirium will likely exacerbate the condition
- There are some drug-drug interactions with benzodiazepines
- Abrupt cessation of long-term benzodiazepine therapy can cause withdrawal symptoms
- May cause hypotension
- Use with caution in severe hepatic disease

Morphine

PHARMACOLOGY

Opioids such as **morphine** act at opioid receptors which are found both within the CNS and peripherally. Metabolism occurs mainly in the liver but can occur in other organs including the CNS. The major metabolites of **morphine** are M3G and M6G. In the setting of renal failure **morphine** metabolites can accumulate and lead to toxicity

Morphine may be given orally, rectally, buccally, SC, IM and intraspinally. The PO: SC/IV **morphine** ratio is 2:1. **Morphine** oral preparations come in short-acting as well as sustained release preparations

Time to peak plasma concentration: 15-60 min PO (short acting preparations); 10-20 min IM/SC
Duration of action: 3-6 h (short acting preparations); 8-12-24 h (sustained release preparations)
Plasma 1/2 life: 1.5-4.5 h PO (short acting preparations)

DOSING

A dose of **morphine** 2.5 mg regularly q4h PO (or 1 to 2 mg SC/IV)

and a breakthrough dose every hour, as required (see Appendix 1) is suitable for an opioid-naive patient. Further titration will be required and the effective dose will vary

- Starting doses for opioid naïve infants less than 6 months: 0.01 mg/kg q4h SC/IV, or 0.02 mg/kg q4h PO
- Starting dose for opioid naïve infants/children more than 6 months: 0.02 mg/kg q4h SC/IV, or 0.04 mg/kg q4h PO

UNWANTED EFFECTS

- Common: Constipation, dry mouth, sweating
- Common (usually temporary): Sedation, nausea/vomiting
- Rare: Pruritis/urticaria, urinary retention, hallucinations/ delirium, respiratory depression

PITFALLS/CONCERNS

- A laxative should be prescribed routinely when a patient is on an opioid
- An anti-emetic should be ordered at least prn for use during the first week when starting opioid therapy (this side-effect usually resolves however over time)
- Hepatic failure severe enough to increase the pro-thrombin time may result in an increased plasma halflife of **morphine**
- Warn patients about the possibility of initial drowsiness
- In the setting of renal failure accumulation of morphine metabolites can sometimes occur causing opioid neuro toxicity

Naproxen

PHARMACOLOGY

NSAIDs block the synthesis of prostaglandins by inhibiting

the enzyme cyclooxgenase. Through this mechanism, NSAIDs decrease inflammation and pain

Onset of action: Analgesic: 1 hour;
Anti-inflammatory: 2 weeks
Time to peak: 1-4 hours
Plasma 1/2 life: 12-17 hours

DOSING

250-500 mg PO/PR bid

5-7 mg/kg q 12h PO

NOTE: *Have patient take with food if possible to decrease GI upset*

UNWANTED EFFECTS

Dizziness, drowsiness, headache, itching/rash, fluid retention, diarrhoea, dyspepsia, heartburn, tinnitus

PITFALLS/CONCERNS

- Many of the toxic effects of NSAIDs are related to their primary mechanism of action (the inhibition of prostaglandin synthesis)
- Common adverse effects:
  - Gastrointestinal complications:
    - Dyspepsia
    - Peptic ulcer disease
    - Gastrointestinal bleeding
  - Renal toxicities:
    - Acute renal failure due to renal vasoconstriction
  - Cardiovascular:
    - Possible increased risk of myocardial infarction, stroke, and new onset or worsening of hypertension

- Tinnitus:
  - Typically reversible after stopping NSAIDs
- Antiplatelet effects:
  - Inhibit platelet aggregation
  - Can increase risk of significant bleeding for patients undergoing surgery, thrombocytopenic patients (platelet count < 50,000), or patients on anticoagulant therapy such as **warfarin**
- Respiratory:
  - Can precipitate bronchospasm or worsen asthma in small percentage of individuals

❍ NSAIDs should generally be avoided in pediatric patients with fever due to risk of Reye Syndrome. **Acetaminophen/paracetamol** should be used instead

Bottom Line: NSAIDs are effective, inexpensive, anti-inflammatory drugs that are well tolerated in most people and can provide significant pain relief. However, patients with significant gastrointestinal problems, bleeding risks, or renal or cardiac compromise should be carefully evaluated before beginning therapy with NSAIDs. May need to adjust dose and monitor renal function for patients with renal compromise.

Octreotide

PHARMACOLOGY

Synthetic analogue of **somatostatin**

Inhibits secretions in the gastro-enteropancreatic system. Reduces splanchnic blood flow, GI motility, gastric/pancreatic/small bowel secretions

Onset of action: 30 minutes
Time to peak: 30 minutes SC
Duration of action: 8 hours
Plasma 1/2 life: 1.5 hours SC

DOSING

200 mcg-500 mcg in divided doses (bid or tid) SC
or 300-1200 mcg/24hrs by SC infusion
1-10 mcg/kg/24h or in divided doses q12-q24h SC

UNWANTED EFFECTS

Sinus bradycardia, hyperglycemia, abdominal pain, constipation, nausea, flatulence, dry mouth, flushing

Olanzapine

PHARMACOLOGY

Atypical antipsychotic. Dopamine-receptor and 5HT2A-receptor antagonist. Compared with typical antipsychotics (eg. **haloperidol**) the incidence of drug-induced movement disorders is less. It is used in palliative care for delirium and nausea.

Tablets and dispersible tablets exist

Onset of action: hours to days
Duration of action: 12 to 48 hours (sometimes longer)
Plasma 1/2 life: 34 hours

DOSING

❍ Agitation: 2.5 mg PO HS and prn
(increase if necessary to 5-10 mg)

- Anti-emetic: 1.25-2.5 mg PO HS and q2h prn (increase to 5 mg PO HS if necessary)

UNWANTED EFFECTS

Sedation, weight gain, hypotension, dry mouth, constipation, agitation, peripheral oedema, lightheadedness

PITFALLS/CONCERNS

- May cause orthostatic hypotension
- Should not be used in Parkinson's disease
- Watch for extrapyramidal effects (EPS) – if present decrease or discontinue and treat EPS symptoms using anticholinergics (benztropine), beta-blockers or benzodiazepines if necessary
- Drug interactions exist
- Increased of risk cerebrovascular adverse events and death in elderly patients with dementia

Ondansetron

PHARMACOLOGY

$5HT_3$-receptor antagonist

Onset of action: 30 min PO, 5 min IV
Time to peak: 1-2 hours PO
Duration of action: 12 hours
Plasma 1/2 life: 3-5 hours

DOSING

4-8 mg every 8-12 hours

0.15 mg/kg/dose q8h IV/PO (max 8 mg/dose)

UNWANTED EFFECTS

Common: Constipation, headache
Rare: Dystonic reaction, sensation of warmth or flushing, hiccup

Oxycodone

PHARMACOLOGY

Oxycodone hydrochloride is an opioid analgesic with several actions qualitatively similar to those of **morphine** although the two drugs may act on different opioid receptors

Onset of action: 20-30 minutes
Time to peak: 1-1.5 hrs
Duration of action: 3.5 hrs
Plasma ½ life: 4-6 hrs

DOSING

starting dose in opioid naïve adult:
2.5 to 5 mg every 6 hrs as needed and then titrate
(see **morphine** titration in 'Pain' section)

Starting dose in opioid naïve children:
0.2 mg/kg every 6 hrs and then titrate
(see **morphine** titration in 'Pain' section)

*For conversion to **morphine** and other opioids see Appendix 3*

UNWANTED EFFECTS

Lightheadedness, pruritus, constipation, nausea, vomiting, dry mouth, drowsiness, rarely hypotension, and in overdose, respiratory depression.

Phenytoin

PHARMACOLOGY

Onset of action: IV 0.5-1 h
Time to peak: 4-8 hours
Plasma 1/2 life: 9-40 hours

DOSING

Loading dose 15-20 mg/kg oral in 3 divided doses every 2-4 hours; maintenance dose 300 mg/day (range 200-1200 mg/day)

4-8 mg/kg/24hrs PO in divided doses bid or tid

UNWANTED EFFECTS

Nausea, vomiting, nystagmus, delirium, dizziness, ataxia altered speech, gingival hypertrophy and acne

- There are many drug interactions with anti-epileptics

Phenobarbital

PHARMACOLOGY

Onset of action: 60 min
Time to peak: 4-12 hours
Duration of action: 10-12 hours
Plasma 1/2 life: 72-144 hours

DOSING

Phenobarbital 30-240 SC/IV q8h & prn

- 10-20 mg/kg IV or PO;
- Followed by 3-5 mg/kg/day IV SC or PO

Prochlorperazine

PHARMACOLOGY

Acts as a dopamine antagonist and blocks dopamine (D1 and D2) receptors in the brain

Onset of action:
- Oral: 30-40 minutes
- Parenteral: 10-20 minutes
- Rectal: 60 minutes

Duration of action:
- Parenteral and oral-extended release: 12 hours
- Rectal and oral immediate release: 3-4 hours

Time to peak:
- Plasma 1/2 half: Oral: 3-5 hours, parenteral: 7 hours

DOSING

5-20 mg q6h PO/IV or 25 mg q6h PR

Children more than 10 kg or more than 2 years: 0.4 mg/kg/24 hr in divided doses tid or qid PO/PR

UNWANTED EFFECTS

- Anticholinergic effects: (constipation, dry mouth, blurred vision, urinary retention)
- Extrapyramidal symptoms: (pseudoparkinsonism, akathisia, dystonias, tardive dyskinesia)
- Sedation, orthostatic hypotension, paradoxical agitation/ excitement, restlessness, rash, photosensitivity

Risperidone

PHARMACOLOGY

Atypical antipsychotic.
Dopamine-receptor and $5HT_{2A}$- receptor antagonist

Compared with typical antipsychotics (eg. **haloperidol**) the incidence of drug-induced movement disorders is less

Onset of action: hours to days
Duration of action: 12 to 48 hours (sometimes longer)
Plasma 1/2 life: 24 hours

DOSING

Starting: 0.5 mg PO BID and prn
Increase by 0.5 mg PO BID every other day

UNWANTED EFFECTS

Headache, agitation, anxiety, insomnia, movement disorders, sedation, fatigue, dizziness, impaired concentration, blurred vision, dyspepsia, nausea and vomiting, constipation, urinary incontinence, rhinitis

PITFALLS/CONCERNS

- Increased of risk cerebrovascular adverse events and death in elderly patients with dementia
- May cause orthostatic hypotension
- Should not be used in Parkinson's disease
- Watch for extrapyramidal effects (EPS) - if present decrease or discontinue and treat EPS symptoms using anticholinergics (benztropine), beta-blockers or benzodiazepines if necessary
- Drug interactions exist

Senokot

PHARMACOLOGY

Stimulant laxative
Onset of action: 8-12 hrs

DOSING

15 mg hs increasing up to 15 mg bid

- 2-6 years one half daily to one tab bid PO
- 6-12 years one tab daily to two tabs bid PO

UNWANTED EFFECTS

May discolour urine or feces, diarrhoea, intestinal colic

Tramadol

PHARMACOLOGY

It is a centrally-acting synthetic opioid analgesic. It inhibits reuptake of norepinephrine and serotonin.

Onset of action: 30 minutes
Time to peak: 2 hrs
Duration of action: 4-6 hrs
Plasma ½ life: 6 hrs

DOSING

50-100 mg po every 4-6 hours (max 400 mg/day)
Unwanted Effects: Pruritus, constipation, nausea, vomiting, dizziness, headache, somnolence

- Not recommended in children under 12 years;
- Over 12 years: 100 mg bid PO

Tranexamic Acid

PHARMACOLOGY

Inhibits the breakdown of fibrin clots

Tranexamic acid has been used PO, topically and IV

It accumulates in renal failure

Duration of action: 24 h
Plasma 1/2 life: 2 h

DOSING

500-1000 mg tid PO/IV
Topical solution 500 mg in 5 mls soaked in gauze – apply for 10 minutes

- 10-20 mg/kg/dose bid to tid IV;
- 25 mg/kg/dose tid to qid PO

UNWANTED EFFECTS

Nausea, vomiting, diarrhoea, disturbance in colour vision, hypotension (IV), thrombo-embolism

PITFALLS/CONCERNS

- In patients with hematuria there is a risk of ureteric obstruction and retention
- There exist serious drug interactions which can increase the risk of thrombosis

Trazodone

PHARMACOLOGY

Trazodone hydrochloride is an antidepressant with unknown mechanism of action, however it shows selective inhibition of serotonin uptake by brain synaptosomes

DOSING

150 mg/day PO in divided doses; may increase dosage by 50 mg/day every 3-4 days; max dosage 400 mg/day

UNWANTED EFFECTS

sweating, constipation, diarrhoea, nausea, vomiting, xerostomia, dizziness, headache, insomnia, lethargy, memory impairment, somnolence, blurred vision

Self care checklist

The following list is intended to remind and encourage professional caregivers to pay attention to the physical, emotional, social, and spiritual ways they are caring for themselves while they are caring for others:

- ❍ Maintain a well-balanced diet
- ❍ Get adequate sleep (ideally 6-8 hrs/day)
- ❍ Participate in regular exercise (at least 15-20 minutes/day – 3 days/wk)
- ❍ Find balance between work and personal life
- ❍ Set aside regular times to do things you enjoy
- ❍ Access members of health care team for support
- ❍ Access social support networks
- ❍ Take time for rest and relaxation
- ❍ Attend to your own health needs
- ❍ Explore healthy strategies to cope with stress
- ❍ Access positive outlets to process emotions and experiences
- ❍ Access resources to support spiritual needs
- ❍ Acknowledge what you are doing well in your caregiving
- ❍ Set manageable short term and long term self-care goals

Personal Notes

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FURTHER INFORMATION ON DRUGS CAN BE OBTAINED FROM:

Goodman and Gilman's: The Pharmacological Basis of Therapeutics (11th edition)
Editors Brunton, Lazo, Parker
McGraw-Hill Professional; 2006

Palliative Care Formulary (3rd edition)
Editors Twycross, Wilcock
Radcliffe Medical Press Ltd; 2008

Compendium of Pharmaceuticals and Specialties
The Canadian Drug Reference for Health Professionals
Canadian Pharmacists Association; 2008

Oxford Textbook Palliative Care for Children
Goldman, Liben, Hain
Oxford University Press; 2006

Example of 'pain ruler'
adapted from Hospice Nepal

www.inctr.org

ISBN 978-2-9600839

0 - 10 Numeric Pain Intensity Scale