Foreword

Provision of Palliative Care is an integral part of health services. Primary Health Providers are key members of a patient’s care team and as such are often the first point of contact for them. It is vital therefore that Primary providers have access to resources to assist them provide best practice assessment, care and support, so as to ensure patients and their family/whanau are able to “Live while they are dying”.

Hospice has been a part of health care within Taranaki for over 20 years. The growth and development of the hospice services in Taranaki has expanded considerably. The utilisation of these services has increased with this development and hospice care is a more accepted service now than 20 years ago. Cancer is no longer the only diagnosis referred to hospices. Today hospices are caring for more people (of all ages) with life-limiting illnesses such as end stage organ failure (heart, kidney, lung), neurological disorders, accident victims etc, as well as those who have a malignant diagnosis.

Over the years, various disciplines from different organisations have requested a set of guidelines to standardize generalist palliative care across Taranaki. We would like to thank the Hospices of Northland and Hospice South Auckland for sharing their guidelines which have been adapted for our region. It takes a holistic view on symptom management for common symptoms/issues faced by generalists in their care of those who have a life-limiting illness.

These guidelines are a work in progress and will be reviewed regularly to ensure supporting evidence is current. We welcome your feedback so that this can be incorporated into the next review.

I trust you will find these guidelines of great help to you as you journey with families as they seek to LIVE Every Moment while on the last journey of life.

He aha te mea nui o te ao? Maku a ki atu.
He tangata
He tangata
He tangata
He tangata

If you should ask me, what is the greatest thing in this world? I would answer, it is people, it is people, it is people. (Anonymous, n.d.)

Kevin Nielsen
Chief Executive
Hospice Taranaki
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Palliative Care

What is palliative care?
Palliative care is a branch of health care that attends to those with an advanced life-limiting illness. A life-limiting illness is one that has no cure. The focus of this area of care is the patients and their family/whānau total care i.e. physical/tinana, social/whānaungatanga, emotional/hinengaro, and spiritual/wairua wellbeing. Care is specific to each person and focuses on helping them to live the best that they can for as long as they are able. This care can be provided in home or in another place e.g. hospice, hospital or long term residential facility. Specialist palliative care is provided by a skilled team of health professionals who have undergone specific training and/or accreditation in palliative care.

The care that Hospices provide is free to patients. Hospice Taranaki has a contract with the Taranaki District Health Board to provide palliative services to the residents of Taranaki. This contract only covers about 55% of the cost of providing this service. The rest is funded by donations, grants, fundraising and bequests.

What is the difference between specialist & generalist palliative care?
The Palliative Care Working Party, 2008 defined two separate levels for the provision of palliative care. These are:

**Generalist Palliative Care** is palliative care provided for those affected by life-limiting illness as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team. It is provided in the community by general practice teams, Maori and Pacific health providers, allied health teams, district nurses, residential care staff, community support services and community paediatric teams. It is provided in hospitals by general adult and paediatric medical and surgical teams, as well as disease specific teams for instance oncology, respiratory, renal, intensive care and cardiac teams.

Providers of generalist palliative care will have defined links with specialist palliative care team(s) for the purposes of support and advice, or in order to refer persons with complex needs. They will also have access to palliative care education and learning to support their practice.

**Specialist palliative care** is palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine working in the context of an expert interdisciplinary team of palliative care health professionals. Specialist palliative care may be provided by hospices (community), hospital bases palliative care services, and paediatric specialist palliative care teams. Specialist palliative care will increasingly be provided through services that meet standards developed nationally and that work exclusively in palliative care. Specialist palliative care practice builds on the palliative care provided by generalist providers and reflects a higher level of expertise in complex symptom management, spiritual support, psychosocial support, cultural support, and grief and loss support. Specialist palliative care provision works in two ways:

1. **Directly:** to provide direct management and support to person, their families and whānau where complex palliative care needs exceeds the resources of the generalist provider. Specialist palliative care involvement with any person and their
family/whānau can be continuous or episodic depending on their assessed changing need. Complex need in this context is defined as a level of need that exceeds the resources of the generalist team: this may be in any of the domains of care - physical, psychosocial, spiritual or cultural for example.

2. Indirectly: to provide advice, support, education and training to other health professionals and volunteers to support their generalist provision of palliative care. The teams/services involved in providing comprehensive and interdisciplinary specialist palliative care may vary in the type and complexity of need that they are able to address, depending on the populations they serve and the funding available.

Ministry of Health, 2008

What services does Hospice Taranaki offer:

Hospice prides itself on the range of services that it offers. These include:

- Community care including after hours visits
- Inpatient care; for respite (booked or acute), intensive symptom management and end of life care
- Shared care with other health professionals
- Counselling
- Social work
- Volunteer services
- Bereavement support
- Family support
- Chaplaincy support
- An extensive pool of equipment for in the home
- 24 hour telephone advice support

Referrals to Specialist Support

When is referral appropriate?

Specialist Palliative Care support for those with a diagnosis of an advanced/progressive life-limiting illness may be required when:

- Symptoms relating to their illness are not able to be managed effectively
- The patient and their family/whānau require more intensive care of holistic issues related to the illness – i.e. spiritual, psycho-social, psychological factors
- Respite care is required to maintain care at home
- Occasionally in-patient care is required for the final stages of their disease
- Staff members require support to care effectively for patients.

How do I make a referral for palliative care support?

In general, Hospice care is available to anyone with a life-threatening illness, malignant or non-malignant. People can refer themselves, or a friend, family member or doctor or nurse may refer them to the service.
People have to be agreeable to having Hospice involved. Hospice staff always check, that, what is offered is acceptable and wanted. If you are not sure if referral is appropriate or what your local Hospice is able to offer, please contact them directly for further advice.

www.hospicetaranaki.co.nz

Hospice Taranaki 06 753 7830
Fax 06 753 7806

At the time of referral it is helpful to include copies of important letters and copies of test results as well as discharge summaries from recent hospital admissions. This will help hospice staff gain a clearer picture of the current situation.

Hospice Taranaki document patient notes on PalCare (a web-based patient management system) and if you wish, you (General Practitioners, District Nurses) can be provided access to these notes to assist in a patient’s on-going care.

**Generalist Palliative Care Guidelines**

Managing symptoms for those with life-threatening conditions requires thorough assessment, appropriate intervention and attention to detail. Many physical symptoms that arise during this period have underlying holistic roots so listening to the “words behind the words” is important.

Anticipatory care and prescribing is fundamental to seamless care with minimal crisis incidents. Empowering patients and family members and other team members to know what to do in the “what if” scenarios ensures the patient can remain where they wish to be and are able to do so by managing their care in partnership with the professionals.

The following guidelines are written as an overview of how to manage the more common issues that occur within generalist palliative care. They are not prescriptive and it is acknowledged that there are many guidelines within palliative care that may differ from these ones. These are for Taranaki and have been adapted to suit what is accepted practice in Taranaki.

It is difficult to prioritise issues and therefore these have been placed within the holistic quadrant that they fall in and then alphabetical order for ease of access and to place equal importance on all issues.

It is acknowledged that there are many more issues (other than what is represented here) for those who are dying and those who are caring for them. For assistance with any areas of palliative care, please seek the specialist advice of your local specialist palliative care team. [Hospice Taranaki Contacts.](#)
These guidelines are formatted in the following way for ease of use:

- Definition of symptom (if not obvious)
- Symptoms
- Possible causes
- Holistic considerations of symptom
- How to treat reversible causes
- How to palliative symptoms
- How to treat symptoms in pharmacological way.

In Palliative Care the following assessment tools Appendix Four are regularly used to assess symptoms and the functional status of patients:

- **PPS v2** (Palliative Performance version 2)
- **ECOG** (Eastern Cooperative Oncology Group Status)
- **ESAS** (Edmonton Symptom Assessment Scale).

### Managing Physical Issues – Pain

### Guidelines for the General Management of Pain

#### What is pain?

Pain is subjective and is essentially what someone says it is, where it is and how it is. It is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage”.

#### Pain assessment.

Pain can be the result of many different factors. A thorough assessment of the patient will help to elicit areas other than those that are physical that may have relevance to their pain.

Consider the following assessing of their pain using the **PQRST format**:

- **P** Palliative factors
  - **P**Provoking factors
    - “What makes it better?”
    - “What makes it worse?”
- **Q** Quality
  - “What is your pain like? Give me some words that tell me about it.”
- **R** Radiation
  - “Does the pain go anywhere else?”
- **S** Severity
  - “How severe is it?”
  - Measured on numbered scale
- **T** Time
  - “Is it there all the time?”
  - “Does it come and go?”
- **U** Understanding
  - “What does your pain mean to you?”
  - Does their pain have meaning?

### Visual Analogue Scale
Using a simple face scale (using 1-10) can help to guide where a person sees their level of pain. For an example of this [click here](page 42)

**Using the Analgesic Ladder as a guide**

The WHO’s analgesic ladder is a systematic way of managing increasing or uncontrolled pain. The three steps are as follows:

- **Step 1** – non-opioids e.g. Paracetamol 1g three or four times a day
- **Step 2** – weak opioids – e.g. Codeine, Dihydrocodeine, Tramadol
- **Step 3** – strong opioids – e.g. Morphine, Methadone, Oxycodone, Fentanyl.

**Types of Pain:** [medical dictionary]

**Somatic Pain** is pain emanating from muscles, skeleton, skin; pain in parts of the body other than the viscera.

**Visceral Pain** is pain caused by inflammation of serous surfaces, distension of viscera and inflammation or compression of peripheral nerves. The pain caused by stretching of the wall of a hollow viscous is often intermittent because of its alternating relaxation and spasm in response to distension.

**Neuropathic pain** results from direct stimulation of the myelin or nervous tissue of the peripheral or central nervous system (except for sensitized C fibers), generally felt as burning or tingling and often occurring in an area of sensory loss.

**Incident Pain** occurs as a direct result of an incident e.g. movement.

**Breakthrough pain** is a transient increase in pain intensity that occurs in patients with stable, baseline persistent pain.

Consider the use of co-analgesics for the management of different types of pain:

- Bone Pain – NSAIDs, Biphosphonates
- Skeletal Muscle Spasm pain – Diazepam, Clonazepam, Baclofen
- Smooth Muscle Spasm pain – Hyoscine Butylbromide
- Tenesmus – Dexamethasone, Prednisone
- Raised Intracranial pressure – Dexamethasone, NSAIDs
- Liver Capsule Stretch pain – Dexamethasone
- Neuropathic pain – Tricyclics, anticonvulsants

**DO NOT FORGET THAT PAIN IS NOT ALWAYS PHYSICAL**

**Psychological pain** is any mental, psychological, or non physical suffering. This can be from causes related to emotions (emotional pain), spiritual/soul (existential pain), or practical matters (financial, parental etc).

Consider discussing issues that could be causing emotional and spiritual distress and explore these sensitively with your patient. The skills of specially trained professionals in this field e.g. counsellors, social workers, chaplains can help to reveal and support such issues.
Commencing an initial opioid – Morphine and Oxycodone

**Is patient experiencing pain which is not controlled by non-opioid**

- **No**
  - Continue with current medication regimen

- **Yes**
  - Prescribe 2.5-5mg immediate release opioid liquid to be taken 4-6 hourly. Titrate as required.
  - After 48 hrs total the milligrams of Morphine/Oxycodone given over the **48hr period** and divide by 2 to get the 24-hour dose. Divide this 24hr total by 2 and commence long acting preparation to be given 12 hourly
  - Consider ongoing laxatives
  - For intermittent **breakthrough pain** or **incident pain**?
    - Prescribe short-acting preparation: equivalent to 1/10 - 1/5 of total 24 hr oral dose. **Breakthrough pain**: to be taken prn Q½hrly (morphine) Q1hrly (Oxycodone) to maximum of 3 doses per episode. **Incident pain**: to be taken ¼ hour prior to pain provoking incident.
    - Is pain controlled the majority of the time as well as during intermittent breakthrough periods?
      - **Yes**
      - **No**

Please contact Hospice Taranaki if you have any concerns or require further information
Commencing an initial opioid - Methadone

Do NOT initiate Methadone without consulting a Specialist

Is patient experiencing pain which is not controlled by non-opioid medication?

Is Methadone the preferred opioid?

No

Continue with current medication regimen

Yes

Prescribe 2.5mg Methadone bd.

Review in 72 hours. If pain not controlled increase dose by 2.5 bd if required (to maximum of 10mg b.d.)

After 72 hours is pain controlled?

No

Consider ongoing laxatives

Yes

For breakthrough and incident pain prescribe short-acting morphine preparation:
2.5-5mg Morphine elixir

Breakthrough pain: to be taken prn Q½hrly to maximum of 3 doses
Incident pain: to be taken ¼ hour prior to pain provoking

Is pain controlled the majority of the time as well as during intermittent breakthrough periods?

Yes

No

Contact a Specialist

Note:
1. **PRN Methadone should not be used** (see box above for alternatives)
2. For doses over 10mg b.d or if pain is not controlled, please consult your specialist service. contact Hospice Taranaki
Management of Fentanyl Patches (for those with stable pain)

Patient Criteria for use of Fentanyl Patches
- The person has a terminal condition
- Opioid responsive
- Stable pain for previous 24 hours
- No contraindications to fentanyl

Has patient been previously exposed to opioids?

Consult with Specialist Service

Yes

Determine dose of Fentanyl using morphine: fentanyl conversion charts
Apply patch in nearest dosage for this amount

Review in 72 hours. If pain not controlled during initial 72 hours give 1/10 - 1/5 dose of previous daily morphine as required.

After 72 hours is pain controlled?

Yes

Continue patch – change every 72 hrs.

No

Increase patch dose by 12.5 - 25 mcg/hr according to prn morphine requirement AFTER first 48 hr.

Prescribe short-acting morphine preparation: equivalent to 1/10 - 1/5 of total 24 hr oral Morphine dose.

Breakthrough pain: to be taken prn ½ hrly to maximum of 3 doses.

Incident pain: to be taken ¼ hrly prior to pain provoking incident

Note:
1. If breakthrough pain occurs consistently in the last 24 hours of patch application in cachectic patient with minimal subcutaneous “fat” consider changing patch frequency to every 48 hrs.
2. Please consult your specialist service for any queries regarding Fentanyl Patches. Hospice Taranaki Contacts

Please contact Hospice Taranaki if you have any concerns or require further information
Managing Physical Issues – Other
Bowel Management – Constipation

**Constipation is:** irregular and infrequent or difficult evacuation of the bowels.

**Symptoms include:** Anorexia, vomiting/nausea, abdominal discomfort, diarrhoea or faecal overflow, abdominal distension, confusion, anxiety, bowel obstruction, pain.

**Causes include:** Hypercalcaemia, spinal cord abnormalities/injuries, drugs, dehydration, low fibre diet, immobility, intestinal obstruction, nerve compression/neuropathy, haemorrhoids, anal fissure, diabetes and hypothyroidism.

**Holistic Reflection**
PQRSTU assessment: Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines](#) (page 41)

**Emotional Considerations:** Fear regarding other issues surrounded defecation e.g. pain can impact on regularity. Is the presence of toilet equipment “outside of the usual place” causing emotional anguish?

**Spiritual Considerations:** Are there issues regarding ongoing defecation e.g. colostomy. Has the “routine” changed? How does this affect the person and their lifestyle? Has the patient/family changed their language around describing themselves? (i.e.) Has their identity changed?

**Social Considerations:** How does constipation affect family life? How is this affecting your relationship with your partner/friends?

**Bristol Stool Chart**
This chart is a good visual resource to “describe” faecal matter. This also gives a good indication of how long it has been in the bowel. (i.e.) Type 1-3 have been in the bowel longer and therefore have less water content and may be harder to pass.

[Click here to view Bristol Stool Chart](#) (Appendix Two)
## Types of Laxative and Uses

<table>
<thead>
<tr>
<th>Type</th>
<th>Action</th>
<th>Example</th>
<th>Administration Hints</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stimulant</strong></td>
<td>Stimulate the peristaltic movement.</td>
<td>Senna (in Laxsol™)</td>
<td>• Contraindicated in suspected obstruction</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Bisacodyl</td>
<td>• Can increase abdominal pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Fleet™</td>
<td>• If given rectally must be inserted at least 4cm into the rectum against the mucous membrane of the rectum not into the faeces – <strong>blunt end first</strong>.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dulcolax™</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Contraindicated in suspected obstruction</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Can increase abdominal pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• If given rectally must be inserted at least 4cm into the rectum against the mucous membrane of the rectum not into the faeces – <strong>blunt end first</strong>.</td>
</tr>
<tr>
<td><strong>Lubricant</strong></td>
<td>Lubricate the anorectum and have a stimulant effect</td>
<td>Glycerine</td>
<td>• Insert into the faeces – ** pointed end first**</td>
</tr>
<tr>
<td><strong>Softeners</strong></td>
<td>Change consistency of faeces</td>
<td>Docusate Sodium (in Laxsol™)</td>
<td>• Avoid using lubricant with suppositories</td>
</tr>
<tr>
<td></td>
<td>Not the laxative of choice</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>where peristaltic action impaired e.g. stroke, parkinsons, impaction, bowel obstruction</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Osmotic Agents</strong></td>
<td>Draw water into the faeces</td>
<td>Lactulose™ – needs to be taken with adequate water Movicol™ – similar to an osmotic as it draws water but does not affect the electrolyte balance.</td>
<td>• At least 125mls of water needs to be taken at the time of administration.</td>
</tr>
</tbody>
</table>

### Manual Evacuation Guidelines

Manual evacuations are to be avoided if possible.

- Obtain prescription for relaxant eg midazolam nasal spray
- Obtain consent and explain procedure
- Left lateral position
- Use plenty of lubricant
- Remove small amounts of faeces with one finger
Is the patient constipated?

No

Take thorough history and assessment to determine cause.
Assessment should include: what is normal for that patient, date of last bowel motion (BM), type of last BM, bowel sounds, pain assessment, and medication.+/- rectal examination

Continue with vigilant assessment of bowel habits, history and laxatives if/when indicated.

Yes

Treat or palliate presenting symptoms

Treat underlying resolvable causes
e.g. chemical imbalances, fear and anxiety.
Ensure long-term laxatives are prescribed at the same time as opioids.

NB: Is there a possibility that this patient has intestinal obstruction?

No

Click here for Intestinal obstruction guideline

Yes

NB: Not all patients have a bowel motion daily. Their normal will depend on the "days" for treatment to be taken.

First Line Treatment
(Day 1-3 BNO):
- Increase exercise
- Increase total daily fluid intake
- Increase dietary fibre. (e.g. porridge, kiwifruit, prunes)
- Use softener/stimulant e.g. Laxsol or increase current dose

Second Line Treatment
(Day 4-5 BNO):
- If BNO – rectal exam
- Try Movicol for 2 days
- If soft faeces present administer or increase stimulant orally or rectally (if patient uncomfortable)
- Repeat Day 5 if BNO.
- If hard faeces present administer softening agent (oil retention enema) and leave overnight. Follow the next day with a stimulant laxative.

Third Line Treatment
(Day 5+ BNO):
- Repeat actions from Day 4-5 increasing dose of stimulant to maximum
- Manual removal if indicated.
- Review long term laxative

Please contact Hospice Taranaki if you have any concerns or require further information
**Bowel Management – Diarrhoea**

**Diarrhoea is:** an increase in the frequency of bowel motions, or increased stool liquidity.

**Symptoms include:** watery, loose stool, passing stools more than three times per day. Person may experience an urgency to pass faeces.

**Causes:** faecal impaction, carcinoma, spinal cord compression, incomplete gastrointestinal obstruction, malabsorption, food intolerance, overfeeding (e.g. PEG) concurrent disease e.g. diabetes, hyperthyroidism, inflammatory bowel disease, radiotherapy to torso, drugs, bowel surgery, fistula formation between small and large bowel, anxiety.

**Holistic Reflection**

**PQRSTU assessment:** Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines](page 41)

**Emotional Considerations:** Fear regarding other issues surrounded defecation e.g. Will I make it to the toilet? Do you experience pain on defecation? Is the presence of toilet equipment “outside of the usual place” causing emotional anguish?

**Spiritual Considerations:** Are there issues regarding ongoing defecation e.g. colostomy. Has the “routine” changed? How does this affect the person, and their lifestyle?

**Social Considerations:** How does diarrhoea affect family life? How is this affecting your relationship with your partner/friends?

---

Is the patient experiencing diarrhoea or more bowel motions than is normal for them?

- **Yes**
  - Take thorough history and assessment to determine cause.
  - Assessment should include: what is normal for that patient, date of last bowel motion (BM), type of last BM, bowel sounds, pain assessment, and medication. +/- rectal examination

- **No**
  - Continue with vigilant assessment of bowel habits, history and laxatives if/when indicated.

---

- **Treat underlying resolvable causes** e.g. infection, faecal impaction, drug causes, fear and anxiety. Ensure long-term laxatives are prescribed at the same time as opioids.

---

- Consider abdominal examination X-ray to exclude abdominal obstruction
- Consideration of surgical options if colo-rectal carcinoma
- Consider possible causes of infection – test and treat as indicated
- Assess if constipated and if so take appropriate action to remedy this cause.
- Supplement with pancreatic enzymes as indicated (pale, floating stool)
- Secretory diarrhoea may respond to Octreotide
- Consider symptomatic treatment with codeine or loperamide

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- Maintain skin integrity; barrier cream (e.g. zinc oxide), soft toilet paper
- Restrict oral intake (to rest bowel)
- Use of equipment e.g. commode for ease of access to toilet facilities
- Education regarding laxative use – type, regularity, fluids

---

NB: Not all patients have a bowel motion daily. Their normal will depend on the “days” for treatment to be taken.

[NB: Is there a possibility that this patient has intestinal obstruction?](Intestinal obstruction guideline)
Bowel Management – Intestinal Obstruction

**Intestinal Obstruction is:** a mechanical or functional obstruction of the intestines, preventing the normal transit of the products of digestion

**Symptoms include:** colic pain, vomiting, dehydration

**Causes:**
Can be mechanical or paralytical: blockage of intestine by tumour or inflammation, aggravated by drugs (anticholinergics, opioids), radiation fibrosis, autonomic nerve disruption due to tumour.

**Holistic Reflection**

**PQRSTU assessment:** Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines](#) (page 41)

**Emotional Considerations:** Fear regarding what obstruction means long-term.

**Spiritual Considerations:** How does this affect the person, their perception of self and their lifestyle?

**Social Considerations:** How this diagnosis impacts on the remainder of life. How does diagnosis affect family life? How is this affecting your relationship with your partner/friends?

**Are there symptoms present which could indicate intestinal obstruction?**

- **No**
  - Continue with vigilant assessment of bowel habits, history and laxative use.
  - Ongoing review is vital to assess recurrence of this symptom.

- **Yes**
  - Symptoms include: Abdominal pain (colic type pain), nausea/vomiting, constipation, or diarrhoea, faeculent vomiting.
  - Use medical interventions to minimise effects
  - Palliate presenting symptoms
  - **Restrict oral intake (to rest bowel) unless patient wishes to eat/drink limited amounts. Educate re: outcome of this.**
  - **Use of equipment e.g. commode for ease of access to toilet facilities**
  - **Education regarding laxative use – type, regularity, fluids**

**Please Note:** Oral medication is not always absorbed adequately. If intestinal obstruction is suspected be aware of this and use other modes of delivery for drugs e.g. subcutaneous. Please consult your specialist service for advice regarding this. [Hospice Taranaki Contact](#)
Breathlessness (Dyspnoea)

**Breathlessness or Dyspnoea** is a state or sensation of being breathless or out of breath.

**Symptoms include:** inability to catch breath, gasping, short breaths, shallow breathing. In addition cough, hiccup and pleural pain are common in people who have breathlessness.

**Causes include:** Obstruction of airways, decreased lung volume (e.g. from effusions, infections, chronic conditions, lung collapse), increase lung stiffness (e.g. from pulmonary oedema, lymphangitis, carcinomatosis, pulmonary fibrosis, mesothelioma), decreased gas exchange (e.g. from pulmonary thrombus, tumour effect on pulmonary circulation), pain (pleurisy, infiltration of chest wall, rib or vertebral fractures), neuromuscular failure e.g. (paraplegia, motor neurone disease, phrenic nerve palsy, cachexia, paraneoplastic syndrome), congestive heart failure, ascites/pleural effusion, anxiety, anaemia, metabolic acidosis.

**Holistic Reflection**

**PQRSTU assessment:** Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines]

**Emotional Considerations:** How does it feel to be out of breath all the time? How is your distress perceived by those around you?

**Spiritual Considerations:** What does being breathless mean to you? How does this affect the person, their perception of self and their lifestyle?

**Social Considerations:** How does being breathless affect your lifestyle? And the lifestyle of those around you.

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**Does patient experience breathlessness which is distressing to them?**

- No
  - Be aware of this common symptom as it occurs in 29-74% of people at end of life
- Yes – Identify the cause
  - Air Hunger – the perception of not getting enough air
  - Anxiety – about not getting enough air
  - Obstruction – Difficulty getting breath in/out

**Treat conditions that are treatable**
- hypoxia → oxygen via nasal prongs
- asthma → bronchodilators
- anaemia → blood transfusion
- obstruction → consider bronchial stents, DXR, BIPAP or CPAP
- pleural effusion → drain
- pulmonary embolism - consider cleaxane
- infection → consider antibiotics
- acute ventilatory failure → consider diuretic
- pain → effective pain relief

**Utilise Non-Pharmacological Interventions**
- Increase ventilation across patient face e.g. fan, open window
- Sit upright or lean on pillows
- address anxiety & thorough explanations,
- training re coping strategies and relaxation techniques
- breathing exercises and routines
- use of complementary therapies e.g. aromatherapy, massage

**Utilise Pharmacological Interventions 2nd line**
- Morphine elixir – 2.5mg 2-4hrly titrating upwards until effective
- Anxiolytic e.g. Midazolam nasal spray, Clonazepam drops
- Steroids - e.g. Dexamethasone if bronchial obstruction or lymphangitis
- Anticholinergics – e.g. Buscopan/Hyoscine if secretions bothersome
End of Life Renal Failure Management Considerations

**Renal Failure:** occurs when the kidneys are no longer able to sustain their normal bodily functions.

**Symptoms:** oedema (from sodium and water retention), restless legs, itch (from raised urea or phosphate), nausea and vomiting, confusion or delirium, (from increased toxins), fatigue (from anaemia), possibility of seizures.

**Causes include:** chronic (multiple causes), acute (obstruction, drug induced)

**Holistic Reflection**

**PQRSTU assessment:** Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines](page 41)

**Emotional Considerations:** What does this symptom mean for the family/whānau?

**Spiritual Considerations:** Are there any considerations that need to be taken into account around this time? What things are left to do that need addressing at this time? Fluctuating levels of cognition can make issues difficult to deal with. Opportunities should be taken to clarify wishes, provide reassurance during these lucid times. How does this affect the person, their perception of self and their lifestyle?

**Social Considerations:** How does this symptom affect your relationship with family/whānau? How will they manage this symptom?

**Management Considerations**

- Nausea and Vomiting – [refer to guideline](page 41)
- Confusion/ delirium- [refer to guidelines on psychological issues](page 41)
- Breathlessness- [refer to guideline](page 41)
- Pain – [refer to pain guideline](page 41) BUT remember:
  - As the kidneys fail, the creatinine plasma concentrations will rise – this is important for drugs whose metabolites are renally cleared. These drugs need to be reviewed, ceased or given at a smaller dose dependent on creatinine clearance. [see formula McLeod, Vella-Brincat, MacLeod, p61].
  - Morphine’s metabolite is renally cleared so use methadone or fentanyl instead, when appropriate.
  - NSAID’s increase sodium and water retention and are nephrotoxic and so if urea is raised there is an increased risk of GI bleed.
- Itch - [refer to guideline](page 41)

N.B. Preparation and anticipation of possible issues reduces anxiety for the patient and family/whānau. Discuss the possible pathway with the level of information determined by patient and family/whānau.
End of Life Liver Failure - Management Considerations

Liver Failure: occurs when the liver is no longer able to sustain its normal bodily function.

Symptoms include: raised liver enzymes, jaundice, ascites, itch, encephalopathy, low albumin and raised INR.

Causes include: liver metastases, previous raised alcohol intake, drugs.

Holistic Reflection
PQRSTU assessment: Consider this framework as a tool to assess the symptom holistically. Click here for PQRSTU guidelines (page 41)

Emotional Considerations: What does this symptom mean for the family/whānau?

Spiritual Considerations: Are there any considerations that need to be taken into account around this time? What things are left to do that need addressing at this time? How does this affect the person, their perception of self and their lifestyle?

Social Considerations: How does this symptom affect your relationship with family/whānau? How will they manage this symptom?

Management Considerations
- Liver failure affects metabolism of drugs cleared from the body via the liver
- Decrease most metabolised drug doses by 25%
- In severe liver failure (albumin 30, INR>1.2); consider decreasing relevant drug dosage by 50%
  - e.g. Phenothiazines
  - SSRI’s e.g. Paroxetine
  - Tricyclics e.g. Amitriptyline
  - Some opioids e.g. morphine.
Malignant Ascites

**Malignant Ascites** is a condition in which fluid containing cancer cells collects in the abdomen.

**Symptoms include:** breathlessness, squashed stomach → nausea/vomiting, pain/discomfort as consequences of increased abdominal size/girth.

**Causes:** Fluid build up can be attributed to failure of the lymph system to adequately drain, tumour in the peritoneal cavity, low serum albumin (such as in Liver Failure) or excess fluid production.

**Holistic Reflection**

**PQRSTU assessment:** Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines](page 41)

**Emotional Considerations:** Anxiety regarding perception of self, body image and mobility due to oral hygiene. Dependence issues with not being able to care for oral cares independently.

**Spiritual Considerations:** How does this affect the person, their perception of self and their lifestyle?

**Social Considerations:** How this diagnosis impacts on the remainder of life.

---

**Does patient exhibit symptoms of malignant ascites?**

- **No**
  - Be aware of the possibility of this symptom especially for those with breast, colon, endometrial, ovarian, pancreatic or gastric cancers.

- **Yes**
  - Use medical interventions to minimize effects
  - Palliate presenting symptoms

**Treat conditions that are treatable e.g.:**
- If prognosis is short and symptoms acceptable to patient – consider no action
- If prognosis longer than 3 months consider surgical options e.g. peritoneo-venous shunt.
- Monitor biochemistry if indicated.
- Consider paracentesis
  - Consider USS/CT to assess loculation of fluid
  - Drain no more than 2 litres in the first hour, then drain slowly for the next 12-24hrs (max 5 litres)
  - Consider referral for intra-abdominally placed drain (Pleurex) if prognosis is >3 months and large volume ascites.
  - Oesomy bag can collect leakage from drain site.

**Utilise Non-Pharmacological Interventions**
- Sit upright or use pillows to increase comfort in/out of bed
- Address anxiety & provide thorough explanations
- Training re coping strategies and relaxation techniques
- Use of complementary therapies e.g. aromatherapy, massage (massage of abdomen not recommended)

**Utilise Pharmacological Interventions**
- **Spironolactone** – 100mg (or more) daily
- **Furosemide** – 40mg daily (combined with Spironolactone as indicated)
- **Metoclopramide** - if indicated for gastric stasis
- **Steroids** - e.g. Dexamethasone if liver capsule pain.
- **Pain relief** – as indicated for overall comfort

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Please contact Hospice Taranaki if you have any concerns or require further information.
Mouth Care Management

**Mouth Care Management:** involves the management of any abnormal condition within the oral cavity.

**Symptoms include:** sore mouth, dry mouth, ulceration of mouth, tongue, gums or lips, infection of oral cavity.

**Causes can include:** radiotherapy, infection (e.g. fungal, herpes), decreased fluid intake, decreased nutritional status, oral tumour, inability to brush/care for teeth/mouth, oxygen therapy, mouth breathing.

**Holistic Reflection**

**PQRSTU assessment:** Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines](page 41)

**Emotional Considerations:** Anxiety regarding perception of self due to oral hygiene. Dependence issues with not being able to care for oral cares independently.

**Spiritual Considerations:** How does this affect the person, their perception of self and their lifestyle?

**Social Considerations:** How this diagnosis impacts on the remainder of their life.

Using a pen torch and spatula conduct a full oral assessment with particular regard to tongue, teeth, mucous membranes, lips and type/quantity of saliva. Dentures must be removed prior to examination.

Does the patient require intensive mouth care?

- **No**
  - Continue with their current mouth care regimen

- **Yes**
  - Consider the impact of the following on mouth hygiene:
    - Mental state
    - Nutritional state
    - Physical state
    - Radiotherapy/Chemotherapy

  - Mediate underlying resolvable causes e.g. infection, dehydration, pain
  - **Palliate presenting symptoms**
    - Benzydamine as analgesic for mouth
    - Nystatin suspension or Miconazole for treatment of oral thrush
    - Fluconazole (systemically) if topical applications are ineffective
    - Acyclovir for herpetic infections
    - Topical corticosteroids for aphthous ulcers
    - Pilocarpine solution (1mg/ml, 5ml rinse three times/day) for dry mouth
    - Atropine eye drops (1%, 1-2 drops three to four times a day) or hyoscine hydrobromide (scopoderm) patch or radiotherapy for hypersalivation
    - Increase oral fluids or fluids in diet
    - Increase frequency of mouthwashes (salt/baking soda, chlorhexidine)
    - Administer salivary stimulants e.g. lime/lemon/pineapple/melon (fresh/frozen juice or cubes)
    - Clean mouth with soft toothbrush or tooth swab
    - Reassess medications
**Nausea and Vomiting**

**Nausea is:** “an unpleasant feeling of the need to vomit often accompanied by autonomic symptoms”

**Vomiting is:** “the forceful expulsion of gastric contents through the mouth”

*Watson, Lucas and Hoy, 2006*

---

**Causes within table below**

**Holistic Reflection**

PQRSTU assessment: Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines](#)

**Emotional Considerations:** Fear and anxiety can be both cause and consequence.

**Spiritual Considerations:** Cultural considerations e.g. Maori/Asian/Pacific peoples.

How does this affect the person, their self identity and their lifestyle?

Is there pressure from other people for you to eat? Does the smell of cooking/food around you cause you to feel sick?

---

### What is the cause of the Nausea/Vomiting?

<table>
<thead>
<tr>
<th>Causes</th>
<th>Higher Vomiting Centre – Cerebral Cordex</th>
<th>Vomiting Centre Stimulation</th>
<th>Vagal and Sympathetic Afferent stimulation</th>
<th>Chemo-receptor Trigger zone Stimulation</th>
<th>Vestibular Nerve Stimulation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sights, smells, memories</td>
<td>Primary or metastatic tumour</td>
<td>Distension – over-eating, gastric stasis, hepatomegaly</td>
<td>Toxic – cancer, infection, radiation</td>
<td>Opioids</td>
<td>Cerebellar Tumour</td>
</tr>
<tr>
<td>Emotion</td>
<td>Radiotherapy to head</td>
<td>Cough</td>
<td>Drugs – Chemotherapy, Opioids, Digoxin etc</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety &amp; fear</td>
<td>Raised intracranial pressure</td>
<td>Bronchial secretions</td>
<td>Biochemical – Uraemia, Hypercalcaemia</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Possible Solutions**

- Relaxation
- Benzodiazepines
- Midazolam – 2.5mg SC prn or
- Clonazepam 1-2 drops S/L prn.

<table>
<thead>
<tr>
<th>Causes</th>
<th>Solutions</th>
<th>Possible</th>
<th>Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cyclizine 50mg O/SC 8hrly PRN Review after 24 hrs</td>
<td>If bowel obstruction sustained ring Specialist Team for advise If not: Regular Q6h Metoclopramide 10mg orally If more than 2 doses given consider use of Syringe Driver at 30-60mg Metoclopramide over 24h.</td>
<td>Haloperidol Oral 1 - 2.5mg OR SC 1.5mg prn Review after 24 hrs</td>
<td>Haloperidol Oral 1 - 2.5mg OR SC 1.5mg pm (limit to 3 doses) Review after 24 hrs</td>
</tr>
<tr>
<td>Review after 24 hrs</td>
<td>If more than 2 doses given consider use of Syringe Driver of 5-7.5mg Haloperidol SC over 24hrs.</td>
<td>Review after 24 hrs</td>
<td>Review after 24 hrs</td>
</tr>
<tr>
<td>If not effective use combination of Cyclizine/Haloperidol OR Change to Levomepromazine (Nozinan) 6.25 -12.5 mg SC over 24 hours.</td>
<td>If not effective use combination of Cyclizine/Haloperidol OR Change to Levomepromazine (Nozinan) 6.25 -12.5 mg SC over 24 hours.</td>
<td>If not effective use combination of Cyclizine/Haloperidol OR Change to Levomepromazine (Nozinan) 6.25 -12.5 mg SC over 24 hours.</td>
<td>If not effective use combination of Cyclizine/Haloperidol OR Change to Levomepromazine (Nozinan) 6.25 -12.5 mg SC over 24 hours.</td>
</tr>
</tbody>
</table>

If these doses are exceeded please consult your specialist service for advice regarding further options. [Hospice Taranaki Contacts](#)
Other Respiratory Symptoms - Cough

**Cough:** a forceful exhalation of air to clear the airways as a means of defense to protect the airways.

**Symptoms include:** constant exhalation of air

**Causes include:** see chart below.

**Holistic Reflection**

PQRSTU assessment: Consider this framework as a tool to assess the symptom holistically. Click here for PQRSTU guidelines (page 41)

**Emotional Considerations:** How does it feel to cough all the time? How does this affect your sleep and your overall wellness?

**Spiritual Considerations:** What does coughing mean to you? How does this affect the person, their perception of self and their lifestyle?

**Social Considerations:** How does constantly coughing affect your lifestyle? And the lifestyle of those around you?

<table>
<thead>
<tr>
<th>Cause</th>
<th>First Line Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute Respiratory Infection</td>
<td>• Physiotherapy</td>
</tr>
<tr>
<td></td>
<td>• Nebulised saline</td>
</tr>
<tr>
<td></td>
<td>• Antibiotics</td>
</tr>
<tr>
<td>Airways Disease</td>
<td>• Physiotherapy</td>
</tr>
<tr>
<td></td>
<td>• Bronchodilator</td>
</tr>
<tr>
<td></td>
<td>• Inhaled corticosteroids</td>
</tr>
<tr>
<td></td>
<td>• Systemic corticosteroids</td>
</tr>
<tr>
<td>Malignant Obstruction/Tumour</td>
<td>• As above</td>
</tr>
<tr>
<td></td>
<td>• Nebulised local anaesthetic</td>
</tr>
<tr>
<td>Oesophageal reflux</td>
<td>• Positioning</td>
</tr>
<tr>
<td></td>
<td>• Proton pump inhibitors e.g. Omeprazole</td>
</tr>
<tr>
<td></td>
<td>• Prokinetic agents e.g. Metoclopramide</td>
</tr>
<tr>
<td>Salivary Aspiration</td>
<td>• Anticholinergic agent</td>
</tr>
<tr>
<td>Cardiovascular Causes</td>
<td>• Cardiac drugs</td>
</tr>
<tr>
<td>Pulmonary Oedema</td>
<td>• Assuming regular dose of Frusemide is not greater than 120mg PO daily → 40mg oral/IV stat</td>
</tr>
<tr>
<td>Drugs which cause cough e.g.</td>
<td>• Reduce dose or change drug.</td>
</tr>
<tr>
<td>Captopril</td>
<td></td>
</tr>
<tr>
<td>Cough with tenacious sputum</td>
<td>• Steam inhalation</td>
</tr>
<tr>
<td></td>
<td>• Nebulised saline</td>
</tr>
<tr>
<td></td>
<td>• Bronchodilators</td>
</tr>
<tr>
<td></td>
<td>• Physiotherapy</td>
</tr>
</tbody>
</table>

**Pharmacological Interventions**

<table>
<thead>
<tr>
<th>Issue</th>
<th>Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Simple Linctus e.g. Gee’s Linctus</td>
<td>• Soothing first line suppressant</td>
</tr>
<tr>
<td>Cough Suppressant e.g. Codeine, Pholcodine, morphine</td>
<td>• Titrate dose to effect</td>
</tr>
<tr>
<td></td>
<td>• May be useful in dry non-productive coughs</td>
</tr>
<tr>
<td></td>
<td>• In productive coughs suppressing cough may lead to infection.</td>
</tr>
<tr>
<td>Oxygen</td>
<td>• Useful in emphysema related cough</td>
</tr>
<tr>
<td>Corticosteroids e.g. Dexamethasone 4mg mane.</td>
<td>• Often used to treat cough associated with endobronchial tumours, lymphangitis or radiation pneumonitis.</td>
</tr>
</tbody>
</table>
Other Respiratory Symptoms - Hiccup

**Hiccup is:** is the spasmodic contraction of the diaphragm.

**Symptoms include:** sudden inspiration of air and closure of the vocal cords.

**Causes include:** Gastric distension, diaphragmatic irritation, phrenic or vagal nerve irritation, uraemia, neurological disease affecting the medulla e.g. brain cell tumour, infarction, encephalitis, liver disease.

**Holistic Reflection**

PQRSTU assessment: Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines](page 41)

**Emotional Considerations:** How does it feel to be out of breath all the time? How is your distress perceived by those around you?

**Spiritual Considerations:** What does being breathless mean to you? How does this affect the person, their perception of self and their lifestyle?

**Social Considerations:** How does being breathless affect your lifestyle? And the lifestyle of those around you.

---

**Is patient experiencing hiccups?**

- **No**
  - Be aware of this common symptom

- **Yes**
  - Use medical interventions to minimise effects
  - Palliate presenting symptoms

**Treat conditions that are treatable e.g.**
- Reduce gastric distension with prokinetic agent e.g. Metoclopramide 10mg orally TDS (if obstruction not suspected). If so refer to guideline.

**Utilise Non-Pharmacological Interventions**
- Pharyngeal stimulation by swallowing cold water with crushed ice
- Elevation of pCO2 (paper bag rebreathing or breath holding)

**Utilise 1st line - Pharmacological Interventions**
- **Neuroleptics** – Haloperidol (1.5mg-5mg daily), Levomepromazine (6.25mg to 12.5mg daily), Chlorpromazine (up to 100mg daily)
- ** Muscle relaxants** – Baclofen 5-10mg tid

**Utilise 2nd line - Pharmacological Interventions**
- ** Benztrapine**
- **Anticonvulsants** - e.g. Phenytoin, Valproate, Carbamazepine, Gabapentin
- **Corticosteroids** – Dexamethasone

For relevant doses of these drugs please consult [Hospice Taranaki Contacts](page 41)

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**Please contact Hospice Taranaki if you have any concerns or require further information**
Other Respiratory Symptoms - Secretions

Noisy breathing/Secretions (Death rattle): occurs when a person is unable to physically clear respiratory secretions. This is a common symptom leading up to the end of life. Can be referred to as the “death rattle”. This is not usually distressing for the patient but may be for the family/whānau.

Symptoms include: noisy, gurgling, rattling sound associated with breathing.

Causes include: weakening of physical strength to enable forceful expulsion of secretions from the back of the throat, weakening of cough reflex. Early identification of patients who could potentially develop/experience this symptom is the key to good management.

Holistic Reflection
PQRSTU assessment: Consider this framework as a tool to assess the symptom holistically. Click here for PQRSTU guidelines(page 41)
Emotional Considerations: What does this symptom mean for the family/whānau?
Spiritual Considerations: Is there any considerations that need to be taken into account around this time? How does this affect the person, their perception of self and their lifestyle?
Social Considerations: How does this symptom affect family/whānau staying close by?

Is patient developing/experiencing excessive secretions?

- No
  - Be aware of this common symptom and act early to prevent it.

- Yes
  - Use medical interventions to minimise effects
  - Palliate presenting symptoms
  - Explanations and Education to/of the family/whānau
  - Treat conditions that are treatable e.g.
    - Suction to remove plugs of mucous (ONLY if absolutely necessary).

  Utilise Non-Pharmacological Interventions
  - Positioning to allow postural drainage
  - Elevate head of the bed

  Utilise Pharmacological Interventions
  Anticholinergics – Hyoscine Butylbromide (Buscopan™, 20mg daily p.o or subcut, increasing to 60mg if not effective)
  - Hyoscine Hydrobromide 400mcg 4hrly subcut

Please contact Hospice Taranaki if you have any concerns or require further information.
Skin – Itch

**Itch is:** an irritating skin sensation causing a desire to scratch.

**Symptoms include:** an intense desire to continually scratch.

**Causes include:** hepatic/renal disease (obstructive jaundice, cholestatic and uraemic itch), drug allergy, drugs (opioids, vasodilators), endocrine disease, iron deficiency, lymphoma, provocative sensory influence such as rough clothing, parasites.

**Holistic Reflection**

**PQRSTU assessment:** Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines](page 41)

**Emotional Considerations:** What does this symptom mean for the family/whānau?

**Spiritual Considerations:** Is there any considerations that need to be taken into account around this time? How does this affect the person, their perception of self and their lifestyle?

**Social Considerations:** How does this symptom affect family/whānau staying close by?

---

Is patient experiencing irritating itching?

- **No**
  - Be aware of this common symptom

- **Yes**
  - Palliate presenting symptoms

<table>
<thead>
<tr>
<th>Utilise Non-Pharmacological Interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td>▪ Antihistamines – e.g. cetirizine, promethazine (allergies)</td>
</tr>
<tr>
<td>▪ Bile Sequestrant - e.g. cholestyramine (biliary obstruction)</td>
</tr>
<tr>
<td>▪ Night Sedation - e.g. Temazepam</td>
</tr>
<tr>
<td>▪ H2 antagonists - e.g. Cimetidine 400mg bd</td>
</tr>
<tr>
<td>▪ NSAIDS - e.g. Diclofenac</td>
</tr>
<tr>
<td>▪ Anxiolytics - e.g. Benzodiazepines</td>
</tr>
<tr>
<td>▪ Steroids - e.g. Dexamethasone (lymphoma), topical hydrocortisone</td>
</tr>
<tr>
<td>▪ 5HT3 antagonists e.g. Ondansetron (opioid-induced pruritus, uraemia, biliary cholestasis)</td>
</tr>
<tr>
<td>▪ Doxepin capsules or cream</td>
</tr>
<tr>
<td>▪ Thalidomide (Uraemia)</td>
</tr>
<tr>
<td>▪ Paroxetine (paraneoplastic pruritus)</td>
</tr>
</tbody>
</table>

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Please contact Hospice Taranaki if you have any concerns or require further information
**Skin – Sweating**

**Sweating is:** the secretion of fluid from the skin by sweat glands within and under the skin.

**Symptoms include:** an overproduction and secretion of sweat for no apparent usual cause.

**Causes include:** environmental temperature changes, emotion, lymphomas, hepatic metastases and carcinoid, intense pain, anxiety and fear, infection, drugs (alcohol, tricyclic antidepressants, and opioids)

---

**Holistic Reflection**

**PQRSTU assessment:** Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines](page 41)

**Emotional Considerations:** What does this symptom mean for the family/whānau?

**Spiritual Considerations:** Is there any considerations that need to be taken into account around this time? How does this affect the person, their perception of self and their lifestyle?

**Social Considerations:** How does this symptom affect family/whānau staying close by?

---

**Is patient experiencing excessive sweating?**

- **No**
  - Be aware of this common symptom especially for those with hepatic metastases and lymphoma

- **Yes**
  - Palliate presenting symptoms

**Utilise Non-Pharmacological Interventions**
- Manage temperature and keep as consistent as possible.
- Ensure hygiene practices are adhered to.
- Ensure light clothes are worn when necessary.
- Ensure towels/cloths are available to “mop” up sweat.
- Use of fans as needed.
- Minimise alcohol (if precipitating factor).
- Review medications that can cause sweating (antipyretics, antidepressants, etc.)

**Utilise Pharmacological Interventions**
- NSAIDS – e.g. Diclofenac
- Cimetidine – 400-800mg at night.
- Steroids – e.g. Dexamethasone

---

**Please contact Hospice Taranaki if you have any concerns or require further information**
Wound Management

**Wounds** and their management are an integral part of holistic care. They are a result of impairment of the skin integument that is not healed or not healing.

**Symptoms include:** A wound/ulcer that has not healed. Odour and exudate are the main manifestations of this symptom.

**Causes include:** Primary skin tumour, invasion of nearby tissue by tumour, metastatic involvement, anaerobic activity within a cavity, erosion of blood vessels as the wound enlarges.

**Holistic Reflection**

**PQRSTU assessment:** Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines](#) (page 41)

**Emotional Considerations:** What does this symptom mean for the family/whānau?

**Spiritual Considerations:** Is there any considerations that need to be taken into account around this time? How does this affect the person, their perception of self, their body image and their lifestyle?

**Social Considerations:** How does this symptom affect family/whānau staying close by?

For in-depth information regarding management of wounds please click here to view “Guidelines for Wound Management in Palliative Care.”
Managing Psychological Issues

Terminal Restlessness

**Terminal Restlessness is:** a common symptom towards the end of life resulting in an uneasy, nervous state where the person is unable to rest, relax or be still.

**Symptoms include:** inability to relax, picking at the sheets/clothes, confusion, agitation, talking to “people”.

**Causes include:** Uncomfortable bed, full bladder/rectum, cold/hot, insomnia, pain, delirium, anger, fear, guilt, unfinished business, helplessness, hopelessness, drugs, and hypoxia.

**Holistic Reflection**

**PQRSTU assessment:** Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines](#) (page 41)

**Emotional Considerations:** How can emotional issues be identified and addressed at this time? Is there time to address these prior to death?

**Spiritual Considerations:** How can feelings of hopelessness and helplessness (by patient/family/whānau) be addressed? Would the patient like to see/benefit from a chaplain visiting? How does this affect the person, their perception of self and their lifestyle?

**Social Considerations:** Is the patient safe where they are at the moment? Can they remain there until they die? What other support does the family/whānau need at this time?

**Physical Considerations:** How can we make this person safe? How is this symptom affecting physical needs for this person?

---

**Does patient have signs and symptoms of Terminal Restlessness?**

<table>
<thead>
<tr>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be aware of this if similar symptoms arise</td>
<td>Use medical interventions to minimise effects</td>
</tr>
</tbody>
</table>

**Treat conditions that are treatable e.g.**

- Reposition – +/- heating
- Hypoxia → oxygen via nasal prongs
- Constipation → refer guideline
- Full bladder → insert catheter
- Fever → palliate
- Pain → refer guideline
- Treat delirium → refer guideline
- Fear and anxiety → refer guideline
- Drug induced – decrease/cease drugs
- Helplessness/Hopelessness – openly discuss issues if appropriate
  (+/- referral to Family Support Team/Counsellor)

**Utilise Non-Pharmacological Interventions**

- Ensure safe and secure environment (assess and monitor risks)
- Consider family/friends staying with patient on a rostered system
- Create familiar environment (photos, music etc)
- Ensure family are informed and understand what is happening
- Consider safe staffing levels and continuity of staff to patient
- Use of complementary therapies e.g. aromatherapy, massage

**Utilise Pharmacological Interventions 1st line**

Midazolam 2.5mg
SC stat PRN

Review after 24 hrs

If more than 2 doses given consider use of Syringe Driver of 5-20mg Midazolam
SC over 24hrs.

Review after 24 hrs

Can be increased to 60mg/24hrs

N.B Delirium is not uncommon in Terminal Restlessness. Midazolam can cause paradoxical restlessness.
Anxiety and Fear

Anxiety and Fear is a common symptom of excessive uneasiness and being afraid and frightened.

Symptoms include: inability to relax, expressing feelings of anxiousness, isolating behaviours.

Causes include: medical condition (e.g. delirium, depression, hormone secreting tumour), drug reaction (steroids, bronchodilators), may be a symptom of an impending medical catastrophe, learned phobic reaction (e.g. to needles, chemotherapy, death).

Holistic Reflection

PQRSTU assessment: Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines](page 41)

Emotional Considerations: How can emotional issues be identified and addressed at this time? Is there time to address these prior to death?

Spiritual Considerations: How can feelings of hopelessness and helplessness (by patient/family/whānau) be addressed? Would the patient like to see/benefit from a chaplain visiting? How does this affect the person, their perception of self and their lifestyle?

Social Considerations: Is the patient safe where they are at the moment? Can they remain there until they die? What other support does the family/whānau need at this time?

Physical Considerations: How can we make this person safe? How is this symptom affecting physical needs for this person?

Does patient exhibit symptoms of anxiety or fear?

<table>
<thead>
<tr>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anticipate symptom at a later date and act as required</td>
<td>Administrer PRN dose of 1.5-Sing Midazolam SC if/as required</td>
</tr>
</tbody>
</table>

Consider reasons for anxiety and fear
- Separation from loved ones, homes or jobs
- Becoming dependent on others as illness progresses
- Losing control of faculties
- Failing to complete life goals/obligations
- Uncontrolled pain or other symptoms
- Abandonment
- Not knowing how death will occur
- “death anxiety” (the fear of “non-being”)
- Spiritual issues

Treat conditions that are treatable
- Pain - refer guideline
- Treat delirium - refer guideline
- Drug induced – decrease/cease drugs
- Helplessness/Helplessness – openly discuss issues if appropriate (+/- referral to Family Support Team/Counsellor)

Utilise Non-Pharmacological Interventions
- Ensure family are informed and understand what is happening
- Consider safe staffing levels and continuity of staff to patient
- Maximise multidisciplinary approach using social workers, counsellors, chaplains, etc
- Use of complementary therapies e.g. aromatherapy, massage
- Open, honest communication

Utilise Pharmacological Interventions
- Benzodiazepines e.g. Diazepam, Midazolam, Clonazepam
- Antidepressants – Citalopram, Paroxetine
- Beta-blockers e.g. Propanolol (may block the peripheral symptoms and ease the unease)

Please contact Hospice Taranaki if you have any concerns or require further information.
**Delirium**

Delirium is "a reversible toxic state".

**Symptoms include:** disorientation, fear and dysphoria, memory impairment, reduced attention span, hyperactive, hypoactive, reversal of sleep-wake cycle, perceptual disturbances, disorganised thinking, dysgraphia, and sundowner effect.

**Causes:**
- Infection
- Organ Failure
- Drugs
- Metabolic disturbances
- Hypoxia
- Severe Anaemia
- Vitamin Deficiency
- Cerebral Haemorrhage
- Cerebral Metastases
- Epilepsy – post-ictal
- Dehydration

**Aggravating factors:**
- Dementia
- Pain
- Fatigue
- Urinary Retention
- Constipation
- Change of environment
- Unfamiliar excessive stimuli

**Holistic Reflection**

**PQRSTU assessment:** Consider this framework as a tool to assess the symptom holistically. [Click here for PQRSTU guidelines](#) (page 41)

**Emotional Considerations:** How does this diagnosis affect the family? Is there any perception or understanding of this diagnosis?

**Spiritual Considerations:** How does this affect the person, their family and their lifestyle?

**Social Considerations:** How does this diagnosis impacts on the remainder of their life?

**Physical Considerations:** How can we make this person safe? How is this symptom affecting physical needs for this person?

Is patient exhibiting signs and symptoms of delirium?

- **No**
  - Be aware of this if similar symptoms arise

- **Yes**
  - Use medical interventions to minimise effects
  - Palliate presenting symptoms

**Utilise Non-Pharmacological Interventions**
- Ensure safe and secure environment (assess and monitor risks)
- Consider safe staffing levels and continuity of staff to patient
- Keep environment warm and comfortable
- Use orienting aids (clock, family member, own belongings in room)
- Minimise external stimuli
- Use of complementary therapies e.g. aromatherapy, massage
- Cognitive therapies (clarification, reality testing, validation and repetition during lucid periods).

**Utilise Pharmacological Interventions**
- **Anti-psychotics** – Haloperidol (5-20mg daily), Levomepromazine (6.25-100mg daily), Risperidone (1-3mg daily), Quetiapine (but not in AIDS delirium, hepatic encephalopathy or alcohol withdrawal)
- **Sedatives** – often used in conjunction with Anti-psychotics when restless [see guideline]

Only 10% to 20% of patients with terminal delirium should require ongoing sedation to achieve control.

Please contact Hospice Taranaki if you have any concerns or require further information.
Managing Social Issues

Discharge planning

Discharge planning can mean the difference between a smooth transition and a rough one. Rough transitions often increase the anxiety and stress for families/whanau. Discharge planning involves ALL involved in someone’s care and helps to ensure that all necessary requirements are in place at the time of discharge from Hospital or Hospice. This includes:

- Communication between ALL providers involved in patient care (e.g. Hospice Taranaki IPU staff, General Practitioners, Palliative Care Community Nurses, District Nurses, Social Workers)
- The delivery of (or access to) necessary equipment
- The preparation of necessary prescriptions (ensuring that immediate medications are on hand if needed)
- Follow up planning

Equipment

Each of the Hospice regional services has loan equipment that can be utilised when caring for palliative patients. Phone your local specialist palliative care team for further information. Hospice Taranaki Contacts (page 5).

Some of the equipment that is available is:
- Electric beds
- Pressure relief mattresses e.g. Spenco
- Alternating Air Pressure mattresses
- Syringe Drivers
- Wheelchairs
- Commodes
- Over toilet chairs
- Shower chairs

Home Help/Personal Care

Refer to TDHB home support unit for assessment.

Placement in a long term care facility

The process of placement of a palliative patient is one that requires assessment, co-ordination and communication. Placement can not occur without assessment by COMMUNITY SUPPORT SERVICES at TDHB.

Support for Family/Carer

If you feel your patient and family/whānau could benefit from bereavement or counselling support, please contact a member of the Hospice Taranaki team to discuss this further. Hospice Taranaki Contacts
Volunteer Support
Volunteer support can be invaluable when caring for patients during the palliative stage of their life. If you feel your patient and family/whānau could benefit from this type of support, please contact a member of the Hospice Taranaki team to discuss this further. Hospice Taranaki Contacts

Nutritional Support
In palliative care it is rare that Intravenous fluids and nasogastric tubes are required. Treatment centres around minimising discomfort from symptoms in an active and yet as free from medical technology and tubes as possible. Patients and their family/whānau must always be fully informed to make the decision that is right for them.
Syringe Driver Management

Commencing Subcutaneous Syringe Driver Medications

“A Syringe Driver is a battery powered device that administers drugs subcutaneously over a chosen period of time. The Niki T34 Syringe Driver is used within NZ. It is preferable that individuals who are working with syringe drivers have gained competency after attending and updating their knowledge via the Hospice New Zealand syringe driver competency programme. Details of training can be accessed via www.hospicetaranaki.org.nz.

Does patient require subcutaneous syringe driver opioids?

- **No**
  - Continue with current medication regimen

- **Yes**
  - Add up the amount of opioid taken orally in the last 24 hours (consider the long-acting & short-acting doses).
  - Convert this 24hr dose to a morphine equivalent dose.
    - Codeine – 60mg oral = 6mg oral morphine
    - Tramadol 100mg = 10 mg oral morphine
    - Oxycodone 5mg = 10mg oral morphine
    - Oxycodone 5mg SC = 5mg SC morphine
    - Fentanyl (seek advice)
    - Methadone (seek specialist advice)
    - Pethidine (see specialist advice)
  - Divide this amount by two. This is the amount of morphine required to commence the syringe driver.

  Organise other medications to be prescribed with the morphine in syringe driver & prescribe PRN meds:
  - Pain/Breathlessness short acting oral morphine preparation or subcut equivalent to 1/10 – 1/5 of 24hr dose pm every 30 minutes to a maximum of 3 doses.

  **Please contact Hospice Taranaki if you have any concerns or require further information**

  Assess effectiveness of syringe driver medications after 2-3 hrs then every 24hours. Revise medications for each symptom as required and alter medications in the syringe driver pm.

  Review every 24 hours

  Draw up syringe for the syringe driver in line with manufactures policy. Commence/continue subcutaneous infusion.
## Choice of Drugs for Use in Syringe Drivers

**MORPHINE N.B.** Parenteral Morphine is 2x as strong as oral Morphine. If pain not controlled on oral medication, consider increasing the oral dose by 30-50%. When converting to subcutaneous and convert to a subcutaneous dose from this dose.

<table>
<thead>
<tr>
<th>DRUG</th>
<th>usual dose ranges quoted</th>
<th>USE</th>
<th>STAT DOSE</th>
<th>S/C DOSE OVER 24 HRS</th>
</tr>
</thead>
<tbody>
<tr>
<td>CYCLIZINE</td>
<td>50mg/ml injection</td>
<td>Antiemetic, centrally acting on vomiting centre. Good for nausea associated with bowel obstruction or increased intracranial pressure. Dilute with water.</td>
<td>50mg</td>
<td>100-150mg</td>
</tr>
<tr>
<td>HALOPERIDOL</td>
<td>5mg/ml injection</td>
<td>Antiemetic – good for chemically induced nausea. Control of hallucinations. Caution in terminal restlessness with twitching – lowers seizure threshold.</td>
<td>0.5-1.5mg</td>
<td>2-5mg</td>
</tr>
<tr>
<td>METOCLOPRAMIDE</td>
<td>10mg in 2ml injection</td>
<td>Antiemetic (1) prokinetic (accelerates GI transit) (2) centrally acting on chemo-receptor trigger zone (CTZ), blocking transmission to vomiting centre. N.B. Don’t use in combination with HYOSCINE.</td>
<td>10mg</td>
<td>40 - 60mg</td>
</tr>
<tr>
<td>METHOTRIMEPRAZINE / LEVOMEPRAMAZINE</td>
<td>25mg/ml injection</td>
<td>Broad spectrum antiemetic, works on CTZ and vomiting centre (at lower doses). Terminal agitation. Dilute with saline when used alone.</td>
<td>5 - 6.25mg</td>
<td>5 - 25mg</td>
</tr>
<tr>
<td>MIDAZOLAM</td>
<td>10mg in 2ml</td>
<td>Sedative/anxiolytic (terminal agitation), anticonvulsant, muscle relaxant, controls myoclonus.</td>
<td>2.5 – 10mg</td>
<td>5 - 60mg</td>
</tr>
<tr>
<td>HYOSCINE BUTYLBROMIDE</td>
<td>20mg /ml injection</td>
<td>Antisecretory and antispasmodic properties. Useful in reducing respiratory tract secretions. Less sedating than HYOSCINE HYDROBROMIDE.</td>
<td>20mg</td>
<td>40 - 60mg</td>
</tr>
<tr>
<td>HYOSCINE HYDROBROMIDE</td>
<td>0.4mg/ml injection</td>
<td>Antisecretory and antispasmodic properties. Useful in reducing respiratory tract secretions.</td>
<td>400mcg</td>
<td>400mcg - 2.4mg</td>
</tr>
</tbody>
</table>

### Syringe Driver Compatibility Table

To see if the drugs you wish to give are compatible, check the [compatibility table](#).

---

*Please contact Hospice Taranaki if you have any concerns or require further information.*
Managing Palliative Emergencies

Palliative Care emergencies involve situations that can cause imminent death or result in extreme changes to quality of the remainder of life for the patient and their family/whānau. Being aware of such emergencies and the symptoms of these results in proactive planning for the patient and their family/whānau.

Having the relevant drugs correctly charted and readily available for patients with the potential for an emergency will ensure any emergency is managed efficiently and effectively.

All emergencies should be considered as having a holistic impact on the patient and their family/whānau.

Holistic Reflection
PQRSTU assessment: Consider this framework as a tool to assess the symptom holistically. Click here for PQRSTU guidelines

Emotional Considerations: How does this diagnosis affect the family? Is there any perception or understanding of this diagnosis?

Spiritual Considerations: How does this affect the person, their family and their lifestyle?

Social Considerations: How does this diagnosis impacts on the remainder of their life?

Physical Considerations: How can we make this person safe? How is this symptom affecting physical needs for this person?

Spinal Cord Compression

Assessment of History and current findings
If the clinical history includes advancing metastatic disease (in particular cancer of lung, breast, prostate, kidney, multiple myeloma and non-Hodgkins lymphoma), consider with a high level of suspicion if the patient exhibits the following symptoms:

- Pain (banded in nature in line with dermatomes)
- Weakness (especially in lower limbs)
- Sensory disturbance
- Bladder symptoms
- Bowel symptoms (constipation)

Dexamethasone 16mg PO/SC/IV

Limit mobility and urgently discuss with Hospice team/radiation oncologist, about referral for MRI.

If appropriate and patient and family amenable to treatment, urgent Referral to Radiotherapy – through ED or Hospice IPU.

Please contact a member of the Specialist Team to discuss this further.

Hospice Taranaki Contacts
**Hypercalcaemia**

**Assessment of History and Current Findings**
If the clinical history includes advancing metastatic disease (in particular cancer of lung, breast, prostate, kidney, multiple myeloma and non-hodgkins lymphoma), consider with a high level of suspicion if the patient exhibits the following symptoms:

- Thirst and dehydration
- Constipation
- Nausea/vomiting
- Pain (Back/Abdomen)

Increased urinary output
Loss of Appetite
Fatigue
Confusion

Is further intervention/treatment appropriate and acceptable to patient and their family/whānau?

Arrange Blood Test to measure Serum Calcium & renal function

Rehydration and IV Pamidronate as in-patient
NB: treatment may take 72 hrs to be effective.

Please contact a member of the Specialist Team to discuss ongoing management of this symptom. **Hospice Taranaki Contacts**

**Massive Haemorrhage**

**Assessment of History and Current Findings**
If the clinical history includes:

- Advancing metastatic disease (in particular cancer)
- Platelet dysfunction
- Drug risk e.g. NSAIDS, anticoagulants

Chemotherapy
Hepatic dysfunction
Known Tumour invasion

Discussion with patient and family/whānau is suggested regarding the possibilities that might occur, use of sedation, family/whānau presence at time of emergency, and appropriate resuscitation measures.

Ensure supplies of dark coloured absorptive towels are in the room at all times.

Ensure adequate drugs (Midazolam/Clonazepam) are charted and readily available for use if/when needed.

Please contact a member of the Specialist Team to discuss this further. **Hospice Taranaki Contacts**
Neutropenic Sepsis

Assessment of History and Current Findings
If the clinical history includes:
- Chemotherapy
- Neutropenic dysfunction
- Known septic state
- Hepatic dysfunction

Discussion with patient and family/whanau is suggested regarding the possibilities that might occur, use of sedation, antibiotics and preference for active vs comfort care.

Administer care in consultation with patient/family/whanau. REFER URGENTLY THROUGH ED IF MEDICAL ONCOLOGY PATIENT.

Please contact a member of the Specialist Team to discuss this further. Hospice Taranaki Contacts

Superior Vena Cava Obstruction

Assessment of History and Current Findings
Advancing metastatic disease (in particular lung cancer and Lymphoma) with increasing dyspnoea, facial oedema, and venous distention of neck. It may be appropriate to refer for active treatment, depending on physical condition of patient/discuss with duty Hospice Doctor/oncologist.

Discussion with patient and family/whanau is suggested regarding the possibilities that might occur, use of sedation, palliative radiotherapy, palliative chemotherapy, and preference for active vs comfort care.

Urgent CT Scan or MRI. Limit mobility and then referral to Radiotherapy

Dexamethasone 16mg PO/SC/IV

Please contact Hospice Taranaki if you have any concerns or require further information.
Seizures

Assessment of History and Current Findings

If the clinical history includes:
Brain Tumour, Renal Dysfunction, Epilepsy

Discussion with patient and family/whanau is suggested regarding the possibilities that might occur, use of sedation, antibiotics and preference for active vs comfort care.

Ensure adequate drugs (Midazolam 2.5-5mg SC/IM every 5 minutes as required or Clonazepam 5 drops (with repeats every 5 minutes) are charted and readily available for use if/when needed.
Appendix One - PQRST format

Consider the following assessing their pain using the PQRST format:

- **P** Palliative factors
  - Provoking factors
    - “What makes it better?”
    - “What makes it worse?”

- **Q** Quality
  - “What is the symptom like?
    Give me some words that tell me about it.”

- **R** Radiation
  - “Does the pain go anywhere else?”

- **S** Severity
  - “How severe is it?”
    Measured on numbered scale

- **T** Time
  - “Is this problem (with you) there all the time?”
  - “Does it come and go at different times of the day?”

- **U** Understanding
  - “What does this symptom mean to/for you?”
  - “How does this symptom affect your daily life?”

---

Example of a Visual Analogue Scale
### Appendix Two - Bristol Stool Chart

This chart is a good visual resource to “describe” faecal matter. This also gives a good indication of how long it has been in the bowel. I.e. Type 1-3 have been in the bowel longer and therefore have less water content and may be harder to pass.

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type 1</td>
<td>Separate hard lumps, like nuts (hard to pass)</td>
</tr>
<tr>
<td>Type 2</td>
<td>Sausage-shaped but lumpy</td>
</tr>
<tr>
<td>Type 3</td>
<td>Like a sausage but with cracks on its surface</td>
</tr>
<tr>
<td>Type 4</td>
<td>Like a sausage or snake, smooth and soft</td>
</tr>
<tr>
<td>Type 5</td>
<td>Soft blobs with clear-cut edges (passed easily)</td>
</tr>
<tr>
<td>Type 6</td>
<td>Fluffy pieces with ragged edges, a mushy stool</td>
</tr>
<tr>
<td>Type 7</td>
<td>Watery, no solid pieces. Entirely liquid</td>
</tr>
</tbody>
</table>
## Compatibility of drugs for use in syringe drivers over 24 hours of subcutaneous infusions

<table>
<thead>
<tr>
<th>Drug</th>
<th>Clonazepam</th>
<th>Cycloine</th>
<th>Desmethylhexane</th>
<th>Fentanyl</th>
<th>Glucopyrolone</th>
<th>Haloperidol</th>
<th>Hyoscine Butyl Bromide</th>
<th>Hyoscine Hydrobromide</th>
<th>Ketamine</th>
<th>Levoamphetamine</th>
<th>Methadone</th>
<th>Metoclopramide</th>
<th>Meprobamate</th>
<th>Morphine</th>
<th>Morphine Sulfate</th>
<th>Noradrenaline</th>
<th>Oxycodone</th>
<th>Phenobarbital</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clonazepam</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>Cycloine</td>
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<td>Glucopyrolone</td>
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<td>Haloperidol</td>
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<td>Ketamine</td>
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<td>Levomepromazine</td>
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<td>Meprobamate</td>
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<td>Morphine Sulfate</td>
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<td>Morphine Tartrate</td>
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<tr>
<td>Ondansetron</td>
<td>?</td>
<td>SI</td>
<td>SI</td>
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<td>Y</td>
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<tr>
<td>Phenobarbital</td>
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</tr>
</tbody>
</table>

### Diluent: water is recommended for all infusions except ketamine, oxycodone, ondansetron and levomepromazine where sodium chloride 0.9% should be used although in combinations consider water.

### Table: Combinations that have been used

- **Y = compatible**
- **N = incompatible**
- **S1 = sometimes incompatible (usually at higher concentrations)**
- **NA = not usually used together**
- **? = unknown**

### Info from:
4. Palliative Care Formulary online at [www.palliativedrs.net](http://www.palliativedrs.net)
5. Gardner P R Compatibility of an injectable oxydcono formulation with topical diluents, synges, tubing, infusion bags and drugs for potential co-administration. Hospital Pharmacist 2003; 16: 354-61
# Appendix Four – Assessment Tools

## Palliative Performance Scale (PPS) version 2

The PPS measures the functional status of a patient and serves as a communication tool for quickly describing a patient’s current functional level.

<table>
<thead>
<tr>
<th>%</th>
<th>Ambulation</th>
<th>Activity and Evidence of Disease</th>
<th>Self-Care</th>
<th>Intake</th>
<th>Conscious Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>100</td>
<td>Full</td>
<td>Normal Activity</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No Evidence of Disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>90</td>
<td>Full</td>
<td>Normal Activity with Effort</td>
<td>Full</td>
<td>Normal or Reduced</td>
<td>Full</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some Evidence of Disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>80</td>
<td>Full</td>
<td>Normal Activity with Effort</td>
<td>Full</td>
<td>Normal or Reduced</td>
<td>Full</td>
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<td></td>
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<td>Some Evidence of Disease</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>70</td>
<td>Reduced</td>
<td>Unable Normal Job / Work</td>
<td>Full</td>
<td>Normal or Reduced</td>
<td>Full</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some Evidence of Disease</td>
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<td></td>
</tr>
<tr>
<td>60</td>
<td>Reduced</td>
<td>Unable Hobby / House Work</td>
<td>Occasional Assistance Necessary</td>
<td>Normal or Reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Significant Disease</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>50</td>
<td>Mainly Sit/Lie</td>
<td>Unable to Do Any Work</td>
<td>Considerable Assistance Necessary</td>
<td>Normal or Reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extensive Disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>40</td>
<td>Mainly in Bed</td>
<td>As Above</td>
<td>Mainly Assistance</td>
<td>Normal or Reduced</td>
<td>Full or Drowsy or Confusion</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>Totally Bed Bound</td>
<td>As Above</td>
<td>Total Care</td>
<td>Reduced</td>
<td>Full or Drowsy or Confusion</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>20</td>
<td>As Above</td>
<td>As Above</td>
<td>Total Care</td>
<td>Minimal Sips</td>
<td>Full or Drowsy or Confusion</td>
</tr>
<tr>
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<td></td>
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</tr>
<tr>
<td>10</td>
<td>As Above</td>
<td>As Above</td>
<td>Total Care</td>
<td>Mouth Care Only</td>
<td>Drowsy or Coma</td>
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</tr>
<tr>
<td>0</td>
<td>Death</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

### 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 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 & 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.

The Palliative Performance Scale version 2 (PPSv2) tool is copyright to Victoria Hospice Society 1952 Bay Street, Victoria, BC, V8R 1J8, Canada. It cannot be altered or used in any way other than as intended and described here.
**ECOG Performance Status**

This tool designed by the Eastern Cooperative Oncology Group (ECOG) is used by doctors and researchers to assess how a patient’s disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis.

<table>
<thead>
<tr>
<th>Grade</th>
<th>ECOG Performance Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Fully active, able to carry on all pre-disease performance without restriction</td>
</tr>
<tr>
<td>1</td>
<td>Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours</td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited self-care, confined to bed or chair more than 50% of waking hours</td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair</td>
</tr>
<tr>
<td>5</td>
<td>Dead</td>
</tr>
</tbody>
</table>
ESAS

The ESAS (Edmonton Symptom Assessment Scale) tool is designed to assist in the assessment of 11 symptoms common in palliative patients: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing and shortness of breath, complexity of care and constipation.

The severity at the time of assessment or over the last 24 hours of each symptom is rated from 0 to 10 on a numerical scale (0 meaning that the symptom is absent/positive and 10 that it is of the worst possible severity).

It is the patient's opinion of the severity of the symptoms that is the “gold standard” for symptom assessment.

The ESAS provides a clinical profile of symptom severity over time and a context within which symptoms can begin to be understood. However, it is not a complete symptom assessment in itself. For good symptom management to be attained the ESAS must be used as just one part of a holistic clinical assessment.

The circled number is then transcribed onto the symptom assessment graph (see “ESAS Graph” below).

Synonyms for words that may be difficult for some patients to comprehend include the following:

- **Depression** – blue or sad
- **Anxiety** – nervousness or restlessness
- **Tiredness** – decreased energy level (but not necessarily sleepy)
- **Drowsiness** – sleepiness
- **Wellbeing overall** - comfort, both physical and otherwise; truthfully answering the question, “How are you?”
ESAS

Name:______________________    Date:____________________      Time:_______

Scale range is 0 (absent/good) to 10 (worst possible/ bad) Enter NA if not assessed

<table>
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<th>Symptom</th>
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<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
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<th>9</th>
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</tr>
</tbody>
</table>

Completed by:  □ Patient    □ Carer    □ Health Professional Team Member
References
Adapted from Northland Generalist Guidelines revised 2010

DISCLAIMER & ACKNOWLEDGEMENTS

At the time of writing, these guidelines are indicative of generalist palliative care practice under the guidance of Hospice Taranaki Medical Specialist Dr Suresh Joishy. Much of the information contained within these guidelines is based on “The Palliative Care Handbook” (McLeod, Vella-Brincat, Macleod, 2012). We acknowledge the authors for granting us permission to use this information freely when developing these guidelines.

These guidelines are provided to guide practice alongside personal clinical judgement and formulary information. Using these guidelines does not diminish practitioners from the necessity to exercise their own clinical judgement. The staff of Hospice Taranaki do not accept any responsibility for the use of these guidelines in practice and encourage collaboration in the practice of palliative care for the benefit of patients and their families.

Information regarding medication can be found in the normal formulary sources. Some medications are used for indications, by routes or in doses that are not approved by New Zealand licensing. This is common practice and validated internationally. For further information: ‘The Use of Unapproved Medicines in Palliative Care’.

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