Palliative Care Information

If you need further information to assist in the provision of Palliative Care contact:

Clare Holland House
6273 0336 (24 hrs)

Home Based Palliative Care
6273 0336 (24 hrs)

Palliative Care Medical Specialist
6273 0336 (24 hrs)

The Canberra Hospital – Palliative Care Liaison Nurse
6244 2222 (Monday – Friday 9am-5pm)
Acknowledgments

This resource booklet has been adapted for the ACT from a resource developed by the Adelaide North East and Adelaide Central and Eastern Divisions of General Practice. It was written in recognition of the need to encourage general practitioners and nursing staff in residential aged care facilities to support older people's desire to die with dignity in their home, the residential aged care facility.

Key contributions from staff at
- ACT Division of General Practice's Aged Care GP Panel
- Clare Holland House
- Dr Andrew Skeels, Medical Director ACT Palliative Care Service
- Program of Experience in the Palliative Approach (PEPA – ACT)
- Respecting Patient Choices Program (ACT)

This document is a guide only and should be checked with specific prescribing information as well as support through ACT Palliative Care Service at Clare Holland House as required. These notes were updated in 2007.

The *Therapeutic Guidelines, Palliative Care, version 2: 2005* underpins this resource.
What is Palliative care?

Palliative Care Australia (2005) states:

‘Palliative Care is care provided for people of all ages who have a life limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life’.

WHO states Palliative Care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates psychosocial and spiritual aspects of care
- Supports people to live as actively as possible until death
- Supports families during the illness and in bereavement
- Uses a team approach

A palliative approach is linked to palliative care and is used by primary care services and practitioners to improve the quality of life for those with a life limiting illness. Application of the palliative approach to care is not delayed until the end stages of an illness.

Specialist palliative care builds on the palliative approach adopted by primary care providers and reflects a higher level of expertise for those persons and their families with complex care needs.
Symptom Management in Palliative Care

The following is an outline of some of the usual approaches in managing the symptoms of advanced illness. It is not intended to be exhaustive, but will mention the most frequently encountered symptoms.

No patient should be left without satisfactory symptom management. Regular and frequent review, and change of management if required, is essential. Doses may need adjusting as patients lose weight, or when liver and particularly renal function are impaired.

Consultation with a specialist Palliative Care service is encouraged whenever a particular symptom proves refractory to usual measures.

The emphasis is on anticipation and, where possible, prevention of problems rather than crisis intervention.

N.B. Some of the drugs used, particularly routes of administration, have been adopted to address particular problems in Palliative Care and are not registered uses or routes for that drug. Please be aware of prescribing regulations and where variations might need to be explained to patients.

Refer to the section on Resources for specific text to support evidence-based practice. In case of any doubt, discuss with specialist Palliative Care service.

**Principles of symptom management:**

- Diagnosis and assessment
- Explanation
- Treatment based on:
  - Aetiology
  - Options
  - Patient preference
  - Dose titration with monitoring of response
  - Frequent review

**Suffering and Symptoms**

Remember the suffering of a patient may arise from pain or other physical symptoms due to their illness, but may also derive from many other aspects of their life such as social or spiritual issues. Whilst the emphasis here is on relief of physical symptoms, this may not be possible if other dimensions are overlooked or ignored.

*(Brooksbank, M. 2003)*
General

Asthenia
This is the most common symptom of advanced illness and includes:
• Lethargy – can not get going
• Tiredness – exhausted after any activity
• Weakness – can not get up

Look for depression, anaemia, steroid effects as well as disease progression.
Patients should be encouraged and supported in what they want or feel able to do.

Oedema, Lymphoedema, Ascites

• Peripheral oedema
  Often due to a combination of low serum albumin, lymphatic obstruction, cardiac failure and immobility:
  – May be limited response to diuretics
  – Elevating legs may be helpful

• Lymphoedema
  Complication of lymphatic obstruction in malignant disease:
  – May benefit from elevation, massage, supportive bandaging to avoid lymphorrhoea
  – Seek advice from physiotherapist and/or Lymphoedema Clinic at Calvary Hospital
  – Beware of cellulitis

• Ascites
  – Paracentesis (drainage of ascites) only provides temporary relief but can be considered
  – Diuretics: *Spironolactone* 50 to 100mg daily and *Furosemide* 20 to 40mg daily or second daily may be considered with caution
  – Diuretics may cause worsening renal function or lowering of blood pressure

Symptom Management
Gastro-intestinal Symptoms

Anorexia
Very common at end of life but can cause considerable family distress.
Look for possible reversible causes for anorexia:
• Dry mouth
• Nausea
• Pain
• Mouth ulcers
Management:
• Serve small meals, snacks
• Support family
• Corticosteroids can temporarily boost appetite:
  – Prednisolone 12.5 to 25mg mane
  – Dexamethasone 2 to 4mg mane

Cachexia
Very common in terminal illness. Usually a secondary response to tumour rather than malnutrition. Family frequently requires support to understand reducing nutritional intake and requirements.

Nausea and vomiting
Often multifactorial but clinical diagnosis can help guide anti-emetic prescribing.
  Consider – Metoclopramide 10mg S/C or oral 4 hourly unless otherwise indicated

Toxic causes
• Drugs
• Liver failure
  Consider – Haloperidol 1-2mg oral or sc bd
  – Stemetil 5mg oral tds (NOT subcut)

Gastrointestinal causes
• Sub acute bowel obstruction
• Paralytic Ileus
• Extensive peritoneal disease
  Consider – Phenergan 10-25mg oral tds or 25-75mg in syringe driver over 24 hours
  – Cyclizine may be considered (contact Palliative Care Specialist)

Vestibular causes
• Stroke
  Consider – Phenergan A/A

Intra cranial causes
• Raised intra cranial pressure
  Consider – Steroids 4-16 mg/day given as am + midday dose to avoid insomnia
  – Ondansetron used predominantly for the prevention of nausea following chemotherapy.
  – May be effective in some individuals but often not useful in chronic nausea (if used, beware of constipation).
• Anxiety may be a cause of ongoing nausea
  Consider – Benzodiazepines
  e.g. Lorazepam 0.5-1mg bd
Seek support from a Palliative Care service as required
**Constipation**
There is an increased risk of constipation in Palliative Care for various reasons including decreased fluid and dietary intake, reduced mobility, drugs such as opioids; this is compounded in the frail elderly patient.
- Fluid intake can be encouraged
- Regular faecal softener and bowel stimulant or osmotic laxative must be given when commencing opioids

**Laxatives in Palliative Care**
- Combined softening agent and peristaltic stimulant
  Consider – *Coloxyl with Senna* 1 to 6 tablets daily
- Osmotic laxatives
  Consider – *Movicol*
- Avoid laxatives that require a large volume of water, e.g. lactulose

Malignant bowel obstruction in terminal illness requires specialist Palliative Care consultation.
*(Brooksbank, M. 2003)*

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**Gastro-intestinal Symptoms**
Respiratory Symptoms

Dyspnoea
Consider diagnosis and look for reversible causes:
• Heart failure
• COPD
• Anaemia
• Pulmonary embolus
• Infection
• SVC obstruction
• Pericardial disease
• Major airway obstruction
• Lymphatic carcinomatosis
• Lung cancer

Treat underlying cause if possible and appropriate.

Symptomatic relief of dyspnoea:
• Non-pharmacological measures:
  – Well ventilated room
  – Fan blowing on face
  – Relaxation
• Opioids in low doses relieve the sensation of dyspnoea without depressing respiratory function.
  Consider – Morphine 1 to 2.5mg orally (opioid naïve) or titrate upwards from usual background dose
  – Oral dosing is effective
  – Long acting opioids are effective, e.g. MS Contin 10mg bd.
  SC administration may be used
• Benzodiazepines will help with the associated anxiety. Start gently creating a non-sedating background initially, with the opportunity for rescue doses or sedation if required.
  Consider – Lorazepam sublingual 0.5mg for medium to long term use
  – Midazolam 1 to 5mg S/C as hourly boluses or by continuous infusion
  – end of life related
• Steroids may be helpful in airways obstruction from carcinoma, COPD and lymphangitis carcinomatosis.
  Consider – Dexamethasone 4 to 8mg daily oral or S/C
• Oxygen may provide symptomatic relief and is available for palliative care patients
• Severe dyspnoea is one symptom that may require sedation for relief in the terminal stages
Cough
• Dry, non-productive cough, aim for cough suppression with opioids or opioid analogues
  Consider – *Dextromethorphan syrup*
  – *Pholcodine or codeine linctus*
  – Opioids, e.g. *Morphine 1 to 2.5mg orally 1 to 2 hourly prn* in opioid naïve patient or nebulised normal saline
• Moist productive cough, assist expectoration:
  – Humidification: steam, inhalations (e.g. eucalyptus), nebulised saline
  – Bronchodilators (e.g. *Salbutamol*)
  – Antibiotics – consider for symptom relief
  – Opioids to suppress cough

When patient is unable to cough, in the terminal phase, or if there are excess secretions which cannot be expectorated consider:
  – *Hyoscine hydrobromide 0.4mg S/C 3 to 4 hourly prn*, only useful for retention of oral secretions
  – *Glycopyrrolate 0.4 mg S/C q1H prn* is preferred as it does not cross blood-brain-barrier and cause delirium
Cognitive and Emotional

**Acute Delirium**
Characterised by fluctuating delusions, hallucinations, confusion, memory loss, disorientation. Patient may be agitated or somnolent or may fluctuate between both. Delirium is characteristically worse in the evening.

Correctable causes to consider include:
- Sepsis, e.g. urine, chest
- Metabolic, e.g. hypoxia, hypercalcaemia, renal failure, hyponatraemia
- Drugs, e.g. anticholinergics, opioids
- Physical stimuli, e.g. constipation, urinary retention
- Intracranial pathology (less commonly)

**Management**
- Diagnosis and assessment:
  - Look for reversible causes but intrusive investigations may no longer be appropriate
  - Review and simplify drug regimens, e.g. many drugs have anti-cholinergic side effects that may become cumulative to produce delirium “anticholinergic load”
  - Reassurance, reorientation to try to reduce misperceptions and allay fears
  - Avoid restraints
- Drug management:
  - *Haloperidol* 1.5 to 10mg orally daily in divided doses or 2.5 to 5mg S/C 2 to 3 times daily as necessary
  - Atypical antipsychotics, e.g. *Olanzapine* 2.5 to 10mg daily
  - Benzodiazepines, e.g. *Midazolam* 2.5 to 5mg S/C hourly prn or *Diazepam* 2.5 to 10 mg orally, or rectally. (IM when patient is agitated). Do not use without major tranquiliser as will worsen confusion

**Anxiety**
Fear of death and anxiety about dying are common reactions to approaching death. Fear of dying may cause breathlessness.
- Initially managed by good symptom control, emotional and spiritual support for patient and family, and supportive counselling/care
- May also benefit from specific anxiolytic medication, e.g. Benzodiazepines

**Depression**
Often under-diagnosed in terminal illness. A wish to hasten death is an important prompt to ask about depression.
- Simply ask, “Are you depressed?” or “How would you describe your mood?”
- Consider specific anti-depressant treatment
- Occurs in up to 50% of palliative patients and is treatable

Physical signs of depression often occur with diagnosis of primary disease. Look for emotional symptoms such as anhedonia.
Pain

Pain is defined by the International Association for the Study of Pain in the Therapeutic Guidelines (2005:167) as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”. In clinical practice pain is understood in terms of the experience of the individual.

**Overall pain in the elderly is often under treated.**

The ACT Medical Treatment Act 2006, Part 3, Section 15 specifically states:

- The person has a right to relief from pain and suffering to the maximum extent that is reasonable under the circumstances
- In providing relief from pain and suffering to the person, the health professional must give adequate consideration to the person’s account of the person’s level of pain and suffering.

**Analgesics for use in cancer pain**

Drug choice depends on mechanism and severity of pain. Episodic pain can be managed with prn analgesia, persistent or ongoing pain requires pain relief.

1. Paracetamol
   - Use for mild to moderate skeletal and soft tissue pain. Dose 500 to 1000 mg every 4 to 6 hours orally or by rectal suppository up to 4g daily.

2. For more severe musculo-skeletal pain
   - NSAIDS (remember to consider proton pump inhibitor).

3. Use opioids when pain does not respond to simple measures. Patients who take opioids/ morphine for opioid responsive pain DO NOT become addicted to them.
   - Codeine is not recommended for ongoing pain due to constipating effect.

**Using Subcutaneous Morphine, an example**

A patient using oral Morphine such as *MS Contin 30mg bd* (total daily dose of 60mg) will need *S/C Morphine 20mg/24hours* which could be given as a continuous infusion via a syringe driver (remembering to order S/C breakthrough dose of 1/6 to 1/10 total daily dose).

- **Opioids**
  - While regular immediate release (IR) opioids are often recommended to titrate pain relief, this may be impractical and slow release (SR) opioids, whether oral, by patch or in syringe driver may be preferable.

**Commencing opioids in opioid naïve patients:**

- Start with lowest dose
- Review regularly after drug has reached steady state:  
  - For IR/SR 24 hours
  - For *Durogesic* 72 hours
  - For *Norspan* 1 week

**Possible Options:**

- *MS Contin* or *Oxycontin* 10mg bd
- *Norspan* 5mcg patch weekly
- Immediate release (IR) *morphine* or *oxycodone* 2.5mg qid

**Issues to consider:**

- Always provide breakthrough dose (for *Norspan* & *Durogesic* use *oral Morphine* or *Oxycodone*).
- Dose usually 1/6 to 1/10 daily dose. Remember as daily dose increases breakthrough doses will need to be increased
- Constipation – always prescribe a laxative in conjunction with opioid (*Coloxyl with senna, Movicol*)
- Patches or Syringe Driver should be used where patients have difficulty swallowing
- Morphine accumulates in patients with renal impairment and *Oxycodone, Buprenorphine* and *Fentanyl* preparations are safer

If a patient experiences side effects from morphine consider changing to an alternative opioid.
**Equivalence Charts**

All equivalence charts are approximations and there are large variations between individuals.

- **Morphine parenteral** (SCI/IMI/IVI) Morphine is x 3 more potent than oral due to increased bioavailability, i.e. *Morphine 10mg sci = 30mg po*
- **Oxycodone** x 1.5 more potent than *Morphine*, i.e. *Oxycodone 10mg po = Morphine 15mg po*
- **Hydromorphone** x 5 more potent than *Morphine*, i.e. *Hydromorphone 1mg po = Morphine 5mg po*
- **Methadone** complex opioid and should only be used with advice from Palliative Care Specialist
- **Buprenorphine** 5mcg patch = *Oxycodone 20mg daily*
- **Fentanyl** 12mcg patch = *Morphine 30mg/day*

*Note: Pethidine is not recommended for use in ongoing cancer pain.*

- **Co analgesics in Neuropathic pain**
  - Tricyclic antidepressants response is usually in the first few days but worth persevering ing for 2 weeks (e.g. *Amitriptyline 10 to 50mg orally nocte*, start with the lowest dose and titrate)
  - Anticonvulsants worth a try in neuropathic pain e.g. *Sodium Valproate 100-200mg bd oral* with meals or *Tegretol 100mg bd* *(Brooksbank, M. 2003)*

If pain does not settle refer to Palliative Care Specialist.

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**Palliation of non-cancer patients**

The principles of palliative care apply equally to patients with a non-cancer diagnosis. The focus will vary depending on the symptoms experienced by the patient. Pain is frequently present and needs to be addressed. Causes of pain in the non-cancer patient may be non-specific and diffuse. They may be related to:

- Arthritis
- Immobility
- Pressure areas
- Arterial/venous problems
- Contractures

Paracetamol is useful in this setting and low dose opioids may be a better second choice than NSAIDS where renal function and GIT symptoms are a concern.

**Opioid of choice:**

- *Oxycontin 5mg bd* and titrate
- *Norspan 5mcg patch* and titrate

Prognosis is often less certain than in patients with a cancer diagnosis but should not be preclusion to good symptom management.
Palliative Care Emergencies

Torrential Bleeding
• Haemoptysis
• Haematemesis
• Melaena

Aim is to provide rapid sedation and comfort
Need to anticipate and provide orders in advance

Treatment
– Midazolam 10-20mg sci stat
– Clonazepam 1-2mg sci stat

Major Airway Obstruction
Treatment as above

Severe Pain
Patients may experience onset of severe pain due to a number of causes
• Acute bleed into liver
• Tumour mass
• Pathological fracture
• Nerve compression with severe neuropathic pain

Treatment
– Immediately give breakthrough opioid analgesia and repeat every 30min + benzodiazepine
e.g. Midazolam 2.5-5mg sci

If not settling seek Palliative Care Specialist advice.
What are Advance Care Plans?

An Advance Care Plan is any written statement that expresses a person’s wishes or directions in advance, should mental capacity (competence) be lost in the future.

In the ACT, a patient can complete an **enduring power of attorney** form to appoint someone to make their personal or medical decisions in case they are unable to decide for themselves due to impaired capacity. If they cannot appoint anyone to make their decisions, their spouse or next of kin is not legally entitled to make formal decisions on their behalf. Once a patient’s decision-making ability is lost, the Guardianship and Management of Property Tribunal will appoint a guardian and/or manager. The person a patient appoints under enduring power of attorney must complete the section of the form to show that they understand and accept their responsibilities.

The legal framework that supports the recording of an Advance Care Plan include:

- **Enduring Power if Attorney (EPA) (Powers of Attorney Act 2006)**
- **Guardianship and Management of Property Act 1991**
- **Medical Treatment (Health Directions) Act 2006**

**When a person enters an aged care facility they should be offered the following advice.**

- **If they have capacity:**
  - Given information about various options available to make an Advance Care Plan
  - Provided information on how to appoint an alternative decision maker via the Powers of Attorney Act 2006 for matters pertaining to financial, personal matters and/or medical decisions.

An Advance Care Plan negates the need for any informal notes in the person’s medical records.

If the person who makes the Advance Care Plan loses capacity, it gives direction to those providing care about end of life decisions as a guide. Mentally competent people wanting to make their wishes known about end of life decisions, who don’t want or don’t have someone to appoint on their behalf, may still complete an Advance Care Plan or can complete a Health Direction under the Medical Treatment (Health Directions) Act 2006, section 21 for section 7.

- **If they do not have capacity:**
  - Advise that if advance directives are not in place, where possible, informal arrangements will be used to make decisions. However, if this is not possible for reasons such as conflict or dispute the Guardianship Board may be required to appoint a guardian or administrator to make necessary decisions.

**Where does a good Palliative Care Plan fit in?**

A good Palliative Care plan has been designed to allow a medical officer, in conjunction with the family, to instruct those providing care to a dying person. It is not a legally binding document but rather the evidence of a discussion having taken place between the family and the treating professionals. It is no substitute for a legally binding Advance Directive. It is often used when a person longer has mental capacity and is in the terminal phase of a terminal illness.

For more information contact the Office of the Public Advocate of the ACT – Phone (02) 6207 0707 or Fax (02) 6207 0688.

Reference site: [www.respectingpatientchoices.org.au](http://www.respectingpatientchoices.org.au)

It is recommended that these documents be kept in the front of the older person’s medical records to ensure quick access and communication by all staff.
End of Life Care

Prognosis

While it may be difficult to give a clear time frame for approaching death, some indication may help the patient and family prepare and this should be clearly communicated to family and carers.

The aim of care is one of comfort so:
- Cease all non-appropriate medications
- Food and fluid only if requested by patient
- Attend to bowel, bladder, mouth care
- Provide family support and information

Treatment of choice is benzodiazepines, e.g.
- *Midazolam*: 2.5 to 5mg sci q4h prn or syringe driver 10 to 30mg over 24 hours
- *Clonazepam*: 0.5-1mg sl/sci q4h prn or syringe driver 1-2mg over 24 hours

If not settling seek Palliative Care Specialist advice.

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<thead>
<tr>
<th>Signs of imminent death (days/weeks)</th>
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<tbody>
<tr>
<td>Decreased interest in food and fluid</td>
</tr>
<tr>
<td>Increasing weakness</td>
</tr>
<tr>
<td>Difficulty swallowing</td>
</tr>
<tr>
<td>Increased confusion</td>
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</tbody>
</table>

<table>
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<th>Signs of imminent death (days/hours)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bed bound</td>
</tr>
<tr>
<td>Increasing confusion</td>
</tr>
<tr>
<td>Inability to swallow</td>
</tr>
<tr>
<td>Changes in breathing, e.g. Cheyne-Stokes</td>
</tr>
<tr>
<td>Decreasing consciousness</td>
</tr>
<tr>
<td>Changes in circulation, e.g. peripheral cooling</td>
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<tr>
<td>Rattly respirations</td>
</tr>
</tbody>
</table>

**Terminal Restlessness**
- Characterised by increasing restlessness and agitation in last few days of life
- Is a sign of ‘failing’ brain with signs and symptoms of dying in hours/days and also marked by vocalisation and myoclonic jerks
Bereavement

Grief is a normal response to loss. Emotions and thoughts are often overwhelming.

Most people do not require professional counselling for bereavement but need the loving support of family and friends as they make this very big adjustment to their lives.

It may be appropriate for the bereaved person to connect with the aged care facility chaplain or contact one of the following bereavement services:

<table>
<thead>
<tr>
<th>Service</th>
<th>Description</th>
<th>Contact Number</th>
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<tbody>
<tr>
<td>Alzheimer’s ACT</td>
<td>support group and education for people bereaved by dementia</td>
<td>6255 0722</td>
</tr>
<tr>
<td>Carers ACT</td>
<td>grief and loss counselling, Seasons for Growth groups and education for carers</td>
<td>6296 9900</td>
</tr>
<tr>
<td>Clare Holland House</td>
<td>bereavement counselling for patients and families registered with the ACT Palliative Care Service</td>
<td>6273 0336</td>
</tr>
<tr>
<td>Lifeline</td>
<td>free, anonymous, confidential 24 hour phone counselling</td>
<td>13 11 14</td>
</tr>
<tr>
<td>National Association of Loss and Grief</td>
<td>offers support/counselling on most issues of loss and grief</td>
<td>6292 6847</td>
</tr>
<tr>
<td>Solace ACT</td>
<td>phone support and regular support group meetings for people whose partners have died</td>
<td>6297 1052</td>
</tr>
<tr>
<td>Winnunga Nimmityjah Aboriginal Health Counselling</td>
<td>support and counselling for social and emotional issues</td>
<td>6284 6222</td>
</tr>
</tbody>
</table>
References and Resources

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