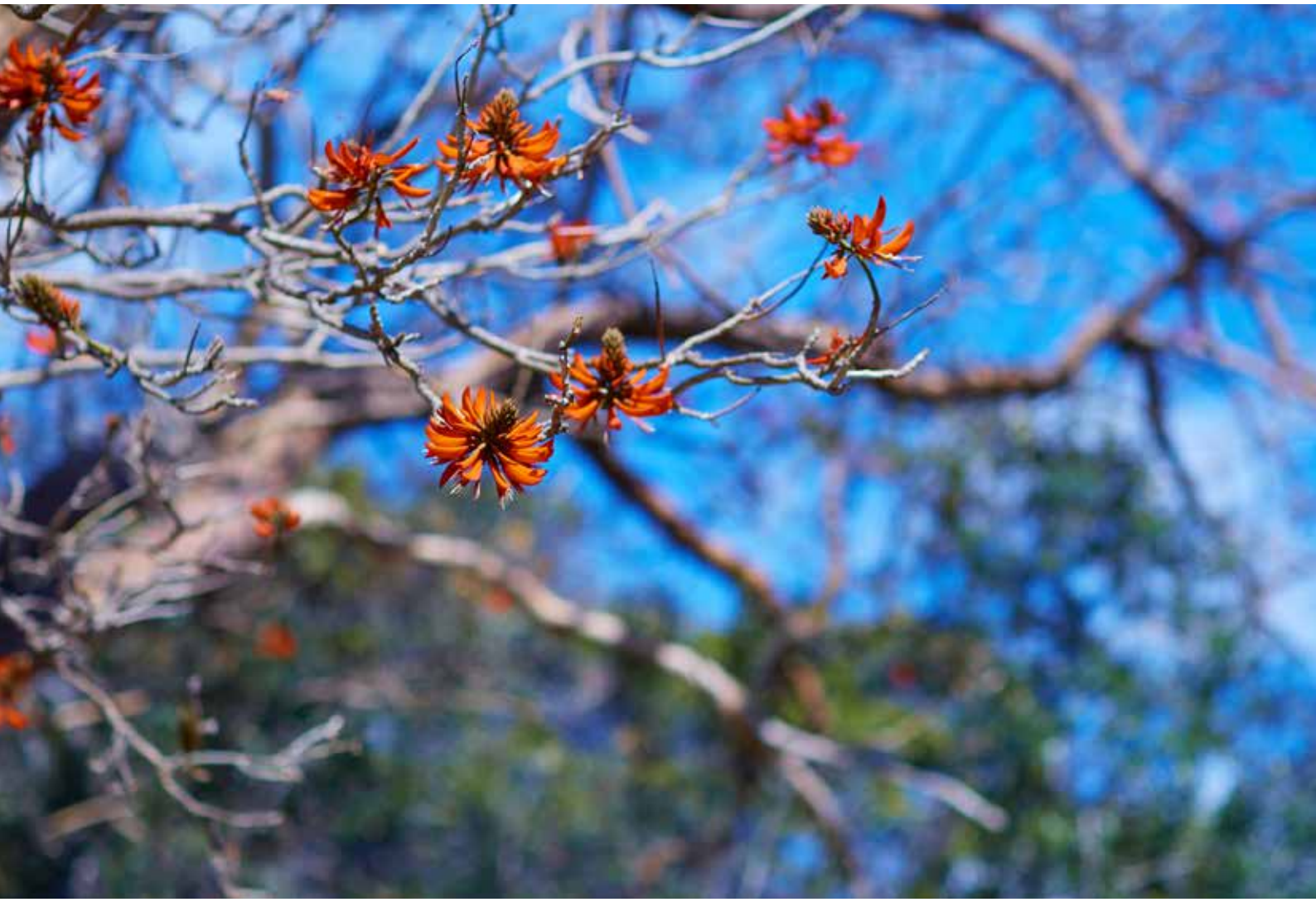
Assessment Tools

Palliative Care Bridge



Supporting living to the end

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Introduction

Caring for people near the end of life is a challenging aspect of clinical practice. One of the ways to ensure optimum care is offered is to ensure accurate and systematic assessment and planning. The needs of palliative care patients and their family caregivers are often complex. By using clinical tools that can enhance assessment and guide care across different settings, improved patient and family outcomes are likely to be achieved.

This booklet contains some of the many assessment tools available. It is not intended to be an exhaustive collection, merely a selection that may prove useful. For a more comprehensive set of assessments readers are recommended to go to the Palliative Care Outcomes Collaboration at http://ahsri.uow.edu.au/pcoc/about/index.html

The Palliative Care Outcomes Collaboration (PCOC) is a national program that utilises standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. Participation in PCOC is voluntary and can assist palliative care service providers to improve practice and meet the Palliative Care Australia (PCA) Standards for Providing Quality Palliative Care for all Australians. This is achieved via the PCOC dataset; a multi-purpose framework designed to:

- provide clinicians with an approach to systematically assess individual patient experiences,
- define a common clinical language to streamline communication between palliative care providers and
- facilitate the routine collection of national palliative care data to drive quality improvement through reporting and benchmarking.

Contained in this booklet is a selection of tools that may assist in practice.

Rod MacLeod
Sydney, 2014

Contents

Essentials for Assessment for Palliative Care patients

This programme is designed to enable a flexible and proactive package of care for Palliative Care Patients. Undertaking an accurate assessment of the patient's health needs is the first step.

Patients who might benefit from such assessments include:

- A patient who has been diagnosed with having a terminal illness for whom curative treatment is no longer an option
- A patient who will probably die within the next twelve months
- A patient who requires, or is likely to require, special care or services

The aim of these guides are to provide appropriate care for your patients

Palliative Care is an approach that improves the quality of life for patients and their families facing problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, emotional and spiritual as appropriate (WHO, 2002)

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively, and positively as possible
- Offers a support system to families during the patient's illness and their own bereavement
- Uses a team approach to address the needs of the patients and their families, including bereavement counselling
- Will enhance quality of life, and influence the course of the illness in a positive manner
- Is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

Other specific issues that should not be overlooked include:

- Pain control, other symptoms, psychological, social and spiritual problems
- Assessment and management of pain is the cornerstone of effective palliative care
- A full and accurate assessment is essential
- Many symptoms in palliative care may have more than one cause

Functional Ability Assessment

The intent of this assessment is to establish independence over dependence. All people fall on a continuum from independence to dependence. It is important to determine what appropriate interventions are required to sustain independence as far as possible.

The Barthel Index of Activities of Daily Living (ADLs)		
	Activity	**Score**
Feeding	0 = unable 5 = needs help cutting, spreading butter, etc., or requires modified diet 10 = independent	
Bathing	0 = dependent 5 = independent (or in shower)	
Grooming	0 = needs to help with personal care 5 = independent face/hair/teeth/shaving (implements provided)	
Dressing	0 = dependent 5 = needs help but can do about half unaided 10 = independent (including buttons, zips, laces, etc.)	
Bowels	0 = incontinent (or needs to be given enemas) 5 = occasional accident 10 = continent	
Bladder	0 = incontinent, or catheterised and unable to manage alone 5 = occasional accident 10 = continent	
Toilet Use	0 = dependent 5 = needs some help, but can do something alone 10 = independent (on and off, dressing, wiping)	
Transfers (bed to chair and back)	0 = unable, no sitting balance 5 = major help (one or two people, physical), can sit 10 = minor help (verbal or physical) 15 = independent	
Mobility (on level surfaces)	0 = immobile or < 45 metres 5 = wheelchair independent, including corners, >45m 10 = walks with help of one person (verbal or physical) > 45 m 15 = independent (but may use any aid; for example, stick) > 45 metres	
Stairs	0 = unable 5 = needs help (verbal, physical, carrying aid) 10 = independent	
	Total (0-100)	

A score of 100 indicates full independence, while a score of 0 would indicate complete dependence.

Mahoney FI, Barthel D. “Functional evaluation: the Barthel Index.” Maryland State Medical Journal 1965;14:56--61. Used with permission.

Functional Ability Assessment

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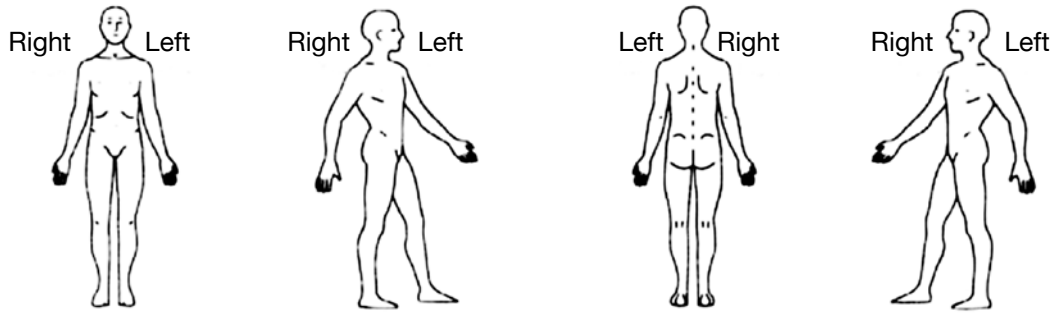
Lawton Instrumental Activities of Daily Living Scale (IADLs)	
Activity	**Score**
Can you prepare your own meals? Without help 2 With some help 1 Not at all 0	
Can you do your own housework or handyman work? Without help 2 With some help 1 Not at all 0	
Can you do your own laundry? Without help 2 With some help 1 Not at all 0	
Do you can you take prescribed drugs? Without help 2 With some help 1 Not at all 0	
Can you get to places beyond walking distances? Without help 2 With some help 1 Not at all 0	
Can you go shopping for groceries? Without help 2 With some help 1 Not at all 0	
Can you manage your own money? Without help 2 With some help 1 Not at all 0	
Can you use the telephone? Without help 2 With some help 1 Not at all 0	
Total	

Some questions may be sex specific and can be modified by the interviewer. The maximum score is 16 indicating complete independence), although scores have meaning only for a particular patient (e.g. declining score over time reveals deterioration). Lawton, M.P., and Brody, E.M. "Assessment of older people: Self-maintaining and instrumental activities of daily living." Gerontologist 9:179-186, (1969).

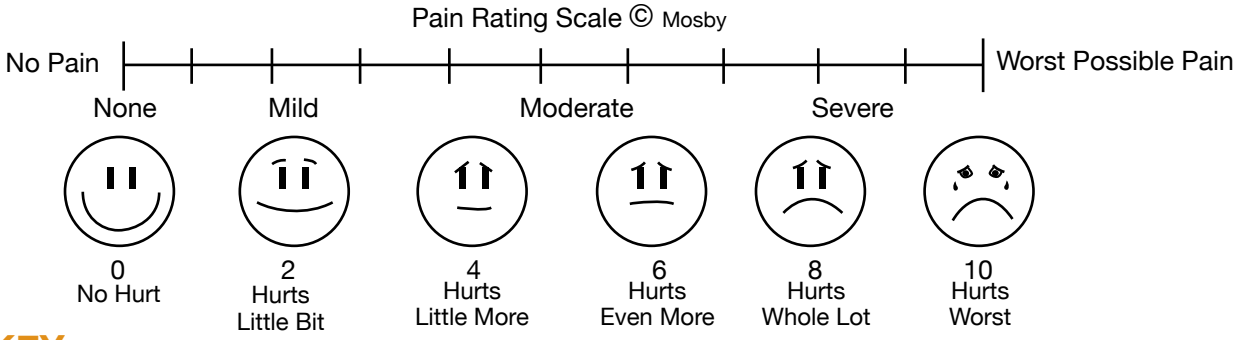
Pain Assessment

When assessing pain in a patient it is important to listen to the patient, as paying attention to the language used to describe pain will help with diagnosis. Type of pain can determine what drug should be used. Attention to detail is essential throughout the assessment.

Mark sites of pain on the diagram below



Use the pain scale below to complete the rest of this form Pain Scale



KEY

Pattern: Onset, duration, persistent, intermittent

Description: Burning, shooting, pins and needles, heavy, aching, throbbing, tender, sharp etc.

Type: Neuropathic, somatic, visceral or bone

Location: _____

Severity (0-10): _____

Pattern: _____

Description: _____

What makes it worse: _____

What makes it better: _____

Where does the pain go to (radiation): _____

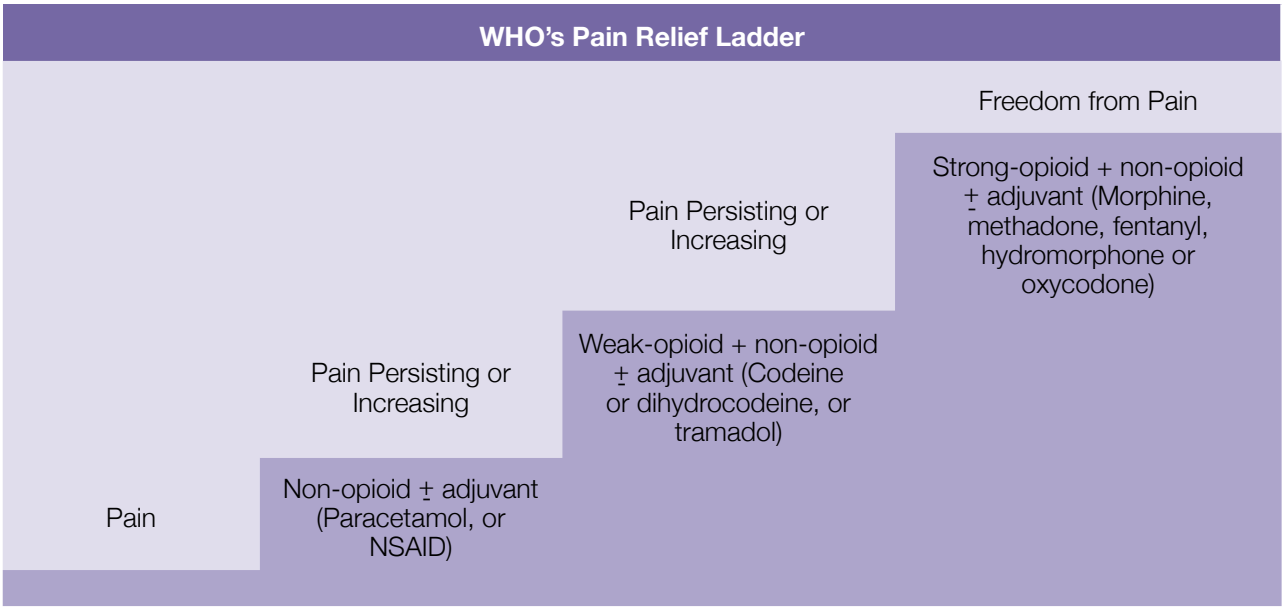
Type: _____

Significance of Pain (how does it affect the patient in terms of activities of daily living and quality of life etc?)

_____

_____

Pain Management



According to the WHO guidelines for management of pain, analgesics should be prescribed in a step-wise manner, commencing with a non-opioid analgesic, to a weak opioid when pain is not controlled, a strong opioid when pain has not been controlled by other methods. The WHO also recommends that pain relief medication be given according to the following framework.

- **By mouth – Oral administration of medication is an effective, convenient and inexpensive method of medicati**ng patients and should be used wherever possible. Medicines are easy to titrate using this route.
- **By the clock -** Medications for persistent pain should be administered around the clock, with additional doses as needed. This allows continuous pain relief by maintaining a constant level of drug in the body, and helps to prevent pain from recurring. The goal is to prevent rather than react to pain.
- **By the ladder –** The WHO ladder is a validated and effective method of ensuring therapy for pain. Medications should be administered according to the severity of the pain and drug suitability.
- **On an individual basis -** Individualise the pain management, different patients will require different dosages and/or intervention to achieve good pain relief.

Patients should be carefully monitored:

1. For any change in pain patterns, or the development of new pain.
2. To ensure adequate pain control.
3. To minimise or prevent side effects from their analgesia.

It is important to remember that both morphine and codeine commonly cause constipation, so the patient's diet may need to be altered to include more fibre/bulk. Laxatives should be prescribed and the patient should be encouraged to exercise if possible. Morphine and other opioids may initially cause nausea, vomiting, drowsiness and confusion. Most of these side effects diminish after a few days so it is important that they are managed effectively and discussed with the patient and family if necessary.

For further information on pain assessment and management please refer to **The Palliative Care Handbook** and **Palliative Care Therapeutic Guidelines**.

A brief summary of

Palliative Care Treatments

Pain & the WHO analgesic ladder:

- First-line: Paracetamol and NSAIDS
- Second-Line: Codeine or Dihydrocodeine
- Third-line: Morphine, Methadone, Fentanyl, Oxycodone and Hydromorphone are useful
- Start with Morphine Elixer: 2.5-5mg q2 – 4 hourly and titrate against pain reported on the 1-10 scale. After 2 -3 days add the total daily dose, divide it in two and administer as long-acting Morphine Sulphate tablets q12hourly.

Adjuvant pain treatments

- Somatic pain: NSAIDs and bisphosphonates, or radiotherapy for metastatic bone pain.
- Neuropathic pain: an anticonvulsant such as gabapentin, pregabalin or a tricyclic antidepressant such as nortriptyline (significant sedation)
- Visceral pain: corticosteroids are useful for hepatic capsular pain.

Other needs

- Nausea & vomiting: metoclopramide, phenothiazines, domperidone, ondansetron
- Constipation: docusate and senna, lactulose, movicol
- Anorexia: prednisone, dexamethasone
- Dry mouth/oral thrush; lemon and glycerine mouth rinses, antifungal oral gels, nystatin lozenges or drops
- Dehydration; if symptomatic give replacement fluids orally, IV or SC but be careful to avoid fluid overload.
- Diarrhoea: loperamide is useful.
- Dyspnoea & pleural effusion: posturing, oxygen, initial thoracocentesis and consider an intercostal drain (+/- a flutter valve to assist mobility).
- Partial bowel obstruction: restrict oral fluids. Try dexamethasone and metoclopramide. Use naso-gastric intubation as a last resort.
- Ascites: spironolactone, frusemide, paracentesis.
- Cerebral oedema: dexamethasone.
- Malignant fungations: normal saline and hydrogen peroxide soaks.
- Anxiety & depression – be there, be sensitive, consider a tricyclic or an SSRI and consider a benzodiazepine – sublingual lorazepam is useful.
- Hypercalcaemia: hydration helps in most cases. Consider biphosphonates.

For other drugs you may wish to consider within these groups refer to The Palliative Care Handbook, MacLeod et al, 7th Edition, 2014

All page number references refer to The Palliative Care Handbook.

System	Symptoms / Issues	Examples of Possible Problems	Possible Intervention
Pain (refer pg 8-14) (refer pain assessment, pain management neuropathic pain sections)	Use pain assessment tool to identify • Site, severity, nature • What relieves/ exacerbates pain • Significance to patient	• Inability to rest and sleep • Limitation to quality of life • Anxiety and depression	• Complete pain assessment form • Further investigation only if result will influence ongoing management eg x-ray, CT, MRI • Management is multidisciplinary ■ Drugs ■ Behaviour modification ■ Complementary therapies
Mouth (refer pg 21-22) (refer mouth care section)	• Does the patient have dry mouth / coated tongue? • Does the patient have mouth pain?	• Poor oral hygiene • Poor mental state (determines willingness and ability to participate in their care) • Nutritional status (low haemoglobin increases susceptibility to infection)	• Daily oral assessment • Mouthwashes • Frequency of care dependent on condition of patient • Well balanced diet and fluid intake if possible
Throat (refer pg 23-24)	• Swallowing difficulties	• Unable to manage oral medications	• Prescribe medication in capsule form if possible (as easier to swallow using “leaning forward technique’)
Cardiovascular and respiratory (refer pg 36-41)	**Dyspnoea** (breathlessness) • What does this feel like for the patient? (sensation) • How is this symptom viewed in the context of the illness (perception) • Does it cause grief or anxiety? (distress) • How does the patient react to this symptom? (response) • What language is used to relay the above elements? (reporting)	1) Impaired performance – airway obstruction, decreased lung volume, increased lung stiffness, decreased gas exchange, pain, neuromuscular failure, left ventricle failure 2) Increased ventilator demand	• Treat identified causes • Address anxiety and fear • Positioning, breathing control, teaching coping strategies • Drainage of effusions / ascites • Blood transfusion (if anaemic and appropriate) • Bronchial stents, brachytherapy? • Complementary therapy • Physiotherapy • Drugs
	Cough • Defensive mechanism, often associated with dyspnoea, wheezing or chest tightness • Can have a detrimental effect on quality of life if persistent	• Acute respiratory infection • Airways disease • Malignant obstruction • Oesophageal reflux • Salivary aspiration • Cardiovascular causes • Pulmonary oedema • Drugs	• Steam inhalations • Nebulised saline • Bronchodilators • Physiotherapy • Drugs

All page number references refer to The Palliative Care Handbook.

System	Symptoms / Issues	Examples of Possible Problems	Possible Intervention
Cardiovascular and respiratory (refer pg 36-41)	**Hiccup** • Pathological respiratory reflex • Can be very distressing if prolonged • Treat with urgency	• Gastric distension • Diaphragmatic irritation • Phrenic nerve irritation • Uraemia • Neurological disease affecting the medulla • Remove any correctable cause	• Sip cold water • Breath holding, re-breathing with paper bag (elevates pCO2) • Drug treatment
	Excessive retained secretions • Usually more distressing for family than patient	• Caused by buildup of respiratory secretions that patient is too weak to clear (causes death rattle)	• Positioning to allow postural drainage • Drugs • Suction (rarely, and avoid if possible)
	Haemoptysis • Often frightening symptom for patient and family	• Cause is not always possible to identify	• Reassurance if minor • If persistent or major, drug treatment and/or radiotherapy • If massive, drug treatment to reduce patient's awareness, fear and anxiety. Stay with patient
Gastrointestinal tract (refer pg 15-16)	**Nutrition and hydration** • Has there been any weight change? • Amount in kg (rapid/ gradual) • Can they chew/ swallow effectively? • Is there any blood or nutrient deficiencies?	• Underlying disease • Access to adequate suitable food • Increased risk of infection with anaemia	• Involve nutritionist, community dietician, meals on wheels, community support • Does food need to be mashed or modified for ingestion? • What foods do they like? • Small frequent meals • Consider nutritional supplements and/or blood transfusion • Consider stopping eating
	Nausea and vomiting • It is important to separate these and consider how each affects the patient, as some patients will find a vomit a day (with no nausea) more acceptable than continuous low level nausea.	• Higher centre stimulation – fear/anxiety • Direct vomiting centre stimulation – raised intracranial pressure, radiotherapy • Vagal and sympathetic afferent stimulation – cough, bronchial secretions, intestinal obstructions etc. • Chemoreceptor trigger zone stimulation – uraemia, hypercalcaemia, drugs e.g. morphine, cytotoxics • Vestibular nerve stimulation - motion	• If due to emotional stimulation primary intervention should involve counselling, explanation and listening • If due to coughing, constipation or bronchial secretions see protocols listed • If due to other causes treat with appropriate medications (refer page 16)

All page number references refer to The Palliative Care Handbook.

System	Symptoms / Issues	Examples of Possible Problems	Possible Intervention
Bowels (refer pg 17-20)	**Constipation** • Frequency of normal bowel movement? • Any changes? • Pain?	• Underlying disease, depression or dehydration • Inability to obey the call to stool • Concurrent medical problems • Pain, intestinal obstruction • Neurological, metabolic disturbances	• Drugs • Debility • Diet, dehydration • Prevention is key • Encourage exercise if possible, increase fibre and fluids in diet • Identify cause and remove if possible • Prescribe laxatives prophylactically when opioids are prescribed (refer pg 18 for further drug management)
	Diarrhoea • Relatively uncommon in palliative care	• Faecal impaction, colo-rectal carcinoma, neurological causes, gastrointestinal obstruction, malabsorption/food intolerance, radio or chemotherapy, antibiotics, inflammation of the bowel, anxiety	• Identify cause and treat if possible • Maintain skin integrity around anal area • Restrict oral intake to rest bowel • Withhold laxatives • Anti-diarrhoeal medications
	Intestinal obstruction • Considerable variation in patient symptom (and therefore management of symptoms)	• Can be mechanical or paralytic • Blockage of intestine • Frequently multi-factorial and can occur at multiple sites • May be aggravated by drugs • Radiation fibrosis • Autonomic nerve disruption by tumour	• Explanation and dietary advice (minimal residue) to patient and family • Minimise colic, pain and vomiting with drug management • Consider alternatives – surgery, radiotherapy, steroids • Avoid IV fluids and nasogastric tubes if possible
Neurological/ CNS (refer pg 27-28)	**Delirium** • Toxic confusional states are common • If irreversible may be an indication of impending death • Abrupt onset • Impairment of consciousness • Fluctuating symptoms • Underlying medical conditions • Predisposing factors include: dementia and CNS immaturity • Aggravating/ precipitating factors include: pain, fatigue, urinary retention, constipation, change of environment, unfamiliar excessive stimuli	• Often multiple organic causes • Infection • Organ failure • Drugs • Metabolic disturbance • Hypoxia • Anaemia • Cerebral metastases or haemorrhage • Post-ictal (epilepsy)	• Treat underlying organic cause • Relieve any obvious physical symptoms • Ensure there is a safe and secure environment for the patient • Prevent sensory stimulation • Psychological interventions • Drugs – if symptoms are severe

All page number references refer to The Palliative Care Handbook.

System	Symptoms / Issues	Examples of Possible Problems	Possible Intervention
Disorders of sleep and wakefulness (refer pg 29-30)	**Insomnia** • Undermines coping strategies through residual tiredness • Common and distressing	• Poor symptom control • Environmental changes • Fear of going to sleep and dying • Drugs • Drug withdrawal	• Improve symptom control • Re-establish good sleep habits • Use relaxation techniques • Consider drug management
	Drowsiness/ hypersomnia • Common, particularly as the end of life approaches	• Organ failure • Hypoactive delirium • Metabolic disturbances • Fatigue • Infection • Raised intracranial pressure • Drugs	• Accurate assessment, treat and remove causes if possible
	Sleep Phase Disorder • Deregulation of sleep-wake cycle with profound initial insomnia and an inability to arise at desirable hours • Particularly associated with cerebral tumours	• Major burden for carers	• Sedatives are of limited help • Neuroleptics/melatonin may help • Relief care for family/night nurse
Skin (refer pg 42-45)	**Itch** • Can be as unpleasant and disruptive as pain • Can have an adverse effect on quality of life • Accurate assessment of onset and nature of itching will help	• Hepatic/renal disease • Drug allergy • Drugs • Endocrine disease • Iron deficiency • Lymphoma • Rough clothing • Parasites	• Treat/remove causes • Attempt to break itch/scratch cycle – clip nails,cotton gloves, paste bandages • Apply surface cooling agents with emollients • Avoid washing with soap – use soap substitute or oil • Light therapy may help • Drugs (as listed pg 42) • Referral to skin specialist if no alleviation
	Pressure area care • Assess using risk factor scale provided (daily for high risk, weekly for low risk) (refer pressure sore risk section)	• Decrease in mobility and sensation • Pain/infection at site • Positioning of patient more difficult	• Use pressure relieving aids • Appropriate dressings and movement aids • Check nutritional state • Inform carer of management • Turn patient 2-4 hourly • Protect vulnerable skin
	Sweating • Unpleasant and debilitating symptom affecting patient and (indirectly) carers • Can indicate physical psychological and/or environmental disturbance	• Environmental temperature changes • Emotion • Lymphoma • Hepatic metastases and carcinoid • Intense pain relating to anxiety, fear or infection • Drugs	• Treat/remove causes • Drug therapy (as listed pg 43)

All page number references refer to The Palliative Care Handbook.

System	Symptoms / Issues	Examples of Possible Problems	Possible Intervention
Skin (refer pg 42-45)	**Lymphoedema** • Cannot be cured, aim is to achieve maximum improvement and long term control	• Discomfort and pain • Change in sensation/ mobility of limbs • Risk of infection	• Early referral to trained professional produces the best results • Patient education • Infections must be cleared before treatment starts • Regular measurement of normal and affected limbs • Use containment hosiery/ compression bandaging, exercise and massage if possible
	Fungating wounds and tumours • Causes major distress to patient and family, as it is an obvious manifestation of the disease	• Distortion of body image • Sense of social isolation • Management of dressings and odour	• Primary concern is patient comfort and reduction in distortion of body image • Ensure area is clean and help reduce smell and exudates
Use of stimulants	• Does the patient smoke? • Does the patient consume alcohol? • Does the patient use other stimulants?	• Is their use of stimulants adversely affecting their medical condition(s)?	• Discuss effects with patient; do they have a problem that needs further help? • Medication review

Socio-Environmental Health Assessment (prompt only)

	Symptoms / Issues	Possible Problems	Possible Interventions
Living arrangements	• Lives alone • Lives with spouse • Lives with family • Lives with friend/other • Transport available to patient? • Does the patient live up a lot of steps?	• Isolation, unable to get places	• Liaise with family, access community support services if necessary
Primary caregiver	• Name _____ • What support is in place for them?	• Carer not able to cope/not able to provide adequate care all of the time	• Can more support be provided by community support services?
Family structure / support	• Partner _____ • Children _____ • Neighbours_____ • Friends _____ • Extended family_____ • Pets _____	• Isolation, infrequent contact	• Liaise with family, do they need more support?
Community Support • Home Help • Meals on Wheels • Personal Care • District Nurse • Occupational Therapist • Physiotherapist • Other • Religious Groups • Cultural Groups • Hospice/Palliative Care Program Referral?	Frequency Provider (contact details) _____ _____ _____ _____ _____ _____ _____ _____ _____ _____ _____ _____	• Are these services being utilised appropriately? • Does the patient/ carer have knowledge of what is available and how it may assist them?	• Referral to Community Health Services co-ordinator for assessment or reassessment of needs • Other agencies that might provide support include: ■ Cancer society ■ Carers society ■ Support groups related to specific condition

Socio-Environmental Health Assessment (prompt only)

	Symptoms / Issues	Possible Problems	Possible Interventions
Impressions of living environment and accessibility	• Is it safe for patient and carer? o Cluttered/loose rugs etc. • Is the environment clean and tidy? • Can the patient easily access: ■ Toilet ■ Shower ■ Bed ■ Stairs ■ Outside steps • Is electrical equipment safe? • Is the home appropriately heated? • Do they have access to emergency assistance? • Are they interested in information about a personal "Safe Alarm"? • Are their pets cared for and safe for the patient?	• Is environment increasing risk of falls, or other accidents? • Patient and/or carer may need assistance accessing shower or stairs etc	• Referral to physiotherapy or occupational therapist • Referral to other support agencies
Financial management	• Does the patient need assistance with financial affairs?		• Patient may be eligible for disability support pension, refer to centrelink • Budget advice services listed in local phone directory
Employment/ education support	• Does the patient want to continue with employment or education?	• May need extra support to continue to do this	• Involve social worker to liaise with family / community, employer or education provider to assess practicality
Cultural beliefs	• Do these affect the care given to the patient? • Is the patient satisfied with the cultural support they receive? • How do these impact on the patient's attitude to death and dying?		• Ensure contact with appropriate groups that could provide support
Religious beliefs/ spiritual values	• Do these affect the care given to the patient? • Is the patient satisfied with the spiritual/religious support they receive?	• Is there existential distress? • Are they at peace? • What gives their life meaning?	• Ensure contact with appropriate groups that could provide support

Socio-Environmental Health Assessment (prompt only)

	Symptoms / Issues	Possible Problems	Possible Interventions
Emotional wellbeing	• Does the patient have a history of emotional / psychological disturbance? • Has this been well managed? • Have they withdrawn from activities of social interaction / interest? • Mood and affect at present • How does the patient feel about their health?	• Patient could be socially isolated, suffering from depression or other mental illness	• What support systems can the patient utilise? ■ Friends, family ■ Spiritual, cultural ■ Counsellor • Prescribe medication with caution • Refer for further psychological assessment/treatment if required
Sexual intimacy and satisfaction*	• Does the patient feel they have the opportunity to express passion/affection / loyalty both physically and emotionally?	• Isolation and loneliness • Inability to express desires and emotions	• Counsel as necessary • Facilitate privacy for patient, and those close to them
Anxiety and fear (refer pg 32-33)	• Is the patient excessively uneasy and/ or afraid? • Anxiety and fear is often caused by: ■ Separation ■ Becoming dependent ■ Losing control physically ■ Failing to complete life tasks ■ Uncontrolled pain ■ Not knowing how death will occur ■ Spiritual issues	• These emotions are common in people faced with a life threatening illness • Anxiety may be a normal alerting response or a symptom of a medical condition, an adverse effect of drugs, a symptom of an impending medical catastrophe or a learned phobic reaction	• Support to maintain independence autonomy and confidence • Honest and open discussion about the future • Avoid boredom and excessive self-reflection and distraction • Use desensitisation techniques for phobias • Focused spiritual care (if wanted) • Psychotropic drugs may be useful
Depression (refer pg 25)	• Is the patient feeling depressed? (Refer differential diagnosis pg 26)	• It is important to distinguish between depression and profound sadness • Some risk factors for depression include: inadequate symptom control, poor quality of life, older age and immobility • Many usual physical symptoms of depression may already be present in malignant disease, so are not necessarily diagnostic	• **Mild to moderate depression** - support, empathy, explanation, cognitive therapy, symptomatic relief • **Severe depression** – supportive psychotherapy plus drug therapy

* This is important and is a subject that needs to be handled with dignity and skill. It does need to be included in a general assessment.

Socio-Environmental Health Assessment (prompt only)

	Symptoms / Issues	Possible Problems	Possible Interventions
Terminal restlessness (refer pg 31)	• Is patient suffering from discomfort? • Is patient suffering from delirium? • Does the patient feel they need to resolve unfinished business? • Are they feeling helpless or hopeless?	• Terminal restlessness often indicates physical, psychological or spiritual discomfort • Often seen as "pre-death" event • Could also be caused by drug side effects	• Multidisciplinary approach • Accurate assessment of possible causes – treat/ remove if possible • Have family present for reassurance and support • Listen to and discuss anger, fear and guilt • Drug therapy
Distress at end of life	• Is the patient suffering from: ■ Uncontrolled delirium ■ Severe breathlessness? ■ Neurogenic or cardiogenic pulmonary oedema? ■ Massive haemorrhage?	• Terminal sedation may be considered when all other symptom relieving measures have failed and the patient is clearly distressed	• Sedation should be titrated to manage level of distress • Sedation of this type may be subject to the principle of "double effect" – which has the dual effects of intentional relief of suffering and increased risk of hastening death
Anticipatory grief/ bereavement	• Is the patient and/or family feeling grief at losses caused by the illness? (eg intimacy, independence, money) • Are the patient and/or family feeling angry, sad, depressed, isolated or abandoned?	• Anticipatory grief is a normal process in which past, present and future losses begin to be mourned • This process can help provide time to absorb the reality of the loss and to complete unfinished business	• Allow family and patient to discuss their feelings openly and honestly • Provide patient and family adequate information about the illness, support and means to maintain control over their lives and the journey towards death • Family and close friends can be a good source of support, if not available refer to support groups. A mental health professional may be of considerable value
Attitudes to death and dying	• Does the patient have any wishes relating to resuscitation, as their illness progresses? • Is there an advance care directive?	• Family and patient not aware of each other's feelings	• Intimate discussion • Document wishes • Develop clear management plan in event of emergency

Mouth Care

Category	Four Phases of Oral Status			
	Healthy phase	Early warning (mild dysfunction)	Problem Present (moderate dysfunction)	Serious problem (severe dysfunction)
Lips	Smooth, pink, moist and comfortable	Dry or wrinkled	Dry, cracked and uncomfortable	Dry, cracked, painful with ulcerated areas and bleeding
Tongue	Pink, moist and comfortable	Dry with prominent papillae	Dry and swollen, white coating at base, sore, inflammatory lines of demarkation	Dry with thick coating and blisters, painful, red and demarcation
Mucosa	Pink, moist , intact and comfortable	Pale and dry, with uncomfortable red areas	Dry, inflamed, blistered and sore	Red and shiny with blisters, ulcers and pain
Gingiva	Pink and smooth	Localised redness	Localised redness, oedema or bleeding	Generalised redness, oedema and/or bleeding
Saliva	Adequate	Decreased	Scant, with taste alteration	Thick or absent
Teeth and dentures	Clean, without debris and comfortable Patient able to wear dentures	Dull, with localised areas of debris	Dull, debris on half of the enamel, areas of irritation, intermittent pain	Dull, with debris generalised along gum line or denture area. Patient unable to wear dentures. Frequent dental pain

Principles of Oral Hygiene

- Regular mouth care is essential, the object being to achieve a clean, moist, pain free, non-infected mouth
- Oral assessment can identify sites of infection and chronic irritations, which is important as oral dysfunction can significantly affect the patient's quality of life
- Frequent mechanical cleansing if the mouth is important

Risk Factors for Poor Oral Hygiene

- **Debility**
- **Reduced oral intake**
- **Unable to brush teeth**
- **Chemotherapy**
- **Radiotherapy**
- **Mouth breathing**
- **Saliva-reducing drugs**
- **Dehydration**
- **Oxygen therapy**

Prevention is a Priority

To establish a healthy mouth regimen the following are recommended:

- Regular tooth and denture brushing, twice daily
- Regular use of anti-bacterial and anti-fungal mouthwash
- Check fit of dentures, remember nightly soak
- Regular dental checks
- Regular mouth care: frequency dictated following assessment e.g. for general care treat 6-12 hourly, for at risk patients treat 2 hourly, for high risk patients or for serious problems treat hourly

Possible Problems and Solutions

Dry mouth

- Frequent sips or sprays of water, frequent mouth care, Vaseline on lips, iced drinks, ice cubes
- Salivary stimulants eg citrus juices – lime, fresh melon and pineapple as saliva substitutes
- Chewing gum helps some patients
- Pilocarpine 1mg/1ml, 5ml rinse 8 hourly helps some patients

Dirty Mouth

- Remove dentures if used; clean frequently. Soaking in "Miltons" overnight will ensure no infection is returned to mouth after cleaning
- If have own teeth regular brushing is important
- Alternatively clean mouth with swabs or gauze over gloved finger

o Sodium bicarbonate is effective but unpleasant and does not remove thick tongue coating

o Hydrogen peroxide is effective but will not penetrate thick tongue coating and can cause mucosal damage

o Glycerine thymol useful and refreshing but effect is transient and not bacteriostatic

Painful mouth

- Benzydamine (Difflam) spray or mouthwash for analgesia
- Choline salicylate (Bonjela)
- Benzocaine lozenges – 100mgs sucked as required
- Lidocaine spray

Oral thrush (candidiasis)

- Miconazole gel useful
- Ketoconzole (200mgs once daily for 5 days)
- Fluconazole (150mgs as single dose)
- Nystatin suspension (2mls 6 hourly for at least 10 days) useful but may take up to 2 weeks to clear infection (last resort)

Ulceration and infection

- Viral infections: Acyclovir 200 mgs 4 hourly for 1 week (400mgs if immunosuppressed)
- Apthous ulcers: topical corticosteroid (triamcinolone in oral base or betamethasone tablets) or tetracycline suspension mouthwash (disperse 250mg capsule in water and rinse in mouth for 2 minutes then swallow 6 hourly)
- Systemic antifungals are sometimes needed for intractable infections
- Malignant ulcers: if anaerobic infection present (foul smell) use systemic metronidazole 500 mgs PO 12 hourly or 1gm PR or use topical gel if not tolerated systemically (topical is expensive)

Braden Scale for Predicting Pressure Sore Risk

Patient's Name _____ Evaluator's Name_____ Date of Assessment

SENSORY PERCEPTION ability to respond meaningfully to pressure-related discomfort	**1. Completely Limited** Unresponsive (does not moan, flinch, or grasp) to painful stimuli, due to diminished level of consciousness or sedation. OR limited ability to feel pain over most of body	**2. Very Limited** Responds only to painful stimuli. Cannot communicate discomfort except by moaning or restlessness OR has a sensory impairment which limits the ability to feel pain or discomfort over 2 of body.	**3. Slightly Limited** Responds to verbal commands, but cannot always communicate discomfort or the need to be turned. OR has some sensory impairment which limits ability to feel pain or discomfort in 1 or 2 extremities.	**4. No Impairment** Responds to verbal commands. Has no sensory deficit which would limit ability to feel or voice pain or discomfort.				
MOISTURE degree to which skin is exposed to moisture	**1. Constantly Moist** Skin is kept moist almost constantly by perspiration, urine, etc. Dampness is detected every time patient is moved or turned.	**2. Very Moist** Skin is often, but not always moist. Linen must be changed at least once a shift.	**3. Occasionally Moist:** Skin is occasionally moist, requiring an extra linen change approximately once a day.	**4. Rarely Moist** Skin is usually dry, linen only requires changing at routine intervals.				
ACTIVITY degree of physical activity	**1. Bedfast** Confined to bed.	**2. Chairfast** Ability to walk severely limited or non-existent. Cannot bear own weight and/or must be assisted into chair or wheelchair.	**3. Walks Occasionally** Walks occasionally during day, but for very short distances, with or without assistance. Spends majority of each shift in bed or chair	**4. Walks Frequently** Walks outside room at least twice a day and inside room at least once every two hours during waking hours				
MOBILITY ability to change and control body position	**1. Completely Immobile** Does not make even slight changes in body or extremity position without assistance	**2. Very Limited** Makes occasional slight changes in body or extremity position but unable to make frequent or significant changes independently.	**3. Slightly Limited** Makes frequent though slight changes in body or extremity position ndependently.	**4. No Limitation** Makes major and frequent changes in position without assistance.				
NUTRITION usual food intake pattern	**1. Very Poor** Never eats a complete meal. Rarely eats more than a of any food offered. Eats 2 servings or less of protein (meat or dairy products) per day. Takes fluids poorly. Does not take a liquid dietary supplement OR is NPO and/or maintained on clear liquids or IV=s for more than 5 days.	**2. Probably Inadequate** Rarely eats a complete meal and generally eats only about 2 of any food offered. Protein intake includes only 3 servings of meat or dairy products per day. Occasionally will take a dietary supplement. OR receives less than optimum amount of liquid diet or tube feeding	**3. Adequate** Eats over half of most meals. Eats a total of 4 servings of protein (meat, dairy products) per day. Occasionally will refuse a meal, but will usually take a supplement when offered OR is on a tube feeding or TPN regimen which probably meets most of nutritional needs	**4. Excellent** Eats most of every meal. Never refuses a meal. Usually eats a total of 4 or more servings of meat and dairy products. Occasionally eats between meals. Does not require supplementation.				
FRICTION & SHEAR	**1. Problem** Requires moderate to maximum assistance in moving. Complete lifting without sliding against sheets is impossible. Frequently slides down in bed or chair, requiring frequent repositioning with maximum assistance. Spasticity, contractures or agitation leads to almost constant friction	**2. Potential Problem** Moves feebly or requires minimum assistance. During a move skin probably slides to some extent against sheets, chair, restraints or other devices. Maintains relatively good position in chair or bed most of the time but occasionally slides down.	**3. No Apparent Problem** Moves in bed and in chair independently and has sufficient muscle strength to lift up completely during move. Maintains good position in bed or chair.					
				Total Score				

A Brief Guide to

Bereavement Care in General Practice

- For an experienced practitioner, bereavement care is mostly intuitive; however guidelines can help to avoid underrecognition of need arising from personal loss, and the risk attached to becoming isolated with grief. Guidelines can also address undue intervention in the natural process of grief.
- Employ active listening, empathy and validation of personal loss and felt grief. Seek clarification of felt grief as necessary, understand the context of loss and set realistic expectations for personal adjustment.
- Consider the concept of grief process: disbelief, anger, guilt and despair may occur in quick succession, however subsequent personal adjustment has great variance. Personal adjustment entails emotional relocation and some loss may never be fully reconciled.
- Make the distinction between normal and complicated grief, including major depression. Complicated grief is prolonged, pervasive and disabling. Withdrawal for reflection is normal, however isolation and loneliness can increase risk for deep despair and suicide. The personal context of loss offers the best guide to risk versus recovery

Suggested pro-activities

- Where possible, provide anticipatory care (prepare for loss)
- Scan death notices and record loss in the bereaved's notes
- Make a phone call to the bereaved person
- Offer information about the natural history of grief and about support services
- Stay in touch and be cautious with prescription of antidepressant and hypnotic medication
- Ensure follow-up about six weeks after bereavement
- If isolation raises concern, visit at home to assess risk and provide supportive care
- Recognise complicated grief and arrange for specialist attention as appropriate
- Remember that cultural differences may apply. In general it is helpful to ask people about their cultural requirements
- Recognise and acknowledge your own grief and that of your colleagues
- Consider after death review

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