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# Palliative Care Nurse Practitioner Symptom Assessment Guide



VICTORIAN PALLIATIVE CARE



NURSE  
PRACTITIONER  
COLLABORATIVE



THE UNIVERSITY OF  
MELBOURNE



ST VINCENT'S  
HOSPITAL  
MELBOURNE  
A FACILITY OF ST VINCENT'S HEALTH AUSTRALIA

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THE INSTITUTE FOR  
PALLIATIVE MEDICINE  
at San Diego Hospice

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## Disclaimer

The information contained in the Symptom Assessment Guide is intended to provide recommendations to Nurse Practitioners and candidates for assessing symptoms common to patients with advanced disease. The information within the guide should not be considered to be complete but will be complemented by the clinical experience and skill of the individual nurse.

To download a copy of the Symptom Assessment Guide please go to:  
[www.centreforallcare.org](http://www.centreforallcare.org)

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# Introduction

## Background and purpose

The aim of the Symptom Assessment Guide (SAG) is to provide recommendations to Australian Palliative Care Nurse Practitioners (NP) and Palliative Care Nurse Practitioner Candidates (NPc) on a succinct evidence based approach to assessing the most common symptoms experienced by patients with a life-limiting illness (including malignant and non malignant diseases). The SAG is intended to be complemented by the clinical skills and experience of the NP and NPc. Additionally, the SAG may be an appropriate resource for all palliative care nurses to extend and enhance their assessment skills.

Comprehensive symptom assessment (and management) are core skills for NP and NPc. The SAG is intended to be an essential component of the NP professional tool kit, and to be used in conjunction with other resources, assessment tools and treatment protocols including Therapeutic Guidelines<sup>1</sup>, The Clinical Competencies for Palliative Care Nurse Practitioners<sup>2</sup> and the NP's own service approved formulary.

## What is a Palliative Care Nurse Practitioner?

A palliative care nurse practitioner is a registered nurse educated and authorised to function autonomously and collaboratively in an advanced and extended clinical role in the specialty of palliative care. The nurse practitioner role includes assessment and management of patients using nursing knowledge and skills and may include but is not limited to the direct referral of patients to other health care professionals, prescribing medications and ordering diagnostic investigations. The nurse practitioner role is grounded in the nursing profession's values, knowledge, theories and practice and provides innovative and flexible health care delivery that complements other health care providers. The scope of practice of the nurse practitioner is determined by the context in which the nurse practitioner is authorised to practice<sup>3</sup>.

## What is a Palliative Care Nurse Practitioner Candidate?

A palliative care nurse practitioner candidate is a registered nurse engaged by a service/organisation as they work toward meeting the academic and clinical requirements for endorsement as a Nurse Practitioner (NP) in the specialty of palliative care. During the period of candidature, which can vary in length, the nurse consolidates his/her competence at the level of a nurse practitioner, learning the new role while engaging with mentors and other learning opportunities both within and outside the candidate's organisation. Mentorship in terms of medical and senior nursing support, management skills and clinical teaching are essential components for effective skill development of the nurse practitioner candidate<sup>4</sup>.

## Symptom Assessment Guide development process

The SAG has been adapted from IPM Pocket Guide for Palliative Care, developed by San Diego Hospice and The Institute of Palliative Medicine (IPM). The process for adaptation from the San Diego document to the development of the SAG has involved several factors including:

- ensuring language and terms are consistent with Australian context
- removing all references to specific medications to ensure the SAG can be relevant in all settings and allow for individual practices to be considered
- consultation and review by a palliative care NP and a palliative care physician throughout the adaptation process
- broader review process including NPs, key stakeholders, and the San Diego team.

## Using the SAG

Each symptom has been presented according to the following format:

- Definition
- Causes
- Important points
- Assessment
- Physical examination
- Diagnostic points.

There is a range of tools to assist with overall patient assessment (see Appendix 1, 2, 3, and 4) and tools individualised to specific symptoms. Suggested tools are referred to throughout the SAG as a guide only.

Prior to assessment of each symptom an overall patient assessment should be made to determine the palliative care phase of illness. This will be assessed as either stable, unstable, deteriorating or terminal (see Appendix 5). The phase will guide and inform practice as to the extent of assessment and the level of intervention required. A definition of the phases of illness is provided<sup>5</sup>:

- If the individual has been *stable* and an acute exacerbation of symptom issues occurs, a full and thorough assessment should be undertaken to determine any reversible causes. It would also be appropriate to initiate investigations (pathology and radiology) or referral to aid the diagnosis.
- If the individual has been *unstable* and an acute new problem or unexpected deterioration occurs, a full and thorough assessment should be undertaken to determine any reversible causes. It would also be appropriate to initiate investigations (pathology and radiology) or referral to aid the diagnosis.
- If the individual has been *deteriorating* in a predictable and expected way, the assessment may be modified and investigations limited.
- If the individual is in the *terminal phase* with evidence of well advanced disease and little possibility or expectation of recovery, it would be inappropriate to initiate a full assessment or investigations and the focus should be on the comfort of the patient.

## Key resources to complement the guide

- CareSearch: [www.caresearch.com.au](http://www.caresearch.com.au) is an online resource of palliative care information and evidence. All materials included in this website are reviewed for quality and relevance. The *Finding Evidence* pages are designed specifically for health professionals and are particularly useful. They identify the role, nature and sources of evidence and the application of evidence in practice.
- *Palliative Care Therapeutic Guidelines 2010*: This resource is produced by Therapeutic Guidelines Limited. This is an independent not-for-profit organisation dedicated to deriving guidelines for therapy from the latest world literature, interpreted and distilled by Australia's most eminent and respected experts. This is a useful guide to consult when considering treatment options for patients with a life-limiting illness with particular symptoms.

# Anorexia / Cachexia

## Definition

Anorexia is a lack or loss of appetite. Cachexia is a wasting syndrome characterised by a loss of muscle and fat directly caused by an aberrant response to many diseases in their end stages including HIV, dementia, cancer, and illnesses resulting in dysphagia. It includes a loss of lean tissue, a decline in performance status, fluctuations in resting energy expenditure, and loss of appetite.

## Causes

The anorexia/cachexia syndrome is multi-faceted. The association between contributing factors is not clearly understood. Chronic inflammation has been identified as a core mechanism. Lipolysis, muscle protein catabolism, increases in acute phase proteins (including C-reactive protein) and a rise in pro-inflammatory cytokines are associated with the syndrome.

Malignancies produce chemicals that contribute to cachexia in some patients. Some tumors also directly produce inflammatory cytokines. Raised basal metabolism, alterations in hormone production, eg. reduced testosterone levels are often observed. The interaction between chronic inflammation, tumor cachectic products, and other associated pathophysiologic features is unclear. Anorexia may be due to the effects of inflammatory cytokines on the hypothalamus with consequent changes in the balance of neuro-transmitters stimulating or inhibiting food intake.

## Important points

1. Calories alone cannot reverse cachexia.
2. Total Parenteral Nutrition (TPN)/enteral nutrition are incapable of reversing cachexia.
3. Exercise is an important treatment recommendation.
4. Effective treatment of cachexia will require a multipronged approach (appetite stimulation + anabolic agent + exercise prescription).
5. Do not wait until the patient has lost greater than 10% of pre illness weight to intervene.
6. Corticosteroids stimulate appetite but will cause proximal muscle wasting if treatment is prolonged.

## Assessment

### History

At initial patient contact record weight, appetite, and factors affecting food intake. Note variations in taste and smell, swallowing, and evidence of early satiety. Symptoms of early satiety may be linked to abnormalities in autonomic function such as tachycardia.

### Physical examination

Vital signs. Record weight. Examination of mouth for signs of mucositis. Check skin for pallor.

### Diagnostic tests (if consistent with goals of care)

Specific biochemical markers of the anorexia/ cachexia syndrome are not available, but less specific markers may be helpful. Patients usually exhibit low serum albumin and high C-reactive protein.

## References

- EPEC-O Jan. 2006.
- Blum D, Omlin A, Fearon K, Baracos V, Radbruch L, Kaasa S, Strasser F. (2010). European Palliative Care Research Collaborative. *Evolving classification systems for cancer cachexia: ready for clinical practice?*
- *Supportive Care Cancer*. 18(3):273-9.

# Anxiety

## Definition

Anxiety is defined as *'the apprehensive anticipation of future danger or misfortune accompanied by a feeling of dysphoria or somatic symptoms of tension. The focus of anticipated danger may be internal or external'* (<http://pallipedia.org/>).

A 'generalised anxiety disorder' is a state of excessive anxiety or worry lasting at least six months impacting day to day activities. High levels of concern and unremitting worry usually lead to some level of dysfunction.

A 'panic attack' is the sudden onset of intense terror, apprehension, fearfulness, or a feeling of impending doom, usually occurring with symptoms such as shortness of breath, palpitations, chest discomfort, a sense of choking and fear of 'going crazy' or losing control.

## Causes

Maladaptive or excessive response to stress primarily involving the neurotransmitters norepinephrine, serotonin, and gamma-aminobutyric acid (GABA). Anxiety can be associated with physical conditions such as hypoxia, hyperthyroidism, sepsis, poorly controlled pain and adverse medication reactions or withdrawal.

## Important points

1. Anxiety causes dysfunction in patients and those near them and undermines quality of life and quality of care.
2. Early detection and management is essential.
3. Assess openness to counselling.
4. Consider caffeine and alcohol use and sleep habits.
5. Agitation may be an indication of delirium.

## Assessment

### History

Detailed clinical interview with direct questions such as:

1. Do you find yourself worrying a lot?
2. Are you often fearful?
3. Do you feel anxious?
4. Have you ever experienced or been treated for anxiety in the past?

### What to look for

1. Insomnia
2. Reversible causes such as alcohol, caffeine, or adverse side effects of medications
3. Medical states such as infection, pulmonary embolism, uncontrolled pain, dyspnoea, and abnormal metabolic states

### Suggested assessment tools

- Hospital Anxiety and Depression Scale
- Distress Thermometer (Appendix 6)
- K10 (Appendix 7)

### Physical examination

Vital signs. Observe for signs of nervousness. Examine heart and lungs. Check thyroid if necessary.

### Diagnostic tests (if consistent with goals of care)

Consider Full Blood Examination (FBE), Thyroid Function, toxicology screen if underlying condition is suspected. Document rationale for tests.

## Reference

- EPEC-O, 2006.

# Bronchospasm

## Definition

Bronchospasm is difficulty breathing caused by a sudden constriction of the muscles in the walls of the bronchioles. It is caused by the release (degranulation) of substances from mast cells or basophils under the influence of anaphylatoxins.

## Causes

Opioids, morphine in particular, can cause histamine release. In those patients with respiratory dysfunction, the drugs can decrease the cough reflex, and the histamine release can lead to bronchial constriction. Common causes include asthma, chronic obstructive pulmonary disease, allergies, and infection (anything that causes an inflammatory process).

## Assessment

### History

On examination, bronchospasm is characterised by wheezing, rhonchi, and intercostal retraction. Constriction and inflammation causes a narrowing of the airways and an increase in the mucous production; this reduces the amount of oxygen that is available to the individual causing breathlessness, coughing and hypoxia (that can cause cyanosis).

## Physical examination

Vital signs. Observe respirations. Auscultation of the lungs.

## Diagnostic tests (if consistent with goals of care)

Pulmonary function tests provide an accurate measure of bronchospasm, but are typically impractical with palliative care patients. If bronchospasm is suspected in palliative care, a clinical trial of treatment may be indicated.

## References

- Education in Palliative and End-of-Life Care – Oncology (EPEC-O). Module 3j: Symptoms – Dyspnoea, 2007.
- Woodruff, Roger. *Palliative Medicine: Evidence-based symptomatic and supportive care for patients with advanced cancer*. Oxford, 2005.



# Constipation

## Definition

Stools that are decreased in frequency and may be difficult to evacuate.

Constipation is a symptom, not a diagnosis. In all cases the underlying cause must be sought, as many causes are correctable (<http://pallipedia.org/>).

## Causes

- Medications: opioids, calcium channel blockers, anticholinergic
- Decreased mobility
- Ileus
- Mechanical obstruction
- Metabolic abnormalities
- Spinal cord compression
- Dehydration
- Autonomic dysfunction
- Malignancy

## Important points

Goals of Care: It is important to assess burden to the patient vs. benefit from therapy. If the patient is actively dying (without any signs of discomfort), it may not be necessary to address the constipation.

Accurate documentation of all bowel actions on a bowel management chart is essential to informing the assessment process.

## Assessment

### History

Enquire about usual bowel history and recent changes.

Symptoms may include the following: abdominal distention/bloating, flatulence or absence of, less frequent bowel movements, oozing liquid stools, rectal fullness or pressure, rectal pain at bowel movement, small volume of stool.

### Physical examination

Physical Assessment to include abdomen. Determine abdominal contour from rib to pubic bone. Assess for bloating, distention, bulges, visible masses or asymmetric abdominal shape.

### 1. Auscultation

- Absent bowel sounds: listen for hyperactive or absent bowel sounds. If none are heard, continue to listen for five minutes before establishing the absence of bowel sounds.
- Hypoactive/increased bowel sounds: may indicate paralytic ileus, peritonitis, bowel obstruction, electrolyte imbalance (e.g. altered potassium).
- Hyperactive/increase bowel sounds: may indicate impending diarrhea or early bowel obstruction.

### 2. Percussion

- Assess general density of abdominal contents
- Tympany: indicates presence of gas in the colon
- Hyper resonance: presence of gaseous distention
- Dullness: heard over interstitial fluid, ascites and faeces

### 3. Palpation

- Light palpation can detect abdominal tenderness and muscular resistance associated with chronic constipation.
- Rebound tenderness may indicate peritoneal inflammation.
- Deep palpitation may be used to detect abdominal masses including faecal loading

### Diagnostic tests (if consistent with goals of care)

Dependent on physical findings and patients goals of care, but may include plain abdominal X-ray, CT scan and biochemistry.

Differential Diagnosis: bowel obstruction, ileus.

## Reference

- EPEC-O *Education in Palliative and End-of Life Care – Oncology*, Chicago, IL, 2007.

# Delirium

## Definition

- A disturbance of consciousness with reduced awareness of the environment and reduced ability to focus, sustain, or shift attention, and
- A change in cognition with memory deficits, disorientation, language disturbance, or the development of a perceptual disturbance that is not better accounted for by a pre-existing, established, or evolving dementia.
- In contrast to dementia which develops slowly, delirium develops over a short period of time, usually hours to days, and fluctuates during the course of the day.
- Delirium can have different clinical presentations or sub-types:
  1. 'Hyperactive' subtype is most often recognised due to its associated behavioural disturbances (agitation), and the frequent occurrence of psychotic symptoms such as hallucinations or delusional beliefs.
  2. 'Hypoactive' subtype, or quietly delirious patient, is often mistaken for depression or fatigue.
  3. 'Mixed' subtype with symptoms of both 'hyper' and 'hypo' active subtypes over the course of a day. See Tables 1 and 2 for causes of delirium.

## Important points

1. While delirium presents with psychiatric symptoms, it is important to remember that these symptoms are manifestations of medical abnormalities and not primary psychiatric illness.
2. Delirium is a common, yet under recognised and undertreated, medical condition. It has been reported in up to 80–85% of terminally ill patients.
3. Delirium is associated with an increased risk of complications, protracted hospitalisations, and postoperative recovery. Up to 25% of delirious patients die within six months.
4. Delirious elderly patients are at particular risk for complications such as pneumonia, skin ulceration and falls. In elderly patients, the risk of dying during a hospital admission increases to between 22–76%.

**Table 1. Frequent causes of delirium**

Infection	Encephalitis, meningitis, syphilis, HIV, sepsis, pneumonia, UTI
Withdrawal	Alcohol, barbiturates, sedative hypnotics, benzodiazepines
Acute metabolic	Acidosis, alkalosis, electrolyte disturbance, hypercalcaemia, hepatic failure, renal failure, CO <sub>2</sub> retention
Trauma	Closed head injury, heatstroke, postoperative, severe burns
CNS pathology	Abscess, hemorrhage, hydrocephalus, subdural hematoma, infection, seizures, stroke, tumours, metastases, vasculitis, encephalitis, meningitis
Hypoxia	Anemia, CO poisoning, hypotension, pulmonary or cardiac failure
Deficiencies	Vitamin B12, folate, niacin, thiamine
Endocrinopathies	Hyper/hypoadrenocorticism, hyper/hypoglycemia, myxedema, hyperparathyroidism, hypercalcaemia
Acute vascular	Hypertensive encephalopathy, stroke, arrhythmia, shock, dehydration, MI
Toxins or drugs	Medications, chemotherapeutics, illicit drugs, pesticides, solvents, alcohol
Heavy metals	Lead, Manganese, Mercury

**Table 2. Medications that can cause delirium**

Analgesics	Clonidine
Anesthetics	Corticosteroids
Antiasthmatics	Immunosuppressives
Anticholinergics, including medications with anticholinergic properties	Insulin
Anticonvulsants	Gastrointestinals: (Proton Pump Inhibitors PPI)
Antihistamines	Muscle relaxants
Antihypertensives	Phenytoin
Antimicrobials	Psychotropics, especially those with anticholinergic properties
Antiparkinsonian	Ranitidine
Cardiac glycosides (digoxin)	Salicylates
Cimetidine	Sedatives, benzodiazepines

## Differentiation

**Table 3. Differences between delirium and dementia**

	Delirium	Dementia
Change in alertness/ disturbance of consciousness	Yes	No
Temporal profile of symptoms: onset over hours to days	Usually develop quickly,	Gradual onset
Fluctuate over a 24-hour period	Yes	No

## Assessment

### History/physical examination/diagnostic tests

To assess for delirium, take a careful history, perform a physical examination, carefully observe the patient's ability to maintain attention over time, and order appropriate investigations. Tools that may be useful include NuDesc, CAM (Appendix 8).

**Table 4. Assessment of delirium**

Physical status	Mental status	Basic laboratory	Additional investigations
History Physical and neurological examination Review of vital signs O <sub>2</sub> saturation Review of medical records Review of medications and medication history	Interview Cognitive tests Clock face drawing Mini-mental state examination	Electrolytes Glucose Calcium Albumin Blood urea nitrogen Creatinine Magnesium Phosphate Full Blood Examination Urinalysis and culture Chest X-ray B12, folate TFT (Thyroid Function Test)	SGOT (serum glutamic oxaloacetic transaminase) Bilirubin Alkaline phosphatase VDRL (Venereal Disease Research Laboratory) Serum drug levels Arterial blood gas Urine drug screen ECG (Electrocardiogram) EEG (electroencephalogram) Lumbar puncture CT (Computerised Tomography) or MRI (Magnetic Resonance Imaging) brain Heavy metal screen Antinuclear antibody HIV (human immunodeficiency virus) testing

## References

- EPEC-O Jan. 2006.
- Gaudreau JD, Gagnon P, Harel F, Tremblay A, Roy MA. Fast, systematic, and continuous delirium assessment in hospitalised patients: the nursing delirium screening scale. *J Pain Symptom Management*. 2005 Apr; 29(4): 368–75.
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- Spiller JA, Keen JC. Hypoactive delirium: assessing the extent of the problem for inpatient specialist palliative care. *Palliat Med*. 2006 Jan; 20(1): 17–23.
- Steis MR, Fick DM. Are nurses recognising delirium? A systematic review. *J Gerontol Nurs*. 2008 Sep; 34(9): 40–8.
- Wong CL, Holroyd-Leduc J, Simel DL, Straus SE. Does this patient have delirium?: value of bedside instruments. *JAMA*. 2010 Aug 18; 304(7): 779–86.

# Depression

## Definition

A diagnosis of a major depressive episode is identified by the severity of depressed mood, and a loss of interest and pleasure in activities that used to be enjoyable (anhedonia). Feelings of hopelessness, guilt and worthlessness are frequently present. (National Breast Cancer Centre and National Cancer Control Initiative. 2003). Recurrent tearfulness is often accompanied by social withdrawal and loss of motivation. The essential feature of a major depressive disorder is that the patient feels unable to control the negative feelings and these feelings begin to dominate the day, on most days for two weeks or more. In some instances the patient's mood may present as irritable rather than sad.

Demoralisation is a term used to describe the loss of hope and meaning that some patients experience. Demoralisation can manifest with less severe symptoms of depression, but still cause distress, affect functioning, and be an important focus for intervention (which may be of a psychological, social or spiritual nature).

## Causes

Whilst the cause of depression is unclear, there are some known risk factors including:

- Some cancers have higher incidence (pancreatic, head and neck, breast and lung)
- Advanced disease stage and physical disability
- Presence of multiple chronic diseases in the same patient
- A previous psychiatric history
- A family history of depression
- Uncontrolled pain
- Poor social support and social isolation
- Recent experience of a significant loss
- Low self-esteem (Holland J. 2010)

## Important points

1. It is important to identify the presence of suicidal thoughts or plans.
2. Depression is considered to be the most frequent mental health issue among terminally ill patients.
3. Depression in terminally ill patients is commonly undiagnosed.
4. Depressive disorders are important potentially reversible causes of suffering for patients receiving palliative care, not simply a normal part of dying.
5. Some people may express their distress in terms of unrelieved physical symptoms, rather than focusing on emotional concerns.

## Assessment

The diagnosis of a depressive disorder in a patient who is terminally ill cannot rely alone on the presence of the somatic symptoms of anorexia and weight loss, fatigue and insomnia, which may in fact be linked to physical problems. Assessment requires a full history of current symptoms, their duration and impact on current functioning. Clinical interview and Mental State Examination are the mainstays of assessment. A variety of assessment methods and tools are available (Appendix 6 and 7), but these should be seen as an adjunct to the clinical interview, not a replacement for it. The risk of suicide should be carefully assessed and monitored in any patient with a depressive disorder.

Symptoms suggestive of a major depressive disorder in a terminally ill patient include the following:

- Depressed mood and an inability for this to be lightened
- Loss of pleasure or interest (even within the limitations of the illness)
- A sense of worthlessness or low self-esteem (e.g. feeling a burden to others)
- Fearfulness/anxiety
- Avoiding others or withdrawal
- Brooding or excessive guilt/remorse
- A pervasive sense of hopelessness or helplessness
- Suicidal ideation
- Prominent insomnia
- Excessive irritability
- Indecisiveness

### Diagnosis (if consistent with goals of care)

A range of tools have been developed to screen for depression. A definitive diagnosis of depression is made by a clinical interview and Mental State Examination.

### References

- Holland J, Alici Y. (2010). Management of distress in cancer patients *The Journal of Supportive Oncology* 8: 14–12.
- National Breast Cancer Centre and National Cancer Control Initiative. 2003. *Clinical practice guidelines for the psychosocial care of adults with cancer*. National Breast Cancer Centre, Camperdown, NSW.
- Pessin H, Olden M, Jacobson C. (2005). Clinical assessment of depression in terminally ill cancer patients: a practical guide. *Palliative and Supportive Care* 3: 319–324.

# Diarrhoea

## Definition

Diarrhoea is stools that are looser than normal and may be increased in frequency. It may be acute (<14 days), persistent (>14 days), or chronic (>30 days). Diarrhoea can lead to dehydration, malabsorption, fatigue, hemorrhoids, and perianal skin breakdown. Secondarily, it can lead to electrolyte abnormalities.

## Causes

- Medications (antibiotics, laxatives, antacids), chemotherapy
- Constipation (obstructive overflow due to impaction)
- Radiation to pelvis/lower abdomen
- Malabsorption, enteral feedings
- Anxiety
- Food borne pathogen or irritant (parasites), infections (viral or bacterial), Irritable bowel or colitis
- Hormonal (thyroid, carcinoid)

## Important points

1. Diarrhoea can be a serious symptom.
2. Consider infection risk and use appropriate contact precautions.
3. It is an expected adverse effect of fluorouracil and irinotecan chemotherapy.
4. Consider bowel obstruction.

## Assessment

### History

- Establish the patients' normal bowel habit
- Elicit a description of the stool that is different from normal (i.e. consistency or frequency, urgency, fecal soiling, greasy stools that float, presence of blood, color, volume, etc)
- Duration of diarrhoea
- Nature of onset (sudden or gradual)
- Relationship to food intake
- Travel history

- Weight loss
- Diarrhoea with fasting or at night (suggests secretory)
- Family history of irritable bowel disease
- Chemotherapy and over the counter medications and supplements
- Dietary history, including specific food associations such as dairy products
- Recent antibiotic therapy
- Check for associated symptoms (fever, abdominal pain, N/V)
- Consider systemic symptoms e.g. fever, joint pain, mouth ulcers

### Physical examination

#### Vital signs

Look for signs of dehydration such as tachycardia, hypotension, rapid weight loss.

Examine abdomen for bowel sounds, tenderness, and percussion for dullness/fullness. Consider rectal examination to rule out impaction.

### Diagnostic tests (if consistent with goals of care)

- Stool for ova and parasites and or *C. difficile* if indicated by history, occult blood testing
- FBE (Full Blood Estimation), CRP (C-reactive protein)
- Abdominal X-ray if impaction or obstruction is suspected

## Reference

- Wrete-Seaman, Linda. *Symptom Management Algorithms: A handbook for Palliative Care*. Intellicard, Yakima Washington, 2005.

# Dyspnoea

## Definition

The uncomfortable sensation or awareness of breathing or needing to breathe; shortness of breath.

## Causes

Physical causes may include airway obstruction, bronchospasm, hypoxemia, pleural effusion, pneumonia, pulmonary oedema, pulmonary embolism, thick secretions, anaemia and metabolic derangement. Psychological, social, and spiritual issues may cause dyspnoea. Anxiety may play a factor.

## Important points

1. Titrate opioids to the patient's report of relief.
2. Ensure the patient does not have hypercapnia before prescribing oxygen for patients without hypoxia.

## Assessment

### History

Dyspnoea is diagnosed by subjective reporting. There are no reliable objective measures of dyspnoea. Respiratory rate, oxygen saturation, and arterial blood gas determinations do not always correlate with nor measure dyspnoea. A severity scale 0–10 may be used to assess dyspnoea.

## Physical examination

Auscultation of the heart and lungs. May include pulmonary dullness, crackles, inability to clear secretions, stridor, wheezing, cyanosis and tachypnoea. Examine for oedema.

## Diagnostic studies (if consistent with goals of care)

Pulse Oximetry, FBE (Full Blood Estimation), electrolytes, arterial blood gas, chest X-ray may clarify pathophysiology. Goals of care need to be established before ordering diagnostic tests. Serum bicarb may be used as a crude measure for hypercapnia.

## Reference

- EPEC-O, 2005.

# Fatigue

## Definition

Fatigue is an ambiguous phenomenon commonly described as a persistent sensation of tiredness, lack of energy, or exhaustion. It is often defined as a nonspecific and subjective feeling of tiredness, physically and/or mentally. Although fatigue has been studied by many disciplines, no widely accepted definition exists.

Cancer-related fatigue is a persistent sense of tiredness, which may be secondary to cancer, and other chronic illness, or its treatment and interferes with usual functioning. It is unrelieved by rest and may affect both physical and mental capacity.

## Causes

Usually multi-factorial.

Causes include the following: underlying disease, effects of treatment (chemotherapy, radiotherapy), systemic disorders such as anaemia, infection, medications such as opioids or beta blockers, insomnia, sleep disorders, metabolic disorders, hypoxia, psychiatric disorders such as depression.

## Important points

1. Fatigue is the symptom with the greatest impact on every day life.
2. The pattern of the treatment related fatigue varies with the type of treatment.
3. Anaemia, though an important cause of fatigue, may not be the therapy-resistant etiology of fatigue in many patients with cancer.
4. Anaemia is the most common cause of reversible fatigue. Increases in quality of life appear greatest when the haemoglobin is in the range of 11–13 gm/dl.
5. Try something – this is a major debilitating symptom.
6. Too much ‘rest’ may lead to progressive muscle wasting and further reduction of energy level.
7. Encourage patients to exercise as tolerated.

## Assessment

### History

Screen each patient for the presence and severity of fatigue.

Rate the severity of fatigue on a 0–10 scale, with 0 being ‘no fatigue’ and 10 ‘the worst fatigue imaginable’.

If fatigue is moderate (4–6, on a 0–10 scale) or worse, initiate a thorough history and physical examination.

Include the disease status and treatment; rule out recurrent or progressive disease; review current medications and recent changes; and pursue an in-depth assessment of fatigue, including its onset, pattern, duration, and change over time, associated or alleviating factors, and interference with function.

Evaluate the patient for the presence of:

- Treatable, contributing factors, e.g. pain, depression, insomnia, anaemia, malnutrition
- Deconditioning and comorbidities, e.g. infection, cardiac, pulmonary, renal, hepatic, neurological or endocrine dysfunction

### Physical examination

Vital signs. Weight. Examine heart, lungs, and skin for pallor. Focus on signs of infection, anaemia, respiratory distress or other organ failure.

### Diagnostic tests (if consistent with goals of care)

Consider laboratory tests including FBE (Full Blood Examination), Electrolytes, TFT's (Thyroid Function Tests), CRP (C-reactive protein) and/or X-rays as needed to rule out infection, or anaemia.

## References

- EPEC-O, 2005.
- Textbook of Palliative Medicine, 2006.
- National Cancer Institute. Fatigue PDQ Cited 28/06/2010.



**Table 5. Potential predisposing etiologies of cancer-related fatigue**

Textbook of Palliative Medicine, 2006

Psychosocial factors	Anxiety disorders Depressive disorders Stress-related Environmental
Physiologic factors	Treatment-related: Chemotherapy Radiotherapy Surgery Biologic response modifiers Electrolyte disturbances
Malignancies	
Intercurrent System Disorders	Anaemia Infection Pulmonary disorders Hepatic failure Cardiac failure Renal failure Malnutrition Neuromuscular disease Dehydration or electrolyte imbalance Endocrine dysfunction
Alterations in activity level	Deconditioning
Sleep disorders	
Pain	
Medications (Use of centrally acting medications)	Opioids Antiemetics Hypnotics Anxiolytics Antihistamines Beta Blockers

# Fever

## Definition

The elevation of core body temperature above normal. Normal average adult core body temperature is 37 degrees (98.6F) and displays a circadian rhythm.

## Causes

Often multi-factorial. Infections, malignancies, thrombosis, Central Nervous System metastasis, radiation, blood transfusion reactions, biological response to some drugs (such as antibiotics, cardiovascular drugs, anticonvulsants, cytotoxics and growth factors).

## Assessment

### History

Careful history of symptom to include disease-related history. Medication review.

Diary of temperatures. Initial evaluation may not identify focus of infection in some neutropaenic patients.

### Physical examination

Vital signs. Physical examination of all major body systems including evaluation of the skin, mouth, nose, throat, ears, lungs, heart, abdomen, venipuncture and/or IV sites, lymph nodes, catheters (urinary, suprapubic, renal), implanted devices.

## Diagnostic tests (if consistent with goals of care)

Consider Full Blood Examination, CRP (C-reactive protein), blood cultures, urinalysis, urine culture & sensitivity, chest X-ray to locate cause. (If not conclusive, consult collaborating doctor to consider other testing as appropriate such as lumbar puncture, paracentesis, ultrasound, CT (Computed Tomography), MRI).

## Reference

- Textbook of Palliative Care Medicine, 2006.

# Hiccups

## Definition

Hiccups are the spasmodic contraction of the diaphragm that repeats several times per minute. In humans, the abrupt rush of air into the lungs causes the epiglottis to close, creating the 'hic' noise.

Hiccups can lead to fatigue, insomnia, depression, and weight loss. Hiccups can have a significant effect on quality of life.

## Causes

Tiring easily with decreased capacity to maintain adequate performance.

Conditions associated with hiccups can be grouped into three main categories:

1. Physical causes within the anatomical distribution of the phrenic and vagus nerve: gastritis, bowel obstruction, GORD, hepatic disease, foreign body in ear, pleural effusion, lateral MI, mediastinal disease, thoracic aortic aneurysm, recent thoracic or abdominal procedures.
2. Neurological conditions thought to interfere with the central control mechanisms: brainstem infarction, multiple sclerosis, brainstem tumors, CNS infection (tuberculoma, toxoplasmosis), sarcoidosis.
3. Metabolic/toxic and drug-induced causes: steroids in particular have been linked with the onset of hiccups and are thought to lower the threshold for synaptic transmission in the midbrain: hyponatremia, uraemia, Addison's disease, hypocapnia, alcohol, corticosteroids, midazolam.

## Important points

1. In most cases, the cause of hiccups cannot be found.
2. Hiccups that are short in duration do not require treatment.
3. There are many traditional remedies for hiccups which often involve some form of pharyngeal stimulation or diaphragmatic interruption/splinting.

## Assessment

### History

Detailed history: Description, temporal profile, severity 0–10, effect of treatments.

Assessment of: medications, disease status, sleep disturbances, mood.

### Physical examination

Chest assessment: Evaluate respiratory rate, effort, distress, percussion to evaluate for dullness, lung sounds for crackles.

Abdomen: Observe, auscultate, palpate for hepatosplenomegaly, ascites, masses.

### Diagnostic tests (if consistent with goals of care)

Review current laboratory results: especially metabolic panel for signs of hepatic, renal disease, electrolyte imbalance, calcium level.

Review recent X-rays for signs of mediastinal masses.

## Reference

- Textbook of Palliative Medicine, 2006.

# Insomnia

## Definition

Insomnia is an experience of inadequate or poor quality sleep characterised by one or more of the following: difficulty falling asleep, difficulty maintaining sleep, early morning awakening, non-refreshing sleep or daytime consequences of inadequate sleep (e.g. tiredness or fatigue, poor concentration, or irritability).

## Causes

1. Insomnia can be caused by a variety of factors, ranging from disruptions of the neurophysiology of sleep to the consequences of physical or mental disorders to simple interruption of normal sleep habits.
2. Primary sleep disorders, e.g. sleep apnoea, restless legs syndrome.
3. Physical symptoms common in advanced cancer, e.g. pain, dyspnoea, cough, nausea, or pruritus, whether due to the tumour itself or treatment related.
4. Prescription medications, e.g. psychostimulants, corticosteroids, over-the-counter medications, or other substances with stimulating effects.
5. Caffeine.
6. Depression/anxiety.

## Important points

1. Patients and families may be disturbed by insomnia, particularly day-night reversal.
2. Assess and recommend good sleep hygiene.
3. Antihistamines or benzodiazepines frequently manage insomnia effectively. However, anticholinergic effects of antihistamines and amnesic effects of benzodiazepines may cause frail elderly patients to fall.
4. Low doses of a sedating neuroleptic may be required to manage day-night reversal.

## Assessment

### History

Focus on determining the course and pattern of the sleep problem.

Identify concurrent nighttime symptoms (e.g. pain, dyspnoea, recent medication changes, changes in substance use, especially caffeine and alcohol, stress related to recent life events, or any necessity of sleeping away from home.

Evaluation for restless legs syndrome if needed.

### Physical examination

Vital signs. Examine heart and lung sounds. Observe for signs of anxiety.

### Diagnostic tests (if consistent with goals of care)

Polysomnography and overnight monitoring and observation of sleep are the definitive assessment of primary sleep disorders.

## Reference

- EPEC-O, 2005.

# Mucositis

## Definition

Mucosal barrier injury to the mouth, and is a common complication of chemotherapy, radiation therapy and immunosuppression.

## Causes

Mucositis is a complex problem for patients resulting from damage to the epithelium. The initial insult can be caused by a virus, chemotherapy or radiation. The insult produces inflammation, as well as cytokine and enzyme release. The tissue injury is amplified and leads to ulceration. Oral bacteria then colonise the wound, and produce additional immune response increasing inflammation. Healing eventually occurs spontaneously, and relies on epithelial cell migration and differentiation.

## Important points

1. Viral ulcers are localised and while treatment-induced mucositis is generalised.
2. Treatment focuses on good oral hygiene and comfort measures.

## Assessment

### History

History of mouth pain, decreased oral intake secondary to pain.

### Physical examination

Examine mouth for oral erythema, ulceration, or desquamated epithelium of the oral mucosa.

## References

- Education in Palliative and End of Life Care – Oncology (EPEC-O). Module 30: Symptoms-Mucositis, 2005.
- Potting C, Mistiaen P, Poot E, Blijlevens N, Donnelly P, van Achterberg T. (2009). A review of quality assessment of the methodology used in guidelines and systematic reviews on oral mucositis. *J Clin Nurs*. Jan; 18(1): 3-12.

# Nausea and Vomiting

## Definition

Nausea: Unpleasant, wave-like sensation at the back of the throat and epigastrium which is difficult to suppress.

Vomiting: Forceful ejection of stomach or intestinal contents through the mouth.

## Causes

1. Frequent causes of nausea and vomiting are constipation, bowel obstruction, adverse effects of medications, the underlying terminal illness and an increase in intracranial pressure.
2. In most cases, nausea and vomiting is caused by impulses transmitted to the vomiting center in the medulla oblongata by impulses transmitted to the vomiting center by the cerebral cortex and limbic system, the chemoreceptor trigger zone, the vestibular apparatus in the inner ear, and the peripheral pathways which involve neurotransmitter receptors in the GI tract.

## Important points

1. Be aware of triggers and how to best avoid them.
2. May take medication for anticipatory nausea/vomiting.
3. Certain positions may ease symptoms.

## Assessment

### History

Persistent nausea, vomiting, or both; nausea constant or intermittent; vomiting without nausea; dizziness involved; symptoms occur at mealtimes or with certain medications; triggers e.g. smells or memories; certain movements; what helps, makes worse; pain or coughing; frequency, character; last bowel motion.

### Physical examination

Vital signs including orthostatic vital signs. Eyes: pupils' size and reactivity. Weight. Heart and lung sounds. Examine abdomen for bowel sounds, tenderness, and percussion for dullness.

### Diagnostic tests (to be performed if consistent with goals of care)

Electrolytes – particularly looking for hypercalcaemia, hyponatremia, uremia, or drug levels that may be toxic; X-ray for constipation, tumor, obstruction.

## References

- Education in Palliative and End of Life Care – Oncology (EPEC-O), Module 10: Common Physical Symptoms, 2005.
- Naughney, Anee. Nausea and Vomiting in End-Stage Cancer, *AJN*, November 2004, Vol. 104, No. 11.
- [http://www.cks.nhs.uk/palliative\\_cancer\\_care\\_nausea\\_vomiting#](http://www.cks.nhs.uk/palliative_cancer_care_nausea_vomiting#)

# Pain

## Definition

Pain is a subjective phenomenon and defined by the International Association for the Study of Pain (<http://www.iasp-pain.org>) 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 as a personal experience, hence pain occurs “When the patient says it hurts”. Pain most often has both a nociceptive and neuropathic component and can be either/or acute and chronic in nature. Chronic pain may not be related to an easily identified pathophysiologic phenomenon and may be present for an indeterminate period.

## Nociceptive pain

The commonest type of pain (either somatic or visceral), which originates in peripheral pain receptors that are being pressed upon, squeezed, stretched or stimulated by chemical mediators such as prostaglandins (for example a cancer infiltrating into soft tissue, stretching the liver capsule, or eroding bone).

## Neurogenic pain

Neuropathic pain arises in nerves that have been damaged (e.g. by chemotherapy, diabetic neuropathy, surgery or direct invasion by cancer), or are behaving abnormally in response to persistent uncontrolled pain (sensitisation/wind-up) (Therapeutic Guidelines 2010 <http://online.tg.org.au/ip/>).

Breakthrough pain (occurs between regular doses of an analgesic and reflects an increase in the pain level beyond the control of the baseline analgesia) and incident pain (occurs with, or is exacerbated by, activity) are terms that describe the pattern of pain. These pains can be nociceptive, neuropathic, or both.

## Causes

Injury to tissues results in the production or release of a wide variety of substances that cause sensitisation and activation of peripheral nociceptors, resulting ultimately in the sensation of pain. These substances include potassium, prostaglandins, histamine, leukotrienes, thromboxanes, tumour necrosis factor and substance P (Therapeutic Guidelines, 2010 <http://online.tg.org.au/ip/>). The pain signals resulting from the activation

of peripheral nociceptors are transmitted via afferent neurones to the dorsal horn of the spinal cord. Second-order neurones then cross the midline and ascend as the spinothalamic tract.

Neurotransmitters are substances involved in neuronal transmission of the impulse across the synapse between neurones. The neurotransmitters involved in afferent nociceptive pathways are:

- Neuropeptides (e.g. neurokinins A and B, substance P, vasoactive intestinal peptide, calcitonin gene-related peptide)
- Excitatory amino acids such as glutamate and aspartate acting on alpha-amino-3-hydroxy-5-methyl-4-isoxazole-propionic acid (AMPA) and N-methyl-D-aspartate (NMDA) receptors (Therapeutic Guidelines 2010 <http://online.tg.org.au/ip/>).

## Important points

In addition to a good general screening examination, appropriate attention should be paid to:

- Movement and the patient's ability to perform activities of daily living
- Palpation for tender spots
- Changes to bowel or bladder function
- Percussion
- Nerve stretch tests
- Observation of 'pain behaviours'
- Observation of nonverbal cues
- Sensation (pinprick, light touch and temperature)
- Assessment of areas of allodynia, hyperalgesia or hyperpathia
- Mental state examination.

## Assessment

### History

The most reliable way to assess what the patient is experiencing is to ask the patient. The gold standard of assessing pain is to believe the patient. For cognitively intact patients, assess location, radiation, quality, intensity, factors that exacerbate or relieve the pain, and temporal aspects such as whether it is continuous or paroxysmal, as well as its duration and meaning to the patient.

Quantify the pain intensity by asking the patient to rate their pain/s. This rating can be accomplished with a verbal rank on a scale of 1–10 where 10 is the worst pain. Along with the characteristics of the pain/s, it is important to assess the personal context and impact, including: psychological, social, spiritual, emotional and practical issues. The underlying pathophysiology should also be considered. Many tools are available to assist with assessment including the Brief Pain Inventory (Appendix 9).

Patient assessment in the non-cognitively intact person, such as the elderly patient with dementia, is challenging. In those instances, the Abbey Pain Scale (Appendix 10) or PAINAD (Appendix 11) is used which assesses breathing, vocalisation, facial expression, body language, and consolability. Similar challenges are present in pre-verbal children. The FACES pain rating scale may be helpful (Appendix 12).

### Physical examination

Vital signs to include blood pressure. Note changes in behaviour such as not moving, or guarding. Note changes in mood withdrawn, anxious, or depressed appearing. Feel for masses, tenderness in guarded areas. Pay attention to the specific area of complaint.

### Diagnostic tests (if consistent with goals of care)

Radiology and laboratory studies may be performed to detect the cause of the pain, and for the purpose of confirming clinical impressions and influencing management decisions. For example, if bone metastases are suspected, then a bone scan may be indicated, or some situations where a CT, MRI would be indicated recognising the need to collaborate with medical colleagues to order these and plan for the management of the patient.

For examples of assessment tools (see Appendices 11 and 12).

### Reference

- Therapeutic Guidelines 2010  
<http://online.tg.org.au/ip/>



# Pruritus (itching)

## Definition

Unpleasant sensation that provokes desire to scratch.

## Causes

1. Both central and peripheral mechanisms are involved.
2. Pruritoceptive itch: originated from skin and transmitted via C fibers (scabies, urticaria).
3. Neuropathic itch: originates from disease located along the afferent pathway (herpes zoster, brain tumors).
4. Neurogenic itch: originates centrally without evidence of neural pathology (caused by cholestasis which is due to the action of opioid neuropeptides on opioid receptors).
5. Psychogenetic itch: parasitophobia, physical cause not known.

## Important points

Pruritus is a complex symptom involving both central and peripheral mechanisms.

1. Treat underlying cause if possible
2. Avoid triggers
3. Antihistamines may cause drowsiness
4. Use hypoallergenic aqueous soaps
5. Trim fingernails
6. Relaxation techniques
7. Positive imagery
8. Cotton gloves to prevent scratching
9. Reduce bathing
10. Reduce sweating
11. Avoid vasodilators such as caffeine, alcohol, spices, hot water

## Assessment

### History

Onset, frequency, duration, and intensity.

Subjective data, aggravating factors, alleviating factors, history of liver or renal failure, recent infection or fever, medication review – recent changes, history of soaps and detergents, history of opioid use, allergies, history of depression or anxiety.

### Physical examination

Presence of rash, scratching, other skin conditions.

Signs of infection such as scabies, lice or candida.

Metabolic conditions such as liver or kidney failure, Hypothyroidism.

### Diagnostic tests (if consistent with goals of care)

Consider laboratory tests such as Full Blood Estimation, TFTs (Thyroid Function Tests), Bilirubin, Alkaline phosphatase, Creatinine, BUN (Blood Urea Nitrogen), consider a biopsy or culture skin lesions.

## Reference

- Textbook of Palliative Medicine, 2006.

# Seizure

## Definition

A seizure episode is a paroxysmal hyper-synchronous discharge of neurons in the brain. It begins with prolonged contractions of muscles in extension followed by cyanosis due to arrested breathing. Whole body clonic jerks then may occur if the seizure generalises. Most common types in palliative care setting are focal seizures or tonic-clonic (grand mal) seizures (difference is the number of neuronal discharges in one area of the brain vs. all areas of the brain).

## Causes

Often multi-factorial and occur in 1% of cancer cases overall with 15–20% in those with primary or metastatic brain cancer or benign brain tumours.

1. Increased risk pre-existing seizure disorder/localised organic lesion.
2. Congenitally deranged local circuitry in the brain.
3. Functional abnormality:
  - Scar tissue that pulls on adjacent tissue
  - A tumour that compresses area of brain
  - A destroyed area of brain tissue
  - Vascular events (hemorrhage/thrombosis/ischemia)
4. Metabolic or toxic disturbances:
  - Poor renal perfusion may cause accumulation of opioid metabolites leading to confusion, myoclonus and nausea (opioid toxicity).
  - Medications may cause or contribute to seizure activity with drug toxicity or abrupt withdrawal of a drug induces a lowering of seizure threshold, producing excitatory toxicity:
    - Morphine (related to accumulation Morphine-3-glucuronide), other opioids such as Hydromorphone, Oxycodone
    - Phenothiazine Drugs: Chlorpromazine, Prochlorperazine, Haloperidol
  - Frequent increases in opioids or poor excretion: can lead to Myoclonus/gran mal seizures
  - Fever
  - Alkalosis caused by over-breathing
  - Infection
  - Hypoglycaemia

## Important points

1. Seizures in the palliative care environment are multi-factorial in origin.
2. Patients with brain cancer/CNS metastases or tumours of the brain have a particular risk for seizure activity.
3. Patients with a prior history of seizure activity impart an important clue in the choosing and titrating of drugs.
4. Alertness to physical signs of myoclonic activity with swift intervention can reduce the incidence of gran mal seizure activity.
5. The multi-origins of seizure activity demands a diagnostic laboratory work-up of varying degrees based on provider and family willingness.

## Assessment

### History

Previous seizure activity, patient's DX, effectiveness of previous anticonvulsant therapy. Drugs that lower seizure threshold in susceptible individuals:

- Chlorpromazine
- Haloperidol
- Tramadol
- Amitriptylline
- Metoclopramide

The sudden withdrawal of Alcohol, Benzodiazepines, Barbituates, Baclofen.

Medication review, titration, interactions that alter anticonvulsant levels (corticosteroids, other anticonvulsants)

### Physical examination

Vital signs. Basic neurological examination. Chest X-ray – look for signs of aspiration.

### Diagnostic tests (when appropriate within goals of care and clinical situation)

Blood Glucose, Full Blood Estimation, Culture(s) as appropriate, suspected brain tumour: CT scanning or MRI after neurologist consultation.

Serum Blood Levels: Monitor levels of anticonvulsants to ensure drug(s) are within therapeutic levels.

### References

- Adam: ABC of Palliative Care: The Last 48 hours. *BMJ* 1997;315:1600-1603 (13 December).
- EPEC-O, 2005.

# Terminal secretions

## Definition

Noisy, rattled breathing caused by an accumulation of secretions (oral + gastric + pulmonary) in a patient who is either weak or tired, has lost their cough and swallowing reflexes is semi-conscious, unconscious or poorly positioned.

## Causes

A consequence of pooled salivary secretions that accumulate when the patient is close to death.

Caused mainly by bronchial secretions when the patient's condition has been deteriorating over a few days.

## Important points

1. Anticholinergic medications are more effective at reducing saliva secretion and dilating bronchial smooth muscle than reducing bronchial secretions. They have no effect upon secretions which have already accumulated and are therefore more effective in preventing rattle if used early.
2. Secretions from GORD (Gastro Oesophageal Reflux Disease), Pneumonia are generally unaffected by anticholinergic medications.

## Assessment

### History

When did symptoms begin? Is patient comfortable? Assess patient and family concerns regarding this symptom.

### Physical examination

Auscultation of lungs. Observation.

### Education

Secretions are a common problem at end of life. Family education focuses on the process of dying. Treatment is based on patient's goals of care. Patient and family education on medications including their side effects. Most patients with terminal secretions are not aware or distressed by the congestion; thus therapy may be to provide comfort to family and others.

## References

- EPEC-O, 2005.
- Textbook of Palliative Medicine, 2006.
- Wrede-Seaman, Linda. *Symptom Management Algorithms: A handbook for Palliative Care*. Intellicard. Yakima, Washington (2005).

# Wounds

## Definition

A wound is an injury in which the skin or another external surface is torn, pierced, cut, or otherwise broken.

## Causes

Patho-physiology of skin:

- Pressure: capillary closure
- Malignant
- Venous: oedema compresses vessels and causes lymphoedema
- Arterial: poor proximal perfusion
- Diabetic: damaged microarterials

## Important points

1. Pressure is highest inferiorly (near bone).
2. Don't let the wound dry out because dry nerve endings exposed to air = pain.
3. Low albumin increases risk of pressure ulceration.
4. With inflammation, opioid receptors migrate to the periphery; therefore, receptors are increased in the wound bed.
5. If the wound is not painful, it is less likely to be infected.
6. Nociceptive pain is due to inflammation from infection.
7. Neuropathic pain is due to partially destroyed nerve endings.
8. Ensure adequate blood supply.
9. Dressing orders should start with dressing nearest wound surface.
10. Honey is bactericidal (but can cause clostridia if not irradiated).
11. Topical antibiotics penetrate approximately 4 mm.

## Assessment

### History

When and how did the wound begin?

### Physical examination

1. Measure size:
  - Length: longest point from head to toe
  - Width: widest point perpendicular to length
  - Depth: deepest point from horizontal plane (probe from depth for tunneling or cavities)
2. Location: diagram or picture.
3. Staging: according to the National Pressure Ulcer Panel Staging System, 2007.

**Table 6. National Pressure Ulcer Panel Staging System**

Stage 1	Intact skin with non-blanchable redness of a localised area usually over a bony prominence. Darkly pigmented skin may not have visible blanching; its color may differ from the surrounding area.
Stage 2	Partial thickness loss of dermis presenting as a shallow open ulcer with a red pink wound bed, without slough. May also present as an intact or open/ruptured serum-filled blister.
Stage 3	Full thickness tissue loss. Subcutaneous fat may be visible but bone, tendon or muscle are not exposed. Slough may be present but does not obscure the depth of tissue loss. May include undermining and tunneling.
Stage 4	Full thickness tissue loss with exposed bone, tendon or muscle. Slough or eschar may be present on some parts of the wound bed. Often include undermining and tunneling.
Unstageable	Full thickness tissue loss in which the base of the ulcer is covered by slough (yellow, tan, gray, green or brown) and/or eschar (tan, brown or black) in the wound bed.

1. Color:
  - Red: granulation tissue
  - Yellow: slough (= Stage 3, 4 x given yellow is dried eschar)
  - Black: eschar
2. Odour:
  - Fruity: pseudomonas
  - Foul: anaerobes, gangrene/necrosis
3. Exudate: Drainage through gauze = strike through
  - Serous: clear, yellow
  - Bloody
  - Purulent: level of infection
4. Tissue around the wound
  - Cellulitis: erythematous, raised edge
  - Maceration: friable, irritated due to wetness
5. Host/context:
  - Underlying illness/prognosis
  - Nutritional status: O<sub>2</sub>, protein, enzymes
  - Hydration status
  - Symptoms
6. Friability:
  - Oozing
  - Bleeding
  - Weeping

## References

- Adderley U, Smith R. topical agents and dressings for fungating wounds. *Cochrane database of systematic reviews*; 2007: 2.
- Alvarez O, Kalinski C, Nusbaum J, Hernandez L, Pappous E, Kyriannis C, Parker R, Chrzanowski G, Comfort C. (2007). Incorporating wound healing strategies to improve palliation (symptom management) in patients with chronic wounds. *Journal of Palliative Medicine*; 10: 5 p1161–1189.
- Black J, Baharestani M, Cuddington J. et al (2007). National Pressure Ulcer Advisory Panel's New Pressure Ulcer Staging System: History of Pressure Ulcer Staging *Urology Nursing*; 27(2): 144–150. DOI: 1002/14651858.

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1. Palliative Care Expert Group. *Therapeutic guidelines: palliative care. Version 3*. Melbourne: Therapeutic Guidelines Limited; 2010.
2. Quinn K, Glaetzer K, Hudson P, Boughey M. *Palliative Care Nurse Practitioner Candidate Clinical Competencies*. Centre for Palliative Care, St Vincent's Hospital Melbourne: Melbourne, Australia 2011.
3. Nursing and Midwifery Board of Australia (2010) Endorsement as a Nurse Practitioner: registration standard.
4. Victorian Government Health Information <http://www.health.vic.gov.au/nursing/furthering/practitioner/np-candidates> accessed 20 October 2011.
5. Palliative Care Outcomes Collaborative <http://ahsri.uow.edu.au/pcoc/index.html> accessed October 2011.

# Appendix 1

## Palliative Performance Scale (PPS)

Adapted from Anderson F, et al. 1996

PPS%	Ambulation	Activity level Evidence of disease	Self-care	Intake	Level of consciousness
100	Full	Normal No disease	Full	Normal	Full
90	Full	Normal Some disease	Full	Normal	Full
80	Full	Normal with effort Some disease	Full	Normal or less	Full
70	Reduced	Unable to work Significant disease	Full	As above	Full
60	Reduced	Unable to do hobbies/ housework Significant disease	Occasional assistance	As above	Full or confusion
50	Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance	As above	Full or confusion
40	Mainly in bed	Unable to do most activity Extensive disease	Mainly assistance	As above	Full or drowsy +/- confusion
30	Bed bound	Unable to do any activity Extensive disease	Total care	As Above	As above
20	Bed bound	As above	As above	Minimal to sips	As above
10	Bed bound	As above	As above	Mouth care only	Drowsy or coma +/- confusion
0	Death	–	–	–	–

### References

1. Anderson F, Downing GM, Hill J. Palliative Performance Scale (PPS): a new tool. *J Palliat Care*. 1996; 12(1): 5–11.
2. Morita T, Tsunoda J, Inoue S, et al. Validity of the Palliative Performance Scale from a survival perspective. *J Pain Symp Manage*. 1999; 18(1): 2–3.
3. Virik K, Glare P. Validation of the Palliative Performance Scale for inpatients admitted to a palliative care unit in Sydney, Australia. *J Pain Symp Manage*. 2002; 23(6): 455–7



# Appendix 2

## Symptom Assessment Scale (SAS)

### Instructions:

- Score at episode start, at phase change, at episode end, and as clinically required/indicated.
- Assessment may be recorded daily for one or two troublesome symptoms.
- Symptoms are rated by the patient/client except where they are unable due to language barrier, hearing impairment or physical condition such as terminal phase or delirium, in which case a proxy is used. Use the most appropriate proxy. This may be the nurse or the family member.
- Highly rated or problematic symptoms may trigger other assessments or clinical interventions.

### References

1. Kristjanson, L. J. Pickstock, S., Yuen, K., Davis, S., Blight, J., Cummins, A., et al. (1999). *Development and testing of the revised Symptom Assessment Scale*. Perth: Edith Cowan University.
2. Nightingale, E., Yuen, K., Firms, P., Duggan, G., Cummins, A., Kristjanson, L. J., et al. (2000). *Evaluation of a goal specific care model*. Perth: The Cancer Foundation Centre for Palliative Care.
3. Toye, C., Walker, H., Kristjanson, L. J., Popescu, A., & Nightingale, E. (2005). Measuring symptom distress among frail elders capable of providing self reports. *Nursing & Health Sciences*, 7(3), 184–191.

As part of your assessment inform the patient that you are going to ask them about the symptoms they may be experiencing or the symptoms that are causing a problem.

When asking about these symptoms for the first time say:

*I'm going to ask you about some common symptoms you may be experiencing. We would like to know how much they affect you by rating them with a number from 0–10. Can you think about how you have felt over the last 24hrs and when I ask you about your symptoms can you rate them by giving a score of 0 to indicate that you are not having a problem with that symptom, 10 to indicate you are having the worst possible problem and numbers 1 through to 9 indicate somewhere in between, just pick the number that best describes how you feel.*

Please note: Where the person has multiple pains assess each one separately.

If the person has additional symptoms add these in blank rows.

Date \_\_\_\_\_

Insomnia \_\_\_\_\_

Appetite problems \_\_\_\_\_

Nausea \_\_\_\_\_

Bowel problems \_\_\_\_\_

Breathing problems \_\_\_\_\_

Fatigue \_\_\_\_\_

Pain \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Completed by:  
N = Nurse, D = Doctor, F = Family, P = Patient

# Appendix 3

## Australian-Modified Karnofsky Performance Scale

Score	Australian-Modified Karnofsky Performance Scale (AKPS)
100	Normal, no complaints, no evidence of disease
90	Able to carry on normal activity, minor signs or symptoms
80	Normal activity with effort, some signs or symptoms of disease
70	Cares for self, unable to carry on normal activity or to do active work
60	Requires occasional assistance but is able to care for most of his/her needs
50	Requires considerable assistance
40	In bed more than 50% of the time
30	Almost completely bedfast
20	Totally bedfast and requiring extensive day-to-day care
10	Comatose or barely arousable
0	Dead

### References

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3. Nikoletti, S., Porock, D., Kristjanson, L. J., Medigovich, K., Pedler, P., & Smith, M. (2000). Performance status assessment in home hospice patients using a modified form of the Karnofsky Performance Status scale. *Journal of Palliative Medicine*, 3(3), 301–311.

# Appendix 4

## Bereavement Risk Assessment

Risk index: Circle one number in each of the sections below

<b>Changed behaviours of concern</b> Increased alcohol use	None Some Moderate Severe	0 1 2 3
<b>Changed behaviours of concern</b> Increased drug use	None Some Moderate Severe	0 1 2 3
<b>Changed behaviours of concern</b> (note what they are)	None Some Moderate Severe	0 1 2 3
<b>Feelings of preparedness for death</b>	Well prepared Somewhat prepared Not at all prepared	0 2 4
<b>Expressions of dependency/idolisation of deceased</b> (ambivalent relationship, 'we did everything together', limited other networks within marriage)	None Some Moderate Severe	0 1 2 3
<b>Anger</b>	None Some Moderate Severe	0 1 2 3
<b>Multiple bereavements</b>	Expressions of acceptance Some unresolved feelings Strong unresolved feelings	1 2 4
<b>Expressions of self reproach</b> (self blame/guilt/not being there at time of death/should have done more)	None Some Moderate Severe	0 1 2 3
<b>Current relationships</b>	Close supportive relationships actively engaged Supportive network but not readily available Unreliable support Unsupportive/conflicted relationships Absence of relationships	0 1 2 3 4
(Add all circled numbers to find out total score) <b>TOTAL</b>		

Scores: High risk = 19 or higher • Medium risk = 13–18 • Low risk = 12 or lower

### Reference

Parkes CM. 1991. 'Evaluation of bereavement service', *Journal of Preventive Psychiatry*, 1(2), pp. 179–88.

# Appendix 5

## Palliative Care Outcomes Collaborative (PCOC) Tools

### Definitions

#### PHASE

1	Stable	The person's symptoms are adequately controlled by established management
2	Unstable	The person experiences the development of a new problem or a rapid increase in the severity of existing problems
3	Deteriorating	The person experiences a gradual worsening of existing symptoms or the development of new but expected problems
4	Terminal	Death is likely in a matter of days
5	Bereaved	Death of a patient has occurred and the carers are grieving

#### PROBLEM SEVERITY SCORE (PSS)

0	Absent
1	Mild
2	Moderate
3	Severe

#### RUG-ADL

For eating		For bed mobility		For toileting		For transfer	
1	Independent or supervision only	1	Independent or supervision only	1	Independent or supervision only	1	Independent or supervision only
2	Limited assistance	3	Limited physical assistance	3	Limited physical assistance	3	Limited physical assistance
3	Extensive assistance/total dependence/tube fed	4	Other than two person physical assist	4	Other than two person physical assist	4	Other than two person physical assist
		5	Two person physical assist	5	Two person physical assist	5	Two person physical assist

Reported RUG-ADL is combined score from each domain (Eating + Bed + Toileting + Transfer)

### References

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- Nightingale, E., Yuen, K., Firms, P., Duggan, G., Cummins, A., Kristjanson, L. J., et al. (2000). *Evaluation of a goal specific care model*. Perth: The Cancer Foundation Centre for Palliative Care.
- Toye, C., Walker, H., Kristjanson, L. J., Popescu, A., & Nightingale, E. (2005). Measuring symptom distress among frail elders capable of providing self reports. *Nursing & Health Sciences*, 7(3), 184–191.

# Appendix 6

## Distress Thermometer

NCCN<sup>®</sup>

Distress Thermometer

**SCREENING TOOLS FOR MEASURING DISTRESS**

**Instructions:** First please circle the number (0-10) that best describes how much distress you have been experiencing in the past week including today.

Second, please indicate if any of the following has been a problem for you in the past week including today. Be sure to check YES or NO for each.

**YES NO Practical Problems**

Child care

Housing

Insurance/financial

Transportation

Work/school

**Family Problems**

Dealing with children

Dealing with partner

**Emotional Problems**

Depression

Fears

Nervousness

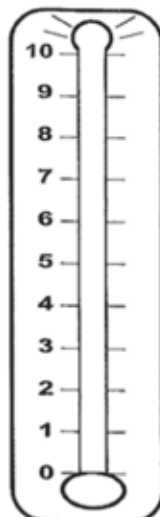
Sadness

Worry

Loss of interest in usual activities

**Spiritual/religious concerns**

**Extreme distress**



**No distress**

**YES NO Physical Problems**

Appearance

Bathing/dressing

Breathing

Changes in urination

Constipation

Diarrhea

Eating

Fatigue

Feeling Swollen

Fevers

Getting around

Indigestion

Memory/concentration

Mouth sores

Nausea

Nose dry/congested

Pain

Sexual

Skin dry/itchy

Sleep

Tingling in hands/feet

Other Problems: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

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DIS-A

Palliative Care Nurse Practitioner Symptom Assessment Guide

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# Appendix 7

## The Kessler Psychological Distress Scale (K10)

This outcome measure was downloaded from [www.beyondblue.org.au](http://www.beyondblue.org.au) 

# K10

### The Kessler Psychological Distress Scale

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Please circle the number that best represents your response.

In the last four weeks, about how often...

		None of the time	A little of the time	Some of the time	Most of the time	All of the time
1.	did you feel tired out for no good reasons?	1	2	3	4	5
2.	did you feel nervous?	1	2	3	4	5
3.	did you feel so nervous that nothing could calm you down?	1	2	3	4	5
4.	did you feel hopeless?	1	2	3	4	5
5.	did you feel restless or fidgety?	1	2	3	4	5
6.	did you feel so restless that you could not sit still?	1	2	3	4	5
7.	did you feel depressed?	1	2	3	4	5
8.	did you feel that everything was an effort?	1	2	3	4	5
9.	did you feel so sad that nothing could cheer you up?	1	2	3	4	5
10.	did you feel worthless?	1	2	3	4	5

Scoring instructions: Sum item scores

Score

Signature of GP

(to note that result has been signed)

Citation: Kessler C, Barker P, Colpe L, Epstein J, Gfroerer J, Hiripi E, Howes M, Normand S, Mandeschild R, Walters E, Zaslavsky A. Screening for serious mental illness in the general population. Archives of General Psychiatry 2003; 60: 184-189.

# Appendix 8

## Confusion Assessment Method (CAM)

<b>Confusion Assessment Method (CAM)</b>			
<small>(Adapted from Inouye et al., 1990)</small>			
Patient's Name: _____	Date: _____		
<b><u>Instructions:</u></b> Assess the following factors.			
<b>Acute Onset</b>			
1. Is there evidence of an acute change in mental status from the patient's baseline?			
<input type="checkbox"/> YES	<input type="checkbox"/> NO	<input type="checkbox"/> UNCERTAIN	<input type="checkbox"/> NOT APPLICABLE
<b>Inattention</b>			
<small>(The questions listed under this topic are repeated for each topic where applicable.)</small>			
2A. Did the patient have difficulty focusing attention (for example, being easily distractible or having difficulty keeping track of what was being said)?			
<input type="checkbox"/> Not present at any time during interview			
<input type="checkbox"/> Present at some time during interview, but in mild form			
<input type="checkbox"/> Present at some time during interview, in marked form			
<input type="checkbox"/> Uncertain			
2B. <small>(If present or abnormal)</small> Did this behavior fluctuate during the interview (that is, tend to come and go or increase and decrease in severity)?			
<input type="checkbox"/> YES	<input type="checkbox"/> NO	<input type="checkbox"/> UNCERTAIN	<input type="checkbox"/> NOT APPLICABLE
2C. <small>(If present or abnormal)</small> Please describe this behavior.			
_____			
_____			
<b>Disorganized Thinking</b>			
3. Was the patient's thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable, switching from subject to subject?			
<input type="checkbox"/> YES	<input type="checkbox"/> NO	<input type="checkbox"/> UNCERTAIN	<input type="checkbox"/> NOT APPLICABLE
<b>Altered Level of Consciousness</b>			
4. Overall, how would you rate this patient's level of consciousness?			
<input type="checkbox"/> Alert ( <i>normal</i> )			
<input type="checkbox"/> Vigilant ( <i>hyperalert, overly sensitive to environmental stimuli, startled very easily</i> )			
<input type="checkbox"/> Lethargic ( <i>drowsy, easily aroused</i> )			
<input type="checkbox"/> Stupor ( <i>difficult to arouse</i> )			
<input type="checkbox"/> Coma ( <i>unarousable</i> )			
<input type="checkbox"/> Uncertain			

**Disorientation**

5. Was the patient disoriented at any time during the interview, such as thinking that he or she was somewhere other than the hospital, using the wrong bed, or misjudging the time of day?

YES       NO       UNCERTAIN       NOT APPLICABLE

**Memory Impairment**

6. Did the patient demonstrate any memory problems during the interview, such as inability to remember events in the hospital or difficulty remembering instructions?

YES       NO       UNCERTAIN       NOT APPLICABLE

**Perceptual Disturbances**

7. Did the patient have any evidence of perceptual disturbances, such as hallucinations, illusions, or misinterpretations (for example, thinking something was moving when it was not)?

YES       NO       UNCERTAIN       NOT APPLICABLE

**Psychomotor Agitation**

- 8A. At any time during the interview, did the patient have an unusually increased level of motor activity, such as restlessness, picking at bedclothes, tapping fingers, or making frequent, sudden changes in position?

YES       NO       UNCERTAIN       NOT APPLICABLE

**Psychomotor Retardation**

- 8B. At any time during the interview, did the patient have an unusually decreased level of motor activity, such as sluggishness, staring into space, staying in one position for a long time, or moving very slowly?

YES       NO       UNCERTAIN       NOT APPLICABLE

**Altered Sleep-Wake Cycle**

9. Did the patient have evidence of disturbance of the sleep-wake cycle, such as excessive daytime sleepiness with insomnia at night?

YES       NO       UNCERTAIN       NOT APPLICABLE

**Scoring:**

For a diagnosis of delirium by CAM, the patient must display:

1. Presence of acute onset and fluctuating discourse

AND

2. Inattention

AND EITHER

3. Disorganized thinking

OR

4. Altered level of consciousness

**Source:**

Inouye SK, van Dyck CH, Alessi CA, Balkin S, Siegel AP, Horwitz RI. Clarifying confusion: the confusion assessment method. A new method for detection of delirium. *Ann Intern Med.* 1990;113(12):941-948.



## Confusion Assessment Method (CAM) Diagnostic Algorithm

### Feature 1: Acute Onset and Fluctuating Course

This feature is usually obtained from a family member or nurse and is shown by positive responses to the following questions: Is there evidence of an acute change in mental status from the patient's baseline? Did the (abnormal) behavior fluctuate during the day; that is, did it tend to come and go, or increase and decrease in severity?

### Feature 2: Inattention

This feature is shown by a positive response to the following question: Did the patient have difficulty focusing attention; for example, being easily distractible, or having difficulty keeping track of what was being said?

### Feature 3: Disorganized Thinking

This feature is shown by a positive response to the following question: Was the patient's thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?

### Feature 4: Altered Level of Consciousness

This feature is shown by any answer other than "alert" to the following question: Overall, how would you rate this patient's level of consciousness? (alert [normal], vigilant [hyperalert], lethargic [drowsy, easily aroused], stupor [difficult to arouse], or coma [unarousable])

### Source:

Inouye SK, van Dyck CH, Alessi CA, Balkin S, Siegel AP, Horwitz RI. Clarifying confusion: the confusion assessment method. A new method for detection of delirium. *Ann Intern Med.* 1990;113(12):941-948.

# Appendix 9

## Brief Pain Inventory

STUDY ID #: \_\_\_\_\_ DO NOT WRITE ABOVE THIS LINE HOSPITAL #: \_\_\_\_\_

### Brief Pain Inventory (Short Form)

Date: \_\_\_\_/\_\_\_\_/\_\_\_\_ Time: \_\_\_\_\_


Name: \_\_\_\_\_  
 Last First Middle Initial

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

1. Yes 2. No


2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.

Front



Right Left

Back



Left Right

3. Please rate your pain by circling the one number that best describes your pain at its worst in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10  
 No Pain Pain as bad as you can imagine

4. Please rate your pain by circling the one number that best describes your pain at its least in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10  
 No Pain Pain as bad as you can imagine

5. Please rate your pain by circling the one number that best describes your pain on the average.

0 1 2 3 4 5 6 7 8 9 10  
 No Pain Pain as bad as you can imagine

6. Please rate your pain by circling the one number that tells how much pain you have right now.

0 1 2 3 4 5 6 7 8 9 10  
 No Pain Pain as bad as you can imagine

Page 1 of 2

STUDY ID #: \_\_\_\_\_ DO NOT WRITE ABOVE THIS LINE HOSPITAL #: \_\_\_\_\_

Date: \_\_\_ / \_\_\_ / \_\_\_ Time: \_\_\_\_\_  
Name: \_\_\_\_\_  
Last First Middle Initial

7. What treatments or medications are you receiving for your pain?

8. In the last 24 hours, how much relief have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you have received.

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%  
No Complete  
Relief Relief

9. Circle the one number that describes how, during the past 24 hours, pain has interfered with your:

**A. General Activity**  
0 1 2 3 4 5 6 7 8 9 10  
Does not Completely  
Interfere Interferes

**B. Mood**  
0 1 2 3 4 5 6 7 8 9 10  
Does not Completely  
Interfere Interferes

**C. Walking Ability**  
0 1 2 3 4 5 6 7 8 9 10  
Does not Completely  
Interfere Interferes

**D. Normal Work (includes both work outside the home and housework)**  
0 1 2 3 4 5 6 7 8 9 10  
Does not Completely  
Interfere Interferes

**E. Relations with other people**  
0 1 2 3 4 5 6 7 8 9 10  
Does not Completely  
Interfere Interferes

**F. Sleep**  
0 1 2 3 4 5 6 7 8 9 10  
Does not Completely  
Interfere Interferes

**G. Enjoyment of life**  
0 1 2 3 4 5 6 7 8 9 10  
Does not Completely  
Interfere Interferes

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Pain Research Group  
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Ref: Cleeland C. Pain Research Group (with permission) Copyright 1991

# Appendix 10

## Abbey Pain Scale

**Abbey Pain Scale**  
For measurement of pain in people with dementia who cannot verbalise.

**How to use scale :** While observing the resident, score questions 1 to 6.

**Name of resident :** .....

**Name and designation of person completing the scale :** .....

**Date :** ..... **Time :** .....

**Latest pain relief given was**.....**at**.....**hrs.**

<p><b>Q1. Vocalisation</b> eg whimpering, groaning, crying <i>Absent 0 Mild 1 Moderate 2 Severe 3</i></p>	Q1	<input style="width: 40px; height: 25px;" type="text"/>
<p><b>Q2. Facial expression</b> eg looking tense, frowning, grimacing, looking frightened <i>Absent 0 Mild 1 Moderate 2 Severe 3</i></p>	Q2	<input style="width: 40px; height: 25px;" type="text"/>
<p><b>Q3. Change in body language</b> eg fidgeting, rocking, guarding part of body, withdrawn <i>Absent 0 Mild 1 Moderate 2 Severe 3</i></p>	Q3	<input style="width: 40px; height: 25px;" type="text"/>
<p><b>Q4. Behavioural Change</b> eg increased confusion, refusing to eat, alteration in usual patterns <i>Absent 0 Mild 1 Moderate 2 Severe 3</i></p>	Q4	<input style="width: 40px; height: 25px;" type="text"/>
<p><b>Q5. Physiological change</b> eg temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor <i>Absent 0 Mild 1 Moderate 2 Severe 3</i></p>	Q5	<input style="width: 40px; height: 25px;" type="text"/>
<p><b>Q6. Physical changes</b> eg skin tears, pressure areas, arthritis, contractures, previous injuries <i>Absent 0 Mild 1 Moderate 2 Severe 3</i></p>	Q6	<input style="width: 40px; height: 25px;" type="text"/>

**Add scores for 1 - 6 and record here**           **Total Pain Score**     

**Now tick the box that matches the Total Pain Score**

0 - 2 No pain	3 - 7 Mild	8 - 13 Moderate	14 + Severe
------------------	---------------	--------------------	----------------

**Finally, tick the box which matches the type of pain**

Chronic	Acute	Acute on Chronic
---------	-------	------------------

Abbey, J; De Bellis, A; Piller, N; Esterman, A; Giles, L; Parker, D and Lowcay, B.  
Funded by the JH & JD Gunn Medical Research Foundation 1998 - 2002  
(This document may be reproduced with this acknowledgement retained)

Ref: Abbey J, De Bellis A, Piller N, Esterman A, Giles L, Parker D, Lowcay B. Funded by the JH & HD Gunn Medical Research Foundation 1998-2002.

# Appendix 11

## PAINAD

Indicator	Score = 0	Score = 1	Score = 2	Total score
Breathing	Normal breathing	Occasional labored breathing, short period of hyperventilation	Noisy labored breathing, long period of hyperventilation, Cheyne-Stokes respiration	
Native vocalisations	None	Occasional moan/groan, low level, speech with a negative or disapproving quality	Repeated trouble calling out, loud moaning or groaning, crying	
Facial expression	Smiling or inexpressive	Sad, frightened, frown	Facial grimace	
Body language	Relaxed	Tense, distressed, pacing, fidgeting	Rigid fists clenched, knees pulled up, striking out, pulling or pushing away	
Consolability	No need to console	Distracted by voice or touch	Unable to console, distract or reassure	
			<b>TOTAL</b>	

### Description

The Pain Assessment in Advanced Dementia (PAINAD) was developed to assess pain in patients who are cognitively impaired, non-communicative, or suffering from dementia and unable to use self report methods to describe pain. Observation of patients during activity records behavioural indicators of pain: breathing, negative vocalisation, facial expression, body language, and consolability.

### How to use

PAINAD is a five item observational tool with numerical equivalents for each of the five behaviour items listed, with total scores ranging from 0 to 10. Each of the five assessments contains a range from 0 to 2 and the summation of each of the five categories results in the total numerical score. Please refer to the attached item descriptions. To use:

- Assess patient during periods of activity, such as turning, ambulating, transferring.
- Assess patient for each of the 5 indicators: breathing, negative vocalisation, facial expression, body language, and consolability.
- Assign a numerical point value based on each of the 5 assessments observed.
- Obtain a total score, by adding scores from the 5 indicators. Total score ranges from a minimum of 0 to a maximum of 10.

### Populations for use

The primary population for use of the PAINAD is the adult patient with dementia who is unable to self report pain level.

### Validity and reliability

While self-report remains the 'gold standard' for pain assessment, several studies have indicated that the PAINAD is an accurate assessment tool for use in the adult patient population for whom self-report is not a reliable tool due to their altered cognitive abilities.

### References

- Herr, K. & Garand, L. (2001). Assessment and measurement of pain in older adults. *Clinics in Geriatric Medicine*, 17, 457–478.
- Leong, I., Chong, M., & Gibson, S. (2006). The use of self-reported pain measure, a nurse-reported pain measure, and the PAINAD in nursing home residents with moderate and severe dementia: a validation study. *Age and aging*, 35, 252–256.
- Warden, V., Hurley, a., Volicer, L. (2003). Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. *American Medical Directors Association*, 4, 9–15.

## **PAINAD: item definitions**

*Breathing: normal breathing is characterised by effortless, quiet, rhythmic (smooth) respirations*

- Occasional labored breathing: episodic bursts of harsh, difficult or wearing respirations.
- Short period of hyperventilation: intervals of rapid, deep breaths lasting a short period of time.
- Noisy labored breathing: sounds on inspiration or expiration. They may be loud, gurgling, wheezing. They appear strenuous or wearing.
- Long period of hyperventilation: an excessive rate and depth of respirations lasting a considerable time.
- Cheyne-Stokes respirations: rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea.

*Negative vocalisation: none is characterised by speech or vocalisation that has a neutral or pleasant quality*

- Occasional moan or groan: Moaning is mournful or murmuring sounds, wails or laments. Groaning is louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
- Low level speech: negative or disapproving quality: muttering, whining, or swearing in a low volume. Complaining, sarcastic or caustic.
- Repeated troubled calling out: phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
- Loud moaning or groaning: mournful or murmuring sounds, wails or laments in much louder than usual volume. Loud groaning is characterised by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
- Crying: an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

*Facial expression: smiling (upturned corners of the mouth with a look of pleasure or contentment) or inexpressive (neutral, at ease, relaxed)*

- Sad: an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
- Frightened: a look of fear, alarm or heightened anxiety. Eyes appear wide open.
- Frown: a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
- Facial grimacing: a distorted, distressed look. The brow is more wrinkled as is the area around the mouth. Eyes may be squeezed shut.

*Body language: relaxed: a calm, restful, mellow appearance – the person seems to be taking it easy*

- Tense: a strained, apprehensive or worried appearance. The jaw may be clenched. (exclude any contractures).
- Distressed pacing: activity that seems unsettled. May appear fearful, worried, or disturbed. Pacing may be faster or slower than usual.
- Fidgeting: restless movement. Squirming about or wiggling, may hitch a chair across the room. Repetitive touching, tugging or rubbing.
- Rigid: stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding (not contractures).
- Fists clenched: tightly closed hands. They may be opened and closed repeatedly or held tightly shut.
- Knees pulled up: flexing the legs and drawing the knees up toward the chest. An overall troubled appearance (exclude any contractures).
- Pulling or pushing away: Resists attempts of others to help. Tries to escape by yanking or wrenching free or shoving helpers away.
- Striking out: hitting, kicking, grabbing, punching, biting, or other form of personal assault.

*Consolability: no need to console: a sense of well being – the person appears content*

- Distracted or reassured by voice or touch: behaviour suggestive of distress stops when the person is spoken to or touched.
- Unable to console, distract or reassure: the inability to soothe the person or stop a behaviour with words or actions. No amount of comforting, verbal or physical, will alleviate the behaviour suggestive of distress.



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