المجلس الصحي السعودي
Saudi Health Council

Saudi Palliative Care National Clinical Guidelines for Oncology

2019

The National Cancer Center (NCC)

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Saudi Palliative Care National Clinical Guidelines for Oncology

Executive summary

The Saudi Palliative Care National Clinical Guidelines are a compilation of evidence of best practices in the management of adult patients with life-limiting illnesses. The guidelines are designed for use by healthcare professionals at any care setting who are involved in supporting people with a palliative life-limiting condition.

The guidelines have been developed by a multidisciplinary group of professionals working in the community, hospitals, and specialist palliative care services throughout Saudi Arabia. They have been developed in accordance with AGREE Criteria and are supported by the National Cancer Center (NCC) at the Saudi Health Council.

The purpose of the Saudi Palliative Care Guidelines is to provide in a readily usable format, practical, evidence-based or best-practice guidance on a range of common clinical issues. This will be of benefit to both generalist and specialist providers of palliative care. Development of these guidelines provides a practical guide to standardize practice among healthcare professional to deliver the best quality care for palliative care patients and their families. The guidelines have been adapted from recognized palliative care resources and institutions.

Adherence to guidelines recommendations will not ensure a successful outcome in every case. It is the responsibility of all professionals to exercise clinical judgment in the management of individual patients. Palliative care specialists may occasionally use or recommend other drugs, doses, or drug combinations.

 The NCC would like to thank all those involved in the preparation of these resources.

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Table of Contents

Introduction

The aim of the Saudi Palliative Care National Clinical Guidelines for Oncology is to help assure that each patient with cancer experiences the best quality of life possible through the illness path by providing guidance to the oncology team. The palliative care guidelines committee is a multidisciplinary team of representatives from different health sectors in Saudi Arabia, consisting of family medicine, oncologists, palliative care consultants, palliative care and pain management specialists, palliative care nurses, psychiatrists, social workers, researchers, and public health specialists. These guidelines were developed and updated annually by the support of the National Cancer Center (NCC) at the Saudi Health Council, and by the collaborative efforts of these experts based on their clinical experience, and up to date evidence-based science.

Palliative care

The World Health Organization (WHO) describes palliative care as services designed to prevent and relieve suffering for patients and families facing life-threatening illness, through early management of pain and other physical, psychosocial, and spiritual problems.[1] This care includes addressing practical needs and providing bereavement counseling, and offers a support system to help patients live as actively as possible until death.[1]

End of life care

End of life care is defined as a phase of life when a person is living with an illness that will worsen and eventually cause death. It is not limited to a short period of time when the person is moribund. [1]

Background

Palliative care is required for a wide range of diseases. Worldwide, there is a major population of adults in need of palliative care who have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%).[1] Many other conditions may require palliative care, including kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies, and drug-resistant tuberculosis. [1]

Today, Saudi Arabia has a total population of over 32.3 million, the majority are Saudis based on 2016 statistics. The percentage of the population living in urban areas is 82.3%d and the life expectancy at birth is 76 years.[2]

The burden of disease (2016) attributable to communicable diseases is 11%, non-communicable diseases 73.0% and injuries 16%(Figure 1).[2] The share of out-of-pocket expenditure was 19.8% in 2013 and the health workforce density is 26.5 physicians and 53.73 nurses and midwives per 10 000 population (2014) [3]

The total deaths are over 114,000 and non-communicable diseases are accounted for 73% of these deaths. [2] This population can benefit tremendously if they were managed by palliative care services when access is guaranteed for them before death (Figure 1).[2]

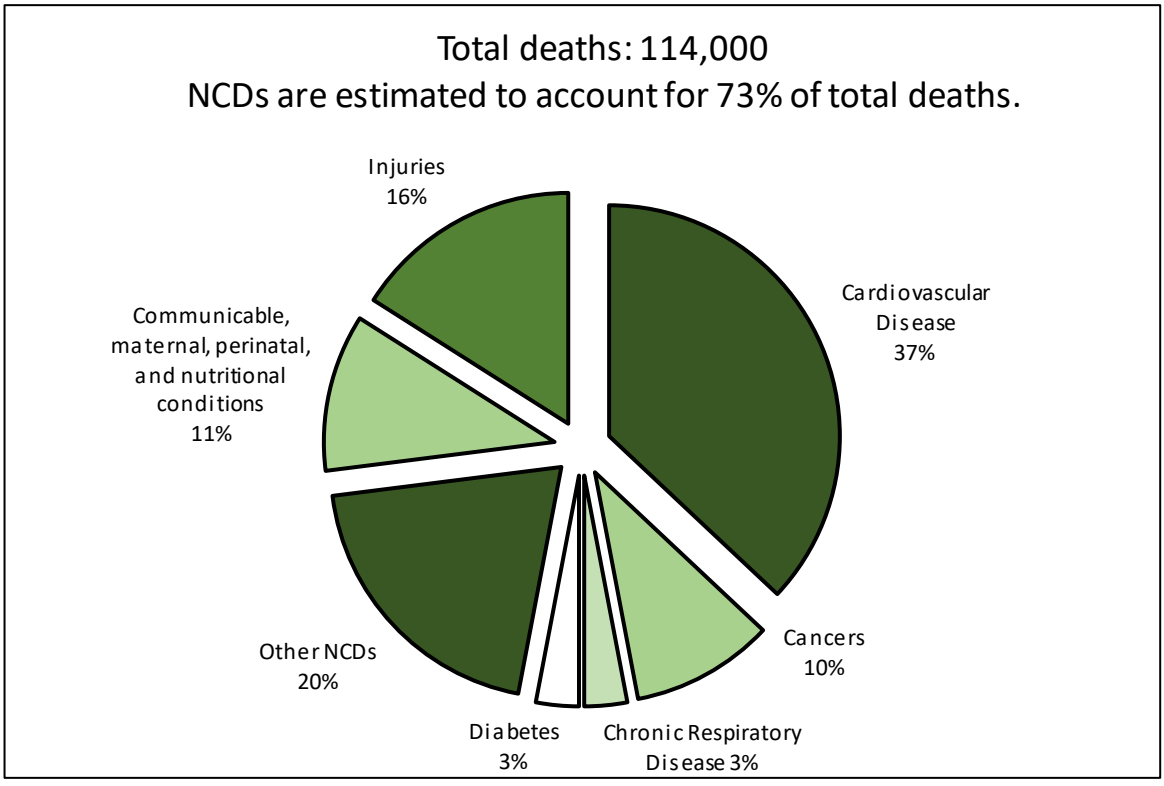

Figure 1. *Proportional Mortality (% of total deaths, all ages, both sexes)*[2]

Guidelines Summary

Scope and Target Population

- These guidelines were developed for healthcare professionals in Oncology settings caring for adult and pediatric patients with life-limiting, life-threatening or chronic, progressive illnesses.
- Also for patients seeking curative or life-prolonging treatments; or patients who are best served by active end-of-life management.

Clinical Highlights:

- Palliative care improves the quality of life of patients and their families who are facing problems associated with a life-threatening illness, whether physical, psychosocial or spiritual. [1]
- Each year, an estimated 40 million people need palliative care, 78% of them people live in low- and middle-income countries. [1]
- Worldwide, only about 14% of people who need palliative care currently receive it. [1]
- Overly restrictive regulations for morphine and other essential controlled palliative medicines deny access to adequate pain relief and palliative care. [1]
- Lack of training and awareness of palliative care among health professionals is a major barrier to improving access. [1]
- The global need for palliative care will continue to grow as a result of the rising burden of non-communicable diseases and aging populations. [1]
- Early palliative care reduces unnecessary hospital admissions and the use of health services. [1]

General Guidelines

- Palliative care is applicable to oncology patients regardless of age, race, and setting. [4]
- Palliative care is holistic care provided to patients who need comprehensive and supportive care throughout the illness trajectory. [4]
- Patients and families are the unit and focus of this type of care. [4]
- End of life care and care of dying is only one component of palliative care which can be provided aggressively when patients have six months or less of life expectancy in accordance with their prognosis. [4]
- Comprehensive assessment of the patient's and family's physical, psychological, social, cultural, and spiritual symptoms/ dimensions by interdisciplinary team IDT is the key to proper management and delivery of optimum care. [4]
- Patient and family beliefs, values, and culture should be respected and taken into consideration in developing plans of care. [4]
- Advanced care planning, short and long-term goals of care should always be discussed and agreed upon by the patient/ family through regular family meetings. [4]
- Developing successful plans of care should take into consideration patient and family readiness and the possibility of meeting the proposed care plans, as well as, the suitability of the plan with the current family situation/condition. [4]
- There is no time limit in terms of life expectancy – patients may or may not be dying. All hospice is palliative care, but not all palliative care is hospice. [4]
- Assessment, reassessment, and adjustment of the patient's plan of care as the condition progress, utilizing the domains of palliative care is an ongoing process. [5]
- Planning for palliative care should begin early in the patient's journey of serious illness regardless if the patient was in primary, secondary, or tertiary level of care. [5]
- Suffering is common in this patient population. All efforts should be made to ensure the alleviation of suffering in physical, cultural, psychological, social, spiritual, financial, ethical and legal issues. [5]

- Managing symptoms/ issues depends on the quality of communication with patients and families through setting realistic goals of care, and providing realistic hope. [5]
- Engaging patients in decisions about their care increases their involvement and satisfaction through Shared Decision-Making (SDM) is a method to engage patients and ensure satisfaction with care. [5]
- Palliative care is compatible with all other medical treatments. [5]
- Healthcare professionals play an important role in the grief and bereavement processes by supporting the patient and family throughout the course of illness and following the patient's death. [5]

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CHAPTER 1
CANCER PAIN MANAGEMENT

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CHAPTER 1:- CANCER PAIN MANAGEMENT

1. STATEMENT OF PURPOSE

1.1 To provide guidance for Palliative Care Physicians on how to assess and treat cancer pain effectively and safely in patients aged 14 years and above.

2. RELATED DOCUMENTS

2.1 Pain Assessment and Management

2.2 Cancer Pain Assessment, Re-Assessment and Management Form

2.3 Management of Delirium in Palliative Care

3. DEFINITIONS

3.1 **Cancer pain:** A complex, temporally changing symptom which is the end result of mixed mechanism pain. It involves inflammatory, neuropathic, ischemic, and compression mechanisms at multiple sites. It is a subjective, heterogeneous experience that is modified by individual genetics, past history, mood, expectation, and culture.

3.2 **Cancer Centre (CC) Pain Assessment/Reassessment and Management form:** A form used to document pain assessment/re-assessment and management following the administration of PRN and STAT medications for palliative related pain in CC patients.

3.3 **Physical dependence:** a normal physiological response to the pharmacological effects of chronic opioid administration. It is only seen when the administration of the opioid is abruptly stopped or an antagonist is administrated.

3.4 **Withdrawal syndrome:** Typically characterized by sweating tremors, agitation, muscle cramps, tachycardia, fever and dilated pupils.

3.5 **Addiction (psychological dependence)**: Is a pathologic psychological condition that includes a compulsion to take a specific drug (e.g., opioid) to experience its psychic effects.

3.6 **Tolerance**: A normal physiological phenomenon in which increasing doses of an opioid are required overtime to produce the same analgesic effect.

4. GENERAL GUIDELINES:

4.1 Palliative Care Physicians should treat cancer-related pain promptly.

4.2 Palliative Care Physicians shall explain and educate patients, their family and other caregivers about pain and its management.

4.3 In relation to pain assessment, Palliative Care Physicians shall consider the following:

4.3.1 Patients on opioid will require regular assessments.

4.3.2 Assessments must include monitoring for opioid adverse effects and signs of disease progression.

4.3.3 Opioid titrations shall be required to manage increased pain that results from disease progression or opioid tolerance.

4.3.4 Failure to assess pain can lead to less than optimal pain control for the patient.

4.3.5 Assessments shall occur:

4.3.5.1 At regular intervals after initiation of the treatment;

4.3.5.2 At each new report of pain or change in quality/intensity of pain; and

4.3.5.3 At a suitable interval after pharmacological or non-pharmacological interventions.

4.3.6 The goal of the initial pain assessment is to characterize the pain by location, intensity and etiology.

4.3.7 Essential to the initial pain assessment is:

4.3.7.1 A detailed history.

4.3.7.2 A physical examination.

4.3.7.3 A psychosocial assessment.

4.3.7.4 A diagnostic evaluation.

4.4 In treating cancer pain, Palliative Care Physicians shall follow a stepped approach that depends on the severity of pain.

4.5 When initiating opioid, Palliative Care Physicians shall use the following opiate agonists: Codeine, Oxycodone, Morphine, Hydromorphone, Fentanyl and Methadone. Their effectiveness is not limited by a 'ceiling' with increasing doses. Full agonists, unlike the partial agonists or mixed agonists-antagonists, will also not reverse or antagonize the effects of other full agonists.

4.6 Analgesics shall be regularly administered if patients are experiencing constant pain.

4.7 Patient shall be started on an analgesic according to the severity of his/her pain. The following steps shall be considered:

4.7.1 For mild pain: Start with a non-opioid (e.g.: Acetaminophen) or a weak opioid (e.g., codeine):

4.7.1.1 Acetaminophen (325 mg to 650 mg q4hr PO and 325 mg to 650 mg q1h PRN). (Maximum number of acetaminophen tablets: 14-16/day- each tablet being 325mg).

4.7.1.2 Codeine 30-60 mg q4hr PO regularly and q1hr PO PRN for rescue doses (Codeine can also be given subcutaneously for patients who are unable to take oral medications).

4.7.1.3 If the pain persists or worsens: Optimize the above dose of the analgesic and if this does not improve the pain, switch to a stronger opioid (e.g. Morphine, Hydromorphone): E.g., If morphine is chosen, the starting dose is 5mg q4h PO regularly and 2.5 mg q1hr PO PRN for rescue doses.

4.7.2 For moderate to severe pain: Start with a stronger opioid (e.g., Oxycodone, Morphine or Hydromorphone).

4.7.2.1 If the pain persists or worsens, optimize the opioid dose by increasing the dose progressively. The upper limit is determined primarily by toxicity. If using combination drugs, (e.g., Oxycodone with Acetaminophen or Acetylsalicylic Acid), the dose is limited by the risk of Acetaminophen or Acetylsalicylic acid toxicity.

4.7.2.2 If unsuccessful in controlling the pain with the above measures, or if toxicity occurs, switch to a different opioid.

4.7.2.3 Adjuvants may be used but first optimize the opioids.

4.7.2.3.1 Note non-opioid drugs also cause adverse effects. For example, NSAIDS can result in renal impairment or GI effects.

4.7.2.4 Where possible avoid polypharmacy.

4.7.2.5 Always consider non-drug modalities e.g., radiotherapy for bone pain, surgical repair of a pathological fracture.

4.8 Palliative Care Physicians shall always prescribe "breakthrough" analgesic doses.

4.9 In general, Palliative Care Physicians must consider opioids as only one part of the total management of pain.

4.10 Patients with rapidly changing clinical circumstances, such as terminally ill patients, shall require on-going assessments.

4.11 If following non-pharmacological measures, such as surgery neurosurgery, radiation or anaesthetic procedures, a patient's pain is alleviated his/her opioid dose should be reduced at a rate of 15-20% per day rather than being abruptly discontinued.

4.12 Palliative Care Physicians shall note that cross-tolerance between various opioids is not complete and an alternative drug can be substituted if the rate of development of tolerance is a problem or if the patient experiences dose-limiting side effects from one particular opioid. However, they shall remember that for patients with cancer, the most frequent reason for dose escalation is the progression of the disease-causing increased pain.

4.13 Palliative Care Physicians should be aware that almost all patients with pain due to advanced cancer would require treatment until death.

4.14 Palliative Care Physicians should consider that placebos should not be used in the management of cancer pain.

4.15 Palliative Care Physicians shall be aware that opioid toxicity (myoclonus, delirium, hyperalgesia, hallucinations, intractable nausea) occurring in patients taking opioids in high doses or for prolonged periods of time or in patients who develop renal impairment, it believed to be a result of active opioid metabolite accumulation.

4.16 If opioid-related toxicity occurs, palliative care physicians shall manage it by switching from one opioid to another opioid agonist, hydration, and reducing the opioid dose. Reducing the opioid dose is an option if the pain is well controlled and the toxicity is minimal. A combination of rotating to an alternative opioid and hydration is often effective.

5.

5.1 Determine the nature and possible causes of pain with the following considerations (see also Appendix 3):

5.1.1 Identifying the etiology of pain is essential to its management.

5.1.2 Prompt diagnosis and treatment of these syndromes can reduce morbidity associated with unrelieved pain.

5.1.3 In the great majority of patients, the history, physical examination and, occasionally, an x-ray, are adequate to appropriately assess the pain. In most cases, the pain is caused by direct tumor involvement.

5.1.4 Psychological, cultural and chemical addiction factors can further influence a patient's pain experience

5.1.5 The pathophysiology of neuropathic pain can be very complex.

5.1.6 The initial injury to the nervous tissue can occur peripherally, in the central nervous system, or a mixture of both peripheral and central (e.g., brachial plexopathy), but the pain can be propagated and maintained by processes proximal to the initial injury site, including processes in the central nervous system. The autonomic nervous system is also occasionally involved.

5.2 Measure the pain intensity as follows:

5.2.1 A mainstay of assessment is the patient's self-reporting of the pain intensity. However, in patients with significant cognitive impairment, this may not be possible.

5.2.2 Palliative care physicians should teach patients and families to use pain assessment tools in their homes. Numerical, verbal or visual analogue scales (0=no pain to 10= worst possible pain) are common. These scales can be used for symptoms other than pain (See Appendix 4: Suggested Pain Scales, Pain Assessment and Management, Cancer Pain Assessment, Re-Assessment and Management Form). However, words, fingers of a hand, etc., are all valid and reproducible ways of assessing pain intensity.

5.2.3 The usefulness of these scales becomes even more evident when they are used on an ongoing basis for the same patient.

5.3 Perform a multidimensional assessment (see Appendix 6) and note that:

5.3.1 Terminally ill patients should be assessed regularly since symptoms can change rapidly.

5.3.2 A pain assessment that considers the multiple dimensions of a patient's expression of pain is required.

5.3.3 Generally, nociception remains the main component of pain. Therefore, most patients are likely to experience excellent pain control if regular analgesics are administered.

5.3.4 Approximately 25% of patients are unable to achieve pain relief by simple measures. This is generally a result of poor prognostic factors such as bone or nerve pain. Palliative Care Physicians are therefore advised to consider the presence of poor prognostic factors in patients who do not achieve effective pain relief, perform comprehensive assessments and administer alternative agents.

5.4 Identify poor prognostic factors by considering the following:

5.4.1 Poor prognostic factors for pain control are:

5.4.1.1 Neuropathic pain.

5.4.1.2 Incidental pain (pain severely exacerbated by an incident such as movement, coughing, etc.)

5.4.1.3 Impaired cognitive functioning.

5.4.1.4 Major psychological distress.

5.4.1.5 Positive history of alcohol abuse or drug addiction (indicates poor coping strategies).

5.4.2 Somatization factor:

5.4.2.1 Pain that has a large psychosocial or spiritual component is often referred to as "total pain" or "total suffering". Suspect somatization if:

5.4.2.1.1 Significant psychosocial or spiritual issues are identified.

5.4.2.1.2 The patient describes pain as "all over" (in absence of physical cause for "all over" pain such as widespread skeletal metastases or accumulation of opioid metabolites).

5.4.2.1.3 Pain appears to improve with socialization, physical activity or other distraction, and increases when alone.

5.4.2.1.4 Escalating doses of opioids produce toxicity with little or no pain relief.

5.4.2.1.5 There is a history of somatization under stress.

5.5 Start a patient on opioid as follows:

5.5.1 Initiate opioid by using the following opiate agonists:

5.5.1.1 Codeine

5.5.1.2 Oxycodone

5.5.1.3 Morphine

5.5.1.4 Hydromorphone

5.5.1.5 Fentanyl

5.5.1.6 Methadone

5.5.2 Use the following starting doses:

5.5.2.1 Morphine 5mg q4h regularly and 2.5mg or 5mg PO 1qh PRN for breakthrough pain.

5.5.2.2 Hydromorphone 1mg q4h regularly and 0.5mg (1mg is more practical) q1h PO for PRN.

5.5.2.3 Oxycodone 5mg q4h PO regularly and 5mg q1h PO PRN.

5.5.3 Titrate the dose, over the next few days, to achieve good pain control noting that:

5.5.3.1 More than three PRN doses per day can be an indicator that pain may not be adequately controlled.

5.5.4 Determine the new dose by increasing the total daily opioid dose by 25-75% depending on the severity of the pain or by using the following formula:

5.5.4.1 Add the number of breakthroughs being used in a 24-hour period to the total daily dose. Then divide by 6 to get the 4qh doses.

5.5.5 Prescribe breakthrough doses/rescue dose (PRN) noting that:

5.5.5.1 These are an important component of the analgesic strategy since patients may experience pain in between their regularly scheduled opioid doses and will require a rescue dose of opioid to provide relief of this breakthrough pain.

5.5.5.2 Breakthrough doses are generally approximately 5-20% of the total daily dose and are usually ordered q1h on an as-needed basis (PRN).

5.5.5.3 An assessment of their effectiveness must be sought and further titration used if needed.

5.5.6 Select the route of administration noting the following:

5.5.6.1 As a first choice use oral administration because it is convenient and usually effective.

5.5.6.2 When patients cannot take oral medications, other routes should be considered (e.g. subcutaneous, rectal transdermal).

5.5.6.3 Do not use a slow-release opioid formulation to start a patient on opioids. These can be difficult to titrate.

5.5.6.4 Avoid controlled-release formulations when switching opioids or in unstable situations.

5.5.7 Warn/inform the patient of potential side effects of opioids such as nausea-myclonus (jerking of limbs or facial muscles), constipation, hyperalgesia/allodynia, somnolence, delirium, dry mouth (xerostomia), hallucinations, pruritus, and cognitive impairment. Noting that usual manifestations are:

5.5.7.1 Increased nausea for the first three to four days.

5.5.7.2 Increased somnolence for the first three to four days (both of these side effects usually disappear with continued use of the drug).

5.5.7.3 Constipation.

5.5.8 Treat any opioid side-effects by noting and prescribing the following:

5.5.8.1 Antiemetic: Metoclopramide 10mg PO/SC q1h PRN for nausea. If nausea is a problem, regular Metoclopramide can be given (e.g., QID or q4hrs) for the first three to four days.

5.5.8.2 Laxatives: Use both a stimulant and a stool softener, e.g., Senna two tabs PO at bedtime and Docusate 100-240 mg PO BID to start with. These can then be further increased to ensure a bowel movement at least every 2nd to 3rd day. Avoid bulk laxatives. These patients frequently have anorexia, early satiety and chronic nausea, and are not able to ingest the necessary amounts of liquids for these laxatives to be effective.

5.5.9 Explain to patients that the opioid needs to be taken every four hours if immediate release formulations are used.

5.5.10 Consider the following if the patient is experiencing disturbed sleep:

5.5.10.1 Double the regular bedtime dose

5.5.10.2 Give regular dose then offer breakthrough doses whenever he or she wakes up during the night and resume regular regimen in the early morning on awakening.

5.5.10.3 Encourage normal activity and good fluid intake.

5.5.10.4 Avoid activities that can be affected by increased somnolence.

5.5.10.5 Reassure the patient and family.

5.5.10.6 Ask the patient and family about fears regarding opioids and address these fears if present.

5.5.10.7 Explain to the patient the difference between physical dependence, addiction, and tolerance.

5.6 Manage opioid toxicity as follows:

5.6.1 Hydrate. The rationale for hydration is that it can correct delirium caused by dehydration and renal impairment which, in turn, causes metabolites to accumulate.

5.6.1.1 If oral intake is limited, parenteral hydration may need to be started. Hypodermoclysis (subcutaneous hydration) can be used. E.g., hypodermoclysis: N/S @ 80-100 ml/hr. (hyaluronidase 150U to each liter is only required if the subcutaneous site leaks significantly.

5.6.1.2 Warn the patient that the site will swell up but as long as it is not inflamed, the swelling should subside.

5.6.2 Rotate opioid (see Appendix 9).

5.6.3 Exclude underlying aggravating metabolic factors. E.g., uremia or Hypercalcemia

5.6.4 Treat symptoms. E.g., Hallucinations, Agitation noting that:

5.6.4.1 Haloperidol is the drug of choice (see Management of Delirium in Palliative Care).

5.6.4.2 Benzodiazepines or other drugs such as Baclofen or Clonazepam are almost never required to treat opioid metabolite induced myoclonus or toxicity. Increased benzodiazepines are only required if the myoclonus is so severe that a generalized seizure appears to be imminent or of the myoclonic jerks are painful.

5.6.4.3 In the presence of renal impairment with no clinical signs of opioid toxicity, the opioid dose may need to be decreased of the probable accumulation of opioid metabolites.

5.6.4.4 Use controlled release (CR) opioid formulations. Several opioids are now available in controlled-release formulations.

5.6.4.4.1 Codeine (PO),

5.6.4.4.2 Oxycodone (PR),

5.6.4.4.3 Morphine (PO and PR),

5.6.4.4.4 Hydromorphone (PO),

5.6.4.4.5 Fentanyl (TID).

6. APPENDIX

6.1 Appendix 1: Algorithm for Cancer Pain Management

6.2 Appendix 2: Algorithm for Cancer Pain Management – Cancer Progression

6.3 Appendix 3: Causes of Pain in a Patient with Advanced Cancer

6.4 Appendix 4: Steps in the Pain Experience

6.5 Appendix 5: Components of Multidimensional Pain Assessment

6.6 Appendix 6: Opioids not to be Used

6.7 Appendix 7: Titrating Opioids

6.8 Appendix 8: Opioid Rotations

6.9 Appendix 9: Comprehensive Cancer Centre Pain Assessment/Reassessment and Management form

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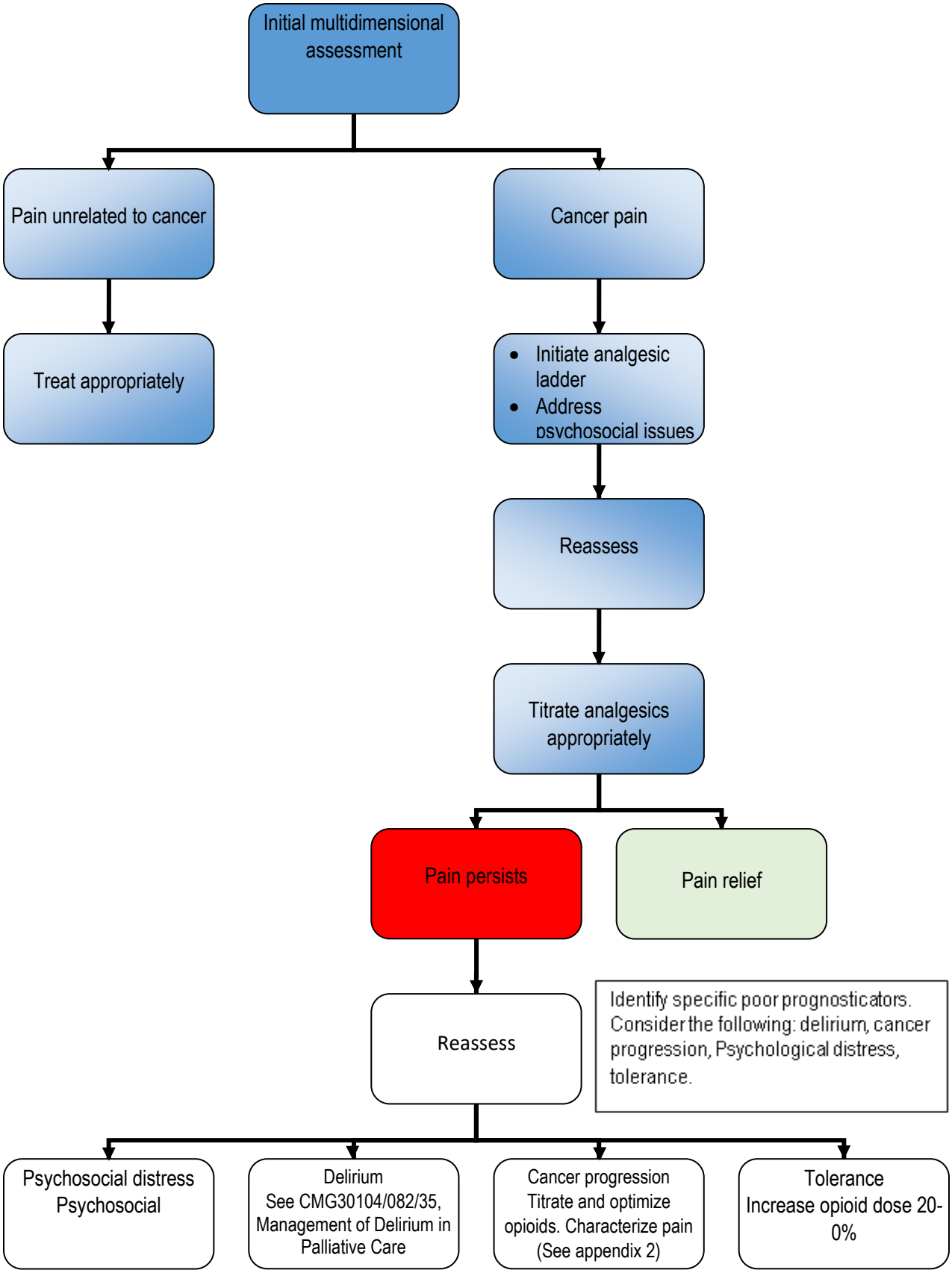
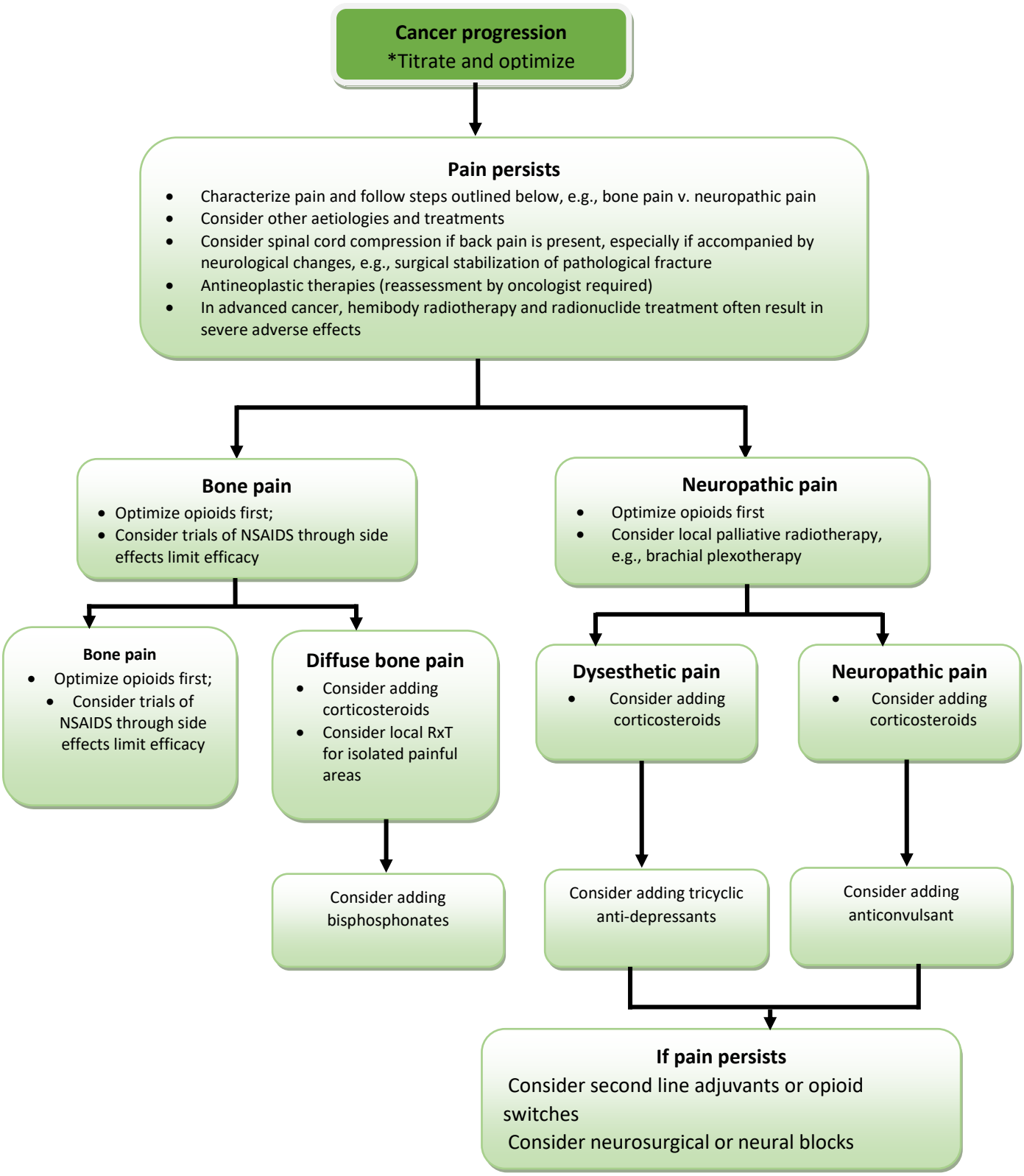
Appendix 1: Algorithm for cancer pain management



Appendix 2: Algorithm for cancer pain management – cancer progression



Appendix 3: Causes of Pain in a Patient with Advanced Cancer

What are the causes of pain in a patient with advanced cancer?

Direct tumor involvement (78%), which might include:

- Bone metastases,
- Nerve compression/infiltration,
- Hollow viscus, or
- Visceral organs.

Related to cancer therapy (19%), which might include:

- Surgery,
- Radiotherapy, or
- Chemotherapy – neuritis.

Pain unrelated to cancer or cancer therapy (3%), which might include:

- Post herpetic neuralgia,
- Arthritic pain, or
- Pain of any kind significantly influenced by a large psychosocial or spiritual component.

Why do we classify pain?

- Assists in understanding the underlying pathology.
- Certain types of pain such as neuropathic pain and incidental pain can be difficult to control and may require higher doses of opioids, trials pf different opioids or the addition of appropriate adjuvant analgesics.

Characterize the pain. The following are various clinical presentations of pain.

Nociceptive pain

a.) Somatic

- Constant or intermittent
- Usually gnawing, aching
- Occasionally cramping
- Well localized

Mechanism: activation of nociceptive receptors, e.g., bone metastases or muscle/soft tissue tumour infiltration.

b.) Visceral pain

- Constant
- Aching, squeezing, cramping
- Poorly localized, occ. Referred, Occasionally well localized

Mechanism: activation of nociceptors, e.g., intra-abdominal metastases liver metastases.

Neu7opathic pain

Mechanism: destruction, infiltration, compression of nerve tissue. Neuropathic cancer pain can have two main clinical manifestations.

a.) Dysesthetic pain (deafferentation)

- Constant burning
- Occasionally radiates, e.g., post herpetic pain

b.) Neuraligic pain

- paroxysms of lancinating pain
- sharp, shooting pain, e.g., trigeminal neuralgia

Appendix 4: Steps in the Pain Experience

Keep in mind that there are those steps in the pain experience:

Production of pain (nociception). This occurs at the site of the cancer. This cannot be measured directly and can be different from cancer to cancer, site to site, etc.

Perception. This occurs at the level of the central nervous system/brain. This component too cannot be measured and is also subject to the influence of modulation.

Expression. The expression of pain is the main target of all our assessments and treatment. Two patients with the same level of perception may express dramatically different pain intensity. Therefore, we should not equate the intensity of pain expression directly with no nociception. Doing this would be a one-dimensional approach that ignores the complexity of the pain experience.

Appendix 5: Components of Multidimensional Pain Assessment	
The components of multidimensional pain assessment:	
Pain syndrome	What type of pain is it? ➢ Location, radiation, intensity (use pain assessment scale), triggers ➢ Bone pain ➢ Visceral pain ➢ Neuropathic pain ➢ Incidental ➢ Are there other symptoms that need controlling?
Drug	➢ What is the dose? ➢ Are there indications of tolerance? ➢ Are there signs of toxicity? ➢ What has been the response to individual opioids? ➢ What other treatments have been/are being used for pain relief?
Patient	➢ Are there underlying metabolic abnormalities (e.g., renal impairment, hypercalcemia, hepatic encephalopathy, etc.)? ➢ Is there significant psychological distress? ➢ How has the patient coped previously with life stressors? ➢ Is there a history of drug/alcohol addiction? ➢ Is the patient cognitively impaired/delirious? (Use screening tools such as Folstein MMSE to assess cognition? ➢ Are there spiritual issues that need to be addressed (e.g. what is the meaning of pain to the patient?)
Social	➢ How does pain influence the patient's daily living? ➢ What are the family and social support systems? ➢ Is there severe family dysfunction? ➢ Are there financial concerns? ➢ Are there cultural issues influencing the illness experience?
Alert Back pain that radiates and increases with straight leg raise may indicate a cord compression.	

Appendix 6: Opioids not to be used

Avoid the following opioids

- Meperidine: with chronic use its metabolite (Normeperidine) often accumulates and causes neurotoxicity such as delirium and seizures.
- Partial agonists e.g., Buprenorphine, these opioids have less effect than full agonists at opioid receptors. They are also subject to a ceiling effect – i.e., increasing the doses above a specific point does not result in increased analgesia but, rather, in more side effects. Patients taking opioid agonists (e.g., Morphine or Hydromorphone) may develop withdrawal problems when Buprenorphine is started. When patients are changed from buprenorphine to a full agmionists opioid, the action of the agonists will be delayed.
- Mixed agonists-antagonists, e.g., Butorphanol, Nalbuphine, Pentazocine: they block or are neutral with one type of opiate receptor while activating a different opiate receptor. These have a high incidence of psychotomimetic side effects and they may cause withdrawal symptoms when given to patients receiving opioid antagonists. Their analgesic effectiveness is also limited by a dose-related ceiling effect.

Appendix 7: Titrating Opioids

Titrating opioids

In most cases, titration involves an increase in opioid dose. Dose increases can either be:

i.) 30-50% increases of the previous dose – e.g., if the previous dose was morphine 120mg PO/day, the new dose, if a 50% increase is decided upon, will be 180mg/day; or

ii.) The new dose may be determined by the average amount of opioid used as breakthrough doses per 24 hours – e.g., a patient is taking morphine 20mg PO regularly every four hours and has used on average, five breakthrough doses per day in the previous couple of days. Each breakthrough dose consists of morphine 12mg PO The total amount of breakthrough opioid is, therefore, 60 mg of PO morphine per day. This is then added to the regular dose of 120 mg per day, giving a total daily dose of 180 mg (morphine 30mg PO 4qh around the clock.

If the pain is severe, a further 20-30% of the total daily dose may be required.

Occasionally, opioid doses may need to be reduced.

i.) If pain improves dramatically as a result of other interventions (e.g., palliative radiotherapy, surgical fixation of a pathological fracture);

ii.) Severe sedation due to opioids is accompanied by good pain control; or

iii.) Renal impairment is present.

One to three regular opioid doses can be withheld in patients with very severe side effects – i.e., severe sedation, miosis, respiratory depression. If an acute overdose occurs, naloxone may need to be administered if respiratory rate is less than eight per minute.

What is the maximum dose of an opioid agonist?

Contrary to other drugs, such as anticoagulants or anticonvulsants, that have an established safety dose range, the adequate dose of opioid agonist is extremely variable and it should be titrated according to analgesic effects and toxicity, e.g., while one patient may achieve excellent pain control on 5mg of morphine orally every four hours, another may require 50mg of morphine every four hours and another 500mg every four hours. The maximum dose is limited by toxicity and this varies widely from patient to patient.

Appendix 9: Pain Assessment and Reassessment Form

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Patient ID Label

PAIN ASSESSMENT AND REASSESSMENT FORM

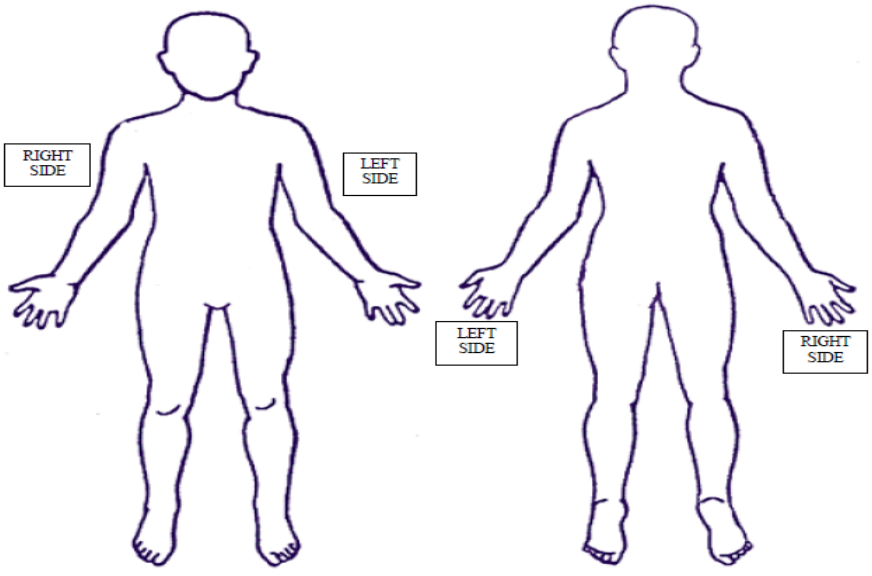
Date			
Time			
Location (Refer to figure below)			
Pain Intensity			
Pain Rating Scale Used (Refer to page 2)			
Character Code			
Duration			
Pain Radiation	☐ YES ☐ NO Location _____	☐ YES ☐ NO Location: _____	☐ YES ☐ NO Location _____
Pain Pattern	☐ Constant ☐ Intermittent	☐ Constant ☐ Intermittent	☐ Constant ☐ Intermittent
Pain Onset	☐ Acute ☐ Chronic	☐ Acute ☐ Chronic	☐ Acute ☐ Chronic
Alleviating Factor			
Aggravating Factor			
Non-medication Intervention (Heat packs, Cold packs, Repositioning/turning, ambulation, Relaxation Exercises			
Medication/s (Type, Dose, Frequency)	1 _____ 2 _____ 3	1 _____ 2 _____ 3	1 _____ 2 _____ 3
Assessor's Initial and ID#			

CHARACTER CODES

1	Sharp حاد	5	Crushing ساحق	9	Colic مغص	13	Pressing ضاغط
2	Dull غيرواضح	6	Deep عميق	10	Throbbing نابض	14	Tight ماسك
3	Stabbing طعن	7	Sore متقرح	11	Numb خدر	15	Pulling شد
4	Burning ملتهب	8	Aching موجع	12	Shooting ضارب/صارخ	16	Squeezing عصر

PAIN IN NUMERICAL REPRESENTATION (e.g 1 - shoulder pain; 2- lower back pain):

Instruction: Please mark on the specific location of pain on the figures below using numbers to represent the pain.



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PAIN RATING SCALES

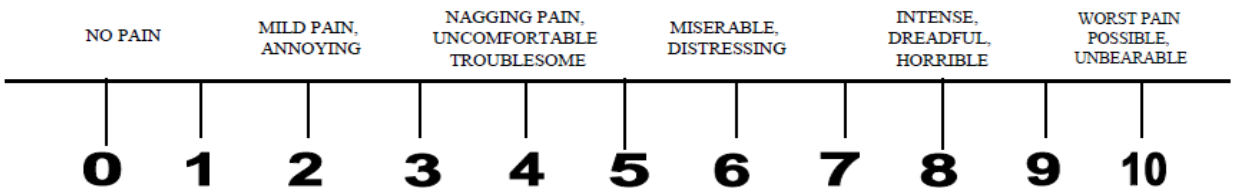
General Instructions: Choose only one appropriate scale based upon the patient's ability to respond. Identify the scale used and the score for that scale on the bottom of this form. Any score above 4 requires Pain Assessment.

FACES SCALE:

Initial Intructions: Explain to the patient that each face is for a person who feels happy because he or she has no pain (hurt) or sad because he or she has some or a lot of pain. FACE 0 is happy because he or she doesn't hurt at all. FACE 2 hurts just a little bit FACE 4 hurts a little more. FACE 6 hurts even more. FACE 8 hurts a a whole lot. FACE 10 hurts as much as you can you don't have to be crying to feel this bad. Ask the patient to choose the face that best describes how he or she is feeling.

لايوجد الم	عدم ارتياح بسيط	ألم محتمل	ألم متعب	ألم شديد	ألم لا يحتمل
MAFE ALAM	ALAM MOUTADEL	ALAM MOUHTAMAL	ALAM MUTEEB	ALAM SHADEED	ALAM LA'UHTAMAL

NUMERIC SCALE: Choose a number from 0-10 that best describes the level of pain



FLACC SCALE:

Initial Instructions: The FLACC is a behavior pain assessment scale for use with nonverbal patients who are unable to provide reports of pain. Rate the patient in of the five measurement categories, add the scores together , and document the total pain score

	0	1	2
FACE	No particular expression of smile	Occassional grimace or frown, withdrawn, disinterested	Frequent to constant frown, clenched jaw, quivering chin
LEGS	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drwan up
ACTIVITY	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid or jerking
CRY	No crying (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
CONSOLABILITY	Content, relaxed	Reassured by occassional touching, hugging or "talking to". Distractible.	Difficult to console or comfort

ABBEY PAIN SCALE:

A tool developed to measure severity of pain in people with late-stafe dementia or people who cannot verbalize. Each item is leveled on a four point scale for severity of the behaviour (Absent: 0; Mild: 1; Moderate: 2; Severe: 3) with total score ranging from 0-18. The total score is then interpreted as severity of pain: **No pain 0-2; Mild: 3-7; Moderate: 8-13; Severe: 14+.**

Q1: Vocalization (eg whimpering, groaning, crying)	**Q4: Behavioural change** (eg increased confusion, refusing to eat, alteration in usual patterns)
Q2: Facial expression (eg looking tense, frowning, grimacing, looking frightened)	**Q5: Physiological change** (eg temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor)
Q3:Change in body language (eg fidgeting, rocking, guarding part of body, withdrawn)	**Q6: Physical changes** (eg skin tears, pressure areas, arthritis, contractures, previous injuries)

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Patient ID Label

PAIN ASSESSMENT AND REASSESSMENT FORM

Ongoing pain assessment																												
Date																												
Time																												
Intervention																												
Character code																												
10																												
Pain location & pain score																												
0																												
Date																												
Time																												
Intervention																												
Character code																												
10																												
Pain location & pain score																												
0																												
Date																												
Time																												
Intervention																												
Character code																												
10																												
Pain location & pain score																												
0																												
Assessor's initial																												

Nurse's Remarks (note any unusual occurrence with initial and ID number at the end of each entry)

1 ______________________________

2 ______________________________

3 ______________________________

4 ______________________________

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CHAPTER 2
MANAGEMENT OF DELIRIUM

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CHAPTER 2:- MANAGEMENT OF DELIRIUM IN PALLIATIVE CARE

1. STATEMENT OF PURPOSE

1.1 To provide practical guidance in the identification, diagnosis and management of adult patients (age 14 years and older) who have advanced life-threatening illness and are experiencing delirium.

2. DEFINITIONS

2.1 **Delirium:** sudden onset, altered level of consciousness, clouded sensorium, occasionally reversible.

2.2 **Dementia:** gradual onset, unimpaired level of consciousness, chronic.

2.3 **Hyperactive delirium:** confusion, agitation, hallucinations, myoclonus (consider this is if patient presents with apparently uncontrolled pain).

2.4 **Hypoactive deliriu**m: confusion and somnolence ± withdrawn.

2.5 **Mixed delirium:** features of both above.

2.6 **Hypodermoclysis:** is a method of infusing fluid into subcutaneous tissue that requires only minimal equipment. It is a useful and easy hydration technique suitable for mildly to moderately dehydrated adult patients, especially the elderly.

3. GENERAL GUIDELINES ON DELIRIUM

3.1 All admitted palliative patients aged 14 years and older experiencing the symptom of delirium shall be assessed, diagnosed and managed by palliative care physicians.

3.2 Palliative care physicians shall observe/assess patients experiencing delirium for other symptoms such as optimal pain control.

3.3 If a patient is not able to self-report symptoms then the Physician will make his/her own assessment of findings.

3.4 Palliative care physicians shall remember the following when considering a diagnosis of delirium:

i. That there can be variability in symptoms and signs of delirium

ii. That delirium has a fluctuating course

iii. That delirium can be confused with other psychiatric disorders such as depression, dementia and psychosis.

iv. That regular screening is important.

3.5 Although it is very challenging to distinguish delirium-related symptoms and signs from pain control, palliative care physicians shall manage first the delirium.

3.6 Palliative Care Physicians shall be aware of the following common causes of delirium in palliative care:

3.6.1 Drugs: opioids, anticholinergic drugs such as tricyclic antidepressants, anticonvulsants and Benzodiazepines.

3.6.2 Infections

3.6.3 Dehydration

3.6.4 Metabolic/Organ Failure

3.6.5 Hypoxemia

3.6.6 Brain disease: metastases or primary brain tumours

3.6.7 Often multiple causes of delirium at the same time (E.g. opioid neurotoxicity, dehydration and Hypercalcemia.

3.7 Palliative Care Physicians shall also note that:

3.7.1 Etiology of delirium is unclear in approximately 50% of episodes

3.7.2 They need to consider underlying dementias in elderly patients.

3.7.3 That there is a potential to misdiagnose hypoactive delirium as depression and treat inappropriately with antidepressants.

3.7.4 That there is a potential to misinterpret agitation and the accompanying moaning and grimacing of delirium as an indication of poor pain control and respond by increasing opioid doses.

3.7.4.1 This is particularly important to remember since opioids can be a cause of delirium and prescribing more will aggravate the situation.

3.7.5 A careful review of all patient medications is essential as failing to discontinue a certain drug could be aggravating the delirium.

3.7.6 Occasionally delirium is superimposed on pre-existing dementia. Some medications that are used for symptom control in advanced disease may unmask

a pre-existing cognitive problem that was previously unrecognized by the patient's family.

3.7.7 Urinary retention can aggravate delirium.

3.7.7.1 Of particular note in cognitively impaired patients as urinary retention and constipation are common problems and increased agitated behavior can occur due to discomfort and the inability of these patients to communicate the source of their discomfort.

3.7.7.2 Note: Catheterization or dis-impaction will be unlikely to resolve the delirium but may decrease the agitation.

4 ASSESSMENT

4.1 Assessment of the patient

4.1.1 Maintain a high index of suspicion for delirium.

4.1.2 Use a screening tool to assess for cognitive decline or other signs of delirium.

4.1.2.1 Mini-Mental State Examination (MMSE- Appendix 4)

4.1.2.2 Confusion Assessment Method (CAM)

4.1.3 Ask the patient specifically about hallucinations (usually visual and tactile) and assess for paranoid ideation.

4.1.4 Examine and look for clinical signs of infection, opioid toxicity (myoclonus, hyperalgesia), dehydration, uremia, hepatic encephalopathy, etc.

4.1.5 Order appropriate investigations, e.g., CBC, electrolytes, calcium (with albumin), urea and creatinine, CXR, O_2, saturations, etc.

4.1.6 Assess for psychosocial issues/ problems or history

4.2 Identify the underlying etiology of the delirium using the following acronym (see also Appendix 2):

4.2.1.1 D - Drugs, dehydration, depression.

4.2.1.2 E- Electrolytes, endocrine dysfunction (thyroid, adrenal), ETOH (alcohol) and/or drug use, abuse or withdrawal.

4.2.1.3 L - Liver failure.

4.2.1.4 I - Infection (urinary tract infection, pneumonia, sepsis).

4.2.1.5 R - Respiratory problems (hypoxia), retention of urine or stool (constipation).

4.2.1.6 I - Increased intracranial pressure.

4.2.1.7 U - Uremia (renal failure), under treated pain.

4.2.1.8 M - Metabolic disease, metastasis to the brain, medication errors/omissions, malnutrition (thiamine, folate or B12 deficiency).

5 MANAGEMENT

5.1 Treat the underlying cause of delirium based on the following:

5.1.1 Dehydration: if a patient is unable to take in enough oral fluids, then consider hypodermoclysis with normal saline at 60-100 mg/hour subcutaneously and reassess daily. If an intravenous line is already established, hydration can be given intravenously.

5.1.2 Opioid toxicity: switch to another opioid.

5.1.3 Sepsis: start antibiotics if appropriate. Obtain consent from the patient and family where possible.

5.1.4 Drugs: discontinue drugs that aggravate the delirium, e.g., tricyclic antidepressants, benzodiazepines (based on agreed guidelines/ protocol).

5.1.5 Hypercalcemia: consider hydration and bisphosphonate or calcitonin treatment.

5.1.6 Hypoxia: treat the underlying cause and administer O_2.

5.1.7 Brain metastases: cognitive impairment induced by brain metastases may respond, at least temporarily, to corticosteroid therapy.

5.2 Treat symptoms of delirium (agitation/ hallucinations) as follows:

5.2.1 Start haloperidol:

5.2.1.1 Use 1 mg orally/subcutaneously q8 – 12hrs and 1 mg q1hour orally/subcutaneously PRN for agitation.

5.2.1.2 If the agitation/hallucinations are severe, higher doses of haloperidol are indicated, e.g., haloperidol 2mg q6-8hourly orally/subcutaneously with breakthrough orders of 2 mg q1h orally/subcutaneously

5.2.1.3 To bring severe agitation rapidly under control, it may be necessary to give haloperidol more frequently initially e.g., haloperidol 2mg q30 minutes orally/subcutaneously PRN in the first few hours and thereafter q1h PRN. It is appropriate to bring an agitated delirium under control rapidly to prevent patient, family and staff distress.

5.2.1.4 If symptoms persist, or worsen, the dose of haloperidol can be increased up to maximum of 20-30 mg/day.

5.2.1.5 Always assess for the possible occurrence of extra-pyramidal adverse effects or other adverse effects.

5.2.2 Consider using an alternative drug if symptoms persist after 36-48 hours despite optimal Haloperidol doses e.g.: use Methotrimoprazine as follows.

5.2.2.1 Starting doses are 6.25 mg to 12.5 mg orally/subcutaneously q8-12hourly. This drug can be sedating and the family needs to be informed of this.

5.2.2.2 Breakthrough doses for agitation/hallucinations can also be ordered, e.g.: 6.25 mg or 12.5 mg q1hourly orally/subcutaneously PRN.

5.2.3 Consider sedation for uncontrolled agitation, only in exceptional situations, and use Midazolam as follows:

5.2.3.1 Start a continuous subcutaneous infusion at 1 mg/hour and titrate up to 4 mg/hour.

5.3 Use the following steps if delirium worsens or persists despite the above treatment:

5.3.1 Review potential causes again.

5.3.2 Consider indefinite palliative sedation if agitation/hallucinations are severe and intractable

5.3.3 Consider temporary palliative care sedation if agitation/hallucination is very severe.

6 APPENDIX

6.1 Appendix 1: Algorithm for cancer pain management – cancer progression

6.2 Appendix 2: Algorithm for Delirium in Adults with Cancer: Screening and Assessment

6.3 Appendix 3: Delirium in Adults with Cancer: Care Map

6.4 Appendix 4: Mini-Mental State Examination (MMSE)

6.5 Appendix 5: The Confusion Assessment Method (CAM) Diagnostic Algorith

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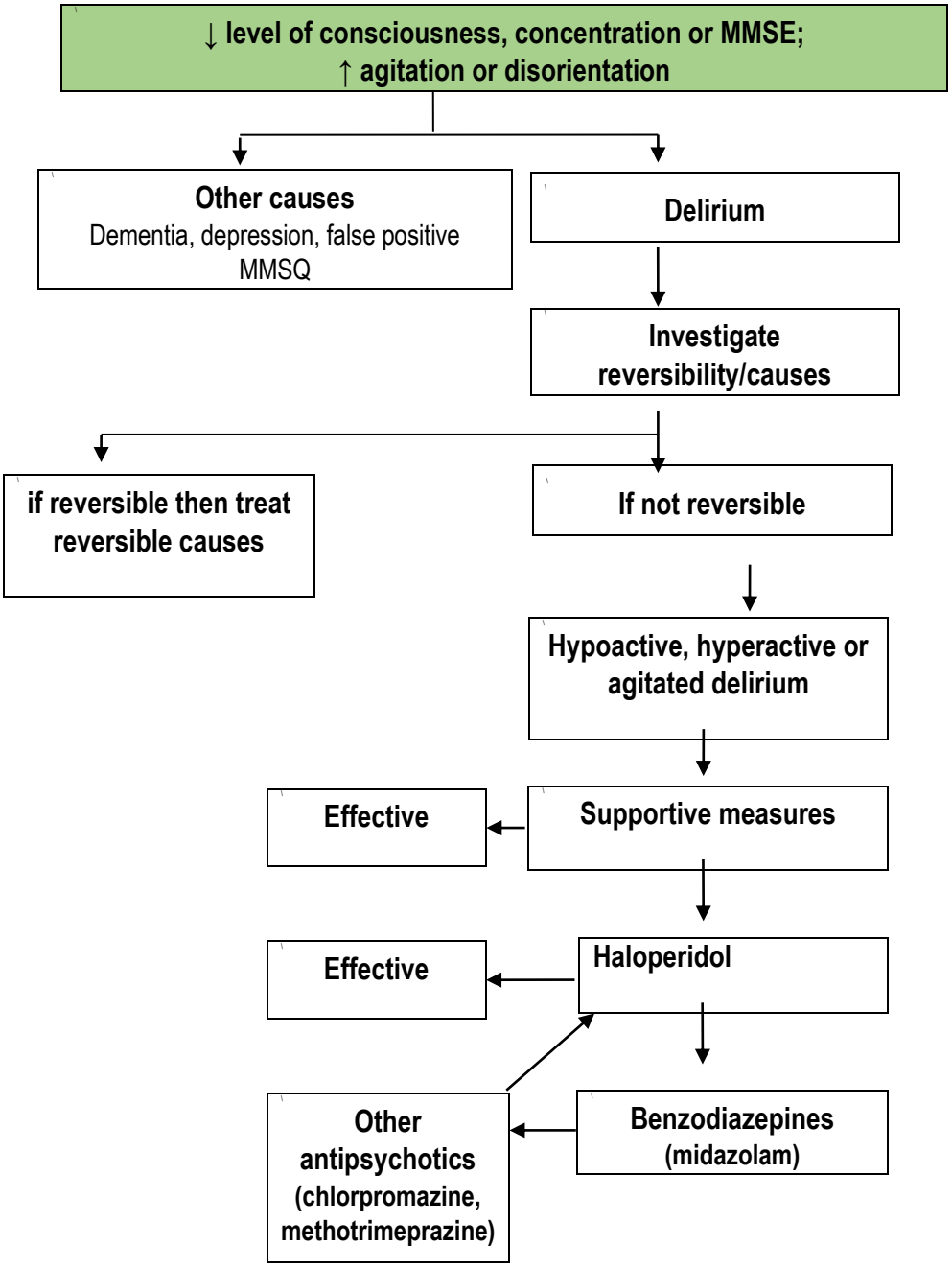
Appendix 1: Algorithm for Delirium



*MMSE **Mini-Mental State Examination**

MMSQ **Mini-Mental State Questions

Appendix 2: Algorithm for Delirium in Adults with Cancer: Screening and Assessment

Screen for delirium at each visit

⬇

Assessment using Acronym O, P, Q, R, S, T, U and V (adapted from Fraser Health)	
Onset	When did it begin? Has it happened before?
Provoking / Palliating	Are there things, which worsen the agitation? What makes it better? What makes it worse? How are you sleeping?
Quality	What does it feel like? Do you feel confused? Are you seeing or hearing anything unusual?
Region / Radiation	Do you know what day/month/year it is? Do you know where you are right now? Can you tell me your full name?
Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right Now? At Best? At Worst? On Average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?
Treatment	What medications or treatments are you currently using? How effective are these? Do you have any side effects from the medications/treatments? What medications/treatments have you used in the past?
Understanding / Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and/or your family?
Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?
Note: Where a patient is not able to complete an assessment by self-reporting, then the health professional and/or the caregiver may act as a surrogate	

⬇

Causes of Delirium Acronym *(adapted from Capital Health)*

D	Drugs, dehydration, depression
E	Electrolyte, endocrine dysfunction (thyroid, adrenal), ETOH (alcohol) and/or drug use, abuse or withdrawal
L	Liver failure
I	Infection (urinary tract infection, pneumonia, sepsis)
R	Respiratory problems (hypoxia), retention of urine or stool (constipation)
I	Increased intracranial pressure;
U	Uremia (renal failure), under treated pain
M	Metabolic disease, metastasis to brain, medication errors/omissions, malnutrition (thiamine, folate or B12 deficiency)

⬇

Interventions for all patients, as appropriate
• The underlying etiology needs to be identified in order to intervene. • Orientation questions alone do not provide accurate assessment. • Delirium may interfere with the patient's ability to report other symptom experiences (e.g. pain). • Provide explanation and reassure the family that the symptoms of delirium will fluctuate; are caused by the illness; are not within the patient's control; and the patient is not going „insane". • It is important to understand that some hallucinations, nightmares, and misperceptions may reflect unresolved fears, anxiety • Include the family in decision making, emphasizing the shared goals of care; support caregivers. • Correct reversible factors – infection, constipation, pain, withdrawal, drug toxicity. • Review medications; consider opioid rotation to reverse opioid neurotoxicity, discontinue unnecessary drugs or prolong dosing interval for necessary drugs. • Anticipate the need to change treatment options if agitation develops, particularly in cases where patient, family and staff safety may become threatened. • Misinterpreting symptoms of agitation/restlessness, moaning and/or grimacing as poorly controlled pain, with

subsequent administration of more opioids, can potentially aggravate the symptom and cause opioid neurotoxicity.

Appendix 3: Delirium in Adults with Cancer: Care Map

Mild Delirium *Care Pathway 1*	Moderate Delirium *Care Pathway 2*	Severe Delirium *Care Pathway 3*

NON-PHARMACOLOGICAL

- Report hallucinations that become threatening.
- Instruct the family to provide gentle, repeated reassurance and avoid arguing with the patient.
- Watch for the "sun downing" effect (nocturnal confusion), as it may be the first symptom of early delirium.
- Provide a calm, quiet environment and help the patient reorient to time, place and person (visible clock, calendar, well known or familiar objects).
- Presence of a well-known family member is preferred.
- Provide a well-lit, quiet environment. Provide night light.
- To prevent over-stimulation, keep visitors to a minimum, and minimize staff changes and room changes.
- Correct reversible factors – dehydration, nutrition, alteration in visual or auditory acuity (provide aids), sleep deprivation.
- Avoid the use of physical restraints and other impediments to ambulation. Avoid catheterization unless urinary retention is present.
- Encourage activity if patient is physically able.
- When mildly restless provide observation and relaxation techniques (massage, tub baths, gentle music) as applicable.

- Encourage the family to be present in a calming way.

⇩ ⇩ ⇩

PHARMACOLOGICAL	PHARMACOLOGICAL	PHARMACOLOGICAL
• Titrate starting dose to optimal effect • If a patient is developing "sun downing" effect (confusion in the evening), psychotropic drugs have a place in treatment. • If a patient has known or suspected brain metastases a trial of corticosteroids is worthwhile. Dexamethasone 16 - 32 mg per oral daily in the morning may be used however, this suggestion is made based on expert opinion and doses may vary from region to region. • Haloperidol is the gold standard for management of delirium. • If titration with haloperidol is not effective, consider using Methotrimeprazine. • Haloperidol 0.5-1 mg orally/subcutaneously BID-TID	• Titrate starting dose to optimal effect • Haloperidol 0.5-2 mg subcutaneously q1h PRN until episode under control; may require a starting dose of 5 mg subcutaneously • Alternate agents: • Risperidone 0.5-1 mg orally BID • Olanzapine 2.5-15 mg orally daily • Quetiapine fumarate 50-100 mg orally BID • Benzodiazepines may paradoxically excite some patients and should be avoided unless the source of delirium is alcohol or sedative drug withdrawal, or when severe agitation is not controlled by the neuroleptic	• Titrate starting dose to optimal effect • If agitation is refractory to high doses of neuroleptics, consider adding lorazepam 0.5-2 mg subcutaneously q4-6h PRN or midazolam 2.5-5 mg subcutaneously q1-2h PRN in conjunction with the neuroleptic • Alternate agents to consider: • Methotrimeprazine 12.5–25 mg subcutaneously q8-12h and q1h PRN or • Chlorpromazine 25-50 mg orally/subcutaneously q4-6h PRN • If above not effective consider: • Haloperidol 10 mg subcutaneously Typically, in palliative care the maximum dose of haloperidol is 20 mg per day or • Methotrimeprazine 25-50 mg subcutaneously q6-8h and q1h

Alternate agents: ○ Risperidone 0.5-1 mg orally BID ○ Olanzapine 2.5 – 15 mg orally daily ○ Quetiapine fumarate 50-100 mg orally BID ○ Methotrimeprazine 5-12.5 mg orally or 6.25-12.5 mg subcutaneously q4-6h PRN ○ Chlorpromazine 12.5-50 mg orally/subcutaneously q4-12h PRN		PRN

Appendix 4: Mini-Mental State Examination (MMSE)

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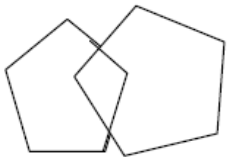
Mini - Mental State Examination (MMSE) form

Diagnosis:	

Category	Item	Score guide	Score
Orientation 1 point for each answer	Ask: What is the:	1 = Date 1 = Day 1 = Month 1 = Year 1 = Season or Time	/5
	Ask: Where we are:	1 = Country 1 = City 1 = Hospital 1 = Ward or room number 1 = What city is the Kabba in?	/5
Registration Score 1,2,3 points according to how many are repeated	Name three objects give the patient one second to say each. Then ask the patient to repeat all three after you have said them. Repeat until the patient learns the three.	1 = Cup 1 = Book 1 = Table	/3
Attention & Calculation One point for each correct subtraction	As the patient to: begin from 100 and count backwards by 7. Stop after 5 correct answers.	1 = 93 1 = 86 1 = 79 1 = 72 1 = 65	/5
Recall One point for each correct answer.	Ask the patient to: name the three objects from above.	1 = Cup 1 = Book 1 = Table	/3
Language 	Ask the patient to: to identify and name a pencil and a watch.	1 = Pencil 1 = Watch	/2
	Ask the patient to: repeat the phrase "No" ifs, ands, or buts." Or repeat " Kul Am wa antum Bekhair"	1 = correct repetition	/1
	Ask the patient to: take a paper in right hand, fold it in half & put it on the floor.	1 = Take paper in right hand 1 = Fold it in half 1 = Put it on the floor	/3
	Ask the patient to: write a meaningful sentence.	1 = if written including subject and verb.	/1
	Ask the patient to: read and obey the following "close your eyes"	1 = if read and performed correctly.	/1
	Ask the patient to: copy a complex diagram of two interlocking pentagons.	1 = If correctly copied	/1
		Total Score	/30

Total MMSE Score and Level of Disability: ☐*Normal (24-30)* ☐ *Mild (20-23)* ☐ *Moderate (11-19)* ☐*Severe (2-10)* ☐*Profound (0-1)*

Name and Stamp:		***Assessment Date:***	
Signature:		***Assessment Time:***	

Appendix 5: The 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, 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])

The diagnosis of delirium by CAM requires the presence of features 1 and 2 and either 3 or 4.

Inouye, S., van Dyck, C., Alessi, C., Balkin, S., Siegal, A. & Horwitz, R. (1990). Clarifying confusion: The confusion assessment method. Annals of Internal Medicine, 113(12), 941-948.

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CHAPTER 3

USE OF EDMONTON SYMPTOM ASSESSMENT SYSTEM (ESAS-R)

المجلس الصحي السعودي
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CHAPTER 3:- USE OF EDMONTON SYMPTOM ASSESSMENT SYSTEM (ESAS-R)

1 STATEMENT OF PURPOSE

1.1 To provide guidelines for the use of the Edmonton Symptom Assessment System (ESAS-r).

1.2 To ensure that palliative care interventions are evaluated by a validated assessment tool.

2 DEFINITIONS

2.1 **Edmonton Symptom Assessment System (ESAS)**: a tool that was developed to assist in the assessment of nine symptoms that are common in palliative care patients: pain, tiredness, drowsiness, nausea, lack of appetite, depression, anxiety, shortness of breath, and wellbeing. It is intended to capture the patient's perspective of their symptoms, though in some situations, a caregiver's perspective may be needed, and repeated use can give an indication of symptom progression.

2.2 **ESAS**-r: Is the revised version of the tool. Changes include specifying a timeframe of "now", adding definitions for potentially confusing symptoms, modifying the order of symptoms, adding an example for "other symptom", and altering the format for improved readability.

2.3 **PPS:** Palliative Performance Scale. It is a tool developed as an excellent communication tool for quickly describing a patient's current functional level. It appears to have prognostic value. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient, which is then assigned as the PPS% score.

2.4 **Palliative Home Care**: palliative patients who are being cared for at home team.

2.5 **Palliative Care Inpatients:** all admitted patients who are under the care of the Palliative Care team.

3 GENERAL GUIDELINES

3.1 Patients shall complete the ESAS-r with guidance from Nursing Staff/Physicians, especially on the first occasion.

3.2 Patients shall be instructed to rate the severity of each symptom from 0 to 10, where 0 represents the absence of the symptom and 10 represents the worst possible severity.

3.3 Patients shall be instructed to rate each symptom according to how they currently feel. Nursing Staff/Physicians may choose to ask additional questions about the severity of symptoms at other time points e.g. symptom severity at best and at worst over the past 24 hours.

3.4 Nursing Staff/Physicians must ensure that the patient has a full understanding of the what is inferred by each symptom and where necessary additionally use the definitions that are included under certain symptoms:

3.4.1 Tiredness: lack of energy

3.4.2 Drowsiness: feeling sleepy

3.4.3 Depression: feeling sad

3.4.4 Anxiety: feeling nervous wellbeing - how you feel overall

3.5 When indicated, patients shall be instructed to use the body diagram on the reverse side of the ESAS-r to indicate sites of pain.

3.6 Nursing/Staff Physicians shall transfer the scores given by the patient on to the ESAS-r graph.

3.7 The ESAS-r shall be completed for palliative care patients at home as follows:

3.7.1 Each time the patient is contacted by telephone or in-person

3.7.2 Weekly if symptoms are in good control, and there are no predominant psychosocial issues

3.8 For all admitted palliative care patients the ESAS-r shall be completed on admission and thereafter weekly

3.9 In other settings, palliative care consultants' shall utilize the ESAS-r upon the initial assessment and at each follow-up visit.

3.10 In situations where the patient is unable to independently provide ratings of symptom severity but can still provide input (e.g. when the patient is mildly cognitively impaired), then the ESAS shall be completed with the assistance of a caregiver (a family, friend, or health professional closely involved in the patient's care).

3.11 In situations where the patient cannot participate in the symptom assessment at all, or refuses to do so, the ESAS-r shall be completed by the caregiver alone. He/she shall be asked to assess symptoms as objectively as possible using the following objective indicators:

3.11.1 Pain: grimacing, guarding against painful maneuvers

3.11.2 Tiredness: increased amount of time spent resting

3.11.3 Drowsiness: decreased level of alertness

3.11.4 Nausea: retching or vomiting

3.11.5 Appetite: quantity of food intake

3.11.6 Shortness of breath: increased respiratory rate or effort that appears to cause distress to the patient.

3.11.7 Depression: tearfulness, flat affect, withdrawal from social interactions, irritability, decreased concentration and/or memory, disturbed sleep pattern

3.11.8 Anxiety: agitation, flushing, restlessness, sweating, increased heart rate intermittent), shortness of breath

3.11.9 Wellbeing: how the patient appears overall.

3.12 I

f it is not possible to rate a symptom, the caregiver shall be instructed to indicate "U" for "Unable to assess" on the ESAS-r and ESAS-r Graph.

4 ASSESSMENT AND MANAGEMENT

4.1 Discuss ESAS-r with the patient and explain its use.

4.2 Ask the patient to rate each symptom from 0 - 10 and to circle the corresponding number on the scale.

4.2.1 If the patient is unable or unwilling to complete the ESAS-r seek input from the patient's caregiver.

4.3 Clarify the meaning of any symptoms that the patient/caregiver is unsure of.

4.4 Advise the patient, when applicable, to mark their sites of experienced pain on the body drawings.

4.5 Mark the given scores of the ESAS-r graph.

4.6 Indicate who completed the form by placing a checkmark against the relevant individual in the space provided at the bottom of the ESAS-r and the ESAS-r graph.

4.7 Insert the following letter keys at the base of the ESAS-r graph to indicate who completed the assessment:

4.7.1 P = Patient

4.7.2 F = Family caregiver

4.7.3 H = Health care professional caregiver

4.7.4 A = Caregiver-assisted

4.8 Enter the Palliative Performance Scale (PPS) in the provided space. [see Palliative Performance Scale (PPS)]

5 APPENDIX

5.1 Appendix 1: Edmonton Symptom Assessment System: (revised version) (ESAS-R) - English

5.2 Appendix 2: Edmonton Symptom Assessment System: (revised version) (ESAS-R) - Arabic

6 REFERENCES

6.1 Palliative Performance Scale (PPSv2) [Internet]. Nhhpco.org. 2019 [cited 15 September 2019]. Available from: http://www.nhhpco.org/s-content/uploads/files/Palliative_Performance_Scale1.pdf

6.2 Seniors Health – Edmonton Zone Regional Palliative Care Program: Assessment Tools\Guidelines for revised Edmonton Symptom Assessment System (ESAS-r)

APPENDIX 1: ESAS ENGLISH VERSION

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Patient ID Label

Edmonton Symptom Assessment System
(Revised version) (ESAS-R)

No Pain	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Pain**
No Tiredness *(Tiredness = lack of energy)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Tiredness**
No Drowsiness *(Drowsiness = feeling sleepy)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Drowsiness**
No Nausea	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Nausea**
No Lack of Appetite	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Lack of Appetite**
No Shortness of Breath	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Shortness of Breath**
No Depression *(Depression = feeling sad)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Depression**
No Anxiety *(Anxiety = feeling nervous)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Anxiety**
Best Wellbeing *(Wellbeing = how you feel overall)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Wellbeing**
No _____ **Other Problem** *(for example constipation)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible** _____

Completed by (check one)

☐ **Patient**

☐ **Family Caregiver**

☐ **Healthcare professional caregiver**

☐ **Caregiver assisted**

Name: _____ **Date:** _____

Signature: _____ **Time:** _____

"BODY DIAGRAM ON PAGE 2"

المجلس الصحي السعودي
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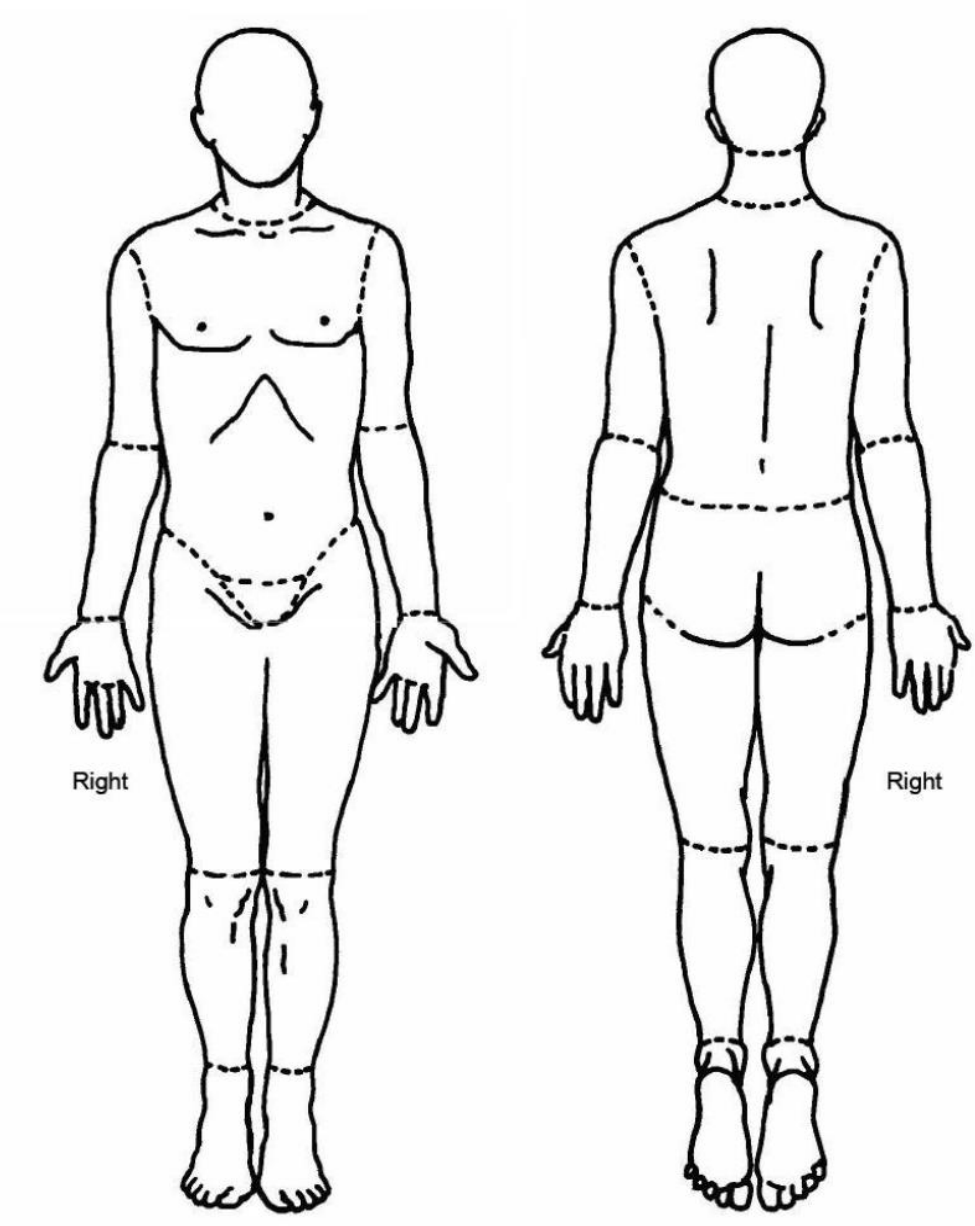
Patient ID Label

Please mark on these pictures where it is that you hurt:



APPENDIX 2: ESAS ARABIC VERSION

المجلس الصحي السعودي
Saudi Health Council

Patient ID Label

Edmonton Symptom Assessment System:
(Revised version) (ESAS-R)

Date																										
Pain 10 0																										
Tiredness 10 0																										
Nausea 10 0																										
Depression 10 0																										
Anxiety 10 0																										
Drowsiness 10 0																										
Appetite 10 0																										
Wellbeing 10 0																										
Shortness of breath 10 0																										
Other 10 0																										
Palliative Performance Scale																										
Completed by P = Patient F = Family caregiver H = Health care professional caregiver A = Caregiver-assisted	Level of Education _____ Cage Score _____																									

المجلس الصحي السعودي
Saudi Health Council

Patient ID Label

تقييم أعراض أدمونتون
(نسخة مراجعة)

لا يوجد ألم	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ **أسوأ شعور ممكن**
لا يوجد تعب *(التعب = نقص الطاقة)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ **أسوأ شعور ممكن**
لا يوجد شعور بالنعاس *(النعاس = الشعور بالنوم)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ **أسوأ شعور ممكن**
لا يوجد غثيان	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ **أسوأ شعور ممكن**
لا يوجد نقص في الشهية	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ **أسوأ شعور ممكن**
لا يوجد ضيق في التنفس	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ **أسوأ شعور ممكن**
لا يوجد اكتئاب *(الاكتئاب = الشعور بالحزن)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ **أسوأ شعور ممكن**
لا يوجد قلق *(القلق= الشعور بالإضراب العصبي)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ **أسوأ شعور ممكن**
الشعور التام بالصحة والسعادة *(ما تشعر به عموماً)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ **أسوأ شعور ممكن**
لا يوجد _____ **أي مشكلة أخرى** *(الإمساك على سبيل المثال)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ **أسوأ شعور ممكن**

تم تعبئة النموذج من قبل (اختر واحداً):

- ☐ المريض
- ☐ مقدم الرعاية الصحية من أسرة المريض
- ☐ مقدم الرعاية الصحية في المستشفى
- ☐ بمساعدة مقدم الرعاية الصحية

اسم المريض _____ التاريخ _____

التوقيع _____ الوقت _____

"رسم توضيحي للجسم من الجهة الخلفية"

المجلس الصحي السعودي
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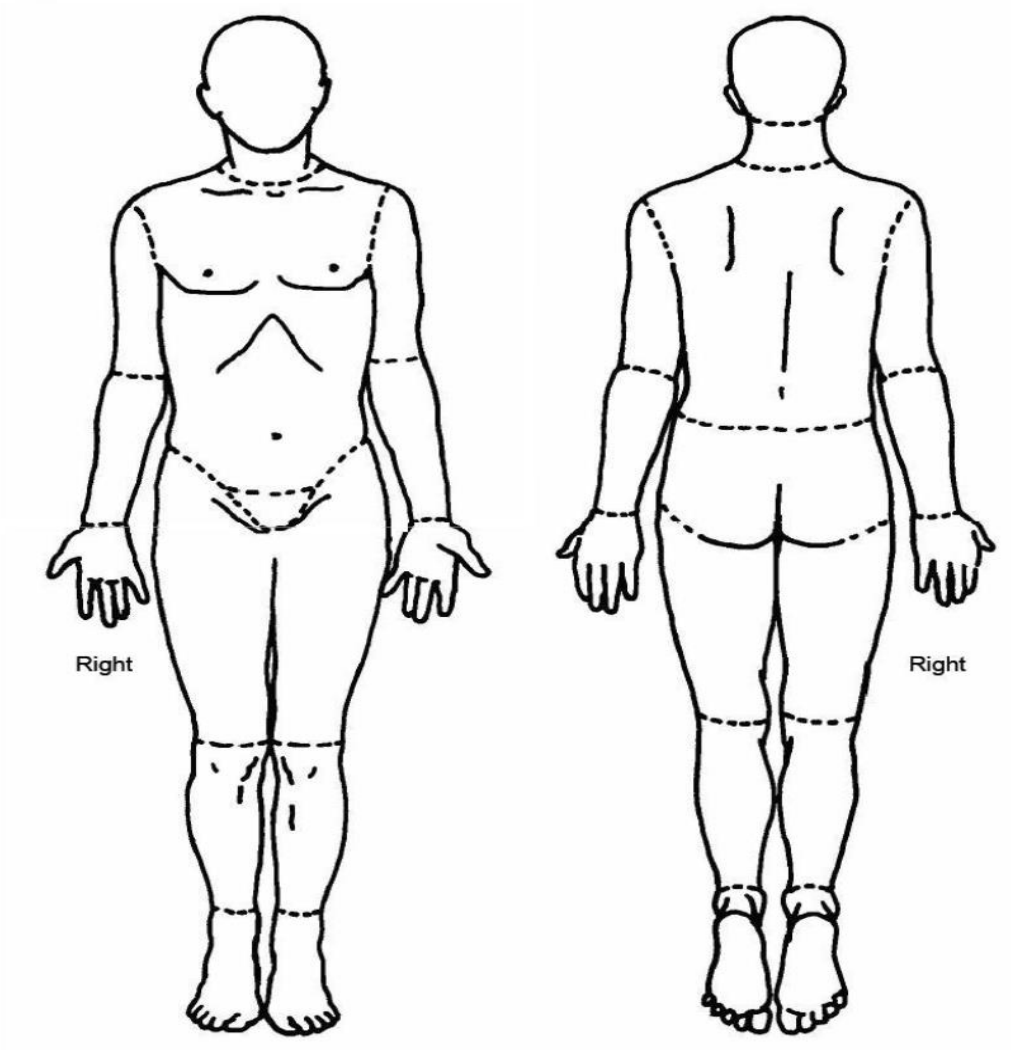
Patient ID Label

فضلاً، حدد على الرسم التالي موضع الألم الذي تشعر به:



المجلس الصحي السعودي
Saudi Health Council

تقييم أعراض أدمونتون
(نسخة مراجعة)

Patient ID Label

التاريخ										
الألم	١٠									صفر
تعب	١٠									صفر
غثيان	١٠									صفر
إكتئاب	١٠									صفر
قلق	١٠									صفر
نعاس	١٠									صفر
الشهية	١٠									صفر
الصحة والسعادة	١٠									صفر
ضيق التنفس	١٠									صفر
أخرى	١٠									صفر
مقياس الاداء التطليفي										

تم تعبئة النموذج من قبل
المريض
مقدم الرعاية الصحية
بمساعدة
أحد العاملين

المستوى التعليمي _____
المجموع حسب مقياس (Cage) _____

المجلس الصحي السعودي
Saudi Health Council

CHAPTER 4
USE OF THE PALLIATIVE PERFORMANCE SCALE (PPS)

المجلس الصحي السعودي
Saudi Health Council

CHAPTER 4:- USE OF THE PALLIATIVE PERFORMANCE SCALE (PPS)

1. STATEMENT OF PURPOSE

1.1 To document performance measures in palliative care patients by using a reliable and valid tool that has been proven to correlate well with actual and median survival time for cancer patients.

1.2 To identify and track potential care needs of palliative care patients, particularly as these needs change with disease progression.

2. DEFINITIONS

2.1. Palliative Performance Scale. It is a tool developed as an excellent communication tool for quickly describing a patient's current functional level. It appears to have prognostic value. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score

2.2. Ambulation:

2.2.1. Refers to the extent in which a patient is able to ambulate, classified as follows:

2.2.1.1. Mainly sit/lie: patient is able to sit up rather than needing to lie down most of the time

2.2.1.2. Mainly in bed: patient needs to lie down most of the time

2.2.1.3. Totally bed bound; patient has profound weakness or paralysis, can't get out of bed or perform any self-care.

2.2.1.4. Reduced ambulation: patient is unable to carry out their normal job, work occupation, hobbies and/or housework activities.

2.3. Activity & Extent of disease:

2.3.1. Refers to physical and investigative evidence of disease progression, classified into three progressive categories such as some disease, significant disease and extensive disease.

2.3.2. Disease extent is also judged in context with the patient's ability to continue to work, complete hobbies and/or other physical activities.

2.4. Self-Care:

2.4.1. Refers to the patient's abilities to independently perform their own care, classified as follows:

2.4.1.1. Occasional assistance: the patient is able to transfer out of bed, walk, wash, toilet and eat by their own means, but on occasion (perhaps once daily or a few times weekly) they require minor assistance.

2.4.1.2. Considerable assistance: the patient needs help every day, usually by one person, to do some activities

2.4.1.3. Mainly assistance: the patient needs more help than outlined in 'considerable assistance.

2.4.1.4. Total care: the patient is completely unable to eat, toilet or do any self-care without help.

2.5. Intake:

2.5.1. Refers to a patient's ability to take in food, classified as follows:

2.5.2. Normal intake: the patient is maintaining his/her normal eating habits

2.5.3. Reduced intake: the patient is experiencing a reduction in the amount of food he/she eats and is highly variable according to the unique individual circumstances

2.5.4. Minimal intake: the patient is only eating very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

2.6. Conscious Level:

2.6.1. Refers to the patient's level of alertness and orientation, classified as follows:

2.6.1.1. Full consciousness: the patient is fully alert and orientated with good cognitive abilities in various domains of thinking, memory, etc.

2.6.1.2. Confusion: the patient has either delirium or dementia and has a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies.

2.6.1.3. Drowsiness: the patient is less alert and/or orientated as a result of fatigue, drug side effects, delirium or closeness to death

2.6.1.4. Coma: the patient does not respond to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

3. GENERAL GUIDELINES

3.1. For all admitted palliative care patients the PPS shall be completed daily.

3.2. In other settings, palliative care consultants' shall utilize the PPS upon initial assessment and at each follow-up visit.

3.3. When utilizing the PPS Physicians/Nursing Staff are to note that:

3.3.1. PPS scores in "leftward" columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

3.3.2. The PPS score shall be determined only in increments of 10%. A "best fit" decision must be made if patients appear to be in between values by using a combination of clinical judgement and "leftward" precedence.

4. ASSESSMENT AND MANAGEMENT

4.1. Discuss use of PPS with patient and determine scores by reading chart horizontally, beginning with the left column (Ambulation) as follows:

4.2. Read Ambulation column until the appropriate ambulation level is reached then

4.3. Read next column moving downwards again until the activity/evidence of disease is located

4.4. Repeat these steps until all five columns have been completed in the same manner

4.5. Assign the actual PPS by utilizing leftward precedence and clinical judgement

5. APPENDIX

5.1. Appendix One: Palliative Performance Scale (PPSv2) version 2

5.2. Appendix Two: PPS Scoring Examples

6. REFERENCES

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6.5 Clinical Tools -Palliative Performance Scale (PPSv2) [Internet]. Victoria Hospice. 2019 [cited 15 September 2019]. Available from: https://victoriahospice.org/how-we-can-help/clinical-tools/

Appendix One: Palliative Performance Scale (PPSv2) version 2 Form

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☑	PPS Level	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
☐	100%	Full	Normal activity and work No evidence of disease	Full	Normal	Full
☐	90%	Full	Normal activity and work Some evidence of disease	Full	Normal	Full
☐	80%	Full	Normal activity and work Some evidence of disease	Full	Normal or Reduced	Full
☐	70%	Reduced	Unable Normal Job or Work Significant Disease	Full	Normal or Reduced	Full
☐	60%	Reduced	Unable to do hobby or house work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
☐	50%	Mainly Sit or Lie	Unable to do any work Extensive Disease	Considerable Assistance Required	Normal or Reduced	Full or Confusion
☐	40%	Mainly in Bed	Unable to do most activity Extensive Disease	Mainly Assistance	Normal or Reduced	Full or Drowsy + or - Confusion
☐	30%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Normal or Reduced	Full or Drowsy + or - Confusion
☐	20%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Minimal to Sips	Full or Drowsy + or - Confusion
☐	10%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Mouth Care Only	Drowsy or Coma + or - Confusion
☐	0%	Death	Not Applicable	Not Applicable	Not Applicable	Not Applicable

Name and Stamp: _____ **Signature:** _____ **Date:** _____ **Time:** _____

Palliative Performance Scale (PPSv2) version 2

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Appendix Two: PPS scoring examples

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

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

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

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal Patient One	Full Patient One
90%	Full	Normal activity & work Some evidence of disease	Full	Normal Patient Two /Patient Three	Full Patient Two / Patient Three
80%	Full	Normal activity with Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full

60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie Patient One	Unable to do any work Extensive disease Patient One	Considerable assistance required Patient One	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance Patient Three	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound Patient Two / Patient Three	Unable to do any activity Extensive disease Patient Two/Patient Three	Total Care Patient Two	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

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CHAPTER 5
MANAGEMENT OF DYSPNEA IN PALLIATIVE CARE

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CHAPTER 5:- MANAGEMENT OF DYSPNEA IN PALLIATIVE CARE

1. STATEMENT OF PURPOSE

1.1 To provide practical guidance in the identification, diagnose and management of adult patients (age 14years and older) who have advanced life-threatening illness and are experiencing dyspnea (shortness of breath).

2. DEFINITIONS

2.1 Dyspnea (Shortness of Breath): Is a term used to characterize a subjective experience of breathing discomfort that consists of qualitative distinct sensations that vary in intensity. The experience derives from interactions among multiple physiological, psychological, social and environmental factors, and may induce secondary histological and behavioural responses. Dyspnea may or may not be associated with hypoxemia, tachypnea or orthopnea.

2.2 Edmonton Symptom Assessment System-revised (ESAS-r): Is the revised version of the tool that was developed to assist in the assessment of symptoms that are common in palliative care patients.

2.3 Palliative Performance Scale (PPS): Is a tool for measurement of performance status in palliative care.

2.4 Eastern Cooperative Oncology Group (ECOG) Performance Status: Is a tool to determine whether cancer patients can receive chemotherapy, whether dose adjustment is necessary, and as a measure for the required intensity of palliative care.

3 GENERAL GUIDELINES

3.1 All admitted palliative patients aged 14 years and older experiencing the symptom of dyspnea shall be assessed, diagnosed and managed by Palliative Care Physician.

3.2 The patient's self-report of symptoms shall be acknowledged and accepted by Palliative Care Physician.

3.3 If a patient is not able to self-report symptoms then the Palliative Care Physician will make his/her own assessment of findings.

3.4 Palliative Care Physicians must perform on-going comprehensive assessments of patients with dyspnea including:

3.4.1 Interview (see Appendix One, Table One).

3.4.2 Physical assessment.

3.4.3 Appropriate diagnostics.

3.4.4 Medication review.

3.4.5 Medical and surgical review.

3.4.6 Psychosocial review.

3.4.7 Review of physical environment.

3.5 Assessment must be conducted by Palliative Care Physician to determine the cause, effectiveness and impact on quality of life for the patient and their family.

3.6 Palliative Care Physicians shall evaluate the impact of anxiety and fear of dyspnea and will treat appropriately using the Edmonton Symptom Assessment System-revised form (ESAS-r form) (see Appendix Two and Three).

3.7 Palliative Care Physician shall identify and treat common exacerbating medical conditions underlying dyspnea e.g. COPD, CHF, pneumonia.

3.8 Palliative Care Physician shall note and consider the following causes of dyspnea:

3.8.1 Often multifactorial etiology.

3.8.2 Pulmonary causes such as airway obstruction, pleural effusion, COPD, lymphangitic carcinomatosis, pneumonia, pulmonary embolism, etc.

3.8.3 Cardiac causes such as CHF, pericardial effusion.

3.8.4 Systematic causes like anemia, etc.

3.8.5 Neurological such as ALS, cachexia (muscle weakness).

3.8.6 Others like ascites.

3.8.7 Psychological.

3.9 Palliative Care Physician shall note the following with regard to dyspnea:
:

3.9.1 Clinical signs do not always correlate with the symptom experience.

3.9.2 Dyspnea is not necessarily related to the respiratory rate or oxygen saturation.

3.9.3 Oxygen saturation levels must not be used as a sole measure of dyspnea.

3.9.4 In last days of life oxygen saturation measurement should not be undertaken.

3.9.5 Assessment of dyspnea pattern should be performed i.e. whether the episodes are intermittent, continuous or acute.

3.9.6 Dyspnea triggers.

3.9.7 Dyspnea alleviating factors.

3.9.8 Dyspnea associate emotions.

3.9.9 Appropriate scales should be used to measure and monitor dyspnea

3.9.10 Investigations should be performed as needed

4 GUIDELINES

4.1 Screen/assess patient for dyspnea as follows:

4.1.1 At each clinic visit for outpatients.

4.1.2 At least daily for inpatients

4.1.3 Complete ESAS-r forms (see Appendices Two and Three).

4.1.4 Use acronym O, P, Q, R, S, T, U and V (see Appendix One, Table One).

4.1.5 Use the Palliative Performance Scale (PPS) (see Appendix Four) or Eastern Cooperative Oncology Group (ECOG) (see Appendix Five) to report the patient's overall functional status.

4.2 Identify and treat underlying causes (Follow Appendix One, Tables 2A and 2B).

4.3 Educate/explain situation to patient and family and reassure.

4.3.1 Involve the patient and family in the discussion so it can enhance the patient and family's ability to cope.

4.4 Treat mild, moderate and severe dyspnea (See Appendix One, Table Three).

5 APPENDIX

5.1 Appendix One: Algorithm for Management of Dyspnea in Adults with Cancer including tables for:

5.1.1 Table 1: Assessment using Acronym O, P, Q, R, S, T, U and V (adapted from Fraser Health)

5.1.2 Table 2A: Identification of underlying cause(s)

5.1.3 Table 2B: Interventions, as appropriate

5.1.4 Table 3: Dyspnea in Adults with Cancer Care Pathway

5.2 Appendix Two: Edmonton Symptom Assessment System-revised form (ESAS-r form) – English

5.3 Appendix Three: Edmonton Symptom Assessment System-revised form (ESAS-r form) – Arabic

5.4 Appendix Four: Palliative Performance Scale (PPS)

5.5 Appendix Five: Eastern Cooperative Oncology Group (ECOG) Performance Status

6. REFERENCES

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6.5 Toronto Central Regional Cancer Program 2019 [cited 15 September 2019]. Available from: https://www.cancercare.on.ca/toolbox/symptools/

Appendix One: Algorithm for Management of Dyspnea in Adults with Cancer

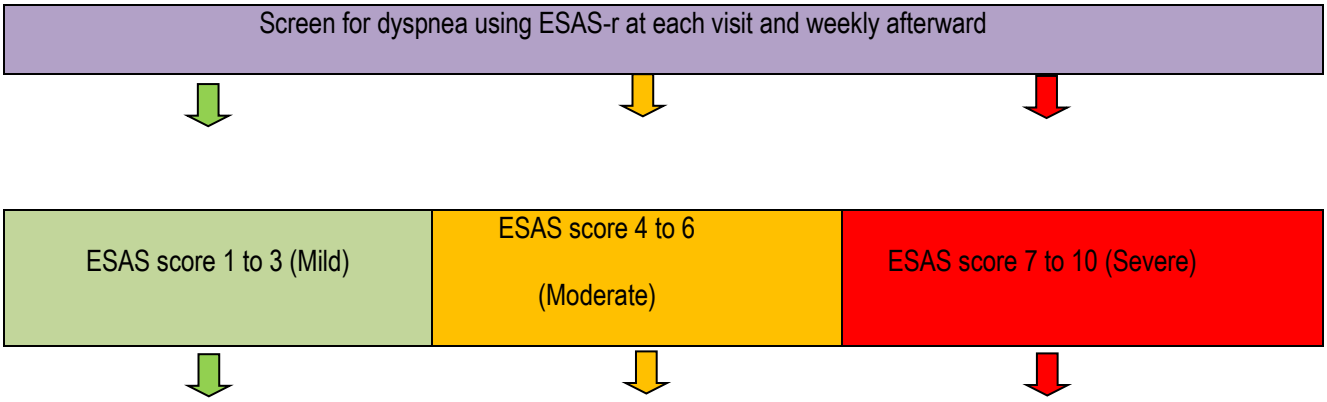

Table 1: Assessment using Acronym O, P, Q, R, S, T, U and V (adapted from Fraser Health)	
Onset	When did it begin? How long does it last? How often does it occur?
Provoking / Palliating	What brings it on? What makes it better? What makes it worse?
Quality	What does it feel like? Can you describe it?
Region / Radiation	Are there any other associated symptoms?
Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right Now? At Best? At Worst? On Average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?
Treatment	What medications or treatments are you currently using? How effective are these? Do you have any side effects from the medications/treatments? What medications/treatments have you used in the past?
Understanding / Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and/or your family?
Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

Note: Where a patient is not able to complete an assessment by self-reporting, then the health professional and/or the caregiver may act as a surrogate.

Table 2A: Identify the underlying cause(s)

Mild Dyspnea	Moderate Dyspnea	Severe Dyspnea
Based on discussion with Patient: • Usually can sit and lie quietly • May be intermittent or persistent • Worsens with exertion • No anxiety or mild anxiety during shortness of breath • Breathing not observed as laboured **Based on Physical Assessment:** • No cyanosis	**Based on discussion with Patient:** • Usually persistent • May be new or chronic • Shortness of breath worsens if walking or with exertion; settles partially with rest • Pauses while talking every 30 seconds • Breathing mildly laboured	**Based on discussion with Patient:** • Often acute or chronic • Worsens over days/weeks • Anxiety present • Wakes suddenly with shortness of breath • Laboured breathing awake and asleep • Pauses while talking every 5-15seconds **Based on Physical Assessment:** • ± cyanosis • ± onset of confusion • Often orthopnea present

Table 2B: Interventions for all patients, as appropriate

Cognitive Behavioural Interventions:

- Provide information and support for management of breathlessness, instructions for breathing control, relaxation, distraction techniques and breathing exercises
- Provide goal setting to enhance breathing and relaxation techniques, enable participation in social activities, and develop coping skills
- Identify early signs of problems that need medical or pharmacotherapy intervention

- Positioning
  - Suggest positions that maximize respiratory function while reducing physical effort.
- Breathing
  - Provide ambient air flow on face & cool facial temperatures (use window, fan, or nasal prongs)
  - Increasing chest expansion can make the most of one's lung capacity and increase oxygen delivery.
  - Consider referral to a respiratory therapist, physiotherapist or nurse with expertise in managing dyspnea
  - Assess the need for oxygen
  - Assess breathlessness – what improves and what hinders
- Supportive Counselling
  - The meaning of symptoms cannot be separated from the symptom experience. In order to relieve suffering and provide good symptom support, the health care professional must explore the meaning of the symptom to the patient.

Table 3: Dyspnea in Adults with Cancer: Care Pathway

Mild Dyspnea
Care Pathway 1

PHARMACOLOGICAL

- Supplemental oxygen is recommended for hypoxic patients experiencing dyspnea.
- Supplemental oxygen is not recommended for non-hypoxic, dyspneic patients.
- Systemic opioids, by the oral or parenteral routes, can be used to manage dyspnea in advanced cancer patients.

Moderate Dyspnea
Care Pathway 2

PHARMACOLOGICAL
For Patients with PPS 100% - 10%:
Non Opioids

- May use benzodiazepines for anxiety.
- There is no evidence for the use of systemic corticosteroids.

Systemic Opioids
For opioid-naïve patients:

- Morphine (or equivalent dose of alternate immediate-release opioid) 5mg PO q4h regularly and 2.5mg PO q2h PRN for breakthrough dyspnea.
- If the oral route is not available or reliable, morphine 3 mg subcutaneous q4h regularly and 2 mg subcutaneous q1h PRN for breakthrough dyspnea.

For patients already taking systemic opioids:

- Increase the patient's regular dose not more than 50% of the total 24h dose, guided by the total breakthrough doses used in the previous 24 hours.
- The breakthrough dose is 10% of the total 24-hour regular opioid dose, using the same opioid by the same route.
  - Oral breakthrough doses q1 hr as needed.
  - Subcutaneous breakthrough doses q1hr as needed, due to more rapid peak effect.
- Do not use nebulized opioids, nebulized furosemide, nebulized lidocaine or benzodiazepines.

For Patients with PPS 100% - 20%

- If patient has or may have COPD, consider a 5-day trial of a corticosteroid.
  - Dexamethasone 8 mg/day PO or subcutaneous or IV
  - Prednisone 50 mg/day PO
  - Discontinue corticosteroid if there is no obvious benefit after 5 days.
- If the patient does not have COPD, but has known or suspected lung involvement by the cancer, weigh the risks before commencing a 5-day trial.
  Other potential benefits, such as for appetite stimulation or pain management, may justify a 5-day trial of a corticosteroid.
- Do not start prophylactic gastric mucosal protection therapy during a 5-day trial of a corticosteroid, but consider such therapy if the corticosteroid is continued past the trial.
- Prochlorperazine is not recommended as a therapy for managing dyspnea.
- No comparative trials are available to support or refute the use of other phenothiazines, such as chlorpromazine, however oral promethazine may be used as a second-line agent if systemic opioids cannot be used or in addition to systemic opioids.

For Patients with PPS 30% - 10%:

- Consider a trial of chlorpromazine, if dyspnea persists despite other therapies.
  - Chlorpromazine 7.5-25 mg PO q6-8h regularly or as needed
- Anxiety, nausea or agitation, may justify a trial of chlorpromazine.

Severe Dyspnea
Care Pathway 3

NON-PHARMACOLOGICAL

- Attend to the meaning of the symptom (or attend to fear/anxiety).
- If dyspnea is acute or there is an unexpected change further assessment may be required to identify potentially treatable causes.

PHARMACOLOGICAL
For Patients with PPS 100% - 10%:
Systemic Opioids
For opioid-naïve patients:

- Give a subcutaneous bolus of morphine 2.5 mg (or an equivalent dose of an alternate opioid).
  - If tolerated, repeat dose every 30 minutes if needed.
  - Consider doubling dose if 2 doses fail to produce an adequate reduction in dyspnea and are tolerated
  - Monitor the patient's respiratory rate closely, since the time to peak effect of a subcutaneous dose of morphine may be longer than 30 minutes.
- If intravenous access is available, consider giving an IV bolus of morphine 2.5 mg (or an equivalent dose of an alternate opioid) to achieve a more rapid effect.
  - If tolerated, repeat dose every 30 minutes if needed.
  - Consider doubling dose if 2 doses fail to produce an adequate reduction in dyspnea and are tolerated
  - Monitor the patient's respiratory rate closely, since IV boluses of morphine result in faster and higher peak effects.
- Start a regular dose of an immediate-release opioid, guided by the bolus doses used.
  - For the breakthrough opioid dose, consider using the subcutaneous route initially for severe dyspnea until the symptom comes under control.

For patients already taking systemic opioids:

- Follow the same suggestions as above for opioid naïve patients, with the following changes.
  - Give a subcutaneous bolus of the patient's current opioid using a dose equal to 10% of the regular, 24-hour, and parenteral-dose-equivalent of the patient's current opioid (a parenteral dose is equivalent to half the oral dose).
  - Consider giving an IV bolus of the patient's current opioid, using a dose equal to 10% of the regular, 24-hour, parenteral-dose-equivalent of the patient's current opioid.
  - Increase the regular opioid dose by not more than 50%, of the total daily dose, guided by the bolus doses used.

Psychoactive medications

- Consider a trial of chlorpromazine, if severe dyspnea persists despite other therapies.
- Chlorpromazine 7.5-25 mg PO or IV q6-8h regularly or as needed.
- Consider benzodiazepine for co-existing anxiety.

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Patient ID Label

Appendix Two: ESAS English Version

Edmonton Symptom Assessment System
(Revised version) (ESAS-R)

No Pain	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Pain**
No Tiredness *(Tiredness = lack of energy)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Tiredness**
No Drowsiness *(Drowsiness = feeling sleepy)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Drowsiness**
No Nausea	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Nausea**
No Lack of Appetite	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Lack of Appetite**
No Shortness of Breath	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Shortness of Breath**
No Depression *(Depression = feeling sad)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Depression**
No Anxiety *(Anxiety = feeling nervous)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Anxiety**
Best Wellbeing *(Wellbeing = how you feel overall)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Wellbeing**
No _____ **Other Problem** *(for example constipation)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible** _____

Completed by (check one)

☐ **Patient**

☐ **Family Caregiver**

☐ **Healthcare professional caregiver**

☐ **Caregiver assisted**

Name: _____ **Date:** _____

Signature: _____ **Time:** _____

"BODY DIAGRAM ON PAGE 2"

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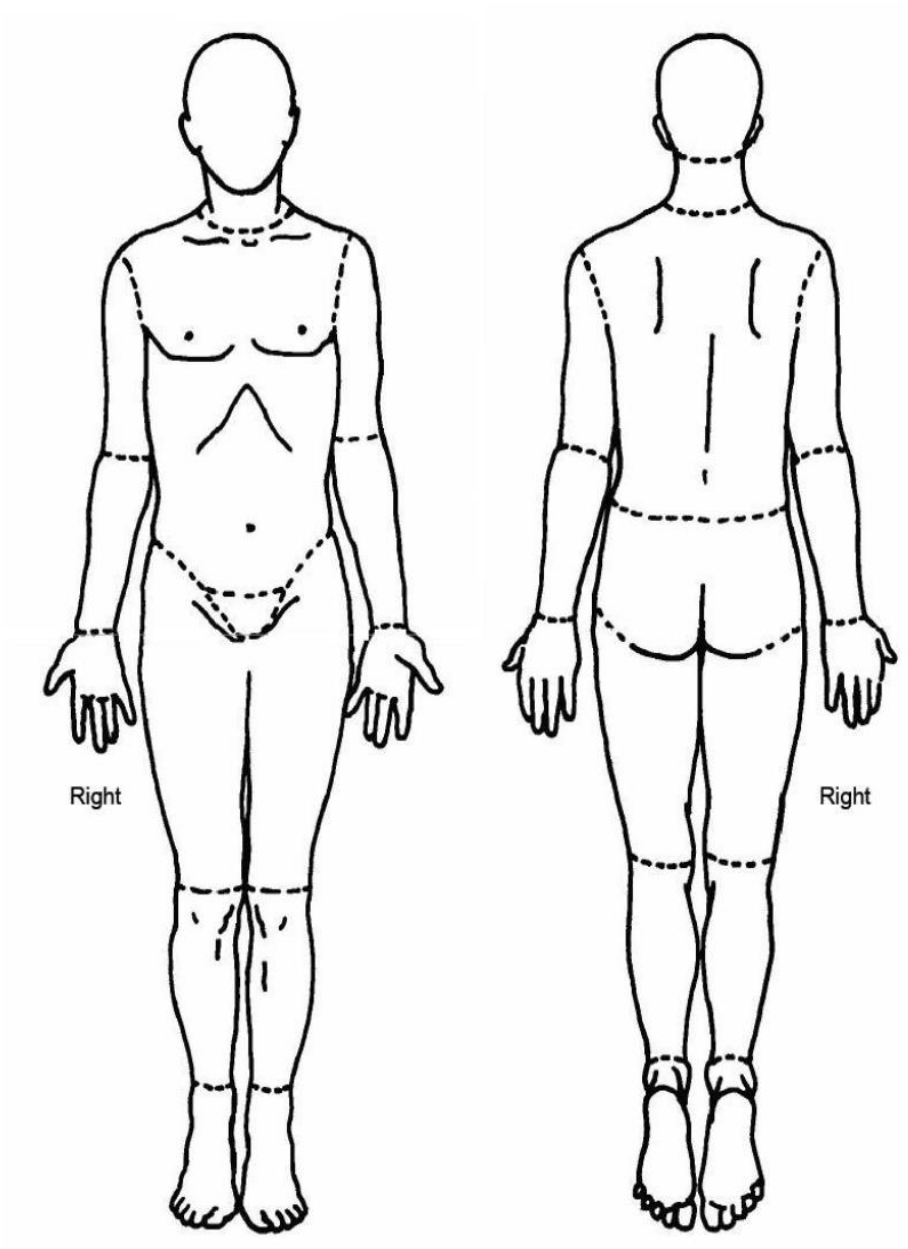
Patient ID Label

Please mark on these pictures where it is that you hurt:



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Patient ID Label

Edmonton Symptom Assessment System:
(Revised version) (ESAS-R)

Date																									
Pain 10 0																									
Tiredness 10 0																									
Nausea 10 0																									
Depression 10 0																									
Anxiety 10 0																									
Drowsiness 10 0																									
Appetite 10 0																									
Wellbeing 10 0																									
Shortness of breath 10 0																									
Other 10 0																									
Palliative Performance Scale																									
Completed by P = Patient F = Family caregiver H = Health care professional caregiver A = Caregiver-assisted	Level of Education _____ Cage Score _____																								

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Appendix Three: ESAS Arabic Version

Patient ID Label

تقييم أعراض أدمونتون
(نسخة مراجعة)

لا يوجد ألم	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد تعب *(التعب = نقص الطاقة)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد شعور بالنعاس *(النعاس = الشعور بالنوم)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد غثيان	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد نقص في الشهية	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد ضيق في التنفس	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد اكتئاب *(الاكتئاب = الشعور بالحزن)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد قلق *(القلق= الشعور بالإضراب العصبي)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
الشعور التام بالصحة والسعادة *(ما تشعر به عموماً)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد _____ أي مشكلة أخرى *(الإمساك على سبيل المثال)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن

تم تعبئة النموذج من قبل (اختر واحداً):
- ☐ المريض
- ☐ مقدم الرعاية الصحية من أسرة المريض
- ☐ مقدم الرعاية الصحية في المستشفى
- ☐ بمساعدة مقدم الرعاية الصحية

اسم المريض _____ التاريخ _____
التوقيع _____ الوقت _____

"رسم توضيحي للجسم من الجهة الخلفية"

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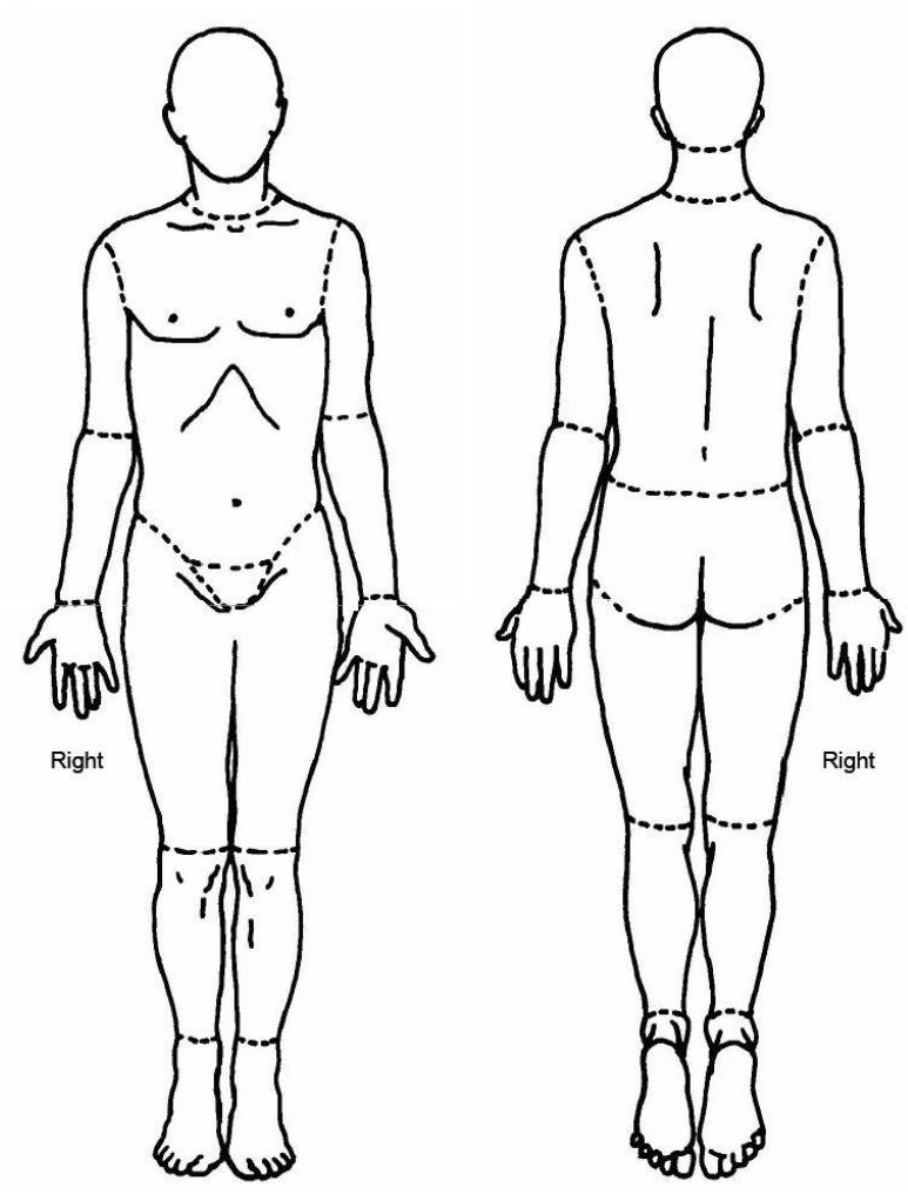
Patient ID Label

فضلاً، حَدد على الرسم التالي موضع الألم الذي تشعر به:



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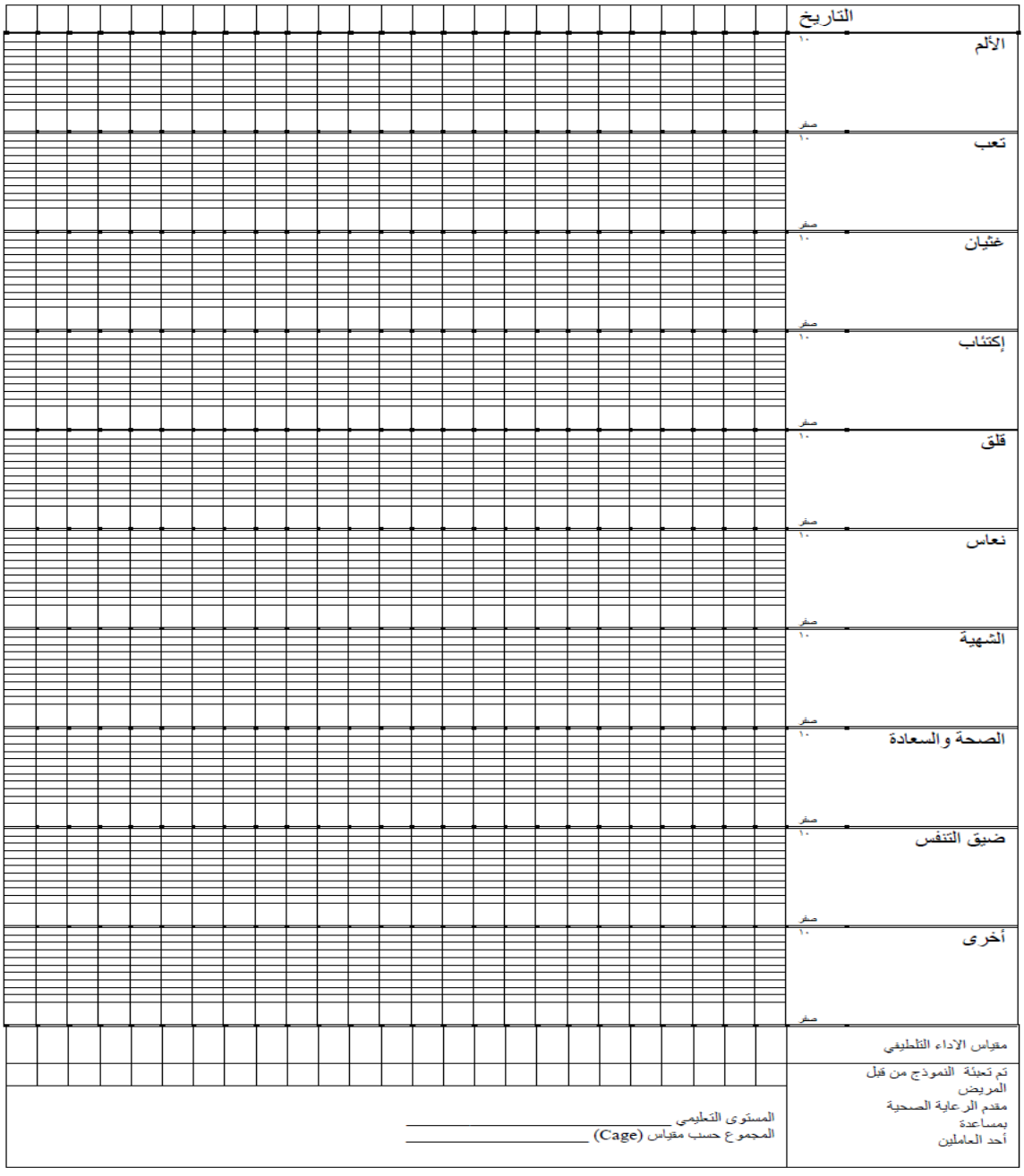
Patient ID Label

تقييم أعراض أدمونتون
(نسخة مراجعة)



Appendix Four: Palliative Performance scale (Ppsv2) version 2 form

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Palliative Performance scale (Ppsv2) version 2 form

☑	PPS Level	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
☐	100%	Full	Normal activity and work No evidence of disease	Full	Normal	Full
☐	90%	Full	Normal activity and work Some evidence of disease	Full	Normal	Full
☐	80%	Full	Normal activity and work Some evidence of disease	Full	Normal or Reduced	Full
☐	70%	Reduced	Unable Normal Job or Work Significant Disease	Full	Normal or Reduced	Full
☐	60%	Reduced	Unable to do hobby or house work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
☐	50%	Mainly Sit or Lie	Unable to do any work Extensive Disease	Considerable Assistance Required	Normal or Reduced	Full or Confusion
☐	40%	Mainly in Bed	Unable to do most activity Extensive Disease	Mainly Assistance	Normal or Reduced	Full or Drowsy + or - Confusion
☐	30%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Normal or Reduced	Full or Drowsy + or - Confusion
☐	20%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Minimal to Sips	Full or Drowsy + or - Confusion
☐	10%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Mouth Care Only	Drowsy or Coma + or - Confusion
☐	0%	Death	Not Applicable	Not Applicable	Not Applicable	Not Applicable

Name and Stamp: _____ **Signature:** _____ **Date:** _____ **Time:** _____

Appendix Five: ECOG Performance Status

Score	Criteria
0	Asymptomatic (Fully active, able to carry on all pre-disease activities without restriction)
1	Symptomatic but completely ambulatory (Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature. For example, light housework, office work)
2	Less than 50% in bed during the day (Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours)
3	More than 50% in bed, but not bedbound (capable of only limited self-care, confined to bed or chair 50% or more of waking hours)
4	Bedbound (Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair
5	Death

* As published in Am. J. Clin. Oncol.:
Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T., Carbone, P.P.: Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group. Am J Clin Oncol 5:649-655, 1982.

The ECOG Performance Status is in the public domain therefore available for public use. To duplicate the scale, please cite the reference above and credit the Eastern Cooperative Oncology Group, Robert Comis M.D., Group Chair

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CHAPTER 6
MANAGEMENT OF GASTROINTESTINAL SYMPTOMS

المجلس الصحي السعودي
Saudi Health Council

CHAPTER 6:- MANAGEMENT OF GASTROINTESTINAL SYMPTOMS IN PALLIATIVE CARE

1 PURPOSE

1.1 To provide practical guidance in the identification, diagnosis and management of adult patients (age 14 years and older) who have advanced life-threatening illness and are experiencing gastrointestinal (GI) conditions/ problems/ symptoms such as constipation, diarrhea, bowel obstruction, nausea and/or vomiting.

2 DEFINITION

2.1 **Constipation:** Is the passage of small, hard faeces infrequently or with difficulty, and less often than is normal for that individual.

2.2 **Diarrhea:** Is defined as 3 or more loose, watery stools per day.

2.3 **Bowel obstruction:** Occurs when there is blockage of the forward flow of gastric and intestinal contents through the gastrointestinal tract and can occur in the large or small bowel. It can be due to direct infiltration, intraluminal obstruction or external obstruction. This may occur due to tumour growth, adhesions, carcinomatosis, fecal impaction, pharmacotherapy and/or neuropathy.

2.4 **Nausea:** Is expressed as an unpleasant subjective sensation as a result from stimulation of the gastrointestinal lining, the chemoreceptor trigger zone in the base of the fourth ventricle, the vestibular apparatus, or the cerebral cortex.

2.5 **Vomiting:** Is an observable neuromuscular reflex that constitutes a final common pathway after stimulation of one or more of these regions. Vomiting can occur without nausea, and nausea does not always lead to vomiting. Both these symptoms, together or alone, can be very disruptive and distressing for patients and families.

2.6 **Gastrointestinal Conditions/problems**: Refer to illnesses of gastrointestinal tract such as constipation, diarrhea, bowel obstruction, and nausea and vomiting.

3 GENERAL GUIDELINES

3.1 All admitted palliative patients aged 14 years and older experiencing gastrointestinal symptoms of shall be assessed, diagnosed and managed by palliative care physicians.

3.2 A systematic symptom assessment to palliative patients must be done by Palliative Care Physician using the following tools:

3.2.1 Edmonton Symptom Assessment System (ESAS-r) revised should be completed for in-patient upon initial assessment and every week, and for out-patient, it shall be done upon initial assessment and at each follow-up visit (see CMG, Use of Edmonton Symptom Assessment System (ESAS-r) revised.

3.2.2 Palliative Performance Scale (PPS) or Eastern Co-operative Oncology Grade (ECOG) should be used to assess performance status and done daily for in-patient; and for out-patient, it shall be done upon initial assessment and at each follow-up visit (see CMG, Use of the Palliative Performance Scale (PPS).

3.3 Palliative Care Physician should identify and treat the underlying cause(s) of GI symptoms.

3.4 Palliative Care Physician should treat GI symptoms on-pharmacologically or/and pharmacologically.

4 ASSESSMENT AND MANAGEMENT

4.1 Assessment: Screen/assess the patient for constipation, diarrhoea, bowel obstruction nausea and/or vomiting as follows:

4.1.1 Complete/ask patient to complete ESAS-r form (see Appendix 1).

4.1.1.1 Note, use acronym O, P, Q, R, S, T, U and V (see Appendix 4)

4.1.2 Use daily the Palliative Performance Scale (PPS) (see Appendix 2) or Eastern Cooperative Oncology Group (ECOG) Performance Status (see Appendix 3) to report the patient's overall functional status

4.1.3 Perform further assessment for constipation and diarrhoea is as follows:

4.1.3.1 Complete a bowel assessment and re-evaluate (see Appendix 9: Palliative Care Bowel Protocol).

4.1.4 Perform further assessment for bowel obstruction by considering need for:

4.1.4.1 Plain abdominal x-ray: may demonstrate dilated loops of bowel, air and fluid levels, fecal impaction and/or the obstruction.

4.1.4.2 CT scan: may be required to determine the extent of the disease and help plan appropriate further treatments.

4.2 Identify and treat underlying causes (follow Appendix 4-8) and:

4.2.1 Consider/observe for the following when assessing clinical symptoms:

4.2.1.1 Pain may be constant, crampy or colicky resulting from the accumulation of secreted bowel fluid. Suspect bowel strangulation if refractory to opioid analgesics.

4.2.1.2 Abdominal distension.

4.2.1.3 Nausea and vomiting are eventually present but may vary in their intensity based on the level of the obstruction and the degree of compromise of bowel patency. In obstructions of the stomach,

duodenum, pancreas or jejunum, vomiting will develop early and in large volumes.

4.2.1.4 Bowel sounds are usually altered and may be tympanic, high pitched, diminished or absent.

4.2.1.5 Abdominal exam may demonstrate visceral or peritoneal irritation or may prove benign.

4.2.1.6 In complete obstruction, there will be an absence of faeces and flatus.

4.2.1.7 Fatigue.

4.2.1.8 Anorexia.

4.2.1.9 Diarrhea with partial obstruction (overflow diarrhea).

4.2.2 Manage/treat reversible causes where possible and desirable according to the goals of care. Intervention aimed at reducing nausea and vomiting must take into account the cause (often multi-factorial) of the symptoms and the central emetogenic pathways and their corresponding neurotransmitter receptors.

4.3 Educate/explain the following to patient and family and reassure:

4.3.1 Bowel Care (constipation and diarrhea)

4.3.1.1 Even in the absence of oral intake, the body continues to produce 1 to 2 ounces of stool per day.

4.3.1.2 It is not necessary to have a bowel movement every day. As long as stools are soft and easy to pass, every 2 to 3 days is acceptable.

4.3.1.3 “Normal” bowel movements vary from person to person.

4.3.1.4 If appetite is small, try to incorporate nutritious liquids such as milkshakes, cream soups, fruit juice.

4.3.2 Malignant Bowel Obstruction

4.3.2.1 The patient and family should be involved in discussions. Information should be reinforced so that appropriate decisions regarding disease modifying or symptom modifying therapies can be made.

4.3.3 Nausea and Vomiting

4.3.3.1 Explain to patient and family that there are multiple triggers for nausea and / or vomiting and that it may take many strategies together to make a difference.

4.3.3.2 consultation to a Clinical Dietician must be considered

4.3.3.3 The following dietary modifications can help and needs to be discussed with patient/ family :

.

4.3.3.3.1 Cut out intolerant foods.

4.3.3.3.2 Restrict intake when gastric distension is a factor. Start with sips, ice chips or popsicles, after nausea settled; gradually increase from fluids to semi-solid to full food. If nausea recurs, step back until nausea resolves.

4.3.3.3.3 Avoid spicy, fatty and salty foods, or ones with strong odors.

4.3.3.3.4 Avoid mixing liquids and solids.
4.3.3.3.5 Eat small frequent, bland meals when hungry.

4.3.3.3.6 Avoid lying flat after eating.

4.4 **Use non-pharmacological treatments as follows:**

4.4.1 Constipation:

4.4.1.1 Incorporate constipation prevention strategies for as long as possible and appropriate, including: fluid intake, dietary fiber (only for those with adequate fluid and mobility), fruit (prunes) and other natural agents, appropriate toileting, and physical activity. A fruit laxative can be made with prunes, dates, figs and raisins.

4.4.1.2 Advice that attempts at defecating should be made 30 to 60 minutes following ingestion of a meal to take advantage of the gastro colic reflex.

4.4.1.3 Bowel action should be initiated when it is “normal and convenient” for the patient in a sitting position. This can be facilitated by using; raised toilet seats, commodes and ensure adequate pain control for movement and comfort.

4.4.1.4 Provide privacy during toileting.

4.4.1.5 Avoid excessive straining (this can complicate some medical conditions).

4.4.1.6 Encourage physical activity.

4.4.2 Diarrhea:

:

4.4.2.1 For most patients with diarrhea decreasing fiber intake is helpful, however if there is excessive liquid in the bowel an absorbent can be helpful (crackers). If over stimulation of the bowel is suspected reducing intake to sips of fluid for 24 to 48 hours can be helpful.

4.4.2.2 Limit consumption of high fiber foods, large meals, fatty foods, caffeine and dairy products.

4.4.2.3 Maintain hydration and electrolytes as appropriate (particularly in cases of severe diarrhea).

4.4.2.4 Rehydration can also be done orally, if the dehydration is not severe, with the rehydration fluid.

4.4.2.5 A single liquid or loose stool usually does not require intervention.

4.4.2.6 Persistent diarrhea can have severe effects on image, mood and relationships, which will need support.

4.4.3 Malignant Bowel Obstruction:

4.4.3.1 Acute or initial treatment may include; keeping patient NPO, administering intravenous or subcutaneous fluids and performing nasogastric tube drainage. Nasogastric tube drainage should be an intermittent and temporary measure for initial treatment and decompression or while waiting to make other treatment decisions.

4.4.3.2 Hydration should be considered on an individual basis in patients where dehydration causes agitated confusion or results in renal failure causing opioid metabolite accumulation leading to myoclonus or seizure.

4.4.3.3 Total parenteral nutrition should only be considered for patients who would have clinical or life-extending benefit. It is not recommended for most terminally ill patients and is best used in patients with a true long-term prognosis.

4.4.3.4 Good mouth care and ice chips should be given for dry mouth.

4.4.3.5 Nasal care should be provided to patients who have a nasogastric tube inserted.

4.4.3.6 Support should be offered to patient and family as they confront the terminal nature of the disease.

4.4.3.7 Give small, low residue meals for patients with controlled nausea and vomiting.

4.4.3.8 Surgical Options.

4.4.3.8.1 While surgery is the primary treatment for malignant bowel obstruction, not every patient will be a suitable candidate because of poor prognosis or advanced disease.

4.4.3.8.2 Surgery should be avoided in patients exhibiting: palpable abdominal and pelvic mass, ascites exceeding three litres,

multiple obstructive sites and pre-operative weight loss of greater than nine kilograms.

4.4.3.8.3 Interventions may include resection, bypass, stenting and venting gastric or jejunal tubes and should be considered when symptoms have not been relieved after 48 to 72 hours of conservative medical management. Stenting and gastric or intestinal venting using percutaneous endoscopic gastrostomy tubes (PEG) are less invasive, generally well tolerated and can be done under sedation.

4.4.3.8.4 Prognosis, disease progression, patient's wishes and co-morbidities must be considered.

4.4.4 Nausea and Vomiting

4.4.4.1 Environmental modification – eliminate strong smells and sights and use air deodorizers or fresheners.

4.4.4.2 Maintain good oral hygiene, especially after episodes of vomiting.

4.4.4.3 Visualization or hypnosis.

4.4.4.4 Distraction.

4.4.4.5 Consult with Social Worker, Spiritual Practitioner, Physiotherapist, Occupational Therapist, Counsellors for psychosocial care/anxiety reduction.

4.5 Manage GI symptoms pharmacologically as follows:

4.5.1 Constipation:

4.5.1.1 Note the following with regard to opioid use and constipation:

4.5.1.1.1 Constipation is a common side effect of all opioids

4.5.1.1.2 Patients often stop opioid therapy because of opioid induced constipation

4.5.1.1.3 Opioid induced constipation is much easier to prevent than treat

4.5.1.1.4 Opioids cause decreased motility (by suppression of intestinal peristalsis) and increased water and electrolyte re-absorption in the small intestine and colon. Transdermal fentanyl and methadone have been shown to produce less constipation

4.5.1.1.5 Consider opioid rotation for severe refractory constipation

4.5.1.1.6 Tolerance will not develop the constipating effects of opioids.

4.5.1.1.7 The constipating effect of opioids is not dose dependant.

4.5.1.2 Consider patient preferences when determining bowel regime.

4.5.1.3 Start laxatives on a regular basis for all patients taking opioids (see Appendix 5).

4.5.1.3.1 Use oral laxatives if possible.

4.5.1.3.2 Combination of stimulant and softener: Senna 2-4 tablets or Bisacodyl 5-10mg, at bedtime in combination with docusate sodium 100mg capsule, twice daily

4.5.1.4 Based on the bowel pattern, time since last bowel movement and bowel medication previously being used, determine the level of the bowel protocol for medications.

4.5.1.5 Use a step wise approach, titrate the laxatives according to the bowel protocol to ensure regular bowel movements. Aim for soft formed stool at least once every 2 to 3 days.

4.5.1.6 Three days without a bowel movement requires intervention.

4.5.1.7 The continued use of Docusate in the palliative care setting is based on inadequate experimental evidence.

4.5.1.8 Rectal laxative should never accompany an inadequate prescription of oral laxative.

4.5.1.9 Avoid use of bulk forming agents (fiber) in patients with poor oral fluid intake. The patient must be able to tolerate 1.5 to 2 litres of fluid per day. This makes bulk forming agents a poor choice in cancer patients. They may worsen with an incipient obstruction.

4.5.1.10 Osmotic laxatives should be accompanied by an increase in fluid intake.

4.5.1.11 Metoclopramide inhibits dopamine centrally and peripherally, therefore increasing peristalsis in the digestive tract as well as combating nausea and vomiting.

4.5.1.11.1 Metoclopramide 10 to 20 mg PO every 6 hours

4.5.1.12 There is some evidence to support the use of polyethylene glycol as a laxative for opioid induced constipation. Polyethylene glycol 10 to 30 g PO daily to BID. or 60 to 240 g for evacuation.

4.5.1.13 Rectal treatment may be needed for faecal impaction, and for paraplegic or bedbound patients.

4.5.1.14 If rectum is ballooned and empty, do not give rectal treatment.

4.5.1.15 Severe intractable opioid induced constipation: we can use peripheral opioid receptors antagonists (e.g. Methylnaltrexone).

4.5.2 Diarrhea:

4.5.2.1 Diarrhea can be caused by over use of laxatives or can be a side effect of radiation, chemotherapy or surgical treatments.

4.5.2.2 Good hygiene and application of hydrocolloid dressings or barrier cream will help prevent excoriation with diarrhea

4.5.2.3 Maintain hydration and electrolytes as appropriate (particularly in cases of severe diarrhea). Ringers lactate is the preferred solution for parenteral hydration.

4.5.2.4 If anal area inflamed or excoriated use a corticosteroid cream for 1 to 2 days

4.5.2.5 Symptomatic relief is generally achieved with non-specific antidiarrheal agents – Loperamide PO up to 16 mg daily or codeine 10 to 60 mg PO every 4 hours.. Unlike constipation, where multiple drugs are used simultaneously, a single drug should be used for diarrhea and care should be taken to avoid sub-therapeutic doses.

4.5.2.6 Metronidazole is recommended for C. Difficile diarrhea Metronidazole 500 mg PO TID

4.5.3 Malignant Bowel Obstruction

4.5.3.1 Treatment should always be parenteral as absorption via PO route is variable.

4.5.3.2 Steroids for inflammation - Dexamethasone 4 to 16 mg S.C. daily for incomplete or small bowel obstruction. Found to work better in patient populations that are not already taking steroids prior to the obstruction and should be discontinued if the patient does not respond to steroid treatment within 4 to 5 days.

4.5.3.3 Antiemetics for nausea – combinations work best. *See* pharmacological management of nausea and vomiting. (6.5.4)

4.5.3.4 Motility agents to stimulate bowel in cases of incomplete obstruction Metoclopramide 5 to 20 mg subcutaneously. QID (contraindicated in complete bowel obstruction).

4.5.3.5 Anti-motility agents may have a role in complete obstruction - Hyoscine Butylbromide 10 to 20 mg S.C. QID

4.5.3.6 Anti-secretory agents - Octreotide 150 mcg S.C. daily to TID or 300 to 900 mcg by continuous S.C. infusion. Octreotide was found to be more effective than Hyoscine Butylbromide in relieving gastrointestinal symptoms of advanced cancer patients. In another study, Octreotide resulted in significantly reduced gastrointestinal secretions by the second day of treatment and it was also shown to reduce levels of nausea and pain when compared to Scopolamine Butylbromide or Hyoscine Butylbromide.

4.5.3.7 Analgesics for pain may be given via S.C. or I.V. or transdermal route.

4.5.3.8 Analgesics should not be avoided due to concerns regarding aggravation of an obstruction.

4.5.3.9 Cathartics via rectal route can be considered in cases of fecal impaction.

4.5.4 Nausea and Vomiting

4.5.4.1 Nausea is mediated by several neurotransmitters: the four main being; serotonin (5HT3), dopamine (D2), acetylcholine (Achm) and histamine (H1).

4.5.4.2 Select antiemetics according to the etiology of nausea, vomiting and site of action of mediation.

4.5.4.3 Metoclopramide is the usual first choice as it targets common causes of nausea in advanced diseases.

4.5.4.4 Titrate up antiemetics to their full dose before adding another drug.

4.5.4.5 If nausea is not controlled with a specific antiemetic, add another antiemetic from another group if nausea continues for 48 hours, but do not stop the initial agent.

4.5.4.6 Consider combinations but monitor overlapping toxicities.

4.5.4.7 Use regular dosing of antiemetics if experiencing constant nausea and / or vomiting.

4.5.4.8 Antiemetics should be prescribed as a regularly scheduled dose with a breakthrough dose.

4.5.4.9 All medications need to be individually titrated and a variety of routes and combinations of medications may be used to alleviate nausea.

4.5.4.10 Give antiemetics prophylactically to prevent nausea with high dose opioids and chemotherapeutic agents.

4.5.4.11 Ondansetron, although useful in chemotherapy-induced nausea is considered as a fourth line therapy in chronic nausea.

5 APPENDIX

5.1 Appendix 1: ESAS–r English and Arabic Versions

5.2 Appendix 2: ECOG Performance Status

5.3 Appendix 3: Palliative Performance Scale (Ppsv2) Version 2

5.4 Appendix 4: Assessment using Acronym O, P, Q, R, S, T, U and V (adapted from Fraser Health).

5.5 Appendix 5: Constipation in Advanced Cancer Patients.

5.6 Appendix 6: Causes of Diarrhea in Advanced Disease.

5.7 Appendix 7: Causes of Bowel Obstruction.

5.8 Appendix 8: Diagnosis: Determining the cause of nausea and / or vomiting.

5.9 Appendix 9: Palliative Care Bowel Protocol

5.10 Appendix 10: Available Laxatives

5.11 Appendix 11: Available drugs for treating nausea, its route, dose and range frequency

6 REFERENCE

6.1 Symptom Guidelines of Hospice Palliative Care Program. [Internet]. 2019 [cited 15 September 2019]. Available from: http://www.fraserhealth.ca/professionals/hospice_palliative_care/

6.2 Palliative Care Guidelines: Constipation. [Internet]. 2019 [cited 15 September 2019]. Available from: https://www.palliativecareguidelines.scot.nhs.uk/guidelines/symptom-control/constipation.aspx

6.3 Northernhealth.ca. 2019 [cited 15 September 2019]. Available from: https://www.northernhealth.ca/for-health-professionals/palliative-care-end-life-care#optional-forms#assessment-tools

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Patient ID Label

APPENDIX 1: ESAS ENGLISH VERSION

Edmonton Symptom Assessment System
(Revised version) (ESAS-R)

No Pain	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Pain**
No Tiredness *(Tiredness = lack of energy)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Tiredness**
No Drowsiness *(Drowsiness = feeling sleepy)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Drowsiness**
No Nausea	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Nausea**
No Lack of Appetite	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Lack of Appetite**
No Shortness of Breath	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Shortness of Breath**
No Depression *(Depression = feeling sad)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Depression**
No Anxiety *(Anxiety = feeling nervous)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Anxiety**
Best Wellbeing *(Wellbeing = how you feel overall)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible Wellbeing**
No _____ **Other Problem** *(for example constipation)*	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Worst Possible** _____

Completed by (check one)

☐ **Patient**

☐ **Family Caregiver**

☐ **Healthcare professional caregiver**

☐ **Caregiver assisted**

Name: _____ **Date:** _____

Signature: _____ **Time:** _____

"BODY DIAGRAM ON PAGE 2"

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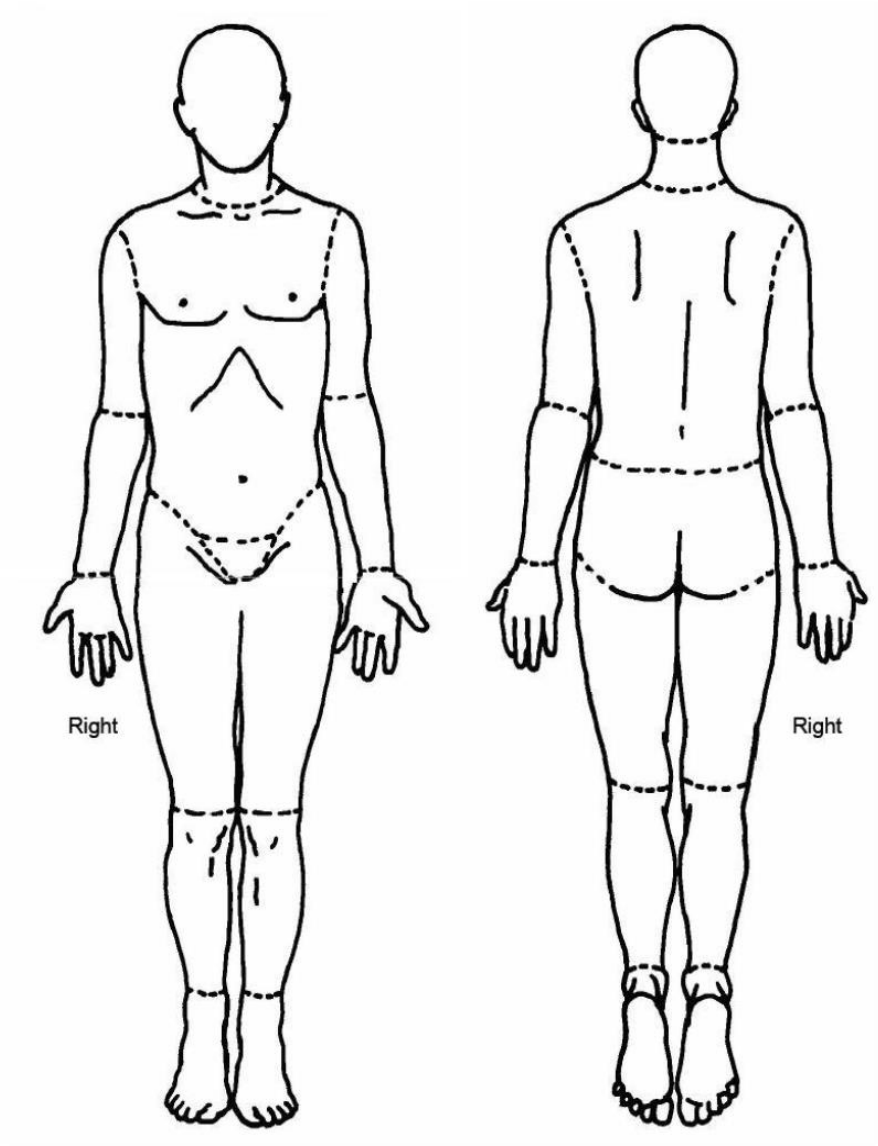
Patient ID Label

Please mark on these pictures where it is that you hurt:



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Edmonton Symptom Assessment System: (Revised version) (ESAS-R)

Date																										
Pain	10 0																									
Tiredness	10 0																									
Nausea	10 0																									
Depression	10 0																									
Anxiety	10 0																									
Drowsiness	10 0																									
Appetite	10 0																									
Wellbeing	10 0																									
Shortness of breath	10 0																									
Other	10 0																									
Palliative Performance Scale																										
Completed by P = Patient F = Family caregiver H = Health care professional caregiver A = Caregiver-assisted		Level of Education _____ Cage Score _____																								

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Patient ID Label

تقييم أعراض أدمونتون
(نسخة مراجعة)

لا يوجد ألم	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد تعب *(التعب = نقص الطاقة)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد شعور بالنعاس *(النعاس = الشعور بالنوم)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد غثيان	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد نقص في الشهية	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد ضيق في التنفس	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد اكتئاب *(الاكتئاب = الشعور بالحزن)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد قلق *(القلق= الشعور بالإضراب العصبي)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
الشعور التام بالصحة والسعادة *(ما تشعر به عموماً)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد _____ أي مشكلة أخرى *(الإمساك على سبيل المثال)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن

تم تعبئة النموذج من قبل (اختر واحداً):

- ☐ المريض
- ☐ مقدم الرعاية الصحية من أسرة المريض
- ☐ مقدم الرعاية الصحية في المستشفى
- ☐ بمساعدة مقدم الرعاية الصحية

اسم المريض _____ التاريخ _____

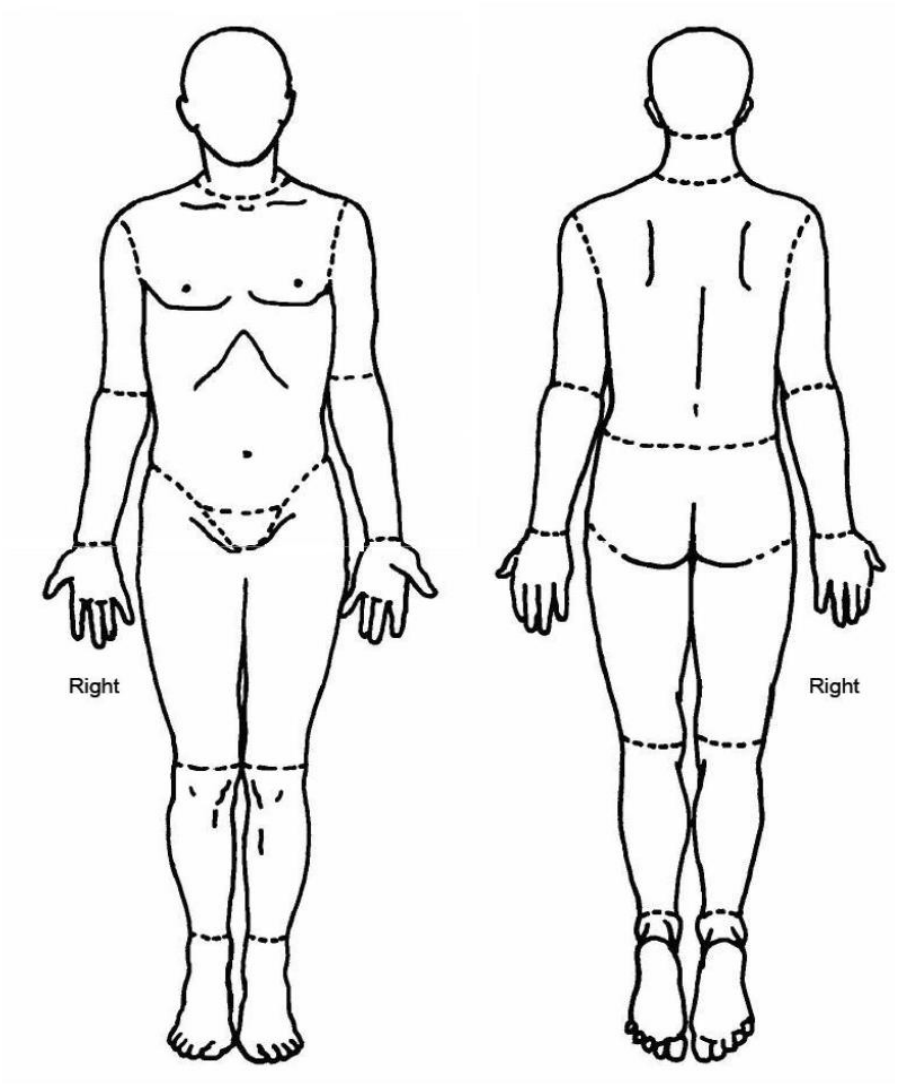
التوقيع _____ الوقت _____

"رسم توضيحي للجسم من الجهة الخلفية"

المجلس الصحي السعودي
Saudi Health Council

Patient ID Label

فضلاً، حدد على الرسم التالي موضع الألم الذي تشعر به:



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Saudi Health Council

Patient ID Label

تقييم أعراض أدمونتون
(نسخة مراجعة)

التاريخ										
الألم	١٠									صفر
تعب	١٠									صفر
غثيان	١٠									صفر
إكتئاب	١٠									صفر
قلق	١٠									صفر
نعاس	١٠									صفر
الشهية	١٠									صفر
الصحة و السعادة	١٠									صفر
ضيق التنفس	١٠									صفر
أخرى	١٠									صفر
مقياس الاداء التلطيفي										
تم تعبئة النموذج من قبل المريض مقدم الرعاية الصحية بمساعدة أحد العاملين	المستوى التعليمي _____ المجموع حسب مقياس (Cage) _____									

APPENDIX 2: ECOG PERFORMANCE STATUS

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Score	Criteria
0	Asymptomatic (Fully active, able to carry on all pre-disease activities without restriction)
1	Symptomatic but completely ambulatory (Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature. For example, light housework, office work)
2	Less than 50% in bed during the day (Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours)
3	More than 50% in bed, but not bedbound (capable of only limited self-care, confined to bed or chair 50% or more of waking hours)
4	Bedbound (Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair
5	Death

* As published in Am. J. Clin. Oncol.:
Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T., Carbone, P.P.: Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group. Am J Clin Oncol 5:649-655, 1982.

The ECOG Performance Status is in the public domain therefore available for public use. To duplicate the scale, please cite the reference above and credit the Eastern Cooperative Oncology Group, Robert Comis M.D., Group Chair

APPENDIX 3: PALLIATIVE PERFORMANCE SCALE (PPSV2) VERSION 2

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☑	PPS Level	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
☐	100%	Full	Normal activity and work No evidence of disease	Full	Normal	Full
☐	90%	Full	Normal activity and work Some evidence of disease	Full	Normal	Full
☐	80%	Full	Normal activity and work Some evidence of disease	Full	Normal or Reduced	Full
☐	70%	Reduced	Unable Normal Job or Work Significant Disease	Full	Normal or Reduced	Full
☐	60%	Reduced	Unable to do hobby or house work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
☐	50%	Mainly Sit or Lie	Unable to do any work Extensive Disease	Considerable Assistance Required	Normal or Reduced	Full or Confusion
☐	40%	Mainly in Bed	Unable to do most activity Extensive Disease	Mainly Assistance	Normal or Reduced	Full or Drowsy + or - Confusion
☐	30%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Normal or Reduced	Full or Drowsy + or - Confusion
☐	20%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Minimal to Sips	Full or Drowsy + or - Confusion
☐	10%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Mouth Care Only	Drowsy or Coma + or - Confusion
☐	0%	Death	Not Applicable	Not Applicable	Not Applicable	Not Applicable

Name and Stamp: _____ **Signature:** _____ **Date:** _____ **Time:** _____

Appendix 4: Assessment using Acronym O, P, Q, R, S, T, U and V (adapted from Fraser Health)	
Onset	When did it begin? How long does it last? How often does it occur?
Provoking / Palliating	What brings it on? What makes it better? What makes it worse?
Quality	What does it feel like? Can you describe it?
Region / Radiation	Are there any other associated symptoms?
Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right Now? At Best? At Worst? On Average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?
Treatment	What medications or treatments are you currently using? How effective are these? Do you have any side effects from the medications/treatments? What medications/treatments have you used in the past?
Understanding / Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and/or your family?
Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?
* Note: Where a patient is not able to complete an assessment by self-reporting, then the health professional and/or the caregiver may act as a surrogate.	

Appendix 5: Constipation in Advanced Cancer Patients

Structural abnormalities	GI Obstruction Pelvic tumour mass Radiation fibrosis Painful anal-rectal conditions (anal fissure, haemorrhoids, perianal abscess
Drugs	Opioids Drugs with anticholinergic action - anticholinergics, antispasmodics, antidepressants, phenothiazines, Haloperidol, antacids Antiemetics – 5HT3 antagonists Diuretics Anticonvulsants Iron Antihypertensives Chemotherapy agents –vinca alkaloids
Metabolic disturbances	Dehydration Hyperglycaemia Hypokalaemia or Hypercalcemia Uraemia Hypothyroidism
Neurological disorders	Cerebral tumours Spinal cord involvement/compression Sacral nerve infiltration
General	Advanced age

	Inactivity Depression Sedation Decreased intake Low fibre diet Poor fluid intake Physical or social impediments

Appendix 6: Causes of Diarrhea in Advanced Disease

Obstruction	Malignant tumour Fecal impaction Opioid bowel syndrome
Drugs	Laxatives Antacids Antibiotics Chemotherapy agents – 5-Flourouracil, Mitomycin NSAID – Diclofenac, Indomethacin Iron preparations Disaccharide containing elixirs
Malabsorption	Pancreatic carcinoma or insufficiency Gastrectomy Ileal resection
Tumour	Cancer of the colon or rectum Pancreatic islet cell tumour Carcinoid tumour
Radiation	Abdominal or pelvic radiation with or without chemotherapy (RT induced enteritis)
Concurrent disease	Diabetes mellitus Hyperthyroidism Inflammatory bowel syndrome – Crohn's Irritable bowel syndrome – Colitis

	Gastrointestinal infection – C. Difficile
Diet	Bran Fruit Hot spices Alcohol

Appendix 7: Causes of Bowel Obstruction

Tumour mass	Single or multiple Invasion and blockage of bowel (apple core) Extrinsic compression
Constipation	Impacted faeces, obstipation
Adhesions	Post-operative Malignant Post-radiation
Volvulus	Around tumour Around adhesions Around fistula
Ileus	Infection, peritonitis Drugs
Peritonitis	Infection, bleeding
Massive ascites	

Appendix 8: Determining the cause of nausea and / or vomiting

Common Causes	Clinical Picture	Principle Site of Action
Chemical • Drugs (opioids, Digoxin, steroids, antibiotics, anticonvulsants, cytotoxics) • Biochemical (hypercalcaemia, uremia, organ failure) • Toxins (tumour factors, infection, drug metabolites, radiation, ischemic bowel, food poisoning)	Symptoms of drug toxicity or underlying disease plus nausea as the prominent symptom. Nausea usually not relieved by vomiting.	Chemotrigger Zone (CTZ), Dopamine (D2), Serotonin receptor antagonist (5-HT3)
Gastrointestinal Tract–Vagal • Gastric irritation (ASA, NSAIDs, steroids, antibiotics, blood, ETOH, stress, radiotherapy) • Obstruction (partial or complete) • Constipation • Gastric stasis • Mass effect (GI, GU, hepatic distension, carcinomatosis) • Anatomic / Structural	Epigastric pain, fullness, acid reflux, early satiety, flatulence, hiccup, intermittent nausea relieved with vomiting. Altered bowel habit, pain may occur with oral intake. Vomitus may be large volume and faecal smelling.	Vagal & sympathetic afferent nerve pathways. Dopamine (D2), Serotonin receptor antagonist (5-HT3) and 5HT4 receptors H2 receptors Acetylcholine

CNS • Increased Intracranial Pressure (brain metastases, infectious meningitis, cerebral oedema, bleeding) • Psychological (fear, anxiety, pain)	Headache +/- cranial nerve signs, (diurnal). Vomiting often without nausea. Anticipatory nausea / vomiting to sights, smells, etc.	Histamine (H1) receptors
Vestibular • Motion sickness • Cerebellar tumour	Nausea +/- vomiting with movement.	Histamine (H1) receptors Acetylcholine

Appendix 9: Palliative Care Bowel Protocol

1. Complete bowel assessment.

2. Determine Level at which to start, based on bowel pattern, time since last bowel movement and bowel medication use prior to admission. Record Level chosen on Bowel Assessment form.

3. Document all bowel medications administered and bowel movement information

4. Document subsequent rectal and/or abdominal examinations.

INDICATIONS	CONTRAINDICATIONS
• To prevent opioid-induced constipation. • To manage constipation where dietary measures have failed, or previous laxative treatment unsatisfactory.	Do not follow protocol for: • Ileostomy. • Complete bowel obstruction. • Diarrhea. • Impaction if present, clear impaction prior to initiating protocol. • Short Bowel Syndrome. • To manage constipation where dietary measures have failed, or previous • Laxative treatment unsatisfactory.
LEVEL 1 – PREVENTION ONCE DAILY (HS)	Meds: 1. Sennosides 12 mg tablets; 12 to 36 mg (1 to 3 tablets) PO Bedtime
LEVEL 2 – PREVENTION	Meds: 1. Sennosides 12 mg tablets; 24 to 36 mg (2 to 3 tablets) PO

TWICE DAILY (BID)	BID 2. Lactulose 15 mL PO BID
LEVEL 3 – CONSTIPATION MANAGEMENT No bowel motion for 3 days or more. Do rectal examination and document .	Continue previous medications PLUS: a), b) or c) Medications: **a) If soft stool in rectum** Bisacodyl 10 mg suppository PR. If not effective within 1 hour, give Fleet enema PR. **b) If hard or impacted stool in rectum** Fleet enema PR. Disimpact if indicated **c) If no stool in rectum** Perform abdominal examination and document. Assess abdomen for bowel sounds. If normal, give Fleet enema PR.
LEVEL 4 – CONSTIPATION MANAGEMENT (Day 2) No bowel motion or insufficient result.	May repeat above
OUTCOME: After a bowel motion, resume Level I or 2 (increasing dose(s) PRN) to maintain a bowel motion at least every 3 days.	

Appendix 10: Available Laxatives

Oral laxatives:	Type	Action
Sodium Docusate	Predominantly softening - surfactant	Detergent, increase water penetration
Lactulose	Predominantly softening – osmotic laxative	Retain water in small gut
Sennosides	Peristalsis stimulating - anthracenes	Reduces water and electrolyte absorption and purgative action
Bisacodyl	Peristalsis stimulating - polyphenolic	Reduces water and electrolyte absorption and purgative action
Rectal laxatives:	**Type**	**Action**
Bisacodyl suppository	Peristalsis stimulating - polyphenolic	Evacuates stools from rectum or stoma: for colonic inertia
Glycerin suppository	Predominantly softening - osmotic laxative	Softens stools in rectum or stoma
Phosphate enema	Peristalsis stimulating – saline laxative	Evacuates stools from lower bowel

Appendix 11. Available drugs at KFMC with route, dose and range frequency

Drug	Route	Dose	Range Frequency
Metoclopramide	S.C. or PO or I.V.	10 to 20 mg	q6h
Domperidone	PO	10 to 20 mg	TID or QID
Haloperidol	S.C. or PO or I.V.	0.5 to 2.5 mg	q6h to q24h
Olanzapine	PO or I.M.	2.5 to 5 mg	Daily
Dimenhydrinate	PO or S.C. or I.M. or I.V.	25 to 50 mg	q4h to q6h
Dexamethasone	PO or S.C. or I.V.	4 to 24 mg	daily or BID. or TID.
Scopolamine Transdermal Patch	Transdermal	1.5 mg patch	Every third day
Ondansetron	PO or I.V.	8 mg	q8h to q24h
Octreotide	S.C.	50 to 250 ug	TID
Lorazepam	PO or S.C. or I.V.	0.5 to 2 mg	q4h to q24h

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CHAPTER 7
End-of-Life Care

المجلس الصحي السعودي
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CHAPTER 7:- End-of-Life Care

1 STATEMENT OF PURPOSE

1.1 To provide guidance for the delivery of high quality end of life care to patients and their families.

1.2 To emphasize the importance of impeccable assessment of psychological, social, spiritual needs as well as assessment and re assessment of physical needs.

1.3 To reiterate the importance of documentation, communication and interdisciplinary teamwork in the management of end of life care.

2 RELATED DOCUMENTS

2.1 End of Life Care

2.2 Use of Edmonton Symptom Assessment System (ESAS-r) revised

2.3 Use of the Palliative Performance Scale (PPS)

2.4 Allow Natural Death Order

3 DEFINITIONS

3.1 **End of Life:** Is that time when death, whether due to illness (acute or chronic), injury, or age, is expected within weeks to months and can no longer be delayed or prevented by medical intervention.

3.2 **End of life Phase One**: Is the period of time when a patient's life expectancy is more than 6 months. At this stage, the patient is with evidence of advancing, life-limiting disease such as end-stage renal disease, or with a life-threatening illness such as cancer and AIDS. The primary physician's measures towards the patient's disease shall be palliative chemotherapy, radiation or surgery and not curative.

3.3 **End of Life Phase Two**: Is the period of time when a patient's life expectancy is less than 6 months, At this stage, the patient has declining performance status (ECOG more than or equal to 1, or PPS less than or equal to 80%) with unexpected benefit from lifesaving procedures. The primary physician should focus his/her care on quality of life and advance care planning (advance directives)

3.4 **End of Life Phase Three**: Is the period of time when a patient's life expectancy is less than 2 weeks i.e. the patient is imminently dying

3.5 **End of Life Phrase Four**: Is the day of death, the time when the patient has no response, no heart sound and no breathing

3.6 **End of Life Phase Five**: is the period of up to one year following the patient's death.

3.7 **End of Life Care:** Is an important part of palliative care; it refers to the care of a person during the latest part of his/her life from the point at which it has become clear that the person is in progressive state of decline.

3.8 **Imminently Dying Patient:** Is the patient in the active process of or associated with the process of ceasing to be or passing from life.

3.9 **Edmonton Symptom Assessment System** a tool that was developed to assist in the assessment of nine symptoms that are common in palliative care patients: pain, tiredness, drowsiness, nausea, lack of appetite, depression, anxiety, shortness of breath, and wellbeing. It is intended to capture the patient's perspective of their symptoms, though in some situations a caregiver's perspective may be needed, and repeated use can give an indication of symptom progression.

3.10 **ESAS**-r: Is the revised version of the tool. Changes include specifying a timeframe of "now", adding definitions for potentially confusing symptoms, modifying the order of symptoms, adding an example for "other symptom", and altering the format for improved readability.

3.11 **Palliative Performance Scale (PPS):** Is a tool for measurement of performance status in palliative care.

3.12 **Eastern Cooperative Oncology Group (ECOG) Performance Status:** Is a tool to determine whether cancer patients can receive chemotherapy, whether dose adjustment is necessary, and as a measure for the required intensity of palliative care.

4 GENERAL GUIDELINES

4.1 When the patient reaches End of Life Phase Two the following shall be completed:

4.1.1 Primary Physician must discuss the following advance care plan with the patient and get his/her agreement on:

4.1.1.1 Code status: DNR/AND.

4.1.1.2 The patient's proxy/representative when he/she is unable to make decisions.

4.1.1.3 Place of care / Death.

4.1.1.4 Goals of care.

4.1.2 Primary physician must perform a systematic symptom assessment using validated tools and continuous assessment/reassessment of symptom control (see Appendices two, three and four).

4.1.2.1 Edmonton Symptom Assessment System (ESAS-r) revised shall be completed for in-patient at initial assessment and every week, and for out-patient, it shall be done upon initial assessment and at each follow-up visit (see CMG, Use of Edmonton Symptom Assessment System (ESAS-r) revised.

4.1.2.2 Palliative Performance Scale (PPS) or Eastern Co-operative Oncology Grade (ECOG) Performance Status shall be used to assess performance status and completed daily (see, Use of the Palliative Performance Scale (PPS).

4.1.3 Multidisciplinary team shall intervene at this phase on issues of breaking bad news, handling grief from loss of function, psychological issues and spiritual distress.

4.1.4 Physical and occupational therapists shall be asked to provide patient and family education regarding adaptation for optimum activities of daily living.

4.2 When the patient reaches End of Life Phase Three the following shall be completed:

4.2.1 Imminent Death Order (see appendices six and seven) form shall be completed on admission and every subsequent week.

4.2.2 Psychologists shall be required to manage the patient's psychological needs like grief, communication and information needs about feeding, caring, fluids etc.

4.2.3 Social worker input regarding family needs must be obtained.

4.2.4 Role of spiritual educator is critical and should be required to meet spiritual needs of the family and patients.

4.3 On the day of the patient's death (End of Life Phase Four) the following must occur:

4.3.1 Prompt verification and certification of death.

4.3.2 Relatives must be given information regarding what they need to do after a death.

4.3.3 Relatives must be advised on how to register the death and make funeral arrangements whilst being sensitive to the psychological, social and spiritual needs of the family.

4.4 Up to one year after death (End of Life Phase Five) support for the family must be provided including:

4.4.1 Offering social and/or financial support through the social services department.

4.4.2 Identifying risk factors for expected complicated grief in the bereaved family members and making necessary referrals to psychologist trained in providing bereavement support.

5 ASSESSMENT AND MANAGEMENT

5.1 Manage Phase One, where patient's life expectancy is more than 6 months, as follows::

5.1.1 Provide the following biomedical care:

5.1.1.1 Document and diagnose advance disease and life-threatening illness.

5.1.1.2 Discuss the treatment options including but not limited to the following:

5.1.1.2.1 Palliative Surgery.

5.1.1.2.2 Palliative Chemotherapy.

5.1.1.2.3 Palliative Radiotherapy.

5.1.1.2.4 Symptoms and pain management.

5.1.1.2.5 Only comfort care.

5.1.1.3 Discuss, when possible, Advance Care Planning including but not limited to:

5.1.1.3.1 DNR/AND.

5.1.1.3.2 Identifying Patient Representative.

5.1.1.3.3 Place of care.

5.1.1.3.4 Goal of care.

5.1.1.4 Screen patient for pain by asking do you have pain.

5.1.1.4.1 If the answer is yes, then perform a comprehensive assessment of pain (see appendix seven).

5.1.1.4.2 Consult Acute Pain service or Palliative Care if pain is not controlled after starting conventional pain treatment including opioids.

5.1.1.5 Assess and manage other symptoms. (see appendices eight, nine and ten)

5.1.2 Provide the following psychological care:

5.1.2.1 Assess and manage psychological issues.

5.1.2.2 Consult Psychiatry, Psychology and/or Palliative Care if appropriate.

5.1.3 Provide the following social needs related care::

5.1.3.1 Assess and document social issues.
5.1.3.2 Identify the social support system of the patient and family.

5.1.3.3 Identify the financial situation of the patient.

5.1.3.4 Consult social service if appropriate.

5.1.3.5 Identify the surrogate decision-maker.

5.1.4 Provide the following spiritual care:

5.1.4.1 Respect individuals' rituals and practices.

5.1.4.2 Make the patient and his family aware that spiritual service is available.

5.1.5 Provide the following home related care:

5.1.5.1 Discuss the option of home care with involvement of home health care services in the delivery of the above care at home with provision for PRN admissions.

5.2 Manage Phase Two where patient's life expectancy is less than 6 months, as follows:

5.2.1 Provide the following biomedical care:

5.2.1.1 Assess and mange pain and symptoms appropriately and efficiently.

5.2.1.2 Use the approved assessment tools for symptoms - Edmonton Symptom Assessment System (ESAS-r) revised (see appendix one and two).

5.2.1.2.1 Note. ESAS-r has to be done at every outpatient visit and weekly/PRN as inpatient.

5.2.1.3 Use approved tool for performance status: ECOG or PPS (see appendices three and four).

5.2.1.4 Discuss Advance Care planning specifically DNR/AND.

5.2.1.5 Consult Palliative Care service for highly symptomatic patients.

5.2.1.6 Use multidisciplinary approach for managing end of life issues.

5.2.2 Provide the following psychological care:

5.2.2.1 Handle reactions from breaking bad news to patient and family.

5.2.2.2 Involve palliative care physician, psychologist with adequate training in handling difficult communication scenarios and with necessary resources.

5.2.3 Provide the following social needs related care:

5.2.3.1 Follow up from previous phase.

5.2.4 Provide the following home related care :

5.2.4.1 Discuss the option of home care with involvement of home health care services in the delivery of the above care at home with provision for PRN admissions.

5.3 Manage Phase Three where patient's life expectancy is less than 2 weeks, as follows:

5.3.1 Provide the following biomedical care:

5.3.1.1 Diagnose imminent death.

5.3.1.2 Document in progress notes: "patient is dying," or "imminently dying" and fill up the Imminent Death order in order sheet (see appendix five and six).

5.3.1.2.1 Complete appendix five.

5.3.1.2.2 Complete appendix six.

5.3.1.3 Recommend stopping treatments that are not contributing to comfort e.g. pulse oxymetry, IV hydration, antibiotics, finger sticks, etc.

5.3.1.4 Order, at least daily, mouth and skin care.

5.3.1.5 Treat symptoms & signs as they arise: common among these are: oral secretions, Nausea and vomiting, delirium, dyspnea and pain.

5.3.2 Provide the following psychological care:

5.3.2.1 Note: Patient may be unconscious or not interested.

5.3.2.2 Provide daily counseling and support to families.

5.3.2.3 Assess grief reaction of families and after care needs.

5.3.3 Provide the following social needs related care:

5.3.3.1 Respect individuals' culture.

5.3.3.2 Move to private room.

5.3.3.3 Confirm family understanding of treatment goal.

5.3.3.4 If family is accepting discuss family concerns such as:

5.3.3.4.1 Pain.

5.3.3.4.2 Other symptoms.

5.3.3.4.3 Feeding & hydration.

5.3.3.4.4 Life expectancy.

5.3.3.4.5 Visiting hours.

5.3.3.4.6 Patient family communication.

5.3.3.4.7 Preferred place of death.

5.3.3.5 If family is not accepting:

5.3.3.5.1 Arrange for family meeting.

5.3.3.5.2 Involve other specialists, social worker and case manager and other needed services.

5.3.4 Provide the following spiritual care:

5.3.4.1 Respect individuals' rituals and practice.

5.3.4.2 Consult spiritual counsellor.

5.3.4.3 Prepare the room according to Islamic sharia law or according to patient's religion and belief.

5.3.5 Provide the following home related care:

5.3.5.1 Discuss the option of home care with involvement of home health care services in the delivery of the above care at home with provision for PRN admissions.

5.4 Manage Phase Four, the day of death, as follows:

5.4.1 Provide the following biomedical care:

5.4.1.1 Diagnose death.

5.4.2 Provide the following psychological care:

5.4.2.1 Assess for risk factors for complicated grief reaction in patient's family.

5.4.3 Provide the following spiritual care:

5.4.3.1 Involve spiritual educator as needed.

5.5 Manage Phase Five, up to one year after death, as follows:

5.5.1 Provide the following psychological care:

5.5.1.1 Make necessary referrals to psychologist and personnel trained in delivering bereavement support.

5.5.2 Provide the following social related needs care:

5.5.2.1 Offer support through social service department as needed.

5.5.2.2 Provide contact information for social services.

5.5.3 Provide the following spiritual care:

5.5.3.1 Involve spiritual educator as needed.

6 APPENDIX

6.1 Appendix One:: ESAS–r English Version

6.2 Appendix Two: ESAS-r Arabic Version

6.3 Appendix Three: ECOG Performance Status

6.4 Appendix Four: Palliative Performance Scale (Ppsv2) Version 2

6.5 Appendix Five: Imminent Death Orders to be filled by the Primary Physician for All Imminently Dying Patients

6.6 Appendix Six: Imminent Death Orders to be filled by Palliative Care Physician If Indicated

6.7 Appendix Seven: Pain Care Pathway

6.8 Appendix Eight: Terminal Restlessness and Agitation Care Pathway

6.9 Appendix Nine: Respiratory Tract Secretions Care Pathway

6.10 Appendix Ten: Nausea and Vomiting Care Pathway

7. REFERENCES

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7.2 EPERC, Fast fact 003. 2017 [cited 31st October 2017]. Available from: http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff_003.htm

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Appendix One: ESAS-r English Version

Edmonton Symptom Assessment System
(Revised version) (ESAS-R)

No Pain	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Pain**
No Tiredness *(Tiredness = lack of energy)*	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Tiredness**
No Drowsiness *(Drowsiness = feeling sleepy)*	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Drowsiness**
No Nausea	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Nausea**
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Lack of Appetite**
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Shortness of Breath**
No Depression *(Depression = feeling sad)*	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Depression**
No Anxiety *(Anxiety = feeling nervous)*	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Anxiety**
Best Wellbeing *(Wellbeing = how you feel overall)*	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Wellbeing**
No _____ **Other Problem** *(for example constipation)*	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible** _____

Completed by (check one)

☐ **Patient**

☐ **Family Caregiver**

☐ **Healthcare professional caregiver**

☐ **Caregiver assisted**

Name: _____ **Date:** _____

Signature: _____ **Time:** _____

"BODY DIAGRAM ON PAGE 2"

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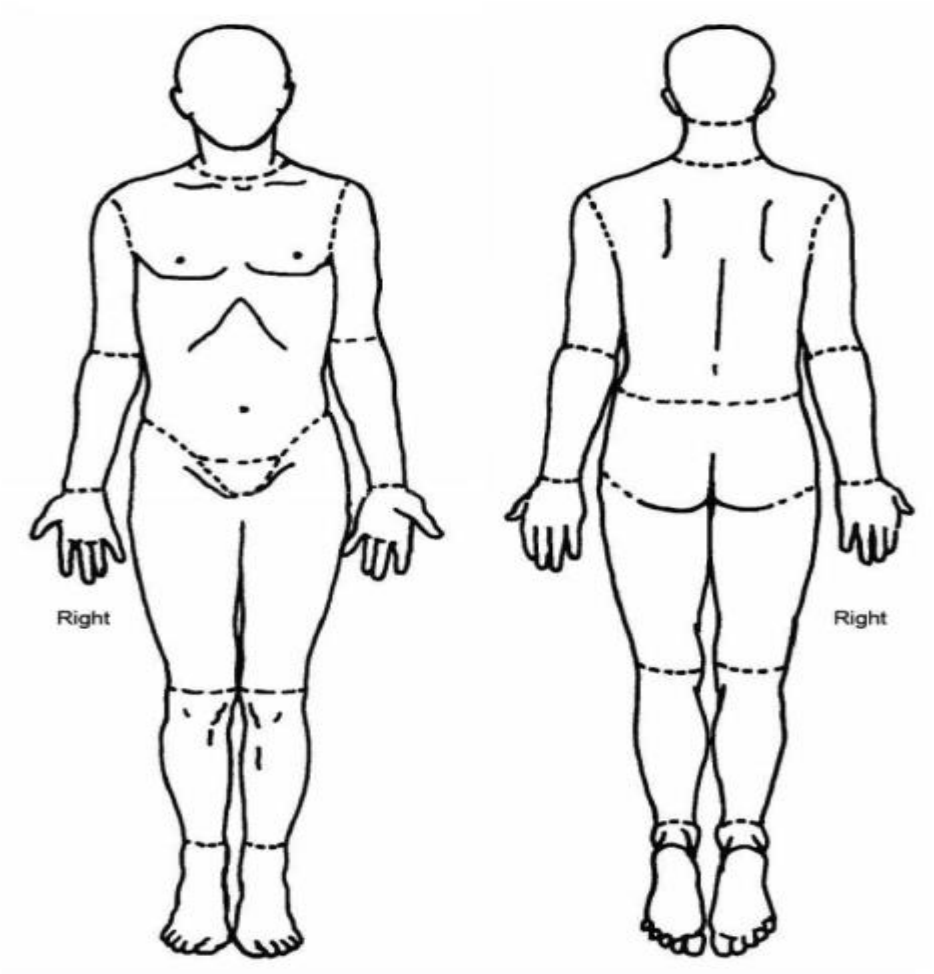
Patient ID Label

Please mark on these pictures where it is that you hurt:



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Appendix Two: ESAS-r Arabic Version

Patient ID Label

Edmonton Symptom Assessment System: (Revised version) (ESAS-R)

Date																										
Pain 10 0																										
Tiredness 10 0																										
Nausea 10 0																										
Depression 10 0																										
Anxiety 10 0																										
Drowsiness 10 0																										
Appetite 10 0																										
Wellbeing 10 0																										
Shortness of breath 10 0																										
Other 10 0																										
Palliative Performance Scale																										
Completed by P = Patient F = Family caregiver H = Health care professional caregiver A = Caregiver-assisted	Level of Education _____ Cage Score _____																									

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Patient ID Label

تقييم أعراض أدمونتون
(نسخة مراجعة)

لا يوجد ألم	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد تعب *(التعب = نقص الطاقة)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد شعور بالتعاس *(التعاس = الشعور بالنوم)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد غثيان	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد نقص في الشهية	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد ضيق في التنفس	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد اكتئاب *(الاكتئاب = الشعور بالحزن)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد قلق *(القلق= الشعور بالإضراب العصبي)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
الشعور التام بالصحة والسعادة *(ما تشعر به عموماً)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد _____ أي مشكلة أخرى *(الإمساك على سبيل المثال)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن

تم تعبئة النموذج من قبل (اختر واحداً):

- ☐ المريض
- ☐ مقدم الرعاية الصحية من أسرة المريض
- ☐ مقدم الرعاية الصحية في المستشفى
- ☐ بمساعدة مقدم الرعاية الصحية

اسم المريض _____ التاريخ _____

التوقيع _____ الوقت _____

"رسم توضيحي للجسم من الجهة الخلفية"

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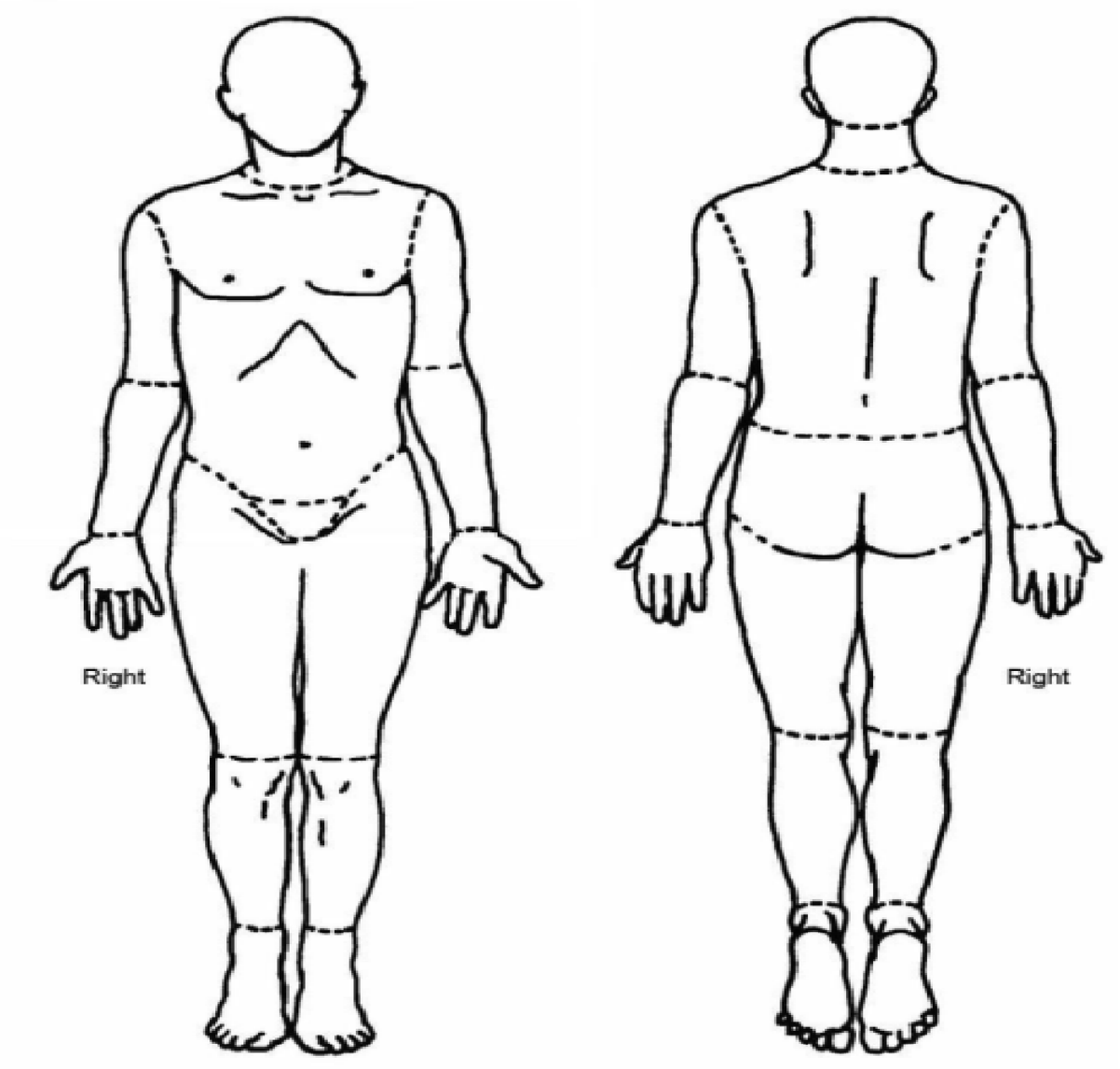
Patient ID Label

فضلاً، حدد على الرسم التالي موضع الألم الذي تشعر به:



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Saudi Health Council

Patient ID Label

تقييم أعراض أدمونتون
(نسخة مراجعة)

Appendix Three: ECOG Performance Status

Score	Criteria
0	Asymptomatic (Fully active, able to carry on all pre-disease activities without restriction)
1	Symptomatic but completely ambulatory (Restricted in physically strenuous activity but ambulatory And able to carry out work of a light or sedentary nature. For example, light housework, office work)
2	<50% in bed during the day (Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours)
3	>50% in bed, but not bedbound (capable of only limited self-care, confined to bed or chair 50% or more of waking hours)
4	Bedbound (Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair
5	Death

* As published in Am. J. Clin. Oncol.:
Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T., Carbone, P.P.: Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group. Am J Clin Oncol 5:649-655, 1982.

The ECOG Performance Status is in the public domain therefore available for public use. To duplicate the scale, please cite the reference above and credit the Eastern Cooperative Oncology Group, Robert Comis M.D., Group Chair

Appendix Four: Palliative Performance Scale (PPSV2) Version 2

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Palliative Performance Scale (PPSv2) Version 2 Form

☑	PPS Level	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
☐	100%	Full	Normal activity and work No evidence of disease	Full	Normal	Full
☐	90%	Full	Normal activity and work Some evidence of disease	Full	Normal	Full
☐	80%	Full	Normal activity and work Some evidence of disease	Full	Normal or Reduced	Full
☐	70%	Reduced	Unable Normal Job or Work Significant Disease	Full	Normal or Reduced	Full
☐	60%	Reduced	Unable to do hobby or house work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
☐	50%	Mainly Sit or Lie	Unable to do any work Extensive Disease	Considerable Assistance Required	Normal or Reduced	Full or Confusion
☐	40%	Mainly in Bed	Unable to do most activity Extensive Disease	Mainly Assistance	Normal or Reduced	Full or Drowsy + or - Confusion
☐	30%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Normal or Reduced	Full or Drowsy + or - Confusion
☐	20%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Minimal to Sips	Full or Drowsy + or - Confusion
☐	10%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Mouth Care Only	Drowsy or Coma + or - Confusion
☐	0%	Death	Not Applicable	Not Applicable	Not Applicable	Not Applicable

Name and Stamp: _____ **Signature:** _____ **Date:** _____ **Time:** _____

Appendix Five: Imminent Death Orders to Be Filled By the Primary Physician for All Imminently Dying Patients

Imminent Death Order
(Primary Physician)

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Ward Number: _____ Room Number: _____ Protocol initiated by: _____

Diagnosis: _____

Part I. To be filled by Primary Physician on the day of initiating Imminent Death Orders		**Comments**
A. Name of Power of Attorney / Proxy _____ Relationship: _____ Contact Number: _____		
B. Do Not Resuscitate ☐ Yes ☐ No	Date: _____	
C. Information and Communication 1. Family Meeting or Breaking Bad News 2. Preferred Place or Care or Death 3. Follow-up Meeting	☐ Yes ☐ No Date: _____ ☐ Hospital ☐ Home Others: _____ ☐ Required ☐ Not Required	
D. Single Room arranged	☐ Yes ☐ No	
E. Allow two family care-givers	☐ Yes ☐ No	
F. Open visiting hours order	☐ Yes ☐ No	
G. Spiritual Support required	☐ Yes ☐ No	
H. Social Support required	☐ Yes ☐ No	
I. Interdisciplinary referrals	☐ Yes ☐ No	
J. After Care Needs and Bereavement Support	☐ Required ☐ Not Required	
Optional Orders Vital once per shift Discontinue laboratories Oral Care once daily Sponging once daily Catheter ☐ Condom ☐ Foleys Stockings for edema	 ☐ Yes ☐ No ☐ Yes ☐ No ☐ Yes ☐ No ☐ Yes ☐ No ☐ Yes ☐ No ☐ Yes ☐ No	
Physician's Name and Stamp: _____ Date: _____ Physician's Signature: _____ Time: _____		

Appendix Six: Imminent Death Orders to Be Filled By the Palliative Care Physician for All Imminently Dying Patients

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Saudi Health Council

DATE/TIME	PHYSICIAN ORDERS
	Imminent Death Orders (Palliative Care Physician if Indicated)
Directions:	Indicate choice when options are available by placing a check in the box ☑
	Diagnosis : _____Allergy:
	Age:_____ weight:_____ kg
	A-List of Medication to be discontinued:
	1-
	2-
	3-
	4-
	B-List of current medications that needs to be Continued (change route or dose)
	1-
	2-
	3-
	4-
	C-Pain Management; give
	☐ Morphine ☐ 1- ☐ 2mg ☐subcut ☐i.v q 4 hours
	☐ Fentanyl ☐ 12.5 mcg/hour ☐25 mcg/hour ☐ IV ☐ subcut infusion (24 hours)
	☐ Hydromorphone ☐ 0.25 mg ☐0.5mg ☐IV☐Subcut q 4 hours
	☐ Other
	10% of the 24 hour dose of the above opioid (1-2mg morphine iv/subcut)
	Q 1 hour PRN Pain/ Dyspnoea.
	D- For Agitation / delirium; give
	☐ Haloperidol ☐ 0.5 ☐1 mg ☐ IV ☐ subcut q 6 hours
	☐ Lorazepam ☐ 0.5 ☐1 mg IV ☐ subcut q 6 hours
	☐ Haloperidol ☐ 0.5 ☐1mg IV/subcut q 4 hours PRN
	E- For excess Respiratory tract secretions; give
	☐ Glycopyrrolate 0.2mg ☐ IV ☐ subcut q 6 hours
	☐ Scopolamine 0.4mg ☐ subcut ☐ IV q 6 hours
	☐ Glycopyrrolate ☐ 0.2mg ☐ subcut ☐ IV q 6 hours PRN for upper airway secretions.

Patient Name Plate

Patient Name Plate

Patient Name Plate

Please provide date, time and beeper number or printed name for each order
Nursing

PHYSICIAN ORDER FORM
Copy Distribution – White-Patient Chart, Pink-Pharmacy, Yellow-

المجلس الصحي السعودي
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F-

DATE/TIME	PHYSICIAN ORDERS
	Imminent Death Orders (Palliative Care Physician if Indicated)
Directions:	Indicate choice when options are available by placing a check in the box ☑
	F- Regular order for Nausea/ vomiting; give
	☐ Metoclopramide 10mg IV q 6 hours
	☐ Haloperidol 0.5 mg IV q 8 hours
	☐ Metoclopromide 10mg IV q 6 hours PRN for nausea, vomiting
	G- For constipation ; give
	☐ Docusate sodium 100mg oral q 12 hours
	☐ Senna 2 tablets oral at bedtime
	☐ Lactulose 15-20ml oral q 8 hours
	☐ Glycerine suppository ☐ 1 ☐ 2 per rectum q 48 hours PRN
	☐ Dulcolax suppository ☐ 1 ☐ 2 per rectum q 48 hours PRN
	H- IV fluids :
	☐ Normal Saline IV 40ml/hour continues infusion

Patient Name Plate

Patient Name Plate

Patient Name Plate

PHYSICIAN ORDER FORM

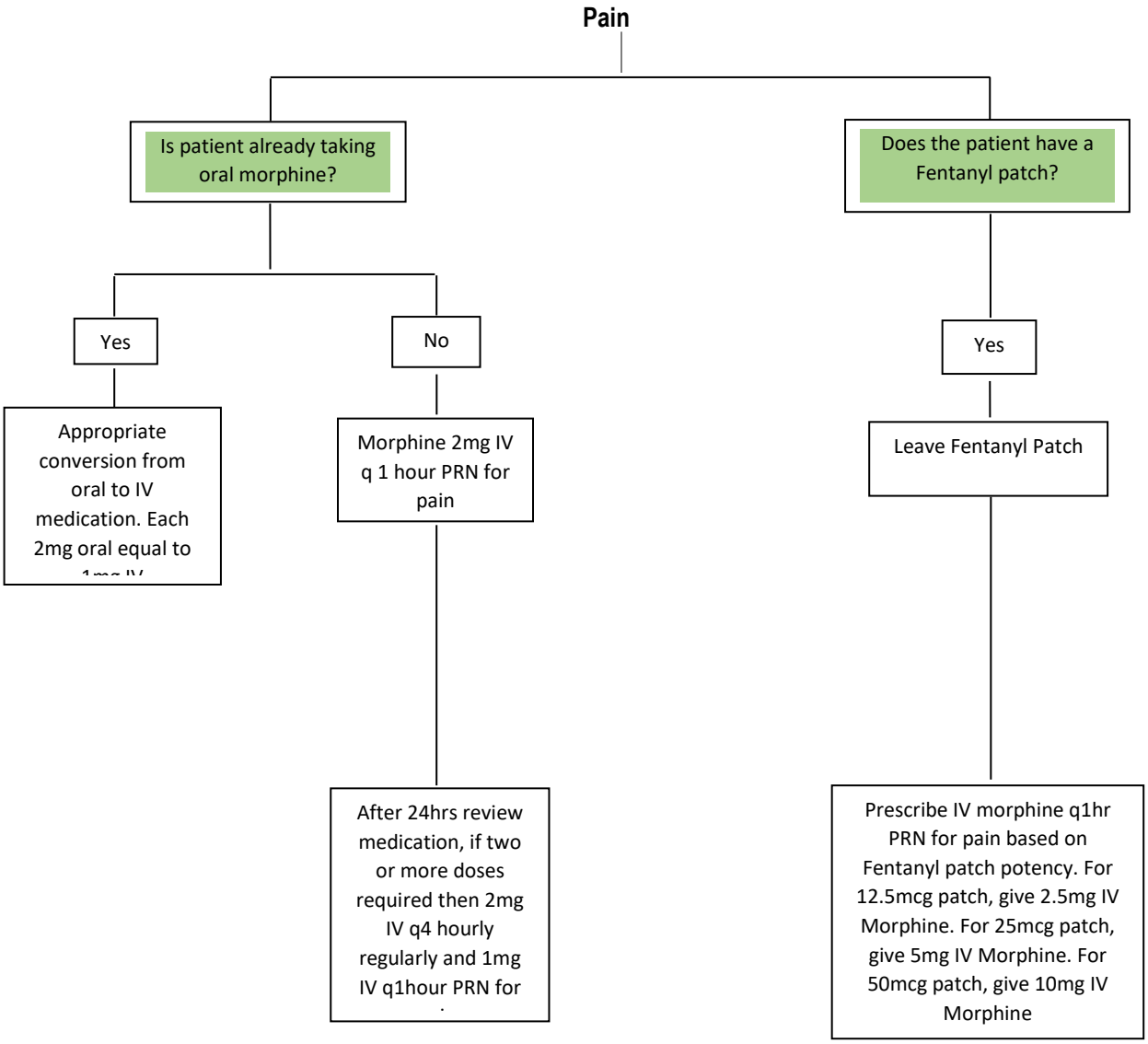
Please provide date, time and beeper number or printed name for each order
Nursing

Copy Distribution – White-Patient Chart, Pink-Pharmacy, Yellow-

Note:-

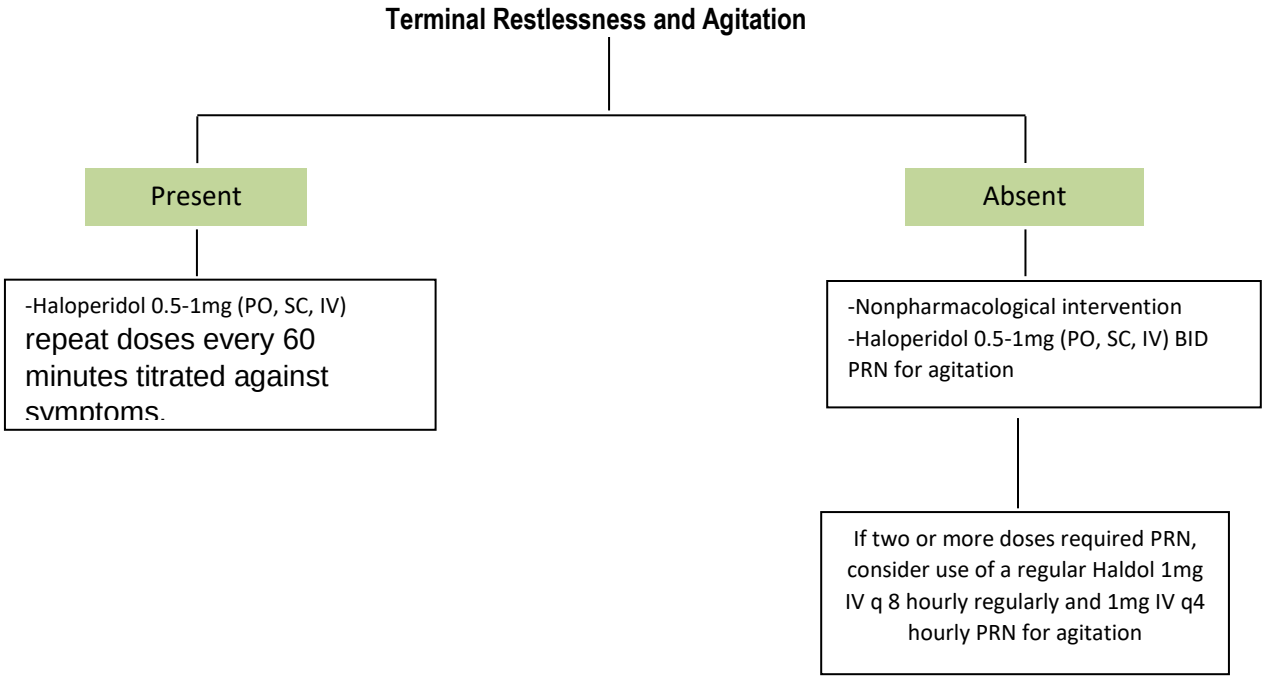
- **Nausea and vomiting; if metoclopramide failed or contraindicated one can add: Phenergan 12.5 IV q8 hours PRN, Ondansetron 8mg IV q8hrs PRN**
- **G- For constipation. the committee suggest to remove the Docusate as studies showed no benefit, and we can add enemas at the end (fleet or soap enemas)**
- **H- IV fluids; also we can add sub cutaneous infusion**

Appendix Seven: Pain Care Pathway



Note: - Morphine may be used for pain and dyspnea

Appendix Eight: Terminal Restlessness and Agitation Care Pathway



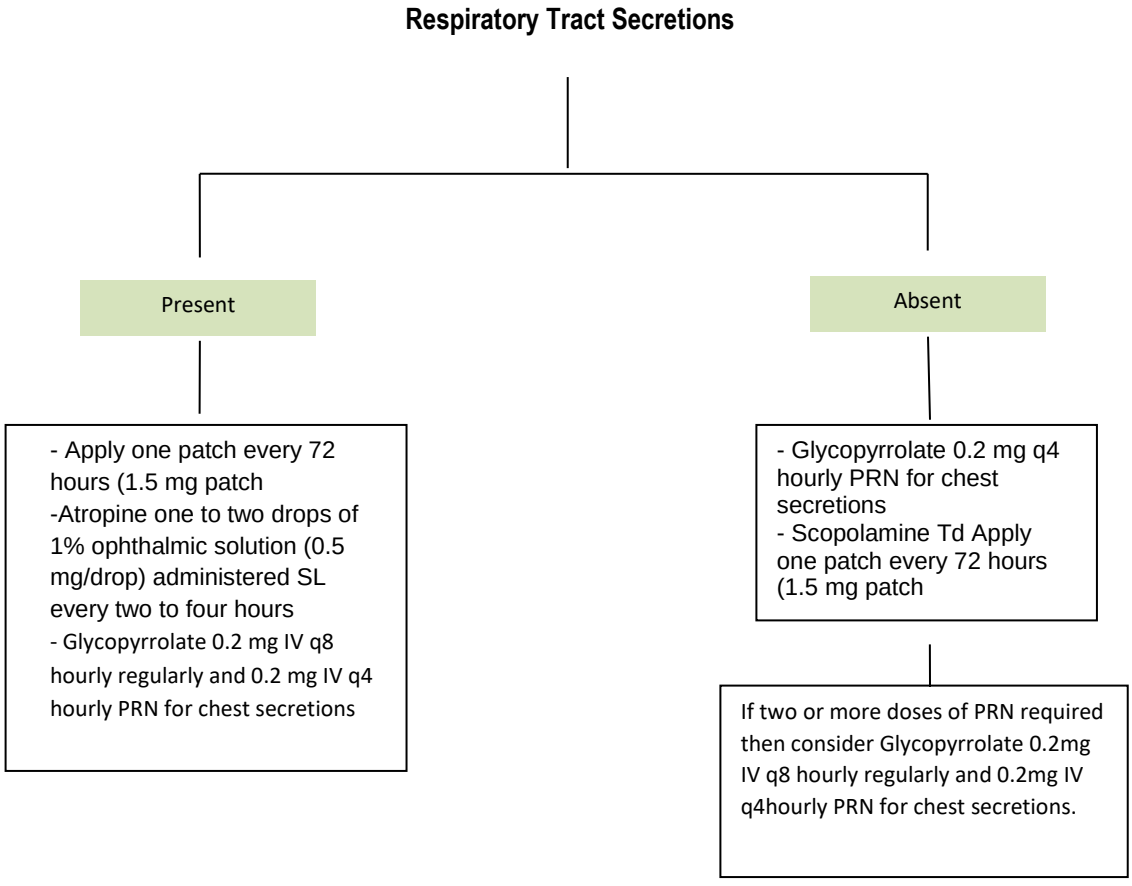
Note:-

- Olanzapine 5mg dose may be used as alternative.
- Terminal Delirium: according to the recommendation specially in geriatrics the drug of choice is Haloperidol 0.5-1mg SC,IM,IV q2-4 hrs. PRN (alternative medications: Chlorpromazine 12.5-50mg q6 hrs. titrate to 25mg q 1hr PRN, olanzapine or quetiapine if patient can swallow)
- Benzodiazepines can cause paradoxical reaction and increase agitation and no longer recommended unless the last option for sedation. Usually used for anxiety or palliative sedation. For patients with persistent agitated delirium and not responding to other medications, a single dose of lorazepam may be beneficial as an adjunct to haloperidol

Nonpharmacological Interventions for Delirium Treatment

Frequent orientation (familiar objects/pictures, introductions, orientation board)
Cognitive exercises
Oral rehydration (beverage of choice available and within reach, frequent prompts to drink)
Attention to lighting (natural lighting, dim lighting at night)
Sensory aides (glasses, hearing aides)
Consistent caregivers (constant companions, sitters, family visits)
Sleep hygiene
Daily routine
Range of motion or physical activity
Limit immobilization (Foley catheters, intravenous lines, restraints)

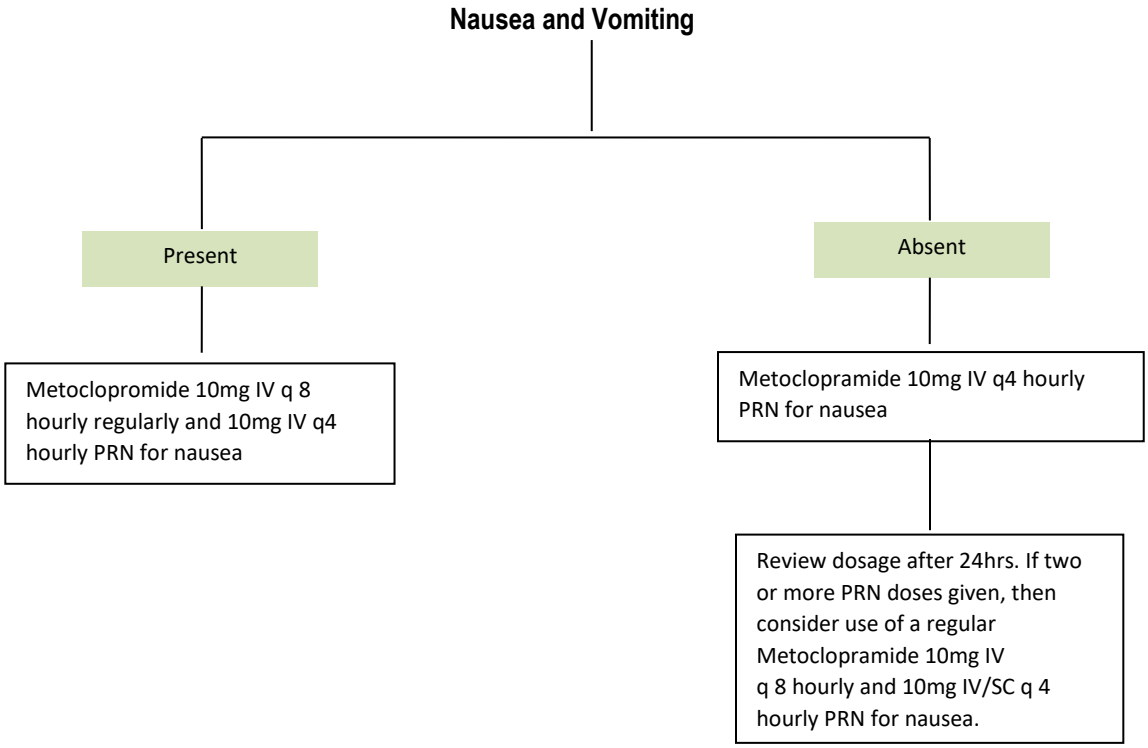
Appendix Nine: Respiratory Tract Secretions Care Pathway



Note:-

- Hydroscine Hydropromide (Scopolamine) 0.3mg IV dose may be used as alternative.
- Subcutaneous injection may be used as alternative to IV if patient has better fly needle.

Appendix Ten: Nausea and Vomiting Care Pathway



Note:-

- Haloperidol 1mg dose may be used as alternative.
- Subcutaneous injection may be used as alternative to IV if patient has better fly needle.
- Nausea and vomiting; if metoclopramide failed or contraindicated we can add : Phenergan 12.5 IV q8 hours PRN, Ondansetron 8mg IV q8hrs PRN

المجلس الصحي السعودي
Saudi Health Council

CHAPTER 8
Management of Pruritis (Itching)

المجلس الصحي السعودي
Saudi Health Council

CHAPTER 8 :-Management of Pruritis (Itching) in Palliative Care

1. STATEMENT OF PURPOSE

1.1 To provide a guideline for identification, diagnose and management of adult patients (age 14 years and older) who have advanced life-threatening illness and are experiencing pruritis (itching).

2. DEFINITIONS

2.1 **Pruritis:** It can be described as an unpleasant sensation of the skin or mucous membranes that provokes the desire to scratch or rub. There are 4 categories of pruritus: pruriioreceptive, neuropathic, neurogenic, and psychogenic. It may be localised or due to systemic disease. Persistent scratching leads to skin damage.

3. GENERAL GUIDELINES

3.1 All admitted palliative patients aged 14 years and older experiencing the symptom of pruritis shall be assessed, diagnosed and managed by Physician.

3.2 Physician should aware that the pruritis can cause discomfort, frustration, poor sleep, anxiety and depression to patients.

3.3 Patients with itch usually have dry skin, the physician should prevent them from dehydration, heat, anxiety and boredom.

3.4 Physician should note that the itching sensation may arise from stimulation of the skin itch receptor via unmyelinated C fibers, or as a central phenomenon without skin involvement (e.g., opioid induced pruritis).

3.5 Physician should also note that although histamine causes pruritis, many patients with pruritis show no signs of histamine release (other mediators of pruritis include: serotonin, prostaglandins, kinins, proteases, bile salts, trypsin, and physical stimuli.)

4. ASSESSMENT AND MANAGEMENT

4.1 Assess all admitted palliative patients as follows:

4.1.1 Location: Assess if it is generalized or focal to a single region or more widespread but in a particular pattern.

4.1.2 Onset/duration: In palliative care, it is more chronic than acute.

4.1.3 Presence or absence of rash.

4.1.4 Quality of symptoms: Assess if the itching is associated with pain or an irresistible and persistent tickling sensation that is relieved by scratching.

4.1.5 Severity: Pruritis that wakes client from sleep is more likely related to a systemic cause.

4.1.6 Triggers: Topical application of heat often worsens itching and cold decreases it.

4.1.6.1 Note, frequency of bathing, use of soaps, shampoos, lotions prevent itching or trigger itching if the patient's skin is sensitive to the product used.

4.1.7 Assess for possible causes:

4.1.7.1 Assess skin: Dry, wet, irritation, eczema and psoriasis.

4.1.7.2 Metabolic: Hepatic failure, renal failure and hypothyroidism.

4.1.7.3 Haematological/oncological: Iron deficiency, polycythemia, thrombocytosis, leukemia and lymphoma.

4.1.7.4 Medications: Opioid and drug reactions.

4.1.7.5 Diabetic assessment.

4.1.7.6 Infection: Scabies, lice and candida.

4.1.7.7 Allergy: Urticaria and contact dermatitis.

4.1.7.8 Lab tests: CBC, liver, renal and thyroid panels.

4.2 Provide general management for patient with pruritis as follows:

4.2.1 Prevent dry skin and excessive heat.

4.2.2 Use a neutral pH product because skin cleansing is important, especially if there are open areas due to scratching.

4.2.3 Use tepid water followed by application of a moisturizer and emollients.

4.2.4 Apply cold compresses.

4.2.5 Wear loose-fitting and cotton clothing.

4.2.6 Use cotton sheets and avoid wool blankets.

4.3 Manage pruritis non-pharmacologically as follows:

4.3.1 Always consider of using Emollients, as dry skin is often an exacerbating factor for most palliative patients with pruritus.

4.3.2 Ultraviolet B light therapy: It decreases the number of mast cells and free nerve endings in the skin, although it is most useful in pruritus secondary to uremia, it can also help with cholestasis and malignant skin infiltrations.

4.3.2.1 Note, procedures often required 3 times per week but it is impractical at end of life.

4.3.3 Biliary stunting: In certain cases, stenting for biliary obstruction is an effective nonpharmacologic treatment that often obviates pharmacotherapy, and eliminating potentially adverse side effects.

4.4 Manage pruritis pharmacologically as follows:

4.4.1 Provide the following topical medications:

4.4.1.1 Use Lidocaine-based cream if the pruritis is described as burning and painful.

4.4.1.2 Apply corticosteroids on affected area to reduce inflammation and itching associated with urticarial and other acute conditions.

4.4.1.2.1 Note, it is not indicated for chronic use.

4.4.1.3 *Candida albicans* is the most frequent superficial fungal infection of the skin with typical areas of infection involving the inframammary areas, inguinal folds and vulvovaginal areas; therefore use topical antifungal agents as classified below:

4.4.1.3.1 Polyene group (e.g., nystatin).

4.4.1.3.2 Azole group (e.g., ketoconazole, fluconazole).

4.4.1.3.3 Allylamine/benzylamine group (e.g., ciclopirox olamine – Loprox).

4.4.2 Provide the following systemic treatment as indicated:

4.4.2.1 Start dose of paroxetine for patient with generalized pruritis by 10mg per oral daily.

4.4.2.1.1 Note, effectiveness starts after 24-48hours.

4.4.2.2 Use Ondansetron, a 5-HT3 antagonist for cholestatic, uremic and opioid-inducted pruritis.

4.4.2.3 Use Cholestyramine for pruritis caused by liver disease (itching is caused by the liver secondary to high bile salts) as follows:

4.4.2.3.1 Use 1 packet mixed with liquid before or after breakfast, if patient has a gallbladder.

4.4.2.3.2 If patient does not have a gallbladder, give him/her on an empty stomach.

4.4.2.3.3 Note, Cholestyramine can cause vitamin K depletion so INR needs to be checked every 2 weeks after initiated.

4.4.2.4 If necessary, use antidepressants such as doxepin, amitriptyline, and imipramine in treating pruritis.

4.4.2.4.1 Note, doxepin is the most antihistaminic of the group and may be most useful.

4.4.2.5 In few cases, use antihistamines such as hydroxyzine hydrochloride – Atarax 25 mg po tid–qid) for histamine-related pruritis only.

4.4.2.5.1 Note, often times it is not effective in palliative patient.

5. APPENDIX

Not Applicable

6. REFERENCES

6.1 Siemens W, Xander C, Meerpohl J, Buroh S, Antes G, Schwarzer G et al. Pharmacological interventions for pruritus in adult palliative care patients. Cochrane Database of Systematic Reviews. 2016;.

6.2 Ferrell, B. & Coyle, N. Eds. Oxford textbook of palliative nursing. Oxford University Press; 2014 Dec 1.

6.3 Seccareccia D , Gebara N. Pruritus in palliative care *Getting up to scratch*. Palliative Care Files. *Canadian Family Physician,* Vol 57; 2011.

6.4 Vancouver Home Hospice Palliative Care Service. *Pruritis, Hospice Manual, Community Palliative Care Clinical Practice Guidelines, VCH Palliative Guidebook.* .Vancouver Canada; 2007.

6.5 Waller, A. & Caroline, NL. *Handbook of palliative care in cancer. Butterworth-Heinemann Medical; 2000.*

6.6 Xander C, Meerpohl JJ, Galandi D, Buroh S. *Pharmacological interventions for pruritus in adult palliative care patients (Protocol)*. The Cochrane Collaboration. JohnWiley & Sons, Ltd; 2010.

المجلس الصحي السعودي
Saudi Health Council

CHAPTER 9
Management of Anorexia & Cachexia

المجلس الصحي السعودي
Saudi Health Council

CHAPTER 9 :- Management of Anorexia & Cachexia in Palliative Care

1. STATEMENT OF PURPOSE

1.1 To provide guidance in the identification, diagnosis and management of anorexia and/or cachexia in adult patients who are aged 14 years and older and have advanced life-threatening illness.

2. RELATED DOCUMENTS

2.1 Management of Gastrointestinal Diseases in Palliative Care

2.2 Management of Fatigue in Palliative Care

3. DEFINITIONS

3.1 **Anorexia**: Loss of appetite and resulting in reduced caloric intake.

3.2 **Cachexia**. Involuntary weight loss of more than 10% of pre-morbid weight, associated with loss of muscle and visceral protein and lipolysis (the breakdown of fat stored in fat cells).

3.3 **Anorexia-Cachexia Syndrome.** Is usually defined in terms of primary or secondary causes. The primary cause is related to changes (metabolic and neuroendocrine) directly associated with underlying disease and an on-going inflammatory state. Secondary causes are aggravating factors (fatigue, pain, dyspnea, infection, etc) that contribute to weight loss.

4. GENERAL GUIDELINES

4.1 All admitted palliative patients aged 14 years and older experiencing the symptom of anorexia and/or cachexia shall be assessed, diagnosed and managed by a Physician.

4.2 Physicians' goal of treatment for cancer anorexia and cachexia shall include but not be limited to the following.

4.2.1 To conserve or restore best quality of life.

4.2.2 To control symptoms that aggravate the problem or distress.

4.2.3 Emphasis should not solely be on nutrition but also on patient/family centered goals and determined prior to initiation of treatment.

4.2.4 A multi-disciplinary approach is needed and the patient's prognosis in addition to the wishes of the patient and family must be considered.

4.3 Physicians shall monitor patient's status and implement plans to address all contributing symptoms. Noting that a patient's death is not solely due to anorexia and cachexia but also metabolic and neuroendocrine changes and other aggravating factors like fatigue, pain, dyspnea, infection, etc.

4.4 Cancer cachexia is a multifactorial problem, Physicians shall note the following:

4.4.1 Cancer anorexia/cachexia occurs in 80%-90% of patients with advanced cancer resulting in the loss of appetite and weight.

4.4.2 Cancer anorexia/cachexia is often accompanied by asthenia (severe fatigue and lethargy).

4.4.3 Cachexia appears to be a consequence of both decreased food intake and metabolic abnormalities.

4.4.4 It can be a limiting factor for treating patients as their cancer progresses.

4.5 Physicians shall recognize the following:

4.5.1 Anorexia - Cachexia syndrome is caused largely by cytokines.

4.5.2 Cytokines are induced by interactions between the immune system and the tumour.

4.5.3 Some of the cytokines implicated are tumour-necrosis factor/cachectin, interleukin 1.

4.5.4 Abnormalities of carbohydrate, protein and lipid metabolism and energy expenditure have been described in association with cachexia. The net result is loss of body protein and fat mass – a catabolic state.

4.5.5 Some patients with anorexia-cachexia have demonstrated delayed gastric emptying and other manifestations of autonomic insufficiency, including chronic nausea.

4.5.6 Factors that aggravate cachexia and anorexia are altered taste, head and neck malignancies, dysphagia and odynophagia.

4.6 Physicians shall prescribe medications that are currently available and those subsequently found to be effective in treating cancer anorexia and cachexia.

5. ASSESSMENT AND MANAGEMENT

5.1 Assess the patient with cachexia and anorexia including:

5.1.1 Interview the patient using acronym O, P, Q, R, S, T, U and V (see Appendix One).

5.1.2 Conduct physical assessment.

5.1.3 Review medication.

5.1.4 Conduct medical and surgical review.

5.1.5 Conduct psychosocial and physical environment review.

5.1.6 Obtain or request for appropriate diagnostics.

5.2 Identify the underlying cause(s) and treat as appropriate (see Appendix two) noting that:

5.2.1 Treat reversible causes where possible and desirable according to the goals of care.

5.2.2 Consider that while underlying cause(s) may be evident, treatment may not be indicated, depending on the stage of the disease.

5.2.3 Note that intervention aimed at reducing cachexia and anorexia must take into account the cause (often multifactorial) of the symptoms.

5.3 Discuss management strategy with the patient and family:

5.3.1 Note that early counseling regarding nutritional aspects is vital.

5.3.2 Emphasize that oral intake will lessen over time (functional dysphagia) and explain the metabolic abnormalities cause anorexia.

5.3.3 Emphasize that the patient is not starving. Help family members understand that anorexia-cachexia is different from starvation.

5.3.4 Help the patient/family understand and accept the benefits and limits of treatment interventions and to look at alternate ways to nurture the patient (oral care, massage, reading, and conversing). This will help to decrease the feelings of helplessness for these individuals.

5.3.5 Help the family to understand that pressuring the patient to eat increases anxiety and stress for them all and can worsen symptoms of nausea and vomiting.

5.3.6 Provide education that includes the nature of the problem, treatment limitations and treatment aims.

5.3.7 Help the family to understand that forcing patients to eat will have no positive impact on well-being or survival.

5.3.8 Encourage favourite foods for comfort and enjoyment of eating. Nutritional value should be of secondary importance in terminally ill patients.

5.3.9 Emphasize that, in order to maintain hydration, fluids are more important than solids.

5.3.10 Advise families to create the best conditions for eating, (i.e. nausea and pain have been addressed, good mouth care, frequent small meals, pleasant setting, etc.)

5.3.11 Explain that parental nutrition has a risk of associated morbidity and proven lack of benefit as this is often helpful in dissuading most families.

5.4 Provide non-pharmacological treatment as follows:

5.4.1 Advise the patient/family that as the illness progresses, the patient's intake will naturally decrease and that ice chips, sips of beverages and good mouth care will become the norm.

5.4.2 Consider hypodermoclysis to correct dehydration related symptoms that could be relieved by parenteral fluids and will improve quality of life.

5.4.3 Consider enteral feeding in patients who have difficulty swallowing but have an appetite and reasonable quality of life.

5.4.3.1 Consider a gastrostomy tube rather than a nasogastric tube for comfort and body image.

5.4.3.2 Note that gastrostomy tubes also provide drainage should total bowel obstruction occur.

5.4.3.3 Note, there is a risk of aspiration pneumonia and diarrhea which remains the same with either nasogastric or gastrostomy tube feeding.

5.4.4 Request consultation with dietician and/or counselor as family education is critical.

5.4.5 Note that total parenteral nutrition should only be considered in exceptional situations; multiple studies have found no benefit on mortality or morbidity rates.

5.5 Provide pharmacological treatment by prescribing the most commonly used drugs as follows:

5.5.1 Consider Metoclopramide when chronic nausea occurs in association with cachexia because of the high incidence of autonomic failure with resulting gastroparesis.

5.5.1.1 Prescribe Metoclopramide 10 mg every four to eight hours.

5.5.2 Consider Megestrol Acetate for the treatment of anorexia in patients with expected survival time of months or for end-stage renal patients for uremic syndrome. Side effects are usually mild (and dose-related) but can include edema, venous thromboembolic events, hypertension, alopecia, adrenal suppression, hypercalcemia and cushingoid fat distribution.

5.5.2.1 Prescribe Megestrol acetate 160 to 800 mg per day, titrating weekly according to response i.e. an improvement in appetite and eventually weight gain.

5.5.2.2 Note that Magestrol acetate increases the fat mass more than lean body mass. Hence, functional improvement will only be modest.

5.5.3 Consider Corticosteroids as these may increase appetite, strength and promote a sense of wellbeing; effects last about 2 to 4 weeks making it appropriate for those whose life expectancy is weeks.

5.5.3.1 Prescribe Dexamethasone 4 to 8 mg per day – titrate for increased appetite.

5.6 Provide pharmacological treatment by prescribing the less commonly used drugs as follows:

5.6.1 Consider NSAIDS like Ibuprofen and Cox Inhibitors as they have been shown to have some beneficial effect on anorexia/weight loss by mediating the inflammatory response of cytokines.

5.6.1.1 Prescribe Ibuprofen 400 mg T.I.D. or indomethacin 50 mg B.I.D.

5.6.2 Consider Melatonin as it has been shown to have some effect on weight loss by mediating circulating tumour necrosis factor.

5.6.2.1 Prescribe Melatonin 20 mg daily at bedtime

5.6.3 Consider prescribing Dronabinol 5 mg daily as it may decrease nausea and stimulate mood and appetite though it has not been proven effective in preventing weight loss.

5.6.4 Consider prescribing Adenosine Triphosphate as it has been shown to have some positive effect on weight gain though needs further study.

5.6.5 Consider prescribing Cyproheptadine as it may cause a mild appetite increase though does not prevent progressive weight loss in advanced cancer and has a sedative side effect.

5.7 Prescribe Anamorelin, as it has recently been found to be consistently beneficial for patients with cancer-related cachexia.

6. APPENDIX

6.1 Appendix 1: Nutrition / Cachexia Assessment using Acronym O, P, Q, R, S, T, U and V

6.2 Appendix 2: Causes of Cachexia

7. REFERENCES

7.1 Alberta Hospice Palliative Care Resource Manual Second edition [cited 15 Sep. 2019]. Available from: http://mhpcn.ca/uploads/ACBPCresourcemanual1280848108.pdf

7.2 Anamorelin: First Ever Drug for Cancer Cachexia? [Internet]. Medscape. 2017 [cited 15 Sep. 2019]. Available from: http://www.medscape.com/viewarticle/832465

7.3 Symptom Guidelines, Nutrition & Cachexia. Hospice Palliative Care Program. 2017 [cited 15 Sep. 2019]. Available from: http://www.fraserhealth.ca/media/15FHSymptomGuidelinesNutritionCachexia.pdf.

Appendix One: Nutrition / Cachexia Assessment using Acronym O, P, Q, R, S, T, U and V

Onset	When did you notice your weight loss or lack of appetite? How long does it last? How often does it occur? Is it there all the time?
Provoking / Palliating	What brings it on? What makes it better? What makes it worse?
Quality	What does it feel like? Can you describe it? How much weight have you lost?
Region / Radiation	How much do you eat and drink?
Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right Now? At Best? At Worst? On Average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?
Treatment	What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?
Understanding / Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and/or your family?
Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

Appendix Two: Causes of Cachexia

Causes of Cachexia	Patients Affected	Interventions
Cancer by-products	Cytokines; tumour necrosis factor, interleukin 1, leptin	Megestrol acetate, NSAIDS, Adenosine Triphosphate, Corticosteroids
Depression or delirium	May cause or be caused by anorexia/cachexia	Haloperidol, anti-depressants, counseling, support
Dysphagia	Head, neck or esophageal tumours	Enteral feeding (gastrostomy preferred), stent, swallowing assessment, laser/ radiation, pain control with topical anesthetics or systemic analgesics
Gastrointestinal Disturbances	Obstruction or constipation	Bowel regime, Domperidone, Metoclopramide or peripheral opioid antagonists and interventions for obstruction
Malabsorption Syndrome	Fats and carbohydrates not metabolized/absorbed	Corticosteroids, Megestrol Acetate, Omega 3 fatty acids
Treatment toxicities: mucositis, nausea/vomiting	Radiation, chemotherapy, Medications	Treat according to toxicity
Uncontrolled symptoms: pain, dyspnea, constipation, and nausea/vomiting	Patients with advanced disease processes	Control symptoms to increase appetite and quality of life
Xerostomia, altered oral condition or taste	Infection, poor hygiene, dehydration, medication, taste bud alteration	Saliva substitutes, good oral hygiene and nutrition, Zinc supplements

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CHAPTER 10
Management of Fatigue

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CHAPTER 10 :- Management of Fatigue in Palliative Care

1. STATEMENT OF PURPOSE

1.1 To provide a guidance in the identification, diagnosis and management of fatigue in adult patients who are aged 14 years and older and have advanced life-threatening illness.

2. RELATED DOCUMENTS

2.1 Use of the Palliative Performance Scale (PPS)

2.2 Management of Anorexia & Cachexia in Palliative Care

2.3 Management of Depression in Palliative Care

2.4 Management of Hypercalcemia in Palliative Care

3. DEFINITIONS

3.1 **Fatigue:** Is a subjective perception and/or experience related to disease, emotional state and/or treatment. Fatigue is a multidimensional symptom involving physical, emotional, social and spiritual well-being and affecting quality of life.

3.2 **Asthenia:** Lack or loss of strength and energy or describing weakness.

3.3 **Palliative Performance Scale (PPS):** Is a tool for measurement of performance status in palliative care.

4. GENERAL GUIDELINES

4.1 All admitted palliative patients aged 14 years and older experiencing the symptom of fatigue shall be assessed, diagnosed and managed by a Physician.

4.2 Physician shall note that fatigue can be caused by:

4.2.1 Disease.

4.2.2 Medical problems related to the disease or treatment (e.g. anemia).

4.2.3 Treatments for the disease (e.g. fatigue may be caused by radiation or chemotherapy).

4.2.4 Other medication.

4.2.5 Immobility.

4.2.6 Sleep disturbance.

4.2.7 Depression and anxiety.

4.3 Physicians shall be aware that fatigue is one of the most common symptoms in advanced cancer and is nearly universal in the terminal stages of illness.

4.4 The patient's self-report of fatigue symptoms shall be accepted by a Physician.

4.5 Physician shall comprehensively document therapeutic outcome in both subjective and objective perspectives of patients.

5. ASSESSMENT AND MANAGEMENT

5.1 Assess the patient with fatigue including.

5.1.1 Interview the patient using acronym O, P, Q, R, S, T, U and V (see Appendix One).

5.1.2 Conduct physical assessment

5.1.3 Review medication.

5.1.4 Conduct medical and surgical review.

5.1.5 Conduct psychosocial and physical environment review.

5.1.6 Obtain or request for appropriate diagnostics as follows:

5.1.6.1 Hemoglobin, WBC count, serum sodium, potassium, calcium, magnesium, blood glucose, serum urea, creatinine, liver enzymes, triiodothyronine, thyroxine, drug levels (phenytoin, digoxin)

5.2 Determine the nature and possible causes of fatigue with the following considerations.

5.2.1 Identify the underlying etiology of weakness as it is essential in determining the interventions required (see Appendix two).

5.2.2 Use the Palliative Performance Scale (PPS) (see Appendix three / refer to, Use of the Palliative Performance Scale (PPS).

5.3 Provide education to patient and family.

5.3.1 Note that patients and family will focus on the symptom rather than its underlying cause. Often this complaint is viewed as the patient has "given up" or is "not fighting". Education must center on what is and is not correctable or beyond the patient's control and giving the patient "permission to rest". Work with patients and family caregivers to improve the assessment of fatigue and identify management strategies.

5.3.2 Assist patient plan periods of rest and periods of activity to maximize the energy the patient has available for things that are really important to him/her.

5.3.3 Assist the patient to delegate tasks that he/she is no longer able to perform and arrange for assistance where necessary.

5.3.4 Encourage moderate physical activity, when fatigue is mild, to preserve muscle function. As weakness progresses use physical aids (walkers, grab bars) to help preserve mobility.

5.3.4.1 Note, rehabilitation goals need to be carefully weighed when the patient has a short life expectancy to assure that the benefits of treatment outweigh the burdens.

5.4 Manage fatigued patients non-pharmacologically as follows:

5.4.1 Anemia – refrain from PRBC transfusion unless the patient is severely symptomatic and capable of benefiting from an increased red cell mass.

5.4.2 Depression/anxiety disorders – give counseling. Patient mobility may help combat depression. Massage and aromatherapy have been found to offer some relief for depression-related fatigue. Consider attention restoring activities (exposure to natural environment).

5.4.3 Dehydration – give fluids orally or parenterally (I.V. or hypodermoclysis).

5.4.4 Hypercalcemia – give hydration.

5.4.5 Hypokalemia – for severe hypokalemia (potassium less than 2.8 mEq per litre) give potassium rich foods (citrus juice, tomatoes, bananas).

5.4.6 Hyponatremia – Manage by fluid restriction although this type of management is frequently undesirable for patients and onerous for caregivers.

5.4.7 Poor nutrition – provide nutritional counseling. Although in late stages, eating becomes more important for pleasure and comfort than nutrition.

5.4.8 Prolonged immobilization – arrange physiotherapy. Exercise has been shown to have the strongest evidence of benefit. Daily stretching or isometric muscle contractions can help maintain muscle strength.

5.4.9 Sleep disturbances – provide sleep therapy such as stimulus control (avoiding caffeine and stimulants, going to bed when sleepy), sleep consolidation strategies (avoiding long naps, limiting time in bed) strategies to reduce cognitive-emotional arousal and cognitive behavioral interventions (relaxation training).

5.5 Manage fatigued patients pharmacologically as follows.

5.5.1 Anorexia/cachexia – give dexamethasone 4 mg PO daily and multivitamins.

5.5.2 Depression – consider psychostimulants. (See Management of Depression in Palliative Care).

5.5.3 Endocrine imbalance – give replacement therapy (thyroid hormone or restart corticosteroids if recently withdrawn).

5.5.4 Hypercalcemia (see CMG Management of Hypercalcemia in Palliative Care).

5.5.5 Hypokalemia – change loop diuretic to potassium sparing diuretic (Spironolactone 100 mg daily) for a few days and recheck serum potassium. Correct hypokalemia with potassium supplement.

5.5.6 Insomnia – give sedative or hypnotic medication.

5.5.7 Sepsis – give antibiotics and antipyretics where appropriate.

6. APPENDIX

6.1 Appendix One: Fatigue Assessment using Acronym O, P, Q, R, S, T, U and V

6.2 Appendix Two: Causes of Fatigue

6.3 Appendix Three: Palliative Performance scale (Ppsv2) version 2

7. REFERENCES

7.1 Alberta Hospice Palliative Care Resource Manual Second edition 2019 [Accessed 10 Sep. 2019]. Available from: http://mhpcn.ca/uploads/ACBPCresourcemanual1280848108.pdf

7.2 Symptom Guidelines, Fatigue. Hospice Palliative Care Program. Fraserhealth.ca. 2017 [cited 31st October 2017]. Available from: http://www.fraserhealth.ca/media/11FHSymptomGuidelinesFatigue.pdf

Appendix One: Fatigue Assessment using Acronym O, P, Q, R, S, T, U and V

Onset	When did it begin? How long does it last? How often does it occur?
Provoking / Palliating	What brings it on? What makes it better? What makes it worse?
Quality	What does it feel like? How are you sleeping? How is your appetite? Have you lost weight?
Region / Radiation	Is this an overall feeling or is it localized?
Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right now? At best? At Worst? On average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?
Treatment	What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications/treatments have you used in the past?
Understanding / Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and/or your family?
Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that is important to you or your family?

Appendix Two: Causes of Fatigue

1) Fatigue usually has multiple causes.
2) Tumour related:
    - Altered metabolism.
    - Cancer cachexia – wasting affects both skeletal and cardiac muscle.
    - Cancer-induced cytokines and other substances.
    - Paraneoplastic syndromes – Eaton-Lambert and other myopathies.
    - Spinal cord compression.
    - Tumour burden.
3) Treatment related:
    - Chemotherapy.
    - Radiation therapy.
    - Surgery.
    - Biotherapy.
4) Non cancer related:
    - Autonomic failure – postural hypotension, occasional syncope, fixed heart rate and gastrointestinal symptoms (nausea, anorexia, constipation or diarrhea).
    - Cardiopulmonary disorders.
5) Reversible causes:
    - Anemia.
    - Bed rest.
    - Bleeding.
    - Depression or anxiety.
    - Dehydration.
    - Drugs – opioids, antidepressants, phenothiazines beta blockers phenytoin, levothyroxine.
    - Endocrine imbalances – hypothyroid, hypoadrenalism (most often due to rapid withdrawal of corticosteroid medication), diabetes mellitus and Addison's disease.
    - Hypercapnia or hypoxia.
    - Insufficient sleep.
    - Metabolic disturbances – hypercalcemia, hypokalemia and hyponatremia.
    - Occult or chronic sepsis.
    - Poor nutrition.
    - Unrelieved symptoms – pain, diarrhea, nausea and vomiting.

Appendix Three: Palliative Performance scale (Ppsv2) version 2

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Palliative Performance Scale (PPSv2) Version 2 Form

☑	PPS Level	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
☐	100%	Full	Normal activity and work No evidence of disease	Full	Normal	Full
☐	90%	Full	Normal activity and work Some evidence of disease	Full	Normal	Full
☐	80%	Full	Normal activity and work Some evidence of disease	Full	Normal or Reduced	Full
☐	70%	Reduced	Unable Normal Job or Work Significant Disease	Full	Normal or Reduced	Full
☐	60%	Reduced	Unable to do hobby or house work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
☐	50%	Mainly Sit or Lie	Unable to do any work Extensive Disease	Considerable Assistance Required	Normal or Reduced	Full or Confusion
☐	40%	Mainly in Bed	Unable to do most activity Extensive Disease	Mainly Assistance	Normal or Reduced	Full or Drowsy + or - Confusion
☐	30%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Normal or Reduced	Full or Drowsy + or - Confusion
☐	20%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Minimal to Sips	Full or Drowsy + or - Confusion
☐	10%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Mouth Care Only	Drowsy or Coma + or - Confusion
☐	0%	Death	Not Applicable	Not Applicable	Not Applicable	Not Applicable

Name and Stamp: _____ **Signature:** _____ **Date:** _____ **Time:** _____

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CHAPTER 11
Management of Hypercalcemia

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CHAPTER 11:- Management of Hypercalcemia in Palliative Care

1. STATEMENT OF PURPOSE

1.1 To provide a guidance in the identification, diagnose and management of hypercalcemia in adult patients who are aged 14years and older and have advanced life-threatening illness.

2 RELATED DOCUMENTS

2.1 Management of Delirium in Palliative Care.

2.2 Management of Fatigue in Palliative Care

3 DEFINITIONS

3.1 Hypercalcemia. Is the loss of balance between osteoclasts (calcium resorbed from bone into circulation) and osteoblasts (calcium absorbed into bone from circulation) resulting in an elevated serum calcium (normal calcium is 2.0 – 2.6 mmol/litre). Serum calcium may appear normal unless adjustment is made for low albumin which is common in a malignancy (corrected calcium = measured calcium + 0.02 [40– albumin grams/litre]).The median survival is approximately 1 month for patients with advanced caner presenting with hypercalcemia.

3.2 Mild hypercalcemia. As serum calcium (corrected) greater than (2.5 - 3.0 mmol/litre).

3.3 Moderate hypercalcemia. As serum calcium (corrected) greater than (3.00 - 3.5 mmol/ litre).

3.4 Severe hypercalcemia. As serum calcium (corrected) greater than (more than 3.5 mmol/ litre).

3.5 Cognition. It is the set of all mental abilities and processes related to knowledge.

4 GENERAL GUIDELINES

4.1 All admitted palliative patients aged 14 years and older experiencing the symptom hypercalcemia shall be assessed, diagnosed and managed by a Physician.

4.2 The main desired outcome in treating hypercalcemia is an improvement in symptoms; the Physician shall, therefore, monitor these clinical outcomes during the course of the treatment.

4.2.1 As an example, cognitive failure may precede the development of hypercalcemia and may therefore not be expected to improve with correction of the calcium.

4.3 If hypercalcemia is the underlying cause of a certain symptom, such as delirium, Physician shall treat first hypercalcemia before treating the delirium or other aggravating symptoms.

4.4 Physician shall be aware that hypercalcemia commonly occurs in:

4.4.1 10% to 40% of patients with breast cancer, lung cancer and multiple myeloma.

4.4.2 In the majority (approximately 80%) of cases, the production of parathyroid hormone-like peptide is responsible for the hypercalcemia and is an indicator of poor prognosis.

4.5 When studying laboratory results, the Physician must always relate serum calcium levels to serum albumin levels. The method for calculating correction of calcium level is reflective of the patient's albumin level as follows:

4.5.1 If serum albumin is less than 40 grams litre, increase measured calcium by 0.20 mmol per litre for every 10 grams of albumin below 40 grams per litre.

4.5.2 If serum albumin is greater than 40 grams per litre, reduce measured calcium by 0.20 mmol per litre for every 10 grams of albumin over 40 grams per litre.

4.5.3 Alternatively, corrected calcium (mmol/L) = Measured calcium (mmol/L) + [0.02 x (40 – measured albumin grams/litre)]

4.6 Physician shall be aware that the severity of symptoms is not always related to the degree of hypercalcemia but often reflect the rapidity of onset. Patients do not always exhibit all of the clinical features. The onset of hypercalcemia may be insidious.

5. ASSESSMENT AND MANAGEMENT

5.1 Assess patient for presence of the following signs and symptoms:

5.1.1 Increased pain, pruritis, dehydration, and polyuria/polydipsia.

5.1.2 Anorexia, nausea/vomiting, and constipation.

5.1.3 Lethargy, weakness, confusion, myopathy, and seizures.

5.1.4 Arrythmias, and bradycardia.

5.2 Obtain or request serum calcium and albumin diagnostics.

5.3 Identify other possible abnormal results as follows:

5.3.1 Alkaline phosphatase – usually elevated, except in myeloma.

5.3.2 Chloride - may be elevated in primary hyperparathyroidism.

5.3.3 Blood Urea Nitrogen- creatinine may be elevated from renal damage.

5.3.4 Electrocardiogram – may observe prolonged PR interval, widened QRS complex, shortened QT, widened T wave, bradycardia

5.4 Identify the underlying cause(s) and treat as appropriate noting that:

5.4.1 Management should include treating reversible causes where possible and desirable according to the goals of care.

5.4.2 While underlying cause(s) may be evident, treatment may not be indicated, depending on the stage of disease.

5.4.3 Whether or not the underlying cause(s) can be relieved or treated, all patients will benefit from management of the symptom using education, hydration and medications.

5.5 Provide education to patient and family related to the signs and symptoms of hypercalcemia in order to promote early recognition of acute rises in serum calcium.

5.6 Provide general management as follows:

5.6.1 Increase fluids (oral or subcutaneously/ IV).

5.6.2 Stop thiazide diuretics, vitamin with mineral supplements, calcium supplements, and antacids.

5.7 Manage patient with hypercalcemia non-pharmacologically as follows:

5.7.1 Provide or instruct re-hydration noting that:

5.7.1.1 Hydration alone may be sufficient for asymptomatic patients with borderline serum calcium elevation.

5.7.1.2 Adequate hydration reduces serum calcium by a median of 0.25 mmol per litre.

5.7.1.3 All hypercalcemic patients are dehydrated due to polyuria and vomiting.

5.7.1.4 Hydration is appropriate for treatable hypercalcemia. Re-hydration with 2 to 3 litres per day is now the accepted practice with daily serum electrolyte measurement to prevent hypokalemia and hyponatremia for patients with severe or symptomatic hypercalcemia.

5.7.1.5 Increase patient's oral fluid intake to 2 to 3 litres per day, as tolerated.

5.7.1.6 Most patients are usually 4 litres behind in their overall fluid balance when a diagnosis of hypercalcemia is made. Rehydration with normal saline should commence at 100 to 120 mL per hour I.V. or by hypodermoclysis based on patient's cardiac status (e.g., a slower rate should be used in patients prone to CHF).

5.7.2 Assist or instruct mobilization noting that:

5.7.2.1 Mobilization of the patient is important, in that it slows down the loss of skeletal calcium associated with immobility.

5.7.3 Advice diet:

5.7.3.1 Low calcium diet is needed to control hypercalcemia caused by other medical cause like hyperparathyroidism but they are unpalatable, impractical, exacerbate malnutrition and have no place in palliative therapy.)

5.8 Manage patient with hypercalcemia pharmacologically as follows:

5.8.1 Prescribe steroids noting the following:

5.8.1.1 Corticosteroids may lower serum calcium if they have an antineoplastic effect on the underlying malignancy. They should be reserved for situations in which bisphosphonates are not easily accessible or are ineffective or in which other indication for corticosteroids (pain or nausea) exist.

5.8.1.2 Prednisone 40 to 100 mg daily or up to one week.

5.8.1.3 Hydrocortisone 100 mg I.V. every 6 hours.

5.8.1.4 Dexamethasone 4 mg subcutaneously every 6 hours for 3 to 5 days.

5.8.1.5 Steroids are particularly useful for hypercalcemia seen with lymphomas and multiple myeloma.

5.8.2 Prescribe Calcitonin noting the following:

5.8.2.1 Calcitonin 4 to 8 international units per kg given subcutaneously or I.M. every 12 hours.

5.8.2.2 Calcitonin has a rapid onset of action; approximately 4 hours after administration but has a shorter duration of action. It is very useful when a rapid lowering of serum calcium is required but needs to be combined with bisphosphonates.

5.8.2.3 Possible side effects include flushing, mild nausea, crampy abdominal pain.

5.8.3 Prescribe Bisphosphonates noting the following:

5.8.3.1 Bisphosphonates are appropriate to administer when serum calcium (corrected) is greater than or equal to 3.0 mmol per litre or when serum calcium (corrected) is less than 3.0 mmol per litre when accompanied by symptoms.

5.8.3.2 Bisphosphonates cause a fall in calcium in 48 hours. These agents are very useful and well tolerated but are quite expensive.

5.8.3.3 Oral bisphosphonates (like Clodronate or Alendronate) can be used, but in many palliative care patients they are not well tolerated. Parenteral drugs including

Pamidronate and Zoledronic acid have been used with success and are better tolerated and more effective than oral.

5.8.3.4 Do not give bisphosphonates until the patient is fully re-hydrated and has an adequate urine output.

5.8.3.5 Recheck serum calcium, electrolytes, urea, and creatinine on the third day after administering bisphosphonates. In general re-check calcium level 7 – 10 days after bisphosphonate and one week before the next dose.

5.8.3.6 Renal failure is the most serious adverse effect. Bisphosphonates are contraindicated in patients with serum creatinine greater than 400 mmol per litre or calculated creatinine clearance of less than 10 ml per minute.

5.8.3.7 Denosumab 120 mg SC every week for 3 weeks for patients with renal failure.

5.8.3.8 In patients with pre-existing renal disease and a serum creatinine less than 265 mmol per litre, no change in dosage, infusion time or interval of is required for multiple myeloma patients.

5.8.3.9 Caution is required in patients receiving other drugs that may affect renal function (NSAIDS, ACE inhibitors, aminoglycosides)

5.8.3.10 Pamidronate 30 to 90 mg I.V. For severely elevated calcium (over 3.5 mmol per Litre) use 90 mg I.V. bolus in 250 mL to 500 mL normal saline over 60 to 90 minutes. Note:

5.8.3.10.1 Pamidronate has been shown to be superior to Clodronate in terms of duration of normal calcium levels achieved.

5.8.3.10.2 Best given with acetaminophen, 500 mg PO or rectally to prevent pamidronate fever.

5.8.3.10.3 Pamidronate usual expected duration of effect of is 3 to 4 weeks.

5.8.3.11 Clodronate 1500 mg I.V. over 4 hours in 250 or 500 mL normal saline or 500 mg I.V. daily for 3 days – dilute in 500 cc normal saline. Note:

5.8.3.11.1 Usual expected duration of action of Clodronate is 2 weeks.

5.8.3.11.2 A dose adjustment for decreased renal function should be made: if creatinine clearance is 10 to 50 ml per minute a dose reduction of 25% to 50% is recommended.

5.8.3.12 Zoledronic acid 4 mg in 100 ml NS over 15 minutes. Zoledronic acid has been shown to achieve normal serum calcium levels in more patients, faster and with longer duration than Pamidronate.

5.8.3.12.1 Usual expected duration of effect of Zoledronic acid is 4 to 6 weeks.

5.8.3.12.2 Useful for refractory hypercalcemia treatment.

5.8.3.12.3 Fever is a common side effect of zoledronic acid, with renal impairment seen rarely.

5.8.3.12.4 Zoledronic acid has been found to be effective in reducing and delaying bone complications across a broad range of solid tumors and multiple myeloma.

5.8.3.12.5 Dose adjustment for decreased renal function (Baseline Creatinine Clearance (ml/min) : Zoledronic Acid Recommended Dose) as follows:

5.8.3.12.5.1 Greater than 60 ml/min : 4.0 mg

5.8.3.12.5.2 50 to 59 ml/min : 3.5 mg

5.8.3.12.5.3 40 to 49 ml/min : 3.3 mg

5.8.3.12.5.4 30 to 39 ml/min : 3.0 mg

5.8.3.13 Drugs promoting hypercalcemia (thiazide diuretics, lithium, ranitidine, cimetidine, vitamins A and D and preparations containing calcium) should be withdrawn.

5.8.3.14 The routine use of furosemide in conjunction with hydration to promote calcium excretion is not recommended, because of the risk of volume and electrolyte depletion.

6. APPENDIX

Not Applicable

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المجلس الصحي السعودي
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CHAPTER 12
Management of Depression

المجلس الصحي السعودي
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CHAPTER 12:- Management of Depression in Palliative Care

1. STATEMENT OF PURPOSE

1.1 To provide a guidance in the identification, diagnosis and management of depression in adult patients who are aged 14 years and older and have advanced life-threatening illness.

2. RELATED DOCUMENTS

2.1 Management of Fatigue in Palliative Care

3. DEFINITIONS

3.1 **Depression**. Is a primary mood disorder which, according to the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR) includes:

3.1.1 A depressed mood and/or

3.1.2 An inability to experience pleasure in normally pleasurable acts (anhedonia).

3.2 **For major depression,** the DSM-IV-TR states that one of the above symptoms must be present for a period of at least two weeks in combination with four or more of the following symptoms:

3.2.1 Feelings of overwhelming sadness and/or fear, or the seeming inability to feel emotion (emptiness).

3.2.2 A decrease in the amount of interest or pleasure in all, or almost all, daily activities.

3.2.3 Changing appetite and marked weight gain or loss.

3.2.3.1 Note, ensure not related to disease process.

3.2.4 Disturbed sleep patterns, such as insomnia, loss of rapid eye movement (REM) sleep, or excessive sleep (hypersomnia).

3.2.5 Psychomotor agitation or retardation nearly every day.

3.2.6 Fatigue, mental or physical, also loss of energy.

3.2.7 Intense feelings of guilt, helplessness, hopelessness, worthlessness, isolation/ loneliness and/or anxiety.

3.2.8 Trouble concentrating, keeping focus or making decisions or a generalized slowing and obtunding (To dull or blunt, especially to blunt sensation or deaden pain) of cognition, including memory.

3.2.9 Recurrent thoughts of death (not just fear of dying), desire to just "lay down and die" or "stop breathing", recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

3.2.10 Feeling and/or fear of being abandoned by those close to one.

3.3 **Minor depression.** It is a less-used term for a subclinical depression that does not meet criteria for major depression but where there are at least two symptoms present for two weeks.

4. GENERAL GUIDELINES

4.1 All admitted palliative patients aged 14 years and older experiencing the symptom of depression shall be assessed, diagnosed and managed by a Physician.

4.2 Physicians shall determine depression's cause and impact on quality of life for the patient and their family.

4.3 If a patient is not able to respond to history and physical examination then the Physician must get collateral information from family members or friends.

4.4 Physicians shall carefully identify depression and not include symptoms that are clearly due to a general medical condition, mood-incongruent delusions and/or hallucinations.

4.5 Physicians shall be aware that patients with advanced illness have a higher incidence of clinical depression than the general population. The prevalence of depression in the general population is 6 to 10%. Terminally ill patients have been found to have a higher level of both physical and emotional distress with 24% having depression. Clinical depression occurs in 15 to 30 % of cancer patients.

4.6 Physicians shall note the following risk factors for depression:

4.6.1 Non-cancer related risk factors:

4.6.1.1 History of depression or family history of depression.

4.6.1.2 Two or more episodes of depression in a lifetime. First episode depression early or late in life.

4.6.1.3 Lack of family or social support.

4.6.1.4 Previous suicide attempts.

4.6.1.5 Concurrent chronic illnesses such as: stroke or myocardial infarction.

4.6.2 Cancer-related risk factors:

4.6.2.1 Depression at time of cancer diagnosis.

4.6.2.2 Advanced stage of cancer.

4.6.2.3 Additional concurrent life stressors.

4.6.2.4 Increased physical impairment or discomfort.

4.6.2.5 Being unmarried

4.6.2.6 Having head and neck cancer.

4.6.2.7 Substance abuse.

4.6.2.8 Pancreatic and primary or metastatic brain cancers.

4.6.2.9 Taking medications that may contribute to depression (e.g. benzodiazepines, corticosteroids, anticonvulsants, methyldopa, propranolol, chemotherapeutic agents).

4.6.2.10 Chronic pain.

5. ASSESSMENT AND MANAGEMENT

5.1 Assess the patient with depression including:

5.1.1 Interview the patient (see Appendix One).

5.1.2 Conduct physical assessment.

5.1.3 Review medication.

5.1.4 Conduct medical and surgical review.

5.1.5 Conduct psychosocial and physical environment review.

5.1.6 Obtain or request for appropriate diagnostics.

5.2 Determine the nature and possible causes of depression with the following considerations.

5.2.1 Identifying the underlying etiology of depression is essential in determining the interventions required.

5.2.2 The usual somatic symptoms of depressed patients (fatigue, loss of appetite, sleep disturbance, poor concentration, etc.) are often present in advanced cancer and terminal illness and cannot always be relied upon for diagnosis.

5.2.3 Psychological symptoms of depression that are persistent, out of character and severe are of greater diagnostic value in patients with advanced illness. In particular, watch for pervasive dysphoria, feelings of helplessness, hopelessness and worthlessness, guilt, loss of self-esteem, loss of interest and wishes to die. Even very mild or passive suicidal ideation is indicative of significant depression in terminally ill patients.

5.2.4 If the diagnosis of depression is uncertain, consider psychiatric referral and a trial of antidepressant medication. When in doubt, treat.

5.3 Provide education to patient and family, advising them.

5.3.1 That depression is a distressing symptom to experience and witness. It is commonly under reported as many of the signs and symptoms are a feature of terminal illness.

5.3.2 Of the importance of reporting symptoms that are causing distress, physical or psychological, as both may influence psychological wellbeing.

5.3.3 That if depression is diagnosed it can be managed. Treatment can be effective even when life expectancy is short.

5.3.4 The purpose of non-pharmacological and pharmacological measures and the goal of each.

5.3.5 That many anti-depressant medications take time to become effective.

5.4 Manage depressed patients non-pharmacologically noting that:

5.4.1 A combination of supportive psychotherapy and cognitive-behavioural techniques is the optimal management

5.4.2 Pain must be well treated or alleviated. Uncontrolled pain is a major risk factor for depression and suicide among patients with cancer.

5.4.3 Psychosocial therapies, relaxation techniques, massage therapy and therapeutic touch can be considered for patient and his/her family.

5.5 Manage depressed patient pharmacologically noting that:

5.5.1 Medication without ongoing contact is often seen as abandonment and never acceptable

5.5.2 Medication should be started with low doses and increased slowly.

5.5.3 When anticipated survival time is short, psychostimulants, due to their more immediate onset of effect, should be considered.

5.5.4 Side effects and additional therapeutic benefit must be considered (e.g. tricyclic antidepressants may benefit neuropathic pain but worsen constipation; tricyclics should be avoided in patients with cardiac conduction delays, etc.).

5.5.5 Withdrawal symptoms may be of significant importance in palliative patients who are unable to continue with oral medications.

5.5.6 There are similar response rates when comparing antidepressant medications.

5.5.7 The facts and prescription requirements for Selective Serotonin Receptor Inhibitors (SSRIs) e.g. Citalopram, Paroxetine, Fluoxetine, Sertraline are:

5.5.7.1 The initial and maintenance doses are specific for each of the SSRI's with fewer side effects than tricyclic antidepressants (TCAs).

5.5.7.2 SSRI are started at half the usual dose for the general population in palliative care patients for the general population.

5.5.7.3 The sudden cessation of SSRI therapy when a patient is unable to swallow can produce a withdrawal syndrome. Withdrawal risk is greater with short half-life drugs such as paroxetine, lowest with long half-life drugs such as fluoxetine, and of intermediate risk for other SSRI's

5.5.7.4 Citalopram should be started at 10 to 20 mg daily, increasing at intervals of no less than one week.

5.5.7.5 Citalopram maximum daily dose is 60 mg, although doses above 40 mg are not ordinarily recommended

5.5.7.6 Paroxetine and fluoxetine are active inhibitors of the enzyme responsible for metabolizing oxycodone and codeine to its active analgesic form. Concurrent use of these opioids and SSRIs can, therefore, result in decreased pain control.

5.5.7.7 Fluoxetine has less selective receptor sites and a much longer half-life than the other SSRIs and should not be the drug of choice. Switching to other antidepressants after having been on fluoxetine can be complicated due to the extended half-life.

5.5.8 The facts and prescription requirements for Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs) e.g. Venlafaxine are:

5.5.8.1 Initial Venlafaxine dose is 75 mg per day then maintenance dose: 150 to 375 mg per day

5.5.9 The facts and prescription requirements for Atypical Antidepressants are:

5.5.9.1 Bupropion

5.5.9.1.1 Has an initial activating dose-related seizure-inducing potential. Contraindicated in patients with a history of seizure, in those with concomitant conditions predisposing to seizure, and in patients taking other drugs that lower seizure threshold.

5.5.9.1.2 Has a low incidence of sedative, hypotension and anticholinergic side effects.

5.5.9.1.3 Can cause over stimulation.

5.5.9.1.4 Generally considered to be a third line treatment.

5.5.9.1.5 The initial Bupropion dose is 100 mg per day then maintenance: 200 mg per day not exceeding 150 mg per dose.

5.5.9.2 Trazodone

5.5.9.2.1 May cause hypotension including orthostatic hypotension and syncope; caution is required if it is given to patients receiving antihypertensive drugs and an adjustment in the dose of the antihypertensive medication may be required.

5.5.9.2.2 Increased serum Digoxin and Phenytoin levels have been reported with concurrent Trazodone use.

5.5.9.2.3 Treatment should be started with low initial doses of Trazodone 25 to 50 mg daily in divided doses or in an evening single dose. The dose may be increased slowly to a maximum of 300 mg daily in ambulatory patients and to 600 mg daily in hospitalized patients.

5.5.9.3 Mirtazapine

5.5.9.3.1 Is a tetracyclic antidepressant.

5.5.9.3.2 Elimination is decreased in elderly persons.

5.5.9.3.3 When used concomitantly with drugs that reduce the seizure threshold (e.g., Phenothiazines), Mirtazapine may increase the risk of seizure.

5.5.9.3.4 The initial Mirtazapine dose is 7.5 to 15 mg daily, maintenance dose: 15 to 45 mg daily.

5.5.10 The facts and prescription requirements for Psychostimulants e.g. Methylphenidate and Dextroamphetamine are:

5.5.10.1 Consider this class of medication when life expectancy may be short, as these drugs work within hours to days.

5.5.10.2 They often enhance opioid analgesia, reduce opioid sedation and improve appetite. They can improve attention, concentration and overall performance.

5.5.10.3 Side effects include agitation, confusion, insomnia, anxiety and paranoia. Use cautiously in the elderly, avoid in delirious patients and underlying medical conditions that may be compromised by increases in blood pressure or heart rate such as pre-existing hypertension, heart failure, recent myocardial infarction, or hyperthyroidism.

5.5.10.4 A common clinical practice is to start a psychostimulant and a SSRI together and then withdraw the stimulant while titrating the SSRI upward.

5.5.10.5 Start Methylphenidate at 5 mg PO at 8 AM and noon. Initial doses could be lower at 2.5 mg BID in very frail patients. Increase 2.5 to 5 mg every 1 or 2 days until desired effect is reached, or to a maximum daily dose of 30 mg per day. Afternoon dosing can affect nighttime sleep and is generally not recommended.

5.5.11 The facts and prescription requirements for Tricyclic Antidepressants (TCA) are:

5.5.11.1 Nortriptyline, Amitriptyline, Imipramine and Doxepin:

5.5.11.1.1 Require a careful risk-benefit ratio analysis because the adverse effect profile may be troubling to patients in a palliative/hospice setting. Effects include sedation and anticholinergic effects; dry mouth, blurred vision, urinary hesitancy, or retention, constipation.

5.5.11.1.2 Avoid Tricyclic Antidepressants in patients with cardiac conduction delays, coronary artery disease, or history of myocardial infarction in past six months.

5.5.11.1.3 Adverse effects usually decrease three to four days after initiation of a Tricyclic Antidepressant or after increasing the dosage.

5.5.11.1.4 The secondary amines (Desipramine and Nortriptyline) generally have fewer side effects, such as sedation and anticholinergic effects, than the tertiary amines (Imipramine, Amitriptyline, and Doxepine).

5.5.11.1.5 Start at low doses (10 to 25 mg PO at bedtime) and increase by 10 to 25 mg PO every 4 days.

5.5.11.1.6 Onset of antidepressant effect may take 2 to 4 weeks.

5.5.11.1.7 May provide additional neuropathic pain benefits.

6. APPENDIX

6.1 Appendix One. Suggested Questions for the Assessment of Depressive Symptoms in Adults with Terminal Illness

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Appendix One. Suggested Questions for the Assessment of Depressive Symptoms in Adults with Terminal Illness

Question	Relates to
How well are you coping with your illness. Well? Poor?	Well being
How are your spirits since diagnosis? During treatment? Down? Blue?	Mood
Do you cry sometimes? How often? Only alone?	Mood
Are there things your still enjoy doing, or have you lost pleasure in things you used to do before you became ill?	Anhedonia
How does the future look to you? Bright? Black?	Hopelessness
Do you feel you can influence your care, or is your care totally under others' control?	Helplessness
Do you worry about being a burden to family and friends during the treatment?	Worthlessness
Physical symptoms (Evaluate in the context of disease related symptoms)	
Do you have pain that is not controlled?	Pain
How much time do you spend in bed?	Fatigue
Do you feel weak? Fatigue easily? Rested after sleep? Any relationship between how you feel and a change in treatment or how you otherwise feel physically?	Fatigue
How is your sleeping? Trouble going to sleep? Awake early? Often?	Insomnia
How is your appetite? Food tastes good? Weight loss or gain?	Appetite
How is your interest in sex? Extent of sexual activity?	Libido
Do you think or move more slowly than usual?	Psychomotor slowing

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CHAPTER 13

Management of Exsanguination (Terminal Bleeding)

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CHAPTER 13:- Management of Exsanguination (Terminal Bleeding) in Palliative Care

1. STATEMENT OF PURPOSE

1.1 To provide a guideline for identification, diagnosis and management of exsanguination (massive terminal bleeding) in adult patients who are aged 14 years and older and have advanced life-threatening illness.

2. RELATED DOCUMENTS

2.1 Allow Natural Death Order

3. DEFINITIONS

3.1 **Bleeding** is the loss of blood or blood escaping from the circulatory system. Associated symptoms depend on the duration and rate of bleeding.[1] The terms **'massive' or 'catastrophic' are sometimes preferred over the term 'terminal' hemorrhage** because not all large bleeds result in death.[2] This guideline will refer to **severe bleeding** which is a large amount of blood loss. The clinical presentation of bleeding in the palliative care setting is variable. It may be visible or invisible; volumes may vary from low-grade oozing to massive and catastrophic, continuous or intermittent. It may be localized or from multiple sites.[2]

3.2 **Exsanguination** is defined as the blood loss of >150 mL per minute or loss of entire blood volume in 24 hours.[3, 4]

3.3 **DIC:** Disseminated Intravascular Coagulation

4. GENERAL GUIDELINES

7.6 All admitted palliative patients aged 14 years and older experiencing the symptom of exsanguination shall be assessed, diagnosed and managed by a Physician.

7.6.1 Physicians shall be aware that although rare, clinically significant bleeding leading to massive blood loss and death occurs in:

7.6.1.1 6% to 10% of all patients with advanced cancer.

7.6.1.2 3% of lung cancer patients due to massive haemoptysis.

7.6.1.3 Some tumours, especially head and neck cancers, as a result of their infiltration into surrounding large vessels and vascular structures

7.6.2 Physicians shall also be aware the other causes of haemorrhage can include thrombocytopenia, liver failure and disseminated intravascular coagulation.

7.6.3 Physicians shall regularly monitor a patient's clinical status for signs and symptoms of potential and/or impending haemorrhage.

8. ASSESSMENT AND MANAGEMENT

8.1 Obtain an Allow Natural Death (AND, DNR) order and keep in patient's medical record.

8.2 Identify underlying cause(s) of exsanguination noting the following examples:

8.2.1 ENT tumour: Carotid artery erosion from neck metastases and oro-pharyngeal tumour erosion in mouth.

8.2.2 Gastrointestinal hemorrhage: Gastro-duodenal hematemesis and small or large bowel bleeding with melena or hematochezia and often associated with severe colic.

8.2.3 Bladder: Hematuria due to tumour, DIC or leukemia.

8.2.4 Leukemia or blood dyscrasia.

8.2.5 DIC: Due to various causes such as sepsis.

8.2.6 Other: E.g. ruptured aortic aneurysm (or thoracic) and tumour lymph node erosion into adjacent vessels.

8.3 Determine required intervention(s) as follows:

8.3.1 Provide education to patient/family:

8.3.1.1 Instruct family ahead of time or provide explanation when unexpected event occurs.

8.3.1.2 Ensure advanced planning is provided for all patients with the potential to bleed, as this symptom is a source of considerable distress for patients, family and staff.

8.3.1.3 Manage patient with exsanguination non-pharmacologically as follows:

8.3.1.3.1 Provide the following immediate care, wherein the patient is conscious for a short period of time (usually twenty seconds to several minutes) before lapsing into a hypoxic coma and cardiac arrest:

8.3.1.3.1.1 Place three to four large towels close to the bedside and cover blood as it occurs to reduce the visual impact.

8.3.1.3.1.2 Note black or dark colored towels will minimize the sight of blood.

8.3.1.3.1.3 Place several face cloths close to bedside and use to wipe the patient's mouth and face.

8.3.1.3.1.4 Hold the patient's hand or hug them while providing quieting and comforting words until they drift into a coma and die.

8.3.1.3.1.5 Ensure the blood is covered and the patient's face is clean particularly prior to the arrival of any family members.

8.3.1.3.1.6 Provide a warm blanket if patient feels cold due to hypotension.

8.3.1.3.2 Provide the following management for prolonged bleeding, wherein the patient may be conscious for a longer period, although confusion and drowsiness will arise from progressive hypoxia and hypotension:

8.3.1.3.2.1 Place towels as above at bedside in case of massive bleeding.

8.3.1.3.2.2 Use suction directly at the site of bleeding to remove all or most of the blood. This can be very effective visually and also help prevent coughing or choking in oral hemorrhage.

8.3.1.3.2.3 Minimize bleeding by applying direct pressure to the site, where possible.

8.3.1.3.2.4 Note towels and suction are more practical at this point.

8.3.1.3.2.5 Have family or provide physical touch and comfort. Family will need frequent support and reassurance during this phase of dying. They may need to leave the room.

8.3.1.3.2.6 Provide a warm blanket if patient feels cold due to hypotension.

8.3.1.3.2.7 Maintain an adequate airway in patients with hemoptysis. This can be accomplished with the Trendelenburg position or positioning the patient with the bleeding side down (if known).

8.3.1.3.2.8 Manage patient with exsanguination pharmacologically as follows:

8.3.1.3.2.9 Provide immediate care for rapid blood loss as follows:

8.3.1.3.2.9.1 Use sedation as quickly as possible to relieve distress, when practical and timely.[14,15]

8.3.1.3.2.9.2 Midazolam 10 mg dose is most commonly used for major bleeds.[9,12,13-18]

8.3.1.3.2.9.3 Give midazolam IV (preferred) bolus, if IV access is possible.[9,12]

8.3.1.3.2.9.4 Alternatively give SC, IM (large deltoid or gluteal muscle), or buccal.[11, 13,15,19]

8.3.1.3.2.9.5 Repeat dose if needed. IV within 5 minutes, SC, IM, buccal within 5 to 15 minutes.[14]

8.3.1.3.2.9.6 Alternatives include: Lorazepam 4 mg IV/SC/sublingual10 and Ketamine 150 to 250 mg IV, or 500 mg IM (large deltoid or gluteal muscle).[14,17]

8.3.1.3.2.9.7 Opioids are indicated for pain or dyspnea.14 Hemorrhage is usually not painful.[9,14,17].

9. APPENDIX

Appendix 1: Medications for management of severe bleeding

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Appendix 1: Medications for management of severe bleeding

Drug (classification)	Dose, Therapeutic Range	Onset, Adverse Effects, Precautions and Dosing Concerns
Midazolam*† (benzodiazepine)	Stat dose: 10 mg IV, SC, IM, Buccal Repeat dose 5 min IV 5 to 15 min SC, IM, buccal	**Onset:** 1 to 5 min IV,20 5 to 10 min SC,21 5 to 15 min IM into deltoid muscle[21,22] **Adverse effects:** IV administration over 2 to 3 minutes suggested to minimize hypotensive effects, reported in up to 30% of patients.[23,24] However, consider immediacy of bolus administration within clinical context. **Contraindicated** if hypersensitivity to benzodiazepines. **Precautions** in patients with prior paradoxical reaction history to benzodiazepines. Prior or concurrent opioid dosing may increase respiratory depressant effects. **Dosing:** Review dose, 10 mg commonly recommended.[9,12,13-18] A single dose in an emergency situation, must be sufficiently adequate for a rapid and predictable effect.[13] Lower doses, such as 2.5 to 5 mg may be appropriate if bleeding is brisk but not rapidly fatal.[9,14] Weight based dosing of 0.2 mg/Kg dose IV or SC suggested for urgent palliative bleed sedation (where known).[20] Higher doses may be needed; if already on background benzodiazepines, heavy alcohol or substance use.[11,12,15] **Effectiveness of route of administration**: Peripheral circulation shutdown during hypovolemic shock has some experts suggesting that bioavailability will be especially compromised for IM and SC administration.[9,12,17] SC route may be unpredictable.[12] Most references continue to suggest SC use.[9,15,18,20] For buccal administration, place dose between the patient's cheek and gum.[16] **Storage of prefilled syringes**: 5 mg/mL undiluted reported stable for 36 days at 25° C when protected from light.[25] Sterility assurance beyond 24 hours of preparation unknown, assess importance, duration of storage within clinical context. Recently, Health Canada has cautioned regarding storage of medications in disposable plastic syringes citing risk of potency concerns.[26] Replacement every 4 to 7 days has been suggested.[16,27]

Medications for management of severe bleeding continued on next page

Appendix 1: Medications for management of severe bleeding (Continued)

Drug (classification)	Dose, Therapeutic Range	Onset, Adverse Effects, Precautions and Dosing Concerns
Lorazepam*† (benzodiazepine)	4 mg x 1 dose IV, SL, SC, IM or buccal	**Onset:** 5 minutes SL.[22,28] May be as long as 20-30 minutes.[29] IV onset faster than SC or SL.[30] Sublingual onset similar to IM, SC. [29,30] For buccal administration: in patients with a dry mouth, the tablet should be dissolved in a few drops of warm water, or drop SL tablet into a syringe, add water to dissolve, then place dose between the patient's cheek and gum.[28,31]
Ketamine*† (anesthetic)	150 to 250 mg IV x 1 dose 500 IM x 1 dose[14,17]	**Onset:** 1 minute IV,[33] 5 min IM.[32] **Adverse effects** include paradoxical excitation. IM injection volume large, requiring multiple sites of injection.

* Dose effect for massive bleed treatment not studied, is expert opinion only.
†Off-label. PO = by mouth IV = Intravenous, SC = Subcutaneous, TID = three times daily, QID = four times daily ODT = oral dissolving tablet CSCI = continuous subcutaneous infusion.

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CHAPTER 14
MANAGEMENT OF DEHYDRATION

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CHAPTER 14:- MANAGEMENT OF DEHYDRATION IN PALLIATIVE CARE

1. STATEMENT OF PURPOSE

1.1 To provide a guideline for identification, diagnosis and management of dehydration in adult patients who are aged 14 years and older and have advanced life-threatening illness.

2. RELATED DOCUMENTS

2.1 Management of Gastrointestinal Diseases in Palliative Care

2.2 Management of Anorexia & Cachexia in Palliative Care

2.3 Management of Hypercalcemia in Palliative Care

2.4 Management of Delirium in Palliative Care

2.5 Management of Seizures in Palliative Care

3. DEFINITIONS

3.1 **Dehydration.** is intracellular water depletion with hypernatremia (hyperosmolality); it usually presents with symptoms of thirst, anorexia, nausea/vomiting, fatigue and irritability. Physical findings may include lethargy, confusion, muscle twitching and hyperreflexia. **Volume depletion** is the loss of intravascular water (with varying sodium levels) and presents with diminished skin turgor/capillary refill and orthostatic hypotension and dizziness.[1] **Artificial hydration** (AH) involves the provision of water or electrolyte solutions by any route other than the mouth. This can be achieved by intravenous, subcutaneous (hypodermoclysis)[2] and dermal (dermoclysis).[3]

3.2 **Overhydration** related symptoms include: bronchial secretions, respiratory congestion, pleural effusion, nausea/vomiting, ascites, peripheral edema.[4]

4. GENERAL GUIDELINES

4.1 All admitted palliative patients aged 14 years and older experiencing the symptom of dehydration shall be assessed, diagnosed and managed by a Physician.

4.2 Physicians shall note that dehydration in the last days may bring about relief from previously distressing symptoms. It has been proposed that the fluid and electrolyte imbalances of dehydration may serve as a natural anesthetic to reduce the patient's suffering.

4.3 Physicians shall assess patient's condition and other factors contributing to dehydration.

4.4 Physicians shall strive to prevent dehydration as early as possible and promptly administer Oral Rehydration Solution (ORS)/ fluids.

4.5 Physicians shall note that following information about hydration:

4.5.1 Clinical studies suggest that terminally ill cancer patients may achieve adequate hydration with much lower volumes (as low as one liter per day) than recommended for the average medical and surgical patient due to:

4.5.1.1 Decreased body weight.

4.5.1.2 Decreased free water clearance.

4.5.1.3 Decreased insensible water losses due to decreased physical activity.

4.5.1.4 Appropriate Use of Parenteral Fluids

4.6 Physicians shall note the theoretical advantages of hydration such as:

4.6.1 May relieve thirst and improve oral comfort.

4.6.2 Improved renal function will lead to increased clearance of drugs and toxic metabolites.

4.6.3 May facilitate resolution of reversible conditions (hypercalcemia, opioid neurotoxicity).

4.6.4 Facilitates productive cough and thereby improves clearing of secretions.

4.6.5 Improves function of unobstructed bowel.

4.6.6 May improve delirium and / or terminal agitation, leading to better communication with family.

4.6.7 Satisfies family's need to provide nourishment and "do everything that can be done"

4.7 Physicians shall also note that the hydration has theoretical disadvantages as follows:

4.7.1 Oral secretions causing need for suctioning.

4.7.2 Urine output causing bed-wetting and bedpans or catheters.

4.7.3 Respiratory tract secretions causing cough, respiratory congestion.

4.7.4 Gastrointestinal secretions causing vomiting.

4.7.5 Edema contributing to pressure sores.

4.7.6 May prolong the agonal period without prolonging life.

4.7.7 Places physical barriers between the patient and family which can inhibit physical contact with the patient.

4.8 Although hypodermoclysis is safe and effective way of providing parenteral hydration, physicians shall utilize the following criteria when deciding if an admitted patient is suitable for this procedure:

4.8.1 Unable to ingest sufficient amounts of fluid orally, is dehydrated and has distressing symptoms that diminish quality of life,

4.8.2 Intravenous access not required, possible or practical,

4.8.3 Patient and / or family wish patient to receive hydration by this route,

4.8.4 Patient does not require either immediate or high volume fluid replacement,

4.8.5 Patient does not have respiratory congestion, large ascites or extensive edema

4.8.6 Patient does not have coagulation problem or bleeding.

5. PRACTICE GUIDELINES

5.1 Assess the dehydrated patient including.

5.1.1 Interview the patient using the acronym O, P, Q, R, S, T, U and V (see Appendix One).

5.1.2 Conduct physical assessment

5.1.3 Review medication.

5.1.4 Conduct medical and surgical review.

5.1.5 Conduct psychosocial and physical environment review.

5.1.6 Obtain or request appropriate diagnostic tests.

5.2 Diagnose the cause (often multi-factorial) of the symptom, the disease trajectory and the patient / family values and goals of care.

5.2.1 Nausea and / or vomiting resulting in reduced intake

5.2.2 Diarrhea resulting in malabsorption

5.2.3 Gastrointestinal Obstruction resulting in reduced intake and malabsorption

5.2.4 Anorexia resulting in reduced intake

5.2.5 Infection resulting in increases insensible losses, reduced intake

5.2.6 Hypercalcemia Medications e.g. diuretics increase urinary losses

5.2.7 Terminal / end-stage disease or illness

5.3 Provide anticipatory guidance and / or education whenever possible to alleviate distress about hydration status:

5.3.1 Advise patients/families of the following:

5.3.1.1 Oral intake will lessen over time due to changes in metabolism and body requirements.

5.3.1.2 Parenteral fluid does not equal nutrition.

5.3.1.3 Hydration has little or no effect on sensation of thirst and dry mouth.

5.3.2 Teach interventions that provide relief from thirst and / or dry mouth such as oral care, offering fluids, ice chips, chewing gum, mist or spraying mouth, lubrication of lips and skin care so family can contribute to care (if desired).

5.3.3 Note that in some situations a team and family conference may be needed.

5.3.4 Provide resources for patients considering the benefits and burdens of parenteral hydration.

5.4 Manage dehydration as follows:

5.4.1 Help family or caregivers to provide good oral care.

5.4.2 Offer oral fluids (with or without lemon), ice chips or mist / spray to hydrate oral tissues.

5.4.3 Consider parenteral hydration (example – hypodermoclysis) when oral intake is severely restricted in the following situations:

5.4.3.1 For patients in good symptom control when maintenance of cognitive status is important.

5.4.3.2 To avoid medication side effects such as myoclonus, discontinuing hydration once side effect resolves or the terminal phase is reached.

5.4.4 Assess relief of symptoms by a short trial of rehydration with clear goals and time frame (48 to 72 hours).

5.5 Consider using hypodermoclysis to hydrate patients if necessary noting the following:

5.5.1 Assess patient to determine whether hydration is indicated.

5.5.2 Recognize that dehydration alone is not a sufficient reason to offer hypodermoclysis. Confusion, delirium and myoclonus are often caused by the accumulation of toxic metabolites of drugs (such as opioids) and may be improved or relieved by rehydration.

5.5.3 Explain and discuss with the patient/family, prior to initiation of hypodermoclysis, the benefits and burdens of hydration, clarify expectations and delineate clear goals.

5.5.3.1 If hypodermoclysis is being offered on a trial basis or for a limited time period, explain the parameters to the patient and family and discuss indications for discontinuing hypodermoclysis prior to its initiation.

5.5.4 Administer if possible hypodermoclysis as an overnight infusion, as a bolus or by continuous infusion.

5.5.5 Administer the recommended volume maximum 1 to 1.5 liters of an isotonic solution daily as follows;

5.5.5.1 Normal Saline (0.9%).

5.5.5.2 2/3 Dextrose (5%) – 1/3 Normal Saline (0.9%).

5.5.5.3 Dextrose 5½ Normal Saline (D5½ NS).

5.5.5.4 Ringers Lactate.

5.5.5.5 Dextrose 5 Water (D5W) should not be used as it becomes hypotonic as the dextrose is absorbed.

5.5.5.6 Potassium chloride up to 40 mEq per liter may be added to the solution

5.5.5.7 Hyaluronidase is no longer felt to be justified or necessary for routine bolus hydration

5.5.6 Consider the following when selecting site for hypodermoclysis:

5.5.6.1 Ask the patient which site he/she prefers

5.5.6.2 Upper chest, back (below scapula), thigh and upper abdominal wall are preferred sites.

5.5.6.3 Do not insert needle for hypodermoclysis into previously irradiated skin as absorption may be impaired.

5.5.6.4 Consider using chest, scapular region and abdomen for ambulatory patients and thighs and abdomen for those patients limited to bed-rest use.

5.5.6.5 Avoid anterior or lateral thigh if edema present; abdomen if ascites present; breast tissue; lateral placement near shoulder; arms and perineum / groin.

5.5.7 Note only use the intravenous route in patients who require intravenous access for other purposes or in situations where the subcutaneous administration of fluids is contraindicated e.g. generalized edema or coagulation disorders.

5.5.8 Undertake with care rehydration in patients with CHF, extensive edema and hypoalbuminaemia.

5.6 Pharmacological interventions

5.6.1 Reduce or remove any drugs, if possible, that may cause or contribute to dehydration such as diuretics, alcohol, excessive laxative use or lithium which also pose a risk.[5, 6]

5.6.2 Consider consultation with a pharmacist when drug-related dehydration problems are suspected such as: Dry mouth (antidepressants, antihistamines, anticholinergic), reduced thirst sensation (antipsychotics), greater sweating (venlafaxine, opioids), or sedation and reduction in judgment (benzodiazepines).[1, 6]

5.6.3 Assess risk of drug toxicity due to fluid loss, or if renal function reduces elimination of drugs or their metabolites.[3]

5.6.4 Adjust dose to accommodate reduced drug clearance, discontinue/taper drugs or switch to drugs more suitable for poorer renal function.

5.6.5 If reduced renal function review analgesics, psychoactive drugs, antibiotics, metoclopramide, gabapentin, digoxin, ACE inhibitors, and others.

5.6.6 Opioids such as morphine and

5.6.7 its metabolite, codeine, should be avoided in presence of kidney disease as they risk inducing toxicity appearing as myoclonus.[7]

5.6.8 There is mixed evidence supporting hydration and possible opioid rotation to improve myoclonus or delirium symptoms related to opioid toxicity.[1, 7]

5.6.9 Monitor patient performance status in dysphagia as medication routes capacity; routes and options may be actively changing when dehydration exists.

5.6.10 Update drug management to best control new or existing symptoms according to goals of care including:

5.6.10.1 Delirium, sedation, cognition – often distressing to families.[1, 3]

5.6.10.2 Nausea, fatigue, anorexia, dry mouth and thirst – as may occur often.

5.6.10.3 Hypotension, dizziness, diarrhea, sweating, constipation, fever (including neoplastic), infection, respiratory congestion, neuromuscular irritability, diabetes, heat-related illness.[8]

5.6.10.4 Overhydration contributes to edema, ascites, respiratory congestion.

5.6.10.5 Electrolyte management.

6. APPENDIX

6.1 Appendix One: Dehydration Assessment using Acronym O, P, Q, R, S, T, U and V.

6.2 Appendix Two: Dehydration extra resources or assessment tools

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Appendix One: Dehydration Assessment using Acronym O, P, Q, R, S, T, U and V

Onset	When did you start to feel dehydrated? Have you experienced it before?
Provoking / Palliating	What brought it on? What makes it better? What makes it worse?
Quality	What does it feel like (dry mouth / skin, thirst)? Can you describe it?
Region / Radiation	Where is it affecting or bothering you?
Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right Now? At Best? At Worst? On Average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?
Treatment	What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?
Understanding / Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and / or your family?
Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

Appendix Two: Dehydration extra resources or assessment tools

Artificial hydration (IV/SC fluids) during the dying phase: to use or not to use?[1,4,11,12,13,14]

Global Benefits of Artificial hydration (AH)	Global Burdens of Artificial Hydration (AH)
No strong evidence exists supporting the use of parenteral hydration for the majority of terminally ill patients; however, a subset of patients may derive some benefit.[11]	
May improve: • Circulation of drugs to relieve symptoms. • Skin turgor and reduce pressure sores (or not) • Alertness and fatigue.	May make death less 'natural', i.e., medicalized. Family may be less able to cuddle and get close with the pump/drip stand. Family may feel inhibited re closeness due to equipment.
May improve cognitive function if related to terminal agitation secondary to neurotoxicity. May prolong survival in specific, reversible causes such as hypercalcemia or opioid neurotoxicity.	May cause iatrogenic overhydration, leading to exacerbation of physical symptoms such as: pulmonary edema, ascites, vomiting, peripheral edema, respiratory congestion, restlessness from full bladder.
May reduce thirst in some patients (note: good mouth care usually does as good a job). Focus on managing dry mouth.	May deter patients from being at home.
Seems less like care providers are just letting the patient die (but remember, he or she is dying from the disease, not dehydration). Ask: who are we treating really—us, the relatives, or the patient?	Infusion set getting in the way of human touch. May encumber the patient's movement, mobility and closeness.
Specific to hypodermoclysis – subcutaneous (S/C) delivery	
S/C usage may avoid need for IV insertion or transfers to acute care setting. Can sometimes be administered in the home or residential care settings.	IV tubing, bags, fluid and S/C needles required.
No venipuncture skills required	
May enhance effectiveness of pain medication.	Potential for overhydration remains.
Can be administered slowly overnight; can administer low fluid volumes. Lower potential for iatrogenic overhydration than with IV hydration.	Not all residential care settings or community care services have capacity to administer.

Dehydration extra resources or assessment tools continued on next page

Specific to Intravenous delivery	
May improve clinical conditions secondary to	Venipuncture skills and equipment required. IV catheters/needles are painful and infusion sets are constraining. IVs are invasive and intrusive and can contribute to patient and family discomfort.
Can be administered in acute care and ER settings.	Transfer to acute care or ER may cause patient distress, discomfort and disruption to personal goals and wishes.
Most rapid response to dehydration: monitor closely.	May cause iatrogenic overhydration leading to exacerbation of physical symptoms such as: pulmonary edema, ascites, vomiting, peripheral edema, respiratory congestion, restlessness from full bladder.
While relatively large hydration volumes can worsen or lead to pleural effusion and/ or excess bronchial secretions, low volumes (<1000 mL daily) appear to be safely tolerated.[3]	

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CHAPTER 15
MANAGEMENT OF TWITCHING/ MYOCLONUS/ SEIZURES

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CHAPTER 15 :- MANAGEMENT OF TWITCHING/ MYOCLONUS/ SEIZURES

1. PURPOSE

1.1 To provide a guideline for identification, diagnosis and management of seizure in adult patients who are aged 14 years and older and have advanced life-threatening illness.

2. DEFINITIONS[3]

2.1 Twitching refers to an involuntary muscle contraction; it tends to be repetitive, unwanted, and lacking obvious cause.

2.2 Myoclonus is defined as involuntary single or irregularly repetitive movement of one part of the body associated with either brief, shock-like muscle contractions or jerks (positive myoclonus), or brief loss of muscle tone (negative myoclonus). Hiccough is a type of myoclonus. Myoclonus may precede onset of opioid-induced neurotoxicity.[33]

2.3 Opioid-induced neurotoxicity is due to the accumulation of toxic metabolites. Impaired renal function, dehydration and electrolyte imbalances contribute to this condition. It may cause myoclonus and seizures.[33]

2.4 Seizures may be varying in intensity and type and may include an absent stare, muscle rigidity, cyanosis, and an altered state of consciousness. They may last from 1-4 minutes.

2.5 Status epileptics is a seizure lasting 5 minutes or longer, or repeated seizures one after another without regaining consciousness.

3. PREVALENCE

3.1. Myoclonus occurs more commonly (2.8-87%) in patients on higher doses of opioids,1 or in the presence of renal failure2; however, causes can be multifactorial.

3.2. Seizures may be the first indication of a brain tumor. They occur in up to 50% of palliative patients with a primary brain tumour,[3] and in 20-45% of patients with brain metastases.[4,5]

4. ASSESSMENT

4.1. Twitching, myoclonus and seizures assessment: Interview the patient Using Mnemonic O, P, Q, R, S, T, U and V[32](see Appendix One).

4.2. Symptom Assessment: Physical assessment as appropriate for symptom

4.3. Diagnostics: consider goals of care before ordering diagnostic testing Degree of investigation depends on severity and goals of care, including desired location.[16] May reveal more than one cause.

4.3.1. CBC and biochemical tests may reveal reversible causes.

4.3.2. CSF culture for infectious causes.

4.3.3. Radiologic: CAT scan or MRI.

4.3.4. Electroencephalogram if suspect seizure activity, but may not be needed.[8]

4.4. Determine possible causes and reverse as possible if in keeping with goals of care

4.4.1. Identifying the underlying etiology of the myoclonus, twitching or seizures is essential in order to provide the appropriate treatment.[3,6]

4.4.2. Opioid-induced myoclonus is often misinterpreted as seizure activity by caregivers and clinicians.[1] This is important as myoclonus tends to respond to correction of the underlying reversible causes.[7]

4.4.3. Terminal delirium can also be misinterpreted as seizure.[1]

4.4.4. Impaired excretion of opioids and their metabolites may cause myoclonus.

4.4.5. Most prevalent in renal impairment with morphine, codeine, meperidine and, to a lesser extent, hydromorphone.[1] Liver impairment also a risk factor.[9] Methadone or fentanyl rarely cause myoclonic neurotoxicity.[1,7,10,11]

4.4.6. Drug causes are extensive and include: tricyclic antidepressants, serotonin reuptake inhibitors, anticonvulsants, ertapenem, pregabalin, trazodone, and levodopa.[12,13]

4.4.7. Assess for drug interactions that may contribute to neurotoxicity, e.g., from antipsychotics, antidepressants, and other central nervous system drugs.[13,14]

4.4.8. Fully review drugs recently introduced, discontinued, or dosing altered. Especially assess benzodiazepines, alcohol, opioids, anticonvulsants, smoking, caffeine, and complementary or alternative medicines.

4.4.9. Dehydration may be a contributing factor.[7]

4.4.10. Other causes may include: pinched nerve, nerve injury, stimulant abuse epilepsy, Parkinson's disease, amyotrophic lateral sclerosis, and benign fasciculation syndrome.[3]

4.5. Seizure:

4.5.1. Seizures may be caused by primary or metastatic brain tumours.[3]

4.5.2. Metabolic causes: hypoglycemia (most common metabolic cause), hyperglycemia, hyponatremia, renal or hepatic failure, and hypercalcemia.

4.5.3. Hypoglycemia can also be caused by prolonged seizure activity.[3]

4.5.4. A wide variety of other causes may be identified including stroke, sepsis or late onset epilepsy.

5. MANAGEMENT

5.1. General guidelines

5.1.1. When considering a management approach, always balance burden of a possible intervention against the likely benefit (e.g., does the intervention require transfer to another care setting?)

5.1.2. Lorazepam is the first-line for all 3 conditions.

5.1.3. Ensure patient safety and comfort during and following a seizure.

5.1.4. Twitching/myoclonus is frequently related to opioids and is often reversible.

5.1.5. Educate patient and family to discern between myoclonus and seizure activity, and to report to their health care team.

5.2. Non-pharmacological interventions:

5.2.1. Interventions available in the home and residential care facilities

5.2.1.1. General rules as follow:

5.2.1.1.1. Recognize that myoclonus or seizures can increase pain, fatigue, and other distressing symptoms. Follow-up assessment and appropriate intervention.[15]

5.2.1.1.2. Myoclonus generally responds to conservative treatment: correct dehydration and renal function, if possible; and reduction and/or rotation of opioid.[7,12]

5.2.1.1.3. Seizure treatment will vary according to the frequency and duration of convulsions, and whether there is a reversible underlying cause.[8]

5.2.1.1.4. Position HOB 30° above level of heart if increased cerebral pressure.[5]

5.2.1.2. Prevention/risk reduction.

5.2.1.2.1. Screen for recent history of recreational drug and alcohol use.

5.2.1.2.2. Review medication for those that reduce seizure threshold, or reduce effectiveness of current meds. Adjust medications and doses appropriately.[22,23] Monitor drug levels as required for patient status and location of care.

5.2.1.2.3. Prevent, monitor for, and minimize adverse effects.

5.2.1.3. Physiotherapy and occupational therapy.

5.2.1.3.1. Mobility and transfer safety. Referral for assessment, patient/family education and recommendations.[15]

5.2.2. Interventions that may require additional equipment or transfer to acute care

5.2.2.1. Environment – injury prevention and maintenance of airway during a seizure.

5.2.2.1.1. As per local seizure protocol.

5.2.2.1.2. Ensure potential aggressive treatments align with patient goals of care and consider patient status and location: hydration; intubation and transfer to ICU.[8]

5.2.3. Hydration

5.2.3.1. Consider for reversible causes of myoclonus2. Depends on patient status, goals of care, and care location Limited evidence of benefit. Requires further study.[17]

5.2.4. Surgical

5.2.4.1. Resection of lesion with clear margins has been successful in patients with primary, low grade brain tumors. Remission of seizures in 80% of patients.[18]

5.2.4.2. Careful consideration must be given to the life expectancy and appropriateness for patient.[15]

5.2.4.3. May allow eventual weaning from long-term anti-consultants after excision.[8]

5.2.5. Radiation Therapy

5.2.5.1. Seizure control can be improved in primary tumors when radiation therapy is offered early, even if no survival benefit.[19,20,21]

5.2.6. Oxygen

5.2.6.1. Status epileptics patients benefit from oxygen,[16] if available and if patient is NOT actively dying. Hypoxia is a risk with longer seizures and can result in significant impairment.

5.3. Pharmacological interventions

5.3.1. Lorazepam is a first-line therapy for twitching, myoclonus and seizures.

5.3.1.1. Advantages include: rapid onset, sustained duration of action, 85-89% response rate in tonic-clonic seizures, lower cardiorespiratory depression than diazepam, familiarity and availability throughout patient care settings.[1,2]

5.3.1.2. Use non-oral routes of administration often to ensure reliable effectiveness

5.3.2. Initial Management with Lorazepam[3]

Myoclonus/ Twitching	Partial Seizure	Tonic-Clonic Seizure	Status Epileptics
0.5 to 2 mg SL or SC Q4H PRN	1 to 2 mg SL or SC stat then 1 to 2 mg Q4H to Q6H	4 to 8 mg IV or SC stat, then 2 to 4 mg Q4H to Q6H	2 to 8 mg IV, SC or SL stat, then q10min to q20min until controlled

5.3.3. Management for Specific Symptoms Outlined in this Guideline

5.3.3.1. Twitching or Myoclonus Management

5.3.3.1.1. Stop the offending drug, whenever possible.[12, 24, 25] Often myoclonus gradually resolves in a few days.[2, 12, 24] Some medications require a gradually tapering to prevent complications, e.g., cardiovascular and central nervous system (CNS).[26]

5.3.3.1.2. Reduce the dose of the offending drug.1 Reduce opioid dose by 20-30%[11] or 30- 50% for high doses,[28] and reduce dosing interval as well with irreversible renal failure for renally excreted opioids.[13]

5.3.3.1.3. The benefit of a dose reduction over rotation may be less certain and only postpone the need to switch opioids.[25]

5.3.3.1.4. Do not use naloxone to treat opioid-induced myoclonus as it will not respond and may reverse control of other symptoms. [1,10,25,27]

5.3.3.1.5. Stop other non-essential medications.[6]

5.3.3.1.6. Switch (rotate) to a different opioid. If hyperalgesia accompanies the myoclonus, a switch is particularly helpful.[24]

5.3.3.1.7. Fentanyl or methadone are useful choices for experienced prescribers as both of these have minimal or no active neurotoxic metabolites.[1,10,24]

5.3.3.1.8. Maintain patient pain and symptom goals. Do not solely reduce opioid to control myoclonus.[24]

5.3.3.1.9. Consider use of non-opioid adjuvant analgesics, e.g., anticonvulsants, acetaminophen, and others.[29] Refer to Pain Management guideline.

5.3.3.1.10. Treat pharmacologically to resolve reversible causative metabolic abnormalities.

5.3.3.1.11. As evidence and topic management guidelines are not robust,[30] utilize further resources including palliative care physician consultants, medical specialists, or experienced multidisciplinary clinicians including clinical pharmacists.

5.3.3.2. Twitching or Myoclonus Drug Dosing

5.3.3.2.1. Choice of second-line anticonvulsants for management is uncertain. Benzodiazepines are commonly selected, in part based on suitability for patient setting, ease of administration, cost and familiarity. Options include:

5.3.3.2.1.1. Midazolam, 1 to 5 mg IV, SC, buccal PRN (especially in uremic induced).[20]

5.3.3.2.1.2. Clonazepam, starting at 0.5 mg orally once or twice daily.[13, 31]

5.3.3.3. Seizure Management

5.3.3.3.1. Avoid starting anticonvulsants prophylaxis in brain tumor patients (primary or metastatic) if the patient has never had any seizures, due to lack of benefit and risk of drug burden.[2,21]

5.3.3.3.2. Initiation of long-term anticonvulsants after a first time seizure may not be required.[8, 23]

5.3.3.3.3. Assess and provide treatment if high risk of reoccurrence, e.g., in brain metastases from melanoma, choriocarcinoma, renal cell carcinoma or thyroid papillary cancer.[21]

5.3.3.3.4. Review the current dose of corticosteroid; consider starting one adjunctively in those with intracranial tumor and seizure or scheduled cerebral radiotherapy.[23]

5.3.3.4. Seizure Drug Dosing

5.3.3.4.1. Review individual seizure type and tailor monotherapy anticonvulsant to patient.[27]

5.3.3.4.2. Midazolam via continuous subcutaneous infusion over 24 hours can be used[23]; however, review use and suitability with local palliative care team**.**

5.3.3.5. Status Epileptics Management

5.3.3.5.1. Status epileptics should be controlled even in the unconscious patient near death because of the distress that continuous seizures cause to the patient's family.[3]

5.3.3.5.2. First line: Lorazepam 2 to 8 mg IV or SC or SL STAT then q10 to 20 min until controlled. IV maximum infusion rate 2 mg per minute.[3]

5.3.3.5.3. Alternatively: Midazolam 5 to 10 mg IV, buccally, or Diazepam 10 to 20 mg IV or rectally.[3, 27]

5.3.3.5.4. Phenytoin 50 mg per min IV until seizure stops or maximum 20mg per kg per 24 hours.[3]

5.3.3.5.5. Valproic acid loading dose 20 mg per kg then 3 to 5 mg per kg per min infusion.[3]

5.3.3.5.6. Failing control: Phenobarbital 120 mg SC or IV and titrating to control.[3]

6. Patient and family education

6.1. Myoclonus is described as brief muscle jerks or spasms. They may appear before or during sleep. While common, they rarely need treatment. Help family members differentiate between myoclonus and seizure activity:

6.1.1. Increased frequency or intensity may indicate an underlying problem; instruct patient and family to inform the care team of any changes.

6.2. Seizures are frightening to the patient and family. Take time afterward to explore concerns of the patient and family, and offer honest reassurance.[23] Address questions,[3,16] dispel fears and maximize comfort.

6.3. Primary focus is on safety during and after seizures, medication use, eliminating the underlying cause if feasible and knowing when to contact the health care provider.[15]

6.4. Ensure alternate medication routes have been made available if needed and instruct patient's family on how to provide medication for active management.[8]

6.5. Do not attempt to restrain the person; loosen tight clothing around the neck.

6.6. Do not shout at the person or expect verbal commands to be obeyed.

6.7. Do not try to force anything into the patient's mouth. Do not give any fluids or food by mouth until the person has fully recovered consciousness.

6.8. When the seizure stops, turn the person onto his/her side until fully alert. Expect a period of sleepiness after the seizure.

6.9. If the patient has been driving or operating machinery, they may not continue until cleared by a physician.

6.10. Contact your health care provider for additional support if needed (during office hours).

6.11. Call after hours Help Line if available in your region, as needed.

7. APPENDIX

7.1. Appendix One: Twitching, myoclonus and seizures assessment using Acronym O, P, Q, R, S, T, U and V

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Appendix One: Twitching, myoclonus and seizures assessment using Acronym O, P, Q, R, S, T, U and V

Mnemonic Letter	**Assessment Questions** *Whenever possible, ask the patient directly. Involve family as appropriate and desired by the patient.*
Onset	*When did it begin? How long does it last?* *How often does it occur?*
Provoking /Palliating	What brings it on? What makes it better? What makes it worse? Have you recently started any new medications or treatments?
Quality	What does it feel like? Can you describe it? How do you feel afterwards?
Region/Radiation	Does your entire body move? Is the movement only in a part of your body? Ask family or caregivers to describe what happens.
Severity	How severe is this symptom? What would you rate it on a scale of 0-10 (0 being none and 10 being the worst possible)? Right now? At worst? On average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?
Treatment	What medications and treatments are you currently using? Are you using any non-prescription treatments, herbal remedies, or traditional healing practices? How effective are these? Do you have any side effects from the medications and treatments? What have you tried in the past? Do you have concerns about side effects or cost of treatments? Have you recently changed a dose or type of treatment? Have you stopped or started alcohol or other substances?
Understanding	Understanding What do you believe is causing this symptom? How is it affecting you and/or your family? What is most concerning to you?
Values	What overall goals do we need to keep in mind as we manage this symptom? What is your acceptable level for this symptom (0-10)? Are there any beliefs, views or feelings about this symptom that are important to you and your family?

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CHAPTER 16
Management of Terminal Secretions and Congestion

المجلس الصحي السعودي
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CHAPTER 16 :- Management of Terminal Secretions and Congestion in Palliative Care

1. STATEMENT OF PURPOSE

1.1 To provide guidelines for identification, diagnosis and management of terminal secretions and congestion in adult patients who are aged 14 years and older and have advanced life-threatening illness.

2. DEFINITIONS

2.1 **Airway secretion.** Refers to mucus secreted by the submucosal glands and goblet cells. The airway secretion can accumulate due to increased production, decreased mucociliary clearance and ineffective cough reflex.

2.2 **Death rattle (Terminal secretion):** Refers to a sound produced by someone who is close to death when fluids such as salvia and bronchial secretions pool in the throat and upper chest. It is a strong predictor of death; 48% of patients with terminal secretions will die within 24 hours and 76% within 48 hours of onset .

2.3 **Congestion Type I:** Refers to salivary secretions accumulating when swallowing reflexes are inhibited.

2.4 **Congestion Type II:** Refers to bronchial secretions which cannot be coughed up or swallowed.

3. GENERAL GUIDELINES:

3.1 All admitted palliative patients aged 14 years and older experiencing secretions and congestion shall be assessed, diagnosed and managed by a Physician.

3.2 Physicians shall identify underlying cause(s) of terminal secretions and congestion and treat them appropriately.

3.3 Physicians shall provide education to patient and family about terminal secretions and congestion.

3.4 If a patient with terminal secretions is not responsive enough to be interviewed then the Physician shall make his/her own observations and interview the family.

4. ASSESSMENT AND MANAGEMENT:

4.1 Interview the patient if possible using acronym O, P, Q, R, S, T, U and V (see Appendix One: Terminal Secretions/Congestion Assessment using Acronym O, P, Q, R, S, T, U and V).

4.2 Conduct physical assessment.

4.3 Review medication.

4.4 Conduct medical and surgical review.

4.5 Conduct psychosocial and physical environment review.

4.6 Obtain or request for appropriate diagnostic tests.

4.7 Determine the location/source of increased airway fluid as follows.

4.7.1 Oropharyngeal secretions (saliva): known as Congestion Type I is fluid accumulation that occurs when the patient's swallowing reflex is inhibited and he/she is near death.

4.7.2 Tracheo-bronchial secretions (normal mucous production): known as Congestion Type II is fluid accumulation that occurs over several days as the patient deteriorates and their ability to cough weakens.

4.7.3 Non-respiratory secretions (aspiration, blood, exudates, tumour debris).

4.8 Determine the cause of any decrease in the patient's airway diameter noting that any narrowing will result in increased resistance and turbulence:

4.8.1 Due to Edema.

4.8.2 Due to smooth muscle hypertrophy.

4.8.3 Due to intrinsic or extrinsic compression.

4.9 Assess the patient's ventilatory rate noting any manifestation of::

4.9.1 Tachypnea

4.9.2 Altered, rapid breathing patterns

4.10 Educate patient and family that the patient suffers from congestion.

4.10.1 Note do not use terms such as "death rattle", drowning and suffocation.

4.11 Prepare the family by reviewing the changes they can expect, in the patient's condition, as death approaches.

4.12 Manage patient with terminal secretions and congestion non-pharmacologically as follows:

4.12.1 Prevent aspiration by repositioning the patient:

4.12.1.1 Move the patient from supine to lateral recumbent with head slightly raised to encourage drainage, maintain a patent airway and decrease pooling of secretions.

4.12.2 Perform suctioning noting the following:

4.12.2.1 While it may seem to the family that suction should help, most secretions are usually below the larynx and inaccessible to suction.

4.12.2.2 Routine use of suctioning in the hospital setting is discouraged.

4.12.2.3 The exception to this is fulminant pulmonary edema (copious "frothing") or thick inspissated mucous, blood or other fluid in the throat or mouth as suctioning may be of value in these situations.

4.12.3 Provide good mouth care.

4.12.4 Avoid over hydration especially in lung cancer patients.

4.13 Manage patient with terminal secretions and congestion pharmacologically as follows:

4.13.1 Prescribe Anti-cholinergics as they reduce both saliva and mucus production.

4.13.1.1 Use at the first sign of congestion as anti-cholinergics do not dry up secretions that are already present.

4.13.2 Prescribe Atropine 0.4 mg to 0.8 mg subcutaneously every 4hours and every 1hour prn.

4.13.3 Note there is anecdotal evidence (as an alternative route to subcutaneous for non-admitted patients) to support use of Atropine eye drops 1 to 2 drops every 1 hour to 2 hours prn. sublingually or via the buccal route.

4.13.4 Prescribe Scopolamine (Hyoscine Hydrobromide) 0.3 mg to 0.6 mg subcutaneously every 4 hours to 6 hours regularly and/or prn.

4.13.5 Prescribe Scopolamine transdermal patch 1 mg every 72hours.

4.13.5.1 Note the onset of action for a Scopolamine transdermal patch is slow thus it is not indicated in terminal phase unless augmented with subcutaneous route for 8 hours to 12 hours.

4.13.6 Prescribe Glycopyrrolate 0.1 mg to 0.2 mg subcutaneously every 6 hours to 8 hours regularly and/or prn. It may also be given orally and sublingually.

5. APPENDIX

5.1 Appendix One: Terminal Secretions/Congestion Assessment using Acronym O, P, Q, R, S, T, U and V

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Appendix One: Terminal Secretions/Congestion Assessment using Acronym O, P, Q, R, S, T, U and V

Onset	When did it begin? Can the secretions be cleared by coughing or swallowing? How often do they occur?
Provoking Palliating	What brings it on? What makes it better? What makes it worse? Is it positional?
Quality	What does it sound like?
Region / Radiation	Where are the secretions? Throat? Chest?
Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right Now? At Best? At Worst? On Average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?
Treatment	What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?
Understanding / Impact on You	What does the person / family believe is causing this congestion? How is this symptom affecting the family? Is the person distressed?
Values	What is the family goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

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CHAPTER 17
MANAGEMENT OF COUGHING

المجلس الصحي السعودي
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CHAPTER 17:- MANAGEMENT OF COUGHING

1. PURPOSE

1.1 To provide a guideline for identification, diagnosis and management of cough in adult patients who are aged 14 years and older and have advanced life-threatening illness.

2. DEFINITIONS

2.1 **Cough.** Is an act/function used to prevent foreign material entering the lower respiratory tract and to clear secretions from the lungs and bronchial tree..

3. GENERAL GUIDELINES

3.1 All admitted palliative patients aged 14 years and older experiencing the symptom of coughing shall be assessed, diagnosed and managed by a Physician.

3.2 Physicians shall be aware that when a cough becomes chronic it can be the source of sleep disturbance, agitation or anxiety and becomes exhausting.

3.3 Physicians shall note that 86% of patients with advanced life-threatening illness experience the symptom of coughing.

3.4 Physicians shall treat coughing both non-pharmacologically and pharmacologically.

4. PRACTICE GUIDELINES

4.1 Assess the patient with a cough including.

4.1.1 Interview the patient using acronym O, P, Q, R, S, T, U and V (see Appendix One: Cough Assessment using Acronym O, P, Q, R, S, T, U and V).

4.1.2 Conduct physical assessment

4.1.3 Review medication(s).

4.1.4 Conduct medical and surgical review.

4.1.5 Conduct psychosocial and physical environment review.

4.1.6 Obtain or request for appropriate diagnostic tests.

4.2 Identify the underlying causes (see Appendix Two: Underlying Causes of Cough & Treatment of Choice) and treat as appropriate noting that:

4.2.1 In management, the treatment of reversible causes where possible and desirable and in accordance with care goals.

4.2.2 While underlying cause(s) may be evident, treatment may not be indicated/ dependent upon the stage of the disease.

4.2.3 Whether or not the underlying cause(s) can be relieved or treated, all patients will benefit from their cough being managed by use of education and/or medications.

4.3 Provide education to patient and family:

4.3.1 Explain to the patient/family that coughing can be distressing to experience and often more difficult to witness. Providing patient/family education regarding the etiology of cough and expectations of treatment is foundational to enhancing their ability to cope.

4.3.2 Help the family to understand as a person weakens, their ability to raise sputum is reduced.

4.3.3 Teach the patient 'huffing or forced expiratory technique' to clear secretions with minimal effort.

4.4 Manage patient with a cough non-pharmacologically as follows:

4.4.1 Position the patient to promote and facilitate secretion drainage (postural drainage), but note that this should not be used during acute exacerbation of chronic bronchitis.

4.4.2 Advise patient to avoid smoking, chemical irritants and/or noxious fumes.

4.4.3 Prescribe nebulized saline, steam or cold air humidifier.

4.4.4 Ensure patient receives adequate hydration.

4.4.5 Suction is not indicated except in the following situations:

4.4.5.1 When acute fulminant pulmonary edema is present.

4.4.5.2 To clear bronchial secretions in patients with tracheostomy.

4.4.5.3 To clear saliva when full esophageal obstruction is present.

4.4.5.4 When bleeding is present in mouth or throat.

4.4.6 Provide instruction in anxiety reduction strategies.

4.5 Manage patient with a cough pharmacologically as follows:

4.5.1 Prescribe Dextromethorphan (non-opioid) 15 mg to 30 mg PO QID for mild to moderate cough.

4.5.2 Consider using any of the following for advanced disease/ a multi-factorial cough as appropriate by case/ condition:

4.5.2.1 Prescribe Methadone 2.5 mg to 10 mg PO. Methadone is a powerful antitussive and has activity superior to those of Morphine and Codeine. Taking it 2 hours before bed is recommended for troublesome night cough.

4.5.2.2 Prescribe Hydromorphone 1 mg to 2 mg PO every 4 hours.

4.5.2.3 Prescribe Hydrocodone 5 mg to 10 mg PO every 4 hours to 6 hours with a daily dose no higher than 60 mg. It has greater antitussive activity than Codeine but less than Morphine.

4.5.2.4 Prescribe Morphine up to 5 mg PO every 4 hours.

4.5.2.5 Prescribe Codeine 10 mg to 20 mg PO every 4 to 6 hours, with a daily dose no higher than 120 mg.

4.5.2.6 Prescribe Oxycodone 5 mg every 4 hours or 10 mg PO sustained-release Oxycodone every 12 hours.

4.5.2.7 Prescribe Dexamethasone 4 mg to 8 mg PO or I.V. or subcutaneously daily depending on severity and cause; taper and avoid long term use if possible (increased risk of proximal myopathy which can be very debilitating).

4.5.3 Consider using nebulized local anesthetics for an intractable cough.

4.5.3.1 Prescribe Bupivacaine 0.25% in 5 mL every 4 hours.

4.5.3.2 Prescribe Lidocaine 2% in 2 to 5 mL in 1 mL of normal saline every 4 hours.

4.5.3.3 But note that:

4.5.3.3.1 They may precipitate bronchospasm in asthmatic patients.

4.5.3.3.2 The gag reflex is inhibited after administration so:

4.5.3.3.2.1 The patient must be kept NPO for 1 to 2 hours afterwards.

4.5.3.3.2.2 The patient must be advised to rinse and spit after nebulization in order to minimize numbness of the lips and tongue.

4.5.3.3.2.3 A mouthpiece rather than a mask must be used for the inhalation.

5. APPENDIX

5.1 Appendix One: Cough Assessment using Acronym O, P, Q, R, S, T, U and V.

5.2 Appendix Two: Underlying Causes of Cough & Treatment of Choice

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Appendix One: Cough Assessment using Acronym O, P, Q, R, S, T, U and V

Onset	When did it begin? How long does it last? How often does it occur?
Provoking / Palliating	What brings it on? What makes it better? What makes it worse?
Quality	What does it feel like? Can you describe it? Is it positional?
Region / Radiation	What areas are involved in your cough? Throat? Chest?
Severity	What is the intensity of this symptom (On a scale of 0 to 10, with 0 being none and 10 being worst possible)? Right Now? At Best? At Worst? On Average? Are there any other symptom(s) that accompany this symptom?
Treatment	What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?
Understanding Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and/or your family?
Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

Appendix Two: Underlying Causes of Cough & Treatment of Choice

Underlying Cause	Treatment of Choice
Amyotrophic Lateral Sclerosis (ALS)	Scopolamine, Atropine or Glycopyrrolate to reduce secretions to normal and comfortable moisture levels
Bronchospasm/Bronchiectasis	Bronchodilators, antibiotics
Chronic Obstructive Pulmonary Disease (COPD)/Asthma	Conventional inhalers, nebulized drugs or saline, steroids to suppress inflammation
Congestive Heart Failure	Conventional medications to decrease excess fluid
End stage weakness	Suppress and settle with suppressant, anxiolytic, Scopolamine or Atropine
Gastroesophageal reflux	H2 inhibitors, proton pump inhibitor, motility agents, elevate head of bed, drain contributing ascites
Infection – Pneumonia	Prevention of aspiration. Oral antibiotics may help decrease productive cough that is disturbing sleep, or causing pain or hemoptysis
Malignant pleural effusion	Thoracentesis or pleurodesis; lying on the same side can decrease related cough
Medications	Stop offending ACE inhibitor
Post radiation lung damage	Steroids
Superior Vena Cava (SVC) Obstruction	Radiotherapy, steroids
Tumour related airway irritation	Radiotherapy/brachytherapy, laser treatment, self-expandable stents or steroids
Upper airway cough syndrome (Postnasal drip) – allergies, infection, sinusitis	Nasal steroids or ipratropium. Oral antibiotics for sinusitis, expectorants (Guaifenesin) or anti-histamine

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CHAPTER 18
MANAGEMENT OF ASCITES

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CHAPTER 18:- MANAGEMENT OF ASCITES IN PALLIATIVE CARE

1. STATEMENT OF PURPOSE

1.1 To provide a guideline for the identification, diagnosis and management of ascites in adult patients who are aged 14 years and older and have advanced life-threatening illness.

2. DEFINITIONS

2.1 **Ascites:** Is the accumulation of fluid within the peritoneal cavity.

2.2 **Diuretic:** Is any substance that promotes the production of urine. This includes forced diuresis. There are several categories of diuretics. All diuretics increase the excretion of water from bodies, although each class does so in a distinct way.

2.3 **Octreotide:** Is an octapeptide that mimics natural somatostatin pharmacologically, though it is a more potent inhibitor of growth hormone, glucagon, and insulin than the natural hormone.

2.4 **Paracentesis:** Is a form of body fluid sampling procedure in which the peritoneal cavity is punctured by a needle to sample peritoneal fluid.

3. GENERAL GUIDELINES

3.1 All admitted palliative patients aged 14 years and older experiencing the symptom of ascites shall be assessed, diagnosed and managed by a Physician.

3.2 Physicians shall identify the underlying cause(s) of ascites and treat them appropriately.

3.3 Physicians shall note the following in relation to ascites:

3.3.1 Ascites may develop in 15% to 50% of patients with malignancies.

3.3.2 Ascites due to cirrhosis is usually a sign of advanced liver disease and generally has a fair prognosis with a 3-year survival rate of about 75%.

3.3.3 Ascites due to heart failure has a fair prognosis as patients may live years with appropriate treatments.

3.4 Physicians shall consider the fact that in most cases of malignant ascites the prognosis is poor. Research shows that, dependent upon the type of malignancy, a mean survival time of between 20 to 58 weeks can be expected. .

4. ASSESSMENT AND MANAGEMENT

4.1 Utilize the following forms of assessment for a patient with ascites.

4.1.1 Interview the patient using acronym O, P, Q, R, S, T, U and V (see Appendix One: Ascites Assessment using Acronym O, P, Q, R, S, T, U and V).

4.1.2 Conduct physical assessment.

4.1.3 Review medication.

4.1.4 Conduct medical and surgical review.

4.1.5 Conduct psychosocial and physical environment review.

4.2 Obtain or request appropriate diagnostics:

4.2.1 Abdominal radiography – ascites may demonstrate a 'ground glass appearance'.

4.2.2 Ultrasound or CT scan – it may be required to demonstrate small volumes of free peritoneal fluid.

4.2.3 Diagnostic paracentesis – it may be required to elucidate the type of ascites and should be done on newly diagnosed cases of ascites.

4.3 Identify the causes of ascites such as:

4.3.1 Cirrhosis – is the predominant cause in 80% of cases. It presents as transudative ascites (ascitic fluid protein concentration of less than 2.5g/dl).

4.3.2 Malignancy – causes 10% of cases. They are mostly (80%) epithelial related ovarian, uterus, breast, colon, gastric and pancreatic however the remaining 20% have tumours of primary unknown origin. The fluid produced in malignancy is exudative (ascitic fluid protein concentration of greater than 2.5g/dl).

4.3.3 Heart failure – is responsible for 3% of cases. The fluid produced is transudative.

4.3.4 Renal related – 3%, tuberculosis, 2%, pancreatitis, 2% and 1% miscellaneous

4.4 Identify types of ascites as follows:

4.4.1 Raised hydrostatic pressure – caused by cirrhosis, congestive heart failure, inferior vena cava obstruction and hepatic vein occlusion.

4.4.2 Decreased osmotic pressure – caused by protein depletion (nephrotic syndrome, protein-losing enteropathy), reduced protein intake (malnutrition) or reduced protein production (cirrhosis).

4.4.3 Fluid production exceeding resorptive capacity – caused by infection or neoplasms.

4.4.4 Chylous – due to obstruction and leakage of the lymphatics draining the gut.

4.5 Discuss with the patient and family treatment methods for ascites and the value of paracentesis when the patient becomes symptomatic.

4.6 Manage patient with ascites non-pharmacologically as follows:

4.6.1 Observe appropriately, if the condition is asymptomatic including measuring the abdominal girth at a marked site each week as well as appropriately scheduled weight measurement.

4.6.2 Perform paracentesis by draining ascitic fluid via a catheter inserted through the abdominal wall.

4.6.2.1 Note: This may be achieved under ultrasound guidance or in an outpatient setting for quick relief of symptoms. Generally, upwards of 5 litres of fluid may be removed with little risk of hypotension or hypovolemic shock when patient screening is applied. Intravenous hydration should be considered if the patient is hypotensive, dehydrated or known to have severe renal impairment and paracentesis is still indicated. If there is leakage over the paracentesis site an ostomy bag can be applied. Single or repeated paracentesis in patients with advanced cancer does not significantly lower serum protein.

4.6.3 Use peritoneal catheters (smaller bore catheter) when ascites is rapidly accumulating and requiring frequent paracentesis for symptom control.

4.6.3.1 Note this significantly exposes the patient to the risk of peritonitis and is usually reserved for patients in the terminal phase of their illness, with a prognosis of weeks.

4.6.4 Use radiation therapy and chemotherapy in cases where a meaningful response to tumour growth may be expected, such as lymphoma.

4.6.5 Ensure salt restriction where fluid is transudative, but may also provide relief in patients with cancer and hepatic metastases.

4.6.6 Advise a low fat diet and increase in medium-chain triglyceride intake as it may be useful in patients with chylous ascites.

4.7 Manage patient with ascites pharmacologically using diuretics treatment as follows:

4.7.1 Use of diuretics in all patients has to be evaluated individually. Patients with malignant ascites due to massive hepatic metastases seem to respond better to diuretics than those with malignant ascites due to peritoneal carcinomatosis or chylous ascites.

4.7.2 Consider diuretics for patients with portal hypertension (hepatic metastases, heart failure and cirrhosis) and should be tried in most patients, after their first abdominal paracentesis, as approximately one-third of patients are shown to benefit.

4.7.3 Evaluate goal of diuretic therapy which is achieved when patient's weight loss is 0.5 to 1 kg per day.

4.7.4 Prescribe Spironolactone 100 mg daily titrated slowly to 400 mg daily.

4.7.4.1 Note: titrate to remove enough fluid for comfort.

4.7.5 Prescribe Furosemide 40 to 120 mg daily adding to Spironolactone to improve the effect and prevent hypokalemia.

4.7.5.1 Note Furosemide given by continuous infusion is reported to produce significant diuresis and marked relief of ascites.

4.7.6 Monitor electrolytes, renal function, drug interactions and blood pressure when utilizing diuretics

4.8 Manage patient with ascites pharmacologically using Octreotide treatment as follows:

4.8.1 Prescribe Octreotide 200 to 600 micrograms subcutaneously daily divided into two-three doses as this has found beneficial in cases of ascites refractory to paracentesis.

5. APPENDIX

5.1 Appendix One: Ascites Assessment using Acronym O, P, Q, R, S, T, U and V.

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Appendix One: Ascites Assessment using Acronym O, P, Q, R, S, T, U and V

Onset	When did it begin? How often does it occur?
Provoking / Palliating	What brings it on? What makes it better? What makes it worse?
Quality	What does it feel like? Can you describe it? Have you noticed weight gain?
Region / Radiation	Where is the pressure? Is it spreading?
Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right Now? At Best? At Worst? On Average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom? Nausea/vomiting, loss of appetite, pain?
Treatment	What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?
Understanding / Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and/or your family?
Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

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CHAPTER 19
ORAL CARE IN PALLIATIVE CARE

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CHAPTER 19:- ORAL CARE IN PALLIATIVE CARE

1. STATEMENT OF PURPOSE

1.1 To provide a guideline for the identification, diagnosis and management of adult patients (age 14 years and older) who have advanced life-threatening illness and are experiencing oral/mouth problems.

2. RELATED DOCUMENTS

2.1 CMG, Management of Anorexia & Cachexia in Palliative Care.

2.2 CMG, Management of Gastrointestinal Diseases in Palliative Care.

3. DEFINITIONS

3.1 **End of Life:** Is defined as a phase of life when a person is living with an illness that will worsen and eventually cause death. It is not limited to the short period of time when the person is moribund.

4. GENERAL GUIDELINES

4.1 All admitted palliative patients aged 14 years and older experiencing oral problems shall be assessed, diagnosed and managed by a Physician.

4.2 Noting that oral complications can significantly affect the patient's morbidity, ability to tolerate treatment, and overall quality of life. Physicians shall perform the following in order to prevent and decrease oral complications:

4.2.1 Assess patients for significant risk factors that are associated with the development of oral complications.

4.2.2 Provide early interventions and care for any oral problems.

4.3 A systematic approach to oral care shall be followed in order to reduce the amount of microbial flora, reduce pain and bleeding, prevent infection and reduce the risk of dental complications.

4.4 Physicians shall aware that at end of life patients have decreased cognitive ability, extreme fatigue and weakness which may contribute to their ability to clear secretions from their nose, mouth and/or throat.

4.5 Physicians shall ensure that patient's nutritional needs are well managed.

4.6 Physicians shall educate patient/family regarding good oral care in order to prevent oral complications and encourage them to cooperate in the treatment of any related oral problems.

5. ASSESSMENT AND MANAGEMENT

5.1 Assess patient for presence of signs and symptoms of oral complications including:

5.1.1 Cavities, bleeding, infections, ulcerations and abnormal lesions.

5.1.2 Taste changes and difficulty with opening/closing of the mouth, Dysphagia, Stomatitis – inflammation of the oral cavity causing pain/soreness, Xerostomia (dry mouth), Candidiasis, and Denture problems.

5.2 Assess patient for the following symptoms of impaired mucosa:

5.2.1 Discomfort of the mucosa and tongue such as burning, soreness with or without the presence of ulcers (that can be caused by chemotherapy, radiation therapy, leukemia, malnutrition, decreased immunity, infection).

5.2.2 Difficulty with chewing food, swallowing and speech.

5.2.3 Taste alterations due to medications, treatment (chemotherapy and/or radiation therapy), or disease process.

5.2.4 Difficulty with dentures.

5.3 Perform an oral examination assessing for:

5.3.1 Dryness (note the presence/absence of saliva).

5.3.2 Candidiasis.

5.3.3 Oral ulceration of mucus membranes, gums, beneath dentures, edge of tongue.

5.3.4 Dry, cracked lips or vesicles (consider herpes simplex)

5.3.5 Proper fit of dentures.

5.4 Consider significant risk factors for the development of oral complications including.

5.4.1 Type of cancer, type of cancer treatments, cumulative doses of chemotherapy or radiation treatment, method of delivery and duration of treatment.

5.4.2 Predisposing medical, dental and lifestyle factors as they may increase the severity of the complications.

5.5 Provide general oral care non-pharmacologically as follows:

5.5.1 Help patient/family to understand that good oral care is fundamental in preventing and decreasing oral complications and has the potential to modify the acute and long term sequel of therapy.

5.5.2 Help patient/family to understand that the major purposes of oral care are to maintain normal function of the oral tissues, to maintain comfort, and to reduce the risk of bleeding, local infection and systemic infection.

5.5.3 Make a uniform systematic education plan for oral care to help patients understand and cope with symptoms of oral complications.

5.5.4 Assess patient's nutritional status, including adequacy of oral solid and fluid intake.

5.5.5 Help patient/family to keep oral mucosa and lips, clean, soft, moist and intact to prevent infection.

5.5.6 Encourage patient/family to perform good dental care.

5.5.7 Instruct patient to rinse mouth with a bland fluid or prescribe Magic Mouth Wash 5ml three times daily to immediately neutralize the mouth and minimize tooth enamel demineralization

5.5.8 Instruct patient to chew xylitol gum or suck on xylitol lozenges up to 6 grams (i.e. 6 lozenges) a day.

5.6 Provide education to patient/family and consider the following factors for oral care at patient's end of life;

5.6.1 Explain to patients/families early and as often as necessary the etiology of mouth complications, determine the goals of care, clarify the declining health status and determine desired levels of care pertaining to nutrition, hydration and interventions.

5.6.2 Help patient/family understand that as end of life approaches the objective of oral care is to avoid complications, treat potentially reversible conditions rapidly and/or provide relief of symptoms caused by the offending oral complication.

5.6.3 Help patient/family understand that the oral cavity should be evaluated at least daily.

5.7 Provide pharmacological interventions by prescribing analgesics:

5.7.1 Oral analgesic regularly to allow for more thorough tooth brushing when patients have continuous pain (e.g., moderate to severe oral mucositis).

5.7.2 Oral opioid analgesics preferably to be administered sixty (60) minutes before brushing.

5.7.3 Two-five (2-5) mls topical anesthetics (e.g., viscous Lidocaine 2% or viscous Xylocaine 2 %,) to be applied ten (10) minutes before eating. Up to a maximum of 6 times per day, to

allow for adequate hydration, nutrition and oral care, for cognitively intact head and neck cancer patients receiving radiation therapy.

5.7.3.1 Note can be used as an alternative to oral analgesic by applying one (1) hour prior to eating.

5.7.3.2 Note that if topical anesthetics are used only for rinsing, without swallowing, then the recommended maximum dose of viscous Lidocaine 2% is 60 ml per day.

5.7.3.3 Dyclonine 0.5% to 1% (5 ml every 6-8 hours, swish and swallow as needed) if patient is allergic to Lidocaine.

5.8 Provide pharmacological intervention by prescribing medications to control excessive secretions:

5.8.1 Tricyclic antidepressants (e.g., Nortriptyline) are a consideration, starting at a low dose and titrating to effect, for excessive salivary secretions.

5.8.2 Scopolamine transdermal 1.5 mg patch every 72 hours.

5.9 Prescribe the following for patients who have decreased cognitive ability, extreme fatigue and weakness and are unable to clear secretions from their nose, mouth and/or throat;

5.9.1 Anticholinergic medications for managing excessive secretions at end of life.

5.9.2 Atropine 1% ophthalmic solution administered sublingually, 1-2 drops (1 drop ~ 0.5 mg) every four (4) hours PRN.

5.9.3 Ipratropium 0.03% nasal spray administered intranasally or sublingually, two (2) sprays at bedtime.

5.9.4 Scopolamine 0.2 mg to 0.8 mg subcutaneously every two - four (2-4) hours PRN.

5.9.5 Glycopyrrolate 0.2mg to 0.6 mg subcutaneously every two - four (2-4) hours PRN

5.9.6 Buscopan (Hyoscine Butylbromide) 10 mg subcutaneously every four (4) hours PRN.

6. APPENDIX

6.1 Appendix One: Management for Other Mouth Diseases in Adults

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Appendix One: Management for Other Mouth Diseases in Adults

A. Oral Mucositis	
Non-pharmacological Management	➢ Advise use of ice chips for the prevention of oral mucositis. ➢ Treat head and neck cancer patients to minimize intra-oral complications using IMRT as the treatment of choice for it. ➢ Advise use of Low Level Laser Therapy as it may reduce the incidence of oral mucositis and its associated pain, in patients receiving high-dose chemotherapy or chemo-radiotherapy before Hematopoietic Stem Cell Transplant (HSCT). ➢ Consider intake of a multivitamin to prevent nutritional deficiencies. ➢ Help family/patient to choose food texture as tolerated and modify as required. ➢ Help family/patient to start with soft, moist, smooth foods; if not tolerated try extra soft/pureed foods. ➢ Help family/patient to choose high calorie, high protein fluids every 2 hours if only liquids are tolerated. ➢ Help family/patient to choose foods high in calories and protein, 6-8 small meals/snacks daily. ➢ Help family/patient to cook solid foods until tender, use moist sauces, choose soft, bland foods. ➢ Avoid foods that irritate the mouth or throat. ➢ Avoid eating foods which are abrasive, rough, tart, salty, spicy, acidic, very hot or very cold. ➢ Use oral commercial nutritional supplements if necessary. ➢ Use Vitamin B12, beta-carotene calcium, chamomile, glutamine, or curcumin in the treatment of oral mucositis as an optional choice. ➢ Use a regular strength multivitamin if oral intake is inadequate for a prolonged period. ➢ Place a feeding tube or total parenteral nutrition (TPN) depending on the patient's goals of care for severe oral mucositis during cancer treatment (grade 3 or 4). ➢ Note that the type of tube (i.e., gastrostomy or jejunostomy) and the method of placement (i.e., surgical or radiological) should be determined by the degree and extent of mucositis and the potential worsening of symptom due to planned cancer treatment. ➢ Consult dietitian if possible.

B. Xerostomia

	➢ Use parotid sparing Intensity Modulated Radiation Therapy (IMRT) for prevention of salivary gland hypofunction and xerostomia in head and neck cancer patients. ➢ Help family/patient ensure their nutritional status is well managed as follows: ➢ Add extra moisture to foods, increase fluid consumption. ➢ Oral rinses may improve swallowing/taste problems. ➢ Soft, mild tasting food is often better tolerated. ➢ Moisten food by adding sauces, gravy, butter, dressings, broth or another liquid. ➢ Food and drinks should be cold or tepid. ➢ Plain ice cubes, sugar-free popsicles, sugar-free gum, frequent sips of cold water or mouth sprays may increase fluid consumption and help cool and moisten mouth. ➢ Avoid foods, fluids and other items which may dry or irritate mouth and teeth, including highly acidic foods and fluids, foods high in sugar, caffeine and alcohol. ➢ Advise patient/family to use regularly of fresh, lightly acidic fruits, slices of cold cucumber and tomato or thin slices of cold apples - to stimulate residual salivary secretion and to ameliorate the condition of the mucosa for patients who are not experiencing mucositis. ➢ Advise patient/family to use of milk, jelly, sherbet, applesauce and ice cream. ➢ Advise use of Acupuncture as it is a possible intervention for the treatment of radiation-induced xerostomia in patients with a residual functional capacity of the salivary glands and is a treatment modality without serious adverse effects. ➢ Consider use of artificial saliva products, it may also be considered for a brief course to determine effectiveness and patient acceptability, followed by continuing therapy when warranted.
Pharmacological Management	➢ Prescribe Oral Pilocarpine (Sialogogue) 5mg TID following radiation therapy in head and neck cancer patients for improvement of xerostomia. ➢ Prescribe as optional the use of Pilocarpine HCl as it has in some patients a beneficial effect on xerostomia.
Dysgeusia Non-pharmacological Management	➢ Help family/patient ensure their nutritional status is well managed as follows As taste changes are unique to each person and can vary over time, an individualized approach needs to be taken to identify tolerable foods. Ongoing follow up is recommended. ➢ To prevent compromised food intake, patients may need encouragement and support to try foods again that may have resulted in food aversions secondary to taste changes. ➢ Encourage patients to enjoy foods that taste good.

	➢ Encourage patients to experiment with food flavours to enhance taste. ➢ Encourage patients to drink plenty of fluids. ➢ Encourage patients to avoid strong smells. ➢ Nutritional counseling is recommended.
Pharmacological Management	➢ Prescribe Zinc Gluconate and/or Amifostine for the prevention of dysgeusia in head and neck cancer patients.
C. Intra-Oral Infections	
Pharmacological Management	➢ Prescribe/Advice to use Clotrimazole lozenges or sugarless Nystatin suspension as first-line therapy for the management of mild oropharyngeal candidiasis. ➢ Prescribe/Advice to use Sugarless Nystatin suspension 100,000 units/ml as follows: ➢ Swish around and hold in the mouth for at least one minute, then swallow; use 5 ml 4 times a day for 7-14 days (works by direct contact). ➢ Soak dentures overnight in sugarless Nystatin 100,000 units/ml solution or use sugarless Nystatin 100,000 units/ml cream to treat dentures. ➢ Prescribe to use Clotrimazole oral suspension (one (1)mg/ml) as follows: ➢ Swish around the mouth for one minute and then swallow; use 10 mL 4 times a day. ➢ Advise to proceed with the use of systemic agents if topical agents are not well tolerated. ➢ Prescribe Fluconazole as it has been found to be very effective in the prevention of clinical oral fungal infections and in reducing oral fungal colonization in patients receiving cancer therapy. ➢ Prescribe Prophylactic Fluconazole 100 mg PO daily (for prevention of oral candidiasis in cancer patients. ➢ Prescribe Itraconazole or Posaconazole, with Voriconazole and Amphotericin B reserved for refractory fluconazole cases. ➢ Prescribe/Advice to use topical agents for the management of mild intra-oral fungal infection due to the lower risk of side effects and drug interactions (e.g., sugarless Nystatin rinse). ➢ Prescribe additional systemic agents includinglipid formulations of Amphotericin B, and the Echinocandins (Caspofungin, Anidulafungin, and Micafungin). ➢ Note that the use of these systemic agents may be limited by their side effects, especially for Amphotericin B for short durations of treatment.

D. Bacterial infections	
Pharmacological Management	➢ Prescribe Amoxicillin 500 mg PO every eight (8) hours for seven - ten (7-10) days as first line medication. ➢ Prescribe Penicillin V 300-600 mg PO every six (6) hours for seven - ten (7-10) days and/or Clindamycin 300-450 mg PO every 6h for 7-10 days as an alternative medication. ➢ Prescribe Amoxicillin/ clavulanic acid (Clavulin®): 500 mg tablet (contains amoxicillin 500 mg and Clavulanic Acid 125 mg) PO every eight (8) hours OR the 875 mg tablet (contains Amoxicillin 875 mg and Clavulanic Acid 125 mg PO every 12 hours for 7-10 days. ➢ Note that if one is certain that the infection is periodontal in origin then the recommendation for first line therapy is Metronidazole 500 mg PO every eight (8) hours for 7-10 days
E. Viral infections (e.g. Herpes simplex)	
Pharmacological Management	➢ Prescribe/Advice to apply Topical Acyclovir to affected area every three – four (3-4) hours, for a total of six (6) times/day for seven (7) days (apply a sufficient quantity to adequately cover all lesions). ➢ Prescribe Acyclovir 200 mg PO every four (4) hours, five (5) times/day for ten (10) days or 400 mg PO TID for seven-ten (7-10_ days (in immunocompromised patients, consider 400 mg PO every four (4) gours five (5) times/day for ten (10) days) for primary Herpes Simplex Virus (HSV). ➢ Prescribe Acyclovir 200 mg PO every four (4) hours five,(5) times/day for 5 days; Valacyclovir 500 mg PO BID (twice daily) or every 12 hours for three (3) days for recurrent HSV
F. Varicella-zoster	
Pharmacological Management	➢ Prescribe Acyclovir 400 mg PO five (5) times/day for seven - ten (7-10) days. ➢ Prescribe Acyclovir 5 mg (base) per kg body weight IV (over at least 1 hour) every eight (8) hours for five-seven (5-7) days for severe infection. ➢ Reduce dose (e.g., Acyclovir 200 mg PO every 12 hours when Creatine clearance is 0-10 mL/min) for acute or chronic renal impairment patients: • Valacyclovir 1000 mg PO TID for seven (7) days (superior to Acyclovir for post-herpetic infections). • Ganciclovir: induction: 5mg/kg IV over 1 hour every 12 hours, maintenance: 5

	mg/kg IV over one hour once per day • Ganciclovir in patients with severe neutropenia (ANC less than 500/μL) or severe thrombocytopenia (platelets less than 25,000/μL) or severe anemia (hemoglobin less than 80 g/L).

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CHAPTER 20
PSYCHOSOCIAL CARE

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CHAPTER 20:- PSYCHOSOCIAL CARE IN PALLIATIVE CARE

1 STATEMENT OF PURPOSE

1.1 To provide a guideline for assessing and addressing psychosocial issues in adult patients who are aged 19 years and older and have advanced life-threatening illness.

2 RELATED DOCUMENTS

2.1 CPP 1430-60, Allow Natural Death Order.

2.2 CMG 30104/092/36, Management of Fatigue in Palliative Care.

2.3 CMG 30104/095/36, Management of Depression in Palliative Care.

3 DEFINITIONS

3.1 **Advance Care Planning.** Is an on-going process of reflection and communication in which a capable adult makes decisions with respect to future health care in the event that they become incapable of giving informed consent. The process should be placed in the context of one's values and beliefs and involve discussions with health care providers and significant others with whom the person has a relationship.

3.2 **Burnout.** Is a process in which one's attitudes and behaviour change in negative ways in response to job strain arising out of work environment triggers such as frustration, powerlessness and an inability to achieve work goals.

3.3 **Coping.** Refers to unique and personal strategies used to manage stressful situations that could be perceived by others as being positive or negative.

3.4 **Comfort Care.** Refers to both a philosophy of care and a program of services aimed at relieving suffering and improving the quality of life for persons who are living with, or dying from, a life limiting illness or who are bereaved.

3.5 **Compassionate Fatigue**. Refers to emotional residue of exposure to working with those who suffer. Natural consequent behaviours and emotions resulting from knowing about a traumatizing

event experienced by a significant other, the stress resulting from helping or wanting to help a traumatized or suffering person.

3.6 Complicated Grief. Is marked by the presence of symptoms such as intrusive thoughts of the deceased, yearning and/or searching for the deceased and excessive loneliness since the death, experienced daily or to a marked degree, for at least 6 months, causing clinically significant impairment in social, occupational or other areas of functioning.

3.7 Culture. Is not a single variable but is comprised of multiple variables, affecting all aspects of experience. It is inseparable from economic, political, religious, psychological and biological conditions. Cultural processes frequently differ within the same ethnic or social group because of differences in age cohort, gender, political association, class, religion, ethnicity and even personality. It is highly desirable for health care providers to be sensitive to cultural difference by engaging in an on-going process of exploring the patient's lived experience of an illness, trying to understand the illness as the patient understands, feels, perceives and responds to it.

3.8 Cumulative grief. Is the occurrence of multiple deaths, either at the same time or in serial fashion. This often occurs in a hospital unit or hospice residence, and may lead to bereavement overload, or what has been called cumulative grief. Cumulative grief is the caregiver's emotional response when there is no time or opportunity to completely or adequately grieve for each person who has died.

3.9 Disenfranchised grief. Is when a person experiences a sense of loss but does not have a socially recognized right, role or capacity to grieve.

3.10 Family. Is a term that is used to describe those who are closest to a patient. It is not exclusive to those who are related by blood or by marriage. It is a term used to describe someone that a patient considers to be "like" a family member, regardless of blood relations.

3.11 Life Review. Is a progressive return of the memories of past experience in search of meaning and in striving for emotional resolution.

3.12 Quality of Life. Refers to an acceptable, if not desired, state of living that suggests fulfilment for an individual. Quality of life is individually defined by each patient.

4 GENERAL INSTRUCTIONS

4.1 Health care providers shall provide effective, compassionate and comprehensive end-of-life care and develop a level of comfort with death and dying.

4.2 Health care providers shall provide psychosocial support for the patient and their family

4.3 Health care providers shall reflect and have awareness of their own issues, attitudes, feelings, values and beliefs, both personal and professional, regarding death and dying.

4.4 Health care providers shall have adequate coping skills to deal with working with patients and families at end of life as providing care to palliative patients and their families can be stressful and emotionally draining.

4.5 It is essential that health care providers have the ability to identify the impact of their work, engage in efforts to recognize and address any negative consequences and utilize skills to clarify and identify the source of any "burnout" or "cumulative grief". This can be done through a combination of self-reflection, education about the effects of caring, development of effective coping skills, and the creation of a work culture that supports self-care. It may mean taking more time for us or debriefing with a trusted co-worker about a specific patient.

4.6 In order to provide comfort, to the patient and his/her family, Health care providers must gain an understanding of the factors that the patient considers adds quality to his/her life.

4.7 The psychosocial assessment shall be focused more on the significance and functioning of the patient in relationship to themselves, others and their environment noting that:

4.7.1 The assessment is not a diagnosis: a psychosocial assessment is an empowering and ongoing collaborative process of moment by moment interactions that begins upon first contact.

4.7.2 An effective assessment is guided by theories rooted in cognitive and behavioural therapy, ego-psychology, family systems and social sciences.

4.7.3 A goal of psychosocial care is to support and assist patients and their families in achieving a peaceful awareness of death, life that has been lived and life as it is by helping to sustain meaning.

4.7.4 It is the groundwork for planning interventions, addressing needs, assisting with informing decision-making, facilitating care planning and delivery as well as contributing towards team functioning.

4.8 Psychosocial interventions shall be implemented with specific goals in mind and should involve health care providers with specialized knowledge and skills, such as Social Workers, Spiritual Counselors and Psychologists. The aim of any psychological intervention is to guide patients through either wellness or towards a comfortable existence or to teach them how to detach themselves from life.

4.9 Health care providers shall explore internal and external resources for the psychosocial management of patients noting that:

4.9.1 Internal resources can include resiliency, having awareness of one's limitations and being able to express them and having an ability to cope.

4.9.2 External resources can include tapping into a patient's supportive network, if one exists, such as: family, friends, organization and/or spiritual affiliations, work colleagues. It may include connecting with new resources to assist with coping e.g. counseling, spiritual care, and massage and/or therapeutic touch.

4.10 Health care providers shall enhance the existing strengths of the patient and family. Through the assessment, staff can identify the history and current functioning of the patient and their family, areas of strength, competence and skill and discuss and explore ways that these strengths can be maximized.

4.11 Health care providers shall familiarize themselves with patient and family strengths and make sure they understand their role in supporting optimal patient and family functioning.

4.12 Health care providers shall assist with patient/family decision making, identification of patient's goals of care and end of life plans. If they experience difficulty in ascertaining information, asking patients' what is most meaningful to them or what their biggest fears can help prioritize needs.

4.13 Health care providers shall demonstrate teamwork noting that palliative care is delivered optimally when there is collaborative involvement of all members of the interdisciplinary team.

4.14 Health care providers shall include the patient and/or family in all discussions relating to the provision of patient care.

4.15 Health care providers shall advocate for the needs, choices, decisions and rights of patients and families in palliative and end of life care. Advocacy shall address clinical and social issues that are affecting the life of the patient and foster human dignity and self-worth.

4.16 Health care providers shall note that the utilization of community resources can play an integral part in the stabilization and/ or maintenance patient and/or family function. Social Workers are often familiar with existing resources in the community as it relates to housing, financial benefits, guardianship for children, , and other means that can provide support and guidance for families.

4.17 Health care providers shall express an intention to bring a respectful, nonjudgmental presence to the dying while liberating them from self-imposed or popular expectations to say or do the right thing.

4.18 Health care providers shall be active listeners; listening and talking to patients is one of the key tasks in palliative care. Active listening is a valuable skill because it enables us to demonstrate that we understand what another person is saying, through empathy, and how he or she is feeling about it. Additionally, it also allows the health care provider to check whether their current understanding is correct. Active listening does not mean the same as agreement but rather a demonstration that you intend to hear and understand another point of view.

4.19 Health care providers shall discuss common and expected outcomes and responses to situations as this can help decrease anxiety about the unknown, apprehension about what "comes next" and for minimize the common response that their feelings are not "healthy".

4.20 Health care providers shall create a safe space for the "telling of their story"; a life review can be an effective way of allowing a person to have closure in their life, review life's accomplishments and/or achievements, highlight unresolved issues, and provide an opportunity for forgiveness of self and others.

4.21 Health care providers shall conduct family meetings; a family meeting can be an effective way to allow all members of the family to be heard and understood, allow for observations of relationships among family members and provide a forum to voice and acknowledge feelings. It is important to prepare for family meetings and to decide, often with the patient, who should be there and who

should facilitate. In the presence of family conflict, the family should do most of the talking as the aim is to help them solve the problem, not to solve it for them.

4.22 Health care providers shall have an obligation to provide patients and families with accurate information about their disease, prognosis, treatment and/or care options (to the degree desired by patient and family). It is not their responsibility to ensure that hope is realistic.

4.23 Health care providers shall foster & explain hope and never give false assurances.

4.24 Health care providers shall understand a patient's culture as it will help them appreciate how he/she experiences and expresses pain, maintains hope in the face of a poor prognosis, makes end-of-life care decisions, and responds to illness, treatment, grief and loss.

4.25 Health care providers she be aware that they are likely to care for persons with very different explanatory models about illness, as well as different expectations about care and views regarding death.

4.26 Health care providers shall disclose to the dying patient the seriousness of his/her diagnosis.

4.27 Health care providers shall talk about dying openly.

4.28 Health care providers shall remember to ask questions which elicit the patient's own perspective toward their illness and expectations for care. They shall offer to make all information available to the patient first, but allow her or him to decide.

4.29 Health care providers shall help the patient's family to provide children with information and support in healthy meaningful ways that respects their experience of grief.

4.30 Health care providers shall provide education, guidance and support to all of the adult caregivers involved with the children, for their own grief as well as for understanding the developmental stages of children as it relates to grief, loss, intellectual and emotional limitations.

4.31 Health care providers shall be aware that typical concerns expressed by the patient/family include fears around the dying process, contemplation of an afterlife, and other existential issues. In particular statements made by patients, that they have a desire to hasten their death, may only be a request to be heard and understood.

4.32 Health care providers shall engage in meaningful communication when responding to a patient's statement of a desire to die by: inquiring about the patient's emotional state, conveying a willingness to talk about their distress, and helping them to identify their motivations for the request to die. The very fact that there is communication and expression of wanting to die, suggests the expectation of an interaction with the physician or health care team. The approach to respond to patients, who express a desire to hasten their death, should be guided by a principle that seeks to understand, rather than to act.

4.33 Through a thorough assessment, a health care provider should ascertain if the patient is an immediate threat to themselves or to others. Health care providers must be careful not to stigmatize their thoughts as suicide but to provide validation of a patient's distress and a commitment to respond to their suffering.

4.34 Health Care providers shall provide a process that supports the continuous evaluation of interventions and outcomes to ensure that needs are clearly identified and

responded to as effectively as possible. Monitoring the efficacy of selected interventions and the progress towards stated goals of care can:

4.35.1 Enhance and assure consistent quality of care.

4.35.2 Recognize successes.

4.35.3 Indicate when a redirection of efforts may be needed.

4.35.4 Assure that health care providers remain accountable to patients.

4.35.5 Facilitate hope.

4.35.6 Help patients mark the completion of important end of life tasks.

4.35 Healthcare providers shall ensure that a collaborative process for assessing and reassessing interventions is performed as this recognizes patients and families as "their own best experts" and actively seeks their guidance and feedback.

4.36 Evaluation processes shall also include the use of open-ended interviews, formal assessment tools to monitor pre-and-post intervention changes and clinician self-reflection.

4.37 Healthcare providers shall note that feedback, from the evaluation of outcomes for a specific patient, may identify themes, issues or patterns on a global level that can be useful in looking at program policies and procedures for working with the palliative population.

5. PROCEDURES

5.1 Provide effective, compassionate and comprehensive end-of-life care and develop a level of comfort with death and dying.

5.2 Improve & maintain self-care as a coping process by using the following ideas:

5.2.1 Deal with your emotions; allowing yourself to deal with emotions, whether they are up or down, is a part of the healing process.

5.2.2 Drink water; dehydration occurs when we are under stress of any kind. This can affect our energy level, etc.

5.2.3 Eat healthy; this is difficult when you don't feel like eating. When you are stressed, your appetite is affected.

5.2.4 Enlist the support of others

5.2.5 Create a personal coping kit; based on what gives you energy; put together a kit. This kit may contain pictures, mementos, videos, letters, crossword puzzles, a good book, magazines, etc.

5.2.6 Write down your thoughts; a journal is one way of sorting through your experiences. Sometimes ideas and thoughts run around in your mind and it is hard to get a handle on what really is happening for you.

5.2.7 Utilize your sense of humor; as it will help carry you through this stressful time. Laughter creates a release of tension and releases endorphins into the system to give you a sense of wellbeing.

5.2.8 Take time out; take breaks to allow your body time to rejuvenate. Take short walks, get some fresh air, even if only for 5 minutes at a time. A change of scenery gives you a break from the intensity of the situation and can give you renewed energy to continue to be present.

5.3 Provide psychosocial support for the patient and their family which is aimed at enhancing their overall well-being, strengthening their skills and abilities and using their resources for overcoming challenges:

5.3.1 Explore internal and external resources.

5.3.2 Explore external resources include tapping into patient's supportive network.

5.3.3 Enhance the existing strengths of the patient and family.

5.3.4 Become familiar with patient and family strengths and make ensure you understand your role in supporting optimal patient and family functioning.

5.3.5 Assist with decision making.

5.3.6 Demonstrate teamwork.

5.3.7 Include patient or family, as they desire, in discussions regarding provision of patient care

5.3.8 Advocate for the needs, choices, decisions and rights of patients and families in palliative and end of life care.

5.3.9 Utilize community resources as they play an integral part in stabilizing and/ or maintaining functioning of a patient and/or family.

5.3.10 Express an intention to bring a respectful, nonjudgmental presence to the dying while liberating them from self-imposed or popular expectations to say or do the right thing.

5.3.11 Be an active listener.

5.3.12 Discuss common and expected outcomes and responses to situations.

5.3.13 Create a safe space that allows the patient to "tell their story".

5.3.14 Conduct family meetings.

5.3.15 Provide patients and families with accurate information about their disease, prognosis, treatment and/or care options.

5.3.16 Articulate a dynamic process that shifts from hope for a cure to:

5.3.16.1 Hope for survival.

5.3.16.2 Hope for comfort.

5.3.16.3 Hope for the energy to keep going.

5.3.16.4 Hope for dignity.

5.3.16.5 Hope for intimacy, reconciliation with what gives the patient meaning for the remainder of his/her life.

5.3.16.6 Hope for a better day or better moments.

5.3.16.7 Hope for a peaceful death.

5.3.16.8 Hope that surviving family will not suffer after patient's death.

5.3.16.9 Hope for an afterlife.

5.3.17 Foster hope by:

5.3.17.1 Being authentic.

5.3.17.2 Facilitating caring relationships.

5.3.17.3 Using humour and play.

5.3.17.4 Encouraging determination and courage.

5.3.17.5 Assisting patients and families to establish short-term, attainable goals.

5.3.17.6 Supporting spirituality.

5.3.17.7 Engaging in reminiscing.

5.3.17.8 Being physically present in crisis.

5.3.17.9 Listening attentively.

5.3.17.10 Managing pain and other symptoms.

5.3.18 Understand patient's culture so it helps you to appreciate how individuals experience and express pain, maintain hope in the face of a poor prognosis, make end-of-life care decisions, and respond to illness, treatment, grief and loss.

5.3.19 Understand that you will care for persons with very different explanatory models about illness, as well as different expectations about care and views regarding death.

5.3.20 Disclose to the dying patient the seriousness of his/her diagnosis.

5.3.21 Talk openly about dying with the patient

5.3.22 Ask questions which elicit the patient's own perspective toward their illness and expectations for care. Offer to provide all available information to the patient but allow her or him to first decide how much they want to receive.

5.3.23 Help family to provide children with information and support in healthy meaningful ways that respects their experience of grief.

5.3.24 Provide education, guidance and support for adults who are involved in the care of the patient's children, for their own grief and to increase their understanding of the developmental stages of children as it relates to grief, loss, intellectual and emotional limitations.

5.3.25 Engage in meaningful communication when responding to a patient's statement of a desire to die by: inquiring about the patient's emotional state, conveying a willingness to talk about their distress, and helping them to identify their motivations for the request to die.

5.3.26 Note the following suggested questions and phrases that can be used in for response to a patient expressing a desire to die:

5.3.26.1 Explore the patient's current feelings and/or fears - "Sometimes people feel so overwhelmed by things that they feel everything is just 'too much'. Would you say that you have felt that way?"

5.3.26.2 Assess their state of suffering and distress (physical, emotional, spiritual) - "What do you feel could be improved in your care and treatment?"

5.3.26.3 Explore their specific reasons and plan for suicide, if present - "Have you thought about or decided how you would end your life?, "If we could relieve the problem, would you still be interested in ending your life?"

5.3.26.4 Explore further their reasons when seeking health care provider assistance with hastening death - "Can you tell me how you've come to feel like this and why you want to take this action?"

5.3.27 Evaluate the interventions and outcomes of all care provided to ensure that patient needs are clearly identified and responded to as effectively as possible.

6 RESPONSIBILITIES

6.1 **Interdisciplinary Palliative Care team: 6.1-6.4**

7 APPENDIX

Not Applicable

8 REFERENCES

8.1 Symptom Guidelines, Psychosocial Care in Palliative Care. Hospice Palliative Care Program. [Date Accessed: 15 September 2019]Available online at : http://www.fraserhealth.ca/media/psychosocial%20care.pdf

8.2 Alberta Hospice Palliative Care Resource Manual Second edition (2001) Division of Palliative Care Medicine University of Alberta. [Date Accessed: 15 September 2019] Available online at: http://www.palliative.org/NewPC/_pdfs/education/ACB%20Hospice%20Palliative%20Manual.pdf

المجلس الصحي السعودي
Saudi Health Council

CHAPTER 21
PALLIATIVE SEDATION THERAPY

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CHAPTER 21:- PALLIATIVE SEDATION THERAPY

1. STATEMENT OF PURPOSE

1.1 To provide guidelines when considering palliative sedation, as a treatment for intractable symptoms during the last days of life, in patients who are aged 14 years and above.

2. RELATED DOCUMENTS

2.1 Do not resuscitate (DNR)

2.2 Cancer Pain Management.

2.3 Management of Delirium in Palliative Care.

2.4 Management of Dyspnea in Palliative Care.

2.5 Management of Gastrointestinal Diseases in Palliative Care.

3. DEFINITIONS

3.1 **Palliative Care:** Is defined by the World Health Organization as "an approach that improves the quality of life of patients and their families facing the 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, psychosocial and spiritual.

3.2 **Refractory Symptoms:** Are physical and emotional symptoms for which all possible treatments have failed, or it is determined that no methods are available for palliation within the time frame and the risk-benefit ratio that the patient can tolerate. Often geography and the relative availability of interventions influence the determination of refractoriness.

3.3 **Suffering:** Is a sense of helplessness or loss in the face of a seemingly relentless and unendurable threat to quality of life or integrity of self. Although pain, dyspnea, delirium, nausea and vomiting are frequent causes of suffering at the end of life, hopelessness, remorse, anxiety, loneliness, and loss of meaning also cause suffering. Suffering involves the whole person in physical, psychological, and spiritual ways and can also affect family, friends, and caregivers.

3.4 **Existential Suffering (also "Psychic" or "Spiritual" Suffering):** Describes the experience of patients facing terminal illness who may or may not have physical symptoms but report distress that is related to the meaninglessness in present life, hopelessness, being a burden on others,

feeling emotionally irrelevant, dependant, isolated or grieving, that is unrelated to a psychiatric disorder or social isolation. Existential distress specifically develops as a result of facing one's own mortality.

3.5 **Moral Distress:** Occurs as an emotional and spiritual response when an individual is obligated to act in a manner which breaches their personal belief and value system and/or arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action.

3.6 **Natural Sedation or drowsiness:** Occurs as part of the dying process. Progressive drowsiness or sedation is expected and occurs as part of reduced consciousness leading through coma to death. This is due to a combination of renal/hepatic/septic/neurologic processes resulting in body shutdown.

3.7 **Consequential (ordinary/mild) Sedation:** Is the unintended but predictable adverse effect of some drugs used for symptom control in patients who are not actively dying. This type of sedation may be transient and is often reduced or eliminated with dose adjustment, or as tolerance develops. Brief periods of sedation may be used in the general management of pain, dyspnea or delirium. This is not palliative sedation therapy.

3.8 **Respite Sedation (intermittent):** Is intended to be temporary. The patient is sedated, then awakened after an agreed upon period (usually 24-48 hours) to assess whether or not the symptom remains refractory. The practice of respite sedation recognizes that either a symptom might respond to continued or future therapy or that the patient's ability to tolerate the symptom may be improved following the rest and stress reduction provided by sedation.

3.9 **Family:** Is a term that is used to describe those who are closest to a patient. It is not exclusive to those who are related by blood or by marriage. It is a term used to describe someone that a patient considers to be "like" a family member, regardless of blood relations.

3.10 **Assisted Suicide:** Is the act of intentionally killing oneself with the assistance of another who provides the knowledge, means, or both. In Physician Assisted Suicide, the other person is a physician.

3.11 **Physician Assisted Suicide:** Means knowingly and intentionally providing a person with the knowledge or means or both required to commit suicide, including counseling about lethal doses of drugs, prescribing such lethal doses or supplying the drugs.

3.12 **Euthanasia:** Means knowingly and intentionally performing an act that is explicitly intended to end another person's life and that includes the following elements: the subject has an incurable illness; the agent knows about the person's condition, and commits the act with the primary intention of ending the life of that person.

3.13 **Do not resuscitate (DNR):** Refers to a written consultant order that prohibits Cardio-Pulmonary Resuscitation (CPR) to a patient who suffers sudden cardiac and/or respiratory arrest. (i.e. No bag-mask ventilation, no Intubations, no chest compression, no code medications, and no defibrillation).

3.14 **End-of-life care.** Is the term used for the range of clinical and support services appropriate for dying people and their families. The goal of end-of-life care is the same regardless of the setting – to ensure the best possible quality of life for dying people and their families".

3.15 **Palliative Sedation Therapy (PST):** Is the intentional lowering of a patient's level of consciousness in the last days of life. It involves the proportional and monitored use of sedative medications to relieve intolerable suffering from refractory symptoms by a reduction in patient consciousness. The patient experiences symptom relief until death occurs by the natural course of the underlying disease, usually within hours to days.

4. GENERAL GUIDELINES

4.1 Palliative Sedation Therapy (PST) shall be an infrequent and extraordinary intervention that shall only be performed by caregivers with the necessary expertise and communication skills..

4.2 PST shall only be performed when:

4.2.1 All possible treatments have failed

4.2.2 No methods are available for palliation within an acceptable time frame

4.2.3 The symptom is determined to be refractory.

4.3 Physicians shall note that the most common refractory symptoms are: delirium, dyspnea, pain, nausea and vomiting.

4.4 Physicians shall determine if the criteria for a refractory symptom is met by asking the following questions regarding possible interventions, time frame and tolerability:

4.4.1 Are further interventions capable of providing adequate relief?

4.4.2 Are interventions likely to provide relief within a tolerable time frame?

4.4.3 Will the intervention itself increase physical or emotional suffering?

4.5 Physicians shall use the Latimer Ethical Decision Making Model (see Appendix Three: Latimer Ethical Decision Making Model) for assessing whether or not PST should be considered:

4.5.1 Patient's Illness - extent of disease, prognosis, and nearness to death

4.5.2 Patient's experience - symptom intensity, impact on quality of life, suffering, demoralization, and lack of dignity.

4.5.3 Patient as a person - goals, hopes, and plans in light of current symptom, and wishes as contained in an advance care plan (if one has been completed).

4.6 A decision to initiate palliative sedation must be preceded by a comprehensive interdisciplinary assessment of the patient and a discussion about treatment expectations and options in order to ensure that all possible options have been explored. Such comprehensive assessment and meeting shall be done and documented by interdisciplinary palliative care team.

4.6.1 Interdisciplinary palliative care team shall include but not be limited to Palliative Care Physicians, Nurse CSC, Psychologist, Psychiatrist, Physical Therapist, Occupational Therapist, Social Worker, Case Manager, Dietician, Health Educator, Spiritual Counsellor.

4.7 Interdisciplinary palliative care team shall document a summary of the discussion(s) and care plan in patient's medical record.

4.8 Family and/or proxy shall be integrated into the plan of care as much as possible by conducting a family meeting.

4.9 The patient's primary physician shall be involved in the decision to initiate palliative sedation. The patient's physician and the palliative care consultant must agree on the decision to implement palliative sedation.

4.10 The reason for PST (i.e. the refractory symptom) must be compelling enough to place the person at risk of catastrophic consequences (i.e. the possibility that their life may be shortened)

4.11 A written consent for palliative sedation shall be obtained from the patient or proxy decision-maker. A discussion of the risks and benefits of palliative sedation will be part of the informed consent process. The decision must be based on whether the adult demonstrates that he or she:

4.11.1 Understands the information being given about his or her health condition

4.11.2 Understands the nature of the proposed health care, including the risks, benefits and alternatives and

4.11.3 Understands that the information applies to his or her situation

4.12 Physicians must adhere to the following conditions when considering PST for the patient:

4.12.1 The patient must be terminally ill and near death with no hope of recovery.

4.12.2 Refractory symptoms must be present.

4.12.3 Death must be imminent i.e. the patient must have an illness that does not have any realistic possibility for recovery and where death is expected within hours to days (and definitely within two weeks).

4.12.4 The patient or his/her proxy decision-maker must have expressed an informed wish for palliative sedation therapy to be initiated.

4.12.5 The patient or his/her proxy decision-maker must be in agreement with the expected outcome of his/her/the patient's illness and the goal of care must be comfort.

4.12.6 Do not resuscitate (DNR), order must be in effect.

4.12.7 Pain management must be maintained.

4.12.8 An interdisciplinary team must be involved in the completion a comprehensive assessment and determining the plan of care. The discussion must be documented.

4.12.9 The criteria for palliative sedation, including the rationale used to determine that the symptom is refractory, must be documented in the patient's medical record.

4.12.10 Palliative sedation must be initiated and monitored by those with expertise in symptom management or under guidance of those with advanced palliative care skills.

4.13 Before discussing PST, the primary physician or other Health Care professional shall first determine whether the patient has an appointed proxy decision maker. Previously expressed wishes or instructions must be followed and carried out through consent by the proxy decision maker(s).

4.14 The Chairman of Palliative Care Department or any in authority shall appoint someone or act as proxy him/herself if no one is available or there is conflict about who should be the proxy.

4.15 A family meeting shall be conducted if conflicts or disagreements arise relative to initiation of palliative sedation.

4.16 The care team shall confirm that the patient's decision is not being affected by psychological or social pressure.

4.17 The patient's Consultant or Palliative Consultant shall write the order for palliative sedation.

4.18 Once the patient is sedated, medications must not be increased unless there is evidence of renewed distress. A lowering of the dose of the sedatives may be attempted at the discretion of the physician, or at the request of the patient's representative.

4.19 Decrease in sedatives shall be initiated if the patient experiences heavy snoring or an abrupt onset of apnea. Gradual deterioration of respiration is expected in terminal patients and should not alone constitute a reason to decrease sedation.

4.20 Sedation shall not be attempted by increasing opioid dosages; however, opioids shall be continued at the previous level in order to ensure pain management and to prevent opioid withdrawal.

4.21 A registered nurse shall assess the patient continuously, monitoring for any adverse effects, during initiation of therapy and every one-hour until the dose is adjusted to a stable dose.

4.22 An organized debriefing session(s) shall be facilitated by an experienced social worker, clinical counselor, psychologist or spiritual care practitioner once PST has been initiated

4.23 The care team shall conduct family meetings, at set times during and after sedation has been initiated, in order to update them and provide a forum for empathetic discussion.

5. ASSESSMENT AND MANAGEMENT

5.1 Assess patient and ascertain if his/her symptoms are refractory.

5.2 Assess the patient for any conditions which may benefit from psychiatric consultation.

5.3 Determine if the criteria/conditions for implementing PST are met.

5.4 Consider the Latimer Ethical Decision Making Model (see Appendix Three: Latimer Ethical Decision Making Model) for assessing whether or not PST should be initiated.

5.5 Involve all members of the interdisciplinary team providing care for the patient.

5.6 Involve the patient and proxy in plan of care and decision making.

5.6.1 Give the patient an opportunity to specify who s/he would like to be present at the meeting, and don't make assumptions about who should or shouldn't be there.

5.6.2 Inform the patient/family/proxy of what to expect, reassure about expected changes in their loved one's condition, what practical things they can do while their loved one is sedated, and provide opportunities to express their emotions.

5.7 Conduct a family meeting with all relevant family/loved ones and health care professionals and complete the following:

5.7.1 Review the patient's condition, explore options and support the patient and family in finding meaning in the dying process.

5.7.2 Elicit patient's values, beliefs and goals from patient, family and proxy decision maker(s).

5.7.3 Determine preferences for information and involvement in decision making.

5.7.4 Refer to previous discussions or advance care planning documentation if patient, family or proxy is unable to participate.

5.7.5 Advise patient, family and proxy that there is no chance of recovery and life expectancy is very limited.

5.7.6 Discuss therapeutic options, including potential benefits and risks

5.7.7 Ensure the patient, family and/or proxy clearly understand that the intent of PST is comfort and symptom management, not hastening death.

5.7.8 Remind the proxy decision maker of their duty to uphold the patient's wishes, or to express what is known about the patient's previously expressed preferences if necessary.

5.7.9 Provide support to family members/proxies who are finding it difficult to make critical decisions for a loved one.

5.7.10 Agree on the goals of care and proportionality of PST.

5.7.11 Elicit any practical and/or ethical/moral concerns of the team regarding use of PST in the particular circumstance.

5.7.12 Consider the needs of all those involved in choosing the time for initiating sedation, whenever possible.

5.8 Document a summary of the discussion(s) in patient's medical record as follows:

5.8.1 The people involved in the decision making.

5.8.2 The information provided.

5.8.3 The decision made.

5.8.4 Record the patient's expressed wishes, in his or her own words, as much as possible, or refer to prior documented conversations between the patient and other healthcare worker(s).

5.8.5 Ensure that the informed consent for PST has been given by the patient or proxy decision maker.

5.9 Write a summary of the plan in patient's medical record as follows:

5.9.1 If "No PST" is desired, document the agreed upon care plan.

5.9.2 If the plan is "No PST", or "Wait and See", determine when this decision might be reviewed.

5.9.3 Document the plan in relation to:

5.9.3.1 Timing of PST initiation.

5.9.3.2 Medical orders for sedation and for concurrent therapies, as needed.

5.9.3.3 Hydration/Nutrition.

5.9.3.4 Plan for managing foreseeable events

5.9.3.5 Anticipate possible crises, and how they will be managed.

5.10 Develop a plan. If the plan is "For PST", consider and plan for:

5.10.1 Timing the initiation of sedation, consider the physical, emotional and physical needs of patient and family

5.10.2 Sedation that is proportional to the symptom distress/requirement for symptom relief

5.10.3 Whether to provide artificial hydration

5.10.4 Need for Foley catheter, continued bowel care

5.10.5 Concurrent medications for control of other symptoms

5.10.6 How to support family and staff if the patient does not die within the expected time frame

5.10.7 Whether the sedation therapy will be discontinued or reversed after a period of time

5.11 Appoint someone or act as proxy decision maker if no one is available or there is conflict about who should be the proxy.

5.12 Obtain a signed Do not resuscitate (DNR): order.

5.13 Comfort and support the patient's family and friends, who play an important role both when palliative sedation is being considered and while it is being carried out.

5.13.1 Communicate with the patient's family using language they can understand.

5.14 Ask family members of information about the well-being of the patient.

5.15 Meet the family at set times for periodic updates or to discuss new circumstances that may arise, watch them for signs of stress or burn-out and encourage them to care for themselves with adequate rest and nutrition.

5.16 Ascertain the level of involvement that the family wants in the process.

5.16.1 Provide an opportunity for the patient, if possible, to express what s/he may want from their loved ones, or would find comforting, during the time they are sedated.

5.16.2 Obtain information on anything that the patient would want or need before sedation is initiated, i.e., rituals, spiritual or religious rites, saying goodbyes or expressing their feelings to family or team members.

5.16.3 Ask if is there anything that a family member or loved one needs to say to the patient prior to the initiation of PST?

5.17 Provide profound empathy for the patient's suffering in cases where PST is being initiated.

5.18 Facilitate a more organized debriefing session, following initiation of PST, for involved care team members.

5.19 Write the order for palliative sedation (follow drug protocol for palliative sedation in see Appendix One: Drug Protocol for Palliative Sedation).

5.20 Prepare/consider the following when initiating PST:

5.20.1 Prime tubing all the way to the tip of the winged infusion set.

5.20.2 Initiate a new subcutaneous site

5.20.3 Connect the tubing to the intravenous pump.

5.20.4 Confirm availability of sufficient Midazolam.

5.20.5 Reassess all prescribed medications and ensure that all are ordered subcutaneously or rectally. All oral medications should be discontinued.

5.20.6 Ensure Foley catheter is available

5.20.7 Ensure that the patient is in a safe and quiet environment.

5.20.8 Educate the family and care providers that:

5.20.8.1 Excessive tactile stimulation, turning and positioning may stimulate arousal of the patient and cause him/her distress

5.20.8.2 Due to impaired swallowing and sedated state, oral secretions may cause a rattle.

5.20.9 The patient's care location (home, tertiary palliative unit, critical care unit) and the availability of medication administration routes, such as intravenous, will primarily guide the type of PST medication used.

5.20.10 Note, the goal of pharmacological treatment is proportional reduction of consciousness to a level sufficient to relieve symptoms.

5.20.11 If a patient is already being treated with opioids and/or antipsychotics, these medications should be continued during sedation in accordance with the patient's needs. When an existing medication is being administered continuously via the parenteral route, it is preferable to administer the sedative drugs via a separate site. This avoids an undesirable increase in the existing medication when the doses of sedatives are increased, and avoids potential drug incompatibilities when mixed together.

5.21 Complete the following once the patient is sedated:

5.21.1 Ensure frequent communication with the family/proxies for reassurance, support, feedback, and ongoing decision-making.

5.21.2 Ensure support is in place for patient, family and proxies, including palliative services, social work and spiritual care as desired by them.

5.21.3 Through presence, intent, words, and touch, convey compassion for the patient, family and proxies.

5.21.4 Assume the patient can hear, and encourage visitors to talk or read to the patient, or play his or her favorite music if appropriate.

5.21.5 Provide meticulous physical care because the patient will have reduced movement (e.g. loss of ability to blink, and other protective reflexes).

5.21.6 Encourage family to continue to touch their loved one.

5.21.7 Discuss with family if they wish to participate in providing care. If desired, show them how to provide mouth care, eye care, hand or foot massage, or skin care as appropriate. If desired, include the family in repositioning the patient.

5.21.8 Monitor the patient for symptom relief.

5.21.9 Assess for bladder emptying and order insertion of a urinary catheter when needed. Continue with bowel care.

5.22 Provide and document in patient's medical record regularly throughout the shift the following, after PST has been initiated:

5.22.1 Response to PST - signs of symptom relief, Richmond Agitation Sedation Scale (RASS) (see Appendix Two: Richmond Agitation Sedation Scale (RASS))

5.22.2 Assessment of the balance between symptom relief and level of sedation, along with appropriate drug and/or dosage changes

5.22.3 Assessment of physical care needs and provision of care – skin care, mouth care, repositioning, bowel care, other care as needed

5.22.4 Family coping and interventions to support the family/proxies

5.22.5 Indicators for need to re-assess continuation of PST

5.22.6 Outcome and care after death

5.23 Monitor the patient on a regular basis to ensure that the goal of relief of refractory symptoms is being met.

5.24 Ensure patient achieves deep sedation demonstrated by no facial expression of discomfort, glazed eyes, eye lid reflex may be absent, present or absent response to mild prodding.

5.25 Observe for local reactions of PST such as bleeding, redness and swelling.

5.26 Re-assess if additional Midazolam is required based on the infusion rate.

5.27 Inform the attending physician when the maximum dose range of Midazolam is reached.

5.28 Ensure that the patient receives regular analgesics during the sedated stage.

5.29 Use RASS as a guide for monitoring the level of the sedation.

5.30 Provide every possible care and sympathy if a patient receiving PST shows indication of impending death (mottling and cooling of the periphery, irregular and/or noisy respirations) and advise the family/proxies that death will occur as a natural outcome of the underlying disease within hours or days.

6. APPENDIX

6.1 Appendix One: Drug Protocol for Palliative Sedation

6.2 Appendix Two: Richmond Agitation Sedation Scale (RASS)

6.3 Appendix Three: Latimer Ethical Decision Making Model

6.4 Appendix Four: Palliative Sedation Therapy Consent

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Appendix One: Drug Protocol for Palliative Sedation

Drug name/Class	Suggested starting dose	Usual maintenance dose	Drug interaction	Side effects	Incremental dose for Titration	Issues to consider/ Incompatibilities
Midazolam/ benzodiazepine	Initial bolus IV/Subcut 0.5-5mg Continuous infusion IV/Subcut 0.5 to 1mg/hour	20-120 mg/day	CNS depressant so use cautiously with opiates or other CNS depressants Diltiazem and Verapamil increase Midazolam levels	Hiccups, decreased respiratory rate ,nausea and vomiting, variations in blood pressure and pulse rates, paradoxical behavior or excitement	***Hourly maintenance dose should be 25-33% of the required induction dose** *Bolus is equal to the hourly rate every two hours *Adjust the maintenance dose every 2 hours based on numbers of rescue doses needed	Drug of choice for "respite sedation" or whenever reversal of sedation is desired. Drug has a short half-life Drug may be mixed with Morphine, Atropine or Scopolamine IV drug is diluted with D5W or Normal Saline Drug has minimal cardiovascular effects at sedating doses
Lorazepam / benzodiazepine	Initial bolus IV/Subcut 1-5mg Continuous infusion IV/Subcut 0.5- 1 mg/hr	4-40mg/day	CNS depressants, May increase Digoxin levels and risk of toxicity	Paradoxical agitation Hypotension, abdominal discomfort, nausea	Titrate dose in increments of 0.5-1mg every 15 minutes times three Subcut or IV push, titrate by 1mg every 2 hours	For bolus dosing, dilute with equal volume of sterile water. Give slowly at no more than 2 mg/minute for injection, Normal Saline for injection, or D5W.
Haloperidol/ butyrophene	Initial bolus IV/Subcut 1-5mg Continuous infusion IV/Subcut 0.5-1mg/hr	5 to 15 mg per day	Increased CNS depression when used with other CNS depressants, Anticholinergic are potentiated when combined with Haldol causing	May cause extra-pyramidal reactions, seizures, neuroleptic malignant syndrome, urinary retention, dyaphoresis,	Generally do not exceed 20mg/day to minimize the risk of neuroleptic malignant syndrome Increase infusion rate by 0.5	Drug is beneficial for patients with dementia

	5mg/day		increased anticholinergic effect	nausea/vomiting	mg/hr	
Phenobarbital/ Long acting barbiturate	60-120 mg per rectal, PO, Subcut Loading dose IV/Subcut 200mg, (1-3 mg/kg) Followed by continuous infusion of 0.5mg/kg/hr	Approx. 50 mg/hour Or 600-1600mg/day	CNS depression potentiated by narcotics, Valproic Acid can increase Phenobarbital levels	Paradoxical excitement in the elderly, hypotension, nausea and vomiting, Stevens Johnson Syndrome, angioedema, rash agranulocytosis, thrombocytopenia	Increase in increments of 30 mg Increase in 1 mg/kg/hr increments to maintain sedation	Drug has long half-life and reversal of sedation is difficult. Drug has no analgesic effect; minimal effect on salivation; respiratory and cardiac depressant effects are dose dependent. Don't mix parenteral drug with any acidic solution. Dilute drug with half Normal Saline, Normal Saline, D5W, Lactated Ringer's or Ringer's solution

Note: Dose ranges are highly variable, determined by patient weight, renal and hepatic function, state of hydration, concurrent medication use and other variables. Start low and titrate the dose to the desired clinical end point. Doses should be increased by approximately 30% every hour until sedation is achieved. Once the desired sedation is achieved the dose is usually maintained at that level as long as the patient seems comfortable. Previous doses of opioids and other symptom relieving medications should be continued

Appendix Two: Richmond Agitation-Sedation Scale (RASS)

Score	Term	Description
+4	Combative	Combative, violent, immediate danger to staff
+3	Very agitated	Pulls or removes tube(s)or catheter(s); aggressive
+2	Agitated	Frequent non purposeful movement, fights ventilator
+1	Restless	Anxious, apprehensive but movements are not aggressive or vigorous
0	Alert and calm	
-1	Drowsy	Not fully alert, but has sustained awakening to voice (eye opening &contact > 10 sec)
-2	Light sedation	Briefly awakens to voice (eye opening & contact < 10 sec)
-3	Moderate sedation	Movement or eye opening. To voice (but no eye contact)
-4	Deep sedation	No response to voice, but movement or eye opening to physical stimulation
-5	Unarousable	No response to voice or physical stimulation

Procedure for RASS Assessment

STEP	PROCEDURE	SCORE
1	Observe patient • Patient is alert , restless, or agitated	0 to +4
2	If not alert, state patient's name and say to open eyes and look at speaker. • Patient awakens with sustained eye opening and eye contact • Patient awakens with eye opening and eye contact, but not sustained • Patient has any movement in response to voice but no eye contact	-1 -2 -3
3	If patient does not respond to voice, physically stimulate patient by shaking shoulder and/or rubbing sternum*. • Patient has any movement to physical stimulation • Patient has no response to any stimulation	-4 -5

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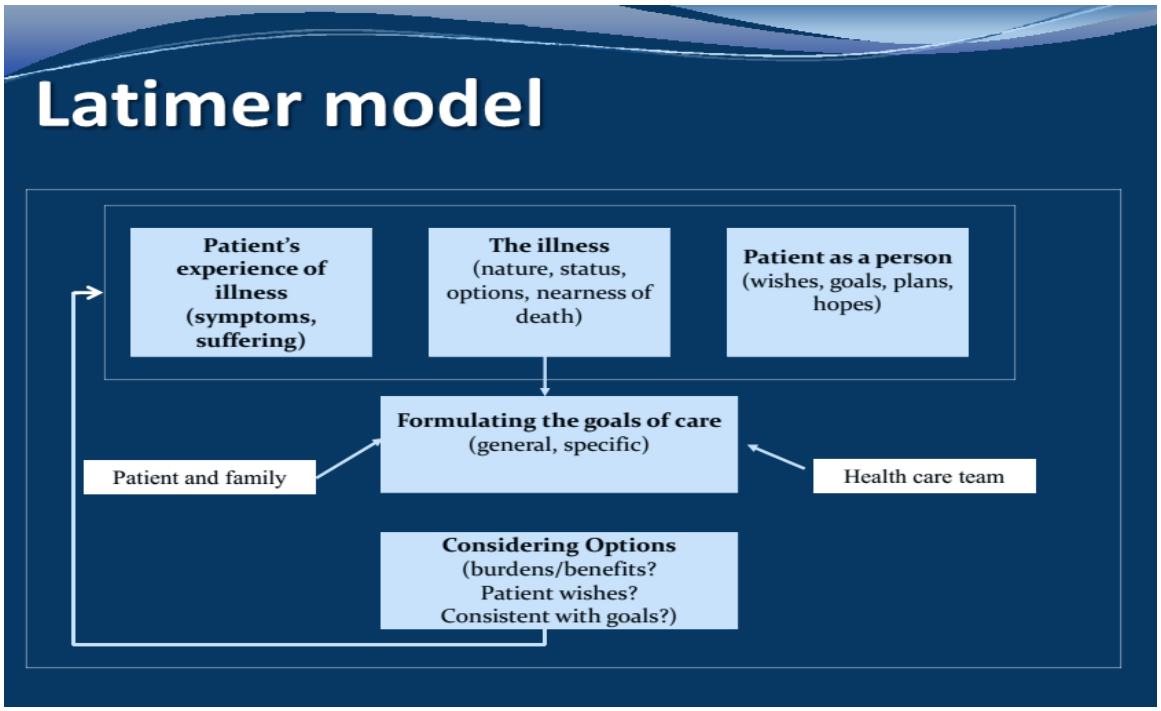
Appendix Three: Latimer Ethical Decision Making Model



Appendix Four: Palliative Sedation Therapy Consent

المجلس الصحي السعودي
Saudi Health Council

Patient ID Label

Consent for Palliative Sedation Therapy

Patient's Name: _____ Date of Admission: _____ Time of Admission: _____ Nationality: _____Marital Status: _____ Documentation of refractory suffering: _____ _____ Palliative measures previously attempted: _____ _____ Outcomes of previously attempted palliative measures: _____ _____ Check one: ☐ Patient ☐ Health Care Proxy/Patient representative That I am: ☐ Able to respond intelligibly to queries ☐ Able to take a part rationally in decision-making ☐ Able to articulate the decision Information presented: ☐ Nature and progress of stage of terminal illness (prognosis) ☐ Nature and possible impact of proposed controlled sedation ☐ Limitation, side effects, and risks of the proposed controlled	Arabic translation here *(note: we will send this form to translation dept for its arabic & then to form committee while the CMG is on review.)*

sedation. ☐Issues related to hydration and nutrition during sedation ☐ I am aware that Dr._____ (primary physician) agrees with the plan to initiate palliative sedation. With knowledge of the risks discussed by the physician(s), I consent to controlled sedation for refractory suffering. Relationship to patient: _____ Patient or authorized representative signature:_____ Patient or authorized representative name: _____ Date: _____ Time: _____	
For official use only Attending Consultant Name/Stamp: _____ Attending Consultant Signature: _____ Date: _____ Time: _____ Palliative Care Consultant Name/Stamp: _____ Palliative Consultant Signature: _____ Date: _____ Time: _____	