Ministry of Health

NATIONAL PALLIATIVE CARE CLINICAL GUIDELINES

2018

FOREWORD

Palliative care is beneficial for all clients and not specific to just cancer or end of life clients. Palliative care is an extremely important practice to manage and control pain and improve the quality of life for all clients. The Government of Eswatini and partners have provided palliative care (PC) services in Eswatini to cater primarily for chronic life-limiting and life-threatening illnesses. This is the second edition of the Palliative Care Clinical Guidelines following the first edition developed in 2011. The review of these guidelines has drawn lessons learnt from the first edition.

Eswatini is a signatory of several international declarations that govern PC; hence, the Government of Eswatini through the Ministry of Health is best positioned to take the lead in the coordination and provision of quality PC services. The Ministry of Health is committed to providing quality PC services to all service recipients in need. This will be achieved through collaboration and partnership with both development and implementing partners in PC. This document aims to standardize PC services through encouraging collaboration between partners to set and meet national PC targets as well as through mobilizing resources and strengthening the capacities of health systems and communities. This in turn will make the continuous supply of PC medicines and commodities possible.

In line with international agreements and commitments, the Ministry of Health has prioritized the expansion of PC services. This is evident through the availability of guiding documents, capacity building of health workers, integration of PC at hospital and health centre level and the availability of PC medicines and supplies. Available medicines include liquid oral morphine which is reconstituted in country and available in different formulations to cater for all in need. The Ministry of Health through partners' support further managed to establish a morphine reconstitution facility at Mbabane Government Hospital (MGH), which meets the necessary quality control standards associated with its intended use.

The Eswatini Ministry of Health hopes that these clinical guidelines will effectively inform and guide health practitioners involved in palliative care service delivery. The Ministry of Health is eager to establish "Pain Free Hospitals" in the country, which will significantly strengthen hospital capability to manage the pain of PC clients.

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ACRONYMS

APCA	African Palliative Care Association
bd	2 times daily
BNF	British National Formulary
CBO	Community Based Organization
CCW	Community Care Workers
CD	Controlled Drugs
CHBC	Community Home Based Care
CHN	Community Health Nursing
CO	Clinical Officer
CPD	Continued Professional Development
CS	Clinical Services
EHCP	Essential Health Care Package
EN	Enrolled Nurse
EOL	End of Life
FBO	Faith Based Organization
GI	Gastrointestinal
GORD	Gastro-Oesophageal Reflux Disease
HAU	Hospice Africa Uganda
HISCC	Health Information System Coordinating Committee
HIV	Human Immunodeficiency Virus
HMIS	Health Management Information System
HPCT	Hospital Palliative Care Team
ICP	Intracranial Pressure
IDSR	Integrated Disease Surveillance and Response
IM	Intramuscular
INR	International Normalized Ratio
IRIS	Immune Reconstitution Inflammatory Syndrome
IV	Intravenous
MO	Medical Officer
MOH	Ministry of Health

ACRONYMS

MSCC	Metastatic Spinal Cord Compression
MST	Modified Release Morphine
M&E	Monitoring and Evaluation
NGO	Non-Governmental Organization
ORS	Oral Rehydration Salts
per os	by mouth
PC	Palliative Care
PLHIV	People Living with HIV
PLWC	People Living with Cancer
po	by mouth
PPI	Proton Pump Inhibitor
prn	as needed
PTB	Pulmonary Tuberculosis
SC	Subcutaneous
SID	Strategic Information Department
SL	Sublingual
SRN	State Registered Nurse
SSRI	Selective Serotonin Reuptake Inhibitors
SVCO	Superior Vena Cava Obstruction
TB	Tuberculosis
TCA	Tricyclic Antidepressants
tds	3 times daily
USAID	United States Agency for International Development
SWAp	Sector Wide Approach
WHO	World Health Organization

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EXECUTIVE SUMMARY

Palliative care is an approach that improves the quality of life of clients (adults and children) 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.

Key Points:

- Palliative care is beneficial for all clients with life-limiting and life-threatening conditions, not just cancer clients.
- Palliative care should be client-centered and responsible to individual needs and preferences.
- Palliative care can address pain and symptoms associated with the disease and those that are unrelated to an underlying medical condition.
- Pain is always treated, pharmacologically or non-pharmacologically, until it is eliminated in every client.
- Palliative care enhances the quality of life of both clients and their families at all stages of client disease.

The purpose of these guidelines is to provide comprehensive and easily accessible information for health professionals to manage pain of clients with chronic life-limiting and life-threatening diseases and effectively manage common symptoms and side effects associated with palliative care provision. These guidelines complement other existing clinical guidelines for palliative care as well as for communicable and non-communicable diseases.

This document provides the following areas of guidance:

- General model for palliative care service delivery
- Pharmacological and non-pharmacological pain assessment and management for adults and children
- Pharmacological and non-pharmacological symptom control of common side effects for adults and children
- Special considerations for palliative care provision including:
  - Provision of care among clients with certain conditions
  - Infection prevention control
  - Psychosocial and spiritual support
  - End of life care
- Monitoring and evaluation system for Eswatini palliative care program

CHAPTER 1: INTRODUCTION

1.1 Overview: Definitions and Rationale

1.1.1 Definition of Palliative Care

The World Health Organization (WHO) defines palliative care (PC) as an approach that improves the quality of life of clients 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.

Palliative care[1]:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and their own bereavement;
- Uses a team approach to address the needs of patients and their families including bereavement counseling, if indicated;
- Enhances the quality of life and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and include those investigations needed to better understand and manage distressing clinical complications.

1.1.2 WHO Definition of Palliative Care for Children

PC for children is defined as the active total care of the child's body, mind and spirit and involves giving support to the family. Such care begins when an illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease. The WHO definition of PC provides a foundation and context for PC in all settings.

1.1.3 Vision for Palliative Care Provision

The social values underpinning PC provision are driven by a rights-based approach. PC should be client-centered and responsible to individual needs and preferences. All PC clients should be referred to the appropriate level of the health system, as detailed in Section 1.2.

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[1]World Health Organization, National Cancer Control Programmes: Policies and Managerial Guidelines, 2nd ed (Geneva, 2003), http://www.who.int/cancer/media/en/408.pdf.

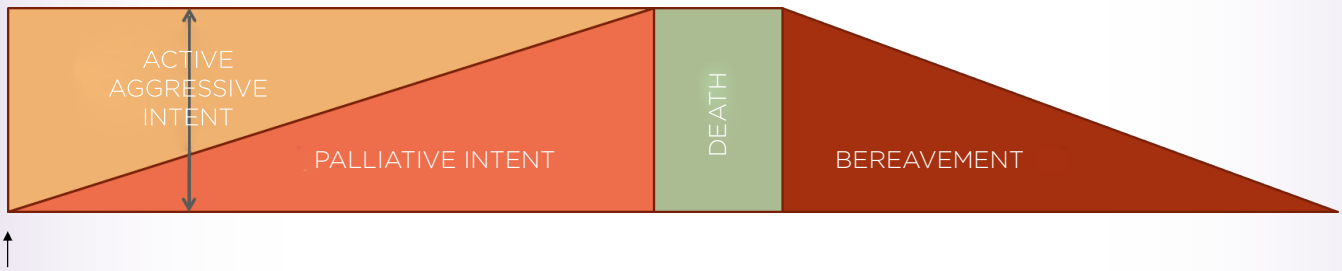
1.1.4 Rationale for the Palliative Care Clinical Guidelines

The purpose of these guidelines is to provide comprehensive and easily accessible information for health professionals to manage pain of clients with chronic life-limiting and life-threatening diseases and effectively manage common symptoms and side effects associated with palliative care provision. These guidelines do not address every symptom and do not intend to replace other clinical guidelines. These guidelines complement other existing clinical guidelines for palliative care, such as *Beating the Pain Clinical Guidelines and National Children Palliative Care Guidelines,* as well as guidelines for communicable and non-communicable diseases. This document includes guidelines related to pain management, symptom control, special considerations for pain assessment and management, and monitoring and evaluation (M&E) in palliative care.

1.2 Palliative Care Service Delivery and Referral

Palliative care begins when illness is diagnosed, which is represented by the adjacent 'active aggressive intent' and 'palliative intent' triangles in Figure 1.1 below. Active aggressive intent refers to the provision of aggressive medical interventions with the intent to cure or prolong life. Meanwhile 'palliative intent' refers to the provision of care to alleviate symptoms or stress associated with the disease. Palliative care continues regardless of whether or not the client receives treatment directed at the disease. As treatment directed at the disease diminishes in efficacy due to worsening disease prognosis, palliative care should be scaled up and maintained until the end of life.

Figure 1.1: Modified Integrated Palliative Care Services Model (Frager, 1997)[i]



Source: Adapted from American Association (1999)

[i]Frager, Gerri, "Palliative Care and Terminal Care of Children," Child and Adolescent Psychiatric Clinics of North America 6,no.4 (1997): 889-909.

CHAPTER 2: PAIN ASSESSMENT AND MANAGEMENT

Pain is one of the most common and impactful symptoms experienced by those in need of palliative care. The experience of moderate to severe pain is very common for people with many different diseases at the end of life, causing distress to both the client and the family. Pain management, therefore, is critical to palliative care.

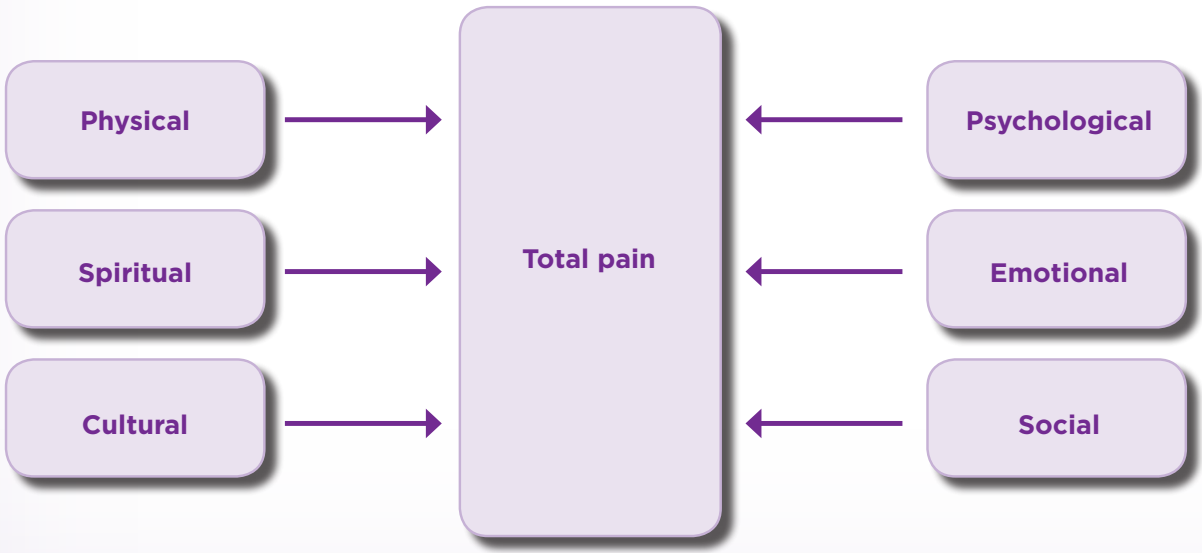
2.1 Pain Classification

Pain is defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage. Pain is always a subjective sensation and is always unpleasant. The experience varies from person to person and from time to time. Pain is whatever the experiencing person says it is, existing wherever he/she says it does.

2.1.1 Classification of Total Pain

PC commonly uses the concept of "total pain", as exemplified in Figure 2.1, to prompt health professionals to consider all possible influences of the pain experience:

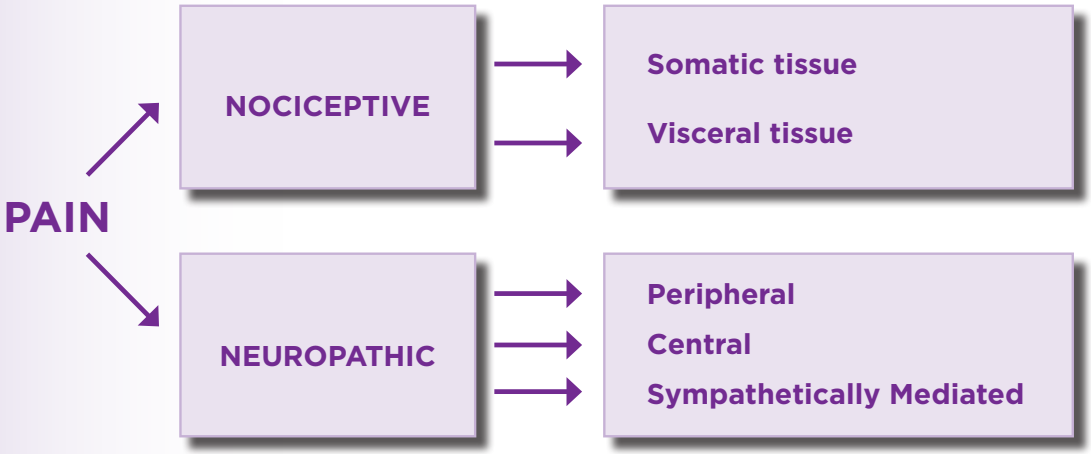
Figure 2.1: Total Pain Model



Effective pain control is central to PC and improves the client-clinician relationship. Pain assessment should always be part of the client assessment and be regarded as the **fifth vital sign**. Each pain should be assessed separately and consideration should be given to pain within the context of disease status, whether each pain is related to the disease (e.g. cancer), to the treatment, to a secondary condition or to a concurrent disorder. Effective pain and symptom management serves as the keystone to palliative care and decreases total pain by promoting psychological, social and spiritual well-being.

2.1.2 Classification of Nociceptive and Neuropathic Pain

Figure 2.2: Nociceptive vs. Neuropathic Pain



Nociceptive: pain that arises when nerve fibers are triggered by inflammation, chemicals or physical events.

Neuropathic: pain that arises when the nervous system is not working properly due to disease or injury. This pain does not arise in response to any specific circumstance or outside stimulus.

2.2 Pain Assessment

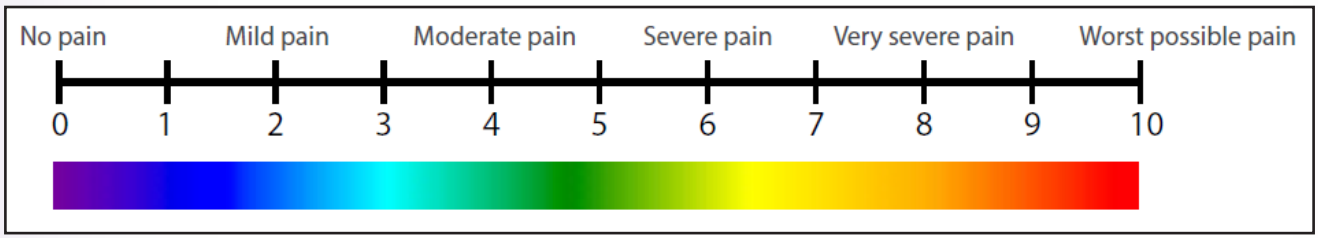
Pain is subjective and two clients may report pain severity differently from each other.

- Despite the fact that pain is specific to each person, clients can usually, accurately and reproducibly, indicate the severity of his or her symptoms by using a pain scale.
- Pain scales enhance the ability of clients to communicate the severity of their pain to health professionals and the ability of health professionals to communicate consistently with each other.
- Pain scales also allow the clinicians to assess the side effects of medications.

Health professionals should carefully conduct the initial pain assessment and clearly document their findings. This allows the assessing health professional, and others, to compare progress in pain management against the symptoms documented in the initial pain assessment. Many pains change with time and frequent reassessment is necessary, especially during and after the clinical intervention. It is common for clients to experience multiple types and/or bodily sites of pain. **EACH** pain should be assessed, documented, managed and reviewed.

2.2.1 Pain Assessment in Adults

Figure 2.3: Adult Numeric Pain Rating Scale



- Pain levels from 0-10 can be explained verbally to the client using a scale in which 0 is no pain and 10 is the worst possible pain imaginable
- Clients are asked to rate their pain from 0 to 10
- Health professionals record the client's reported pain level to make treatment and follow-up decisions and compare reported pain levels between client examinations

2.2.2 Pain Assessment in Children

NB: Please refer to the National Children's Palliative Care Guidelines for comprehensive management (page 23), 2016

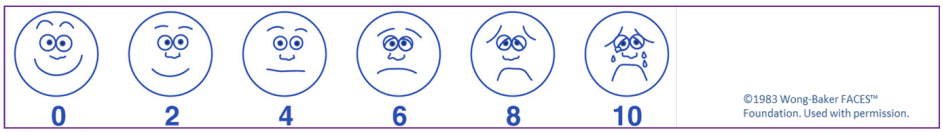
Health professionals should follow the Q.U.E.S.T framework below to conduct a holistic assessment of the child's pain[2].

[2]Baker, Connie Morain, and Donna L. Wong, "QUEST: A Process of Pain Assessment in Children," *Orthopedic Nursing 6,* no. 1 (1987): 11-21.

Table 2.1: Pain Assessment Questions in Children

Framework	Action	Additional Steps
Q	Question the child	
U	Use pain rating scales	• Ask child to rate his or her pain using the Wong-Baker FACES pain rating scale • The child is the best person to report their pain
E	Evaluate child's behavior and psychological changes	• Observe the child using the Face, Legs, Activity, Cry, and Consolability (FLACC) scale to assess pain • Take cause of pain into consideration
S	Sensitize parents	• Ask the parent or caregiver about the child's previous exposure to pain, verbal pain indicators, usual behavior or temperament
T	Take action and evaluate the effect of this action	

Figure 2.4: Wong-Baker FACES Pain Rating Scale



- This pain scale is recommended for use in children who can talk (usually 3 years and older).
- Ask the child to choose the face that best describes how he or she is feeling using Table 2.2.
- Record the number associated with the pain level that the child reports to make treatment and follow-up decisions and compare reported pain level between client examinations.

Table 2.2: Explanation of Wong-Baker FACES Pain Rating Scale to Child

Face Number	Explanation to Child
Face 0	Is happy because this person doesn't hurt at all
Face 2	Hurts just a little bit
Face 4	Hurts a little bit more than Face 2
Face 6	Hurts even more than Face 4
Face 8	Hurts a lot
Face 10	Hurts as much as the person can imagine, although the person doesn't need to be crying to feel this bad

Table 2.3: FLACC scale

Scoring			
Categories	**0**	**1**	**2**
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant quivering chin, clenched jaw
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting, back and forth, tense	Arched, rigid or jerking
Cry	No cry (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging or being talked to, distractible	Difficult to console or comfort
Each of the five categories: **(F)** Face; **(L)** Legs; **(A)** Activity; **(C)** Cry; **(C)** Consolability, is scored from 0-2 which results in a total score between 0 and 10 (*Merkel et al.* 1997)			
Permission 2: Reproduced with permission from the Regents of the University of Michigan, © 2002			

- This pain scale is recommended for use in children between the ages of two months and seven years old.
- Use it like the APGAR (Appearance, Pulse, Grimace, Activity, Respiration) method, a scoring system used to evaluate the health of newborn children, where you give the child a score between zero and two for each of the five criteria and sum the five values to arrive at a score out of 10.

2.2.3 Special Consideration when Taking History from the Client

Health professionals should consider the following elements of pain and associated questions when conducting the client's pain assessment, as outlined in Table 2.4. This will help the health professional better understand the origin of the pain and identify the best course of management or treatment.

Table 2.4: Framework to Assess Pain Elements

Meaning	Example
P = Provocative	What makes the pain better? What makes the pain worse?
Q = Quality	What are the properties and characteristics of the pain? How would you describe the pain?
R = Radiation	Where does the pain start and travel to?
S = Severity	Rate the pain on a scale; how bad is your pain?
T = Temporal	What are the patterns of the pain? Is it constant, or does it come and go?

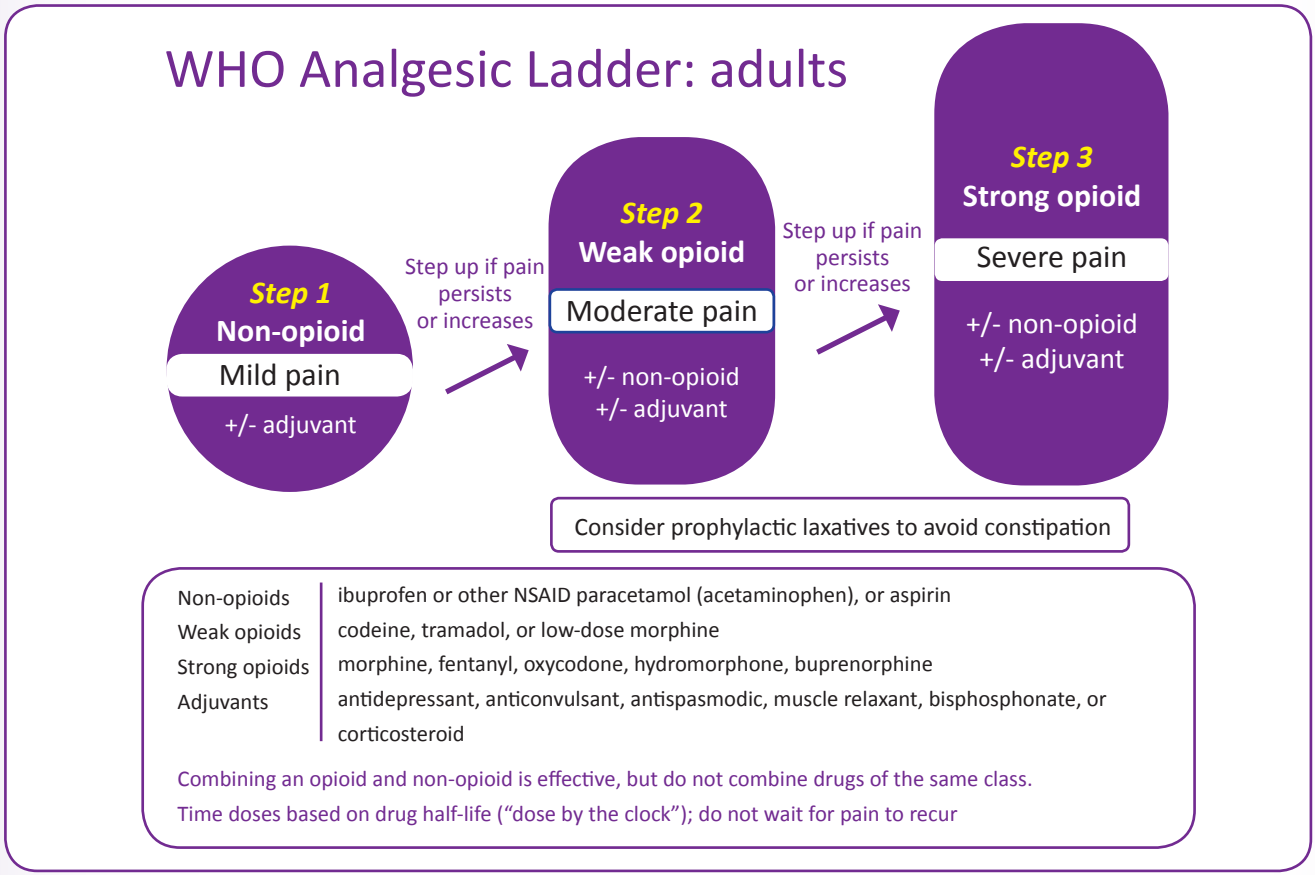
2.3 Pain Management in Adults

Anything that relieves pain can enhance the quality of life. Both **pharmacological and non-pharmacological** measures are essential in pain relief. Providers of palliative care should be able to manage pain in accordance with the WHO analgesic ladder model.

2.3.1 Pharmacological Management of Pain

The WHO analgesic ladder is the fundamental approach to manage all types of pain, both nociceptive and neuropathic, and shall be used as the standard approach to manage pain.

Figure 2.5: WHO Analgesic Ladder Adults[3]



2.3.2 Principles of Pain Management

Whenever possible, medicines for pain control should be administered in the following manner:

- by the clock
- by the mouth
- by the analgesic ladder
- by the client

[3]"WHO's Cancer Pain Ladder for Adults," World Health Organization, accessed June 11, 2018. http://www.who.int/cancer/palliative/painladder/en/.

2.3.3 WHO Step I Analgesics – Treatment of Mild Pain

Mild pain should be treated with non-opioid analgesics such as paracetamol and nonsteroidal anti-inflammatory drugs (NSAID). NSAID include ibuprofen, diclofenac, aspirin, indomethacin, etc.

The main indication of NSAIDs is pain of inflammatory origin especially bone metastases. There is no concrete evidence that NSAIDS selective for cyclo-oxygenase-2 (COX-2) isoenzyme e.g. celecoxib, rofecoxib, etc. are advantageous in treating cancer pain. However, such classes can be recommended in high-risk clients with gastrointestinal or bleeding complications[4].

2.3.4 WHO Step II Analgesics – Treatment of Moderate Pain

Moderate pain should be treated with step II analgesics – weak opioids. The prototype here is ***codeine phosphate*** and others include tramadol, dihydrocodeine, hydrocodone, etc. Traditionally, clients with moderate pain have been treated with a combination product containing paracetamol or NSAID plus codeine, dihydrocodeine, etc. There is evidence of synergistic and opioid dose-sparing effects from co-administration of a NSAID, but no consistent reduction in side effects.

2.3.5 WHO Step III Analgesics – Treatment of Severe Pain

Severe pain should be treated with step III analgesics – strong opioids. Strong opioids include morphine, fentanyl, oxycodone, hydromorphone and burprenorphine.

Morphine is an international "gold standard" against which other opioid analgesics are measured. When used correctly, clients do not become dependent or addicted, intolerance is uncommon and respiratory depression does not usually occur.

Oral administration of morphine is the preferred route for both adults and children. If given parenterally, the equivalent dose is one-third of the oral medication. Other strong opioids include – hydromorphone, oxycodone, fentanyl, methadone etc. Strong opioids may be combined with ongoing use of step I analgesics.

2.3.6 Adult Dosing for Pharmacological Pain Management

Table 2.5 below outlines pain management for adults, including medications, dosages, side effects, and management of side effects.

[4]Mercadante, Sebastiano, "The use of anti-inflammatory drugs in cancer pain," Cancer Treatment Reviews (2001): 27:51.

Table 2.5: Adult Dosing for Pain Management

Analgesic	Starting Dose	Range	Side Effects and Cautions
Step 1: Give non-opioid analgesics			
Paracetamol	1g (2 x 500 mg tablets) every 4 to 6 hours (skip dose at night or give another analgesic to keep total to 8 tablets per day)	• Only one tablet (500 mg) may be required in the elderly or very ill, or when combined with an opioid • Mild pain might be controlled with dosing every 6 hours	Do not exceed 4g in 24 hours to avoid hepatotoxicity
Aspirin (acetylsalicylic acid)	• Give 600 mg (2 tablets of 300 mg) every 4 hours • Do not exceed 4g per day	When used as an extra "rescue" dose, give 600 mg per day as a single dose	• Take with or immediately after food • Avoid use if gastric problems occur • Stop if client has epigastric pain, indigestion, or black stools or if bleeding occurs • Do not give to children under 12 years, clients with renal impairment and clients with thrombocytopenia • For long term use, use with proton pump inhibitors (PPI) e.g. Omeprazole 20 mg daily
Ibuprofen	400 mg 3 times per day	Do not exceed 1,200 mg in a day	Not to be taken on an empty stomach
Diclofenac	50 mg 3 times per day	Do not exceed 150 mg per day	Not to be taken on an empty stomach
Step 2: Give weak opioids for moderate pain. Give in addition to non-opioid and/or adjuvant. ***NB: When step 2 drugs are not available, low dose morphine can be used.***			
Codeine phosphate (tablets)	30 mg every 4 hours	• 30 to 60 mg every 4 to 8 hours • Maximum daily dose 240 mg	Give a laxative to avoid constipation unless client already has diarrhoea
Tramadol HCL (capsules)	50 to 100 mg every 6-8 hours	Do not exceed 400 mg per day	Use with caution in epileptic clients especially if client is taking other drugs that lower risk of seizures

Table 2.5 Adult Dosing for Pain Management (continued)

Analgesic	Starting Dose	Range	Side Effects and Cautions
Step 3: Give strong opioids for moderate to severe pain			
Oral morphine (liquid)	2.5 to 20 mg every 4 hours (starting dose can be increased by 50% after 24 hours if pain persists)	• According to need of the client without restriction in dosage • Very high dosages may be required.	Give a laxative to avoid constipation unless client already has diarrhoea
Slow release morphine tablet	Tablet 30 mg, every 12 hours	There is no ceiling dose for oral morphine	

NB: Do not give morphine to clients with increased Intra Cranial Pressure e.g. Meningitis

2.3.7 Characterization of Breakthrough Pain

- Stable analgesic regimen in the previous 48 hours
- Presence of controlled background pain in the previous 24 hours (i.e. average pain score <5 out of 10)
- Temporary flare of severe or excruciating pain in the previous 24 hours
- A sudden, temporary flare of severe pain that occurs on a background of otherwise controlled pain
- May be more common during first three days of treatment as morphine dose is titrated from starting dose to effective dose
- Healthcare providers routinely under-diagnose and under-treat breakthrough pain

2.3.8 Management of Breakthrough Pain (Rescue Dose)

- A dose of liquid morphine that is the same as the dose given every 4 hours and can be given as often as required to treat breakthrough pain.
  Note these in the client chart
  Write orders that include rescue doses.
- Rescue dose should be administered at the first sign of breakthrough pain
  Pain that is allowed to build up is harder to control.
- When you give a rescue dose of morphine to treat breakthrough pain you should still give the next regular dose on schedule.
- The rescue dose must be increased whenever the regular dose is increased.
- Rescue dosing is suitable for all immediate-release opioids, not just morphine.
- A frequency of 4 or fewer rescue doses per day is normal.
- If a patient requires more than 4 rescue doses per day, you should increase the background dose:
  - ✓ Add total rescue doses to normal daily dose and divide by 6.
  - ✓ **Example: in a client taking 10 mg every 4 hours and 5 rescue doses of 10 mg, new daily dose is (10*6)+(10*5)=110 mg, given as 15 or 20 mg every 4 hours.**

- If there is no need for rescue doses, you may try a small reduction in background dose.

2.3.9 Management of Incident or Procedural Pain

- Pain precipitated by a particular activity or procedure, such as dressing, changing, washing, changing position, eating or disimpaction, can be anticipated.
- Supplement regular analgesic regimen with a rescue dose given 20-30 minutes before the activity.

2.3.10 Management of End of Dose Failure

- Effect of analgesia wears off after a few hours and pain returns
- Treatment:
  - ✓ Change to a longer-acting medicine
  - ✓ Increase the dose of the current medicine
  - ✓ Reduce the dosing interval

2.3.11 Management of Side Effects of Morphine or Other Opioids

Table 2.6: Pharmacological Management of Side Effects Resulting from Morphine or Other Opioids

Side Effects	Treatment
Constipation	• Give bisacodyl 5-10 mg NOCTE as prophylaxis unless the client has diarrhoea • Increase fluids and fibre rich foods
Nausea or vomiting	Give an antiemetic: • Haloperidol 1.5 mg daily for 3 days; or • Metoclopramide 10 mg 3 times per day for 3 days, if needed However, usually there is no need for a prophylactic antiemetic
Confusion or drowsiness; decreased alertness (if due to opioid)	Usually occurs at the start of treatment or when dose is increased. Resolves within a few days but can occur at end of life with renal failure. • Halve dose; or • Increase time between doses; or • Provide time with less analgesia when client wants to be (or needs to be) more fully alert to make decisions. Advise clients not to perform dangerous tasks or operate heavy machinery for two weeks while they adjust to the medication.
Twitching (myoclonus); if severe or bothers client during waking hours	If on high dose, consider reducing dose or changing opioids (consult or refer) Reassess the pain and its treatment, or give diazepam 5 to 10 mg 3 times per day until the effect subsides.

Table 2.6: Pharmacological Management of Side Effects Resulting from Morphine or Other Opioids

Side Effects	Treatment
Somnolence (excessive sleepiness)	Extended sleep can be from exhaustion due to pain. If persists for more than 2 days after starting, reassess level and/or type of pain and then consider reducing the dose.
Itching	May occur with a normal dose. If present for more than a few days and hard to tolerate, give: • Chlorpheniramine 4mg every 8 hours; or • Promethazine hydrochloride 10 mg every 8 hours

2.3.12 Morphine Toxicity

- If you are concerned that a client is experiencing toxicity, **reduce the dose by 50%** and consider giving parenteral fluids to increase excretion
- In severe cases, stop the opioid and give Naloxone, an opioid antagonist
- Naloxone is rarely used and should be used with caution as it will precipitate pain crisis
- Haloperidol 1.5-5 mg at night may help with any hallucinations or confusion
- Be sure to rule out other causes (such as urinary tract infection, hypoxia, or side effect of another medication)

2.3.13 Adjuvant Therapy for Pain in Adults

The principle of adjuvant therapy:
The use of adjuvants that target neuropathic pain may be particularly important because such pain may be difficult to treat with opioids alone. Adjuvants are also useful for managing other pains that are only partially sensitive to opioids such as bone pain, smooth or skeletal muscle spasms or pain related to anxiety.

Use of adjuvant analgesics:

Adjuvant analgesics, or co-analgesics, are medicines that are typically used in conjunction with other analgesics. Adjuvant analgesics can be administered alone but are typically administered with NSAIDs or other opioids to enhance pain management. It is important to note that the use of adjuvant analgesics with other analgesics may produce **both intended and unintended effects**:

- **Enhance** the analgesic activity of the NSAIDs or opioids
- Have **independent analgesic activity** for certain pain types (such as neuropathic or bone pain)
- May **counteract** the side effects of NSAIDs or opioids

Table 2.7: Dosing of Adjuvant Analgesics

Symptom	Medication	Dosage
Neuropathic pain, presenting primarily as burning or dysesthesia	Amitriptyline	Adult 10-75mg at night. Start with a low dose and slowly increase as needed. Can also be given in a dose of 0.5-2mg/kg at night.
	Carbamazepine	Start at 100mg twice a day, and can be increased up to 800mg twice a day.
	Sodium valproate	Adults: 200mg twice a day
Muscle spasm, e.g. colicky abdominal pain or renal colic	Hyoscine butylbromide	Start at 10mg three times per day; can be increased to 40mg three times per day.
Skeletal muscle spasm and anxiety-related pain	Diazepam	Adult: 5mg orally two or three times per day

Table 2.7: Dosing of Adjuvant Analgesics (continued)

Symptom	Medication	Dosage
Bone pain, neuropathic pain, headache due to raised intracranial pressure, and pain associated with oedema and inflammation	Dexamethasone *If Dexamethasone is not available, then adults can also be given* ***Prednisolone***	2-4mg per day A conversion rate of 4mg Dexamethasone to 30mg Prednisolone can be used
Intracranial pressure, nerve compression and spinal cord compression	Dexamethasone	Start at 24mg per day and reduce by 2mg daily to the lowest effective maintenance dose. For pain from nerve compression, 8mg is often used; and for spinal cord compression, 16mg is usually the starting dose.
Intractable bone pain due to metastatic bone disease	Pamidronate	60-90mg can be given intravenously every four weeks

2.4 Pain Management Children

2.4.1 General Principles for Opioid Use in Children

- The WHO considers strong opioids as essential to the treatment of pain in children. The use of strong opioid analgesics is recommended for the relief of moderate to severe persisting pain in children with medical illness.

- Dose at regular intervals so there is no gap in treatment
  - ✓ Medicines should always be given on a regular schedule and not “as needed”, except for rescue doses
  - ✓ Regular doses can be complemented by rescue doses as needed to manage breakthrough pain
- Use the appropriate route of administration
  - ✓ Medicines should be given by the simplest, most effective, and least painful route
  - ✓ **Oral administration is preferred**
  - ✓ Intravenous (IV) or subcutaneous, rectal or transdermal are alternatives when oral is not feasible
  - ✓ Intramuscular (IM) is discouraged because it is painful
  - ✓ **Adapt treatment to the individual child**
    - Titrate to get to the correct dose

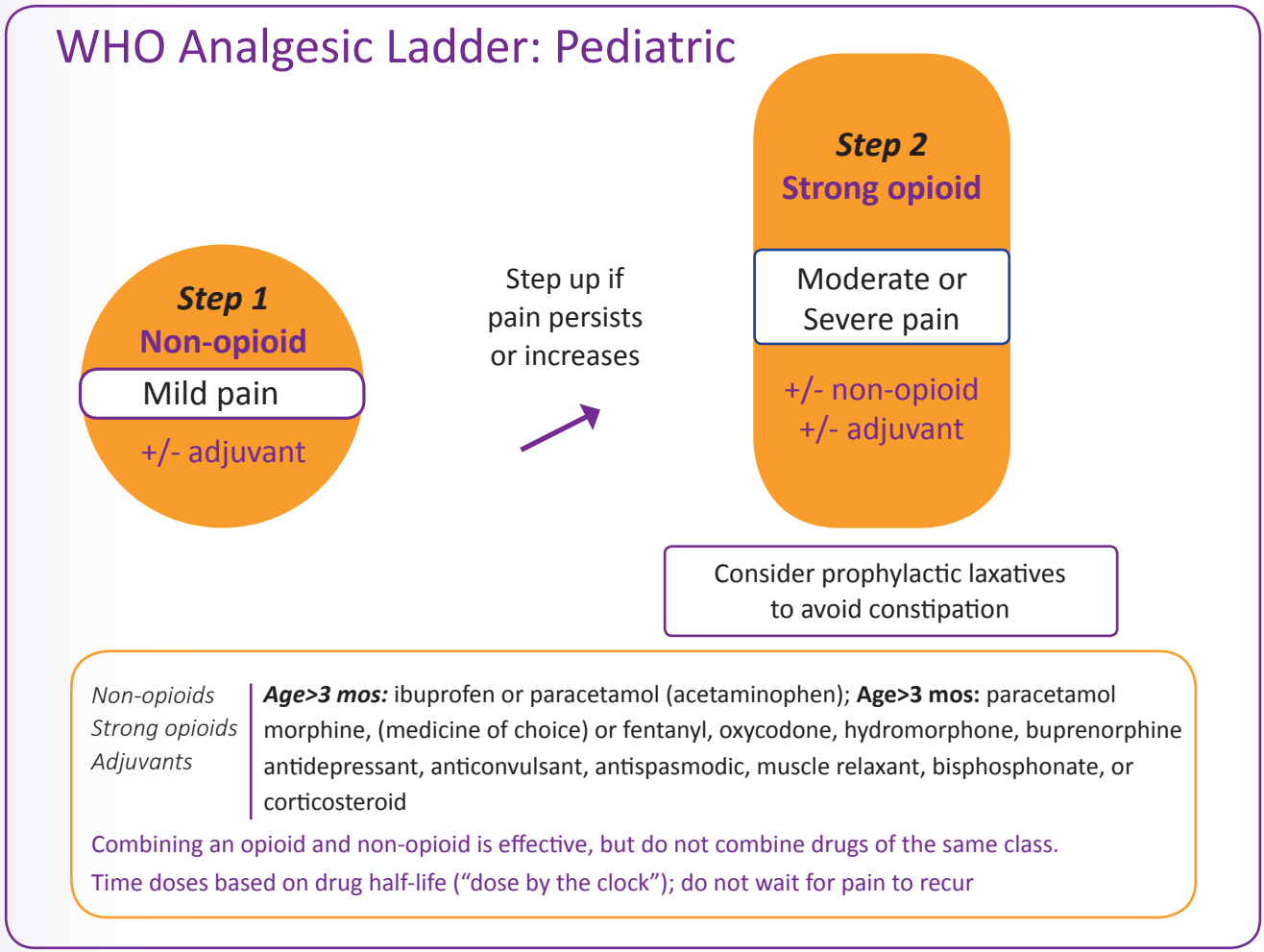
2.4.2 Side Effects of Opioid Use in Children

Opioids are generally well tolerated in children. Table 2.8 outlines potential side effects of opioid use in children and recommended treatment.

Table 2.8: Side Effects of Opioid Use in Children and Recommended Treatment

Side Effect	Recommended Treatment
Mild sedation	Mild sedation for first 48 hours is normal while child catches up on sleep
Constipation	Treat with laxatives
Pruritus	Treat with topical treatments (calamine or hydrocortisone) or oral antihistamines
Urinary retention	Treat with carbachol or bethanechol; catheterization may be required

Figure 2.6: WHO Analgesic Ladder Pediatric[5]



[5]World Health Organization, "WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illness," WHO (2012): 1-156.

Recently updated guidelines from the World Health Organization (WHO) recommend using a 2-step analgesic ladder for children, which does not include the rung for weak opioids.

Weak opioids are not recommended for use in children due to issues with the safety and efficacy in children as described below.

- **Codeine**
  Safety and efficacy problems related to genetic variability that affects metabolism
  Low analgesic effect in infants and young children
- **Tramadol**
  Data is lacking on safety and efficacy in children

2.4.3 WHO Step I: Non-Opioid Treatment of Mild Pain in Children

- Paracetamol and ibuprofen are the only medicines that are recommended to manage mild pain
- No other NSAIDs are recommended
- Infants <3 months' old
  - ✓ Only paracetamol is recommended
- Children >3 months' old
  - ✓ Paracetamol or ibuprofen can be used

Table 2.9: Dosing of Step I Analgesics in Children (Mild Pain)

Medicine	<1 month	1-3 months	3 months-12 years	Maximum daily dose
Paracetamol	5-10mg/kg every 6-8 hours	10mg/kg every 4-6 hours	10-15mg/kg every 4-6 hours (max 1g at a time)	4 doses per day
Ibuprofen	Not recommended	Not recommended	5-10mg/kg every 6-8 hours	40mg/kg/day
*Children with poor nutritional status may be more susceptible to toxicity at standard doses				

2.4.4 WHO Step II: Strong Opioid Treatment of Moderate or Severe Pain in Children

- Strong opioids are the only class of medicines that are effective in the treatment of moderate and severe pain in children. Therefore, strong opioids are an essential element in pain management.
- Morphine is the "gold standard"
- Alternatives can be used if a child experiences intolerable side-effects
- As with adults, there is no maximum dose for opioids
- Titrate upward to find the dose that relieves pain with tolerable side-effects
- Constipation is a common side effect, and all children taking opioids should also take a stimulant laxative and a stool softener

Table 2.10: Starting Dosages for Opioid Analgesics for Opioid-Naïve Neonates (Moderate to Severe Pain)[6]

Medicine	Route	Starting Dose
Morphine	IV/SC injection	0.025-0.05mg/kg every 6 hours
	IV infusion	Initial IV dose 0.025-0.05mg/kg, then 5-10mcg/kg/hour 100mcg/kg every 4 or 6 hours
Fentanyl	IV injection	0.01-0.02mg/kg every 2 to 4 hours
	IV infusion	Initial IV dose 0.01-0.02mcg/kg, then 0.5-1mcg/kg/hour

- Administer IV morphine slowly over at least 5 minutes
- IV doses are based on acute pain management and sedation. Lower doses are required for non-ventilated neonates.
- Administer IV fentanyl slowly over 3-5 minutes

Table 2.11: Starting Dosages for Opioid-Naïve Infants (1 month-1 year)[7]

Medicine	Route	Starting Dose
Morphine	Oral (immediate release)	**0.08-0.2 mg/kg every 4 hours**
	IV/SC injection	1-6 months: • 0.1mg/kg every 6 hours 6-12 months: • 0.1mg/kg every 4 hours (max 2.5mg/dose)
	IV infusion	1-6 months: Initial IV dose: • 0.05mg/kg, then: • 0.01-0.03mg/kg/hour 6-12 months: Initial IV dose: • 0.1-0.2mg/kg then: • 20-30mcg/kg/hour

- Administer IV morphine slowly over at least 5 minutes

[6]World Health Organization, *WHO guidelines on the pharmacological treatment of persisting pain in children with medical illness (Geneva, 2012),*
https://www.ncbi.nlm.nih.gov/books/NBK138354/pdf/Bookshelf_NBK138354.pdf.
[7]World Health Organization, *WHO guidelines on the pharmacological treatment of persisting pain in children with medical illness (Geneva, 2012)*,
https://www.ncbi.nlm.nih.gov/books/NBK138354/pdf/Bookshelf_NBK138354.pdf.

Table 2.12: Starting Dosages for Opioid-Naïve Children (1-12 years)[8]

Medicine	Route	Starting dose
Morphine	Oral (immediate release)	1-2 years: • 0.2-0.4mg/kg every 4 hours 2-12 years: • 0.2-0.5mg/kg every 4 hours (max 5mg)
	Oral (prolonged release)	0.2-0.8 mg/kg every 12 hours
		1-2 years: • 0.1mg/kg every 4 hours 2-12 years: • 0.1-0.2mg/kg every 4 hours (max 2.5mg)
	IV infusion	Initial IV dose: 0.1-0.2mg/kg, then 0.02-0.03 mg/kg/hour
	SC infusion	0.02mg/kg/hour
• Administer IV morphine slowly over at least 5 minutes		

2.4.5 Adjuvant Therapy for Pain in Children

Key Message: Effective pain management often requires a multifaceted approach using some combination of non-opioid, opioid analgesics, adjuvants, and non-pharmacological strategies. Adjuvant analgesics have primary indications other than pain, but may relieve pain of certain conditions.

If the administration of analgesics alone is inadequate, then adjuvant analgesic therapies are recommended for children. However, there have not been many randomized-controlled trials that have investigated the use of various adjuvant analgesics in children and thus recommendations are limited.

[8]World Health Organization, WHO guidelines on the pharmacological treatment of persisting pain in children with medical illness (Geneva, 2012), https://www.ncbi.nlm.nih.gov/books/NBK138354/pdf/Bookshelf_NBK138354.pdf.

Table 2.13: Dosing of Adjuvant Analgesics for Children

Symptom	Medication	Dosage
Neuropathic pain	Amitriptyline	Initial dose: 0.2 to 0.5 mg/kg given once daily at bedtime Increase dose by 25% every 2 to 3 days as needed
Itching	Antihistamines (e.g., chlorpheniramine)	0.1 mg/kg every 8 hours
Muscle spasms	Benzodiazepines (e.g., diazepam)	0.2 to 0.5 mg/kg every 24 hours in 3 to 4 divided doses
General pain	Feeding, sucking and eating are part of children's development and provide comfort, pleasure and stimulation	

2.4.6 Characterization of Pain in Neonates

Newborns' experience of pain can be described in the following way:

"If it would hurt you, it hurts them!"

Pain in the neonate can be classified into three main categories:

1. **Acute or physiological pain:** results from skin-breaking procedures or tissue injury caused by diagnostic or therapeutic interventions.
2. **Established pain:** results from surgery or localized inflammation (e.g. abscess or birth trauma).
3. **Prolonged pain:** results from severe diseases like necrotizing enterocolitis or meningitis.

It is challenging to detect and measure the intensity of pain in neonates because of their inability to communicate with care providers. For example, preterm infants have less ability to demonstrate symptoms of pain.

Untreated or inadequately treated neonatal pain may have both immediate and long-term effects including altered pain sensitivity and reactivity and other adverse health outcomes.

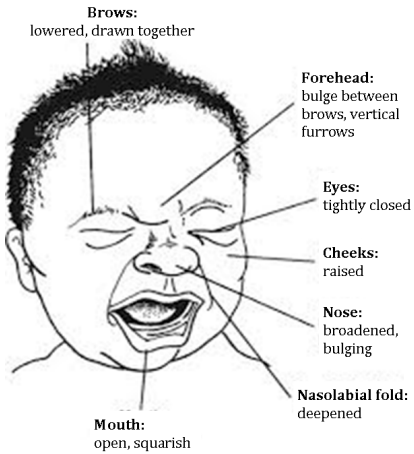
2.4.7 Neonatal Pain Assessment Tools

Available methods for neonatal pain assessment include physiologic, behavioral, and contextual considerations.

Table 2.14: Neonatal Physiologic and Behavioral Parameters for Pain

Physiologic parameters	Behavioral responses
• Changes in heart rate • Respiratory pattern • Blood pressure • Oxygen saturation	• Crying • Changes in facial expressions • Body movements

Figure 2.7: Neonatal Visible Facial Considerations for Pain



In infants, total facial activity and cluster of specific facial findings (brow bulge, eye squeeze, nasolabial furrow, and open mouth) are associated with acute and postoperative pain.

2.4.8 Neonatal Pain Management Recommendations

- Routine assessment for the detection of pain
- Reduction of the number of painful procedures
- Establishment of guidelines and protocols to prevent/reduce pain
- Preemptive provision of analgesics for any painful procedure

Table 2.15: Neonatal Non-Pharmacological and Pharmacological Pain Control

Non-pharmacological analgesic measures (complementary therapy)	Pharmacologic analgesic agents
• Holding • Rocking • Sensorial saturation: use of touch, massage, voice, smell, and sight • 5 S's[9]: • Swaddling including facilitated tucking (defined as maintaining the arms and legs in a flexed position • Breastfeeding or non-nutritive sucking • Skin to skin contact (e.g. kangaroo care) • Side/stomach position • Shushing • Swinging and sucking (alone and combined with sucrose)	• Topical anesthetics • Acetaminophen • Opioids (fentanyl, morphine) • Lidocaine

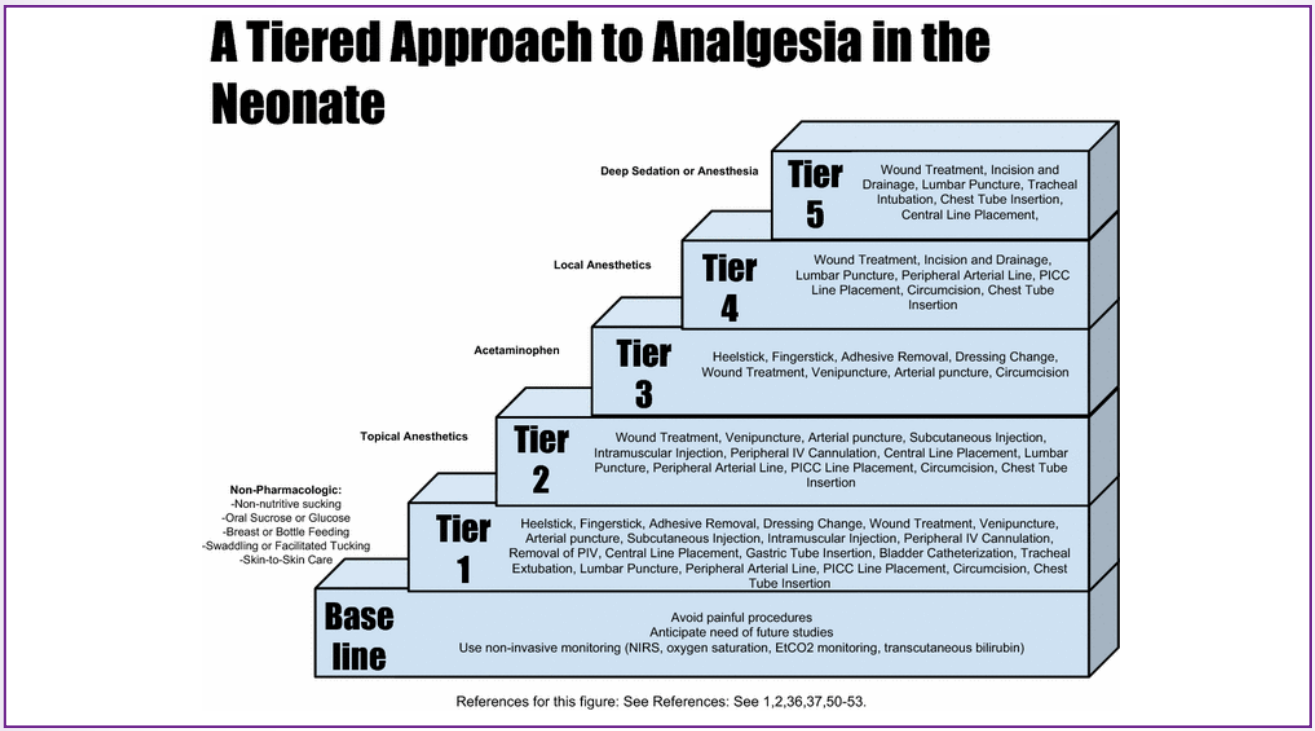
For minor procedures, utilize the 5 S's (e.g. blood draw, IV placement, and lumbar puncture):
- Give sugar water (1 teaspoon sugar in 20 ml clean water)
- Breast feeding
- Comfort measures (e.g. holding and swaddling)

For major procedures (e.g. intubation, chest tube insertion)
- Give morphine 0.02 mg/kg IV, may repeat x1
- ***NB: Morphine may cause dose related respiratory depression.***

For palliative care:
- Give morphine 0.1 mg/kg IV, may repeat as needed.
- Infants who have a devastating neurologic prognosis from congenital or acquired conditions require special consideration. The severity of the expected outcome must be explained to the family honestly and clearly.

[9]Harrington, John W, "Effective Analgesia Using Physical Interventions for Infant Immunizations," Pediatrics 129, no. 5 (2012).

Figure 2.8: A Tiered Approach to Analgesia in the Neonate[10]



Step 1: Non-pharmacologic measures: pacifier, oral sucrose, swaddling, kangaroo care (skin-to-skin contact with the mother), sensorial saturation
Step 2: Topical anesthetics: topical lidocaine, lidocaine-prilocaine cream, amethocaine gel, tetracaine gel
Step 3: Acetaminophen: orally (10-15 mg/kg per dose every 6 to 8 hours) or rectally (20-25 mg/kg per dose every 6 to 8 hours)
Step 4: Opioids: slow intravenous infusion of fentanyl (1-2 mcg/kg per hour) or morphine (10-30 mcg/kg per hour)
Step 5: Lidocaine: subcutaneous infiltration (0.5 mL/kg of 1 percent lidocaine solution **OR** 0.25 mL/kg of 2 percent lidocaine solution) or as nerve block step

[10]Witt, Norina et al, "A Guide to Pain Assessment and Management in the Neonate," *Current Emergency and Hospital Medicine Reports* 4, no. 1 (2016): 1-10, DOI: 10.1007/s40138-016-0089-y.

2.5 Non-Pharmacological Measures (Complimentary Therapy)

Non-pharmacological pain management is the management of pain without medications. This method utilizes ways to alter thoughts and focus concentration in clients to better manage and reduce pain. Methods of non-pharmacological pain management shall include:

- **Education:** Education of the client and family on the client's condition and ways to provide insight and support
- **Psychosocial care:** involves addressing the emotional/psychological, social-cultural, and social-legal needs of the patient and their family. These may include but not limited to: fear of pain/dying, sadness, diminished coping, changes in body image, helplessness, uncertainties, role loss, feeling of abandonment, financial worries, communication breakdown and family & future. Some of the key management approaches are: therapy/counseling, individual counseling, family counseling, restoring family communication through family meetings, recognition of the needs and making appropriate referral for social support, referral for legal support, companionship, music, art, or drama therapy, recognizing and respecting the unique cultural values and practices of the patient and family, formation of support groups and group counseling
- **Physical care:** exercises, hot/cold therapy, lotion/massage therapy, acupuncture, aromatherapy, positioning, etc.
- **Spiritual care:** this aims to address existential needs of patients and their families. Such needs may include, but are not limited to: questioning life's purpose/meaning; relationships with God, family, friends, community; feeling punished or abandoned by God; and existential suffering. Some of the key management approaches are: meditation and religious counseling, allowing practice or religious rituals such as prayer, holy communion etc, recognition of the needs and making appropriate referral to spiritual care workers.

Table 2.15: Non-Pharmacological Pain Management in Adults

Type	Approach and Impact
Dance therapy	Improves self-image and self-esteem Reduces stress, anxiety, and depression Decreases isolation, chronic pain, and body tension
Deep breathing	Easy technique to use with clients, particularly children
Distraction	Focusing the client's attention away from the pain
Pacing	Interrupting activities for short and frequent breaks[11]
Hot and cold therapy	Applying hot or cold compresses helps decrease pain

[11]Marie, Barbara St, "Pain management in patients receiving palliative care," Oncology Nurse Advisor (2013): e1.

Type	Approach and Impact
Massage therapy	Rubbing and manipulating muscles, which increase blood circulation and enhance relaxation ***NB: Avoid with certain conditions such as joint inflammation or injury, open wounds, skin infection, or phlebitis.***
Music therapy	Listening to music, creating music, singing, and discussing music Providing guided imagery with music can also be beneficial Relieves stress, apprehension, and fear
Physical therapy	Breathing exercises, walking, washing and fetching water build strength, maintain energy, and contribute to overall well-being
Positioning therapy	Changing position
Relaxation	Training and intentionally relaxing are psycho-physiological processes that reduce stress and pain
Reflection	Reflecting allows client to acknowledge and honor feelings as they arise
Social support	Supportive counseling, practical assistance such as the provision of aids for daily living, and accessing community resources and services, appropriate referrals
Emotional/ psychological support	Supportive counseling, grief and bereavement support and counselling, simply being there and listening
Spiritual and religious support	Managing spiritual problems Encouraging faith, allowing practice of religious rituals such as prayer and meditation depending on client's beliefs, encouraging a sense of forgiveness, giving hope and creativity, allowing practice in own faith or spiritual context including music, poetry, nature, appropriate referral
Other Non-Pharmacological Interventions	
Palliative surgery	Debulking tumors to reduce pain
Radiotherapy	Providing local radiotherapy to reduce local pain due to tumor infiltration
Reflexology	Stimulating and applying pressure to the feet or hands in the areas that correspond to the site of pain to relieve pain
Aromatherapy	Using essential oils to balance, relax, and stimulate the body, mind and soul (e.g. lavender oil can relive stress and help the client to relax, thereby reducing anxiety and pain)

Table 2.17: Non-Pharmacological Pain Management in Children

Type	Approach
Deep breathing	Asking child to take deep breath through the nose and blow it out through the mouth. Counting the child's respirations focuses child's attention on their breathing Asking school-age children during a painful procedure to hold their breath, which transfers focus to their breathing and away from the procedure
Distraction	Reading books, blowing bubbles, and counting Stroking, patting and rocking infants and children who are in distress
Music therapy	Providing different forms of music therapy to children who have an intimate understanding of music and respond well to different forms of music therapy

NB: Please refer to the online National Palliative Care Research Center for additional resources on pain and symptom management.[12]

[12]"Resources," The National Palliative Care Research Center, last modified 2013, http://www.npcrc.org/content/25/Measurement-and-Evaluation-Tools.aspx.

CHAPTER 3: SYMPTOM CONTROL

The general approach to symptom control in palliative care should include:
- Assessment for the possible cause and severity of the symptom
- Treatment of reversible causes and alleviation of irreversible causes
- Initiation of disease/symptom-specific medicines and non-pharmacological measures
- Involvement of the client and family on the management plan

Referred Practice: Assess and manage symptoms and side effects in a timely, safe and effective manner to a level acceptable to the client and family.

3.1 Anorexia and Cachexia

Anorexia is an eating disorder characterized by markedly reduced appetite or total aversion to food resulting in reduced nutritional intake secondary to chronic or malignant disease.[13]

Cachexia is a wasting disorder characterized by a debilitating state of involuntary weight loss complicating malignant, chronic infectious and inflammatory diseases that contributes to increased morbidity and mortality.

Anorexia or cachexia can lead to metabolic disturbances in the body such as hypercalcaemia or uraemia.

Table 3.1: Non-Pharmacological and Pharmacological Interventions for Anorexia and Cachexia

Causes	General Measures	Non-Pharmacological	Pharmacological
Underlying mechanisms are not fully understood Risk factors include: • Biological • Psychological • Developmental • Socio-cultural	• Ensure no anorexia or malnutrition due to reversible causes • Reduction in food and fluid intake is very normal as terminal phase is reached	• Support should be given to the family and client • Small, appetizing meals should be offered • Emphasis on fluid intake should be given	Corticosteroids may be of short-term benefit. For example: • Dexamethasone: 2-4mg once a day 5 days per os (by mouth) • Prednisolone: 10mg once a day for 5-7 days per os (by mouth)

[13] Tasmanian Government, Care Management *Guidelines Fatigue, Anorexia and Cachexia*, (Tasmania: Specialist Palliative Care Service, 2010), http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0006/36942/Care_Management_Guidelines_-_Fatigue_-_20160622.pdf.

3.2 Breathlessness

Breathlessness is a common and distressing symptom in advanced cancer and other life-limiting conditions, which can be extremely frightening to the client and family.

Table 3.2: Non-Pharmacological and Pharmacological Interventions for Breathlessness

Causes	Non-Pharmacological	Pharmacological
Respiratory: • Lung cancers • Pleural effusion • Pulmonary embolism Cardiac • Superior vena cava obstruction • Anaemia • Cardiac failure Other • Ascites that are secondary to treatment (radiotherapy, chemotherapy or pheumonectomy)	Adjust position – usually best to be sitting up Ensure good ventilation	Treat any reversible causes, if appropriate. Bronchodilators: by inhaler or spacer Steroids: e.g Dexamethasone oral 8-16 mg, stop if no effect after one week Opioids: in a client not taking an opioid, give oral morphine 2.5mg 4-6 hourly • In a client taking an opioid regularly for pain, give 25% of the 4 hourly breakthrough analgesic dose • Client with continuous breathlessness, give modified release (MST) morphine, plus a 4 hourly equivalent dose of immediate release Benzodiazepines: Diazepam 2-5mg PO, at night, only if anxiety is the problem

3.3 Delirium (Acute Confusional State)

Delirium is defined as disturbed consciousness and inattention with cognitive impairment; **acute onset and fluctuating course as a physiological consequence of disease or treatment**.

Studies have found that delirium can occur between 13 and 88% of palliative care clients. Delirium is more common at the end of life, which is known as 'terminal delirium'. [14]

The diagnosis of delirium depends mainly on careful clinical assessment. Health professionals should consider using the Mini-Mental State Examination, a 30-point questionnaire to measure a client's cognitive impairment. Health professionals should identify and manage irreversible causes of delirium and identify drugs that may instigate symptoms of delirium.

[14]Grassi, Luigi et al. "Management of delirium in palliative care: a review," *Current Psychiatry Reports* 17, no. 3 (2015): 550. doi: 10.1007/s11920-015-0550-8.

These strategies will help to promote imposed well-being and mental clarity, which is a desired state especially among terminally ill clients[15]. Table 3.3 outlines causes and non-pharmacological and pharmacological interventions for clients experiencing delirium.

Table 3.3: Non-Pharmacological and Pharmacological Interventions for Delirium

Causes	Non-Pharmacological	Pharmacological
• Uncontrolled pain • Changes in environment, leaving home, transfer from one ward to another • Metabolic disturbance (e.g. uraemia) • Infection (e.g. urinary tract infection, meningitis) • Medications (e.g. opioids, anticholinergics, steroids, benzodiazepines, antidepressants, sedatives) • Dementia • HIV encephalopathy	• Provide quiet area or side room; limit staff changes • Provide adequate lighting, minimize noise, provide a clock the client can see • Gentle repeated reorientation and avoid confronting deficits • Try to maintain normal sleep-wake cycle • Avoid physical restraint unless for reasons of client's safety • Support the family to be able to stay with the client and express their worries and fears	**First Choice:** Haloperidol • Dose 0.5-3mg oral or subcutaneous (SC) • Maintenance treatment: 0.5-3mg oral or 2mg SC, once daily. **Second choice:** Benzodiazepine • Diazepam 5mg 8-12 hourly

3.4 Constipation

Constipation is defined as the passage of small, hard feces infrequently or with difficulty, and less often than is normal for that individual.

[15]Hosker, Christian M G, and Michael I Bennett. "Delirium and agitation at the end of life," *British Medical Journal,* (2016):353. doi: https://doi.org/10.1136/bmj.i3085.

3.4.1 Management of Constipation in Adults

Table 3.4: Non-Pharmacological and Pharmacological Interventions for Constipation

Causes	Non-Pharmacological	Pharmacological
• Side effect of opioids • Intestinal obstruction • Decreased food intake and low-fiber diet • Dehydration • Hard feces, impaction or high obstruction (rectum is empty and ballooned), determined through rectal examination	• Encourage fluid intake and fruit, vegetables and fiber in the diet • Paw paw seeds dried and crushed: 1 teaspoon at night with water • Vegetable oil or margarine: 1 teaspoon at breakfast • Use a pellet of soap softened and inserted with petroleum jelly • Consider digital removal of feces	Prescribe prophylactic laxatives together with opioids, especially in adults: • **Bisacodyl:** 5mg at night (up to 20mg) • **Senna:** 1 to 2 tablets at night

3.4.2 Management of Constipation in Children

For children, an osmotically active laxative (e.g. Lactulose) is preferable to a stimulant laxative (e.g. Bisacodyl) as stimulants may cause severe abdominal pain in children.

Table 3.5: First, Second and Third Choice for Constipation Management in Children

First Choice	Second Choice	Third Choice
Try Lactulose, building the dose up over one week: 1 year of age: • 2.5ml 2 times daily (BD) 1-5 years of age: • 5mls BD 6-12 years of age: • 10mls BD Liquid paraffin:[16] Children under 3 years: • Not recommended, use is contra-indicated in children under 3 years of age Children over 3 years: • 5-20ml when required Adults including elderly: • 10-30ml when required	If no improvement, add **Senna**: 2 – 6 years of age: • 1 tablet BD per os 6 – 12 years of age: • 1 – 2 tablets BD per os	If already on opioids, use the second choice drugs immediately • If the stool is found to be hard through rectal examination, try a **Glycerine** suppository • If stool is found to be soft but not moving through rectal examination, try a **Bisacodyl** or **Senna** suppository • If the rectum is found to be empty through rectal examination, try a **Bisacodyl** suppository to bring the stool down or a high-phosphate enema • For severe constipation, try phosphate enema or a bowel prep product

[16]Liquid Paraffin BP," Medicinesonline, last modified April 13, 2015, https://www.medicines.org.uk/emc/product/4904/smpc.

3.5 Diarrhoea

Diarrhoea is defined as the passage of more than three unformed stools within a 24-hour period.

Table 3.6: Non-Pharmacological and Pharmacological Interventions for Diarrhoea

Causes	Non-Pharmacological	Pharmacological
• Imbalance of laxative therapy • Malabsorption • Concurrent disease • HIV	• Increase fluid intake where possible • Exclude and treat any specific causes	• Discontinue laxatives if prescribed and review • If due to antibiotics, give Metronidazole 400mg 3 times per day (tds) for 7-14 days • If necessary, give Loperamide 2mg, 4mg stat, then 2 mg after each lose stool • If blood is present in a child's stool, give Metronidazole in areas where amoebic dysentery is prevalent

3.6 Depression

Depression is characterized by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, feelings of tiredness and poor concentration. Depression is often misunderstood, under-diagnosed and under-treated.

Health professionals should consider the following interventions to manage cases of depression that require anti-depressant medication and/or psychiatric referral, as described further in Table 3.7:

- Provision of ongoing support and counseling
- Provision of antidepressants for 2-4 weeks, as antidepressants take several weeks to be effective

Table 3.7: Non-Pharmacological and Pharmacological Interventions for Depression

Causes	Non-Pharmacological	Pharmacological
• Low mood more than 50% of each day • Loss of any enjoyment or interest • Excessive or inappropriate guilt • Thoughts of suicide or death • Disturbed sleep • Appetite loss (or increase) • Poor concentration • Irritability or being angered easily • Loss of energy	Counseling and ongoing support	**First line are Selective Serotonin Reuptake Inhibitors (SSRIs), due to fewer side effects:** • **Fluoxetine:** 20mg /day. May be increased by 20mg/day, if required. Maximum 60mg/day. **IF SSRIs have been used with no improvement, provide Tricyclic anti-depressants (TCAs):** • **Amitriptyline:** Start with 25mg at night and increase gradually to 75-150mg (the anti-depressant effect is unlikely to be seen at less than 75mg)

NB: Refer to 2016 Mental Health Desk Guide (pg. 11-14)

3.7 Chronic Fatigue

Chronic fatigue is a complicated disorder characterized by extreme fatigue that cannot be explained by any underlying medical condition. The fatigue may worsen with physical or mental activity, but does not improve with rest. Chronic fatigue is very common in people with advanced disease.

Table 3.8: Non-Pharmacological and Pharmacological Interventions for Fatigue

Causes	Non-Pharmacological	Pharmacological
• Multiple causes, often obscured by coexisting disease processes • Anaemia • Pain • Emotional distress • Sleep disturbances • Poor nutrition	• Try to manage lifestyle around the periods of greater energy or fatigue • Energy conservation and physical exercise, and stress reduction by relaxation and meditation	• Treat the underlying cause of the fatigue where possible (e.g. if anemic, give blood transfusion as appropriate) • Can give low doses of psycho-stimulants (e.g. Fluoxetine)

3.8 Insomnia

Insomnia is a subjective complaint of inadequate nocturnal sleep, manifested as difficulty initiating or maintaining sleep, early-morning awakening, non-restful sleep or a combination of all of these. It is common in those with advanced disease.

Table 3.9: Non-Pharmacological and Pharmacological Interventions for Insomnia

Causes	Non-Pharmacological	Pharmacological
• Transient: secondary to life crisis, bereavement, illness • Chronic: associated with medical or psychiatric disorders, drug intake or maladaptive behavioral patterns • In advanced disease, it emerges as a psychological or physiological side effect of diagnosis and/or treatment	• Try to reduce the intake of nicotine, caffeine and other stimulants and avoid alcohol near bedtime • Exercise regularly in the earlier part of the day	• Lorazepam: 0.5-2mg; half-life 10-22 hours • Diazepam: 2.5-10mg; half-life 20-50 hours Note: However, these medications are not indicated for long-term treatment of chronic insomnia because of the risk of tolerance, dependency and other side effects.

3.9 Nausea and Vomiting

Nausea is the unpleasant sensation of being about to vomit and can occur alone or can accompany vomiting.

Vomiting is the forceful expulsion of gastric contents.

Health professionals should determine that the client is reporting nausea and vomiting as opposed to dyspepsia, retching or regurgitation to determine appropriate treatment.

Table 3.10: Non-Pharmacological and Pharmacological Interventions for Nausea and Vomiting

Causes	Non-Pharmacological	Pharmacological
• **Pharmaceutical:** opioids, digoxin, anticonvulsants, antibiotics • **Toxic:** infection, radiotherapy, chemotherapy • **Metabolic:** hypercalcaemia, ketoacidosis, renal failure • **Physical:** intracranial pressure, intestinal obstruction, gastric stasis	• Ensure client is in well-ventilated areas, to avoid smells permeating which can trigger nausea and vomiting • Avoid the eating of big meals and encourage small appetizing meals • Avoid spicy or fatty meals • The acupressure point for nausea and vomiting is situated 2-3 fingers down from the top crease of the wrist in the groove between the two tendons • Take your thumb and index or middle finger and press firmly on points on both sides of the wrist when nauseous feelings persist	• Use a step-wise approach to prescribing antiemetic medication, depending on client assessment and pattern of symptoms • Refer to Table 3.11 for dosage for adults and children

Table 3.11: Pharmacological Dosage for Nausea and Vomiting for Adults and Children

Pattern	Causes	Suggested medications in adults	Suggested medications in children
Gastric stasis or poor stomach empting: • Vomiting is main symptom • Vomiting often relieves nausea • Client often feels full quickly when eating • May have gastro-oesophageal reflux	• Medications such as morphine • Constipation • Squashed stomach syndrome due to liver enlargement or large volume ascites	• Metoclopramide: 10-20mg 8hrly before meals • Consider Dexamethasone 8mg daily if squashed-stomach syndrome	• Metoclopramide: 1-2 years: 300mcg/kg by mouth (po) in the three divided doses • 12 years and above: less than 60kg: 5mg po tds • Manage GERD by thickening feeds, maintaining upright position after feeds and using an antacid
Blood chemistry disturbances or toxins: • Intractable nausea is the main symptom • Vomiting often does not relieve nausea	• Medications such as morphine • Renal failure • Hypercalcaemia • Liver failure	• Haloperidol: 1.5mg-5mg at night • Prochloperizine: 5-10mg 8hrly	Haloperidol (Oral): • **Less than 12years:** 0.025mg-0.05mg/kg per os per day in two or three divided doses. • **More than 12 years:** 1-4mg per os at nights • Odansetron or Granisetron for chemotherapy-related nausea and vomiting
Raised intracranial pressure: • May be worse in the morning • May be worse on movement • Vomiting does not relieve nausea	• Intracranial tumors or infections such as toxoplasmosis • Meningitis such as TB or Cryptococcus • Malaria	• Dexamethasone 8-16mg daily (give in the morning to avoid disturbing sleep, and take care in prescribing if untreated infections) • Promethazine 25mg 8hrly	• Dexamethasone: 0.03-0.2mg/kg per day in 2-4 divided doses • Haloperidol (as above)

Remember, clients may have more than one cause of nausea and may need more than one antiemetic. This decision can be based on determining the cause of the nausea and vomiting (bodily site) and then identifying the particular drugs which block the receptor at the bodily site.[17]

[17]Glare, Paul, Jeanna Miller, Tanya Nikolova, and Roma Tickoo. "Treating nausea and vomiting in palliative care: a review," *Clinical Interventions in Aging 6* (2011): 243.

3.10 Sore Mouth

A sore mouth is very common in palliative care and may be severe in clients with HIV and AIDS or who are receiving chemotherapy or radiotherapy.

Table 3.12: Non-Pharmacological and Pharmacological Interventions for Sore Mouth Symptoms

Causes	Non-Pharmacological	Pharmacological
• Infections such as candidiasis or herpes simplex • Mucositis due to radiotherapy or chemotherapy • Ulceration • Poor dental hygiene • Dry mouth due to medication, damage to salivary gland due to radiotherapy or tumour, or mouth breathing • Iron deficiency • Vitamin C deficiency	• Keep the mouth clean and treat any infections promptly • Check the mouth, teeth, tongue, palate and gums regularly for dryness, inflammation, ulcers, and infections • Avoid harsh brushing, use a soft brush or a soft cloth instead • Sucking ice or piece of fruit can help dry the mouth • Clients should eat soft and liquid food to promote good nutrition	A simple mouth wash with sodium bicarbonate or saline (a pinch in a glass of water is sufficient) can be very effective

3.11 Malnutrition

Malnutrition is caused by a significant imbalance in the nutritional intake leading to diminished bodily function.

Immediate Causes	Type of Malnutrition	Interventions
• Insufficient dietary intake • Infections, infestations and other diseases	Severe acute malnutrition: • **Pediatrics:** Weight for height <70% and/or a mid-upper arm circumference of < 11cm and presence of pitting bilateral oedema • **Adults:** BMI <16 and mid upper arm circumference of <19cm and weight loss of >10% body weight in a month	• Nutrition support has been shown to benefit palliative care clients by reducing physical deterioration, improving quality of life, and preventing the emotional effect of "starving the client to death". • Palliative care clients of all age groups shall be encouraged to eat the three food groups. Locally available foods are recommended. The successful management of these food interactions requires understanding of clients' individual food access as well as eating habits.

Immediate Causes	Type of Malnutrition	Interventions
	Moderate acute malnutrition: • **Pediatrics:** Weight for height <80% and/or a mid-upper arm circumference of < 12cm • **For adults:** BMI 16-18.5	• Management of clients shall include assessment and counseling on feeding with regard to the nutritional needs specific to the stage of the illness. • Guardians shall be counseled on appropriate feeding according to the stage of the illness.

3.12 Palliative Care Emergencies

3.12.1 Metastatic Spinal Cord Compression (MSCC)

This guidance applies only to cancer clients.

Metastatic Spinal Cord Compression (MSCC) occurs when there is pathological vertebral body collapse or direct tumor growth causing compression to the spinal cord or cauda equine.[18] Clients with suspected MSCC must be assessed as a priority in order to prevent severe and irreversible neurological damage. If MSCC is suspected, the **Acute Oncology Service must be contacted urgently**. Consider this possible diagnosis in any cancer client who goes 'off legs'.

[18]National Collaborating Centre for Cancer (UK), "Metastatic spinal cord compression: diagnosis and management of patients at risk of or with metastatic spinal cord compression," (2008).

Table 3.14: Metastatic Spinal Cord Compression Recognition and Treatment

Recognition	Late Symptoms/Signs	Immediate Action	Referral for Investigation (for client at home or already in hospital)
• Act promptly on clinical grounds. • Do not be reassured by X-rays, as these are normal in 10-20% cases. • Do not wait for late symptoms/signs to appear • Pain: severe, recent onset or worsening, felt as a band around the body or radiating down arm(s) or leg(s), exacerbated by coughing or straining, not relieved by rest. Often precedes neurological signs. • The diagnosis of spinal cord compression should be considered in any cancer client with severe back pain in a nerve root distribution.	• Limb weakness, altered gait, unsteadiness, falls • Urinary retention, dribbling or incontinence; fecal incontinence or constipation • Altered or reduced sensation • Cauda equina syndrome, tumor pressure below L1/L2 • Sciatic pain, often bilateral • Weakness/wasting of gluteal muscles • Bladder problems including retention, overflow and incontinence • Sacral (saddle) anesthesia, loss of anal sphincter tone	• Give Dexamethasone 16mg (oral/IV) unless contraindicated (this dose volume is too large to be tolerated as a single subcutaneous injection). Do not delay giving in order to get IV in community. • Prescribe protein pump inhibitor (PPI) for gastric protection (esp. if GI pathology, NSAIDs, or warfarin) • Give adequate analgesia to enable comfortable transfer for admission/ investigation • Nurse flat if mechanical pain or neurological symptoms/signs suggest spinal instability	• This applies especially to clients who present with severe weakness/ paralysis or who may be too frail for definitive treatment • When indicated whole spine MRI must be done within 24hrs • Clients will need admission to achieve this • In case clients transferred for MRI do not require treatment, a bed must be retained at the referring hospital • **If Metastatic Spinal Cord Compression is diagnosed:** ✓ Urgently contact the Acute Oncology Service to ensure the client is managed on the correct pathway ✓ Definitive treatment, where indicated, must begin within 24hrs

3.12.2 Malignant Hypercalcaemia

This guidance applies only to clients with a known cancer diagnosis.

Table 3.15: Malignant Hypercalcaemia Recognition and Treatment

Recognition	Clinical Presentation	Immediate Action	Drugs of Choice (local guidance applies)	Follow up
• Exclude any client with advanced cancer whose condition deteriorates rapidly • Onset may be insidious and symptoms not evident until corrected calcium well above normal • It is the commonest, paraneoplastic syndrome in clients with advanced cancer, occurs in 10% of cancer clients	• Confusion, drowsiness, and eventually coma • Thirst and polyuria • Dehydration may lead to prerenal failure • Nausea and vomiting • Constipation • Worsening pain or pain responding poorly to treatment	• **Assessment** ✓ Check corrected calcium level in venous blood. Normal < 2.60 mmol/L ✓ Corrected calcium = {serum calcium} + {(40 - serum albumin g/L) x 0.025} ✓ If normal but clinical suspicion remains, recheck in 1 week. Also, check renal function (U&E) • **Management** ✓ Admit to hospital/ hospice unless it is agreed that intervention is not appropriate	• **First Episode:** Disodium Pamidronate: 30-90mg IV in 500ml saline over 2hrs ✓ If effective, this can be repeated for subsequent episodes. ✓ If ineffective or improvement short-lived: Consider a higher dose of Pamidronate or Zoledronic acid 4mg IV in 100ml saline over 15 minutes ✓ (Reduce dose if renal impairment – see manufacturer's SPC for guidance) • **Side effects:** ✓ See British National Formulary (BNF).	• Expect clinical improvement in 24-72 hours. Check for biochemical improvement in 4-7 days. • After 7 days, if no clinical/ biochemical response consider giving further 4 mg Zoledronic acid IV in 100ml of saline. • On discharge ask primary care team to monitor for symptoms and check calcium if clinical suspicion. Also, monitor renal function. • Consider prophylaxis with oral bisphosphonate.

Table 3.15: Malignant Hypercalcaemia Recognition and Treatment (continued)

Recognition	Clinical Presentation	Immediate Action	Drugs of Choice (local guidance applies)	Follow up
• May occur in the absence of bone metastases. Strongly associated with breast, lung, haematological and genitourinary tract malignancies. • Reflects poor prognosis. Median survival 3-4 months, worse if resistant to treatment.		✓ Stop thiazide diuretics – may increase calcium levels ✓ Rehydrate with IV 0.9% saline. Aim for 2-4L/day. Caution if co-morbidities risk fluid overload. ✓ After 1-2 litres saline (to prevent renal damage) give IV bisphosphonate	✓ Flu-like syndrome/ pyrexia is common - treat with paracetamol. ✓ Osteonecrosis of jaw is a rare but a significant side effect. Rebound hypocalcaemia may occur.	• Resistant/ refractory hypercalcaemia may be an end of life event. If so, treat symptoms appropriately.

3.12.3 Major Haemorrhage

This guidance applies only to cancer clients.

Table 3.16: Major Haemorrhage Recognition and Treatment

Recognition	Clinical Presentation	Anticipatory Management	Immediate Action	Follow up
• Bleeding of all types occurs in 14% of clients with advanced disease • Haemorrhage causes death in approximately 6% clients • Catastrophic external haemorrhage is less common than internal unseen bleeding	• Cardiovascular compromise – Hypotension, Tachycardia (>100 beats/min = significant recent bleed) • Identifiable bleeding source, e.g. hematemesis, melaena, hemoptysis, vaginal bleeding (PV bleeding) or rectal bleeding (PR bleeding), hematuria • Erosion of an artery by a malignant ulcer or superficial/fungating tumour	Massive haemorrhage is often preceded by smaller bleeds. Oral/topical treatment may help (See Follow Up). • Review resuscitation status and document decision • Consider stopping anticoagulants • Always monitor international normalized ratio (INR) closely if warfarin continues. Correct any coagulation disorder if possible • Consider referral for radiotherapy or embolisation if client has an erosive tumor	• If a client is close to death from underlying cancer, it is usually appropriate to regard major haemorrhage as a terminal event and not to intervene with resuscitation measures. • Advance decisions or statements (e.g. regarding preferred place of death) should be observed. • **If resuscitation is inappropriate:** ✓ Try to remain calm-this will help a dying client to achieve a peaceful death ✓ Stay with the client, giving as much reassurance/explanation as possible to client and family ✓ Use dark towels to absorb blood loss	• Ensure support available for family and staff following experience of haemorrhage • If the client survives the haemorrhage and remains stable for 24-48 hours, consider transfusion • To prevent re-bleeding: • **ORAL:** Tranexamic acid 1g every 8 hours (avoid in hematuria), OR Etamsylate 500mg every 6 hours

Table 3.16: Major Haemorrhage Recognition and Treatment (Continued)

Recognition	Clinical Presentation	Anticipatory Management	Immediate Action	Follow up
		• Try to discuss possibility of haemorrhage with the client/family. This may enable discussion of options for preferred place of care if haemorrhage occurs or risk of haemorrhage increases. • Dark towels should be available nearby to reduce the visual impact of blood if haemorrhage occurs. • Although confident reassurance and support is most helpful in a crisis like this, it can be useful to have Midazolam available (10mg IV/ IM/buccal/sublingual) with appropriate prescription authorization.	**If resuscitation is appropriate:** ✓ Admit as emergency, secure IV access ✓ Start rapid infusion of 0.9% saline ✓ Crossmatch and follow local haemorrhage protocols ✓ Apply local pressure to any obvious bleeding ✓ Seek specialist help on further management	• **TOPICAL:** Sucralfate paste applied direct to ulcer under non-adherent dressing; Adrenaline 0.1% (1mg/ml) soaks (10ml on gauze); Tranexamic acid (500mg/5ml of injectable formulation). • Consider diathermy, radiotherapy or embolization

3.12.4 Malignant Superior Vena Cava Obstruction (SVCO)

This guidance for superior vena cava obstruction (SVCO) applies only to clients with a known cancer diagnosis.

Table 3.17: Malignant Superior Vena Cava Obstruction Recognition and Treatment

Recognition	Clinical Presentation	Immediate Action	Follow Up
• 95% of cases of SVCO are caused by malignant tumor in the mediastinum preventing venous drainage from the head, arms and upper trunk. SVCO most commonly occurs in lung cancer clients. SVCO also occurs in lymphoma clients and in clients with cancers metastasizing to mediastinal lymph nodes. • Onset usually over weeks or months, but occasionally occurs rapidly over days.	• Facial swelling, redness, headache, periorbital oedema, engorged conjunctivae • Swelling of the arms, prominent distended veins on neck and chest wall • Breathlessness, cough, chest pain, stridor, cyanosis • Other symptoms e.g. dysphagia, visual disturbance	• If SVCO is suspected: Give Dexamethasone 16mg stat (oral or IV) and continue 16mg daily as morning dose Give proton pump inhibitor (PPI) for gastric protection (esp. if gastrointestinal (GI) pathology, NSAIDs or warfarin) Discuss with the local Acute Oncology Team urgently, unless the following applies: If the client presents with features of SVCO towards the end of life and is too unwell for transfer/hospital intervention, or does not wish to be admitted to a hospital, consider treatment with dexamethasone and anticoagulation with low molecular weight heparin at treatment dose, at home • **If SVCO suspected in hospital:** Relieve the acute symptoms with steroids, oxygen and other symptomatic measures. Seek specialist opinion from the **Acute Oncology Team** who will arrange appropriate management.	• If the obstruction is resolved by stent insertion or other intervention, dexamethasone should be reduced gradually and stopped. Consider ongoing prophylactic anticoagulation. • If the obstruction cannot be resolved with intervention, dexamethasone should be gradually reduced to the lowest dose that helps with symptoms

CHAPTER 4: SPECIAL CONSIDERATIONS FOR PALLIATIVE CARE

4.1 Management of Diabetes at the End of Life

Discuss changing the approach to diabetes management with client and/or family if not already explored.

Table 4.1: Diabetes Type 1 and Type 2 Management

Type of Diabetes	Management
Type 1	• Check blood sugar monthly or if clinically indicated • Continue once daily long acting insulin analogue with reduction in dose.
Type 2 diet controlled	• Check blood sugar monthly or if clinically indicated
Type 2 on tablets and/ or insulin:	• Limit/stop oral hypoglycemics • Consider stopping insulin depending on dose

NB: Refer to (page 53) for further detail on end of life care.

NOTE: Keep invasive tests to a minimum.

4.2 Palliative Care for PLHIV

Persons living with HIV (PLHIV) have palliative care needs at each stage, from diagnosis throughout the disease trajectory. As they are living longer, there is also a need to respond to HIV-related cancers.

Table 4.2: Common Sources of Pain in PLHIV

Cutaneous/Oral	Visceral	Somatic	Neurological
• Kaposi sarcoma • Oral cavity pain • Herpes zoster • Oral/ oesophageal candidiasis	• Tumors • Gastritis • Pancreatitis • Infection • Biliary tract disorders	• Rheumatological disease • Back pain • Myopathies	• HIV-related headaches: encephalitis, meningitis, etc. • HIV-unrelated headaches: tension, migraine, etc. • Latrogenic (AZT) • Peripheral neuropathy • Herpes neuritis • Neuropathies associated with didanosine and stavudine toxicities • Alcohol, nutritional deficiencies

4.2.1 Pain Assessment and Management in HIV-Positive Clients

In HIV-positive clients, the assessment and management of pain follows the WHO principles. Some people with HIV and AIDS also have cancer. It is therefore important to be aware of specific pain-related syndromes in HIV and cancer as well as those related to treatment interventions.

Table 4.3: Specific Pain-Related Syndromes in HIV

Pain Type	Clinical Presentation	Causes	Treatment
Peripheral neuropathy	• Burning pain in hands and feet • Pins and needles • Allodynia (the experience of pain from a stimulus that would not usually cause pain in a normal individual) • Pain relieved by local pressure	• HIV itself (distal sensory neuropathy) • Cytomegalovirus nerve entrapments, carpal tunnel syndrome • Post-herpetic neuralgia • ARVs, especially didanosine and stavudine • Other treatments: chemotherapy, Isoniazid, Metronidazole	• Remove offending agents if possible: change stavudine or didanosine to TDF • Treat herpes zoster early with acyclovir to limit post-herpetic neuralgia • Use WHO analgesic ladder—NSAIDs and opioids • Gabapentin in resistant cases • Try topical analgesics • For localized neuropathies-nerve block
Abdominal pain in HIV	Abdominal pain in HIV	• TB abdomen • Mycobacterium avium complex • Pancreatitis • Peptic ulcer disease • GORD • Gall bladder and biliary tract disease • Malabsorption syndromes • Drug side-effects • Neuropathic abdominal pain (diagnosis of exclusion)	• Diagnose and treat underlying cause if possible • Start ARVs if indicated • Treat pain according to WHO analgesic ladder • Beware of ileus/constipation caused by opioids: can make pain worse • Remember morphine causes contraction of sphincter of Oddi, so pethidine is a better choice in pancreatitis • For immune reconstitution inflammatory syndrome (IRIS), try low-dose steroids • Beware of NSAIDs and gastritis

Table 4.3: Specific Pain-Related Syndromes in HIV (Continued)

Pain Type	Clinical Presentation	Causes	Treatment
Muscle spasm in HIV	Muscle spasm	• Caused by HIV itself in the form of HIV encephalopathy with increased tone • Secondary to cerebral insults from bacterial or tuberculosis meningitis	• ARVs • Levodopa (extrapyramidal dysfunction) • Analgesics (Step II: non-opioid + weak opioid) • NSAIDs may help for musculoskeletal pain • Baclofen (for muscle spasm, can cause seizures) • Adjuvants, especially Clonazepam
Raised intracranial pressure	Headache with focal neurological deficits	• Cryptococcal meningitis • Toxoplasmosis	• Treat pain according to WHO analgesic ladder • Morphine and Pethidine are contraindicated for raised intracranial pressure • Lumbar puncture is essential to control intracranial pressure from cryptococcal meningitis
Opportunistic infections	Common opportunistic infections include • TB • Cryptococcal meningitis • Pneumocystis jiroveci pneumonia • Kaposi sarcoma • Cervical cancer • Recurrent bacterial pneumonia • Recurrent oral candidiasis • Oesophagael candidiasis • Herpes zoster • Toxoplasmosis **NB: Refer to Swaziland Standard Treatment Guidelines for detailed management of other opportunistic infections not mentioned here.**	• Clients with advanced immunodeficiency	• Treat adults and children with Co-trimoxazole preventive therapy (CPT) • If client has history of severe allergic reaction to sulphur, do not give client CPT and treat with dapsone instead. • **NB: See HIV Management Guidelines 2018 (pg. 70-73) for specific information on dosing, toxicity, stopping of CPT, and CPT desensitization.**

Table 4.4: Pharmacological Management of Neuropathic Pain

Amitriptyline: Adults: 10-75 mg or 0.5–2 mg/kg at night (then increase slowly as needed).

Sodium valproate: Adults: 200 mg–1.2g once a day

Gabapentin: Adults: 300-400 mg in divided doses, increase gradually according to response. Maximum 2400 mg/day.

If sodium valproate and gabapentin are not available, carbamazepine can be used, but it should be noted that carbamazepine can interact with DTG and EFV. Carbamazepine: Adults: start at 100 mg twice a day and can be increased up to 800 mg twice a day.

NB: For drug interactions refer to ART guidelines

4.3 Management of Tuberculosis (TB) in Palliative Care

Although TB is curable, according to the WHO it is the major cause death in people infected with HIV.

Table 4.5: Key Aspects to Consider in People with TB in Palliative Care

Pain control – Identify and treat the cause as indicated in the section on pain control.

Nausea and vomiting – Identify and treat the specific cause.

Night sweats – These can be severe and require frequent changes of bed linen and pajamas.

Nutritional support – Encourage small frequent meals. If possible, arrange for nutritional supplements and food parcels for impoverished clients

Weight – Monitoring weight gain is important in terms of assessing whether the client is responding to TB treatment or not. Suspect drug resistant TB if there is no weight gain within a few weeks of starting on TB treatment.

4.4 Wound Care in Palliative Care

Management of wounds in palliative care can be complicated because of the advanced nature of the underlying disease or condition. Treatment needs to be appropriate to the stage of the client's disease.

Table 4.6: Management of Wounds in Palliative Care

Type of wound	Management
Pressure sores	• Prevent by frequent (2 hourly) changes of position in bed-ridden clients who are too weak to turn themselves • Keep skin clean and dry • If available, use an egg crate foam mattress to reduce pressure • Avoid further pressure on ulcerated areas • Analgesia • Clean wounds with a normal saline solution as needed (prn) – apply appropriate dressings; use local remedies, e.g. pawpaw or honey • Systemic antibiotics if there are signs of infection • Improve nutrition to promote healing • Antibiotics for infected wounds • Metronidazole tablets, crushed and sprinkled on odorous wounds
Fungating	• Analgesia • Treat topically with Metronidazole • Charcoal dressings • Fresh air • Psychological therapy • Radiotherapy
Fistulas	• Analgesia • Odour control • Fistula repair, where possible

4.5 Infection Prevention and Control

Palliative care services shall operate in accordance with Eswatini National Infection Prevention and Control Strategy. Policy and standard guidelines should be put in place to minimize the risk of infections in clients, families and care providers in order to promote a safe caring environment.

4.6 Psychosocial and Spiritual Support

Caring for clients with chronic illness involves responding to their total needs, including:

- **Social needs:** individual sense of belonging, role in family, community, society at large and friendships.
- **Physical needs:** basic needs such as food, shelter and clothing and also adequate health care, security, and protection from physical pain.

- **Spiritual needs:** the individual's hope for the future, sense of trust, hope for survival and sense of meaning.
- **Emotional needs:** love, security, encouragement, motivation, care, self-care, trust, guidance and understanding.

4.7 Depression

Table 4.7: Depression Assessment Questions

Depression Assessment
Ask the following two questions at each visit:
English: In the past two weeks
1. Have you felt sad, depressed and hopeless?
2. Have you lost interest or pleasure in the things that you usually enjoy?
SiSwati: Kulamaviki lamabili lendlulile, ukhatsateke kangakanani ngaletinkinga letilandzelako?
1. Kutiva uphansi emoyeni, ukhatsatekile nome ute litsemba
2. Kunchishelwa ngumdlandla/Inshisekelo ekwenteni tintfo letikuchazako/letikujabulisako
If 'no' to both questions, then client has no depression. If 'yes' to at least one question, complete the Depression Client Health Questionnaire and Scoring in Tables 4.8—4.10.

Table 4.8: Depression Client Health Questionnaire (SiSwati)

Sebentisa nalu luphawu kuphendvula				
	Akukake kwenteka	**Emalanga lambalwa**	**Lokungetulu kweliviki (7 days)**	**Cishe onkhe emalanga**
Kuncishelwa ngumdlandla/inshisekelo ekwenteni tintfo letikuchazako/letikujabulisako	0	1	2	3
Kutiva uphansi emoyeni, ukhatsatekile noma ute litsemba	0	1	2	3
Bulukhuni bekwehlelwa butfongo noma kuphelelwa butfongo noma kuba nebutfongo lobuningi	0	1	2	3
Kutiva udziniwe noma uphelelwa ngemandla	0	1	2	3
Kungakhanuki kudla (inhlitiyo imnyama) noma kudla kakhulu	0	1	2	3
Kuva utisola/utenyanya noma usehluleki noma utentele phansi noma wentele phansi umndeni wakho	0	1	2	3
Kuba nebulukhuni kubeka umcondvo/kulandzelela etint-fweni lotentako, letinjengekufundza liphephandzaba noma kubukela mabonakudze (TV)	0	1	2	3
Kuhamba kancane noma kunamula lokunakekako kulabanye bantfu. Noma kungahlaliseki kangangekutsi uhlala uphitsitela lokungetulu kwalokutayelekile	0	1	2	3
Kuba nemicabango yekutsi kuncono kufa, noma ucabange kutilimata	0	1	2	3
SEKUKONKHE:				

Sisebenti setemphilo; kutfola inchazelo ngemphumela buka luhla lwetinchazelo ngemuva kuhlatiya umphumela.

Nangabe ubeke luphawu kulenye yaletinkinga, kwente kwaba lukhuni kangakanani kutsi wente umsebenti, unakekele kahle likhaya noma uphil¬isane kahle nebantfu.

Akukabi nebulukhuni
Kube lukhunyana
Kube lukhuni kakhulu
Kube lukhuni ngalokwecile

Table 4.9: Depression Client Health Questionnaire (English)

Over the last 2 weeks, how often have you been bothered by any of the following problems?				
	Not at all	**Several days**	**More than half the days**	**Nearly every day**
Little interest or pleasure in doing things	0	1	2	3
Feeling down, depressed, or hopeless	0	1	2	3
Trouble falling asleep, or sleeping too much	0	1	2	3
Feeling tired or having little energy	0	1	2	3
Poor appetite or overeating	0	1	2	3
Feeling bad about yourself or that you are a failure or have let yourself or your family down	0	1	2	3
Trouble concentrating (on things linked with your usual activities)	0	1	2	3
Moving or speaking so slowly that other people could have noticed, or, on the contrary, being fidgety, restless, or moving around a lot more than usual	0	1	2	3
Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
TOTAL:				

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all...
Somewhat difficult...
Very difficult...
Extremely difficult...

Table 4.10: Depression Assessment Score

Client Health Questionnaire Score	Provisional Diagnosis	Recommendation
5-9	Minimal symptoms	Support and educate to all for support if symptoms get worse.
10-14	Minor to mild depression or chronic depression (symptoms lasting for 2 years)	Support and watchful waiting. Reassess in 1-2 weeks. Consider starting treatment for psychological support.
15-19	Major depression	Refer to social workers/psychologist/nurse. Needed for specific treatment.
>20	Severe depression	Major impairment, need for active treatment.

4.8 Anxiety

Be alert to possible anxiety disorders, especially in people with a history of anxiety disorder, or who have experienced a recent traumatic event

Table 4.11: Anxiety Client Assessment Questions

Use this quick reference to assess the possibility of anxiety

English
Over the last 2 weeks, how often have you been bothered by the following problems?
1. Feeling nervous, anxious or on edge
2. Not being able to stop worrying

Does the client also have 3 or more of the following symptoms?

- Restlessness
- Easy fatigue
- Difficulty concentrating
- Irritability
- Muscle tension
- Insomnia

siSwati
Esikhatsini lesingange maviki lamabili, kube kangakhi utivela uhlushwa nguletimo letingentansi?
1. Kutivela wetfwele nmatima emoyeni, nobe wesaba, nobe wetfukile
2. Kungakhoni kukhweshia kukhatsateka emoyeni

If client answer YES to any of these questions, suspect anxiety and provide counseling.
Refer client to mental health professional for further assessment.

Refer to 2016 Mental Health Desk Guide (pg. 15-16)

Table 4.12: Non-Pharmacological and Pharmacological Management of Depression and Anxiety

Non-Pharmacological	Pharmacological
• Dedicate time for discussion • Explore client's preferred method of treatment • Explain the disorder • Explore support mechanism	First line: SSRIs • Anxiety and Agitation: Lorazepam Second line: TCAs • Depression: Mirtazapine

4.9 End of Life Care

It is important to manage the terminal phase well because it is beneficial to the client, the family and to the health worker.

The goals of end of life care are to:
- Recognize that dying is normal and a part of life
- Neither hasten nor postpone death
- Achieve the best quality of life in the time remaining
- Achieve good control of pain and other symptoms
- Help the dying client and loved ones adjust to the "many losses" they face
- Ensure a dignified death with minimal distress
- Provide support and help cope with bereavement

Table 4.13: Non-Pharmacological and Pharmacological Management of End of Life

Signs and symptoms of impending death	Non-Pharmacological Management	Pharmacological Management
Social withdrawal As death approaches, • Client may talk less • Becomes less involved in the activities around them	Prepare the family for this phase in the dying process to prevent misunderstandings and to enable caregivers to continue supporting the dying person.	No pharmacological treatment required
Reduced dietary intake	Remind the family that the client is not hungry; food is unappealing or nauseating; that the client would likely eat if he or she could; that the client's body is unable to absorb and use nutrients; and that clenching of teeth may be the only way for the client to express his/her desire not to eat.	No pharmacological treatment required

Table 4.13: Non-Pharmacological and Pharmacological Management of End of Life (continued)

Signs and symptoms of impending death	Non-Pharmacological Management	Pharmacological Management
Pain	Provide comfort and spiritual care	Refer to pain management section
Respiratory changes	• Reassure the family that this is a natural process of death • Position client in recovery position/ semi fowler's position	No pharmacological treatment required
Organ shut down	The body begins the final process of shutting down, which will end when all the physical systems cease to function. Usually this is an orderly and undramatic progressive series of physical changes which are not medical emergencies requiring invasive interventions. These physical changes are a normal, natural way in which the body prepares itself to stop, and the most appropriate kinds of responses are comfort enhancing measures.	No pharmacological treatment required
Neurological dysfunction	Keep the client safe and educate the family, as the agitation can be very distressing to them.	No pharmacological treatment required

NB: Refer to the Palliative Care Training Manual for details

4.10 Care of Carers

- The palliative care team shall be assisted to recognize the difficult situations they encounter, personal limitations and ways of utilizing effective coping strategies.
- Carers shall be provided with adequate resources for client care.
- Regular team meetings and social gatherings shall be promoted to help reduce stress and burnout of palliative care personnel.
- Supervision, training and support shall be provided to health workers, family and community members.

- The palliative care team shall be trained to communicate effectively with regard to the following client encounters:[19]
  1) Giving bad news clearly and with empathy
  2) Initiating death and dying conversations with clients and/or their family members
  3) Discussing do not resuscitate status and exploring preferences for end of life care
  4) Initiating conversations regarding religious or spiritual values and practice

4.11 Grief and Bereavement

Grief and bereavement are core components of palliative care.

Bereavement is the state of being sad because a family member or friend has recently died.

Grief is a normal natural response to loss that involves physical, emotional, somatic, cognitive and spiritual responses to actual or threatened loss of a person, thing or place that is emotionally attached to a particular person. Examples include relationship break-up, loss of health, loss of a job or financial stability, miscarriage, loss of a loved one in death etc.

Stages of grief:

Grief and bereavement risk assessment shall be done routinely throughout the illness trajectory for both palliative care clients as well as their family members or guardians. The following are five stages of normal grief as elaborated by Kübler-Ross model:

- **Shock and denial:** person displays disbelief
- **Anger:** person becomes frustrated, irritable and angry about the loss
- **Bargaining:** person negotiates as an attempt to prolong life
- **Depression:** person may start showing clinical signs of depression or just sadness
- **Acceptance:** realization that death is inevitable and acceptable of experience

Normal grief resolves and acute symptoms gradually lesson within one to two weeks. However, some people may experience an abnormal course of grief with symptoms lasting over weeks. If symptoms persist for more than two weeks assess for symptoms of a major depressive episode.

Complicated grief occurs when grief does not progress as expected. The intensity and duration of the above symptoms and stages of grief are prolonged and dramatically interfere with a person's ability to function.

[19]Parikh, Priti P., Mary T. White, Lynne Buckingham, and Kathryn M. Tchorz, "Evaluation of Palliative Care Training and Skills Retention by Medical Students," Journal of Surgical Research 211 (2017): 172-177.

Signs and symptoms	Classification	Recommendation for Referral
If person had a loss and presents with one or more of the following symptoms: • Insomnia, loss of appetite, shock, anger, fear, loneliness, fatigue, sadness, social isolation, disbelief, chest tightness, shortness of breath, lack of energy, panic attack-like symptoms, sense of presence of loved one in case of death, lack of concentration, numbness and dreams of the deceased and absent-minded behaviour	Normal Grief	• Provide health education and psychosocial support • Enquire and assess depressive symptoms and prescribe as indicated
If a bereaved individual presents with: • Prolonged grief symptoms in intensity and duration that dramatically interfere with a person's ability to function normally AND • Using present tense when talking about the deceased or the past matter • Continually reporting that people seen at a distance/crowds are commonly mistaken for the deceased • Making a daily reference to death, tombs in a ritualistic manner • Reporting of establishing daily rituals relating to the deceased • Continued denial of the reality of the death or a changed situation	Complicated Grief	• If no improvement after a month of treatment of normal grief, enquire and assess depression • Provide counselling and refer to mental health professional for further assessment and treatment.

Information on loss and grief and the availability of bereavement support services through hospice and other community programs, should be made routinely available to families before and after the death of the client, as culturally appropriate and desired.

NB: Refer to 2016 Mental Health Desk Guide (page 14) for signs and symptoms of major depressive disorder and (page 27-29) for further detail on treatment and referral for grief and bereavement.

CHAPTER 5: MONITORING AND EVALUATION

The implementation of PC services shall be guided by a Monitoring and Evaluation (M&E) System. This system shall be in line with the MoH M&E system that follows the **"Three Ones Principle"**, which refers to the establishment of and coordination between one coordinating body, **one** strategic framework, and **one** M&E framework.

The MoH M&E system is led by the Strategic Information Department (SID) of the Ministry of Health, which is tasked with overall technical oversight of the MoH M&E System. The SID is comprised of four units:

- **Health Management Information System (HMIS) Unit:** is responsible for all data management (from data collection, collation and database management) of health information at all levels of the health sector and spearheads efforts to conduct data quality assurance within the MoH.
- **M&E Unit:** drives the MoH strategy to engender a culture of results-based monitoring and evaluation and decision-making within MoH.
- **Epidemiology Unit:** is responsible for leading the surveillance of communicable diseases in the context of Integrated Disease Surveillance and Response (IDSR) within the MoH.
- **Research Unit:** capitalizes on the recommendations emanating from trend and statistical analyses conducted by the M&E and Epidemiology Units to formulate, update and implement a research agenda for the health sector

The Palliative Care M&E System will be developed in a participatory manner by all stakeholders involved and shall guide all PC related M&E activities in the health sector. The Palliative Care M&E System will be comprised of shared goals and objectives for PC in the country and will measure progress against agreed upon indicators of inputs, outputs, outcomes and impacts.

5.1 Data Collection and Reporting

Health care workers in all public health facilities including NGOs and community organizations are responsible for the routine collection and reporting of client information receiving PC services. The client data (information) shall be collected and reported using Health Information System Coordinating Committee (HISCC)-approved palliative care data collection and reporting tools **(Palliative Care Register, Palliative Care Monthly Summary Sheet).**

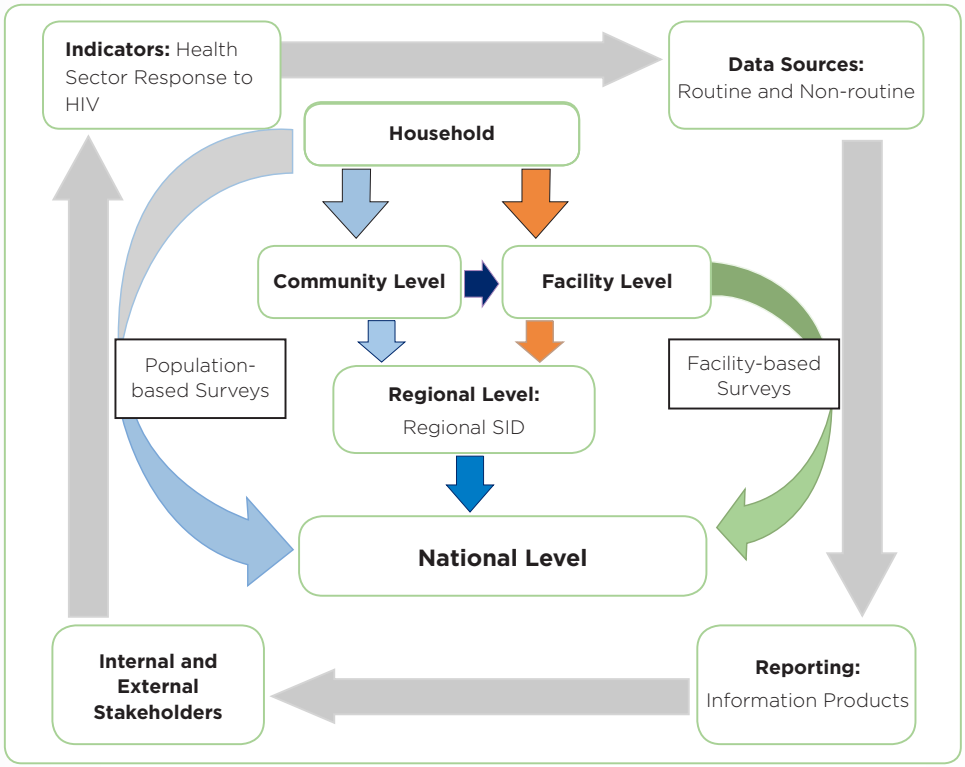
This data shall be collated and reported by all stakeholders on a monthly, quarterly and annual basis to the regional SID offices. The SID offices will aggregate all regional and national data into the HMIS database in order to produce Region-Level and national-level statistics. In the long term, the PC data shall be electronically recorded into the Client Management Information System (CMIS).

The palliative care client information shall be disaggregated according to all demographic and health related characteristics as stated in the PC data collection tools.

5.2 Data Flow

The timely transmission of data is a major concern of a fully functioning M&E system. An explicit data flow mechanism has been put in place for data collection and reporting which shall be followed by each stakeholder involved in the provision of PC services. The data flow mechanism recognizes the need for feedback at all levels of the data management system internally and externally as depicted in Figure 5.1.

Figure 5.1: Data Flow Chart for Palliative Care M&E System



All of the data collected for PC through routine and non-routine data collection sources shall be used by all stakeholders to inform evidence based decision-making and influence new policy direction. This data shall also be used by the civil society

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ANNEXURE A: ESSENTIAL PALLIATIVE CARE MEDICINES LIST

Drug Name	Properties	Clinical Uses	Alternative Drugs
Paracetamol	Non opioid Analgesic Antipyretic	Fever Pain	
Aspirin	Non opioid Analgesic Antipyretic Anti-inflammatory	Pain Fever Sore Mouth	
Ibuprofen	NSAID	Pain (esp. bone pain) Fever Anti inflammatory	Diclofenac Indomethacin
Tramadol	Weak opioid Analgesic	Pain	Codeine
Morphine liquid	Strong opioid Analgesic	Pain Introduction Breakthrough pain Difficulty swallowing children Breathlessness Severe Diarrhoea	Morphine slow release tablets
Morphine (slow release tablets)	Strong opioid	Pain Severe diarrhoea	Morphine liquid
Dexamethasone	Corticosteroid Anti-inflammatory	Painful swelling and inflammation Poor appetite	Prednisolone

Drug Name	Properties	Clinical Uses	Alternative Drugs
Amitriptyline	Tricyclic Antidepressant	Neuropathic pain (nerve pain) depression	Carbamazepine Phenytoin Imipramine
Hyoscine Butyl bromide (Buscopan)	Antimuscarinic Antispasmodic	Abdominal pain (Colic)	Propantheline
Diazepam	Benzodiazepine Anticonvulsant	Muscle spasm Seizure Anxiety, sedation	Lorazepam
Phenobarbitone	Anticonvulsant	Seizure	Diazepam
Metoclopramide	Antiemetic	Vomiting	Haloperidol Domperidone Promethazine
Metoclopramide	Pro-kinetic	Abdominal	
Chlorpromazine	Antipsychotic	Hiccups	Metoclopromide Nifedipine
Magnesium Trisilicate	Antacid	Indigestion Gastro-oesophageal reflux, gastritis	Aluminium Hydroxide Magnesium Hydroxide Ranitidine, Cimetidine
Loperamide	Antidiarrhoeal	Chronic diarrhoea	Codeine Morphine
Bisacodyl	Stimulant laxative	Constipation	Sennakot
ORS	Rehydration Salt	Diarrhoea Rehydration	
Chlorpheniramine	Antihistamine	Drug reactions	Promethazine
Flucloxacillin	Antibiotic	Chest infection Skin infection	Erythromycin
Cotrimoxazole	Broad Spectrum Antibiotic	PCP treatment and prophylaxis Infective diarrhoea in HIV/AIDS Urinary Tract Infection	Ciprofloxacin Amoxicillin, nitrofurantoin,

Drug Name	Properties	Clinical Uses	Alternative Drugs
Metronidazole	Antibacterial for anaerobic infections	Foul smelling wounds gingivitis dysentery Vaginal discharge	Nalidixic acid
Lumefantrine Artemether (LA)	Anti-malarial	Malarial treatment	Quinine sulphate
Acyclovir	Antiviral	Herpes zoster	
Chloramphenicol eye ointment/drops	Antibacterial	Eye infections	Tetracycline, Gentamycin, ointment & drops
Fluconazole	Antifungal	Oral and Oesophageal candidiasis Cryptococcal meningitis	Triconazole Miconazole
Clotrimazole 1% Cream	Topical antifungal	Fungal Skin Infection	Whitfield ointment Miconazole. Griseofulvin
Nystatin Suspension and pessaries	Antifungal	Oral and vaginal candidiasis Prophylaxis for patients on steroids	Clotrimazole pessaries Triconazole Miconazole GV paint
Petroleum jelly	Skin moisturizer and protection.	Dry skin Pressure area care.	Emulsifying ointment
Potassium permanganate	Drying agent antiseptic	Oozing lesions wet skin	
Gentian Violet Paint	Antimicrobial Astringent	Bacterial & fungal skin infection	Clotrimazole pessaries Nystatin Triconazole Miconazole
Chlorinated Lime	Disinfectant	Infection prevention	Chlorine
Calamine Lotion	Itch	Rash	Aqueous Cream 10% salicyclic acid

Notes:

SWAZIS AND AMERICANS IN PARTNERSHIPS TO FIGHT HIV/AIDS
PEPFAR

MOH
HIV /AIDS
SNAP
SWAZILAND NATIONAL AIDS PROGRAM

World Health Organization
REGIONAL OFFICE FOR Africa

The Rocking-Horse Project
Children's Palliative Care

American Cancer Society®

African Palliative Care Association
APCA
Relieving Pain and Suffering

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