

NATIONAL PALLIATIVE CARE GUIDELINE

**Federal Ministry of Health
Ethiopia**

June 2016

Table of Contents

Contents

FOREWORD	VI
ACKNOWLEDGEMENTS	VII
LIST OF ACRONYMS	IX
CHAPTER ONE: INTRODUCTION	1
1.1 BACKGROUND	2
1.2 RATIONALE FOR THE NATIONAL GUIDELINES FOR PALLIATIVE CARE	3
1.3 OBJECTIVES OF PC GUIDELINE	2
1.4 TARGET AUDIENCE	3
CHAPTER TWO: PHYSICAL CARE 1- PAIN MANAGEMENT	3
2.1 SECTION A: CAUSES OF PAIN, ASSESSMENT AND TREATMENT	3
2.2 CAUSE AND CLASSIFICATIONS OF PAIN	4
2.2.1-Acute versus chronic pain	4
2.2.2-Neuropathic versus Nociceptive Pain	6
2.3 ASSESSMENT OF PAIN	7
2.4 PRINCIPLES OF CHRONIC PAIN MANAGEMENT	9
2.5 WHO 3-STEP ANALGESIC LADDER	10
2.6 WHO ANALGESIC LADDER FOR CHILDREN	14
2.7 VARIATION FROM THE WHO PAIN MANAGEMENT PROTOCOL	15
2.8 ADJUVANT FOR PAIN	16
CHAPTER THREE: PHYSICAL CARE II - SYMPTOM MANAGEMENT	18
<i>Fever is elevation of core temperature above 37.4 degree Celsius as measured at the axilla.</i>	19
3.1 RESPIRATORY SYMPTOMS	20
MANAGEMENT OF PULMONARY SECRETIONS	23
COUGH	24
3.3 <i>Gastrointestinal Symptoms</i>	25
1- <i>Hiccups</i>	25
3.4 POSSIBLE CAUSES OF WEIGHT LOSS AND MALNUTRITION IN CHRONIC ILLNESSES	31
3.5 MANAGEMENT OF SYMPTOMS CAUSING WEIGHT LOSS	31
3.6 URINARY SYMPTOMS	37
3.6 SKIN CARE	42
1. <i>Itching</i>	42

●	ANTI-HISTAMINES	44	
	2. Pressure Sores		45
CHAPTER 4: NEUROPSYCHIATRIC SYMPTOMS AND THEIR PHARMACOLOGICAL AND PSYCHOTHERAPEUTIC TREATMENT			
	4.1 INTRODUCTION	52	
	4.1.1 <i>Anxiety</i>		53
	<i>Note: Refer if no response</i>		55
	<i>Delirium/Acute confusion</i>		55
	4.2 INSOMNIA	58	
	4.3 DEPRESSION	60	
	4.4 SUICIDE IDEATION	61	
	4.5 SOCIAL CARE AND SUPPORT IN PALLIATIVE CARE	63	
	4.6 SPIRITUAL CARE	63	
	4.7 ROLE OF COMMUNICATION IN PALLIATIVE CARE	64	
	4.8 CARE OF THE CARE GIVERS	64	
CHAPTER FIVE: END OF LIFE CARE			
	5.1 BEREAVEMENT ISSUES AT THE END OF LIFE	67	
	5.2 AFTER DEATH:	68	
	5.3 GRIEF THERAPY	69	
CHAPTER SIX: PECULIARITIES OF PALLIATIVE CARE IN CHILDREN			
	6.1 PEDIATRICS PAIN MANAGEMENT	70	
	6.2 SPECIAL NEEDS FOR CHILDREN	71	
CHAPTER SEVEN: PROGRAM IMPLEMENTATION			
	7.1 PROVIDING PALLIATIVE CARE SERVICE USING DIFFERENT MODELS	71	
	7.2 LEADERSHIP AND COORDINATION	72	
	7.3 ROLE AND RESPONSIBILITIES	72	
	7.3.1 <i>Federal Ministry of Health</i>		73
	7.3.2 <i>Food, Medicine and Health Administration and Control Authority</i>		73
	7.3.3 <i>Pharmaceutical Fund and Supply Agency (PFSA)</i>		73
	7.3.4 <i>Regional Health Bureaus</i>		73
	7.3.5 <i>Zonal/Woreda Health Departments</i>		73
	7.3.6 <i>Specialized Hospital</i>		73
	7.3.7 <i>General Hospital/Primary hospitals</i>		74
	7.3.8 <i>Health Center/Clinics</i>		74
	7.3.9 <i>Health Post</i>		74
	7.3.10 <i>Patients, Families and Communities</i>		74
	7.3.11 <i>Partners</i>		74

CHAPTER EIGHT : MONITORING AND EVALUATING OF PALLIATIVE CARE PROGRAMS	75
8.1 PALLIATIVE CARE INDICATORS	75
AS PALLIATIVE CARE IS IN THE EARLY STAGE OF PROGRAM DEVELOPMENT IN ETHIOPIA, THE INDICATORS BELOW ADDRESS ONLY CERTAIN ASPECTS OF THE SERVICE. FURTHER INDICATORS WILL BE DEVELOPED AS THE SERVICE PROGRESSES.	75
CHAPTER NINE ANNEX 1- FLACC SCALE	77
9.2 ANNEX 2-DRUGS USED FOR STEP-BY STEP ANALGESIA	78
9.3 ANNEX 3	79
9.4 ANNEX 4-PRESCRIBING MORPHINE	81
9.5 ANNEX 5-ESSENTIAL PALLIATIVE CARE MEDICINES LIST	81
9.6 ANNEX 6- PALLIATIVE CARE EMERGENCIES	83
9.7 ANNEX 7-PEDIATRIC DOSAGES.	85
9.8 ANNEX 8- MINIMUM PROGRAM STANDARDS FOR PALLIATIVE CARE	86
CHAPTER 10 REFERENCES	88

Foreword

Health is not merely about curing disease, but also about avoiding suffering when cure becomes illusive. Palliative care provides support for the patient and family as they deal with life-limiting illness by considering the multidimensional aspects of suffering, namely physical, psychosocial, and spiritual.

Palliative care is a relatively new concept in Ethiopia. It started with palliative care needs arising from the HIV/AIDS epidemic, now rising cancer rates and people suffering from non-communicable conditions require this specialized care. The World Health Organization estimates¹ palliative care needs to be 1% of a country's total population.

Affordable and effective protocols and palliative care service delivery models exist to relieve pain and other symptoms that can be integrated into the Public Health Care system. The Federal Ministry of Health hereby recognizes the pivotal role of palliative care provision towards improving quality of life of people with life-limiting illnesses and it is with these fundamental precepts in mind that this guideline is developed.

It is with great pleasure that I recommend these guidelines to be a primary document for the scale-up of palliative care services in Ethiopia.



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¹Harding R, Higginson IJ. Palliative care in sub-Saharan Africa: An appraisal. Lancet 2005; 365: 1971–7

Acknowledgements

The Ministry of Health expresses its appreciation for the individuals and institutions who have participated in the development of this Comprehensive Palliative Care guideline.

The Ministry also recognizes the following experts for their contribution as a member of the task force involved in the development of the initial draft document for the guideline.

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List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti- Retroviral Treatment
ARV	Anti- Retro Virals
Bid	Twice Daily
Ca	Carcinoma
CBO	Community Based Organization
CHBC	Community Home Based Care
CSO	Civil Society Organization
DPCD	Disease Prevention and Control Directorate
FBO	Faith Based Organization
FMOH	Federal Ministry of Health
HIV	Human Immunodeficiency Virus
IASP	International Association of the Study of Pain
IM	Intramuscular
IV	Intravenous
JVP	Juglar Venous Pressure
M&E	Monitoring and Evaluation
NCD	Non Communicable Diseases
NGO	Non- Governmental Organization
NPO	Nil Per Os- Nothing by Mouth
NSAID	Non-Steroidal Anti- Inflammatory Drug
OI	Opportunistic Infection

PC	Palliative Care
PHC	Primary Health Care
PHCU	Primary Health Care Unit
PND	Proximal Nocturnal Dyspnea
PO	Orally
PRN	As Required
qid	Four times daily
RHB	Regional Health Bureau
RR	Respiratory Rate
SC	Subcutaneous
SOB	Shortness of Breath
tid	Three times daily
TOT	Training of Trainers
WHO	World Health Organization
WHO	Woreda Health Organization
ZHD	Zonal Health Department

Chapter one: Introduction

1.1 Background

Palliative care is an approach that improves the quality of life of patients and their families facing the problem 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:

- 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 in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Will enhance 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 includes those investigations needed to better understand and manage distressing clinical complications.

We should not just focus on preventing avoidable deaths but also on preventing avoidable suffering. Positioning palliative care within a continuum of care is a must. Palliative care is required throughout the course of illness regardless of access to disease modifying treatment. It covers a variety of responses including providing physical, psychological, social, and spiritual support, supporting both for patients and their care givers throughout the course of the illness. Palliative care is a cross cutting issue that is a vital component of an effective and functioning health system and is a key to ensuring the quality of life

and productivity of people living with life limiting conditions and their carers. It is a necessity in the response, not a luxury – both for the people living with the conditions and the health system as a whole.

Palliative care is an emerging discipline worldwide with the majority of services located in developed countries and mainly in response to the challenges of cancer care and other chronic life threatening illnesses. In developing countries, however, the need arose out of the HIV/AIDS epidemic initially and with the burden of cancer in recent years. According to WHO estimates, 1% of total population of Africa will need palliative care ² which means about 900,000 people in the case of Ethiopia. This does not take into account the further demand created by other chronic illnesses like diabetes, heart disease and lung disease, which also cause distressing symptoms.

The HIV/AIDS epidemic has been a powerful mechanism for mobilizing attention and compelling response to the issue of palliative care in Ethiopia. To cope with the HIV/AIDS crisis of increasing bed occupancy with terminally ill patients, many community organizations in Ethiopia introduced community "home-based care" (CHBC) schemes for persons with an HIV or AIDS diagnosis. As a response to the growing cancer burden and increase of other non-communicable diseases, FMOH has commenced a Pain Free Hospital Initiative and hospice- based palliative care services Addis Ababa.

To ensure that palliative care is available and accessible to the majority of the needy, a major thrust should be on a public health care approach. The principles of task shifting, decentralization of service, standardization and simplification are highly crucial.

1.2 Rationale for the National Guidelines for Palliative Care

The rationale for developing the National Guideline for Palliative Care is to enhance the provision of quality services as part of the national health sector response to chronic life threatening conditions such as, HIV/AIDS, cancer and other non-communicable diseases (NCDs). It will provide guidance and direction towards the implementation of a Palliative Care policy in Ethiopia. These guidelines are applicable to both the Public and private health sector.

1.3 Objectives of PC Guideline

- To assure palliative care access to the wider population by integrating PC services into Primary Health Care (PHC) and through leveraging the already existing community/home based care delivery system
- To provide basis for the development and implementation of palliative care standards in Ethiopia

² Powell, R., Mwangi-Powell, F., Kiyange, F., Radbruch, L. and Harding, R. (2011) 'Palliative care development in Africa: how can we provide enough quality care?' *BMJ Supportive and Palliative Care*, 1, pp.113-114.

- To promote access to quality palliative care services, including pain and symptom control
- To strengthen patient referral and linkage
- To encourage the inter-disciplinary care approach in providing palliative care services
- To serve as a guide for training materials and job aids preparation
- To standardize program monitoring and evaluation activities regarding palliative care services

1.4 Target Audience

This guideline is intended to be used by health care providers and program managers who are involved in the provision of palliative care services.

Chapter two: Physical care 1- Pain management

“Pain is a more terrible lord of mankind than even death itself”

Albert Schweitzer

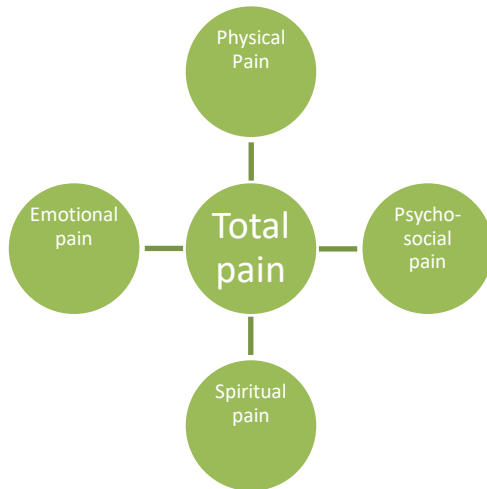
Section A will consider causes of pain, how to assess and treat it, Section B will go on to discuss special consideration for HIV/AIDS patients and Section 3 will address Non-Pharmacological Interventions.

2.1 Section A: Causes of Pain, Assessment and Treatment

The International Association for Study of Pain (IASP) defines pain as **an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage**. This highlights that pain is not just a physical sensation but an emotional experience too. In simple words **pain is what the patient says, hurts**, which gives emphasis on the patient’s experience.

The concept of total pain, refers to the global nature of pain perception not only as a physical ailment but that it has a psychological, spiritual and social consequences.

Figure 2. The concept of Total Pain (first described by Cecily Saunders)



2.2 Cause and classifications of pain

Though pain sensation, perception and interpretation is a complex phenomenon, here is the simplified explanation. A noxious stimulus stimulates the bare nerve endings (the nociceptors) and the impulse is transmitted to the dorsal horn, then to the thalamus and cortex resulting in appreciation of pain. This mechanism accounts for most of the pain stimuli.

Pain is always subjective and the perception of pain may be modified by problems or influences related to any, or all, of the potential causes of suffering. The experience of pain depends also upon the patient's mood, morale and the meaning of the pain for the individual. Pain is classified as acute vs chronic and nociceptive vs neuropathic.

2.2.1-Acute versus chronic pain

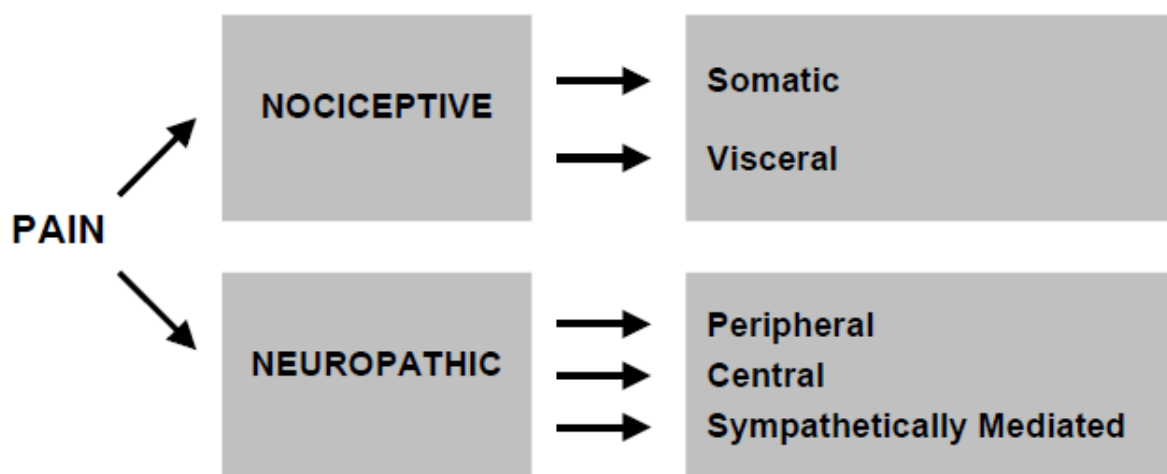
Acute pain is due to a definable acute disease or injury, duration limited to healing of tissue in days or weeks, accompanied by anxiety and sympathetic over-activity (sweating, tachycardia, tachypnea etc.). It has the physiologic purpose of protecting the body from further injury or facilitating healing. Chronic pain on the other hand persists months beyond the usual course of an acute disease reasonable time for an injury to heal, or is associated with a chronic pathological process which causes continuous pain or pain which recurs at intervals for months or years. It is accompanied by psychological problems such as depression but no sympathetic response due to adaptation of the sympathetic nervous system.

Acute Pain	Chronic Pain
Usually due to definable acute injury or illness	Results from a chronic pathological process
Well defined onset	Gradual or ill-defined onset
Duration limited to days/weeks. Transient and foreseeable end or clear means of relief. Predictable	Continues unabated for months/years and may become progressively more severe. Unpredictable
Accompanied by clinical signs of sympathetic over-activity, e.g. - sweating - tachycardia - tachypnoea - pupil dilation 'obviously in pain'	No sympathetic over-activity, patients frequently labelled as "not looking like somebody in pain"
Accompanied by anxiety	Patient depressed, other psychological changes and withdrawn
A "positive" pain in that it has meaning, draws attention to injury or illness and is protective	Has no meaning, serves no useful purpose and so a patient should never be allowed to suffer with chronic pain

2.2.2-Neuropathic versus Nociceptive Pain

Neuropathic pain is caused by damage to the central or peripheral nervous system. Neuropathic pain can be caused by injury, compression or infiltration of a nerve. Examples include post herpetic neuralgia or sciatic pain resulting from prolapsed intervertebral disc. Injured nerves react abnormally to stimuli or discharge spontaneously as they become hyper-excitabile. Often neuropathic pain is described as a burning, tingling or stinging sensation or a shooting electric shock-like sensation – ‘pins and needles’. On the other hand, **nociceptive pain** arises from noxious stimuli, potential or actual injury of somatic or visceral tissues of the body.

Classification of Pain



Nociceptive pain	Neuropathic pain
Caused by damage to non-neural tissue	Caused by compression or damage to nerve tissue
Stimulates nociceptive nerve endings	Neural dysfunction results in spontaneous impulses
· Impulse follows known nerve pathways to brain	These do not follow known pathways. Complex disorganized blasts of impulses
· Usually sensitive to opioids –	Reduced responsiveness to opioids

2.3 Assessment of Pain

Pain should be considered as the **5th vital sign**. A proper assessment of pain is essential for successful treatment. Patients often have more than one type of pain. Some may be unrelated to or only indirectly related to the primary disease and they would need different modalities of treatment. The initial assessment involves the following: detailed history taking including psychosocial assessment, physical assessment, and diagnostic evaluation.

In palliative care there are many different possible causes of pain. It is important to establish the cause of pain. Therapy should be directed at the cause wherever possible. The best approach to differentiate cause and origin is to attempt to characterize pain through the well-known mnemonic “**P Q R S T**”.

- **P** refers to Precipitating and palliating (relieving) factors,
- **Q** refers to Quality of pain (e.g. burning, stabbing, throbbing, aching, stinging)
- **R** to Radiation of pain
- **S** to Site(document on body diagram) and
- **T** to Timing (duration of pain, recurrence, whether constant or intermittent) and Treatment (the effect of current and previous medications)

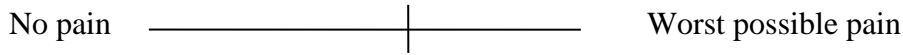
In palliative care it is not only sufficient to characterize the pain but also measure the degree of severity as objectively as possible. To assess success of treatment some form of quantization of pain is necessary. The simplest and most reliable index of pain is the patient’s verbal report. For regular follow-up, it will be useful to grade the pain at every visit on a pain scale. Many pain-scoring systems (pain scales) are available, but the numerical scale of ten is the most recommended in adults while the facial scale is effective in pediatric age.

Scales

- 1- *Categorical or verbal rating scale*: - A four or five point scale could grade the pain as none, mild, moderate, severe and excruciating etc. This scale is simple to apply but is not sensitive enough.
- 2- *Numerical Scale*: - It has 0 at one end meaning no pain and 10 at the other end meaning worst imaginable pain

(No pain) **0** 1 2 3 4 5 6 7 8 9 **10** (Worst possible pain)

3- *Visual Analogue Scale (VAS)*: - A 100 mm scale with no pain at one end worst imaginable pain at the other is particularly used in clinical trials, as it is more amenable to statistical analysis than numerical scale. It is a simple line on which the patient marks **X** to denote how strong their pain is



4- *Palms Pain Scale or Five-finger score (0-5)*

Figure 1- Five-finger score



The hand scale ranges from a clenched hand (which represents ‘No hurt’) to five extended digits (which represents ‘Hurts worst’), with each extended digit indicating increasing levels of pain. **Note:** it is important to explain this to the patient as a closed fist could be interpreted as worst possible pain in some cultures.

5- For children: *The Faces pain scale*

Figure 2- The Faces pain scale for children

(The Faces pain scale has been revised so that the scale is from zero to ten).



- Use with children who can talk (usually 3 years and older)
- Explain to the child that each face is for a person who feels happy because he has no pain, or a little sad because he has a little pain, or very sad because he has a lot of pain
- Ask the child to pick one face that best describes his or her current pain intensity
- Record the number of the pain level that the child reports to make treatment decisions, follow-up, and compare between examinations
- For use in children less than three years of age or older non-verbal children FLACC Scale is used to assess pain. See Annex 1.

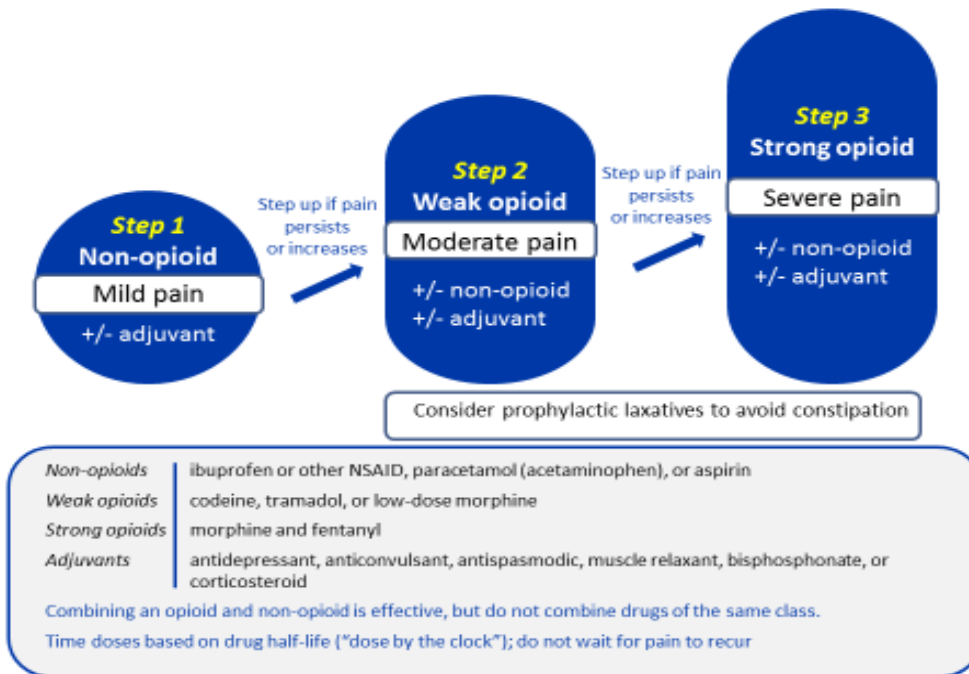
2.4 Principles of chronic pain management

The management of chronic pain involves the use of oral drug therapy by the clock depending on the duration of action of the drug.

- Pain should be treated whenever possible, consider pharmacologic precautions for all analgesic drugs as indicated in the annex.
- **‘By the mouth’**: The oral route is best for the management of chronic pain. Oral medications should only be abandoned if the patient is unable to take or retain them.
- **‘By the clock’**: Analgesics should be given *‘by the clock’*, i.e. at regular intervals. Analgesics are given according to a strict schedule determined by the duration of action, in order to prevent recurrence of pain. A patient on a regular schedule of analgesia will also need to have available a ‘breakthrough’ dose for any episodes of breakthrough pain.
- **‘By the ladder’**: the two/three step analgesic ladder (two step for pediatric, three step for adults) which is meant for mild, moderate and severe pain is to be followed. Unless the patient is in severe pain, begin by prescribing a non-opioid drug and adjust the dose, if necessary, to the maximum recommended dose.
- **‘For the individual’**: the right dose of an analgesic is the dose that relieves the pain.
- **‘Attention to detail’**: it is essential to monitor the patient’s response to the treatment to ensure that the patient obtains maximum benefit with as few adverse effects as possible
- **‘Combination therapy’** using two or more analgesia of different mechanism of action is evidence-based practice.

WHO Analgesic Ladder

Figure 3- The World Health Organization 3-Step Analgesic Ladder for Adults



2.5 WHO 3-step analgesic ladder

If pain is not controlled on Step 1 analgesics, a weak opioid (step 2) can be added. If a weak opioid has been used to a maximum dose and the patient still has pain, then move to Step 3. If a weak opioid is no longer effective on optimal dose, it is important *not to switch to another weak opioid* on the same step of the ladder. A combination of a non-opioid and an opioid drug is effective in that the different drugs have different mechanisms of action and they potentiate each-others' actions (see annex 2).

If the patient still experiences pain on optimal dosage of Step 2 drugs, a strong opioid is prescribed and *the weak opioid stopped*. Morphine oral solution or immediate release morphine is usually prescribed as the initial strong opioid of choice when commencing Step 3, as it is a quick-acting but short-acting drug, hence rapidly effective yet safe. Morphine oral solution is titrated against the patient's pain levels until pain is relieved, many patients who are well controlled on morphine solution can continue to use this as pain relief throughout their illness. If the patient's pain improves they can also 'step down' the analgesic ladder and use a weaker medication.

It is often necessary and beneficial to continue with Step 1 analgesic even when a patient is on Step 3 but do not combine Step 2 and Step 3 analgesics as their effect is produced by binding to the same receptors. In effect the Step 2 analgesic may potentially block the effect of the Step 3 analgesic.

Another group of analgesia are referred to as adjuvants. This include tricyclic antidepressants (e.g. - Amitriptyline), Anticonvulsants (Carbamazepine, Phenytoin), and steroids. These can be used alone or as first line choice in neuropathic type of pain syndromes or in combination with the above step 1, 2, and 3 analgesia in which case treatment has failed and there is only a suspicion of neuropathy.

Step I-Non opioid analgesia

NSAIDs: They have a key role in the management of pain associated with inflammation as in soft tissue infiltration and bone metastases. NSAIDs differ in their effect on platelet function. Aspirin causes irreversible platelet inhibition whereas Ibuprofen, etc. causes reversible platelet inhibition. Diclofenac etc. do not have any commendable effect on platelet function.

The dosage schedule for commonly used NSAIDs is:

- Diclofenac- 50mg tid,
- Ibuprofen- 400-600mg tid,
- Naproxen- 250-500mg bid,
- Indomethacin 25mg tid, and
- Aspirin 500-1000mg qid.

Common adverse effects of NSAIDs are gastric erosion, peptic ulcer and hemorrhage, Impaired renal and platelet function salt and water retention and bronchospasm. It is advised to avoid using aspirin in children and adolescents under 16 yrs because of increased risk of Reye syndrome with exception of idiopathic rheumatoid arthritis and rheumatic fever.

Paracetamol: This is most available and least expensive over the counter analgesia. Paracetamol is an antipyretic analgesic which inhibits Cyclooxygenase in the central nervous system. It has a peripheral analgesic effect but lacks anti-inflammatory effect. Its side effects are far less than NSAIDs. The main drawbacks are the frequency of administration (500-1000mg qid) - maximum dose 4gm/day. In pediatrics age maximum 4doses/day and its potential for renal and hepatotoxicity.

Step II –Weak Opioids

Codeine³: The classic weak opioids are codeine and division of opioids into weak and strong is to a certain extent arbitrary. Their affinity for the receptor is mild to moderate. Codeine is about 1/10 as potent as morphine and is more constipating than other weak opioids. It is the pro-drug of morphine and used as analgesic, antitussive and anti-diarrheal agent. An important rule is ‘not to change or jump from weak opioid to another weak opioid’.

Dose is 30-60mg q4h (10mg and 30mg tablets are available) Maximum dose is 240mg.

Tramadol: This is on the other hand is a synthetic weak opioid analogue of complex structure and available without much restriction. It is an alternative opioid for step 2. These are: action on opioid receptors and pre-synaptic re-uptake blocker of nor adrenaline and serotonin. It can lower seizure threshold and therefore generally not prescribed in patients with history of epilepsy. It is 1/5th to 1/10th as potent as morphine when taken orally and through injection respectively.

Dose: 50-100mg q8h-q6h. Maximum dose is 400mg.

Weak opioids are not recommended for pediatrics age group (see 2 step analgesic ladder)

Step III- Strong Opioids

Morphine is the strong opioid of choice for the management of patients with cancer and other illness who have moderate to severe pain. Strong opioids need to be given and their use is dictated by therapeutic need and response, NOT by brevity of the prognosis. Morphine is available in different dosage formulation such as an aqueous solution (5mg and 20mg/5ml), 10 mg tablets and parenteral preparation which can be given IM, IV, and sc. In patients with hepatic and renal failure and among old aged groups, care must be taken when prescribing and administering opioids. The correct dose is the one, which controls pain while causing minimum side effects. The dose must be titrated for each individual patient starting from the lowest possible dose in elderly and cachectic patients of 2.5mg/4hourly to normal adults of 5mg/4hourly. There is no standard dose for morphine for the treatment of chronic or cancer related pain and hence no ceiling effect, meaning dose is escalated 72 hours and progressively until pain is controlled and side effects such as nausea and drowsiness are tolerated. Always prescribe a laxative along with an opioid regularly as tolerance is never developed for this particular, and, in selected

³The latest FHMCA directive is that Codeine can be used in adults (not pregnant and lactating women) on a case by case basis. Pharmacovigilance is encouraged and any serious side effects should be reported. Codeine should not be used in children.

patients an anti-emetic on as required basis is prescribed if the risk of nausea and vomiting is very disturbing. Another strong opioid is Fentanyl (see Annex 3 for special considerations when prescribing pain medications).

Normal release morphine (NR) is always started on four hourly basis and begins to work after about 20 minutes and analgesia lasts four hours. In an opioid naïve patient, start with 2.5-5 mg morphine. Experienced Patients, who are receiving an opioid, may require higher doses (based on equianalgesic doses). It should be given four hourly. A double dose is given at bedtime and the midnight dose is skipped. A rescue dose is advised for breakthrough pain. This should be the same as the four hourly dose of morphine. If these breakthrough episodes persist and become more than 4 /day, dose adjustment as above is required. The dose is increased by 30-50% every 3 days and it can also be reduced progressively in the same manner (see annex 4).

Adverse effects: Even with the therapeutic dose of opioids the following adverse effects are common.

- 1- Constipation occurs in about 95% of patients and it may last as long as the drug is continued. Constipation should be prevented rather than treated and co- administration of a laxative is a must. Bisacodyl 5mg at night, increasing to 15mg if needed) unless the patient has diarrhea.
- 2- Nausea and vomiting occurs in 1/3rd of patients. It is usually seen in the first few days of therapy and is usually self-limiting. Treat with Metoclopramide 10mg tid or Haloperidol 1.5mg once a day.
- 3- Itching is also seen in less than 7% of the patients sometimes respond to 2-3 days of antihistamine therapy, use Chlorpheniramine.
- 4- Other side effects include dry mouth, urinary hesitancy, and sleepiness.

Signs of toxicity: These appear when the administered dose of morphine is more than what is required for pain relief, or when the pain is not morphine-responsive, yet dose is escalated progressively. The signs are toxicity are delirium, myoclonus and drowsiness. Drowsiness occurs in up to 1/3rd of patients on initiation of treatment or following a significant dose increase. If it persists dose reduction is needed. Dose reduction is recommended in renal impairment and old age and debility. These toxicities can be effectively managed with specific drugs including naloxone, an opioid antagonist.

As long as the dose escalation for morphine is made in a stepwise manner, there is less likelihood of an excessive dose being given toxicities are unlikely to occur. But in situations such as renal failure there

may be accumulations resulting in toxicities. There are reports where compulsive drug seeking behavior is exhibited by few patients who have a past history of psychiatric illness. With the same token respiratory depression and addiction are NOT also problem with oral morphine in patient with a clear indication. On the other hand, physical dependence is a normal physiological response to opioid therapy, which causes withdrawal symptoms, if the drug is abruptly stopped or an opioid antagonist is administered. Withdrawal symptoms can be effectively managed by gradual and supervised reduction of the opioid therapy.

Naloxone – reverses all opioid side effects, so both respiratory depression and pain relief are reversed. Too much naloxone given too quickly and reversing analgesia may result in restlessness hypertension and arrhythmias and has been known to precipitate cardiac arrest in a sensitive patient.

Indications for Naloxone

1. RR < 8/minute.
2. RR <12/minute, difficult to rouse, cyanosis
3. RR < 12/minute, difficult to rouse, SaO₂ <90%

Dose: dilute naloxone 400 micrograms to 10ml with 0.9% saline. Give 0.5ml (20 micrograms) IV every 2min until respiratory status is satisfactory. Further boluses may be necessary because naloxone is shorter-acting than morphine.

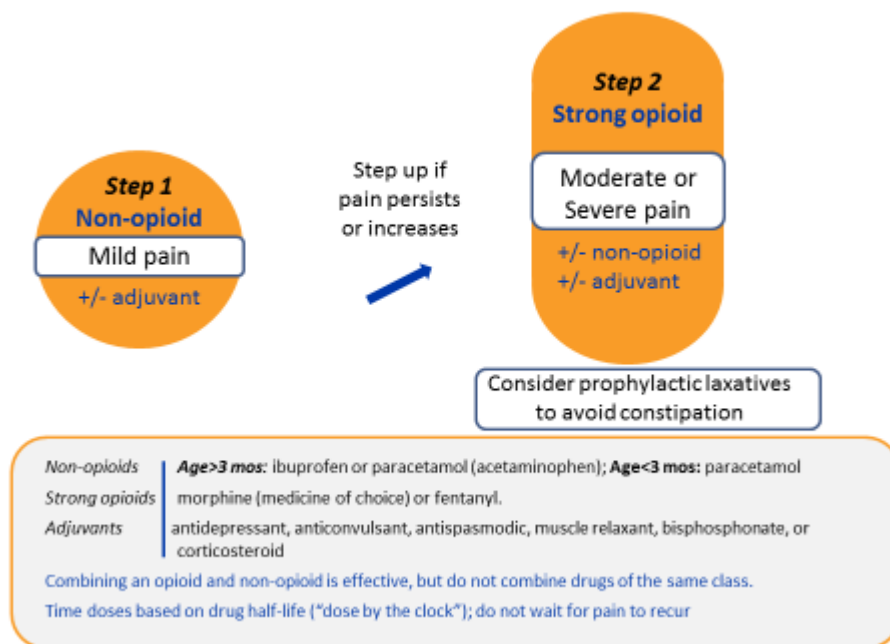
Note:There can be concerns when prescribing morphine that addiction can occur. When used correctly, patients do not become dependent, tolerance is uncommon and respiratory depression does not usually occur. The risk of addiction is commonly overestimated by patients and family, so it is important for healthcare workers to alleviate their fears. When discontinuing morphine, avoid symptoms of withdrawal by titrating the opioid dose down slowly.

2.6 WHO Analgesic Ladder for Children

The two-step approach is an effective strategy for the pharmacological management of persisting pain in children rather than the three-step analgesic ladder used for adults. The three-step analgesic ladder recommends the use of codeine for adults as a weak opioid for the treatment of moderate pain, while the two-step approach considers the use of low doses of strong opioid analgesics for the treatment of

moderate pain as the benefits of using an effective strong opioid analgesic outweigh the benefits of intermediate potency opioids in the pediatric population and although recognized, the risks associated with strong opioids are acceptable when compared with the uncertainty associated with the response to codeine and tramadol in children.

Figure 4- The World Health Organization 2-Step Analgesic Ladder for Children



2.7 Variation from the WHO pain management protocol

- By mouth administration may not be feasible in dysphagia (sub-lingual or per-rectal or parenteral administration)
- By the clock administration may not be possible as well in cases with renal failure and dyspnea where the dose and frequency should be reduced or spaced. In renal failure, morphine interval may need to be longer or the dose reduced. If no urine output, then morphine should be stopped and given PRN.
- For breakthrough pain – the drug has to be given in between the specified intervals.
- In neonates – half life and clearance are variable
- A double dose is used at bed time to avoid waking the patient for medication
- By the ladder administration may be difficult in the following instances:

~ As in morphine trial for quick pain relief and for assessing the dose requirement

~Sticking to step 2 weak opioids when morphine is not available

~ Morphine may be used in smaller doses if step 2 are not available

~ Non opioid may be omitted for poor side effect profile

~Adjuvants may be omitted to minimize the number of drugs

~Go beyond step 3 in pain that is not responsive

2.8 Adjuvant for pain

The adjuvants are not analgesics in the true pharmacological sense, but may contribute significantly to pain relief whether used alone or in combination with the analgesics on the WHO 2/3-step ladder and they may have an analgesic sparing effect. Adjuvant analgesics are of particular use in pain that is partially opioid-sensitive pain. Pain that is less sensitive to opioids includes neuropathic pain, bone pain, pain associated with inflammation and sepsis. Pain associated with smooth or skeletal muscle spasm will not respond to an opioid and will need an adjuvant analgesic. Pain related to anxiety will also benefit from adjuvant analgesics.

Anti-Depressants and Anti-Convulsants: Helpful for neuropathic pain, which may present as burning, pricking, allodynia, paresthesia or sharp, shooting pain, e.g. Amitriptyline 25mg at night. Dose can be increased slowly up to 75mg. Phenytoin: 100mg bid, may increase slowly to 100mg tid.

Corticosteroids: are used as adjuvant treatment if neuropathic pain is suspected to be due to nerve compression e.g. by tumor or inflammation (Betamethasone – 8mg daily or Prednisone 40-60mg daily).

Muscle relaxants/Anxiolytics: are used as an adjuvant for skeletal muscle spasm and anxiety-related pain. For example: Diazepam. Adults. 5mg orally, 2-3 times per day.

Antispasmodics: are helpful in relieving visceral distension pain and colic. E.g. Hyoscine Butylbromide orally or subcutaneous. Dose: Adult: start at 10mg three times /day; can be increased to 40mg three times/day

Section B: Special considerations for HIV and AIDS patients

Pain in HIV and AIDS is highly prevalent, it has various syndromal presentations, which can result from two or three sources at a time and has the potential of being poorly managed. Such pain may be directly related to HIV infection, immunosuppression or HIV therapy.

Common sources of pain in HIV and AIDS

Cutaneous/ Oral	Visceral	Somatic	Neurological/Headache
<ul style="list-style-type: none"> · Kaposi's Sarcoma · Oral cavity pain · Herpes zoster · Oral or oesophageal candidiasis 	<ul style="list-style-type: none"> · Tumours · Gastritis · Pancreatitis · Infection · Biliary tract disorders 	<ul style="list-style-type: none"> · Rheumatological disease · Back pain · Myopathies 	<ul style="list-style-type: none"> · HIV-related headaches from encephalitis, meningitis etc · HIV-unrelated headaches from tension, migraine etc. · Iatrogenic (AZT) · Peripheral neuropathy · Herpes neuritis · Neuropathies associated with DDI, D4T toxicities · Alcohol, nutritional deficiencies

Pharmacological pain management should be as per the WHO analgesic ladder.

NSAIDs, tricyclic antidepressants, anticonvulsants and non-pharmacological interventions are important although NSAIDs could exacerbate bone marrow disease and worsen the gastro-intestinal effects of HIV and ARVs so should be used **with caution**.

Many of the ARVs, especially the protease inhibitors, cause abdominal discomfort, nausea and vomiting.

Headache and peripheral neuropathies are also common side effects of ART.

Some antiretroviral medicines interact with analgesics and so **caution** needs to be used when giving analgesics to patients on ART. The main interactions occur with the adjuvant analgesics such as phenytoin, carbamazepine, dexamethasone and amitriptyline.

Section C: Non Pharmacological management of pain

Palliative care includes many non-pharmacological ways to manage 'total' pain. These therapies address the physical, psychological, social and spiritual dimensions of pain.

The following are a few holistic non pharmacological ways of treating pain.

Anything that enhances quality of life can, in turn, relieve pain.

- Listening and empathy
- Counseling – provides emotional support and practical suggestions
- Companionship and accompaniment – can help ease pain and increase comfort

- Activities such as favorite music, games, gardening, memory book – provides meaning and distraction
- Spiritual/pastoral support and prayer – provides comfort, meaning and hope
- Positioning – enhances comfort and relieves pressure areas
- Bathing, grooming, and other care measures – enhances comfort and self-respect
- Exercise – improves mobility, circulation and skin integrity
- Massage, therapeutic touch
- Traditional therapies that are beneficial, healing and comforting
- Heat/cool applied locally – can reduce swelling and help relaxation
- Treatments such as radiotherapy can reduce inflammation, pain and tumor size.

Chapter three: Physical care II - Symptom management

Symptoms of various illnesses have for a long time been considered ‘sign posts’, and merely indicators to a disease and not important by themselves. This common practice is illustrated in acute illnesses whereby symptoms vanish with addressing of the underlying illness, for instance, fever and headache in malaria. However, in chronic non-curable diseases, symptoms may persist long after the diagnosis of disease, as a result of chronic complications, and, are not always useful indicators of underlying conditions and only contribute to suffering and poor quality of life to those affected. Hence it is strongly advised to control them. The general approach to symptom control in palliative care includes assessment and investigation for the undiagnosed disease and severity of the symptom, treatment of reversible causes, initiation of disease/symptom-specific medicines and non-drug measures as well as involvement of the patient and family in the management plan (A list of essential palliative care drugs can be found in Annex 5 and how to deal with palliative care emergencies can be found in Annex 6).

The common symptoms in palliative care are:

- Fever
- Respiratory Symptoms
- Gastrointestinal Symptoms
- Urinary Symptoms

- Skin and Wound Care

Section A: Common Symptoms

Fever

Fever is elevation of core temperature above 37.4 degree Celsius as measured at the axilla.	
Common Causes	Management
<ul style="list-style-type: none"> • Infections • Inflammatory (autoimmune) • Metabolic • Malignancy • Drugs & toxins 	<p>If new fever, consider cause, work up and treat properly</p> <p>If bacterial infection treat with appropriate antibiotics</p> <p>If malaria treat with antimalarial</p> <p>If neoplastic in origin, treat with appropriate chemotherapy</p> <p>If transfusion related, discontinue and treat and work up</p> <p>For adults-Give paracetamol or aspirin every 6 hours (no more than 8 tablets of paracetamol in 24 hours).</p> <p>For children- provide paracetamol 10-15mg/kg oral per dose, maximum 6 dose in 24 hours, avoid aspirin.</p> <p>Neonate 5-10mg/kg per dose max of 4 doses in 24 hours, avoid aspirin.</p> <p>Alternative to reduce fever are NSAIDs (e.g. ibuprofen, avoid if less than 3 months)</p> <p>Make sure patient stays hydrated</p> <p>Home Care Advice</p> <p>The sick person will lose a lot of water through sweating;</p>

	<p>therefore encourage him or her to frequently</p> <p>Drink water, diluted tea, fruit juices and make sure patient stays hydrated</p> <p>To cool the body temperature, wipe the body with lukewarm water (cloth soaked or give a bath).</p> <p>Encourage febrile patient to wear only light clothes.</p> <p>Paracetamol can be used as above</p> <p><i>Advice: Seek help if fever does not improve or recurs after treatment. Also if fever is accompanied by cough, diarrhea, severe pain, confusion, night sweats, rigors, stiff neck or unconsciousness.</i></p>
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3.1 Respiratory Symptoms

- 1) **Dyspnea or breathlessness** is a subjective sensation that patients describe as chest tightness, breathlessness, air hunger, inability to take a deep breath, a feeling of suffocation or smothering, or an inability to get enough air. The symptoms usually worsen with exertion and often limit the patient's activity.

Approach to Reversible causes of dyspnea /shortness of breath

Possible causes of Dyspnea	Classical signs and symptoms	Treatment
Bronchospasm/asthma	Shortness of Breath Non-productive cough Wheezing	Bronchodilators - e.g. Salbutamol Corticosteroids Oxygen therapy

	Decreased air entry	
COPD (emphysema/ chronic Bronchitis)	Shortness of Breath Productive Cough Wheezing Decreased air entry	Bronchodilators –e.g. Salbutamol Corticosteroids Oxygen therapy Pulmonary rehabilitation Morphine
Congestive Heart Failure	Orthopnea, Proximal Nocturnal Dyspnea Fatigue, Chest pain, Edema, Inspiratory rales, Elevated Jugular Venous Pressure	Diuretics Cardiac medications <i>If indicated, oxygen</i>
Cardiogenic Pulmonary Edema	Severe SOB, Orthopnea, PND, fatigue Inspiratory rales, Edema, Elevated JVP	Oxygen Diuresis Morphine Treatment of Underlying cause
Bacterial Pneumonia	Cough Fever, chills pleuritic chest pain Localized rales or signs of consolidation	Antibiotics Cautious hydration <i>If indicated, oxygen</i>
Tuberculosis	Fever, cough, sweating, chest pain,	Anti TB , <i>if indicated</i> Corticosteroids

	weight loss, loss of appetite.	and oxygen
Pleural Effusion	SOB, chest pain Dullness and decreased air entry with radiographic or ultrasound confirmati	Thoracentesis If indicated chest tube insertion Management of underlying diseas
Upper Airway Compres	Severe shortness of breath Stridor – especially inspiratory Risk factors, such as neck or mediastinal mass	Corticosteroids Small dose Benzodiazepines, Opioids, or Barbiturates for anxie sedation <i>If indicated, consider/refer:</i> External radiation Tracheostomy/Airway stent
Copious airway secretio Bronchiectasis	Coarse crepitation, Ineffective or absent cough	Anticholinergic drugs Antihistamines If indicated antibiotics Rehydration Airway Suctioning
Pulmonary Embolism	Sudden onset of shortness of breath Chest pain Risk factors for venous thromboemb e.g. like bedridden patients	Anticoagulation – Heparin <i>with</i> Warfarin Oxygen Morphine
Lung Interstitial Pneum	Shortness of breathing, hepatosplenomegaly, parotid enlarger cyanosis and clubbing	Oxygen If indicated Corticosteroid Bronchodilators

NB

- Give small dose oral morphine—this can reduce dyspnea in end-of-life care. Monitor closely but do not let fears of respiratory depression prevent trying this drug.

~For a patient not on morphine for pain give 2.5 mg.

~For a patient already on morphine increase the dose by 25%. If this does not work, increase by another 25% till the patient condition improves (read reference on dose limit for dyspnea).

Dyspnea Home Care

In addition to the treatment given by health worker:

- Help the sick person sit in the best position
- Use extra pillows or some back support
- Open windows to allow in fresh air
- Fan with a newspaper or clean cloth
- Give patient water frequently (it loosens sputum)
- Avoid crowding, cooking and smoking in the room of the patient

Management of Pulmonary Secretions

Pulmonary secretions associated with pulmonary infections or chronic bronchitis can produce troubling symptoms for patients, particularly as their increasing weakness and fatigue make coughing exhausting and ineffective. For patients who are still able to cough effectively, interventions should be directed at helping to reduce the exertion required to bring up secretions or reducing excess secretion.

- Use an anti-secretory drug to reduce production of respiratory secretions: Hyoscine butylbromide 20 mg stat and 20–40 mg tid PO
- Humidified oxygen. Inhaled oxygen is a helpful comfort measure to reduce symptoms of upper airway drying when oxygen is being administered.
- Postural drainage: Chest physiotherapy appropriate to the patient's condition is valuable in managing respiratory secretions. Teach caregivers this technique and encourage them to make a

special effort to avoid flat or supine positions that allow pooling of secretions in the pharynx or larynx, and to reposition the patient frequently.

- Hydration: Dehydration can increase sputum viscosity and exacerbate difficulties with expectoration. Hydration—orally or intravenously is useful treatment to this problem.

Cough

Cough	
Common Causes	Management
<ul style="list-style-type: none"> • Respiratory infections • Bronchospasm • Bronchial obstruction • Cardiac causes • Drug related like ACE inhibitors • Esophageal reflux • Foreign body aspiration 	<p>Treatment of underlying cause</p> <ul style="list-style-type: none"> • Treat infections using appropriate anti-infective agents, evaluate for tuberculosis. • Cough from bronchospasm - often responds to bronchodilators including salbutamol with either inhaled or systemic corticosteroids (if indicated) • In patients who are moving little air with each breath, systemic corticosteroids and frequent nebulization of bronchodilators may help. If symptoms improve and tidal volumes increase, hand-held metered dose inhalers may be effective • Steroids, radiation, Surgery chemotherapy • Diuretics, salt and fluid restriction • Avoid ACE inhibitors • H2 receptor antagonists or proton pump inhibitors may be appropriate (for esophageal reflux). <p>Symptom management</p> <ul style="list-style-type: none"> • Use Dextromethorphan syrup(when indicated) • give Codeine 5-10 mg four times daily or, if no response, oral morphine (2.5-5 mg) (when indicated)

	<p>Home care (Soothing remedies)</p> <ul style="list-style-type: none"> • Spice drinks help to relieve some of the many unpleasant symptoms experienced by patients with HIV/AIDS. • Example: • Cinnamon, ginger, and honey are used to soothe the throat and relieve coughing. • Cinnamon: Add one-quarter teaspoon of cinnamon powder to a cup of clean boiled water (about 150–200 mL). <p>Add sugar or honey to taste. The drink is ready for use.</p> <ul style="list-style-type: none"> • Ginger: Add one teaspoon of crushed ginger roots or powder to a cup of clean boiling water. Cover and leave for 5–10 minutes. Add sugar or honey to taste and the drink is ready. Drink as desired. • Honey, ginger, and cinnamon: Add one teaspoon of ginger powder or cinnamon powder to 150 mL honey and stir. <p>Take 5–10 mL of the mixture 4-hourly for 5 days.</p>
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3.3 Gastrointestinal Symptoms

1- Hiccups

Persistent **hiccups** are not unusual in terminally ill patients and can be a distracting and distressing symptom. The interruption of normal activity in patients with intractable hiccups can cause depression, sleep deprivation, decreased oral intake, and weight loss.

Common Causes	Management
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<ul style="list-style-type: none"> • phrenic nerve or diaphragmatic irritation by tumor • Gastric distension • Gastroesophageal reflux, • Severe esophageal candidiasis. • Drugs (benzodiazepines, corticosteroids, barbiturates) • Psychogenic • intracranial mass/lesion 	<p>Treat the underline cause</p> <p>Symptomatic management (pediatric dosage)</p> <ul style="list-style-type: none"> • Metoclopramide (10 mg tablet, 1-2 tablets three or four times daily 7-10) /do • . For children-0.1-0.2mg/kg/dose 4 times daily • Chlorpromazine 25mg PO tid up to 7-10 days (for children 0.5-1mg/kg) • Haloperidol (5 mg tablet: 1/4 to 1/2 tablet once to three times daily). • If patient has brain tumor, try antiepileptic medication (like phenytoin). • Drinking cold water, cold water gargling, <p>Home care</p> <p>Stimulate the throat:</p> <ul style="list-style-type: none"> • Quickly eat 2 heaped teaspoons sugar, or • Drink cold water or eat crushed ice, or • Rub with a clean cloth inside the top of the mouth (feel toward the back, where the top of the mouth is soft). <p>Interrupt the normal breathing:</p> <ul style="list-style-type: none"> • Hold breath or breathe into paper bag, stop when you feel uncomfortable. • Pull knees to chest and lean forward (compress the chest).
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2- Nausea and Vomiting

Conduct a detailed history of the patient's illness including duration of symptoms, precipitating events, what has been tried to alleviate symptoms, and what has been most useful in management of these symptoms.

- Evaluate current medications noting those with known GI side effects.
- Assess for possible infectious conditions
- In women in child bearing age, consider pregnancy

- Increased intracranial pressure can present with nausea and vomiting
- Perform a thorough physical exam to localize the symptoms
- Look for surgical causes of nausea and vomiting
- Presence of fever and signs of dehydration (e.g., hypotension) indicate a more serious process.

Management of nausea and vomiting

I. Treatment for reversible causes	
Nausea and vomiting secondary to Infection or Drug side effects	<ul style="list-style-type: none"> - Treat infections with appropriate antimicrob - And Address drug side effects
II. Symptomatic management of nausea and vomiting	
1. Antiemetic	
Dopamine Antagonists	<ul style="list-style-type: none"> - Most commonly used as first line. - The prototype agents for this class are <ol style="list-style-type: none"> 1-Metoclopramide-the prokinetics agent, a peripheral antagonist. (10 mg every 8 hour For children use 0.1-0.2mg/kg/dose 4 times 2-Haloperidol & Chlorpromazine which exerts its effects centrally (1-2 mg once daily and 25-50mg every 6-12 hours respectively
Histamine Antagonists	<ul style="list-style-type: none"> - Promethazine 25mg 1-4 times daily (For children 0.5mg/kg/dose)
Corticosteroids (for intractable vomiting)	<ul style="list-style-type: none"> - Add Dexamethasone 10mg/m² /dose once
Serotonin antagonist (for intractable vomiting)	<ul style="list-style-type: none"> - Ondansetron 8mg tid
2. Rest Gut	IV fluids -Sometimes it is best to ‘rest the gut’ by administering intravenous fluids that may contain replacement electrolytes and basal metabolic energy

	<p>(e.g.40% dextrose) as needed</p> <p>Keeping NPO</p>
3.Reduction of Increased Intracranial Pressure (ICP)	<p>ICP is often an emergency. Treat the Cause</p> <ul style="list-style-type: none"> - Nursing care-head elevation 30° above horizontal - Give dexamethasone 4-8mg q8 hours to decrease intracranial pressure as indicated, give Mannitol IV 1-1.5g per kg - For Cryptococci do lumbar puncture as required
III. Home care	
	<ul style="list-style-type: none"> • Give clear liquids initially and boil water if not filtered; advance to full liquids as tolerated. • Give small, frequent meals. • Encourage breast feeding in infants and young children • Let the patient select the type of food he prefers. Avoid fried and fatty foods. • Keep patients away from the place where food is being cooked (to avoid smell and sight of food) • Encourage patient to be in a sitting position while eating for at least 30minutes. • Seek help from trained health worker for vomiting more than once a day, or dry heaves, or passing little passing little urine or abdominal distention

3-Dry Mouth (Xerostomia)

Dry mouth (Xerostomia) is a condition whereby salivary flow is reduced due to reduced production or free flow. This aggravates a dry mouth resulting in soreness and difficulty of speech and mastication.

Common Causes	Management
<ul style="list-style-type: none"> • Dehydration, • Mouth breathing • Reduced mastication • HIV-related (OI) infections • anxiety, and depression • Oxygen therapy • Salivary gland diseases • Drugs (antihistamines, anticonvulsants, antidepressants, and anticholinergic) • Radiotherapy which reduce salivary flow 	<p>Treat the underline cause</p> <ul style="list-style-type: none"> • Treating reversible causes • Treat infections and review drug regimens • Idiopathic or aphthous ulcers can be treated Either with a course of Corticosteroids. <p>Symptomatic management at Home</p> <ul style="list-style-type: none"> • Check the mouth, cheeks, palate, gums, tongue, and teeth often to identify and manage any problem early. • Seek help from health worker if dry mouth persists • Take regular sips of water to keep up fluid intake • Keep lips clean, soft, lubricated, and intact as far as possible. • Apply petroleum jelly or moisturizing lotion to lips • Brush teeth with a chew stick or a small, soft toothbrush (a baby's toothbrush is ideal) after each meal and at night. If available, use fluoride toothpaste. • If brushing is not possible due to pain or bleeding use soft sponges, cotton buds, or a gloved finger wrapped with gauze or a soft cloth • Use a mouthwash after each meal and at night (in addition to brushing, not as a substitute). • Avoid mouth washes that contain alcohol as it dries out the mouth.

	<ul style="list-style-type: none"> • Rinse with 15 mL for 60 seconds using alcohol mouth wash solutions. <p>Suggestions for mouthwash:</p> <p>Saline: 1 teaspoon salt in 500 mL boiled, cooled water</p> <p>Vinegar or lemon juice: 1 teaspoon in one liter of boiled cooled water.</p> <p>Antimicrobial mouthwashes: 0.2% chlorhexidine gluconate mouthwash</p> <p>Sodium bicarbonate mouthwash if available: 1 teaspoon in 500 mL boiled, cooled water</p>
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4. Nutrition and Weight loss

General Principles

Nutrition support has been shown to benefit palliative care patients by reducing physical deterioration, improving quality of life, and preventing the emotional effect of “starving the patient to death.”

- Palliative care patients of all age groups should be educated and encouraged to consume the following food groups (carbohydrates, proteins, vitamins, minerals, fats & oils, dietary fiber and water)
- The successful management of these medicine-food interactions requires understanding clients’ individual food access as well as eating habits. Locally available foods are recommended.
- Management of patients shall include assessment and counseling on feeding with regard to the nutritional needs specific to the stage of the illness.
- Patient and carers shall be counseled on appropriate feeding according to the stage of the illness

Weight loss is an extremely common symptom in chronic illness.

3.4 Possible Causes of Weight Loss and Malnutrition in chronic illnesses

Mechanisms	Possible causes
Decreased intake of nutrients	<ul style="list-style-type: none"> • Insufficient resources to procure food (Poverty) • Dysphagia or odynophagia • Anorexia, nausea, or vomiting • Emotional factors (depression, loneliness or grief) • Dementia
Excessive nutrient loss	<ul style="list-style-type: none"> • Chronic illness • Malabsorption or drug-related diarrhea

3.5 Management of Symptoms Causing Weight Loss

Symptom/setting	Dietary Advice
Loss of appetite	<ul style="list-style-type: none"> • Drink high-energy drinks (e.g. milk or yoghurt) • Eat small, frequent meals. • Encourage exercise if possible.
Nausea and vomiting	<ul style="list-style-type: none"> • Eat small, frequent meals. • Restrict intake of fluids after meals. • Eat cold foods or food at room temperature. • Avoid excessively fatty meals. • Avoid lying down after eating. • See relevant section
Sore mouth/throat	<ul style="list-style-type: none"> • Eat soft moist foods, (e.g., mashed potato, minced meat). • Use margarine, butter to moisten cooked food (if diarrhea not present) • Avoid sticky foods (e.g., peanut butter). • Avoid dry, rough foods, (e.g. raw vegetables). • Avoid citrus fruits (e.g. lemon, orange, pineapple) and spicy foods • Eat foods either cold or at room temperature. • See relevant section
Diarrhea	<ul style="list-style-type: none"> • Eat small, frequent meals. • Drink plenty of isotonic fluids.

	<ul style="list-style-type: none"> • Decrease/avoid milk and dairy products. • Fermented dairy products may be tolerated • Decrease high-fat foods • Include foods high in soluble fiber (e.g. bananas, oats). • Avoid caffeine, (e.g. coffee). • Avoid soft drinks (e.g. Mirinda, Coca Cola) • Use anti-diarrheal agent in adults if there is no contraindication • See relevant section
Home Care	<ul style="list-style-type: none"> • Encourage the sick person to eat, but do not use force as the body may not be able to accept it and he or she may vomit. • Offer smaller meals frequently of what the sick person likes. • Accept that intake will reduce as patient gets sicker and during End-of-life care. • Seek help from trained health worker if you notice rapid weight loss or if the sick person consistently refuses to eat any food or is not able to swallow.

- If all other means fail, try Prednisone 5-15 mg daily in the morning to stimulate appetite in end of life care, stop if no effect after 2 weeks.

3. 5. Dysphagia and Odynophagia

Difficulty of swallowing food as a result of pain or obstruction due to various causes affects the nutritional status and general health of certain chronic diseases.	
Common Causes	Management
1-oropharyngeal problems -Candidiasis -Mucositis	I. Treating reversible causes Complications like dehydration, electrolyte disturbance, malnutrition

<p>-Dry mouth</p> <p>-Neurogenic (Stroke, brain tumors or peripheral neuropathies)</p> <p>- Pharyngeal abscess,tumor, tonsillitis</p> <p>2-Esophageal problems</p> <ul style="list-style-type: none"> - Inflammatory/infection (Reflux esophagitis, candida Herpes, CMV, aphthous ulcers, caustic ingestion, Radiation mucositis). - Neoplastic (esophageal ca) - Motility disorder(e.g. achalasia) - Anatomical (hernia, diverticula, stricture) <p>3-Psychogenic</p>	<p>II. Symptomatic treatment</p> <ul style="list-style-type: none"> • Prescribe analgesia • Steroids to reduce inflammation or edema. <p>If no effect by the third day, stop treatment.</p> <ul style="list-style-type: none"> • Nasogastric tube,not recommended for long term use due to patient discomfort • Endo-esophageal tube • Gastrostomy tube –contraindicated in Advanced disease <p>III. Home care</p> <ul style="list-style-type: none"> • Soft diet to decrease discomfort such as yoghurt or smoothies depending on what the patient feels is helpful. • Avoid extremely hot or cold or spicy foods. • Upright position to facilitate swallowing <p>Seek help from health worker for persistent sores, smelly mouth, white patches, decreased urine output or difficult of swallowing</p>
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6-Diarrhea

Diarrhea is defined as the passage of loose stool three or more times in 24 hours.

It can be classified as: **Acute** when the diarrhea lasts for two week or less;

Persistent when the diarrhea last for two to four weeks or as **Chronic** diarrhea lasting more than four weeks

Common Causes	Management
<ul style="list-style-type: none"> • Osmotic (lactose intolerance and laxative) • Motility(drugs) • Secretory (Cholera) 	<p>I. Treating Reversible Causes.</p> <p>II. Prevent dehydration</p> <p>Correct dehydration by ORS, drink extra fluids and intravenous fluids may be appropriate in a patient with severe dehydration secondary to severe acute or Chronic diarrhea. Decisions should be made on a case-by-case basis.</p> <p>III. Symptomatic treatment</p> <p>Symptom treatment is recommended:</p> <ul style="list-style-type: none"> • If the diarrhea becomes chronic and is not helped by specific treatment <p>Contraindications for anti-diarrheal agent</p> <ul style="list-style-type: none"> • It should not be used if there is fever or blood in the stool • Should be avoided in children under the age of one year old. <p>For symptom control, start with anti-motility agents such as:</p> <ul style="list-style-type: none"> • Loperamide 4mg once, then 2mg per loose stool to maximum 16 mg/day, • Oral morphine 2.5–5 mg every 4 hours (if severe). • Codeine 10 mg 3 times daily (up to 60 mg every 4 hours)

IV. Home care

Advise the patient and caregivers to:

- Boil drinking water and store it in a clean container with a cover.
- Wash hands with water and soap before eating food and after visiting a toilet.
- Give the sick person drinks frequently in small amounts, such as porridge, water (with food), other soups, or oral rehydration solution (ORS) but avoid soft drinks.
- Avoid fatty foods, concentrated fruit juices, alcohol, and coffee.
- Use high-fiber foods such as beans, rice, maize meal, green bananas, whole grain bread and potatoes.
 - Eat bananas and tomatoes (for their potassium)
 - Carrot soup helps to replace vitamins and minerals. Carrot soup contains pectin. It soothes the bowels and stimulates the appetite.
 - Eat 5-6 small meals rather than 3 large ones.
 - Protect the peri-anal skin from excoriation by using petroleum jelly or aluminum hydroxide and keep it clean and dry.

Seek help from health worker if:

- Vomiting with fever
- Blood in the stool
- Diarrhea continues more than 5 days
- If patient becomes even weaker

	<ul style="list-style-type: none"> • If broken skin around the rectal area
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7-Constipation

<p>Constipation usually includes a frequency of fewer than three bowel movements a week, but can also include subjective symptoms such as excessive straining, a sensation of lower abdominal fullness, and hard stools.</p>	
Common Causes	Management
<ul style="list-style-type: none"> • Low fluid intake • Irregular bowel habit • Low residue and fiber diet • Limited physical activity • In hospital, unfamiliar toilet arrangements (such as the use of bedpans and lack of privacy) can also lead to constipation • Drugs such as opiates • Medical conditions (diabetes, hypothyroidism, hypokalaemia, rectocele, cerebrovascular accident and Parkinson’s disease) • Mechanical obstruction • (ColonCa, Kaposi) 	<p>I. Treat specific causes</p> <p>II.Symptom management</p> <p>Constipation in persons with chronic diseases is often related to medications and, thus, preventive measures are the most successful. If non-pharmacological measures are not effective, laxatives are appropriate although hard stool requires a softener and soft stool requires a peristaltic stimulant, a combination of both is better with fewer side effects. A variety of different laxatives can be used.</p> <ul style="list-style-type: none"> • Stimulant laxatives, which cause intestinal motility to increase (Commonly stimulant laxatives include, Bisacodyl 5-10 po.) • Emollient laxatives, such as mineral oil and liquid paraffin which are given orally or by enema that act by penetrating and softening the stool. • Hyperosmolar agents like lactulose 15-30 ml PO or PR twice daily. <i>(If available also use polyethylene glycol, non-absorbable sugars, or sorbitol)</i> • Suppositories or enemas can be given; especially when oral laxatives alone are insufficient.

	<p>III. Home care</p> <ul style="list-style-type: none"> • Encourage high fluid intake and regular bowel habit • Treat mild constipation by increasing the patient’s diet fiber intake to a minimum of 20–35 grams daily (fruits, vegetables, porridge, and locally available high fiber food) • Take a tablespoon of vegetable oil before breakfast. • Encourage patients to be mobile and provide them with Privacy when using toilet facilities. • Take preventive measures when constipating drugs like opioids are prescribed. Offer drinks often. • If impacted, gently put petroleum jelly or soapy solution into the rectum. <p>If the patient cannot do it, the caregiver can help—</p> <p style="padding-left: 40px;">always use gloves.</p> <ul style="list-style-type: none"> • Seek help from a trained worker if pain or no stool is in 5 days.
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3.6 Urinary Symptoms

1. Urinary Incontinence

Urinary incontinence is the involuntary loss of urine, which may cause hygienic, physical and/or social problems. It is essential to determine the cause and identify those

patients where the incontinence is due to an inability to reach the toilet in time.

Common Causes	Management
<p>Urge incontinence: sudden, strong desire to void, frequent loss of moderate to large volume of urine, nocturia and/or enuresis usually present due to urethral inflammation or irritation.</p> <p>Stress incontinence: leakage with physical activity (coughing, laughing, lifting etc.), small volume of urine and intermittent dribbling due to weak pelvic floor.</p> <p>Overflow incontinence: strain to void, sense of incomplete emptying, lower abdominal pain/fullness due to urethral obstruction, or bladder under activity (neuropathy).</p> <p>Functional incontinence: inability to reach the toilet in time due to physical, psychological or environmental impediment.</p> <p>Total urethral incontinence: local incompetence of the urethral sphincter due to tumor invasion, fistula or surgery. Central loss of sphincter control, confusion/dementia.</p>	<p>I. Correct reversible factors</p> <ul style="list-style-type: none"> • Avoid excessive volume of liquid late in the day, caffeine, caffeinated drinks, alcohol • Treat medical conditions (delirium, infection, restricted mobility, impaction, diabetes) • Proper use of medication (carbamazepine, diuretics, lithium, opioids (overflow)) • Correct physical/environmental barriers • Odor: identify cause and treat. <p>I. Consider disease-specific palliative therapy</p> <ul style="list-style-type: none"> • Total urethral incontinence: Regular toileting, a female urethral catheter or a male sheath catheter may be tried. • Urge incontinence: Timed voiding and anti-cholinergic drugs may be helpful. • Stress incontinence: Support prosthesis such as a ring-pessary or urethral inserts may be useful. • Overflow incontinence: Catheterization (Permanent or intermittent), urethral stenting or surgical interventions should be explored. <p>Referral to an urologist is essential in this instance.</p>

- Functional incontinence: surgery, psychological

II. Institute non-pharmacological interventions

- Patient education (fluid restriction in the afternoon/evening, early intake hours before bed time)
- Lifestyle modification (e.g. decreased caffeine)
- Behavioural modification: timed voiding
- Invasive devices (e.g. catheter, stent French Gauge(FG) 16 is the smallest useful size for adults, catheters are most appropriate and should be changed 6 weekly.
- External collection of urine (diapers) meticulous skin protection with barrier creams zinc and castor oil is mandatory.
- Intermittent catheterisation together with an absorbent pad.

III. Pharmacologic Therapy

- Infection: Microbial Culture and Sensitivity and appropriate antibiotic
- Barrier preparation to protect the skin (Zinc and castor oil/Vaseline)
- Relieve constipation (see constipation section)

	<ul style="list-style-type: none"> • Review medication for medicines which exacerbate the problem. • Referral to appropriate service/ more experienced clinician: Urologist or Gynaecologist
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2. Hematuria

<p>Blood in the urine (Hematuria) is a frequent presentation in urological disease. Ranging from microscopic hematuria, detected by urinalysis, to clearly visible frank hematuria or passage of clots.</p>	
Causes	Management
<ul style="list-style-type: none"> • Tumor: Renal, ureteric, bladder, prostate. • UTI • Calculi • Trauma • Drug-induced: Warfarin and NSAIDs causing bleeding tendency; Cyclophosphamide causing Hemorrhagic cystitis. • Glomerulonephritis 	<p>I. Correct reversible factors</p> <ul style="list-style-type: none"> • Treat underlying cause • Once the cause of hematuria is established to be self-limiting, reassure patient and family • Complete evacuation of clots (irrigation with water or saline through large bore urethral catheter) • Cystourethroscopy for diagnosis and cauterization if patient fit enough. • We can prevent Cyclophosphamide associated hemorrhage by sticking to rehydration protocols. • If bleeding is due to drugs –discontinue the causative drug and refer • More severe haemorrhage: consider referral • Blood transfusion based on need • Clot retention: <ul style="list-style-type: none"> - Evacuate clots using large bore (22Fr) Foley catheter

	<p>and irrigate with saline 0.9% continuously until urine is clear.</p> <ul style="list-style-type: none"> - Cystoscopic bladder irrigations may be needed, referral to a urologist may be required. - Percutaneous insertion of a suprapubic catheter is contraindicated <p style="text-align: center;">II. Consider disease-specific palliative therapy</p> <ul style="list-style-type: none"> • Palliative radiotherapy • Involve the urologist early in managing this problem
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3. Bladder pain

<p>Bladder pain: more constant pain, from a dull ache in UTI to acute disabling pain and may be a sign of obstruction and retention or excruciating, transient pain due to bladder spasm or urinary retention</p>	
Causes	Management
<p>Cystitis</p> <p>Urinary obstruction (calculi, clot, BPH, PUV)</p> <p>Urinary retention</p> <p>Bladder spasm (irritation hyper-excitability of trigon)</p> <p>Local cancer</p> <p>Bladder fibrosis (radiation, T)</p> <p>Indwelling catheter</p>	<p style="text-align: center;">I. Treat underlying cause</p> <p>Reassess the indwelling catheter where applicable as mechanical irritation can be caused by the catheter balloon - change catheter/ reduce volume of the balloon</p> <p>Catheter slugging with partial retention – bladder washouts or continuous irrigation</p> <p>Bladder irrigation as described in the UTI section</p> <ul style="list-style-type: none"> • Treat cystitis • Relieve obstruction/instability – especially related to catheter • Surgical intervention- tumor, Posterior Urethral Valve, Benign Prostatic Hyperplasia, stone. Remove foreign body

Anxiety	<p>(catheter or stones) if obstructing bladder outlet</p> <ul style="list-style-type: none"> • Treat Inflammatory causes <p>I. Institute non-pharmacological palliative interventions</p> <ul style="list-style-type: none"> • Regular toileting • Appropriate fluid intake • Avoiding caffeine and alcohol <p>II. Prescribe appropriate first-line treatment</p> <p>Treat bladder pain: WHO pain ladder</p> <p>Add treatment for bladder spasms with:</p> <ul style="list-style-type: none"> • Hyoscine Butylbromide 10-20 mg po, IV, IM or S/C tid. <p>Maximum of 100mg per day – avoid if there is urinary retention</p> <p>III. Consider adjuvant/second-line treatment</p> <p>Intravesical morphine and bupivacaine tid (morphine 10-20mg and 0.5% bupivacaine 10ml diluted in 0.9% saline to 20 ml), instill through indwelling catheter and clamp for 30 min.</p> <p>Spinal analgesia, e.g. epidural morphine and 0,5% bupivacaine can be considered if setup allows</p>
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3.6 Skin Care

1. Itching

Itching (pruritus) is an irritation in the skin that elicits an urge to scratch. Itching is a problem

that can be localized or generalized. Sometimes, it may be worse at night. A generalized itch and those without visible lesions are often more difficult to treat than a localized itch and those with visible skin lesions. Generalized itching with invisible lesion are usually due to systemic problems or allergies.

Causes	Management
<p>Infection (Tinea Scabies, Sexually Transmitted Disease, HIV)</p> <p>Contact with any skin irritants</p> <p>Drugs (chemotherapy)</p> <p>Neuropathies (DM, Herpes, MS)</p> <p>Metabolic problems (renal failure, liver failure, hyperthyroidism)</p> <p>Dry skin</p> <p>Sunburn</p> <p>Insects</p> <p>Psychological (Anxiety, Stress)</p>	<p>I. General management options for itching</p> <ul style="list-style-type: none"> • Avoid heat and hot water • Moisturise and hydrate dry skin • Apply calamine lotion • Menthol 1% in aqueous cream. Zinc • To moisturize and hydrate the skin use aqueous cream as a soap substitute and bland bath oils • Apply an emollient (liquid paraffin, coconut oil) immediately after washing <p>II. Outpatient medication:</p> <ul style="list-style-type: none"> • Assess for infectious cause – if present, treat. • Consider and treat other underlying cause • If there are multiple skin infections, use a chlorhexidine (0.05%) rinse after bathing. • Consider that this may be the side-effects of medication • Local steroid creams may be useful if inflammation is present in the absence of any infection-

bacterial, fungal, or viral.

- **Anti-histamines**

Cetirizine-10mg po once daily, Loratadine 10mg (in children less than 30KG use 5mg po daily)

Chlorphenramine 4 mg twice daily, up to 4 mg every 4–6 hours (maximum 24 mg daily),

or another antihistamine, may be useful for severe itching.

- **Diphenhydramine**, If the itching still persists, a short-acting antihistamine and a long-acting antihistamine (from different groups) could be combined for better symptom relief.

III. Home care for itching:

- If the affected person has dry skin, moisturize with aqueous cream or petroleum jelly mixed with water
- Avoid frequent bathing
- Use 1 spoon of oil (bath or vegetable) in the bath water when washing.
- Apply diluted Chlorhexidine (0.05%) after a bath, medicated soap

2. Pressure Sores

Pressure sores (decubitus ulcers) are ulcers of the skin which can extend into the subcutaneous tissue caused by ischemia secondary to extrinsic pressure and shearing forces.

The most vulnerable areas are elbows, shoulder blades, spine, buttocks and heels.

If the patient is more comfortable lying on his/her side, then special attention should be given to ears, shoulders, hips and knees.

Causes	Management
<p>Risk factors:</p> <p>General debility</p> <p>Neurological deficit</p> <p>Reduced mobility</p> <p>Coma</p> <p>Incontinence</p> <p>Cachexia</p> <p>Dehydration</p> <p>Anemia</p> <p>Infection and poor hygiene</p> <p>Others</p>	<p>Prevention of pressure sores:</p> <ul style="list-style-type: none"> • Inspect the skin every time the patient is moved • The skin should be washed and dried regularly, including bed bath • bed ridden patient • Maintain suppleness of skin by regular massage with skin lotion • Avoid trauma – no restraints, lift patients do not drag them to move • in the bed • Regular positional change, family or hospice/hospital carers should be involved • in changing the patient's position every 2-4 hrs. depending on risk factors • Keep the bed linen dry and free from creases • Keep the patient well-nourished and well hydrated • Using cushions to support joints helps the patient relax and prevent ligaments from being overstretched. • Special mattress (air or water mattress) to distribute body weight more evenly

3. Wound Care

General wound care: in palliative care we mainly deal with chronic wounds. Chronic wounds are characterized by ischemia, lengthened inflammatory processes, increased protease

concentration and reduced level of growth factor activity.

Causes	Management
<p>.</p> <ul style="list-style-type: none"> • Classification <p>Mechanical (surgical and trauma)</p> <p>Burns and chemical (thermal, radiological)</p> <p>Chronic ulcerative wounds (pressure sores, leg ulcers, radiotherapy or malignancies)</p> <p>Post-operative</p> <ul style="list-style-type: none"> • Factors that delay wound healing • Nutrition deficiency <p>Anemia</p> <p>Medications that slow wound healing-e.g. steroids, NSAIDs, Chemotherapy, Immunosuppressant's</p> <p>Other: Beta blockers, anticoagulants and phenytoin may delay healing.</p> <p>Radiotherapy depletes dermal fibroblasts</p>	<p>I. Treat reversible factors</p> <p>II. Wound specific treatment</p> <ul style="list-style-type: none"> • Remove Necrotic Tissue <ul style="list-style-type: none"> ○ surgical – tweezers, scissors or a scalpel ○ debridement as appropriate • Bleeding <ul style="list-style-type: none"> ○ Gauze soaked in adrenaline 1:1000 ○ Gentle removal of dressing with normal saline solution or irrigation using a syringe containing warm Normal Saline 0.9% to prevent trauma at dressing change • Infection <ul style="list-style-type: none"> ○ Irrigate wound with warm NS 0.9% or under running water. ○ Use antibiotics if there is spreading inflammation not just a red rim. ○ Use appropriate antibiotics like Cloxacillin or Trimethoprim Sulfamethoxazole or Erythromycin • Choosing a dressing <ul style="list-style-type: none"> ○ Administer appropriate anti-pain during wound

<p>locally and total body irradiation depresses bone marrow which causes minimizing of wound macrophages.</p> <p>Drug and Alcohol abuse cause vascular injury and reduce the immune response</p> <ul style="list-style-type: none"> • Ischemia and reduced blood supply (e.g. pressure) • Necrotizing malignancy • Location: <p>Pressure sores commonly on heel, sacrum and buttocks</p> <p>Peripheral areas with poor local circulation</p> <p>Position affects vascularity e.g. wounds over areas tend to heal slower.</p> <p>Wound circumference and depth – ruler</p> <p>Wound margins – redness could indicate infection, red/grey could be the result of undermining, white typifies maceration (excess moisture)</p>	<ul style="list-style-type: none"> ○ To maintain moisture ○ To add moisture ○ To absorb moisture ○ Protect wound surface ○ Control bacteria - Silver Sulphadiazine cream, Ichthammolglycerine, activated charcoal ± silver dressings ○ Control odor - activated charcoal, see separate guidelines below
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<ul style="list-style-type: none"> • Exudate <p>Amount: A sudden increase may indicate infection but the presence of exudates is a necessary part of the healing process and varies during the different phases.</p> <p>Appearance: serous, haemo serous, sanguinopurulent</p> <p>Odor: an offensive odor usually indicates the presence of high levels of bacteria.</p> <ul style="list-style-type: none"> • Wound base <p>Dry and necrotic</p> <p>Moist and sloughy</p> <p>Granulating</p> <p>Epithelializing</p>	
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4. Malodorous wounds

The wounds seen in palliative care patients are often a result of their advanced illness and/or poor physical or social state. Wound malodor can be a significant and distressing symptom for the patient, his/her family and care givers. Patients may experience embarrassment, disgust, guilt and shame, which can lead to social isolation and relationship problems.

Management

I. Correct reversible factors

Malodor is often caused by anaerobic bacterial infection of the necrotic tissue within a fungating wound. Metronidazole has been shown to be effective.

II. Consider disease-specific treatment

Treatment of lesions depends on the stage of the wound, size and the patient's general health:

- Surgery (debulking) of large fungating tumors
- Chemotherapy
- Palliative radiotherapy
- Hormone therapy for responsive tumors in breast cancer (Tamoxifen)

III. Non-pharmacological treatment of wound malodors

1. Good hygiene:

- Regular wound cleaning
- Regular bedding and clothing changes
- Adequate disposal of soiled dressings
- Adequate ventilation

2. Dressings:

- Use highly absorbent dressings to contain a high level of exudate to control odor.
- Preferably use non-adherent dressings (to make regular changing less painful)

3. Debridement

IV. Pharmacological treatment of malodor in wounds

TOPICAL (For mildly infected wounds without cellulitis):

- Metronidazole solution for cleaning a wound: 2liter saline + 10 (500mg) crushed metronidazole tablets to wash wound or area.
- Metronidazole gel: KY jelly mixed with crushed metronidazole tablets applied to the wound
- Metronidazole powder: crushed metronidazole tablets applied directly on to the wound
- Metronidazole cream: aqueous cream mixed with crushed metronidazole tablets
- Silver Sulphadiazine (Flamazine)
- Bacitracin, Fucidin or antifungal ointments where appropriate
- Charcoal dressings
- Honey and yoghurt

SYSTEMIC antibiotics for significant infections (preferably after obtaining a wound swab if possible)

- Metronidazole 500mg tid/bid pediatric dosage PO until good effect is obtained. (Side-effects: nausea and alcohol intolerance)
- Other antibiotics: Amoxicillin, Erythromycin, Trimethoprim Sulfamethoxazole
- Mono-therapy with Metronidazole is usually sufficient to address clostridial and bacterioids effects but sometimes staphylococcus and pseudomonas may colonize such wounds and need additional antibiotics such as Cloxacillin and/or Aminoglycosides

PAIN: Treat pain appropriately

Section B: Special considerations in HIV and AIDS symptom management

Although the above symptom control management guidelines cover multiple life-threatening illnesses, there are certain specific features with respect to patients with HIV and AIDS. As the immune system becomes exhausted, an individual becomes susceptible to a wide range of opportunistic infections (OIs), which in turn cause different symptoms. Thus prevention and treatment of OIs is an important part of good symptom control. Recurrent or persistent diarrhea

can be a challenge in patients with advanced AIDS (Chronic diarrhea needs to be taken as seriously as pain).

Many of the patients with diarrhea will have an identifiable infection, which should be treated.

Sweating and fever are frequent throughout the course of AIDS – it is important to undertake careful assessment and treat any underlying conditions where possible.

Almost all patients with AIDS will have some form of **skin problem**.

ARVs are the best available form of palliative treatment for AIDS at present and those on ART may well experience a range of symptoms, including:

- Pain, including neuropathic pain
- Diarrhea
- Fever
- Neurological symptoms
- Skin problems
- Nutritional problems
- Emotion and psychological symptoms
- Social and spiritual issues

Palliative care therefore has a key role to play in the care of people on ART.

Section C: Infection prevention and control

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

Core infection prevention and control interventions shall include:

- Hand hygiene
- Safe handling and disposal of patient excreta such as faeces, urine, sweat, and waste products
- Use of personal protective equipment
- Isolation precautions
- Aseptic technique

- Cleaning and disinfection and
- Sterilization

Chapter 4: Neuropsychiatric Symptoms and their Pharmacological and Psychotherapeutic Treatment

4.1 Introduction

Patients and their families/care givers shall be informed of common neuropsychiatric issues. A good assessment is key to support patients. Common neuropsychiatric symptoms in palliative care include

anxiety, depression, insomnia and delirium. Each of these areas will be considered and their treatment discussed below.

4.1.1 Anxiety

Anxiety is defined as a feeling of apprehension and fear characterized by physical symptoms such as palpitations, sweating, and feelings of stress. Anxiety is common in the terminally ill for a variety of reasons such as the fear of uncontrolled symptoms, fear of dying or being left alone to die.

Symptoms of Anxiety

Core features: Persistently tense and unable to relax, worry, more than normal mood variation, cannot distract self.

Symptoms: Poor concentration, indecisiveness, insomnia, irritability, sweating, tremor, nausea, panic attacks.

Assessment to identify cause and severity:

- Is it severe?
- Is it long-standing?
- Is it alcohol withdrawal?
- Is it situational?
- Is it related to a specific fear?
- Are the family anxious?

Management:

- I. Correct reversible factors
- II. Non-pharmacological intervention: Psychological methods for managing anxiety.
Psychotherapeutic Interventions

General treatment for most anxiety problems

1. Psycho-education – this is the first and most important kind of treatment for all of mental health problems, helping people realize that their condition is common, treatable, and not something to be ashamed of.

- These sorts of problems are very common

- It is not a form of weakness – our bodies are designed to have these sorts of reactions
- Though most of these problems will not completely vanish, they almost always improve, though it can take time.

2. Learning skills to reduce the effects of stress is the most effective relief. Help people become aware of when they are anxious and what seems to provoke it. This seems obvious, but, anxious behaviors can be a habit and not noticed.

- Trying to do things too fast or doing too many things at the same time
- Holding the body in a tense position, clenching fists, clenching jaw
- For some people, impulsively eating

When the patient is aware of being anxious or of cues to anxiety, tries a method of relaxation:

- Take a few slow, deep breaths
- Have a motto or something to think about that reminds them to be calm
- Count slowly to 10 and then continue with whatever they were doing

3. Try ‘active coping’- if there is a feared issue or thing, try to work on dealing with it rather than avoiding (but all the while acknowledging that it’s hard).

- For children (or even adults), reward brave behavior

III Pharmacological Intervention

Drugs	Dosage	Description
Benzodiazepine		
Diazepam	2 to 5 mg p.r.n., p.o./day	Diazepam has a long half-life and may therefore accumulate and be sedative. It should be possible to give it once a day, at night, although initially it can be given

		tds (three times a day).
Lorazepam	1 to 2 mg p.r.n., p.o.bid/day	Lorazepam is short-acting, rapidly anxiolytic and less sedating than diazepam. It may be more addictive on a longer-term basis.
Antidepressants		
Amitriptyline	25 to 50 mg po/day	
Imipramine	25 to 50 mg po/day	

Note: Refer if no response

Delirium/Acute confusion

Delirium is an altered state of mind characterized by confusion of recent onset and variable severity. It is the most common and serious neuropsychiatric complication in the patient with advanced illness. It is a collective term for the various causes of acute confusion rather than a specific diagnosis.

There are **4 key features** of delirium that need to be present to make the diagnosis:

- (1) **A changed level of consciousness.** (Difficulty focusing, sustaining attention, agitated, restless or drowsy. Disorientation)
- (2) **A disturbance of the process of thinking/cognition** (short term memory loss, disorganized thinking, speaking and problem solving, hallucinations and delusions)
- (3) The above changes are of **recent onset** and may **fluctuate** over a period of hours.
- (4) There is definite clinical evidence that the disturbance is caused by the abnormal physiology of an underlying **general medical condition.**

There are 3 clinical sub-types of delirium;

- (a) **Hyperactive delirium:** The patient is restless, irritable, agitated and may become aggressive or inappropriate in their behavior.
- (b) **Hypoactive delirium:** The patient is inactive, disinterested and incoherent.

(c) **Mixed delirium:** The patient fluctuates between hypo- and hyperactive delirium. This is the most common sub-type (>50%).

Management

I. Correct reversible factors

II. Consider disease-specific palliative therapy

- Where appropriate rehydrate patients (orally or by infusion).
- Review all medications, stop or reduce the dosage of all non-essential drugs and recheck for previous excessive alcohol or illicit drug use.
- A trial of steroids for suspected brain metastases.
- Most infections should be appropriately treated unless the patient has signs of impending death (within 24-48 hrs.).
- Consider using bisphosphonates for hypercalcemia.

III. Non-pharmacological Interventions

- Calm reassurance of the delirious patient
- Regular orientation for time and place
- Presence of a family member- Limit visitors
- Identify and maintain care giver consistency where possible
- Familiar personal objects or photos
- Encourage walking, or if bedridden, range of motion exercises
- Appropriate lighting at night
- Soothing music
- Gentle back massage and a glass of warm milk rather than a sleeping tablet
- Noise reduction as far as possible
- Optimize vision and hearing (check hearing aid)

NB: Physical restraints are not necessary. They may aggravate the situation and cause injury. Effective calming and if necessary, sedation is possible by means of appropriate medication at effective dosages.

IV. Pharmacological Treatment

Mild delirium without agitation			
Drug	Dose	Frequency	Comment
Haloperido 1	0.5 - 2mg PO	Can be given every hour, for up to 3 doses and then should be reviewed. (Notify Dr if 3 doses not effective. This allows a review of the situation so that the dose can be adjusted if needed)	Usual effective dose is 0.5 -2mg/day Maintenance: Previous day's total used given as a single daily dose & the same p.r.n. dose for break though symptoms NB: Medication is not always needed but as agitation may occur unexpectedly in a new environment consider its use for a short period.

Delirium with mild agitation but no aggression:			
Drug	Dose	Frequency	Comment
Haloperido 1	1-2 mg IM	Can be given every hour, for up to 3 doses and then should be reviewed. (Notify Dr if 3 doses not effective.)	Usual effective dose is 6-12mg/day Maximum 20mg/day Maintenance: Previous day's total used given as a single or divided dose plus the same p.r.n. dose for break though symptoms
Delirium with agitation, restlessness and aggression:			
Drug	Dose	Frequency	Comment
Haloperido 1	3-5mg, SC, IM or IV	Can be given every hour, for up to 3 doses and then should be reviewed (Notify Dr if 3 doses not effective.)	Up to 20 mg IM per day. Occasionally prolongation of the Q-T interval may occur. An aggressive delirious patient may be dangerous and calming the patient must be an urgent priority for all staff. (See

			second line drugs)
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Alternative first line drug:

Drug	Dose	Frequency	Comment
Chlorpromazine	12.5 – 50 mg PO, IM or	Every 2-4 hours p.r.n. x3 (Notify Dr if 3 doses not effective.)	More sedating than haloperidol. May cause hypotension, measure BP

Note: Delirium presents many complex clinical and ethical problems. If the degree of uncertainty about the diagnosis and management is interfering with proper care, consult the advice of a more experienced specialists (Psychiatrists and psychiatric nurses).

4.2 Insomnia

Insomnia is the inability to fall asleep or to remain asleep for an adequate length of time. Insomnia is present when all three of the following criteria are met:

- A complaint of difficulty initiating sleep, difficulty maintaining sleep, and waking up too early
- The above sleep difficulty occurs despite adequate opportunity and circumstances for sleep
- The impaired sleep produces deficits in day time functions

Assessment to identify cause and severity of symptoms

It is important to get a thorough history of the patient’s sleep pattern now and before he/she started to have problems.

- Establish the patient’s understands about insomnia and their expectations

- Identify possible medications that the patient is taking that could be causing the insomnia
- Identify possible emotional stresses that could be causing the insomnia
- Identify possible symptoms such as pain that may be causing the insomnia

Management

I. Correct reversible factors

- Identify and treat the primary condition; e.g. pain
- Eliminate disturbance and noise

II. Consider disease-specific palliative therapy

- Treat insomnia with a holistic approach
- Consider physical, psychosocial and spiritual causes and management options

III. Institute non-pharmacological interventions

- Avoid alcohol and stimulants in the evening
- Relaxation techniques
- Massage
- Warm milk/herbal tea at night
- Cognitive-behavioral therapy
- Progressive muscle relaxation therapy
- Hypnotherapy
- Sleep hygiene
- Substitute radio or relaxed reading
- Avoid large meal near bed time

IV. Pharmacologic Management

Benzodiazepines have been successfully used for short term insomnia, although there are no systematic **studies on long-term use and rare studies in palliative care.**

- Diazepam 5 to 10 mg at night
- Lorazepam 1- 2 mg at night
- Bromazepam 1.5 to 3 mg PO at night
- Amitriptyline can also be used to treat short term insomnia.

4.3 Depression

Depressed mood and sadness may be an appropriate response to approaching death for the terminally ill patient. It is often under diagnosed and under-treated. It is important to identify depression as conventional treatment achieves a good response in the majority of patients. If untreated, depression can result in worsening of symptoms and in social withdrawal and even suicide.

Clinical Features

- Depressed mood
- Loss of interest or pleasure in almost all activities
- Anorexia
- Marked weight loss or gain
- Insomnia / hypersomnia / early morning awakening
- Loss of self esteem
- Feelings of worthlessness / helplessness / guilt
- Poor concentration / indecision
- Thoughts of death or suicide

Common causes

- Uncontrolled pain or other symptoms
- Loss of independence

- Lack of support from family / friends / healthcare workers
- Fear – of dying or death
- Drugs – steroids, diazepam, efavirenz
- Loss of body image, due to disfigurement

Management

- Relieve pain and other distressing symptoms
- Review / modify drug treatment
- Provide counseling, support, reassurance
- Drugs – Treatment of depression can significantly improve quality of life and is as effective in palliative care as in other situations.

Tricyclics

- Amitriptyline 25-75 mg at night
- Imipramine 25-75 mg per day, if available, is an alternative that might be less sedating

Selective serotonin re-uptake inhibitors (SSRIs)

- Fluoxetine 20 to 40 mg in the morning (morning with meal)
- Sertraline 50 to 100 mg per day (morning after meal with meal)

Note:

Consult psychiatrist if there is no improvement.

‘Start low, go slow’

Antidepressants should not be stopped abruptly if at all possible, but withdrawn gradually.

4.4 Suicide Ideation

Clinical Features

The frequency of suicide in the cancer population is higher than in the general population with the highest risk in the months after diagnosis. The risk decreases with survival time and is low in the terminal phase. Depression is a factor in at least 50% of all suicides. Treatment of depression can diminish desire for death. Feelings of hopelessness – loss of purpose in living – may be associated with suicide intent independently of depression. Completed suicide is rare in cancer patients. Suicidal thoughts are common in terminally ill patients but are usually fleeting & are often associated with feelings of loss of control & anxiety about the future. The desire to hasten death is not necessarily synonymous with a request to hasten death.

Assessment of patients who may be at risk of suicide

Depression is common in the general community and more so in patients with advanced illness. Separating the clinically depressed patient from the person overwhelmed or despairing of their illness and circumstances may not be easy.

Questions that can help assessment:

- ‘Are you depressed?’
- ‘Recently have you often been bothered by feeling down, depressed or hopeless?’
- ‘During the last month have you often been bothered by little interest or pleasure or doing things?’
- ‘Have you felt things getting too much for you?’
- ‘Have you been scared you might harm yourself?’
- ‘Do you feel you have lost purpose for your life?’

The above have been shown to be reliable indicators of patients who may need further exploration of their depressive symptoms and possible treatment. It is also important to reassure patients that many people in their circumstances feel this way at times but these thoughts are often fleeting and diminish with time.

Management

- Treat underlying depression

- For a patient who has persistent suicidal thoughts in the absence of an underlying depression, intervention and support from mental health services may be advisable.

Chapter 5: Psychosocial and Spiritual Care and Support

4.5 Social care and support in Palliative care

Social care is an important part of the inter-disciplinary team within palliative care, offering holistic service to patients and families. Social care is potentially a universal service and supports clients facing long-term situations involving life-limiting illness, dying, death, grief, and bereavement. Using the expertise of social workers with populations from varying cultures, ages and socio-economic status social workers help patients & families across the life span in coping with trauma, suicide, and death. Social work practice addressing palliative and end of life care include; hospitals, hospices, home care, nursing homes, child welfare, civil society's organizations, faith based organizations and family service agencies.

Social work to chronically sick people deals with a range of problems associated with patients and of his/her family. These include: stigma and discrimination, isolation, economic crisis, housing, daily living, dependency for physical needs, cultural influences, religion, psychosocial issues and orphan care

4.6 Spiritual care

- Spiritual care involves being a compassionate presence to patients even as they suffer. It recognizes that emotional and spiritual healing can take place even though a physical cure is impossible.
- As a patient approaches end of life they often begin to think about the meaning and purpose of life and feel the need to mend broken relationships by forgiving and being forgiven.
- Areas of life that can generate spiritual peace or spiritual distress are relationship with God/Creator/Higher Being, with self, with others, and with the world around them.
- Spirituality can be defined completely by the individual's culture
- Spirituality can also be individually defined by personal experiences unrelated to the culture

Why is spirituality important?

- Physical healing and psychological coping may be complicated if patients are experiencing spiritual distress
- Appropriately addressing patients' spiritual concerns and needs can contribute to more rapid recovery and better prognosis
- Spirituality can bring an ill person hope, strength, and emotional support

4.7 Role of communication in Palliative care

The foundation of palliative care is built on good communication with patients, family members and health care professionals. People living with a life-threatening illness often have many concerns about their care and feel isolated. The palliative care professional needs to spend time to discuss the patient's problems which may include psychosocial and spiritual problems as well as their physical symptoms.

When discussing a patient's diagnosis or prognosis the palliative care professional needs to be able to communicate effectively with the patient and family. This may take some time and requires a step by step approach. The palliative care professional needs to assess the patient and family's desire to know about the life-threatening illness and ensure that the patient and family receive and understand the information as they request and is culturally appropriate.

4.8 Care of the care givers

Caring for people with a life-threatening illness is a complex process. Family carers support the patient physically, psychologically, spiritually and economically. Palliative care supports the family as they care for their loved one. It is important that the health care professionals assess the needs of the carers as well as the patient and should assess the carers for burnout or exhaustion and provide support as necessary.

Working with palliative care patients is time consuming and can be emotionally exhausting. So it is important that health care professionals have regular support meetings with other colleagues and are offered psychological support as required. Self-care is imperative when working in palliative care.

Health care professionals should ensure that:

- Are able to prioritize activities
- Accept that you can only change things within your control and cannot alleviate all suffering
- Tell superiors when you feel overloaded
- Set yourself realistic/achievable goals
- Monitor your workload

- Take leave regularly (short breaks during the year and one long break annually)
- Do not continuously work excessive hours of overtime
- Are not exposed to any unnecessary risks
- Monitor your own health and well-being.

Chapter Five: End of life care

End of life care is about the total care of a person with an advanced incurable illness and does not just equate with dying. The end of life care phase may last for weeks or months. End of life care provides physical, mental and emotional comfort, as well as social support, to people who are living with and dying of advanced illness.

Health care providers shall prepare both the patient and the family on the impending death:

- Care provider shall be honest, attend to emotional responses and spiritual needs.
- Care providers shall maintain presence and talking to the patient even if he/she is unconscious.
- Comfort measures shall be provided depending on the presenting signs and symptoms of impending death.
- End-of-life concerns, hopes, fears, and expectations shall be openly and honestly addressed in the context of social and cultural customs in developmentally appropriate manner.
- Palliative care practice shall be guided by the medical-ethical principles of autonomy, beneficence, non-maleficence and justice

Care Suggestions for the Family When Death is Imminent	
Changes	Care Suggested
Decreased social interaction	Encourage the family to remain in the same room and not leave the patient alone, explaining the calming effect of a human presence.
Decreased consciousness	Encourage the family to talk to and touch the patient.

	<p>Skin care and pressure relief become crucial at this point.</p>
<p>Increased discomfort, general aches and pains of being bedridden</p>	<p>Continue analgesics even if the patient is comatose or can no longer swallow. Use alternative routes of administration if appropriate.</p> <p>Reduce the dose if there is an increased risk of side effects (such as myoclonic jerks) which may be treated with any benzodiazepine.</p>
<p>Reduced interest in and intake of food and drink</p>	<p>Explain the natural physiological process to the family.</p> <p>Discourage force feeding and allow family to offer sips of water or chips of ice hourly to keep the mouth moist.</p> <p>If the family requests for intravenous fluids in any setting (hospital, clinics, home), explain the consequences.</p>
<p>Decreased urinary and GIT output</p>	<p>Reassure the family that the patient is not uncomfortable.</p> <p>Address possible incontinence and the need for extra careful skin care.</p> <p>Repeat information about measures to protect the care giver against body fluids.</p>
<p>Changes in breathing (irregular, stopping and starting, or noisy—the ‘death rattle’)</p>	<p>Explain what is happening and reassure the family.</p> <p>Keep the mouth moist, especially if the patient is mouth breathing.</p> <p>Consider using hyoscine butylbromide by various routes to reduce secretions.</p>
<p>Changes in circulation (cold and grey or blue/purple hands, feet, nose and ears)</p>	<p>Explain that death is near.</p> <p>Encourage the family to stay with the patient.</p>

If the patient faces social or financial problems	Link with appropriate stake holders
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Euthanasia means the deliberate ‘killing’ of a human being to relieve their suffering or to relieve him/her of life in a body judged to be unable to function normally by others. In Ethiopia, patients may express severe pain in terms of voicing the wish to ‘die than suffer’. It is however important to note that the primary request of patients is actually to be relieved from pain and suffering not a wish to die. This is often in conflict with their family’s pleas to hang on at all costs and their religious conviction that when and how to die should be left to a higher power, but also addressing the immediate suffering of such patients through appropriate management. Euthanasia is condemned according to Ethiopia law.

5.1 Bereavement issues at the End of Life

Bereavement is the **period of adjustment** in which the bereaved learns to live with the loss.

Grief is the normal, dynamic process that occurs in response to any type of loss. It encompasses physical, emotional, cognitive, spiritual, and social **responses to the loss**.

Anticipatory grief begins as soon as a loved one develops symptoms perceived as life-threatening.

Mourning is the public expression of grief. This public expression (perhaps crying or wailing) does not necessarily relate to the significance of the loss; it is usually related to cultural and religious values and encourages social support for the mourner.

Complicated mourning arises from an interrupted or obstructed grief process, and can result in potentially harmful outcomes, from somatic discomfort to chronic emotional distress, and even the possibility of death.

Grief counselling

Most support after a death will be/ should be provided by family and friends. Grief counselling is used to help survivor adapt. A brief contact at time of loss, more extended contact 1 to 2 weeks after funeral

What to do near time of death: Patient and Family need assistance in handling their anticipatory grief in ways that enable them to take care of themselves and their loved one

- Helping to address practical issues, such as food, accommodation, and care for their children
- Identifying and legitimizing feelings of sadness, anger, guilt, and anxiety
- Encouraging expression of feelings in privacy

- Enabling them to complete unfinished business
- Encouraging family to live fully and enjoy life whenever and wherever they can
- As people face their death, they want to know they will be remembered and that their life has had meaning.
- Using religious rituals
- Tradition in Ethiopia requires close family gather around the bedside of the dying person.
- Any important ‘last words’ will be said
- Sensitivity and courteous respect of a dying patient is crucial, with attention to the patient’s family’s needs. These last moments will be remembered in great detail.
- Remark on comfort of patient so family is informed and reassured

5.2 After death:

- Allow time with body
- Practicalities: remove implanted devices, complete death certificate, inform other clinicians
- Acknowledge the loss: share memories of the deceased, give permission to grieve, and do not take sides in family disputes.
- Networking with other resources and organizations: health care professionals should be networked with community and faith-based organizations that can assist bereaved individuals, families, or child-headed households.
- Visiting the bereaved/family: The bereaved appreciate gestures and expressions of condolence and sympathy, including telephone calls, and visits
- Encourage community involvement using existing community based structures like ‘ iddir’
- Encouraging good self-care. Encourage appropriate physical exercise, proper diet, and rest, other spiritual activities if they have.

5.3 Grief Therapy

- Grief Therapy seeks to identify and resolve conflicts that have caused some degree of ‘complicated grief’. For example: chronic grief, delayed grief, exaggerated grief or the response and the presence of persisting somatic pain and other symptoms of distress.
- Patients with complicated grief are best treated by psychiatrists or clinical psychologist

Chapter Six: Peculiarities of Palliative Care in Children

While there is significant overlap between adult and children's palliative care, there are also significant differences and peculiarities.

- Communication with children requires special skill.
- Children's understanding of illness, death and dying and adherence to treatment is variable depending on their maturity level
- The management of physical symptoms in children's palliative care has a lot in common with adults; however, there are differences in choice of medicines and the dosage given.
- The ethical dilemmas vary, as children cannot give consent
- Children are particularly fearful of separation from family, friends, home and school, and so children's palliative care services have to take care to 'normalize' the lives of children with chronic illnesses as much as possible.
- The pharmacokinetics and pharmaco-dynamics of drugs differ in children (**see annex 7**).
- The child's parents or legal guardians shall be acknowledged as the primary caregivers and recognized as full partners in all care and decisions involving their child.

6.1 Pediatrics pain management

- Pain assessment tools shall be age appropriate (see annex 1).
- Aspirin is contraindicated in children less than 12 years.
- Dosages shall be calculated in kilogram per body weight
- Pain is managed using through two stage WHO ladder

6.2 Special needs for children

- Special needs shall be identified through comprehensive assessment and addressed holistically.
- Children often understand more about their illness than we acknowledge.
- Children shall be involved in decisions about their own care in line with their maturity
- Recreation activities such as play activities, drawings, poems, or songs shall be encouraged.
- Appropriate information according to age shall be communicated in clear and simple language at their pace
- Children shall be allowed to lead a normal life which includes access to education within the limitation of their illness. School teachers, community members including other children shall be encouraged to support and deal sensitively with the affected child.
- Palliative care providers shall take into consideration the needs of orphans and vulnerable children and shall refer them to appropriate services for care and support

Chapter seven: Program Implementation

7.1 Providing palliative care service using different models

The critical point in palliative care services is to ensure the continuum of care and address patient need as they pass through the referral pathways between community and facility based palliative care services. There are various models of care being used for palliative care implementation. These include: home-based, facility-based and hospice-based care. These models should be coordinated for successful implementation of PC program

(See annex 8 for minimum standards of palliative care).

- **Home based:** HBC programs are one way of delivering holistic palliative care if volunteers, families, health developmental army, health extension workers community based organizations, faith based organizations, and are taught how to do basic symptom control and health workers provide the necessary drugs and backup support. It is preferred model by patients and is easier for families too. Ethiopia has a strong community infrastructure with FBOs, CSOs, and community

support groups such as iddirs which can be involved in establishing palliative care services. HBC educates and empowers the community and it reduces the isolation and stigma which often comes with incurable illness. Health extension workers, especially level 4, play an important role in the provision of day to day care, in mapping and harmonizing of care given by HDA, CSOs, FBOs and NGO and linking the patient with next level, if need arises.

- **Facility based:** Palliative care should be integrated with routine medical service at all levels. A comprehensive palliative care service should be delivered for out and inpatient clients. Basic palliative care service will be given at health center, clinics, hospitals and patients will be referred to tertiary hospitals in case of difficulty. Tertiary hospitals shall serve as Palliative care hub for advanced care.
- **Hospice:** this is institutional care for those who need care in the advanced stages of their disease and have a poor prognosis. It is ideal for patients who cannot be looked after at home for medical or social reasons.

7.2 Leadership and coordination

Government leadership is a key to palliative care implementation. The FMOH, RHBs, ZHDs, wHOs at all levels of the health system should own the process, have the responsibility to organize and lead palliative care service implementation. Partners, local NGOs, CSOs, private sector will also take part in the palliative care service implementation. Woreda health offices are also expected to work with partners and RHB to continuously support capacity building of health professionals, to coordinate the different model based palliative care services, to create awareness among the general population, to maintain smooth supply chain management and to monitor quality of the palliative care service.

RHB is also expected to oversee the overall program coordination, availability of all necessary logistics and drugs, monitor quality of service and make corrective actions timely while FMOH is responsible to lead the overall national palliative care program.

7.3 Role and responsibilities

There are various levels of responsibility regarding the implementation of palliative care; the roles and responsibilities of each hierarchy are outlined as follows:

7.3.1 Federal Ministry of Health

- Shall provide leadership and coordination of palliative care services at national level.
- Shall conduct training need assessment and provide master TOT on palliative care services.
- Shall conduct regular monitoring and evaluation
- Shall provide normative guidance (such as policies, strategies, guidelines and training packages) regarding provision of the palliative care service

7.3.2 Food, Medicine and Health Administration and Control Authority

- Shall be responsible for regulating and reporting on the importation of morphine and other opioids used for palliative care.
- Shall review legislation on a regular basis to improve access to opioids
- Shall keep accurate records of all transactions on opioids

7.3.3 Pharmaceutical Fund and Supply Agency (PFSA)

- Shall be responsible for quantification, procurement and distribution of palliative care drugs and commodities

7.3.4. Regional Health Bureaus

- Lead and coordinate the overall palliative care activities at regional level
- Shall ensure that basic palliative care medications are available at different levels of the health care delivery system
- Shall provide continuous capacity building activities for health care professionals regarding palliative care services
- Conduct regular monitoring and evaluation regarding the provision of palliative care service at regional level

7.3.5 Zonal/Woreda Health Departments

- Overall managing and coordinating the operation of palliative care services in the PHCU- in a primary hospital, health centers and health posts and community level
- Shall be responsible for implementing, coordinating and supervising palliative care services at all health facilities within the district
- Shall be responsible for monitoring adherence to the guidelines at the PHCU level.

7.3.6 Specialized Hospital

- Shall offer tertiary palliative care services

- Shall provide in service training and mentorship
- Shall network with home based care groups and other health facilities for referral
- Shall keep appropriate records and compile monthly reports
- Shall adhere to guidelines in the management of palliative care patients

7.3.7 General Hospital/Primary hospitals

- Integrated palliative care service provision (in-patient and out-patient)
- Shall have mechanism in place that facilitates referral for specialized palliative care needs such as : complex pain and other symptoms
- Shall establish a mechanism of referral linkage with other facilities in their catchment areas and community palliative care services.
- Shall keep appropriate records and compile monthly reports which shall be submitted to the district coordinator

7.3.8 Health Center/Clinics

- Will serve as a frontline team within the health system for integrated palliative care service provision (community and outpatient)
- Shall have mechanism in place that facilitates referral for specialized interventions for control of complex pain and/or other symptoms
- Supervise health extension workers and adjacent health posts regarding the palliative care services

7.3.9 Health Post

Interface between palliative care in PHC and the community by health extension workers

- Advice, support, education to patients , families and communities
- Case detection and referral
- Closely work with community based palliative care team

7.3.10 Patients, Families and Communities

- Shall be actively involved and contribute towards self-care
- Shall work in collaboration with health professionals and CBOs/FBOs/NGOs in their catchment areas.
- Shall be involved in establishment of palliative care services.

7.3.11 Partners

In collaboration with FMOH and RHB

- Shall provide technical and financial support regarding palliative care services implementation
- Shall mobilize resources needed for palliative care services.

Chapter eight : Monitoring and Evaluating of Palliative Care Programs

Monitoring and evaluation (M&E) is an action-oriented and pre-planned management tool that operates on adequate, relevant, and reliable and timely collected, compiled and analyzed information on program objectives, targets and activities.

- **Monitoring** is the routine tracking of services delivered to patients using recordkeeping and regular reporting. Generally with monitoring, we are concerned with the inputs of resources into our program and the outputs of services we delivered with those resources.
- **Evaluation** determines how effective an intervention or service is at changing outcomes of interest. Although monitoring data may be used for some evaluation activities, it is often the case that program evaluation is conducted using specially designed studies or data collection

The objectives of M&E are to improve the management and optimum use of resources of program and to make timely decisions to resolve constraints and/or problems of implementation. Agreed indicators are the most important management tools for monitoring, review, and evaluation purposes. Monitoring and evaluation shall be used as advocacy tool for use of evidence-based decision making. Palliative care service implementation can be monitored with supportive supervision, review meetings and various assessments.

8.1 Palliative Care Indicators

As palliative care is in the early stage of program development in Ethiopia, the indicators below address only certain aspects of the service. Further indicators will be developed as the service progresses.

	Definition	Method of	Frequency
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PROCESS INDICATORS	of Indicator/Measurement	data collection	
Percentage of health professionals (nurses, doctors, health officers, Pharmacists, Health extension workers) trained and providing palliative care services	<p>Numerator: Number of trained professional health workers providing palliative care services</p> <p>Denominator: Total number of professional health workers</p>	Training Records	Annually
Number and percentage of palliative care sites with minimum staff norms(1 physician ,2 nurses and 1 social worker)	<p>Denominator: Total number of sites currently providing palliative care services</p>	Supervision Reports	Annually
<p>Number of medicines- day availability in reference to the WHO analgesic ladder</p> <ul style="list-style-type: none"> - Level 2- Codeine - Level 3- Morphine 	<p>Denominator: 365 days</p>	Supervision Reports	Annually
OUT PUTS INDICATORS			
Percentage of patients seen as in-patients and outpatientin a health facility	<p>Numerator: Number of palliative care patients seen as in-patients and out patient</p> <p>Denominator: Total number of in-patients</p>	Health facility PC care unit records	Semiannually

Annexes

Chapter nine Annex 1- FLACC Scale

For use in children less than three years of age or older non-verbal children

Use like an Apgar score: evaluating each item and arriving at a total score out of 10

DATE/TIME						
Face 0 – No particular expression or smile 1 – Occasional grimace or frown, withdrawn, disinterested 2 – Frequent to constant quivering chin, clenched jaw						
Legs 0 – Normal position or relaxed 1 – Uneasy, restless, tense 2 – Kicking, or legs drawn up						
Activity 0 – Lying quietly, normal position, moves easily 1 – Squirming, shifting back and forth, tense 2 – Arched, rigid, jerking						
Cry 0 – No cry (awake or asleep) 1 – Moans or whimpers, occasional complaint 2 – Crying steadily, screams or sobs, frequent complaints						
Consolability 0 – Content, relaxed 1 – Reassured by occasional touching, hugging or being talked to, distractible 2 – Difficult to console, comfort						
TOTAL SCORE						

9.2 Annex 2-Drugs used for Step-by Step Analgesia

	NSAIDs	Usual adult dose	Pediatric dose	Comments
STEP 1	Acetaminophen*	500-1000 mg q 4-6hr PO	10-15 mg/kg q 4 hr PO	No peripheral anti-inflammatory activity
	Aspirin	300-900 mg q 4-6hr PO	10-15 mg/kg q 4 hr PO	Inhibits platelet aggregation; may cause postoperative bleeding
	Diclofenac	50 mg q 8hrs orally (max 200 mg per day), 100 mg per rectum every 16 hours 75mg IM q 12hrly	Children:5–10 years: 25mg supp. or IM Children:10– 14 years: 50mg supps or i.m	Diclofenac <u>should not be used in children below 5 years old.</u> Diclofenac is <i>not</i> for i.v. injection
	Ibuprofen	400 mg q 4-6 hr PO	10 mg/kg q 6-8 hr	Available as oral suspension
	Indomethacin	50-200mg/daily PO divided 12hrly 100mg suppository 12hrly	not recommended for Children	3-11hrs Elim ½ life
	Ketorolac	15 or 30 mg IM/IV q 6 hrly Oral dose following IM dosage:10 mg q 6-8 hr stat dose-60mg IM		Intramuscular dose not to exceed 5 days
	STEP 2	Mild Opioids	Recommended starting dose (adults more than 50kg)	Not recommended for children
Codeine		60 mg q 3-4 hr PO 60 mg q 2 hr IM/SCU		
Tramadol		PO 50-100 mg q 6hrs Max. 400 g/day		

		IM/IV 50-100 mg q 4-6hrs Max. 600 g/day			
STEP 3	Strong Opioids	Recommended starting dose (adults more than 50kg)	Recommended starting dose (children and adults less than 50kg)		
		Oral	Parenteral	Oral	parenteral
	Morphine	30 mg q 3-4 hr	10 mg q 3-4 hr	0.3 mg/kg q 3-4 hr	0.1 mg/kg q 3-4 hr

* Generally accepted max dose of acetaminophen is 4g/d adults and 3g/day in elderly.

Source national Pain Management Guidelines (2007) Federal Ministry of Health-Ethiopia

9.3 Annex 3

Caution while prescribing Morphine

Morphine has the potential for **abuse and dependence**. They can also be subjected to **diversion** as well. Clinicians prescribing these medications need to pay attention to the following issues.

Signs of Addiction

Addiction is Psychological dependence leading to craving, impaired control over drug use, and compulsive use to get psychic effects despite harm.

- 1- **Compulsive** drug-seeking -strong (sometimes overwhelming) desire
- 2- **Unauthorized** use or dose escalation(early refillproblems due to lost, spilled, or stolen medications,illegal sources)
- 3- Use **despite harm** to self or others
- 4- Progressive **neglect of alternative pleasures** or interests
- 5- Stealing, multiple prescription

Signs of Diversion

Diversion is the misappropriation of prescribed medications, either by physicians or by other persons who acquire medications from treating sources. Opiate analgesics of all sorts

and varieties can be diverted for their abuse appeal

- 1- Patients may exhaust their prescribed medications shortly after receiving them
- 2- They may complain frequently of medications being spilt or stolen
- 3- Physicians prescribing medication on another patients record for self or colleague

Prevention of addiction and diversion

1- Physician responsibilities

- Tell patients that the substances prescribed are controlled by authorities.
- Specify that prescriptions for controlled substances will be made only during regular office hours, unless there is strong reason to do so.
- Tell patients information regarding potential development of tolerance and physical dependence.
- Specify the grounds for termination of prescription of controlled substances.
- If patient presents with signs of abuse, differentiate between addiction and diversion and manage accordingly.

2- Patient responsibilities

- Prevent loss, misplacement, or theft of controlled substances, understanding that controlled substances will not be readily replaced.
- Be present in person to pick up prescriptions for controlled substances, unless physically unable to do so.
- Take the medication in the dose and at the intervals prescribed.
- Keep track of the amount of medication remaining.
- Do not divert or dispense controlled substances to others.
- Clarify the reasons for any significantly lowering than expected pill counts and the whereabouts of that medication

9.4 Annex 4-Prescribing Morphine

Increasing morphine dose

If patient *still* in pain *after* 24 hours and *no* sign of toxicity increase the morphine dose by 50%.

- *Continue* to increase the dose by 30-50% every few days *until* the patient is pain free or there are signs of toxicity.
- Alternatively, can increase the dose by adding the additional breakthrough doses that have been taken in the last 24 hours to the regular morphine dose.
 - *Remember.....* Check whether the breakthrough doses have been *effective*.

If the patient has taken several doses with *no* effect, *review* the pain as it may *not* be sensitive to morphine.

Example: with NR morphine *only*:

A patient is taking 20mg NR morphine every four hours: They have also taken three breakthrough doses of 20mg in the last 24 hours

9.5 Annex 5-Essential Palliative care medicines list

Drug Name	Properties	Clinical Uses	Alternative Drugs
Paracetamol	Non opioid Analgesic	Fever Pain	
Aspirin	Non opioid Analgesic	Pain Fever	
Ibuprofen	Anti-inflammation NSAID	Some mouth Pain (esp. bone pain) Fever	Diclofenac Indomethacin
Tramadol	Weak opioid	Pain	Low dose morphine
Codaine	Analgesic		

Morphine liquid	Strong opioid Analgesic	Pain Introduction Breakthrough pain Difficulty swallowing	Morphine slow release tablets
Morphine (slow release tablets)	Strong opioid	Pain Severe diarrhea	Morphine Liquid
Dexamethasone	Corticosteroid Anti- inflammatory	Painful swelling and inflammation	Prednisolone
Amitriptyline	Tricyclic Antidepressant	Neuropathic pain (nerve pain)	Carbamazepine Phenytoin
Amitriptyline	Tricyclic Antidepressant	Depression	Imipramine
Hyoscine Butyl bromide	Antimuscarinic Antispasmodic	Abdominal pain (Colic)	Propantheline
Diazepam	Benzodiazepine Anticonvulsant	Muscle spasm Seizure	Lorazepam
Phenobarbitone	Anticonvulsant	Seizure	Diazepam
Metoclopramide	Antiemetic	Vomiting	Haloperidol Domperidone
Metoclopramide	Pro-kinetic	Abdominal Fullness	
Chlorpromazine	Antipsychotic	Hiccups	Metoclopramide Nifedipine

Drug Name	Properties	Clinical Uses	Alternative
Magnesium Trislicate	Antacid	Indigestion Gastro-esophageal	
Loperamide	Antidiarrheal	Chronic diarrhea	
Bisacodyl	Stimulant	Constipation	
ORS	Rehydration	Diarrhea	
Chlorpheniramine	Antihistamine	Drug reactions	
Flucloxacillin	Antibiotic	Chest infection	

Cotrimoxazole	Broad Spectrum Antibiotic	PCP treatment & prophylaxis Infective diarrhea in	
Metronidazole	Antibacterial for anaerobic infections	Foul smelling wounds conjunctivitis dysentery	
Lumefantrine artemether(LA)	Anti- malarial	Malarial treatment	
Acyclovir	Antiviral	Herpes zoster	
Chloramphenicol eye ointment/drops	Antibacterial	Eye infections	
Fluconazole	Antifungal	Oral & esophageal candidiasis	
Clotrimazole 1% Cream	Topical Antifungal	Fungal Skin Infection	
Nystatin Suspension and pessaries	Antifungal	Oral & vaginal candidiasis	
Petroleum jelly	Skin Moisturizer and	Dry skin Pressure area care.	
Potassium Permanganate	Drying agent Antiseptic	Oozing lesions wet skin	
Gentian Violet Paint	Antimicrobial Astringent.	Bacterial & fungal skin infection	Clotrimazole pessaries
Chlorinated Lime	Disinfectant	Infection prevention	Chlorine
Calamine Lotion	Itch	Rash	Aqueous Cream

9.6 Annex 6- Palliative Care Emergencies

Emergency conditions that commonly occur in patients with chronic life threatening diseases that need immediate action and referral for adequate addressing of correctable underlying conditions

Emergency	Common causes	Management
Seizures	ICSOL, Brain metastasis, inflammation, dehydration, hypoglycaemia,	Start: Anticonvulsant(midazolam, pheny

	base/electrolyte disorders,	Treat ICP: Dexamethasone Treat: underlying cause
Spinal cord compression	Metastatic mass effect or vertebral collapse due to bone-lytic process in majority of cases	Start: Dexamethasone Refer: Urgently for surgery or radiotherapy depending 1-on location (cervical) or 2-ability to walk or 3-Severity of pain.
Tamponade	pericardial inflammation or infiltration	Start: Plasma expander if hypotensive Refer: Ultrasound guided Pericardiocent
Superior vena cava obstruction	Involvement of mediastinal lymph nodes by bronchial ca or lymph	Start: Upright position, oxygen, dexamethasone, diuretic, anxiolytic Refer: urgent chemo or Radiotherapy
Hypercalcemia	Product of malignant tissue	Start: Intravenous fluid
Hypoglycemia	Anorexia, refusal or failure to feed	Start: Glucose administration
Hyperviscosity	Leukemia or polycythemia	Start: Phlebotomy, hydration
Sepsis in Neutropenic	Leukemia. radiotherapy , chemotherapy	Start: Empiric broad spectrum antibiotic Refer: for culture and sensitivity

Hemorrhage	<ul style="list-style-type: none"> • Gastric ulcer due to NSAIDS • Drugs causing thrombocytopenia. • hepatic insufficiency • anti-coagulation with warfarin • A generalized clotting Deficiency 	<ul style="list-style-type: none"> -Stop inducing drugs, -for superficial bleeds adrenaline - anxiolytics to decrease fear and agitation -H2 blockers or PPI e.g. ranitidine 150 mg bd , Omeprazole 40 mg po/day -Vitamin K -Palliative radiotherapy if indicated (Cervical ca)
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9.7 Annex 7-Pediatric Dosages.

Drug	No. times/day	Single dose by weight	Approximate single dose by age*		
			<1yr	1-5yrs	6-12 yrs
Paracetamol for pain or Fever	4	10 - 20mg/kg	62.5mg	125mg	250 -500mg
Ibuprofen for pain or fever	3	5 - 10mg/kg	50mg	100mg	100-200mg
Oral morphine for severe pain	6	Starting dose 0.1 -0.3mg/kg	1 - 2mg	2.5mg	2.5-5mg
Bisacodyl for constipation	1	5mg total			5mg
Dexamethasone **	2morning& Lunchtime	0.1 - 0.5mg/kg	0.5 - 1mg	2mg	4mg
Prednisolone ** (if dexamethasone not for	2, morning & lunchtime	1 - 2mg/kg	5mg	15mg	30mg
Amitriptyline for neuropathic pain	1 at night	0.2 -0.5mg/kg max 2mg/kg	-	6.25mg	12.5mg
Metoclopramide for nausea/vomiting	3	0.1 -0.5mg/kg	5mg	10mg	10mg

Diazepam for muscle spasm or agitation	2	0.25mg/kg	1.25mg	2.5mg	5mg
Chlorpheniramine for itching or night sedation	3	0.1mg/kg	0.5mg	1mg	2mg
Nystatin suspension for severe candida	3	1 drop	1 drop	1 drop	100mg

9.8 Annex 8- Minimum program standards for palliative care

The elements listed below, are considered the minimum program standards for palliative care necessary for quality comprehensive care to be provided:

Access to Care: Initial and periodic community needs assessment and planning contribute to the development and implementation of palliative care services, with special attention to securing access for the under-served including people living with HIV/AIDS and cancer.

Interdisciplinary Team: Palliative Care is provided by an interdisciplinary team consisting of professional members and trained & supervised community caregivers. Essential team functions are medical, nursing, psychosocial, and spiritual care.

Home Based Care: The interdisciplinary team of professional members and trained & supervised community caregivers provides home based care.

Pain and Symptom Management: The patient's pain and symptoms are acknowledged and treated in an effective, appropriate, and best available manner to achieve a level of comfort which is acceptable to the patient.

Medication: A safe and effective medication system is utilized by the physician and professional nurse.

Family Care: Team members prepare and support the family in adapting to the changes that arise from illness, dying and bereavement.

Orphan Care: Appropriate care plans are developed and initiated for orphaned children.

Psychosocial Support

Spiritual Support: The patient and family are respectfully supported as they search for meaning and purpose in life, suffering, and loss.

Bereavement Care: The bereaved are supported during the process of mourning and in their adjustment to loss.

Ethical Practice: A forum is established where discussion can be initiated related to clinical problems which have an ethical dimension.

Staff Support: Team members receive support to enable them to work effectively in palliative care.

Training: Ongoing training and learning support is provided for team members, family members, and community & health care professionals. Principles of palliative care, pain & symptom control and safety, AIDS prevention & education, universal precautions etc.

Continuum of Care: Palliative care should be provided through an integrated, collaborative, community resource-linked continuum of care which focuses on home-based care.

Chapter 10 References

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